FINITE LIVES

DYING DEATH AND BEREAVEMENT
AN EXAMINATION OF STATE SERVICES IN IRELAND

SENATOR MARIE LOUISE O’DONNELL

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Senator Marie Louise O'Donnell
This report is the second in a programme of my research into end-of-life care in Ireland and how the State supports people who are facing dying, death and bereavement. Government Departments, the Office of Public Works and the Office of the Revenue Commissioners were involved in this study. The Department of Health was not included.

This study found its beginning and origins in the series of public hearings on end-of-life care before the Oireachtas Joint Committee on Health and Children, chaired by then Deputy Jerry Buttimer. From 24th October to 14th November 2013, experts informed the Committee of the current arrangements around end-of-life care in Ireland and importantly how it could be improved.

Following those hearings, I tabled a motion on End-of-Life Care and Bereavement in Seanad Éireann on 16th April 2014. The motion was carried and called on the Government to explore the components of an overarching strategy on end of life and bereavement, which would look at the wider societal issues including legal issues, finance, economics, education and culture.

Following that motion, An Taoiseach invited me, in a letter on 26th March 2015, to review the end-of-life services provided by Government Departments to the public. A report on how the Departments support their own staff was completed in 2015 and following the 2016 general election, work commenced on reviewing the Departments’ support to the public.

The research was primarily conducted from September 2016 to May 2017. From An Taoiseach’s initial invitation on 26th March 2015 until the launch of this report on 17th May 2017, an estimated 63,440 individuals, of all ages, have died in Ireland and 634,400 people have been bereaved.

These deaths have ranged from being expected following a long life, or anticipated after illness, to deaths which were accidental and violent. This report has attempted to look at how the State cares for people in these circumstances before and upon their death. It has also looked at what supports the loves ones of the deceased need from the State and what they receive. A series of recommendations are made in an effort to close the gap between expectations (if any) and reality.

The report looked at issues around dying, death and bereavement in Ireland today but it did not consider any demands to introduce euthanasia or assisted suicide in this country.

When exploring issues affecting people who are dying, the study considered what (non-health) supports a person might need in the weeks, months or indeed years they live

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1. These figures are based on an average of 80 people dying each day and there were 793 days between 26th March 2015 when An Taoiseach wrote to Senator O’Donnell inviting her to conduct the study to the launch of the final report on 17th May 2017.
with declining health, following a prognosis of a life-limiting condition. The needs of an actively dying person are obviously beyond the scope of this study or indeed the expertise of this author.

The report is divided into a number of chapters:

- The vision provides an overview of the key themes that emerged over the course of the study and my perspective of the issues to be addressed. The vision also includes overall recommendations that need to be considered in order to secure comfort and dignity for individuals and their bereaved loves ones at end of life.

- The methodology chapter explains how the report was approached. A mixed methods approach was adopted with departments completing questionnaires, a survey of TDs and Senators, qualitative interviews and a desk analysis of work of the Departments and relevant issues.

- The research chapter captures the response of each Department, the Office of Public Works and the Office of the Revenue Commissioners to the questionnaire. The structure of this section involves a brief outline of the work of each Department including its mission statement. An outline of the Department’s response is then provided. Following this outline some end-of-life issues relevant to the Department and recommendations are proposed. The Department questionnaires are followed by a section presenting the findings of a survey of 112 TDs and Senators. The third section outlines the key issues raised during qualitative interviews with 34 interviewees.

Finally, this study was an examination of end-of-life issues outside the health arena. The remit was to establish the Departments’ policies, services and procedures around dying, death and bereavement and how they could be improved or developed.

All of the Departments responded to the research and almost all contributed. Each had a different lens through which they interpreted their role around end-of-life issues.

Every effort was made to look at programmes, projects and research relevant to each Department and its response to end-of-life issues. The research was illustrative and within the remit of the study.

This is the beginning of a conversation between the State and the citizen about end of life. A conversation that must span our social, artistic, environmental, legal, administrative, educational lives.

Our living lives. Our finite lives.
In 2015, I began a programme of research on the work of the State in relation to dying, death and bereavement.

I was commissioned by An Taoiseach to undertake this study in 2015 and the Finite Lives report was published in December 2015 which explored how Government Departments handled dying, death and bereavement among their own staff. This earlier study involved a mixed methods approach of questionnaires and qualitative interviews. For this second report in the programme, a mixed methods approach was once again adopted. The research programme involved a questionnaire completed by Government Departments, the Office of Public Works and the Office of the Revenue Commissioners; a survey of TDs and Senators; semi-structured interviews and a desk review of the work of each Department and issues deemed relevant.

DEPARTMENT QUESTIONNAIRE

Questionnaires were distributed to the Secretaries General of 15 Government Departments (excluding Health) as well as to the Office of Public Works and the Office of The Revenue Commissioners in the Autumn of 2015. In the “external” questionnaire for this report, the departments and agencies were asked four open questions:

1. In your policy work in each of these areas please outline any issue relating to dying, death and bereavement which you have identified and the area in which they arise

2. Please tell me how your Department currently engages with the public and/or delivers services in the areas in relation to dying, death and bereavement, including your interaction with other agencies

3. Can you tell me how your Department might possibly engage in the future around these issues?

4. Are there any areas of policy, or other areas where your Department engages with the public around the issues of dying, death and bereavement, which I have not covered?

DESK REVIEW

A desk review of the work of the Departments, the Office of Public Works and the Office of the Revenue Commissioners was conducted which involved reading the corporate information of each department and exploring the relevant policies and strategies related to its work. This review was undertaken in an effort to better understand the work of each Department and to ascertain its relevance to people affected by dying, death and bereavement.

The study also involved an exploration of relevant issues that were being highlighted by a range of community and voluntary organisations. This wider analysis, while not academic and not exhaustive, was also needed in an effort to develop the overall recommendations for An Taoiseach who commissioned the research. Recommendations
were also proposed for each Department which were influenced by the information and insights from the qualitative interviews and the findings from the survey of TDs and Senators.

QUALITATIVE INTERVIEWS

A total of 34 qualitative interviews took place during 2016 and 2017. The interviews were semi-structured and most took place in Leinster House. Some three interviews took place in Cork, six in Limerick and one in Kildare. The people who were approached to be interviewed included commentators who had an interest and an opinion on end-of-life issues; lawyers with expertise in citizen rights and the rights of older people; academics in sociology and ethics who had written or spoken on the issues; a hospital chaplain; an architect, an undertaker, a coroner as well as advocates and senior figures in hospice and palliative care.

The interviewees included academics and practitioners. The National Council of the Forum on End of Life in Ireland, TILDA (The Irish Longitudinal Study on Ageing) and Smart Ageing in Dublin City University were approached as suggested by an Taoiseach. The interviewees also came from diverse disciplines: the arts, law, psychology, ethics, philosophy, specialist palliative care, sociology, social work, the funeral services industry, criminology, the coronial service and architecture. One individual interviewed for the study was using hospice services.

The general public was not invited to participate in this study due to the timeframe and the ethical issues involved. However, an effort was made to gauge the needs of the public dealing with dying, death and bereavement and the State’s response to those needs by surveying their TDs and Senators.

SURVEY OF TDs AND SENATORS

A short self-completion questionnaire, comprising seven questions, was designed and distributed to the 158 TDs and 60 Senators in Dáil Eireann. The TDs and Senators were informed that their replies would remain confidential and that their individual replies would not be disclosed. The questionnaire was circulated to the TDs and Senators in hard copy and electronic format on the 18th October 2016. There were 112 responses to the survey with 72 TDs and 39 Senators revealing the end-of-life issues that are raised by constituents and the kind of response they received from the State. The survey also captured recommendations from TDs and Senators based on their experience in supporting constituents at end of life.
“Now it’s high watermark
and floodtide in the heart
and time to go.
The sea-nymphs in the spray
will be the chorus now.
What’s left to say?
Suspect too much sweet-talk
but never close your mind.
It was a fortunate wind
that blew me here. I leave
half-ready to believe
that a crippled trust might walk
and the half-true rhyme is love.”

SEAMUS HEANEY – THE CURE AT TROY

AS WE WERE BORN, SO TOO MUST WE DIE

Dying, death and bereavement are inevitable and our mortality is the common ground on which we all stand. Over 29,000 of us die each year in Ireland and over 290,000 of us are newly bereaved.

The State is present at our deaths. It counts us in and counts us out. It issues our death certificates - the ultimate bureaucratic full stop. It must be able to create a culture or support a culture, where the issues of dying in all its myriad forms, and the issues of bereavement are dealt with in a more realistic, empathetic and humane way.

When people are vulnerable, when they are facing life-limiting illness, death and bereavement, it is then that we as citizens should see the State operating at its very best.

How does the State respond when our citizens are faced with their most challenging times? How and where does the State measure up at the most testing times in all of our lives? And if it does not measure up, is it because of lack of money, staff or services? Or is it because of the absence of policy, foresight, planning or the energy that is necessary for the creativity of vision?

This report seeks to answer those questions. It is not accusative. But it does challenge. It challenges the Government to do better, to be better, and to respond better to its citizens facing dying, death and loss at whatever age that occurs. Above all, it challenges the Government to build our dying, our death and our bereavement into policy and practice across all its Departments and Agencies.
It does identify areas where practice works, where improvement is needed, especially around clear information, available services and supports and unmet needs. It also suggests some new creative practises which should be considered, observed and supported.

This report did not arise out of the ether. It came from the privilege of being appointed to the Senate in 2011 and learning at first hand the effect that political decisions have, and can have on people’s lives, when they are well and when they are unwell. It also came from being at the Oireachtas Committees and hearing what NGOs from all the different fields of life and work had to say. They taught me to think about dying, death and bereavement politically. It had been for me, up to then, a family issue. Over time I have learned from great educators and leaders in this field, that end of life and bereavement issues are not solely confined to the area of health. They are affected by many areas of public policy - financial, legal, social, cultural, educational and administrative - and must be at the centre of government policy. It is the one life event that government can plan for, as it is inevitable that all citizens and residents of the State will eventually die.

This report is only the beginning. But it is ground-breaking. This an opening of a conversation with the Government.

It is a conversation that has already started within the community, but in isolated and unconnected ways, among all of the different organisations I have met and researched.

This report is both quantitative and qualitative. It is empirical and philosophical. It is about where Government departments and agencies recognise their role in relation to dying, death and bereavement, and where they do not and how we, as a developing republic, need to fill in the services and information gaps. But it is also a plea for political vision. For a vision that will affect 100% of the population and which currently costs the health services alone €1.4 billion a year. How we die is as important as the irrefutable fact, that we will.

And what of the State’s role now around dying, death and bereavement? Does it support, does it enable, does it encourage, does it recognise importance and does it pay? In some ways and in some places it does, but not in others. But it does not prioritize the issues. There is little account taken of the signals it sends out to people who are approaching end of life, or to those whose lives will be changed forever by the loss of a loved one.

One glaring example of this in recent times was the discontinuing of the Bereavement Grant. Whatever the merits of the economic case for its removal, and whatever additional payments were put in its place, the effect of removing the word “bereavement” from the State’s lexicon of support has had a huge psychological and social impact. Study after study has shown that people experiencing loss like to have that loss acknowledged. People who are trying to live in the new and challenging world they encounter following a loss will always be more comforted by the word “bereavement” than they will be by being labelled as having “exceptional needs”. This lack of social and emotional intelligence on the part of the State does more damage than can be undone by a new and (arguably) more user-friendly payment support system.

Death is rarely mentioned in Government reports except in statistics – death on the roads, violent death, drug death, suicide. And where is the State’s responsibility in this? Their responsibility seems to lie in collecting the statistics, and perhaps paying the compensation.
But how can the State be asked to act for us in the avoidance of the death loss and pain? It cannot. This report does not ask the State to promise immortality.

What it asks is that where State services are required, they will be put in place. And where State services are not required, they will help and support communities to put that appropriate response in place. The State must encourage the brilliant, creative projects that are happening around the country, and use the best of them as templates, for how other towns and villages might operate or imitate, in the best sense of that word.

The State cannot take away death. But what we as citizens can legitimately expect, is that the State supports people to cope better with the myriad of practical, social and emotional issues that present before, during and after a death.

The State encourages us to plan for our education, for our employment and our retirement. Why does it not encourage us to plan for our end of life, even when its own legislation signposts the difficulties which can arise in this area? Would it not be better for us all if people at all life stages and ages thought about what they want at end of life? If they discussed it with their families? Surely the State could encourage, support and enable people to discuss and plan for end of life – to Think Ahead.

Throughout all of this report, through the surveys, the research, the interviews, the pamphlets, the papers and the universal reading, around the profound issues at end of life, the centrality of all arguments always came back to the decency and dignity of how we are acknowledged, and how our self-worth and self-respect is regarded, when human fragility, illness and life loss, comes to our door.

The need for comfort, food, financial security, communication, warmth, transport, community care, lack of anxiety around loneliness, education, funeral and fuel surety, adaptive home environments, rights, living well with value and meaning were the issues consistently highlighted across the report when citizens are facing end of life issues. Living well and with ease and contentment, despite having to face our own mortality. Living well until we die.

Whether death is sudden or prolonged whether young or old, it is the time when life ends forever or is altered forever. We have to face the tipping point of a changed life graph for those left behind. It is at this time that we need the state to step in with generous services, facilities, amenities, and information. And it is at this time that we most need to be treated with courtesy and civility, and to feel that we have been so considered.

The State’s biggest fall occurs when it second rates the power of community which is central to and fundamental in people’s lives. It is within the heart of communities that people live. It does not matter what townland, or estate, or county, or city or locale. We live locally. We do not live nationally. We always live locally – communally. We have this year witnessed the greatest example of that community at Blacksod Bay in Co Mayo. The people, woman and man, young and old, fisherman and housewife, retiree and intern, came to help following the tragic loss of life of four of our Irish coast guard helicopter service men and woman. The community are still there as a human protector weeks after the tragedy.
That is what compassionate communities is all about. It is the human shield and protection that surrounds, cares for, and attends to, human loss, death and dying, and the human grief of others.

Meanwhile while talking about the need for rural regeneration, the Government is stripping many of the services and life cycles that allow people to live with renewal and regrowth – communally.

In some way we as human beings have become locked-in as a stalk of an economy. Dots on the economic graph. When politics does not prioritize the human being, as the core of all creativity and communication, in heart and head, and when it ceases to understand the human need for a qualitative way of life and a good death, and a compassionate place for those who are left behind forever, politics can become disconnected. People lose trust. They begin to believe that many decisions are not made for the common good. They begin to feel isolated and unheard.

It is now no longer feasible to hold onto the last franchise in the country - the Post Office. They are being closed down environmentally, architecturally, and as a place of defined purpose and possible growth. The bank structures are becoming technical and silencing human communication within their rural and urban structures.

Meals on Wheels - a genius idea – is now in some instances is becoming buried alive with rules and regulations from health to ingredients and handed in at the door, in a bag, by a stranger, in direct contradiction of its genesis which was communication, human meeting, conversation and a respite from loneliness.

Home Care Packages were a brilliant idea. But they now offer little proper individual training, not enough hours of contract or communication or friendship, and indeed contracts which are handed back very quickly as nobody has the time or is capable of completing them. And there are never enough staff.

We are now not likely to die at home, despite it being our greatest and most hoped for, final wish. Government policy and practice often seems to actively work against people remaining at home, rather than facilitating and supporting them there.

We have no such thing as architectural expectations. We don’t expect the environment in which we live to be beautiful. We know nothing of what is to be erected as our dwellings, how it is to be erected or indeed why. We don’t have any say in the estates in which we must live, or in their design or layout or visual impact. And yet we pay hundreds of thousands to live in them, for the rest of our lives paying interest rates greater than their value.

It is everybody’s right to be around or have access to environmental beauty. And by beauty I mean nature, walks, parks, seats, trees, foliage, sculpture, colour, flowers. Architecture that we can look at and live in and beside, most especially when we are facing our own mortality, or leaving the world forever. We have to come to value the powerful and positive effect of a beautiful environment on preserving a mental health and a comfort and support to those at end of life.

We need to make more effort to preserve beauty in our villages and towns, to create places for people to feel this is a wonderful place to walk around, to look at, to live within. This is well painted. This is well kept. This is the place where I would like to live and to die.
Throughout all of my research around end of life the regenerative and joyous power of the Arts through music, drama, poetry, visual art, poetry and dance were cited as platforms for hope, courage and joy. Their power of personal conversation, private feeling and public expression. Their influence on the human heart and mind and its need to express and have meaning. Most especially around issues at end of life. It is here they have such profundity and transformative effect on how we view our lives. They can become our navigation through the most terrible of times.

Why then is the neglect of the arts so evident across all sections of education when their richness and their transformative nature is so evident? Why do we award extra points to maths and not to music on the Leaving Certificate? The Arts are rural, urban, city, local, national, personal, private, individual and collective to and for all. They are powerful because they exist where the full human being has a need to exist. And they play the greatest and most commanding role around our lives, when we are faced with human suffering loss and despair, and the overwhelming finality of death. They become our best channel.

We commemorate 1916 with Military Parades. Why don’t we have a remembrance day once a year for all those who have died regardless of age or time? That goes to the very core of us all. Our loved ones gone forever. So the question is ‘what about us?’ ‘What about now?’ We need a vision around these issues.

There is an exhaustion among the NGO’s around asking for help or suggesting other ways forward based around on-the-ground evidence, which is consistently and constantly ignored. Silos get in the way of joined up dots and creative thinking. Good practice continues to be subsumed by territory. Government departments are joined together in an ad hoc fashion and outside strategic thinking. That is where vision gets choked and is being choked.

We have lost a landscape vision of a whole life within a whole state, as life style takes precedence over life course.

Dying, death and bereavement are universal. With all our political advancements, research, communications, and all our technology, we have yet to come up with a vision that centralises and emphasises the human being as someone of meaning and value. We keep avoiding this emphasis. We may say we don’t. But evidence suggests otherwise. Human beings are called to meaning. They are called to do more than function. Human beings are value giving people. Getting out of bed is very hard if you are living in a meaningless universe. Meaning has collapsed and meaning is fundamental.

A life and an eternal leaving has meaning and value. When we remove meaning we remove resilience. Hope plays a huge part in people lives or the expectation of it. All Government have responsibilities around that hope and expectation. They have roles to play through education, community care, environment urban and rural, and the rights of the human being from birth to death through the creation of a society where people can grow up and live wholly and healthily, around all the fragilities and problems that life will insist they face.

We all meet on the ground on which we stand. But how does the State make the environment around that death around that loss easier and more helpful? We have to
stop being frightened of not been good at it. We must try to get the State to be more comfortable, more confident, and more competent in dealing with these issues. When my report on dying, death and bereavement informs me about isolation, fuel poverty, community care cut backs, funeral costs, depression, financial fraud, legal anomalies and the burying of elder ethics, questions must be asked and changes must made.

That is what this report is attempting to do.


“When we as citizens have courage
that does not mean we have the means.
But it does mean that we can stand up for ourselves.
And then the Government have to follow on.
I don’t think the Government does anything really creatively,
until they have to do it by the law of necessity.
It is only with necessity that the law changes.”

MARK PATRICK HEEDERMAN FORMER ABBOT GLENSAL
The key recommendations from this study involve the Government reviewing its services, developing supports that are fit-for-purpose and championing the right to a dignified death at home and abroad.

The research in this report shows that end-of-life is relevant to every arm of the State. While many Departments did not have a policy in relation to dying, death and bereavement, almost all were engaged in activities or had developed protocols and practices in response to the recognised needs of people facing dying, death and bereavement.

It was also understandable that Departments do not have policies on end of life as the State itself has no overarching strategy. End of life is corralled into health strategies covering palliative care, dementia, carers and older people. Therefore, it is natural that people defer to the Department of Health on issues around dying, death and bereavement.

Yet people who experience death are citizens and will be attending school as a pupil or teacher; they will be at work; they are family members; they will live in homes that need adaptation as their illness progresses; they will need transportation to live and socialise and get to health appointments; they may be compelled to apply for income supports to cover their growing medical and living expenses......

In most cases, they will approach the State for support. The State cannot be found wanting at the most humane and fragile time of its citizens lives, when they have a right to integration of services and an expectation of contentment.

The primary recommendation in this report is that the State should develop a whole-of-Government strategy on end-of-life-care which is wider than healthcare and extends into bereavement.

We count people into our world. We count them out. We support our citizens every step along their life course from birth to education, to work to retirement. The State’s responsibility to its people does not expire with a person's last breath. It should extend into respecting their remains and caring for the people they leave behind.

While death is a significant personal event in the life of an individual and their family, it is also a process. A person may become ill suddenly or gradually and need engagement with a range of services. The State must ensure that it has made appropriate provisions for the dying, the dead and the bereaved in whatever circumstances the death occurs.
Conduct a National Dialogue on End of Life Issues

The State must engage in a consultation process which will inform the new Strategy. There is much to learn about end of life. The National Council of the Forum on End of Life in Ireland and its work programme developed out of a public consultation process in 2009/2010. The All Ireland Institute of Hospice and Palliative Care has developed an innovative consultation programme with people using hospice and palliative care services. Most recently, the Irish Hospice Foundation (IHF) was engaged in a public consultation to develop a Charter on End of Life.

The State should engage in a listening exercise to learn about people’s direct experience of end of life or their expectations for that period in their life. Therefore, public meetings and national workshops should form part of any process of consultation.

The views of people who could unfortunately be overlooked in any process such as people living with dementia, residents of nursing homes, migrants and refugees, should be included as well as the views of the ordinary and everyday citizen.

An inter-departmental committee should be tasked to develop a Strategy and its related elements – a review of services and a consultation process – and report directly to the Taoiseach.

Conduct a Socio-Economic Review of Costs Linked to End of Life

We do not know the socio-economic costs of dying, death and bereavement in Ireland. Yet death and bereavement is a universal experience and the State plays a key role in supporting people during this vulnerable time. It is believed that about 10% of a healthcare budget alone is spent on caring for people at end of life. This would amount to €1.4bn annually for the Irish health service. The motivation in recommending a
There is a need for a website which will provide a comprehensive outline of all State services that are available to support people at end of life. It can be a stressful period in the life of an individual and their family. The State should not add to this burden. But not being able to access timely and accurate information at this crucial time can add to distress. The website could provide comprehensive and up to date information on the relevant services and supports offered by each Government Department. A multi-media approach should be adopted with the use of videos, audio and infographics to meet the information needs and learning styles of the entire population, particularly those with literacy issues. This website/portal should be hosted by the Department of the Taoiseach.

Each Department should review its activities and services from an end-of-life perspective and develop a plan to ensure it clearly communicates how it can support people at end of life. All civil service staff but particularly frontline officials should receive training in good communications, to ensure that people have a clear understanding of their rights and entitlements. A person should leave any interaction with the State feeling that they were heard and respected. The training should also include the skill of breaking bad news as officials may, on occasion, have to impart disappointing news about expected entitlements that are not due. Finally, each Department should also develop a Bereavement Policy and a range of supports for its own staff as recommended in the Finite Lives Report (1) on how the Civil Service deals with dying, death and bereavement among its own members.

socio-economic review is not to initiate some cost-cutting exercise but to ensure that the State develops the most appropriate, the most effective and naturally, the most efficient, supports and services for the dying, the dead and the bereaved. This review could be conducted by the National Economic and Social Council and include such wide ranging elements as fuel and funeral poverty.
REDUCE THE ADMINISTRATIVE BURDEN BY DEVELOPING A "CALL US ONCE" SERVICE AND A BEREAVEMENT SERVICE HELPLINE

The administrative burden on people who are newly bereaved can be happening particularly at a time when people are at their most fragile and are least able to cope. They may have to make multiple phone calls, emails or office visits to notify the relevant authorities when putting their affairs in order.

Communication initiatives that could reduce the administrative burden on individuals and their families could include the "Call Us Once" service and the bereavement services helpline that operates in the UK. The "Call Us Once" service allows a person to make a phone call on the death of a loved one and this information is disseminated to most government departments. A similar system should be considered for Ireland which would negate the need for relatives to make multiple calls with the same information to multiple Departments. A Bereavement Services helpline could inform people of the steps they need to take following a bereavement, as well as their rights and entitlements.

There is a lot of information available from a number of sources on death and bereavement. However, it is largely text based and it would be appropriate for the State to develop other ways of disseminating information such as videos or animation.

REVIEW INCOME SUPPORTS AND ALLOWANCES

The Government should review the income supports available to people who are bereaved as a result of the death of a spouse or partner. This review should also include an analysis of the telephone and fuel allowances with a view to increasing them.

Particular attention should be paid to the needs of young widows with children and those whose incomes have been reduced by the death of a spouse, partner or close family member. The review should look at anomalies and barriers thrown up in certain circumstances, such as when people are unmarried and have children and lose a partner.

Living alone is estimated to cost about 80% of what it costs a couple. The Living Alone Allowance is a weekly payment provided to people who are living alone and aged over 66. This should be increased to ensure that people who are older, and therefore in the final stage of life, can age well and later die with comfort and dignity.
SUPPORT PEOPLE TO LIVE AND DIE IN THE COMMUNITY

The Government is reviewing putting community care on a statutory footing. This is a welcome development. The crucial issues around quality standards and staff training should be as highly valued in the development of a statutory scheme as the financial implications. Our elderly population, particularly those at end of life, should enjoy access, as a right, to a multi-disciplinary team of professionals in the community. The Government must recognise that there are a myriad of supports outside health and social care, which are essential if people are to achieve their wish to live well and to die at home.

REINSTATE THE BEREAVEMENT GRANT

The Bereavement Grant should be reinstated. Compared to other social protection payments, it is a relatively small cost to the State, but it is an official recognition of a particularly difficult time in a person’s life. It recognises the psychology of a profound human loss which is a universal experience. It also acknowledges the significant financial expenses that many people face following a death, and helps to allay some of those costs.

FULLY COMMENCE THE ADVANCE DECISION MAKING (CAPACITY) ACT 2015

The Advance Decision Making (Capacity) Act 2015 is an important piece of legislation which promotes citizen autonomy. It must be speedily implemented in full and appropriately resourced. The Decision Support Service, located within the Mental Health Commission, is charged with raising public awareness of the new Act governing decision-making capacity. This will be a vital but challenging task which must be adequately resourced. This legislation underpins the right of citizens to make an Advanced Health Care Directive, and indeed other decisions.
ADOPT THINK AHEAD PLANNING TOOL AND ENCOURAGE PEOPLE TO PLAN AHEAD

The State should promote a dialogue around all aspects of end of life as part of its strategic development process. It should also encourage people to plan ahead. While Irish people claim to be happy to discuss end of life issues, they generally do not take practical steps to plan ahead. Therefore, the State should adopt the *Think Ahead* planning tool, adapt it as required, and make it available free of charge to every citizen. This initiative should be led by the Department of the Taoiseach. Developed by the Irish Hospice Foundation, *Think Ahead* allows people to make preparations for their future care and to put their affairs in order.

PROMOTE THE DEVELOPMENT OF PALLIATIVE CARE INTERNATIONALLY

Ireland has a strong record of service with the United Nations (UN) thanks to our diplomats, our peacekeepers, our humanitarian workers and our politicians. Ireland, along with Kenya, helped in the negotiation of the sustainable development goals which were adopted by the UN in September 2015. Ireland is to campaign for election to a non-permanent seat on the UN Security Council for the 2021-2022 term, and is on the International Labour Organisation’s governing body for its 2017-2020 term. The Government should use its global influence to support the development of hospice and palliative care services worldwide, and particularly the availability of essential palliative care medicines. It follows, of course, that Ireland’s palliative care services should be further developed.

DEVELOP QUALITY STANDARDS FOR BEREAVEMENT

There is currently no statutory policy or standards in relation to bereavement services in Ireland for adults or children. Not every bereaved person will need specialist support. But for those who do, they should be able to access a professional, qualitative, consistent and equitable service. The State should devise such a programme or support efforts that are already underway to ensure that all bereavement supports including counselling offers a consistently high standard of service.
Our schools play a crucial role in supporting children and families who are dealing with ill health, death and bereavement. Supporting a grieving child is a significant responsibility for any school and individual teacher. Many feel ill prepared for the role. The Department of Education and Skills should establish a Working Group involving teachers and civil society to look at this area. The group should define the role of the teacher in these circumstances, devise evidence-based guidelines and develop education and training programmes. Ideally, a module on bereavement should be a core part of the undergraduate curriculum within the teacher training programme. The role of the arts in promoting self expression particularly for grieving children should be central to any education programme. Education initiatives which are currently underway in childhood bereavement should be supported and integrated into any future Department programme.

The creative arts are an essential component of our humanity and enable communications in a myriad of ways. Their complexity enriches, enlivens, soothes, challenges, moves and comforts us throughout our life course. It is at the end of life and in bereavement perhaps that they come into sharp focus – allowing the expression of emotions, the externalising of thoughts and ideas, making connection rather than isolation, focussing identity rather than confusion.

Given those facts we must acknowledge that the arts are imaginative ways of seeing and of being and of expression and understanding. They matter because of their emotional powers, because creativity which is at their core is the ability to go beyond what is given, outside any boundaries.

They can be the greatest conduit and channel for the expression of grief and loss across end of life issues, creating platforms for understanding and withstanding, in relation to loss and grief.

The arts need to be given the status they deserve and they warrant. That means that they are given equal status with other subjects on the curriculum in our schools and colleges. That they are not seen as an add-on in education or in public policy.

It is vitally important that teachers are supported in specific training in arts and creativity around end of life issues and especially bereavement.
Over half of all deaths are reported to the Coroners Office. There is very little known about this essential State service even though it touches tens of thousands of people every year. In relation to the Coroners service, urgent action must be taken on three levels: legislation, structures and resourcing.

The Coroners Bill 2007 was originally introduced 10 years ago. However, the process of reviewing the service began in 1998. The Bill was written in 2005 and introduced to the Dail in 2007. It reached Committee stage in 2008 where it has remained. It is now outdated and is being reviewed.

The Bill must be updated to bring it into line with the Constitution and the European Convention on Human Rights. This has to be a priority as it concerns the lives of all our citizens.

When we consider that coroners speak for both the dead and the living, it is imperative that legislation is enacted which will give them the facility to do their job well, especially as their job touches the lives of so many citizens of our State, and touches them in such a unique way.
CHAPTER 1

Government Departments
Quantitative Research

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Government Departments Quantitative Research
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INTRODUCTION

The remit for this report was to examine the work of Government Departments in supporting citizens at end of life and in bereavement. The Department of Health was excluded from the report as it was conducting its own review. Therefore, 15 Government Departments along with the Office of Public Works and the Office of the Revenue Commissioners – 17 government bodies in total - were approached about the research. Each body was asked to fill out a questionnaire and the following section captures their activities and also proposes some recommendations for the future.

For each Department, the format is as follows:

- Photographs are produced to visually represent the work of the Department
- There is a summary of key recommendations for each Department
- The Department’s Mission statement is reproduced
- Background information is outlined
- The Department’s response to the questionnaire was reproduced but generally summarised
- Comments and recommendations conclude each section.

The background information on each Department is not definitive and simply provides an overview of its responsibilities and functions. It was relevant to understand the work of each body so that relevant recommendations could be proposed.

Each department took a different approach to the questionnaire from submitting multiple questionnaires from different units to focusing on one aspect of its work that was perhaps deemed particularly relevant. Only two departments answered that they did not have any involvement in end-of-life issues. In these two cases, background information was provided and recommendations were prepared which I would encourage them to study.

This section shows that while there is no overarching Government strategy on end-of-life care, some departments have recognised the needs of the ill and bereaved and organically developed services such as developing units and protocols around communication following a death. The research has found that the State is dealing with a range of end-of-life issues spanning the justice arena to taxation and academics. What is also interesting is the State’s response to these challenges and the issues that have been highlighted for the future.
RECOMMENDATIONS

- Promote humane succession planning with a particular emphasis on ensuring arrangements, including pensions, meet the future financial needs of the older farmer and their spouse.

- Encourage everyone involved in farming, fisheries and forestry to use a life planning tool such as Think Ahead.

- Implement the recommendations in the Seanad Public Consultation Committee Report on Farm Safety in 2015 with particular reference to:
  
  i) Assistance for bereaved families
  
  ii) Government co-funding of a Farm Safety Awareness Officer through the GAA
  
  iii) Grants for machinery adaptation for accident survivors with disabilities

- Train Department staff to identify and respond to elder abuse.
CHAPTER 1

BACKGROUND

Agri-food is the largest indigenous industry in Ireland employing 8.4% of the total working population and comprises of primary agriculture, food and beverage production, fisheries, fish processing, forestry and forestry outputs. FoodWise 2025 states: "Agri-Food is Ireland’s oldest and largest indigenous industry, deeply embedded in the landscape, history and personality of the country." Department of Agriculture Food and the Marine (DAFM, 2015)

There are about 139,600 farms in Ireland (DAFM, 2016a). The Teagasc National Farm survey has been published each year since 1972. Some 84,259 farms were represented by the 2015 survey which found the average farm income was €26,303 (Hennessy and Moran, 2016: 2). Some €17,168 was the average total direct payment in 2015. This represented 65% of income on average (ibid: 5). The southeast had the largest and most profitable farms while the Border had the lowest farm incomes (ibid: 7). Dairy farms were the most profitable farms (ibid: 3).

The DAFM’s Annual Review and Outlook for Agriculture Food and the Marine 2015/2016 reported that 75% of farmers and/or spouses had some source of off-farm income and more than one in four farmers was 65 years and older (2016b: 11-12).

A series of strategies have been developed to guide the agri-food business. Food Wise 2025 aims to increase exports by 85% to €19bn while the target of Harnessing our Ocean Wealth (2012) includes increasing the turnover from our ocean economy to exceed €6.4bn by 2020. In forestry, the Government is undertaking an intense afforestation programme.

The Programme for a Partnership Government (2016: 108) stated that farm families and rural communities must benefit from the positive economic and social change with the priority being to reward farmers for producing quality food.

Some 8,790 low income farmers – 6.3% of all farms – received Farm Assist in 2015 from the Department of Social Protection. Total expenditure on this means-tested scheme for farmers aged from 18 to 66 years was €88m. Some farmers also received the Rural Social Scheme. This is a supplementary income to farmers and fishermen/women who receive a social welfare payment, including Farm Assist. Under the scheme, participants work for 19.5 hours each week providing services beneficial to the local community (DAFM, 2016b: 27).
In its response, the DAFM stated that most of the issues it deals with relate to inheritance and particularly to financial issues including land/herd number transfers, outstanding payments, transfers of entitlements to Funds etc. The issue of farm safety was also an important area of relevance.

The Department has two units which support the bereaved – an Inheritance Enquiry Unit and the Quality Customer Service Unit. The Inheritance Enquiry Unit is a central point of contact for representatives of deceased farmers. It helps them to secure any outstanding payments due to the estate. It arranges, where it applies, for the transfer of Basic Payment entitlements or any other schemes in which the deceased took part. The unit is also a single repository for legal documentation submitted by representatives of the deceased and this removes the need to forward duplicate copies to several of the Department’s sections.

The DAFM’s publication *Schemes and Services* is an information booklet providing information on the Inheritance Enquiry Unit. The DAFM stated that the Department was committed to dealing with bereavement compassionately and it will temporarily adjust its requirements in such incidents. *The Farmers’ Charter* gives a commitment to reschedule farm inspections in the event of a family bereavement.

The Department’s Corporate Affairs Division provides a single point of contact in its Quality Customer Service Unit. It assists bereaved families who have a sudden loss due to a farm accident and who may not be experienced, in dealing with the daily issues that might bring them in touch with the Department on schemes and services. The Department said that every assistance was provided to make dealing with the Department as easy as possible.

On how the Department might engage in the future around these issues, it stated that it continually assesses its systems and would expand or adapt services in line with best practice and feedback from customer consultation.

The DAFM added that it works with relevant public sector organisations on farm safety and provides farm safety information on its website. It referenced its Farm Safety Scheme which aims to improve safety standards by providing grant-aid for a number of specified investment items. It was also committed to participating in the Department of Health’s initiative “Connecting for Life” which is Ireland’s National Strategy for Suicide Prevention.

**COMMENTS AND RECOMMENDATIONS**

In its reply, the DAFM focused on its work in agriculture and areas such as support for the bereaved and farm safety. The existence of these specific units within the Department is very positive. Dying, death and bereavement are significant issues around agriculture which fatality figures reveal to be a dangerous place to work. Yet a family farm is not only a place of occupation but a home for families and children.

There are nearly 140,000 active farms in Ireland and between family members and employees, an estimated 400,000 people are exposed to health and safety risk on Irish
farms (Irish Farmers Association, 2015: 3). The recommendations in this report will focus on the issues around advance planning, training and support for the bereaved. While agriculture was the focus of the Department's response, fishing and forestry are also risky sectors in terms of fatal injuries and the recommendations will be relevant to them. According to the Health and Safety Authority (HSA), there were 21 farm deaths and three fishing related deaths in 2016. The Tit Bonhomme tragedy in Union Hall, Co Cork claimed the lives of five fishermen in 2012.

DEATH ON THE FARM

In a submission to the Seanad Public Consultation Committee on Farm Safety in 2015, the HSA stated that the rate of workplace fatalities in the total working population had almost halved over the past 25 years. But there has been no sustained drop in the rate of farm deaths.

Agriculture represents about 6% of the working population but consistently has the highest proportion of fatal incidents – generally between 35% and 45% of all annual workplace fatalities. Between 2005 and 2014, there were 193 farm fatalities (HSA, 2015:78). The HSA stated: “Put simply there is no significant reduction in fatality rates and you are almost 7 times more likely to die working on a farm in Ireland than in the general working population” (ibid).

Figures on the HSA website in April 2017 reveal that from 2007 to 2016, there were 197 deaths on Irish farms. Some 23 children died on farms during that time representing 12% of total fatalities.

“Summer time tends to bring the urban cousins onto farms during holiday periods and with little experience around machinery and farm animals this can be high risk to all. Likewise young lads not always from a farming background are employed by contractors during the silage season with little or no experience in the operation of silage gear some of which is large and powerful in the present day. We feel that it is unbelievable that young lads of 16 years are allowed take charge of huge high powered tractors with no prior experience or tuition.” (MIZEN ROVERS UNDERAGE GAA CLUB, GOLEEN CO CORK. SUBMISSION TO SEANAD COMMITTEE ON FARM SAFETY).

There is also gross under reporting of non-fatal incidents and injuries. Only 100 incidents on average are reported to the HSA each year. But Teagasc’s 2011 National Farm survey reported 2,459 injuries per 100,000 farms for 2010 - an increase of 35% on the previous survey in 2006. Some 95% of reported injuries needed medical treatment and of these, 49% required hospital inpatient care. (McNamara, 2012).

The Seanad Public Consultation Committee published a report on Farm Safety in 2015 following concern at the significant increase in farm related fatalities in 2014. In that year, there were 30 deaths on Irish farms. The report made a number of recommendations including actions to assist bereaved families. It stated (2015: 10): “the Committee was made aware of the considerable practical administrative and legal difficulties that may arise for farming families following a farm fatality”.
The Committee recommended that changes be made to banking arrangements to allow bereaved families to have access to the farm bank account, to enable the business to continue and to provide for the family. Life assurance cover, with no opt-out facility, should operate immediately when a farmer secures a mortgage from a bank and farmers should be made to prepare a will.

*Awareness raising, assessing compliance and enforcing minimum standards of workplace safety and health is extremely costly particularly in agriculture and the Authority’s capacity and that of other national competent authorities is reduced significantly due to the general economic climate.*

*It is essential that we develop a culture of safety and health in agriculture through a balanced mix of prevention and enforcement activities. Farmers deserve a quality of life where they are not continuously working ever longer hours, exposed to risks to life and limb and under ever greater pressure to make a basic living. Given the demographics of farming with aging farmers, the lack of training, the predominance of self-employed individuals, unfortunately an increase in the overall rates of fatalities, serious injury and ill-health among Irish and EU farmers may materialise if some major policy shifts are not undertaken.*” (The Health and Safety Authority Seanad Public Consultation Committee Report on Farm Safety).

Embrace FARM was founded in 2014 by Brian and Norma Rohan from Co Laois following the death of Brian’s father Liam in 2012. It provides a bereavement support group for farm families and organises an annual National Day of Remembrance for people affected by farm accidents. Speaking to the Committee, Brian Rohan highlighted the financial and legal issues facing widows when the main breadwinner dies. There can be complications in situations where a couple are not married or when a farm has debt but no will or life cover in place. Embrace FARM has highlighted these legacy issues through a “What’s Left Behind” video campaign.

Farm organisations are taking individual action with safety campaigns and are involved with the Farm Safety Partnership Advisory Committee which has a Farm Safety Action Plan. It is positive to see the steps that are being taken by stakeholders individually and collectively to tackle the issue of tragically high fatality rates on Irish farms. It seems clear that the issue is complicated and a multifaceted approach needs to be taken, including further education and training as well as behavioural change among farmers.

Action should be taken on the recommendations of the 2015 Seanad report to address the many financial and legal issues facing the bereaved. A planning tool such as *Think Ahead* should also be promoted widely in the agriculture, fisheries and forestry sectors to facilitate the storing and sharing of financial and administrative matters for the business.

Progress is needed on the recommendations in the Seanad report on safety including the appointment of a GAA national farm safety officer, and grants being made available to adapt tractors and other farm machinery for accident survivors.
The farming community – as with all citizens – should continue to be encouraged to plan ahead for all aspects of their lives particularly their financial affairs. Engaging in a process of communication around succession planning is vital for the farming community, when assets such as land is involved. A farmer may have no successor, there may be multiple children with an interest in a farming career, or relatives may have views on their entitlements.

The DAFM should promote succession planning with a particular emphasis on the need to ensure the avoidance of financial abuse of an older person. When a farm is being transferred to the next generation to avail of tax reliefs/concessions, adequate pension arrangements need to be in place to meet the future needs of the older person.

A balance must be struck between promoting the interests of the next generation of educated and innovative farmers, with the right of an older farmer to have his/her property structured in a way to provide for his or her future needs.

It is recommended that staff with the DAFM who are involved in this area should be trained on the issue of elder abuse and to recognise if farmers are making decisions under duress. In instances where pressure is identified, a protocol needs to be developed to support the individual involved.

COMMUNICATIONS

Generally, the HSA engages directly with those who have suffered bereavement. The HSA is represented on the board of directors of Embrace Farm. Since 2004, the HSA has a policy and procedure relating to its engagement with the bereaved. It provides information in the form of a bereavement pack. The Authority has organised training for staff to support them in their engagement with the bereaved and to help staff themselves. In its written submission to the Seanad, the HSA (2015:101) made the point:

“...almost unique to agriculture is the fact that those left behind following a fatal or very serious incident in agriculture (generally immediate family) have the added trauma of facing the machinery and/or location of these devastating events on a daily basis which can lead to other consequences.”

It is recommended that the information that is provided to families should be kept continually under review to ensure that the material is appropriate and meets their needs.

As this report was being finalised, the tragedy of deaths on the farm was again highlighted with the deaths of a four-year-old boy in an accident in Co Fermanagh on 6th April and of a Co Offaly farmer in his ‘80s the day before, on 5th April, in a farm accident involving a quad bike.

The HSA should continue to develop creative ways of getting the safety message across to all workers and their employers in Ireland but particularly in the high-risk agri-food sector. RTE, the national public service broadcaster, has a role to play in helping agencies to promote the safety message. Advertisements on farm and marine safety
were being broadcast in early 2017 and, in the public interest, RTE should promote the safety agenda across its programming.

Embrace FARM was set up to hold a rememberance service for those who died on Irish farms. The first national rememberance service took place in June 2014 in honour of those killed or seriously injured in accidents on the farm.

Speaking before the Seanad Committee, Brian Rohan (2015:158) stated:

“As families made contact to ask that their loved ones’ names be remembered at the service, many relayed quite harrowing stories of the practical fallout of farm fatalities which added to the awful emotional toll. The practical toll included financial legal issues particularly for widows.

Not only do they have to take over the farm, but their hardship is compounded by their bank accounts being frozen and the fact that they cannot provide an income for their families or pay bills on the farm, no matter how well the business is operating.

In some cases widows are completely new to the business of farming and have no knowledge of what to do on the farm or how to deal with the reams of paperwork.”
RECOMMENDATIONS

- Recognise and actively promote the importance of and the right to the arts and creativity around dying, death and bereavement, for people of all ages, and in all community and care environments.

- Fulfill the artistic and creative commitments promised in the Arts in Education Charter for all children in primary and secondary education.

- Develop a database of professionals who would be available to support individuals who wish to use the Irish language or other languages when putting their affairs in order.

- Implement the recommendations of the 2015 report of the Post Office Network Business Development Group.

- Adequately resource and enhance services in the community such as computer training and Meals on Wheels.
The Department of Arts, Heritage, Regional, Rural and Gaeltacht Affairs (DAHRRGA) spans a huge area of public life from the past to the present. It also has to handle some of the most pressing issues affecting a significant number of people who are living in rural parts of Ireland. It is responsible for the presentation and development of Ireland’s heritage, culture and creative arts. It is also tasked with promoting the Irish language and supporting the Gaeltacht and island communities. Since 2015, it has become responsible for promoting the development of Ireland’s rural and regional areas.

The Department was central in organising the acclaimed Ireland 2016 Centenary Programme to mark 100 years since the 1916 Rising. This was the largest commemorative programme in the history of the State. Commemorations in 2015 included the 100th anniversary of the Gallipoli campaign of April 1915 and the annual National Famine Commemoration in Newry in September 2015 - the first time that the commemoration took place in Northern Ireland.

The 2015 annual report highlighted that the country’s National Cultural Institutions saw a 13% rise in visitor numbers with over 4.5 million visitors (DAHRRGA 2016a: 8). A €9m investment scheme for arts and culture centres under Building on Recovery: Infrastructure and Capital investment 2016-2021 will allow the refurbishment and upgrade of facilities. The capital plan also committed to protecting Ireland’s natural heritage and investing in our cultural infrastructure - the National Cultural Institutions, Regional Arts and Cultural Centres.

In the Built and Natural Heritage, the National Landscape Strategy 2015-2025 was launched in 2015 while Ireland’s first national cultural policy Culture 2025 was launched in 2016.

The Irish film sector has enjoyed many successes in recent years with nominations in a number of categories in the 2016 and 2017 Academy Awards. The Irish short film “Stutterer” from Benjamin Cleary won the Oscar for Best Short Film in 2016. The UNESCO World Heritage Site, Skellig Michael, featured in “Star Wars: The Force Awakens” and its prominence in the film “helped reinforce Ireland’s world-class reputation as a film location” (ibid: 11).

In October 2015, it was announced that a major international exhibition celebrating the life and work of Nobel Laureate Seamus Heaney would be housed at the new Cultural and Heritage Centre in the Bank of Ireland’s College Green complex (ibid: 10). The Programme for a Partnership Government committed to revitalise rural Ireland. A Charter for Rural Ireland was launched in January 2016 as was the Department’s new
Realising our Rural Potential. Action Plan for Rural Development. The Plan was hailed by the Department as the “first ever whole-of-government strategy aimed at delivering real change for people living and working in rural Ireland”. The strategy pledges to create 135,000 new jobs by 2020, increase Foreign Direct Investment in regional areas by up to 40%, increase visitor numbers by 12% over three years and rejuvenate over 600 rural and regional towns. It is the intention of the DAHRGGA to work closely with Departments and agencies on an ongoing basis to ensure that progress is on track.

A new division has been established in the DAHRGGA to coordinate the implementation of the action plan across government and to service the monitoring committee that is being set up for this specific purpose. In relation to the arts, some key objectives include the establishment of culture teams and creativity hubs in an effort to enhance culture and creativity.

Meanwhile, in March 2017, the Department undertook a public consultation process on both the German Sparkassen model for the development of local public banks and a new model of community banking through the Post Office Network such as New Zealand’s Kiwibank model. In 2017, responsibility for the post office network returned to the Department of Communications, Climate Action and Environment.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

A questionnaire was distributed to all Departments in 2015. At that time, the Department of Arts, Heritage, Regional, Rural and Gaeltacht Affairs was called the Department of Arts, Heritage and the Gaeltacht. The Department was contacted in late 2016 in the light of the new title and responsibilities. The Department responded that while the Department’s title had changed there had been no change in the Department’s policy and practice on dying, death and bereavement.

The Department’s response to the questionnaire was that issues around dying, death and bereavement were not within its remit. Neither the Department nor its agencies engaged with the public or delivered services.

COMMENTS AND RECOMMENDATIONS

In its response, the Department stated that it had no policy remit in the areas of dying, death and bereavement. The Department does not have a direct mandate to deliver services to people who are at end of life or are bereaved. However, it does have an indirect role through the positive, transformative emotional and cognitive impact of all of the arts and creativity on the human condition and the sense of self throughout all our lives. But most especially for those facing serious illness, death or who are bereaved.

The Department itself in its Statement of Strategy sets out actions which it states will “enrich the quality of life in Ireland” by protecting and promoting our culture, arts, heritage and language (2016b: 1). It is assumed that this commitment to enrich quality of life extends to all life stages including end of life and bereavement.

Much of the work of the Department in recent years have been involved in commemorative events including the successful 1916 commemoration. All of the commemorations and remembrance events involve remembering and honouring the dead. Therefore, we can assert that the State helps to keep the memory of past generations, as a collective, alive.
Indeed, the dead can contribute to how we live today through the lessons we learn of how they lived, the values they espoused, the choices they made and ultimately how they died. This can be best expressed through music, dance, the visual arts, literature, poetry and drama.

One of the greatest examples of history, arts, creativity, imagination and indeed life, is our national necropolis – Glasnevin cemetery. The final home for our illustrious dead: patriots, presidents, writers, bishops, the poor and the gentry, musicians, and footballers, engineers, architects and builders, creators, poets, dramatists and military leaders, children, wives, soldiers, mothers and lovers. It is a place where we can stroll through and around lives lived, and now gone but which changed ours. It is also the home for living artists and sculptures, writers and photographers to exhibit their work. An artistic and creative space for the dead and for the living.

James Joyce, whose father is buried there, wrote of this 140 acre cemetery which houses one and a half million people of all denominations.

“How many?
All these here once
Walked around Dublin
Faithfully departed
As you are now
So once were we”

(James Joyce)

“The great thing about the arts is that they may centre death, but they transcend it by sheer joy, exuberance and transformation. That is why they are so important. They are actually vitalising.”

(REDMOND O’HANLON).

Creative Ireland is a five-year legacy programme which was launched following the success of the 2016 centenary. It places “creativity at the heart of public policy” (DAHHRGA, 2016c: 7). In its programme, it highlighted examples of arts and wellbeing including Design & Dignity which brings “high standards of art, design and architecture to end-of-life settings” (ibid: 17). This is a joint project between the Health Service Executive and the Irish Hospice Foundation. It was stated that the project “...is acknowledged as having extraordinarily positive outcomes for the dying, the bereaved and for hospital staff and carers” (ibid).

Meanwhile, the Heritage Council published booklets in 2006 and 2011 offering guidance on how communities can care for historic graveyards and churches. The Heritage Council (2011: 4) acknowledges:

“Our historical graveyards are places of intense human activity. Along with providing a resting place for our departed and a place of remembrance, graveyards are of immense heritage value as sites of archaeological and architectural interest, as wildlife habitats and as repositories of local genealogy, sculpture and art.”
The late Shane Mac Thomais, chief guide at Glasnevin Cemetery, was correct when he said:

“you will always find hope in a graveyard”.

The arts and creativity are always about hope.

With its new responsibilities in rural and regional affairs, the Department will have more direct involvement in managing services which will affect the quality of life of people who are seriously ill, dying or bereaved.

“The arts matter because they are about transformation. A safe place for ideas and for human elevation. A vision of what might be. An innovation and an imagination beyond what is given.”

(Redmond O’Hanlon).

The Department needs to be cognisant of its role and the role of the arts and creativity and imagination in end-of-life issues. It must be visionary in how it guides the arts and creativity in engaging with and reflecting the profundity of loss and bereavement that people face regardless of their age. The arts and the artist can intuit faultlines long before others intuit them. Because creativity is the ability to go beyond what is given.

Every known society understood the arts as central to the definition of who they were – and what they were, self-definition – the centre of action – healing - the core of individual distress – communal conflict with the other – negotiating change and of course human joy and human happiness. Agelessness. The arts also do not recognise or answer boundaries. They have given death, destruction, fractures and fractions and appalling grief a route to healing through playing, dancing, painting and imaginative expression that comes from somewhere deep in our souls. Daniel Barenboim’s West – East Divan orchestra is an example of this. Arab and Israeli on an orchestral platform without knives and death but with musical instruments creating something new together.

“I am an emotional, psychological and spiritual being. And it is the arts that is going to make me definitely feel better. My hearing, my touch, my taste, my sight and my thoughts. All of which are not being looked at or being addressed at all. They really are the things that make a difference. Not how I live my life day to day, or how I look forward or how I am going to be tomorrow”. (Margharita Solan).

Below are some recommendations which should be considered for the future.

**CREATIVE ARTS AND CULTURE**

There is a growing awareness of the value of arts and health. The Arts Council of Ireland published a five year Arts and Health. Policy and Strategy in 2010 which included a commitment to “strategically place Ireland at the forefront of international Arts and Health practice” (2010: 10). The Arts Council funded the development phase of the national art and health website www.artsandhealth.ie. This website was developed by
the Waterford Healing Arts Trust (WHAT) and Create, the national development agency for collaborative arts in social and community contexts.

The National Centre for Arts and Health at Tallaght Hospital promotes the benefits of arts and health. In 2009 WHAT opened the first arts and health Centre in the Republic of Ireland. An Arts and Health research cluster has been established at the University of Limerick to support collaborative research between arts and health disciplines.

Author of Out of Our Minds, Learning to be Creative, Ken Robinson, argues: “We may not be able to predict the future but creativity and the arts can help to shape it”.

The arts are generally used in specialist hospice care to support patients and their families. Our Lady’s Hospice & Care Services offer complementary and creative arts therapy through which: "...palliative care patients can experience physical, emotional, psychological and spiritual wellness, thereby enhancing their quality of life".

Daniel Leader in his new book The New Black – Morning, Melancholia and Depression – argues that the arts have a unique and essential role to play around the more complex area of profound grief and loss. He feels that the artists work is always a protest against such loss. The artists make something where nothing was before, and often makes it out of the mourning clothes of his own life. He cites communication and creativity as central to how we heal. It is the arts that can save us.

“Convincing people that arts buffer but also hugely educate, massively, is not easy. Actually in a way they are even more palatable and insulate. That is very important, because dying, death and bereavement are very difficult topics and you need to be part of a safe environment to be discussing them.”

(Sinead Dinneen).

The arts are also harnessed to support the bereaved. The 2016 workshop programme from the IHF featured a workshop entitled: Stop all the clocks! – How the creative arts can be helpful in bereavement support. The workshop brochure stated: “The creative arts (including poetry, art, music, dance, drama and ritual) can be great resources to people who are grieving. They can provide different ways of expressing grief which go beyond words and help people to tap in to their own creativity. At the same time, they can provide an enjoyable way of engaging with the grieving process” (IHF, 2015a:17).

Writing on art and grief, Neimeyer and Thompson (2014:3) stated:

“Grief, understood in human terms, has existed as long as humanity itself, standing as it does at the intersection of attachment and separation, of love and loss. And for nearly as long the anguish and hope uniquely associated with the death of members of the community have found expression in art, from Paleolithic cave paintings to ritual chants, music and dances across cultures, and from religious art in innumerable spiritual traditions to secular poetry and prose.”

The beneficial effects of the arts generally are widely acknowledged. Objective 1.4 of the National Positive Ageing Strategy (2013) commits to promote the development of opportunities for people of all ages to engage and participate in a range of activities
including arts and culture in their communities (ibid: 27).

To fulfil this objective, it highlighted the need to tackle barriers including lack of transportation, lack of venue and to provide supports to the community and voluntary sector to provide opportunities for participation (ibid: 51).

“Works of art share something very simple. They have been made and made usually out of an experience of loss or catastrophe. Our very exposure to this process can encourage us in turn to create, from keeping a journal to writing fiction or poetry or taking brush to canvas. Or simply to speak and think. Each person must invent a way to save himself or herself.” (Darian Leader).

Established in 1995 by Age & Opportunity, Bealtaine is Ireland’s national festival celebrating the arts and creativity as we age. It is the world’s first national celebration of creativity in older age. It brings together artists and people from all over the Ireland to: “support a rich creative life for all older people and support the work and careers of mature artists” (2017: 3). We know that participating in the arts enhancing our quality of life no matter what age we are. Bealtaine has grown to over 3,000 events involving 100,000 people in towns and villages throughout the country. The festival is run in May every year. This is an example of the extraordinary appetite for the arts both as audience and participants.

Meanwhile, the Arts in Education Charter (2012) commits to promote and integrate the arts in education. In the preface, then Ministers Jimmy Deenihan and Ruairi Quinn (2012: 3-4) stated:

“We believe creativity must be placed at the heart of our future as a society and a country. The arts are our first encounter with that rich world of creativity, and we believe in placing the arts, alongside other subjects, at the core of our education system.”

A highly regarded programme is the Pushkin Trust in Northern Ireland which supports creative learning and operates “a cross-curricular, cross-community and cross-border” Schools’ Programme. Creative writing is at the core of the programme which also integrates various creative art forms.

Realising our Rural Potential. The Action Plan for Rural Development (2017: 49) makes a commitment under Pillar 4 to foster culture and creativity in Rural Communities. It states: “Access to the arts, in all its forms, enriches society in many ways, including by improving the health and wellbeing of individuals”. Even when people are in failing physical health, the arts has a role to play in their psychological, spiritual, emotional wellbeing (ibid). There are 29 actions identified under Pillar 4 to promote access to the arts, enhance culture and creativity and promote the Irish language as a resource.

The actions – some captured in the Creative Ireland programme – include developing a national network of culture teams and creativity hubs to coordinate cultural activities in local authority areas as well as developing a national plan to enable every Irish child to access tuition in music, drama, art and coding (ibid: 50). In these initiatives, the needs of people at end of life of all ages as well as the bereaved should be a group to be given special consideration.
The premise of Culture 2025 is that everyone has the right to participate in the cultural life of the nation.” (2016d: 1). It also maintains that “a healthy cultural life is important for both the individual and society. It helps the individual achieve a more meaningful and happy life” (ibid: 6). Culture 2025 states that investment in our natural heritage sites “has a dual benefit of preserving our natural environment while also improving health, well-being and the local and national economy” (ibid: 12).

The National Landscape Strategy states that landscapes have a crucial bearing on quality of life. A study commissioned by the Heritage Council entitled Children and the Outdoors (2016) outlined the significant benefits for children including to their health and well-being of having contact with the outdoors and the environment.

Age Action (2014a) has raised the issue of “emotional poverty” and the isolation of older people particularly in rural areas. It is recommended that people, of all ages, who are at the end of their lives, but are able and willing to participate in cultural and creative undertakings should be facilitated to do so. Their creative efforts should be nurtured in their community and in their care setting.

Similarly, those who are bereaved – children, middle aged and older people - should be supported to use the arts to find new meaning in their loss. Loss and mourning have been the great motors of creative writing – not happiness. This is a golden opportunity for the dying and the bereaved.

“We cannot prescribe, but we can provide occasions and possibilities and art and creativity and artistry for people in the most awful life-limiting situations, when they most need it as individuals.”

(MARK PATRICK HEDERMAN).

IRISH LANGUAGE

In the 2016 census (CSO, 2017: 66), 1.76 million people said they speak Irish. Some 73,803 said they speak Irish every day - outside the education system- and another 111,473 speak the language each week.

As the Department responsible for promoting the Irish language, the DACHRRGA should ensure that all who interact with people who are at end of life communicate with that person in Irish if it is their preferred language. It is understood that some older Irish people with dementia may revert to their native language. Therefore, the Department should liaise with the Law Society, local bar associations and accountancy bodies to develop a list of professionals who have the ability to speak in Irish and can help individuals to put their affairs in order.

Under the Official Languages Act 2003, each government department is obliged to prepare an Irish Language Scheme detailing the current services it provides through Irish and developing a timeline for providing other services through Irish. There must be cohesion with the implementation of the 2003 Act to ensure that citizens can access services in the language of their choice.
"We have to approach our ageing creatively, finding new ways to age in place to be part of a community that encompasses us rather than isolates us, and which see in us the hidden wonders that can be shared across generations."

(PRESIDENT MICHAEL D. HIGGINS).

The report of the Commission for the Economic Development of Rural Areas (CEDRA) was published in 2014 and recommended action to secure the development of rural Ireland. It stated that the national population increased by 30% from 1991 to 2011. There was a 44% increase in the population living in the countrywide. Some 57% of the Irish population lives in areas outside of cities and towns.

Generally, rural areas close to main cities and larger towns saw population growth while rural areas which were less accessible to towns and cities experienced a population decline (CEDRA, 2014: 26). The 2016 census reported that the population of all provinces had grown but the change in population varied widely by county (CSO, 2017: 11). Donegal and Mayo experienced population falls and the population in nine other counties grew by less than 2% (ibid).

The government’s Realising our Rural Potential. Action Plan for Rural Development (2017) pledged to combat rural isolation by improving connectivity such as bringing high speed broadband and improving mobile phone access. The Department is responsible for ensuring that there are no local barriers and for identifying priority areas for the rollout of the National Broadband Plan.

Broadband is an essential resource to allow families affected by emigration to keep in touch. The Irish Longitudinal Study on Ageing (TILDA) report states that “the mental health of mothers suffered as a result of the emigration of their children” and older fathers showed greater loneliness because of their children emigrating (Mosca & Barrett, 2014: 19). A study in University College Cork found that at least one in four households in the most rural areas had experienced the emigration of at least one member since 2006 (Flynn, Kelly and MacÉinríi, 2013:11). The study also found that a family illness or death would “significantly influence” a decision to return home (ibid: 104).

It is important that a plan of action is developed to facilitate older people in rural areas to learn how to use and access computers. This would allow them to maintain contact with their children and grandchildren abroad. This is important when elderly parents come to the end of their lives and family members may not be able to return to Ireland to support them in their illness or for their funerals.

It is vital that the Government invests in services in rural Ireland particularly for our citizens of all ages who are coming to the end of their lives or are bereaved. A 2016 Irish Rural Link (IRL) report stated that poverty can be exacerbated in rural settings due to lack of services (2016a: 4). Using Census 2011 figures, the Central Statistics Office (2013) reported that older people in rural areas had a lower income than their urban counterparts. Social Transfers accounted for 70% of their income in 2011. From 2009 to 2011 the elderly groups with some of the highest at risk of poverty rates were those living in rural areas – 13% during this period. IRL also highlighted that people in rural areas including older people and people living alone in rural areas “suffer higher levels..."
of rural isolation than the general population (2016a: 21). IRL described community services such as Meals on Wheels and the Rural Transport Programme as “lifelines” for people who are isolated.

**COMMUNITY SERVICES**

It is noted that the Government’s plan for rural Ireland (2017: 22) has earmarked €435m for 90 projects in public nursing facilities and district and community hospitals up to 2021. This measure will create up to 5,000 construction jobs. There is, of course, a place for nursing homes in the caring infrastructure. But most people wish to be cared for and to die at home and these wishes are not being realised.

“We end up with institutions that address any number of societal goals – from freeing up hospital beds to taking burdens off families’ hands to coping with poverty among the elderly – but never the goal that matters to the people who reside in them: how to make life worth living when we’re weak and frail and can’t fend for ourselves anymore.” (Atul Gawande).

A collaborative research project undertaken by the Irish Association of Social Workers, Age Action Ireland, the Alzheimer Society of Ireland and the School of Social Policy, Social Work and Social Justice at University College Dublin found that the Health Service Executive is spending less on home support services today than in 2008. The report on the research stated: “Older people cannot access safe, compassionate, individualised and quality care when they need it” (Donnelly, O’Brien, Begley and Brennan, 2016: 5).

A working paper from the Rural Ageing Observatory at NUI Galways has stated that “fragmented and inadequate” home help and domiciliary care services in rural areas which are sparsely populated “may result in accelerated entry for some older people into residential care homes” (Connolly, Finn, O’Shea, 2012: 6). ALONE estimates that more than one third of older people currently in nursing home care could be given the choice to live independently if they had the proper supports (Moynihan: 2015b).

Older people should have a statutory entitlement to home care just as they are currently entitled to a nursing home bed under the Fair Deal scheme. Investing in community services is ultimately cheaper for the taxpayer and allows people to live and end their days in their own homes. ALONE estimated that home help three times a day was between €50 and €70 while the daily charge of an acute hospital bed cost up to €900 (Moynihan: 2015a).

The Department of Health is developing a statutory home care scheme for older people. An evidence review was published on 11th April 2017 to inform the regulation and financing of a new scheme. This is a welcome move. However, this will only be a positive move if we secure a high quality service for our vulnerable older people.

Significant attention must also be invested in determining the recruitment, the required qualifications and ongoing training needs of staff who will deliver home care. A key part of any training programme must be an identification of the needs and rights of people at end of life.
As we are planning this statutory scheme, we should look at extending it to our population groups including the middle aged and the young who are at end of life and wish to be cared for at home.

**POST OFFICES**

In relation to the wider rural infrastructure, the fate of the post office network has been the topic of much commentary and reports. It appears that hundreds of post offices are destined for closure (McCaughren, 2017). It is positive to see the consultation process for a new model of community banking through the Post Office Network. It is important the recommendations of the report of the Post Office Network Business Development Group (2015) are implemented to ensure the survival of as many offices in the network as possible as they play a key role in the social fabric of rural Ireland. See the Department of Communication. Climate Action and Environment for further discussion.

“The post office is the oldest franchise in the world. I am talking about the mail service and the postal service. Either we put up our prices dramatically or we reduce services dramatically. They are the only two solutions. There is not another solution. And I am saying don’t reduce services. It is too important a service.”

(David McDredmond).
RECOMMENDATIONS

- Put supports in place to equip and sustain the natural network of a bereaved child: parent(s), teachers, sports coaches, youth workers etc.

- Ensure sustainable funding for organisations such as the Irish Childhood Bereavement Network, to allow them to support bereaved children and their parents, teachers and community.

- Increase Tusla’s bereavement counselling budget and ensure there are enough counsellors trained in bereavement care.

- Integrate childhood bereavement into the undergraduate studies and Continued Professional Development courses of key professionals, including teachers and general practitioners.

- Prioritise supports for children and young people who are caring for a loved one who is approaching the end of life, and support them following the death.

- Review the financial supports provided by the State to families with young children who lose the main breadwinner.
BACKGROUND

According to the 2016 census there were 1,190,502 children under the age of 18 and 1,528,389 under the age of 24 years in Ireland. A European study found that in 2014, Ireland recorded the largest proportion of children aged under 15 in the EU Member States, with 22% of the total population under 15 years that year (Eurostat, 2015: 2).

*Better Outcomes, Brighter Futures. The national policy framework for children and young people 2014 – 2020* is the national policy framework for children and young people aged from 0 to 24 years. It outlines some of the challenges facing Irish children: 15-20% showing significant levels of emotional or behavioural problems; 13% of traveller children not completing secondary school and 21,000 child welfare and 19,000 child abuse referrals to Tusla each year (2015: ix).

Central Statistics Office (CSO) figures in 2015 show that 205 children died under the age of one and 157 children aged from 1 to 19 years. An estimated 3,840 children have a life-limiting condition (Breen, 2015).

*Better Outcomes, Brighter Futures* has five national outcomes. Outcome 3 “Safe and protected from harm” has a number of aims. The framework (2014: 77) states that most cases of injury and death in children and young people were avoidable accidents occurring “in the home, on the farm or on the roads.” Aim 3.1 is to have “a secure, stable and caring home environment”. The aim acknowledges the importance of recognising “life consequences of trauma experienced by children” and specifically mentions bereavement (ibid).

The Department was set up in June 2011 to develop a unified framework of policy, legislation and service provision for children and young people across Government.

The Department’s vision is:

“For Ireland to be one of the best small countries in the world in which to grow up and raise a family, where the rights of all children and young people are respected, protected and fulfilled; where their voices are heard; and where they are supported to realise their maximum potential now and in the future.”

A number of strategies have been produced in recent years particularly the *National Policy Framework for Children and Young People 2014-2020 – Better Outcomes, Brighter Futures*. Among the aims are to lift over 70,000 children out of consistent poverty by 2020 and create a culture that listens to and involves children and young people. A *National Youth Strategy* was published in October 2015 which sets out the aims for young people aged 10 to 24 years. In June 2015, the *National Strategy on Children*
and Young People’s Participation in Decision Making 2015-2019 – the first of its kind in Europe - was unveiled.

The Department’s annual report for 2015 shows that laws were passed to stop sending children to adult prisons and the Children First Act 2015 was enacted. Three commissioners were announced to lead the Commission of Investigation into Mother and Baby Homes. Other appointments included that of Dr Niall Muldoon, the New Ombudsman for Children, who was appointed in February 2015. The Supreme Court upheld the result of the 31st Amendment to the Constitution and a commencement order was signed to remove the defence of “reasonable chastisement” in the case of corporal punishment of a child.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

In its response to the question about what issues around dying, death and bereavement were identified in its policy work, the Department stated that the National Review Panel reviews cases where “children who are in the care of the State or in aftercare, or have been known to the child protection services, die or experience serious incidents”. The function, it stated, is to determine the quality of service provided before the death or serious incident. A major function is also “the identification of learning points” which may positively influence the quality of practice.

On the Department’s engagement with the public and how it delivers services, it stated that Tusla, the Child and Family Agency, fell under its remit. It offer support through its Family Support Services when a child dies who has been in the care of the state or in aftercare, or has been known to its child protection services.

Counselling services for the bereaved –directly by Tusla or commissioned by Tusla - can be provided. It explained that the total budget for the counselling grant scheme – covering marriage, child and bereavement counselling - was €5.8m in 2015. As part of the scheme, bereavement counselling funding in 2015 was €930,450. A total of €235,000 was awarded to Rainbows Ireland for the provision of Rainbows groups in schools. Rainbow focuses on children who have been bereaved or experienced parental separation. The counselling grant scheme was open to voluntary organisations offering counselling and support. Some 541 groups were funded in 2006. This was reduced to 330 in 2015. Some €9m was allocated to counselling in 2006. In 2015, the figure was €5.85m. “Progressive cuts” were made to counselling organisations from 2012 to 2014 in line with the Government’s Comprehensive Review of Expenditure in 2011.

A total of 47 people were interviewed by the National Review Panel in 2014 comprising 15 family members of foster carers of the children whose cases were under review and 32 staff of Tusla or other agencies.

On future engagement on dying, death and bereavement, the Department wrote that Tusla is to move from a grant-giving approach to a commissioning approach for services. The National Strategy on Children and Young People’s Participation in Decision-Making (2015-2020) includes a cross-government commitment that departments and agencies will consult with children and young people appropriately in development of policy, legislation, research and services. This commitment would apply to any policy, legislation, research or services provided to or relevant to children and young people in the areas of dying, death and bereavement. Support will be provided through the Department’s Participation Hub.
**COMMENTS AND RECOMMENDATIONS**

“Grief fills the room up of my absent child,
Lies in his bed, walks up and down with me,
Puts on his pretty looks, repeats his words,
Remembers me of all his gracious parts,
Then have I reason to be fond of grief?
Fare you well: had you such a loss as I
I could give better comfort than you do.”

**CONSTANCE, KING JOHN, SHAKESPEARE**

**INCREASE TUSLA FUNDING**

Both the number of organisations offering counselling and support (wider than bereavement) and the funding provided has fallen significantly by over €3m in the 10 years from 2006 to 2015. The Department explained that “progressive cuts” were made in line with government policy. However, we are now emerging out of the financial crisis. It is understandable that State funding is rigorously policed and what matters most is not the number of organisations providing a service but the quality of the service. However, it is recommended that the budget for bereavement counselling following a death should be increased. The Department pointed out that its scheme of grants for counselling services ensured that counselling was available to those who could not otherwise afford it. This is a service that is not only needed by vulnerable people but it could make long-term savings for the State. A child provided with appropriate counselling may not require more expensive intervention at a later stage in their life. Early intervention will also ensure that their life chances are not compromised. An ESRI report (2010) found that “high-impact personal issues, such as bereavement” could trigger early school leaving.

It is also essential that the Department ensures that counsellors are properly trained in bereavement care and have procedures and protocols in place to confirm their bereavement service for children operates to standards of best practice.

**NATIONAL REVIEW PANEL**

The Department referenced the work of the National Review Panel (NRP) in its response to this report. The 2014 annual report of the NRP reported that it had been notified of 103 deaths from the time of its establishment in late 2010 to the end of 2014. In its overview of learning points from NRP reports, the 2014 annual report highlighted the area of bereavement. It noted that it was not always the case that Children and Family Services offered support to families after the death of a child or young person. Some staff in different services only learned of a death when contacted by the NRP. The reports on these cases suggested that there should be an immediate offer of sympathy and support following a death even if contact with the family had stopped or relationships had been difficult. Efforts should be made to contact staff members who worked with the child or young person to inform them about the death (NRP, 2015: 12). This report supports this suggested protocol.
MAKING CHILDHOOD BEREAVEMENT EVERYONE’S BUSINESS

The Growing Up in Ireland. National Longitudinal Study of Children (2009: 81) found that 78% of nine-year-olds had experienced "some form of stressful life event". The most common events included loss of a close family member (43%). The serious illness or injury of a family member was experienced by 13% of the children. There are no official figures for childhood bereavement in Ireland. According to the Irish Childhood Bereavement Network (ICBN), between 36,000 and 60,000 Irish children could have experienced a significant bereavement. The ICBN states: “Population studies show long-term physical and mental health implications well into older adulthood for those bereaved of a parent in childhood” (2016: 5).

In addition to the Irish children who have experienced bereavement, there are an estimated 1,400 refugee children who are in direct provision who may have experienced trauma such as the death of a loved one. In addition to bereaved children, there are 3,840 Irish children living with life-limiting conditions. This is almost three times the previous estimate (Breen, 2015).

Speaking before the Joint Oireachtas Committee on Health and Children in 2013, Brid Carroll, Chair of the ICBN, explained the impact of a death on a child saying:

“A child who is bereaved in childhood is bereaved for life. Every milestone of his or her life, including the transitions of First Holy Communion, Confirmation, changing school, going to college, getting a job, getting married and having children, will have the shadow of the loss of childhood hanging over it.” (2013a: 7).

A report commissioned by the Irish Hospice Foundation (IHF) and funded by the Family Support Agency noted a lack of emphasis in government policy on children’s bereavement. There was an inequity and fragmentation of services particularly outside Dublin. The report also mentioned long waiting lists for children with complex needs (McLoughlin, 2012a: 12).

Experts in child bereavement generally agree on what grieving children need including information, encouragement to speak about their feelings and access to support. As adults and their peers may be unsure how to support a bereaved child, many children report that they have no one to talk to (McLoughlin, 2012b: 3). There is also limited formal support services for children and a need for more community awareness of the impact bereavement can have on children and how to support them (ibid: 4).

Events such as the ICBN’s National Bereaved Children’s Awareness Day in 2015 and Bereaved Children’s Week in 2016 are important and these national campaigns should receive appropriate State funding to ensure that their messages reach as many people as possible. Organisations such as the ICBN should receive sustainable and ongoing State funding to allow them to support children and their parents, teachers and community.

BEREAVEMENT INCLUDED IN PROFESSIONAL DEVELOPMENT

The key messages for Bereaved Children’s Week in 2016 included the fact that “Bereaved children protect the adults in their lives”. While grieving children may protect adults, it is understood that one trusted adult can make a huge difference to a child who is faced with a significant life event such as a bereavement.
It is recommended that all professionals who have contact with bereaved children from doctors to teachers should have an understanding of childhood bereavement and use the valuable material that is being produced by organisations such as the ICBN.

Professor Sir Al Aynsley-Green, the UK’s first Children’s Commissioner and former President of the British Medical Association, has spoken about children as “hidden mourners” and stated that childhood bereavement was not just an issue for health services but should be “everybody’s business” (ehospice, 2016). It is recommended that childhood bereavement is integrated as modules into both the undergraduate studies and Continued Professional Development courses of key professionals including teachers and general practitioners.

It is recommended that the Department should take the lead and work with other Departments to put supports in place to equip and sustain the natural network of a bereaved child: parent(s), teachers, sports coaches, youth workers etc.

BEREAVEMENT AS CORE PART OF UNDERGRADUATE STUDIES FOR TEACHERS

When parents are consumed with their own grief following the death of a child, or if a surviving parent is struggling to manage after the death of a spouse, the school offers continuity and an individual teacher can offer the vital comfort and support that a child needs.

The central role of the school is recognised by the ICBN (2013) which stated:

“The view of the ICBN is that particular emphasis should be focussed on schools. Given that bereavement occurs in a family context, and that the family can be undermined just at the time when it needs to be most supportive to children, school takes on a significant role in providing a predictable, stable and understanding environment.”

In an article about how guidance counsellors can help grieving students, O’Brien and McGuckin (2013: 4) wrote:

“If we seek a brave new world for these brave new children we also need to provide help and support for the trials and tribulations of their lives. One notable experience that has the potential to have long-lasting educational, psychological, and health effects is that of bereavement.”

A number of resources have been produced by the Department of Education and Skills to support students generally. These include the Well-Being guidelines for primary and post primary students, Student Support Teams in Post-Primary Schools, the Friends for Life programme in primary schools and the Continuum of Support framework developed by NEPS.

There is a need for additional resources and more of a focus on teacher competencies. The training of teachers is important, and it needs to be done in a processed based way
so that the teachers can go back in to their classrooms, and deliver on the training they have received. This has to be done by both the school and the management of the school. Teachers who are trained about bereavement need to be facilitated to use their training.

Teachers should be educated during their undergraduate courses on bereavement, its impact on children and their role in supporting children. The ICBN’s *Childhood Bereavement in Ireland – Factsheet* explains that children’s grief can be “intermittent and intense but can also pass quickly”. It states that a child’s grief is often unrecognised as they tend to protect parents from their pain. Children’s grief also affects them at milestone times such as going to a new school and they might revisit their loss at different points in their development. It is crucial that teachers learn about bereavement and young people so that they can support them in the classroom.

In addition to their undergraduate education, teachers must be given the resources they need by principals and school boards of management to attend any training they require on bereavement. They also need to be supported as they care for a grieving child in their classroom. Teachers should be made aware of resources such as the ICBN’s Teacher Toolkit which was launched in 2015.

### BEREAVEMENT HELPLINE

The children’s charity Barnardos has a Children’s Bereavement service which includes operating a Bereavement Helpline service. Members of the public can telephone 01-4732110 for information and support from trained volunteers. This is a limited daily service. It currently operates for two hours (10am-12pm) and for four days (Monday to Thursday) each week. It is important that people who have concerns about a grieving child can access a range of supports including a helpline. In 2015 Tusla funded about 55% of Barnardo’s work with children and families. It is recommended that the Government should review and expand its contribution to the cost of the helpline so that it has sustainable funding and can extend its operation. The funding allocated should also cover a public awareness campaign so that all significant adults in a child’s life, including teachers, are aware of the helpline.

### MORE PSYCHOLOGISTS

The Department should support the recruitment of more psychologists for the National Educational Psychological Service (NEPS). This service operates on a systems level with NEPS supporting schools in managing critical incidents. It is recommended that NEPS should work with schools to develop bereavement policies for staff and students. The interviews conducted for this study indicated the standard, quality and professionalism of NEPS. See the Department of Education and Skills for further discussion.

### YOUNG CARERS

The 2011 census figures put the number of carers under the age of 15 years at 4,228. In terms of hours of caring, the CSO reported that the 2011 census found that children aged nine years and younger provided 13,738 hours of care while children in the 10 to 14 age bracket provided 24,758 caring hours. Most of the daily caring took place over less than two hours.
A study by the National University of Ireland, Galway stated that 11.5% of 10-17 year olds reported that they were a carer (Callaghan, Keane and Molcho, 2016: 2). In its 2017 pre-budget submission, Family Carers Ireland (FCI) stated that “Extrapolation from the sample to the national population would suggest that some 56,118 young people in the 10-17 year age-group alone provide regular unpaid care” (FCI, 2016: 6).

The National Carers’ Strategy (2012) acknowledged the role of young carers and the fact that “this role can have adverse impacts on their social, educational, emotional and health needs; and on their future life opportunities” (2012: 5). Objective 2.2 of National Goal 2 of the strategy specifically pledged to support young carers.

The first national qualitative study of young carers in Ireland was conducted for the Office of the Minister for Children and Youth Affairs. Published in 2010, the study was carried out by the Child and Family Research Centre at NUI Galway among 26 young carers and 30 agency workers in statutory and non-statutory sectors. It found that caring began at a very young age. While some children and young people were primary carers, others were helpers. In many cases, the care provided involved intimate care and general care (Child & Family Research Center 2010: 8).

The report (2010: 8) stated:

“Although there are many positive impacts of caring, and although it is not the case that all or even most caring is ‘inappropriate,’ negative impacts can be serious and require a concerted response in terms of policy, legislation and service provision.”

Agency staff who were interviewed in the study suggested that “young carers may have behavioural or psychological problems if their caring role is not properly managed” (2010: 14). The report made a number of recommendations including that a “proactive approach” be taken to identify carers in households with known care needs and referral pathways be developed to refer young carers to other support (ibid).

In the eighth report of the Special Rapporteur on Child Protection, Dr Geoffrey Shannon made a number of recommendations on young carers. A key initiative Dr Shannon (2015: 101) recommended was the development of “a clear, positive statement of the rights, value and importance of (heretofore largely unheralded) young carers in society”.

This report recommends that more research is conducted into the lives of our young carers particularly those who are caring for a family member with a life-limiting condition. Any child or young person who is caring for a relative who is approaching the end of life should have priority access to advice and support from the State and this support should continue following the death.

PARENTING AND FAMILY SUPPORT

The Department produced High-Level Policy Statement on Supporting Parents and Families in 2015 which acknowledged the key role of parents in the healthy development of their children.

While not specifically mentioned in the Statement, it is crucial that parents are supported to care and rear their children following a family bereavement and have access to supports they need to fulfil their role. The work of the ICBN and organisations such as
Anam Cara and Rainbows are vital in this regard and should either receive State funding or where funding is currently in place, it should be reviewed to see that it is adequate.

"My father died suddenly when I was ten. He went out one Saturday afternoon with his three friends and never came back. I never said goodbye to him." (MARY PAULA WALSH).

In the year 2014, psychotherapist and co-founder of Turning Point, the late Mary Paula Walsh, published Helping Your Child Through Bereavement and urged parents to “take good care of yourself before, and while attending to your child” (2014: 32). She noted that in a bereavement, children can be “both a worry and a life-saver” and “If you are grieving well and dealing and coping with all that death entails, your children will almost certainly come through the experience – changed irrevocably of course – but not scarred or damaged. In 2000 she published her book Living After a Death. A Guide for the Bereaved. She was a forerunner in Ireland for psychotherapeutic counselling for both adults and children.

Therefore, it is vital that a range of supports are put in place which could range from the State funding a stock of bereavement books in every public and school library; funding bereavement support groups and securing the availability of qualified and quality counselling services to support parents to manage their own grief and to meet the needs of their bereaved children.

"It is not just the loss of your child now, it is the loss of your future with that child. So all the milestones, first communion, confirmation, twenty-first, college, getting married, seeing their friends getting married, is ongoing. It is the loss of the future. So it is a very complex loss.” (SHARON VARD).

The Department should also look at the links between bereavement and poverty in Ireland. The UK’s Childhood Bereavement Network (2014: 2) highlighted that children in poverty are “more likely to be bereaved” and bereavement is “a route into child poverty”. It has also raised awareness of the fact that bereavement has “particularly harmful effects for disadvantaged children” and childhood bereavement increases the risk of adult poverty.

The Irish children’s strategy aims to promote secure stable and caring home environments for children. It recognises the “life consequences” of traumatic events such as bereavement on children (DCYA, 201: 126). It is recommended that the State reviews the supports it offers to bereaved parents including income supports and access to counselling or other supportive services to enable them to support their children.

Gordon Livingstone observed after losing his six year son to leukaemia: “Perhaps that is how it is with a permanent loss. You examine it from every angle you can think of and then just carry it like a weight. Just beneath the anger is my bottomless sadness that the one person who loved without reservation is gone” (Leader, 2008). This bottomless sadness is also extended to grandparents, who are mourning the loss for their child and their child’s child.
RECOMMENDATIONS

- Ensure that the Sustainable Energy Authority of Ireland fast track the applications of people who are diagnosed with life-limiting conditions.

- Investigate the use of the UK’s “Tell Us Once” service with a view to developing a similar service.

- Implement the recommendations of the report of the Post Office Network Business Development Group as the interaction with the post office staff can be a lifeline for people in challenging circumstances, such as serious ill health and bereavement.

- Recognise that broadband is not simply a commercial tool, but has societal benefits in allowing people to access information, and take this into account when prioritising development.

- Develop an awareness campaign around people’s digital estate should they become incapacitated or die.
BACKGROUND
At the time that this research began, the Department was called the Department for Communications, Energy and Natural Resources. On 23rd July 2016, following the general election, it acquired a new name and new functions. The environment function from the previous Department of Environment, Community and Local Government was transferred to the renamed Department for Communications, Climate Action and the Environment (DCCAE). The core responsibilities remain and include the management of developments in communications such as An Post and the post office network and the media including public service broadcasting, managing the roll out of broadband infrastructure countrywide and facilitating digital training for citizens. The Department also works to promote energy efficiency and to protect Ireland’s natural environment.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT
In its response, the department noted that “in some areas issues are avoided by not addressing mail to individuals, but getting it delivered to households/residents and unaddressed”.

When An Post is alerted to the fact that the occupier of an address has died, no correspondence is sent in that person’s name. Future correspondence is mailed to “the occupant” until the An Post is informed of the name of the new person living at the address. For rural unique addresses and to identify the house in which to send correspondence, the name is recorded as the “previous resident of Mr Joe Bloggs.” This prevents having duplicate records on the database for the name address.

An Post learns of a death in a number of ways. A family member may notify the television license records office. In the case of most non-free lifetime licences, An Post would be informed only after a reminder notice or a mail shot has gone out and a family member has contacted them. If there is no one living in the house, the postperson will return the letter endorsed “deceased”. The Department of Social Protection sends An Post a list each month of “deceased termination”. Each month, they will get one or two returns from the bank followed endorsed “Deceased Debtor”.

DEPARTMENT OF COMMUNICATIONS, CLIMATE ACTION AND ENVIRONMENT
Our mission is support economic and social progress and help the country reach its full potential by:

- facilitating the development of communications and energy infrastructure and markets;
- Leading the national transition to a sustainable, low-carbon, resource-efficient economy;
- Protecting and improving our high-quality natural environment;
- Ensuring the sustainable and productive use of our natural resources; and
- Promoting the development of the public and private broadcasting sectors.
The Sustainable Energy Authority of Ireland conducts mass communications via the Department of Social Protection (DSP). To promote the availability of the “Warmer Homes Scheme” to people in energy poverty, it will occasionally do limited mail drops – usually in one county – to people receiving the fuel allowance. It relies on the Department of Social Protection to have appropriate safeguards in place to ensure an up-to-date fuel allowance database.

The SEAI audits a sample of grant recipients under the “Better Energy Homes and Warmer Homes scheme” to ensure the quality of the work is satisfactory. Where a grant recipient has died before an inspection, the SEAI will only carry out the inspection when requested to do so by the next of kin.

In relation to future work, it was stated that the SEAI reported that reputation was extremely important to SEAI. It claimed that about one sixth of homes had received a Government supported energy efficiency intervention and the positive experience of these households was critical to encouraging others to make similar investments.

The SEAI said it was focusing on building a better consumer experience and “a respectful treatment of dying, death and bereavement will be a part of this.” The Department is working with the Department of Health and the Health Service Executive (HSE) on an energy efficiency scheme targeting people with acute respiratory and circulatory medical conditions who are living in poor quality homes. The scheme aims to demonstrate the health benefits of improving the energy efficiency of cold and damp homes. It stated “...But given the target demographic, an appropriate methodology for dealing with dying, death and bereavement among the participants will be a necessary part of the scheme.” The Steering Group developing the scheme would consult with the HSE and the Public Health Nurses who will be responsible for referring participants to the scheme “to determine how these issues are best handled”.

**COMMENTS AND RECOMMENDATIONS**

It is essential that every effort is made to ensure that information such as bills are not sent to the deceased. This can be distressing for the bereaved. While efforts are made between different arms of the state to ensure that databases were updated, vigilance is required in this area and new approaches should be investigated. The use of a system similar to the UK’s Tell Us Once service should be considered in Ireland. With the Tell Us Once service, a death can be reported by telephone or on-line and this information is communicated to most government organisations.

It is important that when schemes such as the Warmth and Wellbeing Scheme are being piloted and are therefore evolving, that up-to-date information is available to the public and the information available on mediums such as the website are accurate and accessible.

There is anecdotal evidence of long waiting times for the energy schemes and a heavy administrative and bureaucratic burden being placed on applicants for these schemes.
POST OFFICES

The network of 1,135 post offices are part of the fabric of our country particularly in rural Ireland (Post Office Network Business Development Group, 2016: 9). They serve about 1.7 million customers every week (ibid: 10). However, post offices are threatened by modern life and online activity. The ‘Hub’ concept which has been advocated by the Post Office Network Business Development Group is welcome. Under this proposal post offices could act as ‘hubs’ around which local social and economic activity would evolve” (ibid: 7). They could allow people to access State and commercial services. The report noted that given the age and income of many post office customers, the services offered by the post offices “allow people to fully participate in modern society”. The report also stated that many customers had limited or no internet access and the Post Office “may be a focal point for weekly face-to-face interaction and communication” (ibid: 11).

This report agrees that these social relationships can be a lifeline for people particularly those of us who are living with ill health, facing death or coming to terms with a bereavement. As this report was being finalised, the fate of hundreds of post offices were under threat.

ENERGY POVERTY

The 2016 census found that 23,174 homes did not have central heating (CSO, 2017: 81). Energy poverty has been defined as an inability to heat or power a home to an adequate degree (DCENR, 2016: 8). A household that spends more than 10% of their income on energy is considered to be in energy poverty. As many as 28% of Irish households could be living in energy poverty (ibid: 3). There is a high percentage of households in fuel or energy poverty where a person is looking after someone at home or is unable to work due to permanent sickness/disability. The fuel poverty prevalence rate is also high among the unemployed and retired households (DCENR, 2015: 21).

“Fuel poverty is something that is becoming hidden now. One of our biggest client category was people who were in arrears with their electricity or gas bills and were subject to disconnection. But now we have metering. So the fuel poverty has become hidden. And if you don’t have the money you can’t feed the meter. So we don’t know how many people are sitting in the cold. People have pride.”

(MICHAEL CULLOTY).

The roll out of a three year €20m pilot programme in 2016 addressing energy poverty as a public health issue is welcome. This Warmth and Wellbeing Scheme was developed by the DCCAE in cooperation with the Department of Health (Naughten, 2016). It is being operated by the SEAI and the HSE and is being rolled out from 2016 to 2018. The pilot is for people over the age of 55 or under the age of 12 who have chronic respiratory disease (i.e. Chronic Obstructive Pulmonary Disease or asthma) and are living in the Dublin 8, 10, 12, 22 and 24 areas. Under this means-tested scheme, a member of the household must be in receipt of fuel allowance or receiving the One-Parent Family payment. The home must be owner-occupied or rented from a local authority/approved housing association. The applicant must be referred to the scheme by a HSE official.
Some €4m was to be spent on the pilot in 2016. The scheme is to be evaluated by the London School of Hygiene and Tropical Medicine (Naughten, 2017).

Figures provided by the HSE on 21st April 2017 showed that there had been a total of 896 referrals to the scheme and 422 completed referrals had been sent to the SEAI. Some 147 had been assessed by the SEAI. It is recommended that people who are at the end of their lives should be given priority consideration for inclusion in the pilot. It is inappropriate that people at the end of their lives should live in cold and damp conditions which itself could shorten their lives. We know from research that Irish people wish to die in comfort and dignity and pain free. There is no comfort and dignity in a cold house.

Age Action Ireland issued guidelines in January 2013 following a number of hypothermia deaths. Eamon Timmins, CEO of Age Action Ireland, stated:

"Between 1,500 and 2,000 excess deaths occur during the winter in Ireland, compared to the summer. Many of these are older people who die as a result of respiratory illness or cardiovascular disease. The cold weather, inadequate heating, low incomes and poorly insulated homes are contributory factors in some of these deaths."

A warm home is also, of course, not only essential, but a right for people who are undergoing treatment for any medical condition. Irish Cancer Society (ICS) research on the financial costs of cancer has found that cancer patients spend €140 each month on increased heating and electricity bills, as patients undergoing chemotherapy often feel the cold worse than people who are not going through treatment. The research conducted by Millward Brown in 2015 found that the average additional cost was €862 each month. Many patients faced extra monthly costs of up to €1,200 (ICS, 2015: 4). Some three quarters of cancer patients and their families faced hardship through more everyday household expenses with 55% experiencing higher heating and electricity bills (ibid: 11).


"There is a growing body of evidence that points to the specific debilitating consequences of energy poverty, not just of individuals but on society as a whole. Energy Poverty has links to excess winter mortality, to increased rates of cardiovascular and respiratory disease and increasingly, to overall states of mental health and wellbeing."

A report on housing conditions by The Irish Longitudinal Study on Ageing (TILDA) found that older people were more likely to live in older houses and people who lived in rural areas and were aged over 50, were more likely to live in an older house than their urban counterparts (Orr, Scarlett, Donoghue, McGarrigle, 2016: 7). More than half of adults experience some housing difficulties with damp/mould, structural issues and heating difficulties being the most commonly reported problems (ibid: 20). The report found lower reports of problems in modern housing, which it stated may reflect the improvements in building standards since the 1990s. Poor housing conditions are linked with poorer physical and mental health in middle aged and older Irish adults.
CHAPTER 1

FACILITATING A NATIONAL CONVERSATION

The media and national institutions such as RTE play a central role in Ireland in terms of reflecting, informing and challenging our society. Ireland has an aging population. It is important that older people and citizens at the end of their lives should see themselves and their concerns reflected over the national airwaves, or on our television screens.

The Society of St Vincent De Paul’s (SVDP) research (Walsh & Harvey, 2012: 9) with older people has found that loneliness was the “biggest individual problem” for older people who live alone. People in these circumstances or people who are facing the end of their lives are not as mobile and rely on the media for information and for entertainment. They are generally living within a fixed and limited income as they are pensioners. This could also be because of the expenses associated with ill health (ICS, 2015). It is vital that significant cultural and sports events in Irish life continue to be free to air under RTE’s Designation of Major events.

The media plays a key role in educating the public on topics of and in the public interest. Comedian Billy Connolly, who has been diagnosed with Prostate cancer and Parkinson’s Disease, explored the attitudes and customs around death for the two part documentary Big Send Off which was broadcast in Ireland on TV3/B3 in April and May 2017 as this report was being written. In 2014, RTE broadcast its month-long Once in a Lifetime season which explored aspects of death in Ireland today. The season started A Parting Gift on October 30th which was a two-part documentary on the body donation programme in Trinity College Dublin. Guess Who’s Dead on 13th November with Ardal O’Hanlon explored Irish death notices and on 20th November, the acclaimed One Million Dubliners was broadcast. The Joe Duffy’s Spirit Level on 16th November reflected on ideas and beliefs about death and the afterlife.

Over the past decade, a series of documentaries on dying, primarily around hospices, have been broadcast. The four-part series The Hospice about St Francis Hospice was broadcast on RTE 1 in 2007. A two-part documentary about the Cork hospice Marymount was broadcast on TV3 in 2012. The following year, the No Time to Die documentary on RTE 1 explored paediatric palliative care and featured families using the services of the Lauralynn Children’s Hospice. Programmes have also looked at wider issues. A Time to Die? on RTE 1 in 2012 exploring the issue of assisted suicide or euthanasia and Way to Go on RTE 1 in 2014 examining why people don’t want to talk about death.

Furthermore, valuable investigative work has been undertaken by the Irish media which has allowed abuses of our vulnerable citizens to be highlighted. This was an invaluable public service.

Further afield, the 2009 documentary on BBC Two Feet in the Grave was presented by actor Richard Wilson of One Foot in the Grave fame and explored why people are so afraid of death. The documentary was a co-production between the BBC and Open University and was described by Dr Carol Komaromy, one of the Open University academic advisors to the programme, as an attempt to “de-terrorise death” (Open University/BBC, 2009). The documentary was accompanied by a free booklet entitled Death and Dying: Making sense of the end of life.

In BBC Northern Ireland, the True North series of documentaries looks at life in modern day Northern Ireland. In series seven in 2016, it featured My Wig and Me about women losing their hair through cancer and alopecia and Liam Clarke – A Matter of Life and
Death which captured the Belfast Telegraph’s Political Editor coming to terms with his life and death following his cancer diagnosis.

This is just some of the media work that has featured issues around dying, death and bereavement. There appears to be a receptive audience to this material. Research in Ireland has found that 57% of people believe that the amount of discourse about death and dying in Irish society is not enough and 85% of people are comfortable to discuss death and dying (Weafer, 2014). Yet Irish research has also found that most people have a poor understanding of end-of-life treatments and terminology (Weafer, McCarthy and Loughrey, 2009). Most of us have not made arrangements for what we would like to happen if we became terminally ill or die (Weafer, 2014).

It is recommended that all the media, particularly the public broadcasters, assume a key role in a national conversation on dying, death and bereavement – issues which affect up to 300,000 people annually. Adopting dying, death and bereavement as a theme under the BAI’s Sound and Vision 3 funding scheme could contribute significantly to the national dialogue.

MEDI A GUIDELINES

A free media is essential for a healthy and functioning democracy. But the media – print, broadcast and online - has responsibilities. The Code of Practice for Newspapers and Magazines – with the Code Committee of the Press Council of Ireland as the oversight body – is a set of principles by which journalism can be judged. The Code has no legal effect. Principle five covers privacy (Code of Practice for Newspaper and Magazines):

“5.3 Sympathy and discretion must be shown at all times in seeking information in situations of personal grief or shock. In publishing such information, the feelings of grieving families should be taken into account. This should not be interpreted as restricting the right to report judicial proceedings.

5.4 In the reporting of suicide, excessive detail of the means of suicide should be avoided.”

The Press Ombudsman can issue a confidential advisory notice to editors on behalf of individuals or families when they have unexpectedly become the subject of intense media interest, sometimes at a time of great distress. According to the Code of Practice for Newspapers and Magazines January 2014 Handbook, the original code was drafted during the period of the Press Industry Steering Committee (2003-2007) and has been largely unchanged since then (ibid: 3). It is recommended that consideration should be given to reviewing the media guidelines specifically in relation to media coverage of traumatic deaths such as murder-suicide.

The recent deaths of the crew members of Rescue 116 - Captain Dara Fitzpatrick, Capt Mark Duffy, winch operator Paul Ormsby and winchman Ciarán Smith – and the media coverage following the publication of the preliminary report of the Air Accident Investigation Unit (AAIU) raised some issues. The details of the last dialogue between the crew featured in the report and was extensively covered in the media including the front page of a national newspaper. It raises the question of what interest did it serve to
have the details of the last dialogue published in the AAIU report itself and in the media? I would contest that the public interest was not served by producing the full transcript and a narrative summary would have sufficed. Sometimes, what we think is serving the public interest, may be satiating a certain sensationalism.

**LANGUAGE ON DEATH, DYING AND BEREAVEMENT**

Language is important. Euphemisms for dying and death can be used to shield us from the profundity of the process of dying and death itself.

"He passed"

"Did he? But when did he die?"

As part of an open conversation on dying, death and bereavement, it is recommended that a glossary of terms and key facts in relation to dying, death and bereavement should also be developed and disseminated to national and local media outlets.

**ACCESS TO BROADBAND**

The 2016 census revealed that 70.7% of private households have broadband internet access. Some 18% of households or 312,982 dwellings had no internet connection (CSO, 2017: 83). Leitrim has the lowest broadband internet access in the country at 58% while access levels in Dun Laoghaire-Rathdown were the highest in Ireland at 86% of households. The CSO (ibid) reported the “urban/rural disconnect” with a higher proportion of rural households (31.2%) with no internet connection than urban households (22.8%).

It is government policy to deliver high speed broadband (HSB) to every citizen and business. On 4th April 2017 it was announced that an agreement had been reached with Eir that would see 300,000 premises in rural areas removed from the National Broadband Plan with Eir connecting them to high speed broadband within 90 weeks (Naughten, 2017). The Minister for Communications, Climate Action and Environment, Denis Naughten also announced that the Broadband Intervention Map for National Broadband Plan had been finalised and 84,500 premises had been added to the State Intervention Area. The Department stated that 77% of premises would have HSB access by the end of 2018 with most of the remainder having access by the end of 2020.

The value of broadband for ehealth and for helping people to keep in touch with loved ones have been highlighted as positive features of broadband access. In its 2017 pre-budget submission, Age Action Ireland (2016a) highlighted the high demand for older people to learn basic skills. It had a national waiting list of 1,300 people who were keen to participate in the Getting Started class for the first time. The Getting Started training is funded by the DCCAE’s Benefit Programme. More State funding should be allocated to training people to use the internet.
While the digital age has facilitated communication and allowed access to information and knowledge, the internet is also presenting many challenges in relation to end of life. More and more people have social media accounts and share their lives online. This is their “digital legacy” when they die. Learning about a loved one’s digital accounts can be another administrative issue for bereaved families to handle after a death. There is now discussion about how people should put their digital affairs in order and provide directions for their digital estate. Each service provider such as Facebook has its own “terms of service” and methods of addressing the death of users which people agree to when they sign up to a service. Therefore, people must become more educated about the status of their online accounts should they become incapacitated or die. The advancing planning tool **Think Ahead** has a section where people can record their social media accounts.

The bereaved are using social media in different ways to remember someone who has died or keep in touch with “their community of grievers”. In the Digital Death Survey 2015 from Deadsocial, 53% of people replied that if someone they cared had died, it was important for them to be able to view their social media accounts. Other issues have been highlighted. Speaking in Trinity College Dublin in September 2016, Professor Charles Ess of the University of Oslo said that the internet had some positive effects on the grieving process but highlighted some difficulties such as people finding out about the deaths of loved ones on Facebook (Murphy, 2016). There is also what has been called, the phenomenon of the “dianification” of western culture where people publicly mourn people they have never met (ibid). Professor Ess urged people to “exercise empathy” when people had died.

While the Irish Government is pursuing an ambitious digital strategy which is important for our economy and society, it is in the interests of our society that we communicate with civility and empathy towards each other. An awareness campaign on social media and death will be needed in the future to ensure that people are cognisant of the issues around digital legacy. Any awareness campaign should also address the issue of civility and empathy in communications particularly around dying, death and bereavement. Facebook’s Chief Operating Officer Sheryl Sandberg, who herself became a widow in 2015, has recently co-written a book about her experience of bereavement entitled **Option B: Facing Adversity, Building Resilience, and Finding Joy**, and in this regard has featured on the cover of the influential Time magazine.

A number of instances have emerged in recent months where users of social media have made recordings as they committed horrific crimes such as murdering a child and fatally shooting an elderly man on the street. They then disseminated those recordings on their Facebook pages. People have died by suicide while others have watched. The beheadings in Iraq by terrorists have been posted on the web for propaganda purposes. While action was taken to block these recordings, the public must be educated, on an ongoing basis, on being cautious about their online activity.
RECOMMENDATIONS

- Integrate advance planning into the briefing material for defence force personnel who are being posted overseas.

- Provide regular bereavement training for personnel of all grades at all stages of their careers, which will ensure they respond appropriately to emergencies at home and abroad.

- Ensure information on cultural attitudes to dying, death and bereavement are part of the briefings for troops being deployed overseas.
The Department of Defence has a “unique civil/military structure” (Dept. of Defence, 2016a: 2). The Minister for Defence is head of the Department and the Secretary General is the principal policy adviser to the Minister. The Defence Forces headquarters is the military element of the Department of Defence. It is headed by the Chief of State who is the principal military adviser to the Minister for Defence.

The department plays a key role in providing aid to the civil authorities particularly in security, fishery protection, maritime search and rescue and air ambulance services, government air transport, and international peacekeeping. It coordinates the delivery of these security, emergency and community services by the Defence Forces. The civil element provides liaison between the Defence Forces and other Government Departments, public authorities, the EU and public representatives. Policy in respect of overseas operations is also coordinated by the civil element.

The Department’s Office of Emergency Planning, set up after September 11th 2001, supports the Government Task Force on Emergency Planning and coordinates the work of an Inter-Departmental Working Group on Emergency Planning. The department also has responsibilities for the Irish Red Cross Society and Civil Defence.

The Defence Forces comprises a Permanent Defence Force (PDF) and a Reserve Defence Force (RDF). The PDF is made up of the Army, the Air Corps and the Naval Service and totalled 9,140 personnel by the end of 2015 (Dept. of Defence 2016b: 23). The Programme for a Partnership Government (2016: 139) has committed to ensure that the PDF is at least 9,500 strong. It also made a commitment that the RDF would reach 4,000 personnel (ibid). Civil Defence consists of 4,500 volunteers who support the frontline emergency and assist local communities.

The role of the Irish defence forces is diverse. It prepares and monitors the defence of the country and also promotes international peace and security. In Ireland, it supports the civil authorities by developing Memorandum of Understandings and Service Level Agreements with a range of departments.

In 2015, 1,383 members of the PDF were serving overseas with the United Nations (UN), the European Union, the Organisation for Security and Co-operation in Europe and NATO’s Partnership for Peace (Dept. of Defence 2016b). Some 85 members of the Defence Forces have died during Ireland’s involved with the UN. In 2015, Óglaigh na hÉireann was recognised with a People of the Year Award for the work of the Irish Naval Service in the humanitarian mission in the Mediterranean under Operation Pontus from May 2015. By December 2016, the Minister with responsibility for Defence, Paul Kehoe stated that over 15,500 migrants had been rescued by the Irish Naval Service (Kehoe, 2016a). According to the United Nations High Commission for Refugees, an estimated
12,945 migrants have died while making the journey across the Mediterranean from 2014 to 7th April 2017.

2016 marked the 55th anniversary of the Siege of Jadotville in the Congo in September 1961 when about 150 soldiers – with no support or reinforcements - were attacked and later captured by rebels. Minster Kehoe presented a Unit Citation to ‘A’ company, 35th Infantry Battalion in recognition of their bravery. It was the first time a Unit Citation was awarded within the Defence Forces. Two days after the citation was presented, the film capturing the story, *The Siege of Jadotville*, premiered in Ireland. On February 23rd 2017, it was reported that the Taoiseach had ordered a review into why Siege of Jadotville soldiers had not been awarded medals.

A key development in recent years was the White Paper on Defence which was approved by the Government in 2015. The White Paper provides a defence policy framework for 10 years until 2025. The Strategic Statement (Dept. of Defence, 2016a) states: “This policy framework is flexible and responsive given the dynamic nature of the security environment and enables the Defence Organisation to be adaptive to changing circumstances”. The White Paper identified the need for capital investment on replacement defensive equipment and upgrading infrastructure. A total of €437m has been allocated to the Department of Defence from 2016 to 2021 under the Capital Investment Plan, and an additional €7m capital funding was allocated to the Department in 2017 (Kehoe, 2016a). This is in addition to the €67m already provided for in the capital plan for 2017.

An initiative was unveiled in February 2016, when then Minister for Defence, Simon Coveney, launched the Defence Forces Employment Support Scheme to help unemployed and disadvantaged young people, aged between 18 and 24, to develop their life skills and confidence.

Military medicine was recognised as a speciality in October 2015 with Ireland becoming the first country in the world, to formally recognise the specialty of military medicine.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

In its response, the Department (Civil Service), “in the normal course of business”, does not interact with the public on a daily basis. It has practices in place to deal with bereavement internally. These practices would not necessarily extend to the wider public. The Department stated that it was developing its own internal Bereavement Policy.

COMMENTS AND RECOMMENDATIONS

It is clear that while the Department generally does not deal with the public, members of the Defence Forces have a direct involvement in people’s lives during particularly difficult times and often when life is at stake. The Air Corps Air Ambulance Service provides for emergency inter-hospital transfer for patients and the transport of emergency organ retrieval teams. The Air Corps supports the HSE’s Emergency Aeromedical Support Service and undertook 397 missions in 2015. The Air Corps also flew 60 civil assistance missions in 2015 which involved responses to incidents including major accident,
major fire and flood relief (Dept. of Defence, 2016b: 49-50). In 2015, Defence Forces were deployed to assist in the search for a number of missing people during the year and 1,304 troops assisted the Principal Response Agencies during severe floods in December 2015 (ibid: 48).

Therefore, Defence Force personnel come to our assistance during particularly difficult periods in the life of an individual and the country. A report on wellbeing in the Defence Forces Report on the Defence Forces ‘Your Say’ Climate Survey 2015 found that 60% of respondents felt they were doing something worthwhile for Ireland (Dept. of Defence, 2016c: 18).

**RESOURCE THE AIR CORPS**

The issue of staff shortages for pilots and air traffic controllers affecting the air corps were raised in 2017. They are literally providing life and death service to our most vulnerable citizens. In a written answer on Air Ambulance Service Provision in the Dail on 8th March 2017 the Minister for Health Simon Harris stated that his Department had been advised that “…in the coming months, availability of aircraft will be restricted due to a shortage of pilots and difficulties arising from the loss of Air Traffic Control personnel”. (Harris: 2017). The restrictions, he stated, were particularly problematic for paediatric transplant patients who needed to be transferred to the UK urgently when organs became available. Contingency plans were in place involving Irish Coast Guard and private air ambulance services. It takes many years of training to become a pilot and more years again to become an experienced pilot. The Air Corps must be adequately resourced to attract new recruits and to incentivise existing pilots to remain.

**TRAINING ON BEREAVEMENT**

While aware that much work is being carried out to support military personnel, it is recommended that senior officers and trainers should receive regular training on issues around loss and bereavement to ensure that they can provide the most appropriate support for their own personnel and for members of the public who they encounter in emergency situations. Training in communications skills particularly in how to break bad news should also be on the agenda and would benefit the public who are in emergency situations.

**BRIEFINGS ON CULTURAL NORMS**

Cultural attitudes to death, dying and bereavement should – if they are not already – form part of the briefings for troops who are travelling overseas on peacekeeping missions.

**ADVANCE PLANNING**

The issue of advance planning has become more topical in Ireland with the enactment of the Assisted Decision-Making (Capacity) Act 2015. It is recommended that personnel on peacekeeping missions should be briefed on “Things To Do Before You Go” and any
information pack should include information on Enduring Power of Attorney, Advance Healthcare Directives and their general wishes. This material would be beneficial for families in the event of a fatality overseas. An existing tool such as Think Ahead – developed by the Irish Hospice Foundation – should be considered or redeveloped to meet the needs of the Defence Forces.

TECHNOLOGY ACCESS FOR FAMILIES

Meanwhile, for personnel who are posted abroad with elderly parents or seriously ill relatives, it is recommended that officers ensure the availability of SKYPE for those affected personnel to keep in contact with their family in Ireland. With hundreds of Defence Force personnel overseas in any year, there will be family difficulties that arise. How the organisation supports individuals at this time has a direct and significant impact on the individual who is affected, as well as indirectly affecting the morale of his/her colleagues. However, such a recommendation may depend on local conditions and where defence forces are posted.

HARNESSING DEFENCE FORCE EXPERIENCE

There is much that our young people can learn from our defence forces who have served Ireland with distinction at home and overseas. Our defence force personnel have been involved in challenging scenarios at home and have witnessed human desperation internationally as people escape war, persecution and famine. They have encountered people who have risked death in order to escape death. They have rescued people who have risked life itself so that they might have a life. It will be instructive to learn about the experience of the Employment Support Scheme, and to explore if there is an opportunity to develop a programme for a wider audience or a mentoring programme which will help develop skills such as resilience in our young people.
RECOMMENDATIONS

- Recruit more psychologists for the National Educational Psychology Service (NEPS) to ensure that every school is supported, when required.

- Encourage all schools and educational institutions to develop a Bereavement Policy.

- Take action to ensure that bereavement is part of the core curriculum of teachers’ undergraduate studies.

- Ensure training on bereavement is part of the Continued Professional Development courses for school leaders and all staff.

- Fund books on grieving and loss for children, teachers and parents in school libraries.

- Encourage schools to allocate a flexible/quiet space for the use of grieving children and staff who need respite during the school day.

- Provide funding for bereavement services which support children and young adults.

- Recognise the essential profound, transformative and joyful role the creative and expressive arts play in supporting children of all ages, who are facing challenging life events such as dying, death and bereavement.
The vision for the Department of Education and Skills’ (DES) Statement of Strategy and Action Plan for Education is that the Irish Educational and Training System “should become the best in Europe over the next decade”. (DES 2016a: 1).

DES figures for 2015/2016 put the number of primary and second-level pupils in schools aided by the Department at 930,883. There were 179,850 students in third level in the same period. The number of exam candidates (inter and leaving certificate) in 2015 was 117,452. Some 61,380 teachers at first and second levels were funded by DES. In terms of the school network, there were 3,997 DES aided schools at first and second level with another 152 second-level schools offering Post Leaving Certificate courses. A total of 39 third-level institutions were supported by the Department. Some 94,000 people were employed in the sector in 2015 (Institute of Public Administration, 2015: 15).

The Organisation for Economic Cooperation and Development (OECD) Programme for International Student Assessment (PISA) survey found that Ireland ranked higher than the European average in maths, sciences and reading 2012. PISA is an internationally standardised assessment which is administered to 4,500 to 10,000 15-year-old school students in each country (Institute of Public Administration: 44). The Department reported that the overall performance in reading and maths in second and sixth classes in National Assessments 2014 was “significantly higher” than the National Assessments 2009 (Shiel, Kavanagh & Miller, 2014: xii). Meanwhile, 83% of the Irish public was satisfied with the Irish education system in 2014 which was the second highest of all the European countries surveyed. The figure was 89% in 2007 (IPA: 60).

A key theme in the Action Plan for Education 2017 is promoting and supporting wellbeing. A DES Wellbeing Steering Committee is to be established and a review undertaken of the current range of supports and programmes on wellbeing which are offered by DES to schools. The Incredible Years Teacher Programme and the FRIENDS Programme are to be rolled out to disadvantaged DEIS schools and schools will start providing the Wellbeing programme to all students in the first year of Junior Cycle.

Issues relating to Dying, Death and Bereavement are dealt with by the Pension Unit staff who administer the Statutory Teachers Superannuation Schemes as well as pension schemes for non-teaching staff. This work may involve paying a death gratuity where a teacher dies in service or processing applications for Spouse’s and Children’s pensions, or applications for ill health retirement. A Spouse’s and Children’s Pension is generally paid one month after the application form and relevant documents are received. This
work receives a high priority, with communications dealt with “sensitively and with compassion”.

Information on whether someone is a member of the optional Spouses’ and Children’s Pension Scheme is included in retirement letters. Difficulties have emerged in the past where a widow/widower made contact with the Pension Unit following the death of a former member about entitlement to their spouse’s pension. They then learned that their spouse had opted out of making the provision. However, including the information in the retirement letters, the Department commented. “...goes some way towards addressing this difficulty for bereaved family of former members.”

NATIONAL EDUCATIONAL PSYCHOLOGY SERVICE

The Department’s submission outlined the work of the National Educational Psychology Service (NEPS) which provides advice and assistance to schools directly and indirectly through the Critical Incident process. The submission explained:

_A critical incident is defined broadly as any traumatic event which has the potential to overwhelm the orderly and normal running of a school. The nature of the trauma can be varied, but is commonly related to the death of a pupil or staff member due to accident, illness, suicide or even murder._

The NEPs response focuses on preparing the school as well as direct support during the incident and support after the incident. Schools are encouraged and supported to develop a Critical Incident Management Team (CIMT) and to develop a Critical Incident Management Plan (CIMP). There is specific information and advice for teachers and parents in the Critical Incident Resource document focusing on grief and bereavement.

NEPS stress that critical incident response is part of a wider school planning process that includes catering for the general health and wellbeing of pupils and staff and includes “focus on a school ethos which fosters connectedness, belonging, development of resilience and quality communications within the school and with the wider school community”.

The submission explained:

_The reality of death, dying and bereavement is a constant of daily life which has effect across society but including individual pupils, school classes and whole school communities and which can impact upon social, emotional and educational development of those adversely impacted. It is therefore a direct concern for the Department, school management and the teacher._

DES stated that, at an overarching level, it was strongly supportive of the promotion of positive mental health awareness in primary and post-primary schools.

It stated: “The process spans the curriculum in schools, whole-school ethos, quality of teaching, learning and assessment, student support and pastoral care and the provision of professional development for teachers”. It also involved supports such as educational psychological services, guidance and counselling services and local and national agencies.
A number of documents have been produced to assist schools including *Well-Being in Post-Primary Schools: Guidelines for Mental Health Promotion and Suicide Prevention* (2012) and *The Well-Being Guidelines for Primary Schools* (2015). The guidelines build on the work taking place in schools including through the Social, Personal and Health Educational (SPHE) curriculum, whole-school guidance plan, the NEPS continuum of support model and the HSE’s Health Promoting Schools process.

The Department explained:

*The overall focus is on promoting structures, processes and knowledge within schools to provide a supportive and caring environment within which children and adolescents can flourish and which is sensitive to and vigilant of the needs of those under emotional or mental pressure. Clear referral pathways are provided for pupils with the higher levels of need.*

### HOSPITAL/HOME TUITION

The Department provides staffing for a small number of hospital schools. The submission stated that since this provision began, no issues have been raised concerning end-of-life issues. Home Tuition is provided for children who are unable to attend school for long periods because of illness. In a small number of cases, flexibility on times of tuition or payment arrangements will be sought for children who are in long-term medical care. The Department cited the case of a terminally ill child where DES made arrangements that were requested by representatives of the parents in an effort to assist the parents and to reduce any unnecessary administrative burden.

### COMMENTS AND RECOMMENDATIONS

“I have never seen anything so profound as the effect of a funeral on a group of young people whose peer is the one who is being buried. That is a shock of the most incredible kind. There is no education until it touches something in you that is real.” *(MARK PATRICK HEDERMAN).*

Positive work is being done in schools to support our children to reach their full potential and to support them with issues they encounter on their academic journey. It is interesting that there was no reference in the Department’s wide-ranging questionnaire to the bereavement experience of children with disabilities or to the needs of young people at Third Level institutions. It is hoped that, while not outlined here, arrangements are in place for these specific groups.

Figures provided on request by DES reveal 19 teachers are working in seven hospital schools while 1,200 tutors provide home tuition on an annual basis. Teachers and tutors must be registered with the Teaching Council. About 220 pupils attend the schools while in hospitals – the exact number depending on the number of children in hospital. In the 2015/16 school year, 1,455 children were sanctioned for home tuition under the Special Education and Medical strands of the Home Tuition Grant Scheme. The aim of the scheme is to “provide a compensatory educational service” for children including students with significant medical conditions which causes major disruption to their school attendance.
The range and quality of information resources and programmes that have been developed by the Department particularly in response to critical incidents is impressive. Media reports indicated that there were 77 suicides among secondary school students in 2016. This comprised 66 boys and 11 girls with the youngest being 12 years old (McGuire, 2017). About six bereaved students each year are faced with the death of a loved one during their exams (O’Brien, 2017). It is vital that our schools are informed of the needs of bereaved who are often “hidden mourners” (ehospice, 2016) particularly as about one third of a young person’s life is spent in school (O’Brien and McGuckin, 2014).

GAPS IN THE CURRICULUM

While the issue of bereavement can be raised with children in religious class or in Social Personal and Health Education (SPHE), fewer opportunities were identified in the rest of the curriculum as illustrated below.

“I lectured in Mary Immaculate College for eleven years and I have retired. But I think when I started to look at issues to do with dying and death across the curriculum, I found it very difficult to find it. I found it referred to a lot in the religious curriculum and maybe SPHE in relation to wellbeing. But I didn’t find it anywhere else and I was interested in cross curricular collaborations. Loss, grief, death and compassion – is our bread and butter. It’s made for us. But I found the research on the ground – information across the curricular subjects – was limited.” (Sinead Dinneen).

DEPARTMENTAL WORKING GROUP ON CHILDHOOD BEREAVEMENT

It emerged from the research for this report that the Department must pay more heed to death and bereavement in order to support schools, pupils, teachers and their wider communities. While a number of documents have been produced by DES which cover death and bereavement and it is contained in the Social, Personal and Health Education curriculum as well as religious education, teachers are looking for more support. They need up-to-date and consistent information on how to support children who experience a bereavement and loss. There have been many positive developments in the academic and NGO community in relation to childhood bereavement. But to have an impact, DES must become involved.

It is recommended that a Working Group on Childhood Bereavement is established which would include Department officials as well as academics and representatives of relevant community and voluntary groups. This Working Group should develop an education and training programme. Ideally, a module on bereavement should be a core part of the undergraduate curriculum within the teacher training programme. Education initiatives which are currently underway in childhood bereavement should be supported and integrated into any future Department programme. The role of the arts in promoting self expression particularly for grieving children should be central to any education programme.
GATHERING STATISTICS

The Growing Up in Ireland. National Longitudinal Study of Children. The Lives of 9-Year-Olds found that 78% of nine-year-olds had experienced "some form of stressful life event" (Williams, Greene, Doyle, Harris, Layte, McCoy, McCrory, Murray, Nixon, O’Dowd, O'Moore, Quail, Smyth, Swords, Thornton, 2009: 81). The most common events were loss of a close family member (43%) and moving house (42%). The serious illness or injury of a family member was experienced by 13% of the children.

“There are no official figures for childhood bereavement in Ireland. However, an estimated 36,000 to 60,000 Irish children could have experienced a significant bereavement.” (McLoughlin, 2012a).

Research should be funded to determine the number of children who are bereaved in Ireland and to ascertain the effectiveness of interventions for grieving children.

BEREAVED EXAM STUDENTS

A motion calling on DES to arrange a second set of exams for pupils bereaved by the death of a close family member, or one who is seriously ill, close to a State exam was passed at the annual conference of the Association of Secondary Teachers in Ireland (ASTI) in April 2017 (O’Brien, 2017). James Howley of ASTI’s East Mayo branch stated that about six pupils would experience the death of a parent, brother or sister during their exams. Another small number may experience a “major physical trauma or mental crisis”.

This report supports the ASTI motion and would encourage DES to make the necessary provisions to support the limited number of young people who would be affected. It places an unacceptable hardship on a person to have to attempt to sit a State exam on the day s/he is attending the funeral of a loved one.

IMPORTANCE OF SCHOOLS

The Irish Childhood Bereavement Network (ICBN) explains that children’s grief can be “intermittent and intense but can also pass quickly” (ICBN factsheet). The grief of a child is often unrecognised as they tend to protect parents from their pain. Children's grief also affects them at milestone times such as going to a new school, and, as a child gets older, they might revisit their loss at different points in their development. It is crucial that teachers learn about bereavement and young people so that they can support them in the classroom.

When parents are consumed with their own grief following the death of a child or if a surviving parent is challenged to cope after the death of a spouse, the school offers continuity and an individual teacher can offer the vital comfort and support that a child needs. Shane Moran, counselling psychologist, teacher and chaplain, has written a book on responding to a critical incident in schools. He has spoken about the “wallop effect” which affects a school in the days after a death. O’Brien (2013) states that the three human attributes needed to support a grieving child are “honesty, patience and empathy”.

O’Brien and McGuckin (2013: 4) state:

“Grief management and support, if it is to be effective, cannot be separated from the academic components of the curriculum, nor can it be disassociated from the school community at large. What students need most at such times is to be in a supportive, caring and helpful environment.”

The central role of the school is also recognised by the ICBN in a written submission to the Oireachtas Committee on Health and Children Public Hearing on End-of-Life Care in 2013 which stated:

The view of the ICBN is that particular emphasis should be focussed on schools. Given that bereavement occurs in a family context, and that the family can be undermined just at the time when it needs to be most supportive to children, school takes on a significant role in providing a predictable, stable and understanding environment.

If a school embraces its role in providing holistic support to a child – addressing emotional and mental health issues as well as academic matters - students will find it to be a supportive environment during challenging times in their lives, and teachers will recognise and fulfil a supportive role when required. Some schools may require a change in culture.

The 2017 budget for the Department included funding for enhancements to school leadership - additional deputy principal posts for larger second level schools and middle management posts for primary and post-primary schools. Announcing the budget, the Department stated: “This recognises the key role school leadership has in promoting a school environment which is welcoming, inclusive, accountable and focused on high quality teaching and learning” (DES, 2016).

In its briefing document on the budget, the Department (DES, 2016: 3) commented:

“The aim is to contribute to the further development of a distributed leadership model in schools, involving the establishment and facilitation of leadership teams with appropriately defined and shared responsibility for areas such as curriculum and learning, student support and wellbeing, school improvement and leadership and development of staff teams.”

It is recommended that with more capacity at a senior level in school’s, more resources – particularly time and personnel - should be allocated to improving schools responses’ to life events such as bereavement by supporting staff and developing a bereavement policy.

BEREAVEMENT POLICY

Schools are encouraged to develop a Critical Incident Policy to react to incidents which can overwhelm the normal functioning of a school such as a suicide or a death in the school. While the Critical Incident Policy covers issues around bereavement, it is recommended that a separate and specific policy on bereavement and loss, applicable
for both staff and students, should also be developed. Putting a policy in place will ensure that a child experiencing a bereavement gets the support they need, their classmates and friends are managed and their teacher is also supported as they fulfil this crucial role.

**BEREAVEMENT AS CORE PART OF UNDERGRADUATE STUDIES**

In an interview for this study, Anne Staunton of Rainbows stated that we need to acknowledge that events in a child’s life can affect their experience of learning. There was, she said, no training at teacher training level around bereavement and loss and difficult issues in a child’s life.

Teachers should be educated on bereavement, its impact on children and their role in supporting children during their undergraduate courses.

The preliminary results of cross-border research currently being undertaken on pre-service teachers’ response to pupil wellbeing in relation to bereavement, separation and divorce found that 84% of participants said that supporting bereaved children was either “not included” or they were “unsure” that it was provided in their training. Yet almost half (48%) had met grieving children on their school placement and witnessed the emotional and concentration issues experienced by the children. The research, which is being conducted by Principal Investigator, Dr Aoife Lynam with Prof. MC Guckin at Trinity College Dublin and Dr McConnell from Stranmillis University, found that 82% of pre-service teachers rated supporting bereaved children as important – 57% rated it “extremely important”. However, 93% said they were not aware or were unsure of any bereavement support policies or directives from DES.

These preliminary figures and the interviews for this report confirm that DES needs to do more work in terms of raising awareness of bereavement among student teachers, better communication on the relevant resources it has developed and the preparation of more specific resources on childhood bereavement. This is important as nearly two thirds or 74% of the pre-service teachers in the research were not confident or were unsure in supporting grieving children.

**THE ARTS SHOULD PLAY A CENTRAL ROLE IN SUCH A PROGRAMME.**

The arts should play a central role in any training programme for teachers. The arts are possibly the greatest conduit through which grief and loss can be expressed. An arts programme could be developed to answer the complexities of grief whether normative and complicated.

**STAFF SUPPORTS**

In addition to their undergraduate education, teachers must be given the resources they need by principals and school boards of management to attend any training they require on bereavement. They also need to be supported as they care for a grieving child in their classroom. The UK bereavement charity Seasaw explains: “Knowing your support network lightens the load and enables clearer thinking about ways forward”.


Research has found that Irish schools are supporting students but are themselves looking for more support in areas of policy and training (O’Brien, 2014: 1).

A survey of recently qualified teachers was released by the ASTI in April 2017. When asked about the barriers to taking part in professional development/Continued Professional Development (CPD), 55% of those surveyed felt that after school preparation and marking meant that they had no time for CPD. Some 53% had no incentive to do postgraduate study due to the abolition of the Degree allowance for teachers post February 2012 and 43% cited the financial costs. A total of 42% considered that they were too busy establishing themselves as classroom teachers to undertake CPD (ASTI, 2017: 14).

Bereavement, grief and loss should be seen as a core integral to the job when dealing with young minds, teenagers and young adults. The recommendation in this report is that bereavement should be a full module in undergraduate, post-graduate and relevant CPD courses. Where time and costs challenge a teacher’s ability to commit to a course, there should be a range of educational tools across all multi-media made available. Teachers should be exposed to existing and new tools that are developed such as the ICBN’s Teacher Toolkit.

MORE PSYCHOLOGISTS

At December 2016, there were 162 Full-Time Equivalence (FTE) psychologists supporting all primary and post-primary schools in Ireland. There was sanction for 173 FTE psychologists.

The Programme for a Partnership Government (2016: 86) pledged to increase the number of education psychologists by 25% to a total of 238. A pledge to expand the National Educational Psychological Service (NEPS) was also made in the Action Plan for Education 2016-2019. Meanwhile, the Action Plan for Education 2017 (2017: 16) reiterated commitments to expand the service and stated it would recruit an extra 10 educational psychologists in 2017.

At a briefing in December 2016, the NEPS branch of IMPACT trade union called for the immediate recruitment of at least 94 psychologists to meet needs. At the time, the union sought further commitment from the Government to recruit an additional 17 psychologists to meet expected demands on the service by 2021.

The internationally accepted psychologist-to-student ratio is 1:3,500 but IMPACT stated that the ratio in the educational psychology service placed Ireland 26th out of 33 countries. Some 250 psychologists were needed to meet international standards and 267 psychologists would be required by 2021. IMPACT highlighted that 15-20% of students had significant emotional or behavioural needs.

NEPS work with schools facing critical incidents. St Mary’s College in Dublin had two past students involved in the Berkeley tragedy when six students died following a balcony collapse in 2015. Former Deputy Principal in St Mary’s College, now Principal in Rathdown Senior School, Brian Moore, spoke highly of NEPS’ support:

“After any critical incidents we would ring NEPS immediately and then they would form part of the advisory response group. And again we find the people in NEPS move quickly. They will be with us within the hour and again it is sharing mobile numbers. If it suits...
you to meet at 7 or 8 in the evening that is the timetable, if that is the way it is. And NEPS would be very strong around helping you through your checklist and making sure stuff doesn’t get lost and that you have done everything that you need to do…”

Denis Murphy, former Principal in St Mary’s College, Rathmines commented:

“We would find that you are dealing with people who have a great work ethic in NEPS and the HSE, who will drop everything to be with you, who have lots of common sense. They are an addition to the group. They are not a nuisance. They are not there to take over. They are there to support.”

However, he noted that in relation to longer term support for staff, that was when resources get tight. In her interview for this study, Emma Dineen, School Principal and former President of the Irish National Teachers Organisation, highlighted the difficulty of getting access to a NEPS Psychologist.

“Each school has to have a policy in place to manage tragedies like suicide. Our first port of call is NEPS but it can be very difficult accessing a NEPS psychologist because they are under-staffed. When you get them, they are great but very often their brief is to give you strategies to implement, when very often classroom teachers would have used these strategies already. At the end of the day, NEPS cannot do much more than the class teacher. Teachers are the people who need access to trained counsellors in order to best help the children.”

(Emma Dineen).

This report would support the recruitment of more psychologists in the NEPS. This service operates on a systems level rather than offering a therapeutic service. Its guidance and advice to the education system is valuable. While NEPS works with schools in managing critical incidents, it is recommended that it should work proactively with schools to develop general bereavement policies for their staff and students. A study in 2012 on childhood bereavement stated that there was “a limited response by NEPS to bereavement in school situation” (McLoughlin, 2012a: 12). It would be hoped that limitations in this regard could be remedied with an increase in staffing.

VALUE OF SCHOOL LIBRARIES

School libraries should stock books on bereavement and loss for parents, teachers and children.
FLEXIBLE/SILENT SPACE

“We all feel a certain kind of guilt and we all feel a certain kind of pressure that we have to do something. What they need is space - an articulated space. The truth is that when someone is bereaved there’s a huge loss there and the impertinence is to imagine that anything can fill it. An articulated space in which people who are nearest to the bereaved and who know them, can actually tell them what would be useful and what would not be useful. To respect the hierarchy of affection.” (MARK PATRICK HEDERMAN).

Responding to Critical Incidents. Guidelines for Schools (DES, 2007: 24) suggests that a room could be designated as a “quiet room” for about a week following a tragedy which would offer people a quiet space if they are feeling overwhelmed. It notes that staff should be clearly informed about procedures for the running of the quiet room. The Department should look at policies in relation to using comfortable spaces in the long-term within the school and its grounds for bereaved children and staff who need respite from the classroom. Other people who may require a break from the class could be young carers. A study commissioned by the Heritage Council entitled Children and the Outdoors (2016: 29) outlined the significant benefits for children including to their health and well-being of having contact with the outdoors and the environment. It is important that when our schools are designed, attention is paid to landscaping.

HARNESSING THE ARTS

“I rhyme
To see myself
To see the darkness echoing……
....to let down a shaft into real life”

(SEAMUS HEANEY, DEATH OF A NATURALIST)

Arts education encompasses a range of activities in the visual arts in music, in drama, in dance and in literature. These activities and experiences help the child to make sense of the world; to question, to speculate and to find solutions; to deal with feelings and to respond to creative experiences (Arts and Education Charter).

The arts matter essentially throughout all of our lives. They are the language of human feelings and when we neglect them, we neglect ourselves.

The arts are really ways of seeing and ways of being. As such the world of the arts is really the world of the full human being. They therefore become essential and have essential and defining roles to play around grief and loss. Their harness lies in their emotional powers. They matter because they are about human wellbeing. The matter because they are educative.

“It is the arts that can play an essential role here especially with your children and young adults. They are a vital tool in helping us to make sense of inevitable grief in our lives. The arts can teach the young mind to live with a loss. Writers and artists can show us how this is done.” (DARIAN LEADER).
The arts matter because understanding matters. The inevitability of dying, death and bereavement in the lives of young people can be best understood and withstood through the creativity and the imagination of the arts. The creative arts as expressed through the eye, the ear, the voice, the body and the heart, can find a way, or a conduct or a channel for loss and grief to be expressed far more powerfully than the workings of the head.

The arts matter around end-of-life issues because they do not recognise age and because they gift intergenerational communication.

The arts matter because they enrich lives across communities from the most disadvantaged and the poorest to the most privileged. A bellcurve that dying, death and bereavement does not exclude. Sing Out With Strings created by the Irish Chamber Orchestra in the University of Limerick for 300 children, reaching into disadvantaged communities and creating vehicles of expression; the DIT Ballymun Music Programme; Music Generation created by U2 ensuring that all children, whatever their background, get access to music tuition; or as far afield as EL Sistema Venezuela are some of the greatest examples of music programmes that can change the lives of the poorest and the neediest of children.

The nucleus of all of these programmes is community, culture and joy. Expressiveness and rhythms being central to the teaching. El Sistema graduates leave with a sense of capability, endurance and resilience, to take on the insurmountable challenges in their lives. These are exactly the human skills young people need and will need, when profound loss and grief visit their lives when they are young or as they age. I write about these extraordinary schemes and programmes because they are life altering and life affirming. Across all the arts and schemes and programmes such as these, young people can be helped to understand, express, survive and move on after death and grievous personal loss. We all have to find ways to save ourselves, and it is my belief that the arts are the greatest heart and soul rescuers.

The arts require doing, crafting and "poiein", the origin of our word poetry. The opposite of suffering being done to. They bring thoughts and feelings together in a vibrant whole.

We need to elevate the arts to the same metaphysical level as we have elevated technology. Technology can only answer grief and loss in a limited, informative way. The arts can break new emotional, human ground and go beyond what is given.

**BEREAVEMENT COUNSELLING**

It is important that people who are providing counselling support to the bereaved including children should be appropriately qualified and supported. Standard 4 of the ICBN’s draft *Standards for Supporting Bereaved Children* covers service providers and states: “All service providers must ensure that governance, procedures and protocols are in place to ensure ethical, safe and appropriate bereavement service delivery to the children in their care” (ICBN, 2016: 23).

It is understood that qualified and accredited graduates of psychotherapy and counselling programmes are not eligible for HSE counselling/psychotherapy positions. Only graduates with prior degrees in psychology, nursing, social work and occupational
therapy can be employed as a clinical support worker. This must be reviewed. It is incomprehensible that a person who is educated to Master's level in the Irish university system and is then accredited by their professional body is not considered for a position in the Irish health system but must emigrate and work in another health service.

HEALTHCARE ETHICS EDUCATION AT THIRD LEVEL

Speaking before the Oireachtas Joint Committee on Health and Children during public hearings on end-of-life care issues in Ireland in 2013, Dr Joan McCarthy proposed two initiatives on healthcare ethics – a national clinical ethics committee network and a national end-of-life health care ethics observatory.

Dr McCarthy, lecturer in the School of Nursing and Midwifery, University College Cork and Coordinator of the MSc in End-of-life Healthcare Ethics, explained that the observatory would be a joint initiative of institutes and universities working in partnership with hospital education centres and professional bodies. Its role would include providing educational support to the general public as well as improving the training and professional development of clinicians and health care staff. Dr McCarthy suggested that the observatory could start as a virtual observatory before being sited in the longer term in a large hospital.

Speaking before the Committee, Dr McCarthy stated:

"Where ethics support is part of a standard practice of health care organisations, the international evidence indicates that health care staff are more ethically literate leading to improved patient and family outcomes and less moral stress, desensitisation and burnout for health professionals who are struggling at the coalface due to current budgetary constraints."

This report would support Dr McCarthy’s initiatives and encourage funding for the development of the observatory.

"Education is where it’s at.
...Emotional education and emotional education is about music and dance and the visual arts and psychotherapeutic education. Teachers have a huge part to play”. (TOM INGLIS).
RECOMMENDATIONS

- Support a public information campaign to encourage people to plan for the future, including preparing a will.

- Support the development of financial education starting in schools, which will help guide a whole life course approach to financial planning.

- Develop a campaign to promote awareness and action against the financial abuse of older people.

- Take the lead in ensuring all agencies and regulators including the Central Bank have policies in place to combat financial abuse of the elderly.

- Support putting home care on a statutory footing, to allow people the right to remain in their own home.

- Review the granting of licences to money lenders.
BACKGROUND

The Department of Finance is responsible for producing the country’s annual budget. It manages Ireland’s policies in relation to the economy, taxation, the banking sector and public finances. It also represents Ireland’s interests at the EU and with international organisations.

Ireland is an open economy which is currently undergoing a revival following an economic crisis. This crisis prompted the government in 2010 to enter a financial agreement with the European Commission, the European Central Bank and the International Monetary Fund (the Troika). Ireland exited its EU-IMF programme of financial support in December 2013.

In his foreword to the Department’s Statement of Strategy (2016a: 4), Minister Noonan wrote of creating “a virtuous circle in which continued robust economic growth provides the resources necessary to advance social progress, promote inclusivity, fairness and provide high-quality public services to all citizens”.

Future challenges for the Department include managing the post-exist economic relationship between Ireland and the UK and influencing the debate around corporate taxation and the legal challenge to the European Commission’s ruling on State Aid. Budget 2017 introduced measures to support the economy in response to the UK referendum on Brexit. While about 16% of Irish exports go to the UK, 40% of indigenous company exports are destined for the UK (Noonan: 2016a).

Measures announced for Budget 2017 included steps to help with the transfer of farms from one generation to the next. The State pension and all weekly social welfare payments increased by €5 per week. The 2016 Christmas bonus increased to 85%. There was an increase in the Home Carers’ Credit by €100 to support one income families who care for children or the elderly in the home.

The Programme for a Partnership Government (2016: 33) committed to tackle unmet needs by introducing budgets with at least a 2:1 split between public spending and tax reductions. It pledged to spend at least an additional €6.75bn in delivering public services by 2021. This would cover the cost of areas including an ageing and growing population and targeted improvements in public services with a focus on health, education, disability and child development and care. There would also be targeted improvements in welfare payments for the elderly, people with disabilities, the sick and carers among others.
Chapter 1

Department of Finance

The Department and Dying, Death and Bereavement

In its response, the Department focused on taxation policy and in Capital Acquisitions Tax (CAT) and inheritance. CAT applies to gifts and inheritance “at a rate of 33% above a range of tax-free thresholds which differ depending on the relationships between the disponent (the bequester) and the beneficiary”.

Tax policy is aimed at ensuring that capital taxes contribute to State revenues. The yield from CAT has represented just 1% of overall tax revenues. The Department noted that, unlike taxes on earned income, capital taxes have less negative impacts on economic activity or employment. It also stated that there were exemptions from CAT which seek to deal with hardship for individuals. The CAT that is due can be paid in instalments over five years.

The Department dealt with members of the public by answering Parliamentary Questions, Ministerial representations, Freedom of Information requests and telephone queries.

Letters have been received that relate to an individual’s debts. It stated: “At times, there have been content in the letters received that suggest that because of pressures that the individual is under, that there is a threat to their life (suicide) or where a death has occurred”.

In replies, the staff offer their condolences and reply to the substantive issue. Departmental correspondence is proofed to include referring the individual to their GP, nearest hospital and contact names and telephone numbers for the Samaritans/Console/Pieta House and Suicide Prevention. On telephone calls, staff have a tip sheet which include the telephone numbers/websites of supportive organisations. Staff who deal with the public can use the Civil Service Employee Assistance Service if required.

In relation to future activity around dying, death and bereavement, the Department referred to its role in achieving the Government’s economic and social goals. It was always cognisant of its role for citizens “from the cradle to the grave”. The Department stated it could always evaluate its performance with the public through a range of methods to ensure that a quality customer service was delivered.

Comments and Recommendations

Nothing is certain in this world except death and taxes. The focus naturally turns to the Department of Health when it comes to managing the health of a nation but the financial policy pursued by a country has an impact on how much money a person has to manage their health, their quality of life and ultimately how much they can leave behind.

The Department of Finance is one of the most powerful Ministries. In its response to the questionnaire, it recognised its role in people’s lives from the cradle to the grave and its role in delivering social goals. The Department’s dealings with individuals can come at difficult times in people’s lives and the Department’s recognition of this facts and efforts to communicate sensitively at these times is welcome.

A number of recommendations are made which cover issues around communications, financial management and education and credit unions.
COMMUNICATIONS

It is recommended that all staff who have to deal with the public are regularly trained to ensure that they communicate appropriately and sensitively to people who are in contact with the department following a bereavement. The Department is dealing with complex financial issues. The Department should pay particular attention to how it communicates its work and translate its information into simple English. It should use multi-media to its full advantage to give a general explanation of rights and responsibilities following a death.

MAKING WILLS

A study by Amárach Research (2015) for MyLegacy found that only three in 10 Irish people have drafted a will. The preparation of a Will is most popular with the over 55s. The Irish Hospice Foundation’s research in 2014 found that 39% of people had not given any thought to drawing up a will (Weafer, 2014: 31).

The Department of Finance should support a public information campaign to encourage people to plan for the future which would include preparing a will. In his interview for this study, Michael Culloty of MABS raised the issue of financial education and highlighted that consumers in Ireland are not educated to read the small print. He highlighted the need to talk to people about basic budgeting, insurance products and saving products.

“Many living on very low incomes are often excluded from financial services. For them there are very few options for borrowing to cover the cost of contingencies as they arise. There are no suitable insurance products available to them to defray costs. All of this impacts on people’s capabilities to pay for emergencies that crop up in life like the cost of a funeral, with the result that low income families have to borrow, often from moneylenders at very high interest rates, to cover costs.” (Michael Culloty).

It is interesting that many credit unions will arrange with local solicitors to facilitate their members in the drawing up of a will free of charge.

FINANCIAL EDUCATION

It is recommended that the Department should collaborate with other Departments in the development of education tools on finance which can be used in our schools. This will ensure that people are exposed early in their education to issues around money management.

“MABS has responsibility for education with regards to budgeting and money management but our remit and resources do not allow us to cover general financial education. It is the Central Bank that have both the prudential responsibility and the consumer protection responsibility, but they don’t have the responsibility to educate the consumer. They have a responsibility to protect but not to educate.” (Michael Culloty).
A role for the Central Bank in financial education for the general population should be examined. MABS should also be better resourced to manage its community education brief.

**GENDER PENSION GAP**

There have been calls on the Government to undertake pension reform with a report by Age Action in February 2017 stating that about 36,000 older people are living on pensions reduced due to changes introduced by the Government in 2012 (Basset, 2017: 33). Some 40% of those affected were losing €1,500 each year and 62% of those affected are women (ibid). The research also highlighted “a refusal at Government level to address legacy issues from the marriage bar and other gendered State policies” (ibid).

This report supports a review of the State Pension. As this report is concerned with issues around dying, death and bereavement, a wider examination of income supports to look at the needs of widows/widowers and their dependents is also necessary.

This review should also look at the Homemaker’s Scheme which allows a disregard for up to 20 years for people who took time away from work to care full-time for children or a person with a disability. However, this scheme only applies to periods of caring from 1994.

It is unfair that many women are being penalised for taking time out of paid employment to care for their family and are therefore living on a small pension in their later years – especially when many of them had no choice. The particular needs of widows, widowers and surviving partners are dealt with in the Department of Social Protection.

**CREDIT UNIONS**

Credit Unions come under the remit of the Department of Finance. Credit unions affiliated to the Irish League of Credit Unions (ICLU) have over 3 million members. The *Programme for a Partnership Government* (2016: 49) pledged to lift the current lending restrictions and to develop a strategy of growth and development for the credit union sector. It also committed to support the extension of the Personal Microcredit Scheme.

It is important that the credit union are supported and the extension of the Personal Microcredit Scheme, “It Makes Sense”, in 2016 is welcome. The scheme involves credit unions giving small low-interest rate loans ranging from €100 to €2,000 to low income families. This scheme can help people to cover some costs around ill health or funerals as the loans can be used for any purpose and can be accessed within 24 hours.

**POST OFFICES**

The Scheme also demonstrates the value of the post office network. The “It Makes Sense” scheme is available to social welfare recipients who qualify for An Post’s Household Budget Scheme. The repayments are deducted from the borrower’s social welfare via the Household Budget Scheme in the local post office.
The *Programme for a Partnership Government* (2016: 48) contains a commitment to advance a model of community banking. It pledged to request An Post and the ILCU and other interested stakeholders to propose a new model of community banking, offering banking services through post offices.

In March 2017, the Department of Arts, Heritage, Regional, Rural and Gaeltacht Affairs undertook a public consultation process on the German Sparkassen model for the development of local public banks and community banking through the Post Office Network such as the Kiwibank model in New Zealand.

Responsibility for the Post Office Network has now reverted to the Department of Communications, Climate Action and Environment.

Regardless of which department is responsible for the Post Office Network the development of the country’s post offices is important because of their essential role in the local community and the profile of its customers. The Department of Finance should recognise and support post office network and their role in financial management for low income families.

**MONEY LENDING**

> “In our country, we have 330,000 customers of licenced money lenders. Nobody has any idea how many unlicenced moneylenders there are. But if you have 330,000 in a population like Ireland as individuals, and if you connect them to their families, let’s say an average of five or six people in a family, you are talking about 1.5m people that are affected by moneylenders.” (BRENDAN WHELAN).

It is strongly recommend that the Department of Finance take a more proactive role in the control of licenced and unlicenced moneylenders. Many of whom can charge an APR of between 120% and 190%.

**ELDER ABUSE**

Financial abuse is a serious issue for our citizens who are older and whose mental capacity is challenged. The Department of Finance should take a lead in ensuring all agencies or regulators have policies in place to combat abuse.

The Central Bank must expand the protection in its Consumer Code to ensure that all financial institutions have a robust “red flag” policy to identify possible financial abuse of older people. This is also relevant to An Post which must deal with abuse of accounts and in particular joint agency accounts.

There should also be defined and definitive safeguards put in place most especially for the collection of social welfare payments but also in relation to State Savings products in areas such as names on various accounts and the cashing in of the accounts.
“You are in private practice. You are saving for your pension. You have worked very hard. You have put your money into your pension. You’ve reached the age of 65. You have a personal pension fund. You have saved for your future full time care when you are 80 or 85. You need that money then.

When you are 65 you must turn that into an ARF - Approved Retirement Fund. You must nominate an intermediary, who charges you a fee. In addition the State will charge a levy each year. It is also mandatory that you draw down 4% to 6% of the capital each year and you are taxed on that sum.

If you do not draw down the money you are still taxed. So you have to draw down the capital. Then by the time you reach 80 you’ve no money left. And you will then be obliged to rely on the state to fund your care. All I’m saying is tax around private pensions is not right.” (PATRICIA RICKARD-CLARKE).

FAIR DEAL

The Department of Finance manages Ireland’s finances and its mission statement speaks of taking a leadership role in improving living standards. The vast majority of people wish to be cared for at home if they are dying (Weafer, 2014: 6) but most Irish people are dying outside their homes with 43% dying in hospital (IHF, 2013: 7). A 2016 report of social workers on the issue of community care concluded:

“Older people requiring care and support in many instances have no choice but to move into residential care settings, due to the under-development of community-based services and inconsistency of provision across the country. This is despite the overwhelming preference of older people for ‘ageing-in-place’, their right to private and family life and a state policy that commits to support older people to remain in their homes for as long as possible.” (DONELLY ET AL, 2016: 43).

The report found that “older people were regularly obliged to go into long-term care prematurely” because of problems with services (Donnelly et al, 2016: 7). Social workers in acute hospitals reported that more than half of their clients could have remained at home if the community supports were available (ibid: 35).

Speaking at the 2016 McGill Summer School, human rights barrister Maeve O’Rourke stated that the Fair Deal scheme allows the State to financially support older people in paying for their own nursing home care. She continued: “It’s not a statutory entitlement to care, in the sense that if State funding dries up, an older person can’t demand support”.

“Statutory entitlements do not guarantee you anything but queues, if you don’t have the resources.” (JOHN DUNNE).

The Nursing Homes Support Scheme (NHSS), A Fair Deal, was reviewed in 2015 when
the budget was €993m (Department of Health, 2015: 13). The review estimated that there would be a need for over 33,000 NHSS beds by 2024 – 9,000 more beds than in 2015 (ibid: 12).

In responding to the review, Sean Moynihan of ALONE stated: “35% of older people currently in nursing home care could be given the choice to live independently if they had the proper supports” (Moynihan: 2015b). ALONE estimated that home help three times a day was between €50 and €70 with an acute hospital bed cost between €800 and €900 a day (Moynihan: 2015a).

Meanwhile, Fianna Fail’s Willie O’Dea T.D. introduced a Bill – Nursing Home Support Scheme (Amendment) Bill 2016 – in the Dail on 13th July 2016 in an effort to put Home Care Packages on a statutory footing. The Bill is expected to complete Second Stage at the end of July 2017. People currently only have a statutory right to a nursing home place.

In November 2016, the Minister for Older People, Helen McEntee T.D. confirmed that Government policy was to help older people to stay in their homes and communities for as long as possible and long-term nursing care was a last resort (McEntee, 2016a). Minister McEntee also announced in November 2016 that work on developing an appropriate regulatory system for Home Care was underway and a Home Care Unit was being established in the Older Persons Services function of the Department of Health.

As part of its work to develop a statutory home care scheme for older people, the Department commissioned a review by the Health Research Board on how other European countries fund and regulate homecare services (McEntee 206b). This review was published in April 2017.

It is recommended that the Department should support the extension of the equivalent of the Fair Deal to support care/residence irrespective of where it is provided – nursing homes, sheltered residence, assisted housing and a person’s own home. In the long-term, home care should be put on a statutory footing. In the review, particular attention should be given to assessing the needs of those who wish to die at home.

**COSTING EXERCISE**

It is recommended that the Department supports a costing exercise to determine the entire costs (not exclusively health costs) of being seriously ill, dying and bereaved on an individual and on the state.

International studies have found that “the healthcare budgets of most countries are skewed towards spending on care in the last year of life” (IHF: 2013: 37). It is estimated that between 10% and 12% of a country’s total health budget is spent on caring for people in the last year of life (ibid) care. This would be €1.4bn in 2017. This is just the health budget.

Research in Ireland and the UK has found that there are significant costs for individuals and families to bear when they are ill. The UK consumer magazine Which? found that consumers face unforeseen costs in areas such as travel, heating, special foods and clothes (Which?, 2015: 4) while ICS research in 2015 also found that patients and their families faced additional costs including more household expenses (ICS, 2015: 4).
"If you are sick – it has an effect on your finances, on your sense of self, on your role in the family, on you as a breadwinner. Being sick is very expensive." (Irene Murphy).

There are other costs that the State bears when an individual is sick and needs income supports or the support of a carer. These are explored in more detail in the Department of Social Protection.

As part of the costing exercise, the Department should look at Canadian arrangements around compassionate care leave and benefits which allows employees to take time off work to care for a dying relative.

Brendan Whelan of the Social Financial Foundation suggested in his interview for this study that any research that is conducted into bereavement and terminal illness should speak to the people who are actually affected by financial difficulties.
RECOMMENDATIONS

- Provide annual funding to the Kevin Bell Repatriation Fund to ensure it is sustainable and can continue its vital work.

- Ensure that all staff receive regular training on communicating in difficult circumstances and on the needs of the bereaved.

- Develop a standard protocol where all Irish embassies and consulates prepare information clearly outlining the culture and administrative processes that authorities in the relevant jurisdictions undertake, following a death. It should include what communications bereaved families can expect to receive from these authorities on their return to Ireland. This information should be presented through a number of mediums.

- Consider how to support the specific bereavement needs of undocumented Irish in the USA, who cannot be present in Ireland when a loved one is dying or is buried.

- Champion the promotion of palliative care worldwide, including the right to access to essential palliative care medicines.

- Organise an awareness campaign on the need for people to take out travel insurance to cover circumstances such as an accident or death overseas.
BACKGROUND

Ireland’s relations with 178 countries worldwide are managed through a network of 80 diplomatic and consular offices and state agency offices in 42 countries (Dept. of Foreign Affairs and Trade, 2016a: 10-11). The network is supported by over 100 Honorary Consuls.

There were over six million visits abroad by Irish people in 2013. In 2014, the Department of Foreign Affairs and Trade (DFAT) dealt with over 1,650 serious consular emergencies and cases of Irish people injured, hospitalised or dying abroad (ibid: 16).

Some 669,806 Irish passports were issued in 2015 (DFAT, 2016a). A total of 733,060 passports were issued in 2016 and the 2017 figure is expected to exceed one million. This demand is driven by Brexit related applications from Great Britain and Northern Ireland (Deegan, 2017).

An estimated 70 million worldwide claim Irish descent. A Minister of State with responsibility for the Diaspora was appointed in 2014 and a Diaspora Strategy followed in 2015. In 2015, Irish Aid provided €647.51m in Overseas Development Assistance which included €140m in humanitarian assistance. At least half of Ireland’s aid budget goes to the least developed countries.

Ireland supports the authority of the United Nations (UN) and 2015 marked the 60th anniversary of Ireland joining the UN (DFAT, 2016b: 6). Since then, it has served three times as a non-permanent member of the UN Security Council. In 2015, along with Kenya, it co-facilitated the international negotiations on the UN’s new global development framework: the 2030 Agenda for Sustainable Development.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

DFAT reported that its Consular Section sets out procedures for assisting with the “large” number of deaths of Irish citizens overseas every year which Irish Missions assist. Most of these deaths are the “sudden or tragic” deaths of holidaymakers. In 2014, consular assistance was provided to the families of 217 people who died overseas.

It wrote: “With increasing numbers of citizens travelling overseas, our statistics show increased numbers of Irish requesting consular assistance abroad, including an increase in the number of deaths”.

DEPARTMENT OF FOREIGN AFFAIRS AND TRADE

The mission of the Department of Foreign Affairs and Trade is to serve the Irish people, promote their values and advance their prosperity and interests abroad, and to provide the Government with the capabilities, analysis and influence to ensure that Ireland derives the maximum benefit from all areas of its external engagement.
The Consular role is to assist families to “navigate the official processes that are required when a person dies abroad.” Its key role is to ensure that the family is informed of the death as soon as possible and in most cases, families in Ireland are informed through the Garda Síochána.

DFAT can assist families in practical ways: contacting the authorities in the host country, informing them on the various aspects of repatriation, such as the documents that are needed, the timeframe involved and providing a list of undertakers. Assistance is often needed to overcome language difficulties or to contact the relevant authority. DFAT operates a 24 hour service - a duty officer is on call after hours and at weekends.

Officials going on overseas postings receive training on bereavement issues as part of their preparation. In 2015, the Irish Hospice Foundation (IHF) delivered bereavement training sessions to officers in the Consular Assistance Section in Dublin and at the Embassy in Madrid. The focus was on improving the personal resilience of staff to ensure they could deliver a professional service. DFAT commented that the possibility of extending the training to other Missions from 2016 would be examined.

COMMENTS AND RECOMMENDATIONS

While the work of diplomats may not immediately be associated with dying, death and bereavement, a review of DFAT’s responsibilities reveals that these are issues to emerge across a range of activities.

The Department assists our citizens when they are most vulnerable when death or illness strikes on holiday. It is supporting reconciliation in Northern Ireland following decades of conflict and death. DFAT’s work in the developing world and with the UN is, simply put, to prevent avoidable or premature death.

Ireland has a strong and recognised commitment to human rights. Ireland was elected to the UN Human Rights Council in 2012. In One World, One Future, Ireland’s Policy for International Development, it states it will “reinvigorate its approach to human rights” devote more resources to gender equality and disability (DFAT, 2013: 3). The Programme for a Partnership Government (2016: 144) pledged to campaign for Ireland’s election to a non-permanent seat on the UN Security Council for the 2021-2022 term.

This section will outline some recommendations for the Department to consider, to ensure that it provides effective support for individuals, their families and in promoting the human right to a good death.

THE HUMAN RIGHT TO A GOOD DEATH

Ireland’s Overseas Development Assistance – Irish Aid - is a highly regarded donor programme. A 2014 report from the OECD (2014: 14) stated that Ireland delivered “effectively on its commitment to international development and to promoting global public goods such as peace, human rights and food security”.

Irish Aid’s strategic plan One World, One Future. Ireland’s Policy for International Development was published in 2013 and its vision (DFAT, 2013: ii) is: "A sustainable and just world, where people are empowered to overcome poverty and hunger and fully
realise their rights and potential”. It has six priority areas for action including essential services and human rights and accountability.

In essential services, the policy pledges to concentrate on strengthening health systems including a trained health workforce to deliver quality services, reaching those most in need (ibid: 22). On HIV and AIDS, it also committed to draw more attention to effective prevention.

A joint report entitled *Palliative Care and the Global Goal for Health* was produced by the Worldwide Hospice Palliative Care Alliance, International Association for Hospice and Palliative Care and the International Children’s Palliative Care Network in 2015.

The report concerned the sustainable development goals – negotiated by Kenya and Ireland - which were adopted by the United Nations in September 2015. It stated that “palliative care is an essential component of the Global Goals, being a key part of Goal 3: ‘Good health and well-being: Ensure healthy lives and promote well-being for all at all ages.’” (Jackson, 2015: 2). The report argues that many of the 13 targets in the global goal for health cannot be reached “without a focus on palliative care” (ibid: 4). It recommended that palliative care should be included in international and national policies and strategies for the global goals (ibid: 24).

The Irish Government and the Irish Aid programme should champion the promotion of palliative care worldwide including access to essential palliative care medicines. World Health Organisation (WHO) and the Worldwide Hospice Palliative Care Alliance’s (WPCAP) *Global Atlas of Palliative Care at End of Life* estimates that 20 million people worldwide need palliative care at the end of life every year (2014: 3). Only 14% of these people receive palliative care (ibid: 45).

Globally, 75% of people do not have adequate access to controlled pain relief medications (WHPCA: 2016a). A WHO resolution on strengthening palliative care in national health systems was unanimously adopted at the 67th World Health Assembly (WHA) in May 2014. Meanwhile, African Ministers of Health adopted the Kampala Declaration on Palliative Care in August 2016 which affirms their commitment to the WHA resolution on palliative care (WHPCA: 2016b).

Ireland was one of the first countries worldwide to develop a national palliative care policy in 2001. Ireland’s palliative care services were ranked fourth in the world in the 2015 Quality of Death Index from the Economist Intelligence Unit (2010: 23). A woman of Irish descent and UCD educated, Dr Anne Merriman, is a recognised pioneer in palliative care for her work in Africa.

The development of palliative care will support Irish Aid’s work in Africa, its focus on human rights, the provision of essential services as well as its work among individuals with HIV and AIDS. There is more recognition that palliative care is a basic human right. While the Irish Aid focus is on prevention, making quality palliative care services available ensures a holistic approach to care for people living with HIV and AIDS.
The UN Principles for Older Persons are the operating principles which underpin Ireland’s National Positive Ageing Strategy (2013: 18). The 18 principles were adopted by the General Assembly in 1991 and cover independence, participation, care, self-fulfilment and dignity. The UN, through the Open Ended Working Group on Ageing, has been discussing whether a new International Convention should be developed.

The Seanad Public Consultation Committee Report on the Rights of Older People in March 2012 recommended that the Government advance the case for drafting a new UN Treaty. This report supports that recommendation. Any human rights instrument for older people should include the right for older people to access pain relief, palliative care and bereavement support.

### REGULAR BEREAVEMENT TRAINING

The bereavement training for staff travelling to overseas missions is positive. The involvement of the IHF is also a welcome development. It is important that all DFAT officials receive this training on an ongoing basis to ensure a consistent, compassionate and professional response to challenging situations such as dying, death and bereavement. A template document should also be developed which will be used by each Embassy or Consulate to prepare information on the specific culture and administration of the relevant jurisdiction. It would outline what the family can expect to receive from the authorities in the country where their loved one died, when the bereaved family returns home.

The varied information needs of families whose loved one has died abroad need to be considered with tools such as an information pack with relevant details on repatriation and bereavement sent from Iveagh House or available from Embassies or Consulates overseas. Other resources such as an information video should be considered.

“As regards Irish citizens who die abroad we get notified of every case that comes to Dublin Airport. These are the people being repatriated to Ireland who have died in America, or on the continent or in other countries. We will touch base with the families in every case to see if there are any issues in those countries that they need us to look at.

Because sometimes coming back, there will have been no autopsy done.

The medico legal system is very variable around the world.

Sometimes it is appalling and the families are treated with no information.” (Dr Brian Farrell).

It is also important that attention is paid to the need for a physical space in Embassy or Consulate offices which can be used for private conversations with families in these distressing circumstances. If not already in place, DFAT should devise self-care and debriefing protocols and procedures for staff.
A positive response from DFAT has a significant impact at home. Brian Moore, former Deputy Principal at St Mary’s College, Rathmines in Dublin and now Principal of Rathdown Senior School, described the support from DFAT to the school as “outstanding” following the deaths of former pupils in the 2015 Berkeley tragedy. He stated: “...they were swift, they were collaborative and they were available and from the very highest level, from Secretary General level, they would say, this is my mobile.” He continued: “They treated trauma as an injury and they were conscious that there was physical trauma, but there was also a profound psychological trauma”.

FUNDING FOR REPATRIATION

Following a death overseas, DFAT will provide vital supports to the family. DFAT does not pay for any costs associated with the death – repatriation of the body to Ireland, funeral expenses, or relatives travel to where the death occurred, or to accompany the remains home.

The Kevin Bell Repatriation Trust (KBRT) was set up in 2013 following the sudden death in New York of young Newry man Kevin Bell. His community raised funds to bring Kevin’s body home. As Kevin’s employers paid for his body to be returned to Ireland, his family have used the funds raised by the community to support other families in similar situations. The KBRT receive donations from the public and it was one of the GAA’s five official charity partners in 2016.

As of March 8th 2017, the Trust had repatriated 280 Irish citizens. The Trust pays and arranges for the return of the remains. Following a meeting with former Minister of State for the Diaspora, Jimmy Deenihan, every Irish consulate and Embassy has the contact details for KBRT. They relay these details to families in these circumstances. The numbers seeking support from the Trust has increased since then. The Trust is run by the Bell family and it has an office with one administrator.

In addressing the Oireachtas Committee on Foreign Affair and Trade and Defence on September 22nd 2016, Mr Colin Bell outlined that they were looking to get approximately €30,000 per year to cover the cost of the office and part-time staff. The Trust had charitable status in Northern Ireland and as of March 2017, it was still awaiting charitable status in the Republic of Ireland.

KBRT is performing an essential function for families and it is recommended that they are provided with the financial support from DFAT to ensure their operation can continue into the future.

AWARENESS AROUND TRAVEL INSURANCE

The issue of travel insurance was raised during the discussion with Colin Bell at the Oireachtas Committee on Foreign Affairs and Trade and Defence on September 22nd 2016. The government should engage in an awareness campaign for Irish people travelling abroad to ensure that they take out travel insurance while overseas, so that in the event of an accident or death, some costs are covered.
SUPPORTING THE UNDOCUMENTED IRISH

Immigration reform is a key issue for the DFAT. An estimated 50,000 Irish people are undocumented in the USA. People caught in this situation cannot physically take part in family events in Ireland such as weddings because of the risk of being denied re-entry to the USA. Their status in the USA can also deny them the opportunity to be present in Ireland when close relatives are dying or to attend their funeral upon their death. While some Churches and funeral undertakers can make arrangements for people to remotely access the service, this is a heavy burden on the individuals.

It is recommended that DFAT should be conscious of the bereavement experience of the undocumented Irish and ensure that diaspora networks receive appropriate bereavement information.
RECOMMENDATIONS

- Encourage all local authorities to explore the possibilities that the Compassionate Communities project of Limerick could offer in their area.

- Develop a specific plan to support homeless people who are dying.

- Promote a national dialogue on the concepts of smart ageing, the lifetime adaptable house and building homes to universal design principles.

- Learn from pioneering housing developments such as McAuley Place in Naas, Co Kildare and use it as a template across the country.

- Increase public awareness and fund adaptation grants for homes.

- Ensure issues around dying, death and bereavement are included in local economic and community plans.

- Provide mobility aids to allow people to access public facilities such as parks.
Minister Coveney states in the Department's Statement of Strategy 2016 that the Department of Housing, Planning, Community and Local Government (DHPCLG) has an impact on the life of every citizen every day. He stated (DHPCLG, 2016a: 1):

“How we plan for development, how we provide homes for our people, how we provide water services and manage our water resources, how we fund and structure our local government for optimal service delivery directly to citizens, how we support vibrant, inclusive communities, how we produce and provide reliable weather and climate information - these are all key cornerstones of daily life.”

The Department's main strategic focus over the coming years is the housing crisis and implementing the Rebuilding Ireland – Action Plan for Housing and Homelessness. The aims under this action plan is to double residential construction to 25,000 homes and deliver 47,000 social housing units in the five years up to 2021 (DHPCLG, 2017: 1). Other objectives include providing access to the Housing Assistance Payment (HAP) to households that can benefit for the secure housing support.

There has been significant reform of local authorities in recent years with the number of local authorities reduced from 114 to 31 and a reduction of 500 councillors (Dept. of Environment, Heritage and Local Government, 2012: vii). Recognised by the Constitution, local authorities have their own democratic mandate and are independent corporate entities. The Department is responsible for fire services policy and is the lead Government Department which is responsible for coordinating the response in 10 emergency/crisis scenarios.

It is also responsible for arrangements for all elections – general, referendum, Presidential and bye. In 2015, DHPCLG provided support for a Dáil bye election, a Seanad bye election and two referendums (DHPCLG 2016b: 11). It organised the 2016 general election and in March 2017 it published an Options paper on the issue of extending eligibility for citizens resident outside Ireland to vote during Presidential elections.

DHPCLG stated that greater effectiveness and efficiencies in the delivery of local services was a priority and enhancing the role of local government in local and community development was central to this. Our Communities: A Framework Policy for Local and Community Development in Ireland was launched in January 2016. Local Community Development Committees had been established in all local authority areas to manage and coordinate local and community development programmes including the Social Inclusion and Community Activation Programme (SICAP). The aim of SICAP is to
tackle poverty, social exclusion and long-term unemployment. The Local Community Development Committees also develop community elements of the new six year Local Economic and Community Plans which have been adopted for all 31 local authority areas. A new revamped RAPID programme will be rolled out in areas in 2017. A new Community Facilities Fund provides small scale capital funds to enhance community, infrastructure and social cohesion in urban and rural areas.

The Department is responsible for Ireland’s national meteorological service which is to expand and develop its range of services. Digital services will be upgraded and more localised weather forecasts delivered on a new website and app.

**THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT**

A questionnaire was distributed to all Departments in 2015. The Department of Housing, Planning, Community and Local Government was called the Department of Environment, Community and Local Government. Following the 2016 general election, some community functions were transferred to the Department of Arts, Heritage, Regional, Rural and Gaeltacht Affairs. Some environmental functions transferred to the Department of Communications, Climate Action and Environment. The Department was contacted in late 2016 to ask it to review its questionnaire in the light of the new title and responsibilities. The Department responded with a letter which outlined the change in its functions. It also updated version of its submission on the work of the Directorate for Fire and Emergency Management. In its letter, it pointed out that the Department did not regularly have a role in engaging or interacting with the public on dying, death and bereavement. It does not provide direct services to the public in that regard. The Social Inclusion and Community Unit in the Department retained responsibility for Burial Grounds Regulation.

**NATIONAL DIRECTORATE FOR FIRE AND EMERGENCY MANAGEMENT**

The Directorate gives “central direction and leadership” for the fire and emergency services on a national level. Its mandate includes developing national policies and standards and overseeing their local implementation. The local authorities are responsible for the daily operation of fire services.

The policy document, *Keeping Communities Safe* sets out the strategy and is consistent with international best practice and uses a risk management approach. The submission stated: "It sets challenging targets for improved fire safety through a reduction in incident levels, improving the number of dwellings with smoke alarms and further reducing the annual fire death rate of 6 per million of population”.

**FIRE FATALITY STATISTICS AND REPORTING**

The National Directorate for Fire and Emergency Management (NDFEM) compiles information on fire fatalities on an ongoing basis from local authority returns. The information is published annually on the department website. 2012 and 2013 had the lowest annual death toll in the past 40 years at 24 and 26 respectively. In 2015 the figure was 41 persons.
CRITICAL INCIDENT STRESS MANAGEMENT

The submission stated that the provision of Critical Incident Stress Management services (CISM) for fire service personnel may be relevant to the enquiry. Fire Services have systems in place for safety, health and welfare. They are aimed at protecting the physical or psychological health of staff. This is also in compliance with the Safety, Health and Welfare at Work Act, 2005.

The NDFEM conducted a review of CISM services in 2015 and 2016. The review included a study by the School of Psychology in Trinity College Dublin and a survey among Fire Service personnel. Some changes were recommended but the review found that the CISM arrangements were “fit for purpose”.

MASS FATALITY PLANNING

There have been a number of mass fatality disasters in Ireland in recent history: Spanish Influenza (1918/19), The Whiddy Oil Terminal Explosion (1979), Buttevant Rail Crash (1980), Bundoran Hotel Fire (1980), the Stardust Fire (1981) and the Air India explosion (1985).

The Principal Response Agencies (An Garda Síochána, HSE, local authorities) establish plans to deal with such eventualities. The submission stated:

“The Cork Airport Tragedy and the Carrickmines Fire Tragedy are recent reminders of the necessity for planning to deal with mass fatality disasters. It should be noted that lessons are identified from numerous international incidents regarding the need for sensitivity and preparedness when dealing with deceased victims of a major emergency/disaster.”

It stated that following a mass fatality disaster, hospital mortuaries become overwhelmed. Programmes are required to effectively carry out the management of human remains and respond to the needs of families of the deceased. Good practice suggests that a single facility be used for all the deceased victims. Many specialists will be involved in providing and operating a temporary mortuary facility and in supporting the coroner.

The structures and procedures for a co-ordinated response are set out in Ireland’s Framework for Major Emergency Management (2006). Mass fatality planning ensures the appropriate arrangements, resources and services can be assembled and work together effectively to deal with an emergency resulting in a large number of fatalities. The response will most likely involve recovery of fatal casualties, identifying and certifying the dead and investigating the cause of death, both for coroner’s purposes and if there is a suspected criminal involvement.

The submission explained:

“The objectives of the mass fatality project include maintaining respect in dealing with deceased victims in a safe and appropriate manner, whilst linking with and caring for the interests of the bereaved families in the quasi-judicial processes associated with the aftermath of such disasters.”
Where necessary, relevant local authority will provide temporary mortuary facilities to manage the processing of deceased victims by those with defined roles (coroners, pathologists, anthropologists, odontologists and forensic specialists etc) “in the fatality process”.

A first draft of a Guide to Mass Fatality Planning has been circulated to the Mass Fatality Expert Group. The document aims to support Principal Response Agencies inter-agency planning for mass fatality events on a regional basis. The guide provides information on a range of issues including public information and “communicating with families of deceased victims”.

Work is underway to develop a mass fatality plan for each Major Emergency Management region (8) supported by appropriate resources, procedures and structures in line with the 2006 Framework. The Health Service Executive has developed a guide for psychosocial care following major emergencies.

**COMMENTS AND RECOMMENDATIONS**

The *Framework for Major Emergency Management* is an extensive document which details the management of casualties including fatalities of a major disaster, the care of people affected including vulnerable persons and non-nationals and refers to the physical and psycho-social needs of survivors. On the establishment of Friends’ and Relatives’ Reception Centres, it advises that there should be sufficient room to afford privacy for families receiving information about relatives.

A key issue for all healthcare personnel is communications and particularly the task of breaking bad news to relatives. Comforting survivors, relatives waiting for news of the fate of a loved one or the bereaved in an emergency situation as well as meeting their information needs is very challenging. The guide on communicating with families of deceased victims is welcome. It is recommended that the guide should be supplemented with regular and appropriate ongoing training for emergency services on caring for people in these difficult situations and in breaking bad news.

**QUALITY HOUSING**

An objective of the Department’s *Statement of Strategy* in the area of housing includes supporting Local Authorities in responding to the needs of tenants particularly those with distinct needs such as people with disabilities and the elderly and to improve the quality of social housing (DHPCLG 2016a: 19). The actions identified included supporting the implementation of the Energy Efficiency Retrofitting Programme to improve the fuel efficiency of social houses nationwide and tackling fuel poverty. It also committed to adapt social housing to meet the needs of people with a disability and older people.

In its submission to DHPCLG for the consultation on its Statement of Strategy, the Society of St Vincent de Paul (SVP) identified a number of priority actions including the development of “quality, energy-efficient homes in all tenures that meet housing need across the lifecycle” (SVP, 2016: 2).
One of the key issues to emerge from the research conducted among TDs and Senators for this report was that information on services such as adaptations to homes were the top three issues raised most often by the public. The DHPCLG was one of the departments most contacted by TDs and Senators to deal with on end-of-life issues. When asked what they believed the State should do to improve services, most TDs and Senators suggested information provision such as a public campaign to highlight the benefits that are available. Other suggestions included downsizing options for housing in the community.

NEW HOUSING MODELS

The Department’s Statement of Strategy (2016a: 19) pledged to work with the Department of Health to develop policy options for supported housing/housing with care so that older people have a wider range of residential care choices available to them. It also committed to taking a “cross-Departmental/inter-agency approach” to advance pilot housing projects to cater for people with healthcare needs that can be met in the community (ibid).

In January 2017, Damien English T.D., Minister for Housing and Urban Renewal launched the 2017 Homes for Smart Ageing Universal Design Challenge. This is an initiative under the Rebuilding Ireland Programme and aims to encourage innovation in design and delivery of housing solutions for older people. Minister English stated: “...with the number of people over the age of 65 expected to reach 1.4 million by 2041, the implications for public policy in areas such as housing, health and urban and rural planning are considerable”.

On the use of existing housing, the Department pledged to explore ways to promote the availability of "step-down, specialist housing, for older people and incentivise downsizing, where appropriate" (2017: 21).

In its submission on the development of the Department’s Strategy, Age Action (2016b: 4) wrote that arguably the most important of the Department’s actions on housing would be the need to develop alternative housing options. It stated: “The near universal preference among older people is to stay at home as long as possible but, if and when this becomes no longer practicable, there are few housing options other than the local nursing home” (ibid).

The Dublin City Age Friendly Programme’s Housing Working Group (HWG) has identified a site in Inchicore for a "Housing with Support demonstration project" of 50/60 units which will "incorporate universal design principles and age friendly design recommendations which allows for the adaptability of the home over the life-course" (2016: 3). In its 2016 report, the HWG stated: “The interplay between appropriate housing design, suitable location and the availability of supports is recognised to be the key determinant of quality of life for older people. With the right tailored supports in the right setting, older people can become more independent, not less, as they age" (2016: 9).

The report also observed (2016: 6):

"Most of us want to stay in our own homes as we grow older. Many homes are unsuitable for reasons of poor quality, inaccessibility,
isolation etc. There are insufficient community-based supports for older people, so that the system is often slanted towards residential care. Inevitably, many older people who could be supported to live in the community, find themselves in expensive and unwanted, residential settings.”

This report recommends that DHPCLG learns from pioneering housing developments such as McAuley Place in Naas, Co Kildare and use it as a template across the country. McAuley Place is a complex of 53 self-contained one-bedroomed apartments in the former Convent of Mercy in the centre of Naas town. It was developed “as an alternative to institutional residential care for older people and a model that would create a society for all ages”. The development – an initiative of the Nás na Ríogh Housing Association - has incorporated the United Nations Principles for Older Persons. It boasts facilities such as Convent Tea Rooms, an Arts and Culture Centre and a Community Centre. The emphasis is on wellness rather than illness. It has a vibrant Volunteer Hub with over 80 individuals from the local community ranging from the age of 12 to mid-80s supporting the development. A Health through Learning Centre in currently under construction with an associated garden. When completed, it will consist of a community lounge, three creative/making rooms, accommodation for an artist in residence and ancillary services. This facility leads out to the Luisne garden which was officially opened by Minister Helen McEntee T.D. at the end of 2016. President Higgins visited the McAuley Place on 13th June 2012 and was reported as telling politicians to “take this as an example of what should be done around the country” (O’Meara, 2012).

“I wanted to create an intergenerational community. A community of interest, not of age. A community of connection, not of fragmentation.” (MARGHRITA SOLAN).

There is also a need for public dialogue on the concepts of smart ageing, the lifetime adaptable house, building homes to universal design principles and Assistive SMART Technologies. These are not remote academic concepts but can enhance people’s experience of life in the future. Part M of the 2010 Building Regulations covers issues around access and use. However, we need to look at our built environment particularly our homes from an end-of-life perspective to ensure that the interiors are flexible and adaptable to our changing health needs. We are not building homes that we can live in when we are over 65. We need support if we are to age in place.

ADAPTATIONS

The relevant schemes for adaptations are the Housing Adaptation Grant for People with a Disability where the maximum grant is €30,000. There is a Mobility Aids Grant Scheme which is also means-tested and provides a maximum grant of €6,000. Finally, the Housing Aid for Older Persons Scheme is available and local authorities vary on the work they will grant aid.

Under the rules governing the Mobility Aids Grant Scheme, the highest priority is given to people who are terminally ill, or where alterations or adaptations would facilitate
their discharge from hospital or the continuance of care in their own home. Similarly with the Housing Adaptation Grant for People with a Disability, a person with a terminal illnesses is classified as priority 1. The recognition of the needs of people at end of life is welcomed. However, it is important that these grants are adequately resourced in the long term.

A 2013 review of the Housing Grants stated that it was aware of the positive impact the grants had but the lack of funding for local authorities would impact on grant availability (Housing Agency, 2013: 9). Minister Coveney announced increased funding for housing adaptation grants in 2017, which would enable 9,000 grants to be made. This is welcome but funding must be sustained. We are aware that our population is ageing, therefore it is imperative that this funding is expanded. An analysis from Age Action revealed falling levels of funding and allocations in housing aid for older people from 2010 to 2015. Some €30.3m was distributed to 7,160 recipients in 2010. In 2015, €11.2m was dispersed to 3,127 recipients (2016b: 3). Ensuring that older people live in a “well-maintained” safe home is part of the National Positive Ageing Strategy (2013) and will ensure that people live longer in the community – in their own homes. This is not only in the interests of the individual but of the State, as providing supports such as adaptations and community care is ultimately less expensive than hospital or institutional care.

In the survey of TDs and Senators conducted for this report, 81% of respondents stated that their constituents had raised the issue of Information on services, such as adaptations to home with them over the past year.

It is recommended that the budget for adaptations be optimised. While it is welcome that people with a terminal diagnosis are prioritised for grants, a system should be developed to fast track adaptations for people who are diagnosed with a life-limiting or life-threatening condition, to ensure that they can live for as long as possible in their own homes. There should be campaign to raise public awareness of the adaptation grants that are available.

**HOMELESS WHO ARE DYING**

“Homelessness isn’t all about housing. It’s a much deeper problem, and its much harder for people to accept that there are those who are different, and just don’t fit in and aren’t going to fit in, and they will always be outsiders in our world. They are always going to be outsiders even when it comes to dying.” (Alice Leahy).

A person who is homeless has a reduced life expectancy – on average 47 years for men and 43 for women (Walsh: 2014: 44). This compares with average life expectancy of 79.3 for men and 83.5 for women for the general Irish population in 2014 (Department of Health, 2016: 14). A 2014 report from the Simon Community looked at the needs of older homeless people who are faced with serious ill-health and dying. The report stated that research suggested that most homeless people probably die in acute hospitals and the most common causes of death include multiple organ and liver failure. It stated: “Delivering high quality end-of-life-care for people who are homeless clearly presents particular challenges for housing and healthcare” (Walsh, 2014: 47).
Interviews were conducted with 16 homeless individuals who gave valuable insights into their views on the dying of the homeless. Most had thought about and were fearful of death. Few had thoughts about what they might want at the end of their lives, but for those who did, they wanted to have family close, or to make peace with their family and children before they died. The vast majority did not want to die alone and the transfer to a nursing home was what they feared most. If they died alone, the interviewees wanted to die in their sleep and be found quickly (ibid).

The report recommended that people working with the homeless should receive end of life training. It stated that particular provision was needed within the health service for end-of-life care for homeless older people. The report suggested that the Think Ahead initiative promoting discussions on end of life might be beneficial for staff. It also recommended the appointment of a Palliative Care Coordinator shared between different services and organisations and work to be conducted on ensuring that palliative care beds in community hospitals countrywide were accessible to the homeless. (ibid: 48). This report supports the development of a specific plan to meet the end-of-life needs of the homeless within a national strategy.

“One of the issues is the hostels, if it is a hostel where people can stay fairly long-term, they would have built up relationships with the staff. The staff on the ground are generally people they can relate to, and they can talk to and they can share with. Very often they know more about the people than those who come in because suddenly when they become ill they have services coming and very often the emphasis is to get them out of where they are and get them into a better facility. But that may be very alien to the surroundings they were in and they were happy to be in. Now hostels may not be considered fashionable, not good enough. You have to move people on but often you are moving them on to lonely rooms. The only support they may have is from some young person who is not from this country and who not understand them. If they are facing death, they can become displaced by the services. They have to kind of fit in to the service that is there which can be very far removed from what they’re used to.” (Alice Leahy).

NATIONAL PLANNING FRAMEWORK

A national consultation for the preparation of Ireland 2040 – Our Plan, the strategic planning and development framework plan for the country, began in February 2017. By 2020, it is projected that there will be an extra one million people on the island and the number of people over 65 years will be double the current level reaching over 20% of the population (DHPCLG, 2017b). According to the National Positive Ageing Strategy (2013: 7), Ireland will have 1.3 million to 1.4 million people aged over 65 by the year 2041.

Writing in the Framework, Minister Coveney stated: “In an increasingly globalised but uncertain world, our sense of belonging to both community and place, our unique artistic and cultural inheritance and the value we place on social justice, a European model of inclusion and ‘fair play’ are key ‘place-making’ assets that set us apart” (DHPCLG, 2017c: 2).
The interests of our citizens at end of life – of all ages and all diagnoses – and the bereaved should be considered when this Framework is drawn up to ensure that our infrastructure supports people to live and die well in the location of their choice and with access to the services they need. This is key to any Ireland 2040 plan.

Policy makers are conscious of the role of the built environment including our green open spaces as a determinant of health stating: “How we ‘make’ places can have a huge influence on people’s health and wellbeing” (ibid: 7).

“If an environment is badly designed it can actually limit your life. It is going to have an effect on how you experience life. It is going to have an effect on how you relate to people. And how you see yourself and your own sense of self-worth. If you provide an environment for somebody where it is clear from the quality of the place that time and effort and money has been put into it, I think that sense of respect that has been invested will be given back. That goes for a house or a street or a town.” (RONAN ROSE ROBERTS).

The issue of mobility facilities for individuals – regardless of age or disability – to enable them to enjoy our natural resources and parks should be addressed. This would include the provision of buggy/golf cart/mobility frames to enable those at end of life to be able to enjoy our outdoor areas and get around and live.

COMMUNITY

“Where I live now there is a little park on a flat stretch of road and there is a playground for children, and there are exercise machines for older people, and it is safe. And there is a good public library and it is easily accessible, and we go there to read the paper because it is warm and comfortable. And in the foyer of the library there are photographic exhibitions and crafts. We need to have a life and live in our own community. And if your house was fine when you were young, and is no longer suitable for your needs, it should be adapted so that you don’t have to go into a nursing home, or live on the other side of town.” (IRENE MURPHY).

The 2015 Framework Policy for local and community development (2015: 21) states that one of the purposes of local government is to “promote the well-being and quality of life of individuals and communities”. The local authorities have a key role to play in the lives of individuals at the end of life or coping with a bereavement through the provision of quality homes, safe infrastructure such as the design of roads and well maintained roads and access to a pleasant built environment such as parks. But the local authorities can also play a role in promoting community awareness of end-of-life issues. Initiatives such as Compassionate Communities project in Limerick which has been in development since 2009 should be reviewed by all local authorities and adopted nationwide.
Jim Rhatigan, Head of Therapy and Social Care Services at Milford Care Centre, explained that:

“The experiences of illness, dying and death are fundamentally social experiences, in terms of people live with those experiences in their families and in their communities. Their interaction with the health and social services are intermittent and relatively minor in the context of their life.”

This highly regarded project encourages the community to provide practical support to those who are at end of life or bereaved.

It is recommended that an approach akin to affirmative action is taken to ensure that individuals or organisations with a knowledge of the needs of people at end of life and the bereaved, are represented on the Public Participation Networks in each local authority, and end-of-life issues are considered as part of local Economic and Community Plans. All local authorities should explore the possibilities that the Compassionate Communities project of Limerick could offer in their area.

Professor Allan Kellehear of the University of Bradford has developed the concept of the Compassionate Cities and at a public talk in Dublin in 2009, he was reported as stating that “without support, autonomy is not sustainable in the face of deteriorating health, social networks, or finances” (McGarry, 2009). Community development and health promotion, he said, were crucial at the end of life to preserve our independence.

Compassionate City is “…a community that recognizes that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone’s responsibility” (Kellehear, 2015). A Compassionate City Charter has been developed which consists of a number of principles and in adopting these principles, organisations including State institutions and communities work together to support people at end of life and into bereavement.

Speaking before the Oireachtas Joint Committee on Health and Children during public hearings on end-of-life care issues on 24th October 2013, Professor O’Shea stated:

“In respect of how communities are changing, particularly with regard to age and family structures, a good death requires communities of the living.

By that, I mean that we need living and vibrant communities in order for all of us to die well. There must be some public visibility around death and that understanding of death to support the private grief that is associated with it.

This is something we need to think about in terms of how we organise health and social care services, and how we integrate voluntary, statutory and family views about death.

It is critical to keep that community focus on the way we think about a holistic view of health rather than a clinical one all the time.”

(O’Shea, 2013).
RECOMMENDATIONS

- Develop its own bereavement policy and promote the value of a Bereavement Policy to its own agencies and businesses countrywide.

- Encourage more bereavement-friendly workplaces where companies develop bereavement policies, and managers are trained to support their grieving workers in the pre and post death period.

- Highlight the value of bereavement policies while on the International Labour Organisation governing body for its 2017-2020 term.

- Review the issue of bereavement leave to bring the public and private sectors into line with the civil service.

- Promote fair succession planning among businesses, to ensure there is adequate pension provision for the future needs of the older person.

- Encourage employers to provide pre-retirement courses for staff and promote future planning using tools such as *Think Ahead*. 
BACKGROUND

The role of the Department of Jobs, Enterprise and Innovation (DJEI) is to help deliver jobs for Ireland by supporting indigenous enterprises and attracting foreign direct investment, while also protecting worker and consumer rights.

The target is to have 2.1 million people in employment in 2018 and 2.18 million in jobs by 2020 (DJEI, 2016: 16). A key document in this endeavour is the Action Plan for Jobs which is an integrated, whole of government initiative under which department and agencies work to support job creation in the enterprise sector. The 2016 Action Plan for Jobs is the fifth such plan. The Action Plan for Jobs process was described by the OECD in 2013 as “an important innovation in Irish governance” (DJEI, 2014: 10).

The delivery of this ambitious employment commitment involves a multifaceted approach, including skills development such as apprenticeships, facilitating access to financing and marketing of Ireland to overseas markets.

A number of strategies have been developed including Enterprise 2025 which is a 10 year jobs and enterprise strategy and Innovation 2020, a five year strategy for research and development, science and technology. Sectoral strategies have been devised such as Food Wise 2025 for the agri-food sector; IFS2020 for international financial services sector; People, Place and Policy – Growing Tourism to 2025 for the tourism sector and the new National Aviation Policy for Ireland.

Another key aspect of the work of the Department is the wellbeing of workers. In the 10 years from 2007 to 2016, there were 520 deaths in work-related accidents. Some 44 people died in workplaces in 2016 which was a drop of 21% on the 56 work related deaths in 2015. There were also 55 work related fatalities reported to the HSA in 2014, 47 fatalities in 2013 and 48 deaths in 2012 (HSA, 2015: 6). In the EU fatality statistics, Ireland had the sixth highest worker fatality rate within the EU15 in 2012 (ibid: 7).

It is estimated that in 2014, there were 750,000 days lost across the entire economy due to work related injury. The estimated number of days lost due to work related illness was 1.1 million in 2014.
THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

The Health and Safety Authority (HSA) comes under the remit of the DJEI and is the national statutory body responsible for ensuring that Ireland’s 1.8 million workers and those affected by work activity are protected from work related injury and ill-health. The HSA enforces occupational health and safety law, promotes accident prevention and provides information and advice. The Department stated that the current workplace fatality rate for all sectors was approximately 2.2 per 100,000.

The HSA is responsible for investigating workplace fatalities and engages directly with those who have suffered bereavement. Since 2004, it has a policy and procedure relating to this engagement. Where possible, it has a single point of contact for the bereaved. The point of contact is a Grade 1 Inspector and not the investigating inspector. A bereavement pack is provided and the bereaved are also provided with information on the inquest process. There might be a prosecution following an investigation and the HSA maintains contact until any prosecution is completed.

The Authority identified the need for training to support staff who are engaging with bereaved families and to help the staff themselves to cope. This training was last provided in 2013 by an external service. The HSA has engaged with An Garda Síochána on their procedures around interviewing those affected by a workplace death who may have to be interviewed. An Garda Síochána have also facilitated training in this area.

The HSA was involved in a working group set up by the IHF which supported the production of a resource pack entitled *Grief At Work* which assists employers in dealing with bereavement at work.

Through its investigation and prosecution roles, the HSA engages with the Director of Public Prosecutions. When requested, it has sought victim impact statements for prosecution.

The HSA is represented on the board of directors of Embrace Farm which was founded in 2014 and provides a bereavement support group for farm families who have lost a loved one or been seriously injured in a farming accident. The HSA provides reports to the coroner in relation to deaths that occur at a workplace as a result of a work activity.

The HSA engages with the public on workplace death by issuing an annual statistics report and annual fatality figures to the media at the start of each year. This provides a means of advising the public and raising awareness of the key causes and sectors of concern. Specific media campaigns have been organised to raise awareness of workplace health and safety issues.

The Department, together with the HSA, promote the official commemoration of Workers Memorial Day which was first commemorated in 2015. This event aims to keep the issue of workplace fatalities to the forefront by remembering those killed, injured, made ill and bereaved through work related accidents. Work related fatalities will continue to be a critical area highlighted by the HSA. The approach has been to use survivor stories in the print and audio media.
CHAPTER 1

COMMENTS AND RECOMMENDATIONS

HSA protocols to support bereaved families appear to be thoughtful and thorough. It is recommended that the information that is provided to families should be kept continually under review to ensure that it is appropriate. There are also opportunities for the DJEI to champion the development of bereavement friendly workplaces not only in Ireland but internationally. This would involve encouraging companies to train managers in supporting grieving employees, encouraging flexible work arrangements and developing bereavement policies. It is understood that the DJEI itself does not have a bereavement policy and this should be developed immediately.

BEREAVEMENT POLICY

An estimated one in 10 of the workforce is directly affected by bereavement each year. The Irish Hospice Foundation commissioned a review of bereavement policies and practices in 34 organisations in 2006. It found that all of the organisations had experienced employee bereavement in the previous 12 months. Some 94% of organisations believed an employees’ performance is or could be affected by a bereavement. Some 62% felt there are or could be health and safety implications for grieving employees with 44% finding an increase in sick leave after a bereavement. Half of the organisations or 50% believed that employees behave differently after a loss (IHF, 2006: 47).

The IHF recommends organisations taking a proactive approach to managing workplace grief and building a supportive work environment. This approach may help to reduce sick leave and yield significant savings. It estimates that for each day that bereaved employees can work and not take sick leave, there could be a saving of €14.4 million per year (ibid: 12).

ComRes research from the UK in 2014 found that 56% of people said they would consider leaving their job if their employer did not support them if someone close died. Some 87% agreed all employers should have a compassionate employment policy, including paid bereavement leave and flexible working. A total of 82% said that providing paid bereavement leave was likely to be beneficial to the employer in the long-term (National Council for Palliative Care, National Bereavement Alliance and Dying Matters, 2014: 7).

DJEI, through the HSA, was involved in the development of the IHF’s Grief At Work publication. It should now develop its own Bereavement Policy and disseminate information on the value of a bereavement-friendly workplace and a Bereavement Policy to businesses countrywide. It should also ensure that its use is integrated into management training offered to entrepreneurs or companies which are supported by the taxpayer.

For the first time, Ireland has secured a Titulaire seat on the International Labour Organisation’s governing body for its 2017-2020 term. It is recommended that if and where possible, Ireland should use this opportunity to highlight the needs for businesses, of all sizes, worldwide to learn more about the impact of bereavement and the value of developing a bereavement policy.
PAID BEREAVEMENT LEAVE

The need for paid bereavement leave is something that should be discussed as part of a wider dialogue on end of life in Ireland. In the UK, the National Council for Palliative Care, the National Bereavement Alliance and Dying Matters have called for a national review of employment practice relating to bereavement.

Employers in Ireland typically grant time for the death of a loved one. But there is no statutory entitlement. If there is a family crisis, an employee can get a limited right to leave from work known as force majeure leave. Force majeure leave does not give any entitlement to leave following the death of a close family member. Other compassionate leave not covered by force majeure leave will depend on your employment contract, custom and practice within your workplace, or most importantly the employer's discretion.

Sinn Fein TD Peadar Tóibín introduced legislation - The Parental Leave (Amendment) Bill 2015 - to provide for paid bereavement leave for employees. Deputy Tóibín explained: “The vast majority of employers provide some type of bereavement leave and usually take force majeure as a template, so the legislation is really just to ensure that there are no gray areas, so that a person in grief knows their right at what is obviously a difficult moment for them” (Taylor, 2015).

In a positive move in January 2017, bereavement leave for civil servants was revised with leave for the death of a close family member increasing from five to 20 days, and leave upon the death of other family members increasing from three to five days. The Department should work to bring the wider public sector as well as the private sector, in line with the civil service.

TRAINING FOR RESILIENCE

An educated workforce is obviously important in order to attract foreign investment in a competitive global market. In keeping with the recommendation on developing a bereavement policy, it is important that there is more knowledge in the workplace about bereavement and an acknowledgment that employers have a role to play in supporting staff around their bereavement. It is also important that the training and education curriculum, at all levels, prepares people to cope with the impact of major life events such as death.

Teaching our citizens resilience can only benefit them when challenged in all aspects of their lives including challenging work situations. Employers will find that by respecting the profound loss and grief of others, the work ethic of employees will parallel that respect.
CHAPTER 1

SUCCESSION PLANNING

The Department should encourage employers to provide pre-retirement courses for staff and promote the use of future planning tools such as Think Ahead.

It should also promote fair succession planning and ensure there is adequate pension provision for the future needs of the older person, particularly at the time that a family business is being passed to the younger generation to avail of tax reliefs.

COMPASSIONATE CITIES

Professor Allan Kellehear of the University of Bradford has developed the concept of the Compassionate City which is

“...a community that recognizes that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone’s responsibility” (Kellehear, 2015).

Professor Kellehear introduced the Compassionate City Charter at the 4th International Public Health and Palliative Care Conference in Bristol in May 2015. The charter consists of principles and in adopting these principles organisations such as State institutions, workplaces and communities work together to support people at end of life and into bereavement. Under the charter, at least half of the workplaces in a city or community would review its policies or guidance documents on dying, death, loss and care each year. Most trade unions would also conduct this annual review.

This concept recognises the key role that the workplace has in a person’s life and its role in supporting people who are faced with issues around dying, death and bereavement. Milford Care Centre has organised the Compassionate Communities initiative in Limerick and is making a bid to become Ireland’s first Compassionate City in 2017 (Roberts, 2016). If successful, Limerick would be the third Compassionate City in the world along with Bradford in England and Seville in Spain.

In his foreword to the Department’s Statement of Strategy (2016a: 4), Minister Noonan wrote of creating “a virtuous circle in which continued robust economic growth provides the resources necessary to advance social progress, promote inclusivity, fairness and provide high-quality public services to all citizens”.

Future challenges for the Department include managing the post-exist economic relationship between Ireland and the UK and influencing the debate around corporate taxation and the legal challenge to the European Commission’s ruling on State Aid.

Budget 2017 introduced measures to support the economy in response to the UK referendum on Brexit. While about 16% of Irish exports go to the UK, 40% of indigenous company exports are destined for the UK (Noonan: 2016a).

Measures announced for Budget 2017 included steps to help with the transfer of farms from one generation to the next. The State pension and all weekly social welfare
payments increased by €5 per week. The 2016 Christmas bonus increased to 85%. There was an increase in the Home Carers’ Credit by €100 to support one income families who care for children or the elderly in the home.

The *Programme for a Partnership Government* (2016: 33) committed to tackle unmet needs by introducing budgets with at least a 2:1 split between public spending and tax reductions. It pledged to spend at least an additional €6.75bn in delivering public services by 2021.

This would cover the cost of areas including an ageing and growing population, and targeted improvements in public services with a focus on health, education, disability and child development and care. There would also be targeted improvements in welfare payments for the elderly, people with disabilities, the sick and carers among others.
RECOMMENDATIONS

- Prioritise the drafting of a new Coroners Bill and its speedy enactment and implementation. Resource this vital service.

- Increase funding for the work on dying, death and bereavement being undertaken by many units in the Department from victim support, prisons and probation.

- Commence all sections of the Assisted Decision Making (Capacity) Act 2015. Resource the implementation of this crucial legislation.

- Invest in communication skills training for civil and public servants who are supporting families of homicide victims.

- Support education on the diverse beliefs and practices around end of life among Ireland’s ethnic groups such as Travellers and migrant and refugee communities.

- Develop a database of recommendations from inquests and ensure this information is distributed to relevant Departments and is available to the public on the Department of Justice and Equality website.


- Increase the funding that is provided to Advocates for Victims of Homicide (AdVIC) and Support after Homicide.
BACKGROUND

The Department of Justice and Equality is responsible for promoting the public’s security and safety, their access to justice and their ability to enjoy equality. It also manages Ireland’s system for immigration, asylum and citizenship. In 2015, it published its new Strategy Statement in which it described itself as a “labour intensive, knowledge based organisation” (DJE, 2015: 9).

Work was underway in 2015 to establish the new Policing Authority to oversee the performance of An Garda Síochána from January 1st 2016 (DJE 2016a: 11). The Garda Síochána Ombudsman Commission was strengthened in 2015 and funding was secured to recruit an additional 600 Gardaí (ibid: 12). New Garda Stations were to be built and existing Garda Stations redeveloped, refurbished or upgraded under the Garda Building and Refurbishment programme 2016-2021 which was announced in October 2015 (ibid: 13).

Ireland signed the Council of Europe Convention on preventing and combating violence against women and domestic violence in November 2015 (ibid: 14). A new strategy on Domestic, Sexual and Gender-based Violence was developed in 2015 (ibid: 49).

The prison and probation service worked together for the Community Return initiative (ibid: 14) where selected prisoners receive reviewable temporary release which was conditional on them performing unpaid community work.

Funding was allocated to improving prison accommodation in 2015 including the elimination of the practice of slopping out (ibid: 49) while Culture and Organisation in the Irish Prison Service - a report by the Inspector of Prisons – outlined proposals for the development of the service into the future (ibid: 50).

Plans were announced for a capital programme involving the construction of new courthouses and the refurbishment of court buildings (ibid: 16). The Legal Services Regulation Act 2015 delivered a number of reforms. The Act provided for the establishment, on a phased basis, of the independent Legal Services Regulatory Authority, an independent complaints system, a Legal Practitioners’ Disciplinary Tribunal and the new Office of the Legal Costs Adjudicator (ibid: 17).

Under the EU resettlement & Relocation Programmes, Ireland decided to accept 4,000 people. Some 13,500 people were granted Irish citizenship in 2015. The 2016 census showed that since 2011, 94,000 people have acquired Irish citizenship (CSO, 2017: 50). The Government decided to introduce a single application procedure in the International Protection Bill following a review of the direct provision system.
THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

The Department responded to the questionnaire by contributing five submissions which are summarised in this section.

CIVIL LAW REFORM

The Department stated that the Assisted Decision-Making (Capacity) Bill 20131 "addresses the situation in which decisions have to be made on the withdrawal of life-sustaining treatment from a person lacking capacity".

It explained that while the Bill provides that the decision is "normally" a clinical decision, section 4 provides that "an application for a decision on the withdrawal of life-sustaining treatment must be made to the High Court, reflecting the seriousness of the decision".

There was public engagement in relation to the Assisted Decision Making (Capacity) Bill through a consultation symposium in 2013.

PRISONS POLICY

This submission explained that the end-of-life-care of a prisoner is managed by the healthcare professionals in the respective institutions. End-of-life care usually involves an inpatient admission to an acute hospital or hospice. The care of the dying person is co-ordinated by the medical team in the secondary care institutions.

The submission said that there would normally be increased healthcare interventions "up to the point where remaining in prison is either impracticable from a care perspective or to afford the dying person a more dignified death".

The IPS’s Psychology Services provides supportive counselling to prisoners experiencing bereavement issues. These are often complicated bereavement reactions for many reasons including isolation from family members when death/dying takes place; not being released to attend a removal or funeral ceremony and worrying over loved ones who are ill. Prisoners can available of bereavement counselling courses through the Chaplaincy service.

In looking to the future, the issue of “the number of elderly prisoners with significant healthcare problems who may become critically unwell or terminally ill while in custody” was raised. It was important for the IPS to develop a co-ordinated response to such cases. There were initiatives with the Red Cross which involved prisoners providing "practical and supportive assistance" to frail or infirm prisoners. The needs of elderly prisoners and those with quality of life impairment were being examined by an IPS working group.

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1. The Assisted Decision-Making (Capacity) Act 2015 was at bill stage in 2013 and in its submission, the Department referred to the then 2013 Bill.
PROBATION POLICY

The Office of State Pathologist works with the Coroner Service and an Garda Síochána by providing independent expert advice on forensic pathology and performing post mortems where foul play is suspected.

The Coroner Service is a network of Coroners countrywide who explore the circumstances of any "sudden, unexplained, violent or unnatural death" so that a death certificate can be issued. A post mortem may be needed which may be followed by an inquest.

Offenders subject to Probation Supervision are sometimes seriously injured or may die during the supervision period.

The submission stated that the main issues identified were "confidentiality, the provision of information and sensitivity in dealing with bereaved families".

In relation to engagement with the public, the Office of the State Pathologist has limited contact with the public while the Coroner and/or An Garda Síochána liaise directly with the families of the deceased. Individual coroners interact daily with the bereaved. As trained social worker, Probation Officers can provide advice or referral for individuals when a request arises.

The Department provides information to the public on the coronial process and provides contact details for people who may need to know more about an individual case. People will usually be directed to the Coroner concerned.

On how the Department might engage in the future around issues around dying, death and bereavement, the submission replied that it would implement the Coroners Act, 1962, as amended and/or other relevant legislation.

CRIMINAL INJURIES COMPENSATION TRIBUNAL

The Criminal Injuries Compensation Tribunal (CICT) administers a Scheme of Compensation for Personal Injuries Criminally Inflicted. Fatal injuries fall within its remit. CICT staff advise and assist applicants in completing application forms and answering queries. Meetings are arranged with applicants at Tribunal offices. The scheme was designed to be informal.

The submission stated: “The Tribunal staff endeavours to deal with applicants within this ethos”. No changes to the Scheme are envisaged and the only public engagement possible around the issues of dying, death and bereavement was when an application is made under the scheme.

VICTIMS OF CRIME OFFICE

In its submission, the Victims of Crime Office wrote that Irish citizens may die through homicide which can lead to complex bereavement processes. It stated: “This may be exacerbated where the homicide is intrafamilial”. The Department provides funding annually to AdVIC and Support after Homicide which supports families bereaved by homicide.
In its submission, the Department refers to the Victims Bill\textsuperscript{2}. The Department said that the Bill will give families of homicide victims legal entitlement to information on criminal investigations and proceedings. The Bill is transposing the EU Victims Directive.

Referring to future work on issues around dying, death and bereavement, the Victims of Crime Office stated that it would continue to fund AdVIC and Support After Homicide and the transposition of the victims directive.

**COMMENTS AND RECOMMENDATIONS**

The Department of Justice and Equality provided the most detailed response to the questionnaire that was distributed to the civil service. The responses revealed that in keeping with the Department's broad remit, it was dealing with complex end-of-life issues affecting a range of audiences from victims to offenders.

One of the most significant pieces of legislation in recent years has been the Assisted Decision –Making (Capacity) Act 2015. The Department referred to it in its submission. Solicitor and former Law Reform Commissioner Patricia Rickard-Clarke was interviewed for this study and was also asked to review an early draft of this report on the Department. Ms Rickard-Clarke stated that the information provided by the Department did not accurately reflect the legislative provisions and the panel below presents her response. Among her many roles, Ms Rickard-Clarke is Chairperson of the National Safeguarding Committee.

The Department stated that the Assisted Decision –Making (Capacity) Bill 2013 "addresses the situation in which decisions have to be made on the withdrawal of life-sustaining treatment from a person lacking capacity."

It explained that while the Bill provides that the decision is "normally" a clinical decision, section 4 provides that "an application for a decision on the withdrawal of life-sustaining treatment must be made to the High Court, reflecting the seriousness of the decision".

This statement is not entirely accurate. The legislation is following the recommendation of the Council of Europe which obliges Member States to have appropriate legislation to respect the autonomy of the person. While in common law, the right of a person to refuse life sustaining treatment was respected by the courts, Ireland had no legal framework about that. The 2015 Act fills that gap.

Section 4 provides that 'where an application in connection with the withdrawal of life-sustaining treatment from a person who lacks capacity comes before the courts for adjudication, that application shall be heard by the High Court'. In other words if the person who lacks capacity has not made an advance healthcare directive (AHD) and there

\textsuperscript{2} The Bill in question is the Criminal Justice (Victims of Crime) Bill 2016 which was published in December 2016.
Below are some recommendations which the Government should consider and which are particularly relevant to the Department of Justice and Equality.

ADVANCE CARE DIRECTIVES

A significant event in 2015 was the enactment of the Assisted Decision Making (Capacity) Act which repealed the Marriage of Lunatics Act 1811 and the Lunacy Regulation (Ireland) Act 1871. The new legislation was welcomed by many organisations with Inclusion Ireland (2016) stating that the ground-breaking legislation demonstrated a “seismic cultural shift” away from a paternalistic ‘best interests’ approach to a right-based approach. It also brings Ireland into line with international human rights law.

In October 2016, the Minister for Health Simon Harris and Tanaiste and Minister for Justice and Equality Frances Fitzgerald signed commencement orders to set up the Decision Support Service and the establishment of the multidisciplinary working group to make recommendations for the code of practice for Advance Healthcare Directives. The Department of Justice and Equality has commissioned the National Disability Authority to progress the development of non-health codes of practice under the Assisted Decision-Making (Capacity) Act 2015. These will include codes of practice for the various decision supporters to assist those whose capacity is in question or who lack decision-making capacity.

In December 2016, Sage (Support and Advocacy Service for Older People) stated that up to 70% of the cases it has dealt with have involved family conflicts over care arrangements. In an Irish Times report, Sage stated: “The situation is being exacerbated by a delay in implementing new laws to provide older people with guaranteed rights on
their independence. The Assisted Decision-Making (Capacity) Act was signed into law by President Higgins a year ago but most of it has yet to be commenced” (Cullen: 2016).

The Act provides for a rights-based approach to decision making capacity. The Act provides three types of decision-making support options where decisions can be made on personal welfare (to include healthcare), property and finance or a combination of both. In addition, the Act includes two important ‘planning’ tools - a legislative framework for Advance Healthcare Directives where an adult with capacity can make a legally binding statement and refuse any form of treatment, including life-sustaining treatment to come into effect when the person lacks decision-making capacity and the reform of the law on Enduring Powers of Attorney (to provide mainly for property and affairs decisions). A Decision Support Service will be set up within the Mental Health Commission.

It is essential that the Act commences as soon as possible. While the statutory task of public awareness is given to the Director of the Decision Support Service in the Act (which includes the establishment of a website to disseminate information to the public), the courts and agencies under the remit of the Department of Justice and Equality should also be provided with detailed literature to disseminate to all employees and members of the public.

Information on Enduring Powers of Attorney should also be available on the Courts Service website as should details of the various decision support mechanisms that a person can enter into to provide for the eventuality where they may lack capacity to make decisions personally.

The HSE is implementing an extensive programme of education and developing protocols to familiarise people with the legislation. The legal community must similarly be informed and geared to implement the legislation once it is finally commenced. The Irish Penal Reform Trust (IPRT), in a report on older people in Irish prisons in 2016, recommended that the Irish Prison Service (IPS) should consider the implications of the Assisted Decision-Making (Capacity) Act 2015 and how the prison service will support those with capacity issues to engage in decisions about their welfare (Joyce & Maschi, 2016: 7).

**THINK AHEAD**

“*He made us promise we would help him to pass peacefully away at home. No more hospitals. He was not afraid of dying, as long as he could do so in his much-loved and familiar surroundings. It took time to have that conversation without us falling apart but, somehow, in a strange way, having such discussions with him helped us to cope. It gave us a sense of purpose, to know that he was depending on us to ease him from one life into the next*” (FIONNBAR WALSH, 2014: 174).

In an effort to ensure a culture change and an understanding of the concept of advance planning, the Government should engage in a public awareness raising campaign about the benefits of planning ahead. It should also adopt a consumer-friendly planning tool such as *Think Ahead* which has been developed by the National Council of the Forum on End of Life in Ireland, an initiative of the Irish Hospice Foundation. The National Council was chaired by former Supreme Court Judge Catherine McGuinness⁴.
The form was developed following a public consultation during 2009-2010 when the public was asked what mattered most to them at end of life. *Think Ahead* was piloted in Limerick and Louth before being made available nationwide. Feasibility studies were also conducted with health professionals including GPs and nursing home staff. A study published in the *Irish Medical Journal* in 2014 found that *Think Ahead* was positively received by patients and their GPs and should be made more widely available (O’Shea, Martin, Brennan, Bailey, McElwee, O’Leary, and Darker 2014). Partners to the initiative include the Citizens Information Board, Sage (Support and Advocacy Service for Older People) and the Law Reform Commission. *Think Ahead* is available at www.thinkahead.ie and a pilot project digitising the form on an online platform is currently underway.

The use of a tool such as *Think Ahead* has benefits for the individuals in promoting their autonomy but it also could benefit our health and legal system by reducing the cost – in human and economic terms - of futile treatments and allowing the more targeted use of scarce funds.

“*Think Ahead is a public awareness initiative. It is effectively a form, which allows you to write down your preference. Think Ahead should be adopted by the State and we should say to people here is a way of recording your end of life preferences. Her is a way of recording and keeping all of your important documents and decisions in the event you are not able to speak for yourself. Everybody should get a Think Ahead form when they start work, when they take out a mortgage, and when they have children. It’s all about life stages.*”

(Angela Edghill).

End-of-life planning is wider than healthcare. Professionals and families must support people’s desire to put their affairs in order and be open to listening to and recording people’s preferences for all aspects of their lives including their finances. For people to exercise their rights, they must be aware of them. The Director of the Decision Support Service will have a public awareness function and this must be appropriately resourced. This is particularly important as research by McCarthy, Weafer and Loughrey (2010) has found that people have limited knowledge of end-of-life terminology and procedures. IHF research has also found that while most people claim to be comfortable in talking about end-of-life issues, they tend not to take any practical steps to plan ahead (Weafer, 2004 and 2014).

**ELDER ABUSE**

The Assisted Decision-Making (Capacity) Act 2015 provides for safeguards and oversight structures to ensure that advance planning is a voluntary act and in line with the wishes of the individual. We must be mindful of elder abuse and neglect. According to the HSE Safeguarding Office, in 2016 there were 7,884 safeguarding concerns managed by the nine Safeguarding and Protection teams in the HSE. Of these, 3,029 concerns related to adults over 65 years. Alleged psychological abuse was highest in this age category at 27% followed by alleged physical abuse at 22% and alleged financial abuse at 21%.

3. The National Council of the Forum on End of Life in Ireland has disbanded but Think Ahead continues to be rolled out through the Irish Hospice Foundation.
“Some people look at an elderly relative today and they see them as having assets which they are going to get. This is a serious issue. The great tragedy of our time is family member and relatives, and sometimes outsiders, taking what these people have put together and using it for their own purpose. It is fraud. People growing old and growing old in dire poverty because a son or a daughter or a group of them have come together and literally orchestrated the whole thing so that they have left these parents or parent in the most vulnerable position of their lives. Financial abuse of the elderly is a huge and growing problem. Somebody listen to me please. Their own are taking it. I have seen far too much of it. Your value is not seen as your value that is intrinsic to you as a person. Your value is seen as what you have in your bank account and what you have in your house and what your house is worth. You can hasten a person’s death through this kind of worry.”

(FR. PIERCE CORMAC).

In a survey from the Health Information and Quality Authority (Hiqa), 63% of people reported witnessing poor provision of health and social care services. Meanwhile in April 2017, Patricia Rickard-Clarke urged the Government to introduce legislation to provide for independent advocacy for vulnerable adults who are those who may be unable to protect themselves against harm or exploitation. She also called for a National Safeguarding Authority with a dedicated budget.

A nationwide public opinion survey on vulnerable adults in April 2017 – commissioned by the NSC - found that the public believe there is a problem with safeguarding vulnerable adults. One in three agree that abuse of vulnerable adults is widespread and almost half feel that our society tends not to respect the rights of vulnerable adults. Some 48% claim to have experienced abuse of a vulnerable adult – themselves or a vulnerable adult close to them. One in three had experienced emotional abuse and one in three had witnessed or suspected physical abuse. Some 20% had witnessed/suspected physical abuse in private dwellings.

The support and advocacy service for older people, Sage has reported that its cases include where the views of older people have been ignored, where they have been kept in nursing homes against their will and the Gardaí have had to intervene to protect their property and other rights (Cullen, 2016).

The Decision Support Service must be fully resourced in its role of raising awareness of the new legislation, drawing up codes of practice and handling complaints about decision-making assistants, co-decision makers, decision-making representatives, attorneys of enduring powers and designated healthcare representatives to prevent abusive practices and to ensure the rights and autonomy of people who may be vulnerable are respected. It is also imperative that information in this complex area is translated into plain English. The general public must be able to understand the terms of the capacity legislation. If people do not understand the law, it is highly unlikely they will proactively engage with it.
There is a need to introduce comprehensive social care and safeguarding legislation with the dual purpose of having in place systems that prevent the abuse of vulnerable people in society and to safeguard adults at risk when they experience abuse.

**2000 HAGUE CONVENTION**

The 2000 Hague Convention on international Protection of Adults, which was signed by Ireland in 2008, should be ratified by the State. The convention applies to “the protection in international situations of adults, who, by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interests.” (Convention, 2000: 1). It would therefore protect an Irish person who loses capacity and is resident abroad or who owns property abroad. Similarly, a person who has made arrangements in another country (where that country is a party to the Hague Convention) will have to be honoured in Ireland.

**LEGAL AID**

Legal Aid is available to promote and assist those who cannot afford to pay for legal advice in respect of Enduring Powers of Attorney but this is generally not known. The Legal Aid board should provide detailed information leaflets on legal arrangements that a person can make when they have capacity to come into effect when they lack capacity. The Legal Aid Board should ensure that all its staff are trained in this area of law to ensure that the service is available to those who have need of it.

**EQUALITY FOR LGBT**

The Gay and Lesbian Equality Network (GLEN) has stated that to ensure LGBT people’s needs, end-of-life policy should be based on principles such as equality, diversity and a respect for individual autonomy. LGBT people should be named as a population group with specific needs (Allen, 2013: 5).

Speaking at the end-of-life hearings before the Joint Oireachtas Committee on Health and Children in November 2013, Odhran Allen of GLEN stated: “End of life service provision should be based on a model of inclusive practice that both recognises and responds to the needs of different groups such as LGBT people, and that fully respects LGBT people’s identities, relationships and families”.

While Mr Allen’s comments are in relation to healthcare, all services delivered by the state should be delivered with an inclusive model of practice with civil and public servants trained to communicate in an inclusive manner.

**PRISONERS**

At the end of March 2017, there were 95 men and one female prisoner over the age of 65 years. In 2015 the daily average number of prisoners in custody in the 14 institutions in the Irish prison service was 3,722. The Irish Penal Reform Trust (IRPT) report *In Here, Time Stands Still. The Rights, Needs and Experiences of Older People in Prison* (2016)
states that latest figures indicate that almost 10% of people in prison custody today are over the age of 50. They represented a “substantial minority” within the prison system and their number was likely to increase (Joyce & Maschi, 2016: 19).

A number of reports have been produced on healthcare services in Irish prisons. The 2001 report of the Group to Review the Structure and Organisation of Prison Health Care Services (2001: 52) noted that “traditionally, it had been a rarity” to have older prisoners in significant numbers but there had been a marked increase in the number of older prisoners (2001: 52).

The Irish Prison Service Three Year Strategic Plan 2012-2015 included a commitment to develop a Strategy for the Management of Older Persons. The Irish Prison Services’ (IPS) current Strategic Plan 2016-2018 includes goal 2.5 which aims to ensure that older prisoners are identified as a specific group of individuals who have particular needs within the prison population. The goal includes a number of actions including the commitment to finalise and implement an Older Prisoner Strategy and examine the possibility of developing a specific setting for older prisoners (IPS, 2016: 27). Progress was made in fulfilling these objectives in 2015 when it was reported that all prisoners over 55 years of age had an active nursing care plan and a survey of older prisoners was conducted and was being reviewed. A Policy on Management of Older Prisoners was being drafted as this report went to print and is expected to be finalised in the coming months.

In a follow-up communication with the DJE, it explained that the IPS had started to repurpose the Training Unit Place of Detention at Mountjoy prison into a dedicated unit for older prisoners. The unit will be just for male prisoners and the work will take about two years. Once completed, this purpose built unit will accommodate prisoners who currently have “significant and ongoing” healthcare needs and are dispersed throughout the prison estate. The unit at Mountjoy is within close proximity to a variety of medical facilities. Remedial work will also be carried out to allow for in-cell sanitation.

The IPRT report raised a number of issues of concern including the detention of older people living with dementia and other serious conditions; some older prisoners confined to their cell or bed-bound; in some instances personal care including changing of incontinence pads was being undertaken by other prisoners (Joyce & Maschi, 2016: 3).

The IPRT research included questionnaires completed by 22 older people in prison. A total of 65% had concerns about getting older in prison including a concern about dying in prison (ibid: 47). The IPRT recommended the development of a comprehensive strategy for the management of older prisoners. The current strategic plan pledged to develop an Older Prisoner Strategy and the IPRT (ibid: 4) recommended that:

“In developing this strategy, there should be a wider debate about the appropriateness of detaining old and seriously ill people in a prison environment, particularly those living with dementia or other terminal illnesses. This debate should consider the significant practical and ethical challenges the continued detention of these people presents for prison staff and for other prisoners.”
It also stated (ibid: 24):

“The continued detention of a person with dementia raises significant issues for the Irish Prison Service and for other people in prison. If high levels of medical care are not available this may, in certain circumstances, amount to inhuman or degrading treatment in contravention of Article 3 of the European Convention on Human Rights.”

In a study of older men in Irish prison, the social needs identified included access to information about social welfare entitlements. The report recommended that time and resources be allocated to ensure that staff can undertake specific social work tasks (Alvey, 2013: 213).

A national debate about how to best meet the needs of dying prisoners should form part of any general national end-of-life strategy. It is also recommended that the Think Ahead planning tool should be used by prison staff in helping prisoners to plan for the future.

**NATIONAL WOMEN’S STRATEGY**

The new National Strategy for Women and Girls 2017-2020 has been published and has some welcome commitments on alleviating poverty and increasing social welfare payments for widows and lone parents. The Strategy pledges that future pensions policy will safeguard outcomes for women under the State pension system. It will increase women’s access to their own pensions and the focus will be on female-headed households.

Pension reform is welcome. The focus on female-headed households is also positive as some of these households will be widowed or a partner will have died. Difficulties currently exist in the State pension with research from Age Action Ireland showing that changes to the eligibility criteria for the Contributory State Pension in 2012 “made it more difficult for people with irregular PRSI contributions to get a decent pension” (2017: 1). About 36,000 older people – 62% women - had their pensions cut by €988 to €1,565.20 annually (ibid: 5).

The regulation and financing of the home care sector is obviously a topical issue as the Government prepares to introduce a Fair Deal programme for home care. While it is important to have all the financial regulations in place, the quality of training and service is equally as important. In the national women’s strategy, future aims include improving outcomes for carers and cared-for women. It commits to continue to implement the National Carers Strategy and the National Dementia Strategy.

**TRAVELLERS AND ROMA INCLUSION STRATEGY**

On March 1st 2017, An Taoiseach announced that Travellers had been formally recognised as an ethnic group in Ireland. A new National Traveller and Roma Inclusion Strategy for 2016-2020 is currently being developed. The objectives of the strategy include delivering and developing health services in a culturally appropriate manner. The actions under this objective included cultural awareness at undergraduate and
graduate curricula for health professionals; the development of culturally appropriate and accessible information and healthcare material and promoting the use of clear language (Phase 3, consultation document).

The 2016 census found that there were 30,987 travellers in the Republic of Ireland (CSO, 2017: 61). In her written submission to the Joint Oireachtas Committee on Health and Children, Dr Regina McQuillan explained that the life expectancy of a traveller man was 61 years and had not improved since 1987. Life expectancy for a female traveller was 71 years. While this had improved since 1987, it was equivalent to the life expectancy of the settled woman in 1960 (McQuillan, 2013: 3). On end-of-life care, Van Doorslaer and McQuillan (2005: 7) found that Travellers seldom use palliative care services. This was partly due to cultural differences and institutional barriers such as lack of facilities to accommodate large, extended traveller families. In her submission to the Joint Oireachtas Committee, Dr McQuillan highlighted that traveller societies are collectivist and demonstrative. Their customs, involving large crowds seeking to visit a dying patient or attend a funeral, can cause difficulties with communities or institutions such as hospitals.

Under the theme “Anti-discrimination and equality”, the Phase 3 Consultation document on the National Traveller and Roma Inclusion Strategy stated that Travellers and Roma should have access to “mainstream and targeted financial services such as savings and affordable credit options” (2016: 16). The consultation document pledged to consider “the viability of establishing a sustainable and accessible micro credit scheme for Travellers and Roma” (ibid).

This report supports action to be taken by the State to raise awareness of the needs of travellers around end of life and on the issue of access to finance for Travellers struggling to cover costs relating to serious illness or funerals. National Traveller MABS was established in 2005 and advocates for the financial inclusion of Travellers. Its 2011 study Issues of Personal Finance within the Traveller Community highlighted the issue of coping with “life events” such as funerals (2011: 34). Travellers had problems accessing the now abolished Bereavement Grant as it was a social insurance based payment. Problems were also identified with travellers securing an Exceptional Needs Payment.

“Member of the travelling community have, for the most part, grown up in poverty. The cost for them to die is probably even more than the cost for the rest of us. They don’t have the resources to meet such costs. Even if they did approach it at the same economic level as you or I – at a minimum level – they still may not have the resources to meet it. If you put the cost of a grave, the cost of a funeral director, the cost of a coffin, the cost of a head stone, all of these costs together you are talking about €5,000 to €10,000. Where does anyone on welfare living in a local authority house or a caravan have that kind of money.” (MICHAEL CULLOTY).
CHAPTER 1

IMMIGRANT INTEGRATION STRATEGY

The 2016 census revealed that the number of residents in Ireland who was born outside of the country was 810,406 making up 17.3% of the population (CSO, 2017: 46). Some 82,346 people from 180 countries arrived into Ireland in the year to April 2016 (ibid: 47).

Ireland has become a more diverse society with more migrant workers settling in Ireland and increasing numbers applying for citizenship. The immigrant population and “new Irish” come with different languages, cultural traditions and religious beliefs. These factors will influence their views on healthcare, end-of-life care and death.

A 2013 report in the UK entitled Palliative and End of Life Care stated “There is good evidence that there is low use of end-of-life-care services by people of Black, Asian and Minority Ethnic (BAME) groups” (Calanzani, Koffman and Higginson, 2013: 6). The identified reasons for low uptake included misunderstandings, mistrust and a lack of cultural sensitivity by service providers (Calanzani et al: 6). The literature highlighted the importance of cultural competency and communication skills for healthcare professionals.

This finding on the importance of cultural awareness and communications could be extended to all services provided by any country including Ireland and by public and private bodies such as the Department of Social Protection or the Department of Justice and Equality or the Funeral Services Industry. This report recommends that any civil servant dealing with immigrants, refugees or individuals from an ethnic group should be educated and supported to ensure a culturally sensitive service particularly on end-of-life issues is delivered.

VICTIMS OF CRIME

Under One Plan 2016 - the Strategic implementation plan for 2016 - the Department pledged to implement the EU Victims of Crime Directive to strengthen the rights, supports and protection of victims. Victim support services include Garda Victim Support Offices as a single point of contact in accessing support and information (DJE 2016b: 7). The Garda Victim Liaison Office provides support to the 474 trained Family Liaison Officers who are appointed to victims of crime and their families in serious cases such as murder. It also pledged to support and prioritise crime prevention schemes including Neighbourhood Watch and Text Alert.

The Garda Síochána Victims Charter (2010: 2) makes the following commitment to families of murder victims or victims of other unlawful killing:

“Your local Garda Superintendent will keep contact directly with you and any organisation supporting victims that you have asked to help you. We will keep up contact between you, the Investigating Garda and any relevant support organisation through a named Garda Family Liaison Officer from the investigation team.”

The 2016 Overview Report of the Independent Review Mechanism (IRM) looked into complaints of misconduct by An Garda Síochána. The report stated that “it was impossible to avoid the conclusion” that a significant number of complaints would have
been averted with better liaison and communications (IRM, 2016c: 16). The people who were particularly upset by not receiving support were the bereaved. There was a failure in some of the files presented to the IRM to show understanding of “the near-endless anguish which close family members of deceased persons go through in rehearsing and questioning the last moments and movements of a deceased person’s life” (ibid 17).

“It is layers of dying the victims deal with. The ordinary process of bereavement and then they have these extra deep layers – loss, violent death and no closure. The bereavement journey is for families. It is almost impossible for them to get closure. There are far too many hurdles. There are just too many hurdles for the human condition to close. It is a kind of cyclical horror that never goes away.” (John O’Keefe).

The IRM stated that the absence of complaints in cases of homicide suggested that “the systems in place and individual Garda initiative in dealing with surviving or secondary victims of violent crime are truly effective and appropriate” (ibid: 18). But there were shortcomings in cases where the immediate threat to the security of the community is not apprehended. The deficiency in Garda liaison and communication in these cases ranged “from mildly perfunctory to the highly offensive”.

“The supports provided by the State are farmed out. They are contracted out to organisations such as ADVIC. ADVIC get about €21,000 from the State every year. If you think about counselling on a rotational basis for 200 families, that is not in the halfpenny place and yet we still do it. So what happens is the counsellors who are very specialised – homicide counsellors – give their services for nothing. They occasionally give them for free”. (John O’Keefe).

The IRM also made a number of recommendations to enhance the role or status of Family Liaison Officers to ensure that they can advocate on behalf of families and other victims and not just explain Garda action to them.

In An Garda Síochána Modernisation and Renewal Programme 2016-2021, it was stated that while some surveyed had shown many victims of crime felt they had been treated with compassion and sensitivity, others have complained about inadequate information about the investigation into their complaints or not being fully informed about support services (An Garda Síochána, 2016: 16).

The report of the IRM stated (2016c: 19) that it was safe to assert that the absence of proper communication from investigating Gardaí was “the most recurrent issue” in the complaints it received. Gardaí should receive training on breaking bad news to bereaved families and receive general training on the importance of good communications. Members of the force should be regularly up-skilled on this aspect of their work.
In 2015, the network of coroners nationwide dealt with a total of 16,756 cases which included 11,144 deaths reported to the service, 3,566 post mortems conducted and 2,046 inquests held (Coroners annual report, 2015). The coroner acts as an “independent judicial officer” and establishes the who, when, where and how of unexplained death. The current system operates under the 1962 Coroners Act.

“I speak for the dead and I speak for the living. The Coroner’s job is about investigating death but we are really doing it for the living. Mostly we speak for the dead, of course, they don’t speak to us but their circumstances do. Through them we investigate and understand what happened. It is a privilege to serve bereaved families and communities in this way. It is so profound.” (Dr Brian Farrell).

A Working Group conducted a review of the Coroners Service which was published in 2000. The review recommended the overhaul of the Irish coroner service with a new structure, the rationalisation of the number of coroners and the establishment of a new agency to be known as Central Coroner Services under the aegis of the Department of Justice, Equality and Law Reform.

Following the review and in line with its recommendations, a Rules Committee was established and developed Coroners Rules which were published in 2003. The Coroners Bill 2007 was drafted to replace the outdated 1962 legislation and to give effect to the 2000 Review. However, the bill was not enacted and the Tanaiste and Minister for Justice and Equality Frances Fitzgerald has directed the Department to undertake a comprehensive review of the Bill in order to bring it up to date. This review is ongoing. Deputy Clare Daly introduced the Coroners Bill 2015 on 2nd July 2015 which included the content of the 2007 Bill and provided for mandatory post mortems and inquests in all maternal deaths.

“We’re now almost at the mid-point of 2017, 17 years after the recommendations of the coroners review group, so while we acknowledge the Department has been undertaking work in this area, we would hope that after 17 years this work is at a point that, if necessary, it can be incorporated into the Coroners Bill 2015 at Committee Stage.” (Clare Daly, T.D.)

The Coroners Bill 2015 was referred to a Select Committee on Justice, Defence and Equality on 11th December 2015. The Bill was not on the Legislative Programme Spring/Summer Session 2017.

“People dealing with the Coroners Office want hard information. They want to know how to find the path for that information. What the process is. How it will be done. The timeframe. Our funeral culture is the third fastest in the world. That puts a lot of pressure on us. It is not always possible to meet the expectations of the family. They have lost a family member suddenly, tragically, violently or in an unexplained, unexpected or unnatural manner. There is a huge amount of interaction with them. But it is very arcane for people. They do not understand it. It seems hidden. It is an area, a land, where they have never been before. They are bereft.” (Dr Brian Farrell).
The Overview Report of the IRM also made a number of short term recommendations including an automatic right to early legal assistance for a suitable next-of-kin or bereaved. According to the IRM, the recommendations made by juries should be the subject of a centralised annual assessment or review. If any recommendations are put in place, they should be outlined in an informative document/leaflet providing simple explanations of any assistance that is available for next of kin or family (2016: 46).

While it is appreciated that this is a complex issue with resource implications, it is imperative that an updated Coroners Bill is drafted and enacted as a matter of priority. It is also imperative that adequate resources are allocated to the current coronial service. As stated in the Review (2000: 3):

“In the allocation of scarce resources, society perhaps has not always fully appreciated that the coroner service is a service for the living and indeed for a very precious segment of the living – those traumatised by sudden and unexpected death.” (Dr Brian Farrell).

MISSING PERSONS

Every year, about 8,000 people are reported missing. Some 360 people over the last 10 years have not been located. The Civil Law (Missing Persons) Bill 2016, introduced by Senator Colm Burke in the Seanad in March 2017, would allow for a Presumption of Death order to be made which would permit the court to give a direction as to how the person's affairs are to be managed. A person can then return to the court for a final order. This system has operated successfully in Scotland for the past 10 years. It currently takes seven years from the time a person is missing to secure a Death Order. This can create difficulties for families in accessing bank accounts. The Missing Persons Bill is progressing to committee stage in the Seanad.
RECOMMENDATIONS

- Increase the funding for community care immediately.

- Ensure that a "Fair Deal" entitlement is introduced and fast tracked to support people to live and die in their own homes.

- Undertake a costing exercise to determine the entire costs (outside health costs) of being seriously ill, dying and bereaved on the individual and on the State.

- Develop a protocol for frontline staff across the public service, to allow them time to support the information needs of people who are at end of life or are newly bereaved. Ensure that all frontline staff involved in human communication are trained and have protected time.

- Raise awareness of Think Ahead or similar tools to allow the public to plan ahead.

- Develop a bereavement policy across the civil service and extend the revised and extended civil service bereavement leave to other public services and agencies.
Established in 2011, the Department of Public Expenditure and Reform (DPER) has “a specific remit to place the two important issues of expenditure management and public service reform at the centre of government” (Independent Panel on Strengthening Civil Service Accountability and Performance, 2014: 7).

It is responsible for policy on allocating and managing expenditure across Government Departments. It develops and implements human resource (HR) policies including workforce planning. DPER also manages public service pay and pension policy as well as industrial relations issues and national public procurement policy.

The Programme for a Partnership Government (2016:15) made a number of commitments which are relevant to the Department which include reforming the budgetary process as well as developing the process of budget and policy proofing “as a means of advancing equality, reducing poverty and strengthening economic and social rights”.

While the first Minister for Public Expenditure and Reform, Deputy Brendan Howlin, announced significant spending reductions for 2012, five years later, his successor, Minister Paschal Donohoe, announced in the Expenditure Estimates for 2017 an increase in current spending of almost €4 billion.

The Department is also responsible for the public service and for its reform and renewal. The reforms implemented included reducing public service staff numbers, the establishment of Shared Services models in areas such as HR with the creation of PeoplePoint and rationalising the number of State Agencies and Departmental bodies.

A number of laws were enacted to secure reductions in pensions and pay for public servants including members of the judiciary and members of the Houses of the Oireachtas.

The Civil Service Renewal Plan (Department of An Taoiseach and DPER, 2014) outlined a multi-year programme to develop the capability of the civil service. At that time, the civil service numbered 34,707 or 2% of the total national workforce (ibid: 5). The IPA’s Public Sector Trends 2016 stated that in 2016 the number of public servants reached over 300,000 for the first time since the year 2010 (IPA, 2016: 6).

The IPA found that in 2015, Ireland’s public spending as a percentage of GDP (35%) was joint lowest of the EU 28 countries. Government spending in Ireland was the most centralised in Europe. In relation to public services, the IPA distilled the findings of a number of surveys which found that Ireland was well above the average in Europe for
upholding traditional public service values of “independence from political interference, reliability and administrative fairness”. The perceived quality of public services was just below the European average and the ability to access neighbourhood public services was seen to vary according to the service.

The University of Gothenburg’s quality of government survey ranked Ireland’s public administration as the most professional and least politicised in Europe. It also found Irish government officials relatively impartial in their dealings with the public (ibid: 6). Meanwhile, while half of the Irish population trust the public administration, feelings towards the public service is below the European average. Satisfaction with the civil service is quite high (ibid: 7).

In 2015, a new capital programme of €42bn over six years to 2021 was announced to maintain and improve Ireland’s infrastructure. This included an Exchequer capital spend of €27bn. The Programme for a Partnership Government proposed to seek Oireachtas approval for an additional €4bn (2016: 38) and an extra €1bn was announced in the Summer Economic Statement (Donohoe: 2016a).

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

The Department stated that it did not have policy responsibility for issues relating to dying, death and bereavement. It stated: “Although DPER would appropriate funding for line Departments that may have responsibility for services in these areas, we have not been engaged in any specific policy discussion on these matters”.

The Department expressed willingness to work with other Departments to advance policy proposals by supporting innovations in service delivery, offering expertise on the economic evaluation of proposals, and providing appropriate funding on an agreed and sustainable basis.

COMMENTS AND RECOMMENDATIONS

While the focus of DPER is on managing expenditure and the reform agenda, the Department recognises the impact of its work on securing a fair society. The recommendations for this Department are based on the key role that DPER plays in determining the allocation of resources, evaluating services and reforming the public service. They centre around investing in community services to allow people to exercise choice on where they live and die and determining the costs of dying.

COSTING EXERCISE

International studies have found that “the healthcare budgets of most countries are skewed towards spending on care in the last year of life” (IHF: 2013: 37). It is estimated that between 10% and 12% of a country’s total health budget is spent on caring for people in the last year of life (ibid: 37). This would be €1.4bn in 2017. This is just the health budget.
Research in Ireland and the UK has found that there are significant costs for individuals and families to bear when they are ill. There are also significant costs associated with funerals following a death. A study in Scotland on the socio-economic costs of bereavement estimated that longer stays in hospitals following a bereavement cost the National Health Service £20m annually (Birrell, Corden, Macduff, Newsom, Petrie, Schut, Skar, Stephen, Tseng, Wang, and Wilson, 2013: 19). Bereavement-related primary care consultations cost £2.2m each year. The study suggested that this was a considerable underestimate (ibid: 14).

This report recommends that DPER, in collaboration with the Department of Finance, conducts an exercise to determine the entire costs (not exclusively health costs) of being seriously ill, dying and bereaved on an individual and on the state. This information is essential to allow the State to determine how best to support citizens at end of life. Speaking before the Oireachtas Joint Committee on Health and Children during public hearings on end-of-life care issues in Ireland on 24th October 2013, Professor Eamon O’Shea spoke about his research among older people stating:

“It is interesting that older people, in particular, were willing to speak about death in general, but when it came to being specific about their own deaths, there was reluctance on their part and among care staff in residential settings to address this issue.

We are learning how to speak openly about these issues but until we get to that point the information deficit will remain. Where we have an information deficit or a vacuum, we can sometimes get bad policy.

This is not necessarily because what is going on is wrong, but perhaps it is not what people prefer or need at that particular time. That is related to resource allocation.

Sometimes we get bad resource allocation decisions because we are not concentrating on what is really important.

I do not have extensive expertise in this area but, from an economic point of view, it is important in the last months, weeks and hours of dying.

That is what we have to address in terms of the broader strategy if we are to understand these relationships. It is particularly important to get resources to flow to where they can best be utilised.”

EXTENDING THE FAIR DEAL

Research from 2014 found that 74% of people wish to be cared for at home if they were dying (Weafer, 2014: 6). But the reality is different with 26% dying at home. Some 43% of people are dying in hospital (IHF, 2013: 7). Meanwhile, about 4% of older people live in residential care (NHI, 2016).
Government policy is to support people to live independent lives in their own homes for as long as possible. However, a 2016 report found that due to under-development and inconsistency of community services, people have to move into residential care settings (Donnelly et. al, 2016: 43). Social workers in acute hospitals reported that more than half of their clients could have remained at home if the community supports were available (ibid: 35).

Speaking at the Magill Summer School in 2015, human rights lawyer Maeve O’Rourke cited this research which found that a consequence of not receiving home care hours was often "premature or unnecessary institutionalisation". She stated that this could offend against the right to respect for a person’s private and family life and the right to personal liberty. She stated that interfering with these rights could sometimes be justified but would have to be “necessary and proportionate and in accordance with law”.

She continued:

“It is surely the case that if a person is in residential care, against their wishes, not because it’s the last resort but simply because no one is delivering the home care hours they need – that such type of care might not be necessary and proportionate. If, for example, they’re also prevented from leaving the nursing home or they are restrained, it might even amount to an unlawful deprivation of liberty.”

Ms O’Rourke said that legislation was needed to clarify “whether and if so in what circumstances an older person can be detained or restrained against their wishes”. Sufficient home and community services should also be available to “avoid unnecessary institutionalisation against people’s wishes”. She also contended that protecting older people’s human rights also involved regulation of the community care system.

Fianna Fail’s Willie O’Dea T.D. introduced a Nursing Home Support Scheme (Amendment) Bill 2016 in the Dail which allows for home care services to be provided to a person who qualifies for and is being offered long-term residential care. The Bill is expected to complete Second Stage by the end of July 2017.

The Minister for Older People Helen McEntee T.D. announced in November 2016 that work on developing an appropriate regulatory system for Home Care was underway and a Home Care Unit was being established in the Older Persons Services function of the Department of Health (McEntee, 2016a).

As part of its work to develop a statutory home care scheme for older people, the Department commissioned a review by the Health Research Board on how other European countries fund and regulate homecare services. This review was published in April 2017.

It is recommended that money should be made available to extend the equivalent of the Fair Deal to support care/residence irrespective of where it is provided – nursing homes, sheltered residence, assisted housing and a person’s own home. The right of access to a range of care options including home care should be put on a statutory footing. It makes sense from a financial perspective.
ALONE conducted a cost comparison of options for caring for older people and estimated that home help three times a day was between €50 and €70 with an acute hospital bed cost between €800 and €900 a day (Moynihan: 2015a). ALONE has estimated that 35% of older people in nursing home care could be given the choice to live independently if they had the proper supports (Moynihan: 2015b).

While there will be significant focus on the financing of the scheme, it is also essential that attention is paid to the training of staff particularly in good communication and on the rights of elderly people. In her contribution at the McGill Summer School, Maeve O’Rourke also commented:

“But protecting older people’s human rights isn’t just about keeping them out of nursing homes, when they are not necessary, and about making community care more accessible. It’s also about regulating that community care system to ensure its quality.”

TRAINING STAFF

The 2014 renewal plan addressed the need to build a civil service that more closely reflects the society in which it works. The report stated that: “This means significantly changing how we select and develop staff” (Department of An Taoiseach and DPER, 2014: 20). The plan also spoke about establishing a new shared model to deliver a suite of common learning and development programmes, the need to review the Civil Service Competency Framework periodically and the introduction of a core skills induction programme.

It stated: “Our goal is to ensure that regardless of organisational or geographic boundaries we always have the right people, with the right skills, in the right jobs at the right time. This means taking a whole system view of our resources and capabilities” (ibid: 26).

It is recommended that communications skills should be a core module of any induction or continual training programme for civil servants. A central part of this training should involve sensitising people to the needs of people who are challenged by serious illness, are at the end of their lives or are bereaved. In addition to being given the skills to use simple and concise language, people in frontline posts should also be empowered to give people time to absorb information.

My 2015 Finite Lives report on dying, death and bereavement and how it affected Ireland’s 30,000 civil servants found concern about the centralised civil service HR function, PeoplePoint. There was particular criticism in relation to dying, death and bereavement where PeoplePoint was felt to be processing data and keeping records rather than dealing with humans struggling with critical illness, caring duties and loss. PeoplePoint was felt to be:

“...an encroachment, statistical and inhuman” (O’Donnell, 2015: 85).
There has been a recent and most welcome development by the Department in extending bereavement leave for civil servants who lose a close family member to 20 days. This is a most appropriate and compassionate response. This should act as an exemplar in the wider public service and for private enterprise.

It is important that in addition to communication skills, DPER supports Government Departments in developing Bereavement Policies.

**DATA PROTECTION**

PeoplePoint, which administers the HR and pensions service for the country's civil servants, was criticised by the Data Protection Commissioner Helen Dixon for 350 data breaches in two years. An audit of PeoplePoint found that there were data governance policies was not in place on an operational level. The 2016 annual report from the Data Protection Commissioner stated: “Hence, the audit report highlighted a need for more intense training for staff generally on data-protection matters as well as a focus on the role of data protection in relation to HR issues and specifically in relation to previous breaches”. (2017: 25)

It is imperative that this training is conducted as employees must have confidence that their personal information is secure and respected. This is particularly so for people who are seriously ill and bereaved who may have significant interaction with HR professionals as they manage their treatment or a new transition.

**THINK AHEAD**

DPER, in its role in promoting high and consistent standards in the civil service should encourage the concept of advance planning and make the Think Ahead planning tool available, free of charge, to staff.

**LEGISLATE FOR PLAIN ENGLISH**

The research has shown how crucial good communications is to people at all stages of our lives. This is particularly so when people are getting sicker and more dependent. People are reliant on state services and getting accurate and comprehensive information from an official can be exhausting and ultimately unsuccessful. The idea of legislating for plain English should be considered to ensure that all State communications is consistently clear, jargon-free and accessible.
RECOMMENDATIONS

- Lead in supporting and encouraging people to plan for the future by making initiatives such as *Think Ahead* widely available and supporting a public information campaign on advance planning.

- Lead on the development of a wide ranging, whole-of-government, end-of-life strategy as an issue for Ireland.

- Lead on the development of a comprehensive website where people can access all of the information about what happens when a person is dying, has died and when people are bereaved. This website would outline the supports that are provided by the State and could also signpost people to other departments and to further information they need. It should be developed using multi-media to meet the information needs and learning styles of the entire population.

- Direct the National Economic and Social Council to conduct a socio-economic analysis of dying, death and bereavement.
BACKGROUND

The Department of the Taoiseach provides the secretariat to the Taoiseach and the government. It supports the formulation and implementation of government, as well as EU, policy through the system of Cabinet Committees. The Department co-ordinates Ireland’s engagement with the European Union and supports the Taoiseach in his international engagements. It also supports the implementation of the Civil Service Renewal Plan through the Civil Service Management Board.

The Department’s main divisions deal with policy areas are economic and international; British-Irish and Northern Ireland affairs; Social Policy and Public Service Reform and the European Union Division.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

The Department responded that its primary task was in supporting the Government and the Taoiseach. It had no responsibility for specific policies on dying, death and bereavement. It worked with Departments to ensure implementation of the Programme for Government and to support a co-ordinated approach to policy development and implementation across a wide range of areas including relevant issues in health and social policy.

The National Economic and Social Council (NESC) also provided advice to the government through regular reports on strategic policy issues.

The Department did not, in general, provide services directly to the public. The main interaction between the Department and the public related to the significant levels of correspondence to the Taoiseach.

The Department suggested that there might be scope in the future for NESC to contribute to future policy making in this area building on its 2012 report Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals.

COMMENTS AND RECOMMENDATIONS

“I’ve climbed God’s mountains, faced many struggles for my life and dealt with so much loss. And as much as I’d love to go around to every fool on this planet and open their eyes to the mountains that surround them in life, I can’t. But maybe if I shout from mine, they’ll pay attention.” DONAL WALSH, 1996-2013. (WALSH, 2014: PROLOGUE).
While the Department does not have a direct mandate on dying, death and bereavement, it would be aware of the needs of the bereaved through its work on peace and reconciliation in Northern Ireland.

The Programme for a Partnership Government (2016: 141) states that "Maintaining the needs of the victims and their survivors" was at the core of the government’s approach. The Department could harness its strategic role to promote a national dialogue on end of life. The promotion of the concept of future planning would be very beneficial to Society and to the Exchequer.

### STATE’S ROLE IN OUR LIVES

The Programme for a Partnership Government (ibid: 5) commits the new administration to a “Social Economy” model to deliver both a strong economy and a society which is fair. The social economy is built on four foundations including a Just and Fair Society and a more inclusive prosperity.

Therefore, the State is there to promote the wellbeing of both our economy and our people – at all stages in our lives. Speaking on 12th October 2011 at the Forum on End of Life in Ireland, the Taoiseach recognised that:

> “The end of life is no less precious than any other stage. In fact in many ways it is even more so. Which is why when we’re at that stage, we are entitled to dignity and respect, and to have our wishes and concerns taken on board”. (KENNY, 2011).

National policy on end-of-life care, to date, has largely focused on the development of palliative care services particularly specialist palliative care. Ireland was one of the first countries worldwide to adopt a national policy for palliative care for adults in 2001 and a national policy for children with life-limiting conditions was published in 2009.

In addition to these core policies, commitments to develop palliative care services have also featured in a number of government documents including the national partnership agreement Towards 2016: 10 Year Framework Social Partnership Agreement 2006-2015 as well as the National Positive Ageing Strategy (2013) and the National Dementia Strategy (2014). The National Carers Strategy (2012) was concerned with the needs of our informal carers – many of whom will be caring for a person with a life-limiting condition.

29,000 people die each year in Ireland and is is estimated that 290,000 are newly bereaved. There are also thousands of people who are newly diagnosed annually with life-threatening or life-limiting illness. Their care is wider than healthcare and it affects many, if not all, Departments of State.

On December 2nd 2015, An Taoiseach commented

> “It is clear that despite the universal certainty of death and loss, the issues they present continue to challenge us – as individuals, as family members, as friends, as colleagues, as service providers, as policy makers and as legislators”. (KENNY, 2015).
People who are coming to the end of their lives are still citizens, voters and consumers. They use public transport. They visit their local parks. They may need extra income support to manage the costs of their illness. They are engaged in their world. They watch television or tune into our extensive radio network. They live. Many seriously ill people will continue to work as long as they can. Others cannot. But Ireland’s pension policy and legislation covering employee rights are relevant to their lives. Ireland’s social protection cover is essential for those facing high medical costs and reduced incomes.

Similarly, the bereaved are using public services and contributing to our economy in the midst of their personal and profound loss. For the dying and the bereaved to live well, they need communities and the State to understand their needs and take action to mitigate any difficulties. They also have the right to die in their own homes or the place of their choosing.

It is therefore recommended that the government develops a public health intervention on end of life. The Programme for a Partnership Government includes pledges for interventions on a range of issues from obesity to physical education to the quality of hospital food. The intervention that is recommended is the development of a whole of government strategy on end of life in Ireland which would encompass all aspects of dying, death and bereavement across all Departments.

It would integrate into one strategy the recommendations on end of life which are currently contained in a range of policies. In addition it would cover all aspects of people’s lives from their physical and mental health to their financial and psychological wellbeing. It would also look at our education system, our transport network, the layout of our parks, our benefits scheme, the composition of our housing stock, the architecture of our public facilities, and the communication skills of our civil and public servants.

As part of the preparatory work for the national whole-of-Government, end-of-life strategy, the Department should direct the NESC to conduct an analysis of the socio-economic costs of dying, death and bereavement. This will ensure that the Government is preparing a Strategy which is based on comprehensive data.

**A NATIONAL CONVERSATION**

In developing the strategy, the Department of the Taoiseach should engage in a public consultation or conversation on end-of-life issues to learn about what matters to people and what supports—across the public service—people need in order to live well until they die. The results of the Irish Hospice Foundation’s most recent “Have Your Say” survey (end of 2016) when published may be helpful in this regard.

“The impact of having national conversations about dying and death are harder to quantify. You cannot translate it into report very easily. That is the challenge I think for me and for people who are interested in broadening the conversation beyond medicine. We should have a conversation about dying and death, because in the future we will have an older population, and a more dependent
population. We have to become as a nation more articulate, and more self-conscious. We have to gain more of a sense of control over what is going to happen to us in our old age.

Because while we are good at the rituals around funerals and death, and so on, we are not good at for example acknowledging the rights and concerns of older people.” (Dr Joan McCarthy).

Former Supreme Court Judge, Mrs Justice Catherine McGuinness (2015) has encouraged a conversation on end of life in her role as chair of the Forum on End of Life in Ireland.

In 2014 Ombudsman Peter Tyndall published A Good Death. A Reflection on Ombudsman Complaints about End of Life Care in Irish Hospitals which he hoped (2014: 3) “will make a positive contribution to the national debate on end-of-life-care and the campaign to make Ireland a good place to live and to die in”.

It is interesting that most of the complaints centred around the area of bad communications. Tyndall stated: “Poor communication is a feature of almost every complaint sent to the Ombudsman” (ibid: 11).

We are learning more about what matters to people at end of life through surveys such as the IHF’s national surveys in 2004, 2014 and 2016 and the “Let’s Talk About” survey on palliative care commissioned by the All Ireland Institute of Hospice and Palliative Care. The Irish Hospice Foundation undertook a public consultation in 2016 to inform its forthcoming “Irish Charter on Dying, Death and Bereavement”.

On a political level, the end of life hearings before the Joint Oireachtas Committee on Health and Children, chaired by Jerry Buttimer, in 2013 raised awareness among legislators of the issues around end of life in Ireland. My motion in Seanad Éireann on 16th April 2014 was carried and called on the Government to explore the components of an overarching strategy on end of life and bereavement.

On a legal front, the late campaigner Marie Fleming put the issue of assisted suicide and euthanasia on the agenda. Meanwhile, the Convention of the Constitution recommended in 2016 that the right to die should be one of a number of other important issues that should be prioritised for discussion by the Government, the Oireachtas or any future Convention.

Much positive work has already been done to promote a dialogue on end of life issues, particularly by the hospice movement in Ireland. The Irish Hospice Foundation organised a national year-long public consultation process in 2009. This culminated in the publication of a report Perspectives on End of Life. Report of the Forum 2009 and the establishment of the National Council of the Forum on End of Life in Ireland. It is hoped that this publication as well as the Finite Lives report on the civil service will contribute to more understanding of end-of-life issues. The State must now build on this momentum.

In any general societal discussion on end of life, we need to consider the particular needs of groups such as individuals who have intellectual disabilities. Some work has been done in preparing families and staff to discuss end-of-life issues with people with intellectual disabilities. One example of this is the four-part Live and Let Die bereavement programme from St Michael’s House Services for people with intellectual disability. The resource states that: “People with an intellectual disability have an
intrinsic right to be facilitated to grieve for the loss of their loved one". But, it stated, the bereavement support needs of people with an intellectual disability had only recently been "acknowledged or addressed" (Reynolds and Walsh, 2008).

ROLE OF THE DEPARTMENT OF THE TAOISEACH

The Department of the Taoiseach has a leadership role to play in the development of the strategy and particularly for end-of-life communications and planning. The Taoiseach himself has shown an interest in advance planning and the evolution of the Think Ahead planning tool which allows people to capture their preferences on a range of issues including healthcare.

There must be an emphasis on setting out individual wishes and preferences. The Department can also take a lead role in educating society about the negative effects of the ‘inheritance culture’ and ensure that all older people feel free to use their income and assets to live a happy and meaningful life at the latter part of their lives. It must be acknowledged that following the banking crash, many people are in negative equity and older people can feel obliged to use their savings to support their families.

The enactment of the Assisted Decision-Making (Capacity) Act 2015 was a welcome move. It is now essential that the message is conveyed to the public that it is necessary to avoid, in so far as possible, a court based process for the time when a person may lack capacity. People should therefore outline their wishes when they have capacity and review those wishes periodically.

The Department referred to the work of NESC in its reply for this report. It is recommended that the Department should ensure that the 2010 NESC Report entitled Quality and Standards in Human Services in Ireland: Residential Care for Older People is implemented in relation to person-centred budgeting which should be piloted to allow older people to choose the type of care they wish (NESC, 2010).

The Fair Deal allows an older person to choose their residential centre but they cannot make a decision such as allocating that funding to home care rather than residential care. This has to be changed.

Dr Joan McCarthy was one of the authors of a 2011 publication End-of-Life Care: Ethics and Law and is the Coordinator of the MSc in End-of-life Healthcare Ethics in the School of Nursing and Midwifery, University College Cork. Interviewed for this study, Dr McCarthy stated:

“When I talk about ethics I am talking about a philosophical understanding of ethics. I am talking about setting professional guidelines, codes or laws. Ethics very briefly is the study of what we ought to do to live a good life and be a certain kind of person. So what we are looking at over the last thousands of years in the western world is what does it take to live? What does it mean to do the right thing?”
CHAPTER 1

COMPREHENSIVE WEBSITE ON END OF LIFE SERVICES

The Department should lead in the development of a website to meet all of the information needs of the public who are facing issues around dying, death and bereavement. This comprehensive portal would provide clear information on what happens following a death such as the registration of a death or the involvement of a coroner. It would also provide information on the supports offered by each Government Department and could direct people to relevant departments and other sources of information. It should be developed using multi-media to meet the information needs and learning styles of the entire population. The development of this website would be a valuable service to people who need information and would also showcase the many ways that the State does support the citizen at the end of life.

“Whenever any of us are visited by death or serious illness, then we can access it instantly because we access it through our own experience, and nobody is immune.

But we can rest assured that death will never leave us. There are very few guarantees left on this planet and death is one of them.

How we respond to one another in the face of dying, death and loss is how we are as human beings on this planet.” (MARIE RICHARDSON).
RECOMMENDATIONS

- Review the income supports for individuals and families facing life-limiting conditions and families who are bereaved. This review should particularly look at provision for children when a parent dies young especially if the parents are not married.

- Reverse the decision to abolish the Bereavement Grant.

- Increase the Living Alone Allowance.

- Conduct an audit on agency payments for people who are physically dependent and cannot collect their pensions or other entitlements.

- Conduct research into the number of people affected by funeral poverty in Ireland.

- Carry out research on the socio-economic cost of bereavement.

- Review the licensing and regulation of the funeral services industry which is currently unregulated.

- Consider introducing services in the UK such as Tell us Once and the Bereavement Service Helpline.

- Ensure all information is literacy-proofed and staff receive ongoing communications skills training.
The Department of Social Protection (DSP) has a budget in 2017 of €19.85bn and supports 2.05 million beneficiaries nationwide. It administers over 70 different schemes and services (DSP, 2016a: 11). Over 82 million payments were issued in 2015 (ibid: 72). It is Ireland’s biggest spending Department accounting for approximately 40% of gross current Government expenditure (DSP, 2015: 4). Nearly 1.6 million people receive a weekly social welfare payment (DSP, 2016a: 11). Some 619,308 families receive monthly child benefit payments for almost 1.2 million children (Corporate Governance Framework: 11).

In its Corporate Information Strategy, the DSP (then the Department of Social and Family Affairs) stated:

“The Department interacts with most of the population of Ireland across all phases of the life cycle, and its business is based on regular data collection to ensure that payments/entitlement are quickly and fairly processed.” (2014: 4).

The DSP administers a range of social insurance and social assistance income support schemes. Employment and benefit payment services are integrated through the Intreo service which was launched in 2012. It provides a range of employment supports (internship opportunities, guidance and placement services) to jobseekers as well as services (recruitment services, online publication of job vacancies and employment supports etc.) to employers. The DSP develops appropriate social policies in areas such as pensions, child income support, job seekers and activation. It also co-ordinates the implementation of government strategies for social inclusion under the National Action Plan for Social Inclusion and the Europe 2020 Strategy.

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

In its response to the external questionnaire distributed to all Government Department, the DSP stated that it did not have a policy remit in relation to dying, death and bereavement. It operated the following schemes: Disability allowance; Carer’s allowance; Carer’s benefit; Invalidity pension; Disablement benefit and associated occupational injury schemes and Family income supplement.

Staff dealt regularly with death and bereavement in respect of recipients or applicants for schemes and their relatives and dependents. It was stated: “This interaction consists of ensuring that the bereaved person receives their full financial entitlement in relation to the scheme(s) they are receiving and that they are directed to other DSP supports appropriate to their circumstances.” Staff were encouraged to deal with bereaved and other vulnerable customers with “empathy and sympathy”.

DEPARTMENT OF SOCIAL PROTECTION

To promote active participation and inclusion in society through the provision of income supports, employment services and other services.
In relation to how the Department might engage on the issues in the future, the respondent wrote: “In relation to Departmental staff who deal with customers who are going through the processes of dying or death or bereavement, regular refresher training concerning how to deal with vulnerable customers may be of benefit”.

**COMMENTS AND RECOMMENDATIONS**

The DSP outlines the wide and diverse group of clients that it serves. In the 2015 annual report it states that the clients it supports include “…families, people in employment, unemployed people, people with illness and disabilities, carers and older people” (DSP, 2016a: 10). It also provides a range of services to employers.

It does not overtly state that it supports people who are dying or bereaved. With approximately 29,000 deaths in Ireland each year and 290,000 people who are bereaved, many if not most of these individuals will be engaging with the DSP for their state pensions or for various social welfare payments during sickness, for support in their role as carers or for support as bereft human beings. It is, therefore, important to formally recognise the seriously ill and bereaved as customers of the Department and to recognise their specific needs and to treat them with dignity and civility.

**STAFF TRAINING**

In the *Customer Charter and Action Plan 2016-2018*, the DSP outlines the range of contact channels for customers including telephone; face to face; e-mail; text message and website. It also sets out the Department’s policies in relation to access and staff behaviour and explains that its application forms and information leaflets are compliant with plain English standards (DSP, 2016C: 14).

A UK report by Corden, Hirst and Nice (2008: 125) outlines the information needs of the bereaved stating:

> “People want clear information and easy access routes to appropriate sources of information for bereaved people. They need to be able to speak to staff with skills appropriate for communication with somebody in deep shock or grief. Where access to systems is via automated telephone call centres, standardised response are often experienced by bereaved people as inappropriate and upsetting. When data sharing system and technology reduce the need for recently bereaved people to repeatedly explain their circumstances, or produce the same information and documents, this is appreciated very much.”

As frontline staff will be dealing daily with people who are at the end of their lives, their carers and with the bereaved, it is recommended that the DSP provides information to staff on the needs of people at this stage of life and provides appropriate communications training. The DSP should continually review its information tools to ensure that they are clear and concise and consider using multi-media to disseminate information on its various schemes and people’s entitlements.

It is recommended that the Government introduces a system such as the *Tell Us Once* service in the UK where it is possible, in some areas of the country, to report a death in one
telephone call or online. This information is then communicated to most government organisations. This would reduce the administrative burden that individuals and families face as well as the time that is involved in informing each relevant Government Departments of the death. The Government should also investigate setting up a Bereavement Service Helpline such as that operated by the Department of Work and Pensions in the UK and with a human being at the end of the phone.

**APPROPRIATE SPACE**

The State counts us at key times in our lives – our births, our marriages and our deaths. In turn, the public should be able to rely on the State at the times that count for them such as the death of a loved one. It can do this by being mindful to citizen’s needs and putting in place protocols and systems to meet those needs. An example of this is the Registrars of Births, Marriages and Deaths around the country. These are offices where people register a birth, collect a marriage certificate, buy a birth certificate and ultimately get a certificate to mark the death of a loved one.

Kay Conroy from Dublin registered the death of her lifelong partner on 3rd May. This is what she wrote to the Registrar in Lombard Street on 17th April. Below is an extract of the letter.

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**Dear (name withheld),**

*I attended at your office yesterday 3rd May, to register the death of my beloved partner who died on 17th April.*

*I appreciate you are working from a small administration area for your work as registrars and hopefully you may get a larger area for our work soon.*

*I was most distressed to be surrounded with many, many young mothers and fathers registering a birth. I do not consider it appropriate as a person in early grief, that I should have to take my turn amongst those parents full of the joy of new life and be grieving the end of a loved one’s death. A friend who had to also register a death, also found the lack of consideration, privacy totally inappropriate.*

*May I offer the suggestion, that you put aside a time for the registration of deaths and that one of your registrars be allocated for that time in one of your offices to give the person in deep grieving the dignity and support that is deemed necessary at such a vulnerable time.*

**Yours sincerely**

*Kay Conroy,*

*Templeogue.*
As recommended by Ms Conroy, an appropriate space should be allocated for people who are registering deaths and specific times for registering deaths could be scheduled in an effort to spare the bereaved any upset. In time, any allocated space for the bereaved should be specifically designed to secure dignity and comfort. In this, the Health Service Executive, which is ultimately responsible for the registration function, could look to its Design and Dignity Programme in acute hospitals which it has developed with the Irish Hospice Foundation. These measures would also be in the interests of the officials who should receive regular training in communications and specific information on the needs of the bereaved.

**BURDEN OF PAPERWORK**

In addition to the physical space of our public offices, the State should look at easing the administrative burden it places on the seriously ill and the bereaved. The State should regularly review all of its forms to see if they are necessary and concise. Every effort should be made to eliminate multiple form filling which are confusing for people in the full of their health not to mind people whose health is compromised or who are enduring a stressful period in their life such as a bereavement. The statement below illustrates the negative impact that the State can inadvertently have on people.

> “I have ovarian cancer, stage 4. I am a visual artist. I found the social welfare system challenging and I still find it very difficult. Social welfare is an absolute nightmare. It’s the language, the lawyers, the forms, the 5927 form for this and for that which has to be dotted, it’s bureaucracy and it’s horrible. Choking is a very good word. It’s very intimidating when you’re not feeling very strong. When you are feeling vulnerable even in relation to the words you use, you could be tripping over yourself. I am an educated person. I should be able to do this but I felt very much at a loss.” (Sinead Dinneen).

**BEREAVEMENT GRANT**

The Bereavement Grant was abolished in 2013. The grant was a once-off payment of €850 to help cover funeral expenses. Eligibility for the grant was based on PRSI contributions. In a written answer to a question by Deputy Michael Healy-Rae, DSP Minister Leo Varadkar stated that the abolition of the grant provided a significant annual saving. This allowed the Department to protect other social welfare payments such as the State Pension. He explained: There are a range of supports available for people following bereavement which provide more significant support than the grant” (Varadkar, 2016). Annual savings of €22m were made with the abolition of the grant (Burton, 2016).

Commenting on the controversial decision, the Society of St Vincent De Paul (SVP) encouraged people not to resort to money lenders and informed people that the Exceptional Needs Payments (ENP) were available to help low income families (Barry, 2014). The Irish Hospice Foundation called in October 2012 for the grant to be
reinstated as over 80% of deaths each year were of people aged over 65. It explained: “This cut to the bereavement grant represents a burden on older people’s pockets and on their psychological security concerning funeral arrangements and peace of mind” (Keegan, 2016). In an interview for this study, MAB’s Michael Culloty stated that the bereavement grant was not properly targeted.

A once-off payment can be made under the ENP to help with funeral and burial expenses. There is no automatic entitlement to this means tested payment which is made at the discretion of officials administering the scheme.

In a written answer on 21st March 2017 to a parliamentary question on ENP asked by Deputy Bernard Durkan, Minister Varadkar said there were 8,900 successful applicants for ENP for funeral expenses between January 2014 and December 2016 and they were paid €14.7m to cover funeral and burial costs. The applicants for funeral expenses was nearly 3% of the total number of successful applicants for ENP for those years. If we take an average of 29,000 deaths each year there would have been 87,000 deaths in the period from January 2014 to December 2016. The 8,900 successful ENP applicants for funeral expenses were about 10% of the total number of deaths. We can therefore extrapolate that at least one in 10 bereaved families need support to pay funeral expenses.

It is recommended that the Government should reinstate the Bereavement Grant (even with certain eligibilities) which in itself was a recognition of death and an understanding of the impact of a death on all aspects of a family including their financial wellbeing.

**FUNERALS AND FUNERAL POVERTY**

The Post Insurance Funeral Price index, a new survey from Post Insurance, found that the standard Irish funeral cost in 2016 was €4,062 (excluding "disbursements and the cost of a burial plot or cremation service). A cost of €32,000 was quoted for a double plot at a graveyard in Deansgrange Dublin while the same sized plot in Shanganagh, Dublin was quoted at €5,600. Cremation costs were highest in Cork at €770. Laois at €1,440, Galway at €1,242 and Dublin at €1,177 were the top three most expensive locations for disbursements in Ireland. Waterford offered the most affordable "standard coffin" at €1,177.

Kilternan Cemetery Park in Dublin is one of the country’s new privately-run cemeteries where the cost of a corner plot starts from €13,950 with a plot opening fee of €950.

SunLife’s 2016 Cost of Dying report in the UK found that funerals have more than doubled in price over a 13 year period. Funerals are now one of the UK’s fast rising fixed costs (2016: 3). The Royal London’s National Funeral Cost Index 2016 estimated that the average level of funeral debt had increased to £1,601 with Funeral Poverty nationally standing at £147m (2016: 3). Which? the UK consumer magazine, produced Which? Dying Better. The consumer experience at the end of life and estimates that the average cost of a funeral in the UK will increase to £11,200 by 2020. It stated that it is likely that many households will have to borrow to meet the costs. The International Longevity Centre – UK (2015: 5) has projected that the aggregate spending on funerals in the UK could reach £3.7 billion by 2020. It also estimated that total UK funeral debt could reach a quarter of a billion by the mid-2030s.
UK Councils have reported that the number of burials and cremations for which they pay –pauper funerals- has increased by 50% in four years. Since 2011, they have paid STG £2.2m. Some 216 local authorities responded to a freedom of information request by the Liberal Democrats. Their responses showed that 1,465 paupers funerals took place in 2011. There were 2,202 pauper funerals in 2015. The increase was linked to a range of issues including increasing costs of funerals, diminished savings as people live longer and older people dying with no relatives or friends to “arrange, attend or pay” for a funeral (Morris, 2017).

Funeral poverty has been described as “the gap between the average cost of a funeral and the available resources of those paying those costs” (Citizens Advice Scotland, 2016: 9). Research in the UK has identified key constituents of funeral poverty which are:

- People’s expectations of a ‘funeral’, and what the person who takes responsibility wants to provide and why.
- People’s inability to pay the costs.
- The economic impact of lack of affordability, in particular problematic indebtedness.
- Negative psychological and emotional constituents, including the impact on grief and experience of bereavement. (Corden et al, 2015: 21).

Michael Culloty of MABS offers an insight into spending on funerals by those on low incomes stating:

“MABS, we know from our experience over the last two decades, that people on low income often choose certain times in their lives in order to both celebrate and to make a statement of their love and respect for a family member. Very often a funeral can be one of those occasions”

In relation to funerals, the House of Commons Work and Pensions Committee report Support for the Bereaved (2016: 15) expressed concern at the lack of protection in the market for bereaved customers particularly those on low incomes. Funeral Poverty in Scotland. A Review for Scottish Government (2016: 68) stated that the rise in funeral costs were taking place as incomes were stagnating, state supports reduced and there was a societal expectation of a funeral. It estimated that around 10% of people – 5,500 individuals - struggle to pay the cost of a funeral each year (ibid: 40). However, it cautioned that this figure was not fully robust and it recommended that the Scottish Government undertake further research to understand the number of people affected by funeral poverty. In its response to the report, the Scottish Government pledged to organise a series of stakeholder round table discussions and a national conference to focus on action (2016a: 3). In the Programme for Government, the Scottish government committed to publish a funeral costs plan and to consider plans for a funeral bond (2016b: 77).

“The conversation must take place at government level in terms of money because at the moment the cost of dying is actually beyond most people’s means. And it is unregulated. The government must provide people with the wherewithal to die decently, and to be buried in a way they wish to be buried.” (MARK PATRICK HEDERMAN).
A discussion document on the Irish funeral industry by the National Council of the Forum on End of Life in Ireland estimated that the average cost of a funeral in Ireland was €4,500 - €5,000 in the Greater Dublin area (National Council, 2011: 4-5). A large percentage of the cost of a funeral was spent on the grave. The price of a plot in Ireland was €200 but this rose to between €1,450 and €5,000 in Dublin. There is an opening fee for a plot which can be as high as €1,500 in Dublin. Meanwhile, the average cost of a cremation was set at €500.

The DSP can make an Exceptional Needs Payment to help meet essential, once off expenditure such as help with funeral and burial expenses. This is a means tested payment. An individual has no automatic entitlement to it and it is paid at the discretion of the officers who administer the scheme. It is recommended that more research needs to be conducted in Ireland on the number of people affected by funeral poverty and to see if the current support offered by the DSP is fit for purpose.

The licensing and regulation of the funeral services industry which is composed of approximately 600 funeral service providers (ibid, 2011: 2) should also be considered to guard against sub-standard funeral care and to secure transparency particularly with funeral bills. There are currently no barriers to entry and no licensing in this industry. The Irish Association of Funeral Directors has a voluntary code which covers the budgetary aspects of funerals among other issues.

“The industry needs more policing. The industry is a many headed beast. You have the funerals directors, cemeteries, crematoria, and the embalming side of it. The whole supply side of it. There are lots of moving parts. The public are concerned because they meet us only. Actually, there is a whole phalanx of people behind the scenes that make it all work. I think the case of some form of licencing or policing is very strong. The task is too onerous not to.” (GUS NICHOLS).

INCOME SECURITY

According to the DSP’s 2015 annual report, pensions made up over one third (35.5%) of the Department’s total expenditure in 2016. Some 18% of expenditure was on illness, disability and carers (DSP, 2016a: 29).

Research would indicate that people who are seriously ill incur additional costs. The Irish Cancer Society report on the true cost of treatment revealed an average additional cost of €862 per month with many facing extra monthly costs of up to €1,200.

“If you are sick – it has an effect on your finances, on your sense of self, on your role in the family, on you as a breadwinner. Being sick is very expensive. You cannot plan. You have to drop things. You have to drive to hospital, buy tea, coffee, sandwiches, pay for parking. You may be on sick benefit. You cannot plan your life. You need to go back to hospital, to the doctor, at short notice. You need somebody to mind your children. You may not have a medical card. Your income changes. Planning goes out the window. Extra expenses come in – petrol, people, dietary supplements. The consequence – a ripple effect for years. Lost a job, have substantial loans, may not have life insurance”. (IRENE MURPHY).
The UK consumer magazine Which? (2015: 4) reported that:

“Recent research has shown that consumers face a range of often unforeseen costs at the end of life – for example travel to and from hospitals, increased heating bills, and the price of special foods and clothes. These costs come at a time when real income have fallen significantly with many people reliant on benefits or savings to get by.”

Corden et al. (2008: 151) found that before their partner died, about 20% of couples had experienced “economic decline” over the past year or felt worse off financially because of higher expenses and lower earnings. They concluded (ibid: 153): “…one route to poverty and one cause of deepening of poverty to be the death of a life partner, especially among older women”.

The DSP has a range of income supports for people at different stages of life – ill health, carers, older people and the bereaved.

### SUPPORTS FOR THE ILL

If a person is ill, they may be able to get sick leave and sick pay from their employer. There is no legal requirement for an employer to provide sick leave and pay. A person can be eligible for Illness Benefit and payment from their employer. While they wait for a decision on their Illness Benefit claim, they may be entitled to the Supplementary Welfare Allowance which is a means-tested payment. The DSP also operates the Occupational Injuries Benefit Scheme which is a group of benefits for people injured or incapacitated by an accident at work or while travelling directly to or from work or who have contracted a disease as a result of their work.

### SUPPORTS FOR CARERS

Ireland has 187,112 family carers who provide a weekly total of 6.2 million hours of care. Family Carers Ireland (FCI, 2016: 2) estimates that carers cost the DSP some €900m in income support but actually contribute over €4 billion to the Irish economy each year. The State’s supports for people who are caring for an ill relative include the means-tested Carers Allowance, a reduced rate Carers Allowance, the Carers Benefit, the annual Carers Support Grant and the Domiciliary Care Allowance which is a monthly payment for someone caring for a severely disabled child who is under the age of 16.

For people who save the Irish economy €4 billion each year, it may be time to recognise this in relation to future pension provision. This was an issue which emerged many times during the research for this report.

“Some women have compromised their pensions because they had to leave work when they got married, or reduced their working hours and they are now caring for someone at home. There is a huge poverty trap waiting for women who lost out on work and who provided care to their husbands or some other relation.”

(IRENE MURPHY).
The application process for income support itself can be challenging for people. Evidence of the difficulty of the form is the fact that half of the applications are initially rejected and then allowed on appeal. The DSP improved the Domiciliary Care application form to make it plainer and easier to navigate. The DSP has agreed in principle to review the Carer Allowance application form.

**SUPPORTS FOR OLDER PEOPLE**

Older people in Ireland may qualify for the State Pension (contributory or non-contributory). They may also receive the Increase for Living Alone – a supplementary payment for people who are living alone. Pensioners automatically get an increase when they reach the age of 80. There is an increase for Living on a Specified Island to compensate pensioners for the extra costs of living on these islands. The Household Benefits Package (for those aged 70 and older or individuals between 60 and 70 on low incomes) includes the electricity or Natural Gas Allowance and the Free TV Licence. All residents aged 66 and over are entitled to the Free Travel Pass. These allowances are paltry sums for people who are old and frail and living alone.

Research from Age Action Ireland on the State Pension showed that changes to the eligibility criteria for the Contributory State Pension in 2012 "made it more difficult for people with irregular PRSI contributions to get a decent pension" (2017: 1). About 36,000 older people had their pensions cut by €988 to €1,565.20 annually (ibid: 5). Some 62% of the people affected are women who took time out of workforce to raise a family.

**SUPPORTS FOR THE BEREAVED**

The DSP pays the weekly Widow’s, Widower’s or Surviving Civil Partner’s (contributory) pension which is a social insurance payment and is not means-tested. The Widow’s, Widower’s or Surviving Civil Partner’s (non-contributory) pension is a means-tested payment. A person who is widowed and aged under 66 with qualified children who does not qualify for a Widow’s, Widower’s or Surviving Civil Partner’s (contributory) pension can apply for a One-Parent Family payment. People on low incomes can also access the Supplementary Welfare Allowance Scheme for a weekly supplement to meet needs such as rent or fuel costs.

If a person dies as a result of an occupational injury or disease and had received a Disablement Pension, their widow may be entitled to a Death Benefit instead of a Contributory Pension. A person can receive a once-off Widowed or Surviving Civil Partner Grant of €6,000 when there are dependent children. A couple with children who were co-habiting and not married are not eligible for this grant.

In a written answer on 30th March 2017 to a parliamentary question on widows pensions asked by Deputy Bernard Durkan, Minister Varadkar stated that 119,713 people were receiving the Widows, Widowers and Surviving Civil Partners Contributory Pension in 2015 with expenditure totalling €1.42 billion. The vast majority of recipients were women with 102,389 female claimants and 17,324 male claimants. Some 1,361 claims were rejected that year. In 2016, the total number of recipients of the contributory pension was 120,673 with a provisional spending of €1.43 billion. Some 102,949 women and 17,724 men claimed the contributory pension that year. The number of
In 2016, 246 people comprising 211 women and 35 male were claiming the One-Parent Family Payment and the expenditure that year was €500,699.

In 2015, some €8.2m was spent in paying 655 death benefit pensions. In 2016, the estimated expenditure was €8.3m in paying 711 death benefit pensions.

Some 1,048 people – 296 men and 752 women - received the Widowed or Surviving Civil Partner Grant in 2015. Expenditure that year was €5.7m. In 2016, 1,023 people received the grant - 328 men and 695 women. The provisional expenditure for 2016 was nearly €5.7m. All of these figures show how the loss of a spouse impacts disproportionately on women.

Guardian payments are available for a person caring for an orphaned child. A Funeral Grant of €850 is paid when a person dies because of a workplace accident or occupational disease. As stated earlier, a person on a low income may be eligible for an Exceptional Needs Payment to help with funeral costs.

These payments are essential for income security for people who are ill or the bereaved. Increases in in rates of weekly payments to pensioners, carers, widows, lone parents etc. were announced in Budget 2017. The Government also announced that the Living Alone Allowance, the Over 80 Age Allowance, the Fuel Allowances, the Household Benefits and Free Travel would be protected. Yet over the years, a number of allowances have been discontinued or cut back. The telephone allowance was cut in 2013 and then abolished in 2014 (Age Action 2016: 12). The Bereavement Grant was discontinued in 2014 as was the Diet Supplement. The Fuel Allowance was cut back by six weeks. There was a decrease in the value of the electricity element of the Households Benefits Package but the cost of heating is still exceptionally high.

**THE WIDOW’S PERSPECTIVE**

The National Association of Widows in Ireland was contacted about the study and the concerns of its members were outlined. Following a spousal death, women have to live with the loss of a pension. People found it difficult to meet expenses such as house maintenance on their pension. The Living Alone Allowance was €9 a week. It was stated that it would take a lot of €9 to pay a call out fee for a tradesman like an electrician.

The telephone allowance was discontinued in January 2014. This hurt many widows who live in isolated areas with no mobile coverage and no computer. In these circumstances, a telephone was essential. There was also annoyance at the decision to abolish the Bereavement Grant. It was suggested that there should be some recognition that a person living alone with a pension had the same expenses such as the Property Tax as neighbouring households with two incomes. It should be possible to get some reimbursement in these circumstances. The Christmas bonus should be restored in full.

The Fuel Allowance has been reduced and the duration cut. It was stated that the Fuel Allowance should be restored to its previous levels for everyone and it should be
continued throughout the year for those who are confined to their home or ill. Another worry for widows is the charge for the waste collection and the anticipated charge per weight from July 2017 as the waste waiver has been abolished. Some action was needed on this issue. In relation to the prescription charge, it was stated that the charge should be abolished as promised because people are choosing which prescription is least important and not fulfilling that prescription.

The administrative burden involved in communicating with the State about services was raised. There are waiting lists of many years to have a home adapted. The issue of poor communication by State services with people not receiving the full information they need and phone calls not being returned.

POVERTY AMONG THE BEREAVED

The Corden et al. (2008: 151) report from the UK stated that “...the financial consequences of death of a life partner depend crucially on which partner dies”. Women were more likely to experience an economic downturn as many could not sustain their income levels. Pensioner women had limited opportunities for work “or re-partnering” and initially younger women with dependent children might struggle to join the workforce.

The Vincentian Partnership for Social Justice has an ongoing Minimum Essential Standard of Living (MESL) research which has established what people believe is needed for households to have a “minimum socially acceptable standard of living” (2016: 1). In its 2017 pre-budget mission, it stated that a pensioner living alone is vulnerable to income inadequacy as “the household’s MESL expenditure need is 82% that of Pensioner Couple, but the State Pension and the secondary income supports amount to notably less” (ibid: 8).

A UK report entitled Life after Death points out that the cost of bereavement is too great to ignore. It states: "A death often means other changes for those left behind, such as taking on new responsibilities, moving house, or adjusting to different living standards" (National Council for Palliative Care, et al. 2014: 2).

Another UK report Losing a Partner – Part 1 (2016: 4) stated that the loss of a spouse or partner can hurt people financially for years – for some as many as five years or more. Of 500 bereaved people surveyed, 69% said they were not prepared financially or practically for their partner’s death; 42% were unprepared both practically and financially and just 11% were completely prepared (ibid: 7). Some 39% of those who were unprepared saw their incomes fall (ibid: 12).

Losing a Partner – Part 2 (2015: 6) found that 50% of people reported lower disposable income after a partner’s death; 35% had lower savings and 15% had higher debt. One third or 33% had some kind of debt with 14% finding unexpected debt. More than one in four people (27%) had to sell possessions or assets or borrow money from family or friends.

For women of all ages, the impact of a death on income was greater because men generally had higher earnings. Bereaved women were more likely to make changes to both their daily spending and their lives after a bereavement (ibid: 12).

Younger bereaved people (under 50) were especially badly affected as the financial consequences can be severe. This age group is likely to have dependent children at home and be paying a mortgage. Under 50s are more likely to change job to earn more money or to start working (ibid: 14).
Those in the 50 to 64 age group were more likely to see a drop in disposable income. In many cases the most “dramatic and expensive changes” were made by people in this age group. The over 65s were most likely to find their overall income declining (ibid: 13).

**CHILD POVERTY**

Corden *et al.* (2008: 155) stated that the death of a partner may be one factor contributing to child poverty. The Childhood Bereavement Network (CBN) in the UK stated that caring for grieving children had an impact on parents’ capacity for work. The Irish Childhood Bereavement Network (ICBN) highlights that studies have consistently shown that children’s outcomes are related to how their parent managed to function following their loss. Some of the negative changes linked to childhood bereavement include criminal or disruptive behaviours, reduced educational attainment and employment status and diminished self-esteem (McLoughlin, 2012a: 6). Bereavement by the age of 16 is associated with men and women being unemployed at 30. Childhood bereavement had an indirect link on future poverty through its impact on attainment.

There are no official figures for childhood bereavement in Ireland but it is estimated that between 36,000 and 60,000 Irish children could have experienced a significant bereavement (ibid). It is recommended that income supports directed at bereaved families and children should be safeguarded and enhanced to ensure that bereaved children – who are among our most vulnerable citizens – are supported to reach their potential.

**RESEARCH ON SOCIO-ECONOMIC COSTS OF BEREAVEMENT**

Some research needs to be conducted into the socio-economic cost of ill health, death and bereavement. A 2013 report in Scotland on bereavement found that bereaved spouses have longer stays in hospital which are associated with spousal bereavement. This cost the National Health Service in Scotland an additional £20 million each year (Birrell *et al.*, 2013: 19). The cost of bereavement-related primary care consultations was about £2.2 million annually. Researchers suggested that this was the tip of the iceberg (ibid: 14).

**REVIEW OF INCOME SUPPORTS**

A death in a family has a negative impact on the financial circumstances particularly for women. An older woman may not have significant debt or obligations such as a mortgage. But older women are generally not in a position to improve their finances through employment. Younger women may have the advantage of being able to return to work to supplement the family income, but this may be difficult for the children.

It is recommended that the income supports for individuals and families affected by dying, death and bereavement should be reviewed to see if they are fit-for-purpose. A positive feature of the Irish social protection system is that bereaved spouses are paid the widows, widowers and surviving partner pension into the future. This does not happen in other jurisdictions where there is a time limit. The One Parent Family Payment is structured to encourage the recipient to work. But this may not be in the interests
of their bereaved children who may need their parent to be present. Research from Australia (STEBBINS & Batrouney 2007) estimates average lost income of AUS$59,500, which was directly related to the death of their child. European research ((Pivodic, Van den Block, Pardon, Miccinesi, Vega Alonso, Boffin, Donker, Cancian, Lopez-Maside, Onwuteaka-Philipsen, Deliens, 2014) found that family carers of people at the end of life had difficulties in paying care-related costs.

A number of issues in particular need to be looked at: the adequacy of the provision for the children of parents who die young.

“There is not adequate provision for the children of people who die young. If the father dies in his forties and leaves two or three children, the mother gets the Widows pension and she will get it forever. But it will not in any way compensate for the household income that had been there. If the mother does not have a career in her own right, which is often the case, particularly if the children are small, we do not deal adequately with that”. (ITA MANGAN).

There is also an issue in relation to the rights of cohabiting couples and the lack of pension rights. A family with children and married parents can access the once off Widows or Surviving Civil Partner Grant of €6,000. This is not available to families with children where the parents were not married.

“The widows and the widows pension all apply to civil partners and same sex marriage. But the heterosexual couple who are not married do not have any rights in respect to each other. That is a very general statement and there are some points where they do. But in general, if a couple are living together and they have children, and one of them dies, they do not get any widows/widows pension.” (ITA MANGAN).

Meanwhile, some payments such as the Living Alone Allowance should be increased.

“I’ve long been of the view that we should significantly improve the Living Alone Allowance because I think the difference between a couple living on the Old Age Pension and when one of them dies the bills remain more or less the same. The heating bills are all the same. This would make a big difference to a lot of people. I do think the relative costs of one person on their own is much greater than two.” (ITA MANGAN).

An issue highlighted during the research for this report was the need for audits to be conducted on agency payments so that the DSP can check if pensioners are actually receiving their pensions and if their pension is being used for their benefit.

“What risk analysis and what audits has the Department done amongst those 500,000 people to know if they were getting their pension and was the pension being used for their benefit?” (PATRICIA RICKARD-CLARKE).

What this chapter shows is that the Department needs to look at ensuring that all its staff have the communications skills to deal with people on sensitive issues and it
should examine anomalies that arise in schemes that prevent people from accessing adequate income supports. It is also time that the Department takes a policy role in looking at an audit of all of DSP schemes to see if they are fit for purpose and adequately and equitably address the needs of people at end of life and in bereavement. We can all plan for death. It is incumbent on the DSP to plan ahead. It is, after all, the biggest spending government department administering public money to probably every household in the country. But we need data in order to plan.

Funerals have become so expensive that people cannot afford them. Cost is outrageous. Modest funerals can cost over €5,000. The insurance industry is now creating products and packages to cover the cost of funerals. You now have to save to die.

The Fair Funerals Campaign was set up by Quaker Social Action in the UK in 2014 in response to growing concern over funeral poverty. It points out that the cost of funerals has soared by over 90% in a decade. It highlighted that "Funeral Services" was the most expensive transaction on credit cards in 2013 but the situation was worse for people who could not access affordable credit and had to resort to high-interest lenders. Following a campaign to abolish council charges for child burials, the Welsh Government announced in March 2017 that the charges would no longer apply in Welsh communities.
RECOMMENDATIONS

- Secure the Rural Transport Programme.

- Review the transportation services needed by the seriously ill including people at end of life, to allow them to travel to hospital and to other healthcare settings.

- Champion new hospital protocols where relatives will not be charged car park fees, when visiting members of their families who are dying.

- Urgently develop the accessibility of transport infrastructure.

- Encourage all sporting organisations to develop plans to respond to critical incidents affecting their community.
CHAPTER 1

BACKGROUND

The Department of Transport, Tourism and Sport (DTTAS) is a “central Government Department” which is responsible for developing our roads, our aviation service, public transport, maritime affairs, tourism and sport.

In 2016, there were 187 deaths on the road which was a 15% increase on 2015 when 166 people died. It was announced that there would be a 10% increase in the traffic corps in 2017 (DTTAS: 2017a). In 2015, 63 vulnerable road users (pedestrians, motorcyclists and cyclists) died – a 19% reduction on 2014. The greatest number of these deaths were among the 16-25 and 66 years and older age group (DTTAS, 2016a: 27). The target of the Government’s strategy on road safety is to reduce the number of road collision fatalities to 124 or fewer by 2020. A provisional target is to reduce serious injuries to 330 by 2020 (Road Safety Authority, 2013: 3). These reductions would ‘close the gap’ between Ireland and best practice countries.

There were three fatalities in two General Aviation accidents in Ireland in 2015 (DTTAS, 2016a: 17). The Coast Guard responded to 2,664 incidents in 2015 with a 60% rise in response to support the National Ambulance Service - 292 missions (ibid: 34). In 2015, the Search and Rescue helicopters were tasked 1,013 times to incidents. The Royal National Lifeboat Institute (RNLI) volunteer units responded to 836 incidents and the Coast Guard’s volunteer units responded to 1,289 incidents. A new IT based incident logging system was brought into service within the three Rescue Co-ordination Centres.

ALL MODES OF TRANSPORTATION

According to the Department’s annual report, 224m passengers used state-supported public transport in 2015. Some 1.76m passenger journeys on 242,224 services were funded by the Rural Transport Programme. Following a restructuring, 17 Transport Co-ordination Units or Local Links were established in 2016 to deliver the Rural Transport Programme. Passenger numbers on our rail network stood at 1.9m in 2015 and over one million flights were managed through Irish airspace. About 30m people used Irish airports during the year (ibid: 16).

TOURISM

There were 8.643m visits to Ireland from overseas in 2015 – the year in which the Tourism Policy Statement – “People, Place and Policy” was launched. The aim is that by 2025, overseas tourism revenue (excluding air fares and ferry charges) will have
increased by €5bn per year, there will be 10m overseas visits to Ireland each year and 250,000 people will be employed in the sector (ibid: 36).

**SPORT**

Minister for Transport, Tourism and Sport Shane Ross noted in the Statement of Strategy (2016b: 2) that “We are becoming a country noted for the quality of our sportspeople and the character of our fans”. A high level goal of the Department is the creation of a healthier and more active society. It commits to encourage people to take part in sports, encourage high performance and to provide facilities. It invests in the work of sporting organisation such as the Gaelic Athletic Association, the Football Association of Ireland and the Irish Rugby Football Union. Through the Sports Capital Programme, it develops sports facilities and purchases sports equipment for clubs and organisations. Under the Local Authority Swimming Pools Programme, grants are provided to provide a new pool, replace a pool or refurbish an existing pool. The ‘Go for Life’ Programme aims to help clubs and organisations to support their older members to take part in recreational sport and physical activity.

**EMERGENCY PLANNING**

The Department is represented on the relevant bodies for Emergency Planning and is the lead Department for transport emergencies. It also supports other lead Departments for emergencies which affect travel and transport such as Storm Desmond in December 2015 which damaged transport infrastructure.

**THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT**

The Department’s response came from the Irish Coast Guard. The response stated that in relation to policy work, there was engagement with coast guard services when they are responding to a person threatening suicide. It also referred to post traumatic counselling following the recovery of deceased persons or a traumatic event.

In a general reply to the question about how the Department engages with the public and/or delivers services on dying, death and bereavement, it was highlighted that evidence is given in coroners court. The service uses the Defence Forces in Critical Incident Stress Management.

While there were no plans as to how the Department might possibly engage in the future around dying, death and bereavement, it was stated that they might look at courses to improve engagement with those threatening self-harm.

**COMMENTS AND RECOMMENDATIONS**

The *Programme for a Partnership Government* (2016) outlines a number of commitments on transport including prioritising new investment in local and regional road maintenance and improvements; examining the integration of services in the rural bus network and conducting a review of public transport policy.
The work of the DTTAS is vital for Ireland’s economic and social fortunes. Available and accessible transportation is essential to ensure that citizens can access work, services and fully engage with their communities. The Department's work has an impact on all citizens including those who are facing serious illness, death or those who are coming to terms with a bereavement. A direct relationship does exist in that Funeral Service Drivers fall under the National Transport Authority.

A number of issues are outlined below.

COMMUNICATIONS

The Department’s Customer Action Plan (2017b: 3) pledged that key website editors would be trained in Plain Language best practice to ensure a more user friendly and accessible service. It committed to provide information that is “clear, timely and accurate” and would accommodate people with specific needs (ibid: 9).

The Action Plan also made a number of commitments on accessibility of its offices and information. It pledged to “provide clean, accessible public offices that ensure privacy, comply with occupational safety standards and, as part of this, facilitate access for people with disabilities and others with specific needs” (ibid: 8). This plan is one thing. The reality can be different.

These commitments on accessibility of offices and information are welcome and, if implemented, will benefit all citizens who engage with the Department. They will particularly be welcome for individuals with serious health issues who need to use public transport services.

It is recommended that communications skills should be a core module of any induction or continual training programme for Department staff and the agencies they fund. A central part of this training should involve sensitising people to the needs of people who are challenged by serious or life-limiting illness or are bereaved. In addition to being given the skills to use simple and concise language, people in frontline posts should also be empowered to give people the time that they need to digest information.

All staff should treat customers with respect, general good manners, attention and heed. The public should expect a high standard of communication behaviour. While accessibility of public facilities is a key issue, the cleanliness of these facilities is also important.

PERSONNEL CARE

Emergency personnel such as the Coast Guard work in hazardous conditions to save lives. Coast Guard volunteer Caítriona Lucas died in September 2015 while conducting a search off the coast in Co Clare. Ms Lucas was “the first Irish Coast Guard volunteer to die during a search” (Siggins, 2016). Some six months later in March 2017, the crew of Rescue 116 died off the north Mayo coast with the loss of pilot Captain Dara Fitzpatrick and her colleagues pilot Capt Mark Duffy, winch operator Paul Ormsby and winch man Ciarán Smith. These deaths were made even more poignant by the fact that these individuals lost their lives in the service of saving others.

In relation to Rescue 116, controversy followed the publication of the Air Accident Investigation Unit’s (AAIU) preliminary report on the accident on 14th March 2017.
which included an extract from audio recordings just before the accident. The AAIU had to defend its decision to include the transcript which was criticised by the Irish Air Line Pilots’ Association as well as the International Federation of Air Line Pilots’ Associations and the European Cockpit Association. It is imperative that accidents are investigated, that findings are published and safety recommendations are implemented. This is in the public interest. But sensitivity must always be displayed towards the bereaved families who are coming to terms with their loss.

It is important that personnel are encouraged to use the post traumatic counselling services that are available following a traumatic event and the service makes use of expertise in other arms of the State such as the Defence Forces Critical Incident Stress Management.

Ireland became the first country in Europe to develop a new driving standard for emergency service drivers (DTTAS, 2014). In 2014, the Road Safety Authority launched the Emergency Services Driving Standard which will be voluntarily implemented by the main emergency service organisations. It is important that this Standard is operated to ensure the safety of emergency personnel, patients and other passengers.

TRANSPORT ACCESS TO HOSPITALS

A significant number of people die in our acute hospitals. When people are undergoing treatment or as their health deteriorates, they will spend more time in hospital and will require transportation to get to and from hospital. Their relatives, particularly older spousal carers, will spend time with them in hospital. This may necessitate paying hospital car park fees.

In its submission to the DTTAS as part of the consultation for its new Statement of Strategy, the The Health Service Executive’s (HSE) Estates and Acute Hospitals Division stated that every year, more than 600,000 patients are admitted to acute hospitals. There are over one million day case procedures and more than 3.2 million patients attend hospital outpatient clinics. It recommended that “optimum transport links and public transport services are provided to all acute hospitals to reduce travelling times for patients attending hospitals, ensure ease of access for those travelling by bus, rail, taxi and private car, especially for those with special needs...” (HSE, 2016a: 4). It also stated that there was a need for appropriate transport infrastructure to support the development of primary care and for bus lanes to continue “to support improved access for emergency vehicles” (ibid).

The HSE Non-Emergency Patient Transport Service is provided where a person needs specialist transport and cannot use conventional transport. Priority is given to certain patients such as those undergoing oncology treatment and dialysis. The HSE may assist with transport costs such as taxis (Citizens Information Board, 2009: 24). There is no statutory obligation on the HSE to provide Patient Transport Services. It is provided on a discretionary basis (HSE, 2016b: 3). People may be able to access Travel Supplement or an Exceptional Needs Payment from the Department of Social Protection to cover transport expenses.

A Citizen Information Board (CIB) Social Policy report (2009) described the transport mechanisms to assist people to get to hospital as “unsatisfactory”. It stated that sometimes people could not keep hospital appointments because they could not
access public transport, organise a lift and could not afford taxi fares. It noted a lack of information about what assistance is available for hospital transport. The CIB reported a lack of provision for patients living in rural areas (ibid: 27).

Research from the Irish Cancer Society (ICS, 2015) found that 86\% of cancer patients incurred travel costs of €166 on average per month. Patients from rural areas faced higher costs. The ICS has operated the free Volunteer Driver Service since 2008 where patients undergoing chemotherapy treatment are transported to and from hospital. Over 1,000 volunteer drivers are involved in the service and 16 hospitals countrywide are participating. The ICS also administers the National Cancer Control Programme’s Travel2Care scheme to support patients who have a financial difficulty in meeting travel costs.

It is recommended that the issue of transportation to hospital be urgently reviewed by all the parties – the Health Service Executive and the Department of Transport, Tourism and Sport. Patients who are coming to the end of their lives should be a priority group when it comes to accessing transport for admission to hospital or for discharge if they wish to die at home.

**CAR PARK CHARGES**

A related issue in relation to hospitals is the car park charges that patients and their relatives face. ICS research found that 80\% of cancer patients faced parking costs at a monthly average cost of €62 (ICS, 2015: 10). Car park charges vary countrywide with costs highest for Dublin hospitals. The ICS estimated that in 2015, almost €16m was generated in car parking revenue at the 26 public hospitals offering cancer treatment (ICS, 2016). Some hospitals allow free parking for patients undergoing chemotherapy and radiotherapy (ICS, 2016b: 2). In its *Park the Charges Campaign*, the ICS called on the HSE to issue guidelines to hospitals to provide free or significantly reduced parking for cancer patients undergoing treatment.

It is recommended that hospital authorities should make exceptions for patients of all diagnosis who are receiving end-of-life care in hospital and not charge for car parking for certain of their relatives/carers.

**RURAL TRANSPORT**

Transport is essential for an individual’s wellbeing and ensuring they play an active role in society. Irish Rural Link (IRL) states:

“*Transport in rural areas is very often seen as a lifeline to people and plays an imperative role in preventing isolation for people living in rural and sometimes very remote areas. However, people living in rural areas cannot access a widespread rural transport service or take advantage of free travel entitlements*” (2016: 3).

It is vital that individuals in rural Ireland who are at the end of their lives have access to transportation so they can access the services they need. Access is also important for people who are bereaved and who are living alone in rural communities so they do not become socially isolated.
“The car tends to disappear at the worst time coming into a person’s late sixties when maybe health breaks down for other reasons. And in rural Ireland suddenly you cannot go anywhere. You are absolutely stranded. The community, rural transport programme is company. It brings people to your house, and it brings you out of your house.” (SEAMUS BOLAND).

Therefore, the Rural Transport Programme needs to be adequately resourced. Minister Ross announced an additional €850,000 from savings in his Department to the Rural Transport Programme in 2016 bringing the total allocation to over €14.5m. It was also announced that the programme will receive an extra €2.19m in funding in 2017. The Seanad’s Public Consultation Committee report on older people (2012: 8) cited research by the Centre for Ageing Research and Development in Ireland which identified 37% of rural dwellers had unmet transport needs.

This is confirmed by research from TILDA (2017) which found that just 9% of people aged 50 years and older use public transport and 58% of those living in rural areas rated the public transport as poor or very poor. The research revealed the limited value of the free travel scheme. As few as 3% of people in rural areas entitled to free travel actually use public bus and rail services. In the Greater Dublin areas, about a third of free travel passengers use public transport and this figure drops to 10% for those in towns and other cities (2017: 19). The report highlighted the need to improve transport services for older people particularly rural dwellers.

An increase in rural bus schemes is supported by the HSE’s Office of the National Director of Health and Wellbeing (HSE, 2016c: 6). It has also been recommended that rural transport routes should be assessed against providing access to healthcare facilities and include physical access, safety and proximity of stops to facilities (HSE, 2016a: 4).

ACCESSIBILITY

In recent years, publications have been produced on the design of urban roads and streets and shared spaces, shared surfaces and home zones for urban Ireland which would address issues of accessibility.

The National Disability Authority (NDA) has stated that “considerable progress” has been made in developing accessible vehicles and facilities but encouraged further investment. It highlighted in its submission to the DTTAS consultation process for its Statement of Strategy that while most Bus Éireann coaches had a wheelchair lift, most coach stops could not accommodate them (NDA, 2016: 1). It also highlighted the need for accessibility across vehicles and facilities to allow people to complete their journey (ibid: 5). The NDA recommended that the Department takes a Universal Design approach in developing new facilities and services.

Stephen Cluskey has a disability and is the founder of the award-winning Mobility Mojo which provides people with the information they need to plan a journey. He stated:

“Access to public transport is a vital link in a fully functioning society. It is the vessel which connects everything together. Without this essential link, many can be left stranded, vulnerable and isolated.”
in their communities leading to potential negative knock-on effects including depression, anxiety and mental health issues. Older people and those with disabilities are even more so affected by this issue, considering the lack of infrastructure and isolation they already face.

More than 50% of the 600,000 people in Ireland with a disability won't travel for fear of something going wrong." (Stephen Cluskey).

In its submission to the DTTAS Strategic Statement consultation process, Inclusion Ireland (2012: 3) stated that many citizens were excluded from towns, cities and communities through a lack of fully accessible toilet facilities. Inclusion Ireland has recommended the installation of “Changing Places” facilities countrywide. These facilities are different from the “mainstream accessible toilets” in that they include a hoist and a height-adjustable changing bench.

A Programme for a Partnership Government pledged to introduce a provision where taxi companies who bid for state procurement contracts must have a minimum of 10% of wheelchair accessible vehicles in their fleets.

This report supports the recommendations outlined above which, if fulfilled, would facilitate people who are living with life-limiting conditions to continue to engage in their community, because their need for accessible transport and facilities were being met.

TOURISM

Thanatourism or ‘dark tourism’ has developed where visitors travel to sites of death or disaster. Auschwitz-Birkenau and Ground Zero would be examples of dark tourism destinations. Ireland is currently involved in a decade of commemorations when we are reflecting on the birth of the nation - a period of violence and bloodshed. The study of genealogy is the study of our past and our ancestors.

Some cemeteries are famous tourist attractions such as the Pere-Lachaise Cemetery in Paris which has the graves of Oscar Wilde and Jim Morrison; Arlington National Cemetery in Washington where over 400,000 “active duty service members, veterans and their families” including slain US President John F Kennedy are buried and Highgate Cemetery in London which is the final resting place of Karl Marx. There are also the first WW1 graveyards of the Somme and the well-known WW2 grave sites of the landing beaches of Normandy in Northern France.

Ireland’s tourism authorities should look at promoting visits to our cemeteries where national and international visitors can learn so much about our political and social history. The iconic Glasnevin Cemetery in Dublin is uplifting in terms of its beauty, in its artistry and its inspiration as a city of history.

On 27th April 2017, it was announced that Goldenbridge cemetery was to be reopened as part of a celebration in May to promote the landmarks of Dublin 8 ( McNally, 2017). Integrating our graveyards into contemporary living ensures that our dead and the living co-exist and help to understand death as a natural part of life.
SPORT


It is important that many national and major sports events continue to be free-to-air as they are of major national importance. Key sports events including the All Ireland senior football and hurling finals, the summer Olympics and soccer World Cup and European Championship matches are designated events and people are guaranteed that they can view them free of charge. A review of designated events takes place every three years and has to be approved by the European Commission in accordance with the Audiovisual Media Services Directive. Once approval is granted, the Minister for Communications, Climate Action and Environment can sign a revised designation order. In September 2016, the ladies football and camogie finals were designated as free-to-air events (RTE, 2016).

Sports are uplifting events for an entire nation including people who are at the end of their lives or living with a bereavement. The GAA’s Community and Health Programme is working on a range of social issues: gambling, alcohol and drug education; mental fitness; community development and healthy eating. The GAA recognises its role in supporting its members and communities in the aftermath of “critical incidents”. Every year, it receives 30-40 requests for support from clubs and counties. It has developed a Critical Incident Resource Plan and Resource and organised training in developing a Critical Incident Resource Plan.

The Kevin Bell Repatriation Trust which supports bereaved families by repatriating the bodies of their loved ones who have died abroad in sudden or tragic circumstances back to Ireland, is one of five charities selected by the GAA to be charity partner for 2016/7. The vital community work of organisations such as the GAA is exemplary as they are helping to build a positive community environment.

The power of communication in sports is immeasurable in joy and sadness. Its positive influence was best exemplified recently with the death of Anthony Foley, the Munster Rugby Coach in 2016. The community used sport to come together and used ritual in the form of shape and sound and communication, on a national and international platform, to interpret the sudden loss and the local and national grief when Anthony Foley died. Sport, in that instance and in many on a more local level, was capable of both reflecting the loss and protecting the bereaved, both in a private and public way. The sporting fraternity response was both therapeutic and healing and, in the best sense, ritualistic and unifying. It gave language to grief.
RECOMMENDATIONS

- Organise training for OPW staff on the needs of people at end of life or in bereavement and the therapeutic value and importance of their heritage work.

- Conduct an audit from an end-of-life perspective of the buildings under its control.

- Help to raise awareness of World Hospice and Palliative Care Day by lighting up landmark buildings on this annual global day of action.
BACKGROUND

The key functions of the Office of Public Works (OPW) is in Estate Property Management (including Heritage Services) and Flood Risk Management.

The OPW holds and manages a large property portfolio which includes 567 offices, 840 Garda premises, specialist properties and 780 Heritage sites (2016a: 7). It provides a range of shared services to central Government Departments and Agencies including architectural, engineering, valuation, quantity surveying, project management and facilities management services. In 2015, the OPW was responsible for designing and project managing about 50 building projects (2016a: 5). The OPW is responsible for the conservation and presentation of the State’s National Monuments and Historic Property. This includes two Unesco World Heritage Sites: Bru na Boinne (Newgrange) and Skellig Michael. Of the 780 National Monuments under the OPW’s care, 70 have a guided service such as the Rock of Cashel, Dublin Castle, Newgrange, Kilmainham Gaol and Kilkenny Castle. The OPW is also responsible for managing the State art collection which consists of approximately 15,000 works.

The OPW is the lead agency for flood risk management. It aims to minimise the impact of flooding by providing flood risk guidance and advice on sustainable planning; assisting the development of resilient communities and implementing effective mitigation measures for areas at risk. The Capital Investment Plan 2016-2021 includes a six year programme of capital investment in flood risk management and defence measures at a cost of €430m. Draft Flood Risk Management Plans were developed under the Catchment Flood Risk Assessment and Management (CFRAM) Programme. Minister Canney stated that the CFRAM as “the largest flood risk management planning programme ever undertaken by the State” (OPW, 2016b).

THE DEPARTMENT AND DYING, DEATH AND BEREAVEMENT

The OPW stated that its policies relate to operational aspects of service provision and not specifically to engagement with the public on dying, death and bereavement. It noted that the only area of relevance was in the OPW’s role in maintaining and presenting National Monuments under the National Monuments Acts. Certain members of the public have a right of burial at specified National Monuments sites. The OPW’s Heritage Services support those members of the public in the event of a bereavement.

COMMENTS AND RECOMMENDATIONS

The OPW is a service organisation and identifies its customers as “Government, other Departments, Offices and Agencies and, ultimately, the public” (OPW, 2010: 1). The
OPW stated that a limited number of individuals would receive direct support from its staff following a death. In a follow-up communication, the OPW explained that: "In some cases, there are limited legacy burial rights attaching to certain individuals and families”. The OPW – in concert with the Department of Arts, Heritage, Regional, Rural and Gaeltacht Affairs - manages those records and burials directly. Sites falling into this category include Cashel, the old graveyard at Clonmacnoise and the greyeyard at the Hill of Tara. Permission is required before graves are opened and archaeological supervision may be needed. There are different arrangements in place for sites where there are more general burial rights and the local authority or the local Church may be involved as the graveyard managers. Any burials within National Monuments must have archaeological oversight. There are 12 military cemeteries that have Commonwealth War Graves Commission registered war graves and three are owned by the OPW. The Department of Defence and the OPW jointly manage the Arbour Hill cemetery.

The OPW did not comment on any indirect role that it plays in supporting those members of the general public who are seriously ill, are at the end of life or are bereaved. The OPW, through its heritage work and its work in parks, indirectly plays a critical role in supporting individuals who seek solace during their illness or bereavement in Ireland’s parks and visiting National Monuments.

"An environment- the actual physical environment – is mood altering. I believe it can affect your thinking and feeling from the moment you walk through certain environments. It is all critical. In some ways or in every way our environment defines us.”
(RONAN ROSE ROBERTS).

There were 4.9 million visitors to the OPW’s guided sites in 2015 – a 10% increase on 2014 figures (OPW, 2016a: 5). Some 10 million people each year visit the Phoenix Park – one of the largest designed landscapes in any European city (ibid: 1). There are more than six million visitors to St Stephen’s Green Park every year (OPW, 2016c). Some of the individuals visiting OPW sites will be living with a life-limiting condition. There will also be individuals, of all ages, who are coming to terms with the death of a loved one or are dying.

Research has shown how access to nature enormously benefits the individual. This could be by visiting a park or a garden or by looking through a window. The health benefits are valid for many population groups (Erickson, 2012: 100). Gardens serve many purposes including “relaxation, solace and recovery” (Buck, 2016) while encounters with vegetation greatly benefit people experiencing stress and anxiety (Ulrich, 1986). In relation to healthcare design, nature and patient care, Ulrich (2008: 7) states: “Design that provides patients with window views of nature, access to gardens, and exposure to nature art and pictures, can alleviate pain and emotional duress, and reduce care costs”.

In the Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care, the Hospice Friendly Hospitals Programme of the Irish Hospice Foundation (2008: 7) stated: “Evidence from research proposes that gardens and views of nature have a positive effect on health and well-being and offer opportunities for reducing stress and improving mood”.

The ‘Journey on Earth Garden’ from Our Lady’s Hospice and Care Services in Dublin won the ‘People’s Choice Award’ and a Silver Guild medal at the Bloom Festival 2013. Worpole (2006: 29) has referred to how hospices use their gardens stating that these
organisations: “...would claim that a close relationship – and even engagement with – the natural world of trees, shrubs, plants, flowers and water, can be immensely therapeutic and morale-raising”.

OPW staff should receive training on the therapeutic value of the spaces they are responsible for, so that they gain a deeper appreciation of the needs of some of their clients, and the impact their work has on some visitors. Staff could also learn how they can improve their services and facilities for a person who is not actively dying but is facing their own mortality. The OPW can learn about the comfort - both emotional and psychological – that it can create for individuals in these circumstances.

It is also recommended that they consider engaging in a national creative and imaginative campaign to raise awareness of the OPW resources which are available to the public including those who are facing end of life and bereavement issues. It has been innovative in the exhibitions and initiatives it has organised at various sites. In 2016, the OPW lit some State buildings blue to mark World Autism Awareness Day on 2nd April (OPW, 2016c). It has been involved in "greening" State buildings for the duration of the St Patrick's Festival for a number of years (OPW, 2016d). There is no formal application process to request the OPW to colour State buildings. Decisions are made at Commissioner level on a case by case basis using criteria such as impact, importance and the public interest. World Hospice and Palliative Care Day is an annual global day of action every October to raise awareness of hospice and palliative care. The involvement of the OPW could raise national consciousness of care at end of life and highlight the needs of some of the most vulnerable people in the country.

"Do we, as a society, consider beauty? No we don’t include it. We don’t even consider it. We don’t consider whether something is beautiful or whether we need to include beauty in architecture. If an environment is badly designed it can actually limit your life. It is going to have an effect on how you experience life. It is going to have an effect on how you relate to people. And how you see yourself and your own sense of self-worth. If you provide an environment for somebody where it is clear from the quality of the place the that time and effort and money has been put into it, I think that sense of respect that has been invested will be given back. That goes for a house or a street or a town.” (RONAN ROSE ROBERTS).

DESIGN

In relation to the physical access to sites, the OPW is involved in the Universal Design Programme which is effectively the design of an environment so it can meet the needs of anyone who wants to use it. The 2005 Disability Act defines Universal Design as:

1. The design and composition of an Environment so that it may be accessed, understood and used:
   i. To the greatest possible extent,
   ii. In the most independent and natural manner possible,
   iii. In the widest possible range of situations, and
   iv. Without the need for adaptation, modification, assistive devices or specialised solutions, by any persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability, and
2. Means, in relation to electronic systems, any electronics-based process of creating products, services or systems so that they may be used by any person.

The OPW states that it is working to ensure that any new building or premises will meet best practice in Universal Design and will also work on older buildings to ensure accessibility (OPW, 2010: 6). In the Government’s Policy on Architecture 2009-2015, it is stated that the policy “seeks to promote awareness and understanding of the contribution of good design to the daily life and well being of society as a whole” (Department of Environment, Heritage and Local Government, 2009: 2).

The National Council of the Forum on End of Life in Ireland in 2013 called for “end-of-life proofing” of buildings such as the adaptation of a room for cases when people die at home or local authorities’ considering the use of wider doors in particular rooms in buildings or in communities in their development plans (Rickard-Clarke, 2013).

It is instructive to look at an initiative that is underway in the health service to improve the physical environment in our public hospitals where almost half of all deaths occur each year. The IHF’s Hospice Friendly Hospitals Programme developed quality standards for end-of-life care following a 2007 audit on the quality of the physical environment of hospitals. The audit found significant deficits including the lack of facilities for private consultations or family facilities. Following this study, Design and Dignity Guidelines were developed in 2008 and the IHF is collaborating with Health Service Executive Estates in funding “exemplar” projects such as renovating mortuaries and creating family rooms.

The National Disability Authority has developed a Code of Practice on Accessible Heritage Sites. Future audits of OPW property should be conducted to encompass comfort, ease and contentment as well as places to sit down. They should also think of ways to facilitate people who are not mobile or have reduced mobility. These measures may encourage more people at the end of life or coming to terms with a bereavement to actively use the natural and preserved environments, or provide more comfort to those who are existing customers.

It is worth noting that the Commemorative Avenue in the Phoenix Park, which has been developed to celebrate the significant historical events of 1912 to 1922, also features the Phoenix Park Picnic Cluster which are interlocking tables and benches. This innovative design is more accessible for people with reduced mobility (OPW, 2016e).

**FLOOD RELIEF – COMMUNICATIONS**

The OPW is leading the Government’s efforts to proactively anticipate and manage the flood threat. The needs of people living in flood prone areas who are also dealing with serious ill health or bereavement need to be considered. A person may wish to be cared for at home and to ultimately die in their own home. These aspirations may be compromised because of circumstances outside of their control such as flooding. This could cause a lot of upset for the individual and their family. OPW staff should receive training in communicating bad news or communicating in challenging situations. This training will ensure that the work is carried out in a sensitive and professional manner.

A consistent issue that has emerged during my research on dying, death and bereavement has been the importance of communications and particularly the impact of bad communications in times of distress, profound grief or loss and anxiety.
OFFICE OF THE REVENUE COMMISSIONERS
RECOMMENDATIONS

- Develop a dissemination policy through the use of plain language leaflets, information videos and an outreach programme, particularly for those with low numeracy and literacy difficulties.

- Develop an active education programme for people affected by dying, death and bereavement.

- Ensure frontline personnel are trained on the needs of the bereaved and how to communicate sensitively in difficult times.
BACKGROUND

The core business of the Revenue Commissioners includes assessing, collecting and managing taxes and duties which account for over 93% of Exchequer revenue. It also administers the customs regime and collects duties and levies on behalf of the European Union.

Established in 1923, the work of the Revenue Commissioners is laid out in Statute by the government. It is an independent body but reports on some matters to the Minister for Finance.

The Revenue Commissioner’s Annual Report 2015 reported that net receipts amounted to €45.79 billion – an increase of 10.6% on 2014. This was 7.8% ahead of the target for the year. The annual report stated (2016: 8): “This is the second highest figure for net receipts in the history of the State – only 2007 was higher, at €47.5 billion”. The annual report highlighted that Corporation Tax was up 49%. Capital Gains Tax had risen by 28%, Customs Duty increased by 20% and VAT was up by 7% (ibid).

The Revenue Commissioners has developed a range of online channels to allow people to process their tax affairs - the ‘myAccount’ portal; MyEnquiries; Revenue Online Service (ROS) and the PAYE Anytime service. Customs declarations can be processed using the Automated Entry Processing System. The Revenue Commissioners has to intervene in the case of non-compliant taxpayers and also works with law enforcement bodies in Ireland and overseas to tackle drug and tobacco smuggling.

In the Revenue Commissioners’ first national survey on attitudes and behaviour towards tax and compliance – conducted in 2009 – 90% of people felt that it is everyone’s civic responsibility to pay correct taxes. Some 56% of people believe that tax evasion is not acceptable and the same percentage think that evaders should be jailed (2013: 15). But more than four out of 10 people believe that people report all of their income to the Revenue Commissioners (2013: 18).

A 2015 survey of PAYE Taxpayers found an overall satisfaction rating of 91% with the Revenue Commissioners. More than half of respondents (53%) were satisfied that Revenue explains tax credits and entitlements in a way they can understand – up from 41% in the 2007 survey (Kennedy, McGuinness and Shirran, 2015: 3). Some 19% of people expressed some difficulty claiming refunds, tax credit and other entitlements (ibid: 15). The survey found: “Overall, the results suggest that the most typical PAYE taxpayer contacting Revenue is from Dublin, educated to third-level, younger and with higher income” (ibid:19).
THE DEPARTMENT RESPONSE ON DYING, DEATH AND BEREAVEMENT

The Revenue Commissioners stated that it had “a vast number of contacts” with taxpayers and the general public. In 2014, there were 2.2 million telephone calls, 724,000 personal callers and it received 2.3 million items of correspondence.

It stated: “Inevitably, a number of the people Revenue engages with will have recently been touched by death or bereavement”. Revenue staff were instructed to ensure “uniform treatment in Revenue offices when dealing with the tax and duty affairs of taxpayers who have died”.

It explained that cases were dealt with promptly as there is a time limit to finalise tax and duties liability. The submission stated: “However, Revenue also recognises that death can be a traumatic experience for the next-of-kin and relatives. Revenue officials are mindful of the sensitivities associated with death when making contact – particularly the initial contact – after a death”.

The practice is that no contact is initiated within the first month after a death. This timeframe can be extended depending on the circumstances of the death. Once contact is made, further communications are made through the personal representative or agent.

Revenue has developed an extensive range of “informational supports” for bereaved taxpayers on www.revenue.ie. The information will cover a range of issues from tax exemptions to tax credits and inheritance tax. Issues such as the duties of different parties – the Personal Representative, the Beneficiary and the Trustee – are also covered. In all, there are over 600 items on the Revenue website covering all aspects of the tax implications of a death.

COMMENTS AND RECOMMENDATIONS

It is positive to see a protocol in place in relation to the tax affairs of the bereaved. As the Revenue Commissioners explained, an extensive range of publications are available online at www.revenue.ie.

The recommendations in this section relate to communications. The amount of information on the website – over 600 items – may be overwhelming for people coping with a bereavement. While public satisfaction with Revenue’s explanations of tax terms were high, the Kennedy et al. report found that satisfaction with the over 66 age group was only higher if they had contacted Revenue. Those over 66 not contacting Revenue had lower satisfaction levels (2015: 12).

There may be many reasons why people will not make contact with Revenue, but the service itself should take proactive steps to make sure its information and officials are as accessible as possible. While tax leaflets are well written, the fact remains that tax matters are complex and need to be studied. This can be challenging at the best of times but particularly when a person is stressed through bereavement.
CHAPTER 1

OUTREACH PROGRAMME

Some 81% or four in every five deaths in 2015 was of people aged 65 years and older. The 2016 census recorded a widowed population of 196,200. This was 5,200 more than the 2011 census – a rise of 2.7% (CSO, 2017: 29). Of the one-parent families in 2016, some 50,496 families were widowed (ibid). The census noted that the proportion of widows had dropped while Irish men were living longer (ibid: 28). The 2016 census (ibid: 30) also recorded 587,284 people aged 65 years and older in private households and more than one in four (27%) living alone. Of Ireland’s population aged 75 years and older (numbering 231,304 people), 35.3% live alone. Almost half (45%) of the 51,672 people aged 85 and older are living alone. Women make up over 62% of elderly people who live alone. Of the one-person households, 21,517 or 13% were widowed (ibid: 37).

People aged 65 and older are likely to be in touch with the Revenue Commissioners following the death of a spouse or surviving civil partner. As the research found this cohort expressed satisfaction when they made contact with the Revenue Commissioners. More research should be conducted into the barriers that exist to prevent people from making contact. The Revenue Commissioners should consider a more proactive outreach programme where trained officials deliver talks to groups such as Active Retirement Ireland.

The Kennedy et al. study also found that the most frequent contact was phone followed by calling in person and email. The highest response for “very satisfied” (46%) were observed for those who visited a Revenue public office. While the overall preferred method of contact was the online channel (2015: 21), 14% suggested options other than online access should be available and 13% suggested simplifying tax language (this was down from 23% in 2010). The two most common reasons for dissatisfaction were difficulties understanding credits and entitlements and waiting times on the phone (2015: 23). While we live in a digital age and it is Government policy to promote online business, not every taxpayer will be happy or able to conduct their personal taxation business online. These individuals should be facilitated to make their returns through the more traditional routes.

On the information needs of the bereaved, a UK report by Corden, Hirst and Nice (2008: 125) states:

“People want clear information and easy access routes to appropriate sources of information for bereaved people. They need to be able to speak to staff with skills appropriate for communication with somebody in deep shock or grief. Where access to systems is via automated telephone call centres, standardised response are often experienced by bereaved people as inappropriate and upsetting. When data sharing system and technology reduce the need for recently bereaved people to repeatedly explain their circumstances, or produce the same information and documents, this is appreciated very much.”
CHAPTER 1

SIMPLIFYING INFORMATION

These findings also indicate that more work should be devoted to further simplifying the tax information that is produced. This is particularly important given the literacy and numeracy skills of a significant percentage of the population.

The Organisation for Economic Co-operation and Development’s (OECD) Programme for the International Assessment of Adult Competencies (PIAAC) is a survey of adult skills conducted in 24 countries including Ireland. The Irish survey of adults aged from 16 to 65 years was conducted by the Central Statistics Office from August 2011 to March 2012. It found that 17.9% of Irish adults were at or below Level 1 or had difficulty understanding basic text. In numeracy, 25.6% scored at or below Level 1 and for problem solving in technology-rich environments, 42% scored at or below Level 1 (Central Statistics Office, 2013).

These findings would imply that further efforts to simplify the information on taxes and duties will potentially benefit a significant number of people particularly those who are going through a bereavement. There is a presumption that because we live in a technical age, everyone is computer literate or comfortable in conducting financial transactions or putting personal data online. In 2001, one of the recommendations of the Joint Oireachtas Committee on the Strategy Management Initiative, which examined the customer service in the Revenue Commissioners, was the establishment of a National Forms Agency with responsibility for audit and simplification of all official forms and an annual audit of all Revenue Forms. While no such agency appears to have been set up, the idea of simplifying official forms and regularly reviewing forms is a positive move.

The information on the www.revenue.ie is also very text based and the Revenue Commissioners should consider developing information videos which might be the preferred method of communication for some individuals.

STAFF TRAINING

According to the IHF, people who are bereaved endure a range of emotions including sadness, irritability, anger, fear and helplessness. In these circumstances, people who are bereaved may also feel more comfortable in face-to-face meetings as they sort out the tax affairs of their loved one. People may also need more support in putting the tax affairs of the deceased in order. Therefore, staff in the Revenue Commissioners should receive regular training on sensitive communications to support customers facing difficult circumstances.
CHAPTER 2

A Survey of
TDs and Senators Experiences 2016
BACKGROUND

The aim of this chapter is to establish the range of issues the public are raising with their Deputies and Senators in relation to dying, death and bereavement. It also gauges how well Government Departments are responding to these needs, and shapes recommendations on how to improve services for people affected by dying, death and bereavement. The Department of Health was not included in this study because a separate review of health services’ response to dying, death and bereavement is underway. Other bodies, such as Local Authorities and the HSE, were also excluded because they were outside the parameters of this interdepartmental study.

METHODOLOGY

A short self-completion questionnaire, comprising seven questions, was designed and distributed to the 158 TDs and 60 Senators in Dáil Éireann by my office. The TDs and Senators were informed that their replies would remain confidential and that their individual replies would not be disclosed. The questionnaire was circulated to the TDs and Senators in hard copy and electronic format on the 18th October 2016. The initial response was very poor, and only 30 replies, representing 14% of total possible responses, were received by the first deadline, 28th October 2016. However, following an extension of the deadline to the 11th November 2016, and encouragement by me and my team, the response rate increased to 51% (N=112). A profile of the TDs and Senators who completed this questionnaire is summarised in Table 1.

<table>
<thead>
<tr>
<th>Status</th>
<th>Number</th>
<th>% of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>TDs</td>
<td>72</td>
<td>65%</td>
</tr>
<tr>
<td>Senators</td>
<td>39</td>
<td>35%</td>
</tr>
<tr>
<td>CONSTITUENCY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural Constituency</td>
<td>60</td>
<td>64%</td>
</tr>
<tr>
<td>Urban Constituency</td>
<td>34</td>
<td>36%</td>
</tr>
<tr>
<td>SEX</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>77</td>
<td>73%</td>
</tr>
<tr>
<td>Female</td>
<td>28</td>
<td>27%</td>
</tr>
<tr>
<td>AGE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 40 years</td>
<td>13</td>
<td>13%</td>
</tr>
<tr>
<td>40-55 years</td>
<td>59</td>
<td>58%</td>
</tr>
<tr>
<td>55+ years</td>
<td>30</td>
<td>29%</td>
</tr>
</tbody>
</table>

Note: The figures above do not add to 112 because some TDs and Senators left parts of this question blank. One respondent did not give his/her status; 18 respondents did not distinguish if their constituency was primarily urban or rural; 7 respondents did not indicate their gender; and 10 did not give their age.
Chapter 2

The number of Constituency Contacts each week

On average, a total of 20,567 people communicate with these 112 TDs and Senators each week, either by visiting their constituency office, or by email, letter, or telephone call. This means that, on average, each TD and Senator who replied to this survey is contacted by 184 people each week. This suggests that the 218 members of the Oireachtas deal with more than two million contacts each year.

However, the number of constituency contacts were not spread evenly across the TDs and Senators, with some TDs and Senators receiving more contacts than others.

For example, six TDs/Senators did not receive any contacts/did not engage in constituency work; 16 respondents had at least one and less than 50 contacts in an average week, and eight respondents said they had more than 500 contacts weekly (Table 2).

<table>
<thead>
<tr>
<th>Range of Contacts</th>
<th>Number of TDs and Senators</th>
<th>Total Contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>1-49</td>
<td>16</td>
<td>412 (2%)</td>
</tr>
<tr>
<td>50-99</td>
<td>26</td>
<td>1,580 (8%)</td>
</tr>
<tr>
<td>100-500</td>
<td>56</td>
<td>12,340 (60%)</td>
</tr>
<tr>
<td>501-1000</td>
<td>8</td>
<td>6,235 (30%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>112</strong></td>
<td><strong>20,567 (100%)</strong></td>
</tr>
</tbody>
</table>

Most contacts were to TDs (75%), compared with Senators (25%). The average number of weekly contacts to TDs was 215, compared with 117 contacts for Senators.

1. This calculation assumes that the non-responders to this survey have a similar contact pattern, and that the contacts are consistent throughout the year i.e., 184 contacts x 218 TDs/Senators x 52 weeks of the year.
THE NUMBER OF END-OF-LIFE CONTACTS EACH WEEK

Very few people contacted these TDs and Senators on issues relating to dying, death and bereavement. A total of 617 contacts, representing 3% of all weekly contacts, made contact on topics relating to dying, death and bereavement. A clear majority of TDs and Senators (85%) reported that they had five or less contacts on end-of-life issues each week (Table 3).

**Table 3**

Number of People Who Communicate with TDs and Senators Each Week on Topics Relating to Dying, Death and Bereavement.

<table>
<thead>
<tr>
<th>Number of EoL Contacts Each Week</th>
<th>Number of TDs</th>
<th>Senators</th>
<th>Total Contacts Relating to EoL Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>6</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>16</td>
<td>13</td>
<td>29</td>
</tr>
<tr>
<td>2</td>
<td>17</td>
<td>6</td>
<td>46</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>4</td>
<td>30</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>5</td>
<td>11</td>
<td>1</td>
<td>60</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>1</td>
<td>16</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>15</td>
<td>3</td>
<td>0</td>
<td>45</td>
</tr>
<tr>
<td>20</td>
<td>3</td>
<td>0</td>
<td>60</td>
</tr>
<tr>
<td>25</td>
<td>1</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td>50</td>
<td>0</td>
<td>1</td>
<td>50</td>
</tr>
<tr>
<td>100</td>
<td>2</td>
<td>0</td>
<td>200</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>73</strong></td>
<td><strong>39</strong></td>
<td><strong>617</strong></td>
</tr>
</tbody>
</table>

*Note:* One respondent who did not give their status was recorded as a TD for the purposes of this table.

THE TYPE OF END-OF-LIFE ISSUES RAISED BY CONSTITUENTS DURING THE PAST YEAR

The TDs and Senators were given a list of 21 potential end-of-life issues and asked to indicate which, if any, of the issues around dying, death and bereavement their constituents had raised with them on one or more occasions during the past year. It did not matter how many times the end-of-life issue had been raised. More than eight in ten respondents said that at least one query had been made about ‘information on services’, while the following topics were raised by more than six in ten respondents: ‘income supports’, ‘transport to/from appointments’ and ‘survivors’ social protection payments. Conversely, just over one in ten respondents said that one or more constituents had sought their help with ‘an occupational death’ or ‘death on a farm’ (Table 4) Unsurprisingly, all but one of the queries relating to death on a farm was reported by TDs and Senators from a rural constituency.
End-of-Life Issues Raised by Constituents During the Past Year.

<table>
<thead>
<tr>
<th>End-of-Life Issues</th>
<th>Number</th>
<th>% of Total Respondents (N=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on services, such as adaptations to home</td>
<td>91</td>
<td>81%</td>
</tr>
<tr>
<td>Income supports for those caring for people who are dying at home</td>
<td>77</td>
<td>69%</td>
</tr>
<tr>
<td>Transport to/from appointments</td>
<td>71</td>
<td>63%</td>
</tr>
<tr>
<td>Survivors’ social protection payments</td>
<td>71</td>
<td>63%</td>
</tr>
<tr>
<td>Funeral costs</td>
<td>62</td>
<td>55%</td>
</tr>
<tr>
<td>Support following a death by suicide</td>
<td>52</td>
<td>46%</td>
</tr>
<tr>
<td>Issues with a will</td>
<td>47</td>
<td>42%</td>
</tr>
<tr>
<td>Repatriation of remains following a death abroad</td>
<td>46</td>
<td>41%</td>
</tr>
<tr>
<td>Information on bereavement</td>
<td>40</td>
<td>36%</td>
</tr>
<tr>
<td>Information on death certificates</td>
<td>34</td>
<td>30%</td>
</tr>
<tr>
<td>Support following the death of a child</td>
<td>32</td>
<td>29%</td>
</tr>
<tr>
<td>Making a will</td>
<td>32</td>
<td>29%</td>
</tr>
<tr>
<td>Information for when a person dies intestate</td>
<td>31</td>
<td>28%</td>
</tr>
<tr>
<td>Support following a death on the road</td>
<td>29</td>
<td>26%</td>
</tr>
<tr>
<td>Guardianship issues following a death</td>
<td>29</td>
<td>26%</td>
</tr>
<tr>
<td>Information on inquests</td>
<td>27</td>
<td>24%</td>
</tr>
<tr>
<td>Information on burial/cremation</td>
<td>23</td>
<td>21%</td>
</tr>
<tr>
<td>Issues arising from death as a result of crime</td>
<td>22</td>
<td>20%</td>
</tr>
<tr>
<td>Creating an Enduring Power of Attorney</td>
<td>20</td>
<td>18%</td>
</tr>
<tr>
<td>Death on a farm</td>
<td>16</td>
<td>14%</td>
</tr>
<tr>
<td>Support following an occupational death</td>
<td>13</td>
<td>12%</td>
</tr>
</tbody>
</table>

Other issues surrounding dying, death and bereavement spontaneously mentioned by individual respondents included:

- Assisted suicide
- Mental Health issues
- Inheritance Tax
- Nursing Home care
- Palliative Care at home
- Graveyard Assistance (e.g., problems getting/buying and maintenance of grave plot, headstones),
- Guardianship Entitlements
- Housing Issues (e.g., Succeeding to tenancy rights in Local Authority housing if living with relative)
- Mortgage Arrears
- Social Housing, rent, adaptations)
- Medical Cards, access to relevant health services, passports, hospital appointments, adoption, and euthanasia.
THE END-OF-LIFE ISSUES RAISED MOST OFTEN DURING THE PAST YEAR

The top three issues that were raised most often with TDs and Senators were:

**Information on Services**, such as adaptations to home;
**Income Supports** for those caring with people who are dying at home; and
**Survivors’ Social Protection** payments (Table 5).

Thirty nine TDs/Senators ranked ‘information on services’ as most important, followed by 29 TDs/Senators who ranked this item as next most important. Conversely, the final two items in Table 5 were not ranked in the top 3 items by any respondent (Table 5).

**Table 5**

End-of-Life Issues Raised Most Often

<table>
<thead>
<tr>
<th>Issue</th>
<th>Rank 1</th>
<th>Rank 2</th>
<th>Rank 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on services, such as adaptations to home</td>
<td>39</td>
<td>25</td>
<td>6</td>
</tr>
<tr>
<td>Income supports for those caring for people who are dying at home</td>
<td>29</td>
<td>21</td>
<td>10</td>
</tr>
<tr>
<td>Survivors’ social protection payments</td>
<td>16</td>
<td>13</td>
<td>18</td>
</tr>
<tr>
<td>Transport to/ from appointments</td>
<td>6</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>Support following a death by suicide</td>
<td>5</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Funeral costs</td>
<td>4</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Support following a death on the road</td>
<td>2</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Issues arising from death as a result of crime</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Issues with a will</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Repatriation of remains following a death abroad</td>
<td>1</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Guardianship issues following a death</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Making a will</td>
<td>-</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Information on bereavement</td>
<td>-</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Information on inquests</td>
<td>-</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Death on a farm</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Information for when a person dies intestate</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Creating an Enduring Power of Attorney</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Support following the death of a child</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Information on burial/cremation</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Support following an occupational death</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Information on death certificates</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
GOVERNMENT DEPARTMENTS DEALT WITH MOST OFTEN

When respondents were asked to say which Department they had dealt with on end-of-life issues, the Department of Social Protection was the most frequent choice, with more than seven in ten respondents saying they dealt with this Department most often. Other Departments that were also popular with these respondents included:

Housing, Planning, Community and Local Government;
Justice and Equality; Foreign Affairs and Trade;
Agriculture, Food and Marine;
Children and Youth Affairs (Table 6).

<table>
<thead>
<tr>
<th>Government Department</th>
<th>Rank 1</th>
<th>Rank 2</th>
<th>Rank 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Protection</td>
<td>74</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Housing, Planning, Community and Local Government</td>
<td>16</td>
<td>26</td>
<td>11</td>
</tr>
<tr>
<td>Agriculture, Food and the Marine</td>
<td>4</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Justice and Equality</td>
<td>4</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td>Children and Youth Affairs</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Foreign Affairs and Trade</td>
<td>2</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Arts, Heritage, Regional, Rural and Gaeltacht Affairs</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Finance</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Office of Public Works</td>
<td>0</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Education and Skills</td>
<td>0</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Jobs, Enterprise and Innovation</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Transport, Tourism and Sport</td>
<td>0</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Public Expenditure and Reform</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Taoiseach</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Communications, Climate Action and Environment</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Department of Defence</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
RATING THE PERFORMANCE OF GOVERNMENT DEPARTMENTS

Allowing for the relatively low response rate to this question, which reflects the relatively low number of end-of-life issues dealt within a typical week or year, the TDs and Senators rated the responses received from the Departments that handled their queries in a positive light. This was particularly the case with the Department of Social Protection, where the majority of respondents rated the service as ‘very good’ or ‘good’ (Table 7).

Table 7
End-of-Life Issues Raised Most Often

<table>
<thead>
<tr>
<th>Government Departments</th>
<th>Very Good %</th>
<th>Good %</th>
<th>Fair %</th>
<th>Poor %</th>
<th>Very Poor %</th>
<th>Not Applicable/No Reply %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Protection</td>
<td>34</td>
<td>32</td>
<td>14</td>
<td>4</td>
<td>-</td>
<td>16</td>
</tr>
<tr>
<td>Foreign Affairs and Trade</td>
<td>26</td>
<td>15</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>51</td>
</tr>
<tr>
<td>Children and Youth Affairs</td>
<td>14</td>
<td>20</td>
<td>12</td>
<td>1</td>
<td>-</td>
<td>53</td>
</tr>
<tr>
<td>Education and Skills</td>
<td>13</td>
<td>14</td>
<td>15</td>
<td>1</td>
<td>-</td>
<td>57</td>
</tr>
<tr>
<td>Justice and Equality</td>
<td>13</td>
<td>18</td>
<td>20</td>
<td>4</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>Arts, Heritage, Regional, Rural and Gaeltacht Affairs</td>
<td>11</td>
<td>13</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>66</td>
</tr>
<tr>
<td>Defence</td>
<td>10</td>
<td>11</td>
<td>6</td>
<td>-</td>
<td>-</td>
<td>73</td>
</tr>
<tr>
<td>Finance</td>
<td>10</td>
<td>14</td>
<td>7</td>
<td>2</td>
<td>-</td>
<td>67</td>
</tr>
<tr>
<td>Taoiseach</td>
<td>10</td>
<td>9</td>
<td>8</td>
<td>-</td>
<td>-</td>
<td>73</td>
</tr>
<tr>
<td>Agriculture, Food and the Marine</td>
<td>9</td>
<td>17</td>
<td>10</td>
<td>2</td>
<td>-</td>
<td>62</td>
</tr>
<tr>
<td>Housing, Planning, Community and Local Government</td>
<td>9</td>
<td>28</td>
<td>15</td>
<td>2</td>
<td>2</td>
<td>44</td>
</tr>
<tr>
<td>Jobs, Enterprise and Innovation</td>
<td>9</td>
<td>14</td>
<td>10</td>
<td>1</td>
<td>-</td>
<td>66</td>
</tr>
<tr>
<td>Office of Public Works</td>
<td>8</td>
<td>10</td>
<td>7</td>
<td>3</td>
<td>1</td>
<td>71</td>
</tr>
<tr>
<td>Communications, Climate Action and Environment</td>
<td>7</td>
<td>12</td>
<td>6</td>
<td>3</td>
<td>-</td>
<td>72</td>
</tr>
<tr>
<td>Public Expenditure and Reform</td>
<td>7</td>
<td>12</td>
<td>9</td>
<td>-</td>
<td>-</td>
<td>72</td>
</tr>
<tr>
<td>Transport, Tourism and Sport</td>
<td>7</td>
<td>16</td>
<td>11</td>
<td>3</td>
<td>-</td>
<td>63</td>
</tr>
</tbody>
</table>

Conversely, the research suggests there is room for improvement for many of the Departments, where noticeable numbers of TDs and Senators rated the Departments’ performances as ‘fair/poor’, albeit very few rating the Departments as very poor (Table 8).
## TABLE 8

Rating of Government Departments Handling a Query on Behalf of a Constituent

<table>
<thead>
<tr>
<th>Government Departments</th>
<th>Very Good/Good %</th>
<th>Fair/Poor %</th>
<th>Very Poor %</th>
<th>Not Applicable/No Reply %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Protection</td>
<td>66</td>
<td>18</td>
<td>-</td>
<td>16</td>
</tr>
<tr>
<td>Foreign Affairs and Trade</td>
<td>41</td>
<td>7</td>
<td>1</td>
<td>51</td>
</tr>
<tr>
<td>Housing, Planning, Community and Local Government</td>
<td>37</td>
<td>17</td>
<td>2</td>
<td>44</td>
</tr>
<tr>
<td>Children and Youth Affairs</td>
<td>34</td>
<td>13</td>
<td>-</td>
<td>53</td>
</tr>
<tr>
<td>Justice and Equality</td>
<td>31</td>
<td>24</td>
<td>-</td>
<td>45</td>
</tr>
<tr>
<td>Education and Skills</td>
<td>27</td>
<td>16</td>
<td>-</td>
<td>57</td>
</tr>
<tr>
<td>Agriculture, Food and the Marine</td>
<td>26</td>
<td>12</td>
<td>-</td>
<td>62</td>
</tr>
<tr>
<td>Arts, Heritage, Regional, Rural and Gaeltacht Affairs</td>
<td>24</td>
<td>8</td>
<td>2</td>
<td>66</td>
</tr>
<tr>
<td>Finance</td>
<td>24</td>
<td>9</td>
<td>-</td>
<td>67</td>
</tr>
<tr>
<td>Jobs, Enterprise and Innovation</td>
<td>23</td>
<td>11</td>
<td>-</td>
<td>66</td>
</tr>
<tr>
<td>Transport, Tourism and Sport</td>
<td>23</td>
<td>14</td>
<td>-</td>
<td>63</td>
</tr>
<tr>
<td>Defence</td>
<td>21</td>
<td>6</td>
<td>-</td>
<td>73</td>
</tr>
<tr>
<td>Communications, Climate Action and Environment</td>
<td>19</td>
<td>9</td>
<td>-</td>
<td>72</td>
</tr>
<tr>
<td>Public Expenditure and Reform</td>
<td>19</td>
<td>9</td>
<td>-</td>
<td>72</td>
</tr>
<tr>
<td>Taoiseach</td>
<td>19</td>
<td>8</td>
<td>-</td>
<td>73</td>
</tr>
<tr>
<td>Office of Public Works</td>
<td>18</td>
<td>10</td>
<td>1</td>
<td>71</td>
</tr>
</tbody>
</table>
CHAPTER 2

SUGGESTIONS FOR THE STATE ON END-OF-LIFE ISSUES

The final question asked respondents to indicate what they believed the Irish State should do to improve services and support for people facing dying, death or bereavement. Six in ten respondents gave at least one suggestion, with most of them making at least two suggestions (Table 9).

What the State Should Do to Improve Services for people Facing Dying, Death and Bereavement.

<table>
<thead>
<tr>
<th>Suggestions</th>
<th>No. of Times Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information</strong> on what people need to know, e.g., their entitlements, a one-stop-shop for up-to-date information; a suite of guidance documents on end-of-life care; education; practical and legal advice; public campaign to highlight benefits available.</td>
<td>25</td>
</tr>
<tr>
<td><strong>Bereavement Grant</strong> to be brought back.</td>
<td>16</td>
</tr>
<tr>
<td><strong>Improve Home Care services</strong> for people who want to be cared for and die at home e.g., increase home help hours, homecare packages, Palliative care nurses, Public care nurses visits, medication, health services, more respite care, faster access to services etc.</td>
<td>18</td>
</tr>
<tr>
<td><strong>Finance</strong> – improved access to Exceptional Needs Payments; support for funeral costs; ring fence budget for mental health and suicide; more money for end-of-life issues.</td>
<td>17</td>
</tr>
<tr>
<td><strong>More compassion</strong> and less red tape; less ‘battles’ for access to supports people are entitled to; faster access if referred by consultant or GP; give every support to parents of terminally sick children; provision for faster access to services for special cases; extra support for suicides.</td>
<td>15</td>
</tr>
<tr>
<td><strong>Support organisations</strong> that help people die with dignity in the community e.g., hospice care strengthened, Irish Hospice Foundation; local support groups.</td>
<td>14</td>
</tr>
<tr>
<td><strong>More counselling</strong> services in the community, especially if person terminally ill; mental health issues.</td>
<td>8</td>
</tr>
<tr>
<td><strong>Making a will</strong> – raise awareness of what it involves - the cost of making a will, legal issues, Power of Attorney. Encourage people to make a will.</td>
<td>6</td>
</tr>
<tr>
<td><strong>More support generally</strong>; flexible support; increase support for carers and families; improve all public services.</td>
<td>5</td>
</tr>
<tr>
<td><strong>Skilled and trained staff</strong> e.g., to deal with bereavement and suicide issues in sensitive manner; provide bereavement support locally/ in work place.</td>
<td>4</td>
</tr>
<tr>
<td><strong>Easier access</strong> to medical cards.</td>
<td>4</td>
</tr>
<tr>
<td><strong>Encourage people to talk</strong> about end-of-life issues, engage in advance planning.</td>
<td>4</td>
</tr>
<tr>
<td><strong>Inter-departmental group</strong> co-ordinating end-of-life issues.</td>
<td>3</td>
</tr>
<tr>
<td><strong>Provide support</strong> in schools e.g., guidance counsellors, mental health/suicide talks in CSPE.</td>
<td>2</td>
</tr>
</tbody>
</table>

Other suggestions made by individual respondents included: more access to district nurses, downsizing options for housing in the community, support Minister of State for Training and Skills John Halligan TD’s private member’s Dying with Dignity Bill 2015, investigate possibility of state withholding percentage of pension payments to pay for funeral, dedicated phone line (not email), all citizens to take personal responsibility to prepare for ‘older years’, more resources to speed up probate, provide assistance to undocumented abroad who cannot return home for family funerals, and euthanasia should be a possibility to people approaching end-of-life. Three respondents said that no change was required as dying was treated very well by Irish health services.
CONCLUSIONS

The main findings from this survey of TDs and Senators include the following:

First:
A substantial number of Irish people regard TDs and Senators as a reputable and accessible resource for information and assistance. On average, each of the 218 members of the Oireachtas are contacted by 184 people each week. Conversely, relatively few queries to TDs and Senators relate to dying, death and bereavement. Only 3% of queries related to end-of-life issues.

Second:
Most of the queries that related to end-of-life dealt with the following issues:

- **Information on Services**, such as adaptations to homes;
- **Income Supports** for people who are caring for people dying at home;
- **Transport** to/from appointments; survivors’
- **Social Protection** Payments;
- **Funeral** Costs.

Each of these issues was raised with more than half the TDs and Senators.

Third:
The TDs and Senators dealt with the following Departments most often on end-of-life issues.

- **Social Protection** (ranked most important by 74% of TDs and Senators);
- **Housing, Planning, Community and Local Government** (ranked most important by 16% of TDs and Senators);
- **Agriculture, Food and Marine** (ranked most important by 4% of TDS and Senators);
- **Justice and Equality** (ranked most important by 4% of TDs and Senators).

Thus, except for the Department of Health, the Department of Social Protection emerged as the most important source of information and support on end-of-life issues for these TDs and Senators.

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2 The Department of Health was not included in this study because a separate review of health services is underway.
Fourth:
Most of the TDs and Senators expressed satisfaction with the way the different Government Departments handled a query on behalf of a constituent. This was particularly the case with the Department of Social Protection.

Finally:
The TDs and Senators made several suggestions which indicated what they believed the State should do to improve services and support for people facing dying, death and bereavement, including the following:

- **Improve financial assistance** e.g., restore the Bereavement Grant; improved access to Exceptional Needs Payments.
- **Provide more information** on what people need to know about dying, death and bereavement e.g. provide access to information on end-of-life issues through a one-stop shop.
- **Improve home care services** for people who wish to be cared for and die at home.
- **Less red tape** e.g., easier access to medical cards.
- **Support organisations** that help people to die with dignity in the community.
- **More counselling services** generally and specially in schools.
- **Encourage people** to make a will.
- **Train staff** to deal with bereavement and suicide issues.

These suggestions should be taken in conjunction with the findings of the other chapters in this report, to improve end-of-life services and circumstances in Ireland.
CHAPTER 3

Qualitative Interviews
### INTERVIEWEES

1. Jim Rhatigan (Former Head of Therapy & Social Care, Milford Care Centre)
2. Dr Kathleen McLoughlin (Compassionate Communities Project Co-ordinator, Milford Care Centre)
3. John Dunne (CEO, Family Carers Ireland)
4. Gus Nichols (Managing Director, Nichols Funerals Directors, Dublin)
5. Sinead Dinneen (Visual Artist)
6. Michael Culloty (Social Policy & Communications Officer, MABS)
7. Christina O’Kelly (Age-Friendly University Coordinator, DCU)
8. Mark Patrick Hederman (former Abbot of Glenstal Abbey)
9. Brendan Whelan (CEO, Social Finance Foundation)
10. Angela Edghill (Advocacy and Public Engagement Manager, Irish Hospice Foundation)
11. Seamus Boland (CEO, Irish Rural Link)
12. Dr Brian Farrell (Former Dublin District Coroner)
13. David McRedmond (CEO, An Post)
14. Dr Tom Inglis (Sociologist, UCD)
15. Dr Joan McCarthy (Lecturer Health Care Ethics, UCC)
16. Fr Pierce Cormac (Chaplain, Cork University Hospital & Cork University Maternity Hospital)
17. John O’Keeffe (Criminologist and & Director, AdVIC, Advocates for the Victims of Homicide)
18. Margharita Solan (Director, McAuley Place, Naas)
19. Mervyn Taylor (Former Programme Manager, Hospice Friendly Hospitals)
20. Ronan Rose Roberts (Architect)
21. Anne Staunton (CEO, Rainbows Ireland)
22. Brid Carroll (Counselling Psychologist & Chair of Irish Childhood Bereavement Network)
23. Denis Murphy (Principal, St Mary’s College, Rathmines, Dublin)
24. Emma Dineen (School Principal & former President, INTO)
25. Sharon Vard (CEO, Anam Cara)
26. Irene Murphy (Chair of Hospice & Palliative Care Social Work Group)
27. Ita Mangan (Chair of Citizens Information Board)
28. Patricia Rickard Clarke (Chair of the National Safeguarding Committee)
29. Pat Quinlan (CEO, Milford Care Centre)
30. Marie Richardson (Senior Social Worker, Milford Care Centre)
31. Sharon Foley (CEO, Irish Hospice Foundation)
32. Dr Redmond O’Hanlon
33. Rebecca Lloyd (Compassionate Communities Project Worker)
INTRODUCTION

A total of 33 qualitative interviews took place during 2016 and 2017. The interviews were semi-structured and most took place in Leinster House. Some three interviews took place in Cork, six in Limerick and one in Kildare. The people who were approached to be interviewed included commentators who had an interest and an opinion on end of life issues; lawyers with expertise in citizen rights and the rights of older people; academics in sociology, education and ethics, psychology, arts, drama and literature, who had written or spoken on the issues; a hospital chaplain; an architect, an undertaker, a coroner as well as advocates and senior figures in hospice and palliative care. The interviewees were academic and practitioners. The National Council of the Forum on End of Life in Ireland, TILDA and Smart Ageing in Dublin City University were approached as suggested by An Taoiseach. The interviewees also came from diverse disciplines: the arts, law, psychology, banking, ethics, philosophy, specialist palliative care, finance, sociology, social work, the funeral services industry, criminology, the coronial service and architecture. One individual interviewed for the study was receiving hospice services.

The main themes highlighted by the interviewees have been incorporated in the following eight areas:

1. Perceptions of dying, death and bereavement in Ireland.
2. Cultural change.
3. The financial and social cost of funerals.
4. Community.
5. The vulnerability and abuse of the elderly.
7. Education.
8. The Arts.

The views of the 33 interviewees are summarised in this Chapter, together with quotes to illustrate what they believe, and how they understand and interpret dying, death and bereavement.

PERCEPTIONS AND CULTURE

Ireland is considered to have rich tradition and practices in dealing with death. However, 21st Century advances have distanced us from what were cultural norms and we are now less comfortable with the reality of our mortality.

Very often people deal with the prospect of death by denying its very existence. We feel that we can avoid death because we are living longer. We are bombarded by messages of healthy living and youthfulness, regardless of our age and state of health.

Several interviewees felt that death is increasingly sanitised in contemporary western society, including Ireland, because people are afraid to face the reality of death, especially when it is too personal. While Irish people are quite good with the rituals and traditions surrounding death, we find it difficult to expand the conversation beyond medicine and the dominant Catholic narrative.
“Death is death and not something fanciful. It is real; it is awful and we are all going to have to face the inevitable at some stage. You hear people saying things like 70 is the new 50. It’s almost a way of denying the reality that we are getting older day by day and that we will all have to face the inevitable at some stage.” (FR. PIERCE CORMAC).

‘The language and the rhetoric that people use is still ‘if I die’; there is no ‘when I die’. I think a lot of it is because we just don’t talk about it. It is not on the radio, it’s not on the television, and it’s not within our social circle.” (KATHY MCLUGHLIN).

“People use the expression passing. Passing what? What are they passing? Pass the parcel. Pass out a car on the road? People die. And I think that people have a very strange idea of what it may look like. It is not like in the movies” (IRENE MURPHY).

“We are in denial that we are going to die and I think that is really bad.” (MARGHARITA SOLAN).

DEATH, WHERE IS THY STING?

“Death used to be very much acknowledged and in the past people used to go to funerals, people used to talk about death; now they talk about passing on. We’ve kind of sanitised it. For some people, putting something on Facebook with an emoticon crying is as close as they get or they want to get.” (ANGELA EDGILL).

“Ceremony and ritual has been completely removed. There is nothing to replace it at all so we turn to self help books from America. In America they have absolutely denied the reality of death or bereavement so that what you do is make it look as if this never happened, so that corpses are beautiful to an extent that you don’t believe that this is a corpse. They are meant to look as if they were going to a party somewhere.” (MARK PATRICK HEDERMAN).

“Death is sanitised to the point where we are expected to get on with it, get over it and move on.” (CHRISTINE O’KELLY).

Even when faced with the stark reality of death, we can find diversion and happy distraction in consumerism, entertainment and multi-media images of immortality.
DIVERSIONARY TACTICS

“Nowadays suffering is a bad word and we think that if there is pain, there is a pill for it. Dodging pain is part of our culture. We dodge it by turning on the television, multiple addictions, shopping, being busy, flicking, zapping, staying with nothing. Speeding. We do it through non-attention and non-presence. We are getting less and less present with each other and to our own pain. That is why I have a problem with drugs. Drugs are shooting the messenger.” (Redmond O’Hanlon).

“People who should have died peacefully and calmly two months ago, or whatever, are being kept alive at huge expense to the taxpayer in the most appalling, miserable places they could ever be.” (Mark Patrick Hederman).

“Is it right to be putting this elderly person through all of these procedures, through all of these tests, through everything, when maybe what we should be doing is allowing the person to be more comfortable in an environment that is designed so that they can die with dignity and peace?” (Fr. Pierce Cormac).

“You can go on the internet now and find 17 different ways of getting yourself out of this life from a plastic bag to a trip to Amsterdam. It is all just listed there and people make their own arrangements. But trying to force this as a political point of view on the whole country is far too complicated. What I am saying is let people make their own decisions.” (Mark Patrick Hederman).

DEATH JOURNEYS

There are many types of death journeys and every year approximately 30,000 people die in Ireland. While most of these deaths are expected and many relatively peaceful, a substantial number of deaths are unexpected, sudden or traumatic due to road accidents, homicide or suicide. Each death brings loss and pain to those left behind. However, this loss is magnified exponentially when the death is unexpected or due to violent crime. This is especially true when the bereaved family feels that the sentence does not do justice to the severity of the crime.

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1. There were 29,952 deaths registered in 2015. Of these deaths, 15,150 were male and 14,802 were female. Diseases of the heart and arteries accounted for 9,249 deaths; 8,783 deaths were from malignant cancers; 3761 deaths were from lung diseases, and there were 1,439 deaths due to accidents, suicides and other external causes. Suicide and intentional self-harm accounted for 451 deaths in 2015. http://www.cso.ie/en/releasesandpublications/ep/p-vsyst/vitalstatisticsyearlysummary2015/
“When you lose someone through homicide, it’s not as if they die in a dignified way and go softly into the night. They are out with friends and they breathe their last moments in the gutter, or in a night club or down a dark alley.” (JOHN O’KEEFFE).

“We knew for about three weeks before he died that he was dying and we had a lovely three weeks. We ended up celebrating his life. Clearly there were tears at the appropriate time, particularly on the day of the funeral but I look back on it as a lovely experience.” (BRENDAN WHELAN).

“We would all like to die peacefully in our beds at a ripe old age, with a stream of people saying ‘My God, wasn’t she wonderful’. But it won’t necessarily happen this way and sometimes it will be awful and messy because it may be the result of a terrible trauma and tragedy, sometimes we may have gone through a protracted illness, and sometimes it may be sudden and catastrophic.” (ANGELA EDGHELL).

CULTURAL CHANGE

Dying and death has traditionally been viewed through the lens of the Catholic Church and experienced through its rituals. This made it relatively easy for people to know what to do and what to expect. However, the increase in secularism in Ireland means that people are now less connected to the Church\(^2\), although there is evidence to suggest that people have been relatively slow to jettison the rituals of the Church. For those who no longer wish to use the services of the Church, there is a gap in how they approach death and what, if anything, will replace the rituals, liturgy and structures of the Catholic Church.

REVISING RITUALS

“We live in a Catholic state where going to heaven, bereavement and consolation was the Church’s job, so that anybody who was in such a situation was surrounded by a whole ceremony which was ritualistically helpful to people. But that is no longer the case.

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and there is nothing to replace it; so, we turn to self-help books from America, which have absolutely denied the reality of death or bereavement, and they say we must be happy and healthy.” (TOM INGLIS).

“We should continue to have a conversation about death and dying in Ireland because we have had a script of how death and dying happens in Ireland and we have had it for a long time. Many of our nursing homes, for example, are full of icons of the Catholic Church, and there are expectations of Catholic or other religious prayers at the funeral rituals.” (JOAN MCCARTHY).

“If you search through Catholicism, there is an effective approach to dying and illness which I can harness for myself and which helps me. Our way of dealing with funerals in the past was sociologically, religiously and psychologically extremely effective. Everyone can be carried by this liturgy and everybody has a role to play, so it is consoling for us all that we don’t have to invent it. What people are looking for is something that will give them peace, happiness, tranquility and help.” (MARK PATRICK HEDERMAN).

“Rituals are hugely important. Society is more secular now but rituals represent a coming together, and an acknowledgment that something has happened.” (IRENE MURPHY).

“In the past, when it came to trauma or tragedy, we immediately took on the paraphernalia of the Church to explain what this was about. We made use of it as long as we needed it. We may even have gone back to saying the rosary; or we may have gone to Mass and repeated the sounds and the symbols, and then once we get over the trauma, we went back into our normal lives. However, while many of us gave up these old ways of being and thinking and operating, we haven’t replaced them with anything else. It is a real problem if you try to organise your own funeral outside the Church. In the 20th century, we were obsessed about the creation of life; in the 21st century the big issue will be death; what is a good death and should euthanasia be permitted. The Catholic view of death and dying will be passed on through our schools and just as we can’t talk to the children about sex, we can’t talk about death.” (TOM INGLIS).

ASSISTED DYING

“If the hospice doesn’t start this debate about assisted dying, who will? The debates are happening in mumblings, and they are going to become more and more vocal in the next 10 to 20 years.” (TOM INGLIS).
“I believe that the debate about Assisted Suicide will become mainstream within the next decade – it’s part of a worldwide societal conversation. As a typical Irish person I’m not comfortable with the basic proposition and some of the current issues in other countries are so alien to our current terms of reference that it’s easy to be floored by them. In Belgium at present the debate has already moved on to whether, or in what circumstances, children and prisoners should be allowed to choose to die.” (JOHN DUNNE)

BEREAVEMENT IN IRELAND

For most people it is extremely important that their loss is acknowledged, and even more important that they have space in their lives to deal with profound grief. The pain of loss is a natural part of bereavement. Bereavement counselling has a role to play in helping people to cope. Many interviewees felt that counselling, along with medication, should not always be the first response.

“We all feel a certain kind of guilt and we all feel a certain kind of pressure that we have to do something. What they need is space, an articulated space. The truth is that when someone is bereaved there’s a huge loss there and the impertinence is to imagine that anything can fill it. It is meant to be there because the person you have lost is not meant to be replaced by any other person or by any therapy. You have to be on your own and face the reality that the person you were with for whatever number of years is no longer going to be there. The positive side is that they were fortunate to have had that experience of having somebody so close to them that it now makes a difference. There are so many people in the world who have never had a meaningful relationship with anyone.”
(MARK PATRICK HEDERMAN).

“It is really important someone acknowledges our loss or that a big crowd comes to the funeral. I remember every moment of my mother’s funeral. I remember who was there and who wasn’t there. I remember it because that was a public demonstration of the wonderful woman she was and we wanted other people to acknowledge this. And they did and that was lovely. It was an acknowledgment of her but also of our loss. Life is never the same again, and try as you might to make the waters close over they don’t because there is a huge yawning gap in the middle. The worst thing that somebody can do is treat somebody who has suffered a loss as if nothing had happened. Sure you’ll be grand. It’s alright after the month’s mind, it’s alright after the first anniversary. It is not.” (ANGELA EDGHELL).
“Grief and depression are so close that it is hard to know which is which and a GP can prescribe sleeping tablets and anti-depression pills for depression when the person is actually going through the normal process of grieving.” (Sharon Vard).

“When somebody is grieving, they should not need Diazepam; they should just need people to talk with them and to understand that they are grieving and that it is a perfectly normal emotional reaction to personal loss. I think that is where we go wrong and we go ‘Oh, they are in a terrible way, let’s give them Diazepam or Mommy’s Little Helper or a glass of wine.” (Rebecca Lloyd).

Bereavement is never simple. Nor is it easy for those facing impending loss or those who are thrust into grief by sudden, traumatic or violent death. Sometimes the essential bureaucratic structure - the Courts service, or Coronial service - around violent or unexplained deaths can add a further dimension to the personal grief and loss of family and loved ones.

COMPLEXITIES OF GRIEF

“In common with most people, family carers are often in denial as the death of their loved one approaches. We find it best to approach bereavement preparation in the context of palliative care for progressive chronic conditions. That way it normalises the discussion at a stage when it’s far enough away that they can engage with it intellectually without having to cope with the immediate emotional stuff.” (John Dunne).

“I do believe there is an extra dimension or an extra element to sudden bereavement. There is most certainly an extra element to violent and inexplicable bereavement of a young person particularly but indeed of any age. They are punished, of course, if we can call it that, by the homicide itself and by the simple loss of somebody and then by the less than simple loss of them violently. There is no cognitive closure. There is no end to their bereavement.” (John O’Keeffe).

“It is not just the loss of your child now, it is the loss of your future with that child so all the milestones, first communion, confirmation, twenty first, college, it is ongoing, getting married, seeing their friends getting married, so it is the loss of the future so it is very complex loss.” (Sharon Vard).

“People dealing with the Coroner’s office want hard information. They want to know how to find the path to that information. What the process is. How it will be done. The timeframe. Our funeral
culture is the third fastest in the world. That puts a lot of pressure on us. It is not always possible to meet the expectations of the family. They have lost a family member suddenly, tragically, violently or in an unexplained, unexpected or unnatural manner. There is a huge amount of interaction with them. But it is very arcane for people. They do not understand it. It is an area, a land, where they have never been before. They are bereft.”

(DR. BRIAN FARRELL)

THE FINANCIAL AND SOCIAL COST OF FUNERALS.

There is no hard data in relation to the costs of funerals in Ireland. Costs vary locally, regionally and nationally. Regardless of the location, there are other essential elements to a funeral such as buying a new plot or opening a plot, a grave stone, the funeral director, embalming, flowers, music, hospitality, and transport. A funeral can cost between €5,000 and €10,000, or even higher, depending on the location of the grave and other factors.

The consensus view is that funerals are too expensive and that there should be greater equity and transparency surrounding these costs. It is suggested that this could be achieved by regulation, and ensuring that the bereaved are fully informed of the costs involved at an early stage. Some interviewees felt that when people are grieving, they are fragile and should be protected from exploitation. Most interviewees were very aware of the social mores and pressures which impact on us all, but disproportionately heavily on those who are least able to afford it.

COST

“A modest funeral can cost €8,000 or more if you have to buy a grave in Dublin. People want the best coffin even if they haven’t two peas in a pod to pay for it but they find the money from somewhere or they borrow it. My mother was obsessed with making sure she had the insurance to bury her. In my experience it is a common concern for older people.” (CHRISTINE O’KELLY).

“The cheapest grave in Dublin is €1,900 and in one section of Mount Jerome cemetery it can cost €13,000 to buy a grave The minimum cost to open a grave in Glasnevin is €1,040 and it could cost you €5,000 to buy a grave. It is certainly not in our interests to make people feel obligated to have a big funeral. That would be disastrous. That is why, upfront, we sit down with people and go through all of the costings so that the families can make an informed choice. We ask them what they need and we give them a figure which covers our professional fee, all of the practicalities, the transport, the embalming, and the coffin.” (GUS NICHOLS).
"I don’t think people think too much about it now, but they will get a massive shock when the day comes that somebody dies and they discover how much the funeral costs." (ITA MANGAN).

"The conversation must take place at Government level in terms of money, because, at the moment, the cost of dying is actually beyond most people’s means. And it is unregulated. Funerals are the biggest money-spinners." (MARK PATRICK HEDERMAN).

"Maybe we should look at the overall cost of funerals and see whether all of those costs are legitimate." (MICHAEL CULLOTY).

SOCIAL COST

"Bereaved people are fragile and they haven't the wherewithal to deal with the quagmire of bills from a funeral. The cost of funerals is outrageous and people are obsessed with the fact that they may not have enough money to bury their loved ones, and the shame of it. So where do you go to talk to someone and what is the telephone number?" (KATHY MCLoughlin).

"The funeral bill is one thing we would see quite often in MABS and many of these people are in distress, and in poverty. But sometimes people who have grown up in poverty want to show a little exuberance. Instead of choosing the cheapest option, they may choose a more expensive one like a bigger headstone, a more expensive headstone and to have two limousines, where you or I might be prepared to get the cheaper one to use our own car, and to go to the crematorium and not have a headstone. It is the same for Christmas and a First Communion where we would see people who are on a very low income or in a poverty situation, splash out at these times even though they can’t afford it, and they may have to suffer for 12 months or more to repay the money they borrowed." (MICHAEL CULLOTY).

"My sense of funerals is there is a degree of needing to give them a great send off with the right casket and all of that stuff. I just wonder what people who don’t have the financial resources do, and are there not sort of Ryanair options for them that are far less expensive." (BRENDAN WHELAN).

“I think funerals are a difficult one. You always want to get it right, to put the best show on, and you never want to let them down. So, anecdotally, people go into debt to pay for the funeral. I don’t know why it happens but when people are traumatised, when people are bereaved, all they want is the best for the person who has died. It is often the people who can least afford it who have the showiest funerals. Maybe that is their way of responding to death.” (ANGELA EDGHELL).
The workings of the funeral industry – as an industry - remains a mystery to most. When we need it most, we are rarely in a position to evaluate it.

FUNERAL INDUSTRY

“Behind the undertakers there is a huge team and lots of moving parts – cemeteries, crematoria, embalming. There are 600 funeral directors in the country and there are hundreds who are part-time and they own a pub or shop. There are thousands of graveyards and some are more exclusive and expensive. The industry needs more policing. It is a many-headed beast. You have funeral directors, cemeteries, crematoria, the embalming side, health and safety, and much more. There is a whole phalanx of people behind that makes it all work. Your premises need to be suitable. I think the case for some form of licencing or policing is very strong; the task is too onerous not to.” (GUS NICHOLS).

“I get a sense that the funeral guys have it fairly well sewn up. I don’t get a sense that it is the most competitive. The figures I am hearing for Dublin graves are incredible. I would have loved to have gone out to tender and established the most competitive quote but you don’t do that. You go to the fella across the road. You’ve no idea what their costs are. So, when they come up with a price of six grand you have no idea if they are making four grand or one grand.” (BRENDAN WHELAN).

“You don’t really think about competition in the funeral industry. I think a lot of people would think it is disrespectful of the dead but MABS would tell you that an awful lot of the debt they have to deal with is related to funerals. Maybe we should treat the funeral industry as a competitive environment, no matter how difficult that might be.” (PATRICIA RICKARD CLARKE).

“Funeral directors need to have independent oversight rather than regulation. There is little sense of dignity in how we design or provide our graveyards.” (MERVYN TAYLOR).

“The local authorities don’t want to be involved in funerals because the cost is so high. It is just a nuisance to them and I’d say they lose a fortune because of the costs involved in providing burial space.” (GUS NICHOLS).

“There is no regulation of the funeral industry. Anyone can set up business in the morning. People have to be able to die and we have to provide people with the wherewithal to die decently and to be buried in a way they wish to be buried, so all of this has to be accommodated.” (MARK PATRICK HEDERMAN).
Some interviewees criticised the government for discontinuing the Bereavement Grant, because it helped defray the costs of the funeral, and because it acknowledged the bereaved person’s loss.

THE BEREAVEMENT GRANT

“The abolition of the Bereavement Grant was a disgrace.”
(SHARON FOLEY)

“The bereavement grant acknowledged something had happened and you received a payment towards the cost of the funeral but it has now been abolished.” (IRENE MURPHY).

“This comes up at all café conversations, about the Bereavement Grant being cut. There is a financial burden on people thinking about their own funeral and thinking about how they are going to bury their family member. This is a huge issue. The Bereavement Grant should be reinstated.” (KATHY MCLAUGHLIN).

“We need to adopt a lifecycle approach which recognises that there are additional costs at the beginning of life and at the end of life.”
(MERVYN TAYLOR).

“The bereavement grant wasn’t properly targeted. It was a kind of universal grant and we need something that is more focused.”
(MICHAEL CULLOTY).

COMMUNITY

Community is complex and difficult to define. It can range from neighbourhoods to parishes, to villages, towns, cities, counties, regions and countries. It can even find its greatest definition on a street. It is essentially about social interaction and sometimes identity. Communities can also be the seat of enormous experience and can both support and educate.

KNOWLEDGE AND SUPPORT

“We learnt that people in communities have a lot of knowledge and experience about dying, death and grieving because they’re living with them every day. Those things are difficult but we can make them more manageable, if we take certain actions in advance of things happening. We need to have conversations around what is the experience in your community when someone is seriously ill, when someone dies, and when someone is grieving.” (JIM RATHIGAN).
“In dealing with death I think communities do it extremely well. I am still amazed at the rural areas in particular and in cities as well, at the amount of effort people make to support people in grief. It is wonderful. And they come out and they literally take time off work and they are absolutely brilliant. It is one of the great signs of community at work.” (FR. PIERCE CORMAC).

“The word politics comes from the Greek word polis which is the people. The assembled community. That is its origin. Community is crucial. Studies have shown that community support is the most healing element in physical and mental health. The Men’s Shed movement – that is a great example. The energy is multiplied literally, biochemically, electrochemically when people are together. This is what happens – a circle of energy.” (REDMOND O’HANLON).

The great strength of community is that it enables people to live well, to be supported and supportive and to have a sense of belonging and purpose. This can give the strength and resilience to enjoy life and most particularly to face tragedies. However, communities themselves need to be supported through the political process – local and national – planning to allow people live throughout their life course in the place of their choosing and to which they feel most connected. All of the interviewees felt that this became more important as people age.

SUPPORTING COMMUNITY

“Every day I hear of communities falling apart but research shows that the most important thing in healing a physical and mental impasse is to have community support systems. I would think that if you put vast money into communities to enable communities to do things together artistically, you would save billions on drugs because you are doing stuff meaningfully that engenders passion.” (REDMOND O’HANLON).

“I am sitting in my house. I am not getting out. I am going to die anyway. There is nothing anyone can do to stop it. If I could give up my three or four bedroomed house and move to a one bedroomed apartment in the heart of the community then on a walking frame I can go to the butcher, the baker, the candlestick maker myself. That is keeping me physically active, socially connected and back at the centre of a community. I am now engaged and not isolated. If I am obliged to move out of my community my hairdresser is gone, my doctor is gone, my chemist is gone, my butcher is gone. I am a visitor.” (MARGHRITA SOLAN).
“At some stage, people are going to encounter issues around failing health, chronic illness, serious advanced illness, death, dying and bereavement. It’s a universal fact of life. The Compassionate Cities Charter is an umbrella way of trying to pull together the disparate strands of community. The Compassionate Cities Charter is a way of trying to say that these issues are important to everybody because everybody lives in a network of families, themselves, their friends, their workplace, colleagues, their neighbours.” (JIM RHAUTIGAN).

COMMUNITIES AND PLANNING

Communities cannot be sustained in the ether. They must be structured and supported to allow people live in both aesthetically pleasing and functional spaces. People must feel that the place in which they live has the potential to sustain them and their families, and that there is a future to be found there as a good place to live.

“As people get older they require good services and assistance to modify their living facilities. When buildings are built they should be built in accordance with life-long living. We need to look very seriously at the way rural villages are designed. This means encouraging more young people or professionals, or people with trades, to live in their own areas and to develop the kind of industry based on the internet, or based on broadband. We need to encourage what I would call small, home-based work or industrial enterprises of 15 to 20 people and give them incentives to settle in small villages. And design them in such a way that people are more likely to live there.” (SEAMUS BOLAND).

“I think the Department of the Environment has to put up real challenges in terms of buildings and the built environment. We are building estates of 5 bed-roomed houses. We are building this and that and the other. But all of these areas need to be mixed developments. So if you decide you are going to downsize, you have the chance of buying a two bed-roomed bungalow in your area, where the planning regulations make sure that all doors are wide enough for a wheelchair.” (IRENE MURPHY).

“Really what we are doing is planning the public service of the future. It is not about dying and death. It is actually about living and dying. We need to take a cathedral building approach which means we have to think big and constantly work on the small details over a long period of time. We don’t have a rich tradition of understanding the physical environment. We are still stuck at ownership as mine as opposed to ownership as ours.” (MERVYN TAYLOR).

‘Why does it all have to change at the end? Extra support may be needed but we can live within supportive and supported communities, environments and houses if we plan. If we just accept
that we are mortal beings and we are going to die and none of us know how we are going to die. So we are future proofing that fact that our well being is deteriorating and we may need to be supported to be physically well, emotionally well, psychologically well. Our environment plays a huge part in the house you are living in, the community you are living in, access to shops and services and cultural facilities.” (MARGHARITA SOLAN).

“Do we consider beauty? No we don’t include it. We don’t even consider it. We don’t consider whether something is beautiful or whether we need to include beauty in architecture. If an environment is badly designed it can actually limit your life. It is going to have an effect on how you experience life. It is going to have an effect on how you relate to people. And how you see yourself and your own sense of self-worth. If you provide an environment for somebody where it is clear from the quality of the place the that time and effort and money has been put into it, I think that sense of respect that has been invested will be given back. That goes for a house or a street or a town.” (RONAN ROSE ROBERTS).

AGEING

Some interviewees spoke at length about Ireland as an ageist society. An ageist society where elders were not respected, were ignored, were vulnerable and where many lacked the capacity and strength to stand up for themselves as they did when they were younger. They spoke about elders who have become isolated, lonely, depressed and in many cases confined to their homes or moved into residential care. They also spoke about elders who live in poverty arising from inadequate pension provision or meager and non-existent savings and funds.

“What I find in the public service is a lack of courtesy. I am well able to battle my way now but if I was frail and vulnerable, where would I be? We have no respect for older people. We are a very ageist society and we are less visible when we have grey hair.” (PATRICIA RICKARD CLARKE).

“I am driving today, I am not driving tomorrow. I have arthritis. I cannot walk. My choices have all decreased, my choices have all diminished. My social connections, aren’t as they were anymore. I am stuck in the house. I am not getting out often. I am losing brain function. I am also losing physicality, I am being incubated for long term care without anyone realising it. I am deteriorating on a very slow curve on the graph; gradually, gradually, gradually. When it gets to critical mass I will get a carer for one hour a week who will come in and strip me and wash me and leave me because they are not allowed to sit and have a cup of tea with me. When it gets to such a stage that I need four hours of care, it is easier to put me in a nursing home for €1,000 a week.” (MARGHARITA SOLAN).
“When you are living in rural Ireland, in an isolated area, you need to have access to a car, and most people do, but this disappears in your 60s and 70s when you need it most. You are absolutely stranded, especially if your lifelong partner gets sick or dies. The Community Rural Transport programme fills that gap; it brings people to your house and brings you out of your house. The meals on wheels system has great potential in solving problems around socialisation but it is badly organised and it suffers from too many regulations.” (Seamus Boland).

“We need to think about the privatisation of care in the community. You are powerless, sick, old and you haven’t a fight in you; so, it needs to be well regulated and well policed. The state needs to be leading out on policies and guidelines.” (Irene Murphy).

POVERTY

“I've long been of the opinion that we should significantly increase the living alone allowance. If you have a couple living on the old age pension and one of them dies, bills remain more or less the same. If you are old and at home, you need the heat. There is a fuel allowance but it is very small.” (Ita Mangan).

“Social isolation and loneliness were the biggest contributor to ill health amongst older people, especially in rural areas. As older people get older, they require good services; they require assistance to modify their kitchens and their bedrooms and their living facilities. I believe that hundreds of people die every year from hypothermia because they don’t have the money to heat their homes properly.” (Seamus Boland).

“There is a vast amount of women in Ireland, widows or women who hadn’t married. There is a situation for older women who have very small pensions because they could not carry their pensions forward when they changed jobs and many others left the workforce to take care of their children.” (Christine O’Kelly).

“Some women have compromised their pensions because they had to leave work when they got married or reduced their working hours and they are now are caring for someone at home. There is a huge poverty trap waiting for women who lost out on work and who provided care to their husbands or some other relation.” (Irene Murphy).
ELDER ABUSE

Elder abuse both psychological, social and particularly financial was discussed by many of those interviewed. Fraud within families was cited as prevalent and evident in many cases.

“The older, the poorer, the sicker the higher the level of abuse. National Center for the Protection Older People at UCD prevalence survey of 2011. So your only income is your state pension and that’s pilfered from you. You are old and frail and once you get over 80 the level of the abuse increases.” (PATRICIA RICKARD CLARKE).

“Some people look at an elderly relative today and they see them as having assets which they are going to get. This is a serious issue. The greatest tragedy of our time is family members and relatives, and sometimes outsiders, taking what these people have put together and using it for their own purpose. It is fraud. People growing old and growing old in dire poverty because a son or a daughter or a group of them have come together and literally orchestrated the whole thing so they have left these parents or parent in the most vulnerable positions of their lives. Financial abuse of the elderly is a huge and growing problem. Somebody listen to me please. Their own are taking it. I have seen far too much of it. Your value is not seen as your value that is intrinsic to you as a person. Your value is seen as what you have in your bank account and what you have in your house and what your house is worth. You can hasten a person’s death through this kind of worry.” (FR. PIERCE CORMAC).

“Eighty percent of abuse is in the community, not the HSE, not the hospital, not the nursing home. It is family members. Financial abuse is rife as indeed is psychological abuse. Old frail people, Most of them and they are all not lacking capacity, but they may be frail. They may have huge capacity but they may not have not the ability to execute their decisions personally. They can make the decision, but they cannot go to the post office, or the banks, or take up the telephone.” (PATRICIA RICKARD CLARKE).

“Some elderly people who could stay at home are prevented from doing so because the supports are just too minimal. Others are living in an awful state in the community but they are kept at home because if they went into care, their families would have to declare their assets. They are lonely and isolated and, in some extreme cases, living in unsavoury, unsuitable, and maybe dangerous or dirty conditions. Conditions in nursing homes are now highly monitored. What about the services on offer to people at home?” (IRENE MURPHY).
PLANNING AHEAD

There is evidence that 39% of people in Ireland have never talked about or thought about drawing up a will. Two thirds of people have never discussed their end of life preferences. Recent legislation, the Assisted Decision Making (Capacity) Act 2015, legislatively underpins the making of an Advance Healthcare Directive. The idea of encouraging a population wide approach to advance planning for end of life financially, legally, socially and administratively was endorsed by many interviewees.

“The key advantage of advance healthcare planning and advance healthcare directives is that they involve people in decision-making in relation to their treatment and care. Many people may not be interested in completing advance directive forms. However, the idea of advance planning more generally draws a line in the sand and raising the bar of the kind of involvement that patients should have in their care.” (JOAN MCCARTHY).

“I am presuming that in every Government Department there is an induction programme. So why not at induction invite everyone to make a will, everyone to do a Think Ahead form. It can only be an invitation because you cannot make everybody do it. But if you are putting it on the table in front of the people, more people will do it than if you don’t put it in front them.” (JIM RHATIGAN).

“Think Ahead is a public awareness initiative. It is effectively a form, which allows you to write down your preferences. Think Ahead should be adopted by the State and we should say to people here is a way of recording your end-of-life-care preferences. Here is a way of recording and keeping all of your important documents in the event you are not able to speak for yourself. I think everybody should get a Think Ahead form when they start work, when they take out a mortgage, and when they have children. It is all about life-stages.” (ANGELA EDGHELL).

EDUCATION

The role of the school and the school community in supporting a bereaved child, teenager or young adult cannot be overstated. The same is true if they experience the death of a teacher or school friend, or have themselves a parent or close family member who is approaching end of life. Young people spend one-third of their lives at school. It is, for some, not only an educational space, but a place of stability, security, solace and contentment – an emotional home.

“I have never seen anything so profound as the effect of a funeral on a group of teenagers when one of their peers is being buried. There is no education until it touches something that is real, and death is not real to a younger person.” (MARK PATRICK HEDERMAN).
If schools are to play this essential role, there is an imperative on the Department of Education and Skills, the Boards of Management, principals and the schools themselves, that teachers must be trained, supported and given protected time. It is also an imperative that teachers who have been trained are allowed to apply and use the new skills they have acquired.

SUPPORTING TEACHERS

“One of the things that causes most difficulty in terms of coping with grief and loss in the classroom is the teacher feeling they don’t know what to do or what to say.” (Jim Rhatigan).

“The death or loss of a parent or someone significant in a child’s life can have a profound impact. It can lead to emotional, social and behavioural responses that can impact negatively on a child’s emotional health and well-being. The importance of acknowledging and supporting that loss in a school and classroom environment can be crucial. Teachers are in a unique position to support children in classrooms impacted by significant loss in a child’s life.

Including bereavement awareness training as part of teacher training and as C.P.D. would have significant benefits. Teachers often feel disempowered and can feel they do not have the words to support bereaved children. Teachers already support children in their classes in so many ways, developing awareness and understanding of key issues on how children grieve would add significantly to bereaved children being supported in a caring, supportive school environment.” (Anne Staunton).

“It is all about upskilling all our teachers at primary and second level. They can help to normalise the situation. There can be too much intervention too soon, and what people need initially are psycho-educational services, followed up by more focused counselling in the year’s following, if required. Our services need to be more joined-up where people are trained up to a certain standard to deal with loss in their workplace.” (Brid Carroll).

NATIONAL EDUCATIONAL PSYCHOLOGICAL SERVICE (NEPS)

“The people in NEPS have a great work ethic and they will drop everything to be with you. They are there to support you and not to take over. The resources are tight when it comes to providing support in the long-term. We ask about longer term services available and they have to tell us reluctantly, well not really. There is a helpline for teachers but face-to-face would be better. A certain level of training for teachers would be beneficial, taking into account that we all don’t need to be qualified councillors.” (Denis Murphy).
“Each school has to have a policy in place to manage tragedies like suicide. Our first port of call is NEPS but it can be very difficult accessing a NEPS psychologist because they are under-staffed. When you get them, they are great but very often their brief is to give you strategies to implement, when very often classroom teachers would have used these strategies already. At the end of the day, NEPS cannot do much more than the class teacher. Teachers are the people who need access to trained counsellors in order to best help the children.” (EMMA DINEEN).

SUPPORTING TEACHERS

“There is not enough childhood bereavement services in Ireland to meet the needs of children who have been bereaved. The services are too ad hoc and people don’t know where to go for information and support. We need a hub where people can find out information. We are not educated on death in Ireland. It is like sexuality and relationships in the past, it doesn’t exist. In many cases – with good information on the grieving process – people can work through grief on their own, with the support of their family and community.” (BRID CARROLL).

“We’ve moved on in school from a time when no-one talked about sex education because schools actually do talk about sex education now. But no-one talks about death.” (REBECCA LLOYD).

THE ARTS

For some of the respondents, the arts are healing and uplifting, especially at a time of grief and loss. Most interviewees felt that the arts in all their forms and disciplines had an essential part to play around the profound emotions of grief and loss primarily because they have such emotional powers and because of their unifying powers. They are also boundaryless and ageless.

Music, visual arts, dance, and drama are central to healing at the core of individual distress, and of course human joy and expression and, above all, hope.

WE ARE ARTISTIC PEOPLE

“I am much more than a physical being. I am and emotional, psychological and spiritual being and it is the arts that will make me feel better. My hearing, my touch, my taste, my sight and my thoughts. These are really the things that make a difference into how I live my day. The whole area of the arts is huge.” (MARGARITA SOLAN).
“It is hugely important to include the arts in discussions of end-of-life care because we are visual people, and we are musical people.” (JOAN MCCARTHY).

“Loss, grief, death and compassion – it is our bread and butter. It is kind of what we do as artists. Reality is difficult to negotiate. I think with the arts. People need time to see that the arts can educate massively.” (SINEAD DINNEEN).

“The poets and the writers and the artists do not dodge the depth of pain; they create images for it, rhythms for it and they face it full on and they transform it. The great thing about the arts is that they may centre death but they transcend it by sheer joy, exuberance and transformation. That is why I think they are so important. They are actually vitalising.” (REDMOND O’HANLON).
I have gathered together the various ideas and suggestions made informally by the people interviewed in the course of our conversation.

Some of these naturally find a parallel with what was found in the research and some are based on purely personal experience, opinion and expertise but all are equally valid and worthy of consideration.

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<tr>
<th>Interviewee</th>
<th>Suggestions</th>
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| Milford Care Centre staff (4)    | • Provide funding to promote the concept of a Compassionate Community without restrictions on how the funding is spent.  
• Support communities to minimise the isolation of modern society.  
• Invite civil and public servants Government staff to make a will and complete a Think Ahead form during induction programme.  
• Train teachers to support bereaved children in the classroom.  
• Include issues around dying and death on the curriculum.  
• Organise workshops on coping with bereavement and loss for teachers as part of their CPD.  
• Encourage the sharing of expertise, skills and experience of those who have and are supporting people through serious illness or caring.  
• Educate and encourage teachers and parents on benefits of speaking about dying and death with their children.  
• Help people to understand that grief is a perfectly normal emotional reaction to personal loss and encourage use of communication rather than medication in first instance.  
• Develop a drop-in hub in Limerick city for bereavement supports, information and resources. This hub could be a one-stop shop where agencies could share information and resources in a coordinated way.  
• Reinstate the Bereavement Grant.  
• Organise a cross-department working group to develop a strategy to improve end-of-life care and bereavement care in Ireland. |
| Jim Rhatigan                    |                                                                                                  |
| Dr. Kathy McLoughlin            |                                                                                                  |
| Rebecca Lloyd                   |                                                                                                  |
| Marie Richardson                |                                                                                                  |
| John Dunne                      | • Increase the funding for home adaptations.  
• Level the playing field between home care and residential care (nursing home support scheme)  
• The priority in home care should be providing sufficient quantum and quality of support and whilst the presence of a family carer can be used to justify lower supports in such circumstances if the carer isn’t also offered support as part of the package this will simply represent a perverse incentive against undertaking a caring role.  
• Introduce statutory entitlement to home care in line with the residential home care scheme. |
| Gus Nichols                     | • Appoint a regulator to inspect and maintain standards in the funeral industry.  
• Advise families on full of costs of funerals at time of arrangement. |
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<tr>
<td>Sinead Dinneen</td>
<td>• Increase awareness of the therapeutic and healing effects of Art.</td>
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<td>• Introduce a programme around dying, death, loss and grief into the school</td>
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<td>curriculum.</td>
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<td>• Appoint a Minister who is responsible for everything around dying, death,</td>
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<td>dignity and respect.</td>
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<td>Michael Culloty</td>
<td>• Develop and articulate an agreed vision of society with an underlying ethic</td>
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<td>of agreed values on how to deal with debt and death.</td>
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<td>• Reinvestate a bereavement grant that is more focused than the previous</td>
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<td>version.</td>
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<td>• Resource MABS to educate the community.</td>
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<td>• Require banks and insurance and corporations to exercise social</td>
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<td>responsibility in their dealings with the public.</td>
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<td>• Develop educational modules on financial literacy in schools.</td>
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<td>Christine O’Kelly</td>
<td>• Develop cost-efficient burials and internments.</td>
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<td>• Support people to live and die at home if they so wish.</td>
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<td>• Acknowledge and tackle the poverty trap impacting on women in their 50s</td>
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<td>and 60s who have no pension.</td>
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<td>Mark Patrick Hederman</td>
<td>• Give people the space to grieve.</td>
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<td>• Respect the hierarchy of affection.</td>
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<td>• Regulate the funeral industry.</td>
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<td>• Listen.</td>
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<td>• Look to the arts and creativity for intuition.</td>
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<td>Brendan Whelan</td>
<td>• Legislate to control the interest rates and fees that money lenders charge.</td>
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<td>Angela Edghill</td>
<td>• Reinstate a Bereavement Grant.</td>
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<td>• Initiate a state-led discussion on dying, death and bereavement.</td>
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<td>• Enable, support and encourage people to Think Ahead.</td>
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<td>• Provide training for all public servants on communicating with people in</td>
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<td>difficult circumstances, particularly on issues arising at end of life.</td>
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<td>Seamus Boland</td>
<td>• Support and expand the rural transport scheme.</td>
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<td>• Overhaul the Meals-on-Wheels system.</td>
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<td>• Develop a system to enable people rurally isolated to be relocated closer</td>
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<td>to villages and towns where help is available.</td>
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<td>• Encourage and finance befriending organisations for men who are socially</td>
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<td>isolated.</td>
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<td>• Develop and tailor house restoration programmes to tackle fuel poverty.</td>
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<td>Dr Brian Farrell</td>
<td>• Create a National Database that records all verdicts and recommendations</td>
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<td>and make them available to the public.</td>
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<td>• Properly regulate all care homes for the elderly</td>
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<td>• Enact a Coroner’s Bill immediately.</td>
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<td>• Review the resourcing and structure of the Coroner’s service.</td>
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<td>• Make Coronial training mandatory for solicitors.</td>
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<td>David McRedmond</td>
<td>• Recognise and respond to the difficulties in providing services to isolated homes.</td>
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| Dr Tom Inglis            | • Initiate a debate about death in Ireland and accommodate people who don’t wish to have a religious funeral.  
                             • Develop protocols around dealing with death and dying for guidance for all public servants.  
                             • Develop SPHE programmes to enable children to talk about death. |
| Dr Joan McCarthy         | • Begin and develop a national conversation on dying, death and bereavement which is broader than medicine.  
                             • Recognise that ethics is everyone’s business and ensure that religious dominance is not simply replaced by clinical ethicist or clinician or managerial hierarchies.  
                             • Support a transition to a multicultural, pluralist, multidenominational and secular culture around dying, death and bereavement in Ireland.  
                             • Design a module on end-of-life healthcare ethics in undergraduate and postgraduate healthcare programmes as well as hospital education centers harnessing the expertise of both academia and clinical colleagues.  
                             • Establish clinical ethics committees in hospitals and other healthcare settings to support ethically and legally sound clinical practice through educational initiatives, policy development and case review. |
| Fr. Pierce Cormac         | • Stop financial abuse of the elderly.  
                             • Allow a person to die with dignity and peace, and minimise the number of tests and procedures elderly people are subjected to.  
                             • Consider the development of a new model of Church and State working together in healthcare and in wider society on end-of-life. |
| John O’Keeffe            | • Increase state funding for organisations, such as ADVIC, which supports families of people who have died violently.  
                             • Develop minimum and proportionate sentences that reflect society’s disapproval of violent death.  
                             • Instigate training for judges from people who have been affected by violent death. |
| Margharita Solan         | • Facilitate people who wish to continue living in their own home within a village or town.  
                             • Set up a one-stop shop where people can get all the information they need on issues relating to end-of-life. |
| Mervyn Taylor            | • Design public services that support people at end-of-life in practical ways e.g., transport, Out of Hours GP visits, helpline.  
                             • Introduce a system of oversight (not regulation) for funeral directors.  
                             • Introduce a sense of dignity into the design of graveyards.  
                             • Provide extra financial assistance for funerals because they are significant events in our lifecycle. |
| Ronan Rose Roberts       | • Design and build buildings in accordance with the principles of universal design and informed by the Irish Hospice Foundation’s Design and Dignity guidelines.  
                             • Acknowledge that people have a right to beauty in their environment. |
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<tr>
<th>Interviewee</th>
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| Anne Staunton    | • Train teachers on bereavement and loss in the classroom and include as part of CPD - this training would develop awareness and empower teachers in a classroom - not require skills other than what they already have.  
• Ensure that schools have a bereavement and loss policy, but run in conjunction with the critical incident policy and would contribute to schools being a supportive caring environment.  
• Ensure the issue of Bereavement is highlighted and addressed as part of the Wellbeing Curriculum in teacher training colleges, CPD and supports within the school.  
• Develop a strategic bereavement national policy that includes children and young people in local communities around Ireland, where it could be integrated into the suite of supports in the family resource centres and other local community support agencies. |
| Brid Carroll     | • Provide information on bereavement supports through a central hub.  
• Undertake more community education on understanding bereavement.  
• Upskill teachers to support bereaved children.  
• Provide more childhood bereavement services in Ireland  
• Give universal access to bereavement services nationally.  
• Ensure that childhood bereavement services collaborate and operate to agreed standards. |
| Denis Murphy     | • Provide more resources on issues arising in dying, death and loss to give ongoing support to teachers and students.  
• Review the teacher’s helpline and consider the need for other forms of assistance. |
| Emma Dineen      | • Train and support teachers, principals and members of the board of management in dealing with bereavement.  
• Resource schools and NEPS better. |
| Sharon Vard      | • Avoid duplication of services to those bereaved by the loss of a child by regulation and cooperation between services.  
• Provide funding to help run these services.  
• Ensure parents get information and support from professionals who are trained in working with bereaved parents. |
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<tr>
<td>Irene Murphy</td>
<td>• Provide more financial assistance to the self-employed through income supports.</td>
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<td>• Reinstate the Bereavement Grant.</td>
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<td>• Educate people to have joint bank accounts to facilitate access if one partner dies.</td>
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<td>• Provide credits for women who have compromised their pensions by having to leave work when they married, or if they reduced their working hours and who cannot work now because they are the primary carers in the home.</td>
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<td>• Encourage state leadership for Think Ahead, while ensuring that people are fully aware that they can change their decisions as their life situation changes.</td>
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<td>• Discuss the privatisation of care in the community and regulate the sector effectively.</td>
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<td>• Provide protocols to all departments dealing with the public on end-of-life issues.</td>
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<td>• Make night nursing more readily available.</td>
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<td>• Review social protection/welfare provision for those who are caring for the dying..</td>
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<td>• Adapt the built environment to make it suitable to the needs of elderly and seriously ill people.</td>
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<td>Patricia Rickard Clarke</td>
<td>• Introduce measures to eliminate elder abuse.</td>
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<td>• Introduce a system for checking that people receive their entitlements from agents appointed by the elderly person.</td>
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<td>• Increase awareness of the costs of funerals and promote competition between funeral directors.</td>
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<td>• Enact the advance healthcare directive legislation - have a national campaign for the making of advance healthcare directive and enduring powers of attorney.</td>
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<td>• Audit of Social Protection supports to prevent financial elder abuse.</td>
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<td>Ita Mangan</td>
<td>• Increase the Living Alone Allowance.</td>
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<td>Sharon Foley</td>
<td>• Education of and support for young teachers on dealing with issues arising in schools as a result of life limiting illness, death and loss.</td>
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<td>• Support Compassionate communities issues nationally.</td>
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<td>• Reinstate the Bereavement Grant.</td>
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<td>• Ensure more state coordination of services and involvement encouraging people to Think Ahead.</td>
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<tr>
<td>Dr Redmond O’Hanlon</td>
<td>• Invest in the arts.</td>
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<td>• Promote creativity and the arts in schools to support issues of care, grief and loss.</td>
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<td>• Invest millions in communities to help them regenerate.</td>
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