

IPR Policy Brief
September 2017



Death, Dying and Devolution

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Centre for Death and Society

IPR Institute for
Policy Research

Contents Page

3

Introduction

- 3 Foreword** The Rt Hon Sir Steven Webb, Director of Policy at Royal London and former Minister of State for Pensions
- 4 Introduction** Dr Kate Woodthorpe, Senior Lecturer in Sociology at the University of Bath

8

End of Life

- 9 Palliative and End of Life Care Policy: A Reflection from Scotland**
Richard Meade, Head of Policy and Public Affairs, Scotland at Marie Curie
- 15 Palliative and End of Life Care for Children** James Cooper, Public Affairs and Policy Manager at Together for Short Lives
- 22 Mitigating Poor Financial and Employment Outcomes for Carers of Dying People** Stephen McCauley, Policy and Advocacy Manager at Hospice UK and Kathleen Caper, Head of Policy and Advocacy at Hospice UK
- 27 Dying in Care Homes** Professor Malcolm Johnson, Visiting Professor of Gerontology and End of Life Care at the University of Bath

34

Post-Death

- 35 Organ Donation** Dr Wendy Walker, Reader in Acute and Critical Care Nursing at the University of Wolverhampton and Professor Magi Sque, Chair for Clinical Practice and Innovation at the University of Wolverhampton
- 40 Why Lasting Power of Attorney Should Extend after Death** Helen Morrissey, Personal Finance Specialist at Royal London
- 46 Social Security for Bereaved Partners and their Children** Alison Penny, Coordinator of the Childhood Bereavement Network
- 54 Bereavement Among Older People** Lesley Carter, Interim Head of Health Influencing at AgeUK

- 59 Delays to Funerals** Debbie Kerslake, Chief Executive at Cruse Bereavement Care and Stewart Wilson, Chief Executive at Cruse Bereavement Care Scotland
- 66 Regulation of Funeral Directors** Mandie Lavin, Chief Executive Officer at the National Association of Funeral Directors
- 75 Funeral Standards and Practice** Paul Allcock Dip FD, Immediate Past President, PR Chairman and acting Government Liaison at the National Society of Allied and Independent Funeral Directors
- 80 Funeral Expenses Payment** Heather Kennedy, Fair Funerals Campaigns Manager at Quaker Social Action
- 86 Public Health Act Funerals** Julie Dunk, Deputy Chief Executive of the Institute for Cemetery and Crematorium Management

91

Cemeteries and Crematoria

- 92 Cremation and New Techniques** Brendan Day, Technical Coordinator at the Federation of Burial and Cremation Authorities
- 97 The Shortage of New Burial Space** Tim Morris Dip FCCM, FSBP, Chief Executive of the Institute of Cemetery and Crematorium Management
- 102 The Burial and Cremation (Scotland) Act 2016 and the Management of Historic Graveyards** Dr Susan Buckham, Honorary Research Fellow in History and Politics at the University of Stirling

Foreword

The Rt Hon Sir Steven

Webb, Director of Policy
at Royal London and
former Minister of State for
Pensions

This is a remarkable collection of articles.

As Debbie Kerslake and Stewart Wilson point out in their article (p.59), across the UK last year around 600,000 people died, with each death directly affecting between four and six of us. This means that well over 2 million people last year alone had to wrestle with some or all of the issues raised in this collection.

Yet many of these issues barely feature in public debate at all. For example, beyond the specialist press, the issues of sensitive re-use of burial sites or the particular needs of older bereaved people get precious little attention in wider conversations.

Greater devolution of power within the UK gives an opportunity to start to address this omission, and a common theme of several of the articles is the way in which debate and, to some extent, policy on many of these subjects in Scotland is well advanced compared with the rest of the UK. It is very welcome that different parts of the UK are free to innovate, and it is vital that we all learn from successful innovation. For this to happen however, as Richard Meade points out in the second article (p.9), we need careful data collection and robust evaluation – two things which can be very challenging in such sensitive areas.

The articles in this collection cover what happens before someone dies, including issues around palliative care and support for carers; what happens at death, including issues around the proper regulation of funerals and public financial support for the bereaved; and what happens to those who are left behind, including emotional support for those who have been bereaved and issues around managing the estates of those who have died.

In a series of short essays, this collection gives a flavour of the depth and complexity of the issues around death, dying and bereavement with which we as a society are still grappling. I hope that policymakers around the UK will read the articles and consider what policy innovations they can initiate in order to tackle some of these fundamental challenges.

Introduction

Dr Kate Woodthorpe,

Senior Lecturer in
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of Bath

Why Does Death Matter?

A substantial number of people are impacted by death every year, with sizeable social and economic consequences. Over half a million people currently die in the UK each year. With four to six people estimated to be significantly impacted upon and bereaved by every death (see Debbie Kerslake and Stewart Wilson's article, p.59), there are over 2 million people across the UK dealing with death's emotional, financial and practical consequences every year. A further 1 million people are providing care for someone with a terminal illness every year¹, but only one in six employers have policies in place to support this population (see Stephen McCauley and Kathleen Caper's article, p.22).

At the same time, one in four people who need palliative care miss out (see Richard Meade's article, p.9); 49,000 children and their families are dealing with a life-limiting or life-threatening condition (see James Cooper's article, p.15); and 6,500 are waiting for an organ transplant (see Dr Walker and Professor Sque's article, p.35). 400,000 people live in care homes, a quarter of whom will die there every year (see Professor Johnson's article, p.27), and it costs over £1 billion a year to run charitable hospices across the country, providing end of life care for 200,000 people².

After a death 58% of people bereaved of a partner report lower levels of household or disposable income³. As space for burial decreases (see Tim Morris' article, p.97) and cremation costs rise (see Brendan Day's article, p.92), 45,000 annually seek financial assistance from the state – meaning that just under 10% of all deaths result in requests for funeral expenses support (see Heather Kennedy's article, p.80). This cost the Social Fund £38.6 million in 2016-17, yet only £0.1 million was recovered from estates⁴. At the same time, only a third of the UK population has a will in place (see Helen Morrissey's article, p.40). There is also significant variance in the role played and financial burden assumed by local authorities when it comes to death; the average local authority carries out 12 public health funerals a year but some carry out

1. Marie Curie (2015) The Hidden Costs of Caring, available online at: <https://goo.gl/HH7ffQ>

2. Hospice UK (2017) Facts and Figures, correct at 29/08/17, available online at: <https://goo.gl/oykVV>

3. Royal London (2016) Losing a Partner: the financial and practical consequences part 2, available online at: <https://goo.gl/fiLrWC>

4. DWP (2017) Annual report by the Secretary of State for Work and Pensions on the Social Fund 2016-17, available online at: <https://goo.gl/PQ3nX1>

as many as 500 (see Julie Dunk's article, p.86).

Policy Responses to Death, Dying and Bereavement

Given the volume of people impacted by death every year, it is surprising that it is not more widely regarded as a public policy issue. You will not find it featuring prominently in government departments' agendas, nor at the forefront of parliamentary debates, nor in academic textbooks. Such neglect has been consolidated by the ageing of the UK population and declining death rate throughout the 20th century, resulting in an enormous first-hand experiential knowledge gap of how to handle death at every level from the individual through to the state. We are thus ill prepared for death and its social and economic consequences – as individuals, as families, as employees, as benefit recipients, as policymakers, as businessmen and women, as organisations, as sectors and as a country.

“A lack of attention has meant that public policy associated with death, dying and bereavement has evolved piecemeal over decades and in silos”

A lack of attention has meant that public policy associated with death, dying and bereavement has evolved piecemeal over decades and in silos, leading to significant differences in the quality and quantity of policy and guidance available. There are further knock-on effects from changes (or lack of changes) to policy and practice that currently straddle departments and governments, such as managing child and adult palliative care services; the death registration system and delays to funerals; changes to organ donation legislation; Funeral Expenses Payments and public health funerals; and burial space availability and cremator capacity. Beyond the resource implications of these knock-on effects there are also unresolved competing priorities within policy areas, for example freeing up burial space availability or conserving the cultural value of historic cemeteries and graveyards (see Tim Morris' article, p.97, and Dr Buckham's article, p.102).

As this brief will show, such a disjointed policy environment has resulted in:

- Policy and legislative vacuums (public health funerals, bereaved older people and funeral directors).
- A lack of clarity over policy coherence and overlap (carers and historic cemeteries).
- The need for systematic data generation to understand trends, and the use of robust evidence and analysis to inform policy (palliative care, organ donation, bereavement support, funeral delays and care homes).
- Inadequate funding and reviewing of policies over time and as pressures grow (children's palliative care, public health funerals, Funeral Expenses Payments).
- Insufficient financial planning by both individuals and policymakers (power of attorney, cemeteries and crematoria).

Where Next?

A deficit in policy response and legislation, compounded by and resulting in poor strategising and infrastructure, has led to fragmented approaches to supporting those who are dying or bereaved. This was recognised by the Work and Pensions Select Committee Special Inquiry into Bereavement Benefits in 2016, which recommended that: “The Government should conduct a cross-Departmental review of burials, cremations and funerals. This coordinated review should look to make recommendations that have a long-term impact on funeral inflation and work to reduce funeral poverty” (p.42 recommendation 9).

This recommendation did not go far enough. A review is needed of **all** policy areas that shape what happens before death and immediately afterwards, and for different demographic and geographic groups, so that:

- A holistic picture is created of how different policy areas intersect, and the four nations correspond/differ in their resourcing, targeting, approaches and responses.
- There is understanding as to how dying and bereaved people navigate the varying policy areas and services across the four nations.
- There is recognition of and response to the inequalities experienced by dying and bereaved people owing to geographical location (the focus of this policy brief) along with other social divisions such as socio-economic background, education, gender, age, ethnicity and so on.

By documenting and reviewing 16 policy areas associated with death, dying and bereavement this brief intends to respond to these three aims.

What Can Devolution Do?

Weaving the articles in this brief together is an exploration of the impact of national and regional devolution. As the articles will show, the delegation of policy, resources and organisational structures to nations and regional areas has considerable potential to revolutionise how we regard and respond to the issues raised by death. Such decentralisation does not come without risk however, and raises substantial questions regarding equality, accountability, responsibilities, and data generation and sharing.

As the process of devolution is well underway we are thus at an interesting and landmark crossroads that will shape the very core of the welfare state across the UK in the future. How dying, death and bereavement is recognised, supported and resourced by the state speaks volumes about ideological conceptualisations of citizenship, rights and responsibilities, and social justice. In light of the projected rise in the UK death rate over the next 20 years, with devolution comes a once-in-a-lifetime opportunity to (re)address the neglect of death as a public policy issue, repositioning death as a central concern of the welfare state.

This brief demonstrates the potential and limitations of devolution. Going forward, in creating and implementing innovative and responsive policy that can meet the needs of the population, we need to ensure that:

- The breadth of social and economic consequences associated with death, dying and bereavement is recognised, analysed and addressed as a legitimate area for policy concern and response.
- Robust evidence-gathering mechanisms are in place across all four nations to ensure that there is sufficient data to observe and respond to trends, and that systematic evaluations occur to ensure that policy is up to date and agile.
- There are infrastructural systems in place to ensure that good practice can be shared across the four nations and between the public, commercial and third sector; and that policymakers in each nation are empowered to act when progress is made in a nation or region.
- Policy areas are consolidated and structured within government departments to make best use of expertise and evidence, and there is a sustained acknowledgement of policy and departmental overlaps and knock-on implications of action (or lack of action).

Organisation

For ease of access the brief is organised into three sections: End of Life, Post-Death, and Cemeteries and Crematoria. Contributions to each section are from leading experts in the third sector, commercial world and academia. It is organised so that each contribution and section can be read in isolation, or the brief can be read from cover to cover, depending on time availability and interest.

It is intended that this brief will stimulate, provoke and advocate for change. The aim is that it can be utilised to raise the profile of death, dying and bereavement as a significant public policy issue and make cases for transformation in the policy areas affected.

About the Editor of the Brief

Dr Kate Woodthorpe is a Senior Lecturer in Sociology who has worked in this field for over 15 years. She acted as Special Advisor to the Work and Pensions' Select Committee Special Inquiry into Bereavement Benefits in 2016 and has just finished a secondment with the Department for Work and Pensions supporting improvements to the Funeral Expenses Payment.

Dr Woodthorpe has conducted research and published widely on funeral costs and practice, families at the end of life, the deathcare sector workforce, cemetery usage and researching death, dying and bereavement. She co-edits the inter-disciplinary journal *Mortality*.



End of Life

Palliative and End of Life Care Policy: a Reflection from Scotland

Richard Meade, Head of Policy and Public Affairs, Scotland at Marie Curie

- The devolved governments' approaches to palliative and end of life care policy are broadly similar, but Scotland has gone further by committing to universal access by a set date (2021).
- Palliative care has become an increasing priority in Scotland.
- Data collected on palliative care to date is largely incapable of showing progress at present, and demonstrates that success against key policy initiatives is limited.
- Different commissioning environments in each nation can allow for different approaches, but without robust data and information it is impossible to evaluate their success relative to one another.

Background

Since 1999 the process of devolution has given full responsibility for health and social care to the governing administrations within the four nations of the UK. This has presented them with an opportunity to do things differently and potentially achieve varying outcomes for patients and families. Each nation has chosen different approaches to the design and delivery of health and social care, as well as local policies and strategies to tackle specific local needs and challenges. However, whether this has made any real difference in outcomes for patients and families in the nations still remains to be seen.

Palliative and end of life care policy has been one specific area where each nation within the UK has produced different policy documents and strategies in the hope of improving care. A report by Sheffield Hallam University in 2016, commissioned by Marie Curie, found that all four nations of the UK had produced a strategy or programme of work to commit to improvements in palliative and end of life care¹. These include commitments around access to care and quality of patient care.

1. *State of the Nations Report: Terminal Illness Care in England, Northern Ireland, Scotland and Wales*, June 2016.

“Scotland is [...] the only nation that goes so far as to set a deadline for achieving universal coverage of palliative care”

The English strategy published in 2016, *Our Commitment to you for end of life care*, pledges that “every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected.”²

Wales’ *Palliative and End of Life Care Delivery Plan* sets out the country’s aim “for people in Wales to have a healthy, realistic approach to dying, and to be able to plan appropriately for the event. We want them to be able to end their days in the location of their choice – be that home, hospital or hospice and we want them to have access to high quality care wherever they live and die, whatever their underlying disease or disability.”³

Northern Ireland does not have a strategy document as such, but a Palliative Care Work Plan for 2016-17. This sets out a range of priorities, such as improving identification, advance care planning, commissioning, education and training and data collection. These priorities are very similar to those set out in the strategy documents of other nations.

Scotland has published two significant strategy documents relating to palliative and end of life care in the ten years that the SNP Government has been in power at Holyrood. The latest, *The Strategic Framework for Action on Palliative and End of Life Care*, which was published in December 2015, includes many of the same priorities and commitments set out in the strategy documents of the other nations. However, what marks the Scottish strategy out as different from the other nations is that it has included a target of ensuring that everyone who needs palliative care has access to it by 2021, five years from the launch of the strategy.

Scotland is thus the only nation that goes so far as to set a deadline for achieving universal coverage of palliative care.

Barriers to Measurement

The challenge is understanding whether or not the four nations are making progress against their palliative care ambitions. There is very limited data right across the UK around palliative care, and until this is rectified it will be extremely difficult to know whether policies and strategies are having their desired effect.

Murtagh et al provided a reliable formula to calculate the number of people who need palliative care prior to their death. That formula suggests that around 80% of people who die each year in the UK (in all four nations) need some form of palliative care, whether that is generalist or specialist care⁴.

2. *Our commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care*, July 2016.

3. *Palliative and End of Life Care Delivery Plan*, Welsh Government, March 2017.

4. Murtagh, F.E.M. et al, (2013) ‘How many people need palliative care? A study developing and comparing methods for population-based estimates’, *Palliative Medicine*, 28 (1): 49-58.

“around 47,000 people who die each year in Scotland need some form of palliative care”

However, there has been limited work done to show how that level of need balances against the number of people who are actually receiving palliative care. This has made it very hard to reliably know what the unmet need is in each of the four nations. The work that has been done has shown a snapshot of a particular period and has not been repeated over time, which makes it impossible to confirm improvements or trends.

In the small body of work that has been conducted to measure the level of need in palliative care across the four nations, a report commissioned by Marie Curie, published by the London School of Economics (LSE) in 2015, suggested that one in four people who die with a palliative care need across the UK including Scotland miss out on that care⁵.

The LSE report identifies the unmet need across the UK from estimates made in England. This has then been used to develop similar estimates in Wales, Northern Ireland and Scotland. There are no other current sources of data to show how many people are missing out on care, or how many receive that care from the point of need. This data is not routinely collected by administrations or national statistics bodies.

Elsewhere, some academic studies have provided evidence of need, such as a Scottish study which showed that in a selection of GP practices in Lothian patients with terminal cancer were much more likely to get palliative care than those with other conditions such as organ failure, or frailty and dementia⁶. A follow-up study, again carried out in Lothian, showed some improvement with the introduction of a new anticipatory care plan, the Key Information Summary (KIS), which indicated that more people were in receipt of palliative care – but there are still inequities across conditions⁷. Without replication and a nationwide picture it is impossible to measure true progress nationally.

Scottish Government figures also showed that in Scotland 26,447 people had a KIS on death in 2016⁸. If using the Murtagh formula then we calculate that around 47,000 people who die each year in Scotland need some form of palliative care; this would mean that over 19,000 people are dying without a KIS and advanced care planning. If we believe anticipatory care plans are a good indicator of whether or not a person received some palliative care, as the study noted above does, then this could mean that many more people are missing out on the care they need than the estimated one in four suggested by the LSE study.

Not only does this suggest that the need gap is potentially bigger than thought, but it also highlights just how difficult it is to measure

5. Dixon, J. et al (2015) 'Equity in the Provision of Palliative Care in the UK: review of Evidence' Personal Social Services Research Unit, London School of Economics and Political Science.

6. Zheng, L. et al (2013), 'How good is primary care at identifying patients who need palliative care? A mixed methods study', *European Journal of Palliative Care*, 20.5 (2013): 216-222.

7. Tapsfield et al (2016), 'Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners', *BMJ*.

8. Scottish Parliament, Written Answer to Scottish Parliament Written Question S5W-06770 (2017) <https://goo.gl/sJwZ4q>

who is in receipt of palliative care – and who is not.

In Scotland the lack of data is a real challenge in terms of the Scottish Government being able to meet their 2021 target. In response, KISs are now being routinely collected by the Scottish Government's statistics function to allow for regular monitoring of the number of people dying with a KIS each year. This will give the Scottish Government an opportunity to monitor improvements in anticipatory care planning uptake. If we accept this as an indicator that a person has received palliative care then this could be a way of measuring progress against Scotland's vision of full access to palliative care by 2021.

However, even with this information, there is still a lack of reliable data around access to care from the point of need as well as quality of care. This means that it will be very difficult for Scotland, or any of the other nations, to show exactly what progress (if any) they are making against their framework for action.

Delivery of Services

The nations of the UK may have broadly similar strategies and priorities for palliative care, but there are differences in how these strategies will be delivered by each of the nations.

In England services are designed and commissioned by clinical commissioning groups (CCGs). Recently, the NHS and local councils have formed partnerships in 44 areas, known as Sustainability and Transformation Partnerships, covering all of England and designed to improve health and care. Each area has developed proposals built around the needs of the whole population in the area. In Wales the NHS Boards are responsible for commissioning and in Northern Ireland the Health and Social Care Board is responsible for commissioning services across the province.

In contrast, the Scottish Government has recently integrated its health and social care functions in Scotland through the establishment of 31 new integration authorities responsible for managing and commissioning services for their areas. Palliative care was included in the list of functions that had to be integrated. Integration authorities are responsible for commissioning palliative care services for their area across community and acute settings.

The Scottish Government has ensured that palliative care is a high priority for the integration authorities through its recently published *Health and Social Care Delivery Plan*. The plan included two clear commitments for palliative care: firstly, that integration authorities will double palliative care services in the community; and secondly, that everyone who needs a KIS will have one⁹. The plan was also recently highlighted as a high priority in Scottish Government communications to each of the Integrated Board's Chief Officers for its current budget

9. Scottish Government, *Health and Social Care Delivery Plan*, 2016.

cycle¹⁰.

A key element of palliative and end of life care is the general support that is largely delivered in the community and mostly in primary care and social care settings, including people's homes and care homes. This further highlights the importance for palliative care services of integrating health and social care functions in Scotland. Palliative care can often be seen through the prism of specialist care in hospitals and hospices, but the vast majority of care is delivered outside of these places. In Scotland, on average, a person spends 87% of their last six months of life at home or in a community setting. The majority of the time they do spend in hospital is usually within the last month of their life¹¹.

This information is certainly helpful for the new Scottish integration authorities to support them in commissioning services, especially around the community palliative care services they offer. However, without more complete data around need, it will be difficult for them to know exactly what services they need to commission to meet the needs of their local populations.

Summary

A recent report by the Health Foundation and Nuffield Trust suggests that despite devolution in health and social care policy and powers, the four nations' health outcomes are still, relatively, similar and there has been no real divergence since 1999¹². It goes on to suggest that there is little sign that one country is 'consistently moving ahead of the others'. This might be similar for palliative care outcomes in each country, but without the data it is difficult to know. The report also highlights data issues particularly around comparable data between the nations to show differences in health and social care.

Each of the nations has clear ambitions around improving access, reach and quality of support for those patients in need of palliative care. Interestingly, despite devolution there is very little real difference between the scope, priorities and approach of each nation. The Scottish Government's target of everyone getting the care they need by 2021 does suggest more ambition than the other nations, especially considering the scale of the challenge and the short time within which they have committed to achieving it.

Certainly, devolution has allowed for different ways of commissioning and delivering services in the nations and there are clear differences between them. However, without more robust data across each nation it will be impossible to know with any certainty which nation's approach will best serve its palliative population.

10. Scottish Government, Letter to Chief Officers, *Draft Budget 2017/18*, 15 December 2016.

11. ISD (2016) *End of Life Care*, available online at: <https://goo.gl/SVhAV6>

12. The Health Foundation, Nuffield Trust (2014) *The four health systems of the United Kingdom: how do they compare?*

Recommendations for Policy Change and Research

Future research needs to address the following questions:

- Do the different commissioning environments in each of the four nations lead to different outcomes for patients in need of palliative care?
- What data/research/evidence is needed to show the progress of palliative care services against policy ambitions in each of the nation?
- Are health policies significantly different in each of the nations?

Palliative and End of Life Care for Children

James Cooper, Public Affairs and Policy Manager at Together for Short Lives

- The number of babies, children and young people in the UK living with life-limiting and life-threatening conditions is growing as a result of advances in medical technology and better care. The current policy and funding environment has failed to adequately acknowledge the needs of these children, their families, or those that work to support them.
- The way in which children's palliative care in the UK is planned and funded represents a postcode lottery. Funding gaps exist in parts of the UK between children's and adult palliative care; where this is happening, a judgement is being made that the life of an adult has greater value than that of a child. For example, the Scottish Government has allocated £30 million over five years for children's hospices so that there is parity with funding for adult hospices. No such commitment has been made in England, Northern Ireland or Wales.
- The families of children with life-limiting conditions have to co-ordinate a vast array of professionals and agencies to secure the lifeline care their child relies on. While a number of positive policy initiatives are being developed by the UK's governments and other agencies, more work is needed to make sure that they bring about more joined-up plans, assessments and services with children and families at their centre.

Children's Palliative Care

Children's palliative care is an active and total approach to care, provided from the point at which a life-limiting or life-threatening condition in a child is diagnosed or recognised. It embraces their physical, emotional, social and spiritual care, focusing on enhancing the quality of life for the child or young person and supporting their family. It includes managing symptoms and providing short breaks, as well as delivering care through death and bereavement.

Children's palliative care is often confused with adult palliative care: many people think that only children at the end of their life can benefit from children's palliative care. This is not the case. Palliative care can be introduced at any point throughout a child's life; it is completely individual. Some children may require palliative care from birth, others only as their condition deteriorates.

There are 49,000 babies, children and young people between the ages of 0 and 19 in the UK who have a life-limiting or life-threatening

condition¹. However, too little is known about where these children are or what they need. Life-limiting conditions are those for which there is no reasonable hope of cure and from which people are expected to die. Life-threatening conditions or episodes are those for which curative treatment may be feasible but can fail². Many children with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.

The Policy Challenges Affecting Children Who Need Palliative Care

The current policy and funding environment has largely failed to adequately acknowledge these children, the needs of their families, or those that work tirelessly to support them. The quality of support they receive is largely determined by where they live – depending on what services are planned and funded, rather than on what they need. As a result most families are just about managing, but many are reaching breaking point.

Those commissioners [CCGs and local authorities] who constructively engage continue to do so; those who don't, don't! Without any levers for commissioners to engage with us – or a change of ethos – it is hard to make in-roads. Despite our own efforts and encouragements from both the strategic clinical network and a local MP, engagement in meaningful dialogue with our most local commissioner remains a challenge.

A children's hospice in England

It's a minefield and you get frightened going through it. Services don't join up and people don't explain things to you. By the time I had made it all fit together, my child had passed away. That makes me sad that he could have had so much more out of life.

A parent bereaved of a child with a life-limiting condition

Effective Planning and Parity of Funding – Ensuring the Life of a Child is as Valued as the Life of an Adult

The UK Government's 2016 response to a review of choice in end of life care in England states that to support high-quality personalised care for children, commissioners and providers of services must prioritise children's palliative care in their strategic planning; this is so that services can work together seamlessly and advance care planning can be shared and acted upon.

Together for Short Lives welcomed the commitment and is keen to work with the government and the NHS to realise it. Sadly, our own

1. Fraser et al, 2012. *Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives*. Available online at: <http://bit.ly/1z24ZQw>

2. Together for Short Lives. 2013. *A Core Care Pathway for Children with Life-Limiting and Life-threatening Conditions*. Available online at: <http://bit.ly/18Vd3JV>

“NICE calculate that by investing £12.7 million in implementing [their] guidance, non-cash savings worth £34.7 million would be released back into the NHS in England”

data demonstrates that too many children in England with life-limiting conditions, and their families, are being short-changed and ignored³. Seriously ill children are being forgotten or ignored by nearly one in ten clinical commissioning groups (CCGs) in England. Whether or not families of seriously ill children across the UK have access to round-the-clock community nursing support depends on where they live. For example, only 73% of CCGs commission community children’s nursing for children with life-limiting conditions in England out of hours and at weekends. This means that many seriously ill children need to be admitted to hospital if their condition deteriorates rapidly, rather than receiving palliative care in the community if that is what their families choose.

There is a clear, evidence-based economic case for investing in children’s palliative care. In December 2016, the National Institute for Health and Care Excellence (NICE) published a clinical guideline entitled *End of life care for infants, children and young people with life-limiting conditions: planning and management*⁴. NICE calculate that by investing £12.7 million in implementing the guidance, non-cash savings worth £34.7 million would be released back into the NHS in England. NICE also calculate that if the Welsh Government invested £690,000 in implementing the guidance, non-cash savings worth £1.9 million would be released back into the NHS in Wales. If the Northern Ireland Executive invested £476,769 in implementing the guidance, non-cash savings worth £1.3 million would be released back into the health and social care system.

Despite this, children’s palliative care is woefully under-funded and under-resourced by the state⁵. For example, on average, adult hospices in England receive 33% of their funding from statutory sources and children’s hospices receive an average of 22%. Unless this funding gap is addressed, then we, as a country, are making the judgment that we place greater value on the life of an adult than that of a child. This is neither moral nor fair.

To improve on the way in which children’s palliative care is planned and funded in England, Together for Short Lives is asking the UK Government to work with us and follow the example of the Scottish Government, who have allocated £30 million over five years for children’s hospices⁶ so there is parity with funding for adult hospices. We would also like the UK Government to review the amount of statutory funding being allocated to NHS-provided palliative care services in England. This would be done with a view to making sure that these

3. Together for Short Lives. 2016. *Commissioning map of children’s palliative care*. Available online at: <https://goo.gl/ke89kD>

4. The National Institute for Health and Care Excellence. 2016. *End of life care for infants, children and young people with life-limiting conditions: planning and management* - NICE guideline [NG61]. Available online at: <https://goo.gl/4ckv5N>

5. Together for Short Lives. 2016. *On the brink: a crisis in children’s palliative care funding in England*. Available online at: <https://goo.gl/kXvqrz>

6. Scottish Government. 2016. ‘Children’s Palliative Care Funding Boost’. Available online at: <https://goo.gl/ubjRw7>

services are also put on an equitable and sustainable financial footing.

We also call on the UK Government to work with us to:

- Hold CCGs to account in implementing the end of life choice commitment for children.
- Understand how the range of policy initiatives which can have an impact on children with life-limiting conditions – including Integrated Personal Commissioning, personal budgets and the special educational needs and disability system – can create a joined-up system of assessments, plans and services for their families.
- Take steps to ensure that CCGs understand what they are responsible for commissioning in terms of children’s palliative care.
- Invest in setting up managed clinical networks (MCNs) to bring about joined-up approaches to providing palliative care to children; MCNs are recommended by NICE.

In Northern Ireland, the Department of Health need to allocate funding to implement their own recommendations from *Providing High Quality Palliative Care for Our Children: A Strategy for Children’s Palliative and End-of-Life Care 2016-26*⁷. This includes provide parity of funding between children’s and adult palliative care. This would equate to providing an additional £800,000 per year to Northern Ireland Children’s Hospice.

In Wales, further to the recently published *Palliative and End of Life Care Delivery Plan*⁸, the Welsh Government need to give parity to children who require palliative care by putting it on an equal footing with the adult specialty. Ministers can do this by strengthening the way in which children’s needs are represented on the End of Life Board by recognising the authority of the Paediatric Palliative Care Implementation Group. This could be done through effective resourcing and a mandate by the Cabinet Secretary for Health and Sport. We recommend that the Welsh Government develop a paediatric palliative care implementation plan based on the recommendations from the Sugar Report⁹.

Disability Living Allowance – Lifting the Unfair ‘Baby Benefit Bar’

Across the UK, an anomaly in the welfare and benefits system means that families with children under three are unable to access the mobility component of the disability living allowance available to those with children over three.

7. Department of Health. 2016. *Providing High Quality Palliative Care for Our Children: A Strategy for Children’s Palliative and End-of-Life Care 2016-26*. Available online at: <https://goo.gl/WkgYze>

8. Welsh Government. 2016. *End of Life Care Delivery Plan*. Available online at: <https://goo.gl/ncx3Rj>

9. Sugar et al. 2008. *Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services*. Available online at: <https://goo.gl/JPtSRp>

My daughter has had a tracheotomy with a ventilator attached 24/7 since the age of eight months. She needs these for an undiagnosed neuromuscular condition. She cannot support herself at all. Carrying her, her vent, her suction machine, her oxygen, her emergency equipment to our car and back for two years was extremely difficult. We ended up selling our family car and purchasing a wheelchair accessible vehicle privately as it just became too hard to carry her as she grew.

The parent of a child who needed palliative care

This benefit would allow families to buy or have access to a specially adapted vehicle which would allow families to travel safely with their children and the bulky life support equipment they need. The change required to support these families would amount to just over £8 million a year. It would transform the lives of over 2,700 children and their families across the UK.

Social Care – Ensuring a Further Crisis is Averted by Recognising the Needs of Children Now

The recent focus on social care funding during the general election campaign was encouraging, yet children and their families are still excluded from this debate. Children with life-limiting conditions and their families rely on lifeline social care services like short breaks (respite care), transport, counselling, equipment and home adaptations. Despite this, evidence uncovered by Together for Short Lives has found that four out of five (81%) local authorities are failing to plan and fund care for children who need palliative care¹⁰. One in seven (14%) councils are failing to commission short breaks for children with life-limiting and life-threatening conditions.

Without Naomi House, you just wouldn't be able to take a break. There isn't anywhere else that offers the care and support we get there.

Neil, father of Lloyd, a young man with Duchenne muscular dystrophy¹¹

Local authority funding for children's palliative care charities has fallen dramatically^{12, 13}, down by 61% over the last year – only contributing 1% of the costs incurred by these organisations.

As a result the UK Government needs to hold local authorities to

10. Together for Short Lives. 2016. *Commissioning map of children's palliative care*. Available online at: <https://goo.gl/TPJm9K>

11. From Together for Short Lives guide to jointly commissioning children's palliative care. Available online at: <https://goo.gl/q5rwyV>

12. Together for Short Lives. 2016. *On the brink: a crisis in children's palliative care funding in England*. Available online at: <https://goo.gl/VHU7vY>

13. Together for Short Lives (2016) *Palliative care charities on the brink of state funding crisis*. Available online at: <https://goo.gl/GJg9xy>

account to increase funding for short breaks for disabled children, provided at home, in the community and in children's hospices. In England, the government must include children's services in new proposals for ensuring long-term, sustainable funding for social care in England.

Workforce – Investing in a Children's Palliative Care Workforce to avoid a Crisis in Support

There is currently a shortage of children's palliative care nurses^{14, 15} and this is limiting the care provided to children and families.

The number of children with life-limiting and life-threatening conditions who rely on children's hospice services is increasing. Yet the nursing shortfall means that children's hospices are increasingly being forced to cut back the vital palliative care they can offer to families.

We have recently stopped providing 24/7 care, even for those at end of life, which is very difficult for staff and families as this should be our 'core business'. Previously we have offered 24/7 advice for all, however this is no longer sustainable. We hope that, if we can recruit to vacant posts, we will resume 24/7 end of life care as soon as we can."

A UK children's hospice

The majority of services (58%) say that vacancies are having an impact on care – including a reduced offer to families or reduced short breaks. Nearly one fifth (17%) state that they are being forced to close beds. 13% of services report that vacancies affect their ability to provide 24/7 care.

What is more, the average nurse vacancy rate in UK children's hospice organisations was 11% in December 2016 (an increase of 1% on the rate in 2015), which is equal to the NHS nurse vacancy rate in England. This represents over 130 full-time posts unfilled.

Evidence published by the Royal College of Paediatric and Child Health shows that in the year to September 2015, shortages of nurses and/or doctors led to periods of closure to new admissions by 31% of paediatric inpatient units and 41% of neonatal units across the UK¹⁶. The evidence also highlights substantial vacancies at both consultant and trainee levels, the low number of academic consultants and the fact that general practitioners and practice nurses have limited training in child health.

It is thus becoming critical that the UK Government convene a

14. Together for Short Lives. 2017. *The state of the UK children's hospice nursing workforce: a report on the demand and supply of nurses to children's hospices*. Available online at: <https://goo.gl/1z6Ybm>

15. Together for Short Lives (2016) Children's palliative care nurses need to bridge care gap'. Available online at: <https://goo.gl/hGTqJy>

16. Royal College of Paediatrics and Child Health. 2017. *The State of Child Health: The Paediatric Workforce*. Available online at: <https://goo.gl/QgzbdB>

UK-wide summit to develop an approach to boosting the number of nurses available to provide palliative care to children with life-limiting and life-threatening conditions.

Transition – Building a Bridge over the Cliff Edge of Care between Children’s and Adult Services

The jump into adult services – and it is a big jump – was hard for me. There is very little support specifically for young adults. We are no longer children in the medical and social definition, we are young adults, but adult services aren’t equipped to deal with the wants and needs of young adults.

Lucy Watts MBE, a young woman living with a life-limiting condition

Advances in medical technology mean that the number of young people living with life-limiting and life-threatening conditions is increasing, but a shocking number of young people are not getting the support and care they need. There is an urgent need for new initiatives to transform the experience of young people with life-limiting conditions as they move from children’s to adult services.

Together for Short Lives has launched a grant programme to help support innovative approaches and partnerships to address this gap and generate learning to build an evidence base of good practice. The charity is asking the UK Government to invest in seed funding for voluntary sector organisations to set up age-appropriate services for young people transitioning from children’s to adult services.

Recommendations for Policy Change and Research

- More research is desperately needed to understand the numbers and needs of children in the UK with life-limiting conditions. Only when we know the demand for children’s palliative care can we effectively plan, fund and provide it.
- The UK Government should review the amount of statutory funding being allocated to NHS-provided palliative care services in England. This should be done with a view to making sure that these services are also put on an equitable and sustainable financial footing.
- The UK Government should initiate an inquiry into children’s palliative care and give one minister overall portfolio responsibility for children with life-limiting conditions. This should be done with a view to better joining up plans, assessments and services for these vulnerable children.

Mitigating Poor Financial and Employment Outcomes for Carers of Dying People

Stephen McCauley, Policy and Advocacy Manager at Hospice UK and
Kathleen Caper, Head of Policy and Advocacy at Hospice UK

- Many people leave work to provide care to a friend or family member with a life-limiting or terminal condition.
- Support is difficult to access during the caring phase, and almost non-existent after bereavement, as people struggle to return to employment and have poor financial outcomes.
- Inadequate social care can be a catalyst for people leaving work to care, a policy devolved to local authorities and thus a long-term and complex area for influencing.
- Policy influencers at every level need to look to solutions in civil and community settings, not just statutory and legislative, such as working with employers to guarantee that carers can return to their jobs.

Introduction

When we think of death and dying it can be easy to overlook the role of family and friends in caring for a loved one, and after their loss, the needs of carers can be quickly forgotten. Hospice UK recognises carers as co-deliverers of palliative and end of life care, often providing the care that is intrinsic to meeting people's needs. But the impact of caring can carry on long after bereavement, affecting all aspects of a person's life, including potentially negative short- and long-term labour market and financial outcomes.

In the UK's complex public policy environment, policies which specifically recognise carers, such as welfare benefits, are slowly being devolved to national governments – whereas other policy areas, such as employment legislation, are broadly reserved. This presents a huge challenge to those who seek to influence "carers' policy". Is carers' policy only that which names carers, or does it include all policy that impacts on them, even indirectly? Where should small campaigning organisations focus their efforts, and what is the best use of their resources to deliver positive change?

“As our communities and needs change, it is clear that we will all need to do more to care for people in later life”

It is not just the policies which are specifically aimed at carers which impact them. Decisions taken on the care provided to the person with a life-limiting condition or who is terminally ill also affect carers. For example, the provision of social care can have a huge impact on whether or not a person is able to remain in employment or not. Decisions on the provision of social care are taken at a local level; should this be the target of policy influencing?

In an environment where no single policy provides the complete solution, and where policy areas are split across UK Government, devolved governments, and local authorities, organisations such as Hospice UK are looking to find new ways of understanding policy problems and securing better outcomes for people. The needs of working carers are a good example of this challenge.

Whilst further research is needed to quantify the prevalence of people who leave work to care for a person who is terminally ill, we know that considerable numbers of people leave the workforce as their caring responsibilities increase¹. Leaving employment, especially as an older person, can make it difficult to return to work, or to return to the same level of earnings. For Hospice UK the questions we have asked have been: how can we best support people in this situation, and where can we make the most difference given our capacity and resources?

As our communities and needs change, it is clear that we will all need to do more to care for people in later life. A key issue for policy-makers in UK Government, national governments and local authorities therefore centres on improving support to the people who fulfil this vital role, whilst minimising the negative impacts of caring for carers, employers, communities and the economy.

What We Know about People Who Care for Someone with a Terminal Illness

In order to understand the impact of caring we looked at the wide body of research on the provision of unpaid care. We found that people are often forced to choose between working and caring. People who leave work to provide care for a friend or family member identify inadequate workplace support as a key reason for their decision to leave their jobs². Whilst many employers recognise the importance of supporting people who provide unpaid care, many more do not currently offer sufficiently flexible working arrangements for people in a caring role, particularly when the care is needed over a prolonged period. Just one in six organisations has policies in place to support carers to balance

1. Pickard, L. (2012), *Public expenditure costs of carers leaving employment* LSE Health & Social Care, London School of Economics and Political Science. Available online at: <https://goo.gl/Xz3jFm>

2. Age UK and Carers UK (2016) *Walking the tightrope: The challenges of combining work and care in later life*. Available online at: <https://goo.gl/MBnJuJ>

their work and home lives³. Workers in managerial, professional or higher-skilled roles are also more likely to be able to work flexibly than those in lower-skilled and routine occupations⁴. Access to flexible working is an important factor in whether or not people are able to combine work and caring⁵.

A lack of available social care and support services in the community is also a reason for leaving employment. One survey suggests that a third of carers left employment, retired early or reduced their working hours due to a lack of available care services⁶. In England, the 2014 Care Act mandated local authorities to provide carers with an assessment of the impact of their caring role on all aspects of their life. However, a large study found that three in four carers (73%) who had received an assessment from their local authority felt that support to manage paid employment and unpaid care was not properly considered⁷.

These two main factors behind the decision of many carers to leave the workforce – inadequate workplace support and a lack of available social care and support services – illustrate the influencing challenge for campaigners. The policy areas in question include reserved matters (employment rights and employer obligations) and devolved matters (social care decisions).

When Caring Ends

Leaving work to care can mean facing long periods of unemployment, particularly for those in the peak caring age of 50-64 who can struggle to find employment when their caring responsibilities come to an end, leading to further financial hardship into retirement. Recent research found that those who have given up work to care spend on average five years out of the workforce with many in their 50s and 60s struggling to retrain and return to work⁸.

The financial impacts of caring are often long lasting and continue after caring roles have ended. Nearly half of carers who provided the greatest levels of support say that they are struggling to make ends meet⁹. Further research from Carers UK found that over half of carers surveyed reported using savings to cover everyday living costs, and

3. CIPD Annual Survey Report: Absence Management (2015). Available online at: <https://goo.gl/g7ZnnT>

4. Age UK (2012) A means to many ends: experiences of flexible working, available online at: <https://goo.gl/v5tz8U>

5. Niblett P (2010), The NHS Information Centre, Social Care Team Survey of Carers in Households 2009/10, The Health and Social Care Information Centre. Available online at: <http://bit.ly/2vraegt>

6. Carers UK (2015) *Caring and isolation in the workplace*. Available online at: <https://goo.gl/2u1py7>

7. Carers UK (2017) *State of Caring 2017*. Available online at: <https://goo.gl/R4mCge>

8. Carers UK (2015) *Women and Equalities Committee: Gender Pay Gap Inquiry*. Available online at: <https://goo.gl/aWzWBz>

9. Carers UK (2015) *Valuing Carers 2015: The rising value of carers' support*. Available online at: <https://goo.gl/qLvp9u>

almost half have ended up in debt as a result of caring¹⁰.

Caring responsibilities commonly arise at an age at which many people will have gained valuable skills and experience, and will be at peak earnings for their working life. This is also a time of high financial commitment – to retirement savings, paying off mortgages, raising teenagers, or supporting young adults into university and the wider world.

Targeting Policy Interventions to Drive Better Outcomes for Carers

In a complex policy environment, advocates need to identify where they can best deliver change for people. This can mean choosing between policy interventions at a centralised or devolved national level, or at the local level. Many policy solutions require a long-term approach, but there can be quick wins. For example, one way to support people who provide unpaid care would be to target social care policy, a responsibility devolved to the local level. This is a hugely complex, resource-heavy and long-term policy change commitment. Yet influencing social care policy is vital for sick and disabled people and their carers, and despite the complexity it continues across a wide range of excellent organisations.

“There should be no penalty for providing care”

Alongside long-term influencing Hospice UK have sought other ways to improve outcomes for people who leave work to care for a terminally ill person. We decided to focus on finding ways to mitigate the negative financial and labour market impacts on people who leave work to care for someone at the end of their life. There should be no penalty for providing care. People who leave work to provide unpaid care would have less negative long-term financial and employment consequences if they could be guaranteed a return to work after a period of absence. For example, a person should be able to return to the same or similar role after an absence of up to 12 months to provide care. Policies along these lines are well-established in Ireland and Germany, and could be an important part of giving carers more choice over their working lives.

Another reason to pursue this policy solution is that it does not require immediate legislative change. There are good opportunities here to support better use of current law on flexible working, and encourage good practice in influential sectors and with socially responsible employers.

Government, of course, has a role to play in scaling up and potentially legislating. We are working with the UK Government to take forward the Conservative manifesto commitment at the 2017 General Election to strengthen employment protections for working carers of dying people¹¹.

Our policy proposal for a right to return to work following a defined

10. Carers UK (2014) *Carers Manifesto*. Available online at: <https://goo.gl/eqoQzd>

11. The Conservative and Unionist Party (2017) *Forward, Together: Our Plan for a Stronger Britain and a Prosperous Future*. Available at: <https://goo.gl/g9i5uW>

period of leave will help reduce the long-term financial and employment impacts of being a carer. It has the potential to make a real difference for people in the immediate aftermath of bereavement, and their medium and longer term futures.

Recommendations for Policy Change and Research

- In an increasingly complex policy environment at the country-wide, national and local levels, advocates and campaigners need to look at the needs of people and the impacts of policy on them from all angles.
- As more and more fundamental policy decisions are devolved to national governments and local authorities there is both risk and opportunity: the risk of creating incoherent and inequitable solutions to the same problems, and the opportunity to innovate and be more agile. Policy influencers need to think this way as well.
- A solution is not always direct, nor legislative, and it is not always the sole responsibility of government or statutory bodies. There is no one right answer.

Dying in Care Homes

Professor Malcolm

Johnson, Visiting
Professor of Gerontology
and End of Life Care at the
University of Bath

- Death in modern societies occurs overwhelmingly in old age. A ‘gerontologising’ of end of life care thinking, policy and practice in the four nations is thus essential. We need to respond to the evidence that death is predominantly in the province of old age and that older people die differently from those in the mainstream of adult life.
- Too many people (and almost half of all who die each year) die in hospitals unnecessarily – causing distress to them and their families, whilst absorbing the time and resources of overstretched NHS facilities.
- Care homes already provide the location and care for almost a quarter of all deaths across the UK. With more and better training and improved partnerships with healthcare agencies and professionals, many more people could end their lives in care homes. Given the number of people who die in these environments, care homes need to be better represented in public and policy discussions regarding end of life care.

Death in the Province of Old Age

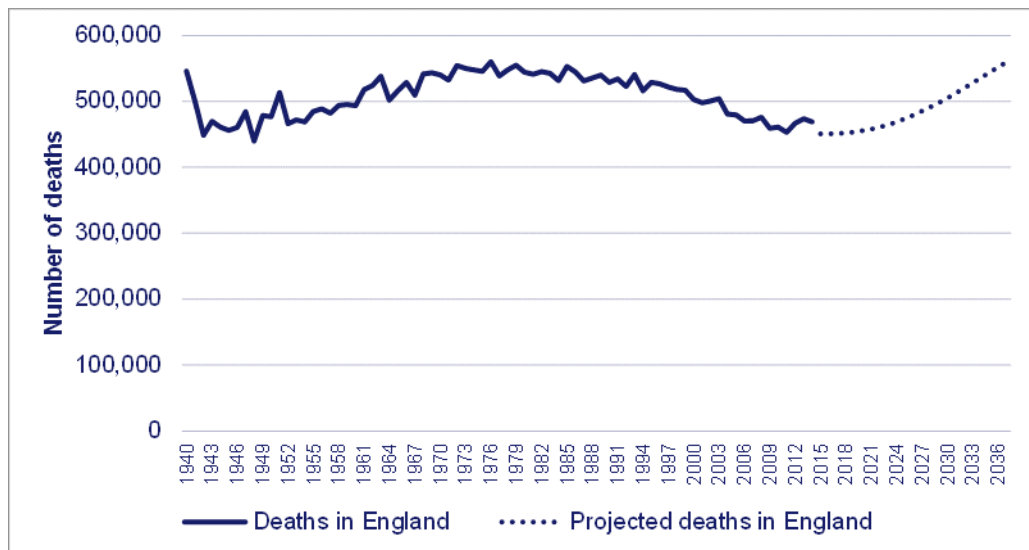
The ageing of populations has been well established for at least six decades, where premature deaths are markedly reduced by: better public health, control of infectious diseases, better housing, more nutritious diet, better medical care, more effective surgery and more efficacious medical care and pharmacy. Demographers and gerontologists have been heralding the systematic extension of life expectation for the past six decades. Yet it has taken until the early years of the 21st century for there to be operational and policy recognition that we live in an ageing world which means more than having rather a lot of people we used to call pensioners. Slowly there has been a dawning understanding that living longer is an enormous benefit, which in turn means we have to re-think the whole of the lifespan.

Perhaps, because the ramifications of the demographic revolution took so long to fully register in the collective mind, it should not be surprising that a significant artefact of death having moved almost exclusively into old age has also failed to properly register. The regular occurrence of what is inelegantly termed hospital ‘elderly bed blockage’ has arrested media and political attention. Yet this situation remains a source of profound healthcare anxiety.

Moreover, there has been an annual gain in expectation of life in Northern Europe, of three months per year, consistently over the last

160 years¹. If the trend was coming to an end, the increments would show signs of tailing off. But the trend has so far remained as strong and consistent as ever. So regardless of any scientific breakthrough which might lead to further reduction in the causes of death, our collective age will continue to rise.

Trends in Deaths in England, 1940 to 2036²



Premature deaths have also greatly reduced, to the point where 84% of deaths in England in 2013 were people aged 65 or older. 75% of all deaths were of people aged over 75, and 39% were 85 or older. All too many of those individuals (48%) end their lives, unsatisfactorily and at considerable public cost, in hospitals. A further 22% die at home, 25% in care homes and 6% in hospice care.

What older people die of is not, however, reflected in the statistics on causes of death across the UK population for all ages, which are generated and used to argue for the priority groups and the necessary forms of treatment and support that are required. A consequence of a disposition to see the predominant illnesses as the indicator of end of life care – and reflected in the origins of the hospice and palliative care movement – is a focus on cancer. Cancer has been a formative influence on thinking and practice, and the considerable charitable funds that flow to the cancer charities and hospices continue to have a disproportionately large voice. So too do major NHS programmes for the diagnosis and treatment of cancers.

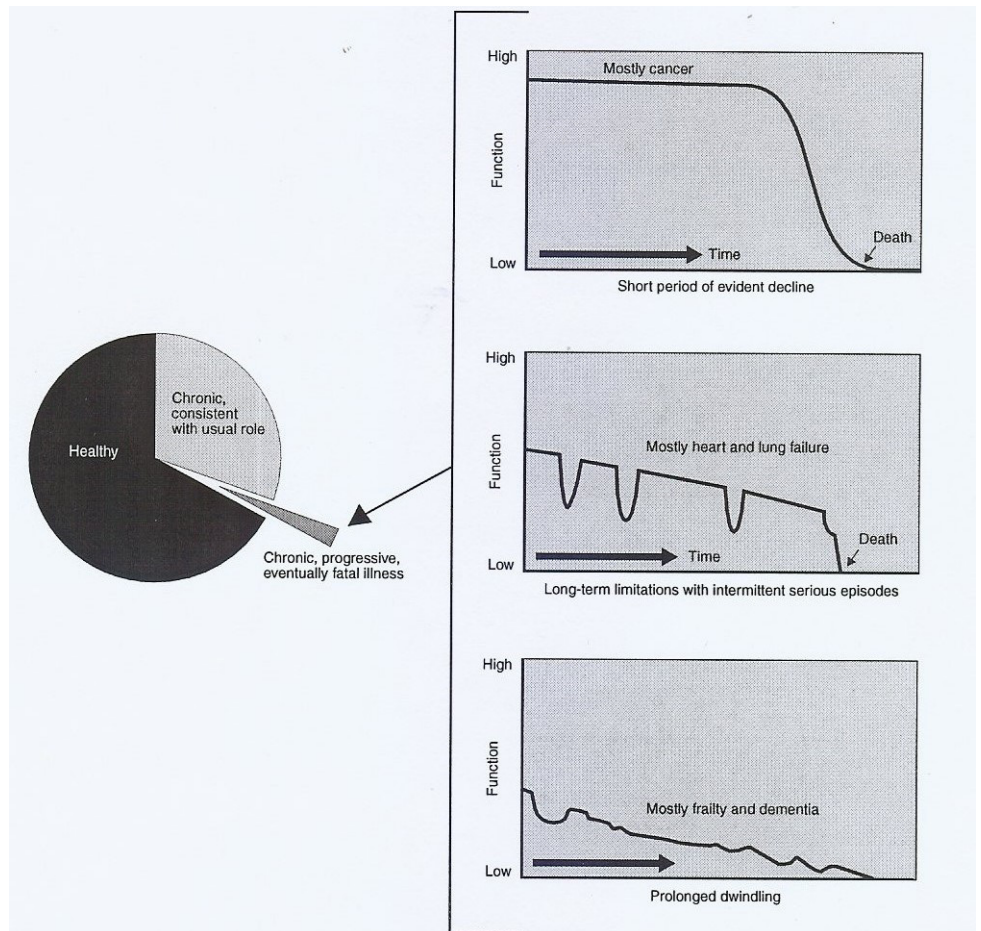
In more recent times there has evolved a recognition that, despite the importance of cancers and a range of neurological conditions, they draw attention away from the dying experiences of a large swathe of older people. Those who die of other causes receive poorer medical

1. Oeppen, J. and Vaupel, J.W. (2002) 'Broken limits of life expectancy', *Science*, 296 (5570): 1029-1031.

2. Office for National Statistics (2015) Death Registrations in England and Wales, summary tables, available online at: <https://goo.gl/murcrr>

care and little or no palliative services. The patterns of illness among the very old present a different set of health and illness profiles.

Chronic Illness in the Elderly Typically Follows Three Trajectories³



Findings from a recent study of 38 care homes, comprising 2,444 total residents in Southern England⁴, reflect the long dwindling trajectory and its growing presence. The table overleaf shows that the nursing care homes which took part in the study half of all residents fell into this category.

3. Lynn, J. and Adamson, D.M. (2003) Living Well at the End of Life. Adapting health care to serious chronic illness in old age (Santa Monica: Rand), available online at: <https://goo.gl/ap5gZi>

4. Ennis, L. et al (2015) The cost of providing end of life care for nursing care home residents: a retrospective cohort study, Health Services Management Research, 28 (1-2): 16-23. Available online at: <https://goo.gl/zBjyWS>

Place of Death, Type of Death and End of Life Care Tools, 38 Care Homes in Southern England (n=2,444)

| Recorded details of end of life care | Number | Percentage |
|--------------------------------------|--------|------------|
| Place of death | | |
| Nursing care home | 1,768 | 72.8 |
| Other | 660 | 27.2 |
| Type of death | | |
| Dwindling | 1,192 | 50.3 |
| Terminal condition | 621 | 26.2 |
| Acute | 454 | 19.2 |
| Sudden | 102 | 4.3 |
| Use of end of life care tools | | |
| Evidence of anticipatory prescribing | 727 | 31 |
| Use of end of life care plan | 341 | 14.5 |
| Advance care planning in place | 1,496 | 63.6 |
| Resuscitation decision in place | 1,365 | 58.2 |

Dying with Dementia

In a detailed analysis of ONS 2014 data drawn from death certificates, the National Dementia Intelligence Network – in partnership with the Public Health England National End of Life Care Intelligence Network – has shown both the marked growth of dementia deaths and the shift in the places where people die (Khera-Butler, 2016). Significant among the findings are the dramatic change in age standardisation rates where there is any mention of dementia, which have risen from 106 per 100,000 in 2001 to 188 per 100,000 in 2014. In parallel there are substantial changes in the place of death. From 2007, when 36% of all dementia deaths were in care homes, the proportion of people over age 65 who died with dementia in a care home had risen to 58%, whilst the proportion who died in hospitals has decreased (Khera-Butler, 2016).

Evidence from senior figures in the end of life care team at the Department of Health shows that they are not unaware of the changing profile of death in old age. In his foreword to the *Deaths in Older Adults 2010* report⁵ Professor Sir Mike Richards, then both National Cancer Director and National Clinical Director for End of Life Care, wrote:

The causes of death change with increasing age at death – Alzheimer’s, senility, pneumonia and stroke becoming more common. The place of death changes too, with a higher proportion of the extreme elderly, who are more likely to be women, dying in

5. Ruth, K. and Verne, J. (2010) *Deaths in Older Adults in England* (London: National End of Life Intelligence Network).

nursing or old people's homes. This in part reflects the frailty of many elderly people before death, which often results in the need for 24-hour care. It also reflects the greater likelihood of older women being widowed and living alone.

Supporting Older People Dying in Care Homes

The landmark publication setting out the national guidelines and policy relating to end of life care across all settings is the 2008 publication *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. It states: "Although every individual may have a different idea about what would, for them, constitute a 'good death', for many this would involve: Being treated as an individual, with dignity and respect; Being without pain and other symptoms; Being in familiar surroundings; and Being in the company of close family and/or friends". Some people do indeed die as they would have wished, but many others do not. Some people experience excellent care in hospitals, hospices and care homes, as well as in their own homes. But the reality is that many, most, do not. Many people experience unnecessary pain and other symptoms. There are distressing reports of people (and evidence from the Care Quality Commission which regulates care provision in England⁶) not being treated with dignity and respect and many people do not die where they would choose to.

The importance of getting end of life care right in care homes is paramount given the number of people who die each year in these environments. In England, the proportion of all deaths each year which occur in Care Homes has risen from 16% in 2004, to 22% in 2013; from 78,867 to 101,991 deaths. As palliative and end of life care only applies to those known to be dying, it is important to exclude the annual 8% of deaths from accidents. Using this reduced base of deaths, those deaths which take place in Care Homes are just short of 25% of all deaths and for the over 85s it is 37%⁷.

Dying in the Four Nations

Most of the preceding data and commentary on dying in care homes relates to England, in part because there is more material to draw upon, in part because the general patterns of dying are similar – though life expectation in Southern England is higher than in Scotland, Wales or Northern Ireland, and the patterns of illness are somewhat distinctive. It is also the case that the significant developments in public policy have moved along common pathways in the four nations. This said, the end of life commonalities exist within markedly different health and social care frameworks – Northern Ireland has long operated joint Health

6. Care Quality Commission (2016) A Different Ending: addressing inequalities in end of life care, overview report, available online at: <https://goo.gl/z1vjDg>

7. Khera-Butler, T. (2016) Data Analysis Report: dying with dementia. National Dementia Intelligence Network. Bristol: Public Health England.

“it would be invidious to rank the four nations in their approach to end of life care in care homes. All four make strong social commitments and policy statements”

& Social Services Boards and Wales and Scotland have made more serious attempts at integration than England. With little data on death in care homes in Scotland, Wales and Northern Ireland, the best we can do at present is establish patterns of dying (see Richard Meade’s article, p.9), in order to frame how dying and death in care homes in the four nations occurs.

Certainly, it would be invidious to rank the four nations in their approach to end of life care in care homes. All four make strong social commitments and policy statements (see Meade, p.9), but at the time of writing none invest significant resources in end of life in care homes for older people. This requires special consideration as when supporting people to die in care homes it is important to recognise that death is **not** a medical event. Dying in this environment needs to be regarded as a normal physical, social and spiritual process which concludes mortality and closes the personal biography at the point when the organism ceases to function. Attending to pain and disturbing discomfort may need nursing or medical assistance, but these are contributions that may or may not be required by all. It is important that, in this setting at least, we therefore resist the re-medicalisation of death.

Policy Futures

Enabling dying in care homes, and a considerable reduction of old age deaths in hospitals, will require cooperation between NHS hospital staff, primary care teams, home carers and the staff of care homes. Arguably Scotland and Wales are better placed to do this given their current organisation of end of life care (see Meade, p.9). In England, there is a potentially very large reduction in costs moving towards more collaborative models, yielding considerable savings to the NHS budget, which the ResPublica Trust⁸ estimate at £3.3 billion per year. This will require the active collaboration of clinical commissioning groups, and there are indications that this collaborative approach is becoming established; in March 2015, NHS England and its national partners announced the first of 29 new care model vanguards⁹. There were seven enhanced health in care home vanguards which offer older people better, joined up health, care and rehabilitation services¹⁰.

8. Crawford, E. Read, C. & Sim, D (2016) *Care After Cure: Creating a fast track pathway from hospitals to homes*. London: ResPublica Trust.

9. NHS England (2015) Five million patients to benefit from new era of patient care, available online at: <http://bit.ly/1Ad4jaG>

10. NHS England (2016) Enhanced health in care homes vanguards, available online at: <http://bit.ly/2xul7yy>

Recommendations for Policy Change and Research

- Given that nearly a quarter of all deaths each year occur in care homes, dying and support for those reaching the end of their life in care homes requires political and public attention. There is a lack of robust data across the four nations on dying in care homes; this needs to be redressed by future research and data capture so that trends in experience(s) can be documented.
- Dying in older age in a care home needs to be seen as a normal end to a long life. We must resist re-medicalising dying in care homes.
- Across the country there needs to be better integration of representative bodies and sector workforces to support dying in care homes. The hospice and palliative care community knows itself very well and uses its networks as sources of consultation, yet care homes providers are almost entirely absent from public and policy discussions of end of life care.

2

Post-Death

Organ Donation

Dr Wendy Walker, Reader in Acute and Critical Care Nursing at the University of Wolverhampton and **Professor Magi Sque**, Chair for Clinical Practice and Innovation at the University of Wolverhampton

- Year on year, the UK has one of the lowest rates of family consent/authorisation to organ donation in Europe.
- The impact of low rates of family consent/authorisation is significant; more than one in ten people will die before they get the transplant they need.
- Societal, individual and organisational factors are known to impact the rate of family consent/authorisation.
- The role of the bereaved family in donation decision-making features in the debate regarding legislative reform, and the introduction of a 'soft opt-out' system for organ and tissue donation.
- Investment and funding for UK-based research is essential for evidence-informed transformative actions aimed at improved donor and family consent.

Introduction

The death of a potential organ donor frequently occurs in the context of catastrophic critical illness or a tragic event that is sudden and unexpected. Donation decision-making therefore takes place in situations of intense grief. Research has shown that organ donation can help grieving families to make sense of an otherwise senseless situation¹. It can be a positive, life-changing decision and should be an integral part of end of life care². Deceased donation is the bedrock of organ transplantation. The Human Tissue Act 2004³ (covering England and Northern Ireland), Human Tissue (Scotland) Act 2006⁴ and Human Transplantation (Wales) Act 2013⁵ describe the legal frameworks for deceased donation in the UK. The term 'consent' applies to England, Wales and Northern Ireland; whereas Scotland uses the principle of 'authorisation'.

This article specifically focuses on the issue of family consent/authorisation to deceased organ donation in the UK. The piece presents: a description of the issue; an overview of the significance of the issue; an outline of one possible solution to the problem in the context of

1. Walker W. and Sque M. (2016) Balancing hope and despair at the end of life: The contribution of organ and tissue donation. *Journal of Critical Care* 32, 73-78.

2. Department of Health (2008) *Organs for Transplants: A report from the Organ Donation Taskforce*. London, DH.

3. Human Tissue Act 2004 <https://goo.gl/KU3oLo>

4. Human Tissue (Scotland) Act 2006 <https://goo.gl/FB2Cz8>

5. Human Transplantation (Wales) Act 2013 <https://goo.gl/ydeG8r>

devolved health administrations; and recommendations for future research. Presented arguments are underpinned by national policy guidance, audit data and media reports primarily originating from NHS Blood and Transplant (NHSBT) – the organisation responsible for organ donation in the UK.

Description of the Issue

Despite a 75% increase in deceased donation over the last nine years, the UK continues to trail behind the donation rates in comparator countries. Family decline rates are the biggest single identified obstacle to deceased organ donation in the UK⁶.

In 2013, the National Health Service achieved a 50% increase in deceased organ donation⁷ – a target originally set by the Organ Donation Taskforce five years earlier. Sally Johnson, NHSBT's Director of Organ Donation and Transplantation, commented:

Although I am delighted that we have made such big advances in the UK, we can and must do more. We need a transformation in donor and family consent to organ donation because the UK's family refusal rate remains one of the highest in Europe. Without that, there is only a limited amount more the NHS can do to offer further hope to those on the waiting list for an organ transplant.

In general, families of eligible Black, Asian, and Minority Ethnic donors are much less likely to agree to organ donation compared with families of eligible White donors⁸. It is also known that fewer families agree to donation when they are unaware of their relative's decision to be a donor⁹. Organ donation campaigns across the UK encourage all people to have the conversation, and to share their donation decision with family and friends. However, it is recognised that people's donation intentions may change in the reality of intense grief and bereavement. Enabling families to make an informed decision about donation requires sensitivity and skill. Best practice recommendations^{10,11} have been developed, aimed at maximising organ donation rates through the consistent use of specialist nurses in organ donation (SN-ODs).

6. NHSBT (2017) Consent and authorisation: Clinical guidance around gaining consent and authorisation from a donor family. Available online at: <http://bit.ly/2eV5HOd>

7. Mirror (2013) Organ donation up by 50% in the last five years leading to huge boost in life-saving transplants, 11th April, available online at: <https://goo.gl/HK4Ubf>

8. Guardian (2016) Organ donation rates for transplants still too low in the UK, says NHS, 1st September, available online at: <https://goo.gl/twNMTf>

9. NHS (2016) Families need to talk about organ donation, to give thousands waiting the chance of a new beginning, available online at: <http://bit.ly/2eCvspE>

10. National Institute for Health and Clinical Excellence (2011) Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation: NICE clinical guideline135. [Last updated 2016]. Available online at: <https://goo.gl/ePUXup>

11. NHSBT (2013) Approaching the families of potential organ donors: Best practice guidance. Available online at: <https://goo.gl/vXcMyH>

However, audit data suggests that these recommendations are not routinely followed¹². The provision and quality of care during the hospital stay¹³, including a positive experience of the approach-request for donation, can also influence family decision-making. The most recent UK strategy *Taking Organ Transplantation to 2020*¹⁴ set a target to increase the rate of consent/authorisation from 57% in 2012/13 to 80% by 2020. However, the family consent/authorisation rate appears resistant to change.

Significance of the Issue

Currently, around 6,500 people are on the UK national active transplant list¹⁵, and more than one in ten people will die before they get the transplant they need¹⁶. Behavioural and social issues that impact health, an ageing population and high disease prevalence will see increasing demand for transplants, further widening the gap between organ supply and demand. Over half a million people die every year in the UK, yet fewer than 6,000 will die in circumstances where organ donation is possible. NHSBT estimates that if 80% of families approached to donate a relative's organs said yes, more than 1,000 additional transplants would take place in the UK each year.

Seeking Solutions to the Issue: Legislative Reform

The laws that govern organ donation are based on a voluntary opt-in system of explicit consent or an opt-out system of deemed consent in the absence of expressed objection. Through devolved health administrations, the legislative framework for organ donation in England, Scotland and Northern Ireland is that of a 'soft opt-in' system of consent to donation, involving the requirement to obtain the family's approval to proceed¹⁷. On 1 December 2015, Wales became the first UK country to introduce a 'soft opt-out' system for organ and tissue donation. This changes the default position to one where adults voluntarily residing in Wales for more than 12 months and with the capacity to understand the system are deemed to have consented to organ donation unless they positively opt out¹⁸. In other words, they are viewed

12. NHSBT (2016) Potential donor audit: Summary report for the 12-month period 1 April 2015 - 31 March 2016. Available online at: <http://bit.ly/2eUVcKr>

13. Walker W. et al (2013) Factors influencing bereaved families' decisions about organ donation: An integrative literature review. *Western Journal of Nursing Research* 35, 10, 1339-59.

14. NHSBT (2013) Taking organ transplantation to 2020: A detailed strategy. Available online at: <http://bit.ly/2vYDHid>

15. NHSBT (2017) Organ Donation and transplantation. Available online at: <http://bit.ly/2gFojCz>

16. NHS (2015) NHS Blood and Transplant reveals nearly 49,000 people in the UK have had to wait for a transplant in the last decade, 20th November, available online at: <http://bit.ly/1mhmf7>

17. NHSBT (2017) Legislative Framework. Available online at: <http://bit.ly/2vELXIM>

18. Assembly in Brief (2015) New organ donation system comes into force in Wales, 1st December, available online at: <https://goo.gl/8qiMee>

“In 2016, the highest overall consent rate was in Scotland (64.1%), compared with 63% in England, 60% in Wales and 58.7% in Northern Ireland”

as having no objection to organ donation unless the evidence is to the contrary. The question of whether an opt-out system for organ donation is right for the UK has generated ‘impassioned debate and a wide range of opinions’¹⁹. Much of the debate has concerned the role of bereaved families in the decision-making process.

The soft opt-out system means that the family will still be involved in the decision-making process; however, an expressed objection to organ donation must be based on the known views of the deceased, rather than the views of the family. Although the Acts give precedence to the decision of the dying or deceased person, when decisions cannot be established (and in Wales when decisions cannot be deemed), authority for decision-making passes to a person in a qualifying relationship to the family – as described in the three Acts. While the soft opt-out system of consent only applies in Wales, changes to the NHS Organ Donor Register²⁰ mean that anyone in the UK can register a decision: not to donate (opt out), to donate (opt in), or to nominate others to decide for them after their death.

Wales’ ‘deemed consent’ is a devolved regional initiative that positively affords comparative evaluation with alternative legislative consent practices across the UK. The findings from this sub-national initiative will inform our knowledge of presumed consent in the UK, rather than relying on evidence from other countries such as France, Spain and Belgium, with the UK asking: ‘Will it work here?’ Currently there is insufficient evidence to decide the effect of introducing a system of presumed consent in Wales, and a trend towards statistically significant improvement may take time. In 2016, the highest overall consent rate was in Scotland (64.1%), compared with 63% in England, 60% in Wales and 58.7% in Northern Ireland²¹. It is important to be mindful of the fact that deemed consent is one possible solution to low rates of family consent in the four nations of the UK. Transformation in donor and family consent requires action from society and individuals, as well as NHS hospitals and staff.

19. Department of Health (2008) The potential impact of an opt-out system for organ donation in the UK: An independent report from the Organ Donation Taskforce. Available online at: <https://goo.gl/PXtetz>

20. NHS (2015) NHS Blood and Transplant launches new Organ Donor Register, 9th July, available online at: <http://bit.ly/2wxQxHy>

21. NHSBT (2017) National Organ Donation Committee. Analysis of the effect of Welsh Legislation on consent/authorisation rates: Quarter 4. Available online at: <https://goo.gl/6XrDpF>

Recommendations for Policy Change and Research

We propose essential research for evidence-informed actions, and provide indication of intended outcomes below. The proposed studies address identified gaps and shortcomings in research evidence, thus contributing to improved evidence-informed organ donation campaigns, clinical guidance, and patient/family care.

| Proposed Research | Intended Outcome |
|--|---|
| Society/individuals | |
| Investigation of the role and influence of mainstream/ social media in shaping public/individual behaviour, decision-making and consent for organ donation. | Evidence to inform social media strategies of public engagement that: increase public awareness, motivate individuals to join the NHS Organ Donor Register and stimulate long-term positive changes in public/individual decision-making regarding consent to organ donation. |
| NHS hospitals and staff | |
| Identification of barriers to, and solutions for implementation of best practice recommendations supporting the inclusion of SN-ODs whenever there is an opportunity for donation. | Evidence of what works to increase the involvement of SN-ODs and the donation rates of transplantable organs. |
| Identification of the hallmarks of quality care and communication, as perceived by the bereaved families of potential donors. | Recommendations of best-practice interventions for quality care and communication. |
| Examination of how the donation discussion between healthcare staff and the grieving family is negotiated in the clinical context. | Recommendations for the linguistic and environmental conduct of the discussion where donation consent is considered. |
| A qualitative evaluation of the impact of deemed consent to organ donation in Wales, as perceived by the bereaved families of potential organ donors. | Experiential data to complement ongoing evaluations of the impact of Welsh legislation on organ donation performed by NHSBT and the Welsh Government. |

Why Lasting Power of Attorney Should Extend after Death

Helen Morrissey, Personal Finance Specialist at Royal London

- Nearly two-thirds of the UK population do not have a will in place. Not having a will can lead to complexity and confusion when someone dies; their wishes may not be honoured and the people chosen to deal with the estate may not be the best placed to do so.
- Those with a power of attorney in place will have chosen someone they trust to deal with their financial affairs. The person acting as attorney will have had conversations with the deceased and know details of bank accounts, investments, debts. The attorney may also know who the deceased person trusted, and most importantly, did not trust.
- There is an argument that if someone dies intestate yet has a power of attorney in place the attorney should be able to step in as executor.

Context

The UK population is living longer than ever before and while this brings benefits, it also poses major challenges. Last year, Office for National Statistics figures¹ showed that dementia, including conditions such as Alzheimer's disease, had overtaken heart disease as the leading cause of death in England and Wales. This brings to the fore significant issues regarding capacity and social care, particularly the question of how to support people suffering from these conditions to manage their lives. Lasting Powers of Attorney (LPAs) were introduced in 2007 to enable people to designate a trusted person to act for them should they lack the mental capacity to make decisions for themselves.

LPAs were brought in to replace the previous Enduring Power of Attorney (EPA) regime which was seen as being open to abuse. EPAs only had to be registered with the Office of the Public Guardian once the person, known as a donor, had lost mental capacity. However, the attorney was able to exercise their powers even if the EPA was not registered. Under the new LPA regime the attorney cannot exercise their powers until the documents are registered.

1. Office for National Statistics (2015) Deaths registered in England and Wales (Series DR), available online at: <https://goo.gl/MDK9wL>

Variation across the Nations

In England and Wales there are two different LPAs available – one for health and wellbeing decisions and one for financial and property decisions. In Northern Ireland there is an EPA which enables someone to deal with your property and affairs should you become mentally incapable of doing so. The situation in Scotland is slightly different with three powers of attorney in play: one for financial matters, called a Continuing Power of Attorney; one for personal welfare, a Welfare Power of Attorney; and a combined one that covers both continuing and welfare. Across all nations a donor can choose more than one person to act as their attorney and it would be good practice to ensure this happens to prevent any one attorney having undue influence on a donor.

There are further differences in how power of attorney can be exercised. LPAs in England and Wales can only be used once registered with the Office of the Public Guardian, and the attorney can act for someone even if they have not yet lost mental capacity. In Northern Ireland EPAs must be registered with the Office of Care and Protection. However, this does not need to be done until the person acting as attorney believes the granter is no longer capable of managing their own financial affairs.

In Scotland a continuing power of attorney may be used as soon as it has been registered. However, a welfare power of attorney may only be used once the granter has lost mental capacity. Powers of attorney set up before 2001 do not have to be registered with the Office of the Public Guardian Scotland, but may still be used.

Are They Successful?

While it can be difficult to get people to think about a time when they may be ill, dying or unable to make decisions for themselves, the introduction of LPAs has overall been successful. The latest figures from the Office of the Public Guardian show that as of April 2017 there were approximately 2.3 million LPAs registered in England and Wales. These are broken down into almost 1.6 million relating to property and finance and a further 732,000 relating to health and wellbeing.

The decision to take out an LPA is not solely that of elderly people either. Figures from the Office of the Public Guardian show that as of September 2016 approximately 30% of registered LPAs were registered for people aged 70 and below (See Table 1). This could be done for people suffering from mental health conditions who may have fluctuating capacity, for instance, or for those who just wish to plan ahead. People deciding to go away travelling for a long time might also choose to put an LPA in place so they do not have to worry about unpaid bills while they are away – however, this would not be the case in Northern Ireland, given that EPAs can only be used once the granter has lost mental capacity. It is clear that people find the power of attorney useful.

Whole Register as of 30 September 2016

| Age Group | LPAs | Percentage |
|-----------|---------|------------|
| 18-30 | 6,442 | 0.32% |
| 31-40 | 14,263 | 0.71% |
| 41-50 | 42,749 | 2.14% |
| 51-60 | 132,656 | 6.64% |
| 61-70 | 388,759 | 19.45% |
| 71-80 | 614,311 | 30.73% |
| 81-90 | 664,201 | 33.23% |
| 91-100 | 131,564 | 6.58% |
| 100-110 | 1,743 | 0.09% |
| Unknown | 2,259 | 0.11% |

Source: Office of the Public Guardian

What if There is a Power of Attorney and No Will?

However, what is not well known is that all powers of attorney, regardless of nation, expire on death. If there is a will in place and the executors named within it are still happy to carry out these duties then the transfer of financial responsibilities should be fairly straightforward.

But what happens if there is no will in place? This could be a particular issue for those younger people with a power of attorney in place, as writing a will may not be seen as a priority. According to current statistics² nearly two thirds of the adult population in the UK do not have a will, and if you die without having one in place then dealing with your estate could be a long and complicated business.

There are other complicating factors that can hinder the administration of an estate. A will may be in place, but could be invalid – or the executors named within it may no longer be willing to act in that capacity. If this is the case then administrators will need to be found who are willing to step in, and this can take a long time. More needs to be done to ensure estates can be wound up in a timely fashion.

By not having a will in place there is no record of what the deceased's intentions for their estate may have been. While there are rules of intestacy in place, they may not accord with the deceased person's wishes – and so are open to manipulation.

In England and Wales if there is a surviving spouse or civil partner then they keep all assets up to £250,000 along with personal possessions. They would receive an absolute interest in half of any remaining estate, while the children would receive the remainder. In the event of there being no children or grandchildren the spouse or civil partner would inherit the entire estate.

2. YouGov (2016) Legal Services Consumer Tracker, available online at: <https://goo.gl/ERmwuH>

“These rules of intestacy work well if they fit in with the deceased’s wishes – but what if they don’t? What if the deceased was cohabiting with someone, for instance?”

In Northern Ireland, again, a surviving spouse or partner would get all personal possessions and assets up to £250,000. However, the difference here is that, if there is only one surviving child, the spouse will get an absolute interest in half the estate – but where there is more than one surviving child, the absolute interest the spouse or civil partner receives reduces to one third of the remaining estate.

In Scotland the rules differ again. The spouse or civil partner inherits the estate up to £473,000 (including property) along with one third of the remaining estate. They are also entitled to up to £50,000 in cash and movable household goods up to £29,000. Children and/or grandchildren would receive the remaining estate³.

These rules of intestacy work well if they fit in with the deceased’s wishes – but what if they don’t? What if the deceased was cohabiting with someone, for instance? Under current rules of intestacy in all UK nations cohabittees have no automatic right to their partner’s property, even if they have children together or have been together for many years. For these people to benefit from an estate they would need to be named in a will.

Delays in the process of administering a will can also leave the administrators out of pocket. Inheritance tax must be paid by the end of the sixth month after death, and assets cannot be distributed until probate has been granted. If there is no will, and therefore no executors, it will take time to arrange for someone to administer the estate – and it may also take time to gather information on what assets the deceased owned. This can mean that executors face having to pay what could be a sizeable inheritance tax bill from their own pockets because assets have yet to be sold, or there are disputes over who should inherit them.

While there are options to get around this situation – for instance writing a life insurance policy under trust so it does not form part of the estate and can release money to pay inheritance tax bills – they are not widely used, and if the death was unexpected then it may not have formed part of the deceased person’s long-term planning.

What Can Be Done?

Given the cost and time issues associated with trying to settle an estate without a will in place, there is a strong argument to make for legislation to be amended to allow attorneys to step in as executors should a financial power of attorney be in place. The person acting as attorney has been appointed because the deceased person trusted them to look after their best interests should a time come when they can no longer make decisions for themselves. If such a person is available then it makes sense to make use of them should the person die intestate.

Certainly, the decision to act as an attorney for someone is a major responsibility and entails detailed knowledge of the subject’s financial

3. Gov.Uk (2017) Intestacy – who inherits if someone dies without a will?, correct at 29/08/17, available online at: <https://goo.gl/QpGE6E>

affairs. The deceased person is likely to have had conversations with the person acting as their attorney about how they want them to act on their behalf and what their wishes are. As a result, the attorney will have a better knowledge of what assets the deceased person had as well as access to passwords, policies and bank account numbers not disclosed to anyone else. Given the difficulties that can be faced in working out someone's estate, it makes sense to involve the attorney in the process, particularly if there is no will to formally set out the deceased's intentions.

Attorneys are also likely to know things about the deceased that others many not. The deceased may have run up significant debts that they have not admitted to anyone else, for instance, and so the attorney can help to locate these creditors and arrange payment where necessary. They are also likely to have discussed family dynamics with the deceased, and will know who they trusted, and – more importantly – who they did not. Such knowledge can be extremely powerful when it comes to allocating the estate as the attorney can prevent/ensure people benefit from the estate in accordance with the deceased's wishes.

Risks

There is a chance that though the donor trusted the attorney there could be instances where the attorney does not act in the donor's best interest, and so they may not be the best person to administer the estate. To minimise the chances of such a situation it might be worth looking at discouraging the use of a single attorney. It is already possible to have more than one attorney acting on someone's behalf, and this could be made a mandatory requirement. Having more than one attorney means individual attorneys' actions would be subject to scrutiny, and it is less likely they would be able to act in a dishonest manner. While there are differences between the systems across England and Wales, Scotland and Northern Ireland, we would encourage the different jurisdictions to make these changes to see whether it would result in better outcomes.

In short it makes sense that where there is a power of attorney in place and no will then those who have acted as an attorney should have the first option to step in as executors to ensure the orderly distribution of the estate. Acting as an attorney is likely to have given these people real insight into the financial and personal affairs of the deceased person, and this knowledge should not be overlooked. Such an approach would enable the estate to be settled as quickly as possible and would make it more likely to be allocated in line with the deceased person's final wishes.

Recommendations for Policy Change and Research

- Where there is a power of attorney in place but no will the person acting as attorney should be able to step in as executor to administer the estate, given their status as someone who was trusted by the deceased person.
- To safeguard against the attorney abusing their position it may be worth stipulating that more than one attorney be appointed on a lasting power of attorney.
- The system does differ between Scotland, Northern Ireland and England and Wales, but we would encourage all jurisdictions to consider making such a change.

Social Security for Bereaved Partners and their Children

Alison Penny, Coordinator
of the Childhood
Bereavement Network

- In April 2017 the Bereavement Support Payment was introduced, replacing the Bereavement Payment, Widowed Parent's Allowance and Bereavement Allowance.
- Intended to provide a more streamlined benefit, the net gainers of this benefit are those under 45 with no children, with the losers of this new payment those with children, particularly those with younger children. 88% of working widowed parents will be worse off than they would have been under the old scheme, with 91% supported for a shorter time.
- Devolution has posed additional challenges to scrutiny and introduction of the new system.

Background and Reform

Support for widowed parents and their children was introduced almost a century ago. Since then, the system has been through a series of incremental changes including extending eligibility to men as well as women, and more recently to civil partners. In 2011, the government embarked on a much more fundamental programme of reform, consulting on bereavement benefits for the 21st century¹.

The old scheme

The old scheme, based on the National Insurance record of the person who died, provided to spouses and civil partners:

- Bereavement Payment (BP): a tax-free lump sum of £2,000.
- Widowed Parent's Allowance (WPA): taxable weekly benefit of up to £112.55 per week paid until the youngest child no longer qualifies for Child Benefit, the claimant remarries or moves in with a partner, or the claimant reaches state pension age.

1. Department for Work and Pensions (2011) *Bereavement Benefit for the 21st Century*. Available online at: <https://goo.gl/fbeJPv> (accessed 31 July 2017).

- Bereavement Allowance (BA): taxable weekly benefit of up to £112.55 per week paid for 12 months to a surviving spouse or civil partner with no dependent children and aged between 45 and state pension age.

Widowed parents were treated differently from those without children, in recognition that 'bereaved spouses with children may have greater difficulty in supporting themselves through work compared with those without dependents, because of their childcare responsibilities'².

The new scheme

Those who are currently claiming WPA or BA will remain on it, but for those whose husband, wife or civil partner died on or after 6 April 2017, the new system of Bereavement Support Payment (BSP) provides:

- A tax-free lump sum of £2,500 to those without children and £3,500 to those with children.
- Monthly tax-free payments for 18 months of £100 to those without children and £350 to those with children. (The government's original proposal was to make these payments over 12 months, at £150 to those without children and £400 to those with children).

These payments will not be taken into account in the calculation of means-tested benefits, nor for the benefit cap.

Expected impacts

The reforms represent a redistribution of support from those with children to those without children.

The main group of notional gainers under the changes are those aged under 45 with no children, who receive monthly payments for the first time, and those aged over 45 with no children whose payment period has been extended from 12 to 18 months.

The main group of notional losers are those with children. 91% of parents with dependent children will be supported for a shorter time than they would have been under the old scheme³, and 75% of them will be worse off in cash terms. This rises to 88% of those who are in work⁴.

A working widowed parent who would have made the median claim

2. Department for Social Security (1998) *A new contract for welfare: support in bereavement* (CM4104) London: The Stationary Office.

3. Calculated by the Childhood Bereavement Network using figures from Department for Work and Pensions (2013) *Further analysis on the reform of bereavement benefits for new claims from April 2016*. Available online at: <https://goo.gl/kP8NHv> (accessed 31 July 2017).

4. Department for Work and Pensions (2013) *Further analysis on the reform of bereavement benefits for new claims from April 2016*. Available online at: <https://goo.gl/vroFZo> (accessed 31 July 2017).

of five to six years under the old scheme will be up to £16,800 worse off under the new scheme. The group with younger children is disproportionately badly affected: a working parent who could have claimed for ten years under the old scheme will be up to £31,000 worse off⁵.

The government has stated repeatedly that the main aim of the reforms was not to save money. However, the Explanatory Memorandum to the Draft Regulations showed that once the reforms reach steady state, savings are expected to be around £100 million per year⁶. This revelation drew condemnation from critics including the Chair of the Work and Pensions Committee⁷. Baroness Sherlock commented in Grand Committee 'in other words, these reforms take £100 million a year from bereaved families and give it to the Exchequer'⁸.

Aims of the Policy Change

The government's justification for the reforms was that bereavement benefits had fallen outside reviews of other aspects of the welfare system and state pensions, and that this growing isolation 'precipitated the need to review the future role of bereavement benefits'⁹. The more specific justification was that the current provision for those with dependent children – Widowed Parent's Allowance – risked creating welfare dependency.

The government's aims for modernised bereavement benefits, outlined in its consultation paper, were that:

- They should be simple to understand and to claim.
- They should provide fast, direct financial help for the provision of immediate needs following the bereavement of a spouse or civil partner.
- They should give recipients the flexibility they need to regain control of their situation in the period immediately following bereavement.
- There should be additional support for families, to recognise the additional costs associated with raising children.
- They should allow recipients to access the financial and work-focused support provided by Universal Credit at a time that is right for them.
- They should be fair and promote self-dependency.

5. Calculated by the Childhood Bereavement Network using figures from Department for Work and Pensions (2013) *Further analysis on the reform of bereavement benefits for new claims from April 2016*. Available online at: <https://goo.gl/P1axUK> (accessed 31 July 2017).

6. Department for Work and Pensions (2017) *Bereavement Support Payment Regulations 2017. Explanatory Memorandum*. Available at: <https://goo.gl/LmRus6> (accessed 21 July 2017).

7. Letter from Rt Hon Frank Field MP to Minister for (8 March 2017). *Bereavement benefits: savings from reform*. Available online at: <https://goo.gl/63xfFC>

8. House of Lords debate 21 February 2017 cc10-11 CG. Available online at: <https://goo.gl/EunS1H> (accessed 31 July 2017).

9. Department for Work and Pensions (2011) *Bereavement Benefit for the 21st Century*. Available online at: <https://goo.gl/aTahvd> (accessed 31 July 2017).

Concerns about the Reforms

Encouraging parents back to work

One of the drivers for the benefit reform was the desire to encourage widowed parents back to work, because of concerns about 'a complicated payment and contribution system which, at its worst, can harm people's long term job prospects by distancing recipients from the labour market.'¹⁰ Now that specific bereavement financial support will end after 18 months, families with longer-term income support needs will be supported through Universal Credit with its associated work conditionality. Conditionality requirements will be suspended for six months following the death, and those with children may in certain circumstances request a limited number of further one-month suspensions. Critics warn that this would be burdensome for families and for DWP work coaches.

Impact on individuals

Concerns have been raised both as to the additional stress that the revised benefit may create as a result of tests to assess capacity for work, and as to the additional pressure to take up work or increase hours. Widowed parents experience work differently, with some finding it a welcome distraction, role and identity, and others finding it a significant strain, struggling to find appropriate childcare and concerned about how their work impacts on their children's grief support needs. The most robust longitudinal survey available found that the availability and consistent, nurturing presence of the surviving parent was one of the strongest predictors of bereaved children's emotional health and behaviour¹¹.

Parents report using their WPA to allow them to work in a more flexible way so that they can support their children's new and emerging grief support needs, including separation anxiety and difficulties at times of further transition^{12,13}. These are very common reactions among bereaved children, who are at increased risk of poor wellbeing, mental health difficulties and suicide¹⁴. Obliging parents to seek or take up work or increase their hours before they are ready could have

10. Department for Work and Pensions (2011) *Bereavement Benefit for the 21st Century*. Available online at: <https://goo.gl/nVn9Lp> (accessed 31 July 2017).

11. Worden, J.W. (1996) *Children and grief: when a parent dies* New York, Guildford Press.

12. Guardian (2017) Cruel benefit cuts put pressure on grieving families, 1st April, available online at <https://goo.gl/wiBWNd>; and The Observer (2017) Young and bereaved – and not facing cuts to crucial financial support, 29th January, available online at <https://goo.gl/aHPRLy>

13. Corden, A. et al (2011) *Financial implications of the death of a partner*. York: Social Policy Research Unit, University of York. Available online at: <https://goo.gl/RK2Psq> (accessed 31 July 2017).

14. Penny, A. and Stubbs, D. (2015) *Bereavement in Childhood. What do we know in 2015?* London: National Children's Bureau.

a detrimental effect on children in two ways: by increasing the parent's stress levels and depressive symptoms (strongly correlated with children's emotional and behavioural difficulties) and by reducing the parent's availability to the child (quality of bond and family routines promote children's healthy adjustment)^{15,16}.

The available evidence on children's grief support needs was not included in the government's consultation. The policy aims take account of 'the additional costs associated with raising children', but not the point that caring for grieving children makes self-support more difficult. Surviving spouses with children report more distress than those without children^{17,18}, and this stress persists beyond six months¹⁹.

Evidence

Concerns about the adequacy of the government's evidence were raised during the consultation and introduction of the new system. There was concern that qualitative evidence from interviews with 30 widowed parents – all within 12-18 months of their bereavement – was used to justify a concentration of support in the early period of bereavement, when the design of the research was such that it could reveal nothing about families' longer-term financial, economic and emotional struggles²⁰.

Further, the government prepared estimates of the notional gainers and losers under the new scheme²¹, but did not update these in the light of parallel reforms to Universal Credit. This meant that parliamentarians did not have up-to-date information about the likely impact of the reforms when scrutinising the draft regulations setting out duration and amounts of benefit.

Eligibility

Despite heralding the reforms as a modernisation, the government explicitly ruled out extending eligibility to unmarried partners, although the rise in the proportion of cohabiting parents is one of the greatest

15. Worden, J.W. (1996) *Children and grief: when a parent dies* New York, Guilford Press.

16. Christ, G. (2000) *Healing Children's Grief. Surviving a parent's death from cancer*. New York: Oxford University Press.

17. Lin, K. et al (2004) Resilience in parentally bereaved children and adolescents seeking preventive services *Journal of Clinical Child and Adolescent Psychology*. 33:4, 673-683.

18. Worden, J.W. (1996) *Children and Grief: When a parent dies* New York: Guilford Press.

19. Worden, J. and Silverman, P. (1993) Grief and depression in newly widowed parents with school age children *Omega* 27 (3) 251-261.

20. Oldfield, K. et al (2012) Department for Work and Pensions Research Report No 790: Bereavement benefits: findings from qualitative research. Available online at: <https://goo.gl/7vJW8c> (accessed 31 July 2017).

21. Department for Work and Pensions (2013) *Further analysis on the reform of bereavement benefits for new claims from April 2016*. Available online at: <https://goo.gl/JPa7Qf> (accessed 31 July 2017).

“Each year, at least 2,000 newly bereaved families with children miss out on [bereavement] benefit because the parents were not married.”

socio-demographic changes the 21st century has already seen²². It maintained that these benefits are, like other contributory benefits, based on the marriage principle²³.

Each year, at least 2,000 newly bereaved families with children miss out on this benefit because the parents were not married²⁴. Unmarried partners are often in a worse position financially than those who were married: they may be ineligible for death benefits or pensions. If the person died without making a will, unmarried partners do not inherit anything automatically.

Many couples do not realise they would not be eligible: more than half (53%) of people cohabiting with a partner believe wrongly that living together for some time brings them the same legal rights as if they were married²⁵ – the stubborn myth of the ‘common law’ marriage. This confusion is partly because the means-tested benefits and tax credit systems treat couples as one unit, whether they are married or not. The Family Test includes cohabitation within its definition of couple relationships²⁶, and the Family Law Reform Act 1987 identifies parents as being parents irrespective of whether they are married or not²⁷.

During passage of the Pensions Bill, which introduced the new BSP, the Minister of State for Pensions raised the practical difficulties of determining the nature of a partnership, saying how uncomfortable it would be to ask intrusive questions about a relationship shortly after one person had died. However, many of the administrative processes around a death could be seen as intrusive, but are recognised as being necessary. The tax credit and means-tested benefit systems are already set up to manage cohabiting couple claims, and many couples will have had such a joint claim before one of them died.

In November 2015, The Social Security Advisory Committee identified that eligibility for BSP is ‘inconsistent with other benefits, including Universal Credit, and appears incompatible with the Family Test’²⁸. Four months later, the Work and Pensions Select Committee said the policy ‘unfairly penalises the bereaved children of cohabitantes’ and

22. The percentage of dependent children living in cohabiting couple families (including both opposite and same sex couples) increased from 7% in 1996 to 15% by 2016. See Office for National Statistics (2016) Families and households in the UK: 2016, available online at <https://goo.gl/Q3e1sQ>

23. Department for Work and Pensions (2012) *Government response to the public consultation. Bereavement Benefit for the 21st Century*. Available online at: <https://goo.gl/XE5rou> (accessed 31 July 2017).

24. Childhood Bereavement Network (2017) *Bereavement benefits and cohabiting parents*. Available online at: <https://goo.gl/Ypk6er> (accessed 31 July 2017).

25. Barlow, A. et al (2008). Cohabitation and the law: myths, money and the media. In Park, A. Curtice, J. Thomson, K. Phillips, M. Johnson, M.C. & Clery, E. (Eds.), *British Social Attitudes: The 24th Report*. (2007/2008, pp. 29-53). London, England: SAGE Publications Ltd.

26. Department for Work and Pensions (2014) *The Family Test: Guidance for Government Departments*. Available online at <https://goo.gl/CXU43C> (accessed 31 July 2017).

27. Family Law Reform Act 1987 <https://goo.gl/B9gH2E>

28. Social Security Advisory Committee (2015) *Bereavement Benefit Reform: Occasional Paper No. 16* p33. Available online at: <https://goo.gl/aDxD4z>

recommended the government should extend eligibility to these families²⁹.

In January 2016, the Belfast High Court ruled that Siobhan McLaughlin, a mother who had been living with her partner for 23 years before he died, should be able to claim Widowed Parent's Allowance on behalf of their four children. This decision was subsequently overturned, but leave to appeal to the Supreme Court³⁰ has been granted.

The challenges of devolution

The McLaughlin case highlights some of the issues which devolution raises for the delivery and reform of bereavement benefits. Had her appeal stood, the ruling would have applied to the Department for Social Development in Northern Ireland, and for it to affect widowed parents in Great Britain, the Department for Work and Pensions would have had to amend its parallel processes or face a judicial review of its own³¹.

The new benefits were introduced through the Pensions Act 2014 in England, Scotland and Wales, and the Pensions Act (NI) 2015 in Northern Ireland. This was subject to a separate parliamentary process but, in line with the parity principle, the rules and rates surrounding the benefit in Northern Ireland mirror those in place in Great Britain.

As the Social Fund Funeral Expenses Payment system is a devolved matter, some MPs assumed that bereavement benefits were also devolved. This led to some confusion about the degree to which Scottish constituents would be affected by the reforms. In fact, the reforms apply in all four nations as described.

Future evaluation of the benefit

The government has committed to reviewing the impact of Bereavement Support Payment 'when sufficient evidence is available to assess all aspects of the policy, including its effectiveness.'³² The government's view of effectiveness will presumably be based on the policy's impact on meeting the short term financial needs of families, and on getting more widowed parents back to work.

29. House of Commons Work and Pensions Committee (2016) *Support for the bereaved. Ninth report of session 2015-16*. Available online at: <https://goo.gl/CxPAca> (accessed 31 July 2017).

30. Belfast Telegraph (2017) Unmarried Northern Ireland mum takes landmark battle for widowed parent's allowance to Supreme Court, 26th January, available online at: <https://goo.gl/4ehscs>

31. Simpson, M. (2016). Case analysis: In the matter of an application by Siobhan McLaughlin for judicial review [2016] NIQB 11. *Journal of Social Security Law*. 23. 106.

32. House of Commons Hansard (2017) Draft Bereavement Support Payment regulations, available online at: <https://goo.gl/7Hg6dX>

Recommendations for Policy Change and Research

- Such a review will require detailed quantitative analysis of labour market trajectories under both the old and the new system, along with qualitative evidence about the impact of conditionality requirements on the emotional health of widowed parents and their children over the mid to long term. Without this analysis, the government will not be able to say it has assessed all aspects of the policy.
- It is surprising and disappointing that the government did not explore likely longer-term impacts before introducing the reforms. This could have included a more ambitious exploration of the ways in which other social security systems across Europe and beyond provide long-term support for grieving children and their surviving parent.
- If the impacts are – as critics predict – found to have a negative impact on children and their parents’ wellbeing, then the case for a rethink or reversal of the reforms will be even more urgent.

Bereavement among Older People

Lesley Carter, Interim
Head of Health Influencing
at AgeUK

- Older people have the right to expect services and support that will help to ensure that they are prepared for death (their own and others’).
- We need to raise awareness of the importance of early family conversations and planning for death and dying and the challenges of bereavement in later life.
- Older people who are bereaved should be able to access responsive services that are appropriate to their needs and offer practical, psychological and social support.

Concerns

Positive advances in health care and public health mean that most of us will die later in life. Public Health England has published a milestone report on the health of the population in England¹. People are living longer than ever – life expectancy in England has now reached 79.5 years for males and 83.1 years for females. In Northern Ireland males can expect to live for 78 years, and females for 82.4 years². In Scotland it’s 77.1 years for males and 81.1 years for females (but with considerable variation between areas)³. In Wales females can expect to reach 85, and males 83⁴. Across the country 85% of all deaths are people over 65, and two-thirds are people over 75⁵.

With this rise in life expectancy comes accountability for older people and the end of their lives. Every person has the right to expect and experience a dignified and pain-free death with access to services and help that will support the person. Older people should be able to have a choice in how and where they are cared for in their final months

1. Gov.UK (2017) State of the nation’s health revealed in landmark report for PHE, available online at: <https://goo.gl/EyxhzC>

2. NISRA (2015) Life expectancy for areas within Northern Ireland 2011-2013, available online at: <https://goo.gl/ngjsTj>

3. National Records of Scotland (2016) Life expectancy in Scottish areas, available online at: <https://goo.gl/XAx26v>

4. Office for National Statistics (2015) Life expectancy at birth and at age 65 by local areas in England and Wales: 2012 to 2014, available online at: <https://goo.gl/m7X62U>

5. Age UK (2017) Later life in the United Kingdom, available online at: <https://goo.gl/Hnr8zK>

and days, regardless of where they live or their diagnosis⁶.

However, research⁷ shows that a significant amount of the extra time that comes with a longer life expectancy is spent in poor health and often with caring responsibilities. This is the case for both older men and women. Yet while there is much in common between the support needs of both men and women, there are also subtle differences that often go unrecognised⁸. Some men find caring, household chores, shopping and cooking difficult, and women find it a challenge to keep up with tasks that had been undertaken by their spouse.

Many common features of older people's health, such as multi-morbidity, frailty, and dementia, are poorly understood in an end of life context. As a result, older people, particularly the oldest (typically regarded as aged over 85), are not able to access specialist palliative care or experience 'seamless' support from different agencies at the end of life as their health deteriorates.

Preparation for Death

Remarkably, the families of older people are often unprepared for life's transitions such as developing frailty⁹, changes in the type and levels of care required and the increase of care needs at end of life, as well as after bereavement. Many of us have no idea of the preferences, wants, fears and expectations of the people we love. Being so unprepared can have a very severe impact both on the experience of the dying and their observers – particularly the spouse and family.

Currently, evidence suggests that older people and their families are often not in positions where they feel confident to initiate conversations or start to make a plan about how they would like to die¹⁰. There are numerous complex barriers including a widespread reluctance to discuss death, dying, and bereavement. The unwillingness to have intergenerational conversations about what to expect before, during, and after death is compounded by the difficulties that health professionals face when identifying older people who are in the last years of life.

Certainly, evidence indicates that staff in hospitals and other care settings can feel that they are not equipped to support these conversations. They feel insufficiently trained to manage the dying person, their families and the recently bereaved with empathy and knowledge, and will often, unfortunately, avoid these issues. This, of course,

6. Age UK (2016) Age UK policy positions 2016 – a quick reference guide, available online at: <https://goo.gl/Q6gi8s>

7. Age UK (2017) A summary of Age UK's index of wellbeing in later life, available online at: <https://goo.gl/Ybn9yg>

8. Guardian (2014) Men Over 65 more likely than women to be carers, 13th February, available online at: <https://goo.gl/wy3ekv>

9. Age UK (2015) Frailty: language and perceptions, available online at: <https://goo.gl/j1R19K>

10. NatCen Social Research (2012) British Social Attitudes: Dying, available online at: <https://goo.gl/nQBb2C>

leaves older people and their families feeling confused, upset and disempowered.

It is so terribly important that this experience is right first time and the best it can possibly be. A poor experience of dying and death will often leave long-lasting, distressing memories for bereaved people to carry, and will have an impact on how well people will personally deal with their loss. This is of paramount importance for older people, as loss becomes an increasingly common event as we age; we lose friends, family, spouses, companions, grown-up children and pets. All of these losses can have a significant negative impact on the wellbeing of older people.

Bereaved Older People

The evidence points to the impact of the common elements of bereavement for older people: deep sadness, depression, altered identity and loneliness, all of which can lead to preventable negative health outcomes. The stress related to changes in life patterns and life routines contributes to older people becoming overwhelmed with grief and showing signs of anxiety, depression or both.

There is a risk of isolation, as older people bereaved of a partner or close companion often withdraw from physical and social activities that they previously enjoyed as a couple. They may begin to neglect their own health and nutritional needs, drink more alcohol, fail to exercise regularly and become more accident-prone because they are paying less attention to their personal safety.

Undoubtedly, one of the most overwhelming losses for older adults is the death of a spouse. Although frequent and predictable, as a society we do little to prepare individuals for such events; there is scant access to professional help to support older people who may need to learn new tasks and feel confident to make important decisions, meet new role expectations, and also take greater responsibility for self-care.

As a result, the progression of the bereavement process will be experienced with variability depending on the actual experience of the loss and the surrounding support network available.

Policy Responses

Health, social care and the voluntary sector need to work more closely together to ensure that awareness of this issue is raised, that older people are better enabled to cope and that there is a greater understanding of the mechanisms of bereavement in later life. To the best of our knowledge, at the point of writing none of the four nations is addressing this as a policy priority, or even an issue. Local governments, already stretched by their social care remit, typically prioritise physical care needs, and when mental health needs are supported, this does not always include bereavement. Support for bereaved older people is therefore highly localised and contingent on the availability and attention of third-sector organisations.

This dearth of policy attention to bereaved older people negates the potential that can also accompany a loss. It is important that support is

available for the bereaved older person to access so that they have the opportunity to take periods of respite from grieving itself. Such respite can help restore a sense of balance and wellbeing, and offer something of a rejuvenation. This could include old or new hobbies, and volunteering for projects, leisure and other meaningful activities, thereby providing opportunities for socialising and being involved with others. This can provide a vital source of renewal for a bereaved older person.

Conclusion

“Older peoples’ bereavement experience and support needs have been largely neglected because of the notion that bereavement is less problematic in old age than in other life stages.”

As a result of a long-standing, significant and potentially damaging policy vacuum, none of the four nations is taking the lead in supporting bereaved older people.

There are unconnected policies around bereavement across the country more generally (see Debbie Kerslake and Stewart Wilson’s article, p.59) and bereavement services are, in our opinion, currently are not fit for purpose. Gaps in provision are not consistently managed, and older people miss out on much-needed support. There are different levels of bereavement support available during the life cycle but these are often reactive – for example, after a major incident, death from cancer, or support for children and younger people.

Older peoples’ bereavement experience and support needs have been largely neglected because of the notion that bereavement is less problematic in old age than in other life stages. It is highly usual for various age-related charities such as AgeUK to fill this void¹¹.

There is scant recognition that older people are a group that will experience bereavement more regularly and differently – that is, the loss of lifelong partners and lifetime friendships. How this relates to and impacts on coping with the proximity of their own end of life has not been recognised, and the question remains unanswered as to whether a lack of support for the bereaved results in a greater need or dependence on health services.

Devolution and the reorganisation of health and social care resourcing may allow for the design and implementation of local services which could better meet the demographic needs of local areas. We are hopeful that this may encourage the joining up of end of life care, bereavement and mental health services, with older people recognised as a group that requires attention.

This still leaves the question of who would have overarching responsibilities across the nations and regions, and who would monitor equity of access. Questions remain therefore about national leadership: who would monitor quality, commission/resource services and set out what is and should be available in each area? Furthermore, assurances and guidelines would need to be in place to ascertain and specify how devolved areas would link to national resources and helplines, and how good and bad practice might be identified and shared.

11. Age UK (2016) Bereavement: support after death, available online at: <https://goo.gl/59seQA>

Recommendations for Policy Change and Research

- We need to establish what an ideal nationwide bereavement service would look like and the level of existing understanding of older peoples' bereavement within health and social care services across the four nations.
- We need to investigate and evidence whether older people are able to access the same level and quality of bereavement support as other age groups, and if they're not, ascertain why.
- We need to understand how better integrated and coordinated care might impact on older peoples' experience of bereavement, and learn how to capture and represent their lived experience as they travel along the various dying and death pathways. What type of outcomes do we want around the way they may be able to regain their independence as a bereaved person?

Delays to Funerals

Debbie Kerslake, Chief

Executive at Cruse
Bereavement Care and

Stewart Wilson, Chief

Executive at Cruse
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Scotland

- There is considerable variation, by region, in the time between a death and the funeral and multiple factors contributing to these delays.
- The impact of these delays on those who are bereaved can be considerable.
- A UK-wide bereavement strategy, with an appointed minister, is needed to ensure that the different organisations and services work together in the interests of bereaved people.

Introduction

Just under 600,000 people died in England, Wales, Northern Ireland and Scotland in 2016. For each person who dies, research¹ suggests that four to six people are directly affected. This can have a huge impact upon the individuals involved, upon their wider circle of family, friends and colleagues and, ultimately, upon the economy. In the absence of statutory bereavement leave, at Cruse Bereavement Care and Cruse Bereavement Care Scotland we hear of people resorting to taking sick leave after a bereavement for a range of reasons, including difficulty in dealing with the emotional impact as well as needing time for all the practical arrangements required – including the funeral.

Those who are bereaved have to be at the centre of all the systems related to the death and burial or cremation of the person who has died. Failure to support bereaved people at this time can exacerbate the distress they are experiencing and could contribute to longer periods of ill health and time away from the workplace.

There is a growing concern regarding the length of time between death and the funeral, burial or cremation of the person who has died. Bereaved people are telling us that in parts of England the waiting time can now be three weeks. In Scotland the situation is broadly similar. However, it is usually possible to hold a funeral more quickly if factors such as religion and culture are important considerations – we know in London, for example, that funerals for people of Islamic faith can be organised within 24-48 hours, and a London-based Sikh or Hindu funeral director aims for a three- to four-day turnaround between death and funeral².

1. Priggerson, H. et al (2008) A case for inclusion of Prolonged Grief Disorder in DSM- V.

2. Royal London (2016) Keeping the Faith, available online at: <https://goo.gl/THUF4u>

“Concerns arise [...] when a delay is not due to choice but rather to other factors coming into play – such as delays to being able to get the death certificate or to register the death, or difficulties arranging the funeral because of financial problems.”

In Northern Ireland it remains normal practice to hold a funeral two or three days after a death, demonstrating that even when the administrative processes prior to a funeral and disposal taking place are not expedited, it is possible for funerals and disposal to occur much more quickly after a death.

There are considerable implications for delays between death and disposal, not least the pressure on hospital and local authority mortuaries where bodies are held, the costs to funeral directors when those bodies are moved into their cold storage facilities and the impact on businesses from employees needing additional time off work to resolve complex arrangements. With the current system already stretched, there is potential for even greater pressure and delays in the event of a pandemic, major incident, or the usual seasonal increases.

The issue of delays to funerals was first raised with the All Party Parliamentary Group for Funerals and Bereavement (APPG) by the late Paul Goggins MP. He relayed the concerns of his constituents who had faced delays in holding the funeral of their loved ones. This led to an inquiry in 2015 into delays between death and burial or cremation³ which sought to determine the scale of delays, their cause and what the government could do to address the situation. The inquiry heard evidence – from a range of witnesses involved in the processes that take place between a death and the funeral, burial or cremation – of a lengthening time gap between death and funeral in England. A range of conclusions and recommendations were identified.

There is no difficulty with having a delay between a death and a funeral if this is the choice of those who are bereaved. Evidence to the inquiry⁴ highlighted that families today often want a more personalised service and are willing to wait while this is planned. There may also be practical considerations for delaying a funeral; for example, if those who are bereaved are travelling from across the world to attend. Indeed, with advances in cold storage and embalming techniques meaning that deceased people’s bodies do not deteriorate over a period of time, there is no problem with delaying a funeral in terms of public health. Concerns arise, however, when a delay is not due to choice but rather to other factors coming into play – such as delays to being able to get the death certificate or to register the death, or difficulties arranging the funeral because of financial problems.

The Impact on Those Bereaved

We know that the funeral service and saying goodbye to the person who has died plays a vital role in helping grieving families⁵. For many, it is what brings home the reality of what has happened. It can reduce

3. Brevia Consulting for the All Party Parliamentary Group for Funerals and Bereavement (2015) Inquiry into delays between death and burial or cremation.

4. Brevia Consulting for the All Party Parliamentary Group for Funerals and Bereavement (2015) Inquiry into delays between death and burial or cremation.

5. Hoy, W. (2013) *Do Funerals Matter?* (London: Routledge).

the sense of isolation following a death, by bringing mourners (including friends and family) together to mark the end of someone's life and enabling them to provide mutual support. It can provide a positive way of celebrating all that the person meant to everyone and expressing collective and personal grief following their death. For many, there are also religious and cultural practices which give meaning and support to this significant and emotional event. At its best, the funeral is a therapeutic act which enables the healing process to start.

Delays to holding the funeral can exacerbate the feelings of distress and disorientation (the feeling of being in limbo). It can also cause significant practical difficulties such as for families travelling from overseas to attend the funeral, as the lack of clarity over the date or length of delay can mean they are unable to attend. Uncertainty makes an already difficult situation so much worse. Where cultural or religious practices around timescales cannot be fully observed, it can significantly add to the distress. For many, there will be distress and anxiety about where and how the body is kept during this time.

All of this highlights the vital importance of addressing the factors that are combining to cause delays.

What are the Factors Contributing to Funeral Delays?

The APPG's inquiry identified the following concerns:

Registration of a death

A Medical Certificate of Cause of Death (MCCD) is required in order to register a death. Delays in the issuing of this are often cited by bereaved people, due to doctors or GPs not having seen the person in the two weeks before they died, or because of shifts or holidays.

The APPG found increased pressure on registration services and pathologists providing post-mortems. Opening hours, backlogs due to weekends, bank holidays and seasonal variations in death rates can all contribute to delays. Factors contributing to the shortage of pathologists included post-mortem fees, lack of mandatory training on autopsy and the NHS requiring pathologists to undertake post-mortems outside of contracted hours⁶.

The regulations around the time within which a death must be registered vary across the UK. In England, Wales and Northern Ireland it must be within five days, whilst in Scotland it is eight days. A 2015 survey carried out by the National Association of Funeral Directors found that respondents were waiting an increasingly long time to see a registrar after a death⁷. Almost 70% of members reported that waiting times had increased over the previous year, with 49% of families waiting at least three days for an appointment and 15% waiting more

6. Brevia Consulting for the All Party Parliamentary Group for Funerals and Bereavement (2015) Inquiry into delays between death and burial or cremation.

7. National Association of Funeral Directors survey results (2015).

than five days.

Delays sometimes occur due to the need to carry out coronial or procurator fiscal (in Scotland) investigations when the death is sudden, violent, unnatural or suspicious. Currently, there is inconsistency in the provision and extent of out-of-hours coroner services across the UK. Bereaved people and funeral directors have raised concerns that coroner's offices accepting email-only contact make it difficult to address queries and concerns⁸.

However, in Northern Ireland – where it is standard for funerals to take place within two or three days of the death – there would appear to be better joined up working between, for example, the coroner, registrar and funeral directors. There is no systematic evidence of why this is the case though, so the potential to share good practice across the other three nations is hampered by limited data collection on issues such as turnaround times.

Uncertainty around Social Fund Funeral Expenses Payment awards

These payments are intended to support the poorest in society who will struggle to fund a funeral for their next of kin. However the system is overly complex and the outcome of applications is often delayed and is received after the funeral has taken place. If an amount is awarded, it is usually insufficient to meet costs.

For those who are not eligible to receive a Funeral Expenses Payment, there can be delays in raising funds to pay for a funeral. The current consultation⁹ presents proposed reforms to the Funeral Expenses Payment scheme largely focused on clarifying issues around eligibility and making the process for claiming the payment simpler.

A lack of core crematoria slots and burial space¹⁰

The availability of cremation slots in peak times (around 10am – 4pm) is limited. Crematoria often have vacant slots on any given day, but these will typically be at the start or end of the day – which may be difficult and more costly for bereaved people to attend. Burial space is also at a premium in some parts of the UK, meaning that locating an appropriate space may take time; and there may be delays in being able to get a grave dug. The Burial and Cremation (Scotland) Act 2016 and consequent secondary legislation will provide for opening and reuse of existing graves in Scotland, where capacity for crematoria in certain parts is also under pressure. Nonetheless, nationwide capacity for the

8. Brevia Consulting for the All Party Parliamentary Group for Funerals and Bereavement (2015) Inquiry into delays between death and burial or cremation and anecdotal evidence from bereaved people contacting Cruse Bereavement Care.

9. Department for Work and Pensions (2017) Reforms to the Social Fund's Funeral Expenses Payments Scheme.

10. Brevia Consulting for the All Party Parliamentary Group for Funerals and Bereavement (2015) Inquiry into delays between death and burial or cremation.

disposal of deceased peoples' bodies is therefore paramount.

Other Contributory Factors

One of the challenges in addressing the delays is that bereaved people may be dealing with complex and unfamiliar processes at a time when they are usually distressed, disorientated, and have more difficulty making decisions. They are not well placed to question information given – for example, if a funeral director states that a funeral cannot be held for three weeks – or to explore and/or challenge the underlying reasons. Our work with bereaved people suggests that few 'shop around' to compare services and prices from different funeral directors.

“The current lack of statutory bereavement leave means employers need to consider what they can give to staff who are bereaved to enable them to deal with the immediate aftermath of a death”

Delays can also occur when it is difficult for those closest to the person who has died to take time off work to make the arrangements or even to attend the funeral. The Employment Rights Act 1996 gives a 'day one' right for an employee to have 'reasonable' time off work to deal with an emergency, such as bereavement involving a dependant. This could be a spouse, partner, child, parent or someone who depends on the employee for care¹¹. The current lack of statutory bereavement leave means employers need to consider what they can give to staff who are bereaved to enable them to deal with the immediate aftermath of a death including to attend a funeral. There are moves to introduce some statutory bereavement leave and this is to be welcomed. In July 2017 the Parental Bereavement (Pay and Leave) Bill was introduced for England, Wales and Scotland – although this only makes provision for employees whose children have died.

Moreover, despite all the excellent work of Dying Matters¹² to increase awareness of the need to plan for end of life care and make funeral wishes known, evidence suggests that the UK population is still failing to do so. In 2016 YouGov's Funeral Matters Research¹³ found that only 7% of British adults had taken out a funeral plan, with 14% saying that nothing would encourage them to think about or plan their own funeral. However, a lack of knowledge about the final wishes of the person who has died including the type of funeral, disposal of the body and any associated gatherings or rituals for mourners, may create not only delays but can also lead to conflict within families. A lack of financial provision can pose immediate problems for whoever is responsible and add to delays in making arrangements.

Factors That May Exacerbate the Problem in the Future

The number of bereaved people is growing. The annual number of

11. ACAS (2014) Managing Bereavement in the Workplace – a good practice guide. Available online at: <https://goo.gl/mtVBt4>

12. Dying Matters is a government-sponsored ongoing campaign to raise the profile of death and dying, see <https://goo.gl/K8kxan>

13. National Association of Funeral Directors (2016) YouGov Funerals Matter.

deaths in England alone is increasing and is predicted to rise by 20% over the next 20 years (ONS, 2015). Such an increase will exacerbate the problems identified above if nothing is done to address them.

The consultation on death certification reforms set out the intention to introduce a unified system of scrutiny by independent medical examiners for all deaths in England, Wales and Northern Ireland that are not investigated by a coroner. The consultation on the Death Certification Reforms¹⁴ asked if the person prescribed should be the individual that collects the MCCD or the death registrant informant. With a fee payable this could lead to delays, with individuals being reluctant to be made liable for the payment. The changes may, however, reduce delays for some families as fewer deaths will need to be referred to the coroner.

Furthermore, when the role of medical examiner is introduced in England and Wales, it will differ from the existing requirements in Scotland – where only one in every ten certificates is examined. In England and Wales every certificate will be scrutinised and fee levels will differ. Not only does this raise concerns regarding further delays in England and Wales (where, in the pilot sites, the new process took approximately half a day longer than the old one to complete requirements), it also raises questions about how cross-border working and situations will be handled when there are differing standards and expectations regarding scrutiny.

Recommendations for Policy Change and Research

- Ascertain the processes in place that enable funerals to be held two to three days after a death in Northern Ireland.
- Withdraw the proposal to charge bereaved people for the medical examiner fee, as it poses the risk of further delays in the future. If a charge is imposed, it should fall on the estate of the person that has died.
- Improve access to registrars by extending opening hours and enhancing staffing levels and out-of-hours services for registry offices.
- Consider and implement measures to address the shortage of pathologists.
- Improve access to out-of-hours coronial services and communication options with coroners.
- Reduce the timeframe required in Scotland for registering a death from eight to five days.
- With public and commercial organisations, co-fund and organise a public awareness campaign to encourage people to make plans for their deaths so that unnecessary delays can be avoided.
- Address problems with the Social Fund Funeral Expenses Payments to speed up the decision-making process, broaden eligibility

14. Department of Health (2016) Introduction of Medical Examiners and Reform to Death Certification in England and Wales: Policy and Draft Regulations.

and ensure it covers the full costs of a basic funeral (see Heather Kennedy's article, p.80).

- Increase cemetery and crematoria capacity in England and Wales (see Brendan Day's article, p.92, and Tim Morris' article, p.97).
- Introduce statutory bereavement leave across the whole of the UK so that individuals have the flexibility to manage leave around the time of death and the funeral, without resorting to taking sick leave.
- Develop a cross-government department, UK-wide bereavement strategy with a named minister¹⁵ with responsibility for bereavement who can make sure that bereaved people are given the priority they deserve in the making and implementation of policy and practice. Responsibility for policy affecting those who have been bereaved is currently split across many government departments including the DWP, the Department of Health, the Ministry of Justice, the Ministry of Defence and the Home Office.

15. National Council for Palliative Care, National Bereavement Alliance, Dying Matters (2014) Life After Death.

Regulation of Funeral Directors

Mandie Lavin, Chief Executive Officer at the National Association of Funeral Directors

- The funeral director's world is changing; the first Inspector of Funeral Directors in Scotland has started in post and the debate on the value of regulation is now at the forefront of our minds.
- This is an important opportunity to establish shared values and principles for the funeral industry, which will instil and uphold public confidence in the sector.
- These are significant moves towards the professionalisation of funeral directors.

Why Does Regulation Matter?

With the introduction of an Inspector for Funeral Directors in Scotland, important questions are being asked about the terms on which inspection will take place, licensing and implications for regulation. Although the legislation detailed here is related mainly to Scotland, there are significant ramifications for the other three nations, both in terms of policy and practice.

Background to the Introduction of Legislation in Scotland

The original impetus for the Burial and Cremation (Scotland) Act 2016 was work undertaken by the independent Burial and Cremation Review Group, chaired by Sheriff Brodie, which met between 2005 and 2007 to look at the law relating to burial, cremation and death certification. Its recommendations on death certification were accepted by ministers, resulting in the current legislation.

The next stage of the burial and cremation reforms was due to commence after death certification reform was completed; however, this was brought forward following concerns about infant cremation practice in Scotland, set out in the Mortonhall Investigation Report of Dame Elish Angiolini¹. Her recommendations were supported and extended in the subsequent Report of the Infant Cremation Commission, a nationally-focused commission chaired by the Rt Hon Lord Iain Bonomy².

1. Dame Elish Angiolini (2016), Report of the National Cremation Investigation.

2. Lord Bonomy (2014), Report of the Infant Cremation Commission.

The Scottish Parliament passed the Burial and Cremation (Scotland) Act 2016 on 22 March 2016 and it received royal assent on 28 April 2016. The Act made much-needed improvements to the burial and cremation process in Scotland and codified legislation, much of which was out of date and in need of clarification. Many of the Act's provisions are in direct response to recommendations made by Lord Bonomy. Although the report of the National Cremation Investigation was published after the Act was passed, many of the report's recommendations were already being addressed by the Act and relevant provisions were included.

Although the Burial and Cremation (Scotland) Act 2016 has been passed by Scottish Parliament, there are still various pieces of secondary legislation which need to be laid before parliament before individual sections of the Act can be brought into force. Secondary legislation is currently being drafted and is subject to consultation.

Details of the Legislation

The purpose of the Burial and Cremation (Scotland) Act 2016 was to provide a comprehensive legislative framework for burial and cremation. The Act provided for the repeal of all existing legislation relating to burial and cremation in Scotland. The Act is in seven parts and contains two schedules. There are some parts of the legislation that will have a direct impact on funeral directors and those they work with, in the public interest. As part of this article I have extracted some of the most relevant parts of the Act and outlined their potential effect.

Inspection

For the first time, there will be a statutory right of inspection and a range of regulatory powers associated with the inspection arrangements. The detail of how this will operate is not yet known and at the time of writing a consultation is underway (from 6 July to 1 September 2017) which addresses the draft regulations being made under the Act and extends to the powers of inspection of funeral directors' businesses. Part 4 of the Act sets out a range of provisions in relation to the inspection of various parts of the funeral industry, including crematoria, cremation authorities, burial grounds, burial authorities and funeral directors. Specific sections detailed below set out specific powers.

Section 89 – appointment of inspectors. This section gives the Scottish ministers the power to appoint inspectors of burial, inspectors of cremation and inspectors of funeral directors. At the time of writing, the Inspector of Funeral Directors has been appointed and commenced in post and the Inspector of Crematoria, Robert Swanson, has just completed his first year. The Inspector of Burial has not yet been appointed.

Section 90 – inspections: regulations. Section 90 gives the Scottish ministers the power to make regulations about the inspection of burial grounds and burial authorities, crematoria and cremation authorities, and funeral directors. The matters that any regulations may include are the frequency of inspections, the steps that can be taken by

“Through this legislation Scottish ministers will be able to suspend the operation of a crematorium, burial ground or the business of a funeral director.”

inspectors to enforce compliance with any legislative or compliance requirements, and the conditions that can be attached to licences and timescales that may apply.

Through this legislation Scottish ministers will be able to suspend the operation of a crematorium, burial ground or the business of a funeral director. It is anticipated that regulations made will set out the steps that may be taken by inspectors to ensure compliance with requirements or conditions contained in enactments, codes of practice or guidance applicable to burial authorities, cremation authorities or funeral directors, and enforce these requirements or conditions. Regulations may also set out arrangements for reviews of or appeals against decisions of inspectors or decisions of the Scottish ministers in relation to recommendations to suspend or revoke any licence necessary to operate as a burial authority, cremation authority or funeral director.

They may also set out arrangements for the investigations of complaints against cremation authorities, burial authorities and funeral directors, and what sanctions inspectors may impose in relation to such investigations.

The juxtaposition between the complaints handling processes of the existing professional associations and that of the Scottish Government is yet to be determined.

Section 91 gives inspectors various powers of entry in the course of carrying out inspections. Parts of the Act allow inspectors to require the production of any documents, records or registers required by the Act, and inspection, including taking copies; these powers can be exercised only in relation to ascertaining whether an offence under this Act has been or is being committed. The Act sets out further details about these powers, including that the inspector may be accompanied by any other person the inspector considers necessary and may take into the premises any materials and equipment that the inspector considers necessary. Entry must take place at a reasonable hour and the inspector must produce identification and proof of authorisation if required to do so.

Section 92 – Section 91: offences. It is an offence for a person to fail to comply, without reasonable excuse, with a requirement to produce a document, record or register in the course of an inspector carrying out their duties and it is an offence for a person to wilfully obstruct an inspector in the exercise of the power of entry, or the power to inspect or take copies of documents, records or registers. A person who commits such an offence is liable on summary conviction to a fine not exceeding level three on the standard scale.

Section 93 – reports. Subsection (1) requires an inspector to prepare and publish annual reports; the first such report prepared by an inspector is to be published before the end of the inspector’s first year in the role, and must cover that period. The first annual report from the Inspector of Crematoria was published on 4 May 2017 and covers

the period 9 March 2015 to 30 September 2016³. Reports must provide information about the activities undertaken by the inspector during the relevant period, and may make recommendations with the aim of improving the services under inspection. Inspectors may also make recommendations to improve the keeping of documents, records and registers. These reports have to be laid before the Scottish Parliament as soon as reasonably practicable after publication.

In addition to annual reports, an inspector can produce other reports on matters he or she thinks appropriate – for example, a report on a crematorium that has serious failings. Such *ad hoc* reports must be sent to the Scottish ministers and may, if the inspector considers it necessary or desirable to do so, be published and/or laid before the Scottish Parliament.

Funeral Directors

Section 94(1) gives the Scottish ministers the power to create a licensing scheme covering the operation of funeral directors' businesses. Subsection (2) provides that a person may not carry on a business as a funeral director unless they hold a licence issued under the scheme in relation to the business. Subsection (3) provides that a person who carries on more than one business as a funeral director must hold a separate licence for each business.

Section 95 – licensing scheme. Section 95(1) allows the Scottish Ministers to make regulations in respect of how a licensing scheme will operate. Subsection (2) sets out what the regulations may contain. This includes: the licence conditions which may apply under regulations; who will administer the scheme; the application procedure; the circumstances under which an application may be refused or granted; for what period the licence may be granted; provisions for suspension or revocation of licences; and any conditions that may be applied, such as the fees that may be payable and provision for appeals against certain decisions of the licensing authority.

Section 96 – licence for funeral director's business: offences. Subsection (1) provides that a person who knowingly carries on a business as a funeral director without a licence commits an offence. Subsection (2) sets out the circumstances in which a person will be considered not to hold a licence. These are that no licence has been issued or that a licence has been issued but has expired without being renewed, or has been suspended or revoked. Subsection (3) provides that a person will also commit an offence if they knowingly or recklessly provide materially false or misleading information in, or in connection with, an application for a licence. A person who is convicted of committing an offence under this section will be liable to a fine not exceeding level three on the standard scale.

The creation of new criminal offences will require more detailed

3. First Annual Report from the Inspector of Crematoria from 9 March 2015 – 30 September 2016. Published on 4 May 2017.

consideration as safeguards will need to be put in place to inform the profession of this new risk. New indemnity and insurance arrangements will also be required.

Section 97 – funeral director: code of practice. Subsection (1) provides that a funeral director must comply with any new or revised codes of practice issued by Scottish ministers in relation to the carrying out of a funeral director’s functions.

Under subsection (2), the Scottish ministers will be required to consult with funeral directors and any other relevant parties before issuing a funeral director’s code or revising an existing code.

Subsection (3) requires the Scottish ministers to lay a draft of the funeral director’s code before the Scottish Parliament, after taking account of any representations made. A funeral director’s code may not be issued until it has been approved by a resolution of the Scottish Parliament. Subsection (5) requires the Scottish ministers to publish such a code in such manner as they consider appropriate, and subsection (6) requires the Scottish ministers to keep any code of practice under review. Subsection (7) provides that references to a funeral director’s code also include references to a revised code.

Miscellaneous

Part 6 sets out various miscellaneous provisions. Some of these are of real significance, especially the Scottish Government’s jurisdiction over costs.

Section 98 – Guidance on funeral costs. Subsection (1) provides the Scottish ministers with a power to issue guidance about the costs associated with making arrangements for a funeral. Subsection (2) sets out that any such guidance may in particular cover the desirability of funeral costs being affordable. Subsection (3) requires Scottish ministers to consult with burial and cremation authorities and with funeral directors, as well as any persons they consider appropriate, before issuing any guidance under this section. Subsection (4) requires that guidance published under this section be laid before the Scottish Parliament.

Impact of the Legislation

The possibilities of criminal action, business suspension or cessation, and the requirements to attend hearings and possibly appealing findings, along with a publicly available register, changes the landscape of funeral directing in Scotland beyond recognition. The requirements for greater attention to record keeping, the potential requirement for an accountable officer to oversee compliance in the business and increased scrutiny of areas of the business that have not routinely been audited will present challenges. Similarly, the introduction of criminal sanctions for offences such as purporting to hold a licence if one is not in place is only one of many new potential offences under the Act. This is a new feature designed to increase professionalism and accountability to the public. This overview of the legislation can only provide a summary of the radical change that statutory regulation will bring

to the funeral industry in Scotland, and in evaluating this we need to consider how other sectors and occupational groups have coped and adapted their practice when comparable legislation and policy has been introduced.

Looking Elsewhere: Learning from Health and Social Care

It is vital to look at the regulatory experience of others to determine what might work or be problematic in the funeral profession. The regulatory framework for health and social care is a good example of lessons learned and good practice; it is well established and has a high profile with the public. Generally, people have some idea of where to go and what to do if they have a complaint. Health and social care regulation has, arguably, completed the journey of improving transparency, developing robust governance and, most importantly, has reached out for and accommodated public input. However, there are concerns that it is still not delivering added value, is too costly and bureaucratic and that many cases being handled by regulators take too long and do not result in outcomes that guarantee patient safety and public trust. An extract from the Law Commission regulation report states:

The history of the legal framework can be traced back to the establishment of the General Medical Council in 1858. Since then it has grown piecemeal through numerous statutes and Orders in Council which have established and sometimes re-established regulatory bodies. Added to this structure is a vast array of orders, rules and regulations that have accumulated over the years. The resulting framework is neither systematic nor coherent and contains a wide range of inconsistencies and idiosyncrasies...The current system is also cumbersome and expensive. It requires continuous Government input for its maintenance. Furthermore, constraints on Government resources mean that only the most pressing matters are taken forward.

There are nine statutory regulators of health professionals and social workers in the UK. They span vastly different professions and occupational groups. Some regulate students and others regulate businesses; still others, such as the Health and Care Professions Council (HCPC), regulate varied professions – 15 health professions on a UK-wide basis and social workers in England are covered by the HCPC. The size of regulators' registers also varies considerably, with the Nursing and Midwifery Council having a register of almost 700,000 and the General Chiropractic Council having 2,846 registrants. Recognising the complexity of the regulatory environment in health and social care, in 2014 the Law Commission's Draft Bill⁴ examined future models of regulation

4. Law Commission, Scottish Law Commission and Northern Ireland Law Commission (2014) Regulation of Healthcare professionals, Regulation of Social Care Professionals in England.

and was an attempt to streamline the legislation of the health and social care regulators. It now sits on a shelf gathering dust.

Establishing Values and Principles

As can be seen in other sectors, for regulation to work it must have proportionality, shared values and principles and achievable outcomes. It also needs to be cost effective and add value. The ability to analyse and evaluate risk and to target regulation where it is really needed is another important factor.

In healthcare the Professional Standards Authority (PSA)⁵ has a statutory remit to promote the health safety and wellbeing of patients and the public by raising standards of regulation and the registration of people working in health and care. It is independent and accountable to Parliament and can review regulators' performance and make recommendations for change.

Under its former name, the Council for Healthcare Regulatory Excellence (CHRE), the PSA published a seminal work in 2012 entitled Right-touch regulation⁶. This document established the principles for regulatory design that could, and should, inform the funeral world in Scotland.

There are eight elements that sit at the heart of Right-touch regulation:

- Identify the problem before the solution.
- Quantify and qualify the risks.
- Get as close to the problem as possible.
- Focus on the outcome.
- Use regulation only when necessary.
- Keep it simple.
- Check for unintended consequences.
- Review and respond to change.

The starting point for design of any regulatory system incorporates the eight elements and these should be adopted and recognised as the benchmarks the funeral profession should sign up to and agree on.

In healthcare, difficulties have emerged between **system** regulators who examine process, policy and places, and **professional** regulators, who examine people, standards and qualifications. These can be avoided if shared systems and objectives are formulated. Information sharing, data gathering and identification of best practice should drive a more preventative strategy underpinning regulation rather than an "after the event", punitively focused regime.

5. Professional Standards Authority. Available online at: <https://goo.gl/DZZUwJ>

6. Right Touch Regulation, CHRE, 2012.

Does Regulation Matter to the Public?

In late spring 2016, and in partnership with Cruse Bereavement Care, the National Association of Funeral Directors commissioned a detailed study into consumer opinions about funerals and funeral directors from the respected polling company YouGov. The aim of the study was to find out from the general public, including those who have been bereaved, their views of the funeral profession, what they want from a funeral service, where they would go for bereavement support and developments or improvements that could be made. The main poll was conducted among a representative sample of 2,070 British adults (aged 18+) and a second, smaller study spoke to 503 people with experience of organising a funeral in the past five years.

“82% of Britons said they think regulation of licensing of funeral directors is important.”

In the main polling exercise, 82% of Britons said they think regulation of licensing of funeral directors is important. In a separate follow-up survey with the same size representative sample 42% of UK adults said they would prefer to use an industry-regulated funeral director, 34% would prefer to use a government-regulated funeral director, 4% said they would prefer to use none of these options, 1% said they would prefer to use an unregulated funeral director and 1% said they didn't know.

The 34% who indicated a preference for government regulation were informed that this may result in higher costs as a result of regulation. In order to see the relative level of importance placed upon regulation when other factors were taken into consideration we then asked, given this new information, how likely did they think they still would be to use a funeral director who is regulated and licensed by the government? 76% of respondents said they would still be likely to, 14% said they would be unlikely to and 10% were not sure. The survey showed that ensuring high standards is very important to Britons and, for some people, this remained the case even if it resulted in higher costs.

Impact in England, Wales and Northern Ireland

There is no doubt that the experience of statutory regulation in Scotland will be watched closely across the UK, as the impact, cost and public benefit will be assessed in due course and will inform politicians and thought leaders considering the case for change in England, Wales and Northern Ireland. There is a duty to find out what works and enhances public trust and confidence, compounded by the duty that the funeral industry has to the public and to those who have died.

The Future

The move from a trade to a craft to a profession is a well-trodden path. In 2005 the Royal College of Physicians⁷ defined professionalism as “a set of values, behaviours and relationships that underpin the trust the public has in doctors.”

Relating this to funeral directors is not difficult, as public trust and confidence, upholding standards of care for those who have died and ensuring that each person gets the funeral that they would have wanted is at the heart of the occupation. The need to increase accountability to the public and politicians for pricing will need to be balanced with requirements for investment in standards, training and compliance.

Recommendations for Policy Change and Research

All of this sets an exciting backdrop to policy thinking and some challenges for policymakers. Several key questions need to be answered to enable us to work collaboratively to set the parameters for policymaking:

- How do we keep the public, those who have died and those who have been bereaved at the heart of any regulatory development?
- How do we ensure that innovation and entrepreneurial spirit is retained in an increasingly regulated sector, at the same time as ensuring that new entrants can still find a way through with new products and ideas?
- What does regulatory success look like, how much should we pay to achieve it and how will it add value?
- How can we learn from the experiences of others?
- How do we ensure that full consultation takes place, and that the impact of change is evaluated and used to inform the rest of the UK?

7. Royal College of Physicians (2005) *Doctors in Society – Medical Professionalism in a Changing World*.

Funeral Standards and Practice

Paul Allcock Dip FD,

Immediate Past President,
PR Chairman and acting
Government Liaison at the
National Society of Allied
and Independent Funeral
Directors

- At the time of writing the funeral industry is self-governing, which means that those working in the industry are tasked with setting and managing standards.
- Scotland is taking the lead with introducing formal regulation; before and when this is introduced it is paramount that clarity, education and appropriate financial solutions are in place to support bereaved people.
- Clarity regarding funeral costs is essential to ensure that bereaved people are not exploited.
- Education is vital for the funeral industry to remain up to date and maintain high standards.
- Solutions are needed to make it easier for bereaved people to carry out their loved ones' wishes without cost being a contributing factor.

Clarity of Information from Funeral Directors, Crematoria and Cemeteries on Services and Costs

At the time of writing, the funeral industry is unregulated and self-governing. The UK Government has taken a 'hands off' approach to regulation, resulting in a legislative vacuum for funeral directors to operate in. In Scotland moves towards licensing indicate that such a hands-off approach is coming to an end in one nation, but in England, Wales and Northern Ireland, there appears to be little political appetite to follow suit. As long as this unregulated situation remains, it is therefore up to the industry to set and uphold standards of practice across the sector.

An estimated 95% of funeral directors in the UK are members of either the National Society of Allied and Independent Funeral Directors (SAIF) or the National Association of Funeral Directors (NAFD). The other 5% are entirely free of association to any recognised professional body and, as such, the quality of their services and premises is not monitored. The recent appointment of an Inspector of Funeral Services in Scotland will hopefully ensure that all funeral service-related businesses across Scotland are regulated, and I for one would wish to see all funeral directors across the UK being registered and monitored in this way. Many bereaved people have no idea of the standard of the service they are going to receive unless they have used the company previously.

“For many years it has not been customary for funeral directors to show clearly their pricing and information about services on their websites. Some would argue that this could allow unscrupulous practice, and that a minority of bereaved families may have been taken advantage of financially”

Within this currently unregulated environment there is a need to protect potentially vulnerable bereaved people from any risk of bad practice, and clarity and transparency over costs is paramount. For many years it has not been customary for funeral directors to show clearly their pricing and information about services on their websites. Some would argue that this could allow unscrupulous practice, and that a minority of bereaved families may have been taken advantage of financially at a time when they are not in a position to question the advice they are given, or what is included in the costs.

Without existing regulation, there has been much work done by the SAIF and NAFD over the past 18 months to ensure that funeral directors' services and prices are easily accessible to the public. To be members of the associations, both organisations insist on price lists being clearly visible in the funeral premises and on funeral directors having them available for the public to take away. Beyond this both SAIF and NAFD have been active in encouraging their members to make services and prices clearly available via business websites. My hope would be that **all** funeral directors across the country should be obliged to follow this digital directive in due course. Such a practice would bring funeral directors up to date and into line with most crematoria and cemeteries, who have their prices available online together with information regarding memorials as well as rules and regulations to be followed by the bereaved.

There are many cemetery price lists, however, which cause confusion. Most cemeteries charge a fee for the exclusive right of burial in a grave and a separate fee for the interment. In some cases (mostly parish council cemeteries), bereaved people are being charged this fee but no grave is dug. Subsequently, it appears that some bereaved people are potentially being charged twice for the interment: once by the cemetery and again by the grave digger¹. If the interment fee is not for the preparation of the grave, then this needs clarification: what is this interment charge for? I have been a funeral director for 34 years and it is not clear to me, so it certainly will not be clear to the bereaved at their time of need.

Education is Vital for the Funeral Industry to Remain Up to Date and Maintain High Standards

The biggest issue regarding standards is the fact that any individual can open a funeral directing business. There is currently no legal requirement in the UK to be registered in any way or to have had any training or continued professional development of any sort. In 2019 this will change when Scotland introduces licensing. For now, however, there are risks in such an unfettered sector.

1. There are many examples online of parish councils not being clear on what an interment fee is. Here are two examples; one clearly states that they don't dig the grave, whilst the other offers no mention of this. Neither explain subsequently what the interment fee is for; see <https://goo.gl/fqJreW> and <https://goo.gl/RHfuix>

“The need for appropriate premises to ensure the dignity, care and respect of the deceased and their bereaved family is vital.”

The funeral sector has seen many new businesses start up over the last 20 years. Most are experienced individuals who have previously worked within the industry. However there is an existing risk of anyone opening a funeral director’s business with either no prior experience or a previous funeral-related conviction. At the very least there is a need for a nationally recognised course of education for anyone wishing to start a business as a funeral director. SAIF, via the Independent Funeral Directors College, and the NAFD and the British Institute of Funeral Directors have recognised programmes which would equip an individual with the necessary training to practice as a funeral director.

There is also a need for ongoing continuing professional development for those within the industry who already hold a recognised qualification. The demands on funeral directors from consumers has increased dramatically in recent years. There are many new products and requests previously unheard of now being presented, including but not limited to personalised coffins, ashes being placed in fireworks and specially designed service sheets on almost every funeral. It is imperative that funeral-related businesses update and improve both their premises and their knowledge to keep up with the modern alternatives, the digital world and the public’s expectations.

Within this, the need for appropriate premises to ensure the dignity, care and respect of the deceased and their bereaved family is vital. This includes a clean, hygienic, appropriately equipped mortuary with cold storage for the deceased, together with comfortable, clean rooms for families to arrange a funeral and visit their loved ones². In their position as the current safe-guarders of standards, SAIF and NAFD do quality inspections every two and three years respectively. These inspections, together with established codes of practice, ensure that the highest standards in premises and practice are attained. There is current discussion within SAIF as to whether the inspections could include a starring process to grade the standard of a premises and the procedural policies of an individual company, akin to the food hygiene rating which we see in high street food outlets. This would give the public some clear and simple information on areas of relevant quality which may assist them in choosing which funeral director they would use, particularly if they have no previous experience of organising a funeral.

Certainly, with regulation on the horizon for Scotland and the subsequent potential for educational and CPD requirements to fulfil a licence, SAIF and NAFD have worked together to produce a joint code of practice in Scotland and are continuing discussions to extend this across the UK. This will provide a consistent quality standard for the whole sector.

2. This article touches on how a funeral director with a history of malpractice can trade again with the lack of licensing: <https://goo.gl/XB3XyF>

Solutions Are Needed to Ensure that All Appropriate Funeral Services are Available for the Bereaved Regardless of the Cost

There has been much discussion over the last couple of years regarding funeral poverty and the increasing cost of funerals. Importantly, there is evidence to show that – outside of the funeral director's control – a significant factor in these increases, and probably the greatest factor, is the very large percentage increases for the cost of cremation and burials. Many local authorities in particular have increased the cost of burials so dramatically that a number of bereaved people have changed their funeral plans simply due to the costs. My nearby local authority Norwich City Council, for example, has increased their charges from £946 to purchase a grave in 2014 to £1,948 in 2017. To prepare the grave in 2014 was £661.50 and is £1,362 today. This is a total increase in three years of £1,702.50. My understanding is that this is not atypical in a number of regions. It is evident that local authorities are looking for additional income streams, and funeral-related services is one area available to them.

Sadly, it is not uncommon for some families to change their preferred choice of burial place due to the cost, and for Social Fund Funeral Expenses Payment claimants to change because they will only receive support for the cheapest burial plot local to them. These rising costs could potentially result in a deceased person not being buried with other family members, even to the extent of a married couple not being buried together due to the excessive increase in burial costs.

A more joined up approach is thus needed, one that includes public and commercial organisations working together for the best interests of the public. The risk within the context of devolution (and Scotland taking such a lead) is that there will be substantial variation in policy and practice across the country, with insufficient mechanisms to share and record good and bad practice across the four nations.

Funeral Delays beyond the Funeral Director's Control

Finally, historically a funeral would take place within a few days of death – but in more recent years this has extended to an average of closer to two to three weeks. A concerning fact emerging is that within SAIF we have had reports of local authorities' lack of availability when arranging a burial leading to delays in excess of four weeks. The reasons for this appear to be that some local authorities are cutting back on their staffing levels and often outsourcing grave digging, resulting in fewer graves being prepared within what would be classed as a reasonable timeframe. These excessive delays again have a huge effect, not only on the bereaved who have to wait such a long time to be able to lay their loved ones to rest, but also on the funeral directors who have to store the deceased for long(er) periods of time. This means that more cold storage space is required as well as having to carry out preservative treatment of the deceased when this would otherwise be unnecessary. All of this adds to the financial burden for the bereaved.

Recommendations for Policy Change and Research

- Require all funeral-related services to be registered with a recognised trade association, and regularly inspected to ensure best practice and high standards – particularly in the unregulated funeral industry in England, Wales and Northern Ireland.
- As part of this registration, insist on appropriate training for all funeral-related staff. This could be a requirement within the inspection process.
- Review progress in Scotland with a view to proposing comparable regulatory change in England, Wales and Northern Ireland in due course.

Funeral Expenses Payment

Heather Kennedy, Fair Funerals Campaigns Manager at Quaker Social Action

- People who meet the tight eligibility criteria can apply to the Social Fund Funeral Expenses Payment after someone dies for help towards funeral costs.
- Questions have been raised regarding the extent to which the Funeral Expenses Payment can respond to the needs of grieving people on low incomes.
- The government is responding to the issue of funeral poverty, but more needs to be done.

Overview of the Funeral Expenses Payment

The Funeral Expenses Payment (FEP) was set up in 1988 as part of the Social Fund, to cover the cost of a basic funeral for families where someone dies without enough money in their estate. Administered by the Department of Work and Pensions (DWP), the FEP can contribute towards cremation or burials costs, travel for the deceased and the applicant, doctors' certificates and £700 towards funeral directors' fees. Over the last 20 years, the amount that can be claimed to cover funeral directors' costs has been capped and there is now a substantial and growing shortfall between the FEP and the cost of a funeral. The powers to devolve the benefit to Scotland were set out in the Scotland Act 2016. The Social Security (Scotland) Bill, which was introduced to the Scottish Parliament in June 2017, will give the Scottish Government the power to deliver the new Funeral Expense Assistance (FEA) benefit along with ten other devolved benefits. The FEA in Scotland will be launched by the summer of 2019 as part of the first wave of Scottish benefits.

Making a claim to the FEP tends to be a lengthy and complex process. It can leave bereaved people confused and frustrated at a very stressful and disorientating time. The emotional and psychological impact of bereavement places people in a particularly disadvantaged position when it comes to making benefit applications, and advocating for themselves if something goes wrong. The financial consequences and distress caused by delays and mistakes with applications can be very damaging. At Down to Earth, a project run by Quaker Social Action to support people struggling with funeral costs, we frequently support people who have been given the wrong information about their claim, or been treated insensitively by DWP advisers.

Eligibility

Eligibility for the FEP is very narrow and many people who need help towards funeral costs do not qualify. The applicant must:

- Be over 18.
- Be on a qualifying benefit as defined by the DWP.
- Be the person the DWP deem responsible for the funeral.

These rules mean that students, under-18s and people in low-paid and unstable work are all very often ineligible for support.

If an applicant has another relative not on a qualifying benefit, this is likely to disqualify them as the 'responsible person' and their application will be rejected. People are frequently rejected because someone else in their family is not on a qualifying benefit, though never-the-less is entirely incapable of paying for the funeral.

I was turned down for the Funeral Payment after my son Alan took his own life. The DWP told me I couldn't apply because I wasn't "Alan's next of kin". How can I not be the next of kin? He was my son. The DWP told me my grandson, Alan's son, would need to apply. My grandson was subsequently turned down because he is working on a zero-hour contract. Some weeks he gets no work at all. When he does work, he's on minimum wage. How is he going to be able to afford his dad's funeral?

Client story – Billy Cargill

Questions about family relationships require applicants to provide complex quantitative information¹. The vulnerable, including those with low literacy skills, undoubtedly lose out. The form does not sufficiently take into consideration the nature of contemporary family relationships and may have the unintended impact of penalising people who do not have straightforward nuclear families.

Joanna's mum died. She is on relevant benefits and meets all the eligibility for the Funeral Payment, but was turned down by the DWP after being told her severely disabled brother should pay the bill. He had an accident when he was younger which left him with severe brain damage, and has lived in a residential home for many years. He has a mental age of 10. He's on Disability Living Allowance, which is not a benefit that qualifies people for the Funeral Payment. Joanna's brother is not mentally capable of making an application or financially capable of paying for a funeral.

Client story – Joanna Beckwith

1. <https://goo.gl/xku3za>

Inadequacy of the Payment

The FEP used to cover the cost of a basic funeral when it was first established. In 2016, the average cost of a funeral was £3,897². By contrast, the average FEP payout between 2015 and 2016 was around £1,400, which as the House of Commons Briefing Paper³ notes, is 'less than 40% of the estimated average cost of a funeral.' The amount spent on the FEP has only increased by £2 million since 1988. In real terms this represents a huge decrease in expenditure.

The substantial shortfall between average funeral costs and average FEP payments pushes bereaved applicants into unaffordable debts which hang over their heads for years to come and often cause subsequent financial problems⁴. Down to Earth clients have spoken about the burden of this debt getting in the way of their ability to grieve.

When I didn't know how I was going to pay for the funeral I was tearing my hair out. It was all I could think about. I couldn't even start saying goodbye to dad.

Client story – Valerie Gallagher

Natalia's severely disabled son died after 49 years. She had taken time off work to care for him, and so had used up all her savings to do so. Natalia arranged a very modest funeral for her son, costing £3,100. She applied for a Funeral Expenses Payment, but this only paid out £1,370. Natalia is on a very low income and is struggling to pay off the debt she's been left with.

Client story – Natalia Carlin

Delays in Processing Times

Applications to the FEP take a long time to process – data from Down to Earth suggests four weeks on average, though we have supported applicants who have waited as long as three months. This causes added distress, uncertainty and financial pressure for applicants, especially those whose religion or culture require a funeral to happen soon after death. Applicants are obliged to commit to funeral costs before they know if they will receive financial support. In so doing, they are forced to make poorly informed financial decisions that may result in substantial debt.

The DWP will not process an application until after the funeral has taken place. Funeral directors on the other hand require a deposit

2. Sunlife (2016) Funeral costs soar by ten times the increase in the cost of living in a year, available online at: <https://goo.gl/Jsghzf>

3. House of Commons Library Briefing Paper (2016) Social Fund Funeral Payments, no. 01419, available online at: <https://goo.gl/NsmBfK>

4. Citizens Advice Bureau (2012) Funeral Payments from the Social Fund, available online at: <https://goo.gl/jLcuou>

(usually the value of the cremation or burial as well as doctors' and ministers' fees) before they will go ahead with the funeral. So people find themselves trapped in a catch-22; they cannot pay for the deposit until they get the FEP, they cannot get the FEP until the funeral goes ahead.

Changes on the Horizon as a Result of Devolution

In 2016 the FEP in Scotland was devolved to the Scottish Government. The ruling Scottish National Party has looked upon this as an opportunity to address many of the widely noted and long-standing problems with the existing FEP. Over the last two years, the Scottish Government have been consulting widely with former applicants for the benefit, funeral directors and other professionals who work with bereaved people, to build a new benefit that departs from the rules and principles of the existing FEP. Within the next 12 months, the Scottish Government will publish specific plans for their new FEA, but they have already committed to shortening the time it takes to process a claim to ten days. This represents a marked improvement on the time applicants have to wait under the existing system. Having a parallel system will create a very immediate point of comparison between Scotland and the rest of the UK. If the Scottish Government are successful in reducing processing times to ten days, as well as other reforms they may implement, this is likely to increase pressure on the Westminster Government to improve their own system for England, Wales and Northern Ireland.

When it comes to responding to funeral poverty, the Westminster Government has yet to catch up with developments in Scotland. The Work and Pensions Select Committee inquiry⁵ into support for the bereaved (2015/2016) made several recommendations calling for a reformed FEP. These included:

- The government should negotiate a reasonable cost of, and items required for, a simple funeral with the industry trade associations.
- The FEP should be increased in line with the price of a simple, dignified funeral.
- An online eligibility checker should be introduced so that claimants can see whether they are likely to be eligible for an FEP and how much they are likely to receive.

In 2016, then-Minister for Welfare Delivery Caroline Nokes stated that she did not feel a digital eligibility checker would be workable; nor did she agree it was the role of government to agree a reasonable cost and the items required for a simple funeral. Thus whilst the recommendations made by the Select Committee were bold and far-ranging, government action in response to them has been underwhelming.

5. Work and Pensions Committee (2016) Support for the Bereaved, Ninth Report of the Session 2015-16, available online at: <https://goo.gl/o57Mzb>

Moreover, instability following the Brexit referendum and the 2017 general election has pushed funeral poverty down the political agenda.

However, there are signs of hope on the horizon. In July 2017 the DWP announced a consultation on a raft of reforms to improve the FEP. For those of us who have been campaigning around the FEP for several years now, this consultation represented a long-overdue acknowledgment that the current FEP is not fit for purpose and requires reform. The reforms proposed are modest, and do not tackle the main flaws within the FEP. Several organisations and industry bodies have called for the reforms to go further. But the reforms, if implemented, are a step in the right direction. They include:

- Letting people keep contributions from charities, friends and relatives. Currently any contributions you receive will be deducted, pound for pound. This is especially unfair when you consider the fund only pays for 40% of a funeral.
- Extending the claim period following a funeral from three to six months.
- Allowing funeral directors to submit funeral invoices for their applications electronically. Currently these have to be submitted by post, which slows the process down even further.

Recommendations for Policy Change and Research

Thus even though Scotland is taking control of their devolved benefit and the Westminster DWP is showing early signs of willingness to change, there are many priority areas for improving the FEP.

Give people access to a basic funeral

The FEP has been allowed to shrink in real terms for 20 years and the result is a state safety net that is no longer fit for purpose. Even those who pass the restrictive eligibility rules are left without the adequate funding to pay for even a very basic funeral. Pressure on the DWP to increase the FEP is mounting, not just from within government and from the cross-party Select Committee, but from respected national charities such as Citizens Advice⁶ and insurers such as Royal London⁷. A House of Commons note states: 'The adequacy of Funeral Payments, in light of actual funeral costs, has long been a source of complaint.'⁸

If the DWP do not favour determining the cost of a basic funeral and setting the FEP at this level, an alternative would be committing to meet the lowest fifteenth percentile of funeral costs, so people can arrange a modest funeral without being forced into unaffordable debts.

6. Citizens Advice (2013) Funeral Payments from the Social Fund, available online at: <https://goo.gl/Gcy7UV>

7. Cover (2017) Govt consults on simplifying Funeral Expenses Payment, available online at: <https://goo.gl/BZ9jfk>

8. House of Commons (2013) Standard Note, SN01419.

“A system of eligibility that hinges on often very complex family dynamics risks penalising people with less ‘traditional’ family relationships, and those with poorer literacy skills.”

Speed up processing times

Speeding up processing times for the FEP would alleviate significant stress and uncertainty on applicants. Speedier decisions around eligibility would allow people to make informed decisions about their options.

The UK Government should follow Scotland’s lead and commit to processing applications within ten days. They should work closely with representatives from the funeral industry to propose and agree practical solutions for speeding up processing times.

Extend eligibility to people in low-paid work

The UK has changed since the FEP began in 1987. 55% of people in poverty live in households where someone is working⁹. Just because someone is in low-paid or uncertain work does not mean they are in a position to pay for a funeral. The DWP should explore mechanisms for extending eligibility to people in low-paid work.

Make the rules around kinship clearer, simpler and fairer

The FEP application form and processing times are lengthened significantly by the DWP seeking to establish the ‘responsible person’ within a family. A system of eligibility that hinges on often very complex family dynamics risks penalising people with less ‘traditional’ family relationships, and those with poorer literacy skills. Down to Earth support people who should be eligible but have been turned down because the eligibility rules were not adequately explained and they were not aware what information they needed to provide.

By simplifying the eligibility rules with regards to family relationships and removing the test concerning kinship responsibility, the form and processing times for the FEP could be sped up considerably. Any cost associated with this change in eligibility could be offset by the money saved in simplifying the system. In our view this would produce a fairer system where eligibility does not hinge of people’s capacity to provide complex information about family relationships in the wake of a bereavement.

9. New Policy Institute (2016) Monitoring Poverty and Social Exclusion, available online at: <https://goo.gl/umfqLD>

Public Health Act Funerals

Julie Dunk, Deputy
Chief Executive of the
Institute for Cemetery and
Crematorium Management

- There are a rising number of Public Health Act Funerals, and an increase in those where there are families who are unable or unwilling to make funeral arrangements.
- With no review of legislation since the Public Health (Control of Disease) Act 1984 in England and Wales and the Welfare Services Act 1971 in Northern Ireland, we are concerned as to whether existing legislation is fit for purpose (nb. in Scotland S87 of the Burial and Cremation (Scotland) Act 2016 replaced the provisions contained in the National Assistance Act 1948).
- There is very little in the Act to assist authorities in carrying out their statutory duties relating to causing the body to be buried or cremated.
- A wide variety of interpretations of the Act by different authorities leads to varying standards in different parts of the country.

Background

Section 46 of the Public Health (Control of Disease) Act 1984 (hereafter referred to as the Act) places a statutory duty on local authorities in England and Wales to cause the body of a deceased person to be buried or cremated when the body is found in their area, and where no other arrangements have been or are being made. The fact that this piece of legislation is contained within a Public Health (Control of Disease) Act indicates it is more about preventing the spread of disease from undisposed bodies rather than providing a fitting funeral. In fact, the Act only specifies that the body should be buried or cremated – it does not actually mention holding a funeral. It does, however, specify that a body should not be cremated where cremation would be contrary to the wishes of the deceased. Conversely, the same is not true for burial.

Scottish local authorities have a similar duty under S87 of the Burial and Cremation (Scotland) Act 2016 (which replaced the same provisions in the National Assistance Act 1948), and in Northern Ireland the Welfare Services Act 1971 has almost the exact same wording as S46 of the Public Health (Control of Disease) Act 1984. In all countries of the UK, therefore, local authorities have a statutory duty to dispose of a body where no other arrangements have been or are being made. In Scotland the law is slightly more detailed than in England, Wales or Northern Ireland, and places a statutory duty on the authority to take consideration of any wishes the deceased expressed regarding the

“Traditionally local authorities carried out their duties under the Act for people who died intestate (without a will) and with no relatives or friends to make the funeral arrangements.”

means of disposal, and of their religion or belief.

It has been the case for a number of years that when a person died in hospital without means or without anybody to make the funeral arrangements, the hospital would take that responsibility. However, there are now a number of NHS Trusts who have stopped providing this service, and instead are referring all such cases to the local authority under S46 of the Public Health (Control of Disease) Act 1984.

Traditionally local authorities carried out their duties under the Act for people who died intestate (without a will) and with no relatives or friends to make the funeral arrangements. In recent years, however, there has been an increase in the number of cases where there are family or friends, but they are unable or unwilling to make the funeral arrangements. Funeral poverty and the cap on financial help available from the Social Fund appear to be the biggest drivers of this increase, together with a lessening of the ‘shame factor’ associated with what have traditionally been termed ‘paupers’ funerals’. This term is something of a misnomer; whilst it is true that in the majority of cases the deceased had little money and few possessions, some have quite sizeable estates. It is not uncommon for estates of several thousand or even millions of pounds to be encountered. Certainly in Bournemouth, for example, which is a large retirement area, many of the cases relate to people who have outlived their relatives, but who own their own property and have considerable savings.

Lack of education about death, the rights of the bereaved and access to sources of financial help may also have helped contribute to the increase in Public Health Act Funerals in recent years. Although death may no longer be a taboo subject, thanks in large part to initiatives such as the Dying Matters Coalition and death cafés (and possibly to a lesser extent due to death storylines in popular TV soaps), there is still a huge gap in most people’s knowledge about what they should do and what they are entitled to following a death. Information about the benefits that are available has not been clear, and the application process is complex and off-putting for many people. A recent consultation exercise by the DWP indicates their desire to improve the system and to make applying for a Funeral Expenses Payment simpler; this could give people better help to make their own funeral arrangements rather than relying on the local authority to provide a service over which they have little or no control.

Local Authority Implementation of the Act

The Act allows local authorities to recover the costs involved in causing the body to be buried or cremated from the estate of the deceased. Some authorities interpret this as meaning that they can reclaim the cost of the funeral only, whereas others include the cost of their administration, together with the funeral costs. It is important to note that there is no statutory provision to recover the costs in making the arrangements from any other source than the deceased’s estate. It is not possible for a local authority to try and recover their costs from a living relative, no matter how rich they may seem. If the deceased did not have an estate, the local authority must meet the cost from

their own budgets. This can place a significant financial burden on those authorities that carry out a high number of Public Health Act Funerals each year. The BBC Freedom of Information request, which covered 463 local authorities in the UK¹, estimated that the cost to local authorities was in the region of £1.7 million. The number of cases dealt with by each authority varies depending on the size and makeup of the local population – some authorities may only carry out a small number each year, whereas others can carry out over 100 cases. The Local Government Association surveys in 2010 and 2011 (see below) estimated that the average local authority carried out 12 Public Health Act Funerals per year, with one authority carrying out over 500.

Although the Act places a statutory duty on local authorities, it does not specify where in a local authority the function should sit. Different authorities have therefore placed the function in different departments, including environmental health, public protection, consumer services, regulatory services, bereavement services, legal services, and social services. The disparity in departments means that no one group of staff within local authorities has taken ownership of Public Health Act Funerals, and they have operated, and continue to operate, in a policy, training and guidance vacuum. Until the Institute of Cemetery and Crematorium Management published guidance and developed a training course in 2011, there was nothing available to those local government officers faced with the task of carrying out the duties under the Act. Moreover, on the first few training courses it became clear that the role was often given to officers as an additional duty, normally with little handover and no training or guidance.

The Consequences of a Policy Vacuum

The result of the policy, training and guidance vacuum is that different authorities adopt differing standards of service. In some authorities a funeral service is arranged via a funeral director at a fixed cost. In others a funeral is arranged according to how much money the deceased had in their estate. Some authorities have contracts or arrangements with funeral directors with this proviso built in, ie. if there is money in the deceased's estate, the funeral director will charge the same price as they would charge a family. If the estate is insolvent, the funeral director will provide a basic service at a cheaper cost. It is difficult to see the benefits of such an arrangement, except to the funeral director.

Ideally a Public Health Funeral should be indistinguishable from any other funeral service. An arrangement between a local authority and a funeral director should therefore include the provision of a basic funeral service with the following elements: collection of the deceased, care of the deceased prior to the funeral, provision of a simple coffin, transport of the deceased to the cemetery or crematorium in an

1. BBC (2015) Paupers' funerals cost councils £1.7m, 30th November, available online at: <https://goo.gl/RKrZ4N>

appropriate vehicle, and services at the time of the funeral. Extra services could be added, such as placing newspaper notices, provision of a simple floral tribute, or procuring the services of a minister or celebrant to lead the service. Some authorities have cut back on this latter element and have removed the actual service part from their arrangements in order to save money. Without a led service, it is then simply a disposal of a body, compliant with the Act but lacking in any compassion or acknowledgment that the deceased had lived.

Although the Act enables local authorities to recover their costs from the estate of the deceased, it contains no guidance on how to actually achieve this. Some authorities will conduct a search of the property that the deceased was living at prior to their death, whereas others do not have the resources to do this. It is unclear what powers of entry the local authority has. The purpose of a search is to determine if the deceased left a will, if there are any contact details for family or friends, and if there is any cash or items that can be sold to help offset the costs of making the arrangements. It can be difficult for local authorities to determine if searching a property is likely to yield positive results; properties are often in a poor state and if the deceased was a hoarder it could take many hours to search, as well as posing a health and safety risk. If property is recovered, the authority is then faced with how to dispose of it; there are occasions when it would cost more in officer time to sell items than the money selling such items would raise.

If the surplus of an estate is over £500.00 once the costs of making the arrangements have been paid, the authority is obliged to refer the estate to the Government Legal Department (formerly the Treasury Solicitor) under *Bona Vacantia* rules (Vacant Goods – ie. ownerless property). However, if there are any family members, the Government Legal Department will not accept the case and will refer everything back to the local authority. This creates a problem for the local authority, as they have no powers to administer an estate. There have been cases where there is a sizeable estate, but the family do not wish to have anything to do with it, and the local authority is therefore faced with assets that they have no powers to deal with.

The disparity in departments also means that it is difficult to gather data about the number of Public Health Act Funerals being carried out and the reasons for them. In 2010 and 2011 the Local Government Association collected data and produced very useful reports detailing statistics about the number of funerals, the demographics of the funerals and the financial implications for local authorities. Unfortunately the Local Government Association has not repeated the data collection, nor does it have any plans to. More recently in 2015, as mentioned above, the BBC submitted a Freedom of Information request to all local authorities in the UK, which led to an update on some of the statistics last reported by the Local Government Association in 2011. The BBC survey found that the number of Public Health Funerals being carried out by local authorities had risen by 11%, and the total spend on them had risen by 30%. No data gathering has since been carried out, so it is not possible to tell whether this trend is continuing, or if the rise has levelled off. Anecdotal evidence is that the numbers are still rising significantly, but it would be preferable to be able to support this with

“There have been cases where there is a sizeable estate, but the family do not wish to have anything to do with it, and the local authority is therefore faced with assets that they have no powers to deal with.”

hard evidence. Ideally a local authority would publish non-personal data concerning the numbers and types of public health act funerals carried out each year on their website so that any researchers could use this data to monitor trends.

A Solution?

One radical solution to the problem of people dying without means or without anybody to make the arrangements would be the provision of a simple state funeral for everybody, paid for by taxation of working people. The state funeral would be a simple funeral, but family and friends could have the option of 'upgrading' should they wish to, choosing a different coffin, floral arrangements, or family transport to the cemetery or crematorium, for example. The local authority could be responsible for carrying out the arrangements at a local level, either directly or through a contract with a local funeral director. The local authority would be reimbursed by the Treasury on submission of quarterly statistics. As a universal benefit there would be no stigma attached to a state funeral, and nobody would suffer the indignity of having an inadequate funeral service.

Recommendations for Policy Change and Research

- Conduct a review of the law and create more detailed legislation setting expected standards to ensure Public Health Act Funerals are not subject to a postcode lottery.
- Gather annual data on numbers of Public Health Funerals to monitor trends.
- Provide better information about and access to financial help for those on low incomes who may otherwise be forced to choose the Public Health Act Funeral route.
- Improve guidance on dealing with estates when the case cannot be referred to the Government Legal Department under *Bona Vacantia*
- Consider ending funeral poverty and the need for Public Health Act Funerals through the provision of a state funeral.

3

Cemeteries and Crematoria

Cremation and New Techniques

Brendan Day, Technical Coordinator at the Federation of Burial and Cremation Authorities

- Crematoria are a significant income stream for local authorities.
- Local authorities may be seen to lack the commercial acumen required to manage crematoria to their full capacity.
- Scotland is leading the way with innovation, opportunities and removing historical barriers to change; England and Wales seem to be suffering from a legislative deficit.

A Period of Expansion Not Experienced for Decades

The cremation sector is currently in a period of expansion that has not been experienced for decades. This expansion indicates that there are market opportunities available to service providers. Local authorities remain the single largest providers of crematoria across the UK, and as they continue to face financial restraint should be ideally placed and eager to take advantage of the commercial opportunities available to them. Failure to do so will not only cost them local market share but, as the sector evolves, could result in the decline of local authority dominance.

Despite their commercial potential, it is widely recognised that local authority crematoria remain low-profile services within most councils. As a result, they receive limited political support and lack financial investment, apart from that required to satisfy legislative requirements – for example compliance with the Environmental Protection Act 1990. As a result, the culture and practice at many crematoria remains unchallenged, lacking innovation and being, on occasions, commercially naïve. At the same time the range and standard of facilities is often poor when compared with those being offered elsewhere.

This is despite crematoria being significant net contributors to local authority finances. In marketing terms, the service could be seen as an excellent example of a ‘cash cow’.

Acceleration of Crematoria Construction

The development of the cremation sector, following World War Two and reaching a peak in the 1960s, was driven by municipal authorities seeking to introduce a less expensive alternative to their cemeteries. Since the 1980s the delivery of new facilities across the UK has been increasingly dominated by the private sector providing excellent new crematoria and entering into agreements to purchase/manage local authority buildings.

Between 1980 and 2010 the number of crematoria in the UK rose by 40, from 220 to 260. In the last six years the pace has accelerated with a further 21 sites opening. This has been an effective overall increase in cremation provision of almost 28%; during the same period the actual number of cremations has only increased by 9%, from 420,717 to 459,693¹.

Significantly, of the last 15 crematoria to open in the UK 13 have been built by the private sector².

Initially these new facilities were 'infilling' between existing crematoria, and thus had minimal impact on the market share and financial viability of the established local authority sites. However, the acceleration of crematoria construction will start to impact on existing facilities as provision increases beyond current demand.

The disparity between demand and increasing provision is likely to continue as the market value continues to be driven by local authorities responding to austerity.

Unprecedented Increases in Cremation Fees

A substantial reduction in local authority funding by central government has led to a projected funding gap of £5.8 billion by 2019/20³. As a result local authorities have had to adopt a range of cost-cutting and income-generating measures. These include substantial increases in cremation fees to generate additional income which will offset budget cuts elsewhere within their organisations. As the dominant provider in the sector these increases have provided 'headroom' for others to increase their fees. In the last ten years the highest adult cremation fee has risen 81% from £552 to £999⁴.

Whilst increasing income for crematoria operators, the higher fees have had the unintended consequence of reducing the volume of cremations required to make a new crematorium financially viable. A site carrying out as few as 600 cremations per annum is now a realistic business proposition.

A Local 'Churchyard Crematorium' Model for Crematoria

The financial viability of small sites raises the possibility of a 'local churchyard' model for crematoria going forward, an increase in the number of smaller sites operating within reduced catchment areas.

Such a model has obvious advantages for the public: local facilities are better able to reflect the needs of their local communities, there is less distance to travel to reach a facility – and fewer 'funeral miles',

1. Annual Cremation Statistics 2016, compiled by the Federation of Burial and Cremation Authorities.

2. List of the first and least ten crematoria to be opened in Great Britain, Crematoria Directory and additional information from the Cremation Society of Great Britain.

3. Local Government Association 'Submission to the 2017 Spring Budget' 20th January 2017.

4. Cremation Fee League Table, UK compiled by the Cremation Society of Great Britain.

benefiting the environment – and sites can be locally managed and operated through local legislation.

The new model is supported by the introduction of smaller, second-generation environmental-compliant cremators and the decline in demand for gardens of remembrance, with the continuing trend towards removing cremated remains from crematoria. In 2006, 61% of cremated remains are recorded as being removed, a figure which rises to 76% by 2016⁵.

A Devolved Scottish Model is Likely to Form the Basis of Any Future Changes

“The key statutory restraint to introducing small local crematoria is the 115-year-old requirement to site crematoria no closer than 200 yards from a dwelling house and 50 yards from any public highway.”

A reforming culture and desire to implement change is common to many newly created organisations. They are characterised, amongst other things, by a willingness to sweep away historic practices, confront self-interest, improve poor standards, harness new technology and think what might previously have been thought of as the unthinkable.

The recently devolved Scottish Government is a clear example of such an organisation. It has chosen to act on a wide range of issues, including the disposal of the dead. The focus and energy it has brought to bear, in terms of government involvement in the sector, is quite remarkable. Scottish Government interest has resulted in a new death certification process⁶, a review of infant cremation chaired by Lord Bonomy⁷, a National Cremation Investigation chaired by Dame Elish Angiolini⁸, the introduction of an Inspector of Crematoria⁹ and Inspector of Funeral Directors¹⁰, and new legislation covering burial and cremation¹¹.

The result is the creation of a whole new framework within which bereavement services – including cremation – will work. This new framework will come under greater scrutiny, but will also provide greater opportunity to developing services.

The key statutory restraint to introducing small local crematoria is the 115-year-old requirement to site crematoria no closer than 200 yards from a dwelling house and 50 yards from any public highway¹². In their updating of key cremation legislation the Scottish Government are amending the process through which cremation is delivered and, crucially, removing location restrictions on the building of new

5. Annual statistics for the disposition of cremated remains compiled by the Federation of Burial and Cremation Authorities.

6. Certification of Death (Scotland) Act 2011.

7. Report of the Infant Cremation Commission, Rt Hon Lord Bonomy 17 June 2014.

8. Report of the National Cremation Investigation, The Rt Hon Dame Elish Angiolini, 17 June 2016.

9. Inspector of Crematoria Scotland, Robert Swanson.

10. Inspector of Funeral Directors Scotland, Natalie McKail.

11. Burial and Cremation (Scotland) Act 2016.

12. Siting crematoria, Section 5, Cremation Act, 1902.

crematoria. As a result, instead of specific siting requirements, new crematoria will be subject to the normal planning process. Importantly, this brings crematoria in Scotland into line with the construction of other buildings and enables local communities to be more involved in the planning process.

Dependent upon its success, the Scottish model may form the basis of any future changes to burial and cremation law in England and Wales, as the introduction of less restrictive siting requirements will greatly increase the number of potential sites available for new small crematoria.

However, in contrast to Scotland the English Government appear, at present, to have little appetite to update this and several other key pieces of burial and cremation legislation.

A New and Evolving Cremation Market

To take advantage of this new and evolving cremation market, it will be necessary for service providers to recognise commercial opportunities as they arise. Private operators experienced in this environment already have the flexibility and financial resources necessary to react quickly to capture opportunities and provide excellent facilities. If local authorities wish to remain, and even flourish, in the cremation sector, it will be necessary for senior politicians and officers to similarly equip their own cremation services. This will require providing them with the necessary capital finance, through measures such as 'spend to save', and the flexibility to intervene quickly where and when necessary. Should local authorities choose not to adapt to this new environment and grasp opportunities as they arise, it will be necessary for them to make provision for the decline in income as catchment areas of established council crematoria are lost to new facilities.

Closed Crematoria Could Become a Reality

A failure on the part of central government in England and Wales to match the level of innovation and ambition demonstrated by the Scottish Government could result in council crematoria being faced with declining income and the rising maintenance costs associated with ageing crematorium facilities, making it increasingly difficult to justify already low levels of funding. A range of options will need to be considered, including selling facilities to the private sector, handing them to community groups to operate and manage under local legislation or, just as there are 'closed churchyards', 'closed crematoria' could become a reality, with buildings demolished whilst the grounds are converted into public open space.

Recommendations for Policy Change and Research

- Councils must recognise that crematoria are important commercial assets that are increasingly having to compete using a ‘red ocean’ strategy¹³.
- To compete with the best, local authorities must focus on delivering real service excellence to customers through ongoing significant investment.
- As income generators, crematoria are different to other local authority services and cannot simply be subject to the same level of cuts. Realistic financial targets must be set for crematoria to deliver, which recognise that investment in the facility receives priority before surpluses are drawn off to subsidise other services.
- Local authorities must recognise that additional crematoria can, if sited close by, have a negative impact on their own facilities. Working together, local authorities should seek to remove the need for the building of such crematoria through establishing additional facilities of their own.
- Local authorities in England and Wales should look to Scotland for sources of inspiration. They currently operate within the framework set by central government, and the failure of central government to update burial and cremation legislation is creating a legislative deficit when compared with Scotland.

13. According to the Blue Ocean Strategy proposed by Kim, W.C and Mauborgne, R. (2004) Blue Ocean Strategy, Harvard Business Review, available online at: <https://goo.gl/Lwh8nH>

The Shortage of New Burial Space

Tim Morris Dip FCCM, FSBP, Chief Executive of the Institute of Cemetery and Crematorium Management

- A crisis of burial across the country is looming.
- Central government's hands-off approach has contributed to this crisis.
- Fragmented legislation means there is little consistency across the nations, with Scotland currently leading the way in creating a sustainable system of provision via devolution.

Background and Recent History

It has been widely reported over the last twenty years that the UK is heading toward a burial space crisis. Diminishing availability of space for burial is having two major effects: firstly, anxiety amongst those whose personal or religious beliefs mean that cremation is not an option and, secondly, the rising cost of burial as the diminishing availability of any resource inevitably pushes up cost.

The lawfulness of the reuse of old abandoned graves across the four nations is very slowly piecing itself together via several elements of pressure, although a few opportunities have been missed along the way.

Certainly, the issue of the shortage of burial space is by no means a new policy issue. A report from the Select Committee Inquiry into Cemeteries published in 2001 stated that "If the public are to continue to have access to affordable, accessible burial in cemeteries fit for the needs of the bereaved, there appears to be no alternative to grave reuse." In the report's recommendations, the Minister at the time stated: "The case [in respect of the reuse of graves] has been made".

Shortly after the publication of the above report the Home Office, having responsibility for cemetery and crematorium matters at that time, formed what was then the Burial and Cemeteries Advisory Group (BCAG). Made up of numerous representatives from interested organisations, the BCAG embarked on a reuse initiative, drafting a code of practice and ethical standards, and considering the practicalities and potential public reaction aspects associated with the disturbance of previously buried remains. Pilot sites across the UK were identified where reuse could be practiced under close scrutiny in order to ensure that 'we got it right' before any major change in legislation was made.

Following changes in London (see overleaf) in 2010, a change of government following a general election shelved the whole notion of grave reuse across the country, and there it rested in peace for quite some time – despite BCAG delegates' attempts to 'exhume' it in

subsequent years. At the same time, the BCAG was renamed the Burial and Cremation Advisory Group.

Localised Legislation Powers to Reuse

Although dropped from the political agenda in 2010, there was cause for hope that reuse could still be possible. Three years earlier the London Local Authorities Act 2007 Section 74 headed Power to Disturb Human Remains generated much excitement amongst cemetery managers as to the potential for grave reuse. This piece of legislation only applied to local authority cemeteries in London, however. Moreover, Section 74 only permitted the reuse of private graves where rights needed to be cancelled and memorials removed (or reused). This was inevitably the more prominent areas of old cemeteries, which is where private graves with memorials exist – whereas the areas used for public graves tend to have no memorials and are in less conspicuous areas of the cemetery.

Arguably the exclusion of public graves for reuse was a missed opportunity in the 2007 Act, since creating a new section by reusing an area of old public graves in an out-of-the-way part of a cemetery, as opposed to destroying memorials and the character of the cemetery, would be a better use of available land. Practised this way, reusing public graves would not impact on existing cemetery landscapes, particularly those Victorian cemeteries where the ability to attract income through reuse would certainly provide funds for conservation.

Arguably this lack of common-sense planning was a lost opportunity for establishing best practice in grave reuse. With concerns that a conservation management plan would not logically identify this, the omission of public graves could be a reason why this legislation was not widely used in London. Certainly, the lack of use of the 2007 Act is being taken as evidence that the shortage of space is **not** critical in London. We know this is not the case. Instead, it is more likely that the legislation is inadequate for the vast majority of cemeteries and boroughs.

Power to Make Change

Alongside this missed opportunity, the Church of England has granted faculty (meaning permission) to reuse public graves on consecrated ground. Through this the power of the Church to circumnavigate Section 25 of the Burial Act 1857 became evident – and the Home Office, the Department of Constitutional Affairs, and the Ministry of Justice (MoJ) could not prevent this change, provided that remains were moved from ‘one consecrated place to another’.

The Church of England demonstrated its power again in 2014/5 when the Church of England (Miscellaneous Provisions) Measure 2014 came into effect on 1 January 2015. This piece of church law effectively amended Section 25 of the Burial Act 1857 to permit the removal of remains from ‘one consecrated place and back to the same consecrated place’. It was effectively permitting the process of ‘lift and deepen’ within graveyards across England.

Indeed, the only power that the Church of England does not have is to give local authorities and cemetery companies the power to cancel burial rights, and hence it can only issue faculty in respect of public graves on consecrated ground. Unconsecrated ground lies fallow, as a license from the MoJ would be required and this would not be forthcoming. Unfortunately, the Church in Wales has no power to authorise reuse and hence finds itself in a much worse position than England.

National and Regional Devolution

Roll forward to 2016, however, and we can start to see that devolution is making an impact. The Burial & Cremation (Scotland) Act 2016 encompasses all burial grounds and cemeteries in Scotland irrespective of ownership and creates the power to reuse graves. Once regulations are made under this Act the grave shortage issue will not exist in Scotland – if elected members and company directors decide to use the legislation. When faced with the severe strain on budgets, the fact that the provision of cemeteries by local authorities in Scotland is a statutory requirement, and given the potentially massive expenditure on creating new cemeteries, the reuse option might finally be taken up across a nation.

More recently we have seen a private bill put forward to Westminster by the private provider Westerleigh Group in respect of its cemetery at New Southgate. When passed, the act will give the company the right to reuse both private and public graves in New Southgate. At the time of writing the bill was making its way through the parliamentary process. There is no reason why this bill should not be made an act and permit the reuse of graves at that cemetery. This will represent a significant and historical shift, as private cemetery companies were excluded from using the London Local Authorities Act 2007 (the reason being in the title). The key fact and difference in respect of the New Southgate bill is that it permits the reuse of both private **and** public graves. This means that no MoJ license is required; the Church will grant faculty in respect of the consecrated ground in the cemetery and ALL graves can be selected for reuse at an appropriate time. This actually gives greater protection to the heritage value of the cemetery as more graves come into the available catchment for reuse.

The Westerleigh bill raises some interesting issues regarding the relationship between government and business, however. Private cemeteries must make a profit to remain trading, with the vast majority of local authority cemeteries subsidised. Westerleigh has obviously taken a commercial decision to commit considerable finance in pursuing a private act to reuse graves. It should be remembered that private bills are not always successful – therefore the company must have felt confident that its bill would be unopposed, and in the main it has been. If there is such confidence in reuse, both governmentally and commercially, then this begs the question: why not create legislation for local authorities in England and Wales?

Where Next?

The present unsustainable nature of cemeteries inevitably brings about the need to construct new facilities at considerable cost. With local authorities being the main providers of cemeteries across the UK, when a cemetery becomes full a local authority will be required to face some serious questions: is a new cemetery affordable? Will fees need to be increased in order to reduce deficits? Will the service be discontinued? The latter might seem unthinkable, yet has already happened in some areas: the London boroughs of Tower Hamlets and Hackney, having no new grave space in their existing cemeteries, no longer provide a cemetery service. Moreover, discontinuing a service actually costs a local authority; Tower Hamlets and Hackney are obliged to honour existing burial rights and maintain existing cemeteries, all with no great/new income stream.

“Discontinuing a service actually costs a local authority; Tower Hamlets and Hackney are obliged to honour existing burial rights and maintain existing cemeteries, all with no great/new income stream.”

In sum, legislation on the management of cemeteries in the UK was very fragmented and was not fit for purpose until Scotland grasped the nettle in 2016. The Church of England is proactive, but governments in England and Wales continue to prevaricate on the issue and lag behind. As stated at the outset of this piece, this is not a new issue and should not be a surprise to policymakers; it was observed over 15 years ago when the Select Committee Inquiry Report of 2001 commented that “The Government’s ‘hands off’ approach to cemetery provision has given local authorities carte blanche to treat cemeteries as the lowest of priorities”.

Perhaps legislative changes in Scotland – and the New Southgate bill, if successful – will be the straw that breaks the proverbial camel’s back and the opportunities for grave reuse will flood in across the four nations. Alternatively, another opportunity might arise to apply pressure for new legislation specifically for London, as it does periodically. If this occurs then on this occasion the opportunity will not be missed to draft more adequate law that includes public graves.

Such pre-emptive action taken by Westerleigh should be viewed alongside the ‘historic’ action of some of the old Victorian private cemeteries. When Nunhead, Highgate, Abney Park and West Norwood private cemeteries became unsustainable they were abandoned by their owners. This, to the Institute of Cemetery and Crematorium Management, confirms that reuse would revitalise an exhausted cemetery and make best use of available land for burial.

Recommendations for Policy Change and Research

Going forward I predict that the following may happen:

- Central government will see that the public are generally comfortable with reusing old abandoned graves via sound legislation that has safeguards for the public and previously buried remains, and cease its 'hands-off approach'.
- Reuse legislation will halt the spiralling cost of burial that can catch those on low income in the funeral poverty trap.
- The issue will become more political as the crisis worsens, as 25% of the population prefer burial over cremation.
- Cuts to central government funding of local authorities will lead to more authorities deciding to cease providing a burial service. Only time will tell what the future holds for burial space and its sustainability – although time is not on the side of the cemetery.

The Burial and Cremation (Scotland) Act 2016 and the Management of Historic Graveyards

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- Gaps in current knowledge and policy limit a consistent assessment of the cultural heritage values associated with historic graveyards to inform managed change¹.
- The Burial and Cremation (Scotland) 2016 Act provides a framework for sustainable burial provision, however secondary legislation guiding implementation is not yet drafted², curtailing the scrutiny of issues on a cross-sectoral basis.
- In particular, the low public engagement with the Bill³, as well as the public attitudes towards historic graveyards, lead to uncertainties over the acceptance of new provisions for new burial ground management and grave reuse.
- New provisions can stop future gravestones from becoming neglected by tighter control over the duration of the right of burial, but it is less clear how the new legislation may protect existing historic gravestones.
- Without further data on current provision, capacity for grave reuse, future demand and regional variations within trends, we cannot begin to model the impact of reuse and develop strategies to maximise benefits and mitigate risks to heritage⁴.

1. See for example: *Future Thinking on Carved Stones in Scotland*, *Scottish Archaeological Research Framework*, 2016. Available online at: <https://goo.gl/aUnVgx>

The Edinburgh Graveyards Project A scoping study, p17-24. Available online at: <https://goo.gl/asxFzT>

2. Guidance for lair restoration to use and for burial ground management regulations is programmed to be produced during 2018. Available online at: <https://goo.gl/72pg9S>

3. Item 18, page 3, Stage 1 Report on the Burial and Cremation (Scotland) Bill, Local Government and Regeneration Committee, Published 1 February 2016 SP Paper 895 2nd Report, 2016 (Session 4) Web. Available online at: <https://goo.gl/mhKDhv>

4. See for example 147 - National Committee on Carved Stones in Scotland Response to consultation on a proposed Bill relating to burial and cremation and other matters in Scotland, 2015. Available online at: <https://goo.gl/tKr85S>

Introduction

Powers for burial matters are fully devolved to the Scottish Government and Scotland has always had separate burial legislation⁵. The majority of churchyards, as well as cemeteries, are owned and managed by local authorities⁶. In March 2016, the Scottish Parliament passed the Burial and Cremation (Scotland) Act, which applies to all burial grounds, including closed sites, and to all burial authorities⁷. This article considers two of the new provisions enabled by the 2016 Act – regulations for burial ground management and grave reuse – from the perspective of heritage management. The paper suggests areas where cross-sectoral actions and research could shape policy development and balance the cultural heritage, recreational and amenity roles of historic graveyards.

Limits of Current Heritage Management of Historic Graveyards

The 2016 Act considers archaeological, historical and architectural values by consulting on the suitability of reusing a lair (the Scottish term for a grave); this includes securing legal permissions where statutory heritage designations and planning laws apply. In the absence of guidance it is at present unclear as to how the new powers to manage burial grounds may take account of cultural heritage. Findings from a 2016 research project⁸ detail how statutory designations, such as scheduled monument and listed building status, and existing knowledge about graveyards, is likely to be more limited than anticipated by policymakers.

Certainly, statutory designations are a strong indicator of perceived importance, notably for archaeological, historical and architectural considerations – but they are neither a full nor a final means to identify cultural values, particularly for environmental, social or public interests⁹. Many burial grounds in Scotland remain undesignated, yet possess considerable historic and archaeological interest not previously recognised. Furthermore, statutory designations are not intended to cover and protect the full range of values that may be present. Moreover, the designation process inherently lags behind new

5. Prior to The Burial and Cremation (Scotland) Act 2016, Burial Grounds (Scotland) Act 1855 was the primary burial legislation. Available online at: <https://goo.gl/WwJai7>

6. The Church of Scotland (Property And Endowments) Act 1925 transferred ownership and responsibilities for Church of Scotland churchyards to Scottish local authorities. Available online at: <https://goo.gl/JvyRfj>

7. The Act is framed to prevent family or ancestral burial grounds which are not intended for use by the general public being inadvertently caught by the Bill. Item 10, page 2, Burial And Cremation (Scotland) Bill Introduction [As Amended At Stage 2] Revised Explanatory Notes, 16 March 2016. Available online at: <https://goo.gl/JQeNBA>

8. Foster S, Forsyth K, Buckham S & Jeffrey S (2016) Future Thinking on Carved Stones in Scotland: A Research Framework (Website). Scottish Archaeology Research Framework. ScARF. Available online at: <https://goo.gl/UUQyHd>

9. For a detailed discussion on statutory heritage designations see <https://goo.gl/QuikRK>

understandings of values emerging through scientific and academic investigation and wider cultural shifts. As a result, there is a real danger that undesignated sites will be regarded as ‘easier’ options for grave reuse or gravestone clearance at the expense of their cultural heritage¹⁰.

Previous heritage management practice has not focussed in any depth on the late Victorian to early 20th century elements of burial grounds, the most likely candidates for grave reuse and gravestone clearance. More generally, in Scotland we lack consistent, basic documentation for gravestones, including chronological and regional overviews to gauge rarity or representativeness of individual or groups of gravestones¹¹. No single archive, organisation or sector possesses a remit for overseeing the full range of cultural values gravestones or graveyards might possess. Conservation management plans are an effective, but currently underused, tool for drawing information and different interests together. They can be particularly effective at recognising the contribution of gravestones to the graveyard’s historic landscape character and documenting social and public values. Public response to the consultation on legislative changes was low, however, and, with the exception of genealogy, it failed to evidence the range of social and public values placed on graveyards¹². This is problematic, as social and public values are likely to be significant in strengthening community attachment and shaping the multifunctional use of graveyards.

Areas of Uncertainty for Headstone Maintenance and Safety under New Powers for Burial Management

The lack of regular maintenance of gravestones and other monuments is a major contributory factor in the neglected condition of Victorian cemeteries and historic churchyards. The 2016 Act enables, for the first time, general provisions to manage Scottish burial grounds and a protocol for dealing with ‘abandoned’ gravestones. Scottish Government policy indicates the intention to place burial authorities under a specific duty to ensure gravestone safety, where the burial authority will determine, in line with guidance, the method of carrying this out (including repairs, laying flat or by removing gravestones)¹³. The guidance is yet to be drafted and will refer to the Local Authorities Cemeteries Order 1977 (England and Wales) – although this does not set out any criteria to lead this area of decision-making. Each of the aforementioned options for intervention presents a very different

10. See for example 126 - ALGAO_Scotland Response to consultation on a proposed Bill relating to burial and cremation and other matters in Scotland, 2015. Available online at: <https://goo.gl/ecAiEC>

11. See footnote 1.

12. Consultation analysis report, Consultation on a proposed Bill relating to burial and cremation and other related matters in Scotland July 2015, p 18. Available online at: <https://goo.gl/zbb2ZS>

13. Burial and Cremation (Scotland Bill) Explanatory Notes session 4 (2015) 8. Available online at: <https://goo.gl/wojnfV>

“Most local authorities carry out regular gravestone health and safety checks, where the majority of unsafe headstones are laid flat or the detached components brought together and propped upright, rather than resetting or repairing stones.”

consequence for the protection of individual heritage values, and possible outcomes for the character of a historic landscape as a whole. Furthermore, each type of action is likely to require different resources and levels of financial investment.

Currently, most local authorities carry out regular gravestone health and safety checks, where the majority of unsafe headstones are laid flat or the detached components brought together and propped upright, rather than resetting or repairing stones. This contributes to a burial ground’s appearance of neglect. Our difficulty in anticipating the likely impact of the new management provisions is compounded by the Scottish Government’s assertion that burial authorities will not incur additional costs as a result of the new powers since ‘burial authorities already carry out maintenance work on headstones and memorial’ – but at the same time their aspiration is for the new powers to maintain burial grounds and protect their cultural heritage and amenity values¹⁴. In 2007, the Graveyard and Cemetery Review Group recommended that general provisions for burial ground management should be introduced, but noted:

Were burial authorities to be given the power to repair and conserve such abandoned memorials/headstones even where, as is usually the case, they do not own them, a very positive difference could be made to the management of graveyards. In view of the significant financial implications which this would have, however, no recommendation is made.¹⁵

The case that routine maintenance presents the best means of long-term preservation and structural stability, potentially forestalling a later need for more complicated and expensive repairs, has been made by burial authorities and heritage managers alike across Scotland¹⁶. However, existing good practice conservation guidance is not effectively informing the day-to-day care of historic cemeteries, graveyards and gravestones currently. In part, this is because the available guidance cannot be implemented since it does not match the available resources and service delivery mechanisms of Scottish burial authorities.

14. Official Report Meeting of The Scottish Parliament, Thursday 11 February 2016, p 93. Available online at: <https://goo.gl/kbdX6u>

15. Burial And Cremation Review Group Report and Recommendations October 2007, item 50, p14. Available online at: <https://goo.gl/LnpyW3>

16. For example see Item 22 PAPER 1 B&C Review Group 16 May 2005 (DRAFT), available online at: <https://goo.gl/v1NpGo>, and *The Edinburgh Graveyards Project A scoping study*, p17-24, available online at: <https://goo.gl/3JDoSA>

Absence of Data to Understand Likely Scale, Scope and Demand for Reuse in Practice

Responses to the Bill consultation process¹⁷ highlighted variability among local authorities' support for reuse, either in principle or when disturbing human remains. Many questioned the financial viability of reuse and their capacity to deliver 'lift and deepen' options on practical and technical grounds. Opinions were mixed on the likely demand or need for burial space locally, particularly in the short term. While heritage bodies are generally supportive of the proposals, they stressed how the absence of contextual information made it impossible to appreciate the fundamental implications in practice, such as the number or types of sites and graves likely to be affected, which made it difficult to provide a fully considered view. The small number of community interest groups and individual members of the public who responded generally opposed reuse, with some expressing concerns over the adverse impact on heritage. The low level of public engagement lacks evidential weight and was noted within parliamentary scrutiny¹⁸.

To stimulate the necessary level of engagement and engender meaningful public debate on grave reuse will require education and coherent cross-sectoral working. Unravelling the history of burial provision and cemetery management may offer a means to stimulate interest¹⁹. It can illustrate how present approaches form part of a longer and ongoing narrative of society's responses to managing death, where grave reuse previously formed part of accepted funerary practices²⁰.

The Bill process further highlights pressure on the availability of burial land in parts of Scotland, although no consistent pattern emerges²¹. There are insufficient details to assess the extent of current burial space in different areas (urban, rural or remote) or the potential capacity for local grave reuse against projected demands for burial in the future. Policymakers drew on practice at the City of London Cemetery²², but this did not identify aspects where this case study may

17. Burial reform has formed the basis of two public consultations: once in 2010 alongside cremation and death certification and again in 2015 with cremation. See <https://goo.gl/BHFxky> and <https://goo.gl/7sTgh8>

18. See footnote 3.

19. See for example Peter C Jupp, Douglas J Davies, Hilary J Grainer, Gordon D Raeburn and Stephen RG White 2017 *Cremation In Modern Scotland History, Architecture and the Law*, John Donald.

20. See for example BUCKHAM, S., 2016. 'Not architects of decay': the influence of graveyard management on Scottish burial landscapes. in: S. BUCKHAM, P.C. JUPP and J. RUGG, eds, *Death in Modern Scotland, 1855–1955 Beliefs, Attitudes and Practices*. *Studies in the History and Culture of Scotland—Volume 6*. Oxford: Peter Lang, pp. 215–240.

21. Item 32, p5, Stage 1 Report on the Burial and Cremation (Scotland) Bill, Local Government and Regeneration Committee, Published 1 February 2016 SP Paper 895 2nd Report, 2016 (Session 4) Web. Available online at: <https://goo.gl/Zy1BsF>

22. The 2015 Scottish Government public consultation on changes to burial legislation included a case study from London. This case study outlined the legislative change that had taken place and summarised how the City of London Cemetery, as a burial authority, has developed various local protocols and techniques to deliver grave reuse in practice.

be too culturally specific to model reuse across Scotland or at other types of burial landscapes. By identifying a range of Scottish models, including sites where mixed use is successfully delivered and sites where it is not, it will be possible to develop cross-cutting strategies to balance multifunctional use of historic graveyards that ensure cultural heritage is protected within wider public values. Such an approach would help us understand if some sites are not suited to reuse for cultural, rather than technical or legal, reasons.

Recommendations for Policy Change and Research

The following actions are recommended as a robust basis to create secondary legislation guidance informed by a sound evidence-base and cognisant of cross-cutting priorities:

- Establish a cross-sectoral forum, similar to the Scottish Graveyard and Cemetery Liaison Group²³, with a specific remit for historic burial grounds within the wider context of burial legislation and policymaking. The group's role would be to integrate the efforts of all relevant bodies, identifying cross-cutting priorities and facilitating the exchange of information and expertise.
- Capitalise on the popular interest in heritage generally and historic graveyards specifically to raise public awareness of the 2016 Act and to stimulate meaningful debate on the linked issues of burial provision and cemetery management. Activities should gauge public attitudes towards new provisions, particularly grave reuse, and encourage participation in any Scottish Government consultations. This will be achieved through collaborative working involving government bodies, third sector and community groups, to draw on the sector's expertise in and systems for public-facing communication and engagement.
- Commission research to quantify and characterise regional variation within current burial provision in Scotland, to establish capacity for grave reuse and future demand. This should be achieved through case studies of urban, rural and remote settlements. Research aims include identifying the range of cultural factors influencing these different areas and highlighting opportunities and risks as a basis to develop management strategies and guidance.
- Initiate a targeted audit of historic gravestones and graveyards to document what survives, and in what condition. Carry out preliminary analytical groupings to identify fundamental aspects of significance and risk, and to define management priorities. Findings should inform conservation management policies and guidance (eg. maintenance guidelines, conservation management plans). Guidance should be tailored to match resources available to

23. The Scottish Graveyard and Cemetery Liaison Group (2003-2006) was convened by Historic Scotland to bring together parties with a vested interest in graveyard management to discuss priorities in common and to exchange information and expertise. See <https://goo.gl/c53uWY>.

- burial authorities and should aspire to improve current standards of care (eg. for grass-cutting and dealing with invasive vegetation).
- Share findings and good practice with other three nations, who also have the issue of managing historic cemeteries and available space for burial.

Conclusion

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This policy brief has shown that national and regional devolution presents opportunities to revise, innovate and modernise policy and services in this area. There is enormous potential at this important juncture to (re)establish the role, purpose and function of the welfare state in supporting individuals and families at the end of life and post-death.

With constructive involvement from the third and commercial sectors, policymakers have an opportunity to reinforce the role of the welfare state in supporting the most vulnerable people in society from the 'cradle to grave'. In so doing, beyond the critical issues of resourcing and equality, attention needs to be paid to the organisation of policy areas and services, overlaps and knock-on effects, ensuring that policy is responsive and future-proofed as the death rate across the UK rises. It will also necessitate robust measures to generate high-quality, meaningful data that can be shared across national and regional boundaries to document and respond to trends, facilitating and spreading good practice and learning from one another.

One thing is for sure: people who are dying or bereaved need and deserve public policy and services that are transparent and simple to access. At such a time in life, individuals and their families should not be subject to extra burdens as a result of inadequate policy, legislative and policy vacuums, incoherence, poor planning and so on. We know that the death rate in the UK is going to rise, and we know that this means that more and more people will be facing their own and other's deaths. As a matter of public interest, death can no longer be neglected as a policy issue.

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Acknowledgements

We gratefully acknowledge all the contributors to this brief, who have shared their insight voluntarily and without incentive.

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