

Life After Death



Six steps to improve
support in bereavement

Introduction

The death of someone close will affect almost all of us at some point, with almost half of people (47%) reporting being bereaved in the last five years aloneⁱ.

Bereavement can influence every aspect of well-being, from physical and mental health to feelings of connectedness and the ability to function at work or school. A death often means other changes for those left behind, such as taking on new responsibilities, moving house, or adjusting to different living standards.

Learning to live with the loss of someone close is one of the most painful experiences we can encounter. Society's response often makes it even harder. All too frequently, people report feeling isolated and being expected to 'get on with it' after a bereavement, even when they had been very close to the person who died or when their death had been unexpected. Three-quarters of people who have been bereaved say they didn't get the support they neededⁱⁱ. In 2012, less than half of those who wanted to talk about their feelings with someone from a health, social care or bereavement service were able to do soⁱⁱⁱ.

This is not least because policy developments have been ad hoc, leading to confusion and complexity, with no clear responsibility for meeting bereaved people's needs. This vacuum of responsibility has unintended consequences, making many people's experiences of bereavement even more difficult and further threatening their wellbeing.

The costs of bereavement are too great to ignore, both for individuals and society. Bereavement increases the risk of mortality and poor health^{iv}. In Scotland, the annual cost of hospital stays following the death of a spouse is estimated at £20 million^v. The greater number of deaths in England will put the total cost here much higher - somewhere between £150 and £190 million. The figure would be even greater if it included the impact of the death of a child, parent or someone else close, and took into account the costs of increased use of other health and social care services and days off work.

The number of people bereaved is also likely to grow, with deaths each year in England predicted to rise by 15% between now and 2035^{vi}. This is alongside increases in the population and a dramatic rise in the proportion of elderly people^{vii}. A recent House of Lords report highlighted how we are 'woefully underprepared' to meet the challenges of an ageing population^{viii}: one of these challenges will be the growing number of people bereaved, and the elderly will be particularly affected.

The National Bereavement Alliance has a vision that all people have awareness of and access to support and services throughout their bereavement experience. Working with the National Council for Palliative Care and the Dying Matters Coalition, its members have identified six crucial steps to address bereavement as a major public policy issue.

These steps could bring great benefits to individuals and to society as a whole: reducing the use of acute health and social care services, lessening the number of days lost to the economy, and improving the wellbeing of those facing such a significant change in their lives.

What could help?

1

A named Minister with responsibility for bereavement

Responsibility for policy affecting people who have been bereaved is split across many government departments, including the Department for Work and Pensions, Department of Health, Ministry of Justice, Ministry of Defence, and Home Office. While it is right that these departments are all involved, there is a lack of joined up thinking and a danger that the needs of bereaved people are overlooked because they are seen as another department's responsibility.

We need a named Minister with responsibility for bereavement, to make sure that those who have been bereaved are given the priority they deserve in the making and implementation of policy and practice. This person would be able to coordinate action across all government departments and review the impact of policies affecting bereaved people.



2

A national review of the impact of financial, administrative and economic changes on those who have been bereaved

An urgent first task for this Minister would be to coordinate a cross-departmental review of the financial impact of current welfare, administrative and economic changes on those who have been bereaved – a review which needs to happen in any event. Money worries are one of the biggest reported concerns: initially meeting the costs of the funeral and disbursements, but also over time adjusting to a changed household income.

Changes to the benefits system, the rising costs of funerals and other processes around a death, and an economic slump are creating a perfect storm for some bereaved families. Without proper scrutiny and overall planning, these are likely to result in greater levels of poverty and distress. The review should cover key issues including:

- **Rising funeral poverty:** the average shortfall among those struggling to pay for a funeral is £1277^{ix}. Without action we will not only see continued distress but also more funerals where the local authority bears the cost, while other vulnerable bereaved people spiral further into debt^x.
- **Changes to bereavement benefit from 2016/17^{xi}** which will make some people newly eligible but are much less generous to many of those with children: 75% of these families will be worse off than they would be under current arrangements^{xii}.

- **Hardship for unmarried partners** who get no help under current or proposed bereavement benefit schemes, even if they had children together. If the person who died didn't leave a will, their unmarried partner has no automatic right to inherit^{xiii}.
- **Introduction of Universal Credit (UC) from autumn 2013.** Benefits will run on for three months after a significant death^{xiv}, but there are serious concerns about UC's introduction, in particular how it will interact with current bereavement benefits where claimants could find themselves getting no net gain from their allowance.
- **The 'under-occupancy charge'** affecting any family in social housing where the death means they have a 'spare' room. Currently, families have 52 weeks after a death before they are re-assessed, but once UC is introduced they will have three months in which to decide whether to move to a smaller property (assuming there is one available) or face a reduction in their housing benefit, which could leave them unable to continue to pay their rent^{xv}.

I visited a lady who is on her own, aged 60, in a two-bedroom flat. She will be affected by the 'bedroom tax' until May 2015. She was a lovely lady, really welcoming. Her flat was beautiful. She explained to me how the spare bedroom was used for her late husband. She cared for him in that bedroom until he sadly passed away. She doesn't want to leave her home to downsize as she has fond memories of her husband there and also in the surrounding areas are her friends and family. What got to me was she said to me that she is already struggling to make her money stretch but in all seriousness she said she would go without food before falling into arrears. After everything she has faced and after the effort she has put into her home, this was heartbreaking.

Case study from staff member, Bron Afon Community Housing
www.bronafon.wordpress.com



3

Clarity about who is responsible locally for commissioning and providing bereavement support, with better coordination and information about services

Many bereaved people find a lack of organised support.

In 2012, less than half of bereaved relatives who wanted to talk about their feelings to someone from a health, social care or bereavement service were able to do so^{xvi}. Limited catchment areas, long journey times, referral procedures, waiting lists and limited provision all exclude people from getting support. Even when services are available, people may not know about them, or the stigma of seeking support can put them off.

The National Council for Palliative Care reported that just 54% of 117 newly created Health and Wellbeing Boards had considered end of life care – including bereavement – in their public strategies by February 2013, shortly before they took on their responsibilities^{xvii}. Bereavement support also doesn't appear in key drivers for health bodies, such as the NHS Mandate, and outcomes frameworks for the NHS, Adult Social Care, and Public Health.

This means that support services are provided patchily. Bereavement services received a blow in 2011 when the Palliative Care Funding Review excluded bereavement support from its proposed new funding tariff for dedicated palliative care. Although the Review didn't propose a way of funding services, it acknowledged that 'we do think it is important that universal access to these services is available for everyone if they need them'^{xviii}.

The reforms to health structures are an ideal opportunity to ensure that the needs of bereaved people are met locally, joining up end of life care and mental health provision to address bereavement as a public health issue in its own right. We need national leadership and clarity about who should commission and fund this support, ending the costly marginalisation of bereavement among health and social care services and giving it parity with other life transitions and difficulties.

A coordinated approach is needed to set out exactly what provision is available in each area: both local services at all stages of the bereavement care pathway, and links to national resources and helplines. Bringing this information together should be the responsibility of the local Health and Wellbeing Board, in partnership with local Clinical Commissioning Groups.

The Laura Centre is a community based bereavement service covering Leicester, established in 1991. It supports bereaved children and anyone affected by the death of a child. In a population of around 1 million, it sees 5-600 clients a year. The Centre's model of support is built around every family's needs and can include short or long-term individual work, and a chance to meet others who have been bereaved. A mother whose child had died said that the service 'literally saved my life'.

www.thelauracentre.org.uk

Cruse Bereavement Care provided one-to-one support to over 28,000 children and adults across England, Northern Ireland and Wales last year, and saw almost 6,000 people in groups. A client said 'I just wanted to thank you for all your help over the past eight weeks, if it wasn't for your guidance I would still be struggling. The support I've had has been incredible.'

www.cruse.org.uk



4

Training in bereavement for all those coming into contact with bereaved people, at a level appropriate to their role

Anyone working on a day to day basis with people is likely to come into contact with those who have been bereaved. They can be anxious about how to acknowledge what has happened and how to respond: worrying about making things worse, saying the wrong thing, or getting upset and overwhelmed themselves. All too often, they end up saying nothing at all.

Initial training covering an awareness of grief reactions, how to respond, and where to refer for more help, should be mandatory for those likely to come into contact with bereaved people through their professional role – GPs, social workers, teachers, benefits employees, healthcare professionals, police, social care workers, registrars, coroners, hospital staff and many others. Those working in greater depth with people facing or following a death will need very much more intensive training, which provides continuing opportunities to learn and improve practice, accompanied by ongoing support and supervision.

Accessing local training from specialist bereavement services can also help to build links with local organisations, making professionals more aware of the support on offer, and more able to refer bereaved families appropriately when they need more help.

Child Bereavement UK provides a day course on 'When a child dies – supporting parents and family members'. Aimed at those in community nursing, paediatrics, chaplaincy, bereavement services and social services, the course aims to build confidence and explore the impact of the death of a child on the family and on the professionals working with them. Sharing experiences is an important part of the workshop. One participant said 'I have learnt a lot today, especially to listen to what families are saying, and not beat myself up for not having all the answers. I feel more confident to approach parents before and after a death.'

www.childbereavement.org.uk/training

5

Better bereavement support at work

In any workforce, bereavement is an issue for employees, their colleagues, line managers and HR staff. Some employees will have needed time off to care for the person who is dying, and then to organise the funeral and to begin to adjust to life without them. Some will want to return to work as quickly as possible, while others will need more time. Some will need to change their working patterns to manage new caring responsibilities – e.g. for children or elderly parents – that emerge as a result of their bereavement.

There is no statutory entitlement to paid bereavement leave in the UK. Although employees do have a right to ‘reasonable’ unpaid time off to deal with the consequences of the death of someone dependent on them, which could include organising and attending a funeral, there is no guidance about how long is ‘reasonable’.

While some employers are sympathetic and flexible, others are less amenable and make it difficult for employees to take the time they need and get the support they require^{xix}. This can be a significant source of stress to bereaved people, with some then needing additional periods of time signed off sick. It is difficult to estimate how many people are in this position and the overall impact on the economy, as their absence is more likely to be put down to stress or depression, rather than linked to the bereavement.

New ComRes research for the National Council for Palliative Care and Dying Matters has found significant levels of public support for improved bereavement support in the workplace^{xx}. Amongst the key findings are:

- The overwhelming majority of British adults (87%) agreed that all employers should have a compassionate employment policy, which includes paid bereavement leave, flexible working and a range of other support available.
- More than four in five people (81%) agreed that there should be a legal right to receive paid bereavement leave where someone close to the person in question (such as a child, parent or partner) has just died.
- 82% of people agreed that providing employees with paid bereavement leave is likely to be beneficial to the employer in the long term.
- The majority of people (56%) said they would consider leaving their job if their employer did not provide proper support if someone close to them died.
- Almost a third (32%) of people who had been bereaved in the past five years who were in a job at the time said that they were not treated with compassion by their employer.



These findings confirm that a national review of employment practice relating to bereavement is needed to improve the way that bereaved people are treated at work, reducing uncertainty and poor practice, and increasing loyalty, staff morale and productivity. This review should explore the feasibility of minimum statutory paid bereavement leave, and identify ways of making fitness to work certification and occupational health support work better for bereaved people. It should make recommendations for individual employers including sample bereavement policies, incentives for good practice, and training and support for line managers, who play a hugely important role in influencing grieving people's experience of the workplace^{xxi}.

Individual employers can also take action now to set out their provision for bereaved employees in a policy, covering how paid and unpaid bereavement leave will be decided and how someone should ask for it, being flexible enough to meet the differing needs of employees. In settings associated with end of life care, such as care homes, hospitals and hospices, the policy should also detail how staff will be supported to deal with bereavement in their professional as well as their personal lives.

Local bereavement services can help employers to develop a compassionate approach, including developing policies and training staff, at the same time increasing awareness of the wider support available.

Lucy Herd has been campaigning for the Government to review statutory bereavement leave since the tragic death of her young son Jack in August 2010. Lucy says 'It was at that time I realised every company has their own Bereavement Policy and 3 days off work seems to be the norm; also one of those days has to be the funeral. You are entitled to sick leave or you can take holiday entitlement from your employer but you shouldn't have to use sick or holiday leave.'

Visit Lucy's petition at www.change.org/en-GB/petitions/david-cameron-legislate-bereavement-leave-for-the-death-of-a-child



6

More compassionate communities where everyone knows enough about grief to play their part in supporting people around a death

Feeling lonely and isolated is one of the most common difficulties for people after the death of someone close. This can be especially hard for those with no family or friendship networks close by – particularly elderly people.

There is an ongoing taboo in society about talking about dying, death and bereavement, which can inhibit people from reaching out and offering support. While support from family, friends, neighbours, employers and others may be good in the immediate aftermath of a death, it often dwindles over time as others get back to ‘normal’ routines. There are strong beliefs in society about how grief ‘should’ be. Comments such as ‘you should be over it now’ can be meant kindly but experienced as hurtful and unhelpful. They can even be frightening for people who may start to think there is something wrong with them and the way they are responding.

There are some simple steps that any of us can take when someone we know has been bereaved, which could make a huge difference to how supported they feel. This might be about having a simple conversation in the street or the shops, or about making time to go round and visit, or about keeping a note of key dates – birthdays, anniversaries – when someone might appreciate some extra support. Doing something concrete such as bringing a meal round on a particular day can be more helpful than making an abstract offer such as ‘let me know if there’s anything I can do’.

Education about bereavement should be the norm, so that children, young people and adults are better equipped to deal with changes and losses themselves, and support others. Talking more openly about our own wishes for the end of our lives and our funerals can be helpful to our families in the future: almost two thirds of people in the British Social Attitudes survey 2012 wanted to make plans to make things easier for their families and friends. The challenge is to turn this into action^{xxii}.

References

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- ⁱ ComRes interviewed 4,038 GB adults online between 15th and 21st November 2013. Specifically, 2,010 adults were asked question 1, 4,038 adults question 2 and 841 adults question 3. Data were weighted to be representative of all GB adults aged 18+. ComRes is a member of the British Polling Council and abides by its rules. Full data tables are available on the ComRes website, www.comres.co.uk. See www.dyingmatters.org for more information on methodology.
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- ^{xii} <https://www.gov.uk/government/publications/further-analysis-on-the-reform-of-bereavement-benefits-for-new-claims-from-april-2016>
- ^{xiii} <http://lawcommission.justice.gov.uk/areas/intestacy-and-family-provision-claims-on-death.htm>
- ^{xiv} Universal Credit Regulations 2013 <http://www.legislation.gov.uk/uksi/2013/376/contents/made>
- ^{xv} <http://www.housing.org.uk/policy/welfare-reform/bedroom-tax>
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- ^{xx} See note ⁱ
- ^{xxi} Shucksmith, J; Hall D and Russell, S (2011) How can Human Resources policies support a Compassionate Community approach to end of life? A report to the University Research Fund
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About the National Council for Palliative Care

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers.
www.ncpc.org.uk

About the National Bereavement Alliance

National Bereavement
Alliance

The National Bereavement Alliance is an emerging group of organisations with a shared vision that all people have awareness of and access to support and services through their bereavement experience. Members include national and regional membership organisations, national providers of bereavement care and local unrepresented bereavement care providers. For more information on the work of the Alliance, please visit
www.nationalbereavementalliance.org.uk

About the Dying Matters Coalition



The Dying Matters Coalition aims to help transform public attitudes towards dying, death and bereavement in England. It is led by the National Council for Palliative Care, and has over 30,000 members including charities, care homes, hospices, GPs, funeral directors and legal and financial organisations.
www.dyingmatters.org

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Registered Charity no. 1005671
A company limited by guarantee no. 2644430

Life After Death
£2.50

ISBN 978-1-898915-98-9

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Published January 2014 by the National Council for Palliative Care.