



Manifesto for better bereavement support

General Election 2019

November 2019

National Bereavement

Alliance

Our manifesto

Over 500,000 people die each year in England, leaving bereaved family and friends to cope with the aftermath of loss. Some are shocked by a sudden and unexpected death, some are exhausted by the strain of caring for someone at the end of their life, all are faced with adjusting to a future without the person – baby, child or adult - who has died.

Our manifesto sets out the commitments we want to see from the next Government:

- A named Minister with responsibility for bereavement including a cross-departmental strategy
- A national review of the impact of financial, administrative and economic changes on those who have been bereaved
- Clarity about who is responsible locally for commissioning and providing bereavement support, with better coordination, secure funding and information about services
- Training in bereavement for all those coming into contact with bereaved people, at a level appropriate to their role
- Better bereavement support at work
- More compassionate communities where everyone knows enough about grief to play their part in supporting people around a death

These manifesto calls are based on our [Life after Death](#) report which set out six key steps that could improve support for bereaved people. Developed in consultation with our members supporting bereaved people, these are the changes that could make the biggest difference to those who are grieving today, tomorrow and in the future.

About the National Bereavement Alliance

The Alliance is a group of organisations with a shared vision that all people have awareness of and access to support and services through their bereavement experience. The core membership of the Alliance comprises national and regional membership organisations with an interest in the field of bereavement care, and national and local providers of bereavement care.

For more information on the work of the Alliance, please visit www.nationalbereavementalliance.org.uk

Introduction

72% of people have been bereaved in the last five yearsⁱ, and almost all of us will be affected by the death of someone close at some point. While grief is not an illness, bereavement can influence every aspect of our well-being, from physical and mental health to feelings of connectedness and the ability to function at work or school. A death in the family often means other changes 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, especially as time goes on. Less than half of those who wanted to talk about their feelings with someone from a health, social care or bereavement service got to do soⁱⁱ.

This is partly 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 makes many people's experiences of bereavement even more difficult, further threatening their well-being.

The costs of bereavement are too great to ignore, both for individuals and society. Bereavement increases the risk of mortality and poor healthⁱⁱⁱ. In Scotland in 2011, the annual cost of hospital stays associated with the death of a spouse was estimated at £20 million^{iv} – across England in 2019 this would equate to annual costs somewhere between £180m and £260m. The figure would be much higher if it included the impact of the death of a child, parent or someone else close, and the costs of increased use of other health and social care services and days off work.

The number of bereaved people is likely to increase over the next five years. If mortality rates stay the same, then with a population that is both growing and ageing, the number of deaths each year in England is predicted to increase by 10% between 2017 and 2023^v. A House of Lords report highlighted how we are 'woefully underprepared' to meet the challenges of an ageing population^{vi}: 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. Our members 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 more acute health and social care services, lessening the number of days lost to the economy, and improving the well-being of those facing such a significant change in their lives.

We are calling on candidates for the General Election to commit to these simple steps.

What could help?

A named Minister with responsibility for bereavement including a cross-departmental strategy

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 through a cross-departmental strategy – like the Loneliness or Suicide Prevention Strategies - and review the impact of policies affecting bereaved people.

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. Money worries are one of the biggest reported concerns: both the immediate costs of the funeral and disbursements, but also over time in adjusting to a changed household income.

Recent policy changes to the Funeral Expenses Payment, Children's Funeral Fund and bereavement leave for parents are welcome but there is much more to do. Changes to the benefits system, the rising costs of funerals and other processes around a death, and economic conditions 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 £1,990^{vii}. Without action we will not only see continued distress but also more funerals where the local authority bears the cost^{viii}, while other vulnerable bereaved people spiral further into debt.
- The impact of changes to bereavement benefit in April 2017 which made some people newly eligible but are much less generous to many of those with children: 75% of these families are worse off than they would have been under the old system^{ix}.
- Hardship for unmarried partners who get no help under the old or the new bereavement benefit schemes, even if they had children together. This is despite a Supreme Court ruling that it was unlawful to deny Widowed Parent's Allowance to a mother because she was living with but not married to her partner^x. If the person who died didn't leave a will, their unmarried partner has no automatic right to inherit^{xi}.
- Introduction of Universal Credit (UC) for those making a new claim following their partner's death, who do not get transitional protection of their income.
- The 'under-occupancy charge' affecting any family in social housing where the death means they have a 'spare' room. Under the old housing benefit system, families had a

'grace period' of 52 weeks, but under Universal Credit, families have just three months in which 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^{xii}.

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

It is generally accepted that people do not need routine referral for bereavement counselling simply because they have been bereaved^{xiii}. Offering counselling routinely may encourage people to use services rather than turning to family and friends or allowing their grief to follow its natural course. It could encourage people to view grief as a mental health problem per se, rather than a normal reaction to loss which can increase vulnerability. It could lead to the unnecessary over-professionalization of bereavement care.

However, some bereaved people will need more support than their families and friends can currently provide. Flexible, non-stigmatising, commissioned support at multiple levels helps communities to respond adequately, and provides more intensive help to those who need it. This includes opportunities to meet other bereaved people, and 1:1 support. This may be commissioned across a range of services including end of life care, carers' support, maternity services, mental health services, suicide postvention, emotional wellbeing and services for specific groups. Commissioners also need to plan to respond at every level to meet the needs of communities affected by local disasters and incidents.

Despite the need, 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 got to do so^{xiv}. Limited catchment areas, long journey times, referral procedures, waiting lists and limited provision all exclude people from getting support. Most services are in the voluntary sector and precarious funding means that support is fragile and under strain.

Even when services are available, people may not know about them, or the stigma of seeking support can put them off.

We welcome recent commitments in the NHS Long Term Plan to fund support services for those bereaved by suicide, and would like to see similar security of funding for services for those bereaved in other ways. We need better join-up between end of life care, mental health provision and strategies to tackle loneliness, so that bereavement can be addressed as a public health issue in its own right. We need national leadership and clarity about who should commission and fund this support, with secure funding, ending the costly marginalisation of bereavement among health and social care services and giving it parity with other life transitions and difficulties.

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.

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.

From April 2020, parents will have the right to two week's statutory leave if their child dies under the age of 18, and will be paid if they have been working for their employer for a certain length of time. There is no such statutory entitlement for other employees. 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^{xv}. 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. 56% of people would consider leaving their job if their employer did not provide proper support if someone close to them died^{xvi}.

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^{xvii}.

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.

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 difficulty 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 meet loss and bereavement 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.

References

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ⁱⁱ Office for National Statistics (2015) National Survey of Bereaved People (VOICES) 2015. Available at <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/datasets/nationalsurveyofbereavedpeoplevoices>

ⁱⁱⁱ Stroebe, M.S., Schut, H., and Stroebe, W (2017) Grief is not a disease but bereavement merits medical awareness. *Lancet* vol 389 pp347-349. Available at https://www.researchgate.net/profile/HAW_Schut/publication/312959954_Grief_is_not_a_disease_but_bereavement_merits_medical_awareness/links/59d9ab05a6fdcc2aad0de4ff/Grief-is-not-a-disease-but-bereavement-merits-medical-awareness.pdf

^{iv} Birrell et al (2013) Socio-Economic Costs of Bereavement in Scotland: Main Study Report. <https://www.artshandwellbeing.org.uk/sites/default/files/Socio-Economic%20Costs%20of%20Bereavement%20in%20Scotland.pdf>

^v <https://www.gov.uk/government/publications/health-profile-for-england-2018/chapter-1-population-change-and-trends-in-life-expectancy>

^{vi} Select Committee on Public Service and Demographic Change (2013) 'Ready for Ageing?' London: The Stationary Office <http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/140.pdf>

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ix <https://www.gov.uk/government/publications/further-analysis-on-the-reform-of-bereavement-benefits-for-new-claims-from-april-2016>

x <http://www.childhoodbereavementnetwork.org.uk/media/92034/bereavement-benefits-and-cohabiting-parents.pdf>

xi <https://www.citizensadvice.org.uk/family/death-and-wills/who-can-inherit-if-there-is-no-will-the-rules-of-intestacy/>

xii <http://researchbriefings.files.parliament.uk/documents/SN06272/SN06272.pdf>

xiii Stroebe, MS; Stroebe, W; Schut, H and Boerner, K (2017) Grief is not a disease but bereavement merits medical awareness. *Lancet*, 347-389.

xiv Office for National Statistics (2013) Statistical Bulletin: National Bereavement Survey (VOICES) 2012

xv McGuinness, B (2009) Grief in the workplace: developing a bereavement policy. *Bereavement Care* 28 (1) 2-8; Hall D, Russell S and Shucksmith J (2013) Building a compassionate community: developing an informed and caring workplace in response to employee bereavement. *Bereavement Care* 32 (1) 4-10

xvi On behalf of the National Council for Palliative Care, ComRes interviewed 4,038 GB adults online between 15th and 21st November 2013. Specifically 2,010 adults were asked for their views about how employers should respond when an employee is bereaved, 4,038 adults were asked whether they were working for an employer when somebody close to them died, and 841 adults were asked about the support they received after they had been bereaved whilst employed. Data were weighted to be representative of all GB adults 18+.

xvii 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 <http://www.tees.ac.uk/docs/DocRepo/About/URF%20HR%20Policies%20Report%20Final.pdf>