

A better grief



palliative,
neurological
and bereavement
support

Background

We all experience bereavement and grief at some stage in our lives. Seventy-two per cent of us have been bereaved at least once in the last five years, according to new research commissioned by Sue Ryder.

Yet, as a nation, we find it hard to talk about and harder still to help people dealing with a bereavement.

Bereavement has an impact not only on those who are grieving their loved ones but on society more widely. Bereaved people are significantly less likely to be in work in the year after their bereavement and that remains the case two years after their loss¹. Bereaved people are also more likely to suffer serious health problems, including disability; to be taking medication; and to be hospitalised. They are also at greater risk of dying prematurely themselves.

Yet policymakers have paid little attention to this important issue. The National Survey of Bereaved People (VOICES), which collects information on the quality of end of life care, has not been conducted in England since 2015² and in Scotland a pilot of the survey has been repeatedly delayed.

The Scottish Government published the 'Shaping Bereavement Care Framework' eight years ago, but palliative care has since been transferred from the NHS to new Health and Social Care partnerships and it is unclear who now has responsibility for bereavement support.

For many people, support from family and friends will be enough to help them through their grief. But for others it is not sufficient. Sue Ryder believes that, wherever someone lives and whatever their circumstances, they should be able to receive bereavement support if they need it. As a charity,

we have expanded our own bereavement support network, growing our Online Community and introducing Online Bereavement Counselling, but we recognise that much more needs to be done on a national level.

This report is intended to trigger a debate about bereavement. It poses three questions: What evidence is there about the range of services offered to the bereaved? What is the demand for these services from the bereaved? Are those people struggling with bereavement receiving the support they need?

We commissioned two pieces of research, an independent review of bereavement services summarising the last 10 years of research, and an opinion poll to survey people's experiences of bereavement. In this report, we bring together the findings and present our recommended actions.



The Academic Evidence

The University of Birmingham's School of Nursing conducted a rapid evidence assessment on behalf of Sue Ryder. They analysed the provision and effectiveness of bereavement services in the UK, including the role of informal support. They also examined the wider social and economic impact of failures to support the bereaved.³

Their key findings were:

1. **The provision of bereavement support is extremely varied**, ranging from counselling and group support to online information. There is no conclusive evidence which types of support are the most effective because existing research is so limited.
2. **Much more research is needed** to map the current scope of bereavement services, identify people's needs and assess what types of support are most helpful.
3. **Practical information about bereavement should be made as widely available as possible** to help people access support. However, bereavement is a very individual experience and people have specific needs depending on their circumstances and the nature of the death. One size does not fit all.
4. **There is widespread recognition of the potentially negative impact of bereavement**, but the evidence on how best to support the bereaved is contested.



The Polling Evidence

The polling agency ComRes was commissioned by Sue Ryder to conduct a nationwide opinion poll of more than 2,000 adults. They surveyed people's own experiences of bereavement and whether they had received support, beyond that provided by family and friends. They also surveyed people's experiences of dealing with others who had suffered a bereavement⁴.

Bereavement support:

- **72% of people had been bereaved at least once in the last five years**
- **Only 9% of people had received any kind of support, aside from the support of family and friends**
- **Amongst this group, only 35% said they had found the support helpful**
- **31% of those who did not receive any formal support said that it would have been helpful**
- **Amongst this group, 38% said they either did not know how to get support or felt uncomfortable asking for it**
- **On average, 36% of people said they would be uncomfortable approaching professionals, such as doctors, nurses, hospice staff, priests or social workers, for support with bereavement.**⁵





51% of people



said that they would be scared of saying the wrong thing to someone who was recently bereaved

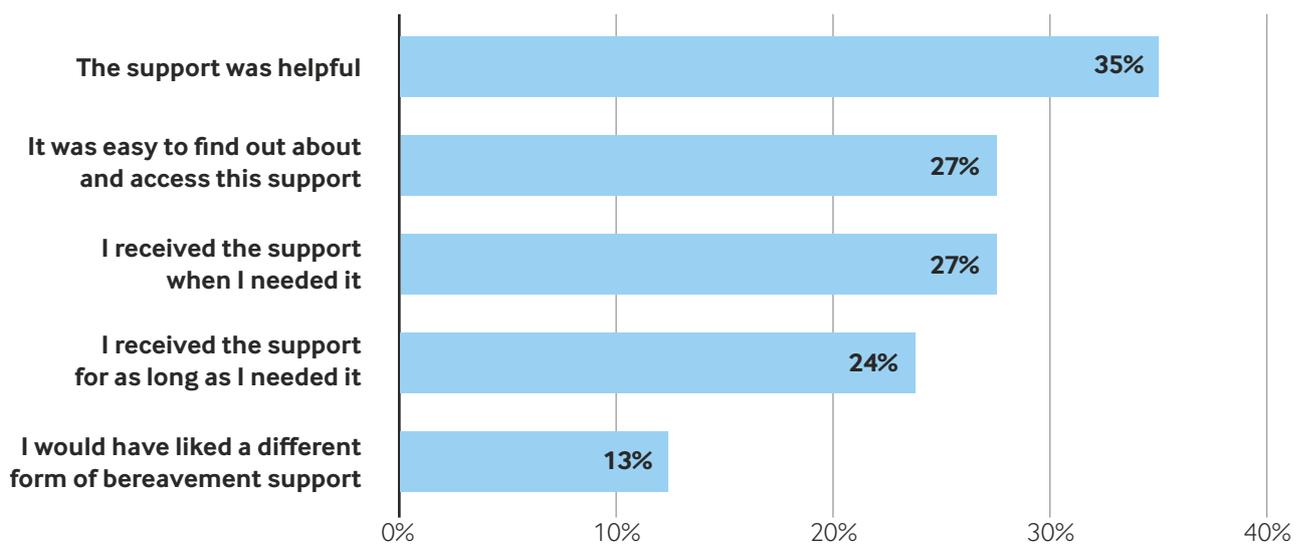
The poll findings suggest there is a gap between the need for support and the numbers who are receiving it. This is partly explained by the fact that only 27% found it easy to discover what was on offer and how to access it. (Figure 1) Others may have thought they could cope with their grief in the immediate aftermath of their bereavement, but later regretted not asking for help.

The findings also suggest that people’s experiences of bereavement support were not always positive. This might be connected to the fact that only 27% felt that they received the support at the right time

and only 24% felt supported for as long as they needed it. (Figure 1)

People who are more socially isolated, were more likely to say that they did not access bereavement support because they did not know how to get it or felt uncomfortable asking for it – reaching this group of people more effectively is a challenge that needs to be addressed. The lower someone’s socioeconomic status, the more likely they were to say they did not receive support because they were uncomfortable asking for it, which represents a further challenge.⁶

Figure 1: What did people who received support with their bereavement feel about it? (Respondents selected all options they agreed with).



Amongst adults aged 18-34

63%



feared saying the wrong thing to bereaved people

Amongst all respondents

48%



said they would know what kind of help or support to offer someone who was bereaved

Figure 2: Why did people who didn't get formal support with their bereavement (but feel it would have helped them) not access it?⁷ (Respondents selected all options they agreed with).

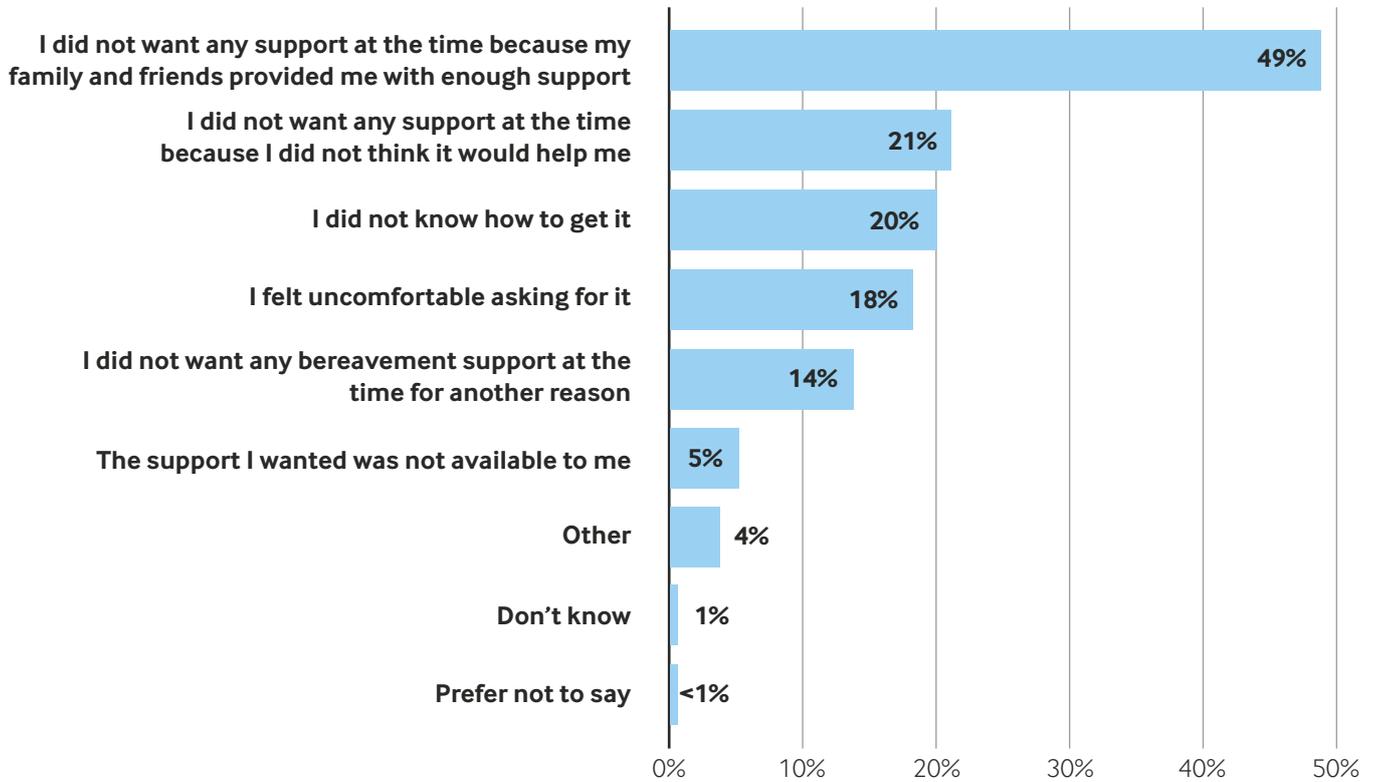
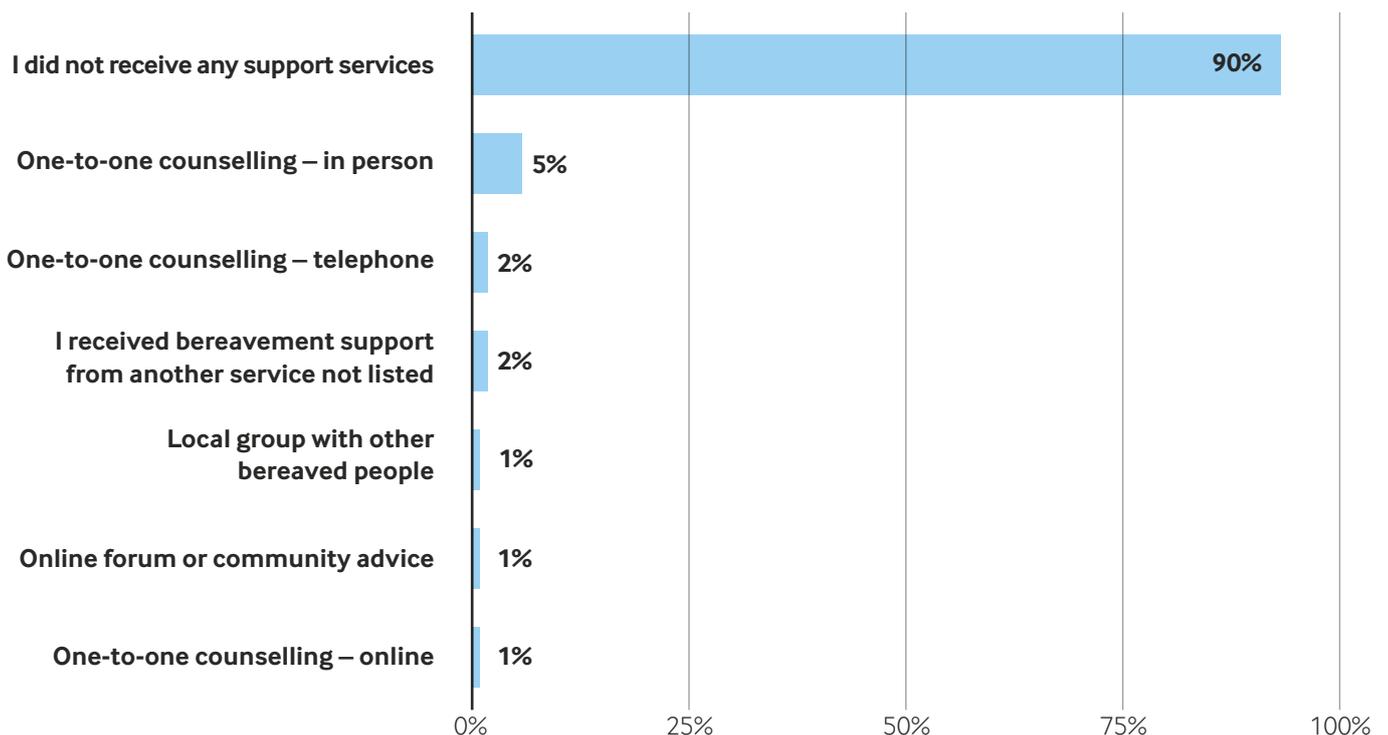


Figure 3: What formal support did people receive for their bereavement? (Respondents selected all options that applied to them).





Attitudes To Bereavement:

- **51% of people admitted that they would be scared of saying the wrong thing to someone who was recently bereaved – in Scotland this figure was even higher: 56%**
- **Amongst adults aged 18-34, 63% feared saying the wrong thing to bereaved people**
- **48% of people said that they would know what kind of help or support to offer someone who was bereaved – in Scotland this figure was even lower: 40%⁸**

The poll findings show that bereavement remains a difficult subject for many people to talk about. Death

is the final taboo in our society. This seems to be partly down to embarrassment and a fear of unintentionally causing offence to the bereaved; perhaps because people are not used to having open conversations about death and the impact of bereavement.

Perhaps unsurprisingly, this trend is most pronounced amongst young adults, some of whom will not have suffered a bereavement themselves. However, on average, people experience their first close bereavement at 20⁹ and the poll found that young adults who had been bereaved were also less comfortable than older generations in asking for support from healthcare professionals. They were also more likely to have admitted not getting support that might have been helpful because they had not felt comfortable asking for it.

Conclusions:

We do not know what forms of support are most helpful to bereaved people because so little research has been done in this area. However, we do know that bereavement has a significant impact on health and wellbeing and that most people would value access to better support to help them cope with bereavement. This knowledge gap needs to be addressed.

Sue Ryder believes that everyone who needs bereavement support, in addition to the informal support provided by family and friends, should be able to get it. Kindness and compassion should be at the heart of all bereavement support. However, it needs to be personalised and provided in a way that works best for the bereaved and at a time when they are ready to receive it.

Bereavement has an impact not only on those who are grieving their loved ones but on society more widely.

We need to start an open, honest national conversation. We need to address our reluctance to talk about death and dying; bereavement is an unavoidable aspect of all our lives and nothing short of a cultural revolution is required to bring it out of the shadows and make it a matter of public debate.

Sue Ryder wants to work with government and with professionals in the health, social care and education sectors, as well as those directly involved in end of life care and bereavement support, to help lead this debate.

Calls to Action:

- 1. We are calling on government to take the lead in commissioning comprehensive research into the availability of bereavement support and the impact of different types of bereavement services. As a first step, a new VOICES survey of bereaved relatives should be conducted throughout the UK.**
- 2. We call on government to work with all relevant agencies in the healthcare and social care sectors to ensure that anyone who wants bereavement support is made aware of what is available and can easily access it in a way that suits them.**
- 3. We ask employers to consider training 'bereavement first aiders' in the workplace, giving them the skills to help bereaved colleagues who want to return to work and might benefit from this support.**
- 4. We want to work with local organisations and voluntary groups to create 'compassionate communities' throughout the UK. As a key part of this, we would like to see a network of bereavement specialists in every community, known to GPs and primary care teams, who can provide informal support.**
- 5. We urge the media, and all those with an opportunity to shape public debate, to promote a cultural sea-change by actively encouraging people to talk more openly about dying, death and bereavement.**

“ By triggering a national conversation about bereavement we can make people realise that avoiding the subject out of embarrassment is often the worst thing you can do. We need to create ‘compassionate communities’, empowering ordinary people to feel they can help, rather than assuming it is the preserve of health professionals.”

Heidi Travis

CEO, Sue Ryder

- 1 Birrell et al. (2013) Socio-Economic Costs of Bereavement in Scotland <https://www.artshealthandwellbeing.org.uk/sites/default/files/Socio-Economic%20Costs%20of%20Bereavement%20in%20Scotland.pdf>
- 2 Office for National Statistics, (2016) National Survey of Bereaved People (VOICES) 2015 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>. In July 2018 the Department of Health and Social Care stated that while work had been done on a new version of the survey, “a timetable for the publication of the next survey cannot be provided at this time.” <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2018-06-28/158729/>
- 3 Hewison A, Zafar S and Efstathiou N (2019). Bereavement Support in the UK – a rapid evidence assessment. Sue Ryder/University of Birmingham, Birmingham.
- 4 ComRes interviewed 2,189 British adults between 14th and 19th December 2018. Data were weighted to be demographically representative of all British adults by age, gender, region and social grade. To see the full data tables for the polling, please visit <https://www.comresglobal.com/polls/sue-ryder-bereavement-support-survey/>
- 5 The professionals asked about in the polling were as follows: a GP/practice nurse; District nurse; a doctor or nurse working in a hospital; a hospice, or a member of hospice staff; a local or national charity; a religious or spiritual advisor; a social worker; a funeral director/undertaker.
- 6 Figures here are indicative due to limited base size.
- 7 Figures here are indicative due to limited base size.
- 8 Figures here are indicative due to limited base size.
- 9 Co-op funeralcare. (2018). Making peace with death: National attitudes to death, dying and bereavement <https://www.co-operativefuneralcare.co.uk/globalassets/media-centre/2018/august/co-op-funeralcare-media-report.pdf>

There when it matters

Sue Ryder supports people through the most difficult times of their lives. For over 65 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can.

We take the time to understand what's important to people and give them choice and control over their care. This might be providing care for someone at the end of their life, in our hospices or at home. Or helping someone manage their grief when they've lost a loved one. Or providing specialist care, rehabilitation or support to someone with a neurological condition.

We want to provide more care for more people when it really matters. We see a future where our palliative and neurological care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

Contact us

call: **0808 164 4572**

email: **info@sueryder.org**

visit: **www.sueryder.org**



[/SueRyderNational](https://www.facebook.com/SueRyderNational)



[@sue_ryder](https://twitter.com/sue_ryder)

Elinor Jayne

Policy and Public Affairs Manager (Scotland)

campaigns@sueryder.org

Duncan Lugton

Policy and Public Affairs Manager (England)

campaigns@sueryder.org

Sue Ryder, 183 Eversholt Street, London NW1 1BU