

Bereavement support in Scotland

A report by
Sue Ryder and Hospice UK
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palliative,
neurological
and bereavement
support

Introduction

Modest estimates put the number of people bereaved each year in Scotland at over 230,000.¹ A crucial component of the Carers (Scotland) Act, in force since April 2018, is the expectation that local authorities will provide information and advice regarding counselling and bereavement support to adult and young carers.² This should mean that more people are aware of what support is out there to help them cope with the hardest of times.

To assist local planning, Hospice UK and Sue Ryder have joined together to explore access to bereavement services by engaging with people who have recently lost someone close to them.

Background to the research

Bereavement has been linked to a number of adverse outcomes, including poor socio-economic and health outcomes.³ Given the scale of the impact of bereavement on individuals, families, communities and the nation it is imperative that a bereaved person is able to access the support they need.

Every 22 minutes a child is bereaved of a parent in Britain.⁴ Bereavement is recognised as an adverse childhood experience (ACE) which can impact on mental and physical health and social outcomes. For instance, it can affect educational attainment and employment status in later life and research suggests a correlation with youth offending.

Bereavement affects people in different ways and how people journey through bereavement cannot be predicted.⁵ For each person, and over time, what they need will vary. Evidence indicates that blanket interventions will not work: for example, not everyone will benefit from intensive one-to-one bereavement counselling.⁶ For some people more informal and online fora might be right, and for many the support of family, friends and colleagues will enable them to manage their grief over time.

If legislation like the Carers (Scotland) Act is to achieve its aims for bereaved people, more people will need to be aware of the support they could be accessing and services will have to be ready to provide different forms of support. For public and third sector providers of such care to respond effectively, there is a need for evidence: how many people access support, why don't people access support and what kinds of support do people find most helpful?

Hospice UK and Sue Ryder commissioned Scotland-wide research to understand who is accessing support, how they access it and what might prevent people getting the support they need.

We surveyed 2,341 adults (18+) in Scotland who have experienced at least one bereavement in the last five years. Most people surveyed (68 per cent) experienced bereavement following the death of a close relative, followed by 16 per cent who lost a friend.

Research was undertaken using the ScotPulse online panel between 4 and 6 September.⁷

Findings

Too many people are missing out on bereavement support

Nearly one third (31 per cent) of respondents say they needed additional support beyond family and friends to manage their bereavement. But:

- Only 6 per cent of all respondents accessed bereavement support.⁸
- A further quarter (23 per cent) of respondents would have liked support but couldn't access it because: they didn't know how (12 per cent); felt uncomfortable asking for it (8 per cent); or couldn't get the type of support they wanted (3 per cent).

Based on the estimate that around 230,000 people in Scotland are bereaved each year, an estimated 53,000 people could be missing out on support that would help them cope with bereavement.

Between 10 – 20 per cent of bereaved people will experience prolonged grief.⁹ This means grief where the experience of debilitating grief does not recede and the risk of experiencing adverse health and social outcomes increases.¹⁰ This group of people are also most unlikely to ask for help.¹¹ With just 6 per cent of all respondents accessing support, it is clear that people experiencing the most profound, isolating and potentially damaging forms of bereavement are going without the support they need.

Scottish hospices provide a wide range of bereavement support, free of charge, to thousands of adults and children every year. They provide this to family and friends of patients, and people from their wider communities.

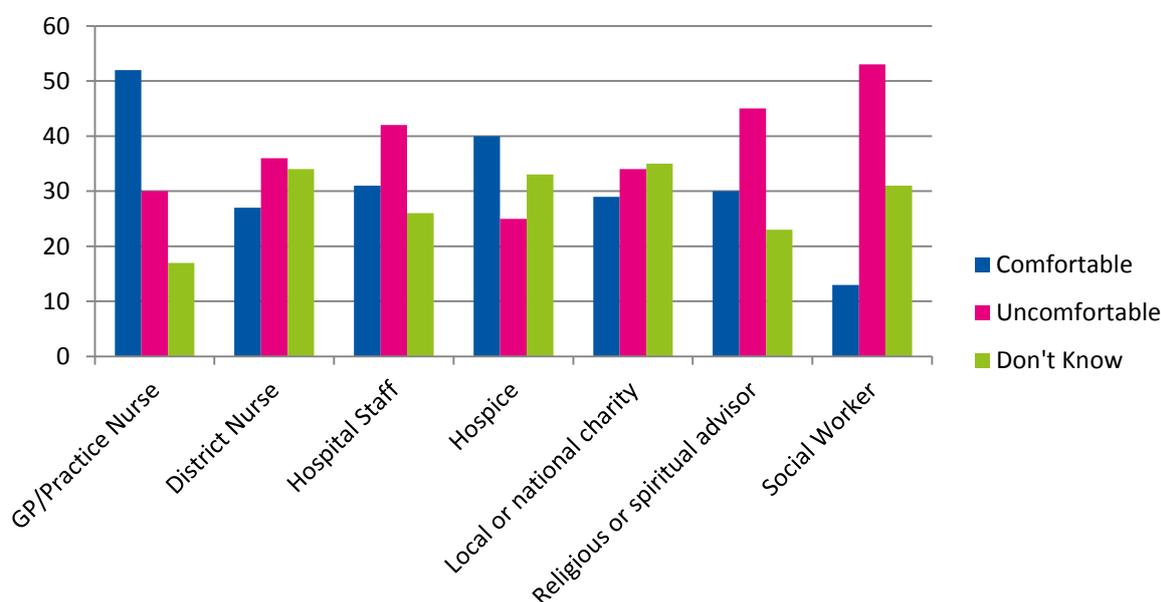
"I have found that I look forward to attending group and for a couple of hours I can relax among people who are willing to listen if I feel I need to discuss my loss. It made a big help with my health and pain of losing my husband."

Participant, Accord Hospice peer support walking group.

How people find out about bereavement support

GP practices, hospices, other local or national charities, hospitals, religious organisations and the internet are good gateways to accessing bereavement support. It is encouraging that many people feel comfortable approaching a range of professionals and organisations, or researching online, but the numbers of people who don't feel comfortable are high.

Fig 1: How comfortable people feel about approaching different professionals and organisations to ask for help (as a percentage of all people who didn't access bereavement support).



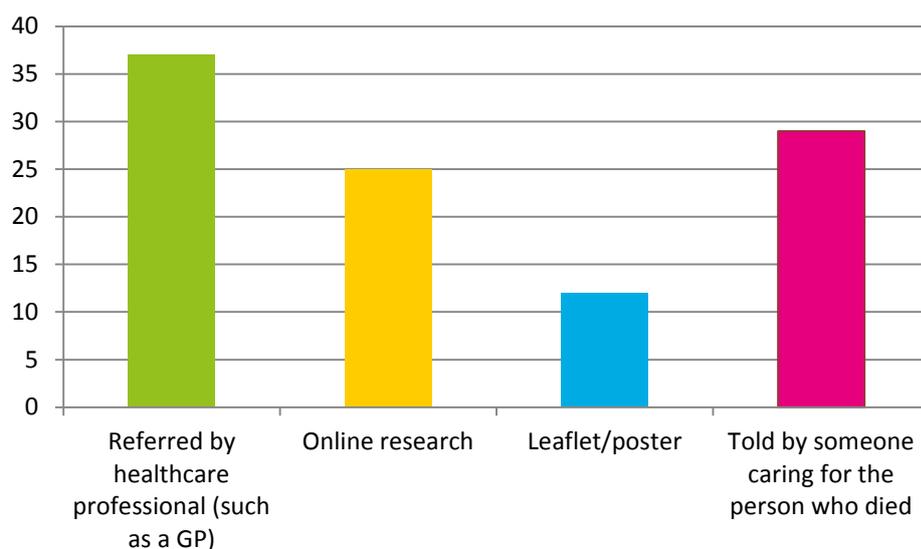
“Having supported my wife through five years of treatment, the support after her passing was a great help, only too often are people forgotten after death, I don't think I would have been here without it.”

Recipient of bereavement support provided by Marie Curie Hospice Edinburgh.

GPs/practice nurses and those in caring roles are well placed to signpost and refer people to bereavement support. Over half of all people who didn't receive support say they would have felt comfortable approaching a GP/practice nurse for help if they needed it. For those who did access support, the most common gateway to support was via a GP (37 per cent accessed support this way) followed by someone caring for the person who died (29 per cent).

The third sector is a well-trusted source of support and signposting with 40 per cent of people saying they would feel comfortable approaching a hospice, followed by 29 per cent who say they would feel comfortable asking a local or national charity for help.

Fig 2: How people find out about bereavement support (as a percentage of all people who accessed support).



The internet is also a popular way to find out about support: a quarter of people (25 per cent) who accessed support found out about it through their own online research.

Not everyone will access services in the same way. For example, we find that socio-economic status impacts on how people access services:

- People on lower incomes are more likely to be referred by a healthcare professional (42 per cent of people on lower incomes were referred by a healthcare professional compared to 31 per cent of people on higher incomes).¹²
- People on higher incomes are more likely to find out about support by doing their own online research (30 per cent of people on higher incomes who accessed support did so via their own online research compared to 20 per cent of people on lower incomes).

Our findings indicate that one of the main barriers to accessing support is that people don't feel comfortable asking for it, and that they are most uncomfortable approaching social workers (53 per cent); religious or spiritual advisors (45 per cent); and hospital staff (42 per cent).

Crocus Group offers a flexible bereavement support service for children and young people. This service is operated under the auspices of Highland Hospice and is open to all children and young people in the Highlands regardless of the cause of death. Crocus helps children understand it is alright to smile again and enjoy what they love without feeling guilty.

A carer for a child helped by Crocus says:

“I feel that Crocus is a gentle way for children to process their feelings following one of the most difficult losses they are ever likely to suffer...it has helped my child to maintain a connection with her mam, encouraging her to keep memories precious and to know it is ok and indeed healthy to maintain a connection.”

Types of support and levels of satisfaction

One-to-one counselling is what most people picture when they think about bereavement support: one to one counselling is by far the most common type of support people have accessed and the most common form of support people think would help them. This presents challenges for provision and also managing expectations given budgetary constraints and evidence that not everyone will benefit from this form of support. We identify an appetite for other forms of support, which are less resource-heavy, which could be developed to ensure more people can access the support that is right for them.

For people who accessed support, one-to-one counselling is the most common type (63 per cent of people who got support received one-to-one counselling), followed by support groups (22 per cent) and online support (11 per cent). Satisfaction with current services among people who accessed support is high:

- Most (86 per cent) say it helped them cope.
- Two thirds (68 per cent) say it was easy to find out about and access the support.
- Three quarters (73 per cent) say they had support for as long as they needed.

When people who didn't access support are asked what support they think could have benefitted them, one-to-one counselling is most commonly cited as potentially helpful (46 per cent of people said this would have helped them). This is followed by local support groups with other bereaved people (25 per cent); online fora/communities/ advice (20 per cent); and counselling by phone (18 per cent).

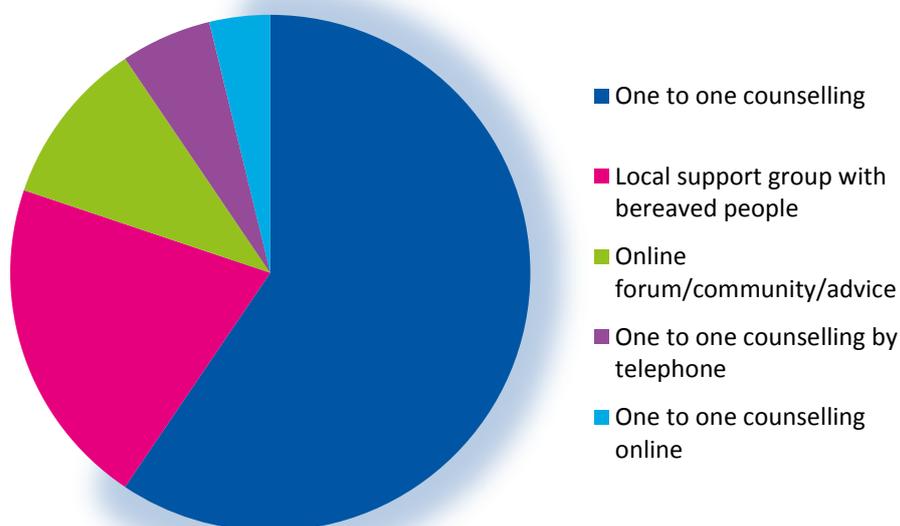
Younger people are more likely to say they would find online support beneficial (31 per cent of under 35s, compared to 15 per cent of 66-84 year olds, with preference for online support decreasing as years increase).

The Sue Ryder Online Community, launched in June 2015, supports people when a loved one is dying or has died. The site is Sue Ryder's first truly national service and aims to bring information and support to people beyond hospice locations. In the 2017/18 user survey 84 per cent of users said that the site has helped them feel less alone, while one fifth have no other sources of support showing just how important the community is in reaching new audiences. So far this year the community has supported over 110,000 people and registered users have posted more than 1,000 times a month.

In May this year Sue Ryder launched a pilot of a new Online Bereavement Counselling Service for community members. More than 90 people have registered for this service so far, which provides free bereavement counselling over video chat.

To find out more visit www.sueryder.org/support.

Fig 4: Support types people accessed



The more socially isolated someone is, the harder it is to access bereavement support.

Our research finds that people who rarely or never interact with people outside their own home tend to find accessing support harder.

People who are socially isolated are more likely to say they would have wanted support beyond family and friends: 38 per cent compared to 30 per cent of those with at least monthly contact with family or friends. Our research indicates potential barriers around confidence, trust and awareness:

- People who experience social isolation are more likely to feel uncomfortable approaching professionals to ask for help than people who are socially active.
- People who experience social isolation are more likely to say they would have liked support but didn't know how to access it: 31 per cent compared to 23 per cent of more socially active people.

Impact of the Carers Act

We find no difference in access since the introduction of the Act – at least, not yet. There was no difference in experiences between people who had experienced bereavement since April 1 2018 (the date the Act came into force). Just six months on, it is possible processes are still embedding. We hope this research helps local authorities to work in partnership with others to ensure everyone who needs bereavement support can access it.

Conclusions and recommendations

Bereavement is a life-changing experience. For most people, the support of family and friends will help them through but for some people extra help is needed. We now know that nearly a quarter of bereaved people say they didn't get the support they wanted. Given the potential harms of bereavement to individuals and wider society, it is imperative that people are able to access the support they need.

OUR VISION: Everyone has a right to bereavement support.

Not everyone will need support beyond family and friends, but everyone who might benefit from bereavement care should be able to access it easily, in a way that suits them at a stage that suits them.

This will be achieved by:

1. **A refreshed national approach to bereavement care.** Scotland needs a refreshed national approach to improving access to bereavement support, building on the previous success of the Scottish Government's 2011 'Shaping Bereavement Care' Framework. This national approach should recognise bereavement support as a right and the actions set out below. It should also ensure that integration authorities prioritise local action to address need. Leadership is a crucial component: the Scottish Government could task a national lead or integration authorities' local NHS bereavement leads to map out what support is available, identify need and steps to address gaps and improve access.
2. **Compassionate Communities across Scotland.** The compassionate communities approach¹³ should be supported across Scotland. This community-based public health approach to supporting people through dying, death and bereavement will lead to fewer people suffering alone and more people being supported to access the help they need. This would see whole communities, workplaces and all the different organisations and people involved in end of life care, from care workers and ambulance crews through to Funeral Directors, able to support people better with more awareness, more open discussions and more signposting to the right types of support.
3. **Better access to bereavement support for all through delivery of the Carers Act.** To fully implement their commitment under the Act, local authorities should resource local bereavement support providers to upscale bereavement support so that different supports are available whenever people need it during their bereavement – without a waiting list. This means more carers, and more bereaved children, young people and adults in the wider community can access the support they need. The Act should deliver not just increased awareness, but a service response able to meet local need.

4. **A flexible service provider response offering a range of support types.**

Upscaling of bereavement support by providers like hospices and Sue Ryder needs to be across all forms. While one-to-one counselling is seen as the most effective form by people experiencing bereavement now, as technology advances, use of online forms of support is set to grow. Awareness is also a factor: there is a need for greater promotion of the range of support available beyond the one-to-one-in-person model of bereavement care.

5. **Local primary care teams equipped to identify and signpost people to support.** GPs and the wider practice team should be aware of the unique, trusted position they hold for bereaved people.. They must have the right tools, training and information to identify people who could benefit from support and enable them to access support that is right for them. This approach must also take into account the particular needs of people experiencing social isolation, who find it harder to ask for help when they need it.

"I think that when someone dies, people like me and my Mum shouldn't just be left to pick up the pieces on their own. It was particularly tough for my Mum who lost her husband of 60 years. Grief affects everyone differently and at different times, and people struggling with a bereavement may well need some proper support, even a few months later. This support and care after a death should be offered as a matter of course."

Sandra, Edinburgh, who used the Sue Ryder online community and counselling

References

- ¹ Estimated figure calculated by applying Prigerson et al (2008) number of bereaved for every death methodology to number of deaths in Scotland in 2017. <https://www.nrscotland.gov.uk/news/2018/5000-more-deaths-than-births-in-2017>; Prigerson, H.G. et al. 2008. A case for inclusion of prolonged grief disorder in DSM-V. 2008. In: M.S. Stroebe et al (eds). Handbook of Bereavement Research and Practice: Advances in Theory and Intervention. Washington D.C.: American Psychological Association. pp. 165-186.
- ² The Carer's (Scotland) Act 2016. <https://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/Carers-scotland-act-2016>
- ³ Birrell J et al. Socio-economic costs of bereavement in Scotland. March 2013. <http://www.childhoodbereavementnetwork.org.uk/research/key-statistics.aspx>
- ⁴ Stroebe, M et al. Cautioning health-care professionals: bereaved persons are misguided through the stages of grief. Journal of Death and Dying. 2017, Vol. 74(4) 455-473.
- ⁵ Auoun, SM et al. Who needs bereavement support? A population based survey of bereavement risk and support need. PLoS ONE 10(3): e0121101. 2015.
- ⁶ Because the survey was conducted online, the sample will necessarily be a digitally included population. The sample was however balanced across factors such as age, location and income.
- ⁷ By 'bereavement support' we mean support beyond family and friends.
- ⁸ Auoun, SM et al *ibid.* ; Prigerson, HG et a. Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. PLoS Medicine. 2009; 6:e1000121.
- ⁹ There are risk factors which can increase the likelihood of experiencing complicated grief such as gender, low education, older age, low socioeconomic status, and low social support both before and after death.
- ¹⁰ Lichtenhal WG et al. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. Psychiatric Services. 2011; 62:1225-1229.
- ¹¹ 'Lower incomes' refers to respondents in NRS social grade group C2DE; 'higher incomes' to respondents in NRS social grade group ABC1.
- ¹² Compassionate Communities is a growing international public health movement. In Scotland there are a number of initiatives locally and across wider geographies such as Compassionate Inverclyde and the Scottish Compassionate Communities Network (https://www.goodlifedeathgrief.org.uk/content/compassionate_communities_network/)