

UK Commission on Bereavement



Submission 16 January 2022

About Sue Ryder

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 compassionate 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. 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 care they deserve.

This response sets out our experiences with regard to the questions posed by the UK Commission on Bereavement, and highlights areas that need attention for the future of bereavement support.

Public attitudes, cultural perspectives and engagement

To what degree are public attitudes to grief, bereavement, support and help-seeking a barrier to effective interventions for people affected by bereavement?

Research shows that there are differences in seeking support depending on factors such as ethnicity, gender, socio-economic background, having poor mental health and having learning difficulties.

- Research confirms that lower income groups are at higher risk of experiencing complicated or persistent grief and this is partly because they face more difficulty accessing appropriate services, information and time off to help them cope with grief.¹
- A 2019 survey commissioned by Sue Ryder found that 18% of women had actively sought psychological support or treatment for how they were feeling after a bereavement, compared to 12% of men.²
- People with learning difficulties who experience bereavement often find that their carers and families avoid having direct conversations about grief which leads to their grief not being recognised and creates a barrier to accessing support.³

¹ Newsom, C., Schut, H., Stroebe, M. S., Wilson, S., Birrell, J., Moerbeek, M., Eisma, M. C. 2017. 'Effectiveness of bereavement counselling through a community-based organization: A naturalistic, controlled trial', *Clinical Psychology & Psychotherapy*, 24

² The PHA Group interviewed 1,061 bereaved British adults (aged 16+), 20-22 November 2019

³ Allen, D. Helping people with learning disabilities make sense of death. *Learning Disability Practice*. Available at: <https://journals.rcni.com/learning-disability-practice/feature/helping-people-with-learning-disabilities-make-sense-of-death-ldp.24.5.6.s2/abs>

- Black, Asian and minority ethnic (BAME) people often face unequal treatment and barriers when accessing bereavement services.⁴ There are also inequalities in access to mental health support. A 2018 UK Government report found that Black people are less likely to receive psychological therapies and are more likely to be compulsorily admitted for treatment.⁵ Research in 2021 found that almost all BAME groups were less likely to receive an IAPT (Improving Access to Psychological Therapies) assessment compared to the White British group, and of those who were assessed, all BAME groups were less likely to receive treatment.⁶ There are also some cultural boundaries around accessing mental health services which stops some people from BAME backgrounds seeking help.^{7 8}

For many people, grief, death and dying are still thought of as taboo subjects, which can act as a barrier to accessing effective interventions. There are differences in attitude across age groups, our 2019 research showed that 63% of adults aged 18-34 feared saying the wrong thing to bereaved people, compared to 51% of all respondents.⁹ Whilst this figure is high across all age groups, it's particularly concerning in the younger cohort as the survey also found that young adults who had been bereaved were less comfortable than older generations in asking for support from healthcare professionals.

Grief can manifest in many ways, but is commonly not recorded or recognised by services as a grief related issue - depression and anxiety are good examples of this. The problem with this is that inconsistent recording of grief across multiple services means that it can be difficult to predict where appropriate support is most needed. Additionally, mental health studies often fail to recognise grief as a mental health disorder, which is a barrier to growing our understanding as a society, and subsequently improving access to support.

What could help to improve public attitudes to bereavement and the support needs of people who have been bereaved?

Sue Ryder believes that as a society, there is much more that can be done when it comes to improving our approach to grief. Bereavement support needs to be more embedded in all public health approaches and incentives. It should be recognised that grief is something that affects everything. As a charity, we have expanded our bereavement support provision by

⁴ Memon A, Taylor K, Mohebati LM, *et al.* 2016. Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England *BMJ Open* 2016.

⁵ Department of Health and Social Care. 2018. Modernising the Mental Health Act – final report from the independent review. Available at: <https://www.gov.uk/government/publications/modernising-the-mental-health-act-final-report-from-the-independent-review>

⁶ Harwood, H., Rhead, R., Chui, Z., Bakolis, I., Connor, L., Gazard, B., Hatch, S. 2021. Variations by ethnicity in referral and treatment pathways for IAPT service users in South London. *Psychological Medicine*, 1-12.

⁷ Rethink Mental Illness. 2020. Black, Asian and Minority Ethnic (BAME) mental health. Available at: <https://www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/black-asian-and-minority-ethnic-mental-health/>

⁸ Memon A, Taylor K, Mohebati LM, *et al.* 2016. Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England *BMJ Open*.

⁹ Sue Ryder. 2019. A better grief. Available at: <https://www.sue Ryder.org/sites/default/files/2019-03/a-better-grief-report-sue-ryder.pdf>

growing our Online Bereavement Community and recruiting more counsellors for our Online Bereavement Counselling service. Bereaved people need to be made aware that such services are available to access.

In order for public attitudes to bereavement and grief to shift positively Sue Ryder believes that the Government needs to invest in improving awareness of grief. There have been successful and wide-reaching government campaigns, such as the road safety campaign around seat belts, and stop smoking campaigns. We believe grief awareness should be tackled in a similar way. In September, we launched our Grief Kind campaign which aims to create a national movement of kindness and help more people get the confidence to support their loved ones through grief.

Many people will struggle with a multitude of issues with bereavement, including with their physical and mental health, finances, social life, work and education. They may also experience struggles with the people and relationships around them such as children and supportive networks. As an example, when the main breadwinner dies, the family might have to move house to somewhere less expensive; they might have had a caring responsibility to someone which can no longer be met, or a job which can no longer be done due to a change of location or childcare needs. Alongside this their health might deteriorate due to having less time to cook healthier food options.

Another example could be of a child at school who has experienced a bereavement, their behaviour changing could be an expression of their grief, it might mean they are then being excluded from lessons. They may have to get a job on weekends or after school to help support the family, this could impact their grades and their chances of getting into college/university. The impact that bereavement can have should be demonstrated to the Government through examples like this to show the huge effect that it can have on people's lives and why it is so important to make sure people can access support.

Bereavement must be viewed as a public health issue and not purely a health and social care issue. To support this, Sue Ryder recommends the need for a deeper understanding of the economic impact that grief can have if we don't support people holistically from the start. Economic modelling should be supported by using examples, such as the ones outlined above, to enable people to understand how multifaceted grief is and the potential knock-on effects it can have.

We need to join up thinking across Whitehall departments, in all areas of policy making and service planning because, as these examples demonstrate, grief is not a standalone issue.

How could employers better support people who have been bereaved?

In 2020, Sue Ryder produced a Grief in the Workplace report. It showed that 24% of the working population in Britain have experienced a bereavement, which equates to around 7.9

million people.¹⁰ This figure will have substantially increased due to the pandemic. A UK-wide survey¹¹ commissioned by Sue Ryder showed 60% of people who felt well supported by their employer after experiencing a bereavement cited being allowed enough time-off and not being pressured to return to work when they were not ready as key actions their employer took.

Sue Ryder believes an entitlement to two weeks of statutory bereavement leave for anyone who has lost a close family member or partner should be introduced. Typically, UK companies offer 3-5 days compassionate leave for the death of a close relative, but it is at the discretion of employers. Currently, statutory bereavement leave of two weeks is available for parents if they experience the death of a child under 18.

While such a right could incur some short term costs, ultimately it would lead to a significant saving for the UK economy and the Treasury through reduced staff absence over the longer-term, higher employee productivity and less reliance on the health and benefits systems post-bereavement. The grief experienced by employees who have lost a loved one costs the UK economy nearly £23bn a year, and costs HM Treasury nearly £8bn a year, through reduced tax revenues and increased use of NHS and social care resources.¹²

There is clear evidence that the introduction of statutory bereavement leave would help to ensure that bereaved employees are better supported.

Based on existing literature and a survey conducted by Sue Ryder, we make several recommendations for employers on how to support bereaved colleagues in the workplace.

- Communication- taking the time to speak to the bereaved employee, offering condolences, seeing how things were going during any time off, establishing if and what a bereaved employee wants colleagues to know about their loss and taking the time to have regular check-ins when the person affected was back in the workplace.
- Empathy- an employer should show understanding and compassion- often empathy can manifest itself in small acts such as ensuring that a recently bereaved employee is not faced with situations that may be difficult for them.
- Encourage time away from the workplace- if people need to be off work they should not fear punishment either by stigma or financially because it's not classed as worthy of sick pay. Employees don't want to hear things about waiting lists growing or work load being high whilst they are absent. This just increases the pressure to be ok and increases feelings of being a burden, which can impact self-worth.
- Offer flexibility in workloads and shift patterns- employees who have recently experienced a bereavement may need a lighter workload, need to work different hours

¹⁰ Sue Ryder. 2021. Grief in the Workplace. Available at: https://www.sueryder.org/sites/default/files/2021-01/Sue_Ryder_Grief_in_the_workplace_report_0.pdf

¹¹ Censuswide survey on behalf of Sue Ryder of 1,061 UK respondents aged 16+ who were bereaved, November 2019.

¹² Sue Ryder commissioned an economist in September 2020 to conduct a literature review of current research.

or shifts, or undertake a slightly different role in order to help reduce stress or deal with practical matters related to the loss.

- Create a working environment where people are comfortable talking about grief- having the courage to talk openly about personal experiences of death and grief or providing time and space for employees to discuss it can help normalise conversations and raise awareness about resources available to staff. Only 30% of those in employment say managers or leadership have shared the organisation's bereavement policy in the last year.¹³
- Signpost external resources- as a key point of contact for an employee who has experienced a bereavement, workplaces can offer information about bereavement support available in the wider community.
- Have a bereavement policy and inform staff about it- this not only gives a bereaved employee a degree of certainty and reassurance about their situation, but can also empower managers.

Should all health and social care staff have training in bereavement awareness and support? If so, what training should be provided?

We believe in creating a culture where people are comfortable talking about grief.¹⁴ Workplaces can play a big role in supporting employees through their grief and mitigating its consequences. We believe that all health and social care staff should have training in bereavement awareness. We ensure people have done mandatory training on topics such as manual handling and health and safety to look after the physical health of employees and members of the public. Bereavement training should be no different as people's mental health is just as important as their physical health.

Bereavement training should be much more widespread as currently people are not getting the bereavement support that they need:

- Analysis from the Continuous Mortality Investigation found that there were 116,900 more deaths than expected from the start of the pandemic until 3rd December 2021.¹⁵ Families and friends left behind are struggling to cope with their grief and loss. The waiting list for our bereavement counselling service continues to grow every day and we urgently need funds to recruit more counsellors.

¹³ Censuswide survey on behalf of Sue Ryder of 1,061 UK respondents aged 16+ who were bereaved, November 2019.

¹⁴ Sue Ryder. 2021. Grief in the Workplace. Available at: https://www.sueryder.org/sites/default/files/2021-01/Sue_Ryder_Grief_in_the_workplace_report_0.pdf

¹⁵ Continuous Mortality Investigation. 2021. England & Wales mortality monitor – COVID-19 update – week 48 of 2021. Available at: <https://www.actuaries.org.uk/system/files/field/document/Mortality%20pandemic%20monitor%20Week%2048%202021%20v01%202021-12-14.pdf>

- Over half of the general public have felt unsure of what to say when someone tells them a close relative or friend has died.¹⁶
- 81% of people who have been bereaved felt that someone didn't know what to do or say when they were grieving.¹⁷

Practical Bereavement Support

How could people be better supported to put in place practical plans for death and bereavement?

These topics could be attached to normal processes like driving licence renewal, sign up at GP practices and dentists and making council tax payments. It could be easy to add writing a will or advanced care plan to these administrative processes to ensure people complete them. It needs to be de-specialised and embedded in all areas.

How do we approach this within hospices to help families prepare?

Most hospices offer family support either for inpatients and their families, or those 'known' to the hospice, and other hospices support those in an open access style in the community, often because of an absence of other services. Information days with workshops and lectures should be held, similar to information days held by Clinical Commissioning Groups (CCGs)/ Integrated Care Systems (ICSs). Roadshows could be held in GP surgeries, schools and workplaces. Signposting information to bereavement support should be available in a wide range of places, for example, stickers and posters should not only be placed in hospice settings and GP surgeries but also in places like motorway services.

Sue Ryder hospices are an example of good practice when it comes to bereavement support. Our hospices co-facilitate bereavement support groups in the community, offer 1:1 counselling and give information to adults to better equip them to talk to their children about death and bereavement. We also train our hospice staff and volunteers in bereavement support.

Infrastructure and Intervention

To what degree is funding for the bereavement support sector sufficient to meet the needs of bereaved people, and sustainable into the future?

Funding for the bereavement support sector is not sufficient to meet the needs of bereaved people, neither is it sustainable. Most bereavement services are not funded, but simply coexist and the costs are absorbed by other services, for example, in our hospices this is often an add-on service because we recognise our community needs this support, but it's without specific funding. Therefore, services often depend on fundraising teams to raise enough to cover costs for these services. Regular funding for staff training and development also needs to be considered as staff can only ensure that they are meeting bereaved people's needs

¹⁶ Sue Ryder. 2019. A better grief. Available at: <https://www.sueryder.org/sites/default/files/2019-03/a-better-grief-report-sue-ryder.pdf>

¹⁷ Survey conducted by Censuswide commissioned by Sue Ryder (July 2021)

when they are up to date with current interventions and approaches, and are confident using outcome and assessment tools.

Ring-fenced funding should be made available for bereavement support services to prevent grief going unaddressed and negatively impacting multiple areas of people's lives - creating an increased cost on wider health and welfare services.

What can be done to better assess the support needs of people who have been bereaved?

The Bereavement Evaluation Forum (BEF) and a vast number of practitioners highlight the need for formal pathways and assessments. This is especially important with the rising number of people accessing services with complex presentations, such as suicidality and pre-existing mental health conditions and often requiring mental health service involvement and/or medication. Grief needs to be viewed as a public health issue because it's multifaceted impact means people struggle in more than one way and grief can impact areas such as their physical health, finances, education and psychosocial needs.

Research and effective data collection based on approved outcome measures must support service delivery to demonstrate that services meet the needs of people using them, and also to question effectiveness and contribute to the wider work.¹⁸ Outcome measures need to be applied at both assessment and at discharge, and ideally at another point during the person's bereavement. This needs to be done by taking a range of factors into account and requires more than simple feedback forms.

We share BEF's concerns that effective assessment, informed monitoring and evaluation of bereavement services remains patchy and inconsistent.¹⁹ We support their call for integrating assessments, informed monitoring and evaluation into organisational infrastructures to deliver high quality evidence-based support, which is crucial to improving the experience of bereaved people.

Ideally there would be a bereavement worker in all GP surgeries providing a similar service as antenatal nurses/ diabetes nurses/ asthma nurses. People should also have access to a bereavement worker in all schools and workplaces, this should not just be for 1:1 formal support, but also for effective assessments and signposting.

¹⁸ Sue Ryder and The University of Birmingham School of Nursing. 2019. Bereavement Support in the UK - a rapid evidence assessment. Available at: <https://www.sueryder.org/sites/default/files/2020-08/Sue%20Ryder%20Bereavement%20Support%20in%20the%20UK%20-%20University%20of%20Birmingham%20School%20of%20Nursing%5B1%5D.pdf>

¹⁹ Sealey, M., Breen, L. J., O'Connor, M., & Aoun, S. M. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliative medicine*, 29(7), 577-589

Wilson, D., Dhanji, N., Playfair, R., Nayak, S., Pupilampu, G., & Macleod, R. (2017). A scoping review of bereavement service outcomes. *Palliative and Supportive Care*, 15(2), 242-259.

What can be done to improve access to services – particularly for those groups who are least well served?

As there is currently no national standard pathway for someone experiencing a bereavement - assessing and signposting individuals to services is patchy. We need to see better awareness of existing services, so that the appropriate intervention and signposting are made at the right time for the individual.

Currently, bereavement services are viewed as something that are optional to provide, instead they should be seen as a basic right for all bereaved people. We believe bereavement services should be commissioned to ensure that anyone who meets the necessary outcome measure at assessment can access high quality bereavement support.

How could services be better coordinated to better meet the holistic needs of people affected by bereavement?

There should be a standardised approach for someone who has experienced a bereavement, ensuring everyone is aware of, and gets access to all of the relevant services.

As we have mentioned in previous answers, there is currently no national standard pathway for someone experiencing a bereavement - assessing and signposting individuals to services is patchy. We need to see a formal bereavement pathway introduced and adopted as well as better awareness of existing services, so that the appropriate intervention and signposting to services are made at the right time for an individual.

Another standardised approach that Sue Ryder believes should be taken is the introduction of an entitlement to two weeks of statutory bereavement leave for anyone who has lost a close family member or partner. To make this change a Government Bill should be brought forward in the House of Commons.

The Impact of the Pandemic

To what degree have new challenges around support for people affected by bereavement emerged as a result of the pandemic, and to what degree has Covid-19 exacerbated existing problems?

Analysis from the Continuous Mortality Investigation found that there were 116,900 more deaths than expected from the start of the pandemic until 3rd December 2021.²⁰ This means the number of people that may need support due to a bereavement has significantly increased in society. This needs to be acknowledged and adequate provisions need to be put in place.

Currently there is a higher than 'usual' suicidal ideation in the population which has been highlighted by mental health services. In our Online Bereavement Counselling service a

²⁰ Continuous Mortality Investigation. 2021. England & Wales mortality monitor – COVID-19 update – week 48 of 2021. Available at: <https://www.actuaries.org.uk/system/files/field/document/Mortality%20pandemic%20monitor%20Week%2048%202021%20v01%202021-12-14.pdf>

random sample of 186 showed 15% were presenting with suicidal ideation. Some people were not accepted into this service as they were presenting with severe mental health issues, very recent suicide attempts (i.e. in the previous week) or very recent mental health inpatient stay. Often they had sought counselling with Sue Ryder due to the unavailability of therapy through secondary mental health services and long waiting lists to access specialist therapy, such as therapy for PTSD. Waiting lists for mental health services have become longer throughout the pandemic.²¹

Covid-19 has meant that more people are presenting as isolated rather than part of a group or network-loneliness and/ or with an inability to make and maintain relationships.

Have models of good practice emerged during the pandemic which should be retained and further developed in the future?

At Sue Ryder we provide online services including free short-term counselling, expert patient/family information and advice, and an online bereavement community. There has been an increased demand for these services since the pandemic began. The use of our video counselling with specialist, trained counsellors saw an increase of 119% in 2020 compared to 2019. Our online bereavement community, which offers peer-to-peer support for those who are grieving, saw an increase of 47% in visitors over the same period. Sue Ryder has grown our bereavement support services in response to this demand and will continue to do so.

In 2021 we launched our #GriefKind campaign, where we are encouraging the nation to help one another through grief by providing them with free advice and prompts to do so. This campaign responds to a 2021 survey commissioned by Sue Ryder that found that 44% of the general public aren't sure what to say when someone tells them a close relative or friend has died.²²

What has been the impact of new approaches to technology use in supporting people affected by bereavement through the pandemic?

Sue Ryder has been able to support a significant number of bereaved people during the pandemic. In 2020–21 our Online Bereavement Support expanded, with over 128,000 people visiting our Online Bereavement Community. 89% of our Online Bereavement Community users said the site helped them to feel less alone.²³

We also saw a significant increase to our team of online bereavement counsellors in response to growing demand, but our waiting list still continues to grow. Last year we delivered over 3,000 free online bereavement counselling sessions and 95% agreed that talking to a trained

²¹ Royal College of Psychiatrists 2021 'Pandemic impact on mental health backlog catastrophic, says Royal College of Psychiatrists' Available at: <https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2021/09/19/pandemic-impact-on-mental-health-backlog-catastrophic-says-royal-college-of-psychiatrists>

²² Survey conducted by Censuwide commissioned by Sue Ryder (July 2021)

²³ Sue Ryder. 2021. There when it matters: How we made an impact 2020-21. Available at: <https://www.sueryder.org/about-us/impact-and-annual-reports/impact-report-2020-21>

bereavement counsellor helped them to feel less alone.²⁴ Online bereavement support can be very effective and should continue after the pandemic is over, people should have the option to access online or face-to-face support, or a combination of both.

During the pandemic practitioners had to be up-skilled in using technology to support people. The public also needs to be upskilled, tech literacy levels need to be improved and measures need to be taken to address digital poverty, to ensure that anyone who needs it can access online bereavement support.

Is there more that needs to be done to prepare for future mass bereavement events like Covid-19?

Covid-19 has led to a significant increase in bereavement across the UK and clearly demonstrates that more needs to be done to prepare for future mass bereavement events. Thousands of families have been left devastated, leading to increased demand for bereavement and family support. The level of emotional distress at not being able to be with a loved one at the end of life has also impacted many people's acceptance and experience of bereavement. Last year, a poll by Sue Ryder²⁵ found that 59% of people who were bereaved during the pandemic feel as though their grief had been forgotten amidst the global crisis. 55% of people who experienced a bereavement during the UK lockdown said that they feel that their loved one's death had become 'just a statistic'. Previous research has also shown that 86% of people who have experienced bereavement in the UK felt alone in their grief.²⁶

A standardised approach to accessing bereavement support needs to be introduced to ensure people can quickly access all the support they need when they are bereaved. Alongside this, bereavement services should be commissioned across the UK to ensure services are available.

²⁴ Sue Ryder. 2021. There when it matters: How we made an impact 2020-21. Available at: <https://www.sueryder.org/about-us/impact-and-annual-reports/impact-report-2020-21>

²⁵ Survey conducted by Censuwide on 21-27 August 2020 with 503 UK respondents (aged 16+) who experienced a close death or bereavement since the end of March.

²⁶ Survey conducted by Censuwide commissioned by Sue Ryder (July 2021)