A better route through grief:

Support for people facing
grief across the UK

Contents

Foreword

Grief can manifest in many ways, it is complex. Issues such as depression and anxiety, financial instability, and loneliness are often not recorded or recognised as grief related.

Sue Ryder believes that as a society, there is much more that can be done when it comes to improving our approach to grief. In March 2019, we published the report, 'A better grief' based upon research with 2,198 British adults, of whom 72% had been bereaved in the last 5 years. The findings suggested there was a gap between those receiving bereavement support and those who need it, as well as highlighting barriers and attitudes towards bereavement among the general public. We called for the Government to undertake detailed research into the availability and impact of different types of bereavement services and ensure people are made aware of what they can access. Then the pandemic struck.

We may never know the full extent of the impact the pandemic has had, but we do know an estimated 3 million people experienced bereavement over those first two years – with an additional 375,000 people bereaved, compared to the previous five-year average[1]. Thousands of families have been left devastated, struggling to cope with how they had to say goodbye and with increased isolation making it difficult to seek the right support for their grief. Those who have been grieving already, often struggled to tend to their grief in their usual ways. For some, this caused distress and deterioration in the way they managed their grief.

We saw the effect of this in our own services with an increase of 119% in the use of our video counselling with specialist, trained counsellors, and our online bereavement community (peer-to-peer support) seeing an increase of 47% in visitors over the same period. In response, we have grown our bereavement support services to meet this demand and will continue to work

towards meeting the demand. Last year we delivered over 3,000 free online bereavement counselling sessions and 95% of people agreed that talking to a trained bereavement counsellor helped them to feel less alone. And, in September 2021, we launched our Grief Kind campaign to create a national movement of kindness and help more people find the confidence to support their loved ones through grief. Since then we've seen nearly 90,000 people sign up to learn how to support friends and family.

Our call for detailed research into the availability and impact of different types of bereavement services seemed even more urgent than it did in 2019. As a result, we took steps to explore this further ourselves. This report is the largest survey of bereaved people to date that looks at access and availability. It details people's access to bereavement support and their assessment of the support they received.

Grief can affect you 24/7. As a society, we need a public health approach to grief and we must equip people's support networks. It makes sense that we make grief everyone's business and provide pathways that don't just focus on service providers, but also community based approaches, through to formal therapy support for those who need it. Grief is a life experience, which will at some point affect us all.

We hope this research will be used as a springboard for further research that will allow us to improve bereavement support across the UK.

Heidi Travis - CEO
Bianca Neumann - Head of Bereavement

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1   UK Commission on bereavement 2021 https://bereavementcommission.org.uk/about-us/#:~:text=Across%20England%20and%20
Wales%2C%20614%2C000,estimated%20additional%20375%2C000%20left%20bereaved

Project Overview

Authors: Beth Swords, Dr Niamh McGarry, Sandra Hicks, Dimitris Raidos & Siobhan Canavan.

We would like to thank the team at Sue Ryder for commissioning ClearView Research to conduct this research project.

This research was commissioned to understand the current access to bereavement support, how it varies across the UK, and the impact this has.

The objectives of the research were:
1. To measure the availability and impact of bereavement support[2] from a user perspective.
2. To evaluate the availability of bereavement support through the eyes of the provider.

To do this, ClearView Research adopted a mixed methods approach that involved:
- A co-creation group supporting the design of the research process itself and the survey/lab questions, as well as analysing the findings.
- A national survey of 8,555 people who had experienced bereavement in the last five years.
- Exploration labs with 20 people who had responded to the survey to explore their responses in more detail.
- Interviews with 10 general practitioners (GPs) from across the UK.
- A mapping exercise of the existing services conducted using web scraping and natural language processing to identify the services advertised online.[3]

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2   Throughout the report, we refer to formal support as tailor-made support, delivered with the contribution and/or oversight from a trained counsellor or healthcare professional. Informal support involves non-specific or not tailor-made support, and/or support that does not involve a trained counsellor or healthcare professional. For context, the NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) provides a component model for supporting people facing bereavement. The End-of-Life Care Strategy subsequently applied this model to bereavement following all expected deaths. Given our definitions of formal and informal, we have defined any support considered Component 2 and above as formal support, and anything termed as Component 1 to be informal support.

3   Whilst the mapping exercise was designed to provide an overview of the services available across the UK, based on those that are advertised online, it will not be comprehensive. There will be provision and services that may not have been advertised through these routes, there may be offline sources of information, and the services may not be well advertised. Similarly, this mapping exercise only outlines the number of services and the type of support available. It does not provide information about the reach of each service or the capacity.

Executive Summary

The research revealed high levels of unmet need, with 70% of respondents who had experienced a close bereavement[4] reporting that they could not access the support they would have liked. This was driven by the low availability of services with some areas lacking variety and provision of services more than others. It was also driven by the high barriers to access for some types of support, with certain demographics finding it harder to access support than others.

The research has demonstrated the need to ensure that the services are delivered in ways that address the diverse cultural beliefs around death and grief, as well as being delivered in a variety of languages, to ensure that everyone who needs support is able to access it.

The research also revealed the need to improve awareness among key healthcare professionals and community leaders to facilitate signposting to appropriate services at the right time. It also showed it is necessary to improve the general public's understanding of grief, equipping them with the self-awareness to reach out for help when they need it or to support others in finding the right support.

The key findings include:

1. **70% of respondents reported they could not access the support they would have liked after they experienced a close bereavement.** The most common types of support that people wanted but did not receive were counselling, financial support, and written information on how to manage their grief. Broader research suggests that mental health conditions left untreated can lead to worsening mental health problems, substance abuse, unemployment, inappropriate incarceration, suicide, and poor quality of life.[5] Although mental health and grief differ, they can be experienced in similar ways and therefore, point to an urgency to addressing the unmet need.

2. **Access to formal support was highest in London, Northern Ireland, and the West Midlands.** 42% of people in London who experienced a close bereavement accessed formal support compared to 40% in the West Midlands and 39% in Northern Ireland. In contrast, access to formal support was the lowest in the South West of England (31%), Wales (30%), Scotland (29%) and South East England (25%).

3. **There were big discrepancies between the support available and the support accessed.** By 'support available', we are referring to the services that are officially advertised for each region and by 'support accessed', we are referring to the percentage of people who received the support as identified through the survey. In this context, despite the high provision of services, South East England and South West England demonstrated low access rates to formal support. Further investigation is required into the awareness and accessibility of services in these areas to understand these discrepancies.

4. **The regions that have lower numbers of services available tend to demonstrate higher than average rates of people accessing prescription drugs.** This is particularly the case for Wales, North East England and Northern Ireland. In contrast, South East England, South West England

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4   Of the 8,555 responses to the survey, 4,403 people experienced a close bereavement. As described by the Chartered Institute of Personnel and Development (CIPD), 'close bereavement' includes a bereavement of 'a child of any age, parent, or sibling (whether by blood or adoption) or partner'. Source: https://www.cipd.co.uk/about/media/press/bereavement-leave-extended#gref.

5   https://namica.org/what-is-mental-illness/

and London show lower than average rates of access to prescription drugs and are in the top three regions for the availability of services.

5. **Almost 1 in 5 people cited that the barriers preventing them from accessing formal support** were a lack of culturally-relevant services and because the service could not be provided in the recipient's language.

6. **People from Black Caribbean and Black African backgrounds showed the highest access to prescription drugs, at 89% compared to a 64% average.** This reflects the broader research that suggests that people from Black, Asian and minority ethnic communities are more likely to be prescribed antidepressants than White patients in the place of other forms of mental health support.[6]

7. **Older people were less likely to access formal support.** Participants aged 55 and above were significantly less likely to see a psychiatrist, join group therapy or use an online chat function with a therapist or counsellor.

Key stakeholders - from the Government to health decision-makers, from charities to broader society - all have a role to play in ensuring that people get the support they need. The key recommendations that have emerged from this research are as follows:

- Creating a formalised pathway to bereavement support, that accounts for individual need.
- Raising the awareness of available services and equipping people with the tools to support each other through grief.
- Continuing to develop research in this area, particularly around the barriers to support for different communities.

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6   https://www.cambridge.org/core/journals/psychological-medicine/article/variations-by-ethnicity-in-referral-and-treatment-pathways-for-iapt-service-users-in-south-london/E02A98DE585A16189A6FCFA63A5290DE.

What We Found - The Details

Support is not always available when it is needed and in the form it is wanted
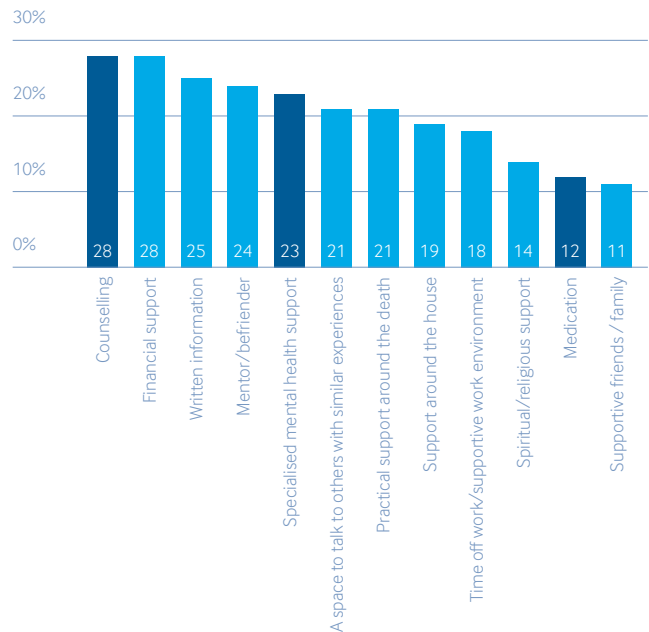
There is a considerable unmet need when it comes to people getting the support they need when they want it.

Areas of unmet need

70% of respondents reported that they could not access the support they would have liked. The most common types of support that people wanted but couldn't access were counselling (28%), financial support (28%) and written information (25%) (see Figure 1). By financial support, people were keen to have access to government welfare support, bereavement support payments, financial support to pay for funeral arrangements, financial support to help make ends meet and tax credits. Similarly, for written information, people were keen to have access to general information about what grief can look like and simple recommendations on how to cope. 70% of people is a considerable majority not receiving the support they wanted. This demonstrates a high unmet need in terms of both clinical and non-clinical support.

Figure 1 - Percentage of people who did not receive the following types of support but would have liked to (those marked in dark blue are considered formal support and those in light blue are informal or other types of support).[7]

Category	%
Counselling	28
Financial support	28
Written information	25
Mentor/befriender	24
Specialised mental health support	23
A space to talk to others with similar experiences	21
Practical support around the death	21
Support around the house	19
Time off work/supportive work environment	18
Spiritual/religious support	14
Medication	12
Supportive friends / family	11

Although mental health and grief are different, there are parallels in how people experience them. If left untreated, mental health conditions can increase in severity, where the longer they are left, the harder they can be to treat or recover from. For example, untreated anxiety may escalate to panic attacks, and failing to address trauma can lead to post-traumatic stress disorder.[8] The mental health condition itself is not only impacted but left untreated, mental health issues can lead to other physical health issues such as chronic pain, strokes, heart attacks and obesity.[9] Other more social aspects of people's lives can also be impacted, with untreated mental health resulting in social isolation, poor performance at work or school, unemployment, homelessness and inappropriate incarceration.[10] The high levels of unmet need revealed through this research should be viewed with urgency in light of the associated risks of untreated mental health issues.

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7   Specialised mental health support refers to receiving long-term mental health support through the healthcare system, such as being allocated a psychiatrist and receiving a long-term treatment plan.

8   https://highfocuscenters.pyramidhealthcarepa.com/dangers-untreated-mental-illness/.

9   https://highfocuscenters.pyramidhealthcarepa.com/dangers-untreated-mental-illness/.

10   https://www.turnbridge.com/news-events/latest-articles/long-term-effects-of-untreated-mental-illness/#.

The research highlights the need to rebalance the way systems work around people who grieve or struggle psychologically in other ways by creating, affecting and nurturing holistic systems that equip and not just 'do-to'. This should put emphasis on the need for proportionate, adequate and timely intervention of community-led bereavement support to prevent similar outcomes.

"When people don't have a sense of good mental health they often experience poor quality of life, distress, lack of control, choice and autonomy. It often comes with low self-esteem and confidence; a sense of not being part of society. It's sad to think that we live in a society that would allow people to live lives where people feel invisible - despite being surrounded by communities so rich in love and support.

Surviving grief is not about striving for some sort of utopian happiness. We need to support people throughout their grief to find meaning in what has been, what is and what could be and empower them to reach positive decisions for their lives for the future."

Bianca Neumann, Head of Bereavement at Sue Ryder.

More specifically, of those who wanted counselling but didn't access it, almost 1 in 5 accessed prescription drugs, such as antidepressants, instead. While prescription drugs can help people facing bereavement, this suggests that they may be being prescribed without additional support.

Through interviews with GPs, most shared that they knew of limited services available to signpost patients to. Of the services that they were aware of, the GPs were concerned with their long wait times, such as for counselling through the NHS or charities.

A high proportion of the GPs shared that they prescribed antidepressants to provide short-term relief while the patients were looking to find other suitable support or self-refer. This reflects the survey findings where 67% of people who received prescription drugs accessed them in the first 6 months. This is compared to an average of 44% of people accessing other formal support services in the first 6 months. The GPs shared that they feared patients tended not to persevere with counselling if they had to self-refer and wait months, and instead would be left with only prescription drugs for support.

"I feel bad because I know there is no immediate care, given the current waiting times for a lot of services. Me referring or signposting someone to counselling with a 6-month waiting list is not really offering a service. If waiting times are bad, I offer antidepressants, but I worry that people will not pursue other forms of support."

GP based in South Belfast, Northern Ireland.

One participant described the frustration he faced having to wait for support: "Unless you're prepared to go private for counselling, the waiting list is too long. I was proud I had been able to reach out for help with my GP to then be told I had to wait for months to receive any actual support. This felt overwhelming at the time." Jason, man aged 35-44, from a White European background, based in Northern Ireland.

Wait times and a lack of available services means that people are not getting the support they want - counselling, financial support, and written information represent the areas where much needed development should be focused.

Grief is nonlinear

85% of people who received formal support stated that the support they had received had led to improvements in how they felt. However, when the respondents were asked to rate different aspects of their lives[11] over a period of time - before the bereavement, immediately after the bereavement and after receiving support - there was no significant change in mood.

Although this is surprising, when considered in the context of a high proportion not receiving the support they would have liked, it is understandable that people are not seeing a result in the longer term. For example, if a significant number of people are visiting their GP to request counselling, but are getting prescription drugs, the impact in the long-term will be limited. Similarly, those who do get a series of counselling sessions, may need more than is provided. Some might be getting help from their family and friends, but because the family or friends are not properly equipped with knowledge of the appropriate services, the impact of this form of support is limited.

When people access support

Across all different types of formal support, the majority of people received formal support within the first 6 months of experiencing bereavement. The most common forms of formal support that people received within the first 6 months were prescription drugs (67%), the use of online forums (55%) and 1-to-1 therapy or counselling (54%).
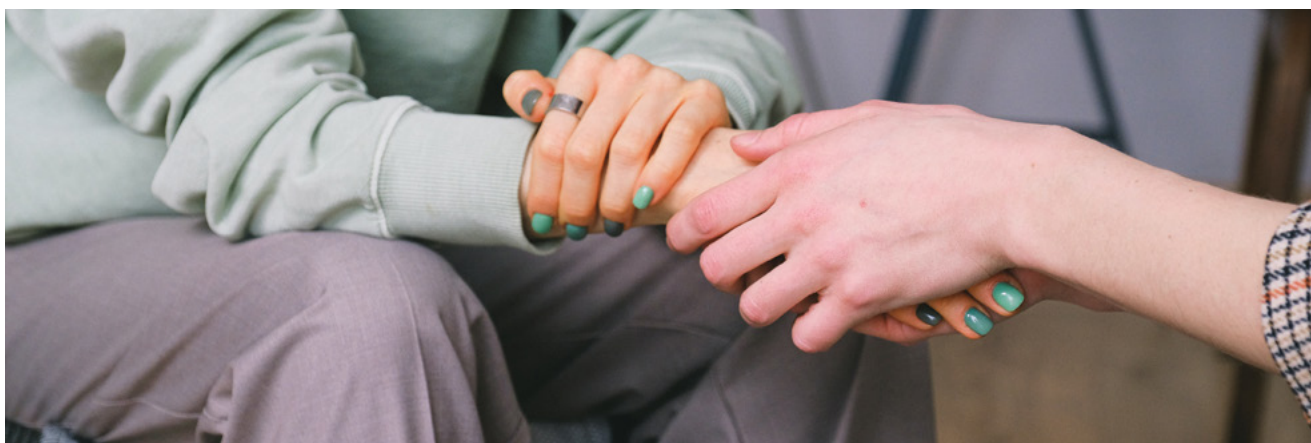
People most commonly wanted to receive prescription drugs (78%), 1-to-1 therapy or counselling (72%) and online forums (66%). Although it is not clear why such a significant proportion of people wanted prescription drugs and counselling early, it could be because of higher awareness levels of these services. When compared to informal forms of support, these were also preferred in the first 6 months, with 71% of people wanting written information in the first 6 months since experiencing bereavement. This shows the importance of early intervention for a variety of different support types.

It is surprising, but encouraging, to hear that people are accessing services within the first 6 months. This is surprising for a couple of reasons. Firstly, because of the waiting times that the GPs have reported around access to such services. Secondly, because there is a view that intervention for grief might be best placed after 6 months to allow for the natural grieving process.[12,13] These findings should be considered in the context that 70% of people could not access the support they would have liked, and that more research is needed to develop a bereavement specific pathway to ensure interventions are appropriate for the individual.

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11 Incl. mental health and wellbeing, friendships and relationships, physical health, money management, managing round the house, substance usage and coping with disabilities/long-term conditions.

12 https://www.psychologicalscience.org/observer/bonanno.

13 https://www.rcpsych.ac.uk/mental-health/problems-disorders/bereavement.
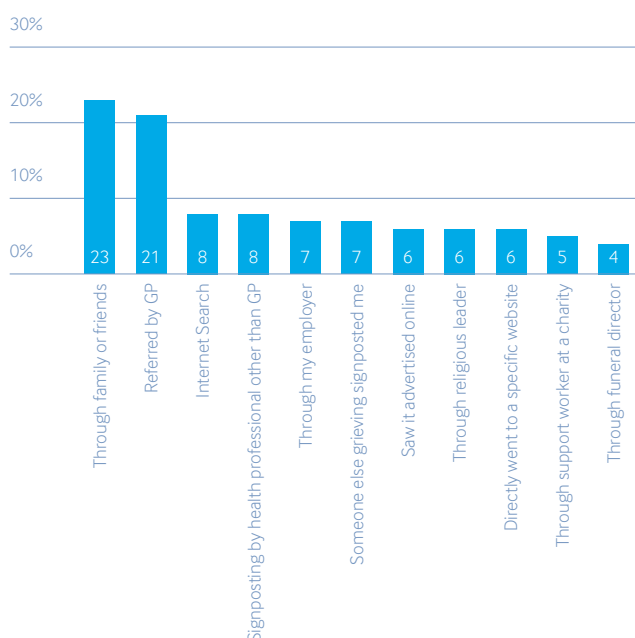
Access rates to formal support decrease as time passes from death. Similarly, the proportion of people wanting support decreased as time progressed, although it is worth noting that these proportions never reached 0%. This suggests that whilst early support is important, for those who need it, sustaining that support is also important. This was particularly the case for more social types of support, such as bereavement cafes. For bereavement cafes, 11% of people wanted access to them 2 to 5 years after a death compared to 4% of people for the other formal support services. It suggests spaces to chat with people with similar experiences can be a helpful way to process these emotions in the longer term, and could play a crucial part in combating loneliness.

How people access support

The main way into support was via friends and family (23%) or a GP appointment (21%). The least common route was through funeral directors (4%) (see Figure 2). Friends and family were more likely to direct people facing bereavement to more informal and holistic services like bereavement cafes, chat functions and informal peer support. In contrast, GPs were more likely to direct people to psychiatry, 1-to-1 therapy, group therapy and prescription drugs.

Figure 2 - Percentage breakdown of how people heard of the formal support they accessed.

Category	Percentage
Through family or friends	23
Referred by GP	21
Internet Search	8
Signposting by health professional other than GP	8
Through my employer	7
Someone else grieving signposted me	7
Saw it advertised online	6
Through religious leader	6
Directly went to a specific website	6
Through support worker at a charity	5
Through funeral director	4

GPs are pivotal in identifying the need of those facing grief. The GPs explained that they were mainly approached by people with concerns broader than bereavement. Sometimes the patients would be asking for absence letters for work, or may mention feeling low as a side note and the conversation would then open up to addressing other support needs. Through these interactions, the GPs were able to signpost to clinical services, such as counselling, and non-clinical services, such as local peer-led support groups or written information.

One GP in the East Midlands spoke highly of the non-clinical or informal support available for people facing more specialised or unexpected deaths, such as the death of a child or baby: "I am aware of multiple good support groups in the area for people who have lost a child. I have been told these are really beneficial to feel like you are not alone and learn coping mechanisms from others like you."

Although GPs are invaluable in this process, there is also scope for earlier intervention through other routes, particularly through the key organisations that people come into contact with, as part of arranging the practical elements of a death. These could include funeral directors, banks, and the Department for Work and Pensions. From the research, we found that the number of people accessing support through funeral directors, for example, was one of the lowest routes into support. However, they, and the other touch points mentioned, have the potential to act as an early source of information and signposting for those facing bereavement. Earlier awareness of the support available and the ways to access this support could reduce pressure on GPs, and ultimately, reduce reliance on clinical approaches later.

There is disparity in access based on where people live and who they are

Access to formal support varied considerably with where people lived and who they were. Not only does this point to gaps in the existing services, but it also suggests the role that health inequalities play in access to services.

Access and availability by region

All respondents to the survey had tried to access some form of support, either formal or informal. Overall, there were low proportions of people who had tried but couldn't access any support (3%).

The most common forms of formal support[14] that people accessed were therapy (24%),[15] an appointment with a GP (17%), and prescription drugs such as antidepressants (13%). The least common type of formal support accessed was bereavement cafes run by a trained counsellor (3%).

However, there were disparities in the availability of bereavement services across the country, creating a patchwork of support. London was most consistent in terms of high provision of services and high rate of access to services, with 42% of people who experienced close bereavement accessing formal support.

Northern Ireland demonstrated low variety and low levels of support availability but high accessibility in terms of what is available (39%). In contrast, a mixed picture emerged in the South East and South West of England. While they both had some of the highest numbers in terms of the services available for formal support, they were in the bottom groups for services accessed. These discrepancies suggest either a low awareness of the services, or high barriers to access.

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14   For context, NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) provides a component model for supporting people facing bereavement. The End of Life Care Strategy subsequently applied this model to bereavement following all expected deaths. Given our definitions of formal and informal, we have defined any support considered Component 2 and above as formal support, and anything termed as Component 1 to be informal support.

   Source: https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005.

15   Including 1-to-1 therapy/counselling, group therapy, online chat with a trained counsellor and seeing a psychiatrist.

Regions	Number of formal bereavement services advertised
South East	129
London	124
South West	90
West Midlands	73
North West	66
East of England	62
Yorkshire and the Humber	61
East Midlands	57
Northern Ireland	32
North East	27
Scotland	8
Wales	5

*Percentage of people accessing formal support after experiencing a close bereavement

Scotland 28.9%*

Northern Ireland 39.1%*

North East 36.0%*

North West 31.8%*

Yorkshire and the Humber 33.7%*

East Midlands 34.5%*

West Midlands 39.7%*

East of England 33.0%*

Wales 29.8%*

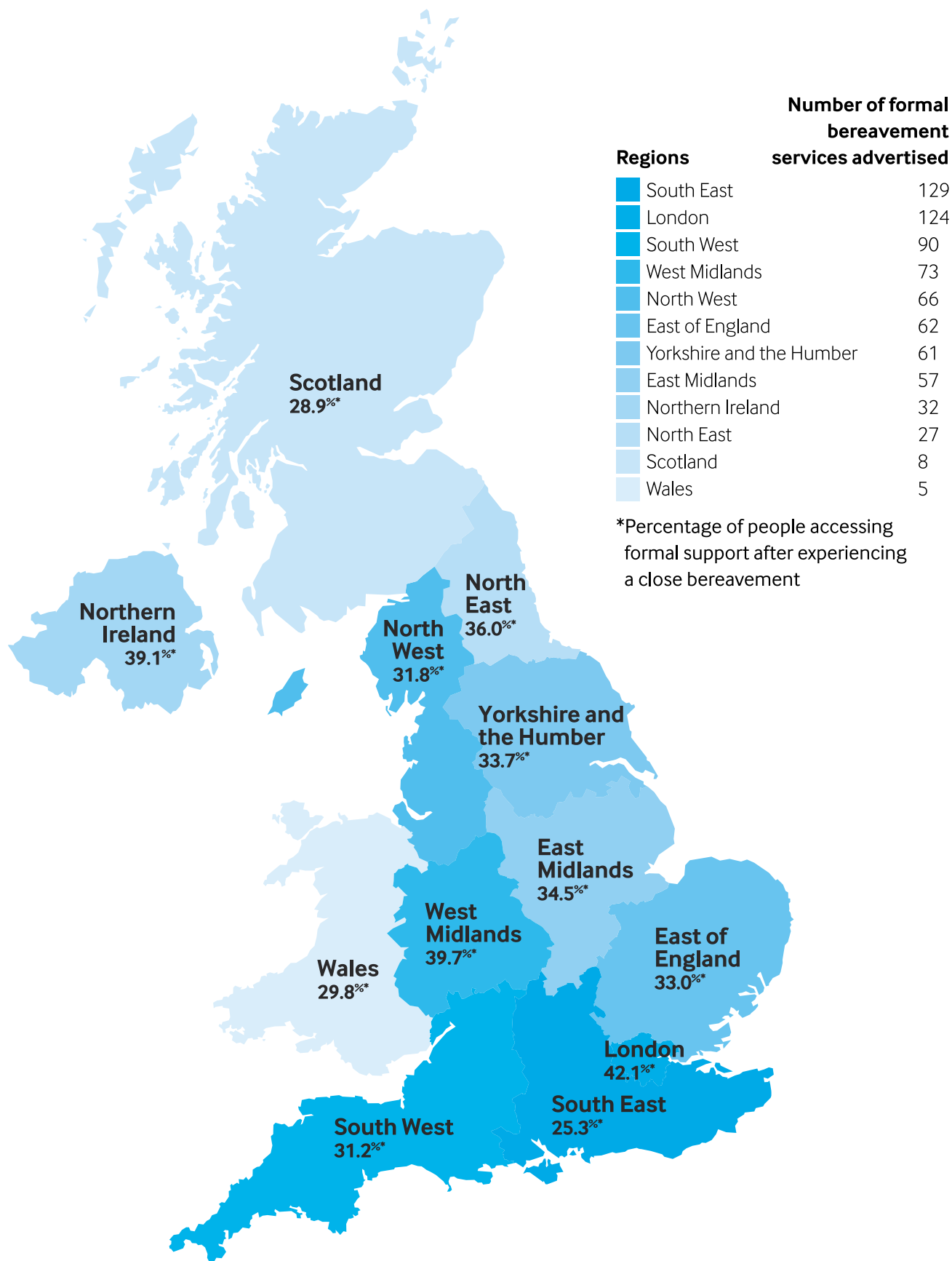London 42.1%*

South East 25.3%*

South West 31.2%*

Figure 3 - Map showing the number of formal bereavement support services advertised and the percentage of people accessing formal support after experiencing a close bereavement, by region (Data collected between Jan–May 2022).

"In one place it might be a charity, in another it might be the council. Then I ask the secretary about the local area and they might not know. Then I'm literally doing what the patient would do - going on Google, and I'm trying to find out because it's not a defined pathway and it's not really linked with NHS services."

Locum GP based in London and South East England, reflecting on the challenges of knowing what services are available in your area.

Scotland and Wales had some of the lowest access rates to formal support. This could be associated with their equally low number of services. Interestingly, the regions that have a lower number of services available tend to demonstrate higher than average rates of people accessing prescription drugs. This is particularly the case for Wales, where 15% of people who experienced close bereavement accessed prescription drugs compared with an average of 10.5% for the other regions. North East England and Northern Ireland also showed higher than average rates of access to prescription drugs in the context of a low number of services. In contrast, South East England, South West England and London show lower than average rates of access to prescription drugs and are among the top three regions for the availability of services. Although prescription drugs, such as antidepressants, can be of benefit for those experiencing grief, this suggests that they might be being used without additional support in place.

Through mapping, the available services were also broken down by Integrated Care Systems (ICS). ICSs were ranked based on the number of services available and the variety of services. Six ICSs appeared in the bottom 10 for both the number of services available and the variety of services provided. This highlights the need to review and invest in services in the following areas:

- Shropshire, Telford and Wrekin
- Bristol, North Somerset and Gloucestershire
- Northamptonshire
- Gloucestershire
- Somerset
- South Yorkshire and Bassetlaw.

Access by demographics
When broken down by demographics, clear inequalities in the access to services emerged.

Age
In terms of age, the older people are, the less likely they are to access formal support, with those over 55 significantly less likely to see a psychiatrist, join group therapy or use an online chat function with a counsellor. This age group tended to prefer an appointment with their GP and a quick chat.

" Many older patients just want to come in for a chat and a cup of tea, rather than asking for any form of specialist support."

GP based in Antrim, Northern Ireland.

The GPs were undecided whether this was due to a generational stigma around mental health or because older people often feel lonely and isolated. The over 55s put this down to the services not feeling relevant to them and therefore, being unlikely to help. This highlights the need to develop the right support for the over 55 group in line with what they want. Not only is the right support important but ensuring that this age group is aware of it at the right time is also key.

Younger people had more formal and informal support in their lives. However, they wanted and did not receive more practical, non-clinical forms of support such as written information, financial support and time off work. There were also younger participants, aged between 18 and 24 years old, who felt that they had to prove the severity of their grief to their GP through repeat visits in order to get the right support. This could help explain why people in this age group were not getting the support they wanted.

" My age also impacted the support I could get. I feel like I couldn't really receive support because doctors told me in a roundabout way that, 'I'm young, I'll get over it'."

Kerry, woman aged 18-24, from a White background, based in Wales.

Another participant said he was told, "You are only young, you will get over it. You have the rest of your life ahead of you." Taylor, man aged 18-24, from a White background, based in Wales.

Gender

Women were more likely to access support in comparison to men. However, this was a marginal difference. Men were more likely to say they did not want counselling or support from their family and friends as it did not feel relevant to them.

> ## "I didn't know we were allowed to ask for help. I would never speak to my friends about this sort of thing either. We don't do that."

Isaiah, man aged 55-64, from a Black-Caribbean background, based in the West Midlands.

The male participants often pointed out that they were in the minority among their friends if they accessed help. They felt that a cultural narrative of "brave men" made them feel they couldn't reach out for support. An interesting point of difference occurred around time off work - men were significantly more likely to have had time off work for bereavement, than women. Reasons for this require more investigation but might suggest that women lack an awareness of their work rights. They may also be being denied time off or could be choosing to continue to work for a variety of reasons.

Ethnicity

Ethnicity played its part in accessibility to services. High proportions (89%) of people from Black Caribbean and Black African backgrounds were provided with prescription drugs, such as antidepressants, after bereavement. This was compared to a 64% average, across all ethnicities. This correlates with the broader research suggesting that people from Black, Asian and minority backgrounds are more likely to be prescribed antidepressants than White patients in place of other types of mental health support.[16]

In terms of access to formal support as a whole, people who identified as White British[17] were less likely than people from Black African, Asian Pakistani and White European backgrounds to access formal support. For people from White British backgrounds, 26% of people from White British backgrounds accessed formal support, compared to 52% from Black African backgrounds, 55% from Asian Pakistani backgrounds and 44% from White European backgrounds. The formal support that these groups were particularly more likely to access included group therapy, online forums, bereavement cafes and online chat functions.

When accounting for the routes into support, people from Black African and Asian Pakistani backgrounds were significantly more likely to hear of support through religious groups than people from White British backgrounds. For example, only 5% of people from White British backgrounds heard of support through religious groups. In contrast, 10% of people from Black African backgrounds and 8% of people from Asian Pakistani backgrounds heard of support through religious groups. For people from Black African communities, this was the second most common way into support. This suggests that religious groups are a clear way into support for people from these communities.

Learning Difficulties and Disabilities

Interestingly, those who live with a learning difficulty or disability were more likely to access formal support than those who do not. This may be because people with learning difficulties or disabilities are already known to the health and/or care system. This could mean that those supporting them may be aware of a change in need in light of a bereavement, and therefore, they have links into the health system, with charitable support or to financial support.

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16 https://www.cambridge.org/core/journals/psychological-medicine/article/variations-by-ethnicity-in-referral-and-treatment-pathways-for-iapt-service-users-in-south-london/E02A98DE585A16189A6FCFA63A5290DE.

17 Including White-English/Welsh/Scottish/British/Northern Irish.

However, people with learning difficulties and disabilities were considerably less likely (36%) to have family and friends as support than those who did not have learning difficulties or disabilities (66%). Given the importance of family and friends as emphasised by the participants, this point needs investigating to ensure that those surrounding people with learning difficulties or disabilities are well equipped to signpost them to support if they face grief.

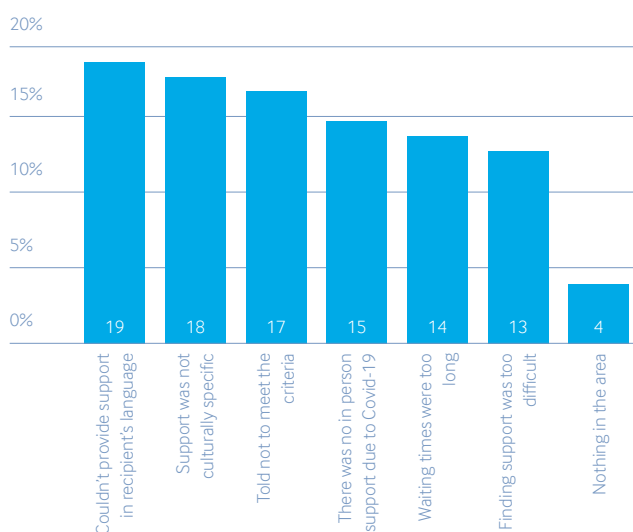### People who did not access support

Although everyone tried to access some form of support, 3% tried to access support but couldn't. In contrast, nearly 1 in 5 people, having accessed informal support of some kind, did not try to access other types of support, such as counselling, bereavement cafes and online chat functions. Of this group, they didn't try to access other types of support because they felt like they had enough support from their immediate network (18%), they didn't think it would help (18%) and they didn't know where to start looking (15%). In part, this demonstrates the need to better promote existing services. However, perhaps most importantly, it demonstrates the power of informal types of support. For example, having a strong network of family and friends evidently can prevent people from needing other types of support.

The most common barriers to accessing support were that the support is not culturally specific (18%) and that a service could not be provided in the recipient's language (19%) (see Figure 4). Some participants felt that services did not show an appreciation of different death and grieving rituals, and therefore, they did not feel confident the service would understand their situation.

" It was quite, very difficult to find support. Trying to understand if the organisation could help us because all the Muslim rites need to be carried out in the correct form. And it was very complicated around burial and support after the death. Even very experienced people in the community did not know what to do."

Jim, man aged 55-64, from a Black-African background, based in Northern Ireland.

Figure 4 - Barriers to accessing support.

Couldn't provide support in recipient's language	Support was not culturally specific	Told not to meet the criteria	There was no in person support due to Covid-19	Waiting times were too long	Finding support was too difficult	Nothing in the area
19	18	17	15	14	13	4

GPs also reflected this sentiment. Multiple GPs stated that because the services adopt a Western understanding of death and grief, people from Black, Asian and minority ethnic communities and/or different religious backgrounds often feel alienated.

"There are cultural differences in how people seek help, how people want to seek help, the type of help and just the openness to it."

GP, based in London and South East England.

Informal support can be powerful in providing people with the permission to grieve

This research has revealed the considerable role of informal and non-clinical support in enabling people to feel supported in the early stages of their journey through grief. Any landscape of bereavement support would be incomplete without informal and non-clinical services as they reflect and support the complex ways people experience grief.

Informal support

Unsurprisingly, 65% of people used the support of family and friends in their journey through grief. Broader research finds that people grieve at work, in education settings, at home and with their family and friends or in care settings 95% of the time.[18] We spend less than 5% with professionals when we are dying or grieving. Friends and family therefore play a key role in ensuring that people feel listened to when facing grief.

"My friends are good listeners. They are always there to lean on. I owe them my life because without them I wouldn't have moved on early, even though I still grieve sometimes."

Sasha, woman aged 25-34, from a mixed White and Black African background, based in London.

For those facing bereavement during the Covid-19 lockdowns, not being able to readily be with their friends and families revealed just how important those lifelines can be.

"The loss was so difficult to process. And three months later, we went into lockdown, so all my support system disappeared....and then I got so desperate one night, I felt lost and suicidal."

Alice, woman aged 45-54, from a White-British background, based in South East England.

Other informal support often came from religious and community groups, peer support groups or charities. The least common type of informal support that people engaged with was consulting a charity for advice, at only 6%. Many felt that they were aware that some charities existed to support people with bereavement, but they did not know their names or how to access them. More work needs to be done to raise awareness of the work that charities do to ensure people find the right support when they need it.

Although such high proportions of people received support from their friends and family and other forms of informal support, the survey suggests that people still felt they needed more support with 79% of people stating that the support did not sufficiently meet their needs. Given how friends and family are the most common form of informal support that people turn to, this highlights that they need to be better equipped to meet their needs and signpost people to support.

18   https://books.google.co.uk/books?id=uL9pEAAAQBAJ&hl=de&lr=.

Gaps in non-clinical offerings

It is clear from the research that non-clinical and informal support is just as crucial in people's journeys through grief as formal or clinical support. Two of the top three services that people did not receive but would have liked fell under informal or non-clinical support. These included financial support (28%) and written information about how to manage grief (25%). In addition, a high number of people also would have liked a mentor or befriender (24%) but did not access them.

One participant described the support he received from a mentor as crucial to processing his grief: "I already had a mentor before my mother passed away, but having them in my life when I experienced grief was really helpful to me. Having someone similar to my age who was able to remind me that I was able to be honest about my emotions was so important. Hearing other people's stories just like your own and knowing you don't have to hide was amazing." Ade, man aged 25 to 30, from Black-African background based in London.

Broader research conducted by Sue Ryder found that 86% of people who have experienced bereavement felt alone in their grief.[19] It also found that 44% of the British public admitted that they have felt unsure of what to say when someone tells them a close relative or friend has died.[20] This emphasises the importance of more social and community-based forms of support for people facing grief and bereavement. Not only do these types of support acknowledge the broad impact grief can have across people's lives, accessing non-clinical or informal support early also could also prevent needing clinical support later down the line.

How people found out about support

As mentioned, friends and family, alongside GPs, were the most common way people heard about support. People would typically hear most about bereavement cafes, church or religious groups, online chat forums or peer to peer support groups through their friends and family.

Family and friends should be equipped with knowledge and understanding of grief, as well as an awareness of the available support services, as they play an important role in getting people the right support. Some of the participants described how they had felt "ashamed to grieve", particularly when it was a long time after the death. They felt that there was a cultural expectation around how long you 'should' grieve for and in what way. This was particularly the case for older, male participants.

"If I'm honest, at points, I felt ashamed to grieve. I was told I should 'get over it' as it had been a long time since it had happened. But I couldn't. I felt really angry at myself that I just couldn't move on. Kind of embarrassed."

Nathan, man aged 18-24, from a White-British background, based in Wales.

"Because no one really asked me about it or I didn't know how to talk about it, I just felt like I should just brush myself off and get over it. It's a fact of life, I should just get on with my life."

Isaiah, man aged 55-64, from a Black-Caribbean background based in the West Midlands.

Therefore, having people in your immediate network who allow you the space to grieve is integral to a healthy grieving process. In recent years, a lot of work and investment has been put into normalising conversations around mental health and creating awareness of everyone's responsibility in encouraging good mental health. It is clear from the research that bereavement requires a similar level of attention.

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19   https://www.sueryder.org/news/sue-ryder-launches-grief-kind-campaign#:~:text=Although%20we%20help%20thousands%20of,made%20getting%20help%20even%20harder.

20   https://www.sueryder.org/news/sue-ryder-launches-grief-kind-campaign#:~:text=Although%20we%20help%20thousands%20of,made%20getting%20help%20even%20harder.

Recommendations

This research has shown there to be high proportions of unmet need for clinical and non-clinical support, as well as disparities in the availability of, and access to services. It is crucial that any actions going forward eliminate the existing barriers to access and address the patchwork nature of the available support.

The key stakeholders, from healthcare professionals to the Government, need better awareness of the available services to ensure that they are leveraged and that people are getting the support they need at the right time. The recommendations for follow-up actions focus on the responsibilities of three distinct parties who all have different roles to play in ensuring that people are better supported through their grief in the UK:

1. **Government and healthcare decision-makers:** to make informed decisions to lead and create systemic change.

2. **Charities and service providers**: to leverage evidence to support unmet needs and to influence positive change.

3. **Society:** to recognise the shared responsibility across society, so people feel able to talk about grief and feel more equipped to find the right support.

Government and healthcare decision-makers

Commit to developing a bereavement specific pathway that adopts a public health approach. The pathway should be informed by evidence of effective clinical and non-clinical interventions and should establish formal referral partnerships and feedback loops. It should draw on the expertise of organisations who support people through bereavement and be co-created with people with lived experience.

To support this:

1. **The Government should lead a public health campaign supported by the bereavement sector** (including charities, grassroots organisations, religious groups, funeral directors, workplaces and others) to promote an awareness of grief and the support available. This will improve earlier interventions and lessen the pressure on clinical services within the pathway, as well as helping to reach people who may not engage with their GPs.

2. **Integrated Care Systems (ICSs) should further establish the adequacy of local bereavement support service provision.** This would involve ICSs working with a shared framework to identify and map what is available in their area, including the reach and capacity of the services identified. This information should be shared with healthcare professionals to support their use of the pathway, and any gaps identified should inform any necessary future commissioning decisions.

Charities and service providers

In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support. An initial area of focus should include building a better understanding of diverse cultural beliefs around death and grief, as well as the barriers that exist for certain groups. These insights should inform service design at both a local and national level.

Society

Acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.

Our Commitment

Sue Ryder are committed to taking the findings of this research forward. We will use the insights gained to work with decision-makers to secure a formalised approach to bereavement support that accounts for individual need. We will work with our partners to advance research on this issue, to build on our #GriefKind movement to equip people to support each other, and to further develop the services we offer to thousands of people, across the UK, every year.

If you would like to find out more about Sue Ryder's bereavement work please visit sueryder.org.

Appendix 1 – Glossary

Close bereavement - As described by the Chartered Institute of Personnel and Development (CIPD), 'close bereavement' includes the bereavement of 'a child of any age, parent, or sibling (whether by blood or adoption) or partner'.[21]

Financial support - this includes government welfare support, bereavement support payment, financial support to pay for funeral arrangements, financial support to help make ends meet and tax credits.

Formal bereavement support - tailor-made support for individuals facing grief delivered with the contribution and/or oversight from a trained counsellor or healthcare professional. The National Institute for Health and Care Excellence (NICE) guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) provides a component model for supporting people facing bereavement. The End-of-Life Care Strategy[22] subsequently applied this model to bereavement following all expected deaths. Given our definitions of formal support, we have defined any support considered Component 2 and above as formal support.[23]

Informal bereavement support - non-specific or not tailor-made support, and/or support that does not involve a trained counsellor or healthcare professional. Under this definition, informal support includes written information about what you can do to manage your grief, support from your church/mosque or another religious group, consulting a charity for advice, friends / family, and your informal peer support group (e.g. social group, running group, knitting group). In the NICE guidance, informal support is termed as Component 1.[24]

Integrated Care Systems (ICS) - partnerships bringing together the NHS, local authorities and third sector bodies to plan and deliver joined up health and care services to improve the lives of the people who live and work in their area.

Practical support around the death – such as arranging the funeral and registering the death. This would not include family/friends.

Specialised mental health support - receiving long-term mental health support through the healthcare system, such as being allocated a psychiatrist and receiving a long-term treatment plan.

Support around the house – such as day-to-day chores and/or childcare.

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21   https://www.cipd.co.uk/about/media/press/bereavement-leave-extended#gref.
22   Department of Health, 2008.
23   https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005.
24   https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005.

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.

For more information about Sue Ryder

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This document is available in alternative formats on request.

palliative, neurological and bereavement support