



**Independent
Age**

Approaches to
commissioning
bereavement services:
**A freedom of information
request with Clinical
Commissioning Groups
and local authorities**

Contents

| | | |
|------------|------------------|----|
| 1. | Introduction | 4 |
| 2. | Key findings | 6 |
| 2.1 | Mapping | 6 |
| 2.2 | Awareness | 8 |
| 2.3 | Commissioning | 9 |
| 2.4 | COVID-19 funding | 10 |
| 3. | Recommendations | 12 |
| 4. | Appendix | 13 |
| 5. | Acknowledgements | 14 |

Key messages

- There is no clear responsibility for providing or commissioning bereavement support, with Clinical Commissioning Groups (CCGs) and local authorities (LAs) adopting different approaches in different areas.
- Only a small proportion of CCGs and LAs have conducted a mapping exercise to understand what bereavement support is available in their local area.
- Many CCGs and LAs have not provided any financial support to provide or commission bereavement support in their local area.
- Only a small minority of CCGs and LAs have invested extra money for bereavement support during the pandemic, despite COVID-19 meaning many more people will be at risk of developing complicated grief.

Key calls

- The government must start to provide strategic oversight of the bereavement sector through a cross-department bereavement strategy led by the Department of Health and Social Care.
- Bereavement support must be made more of a priority area in terms of government expenditure.
- We think it is appropriate for CCGs to take the lead on understanding the landscape of bereavement services in their area, although with support from LAs.
- NHS England must produce clear guidance for CCGs on how to commission bereavement support services.

1. Introduction

Bereavement services are an often-hidden element of health and care services. Bereavement support rarely makes the headlines, but the COVID-19 pandemic has highlighted the essential need for this kind of support. In the first lockdown alone, we estimate that up to 98,000 older people were bereaved of a partner.¹ With people experiencing traumatic bereavements and even more experiencing grief in the midst of restrictions on social contact, the reality is many more people may need to access bereavement support over the years to come.²

It is important to remember that not everyone who is bereaved will need professional support, with many managing with the help of friends and family. However, for some people this either won't be available, or it won't be enough. Typically, 7% of bereaved people go on to develop 'complicated grief', a period of prolonged acute grief.³ This can happen when the 'normal' grieving process is interrupted, which has been the case for many people during the pandemic. We therefore expect more people to develop complicated grief in the wake of COVID-19. Complicated grief can manifest in many ways and it is essential that those in need of help and support are able to get it.

While many bereavement support providers are funded at least partially through voluntary income, we know that grants from Clinical Commissioning Groups (CCGs) and local authorities (LAs) form an important part of the funding landscape. We know anecdotally that levels of investment vary significantly across England and that this can mean where someone lives can determine whether or not they can access professional support. To better understand the commissioning landscape, we submitted a freedom of information (FOI) request to CCGs and LAs in autumn 2020, asking them about their approaches to commissioning services and their knowledge of the current demand and availability of services in their area. Our request asked about both emotional and psychological support, as well as practical information and advice. This did not include local authority financial contributions to burial, cremations and funerals.

This briefing outlines the response to our FOI, our key findings and our recommendations for government on prioritising bereavement support.

¹Independent Age estimate based on combining ONS weekly death figures with data from the Family Resources survey. Note that dates do not match exactly the lockdown period due to when data sets are published – figures have been calculated using the closest available data to the beginning and end of the first national lockdown in 2020.

²Cardiff University and the University of Bristol, 'Supporting people bereaved during COVID-19: Study Report 1', 2020, bristol.ac.uk/primaryhealthcare/news/2020/interim-findings-from-first-uk-wide-survey-of-bereavement-during-the-pandemic.html

³M Katherine Shear, 'Grief and mourning gone awry: pathway and course of complicated grief', *Dialogues in clinical neuroscience*, vol 14, no. 2 (June 2012): pp 119–28, [ncbi.nlm.nih.gov/pmc/articles/PMC3384440](https://pubmed.ncbi.nlm.nih.gov/pmc/articles/PMC3384440)

FOI request response rates

Clinical Commissioning Groups*

106 responses (72%)

Local authorities

121 responses (79%)

Complete data (CCGs and LAs) for local areas

We have complete data for 77 local authority areas.

All percentages within this briefing are based on the number of CCGs or LAs that responded to our FOI request, not the overall number of CCGs or LAs that exist.

*In April 2020 a number of CCGs merged to reduce the overall number of CCGs to 135. However, some CCGs in their responses to us chose to provide multiple parts of data specific to former CCGs. So, while there are officially 135 CCGs, within this briefing we have an overall number of 147 possible CCGs, including former CCGs that have provided responses.

2. Key findings

2.1 Mapping

Key statistics

- 60% of CCGs (64) and 77% of LAs (93) that responded were unable to give any information regarding the number of people who had benefited from bereavement services in their local area.
- 25% of CCGs (27) and 17% of LAs (21) had undertaken some form of mapping of the bereavement services in their population.
- There were at least 49 local authority areas where no mapping had taken place by either the local authority or the local CCG.

Some mapping of the bereavement landscape is happening, but it is not consistent. It is clear that mapping the availability, demand for and use of bereavement services in the area has not been a priority for many CCGs or LAs, with few having conducted work to understand the context of bereavement support in their area.

This was especially true when it came to mapping how many bereavement support providers exist within the area, with only a quarter of CCGs having undertaken such an activity. An even smaller percentage of LAs had done the same, with only 17% stating they had conducted some form of mapping of bereavement services.

For most of the CCGs or LAs that had undertaken a form of mapping, this was usually a basic list of service providers who offer help with health and care services (including bereavement) and they had made this information publicly available in the form of a leaflet.

However, a much more comprehensive form of mapping had been undertaken by Gloucestershire CCG. This CCG had completed a considerable review of bereavement services in the area and accumulated a wide variety of data on these services. This included the type of bereavement the support covered, the type of support provided, the criteria for accessing the service and whether there have been any changes to provision due to the COVID-19 pandemic. But Gloucestershire was an anomaly rather than the norm, and we know of at least 49 local authority areas where neither the local authority nor the relevant CCG have conducted any mapping.

This lack of understanding of what is already available suggests that there is a significant absence of strategic oversight happening across England regarding a fundamental area of much-needed support.

Case study

NHS Gloucestershire CCG

NHS Gloucestershire CCG has conducted an extensive mapping exercise to understand what support is available within the local area. This research has been brought together to give a definitive collection of local support, which includes:

- provider name
- contact details
- localities covered
- type of bereavement
- type of support offered
- age limit
- criteria for access
- charging process
- any changes to provision since COVID-19.

This type of research gives Gloucestershire CCG a robust understanding of the availability of bereavement support and means that they are well placed to identify any gaps in service provision.

Case study

Hertfordshire County Council

Hertfordshire council's Integrated Health and Care Commissioning Team commissioned a mapping and review of adults' and children's bereavement support in Hertfordshire in 2020, as well as a review of support available to people bereaved through suicide. These have not yet been published; however, in response to COVID-19, the team also developed a series of bereavement guides for young people, adults and parents, and an easy-read version for people with learning disabilities. The team has also commissioned bereavement training for school staff and police, and is in the process of securing funding for a coordinator post to fulfil the recommendations of the reviews commissioned.

2.2 Awareness

Key statistics

- 51% of CCGs (54) were unable to name any other organisations that commissioned bereavement services in their local area. Of these CCGs, 21 did not commission any services themselves.
- 48% of LAs (58) were unable to name any other organisations that commissioned bereavement services. Of these LAs, 49 did not commission any services themselves.
- 22% of CCGs (23) identified the local authority as a commissioner of bereavement services.
- 19% of LAs (23) identified the CCG as a commissioner of bereavement services.

There is not always good awareness of other commissioning in the same area. Despite many CCGs and LAs not taking responsibility for overseeing the bereavement services in their area, many also didn't know where this responsibility sits.

Of those CCGs and LAs that were able to suggest other commissioning organisations in their area, they often mentioned the local authority or CCG respectively. There was one example where the local authority believed their local CCG commissioned bereavement support, but where our FOI data showed that that CCG did not, in fact, commission any services. This poor awareness of activity, even from other areas, suggests bereavement support is currently a low priority in many places. We know that that specific CCG does not, in fact, commission any services, so the information relayed to us and the organisation's general understanding was not always accurate.

2.3 Commissioning

Key statistics

- 9% of LAs (11) had directly provided bereavement services within the past three years.
- 57% of CCGs (60) and 26% of LAs (31) had commissioned bereavement services within the past three years.
- 32% of CCGs (34) and 56% of LAs (68) had not commissioned bereavement services within the past three years.
- There are at least 12 local authority areas where no bereavement support is commissioned by either the local authority or CCG.

There's a huge variety in the level of commissioning, with some evidence of areas with no commissioning by either the CCG or local authority. These figures demonstrate the real variation in approaches to commissioning and providing bereavement services. While more than half of CCGs have taken steps to commission services, almost a third of CCGs do not seem to have prioritised bereavement support within their remit (11% referred to other types of commissioning).

However, investing in bereavement support is still more common for CCGs than LAs, with just a quarter of LAs having commissioned services within the past three years.

Even among those CCGs and LAs that did commission bereavement services, there was a significant lack of clarity over the detail. Many were unable to identify how much money they spent specifically on bereavement services, because this support was wrapped up in wider contracts and grants with organisations to provide generic mental health or end-of-life support. Again, this lack of granularity is more evidence of a lack of CCG or local authority understanding of their current offer with regards to bereavement support.

It was also notable that even where CCGs and LAs did commission support and did have the detail to provide exact figures, the level of investment was hugely varied, with one CCG, over the past three years, committing more than £1 million and another committing less than £9,000. The range was also significant for local authorities, with the minimum provision amounting to almost £2,000 and the maximum almost reaching £500,000.

In 12 areas where we had data for both the relevant CCG and local authority, the local CCGs and LAs have not commissioned any bereavement services at all. This does not necessarily mean that residents within these areas cannot access support. There are many community groups funded by voluntary donations that provide support and numerous national providers still offering services in these areas. However, the reality is that without any form of commissioning in the area and no CCG or local authority taking responsibility for this support, it becomes much less likely that every person in need of bereavement support will be able to get it. Access to bereavement support should not depend on whether you happen to live in an area that has been able to fundraise for voluntary support.

2.4 COVID-19 funding

Key statistics

- 22% of CCGs (23) and 17% of LAs (20) have provided additional funding for bereavement support, given COVID-19.
- There are at least 56 local authority areas where no additional bereavement funding has been put in place by either the local authority or the local CCGs.

Not many CCGs or LAs have invested in additional bereavement services in response to COVID-19. Only a small proportion of CCGs and LAs have provided additional funding for bereavement services directly in response to COVID-19. While we recognise that there have been pressures on CCG and local authority budgets during the COVID-19 pandemic, this finding suggests that an essential area of support is being left behind at a time when bereavement support is arguably all the more vital.

One CCG noted that they hadn't increased investment in bereavement support because they had seen demand for services drop during the pandemic. We know from conversations with providers that this is a trend that was experienced by many support providers across the UK during the pandemic, with reductions in call volumes and people requesting support. We know that during lockdown many of the traditional referral pathways for bereavement support – such as face-to-face GP appointments – were not readily available. It is not surprisingly, then, that demand might have dropped temporarily.

People are still struggling with grief now, and will be in the future. We estimate that up to 98,000 older people were bereaved of a partner during the first lockdown.⁴ Research has shown that those bereaved during the COVID-19 pandemic have faced significantly more negative experiences of bereavement.⁵

Given the many challenges people have experienced while grieving during this period, we can reasonably expect the need for bereavement support services to be much higher than usual. Research by the National Bereavement Alliance has actually shown that 40% of service managers have said that referrals during late August/early September 2020 are higher than usual at this time.⁶ Funding decisions should be made on a long-term basis, with an acknowledgment that the pandemic will likely increase demand for bereavement support services in the coming years.

⁴Independent Age estimate based on combining ONS weekly death figures with data from the Family Resources survey. Note that dates do not match exactly the lockdown period due to when data sets are published – figures have been calculated using the closest available data to the beginning and end of the first national lockdown in 2020.

⁵Cardiff University and the University of Bristol, 'Supporting people bereaved during COVID-19: Study Report 1', 2020, bristol.ac.uk/primaryhealthcare/news/2020/interim-findings-from-first-uk-wide-survey-of-bereavement-during-the-pandemic.html

⁶National Bereavement Alliance, 'Covid-19: the response of voluntary sector bereavement services', December 2020, nationalbereavementalliance.org.uk/wp-content/uploads/2020/12/Covid-19-and-the-voluntary-sector-bereavement-service-response.pdf

3. Recommendations

These FOI request results demonstrate the considerable lack of strategic oversight and service commissioning that is occurring within the bereavement sector. With bereavement support being needed now, more than ever, it is vital that this changes quickly.

- The government must provide strategic oversight of the bereavement sector through a cross-department bereavement strategy led by the Department of Health and Social Care. This could start with both a cross-government review of supporting bereaved people and commissioning a significantly expanded version of the 2015 National Survey of Bereaved People (VOICES) in England.
- Bereavement support must be made more of a priority area in terms of government expenditure. The government should commit to funding for CCGs to support bereavement providers in their local area.
- We think it is appropriate for CCGs, as experts in their local area, to take the lead on understanding the landscape of bereavement services in their area, although with support from local authorities. At a minimum they should:
 - conduct research to understand the current demand for bereavement support in their local area. This should be informed by what we know about the likely impact of COVID-19 and the particular challenges of loss and grieving during the pandemic
 - conduct mapping of existing bereavement support providers, including voluntary and community groups, to understand the existing ecosystem of support
 - commit to allocating specific funding for commissioning bereavement support providers to help shape and support this ecosystem.
- NHS England must produce clear guidance for CCGs on how to commission bereavement support services. This guidance should include details of research and mapping activities that should be undertaken, as outlined above.

4. Appendix

Questions asked in FOI request

1. Did you directly provide any bereavement support at any point in the past three financial years? If yes, please indicate which years.
2. Did you commission or provide any grant funding to any organisation that provides bereavement support at any point in the past three years? If yes, please indicate which years.
3. How much money, if any, did you allocate for directly providing bereavement services in each of the past three financial years?
4. How much money, if any, did you allocate for commissioning/grant funding of bereavement services in each of the past three financial years? (Please list grant and contract amounts separately.)
5. Are you aware of other organisations/bodies in the area covered by your CCG that commission bereavement services, for example, the local authority? If yes, please indicate which organisations these are.
6.
 - a) Have you commissioned any additional organisations or provided any additional grant funding to provide bereavement support directly in response to the COVID-19 pandemic? Please include organisations you have existing contracts with but have increased the amount of funding you have given because of the pandemic situation.
 - b) If yes, please outline how much money and to how many organisations your CCG has given, and over what time period – for example, one-year contract, two-year contract?
7. Which organisations do you currently financially contract or provide grant funding to, to supply bereavement services?
8. Please can you tell us the number of adults who benefitted from bereavement services in your CCG area in each of the past three financial years? Please include, where possible, an age profile within this.
9. Have you undertaken any mapping or reviews of the availability of both formal and informal bereavement support services available in your area? If you are able, please do include any links to this work.

5. Acknowledgements

We would like to thank Steven Wibberley from Cruse and Alison Penny from the National Bereavement Alliance for their help and support with this research.




Independent Age
18 Avonmore Road
London
W14 8RR

020 7605 4200
charity@independentage.org
independentage.org
Helpline 0800 319 6789

 Like our page **Independent Age**

 Follow us **independentage**

 Follow us **@independentage**

 Subscribe to **IndependentAge**

© 2021 Independent Age

Independent Age is the operating name of the
Royal United Kingdom Beneficent Association
Registered charity number 210729
(England and Wales) SC047184 (Scotland)