National Bereavement Alliance

Childhood Bereavement Network

Covid-19: the response of voluntary sector bereavement services

December 2020

Executive summary

This report outlines the need for

1. An immediate injection of funding to stabilise the voluntary sector response to bereaved people, enabling the sector to respond to the growing need
2. Significant further investment in the sector, to be unlocked by a government-led review of the whole system of support for bereaved people. This review should
    - decide the relative responsibilities for funding and providing bereavement support between central government, local government, the NHS, voluntary sector and private provision, and
    - what else is needed to make this system work well for bereaved people (e.g. pathways of support, appropriate training, measurement of the difference that bereavement support makes)

Getting support

- Grief is a normal reaction to bereavement and in usual times, many people find that their inner resources, combined with support from family and friends and communities, are enough to help them manage their distress and the life changes and adjustments triggered by loss.
- Generally, people do not need routine referral for bereavement counselling simply because they have been bereaved. However, in usual times, around 40% of bereaved people will need more support than their family and friends can provide. This support might be from others who have also been bereaved, or from a trained volunteer bereavement support worker. Some will need more intense support.
- Even before the pandemic, 20-30% of bereaved adults didn't get the support they would like from organised services. Those in greatest need of support may be most reluctant to seek support.
- Some people don't know about the support available. Others live in areas where there is a waiting list, long travel times, or no suitable services. Palliative care services often provide well-valued continuity of care before and after a death. But when someone dies suddenly in the community, generally their family and

friends do not get proactive immediate support, although they may have very acute health, safety and financial needs.

Who provides support

- Bereavement care services are very diverse, from small local organisations to large national ones; from those working with all bereaved people to those targeted to a particular group such as parents bereaved of a child. Services may be universal, targeted or specialist, reflecting a tiered approach; may involve practical and or emotional support; and be provided in groups or 1:1.
- The NHS provides some bereavement support following hospital deaths, and via mental health services for those with acute needs. Some people access private counselling. However, the bulk of bereavement care is provided by the voluntary sector and is free to bereaved people.
- Voluntary sector services' income comes from community fundraising; individual and corporate donations; grant-making trusts and foundations; contracts with clinical commissioning groups, other health bodies or the local authority; central government departments; traded income (e.g. training and consultancy, charity shops, sale of resources); legacies; charges to service users; investment income.
- The total amount of funding going into the sector each year from grant-making trusts and foundations is at last £9million. However, over three quarters of this funding is for amounts under £15,000, and to be spent over one year or less.
- This provides little ongoing financial security for organisations, which has a knock-on effect on the stability of support for bereaved people. To feel confident about embarking on bereavement support with someone newly referred to the service, organisations must have the financial viability to see that course of support through.

The impact of the pandemic

- The blight of COVID-19 has brought additional pressure into a system that was already struggling. The need for bereavement support is greater than usual because
    - more people are bereaved – we estimate at least 19% more people have been bereaved since 20 March 2020 than would be usual
    - levels of distress in bereavement are higher than usual both as a result of the virus and of social distancing measures
    - social distancing has disrupted funerals and increased isolation and loneliness
    - many people are affected by economic pressures and general anxiety
    - lack of capacity in other services means fewer bereaved people are able to get support from usual channels.
- These differences mean that people's needs are more complex when they reach out for support from bereavement services. Service managers report people are contacting services sooner for support, needing support for longer, and needing more intense, specialist support.

- The pandemic has also had a disproportionate impact on those from certain Black, Asian and Minority Ethnic communities and those in particular occupations, raising the risk of bereavement among these groups.
- While three quarters of services saw the number of people approaching them for support falling early in lockdown, for many these referral rates have now increased again. Over 40% of service managers say that their referrals are higher than usual for this time of year.
- Based on current trends and their experience, the vast majority of service managers – 90% - expect their referrals to rise in the autumn and winter and beyond.
- Services have put huge efforts in place to adapt and convert their ways of working so that they can support bereaved people in ways that comply with physical distancing measures and to respond to the new needs they are seeing. Some of these ways of working make it harder to support groups such as young children and those without reliable internet access.

Falling and insecure income for services

- Just at the time when the complexity and need for voluntary sector bereavement services is growing, their income is less secure.
- Half of voluntary sector managers expect their income to drop this year compared to last. Almost a third expect it to fall by 25% or more. Even those who expect their income to stay roughly the same know that that they will have to make it go further as demand for their service grows.
- Some voluntary sector services have had top-up or emergency funding to respond to the pandemic, establishing new services with all the set-up costs entailed. However, the vast majority of this funding is short-term: some has ended already and more will do so over the next two months. With an anticipated growth in referrals, plus individual bereaved people needing support for longer, it is wasteful and disruptive for services to be stood down just as they are most needed.
- The precariousness of funding has a knock-on effect on support for bereaved people. Without additional funding over the next 12 months, 40% of service managers will have to close, reduce or restrict their services and another 40% will be unable to expand to meet extra demand. A third will have to use their charity's financial reserves this year to balance their budget.
- More funding would help managers to stabilise services, reach more people, reach people sooner, provide more intense support to those with complex needs, and improve equality of access and outcomes.

What is needed?

- Key elements of a system response to bereavement support following mass disasters identified in a recent review are[i]
    - proactive outreach to those in need;
    - central coordination of locally delivered support;

  - training for providers in crisis-specific core competencies;
  - structured psycho-education as well as group-based support and use of existing social networks;
  - formal risk assessment for prolonged grief disorder and
  - referral pathways for specialist mental health support.

- To strengthen the development of these aspects of support, and to respond to the challenges outlined in this paper, we need
  1. An immediate injection of grant funding to stabilise the voluntary sector response to bereaved people, enabling the sector to respond to the growing need we have identified
  2. Significant further investment in the sector, to be unlocked by a government-led review of the whole system of bereavement support. This review should
     a. decide the relative responsibilities for funding and providing bereavement support between central government, local government, the NHS, voluntary sector and private provision, and
     b. what else is needed to make this system work well for bereaved people (e.g. pathways of support, appropriate training, measurement of the difference that bereavement support makes).
- The outcomes we would hope to see for bereaved adults and children would be
  - Clear pathways into appropriate immediate, medium- and long-term support
  - Greater understanding among bereaved people of ways of supporting themselves, understanding how and when to reach out for further help (through easily accessible culturally appropriate content)
  - Upskilling people's natural and usual support networks (e.g. schools, employers) through training and mass communications to respond appropriately
  - Increased link up for the first days and weeks between bereaved people and practical, community help such as mutual aid societies and where necessary statutory services
  - Increased awareness of the range of bereavement support services among the general public and the sector through improved signposting
  - Increased capacity of bereavement support services in the short, medium and long term to provide 1:1 and peer support opportunities in bereavement, reflecting the tiered model approach.

Table of Contents

Acknowledgements

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Introduction

1. The effects of bereavement on families, friends and colleagues are the inevitable and painful legacy of the COVID-19 outbreak. While we succeeded in flattening the peak and maintaining the capacity of the NHS, many thousands of people – both adults and children – have been bereaved, and more will join them if the death rate increases in line with the case rate.
2. Social distancing measures, while reducing the number of deaths to COVID-19, have affected all bereavements through any cause at this time, by thwarting families' opportunities to spend time with dying loved ones, disrupting funerals, and putting barriers up to the invaluable social support that families, friends and communities can usually provide.
3. Supporting bereaved people is everyone's responsibility. We all play a part personally as family members, friends, neighbours and colleagues. For many people, this will be enough. But for others – particularly when the death is shocking or living circumstances are difficult – will need the support of trained bereavement supporters or professionals to find a way through their loss.
4. At the same time, drops in income and changes to the delivery of local and national bereavement services threaten the availability of organised support – already very stretched - for those that need it. This legacy will last for months and years to come.
5. This paper outlines bereavement support needs and how these are met in usual times, including the pressures and gaps in provision. It then looks at the impact of the pandemic on needs and support, including an exploration of the funding needs of the voluntary sector. It ends with a set of recommendations. It draws on evidence from two recent surveys of voluntary sector managers. It lacks the voice of bereaved people themselves: this crucial aspect will be added as findings emerge from the major funded studies underway into the experiences of bereavement at this time of pandemic.

Section 1: bereavement in usual times

Bereavement support needs

6. Grief is a normal reaction to bereavement and in usual times, many people find that their inner resources, combined with support from family and friends and communities, are enough to help them manage their distress and the life changes and adjustments triggered by loss. However, bereavement is associated with risks to health and wellbeing, increasing the risk of mortality, physical health problems, physical disability, use of medication and hospitalisation[ii]. Widow(er)s[iii] and children bereaved of a parent[iv] are more likely to visit their GP.

7. In Scotland in 2011, the annual cost of hospital stays associated with the death of a spouse was estimated at £20 million[v] – we estimate that across England in 2019-2020 (before the pandemic) this would equate to annual costs somewhere between £180m and £260m. The figure would be much higher if it included the impact of the death of a child, parent or someone else close, and the costs of increased use of other health and social care services and days off work or away from school.

8. While many people are resilient and regain their equilibrium, many experience impacts on their physical and mental health and functioning. This can include high levels of distress for a period of time, including disturbing memories of the events leading up to the death or the death itself, blaming others for the death or feelings of remorse for their own past behaviour. Those bereaved in ways that are unexpected and shocking may also face often acute health and safety needs in the immediate aftermath of the death.

9. A minority of people experience high levels of distress and chronic grief symptoms that persist in impacting on their lives for a substantial period[vi] . Around 10% of the general population of bereaved adults are likely to suffer 'complicated' or 'prolonged' grief following a death[vii] (these collections of difficulties are distinct from, but often found alongside, other mental health disorders such as depression, anxiety and PTSD): rates are likely to be higher among those bereaved of a child, or following a traumatic death[viii].

10. Even at the best of times, general awareness and understanding of grief is often lacking, leaving bereaved people feeling lost and misunderstood. All too frequently, people report feeling isolated and being expected to 'get on with it' after a bereavement, especially as time goes on.

11. It is generally accepted that people do not need routine referral for bereavement counselling simply because they have been bereaved[ix]. Offering counselling routinely and quickly after bereavement may encourage people to use services rather than turning to family and friends, finding their own inner strengths, or allowing their grief to follow its natural course[x] [xi]. It could encourage people to view grief as a mental health problem per se, rather than a normal reaction to loss which can increase vulnerability[xii]. It could lead to the unnecessary over-professionalization of bereavement care. However, making sure that people are aware of the services available, assessing practical and

health and safety needs, vulnerabilities and strengths, and providing early, straightforward support that enables people to feel safe, supported and connected to their community can help reduce some of the risk factors contributing to social deprivation, isolation and mental health difficuties.

12. Some bereaved people do need more support than their families and friends can provide[xiii]. The National Bereavement Alliance has built on NICE guidance[xiv] and the public health model of bereavement[xv] to elaborate a three-component model of support shown in figure 1.

13. The three components are interdependent. Without the resources of component 1 and the opportunities for component 2 support, component 3 services would be overwhelmed by people unable to find less intense support, and whose difficulties either may not warrant counselling or therapy, or have escalated because of the lack of easily available support. Without component 2/3 services there would be nowhere to signpost people in greater need, overwhelming friends and families' capacities to support and straining health services.

Figure 1: summary of the three-component model of bereavement care (NBA, 2017)

Who provides bereavement support, and what do they provide?

14. While most bereavement services would be able to locate their provision within the tiered model outlined above, the sector is very diverse in terms of the type of support provided, how it is delivered, to whom, and how it is funded.

15. To get a picture of the sector as a whole, we analysed all website entries on the AtALoss.org directory of bereavement services. We added categories to summarise the focus of the organisation providing bereavement support, whether the organisation was national or local, and then the subtype of organisation.

16. Of the 822 entries in the AtALoss.org website, 21.0% (n=173) were national organisations, 45.5% (n=374) were local organisations, and 33.5% (n=275) were branches of national or regional organisations.

17. 64.8% of entries were from bereavement-specific organisations (n=533), 15.6% were from organisations also offering palliative care or related to a specific

condition or cause of death (n=128) and 12.5% (n=103) offered broader counselling or other mental health support. 7.1% of entries had a wider focus.

Setting of support

18. **Voluntary sector:** the bulk of bereavement support is provided by the voluntary sector, including local organisations such as Cruse branches and local hospices, and large national ones, with diverse service models as outlined below. Support is generally provided free of charge to bereaved people.

19. **NHS acute hospital trusts:** offering immediate emotional support and practical information, e.g. about how to register the death and organise a funeral, managing statutory requirements following a death (e.g. child death review panels, helping families understand post-mortem and other processes), signposting to bereavement support or other relevant services such as welfare benefits

20. **NHS mental health services** for those experiencing bereavement alongside presenting mental health difficulties. However, these services are very stretched and voluntary sector services report difficulties in referral for support both for adults and children.

21. **Private sector:** Many registered counsellors and psychotherapists in private practice specialise in emotional support following bereavement. Funeral directors provide immediate support around organising the funeral, and may also provide some emotional support services such as groups.

Specificity of support

22. Some organisations are set up solely to provide bereavement support: others provide it within wider provision (e.g. a general local counselling services). Much local bereavement support is provided by hospices as part of their wider provision of palliative care services.

Type of support.

23. Different aspects of support include:

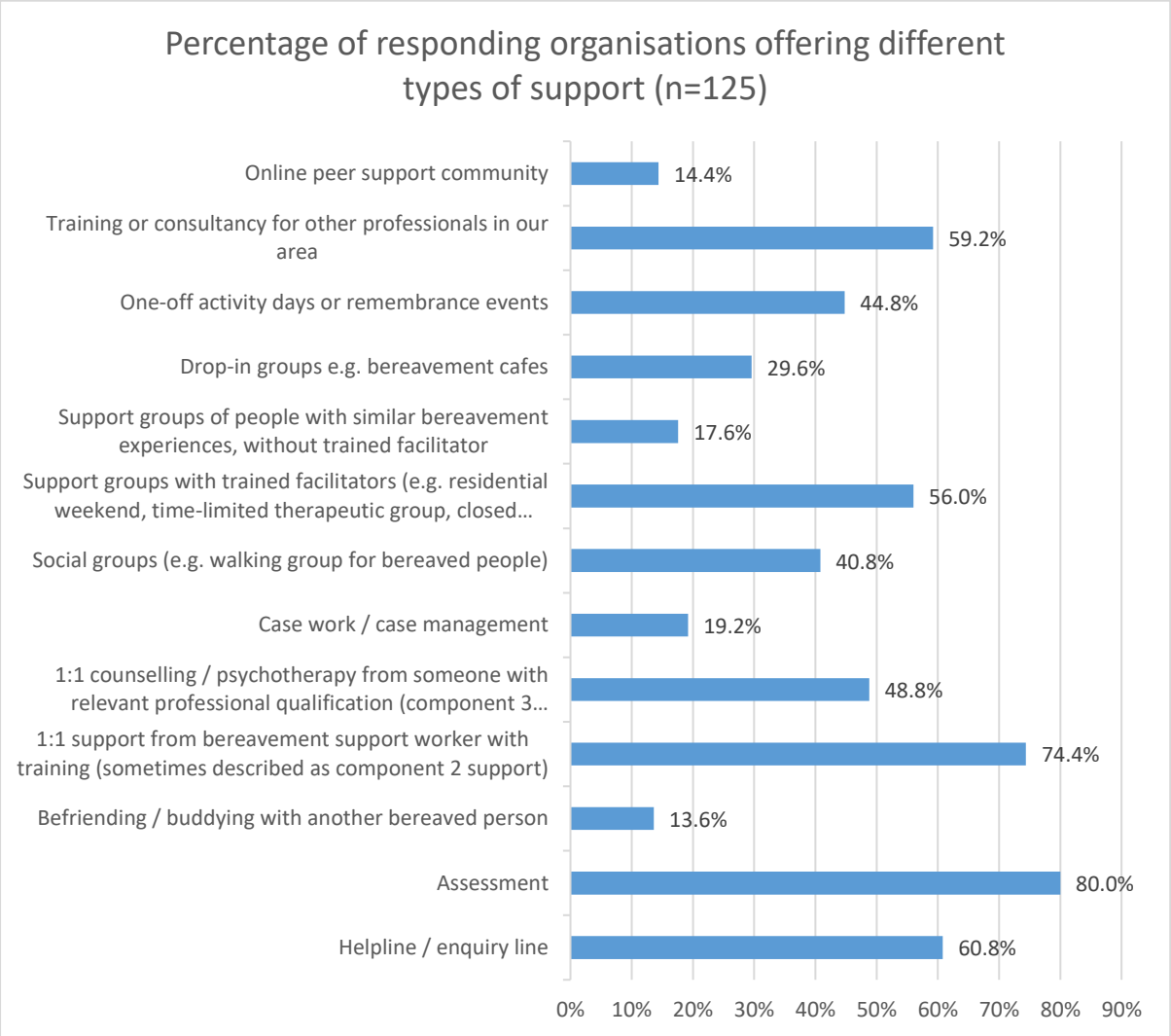
    a. **acute hospital trust bereavement offices** as described above

    b. **practical support services** e.g. Quaker Social Action's Down to Earth project which helps people on a low income organise a meaningful funeral, and benefit support e.g. from palliative care welfare officers

    c. **emotional bereavement support services** e.g. local Cruse branch offering a mix of information about grief, groups for bereaved people to meet others, 1:1 support with a trained volunteer; local palliative care service e.g. St Nicholas' Hospice offering bereavement drop-in cafes, activity groups including for children and young people, therapeutic groups, and 1:1 support with trained volunteer bereavement support workers; bereavement counsellors and interface with local specialist mental health provision.

    d. **peer support** often providing an informal mix of both practical and emotional support (e.g. WAY Widowed and Young peer to peer network).

24. In August 2020 we surveyed managers of voluntary sector bereavement services to understand more about the services they provided before the pandemic. The main types of support offered by respondents are shown in the table below. 80.0% of respondents (n=100) offered assessment. 90.4% organisations (n=113) were offering at least one type of 1:1 support, including support sessions with a trained bereavement support worker, counselling or psychotherapy, or casework. 77.6% (n=97) organisations were offering some form of peer support such as facilitated groups, social groups or drop ins.



Delivery

25. Ways of providing bereavement support include:

a. **Static information with educational material** about grief and how to help/support oneself e.g. websites, social media feeds, booklets and other written information

b. **Virtual in-person support** including telephone helplines, web chat, email support, online counselling

c. **Face to face support** – 1:1 support or counselling; whole family support (especially in the case of children and young people); opportunities to

meet other bereaved people (ranges from social to activity-based to therapeutic groups).

Focus of support

26. **Relationship**: open to all or specific e.g. to children bereaved of a parent/sibling; bereaved spouses;
27. **Type of death**: open to all or specific e.g. to those bereaved of a patient in palliative care, those bereaved through suicide, road accident. Some services based in hospices are open to the wider local community including sudden deaths – known as 'open access' services. In a recent survey conducted by the Association of Bereavement Service Coordinators in Hospices and Palliative Care, just over half of the 63 services were open access (n=33, 53%).
28. **Area**: locally based (e.g. CHUMS child bereavement and trauma services in Luton and Bedfordshire); national organisations (e.g. The Compassionate Friends, WAY Widowed and Young) including those with local branches (e.g. Cruse).
29. **Staffing**: mix of paid staff with a specialist background in counselling or psychology and volunteers, again often with relevant professional training

Funding and income for bereavement services

Services in the NHS

30. Whether hospital bereavement services or mental health provision, this type of support is thought to be largely funded by contracts. We are not aware of any national collation of information on the scale or nature of this funding – it is possible that this is not disaggregated.

Private sector provision

31. Fees for individual sessions with a counsellor/therapist vary by geography and training, qualifications and experience. These may be paid by the client, their employer or health insurer. Some offer low cost sessions, or arrange fees on a sliding scale. The scale of this provision is not known.

Voluntary sector provision

32. We surveyed of managers of voluntary sector bereavement services in August 2020, getting financial information on 51 local and national bereavement organisations. Their annual income is presented in the table below.

	Local organisations		**National organisations**		**All organisations**	
Annual income	**N**	**%**	**N**	**%**	**N**	**%**
Under £5,000	2	5.7	-	-	2	3.9
£5,000 - £14,000	4	11.4	1	6.3	5	9.8
£15,000 - £24,000	2	5.7	1	6.3	3	5.9
£25,000 - £49,000	1	2.9	-	-	1	2.0
£50,000 - £99,000	5	14.3	1	6.3	6	11.8
£100,000 - £199,000	6	17.1	-	-	6	11.8
£200,000 - £999,999	14	40.0	8	50.0	22	43.1
£1.0 - £4.9m	1	2.9	4	25.0	5	9.8

£5m+	-	-	1	6.25	1	2.0
Grand Total	**35**	**100.0**	**16**	**100.0**	**51**	**100.0**

33. To give some idea of aggregate scale, the total annual income for the 36 services who reported an exact income figure, plus the two additional services, was £25,045,227. 13 further services reported their income band, and in total, this group had an income of between £1,440,000 and £6,467,000.

34. Adding these two sets of data together gives a total annual income among the 51 responding organisations of between £26,485,227 and £31,512,227.

35. This is undoubtedly **a significant underestimate of the total income** of voluntary sector bereavement services. A further 50 respondents to our survey did not report their income. Further, as we do not know the true population of bereavement services, we cannot calculate a response rate to our survey and understand how much more data is missing.

Funding for voluntary sector bereavement services

36. Most voluntary sector services have a funding mix which might include community fundraising; individual and corporate donations; grant-making trusts and foundations; contracts with clinical commissioning groups, other health bodies or the local authority; central government departments; traded income (e.g. training and consultancy, charity shops, sale of resources); legacies; charges to service users; investment income. Recently, we tried to estimate the average proportions of each of these by asking voluntary sector managers about the make-up of their income, but it was not possible to draw conclusions from the very varied returns.

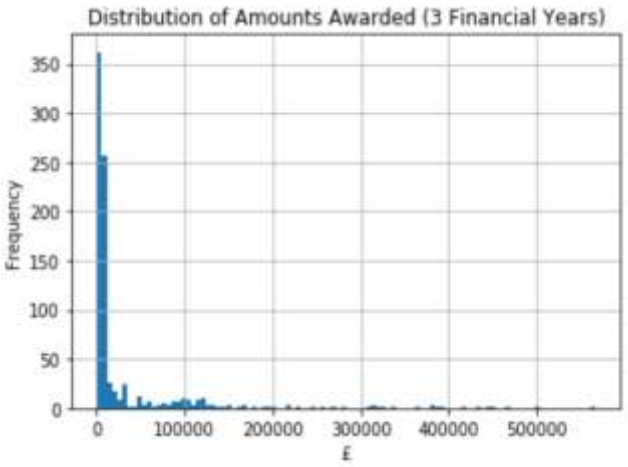
37. Although in theory the value of **contracts and grants** provided to voluntary sector bereavement organisations by public bodies could be collated, we are not aware of any national aggregation of this data. Some contracts and grants for bereavement services provided by hospices and palliative care services may be difficult to disaggregate from funding for wider palliative care services.

Grant-making to voluntary sector bereavement services

38. In August 2020 we analysed the GrantNav database to explore patterns of grants made for bereavement-related services bereavement among 61 different **grant making trusts and foundations** who had shared comprehensive and consistent information about their grant-giving for the last three financial years (see appendix for methods)

39. Our analysis showed that there was at least between £9 million and £10 million of grant funding awarded each year between 2016/17 and 2018/19 by non-governmental grant-making organisations for spending on bereavement related services each year in the UK.

Financial year	Total amount awarded (£)
2017/18	9,726,914
2018/19	8,789,612
2019/20	9,719,130



40. This funding comprised 844 different grants. The histogram shows how amounts awarded were distributed by size of award. There was a high frequency of small awards alongside a sprinkling of larger awards. The statistics for these 844 awards over 3 financial years:

a. mean award is £33, 200

b. median award is about £8,400

c. the maximum amount awarded was about £566,000

d. and the minimum amount awarded was about £100.

41. Further summaries of the data on the size of grants are shown below. While three quarters of grants (74.8%, n=632) were for amounts under £15,000, these grants accounted for only 12.4% of the total value. It is important to remember that the value of a grant is unlikely to be directly proportional to the effort expended in applying for it: clearly there is a huge amount of time being spent by the sector in applying for relatively small grants. Conversely, the 3.9% of grants over £200k accounted for 40.6% of the total value.

Grant value	Number of grants over 3 years	Proportion of total number of grants	Total value of grants over 3 years	Proportion of total value of grants
Under £1k	53	6.3	25,113	0.1
£1k-£1.9k	88	10.4	118,904	0.4
£2k-£4.9k	169	20.0	541,645	1.9
£5k-£14k	322	38.2	2,776,463	9.9
£15k-£49k	73	8.6	1,981,467	7.1
£50k-£99k	50	5.9	3,917,453	14.0
£100k-199k	56	6.6	7,272,875	26.0
£200k+	33	3.9	11,392,202	40.6
Grand Total	**844**	**100.0%**	**28,026,124**	**100.0%**

42. However, some of these grants are multi-year grants, and it is helpful to look at their duration. Data on these are available for 581 of the 844 grants (68.8%), and these are presented in the table below.

Grant size	Grant duration				
	Capital grant or up to 12 months	13-24 months	25-36 months	37+ months	All

	N	% of grants of this size	N	% of grants of this size	N	% of grants of this size	N	% of grants of this size	N	%
Under £1k	25	100.0	-	-	-	-	-	-	25	
£1k-£1.9k	39	97.5	1	2.5	-	-	-	-	40	
£2k-£4.9k	68	94.4	4	5.6	-	-	-	-	72	
£5k-14k	262	99.2	1	0.4	1	0.4	-	-	264	
£15k-£49k	19	37.3	5	9.8	26	51.0	1	2.0	51	
£50k-£99k	3	7.1	10	23.8	28	66.7	1	2.4	42	
£100k-199k	-	-	2	3.7	51	94.4	1	1.9	54	
£200k+	-	-	1	3.0	17	51.5	15	45.5	33	
Grand Total	**416**	**71.6**	**24**	**4.1**	**123**	**21.2**	**18**	**3.1**	**581**	**100.0**

43. Almost three quarters of grants (71.6%, n=416) were for one year or less. As might be expected, generally as the size of the grant increased, so did the likelihood that it was spent over a longer period of time. The preponderance of short-term grants is of concern. While valuable in securing the immediate needs of an organisation, these provide less ongoing financial security, which in turn impacts on the stability of support for bereaved people. To feel confident about embarking on bereavement support with someone newly referred to the service, organisations must know that they have the financial viability to see that course of support through.

How people find their way to services

44. In normal times, while some people seek support beyond their usual networks very soon after the death, others seek it some weeks to months later when support from family and friends falls away, the reality of the death begins to sink in, and symptoms such as difficulty sleeping persist and/or less helpful coping mechanisms become more troublesome. Some parents will seek support for children very early, e.g. for help in explaining the death, others will seek it later if behaviour changes persist, difficulties emerge at school or commonly, if they are worried that children are bottling things up.

45. Before the pandemic, between 20 and 30% of bereaved adults were not getting the support that they would like from organised services - beyond their family and friends[xvi] [xvii]. There is evidence that those in greatest need may be more reluctant to seek help[xviii]. National monitoring data on access to bereavement services for particular groups is lacking, but evidence from similar health and social care services (palliative care and mental health services) suggest that there are particular barriers to accessing support for those from ethnic minorities[xix] [xx] [xxi].

46. This lack of access has a number of causes. First, people may not be aware of the concept of bereavement support, or of the services that are available. While some services reach out proactively to bereaved people, others rely on self-referral or referral from third parties such as registrars, funeral directors, GPs and

family members. The signposting websites AtALoss and the Good Grief Trust have helped improve awareness of services in recent years but many still struggle to hear about support of the type they want.

47. As described, acute hospital trust bereavement offices generally offer immediate emotional support and practical information e.g. about how to register the death and organise a funeral, managing statutory requirements following a death, signposting to bereavement support or other relevant services such as welfare benefits.

48. Most palliative care bereavement services give information to all bereaved families to enable self-referral, and also reach out to those who staff have highlighted as being particularly vulnerable.

49. Those who are bereaved when someone dies suddenly in the community do not receive proactive immediate support (unless the death was through very specific causes areas e.g. through suicide, road crash or homicide). People bereaved in ways not expected or sudden, who are coping with shock in the early weeks, are unlikely to know where to go for support unless they are presented with it or referred into it. Yet this early support is very important to provide for these people, to assess their needs and enable them to feel safe, supported and connected.

50. Even where services are known and wished for, there are other barriers to access. For some, the stigma of seeking support can be a problem. Of concern, the provision of targeted and specialist interventions was patchy and precarious, even before the pandemic. Limited catchment areas, long journey times, referral procedures, waiting lists (particularly for 1:1 support), and limited provision such as restrictions on the number of sessions all exclude people from getting support, both in the early days or later.

Section 2: bereavement during the COVID-19 pandemic

The impact of the pandemic on grief and bereavement

51. COVID-19 and physical distancing have had a profound effect on the picture of bereavement in the UK, both in the number of deaths and thus bereavements, and also the experiences of bereaved people.

Increased number of deaths

52. Since 20 March, there have been over 61,000 more deaths in England than usual for this period[xxii]. This represents 19% more deaths than usual over the last nine months, with a parallel increase in the number of people experiencing bereavement. These figures will be higher if delays in getting diagnosis and medical treatment during lockdown result in increased numbers of deaths through other causes in the coming months.

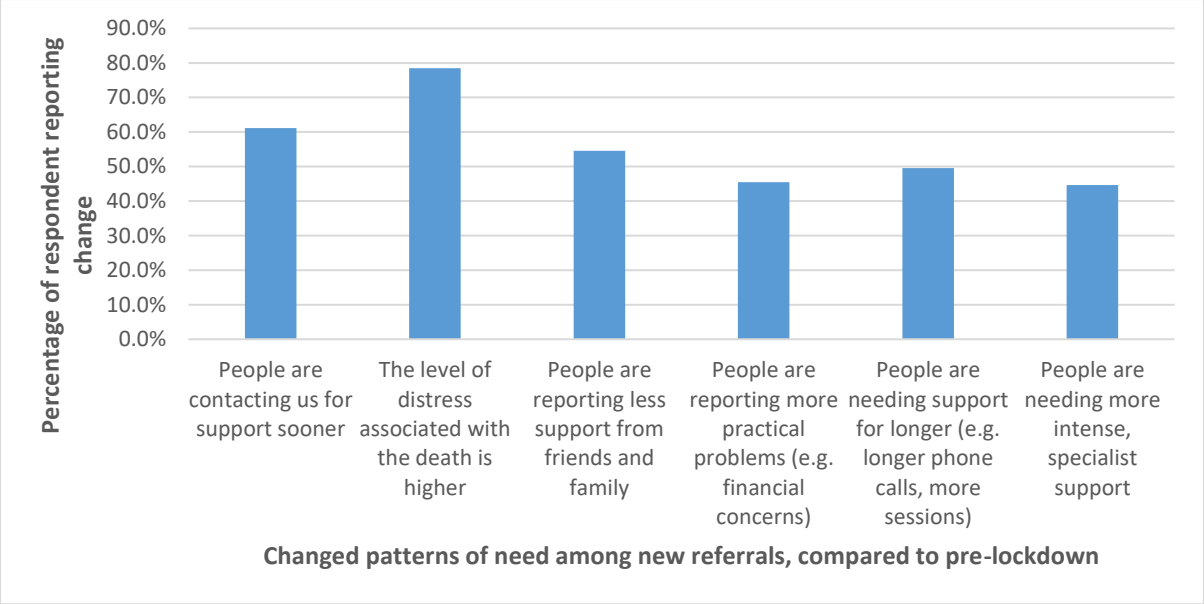
Increased complexity of deaths

53. Risk factors associated with poor bereavement outcomes are heightened due to Covid-19 and while social restrictions are in place[xxiii] [xxiv], meaning that the usual proportion of bereaved adults who are likely to need more support than their family or friends can provide will be higher. In usual times, this is estimated at 40% of the general population of bereaved people but 55% of those bereaved unexpectedly[xxv].

54. Managers of voluntary sector bereavement services are reporting differences in the patterns of needs among those seeking their support. This includes those who work with any deaths – not solely those through COVID-19. In response to our survey, almost four out of five managers (78.5%, n=95) reported an increase in the average **level of distress** associated with the death among people approaching them, compared to before the pandemic. Reasons for this distress included experiencing sudden or untimely deaths that were not expected (in itself a risk factor for Post-Traumatic Stress Disorder (PTSD) and Prolonged Grief Disorder (PGD), being unable to spend time with the person at the end of their life, providing care, saying goodbye and spending time with the person's body.

55. People bereaved by COVID-19 have higher levels of grief in the first six months of their bereavement than those bereaved of other natural causes – levels that are similar to those bereaved of unnatural causes[xxvi]. Acute grief in the first six months is a predictor of problematic grief further down the line[xxvii].

56. Distress was also reported to be associated with **disrupted rituals – the cornerstones for healthy grieving.** All funerals have been disrupted during social distancing, with strict controls on numbers and the ability to hug, hold and comfort members of different households. We estimate that on average, 40 people were prevented from attending each funeral at the height of lockdown.



57. **Thwarting of social support – isolation and loneliness:** the support of family and friends is a protective factor in bereavement but physical distancing means that this support can only be offered at a distance, greatly amplifying the loneliness of bereavement. Most children were out of school for a prolonged period and most employees are working remotely, meaning these usual spheres of normality are not available to them. 55.4% (n=66) managers of voluntary sector bereavement services said that on average, people approaching them for support since lockdown were reporting less support from family and friends. They report bereaved people telling them about greater feelings of isolation, and of being unable to engage in restorative activities that helped them to cope. This included those bereaved before the pandemic, whose grief had re-emerged or worsened under lockdown.

58. **Economic pressures for families:** many families are grieving in the context of great anxiety about securing their basic needs. Almost half of voluntary sector bereavement managers (45.5%, n=55) said that bereaved people were reporting more practical and financial difficulties than before the pandemic. They reported anxiety and stress among people experiencing job insecurity and financial problems during their bereavement. Drops in income and leaving work are known risk factors in bereavement[xxviii] [xxix]. Cuts to bereavement benefits in recent years have also affected working age adults, with 75% of widowed parents worse off than they would have been under the old scheme[xxx].

59. **Grief at a time of general fear:** children and adults who have been bereaved are often very anxious that other loved ones will die. At a time when everyone is scared about the possibility of the virus, these fears are even harder to manage. Voluntary sector service managers reported examples of COVID-19 related anxieties among bereaved people including worries about transmitting the virus.

60. **Lack of capacity in other services** due to the wider impact of social distancing measures and economic pressures, making it less likely that bereaved people are able to access support from usual non-specialist support services, and from mental health services.

Priority groups

61. Groups of particular concern include

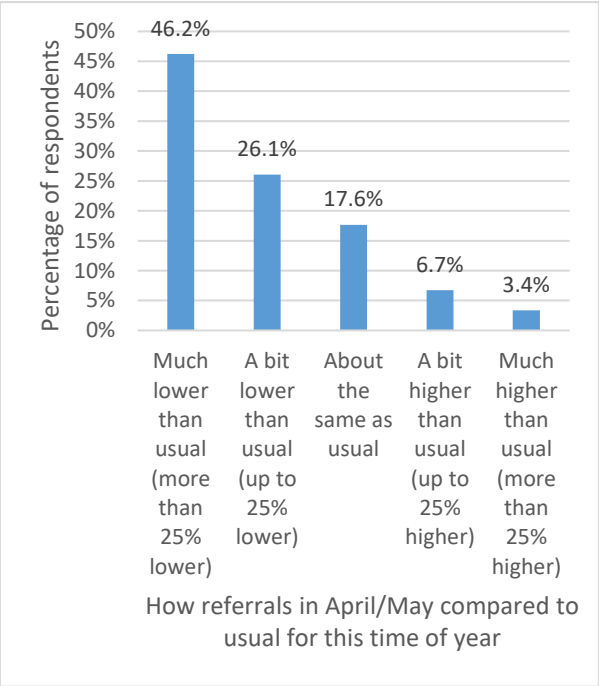
- those groups **most at risk of being bereaved through Covid-19**, including those from Black, Asian and Minority Ethnic (BAME) communities, and certain occupational groups
- those groups **facing the greatest impact from social distancing**, including those who live alone following their bereavement, or who lack support
- those groups who **already faced barriers to accessing bereavement support prior to the pandemic**, including those from BAME communities, children and young people, those with a learning disability, those experiencing homelessness
- those **facing particular risks in their bereavement**, including those whose finances are insecure; those facing multiple, sudden and/or traumatic bereavements; and those who have pre-existing mental or physical health difficulties.

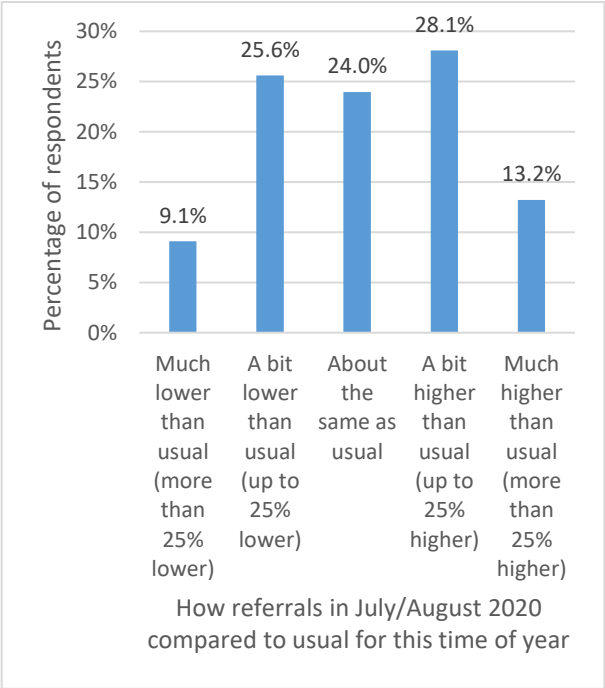
Changes in support needs and referral patterns

62. These changes in grief experiences are contributing to differences in the type of support which bereaved people need and the way in which they seek it. 61.2% of voluntary sector bereavement service managers (n=74) said that people were contacting them for support sooner following the death. Although services in the past might have said that not enough time had passed to know if the person will need external support from organised services, in these cases people are often very distressed and have had harrowing experiences either of being separated from their loved one at the end of life or of having witnessed a death at the community.

63. Half of respondents (49.6%, n=60) said that people were needing support for longer (e.g. more sessions, or longer telephone calls) and almost as many (44.6%, n=54) said that people were needing more intense, specialist support.

64. Managers also described changes in the numbers of people approaching their services for support. Overall, 72.3% of respondents (n=86) reported that referrals had been a bit or much lower in April/May 2020 than usual for that time of year. By July/August, the picture had changed and for many services, levels of referrals had recovered to usual levels or higher, with only a third of respondents (34.7%, n=42) reporting that they were still lower than usual for this time of year.





65. When exploring patterns of changes to referrals, around half of respondents (n=60, 51.3%) reported that their referrals were lower than or the same as usual in April/May but had now overtaken usual referral numbers for July/August. The second largest group (n=37, 31.6%) said that their referrals were lower in April/May and still lower than usual in July/August.

66. Reasons that managers gave for the lower than usual referral rates at the beginning of lockdown (April/May) included people having to prioritise the immediate demands of life such as securing food and medicine, and childcare. Some reported that people lacked time and privacy to access support. Other reasons included assumptions that the service would be closed, a preference for face to face ('in-room') support, and the interruption of usual referral routes, particularly GPs and schools. Many bereaved people get information about support services when they meet a hospital bereavement officer, registrar or funeral director, or visit their GP. Physical distancing means that many of these conversations are happening over the telephone or online (if at all), with potentially less opportunity to share information.

67. Those that had seen referrals rise again attributed this to greater need and complexity among those seeking support, better awareness of services including increased referrals from other agencies, people's increased willingness to access support delivered remotely, the easing of lockdown affording more opportunities to take up support, and difficulties in accessing other services.

68. The vast majority of service managers expect their referrals to during the autumn and winter and beyond (90.9%, n=110). 4.1% (n=5) expect them to stay the same, 1.7% (n=2) anticipated they will drop, and 4 (3.3%) are uncertain about what to expect.

69. Various explanations were given by those who predict referrals will increase. Commonly, respondents pointed to existing trends in increasing referrals outlined

above to inform their predictions – they expected that this trend would continue. In particular, they expect that

a. **Easing of lockdown** The easing of lockdown was expected to mean that usual referral routes would restart, particularly from schools, possibly after some lag in early September. Children's return to school is also predicted to afford more privacy and time to parents, who may then be more able to take up support for themselves.

b. **Changing attitudes to support provided remotely**. As social distancing measures have continued, people have become more familiar with video calling and more willing to take up support offered in this way. The hope that it would be a short wait until support can be provided in traditional face-to-face ways has given way to a resignation that things are not going back to normal, resulting in an increased willingness to take up remote support

c. **Previous experience of seasonal and individual patterns of referrals.** Seasonal patterns of referrals include a general upturn in referrals when schools return in September, during winter months, and following Christmas and New Year, for both adult and children's services.

   People seeking often seek emotional support around three to six months following a death, so participants were expecting to see the wave of COVID-19 related bereavements appearing at services in the next couple of months

   The first anniversary of the death sometimes triggers a search for support, suggesting a possible further increase in March-May 2021

d. **Active marketing and outreach.** Some managers reported that were they actively marketing their support offer and reaching out via social media and to referring agencies in new ways, and expected this to result in increased referrals.

e. **Further increases in numbers of deaths and bereavements.** Some respondents anticipated that a second spike of COVID-19 deaths would result in an increase in numbers seeking help. Increases in other causes of death indirectly caused by lockdown is anticipated to impact on the number of bereavements. These include suicide deaths through economic downturn and increased pressures; and deaths through late diagnosis of malignancies not picked up earlier during routine appointments or early consultations. Some anticipate that these latter referrals will continue well into 2021.

How services have adapted

70. As with all aspects of society and the economy, physical distancing measures have had a significant impact on how bereavement services can be delivered.

71. All respondents to our recent survey of voluntary sector managers (n=125) described changes that they had made to their service offer during the

pandemic, whether this was converting the way in which services were delivered, starting new services, or suspending services.

72. The most frequently reported change was around converting 1:1 support from in-person to online or telephone support (89.6%, n=112). It was less common for respondents to report that they had converted group support (36.0%, n=45).

73. This may be simply because fewer respondents offered group support than 1:1 before the pandemic (77.6% vs 90.4%). However, there are greater practical and clinical challenges to converting group support (e.g. maintaining confidentiality, ensuring new members feel welcome, being able to spot vulnerabilities). Certainly, many respondents described having stopped more informal types of group support such as drop-ins, walk and talk groups and bereavement information sessions. Some also described having stopped some aspects of support that involve longer sessions that would not work so readily online, such as activity or remembrance days, or residential weekends.

74. Other aspects of service delivery that stopped during lockdown included practical and emotional support at inquests, face to face work with children and young people in school, and home visits. With younger children in particular, some respondents had found that it was challenging to provide support online. Some were offering telephone support to parents as an alternative.

75. While some services had ceased, many organisations had shown great creativity and resourcefulness in rising to the significant and urgent challenge of adapting their provision.

76. Beyond this survey, through our regular webinars and contact with the sector, managers have described the effort involved in rapidly converting services to online and phone support, which cannot be overestimated. This has involved consulting with existing clients and practitioners about what would be possible; procuring new software and hardware; revising policies to ensure safeguarding arrangements; liaising with funders and insurers; becoming familiar with the possibilities, limits and risks of phone and online working; training and supporting practitioners; supporting existing clients to make the change to remote support; introducing new service delivery models to newly bereaved people to make the transition to remote support. This has been an extraordinary effort across the sector. For many practitioners, supporting grieving and vulnerable families while working from home has had a significant personal impact.

77. As well as converting services, managers in our survey reported other changes and innovations they had adopted in response to the virus and social distancing measures. These included:

    - developing services specifically for those in early bereavement
    - providing some 1:1 support outside, following physical distancing guidelines
    - establishing new telephone support lines
    - regular telephone calls to those who would otherwise have been attending groups

- posting or emailing activity packs, letters and resources to children and young people
- adding content and functionality to websites, including integrating services such as GriefChat function
- widening access to existing services, for example extending support following specific causes of death to include COVID-19
- providing training online.

78. Some services which, when provided in-person had been limited by geography, were now open to anyone who could access them.

79. While many services had been adapted rapidly, some respondents outlined future or further plans to deliver more aspects of their support remotely.

80. Others had already begun to think ahead about to how they would resume some face to face working, and in some cases had begun to pilot aspects that could be provided in a way that complied with requirements on physical distancing. However, since conducting the survey, new restrictions have been brought into force and some managers have reported anecdotally that they are freezing these plans.

81. We are also aware of a number of other initiatives in the sector. These include

    a. Rapid development of high-quality psychoeducational web and print information on bereavement e.g. on self-care, supporting bereaved children, and supporting grieving friends during the lockdown

    b. Developing ideas around collective national activities such as Body and Soul's #ShineALight campaign, Marie Curie's call for a day of remembrance, plans for National Grief Awareness Week and Children's Grief Awareness Week

    c. Emergence of mutual aid societies providing practical assistance to those most restricted by the lockdown (not specific bereavement support)

    d. Opening up services that were previously restricted to certain types of death (e.g. road death, cancer) to those bereaved by coronavirus or during the pandemic, including agencies working in the early intervention space as well as grief support.

    e. Establishing of regional bereavement networks.

Additional challenges to service delivery

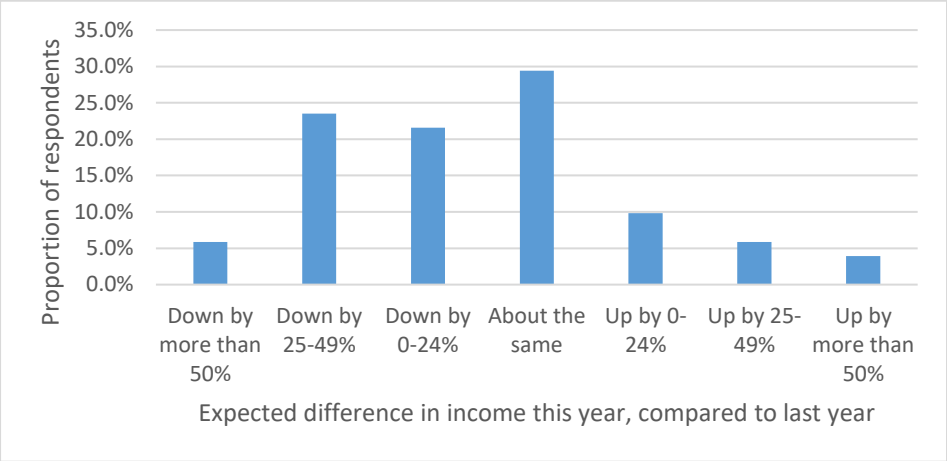
Funding

82. During May, managers of voluntary sector bereavement services were already predicting a drop in income.

83. Half of voluntary sector bereavement service managers (n=26) are expecting a drop in income this year compared to last year. 29.4% are expecting their income to drop by 25% or more.

84. While the same proportion expect their income to remain about the same as last year, all but one of these respondents expect the number of people approaching them for help will increase in the coming months. Essentially, these services are expecting to see demand rise with no increase in resources to meet it, and in many cases cuts to these resources.

85. Of the ten respondents (19.6%) who expect their income will be greater this year than last, seven have received new funding to respond to the COVID-19 crisis and three expect to bring in new income, but this is not secure.



Emergency and top-up funding

86. Respondents were asked if they had received emergency or top-up funding in response to the pandemic from any sources. 9 (14.3%) had received funding from the CCG or local authority, and 33 (54.0%) from a grant making trust.

87. The amounts were not specified but from the descriptions, these ranged considerably, from very small grants to purchase computer equipment to more extensive grants to develop new services. Five respondents (8.2%) had received funding to replace lost income for existing services, and 17 (27.0%) had received funding to deliver new services or through different means (e.g. online rather than face to face).

88. A key issue with this funding was its short-term nature. At least four organisations have already seen this funding end, with a further 5 needing to spend any awards within 2-6 months of allocation. A further 11 will see their funding end between September and January. Only two organisations had been awarded funding beyond March 2021.

89. With an anticipated growth in referrals, plus individual bereaved people needing support for longer, it is wasteful and disruptive for services to be stood down just as they are most needed. The initial set-up costs of new services such as staffing, training, equipment and marketing only make sense if the service will be able to continue once established.

90. The precariousness of funding was borne out by respondents' predictions for the next 12 months. 40.4% (n=23) will have to close, reduce or restrict their services if they do not manage to secure further funding. A further 40.4% (n=23) will only be

able to expand or enhance their services to meet anticipated increased demand if they secure additional funding.

Do you need additional funding for your service in the next 12 months?	n	%
Yes - without additional funding we will have to close within the next 12 months	1	1.8
Yes - without additional funding we will have to reduce or restrict our services	22	38.6
Yes - this would allow us to expand or enhance our services	23	40.4
Not sure	7	12.3
No - we have enough funding	4	7.0
Total	**57**	

Funding needs in the next 12 months (n=57)

91. Of the four services who said they had enough funding for the next six months, three are commissioned services or had multi-year grants in place before lockdown, and one had managed to secure enough further funding for this year.

92. As an indicator of financial stability, we asked whether managers anticipated having to use any of their reserves this year to balance their budget. Of concern, a third reported that they would, and half did not know.

Are you expecting to have to use any of your charity's financial reserves this year to balance your budget?	n	%
Yes	20	32.8
No	8	13.1
We have no reserves	3	4.9
Don't know	30	49.2
Total	**61**	

Anticipated use of reserves this financial year (n=61)

93. A third of managers (32.8%, n=19) were not sure what proportion of their income was secure for the next financial year. 20.7% had secured less than 25% of their income, but 24.1% (n=19) had 50% or more secure. These appeared to be services with multi-year grants or contracts in place before lockdown. Bearing in mind the previous findings about the precariousness of funding in the sector, this reiterates the value of longer term funding arrangements that can tide services over fluctuations in demand and other funding.

The impact of a drop in income on capacity

94. Services' capacity to support bereaved people is largely determined by the number of staff they have – whether supporting people directly or managing volunteers to do so. 45.9% of service managers reported having furloughed staff because of a drop in income. Of longer term concern, more than a quarter of managers had made staff redundant or planned to do this.

95. A similar proportion had or planned to limit the number of sessions offered per client. 14.8% (n=9) had or planned to see fewer clients.

Changes made or planned in light of a drop in income (n=61)	n	%

Furlough staff	28	45.9
Make staff redundant	17	27.9
Limit the number of sessions we can offer per client	17	27.9
See fewer clients	9	14.8
Cut our opening hours (e.g. for helpline)	4	6.6
Organise our services differently	48	78.7

96. Further actual or anticipated cuts and changes included

- withdrawing aspects of support
- reducing support services and training to local schools, other professionals and charities (including seeing fewer children and providing less consultation support)
- losing premises
- pausing staff recruitment or withdrawing job offers,
- not extending staff contracts.

How further funding would support services

97. Participants were asked what, if anything they needed further funding for. The greatest priority was core costs, with which to provide a platform for high quality, sustainable services, which almost three quarters of respondents needed (73.8%, n=45).

98. **Stabilise services.** Many respondents described how funding was needed to stabilise services in response to the challenges outlined above. Additional funding would lessen the 'hand to mouth' situation, providing longer term financial stability, and in some cases prevent closure or use of already limited charitable reserves.

99. Reach more people. Almost four in five respondents said that funding would mean they could support more bereaved adults or children (n=48. 78.7%). Services would be in a stronger position to meet the expected surge in demand. Additional staffing capacity would be used to expand the support offer, ensure more direct support is available either provided directly by paid staff, or increasing the capacity of the staff team to recruit and support appropriately trained volunteers.

100. **Provide more intense support to those with complex needs.** More than half of respondents said that increased funding would allow them provide more intense support to those with complex needs. 52.3% (n=32) needed funding to recruit more paid counsellors/qualified staff, and the same proportion needed it to fund additional training and/or supervision for staff or volunteers. This would give services the skillset and extra capacity to work with those with higher levels of trauma as a result of COVID-19 and social distancing measures.

101. **Reach people sooner.** Closely related to reaching more people, and providing more intense support, many services described how increased funding would allow them to see people sooner, reducing waiting lists or preventing them

from emerging. More people in crisis following a sudden, shocking bereavement could be provided with appropriate early support, mitigating against a deterioration in their mental health and reducing risks to functioning and family income.

102. Improve equality of access and outcomes. Two thirds of respondents (n=40, 65.6%) said additional funding would help them to reach communities they are currently serving less well such as those whose first language is not English, and those without reliable internet access. Managers also described their aspiration to increase support to socio-economically disadvantaged groups, those living in areas where there is little provision currently or where travel times are prohibitive, and those from Black, Asian and ethnic minority groups who have been disproportionately impacted by the pandemic.

103. **Working in partnership to achieve better outcomes for bereaved people.** Increased funding could facilitate more partnership working when referring bereaved people on for additional support (e.g. with housing, welfare benefits). Two thirds of respondents (n=41) said that increased funding would allow them to provide more support to other professionals in the area via training and consultancy, a crucial aspect of 'component 1' support (see fig 1). This could build capacity in schools, community organisations, employers and the health and social care workforce to respond more appropriately to bereaved adults and children. In turn, this could reduce the need for direct bereavement support services, but also increase awareness among potential referrers of when and where to seek extra support for bereaved people.

104. **Strengthen service management.** Funding could also help to diversify and secure income by improving capacity to fundraise in different ways. It could also allow services to invest in websites, record management systems, and cost-effective methods of digital delivery.

What is needed?

105. A recent paper has summarised the evidence on evidence on system responses to bereavement support in the aftermath of a variety of 21st century human-made and natural disasters, to inform the response to the pandemic[xxxi]. Across the six included studies, the key service features identified were

- proactive outreach to those in need;
- central coordination of locally delivered support;
- training for providers in crisis-specific core competencies;
- structured psycho-education as well as group-based support and use of existing social networks;
- formal risk assessment for prolonged grief disorder and
- referral pathways for specialist mental health support.

106. To strengthen the development of these aspects of support, and to respond to the challenges outlined in this paper, we need

- An immediate injection of £9m-14m to stabilise the voluntary sector response to bereaved people, enabling the sector to respond to the growing need
- Significant further investment in the sector, to be unlocked by a government-led review of the whole system of bereavement support. This review should
    - decide the relative responsibilities for funding and providing bereavement support between central government, local government, the NHS, voluntary sector and private provision, and
    - what else is needed to make this system work well for bereaved people (e.g. pathways of support, appropriate training, measurement of the difference that bereavement support makes).

107. The outcomes we would hope to see for bereaved adults and children would be

a. Clear pathways into appropriate immediate, medium- and long-term support
b. Greater understanding among bereaved people of ways of supporting themselves, understanding how and when to reach out for further help (through easily accessible culturally appropriate content)
c. Upskilling people's natural and usual support networks (e.g. schools, employers) through training and mass communications to respond appropriately
d. Increased link up for the first days and weeks between bereaved people and practical, community help such as mutual aid societies and where necessary statutory services
e. Increased awareness of the range of bereavement support services among the general public and the sector through improved signposting
f. Increased capacity of bereavement support services in the short, medium and long term to provide 1:1 and peer support opportunities in bereavement, reflecting the tiered model approach.

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