Submission to the UK Commission on Bereavement

Public attitudes, cultural perspectives and engagement

Public attitudes to grief and bereavement are often a barrier to people seeking bereavement support from friends, family and the community as well as higher-level professional support. For many, talking about death and dying is hard. As a society, we struggle to communicate about loss and that makes it more challenging for people to seek support. Hospice UK’s Dying Matters campaign found that around 75% agreed to some extent that society would be happier if people were more willing to talk about death. But results suggest that while most people want to offer bereavement support, they would not feel confident enough to do so.

While some will need professional bereavement support, the majority of the support most people facing loss need and receive is from family, friends or peers within their community. However, the language used around loss and how the issue is framed and understood makes people feel less able to provide support or to ask for help. There is a perception that ‘bereavement support’ – or any conversation about dying or grief – needs to be a clinically driven, professional conversation, with ‘rules’ regarding what you can say. We should be careful not to over medicalise grief as, in reality, supporting those around us through grief isn’t about saying the right thing, it is about saying something and facilitating an openness to talk about bereavement.

Communities need to be empowered to support the bereaved by campaigns that encourage people to talk about death and dying. Hospice UK’s Dying Matters campaign is driven by this mission, but, while it has been successful through the pandemic, is charitably funded and has limited means. There is a clear need for a national, funded, public campaign if we really want to shift attitudes. Dying Matters has a good footprint and the backing and expertise of the end of life care sector, so could offer a lot of the platform and learning. The sector also needs to reconcile itself to the scale of the challenge of shifting attitudes. It will take many years, and if it is to happen at pace, significant investment and expertise will be required.

Public attitudes around death and dying also prevent good approaches in workplaces, which play an important role in supporting the bereaved. Hospice UK’s Compassionate Employers programme helps employers improve their support for staff affected by terminal illness, caring responsibilities and bereavement. Currently, only 1 in every 3 organisations have a dedicated bereavement policy in place. When a policy is in place, employees often share with us that this reflects a ‘hierarchy’ of grief, labelling some bereavements as more deserving of support.

UK employees have a right to a ‘reasonable’ amount of paid leave in the event of the death of an adult dependant but there is no minimum amount and this does not apply to the deaths of non-dependants. Two weeks of statutory paid bereavement leave is only available for employees who lose a child or suffer a miscarriage. Many employer bereavement policies do
not account for the death of a non-immediate family member. More than 6% of British households (1.8 million people) are multi-generational. Employees who live in multi-generational households may be hugely affected by the death of a distant family member that lives with them, yet many workplaces would not provide them compassionate leave.

The timeline of grief can be long and complicated, however, many bereavement support options only intervene at the point of death. Many employees of Compassionate Employers have requested more support around anticipatory grief, such as in the case of a loved one with a terminal illness, where the impact of grief is felt before a bereavement has occurred. Line managers and colleagues need to be educated on the impact of anticipatory grief on the individual and their performance.

All health and social care staff should have bereavement training. This is not a case of medicalising grief, as staff do not need resource heavy, time consuming training on all aspects of bereavement. The focus should be on the value of making an offer of support to the bereaved and signposting them to support. Having the confidence and knowledge to offer support and a listening ear is valuable.

**Practical Bereavement Support**

If we focus only on formal bereavement services when talking about bereavement support, there is a risk that the majority of support people need and receive will be missed. In April 2021, Dying Matters found that less than 10% of bereaved people sought professional help; most turned to friends and family for both emotional and practical support. This is in part due to a lack of awareness of, and access to, professional support services, which needs to be addressed. However, while seeking to improve access to professional support, we cannot neglect the need to help friends, family and communities to provide the best possible informal support to the bereaved, as this is all many will have.

Being empowered to talk about death, dying and bereavement is central to ensuring everyone is able to access support, navigate loss and cope with the practical challenges that come with a bereavement. Talking about death and dying in advance – not just after death – is critical. It can help someone to process grief if planning and conversations are had in advance, even if this is as informal as conversations about funeral music choices. Difficult decisions, for example those around place of death and funerals, can be eased if conversations have been had over what dying well looks like to people.

Often, those best positioned to guide someone though the tasks that accompany a bereavement are ambassadors in their community or others who have been bereaved. Bereavement support cafes, or Grief Cafes, are community led and connect people to support each other through grief. These have become more common in recent years and this is largely due to the kind of informal peer support they offer. They allow people to relate to others about the experience of grief and to ask questions about how to manage the tasks that follow. This is a model that should be replicated throughout the UK and a mapping exercise to understand how widespread access to these groups is currently would be valuable.

The professional bereavement support and information provided by services needs to be inclusive as practical bereavement support looks different for different groups and cultures.
During the pandemic, information on how the pandemic would impact Christian funeral practices was readily available, if confusing. However, other faith and culture groups had more difficulty finding information on how their grieving practices and ceremonies would be affected by restrictions. There needs to be a focus on equity and inclusion in bereavement resources and support.

Practical bereavement support would also be improved by increased research and evidence into what works for people around bereavement and grief. While there is a growing body of anecdotal evidence, we still do not have enough information actual impact does grief have on people’s physical and mental health in both the short and long term. As the pandemic has seen an increase in complex grief the need for this understanding is particularly urgent.

**Infrastructure and intervention**

The funding for the bereavement support sector is insufficient. We have seen unprecedented need for bereavement support caused by the pandemic. However, there needs to be a widespread understanding that, both in and outside of the pandemic, there is always a percentage of the population that is grieving and therefore there is a need for a constant and consistent level of funding for support. There is also a need to develop and fund local support services within the community, such as those offered by hospices. There is a concern, however, that services keep being implemented and then ended in quick succession due to inconsistent funding. There is a need for consistency and for useful services at all levels to receive adequate funding.

Furthermore, the level of funding needs to be driven by need, and this need has to be worked out by data and population needs assessments. Those assessments should be done routinely for each local population and we need to bring data collection of bereavement support up to speed.

There is a problem of inequity in access to bereavement support and a need for inclusivity at all levels, for example, in the messaging and in the information being shared. Often, white, cis-gender, middle class decision makers decide what support to offer and what will help excluded communities’ access services. People from communities who are often underserved need to be involved in the decision making regarding what services are offered.

There also needs to be meaningful diversity at all levels and services need to be designed with the intention to improve access. People are at their most vulnerable when they’re bereaved and concern that they may risk further traumatisation through micro-aggressions, or by being dismissed, may result in some choosing not to contact a service. Navigating systemic inequality is difficult at the best of times let alone when bereaved and seeking support.

Many groups and communities are not provided with accessible, genuinely helpful, bereavement services. For example, services are often not accessible to people with cognitive disabilities or who are autistic. One example of good practice in improving access for this group is work by the Mary Stevens Hospice. The Mary Stevens Hospice developed group creative sessions, with the help of an art psychotherapist, which allowed people with cognitive
disabilities and who are autistic to explore feelings of loss and grief as well as their own understandings of what a good death looks like. This is an example of work hospices are doing to improve access to services and approaches like this should be replicated across the UK.

Additionally, services are often structured around those in salaried work and their models of access. They are designed around having a healthy relationship with work or are structured around 9-5 working hours. For many that are self-employed or in precarious employment, there is no simple option for time off and no regular schedule in which to attend a regular support service. Precarious employment is currently a blind spot when designing and funding bereavement support services and must be considered when designing accessible services.

There are also systemic problems in supporting more complex bereavement cases, for example bereavement services may be given full responsibility over the care of an individual with mental health or drug-related challenges if they are bereaved, or a lack of understanding of who is responsible for their care may mean they slip through the cracks completely. There needs to be better communication between services and better consideration of complex cases when services are designed.

Quality improvement methodology and virtual provision can also be used to improve access to bereavement services. Hospice UK, working in partnership with nine hospices across England and guided by a Reference Group, set out to develop a gold standard virtual bereavement support programme. Over a six-month period in 2020/21, participating hospices rapidly prototyped models of bereavement support using quality improvement methods to trial and measure impact in 21 discrete projects. Through this project, at least 273 people who were bereaved received direct virtual support from hospice staff or volunteers in a six month period and 187 people gained greater skills and knowledge about supporting people who are bereaved.

The impact of the pandemic

The volume of bereaved people has increased substantially during the pandemic. We estimate more than 5 million people have been bereaved in the UK during the past 18 months and many experienced multiple bereavements. Due to pandemic restrictions, many died in circumstances against their wishes, some in poor conditions, with unmanaged fear, pain and symptoms and without the support they needed. Many loved ones had to take on caring responsibilities and witnessed the most difficult aspects of death first hand. For others, their loved ones died in hospital without being able to receive visitors. Additionally, the pandemic had an impact on funeral arrangements and arrangements for bodies at point of death. These circumstances can result in additional trauma alongside grief. Aspects that can affect how a person copes with a loss, such as mental health or drug-related challenges, have also worsened for many.

We know that social groups that face inequalities more broadly are being disproportionately affected by the impacts of the pandemic. The Office of National Statistics has reported that, during the first wave, people from all ethnic minority groups (except for women in the Chinese or "White Other" groups) had higher rates of death involving coronavirus than the White British population. This also translates to more bereavements.
The pandemic is ongoing and people will continue to be bereaved under traumatic circumstances. There is concern that people will continue to go unsupported as they face further bereavement and increased mental health challenges.

As the volume of bereaved people has increased, as have discussions of death and loss and the visibility of services. Research by Dying Matters in spring 2021 found that a quarter of UK adults (24%) say the pandemic has made them more likely to have casual or informal conversations with family and friends about preferences around their death. The same amount are more likely to express their dying wishes to a close friend or family member. This is a significant shift in attitude in a short amount of time.

Numerous models of good practice have emerged during the pandemic. Zoom has been an incredibly valuable tool in improving access to services for those who are less able to leave their house or travel, such as those with caring responsibilities. However, in a virtual environment, it can be harder to pick up on mental health risks or identify complex bereavement. Therefore some may miss out on the care they need.

People have been looking for creative ways to provide support. People who are bereaved often do not need medical support but benefit from social support other that are grieving. Death Cafes, for example, successfully enable those that have experienced loss to come together and support each other. These services also allow people to access support without feeling like they have been labelled as needing to be ‘fixed’. Arts support has also been helpful for many. For example, The Grief Series by Ellie Harrison explored bereavement through 7 different collaborative projects to create spaces where grief can be discussed and expressed openly.

Hospices have done incredible work expanding their bereavement support during the pandemic. Hospices across the UK have opened up their services beyond those who died in their care, and removed the time window in which people can access support. Individuals are now able to contact a hospice local to them or the hospice where a loved one died (even if it is far away from where they are based) and receive bereavement support. This increased flexibility in the system has been vital during the pandemic.

North Yorkshire Hospice Care is one hospice with a dedicated specialist helpline, ‘Hear to help’, which provides support to all those in their local community. The hospice also provides support for Hospice UK’s Just B helpline which provides emotional wellbeing, bereavement and trauma support nationally to NHS, care sector and emergency service staff.

If we wish to prepare for mass bereavement events in the future and maintain a high standard of bereavement support, hospices need to be at the table, at both a national and local level, and be an integrated as a robust part of the system so they can share vital information and insight.