

Public attitudes, cultural perspectives and engagement

In this section, we are particularly interested in reflections upon the following questions:

- To what degree are public attitudes to grief, bereavement, support and help-seeking a barrier to effective interventions for people affected by bereavement?*
- What could help to improve public attitudes to bereavement and the support needs of people who have been bereaved?*
- How could employers better support people who have been bereaved?*
- How could informal communities (of identity, geography or ethnicity), including neighbourhood groups or faith groups, better support people who have been bereaved?*
- How could schools and other organisations better engage with children and young people around issues of grief and loss, and better support those affected by childhood bereavement?*
- Should all health and social care staff have training in bereavement awareness and support? If so, what training should be provided?*

The experience of many who work in social care delivery - the vast majority of which involves supporting people on a palliative and end of life care pathway- is that there continues to be a significant societal and cultural resistance to talking about issues of death and dying, including planning and making arrangements of care and support in instances where capacity and communication may have diminished. This resistance is further evident in terms of the willingness and openness of individuals to both recognise that their grieving needs support and the ability of others to enable them to access such support.

Scottish Care believes that grief and bereavement needs to become a mainstream issue of debate and discussion, part and parcel of the cultural fabric of our communities, rather than the specialist subject of a few. There has been improvement over the years with festivals and events but the issues of supporting someone who is grieving and bereaved are still on the margins of community priority and societal awareness.

As part of this mainstreaming of death, dying and bereavement those advocates for change need to work with the whole spectrum of our communities, in the arts and entertainment, literary and media, sporting and leisure, business and commerce sectors.

In Scotland the work of the Bereavement Charter for Adults and Children ([A Bereavement Charter for Adults & Children in Scotland - Scottish Care](#)) is focused upon making bereavement support real and meaningful including working with businesses and organisations to not ensure that bereavement does not remain within a policy document but is evident in practical ways for workers. It also advocates greater 'presence' in the community of the awareness of and critical issues relating to grief. We have seen considerable success in campaigns designed to address mental health stigma and we need a

comparable focus on the stigma and stereotypes that surround death, dying, grief and bereavement.

Employers need to consider what the issues are in their own environment and what changes could be made to turn the workplace into a grief positive location. In our experience individuals and organisations feel helpless and de-skilled in the area of bereavement and grief support. People are frightened and reticent about doing or saying the wrong thing so their response is often to do little and to remain silent. Support with policy development and practical steps such as enhanced leave, counselling, anniversary leave etc could merge to ensure that the workplace/organisation potentially could be described as 'grief positive.'

Awareness of the naturalness of death and the communitarian role of grief support must be across the whole of life and there certainly needs to be more focus on these issues in schools and colleges, not least given the high number of children and young people who are themselves living through grief, a grief which is often unnoticed and unsupported. We must at the same time acknowledge the real depth and quality of existing death education and seek to build on this experience in order to see bereavement and grief support from a whole life perspective.

As a national body Scottish Care has long argued that there needs to be mandatory training in grief and bereavement for all who work in health and social care settings – indeed we would extend this to all employees within public bodies. However, this needs to be adequately resourced and prioritised, not simply made into a requirement for registration or as a regulatory oversight. In order to avoid a tick box approach which would do untold damage to the societal acceptance of these issues, what is required is an emphasis through reflective learning and practice, of the critical benefits to be gained at a personal and individual level, as well as an occupational level, of increased knowledge and skill around dealing with grief and loss. Initial training must also thereafter be supported by on job development, shadowing and mentoring approaches to adequately embed the learning and skills development.

Practical Bereavement Support

In this section, we are particularly interested in reflections upon the following questions:

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

- How can people be better supported to deal with administrative tasks following bereavement?

Social care employees and organisations are often involved at the early stages of practical planning for death and bereavement. As stated above there is a sense in which people do not want to think about the issues of death and what happens after someone dies. We strongly believe that the same extensive focus as is put into the planning and preparation surrounding birth should be put into the planning of a death and the end of life. In birth

planning there are a whole host of actors, sources of information, accessible points of advice and guidance but little of this exists in terms of advanced care planning or around the practical steps required when someone dies. This is even more the case in relation to advice available and support which is accessible for those who are struggling with their grief.

We believe that a whole infrastructure of support needs to be co-ordinated and developed in a systematic way around someone who is dying and individuals who are bereaved. For too long this critical life stage around care in relation to death and dying, and support around bereavement has been left to the postcode lottery of local availability and resource. Scottish Care in our belief that bereavement support should be recognised as intrinsic to a citizen pathway and as a human right, argues that the 'realisation' of the human right to bereavement support requires clear duties and responsibilities to be placed upon State actors and public bodies. This is not something which should happen at solely an individual level but also requires the support of informed and sensitive professionals – from the equivalent of a specialist health visitor for someone who is on a palliative and end of life pathway and someone who might be experiencing negative grieving all the way to local authority grief co-ordinators who can co-ordinate the provision of professionalised and regulated grief support. Undeniably there will always be a requirement and space for third sector grief organisations but there is an urgent need for local and national co-ordination, the establishment of clear delivery standards, the investment of adequate resource and the prioritisation of grief support within clearly defined policy and legislative frameworks. .

At an individual level the administrative tasks involved when someone dies are wholly burdensome and disproportionate at a time of very real emotional and physical stress and fatigue. At present there exists a labyrinthine confusion of information, sometimes contradictory advice and very rarely a simple and accessible place to find information. An independent review of what happens at the time of death should be established with a clear aim of simplifying the process, reducing duplication, giving clarity on issues such as data and digital inheritance etc. In addition, we believe that serious thought needs to be given to the establishment of a national grief helpline to be available both to those who may have practical questions around the time of death but also those who require additional bereavement support. We are aware of a growing number of online and digital supports but are cognisant of the very real existence of digital poverty and challenges of accessibility especially amongst some age and socio-economic demographics. Digital dependency should not become evident in bereavement support and there should also at all times be an appreciation of the significant number of people in the United Kingdom who struggle with basic literacy and for whom the whole process around death, dying and bereavement support is often confusing and distressing. There also requires to be sensitivity both to different geographical, cultural and religious/spiritual approaches to issues of bereavement and grief support.

Infrastructure and intervention

In this section, we are particularly interested in reflections upon the following questions:

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

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

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

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

As a representative body with members working across Scotland delivering social care supports, not least in the community, our assessment is that the current state of resourcing and funding for the delivery of bereavement support in Scotland is totally and wholly inadequate. We continually hear evidence of families and individuals who struggle to access support which is both appropriate and local, and which is free at the point of delivery beyond a restricted period of time.

We are very aware of the excellent work undertaken by third sector and charitable bodies on what are often short term contracts and packages of funding. This does not enable these organisations to retain and develop staff, to develop services and to be able to innovate in the manner which is necessary and required to meet fluctuating need and changing cultural and personal dynamics.

Nevertheless, as we have stated above, we do not consider that a piece meal, short or even medium term, increase in resourcing of the third and charitable bereavement and grief support sector is what is solely needed to address the current challenges. We would argue the need for bereavement support to be seen as a core duty of local and national government, outsourced and delivered by third parties if desired, but with the core duties resting with government.

The co-ordination of services at a national and/or regional level would improve the ability of citizens to directly access a service – in part because a potential co-ordinated and national awareness campaign would enable this to occur. In Scotland there is an opportunity for the proposed National Care Service to function as the umbrella body for such co-ordinated delivery. In addition we believe that a strategic framework for grief support delivered at a national level would be of real benefit in addressing the particular and specific geographical, cultural and group/individual identities which to date have experienced more difficulty in accessing bereavement and grief support appropriate to their particular needs.

The nature of bereavement support is always going to be diverse and individual in nature. However, after many decades of delivery, organisations continue to state that there are certain core elements to the support that people request. These range from very practical help and assistance at the time of death, to support through talking therapies when things go wrong, from clear and precise information and communication to in-depth therapy and counselling. The ‘what’ people need is less of an issue when compared to the reality of availability, the depth of local provision and expertise and the flexibility of service provision given current resource and delivery constraints.

We would also comment that social care providers frequently notice that whilst short term (6-12) sessions of professional grief support or counselling result in considerable benefit to

the individual that there is a real gap in the support of the small proportion who need more intensive work and therapy. The inadequacy of older adult mental health supports in our communities combined with the challenge of accessing these services ill serves those with more profound and challenging issues of grief and bereavement.

The impact of the pandemic

In this section, we are particularly interested in reflections upon the following questions:

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

- To what degree have diverse social groups – including ethnic minority communities, and those living in poverty - been affected differently by issues relating to bereavement, through the course of the pandemic?

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

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

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

Social care providers in Scotland together with Scottish Care as the representative body have long argued about the inadequacy of bereavement support provision in Scotland. Despite excellent policy frameworks there has been little action and adequate financial resourcing to support policy. The pandemic has 'shone a light' on the cracks in the existing fabric of provision. It is a light which has burnt through those cracks and shown up very real issues of concern.

As a representative body of many of the care homes in Scotland, Scottish Care is very aware of the profound impact the pandemic has had upon those who have been residents, families and friends, and staff working in our care homes. The traumatic nature of loss of many individuals in a short period of time has created a level of prolonged grief syndrome within the workforce which has never before been experienced and which will have consequence for those individuals involved for many years to come. We are very concerned that there is both a failure to properly understand and appreciate the impact of the pandemic and the deaths of residents and on the other hand a failure to recognise and adequately resource specific and specialist grief support provision. In addition, we are genuinely concerned that the loss of normative and familiar cultural, societal, spiritual and religious patterns and rituals of mourning are having a very real impact on the ability of individuals to do the work of grief. We are additionally concerned about issues of stigma related to Covid but also a tendency to dismiss from notice and priority those who died from other conditions during the period. Scottish Care is especially concerned that the loss of traditional opportunities to

restore relationships and to re-orientate living which are hugely significant in bereavement are disproportionately affecting our older population. The inability to visit clubs and cafes, to use respite and holiday (short break) facilities, to access traditional groups in churches, temples, mosques and local community are deeply impacting those who are now increasingly 'left alone with their loss.' We do not believe that the impact of the pandemic upon those who have lost family and friends is properly understood in a society rushing back to normality and in so doing crossing the road to avoid the grieving.

We would rightly acknowledge that with the crisis of the pandemic there have been innovations and improvements as individuals and communities sought to re-orientate themselves and design their support to meet the circumstance. We are aware that for many moving online and the increased use of technology has worked well and enabled them to access support which they might not have used in a non-digital available context. However, we are also very aware that forming relationships with no prior face to face experience is a hard process for many and that there comes a point in the nature of a grief counselling or support relationship that physical presence is beneficial and necessary. We would be concerned that digital use and dependency limits the ability and use of the human attributes of touch and solidarity, presence and community.

As we move forwards, we hope we can learn from the painful lessons of the Covid19 experience and its effect on those who mourn and grieve. We would hope that the restrictions on visiting and access to those in the latter stages of life whether in care home or hospitals would never be introduced again. It is perfectly possible to be safe in infection prevention terms and still be physically present. We would also hope that the restrictions on funerals re attendance and involvement would only be re-introduced as a very last resort in any future pandemic event, and that there would be specific and focussed awareness on the impacts of isolation and lockdown on those who are older and who may be recently bereaved. Lastly, we would also hope that in a context where many have lost income and the ability to access financial as well as practical and emotional support, that there would be emergency financial assistance offered to those who are bereaved during a major incident.

Do you have anything else you would like to tell the Bereavement Commission about how people affected by bereavement could be better supported in the future?

We have already stated the need for national co-ordination, planning and resourcing but in addition given the work which has been undertaken with a wide range of stakeholders in Scotland around the National Bereavement Charter we would call for that work and the Charter to be mainstreamed and independently funded, believing that much of its focus and direction is in accord with what we have presented here in evidence.