Age Cymru consultation response -
Bereavement Care in Wales

17th May 2021

1: Is it clear who this bereavement framework is for and why it has been developed?

YES

If the answer is no please tell us below what can we do to achieve this?

Age Cymru welcomes the development of a framework to support bereaved people in Wales. This important development will assist in reducing inequalities across Wales in access to bereavement support and help to address the stigma of talking about dying and end of life care.

Access to bereavement services is inconsistent across Wales and this position has been greatly impacted by the coronavirus pandemic. Whilst we know that a lot of bereaved people do not usually require specialist support with their bereavement, during the pandemic people have not been able to access their usual support networks that they would normally have access to. As a result, it seems likely that the number of bereaved people requiring additional support above that from their usual support networks will increase.

We hope that in developing this framework that Welsh Government will consider the resources needed to deliver this framework and provide bereaved people with the support they need to overcome their bereavement. Good quality support can only be delivered when services have sufficient resources to deliver support in the right place and at the right time for bereaved people.

2. How can the provision of and access to bereavement services for people with protected characteristics (section 4) be improved?

Many older people with protected characteristics already have additional barriers to accessing care and support. These barriers vary according to individual circumstances and larger scale factors. In addition to the various barriers, some people with protected characteristics may be more likely to need formal support, which needs full consideration in the development of appropriate bereavement services.

For the older LGBT community, their past is an important consideration when exploring hopes and fears around later life planning and end of life care. A Stonewall study found that lesbian, gay and bisexual people over 55 are more likely to live alone and are less likely to have contact with biological family members. As such they are more likely to need formal support and care services in later life and should be over-represented in numbers of people accessing bereavement support. The study found LGB people over 55 lack confidence in public services to meet their needs, suggesting that there is considerable work to do to challenge the heteronormative assumptions within health and social care services.[1]

The older LGBT community have lived through times when coming out may result in a range of serious negative repercussions, including criminalization, through prejudice and intolerance. Though attitudes have changed, tolerance and understanding are still not universal and so our LGBT community have valid concerns regarding how they are treated, and many older LGBT people are still reluctant to disclose their sexuality or gender identity. One study found that 26% of LGBT people had experienced discrimination related to their gender identity or sexual orientation from health and social care professionals.[2] The same study found that some LGBT people would prefer to receive a LGBT specialist service due to their poor experience of mainstream services. When questioned in detail on this, most would prefer that mainstream services are more inclusive of them so that they have confidence to access them. In order to overcome these difficulties, it is important that information regarding services uses inclusive language and imagery in order to assist with build confidence that services are inclusive.

Older people with a learning disability may be more likely to suffer poor mental health as a result of bereavement and so are more likely to need formal support to cope.[3] Consideration needs to be given as to how their needs can be met in an effective way. It is important that carers (paid and unpaid) understand the impact of bereavement on the cared for and are routinely given advice and information on how to spot signs of complicated grief and where support is available from. This information should also be available in an easy read format.

The coronavirus pandemic has disproportionately impacted Black, Minority and Ethnic communities. Deaths from Coronavirus have distressing symptoms in that there is a rapid progression to end of life; family isolation (such as when the person has been in residential care); and enforced limitations on end-of-life rituals. These factors all impact on cultural norms, rituals and social practices, which has the potential to increase the risk of complicated grief. Each older person that dies is likely to have many loved ones within their communities who will be greatly impacted through the bereavement. As such, an additional focus is required on ensuring that these communities have access to appropriate and sufficient levels of bereavement support. This support should be provided by people with lived experience of such

[1] Lesbian, Gay and Bisexual People in later life (2011) (stonewall.org.uk)
[2] The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people the_last_outing.pdf (lgbtsand.com)
[3] An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability - MacHale - 2002 - British Journal of Learning Disabilities - Wiley Online Library

communities in order for support to be both effective and accessible.

Gender affects people's experiences of bereavement. There is some research evidence to suggest that men and women deal with bereavement in different ways due to gender stereotypes.[4] [5][6] Older people due to their history are more likely to 'conform' to stereotypical responses. Whilst women are more likely to talk to friends and family about their grief, this is often not the case for men. Men may internalize their grief, which may lead to a higher level of need for support at a later date. As such there is the possibility that men may require higher levels of formal support than women. Men and women may find different forms of support work best for them, and as such this needs considering when designing and developing support services.

3: Are there any other models / programmes of support (Section 6) which should be referenced in the Framework?

Is the framework clear in outlining responsibilities across all areas of health and social care for considering support needs and addressing gaps in bereavement provision?

YES

We are not aware of other models of support other than those included in the consultation document that have proven to be effective.

In considering models of support and how bereavement care and support is delivered it is important that quality is prioritised over quantity. During the pandemic service have adapted to deliver support remotely through necessity; not due to the wishes of bereaved people or through any positive outcomes evidence base. Through analysis of our recent survey for people over the age of 50 on experiences of the pandemic, our respondents have told us that they struggle to engage with health and social care professionals over the phone and have more trust in those they can see face-to-face. As such as we move towards the 'new normal,' it is important that bereavement services are resourced to deliver face to face support in all cases where this is the most beneficial and preferred method for the bereaved person.

The framework could be strengthened by including details on which organisations relevant to the framework will be providing signposting and referring into bereavement support services and training available to them to identify when people may require further support, as well as how and where to refer bereaved people to appropriate to their needs. This will assist with future training planning.

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[4] Gender Differences in Grieving - Together (stjude.org)
[5] Are there gender differences in prolonged grief trajectories? A registry-sampled cohort study - ScienceDirect
[6] Gender differences in the effects of bereavement-related psychological distress in health outcomes | Psychological Medicine | Cambridge Core

We echo the Sue Ryder report's call to have a requirement on public services to have workplace 'bereavement first aiders,' that employees can turn to assist with the transition back to the workplace following bereavement.

4: Does the Learning from Covid-19 section (Section 9) sufficiently cover the lessons learned during the pandemic, and the action that needs to be taken to make sure that high quality bereavement care and support is available to everyone who needs it in Wales?

NO

Section 9 does cover the major lessons learned from covid. It is less clear in this section what actions need to be taken specifically with a bereavement framework to address the issues raised.

We know that before the pandemic that access to bereavement services was inconsistent across Wales in both range of services available and in terms of and almost impossible to access from some parts of Wales. We also know that many people are not aware that support is available for them to cope with their bereavement. As such the inclusion of a requirement on providers of bereavement services to reach out to communities that are affected by mass bereavement is welcomed. This requirement may not necessarily be possible currently due to a lack of resources, so it is important that any such 'ask' of services is accompanied by sufficient resources to reach out to communities and also resourcing to provide additional support.

In addition to the above, as a result of the pandemic we are likely to see an increase in the coming months of people needing support with bereavement from the pandemic. Whilst this framework will take some time to finalise, we urge Welsh Government to commit to make additional resources available to bereavement support services for at least the next year to manage this increase and associated backlog.

5: How can the provision of and access to bereavement services for Black, Asian and Minority Ethnic Communities be improved? (Section 10).

Please provide your suggestions below:

Services offering bereavement support recognise there is work to do to make services more inclusive. As previously stated, range and level of provision of bereavement support is not sufficient to meet the level of need. As such services are already struggling to meet demand, which limits their capacity to develop their work and reach out to other groups and communities that do not readily ask for help for a variety of reasons.

The additional work that this takes should be coordinated nationally and delivered locally. This will reduce the need for each area's services to undertake very similar work and so reduce the overall work required to achieve these important aims. The

national Bereavement Steering Group will need to focus their attention on how to actively engage with community groups and leads from Black, Asian and Minority Ethnic Communities.

Evidence from studies in this area tells us that Black, Asian and Minority Ethnic Communities prefer services delivered by and for people from those same communities.[7] It is particularly important that in times of crisis such as bereavement that such services are delivered by those that understand the various needs of those communities in order to both gain trust so that people feel able to ask for help when they need it and also so that they are able to deliver high quality, effective services.

6. Do you consider that the section on Training, Learning and Supervision for individuals providing bereavement support and for professionals who come into contact with people who are bereaved (Section 11) can be strengthened to address bereavement workforce, education and recruitment issues?

YES

Training needs should include wider training opportunities than just counselling. The vulnerabilities of people with protected characteristics often mean that their need for bereavement support is greater than for many other people in Wales. As such it is important that all bereavement services are trained in delivering more inclusive services. This should include understanding diversity in its many forms and in particular meeting religious and faith needs.

We welcome the development of a forum as this will enable services across Wales to have access to a wider range of expertise than may be available within different services.

In addition to training of those whose work is focused entirely on bereavement support, it is important that lower-level training is available to all who are likely to work with bereaved people so that they can signpost and refer as necessary, as not all bereaved people will personally be in contact with public services at the time when they recognise their need for support with their bereavement.

7: Does the section on referral pathways (section 12) provide sufficient information about the route people can take to access bereavement support?

NO

If the answer is no, please provide details of how this can be achieved.

The information contained on referring on to other services and keeping in contact

[7] AS-I-WALK-THE-LAST-MILE-OF-THE-WAY-Dementia-Report-2021-JS-Edits-Final.pdf (diversecymru.org.uk)

with bereaved people is welcomed.

Little is included on identification of those requiring support and there appears to be more emphasis on bereaved people not falling through gaps whilst waiting for support. Whilst this is of great importance, the framework should also include more detail on earlier identification and how and where people wish to access support in more detail.

We already know that the public is generally unaware of the benefits of support or the availability of bereavement services. As such earlier identification and wider referrals routes are an important consideration, particularly when planning for more inclusive services. As the framework becomes embedded over time it is hoped that more information will be available to contribute to service inclusivity and quality.

It would be helpful to include more detail on criteria for the various levels of support so that referrals are more robust. This will assist with ensuring that all agencies providing bereavement support provide the right support at the right time and that bereaved people's stress is not increased through inappropriate referrals.

9. Do the Bereavement Standards (Annex 1) set out what areas need to be addressed in order for bereavement support services to be both safe and effective in meeting the needs of bereaved people? Is it clear who is responsible for delivering these standards?

YES

The Bereavement standards cover the important areas of services that make them safe and effective and the table is clear on who has responsibility in different areas.

Whilst overall responsibility may lie with commissioners, they are highly unlikely to be experts in bereavement care and support or have complete information on the resources necessary to provide a high quality, safe service. This is work that needs to be undertaken by the national group so that appropriate guidance is available to commissioners on their responsibilities.

10. We are interested in your views on how the Welsh Government can ensure that the bereavement framework/standards are appropriately monitored and evaluated? Is it clear how the implementation of the framework will be monitored to see if it will have a practical effect on the provision of bereavement care in Wales?

Please provide your suggestions below:

The information included in the consultation document regarding areas that require monitoring (service standards; ensuring proper coordination of services by commissioners; availability of the three models of care) are an appropriate focus.

It is currently unclear how effective the bereavement support currently available is. A Sue Ryder report found that of the 9% of bereaved people that had accessed bereavement support, only 35% said they found this support helpful.[8] In order to ensure high standards of care and support it is important that monitoring includes outcomes information so that information can be gathered on what support works well. Good practice examples should be shared by the National Group, who should provide support to individual services to meet quality standards in the event that there is evidence that they are failing.

Given that services are already stretched, it is likely that bereavement support services are unable to meet all standards under the current circumstances. Little has been included on what will happen in the event that services do not meet expected standards and whether additional resourcing will be made available to meet expectations. We would welcome a commitment by Welsh Government to fully resource bereavement services.

11. We would like to know your views on the effects that the Draft National Framework for the Delivery of Bereavement Care in Wales would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.

What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?

It is of vital importance that services are delivered through the language that bereaved people are most comfortable with. In particularly stressful times it can be difficult to communicate through a second or third language and so it is important that provision through the medium of Welsh is part of any 'mainstream' commissioned service that delivers support to Welsh speakers.

[8] a-better-grief-report-sue-ryder.pdf