Number: WG42168

Llywodraeth Cymru
Welsh Government

Welsh Government
Consultation Document

Draft National Framework for the Delivery of Bereavement Care in Wales

Date of issue: 22 March 2021
Action required: Responses by 17 May 2021

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

OGL © Crown Copyright

Overview	This consultation seeks your views on the Draft National Framework for the Delivery of Bereavement Services in Wales.
How to respond	Older People's Health Team Population Health Welsh Government Cathays Park Cardiff CF10 3NQ
Further information and related documents	**Large print, Braille and alternative language versions of this document are available on request.**
Contact details	For further information, please contact: Older People's Health Team Population Health Welsh Government Cathays Park Cardiff CF10 3NQ email: BereavementConsultation@gov.wales

General Data Protection Regulation (GDPR)

The Welsh Government will be data controller for any personal data you provide as part of your response to the consultation. Welsh Ministers have statutory powers they will rely on to process this personal data which will enable them to make informed decisions about how they exercise their public functions. Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about or planning future consultations. Where the Welsh Government undertakes further analysis of consultation responses then this work may be commissioned to be carried out by an accredited third party (e.g. a research organisation or a consultancy company). Any such work will only be undertaken under contract. Welsh Government's standard terms and conditions for such contracts set out strict requirements for the processing and safekeeping of personal data.

In order to show that the consultation was carried out properly, the Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

You should also be aware of our responsibilities under Freedom of Information legislation

If your details are published as part of the consultation response then these published reports will be retained indefinitely. Any of your data held otherwise by Welsh Government will be kept for no more than three years.

Your rights

Under the data protection legislation, you have the right:

- to be informed of the personal data held about you and to access it
- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to (in certain circumstances) data portability
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection.

For further details about the information the Welsh Government holds and its use, or if you want to exercise your rights under the GDPR, please see contact details below:
Data Protection Officer:
Welsh Government
Cathays Park
CARDIFF
CF10 3NQ

e-mail:
Data.ProtectionOfficer@gov.wales

The contact details for the Information Commissioner's Office are:
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Tel: 01625 545 745 or
0303 123 1113
Website: https://ico.org.uk/

Consultation Response Form

Your name:

Organisation (if applicable):

email / telephone number:

Your address:

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

YES/NO

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

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

Please provide your suggestions below

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/NO

Please provide details below:

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?

YES/NO

If no, please tell us below how this could be made clearer and what else should be included.

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:

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/NO

Please provide details below:

7: Does the section on referral pathways (section 12) provide sufficient information about the route people can take to access bereavement support? YES/NO

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

8: Are there other forms of self-management/self-care (section 13) that should be referenced in the framework?

YES/NO

If the answer is yes, please provide details of the approaches below:

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/NO

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

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:

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?

12: Please also explain how you believe the proposed policy Draft National Framework for the Delivery of Bereavement Care in Wales could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

13: We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, including on any missing actions/next steps that you think the National Bereavement Steering Group should take please use this space to report them:

NATIONAL FRAMEWORK FOR THE DELIVERY OF BEREAVEMENT CARE IN WALES

CONTENTS

Ministerial Foreword – To be added post consultation

Policy aims and context

Aim of the Document
This framework seeks to set out how in Wales we can respond to those who are facing, or have experienced, a bereavement. Good bereavement support should be something available to everyone who needs it. It is to some extent the responsibility of all of us, whether it is provided by our friends, families, within our communities, our health and social care systems, the voluntary sector, our work or elsewhere.

It is underpinned by a desire to make sure that we do all we can to support people affected by bereavement. This might be during the period leading up to, or following, the death of someone significant in their lives. It is intended that this framework will set the standard and be a catalyst to drive improvements in the quality, provision and availability of bereavement support across Wales.

Vision statement
Wales is a place where everyone has equitable access to high quality bereavement care and support to meet their needs effectively at those times in their lives when they need it most.

Who can use this framework?
The framework is for both commissioners (health boards and local authorities where applicable) and providers of bereavement services, but will also be of interest to Registrars, Funeral Directors, Medical Examiners and anyone who is supporting someone who is bereaved, or who is bereaved themselves.

Why has this guidance been developed?
This framework seeks to support commissioners and providers to understand their responsibilities to ensure the provision of equitable and timely access to high quality bereavement care and support to the local population. Bereavement provision needs to meet the differing needs of differing communities and people of all ages. This framework includes a set of bereavement standards (Annex 1) and offers a general person centred aid to planning, commissioning and delivering bereavement services.

The document has been prepared by the National Bereavement Steering Group, made up of statutory and voluntary agencies who work with people who are dying, and those who are bereaved in Wales. These agencies have taken steps to involve those with lived experience to express their particular needs and to help design services. Membership of the National bereavement Steering Group is attached at Annex 2.

1. Introduction

Bereavement is something that touches all of our lives, sometimes many times over. Grief, our response when someone dies, is a natural and individual process and not an illness but its effects can sometimes be devastating.

It can happen at any age, by the death of a person at any age, and in any place. It can follow a death that is sudden for any reason, or can happen in the context of progressive illness. It can be experienced before the death and during the illness itself, or immediately after a death, or at any stage in the life of the bereaved person, whatever that person's relationship to the person who died. Some providers of bereavement support will encounter people in particular forms of bereavement, but other providers and in particular commissioners of bereavement care will need to be mindful of all people experiencing bereavement to make sure that none is left out. In that sense, while it is addressed to commissioners and providers of bereavement care, this framework is for the people it is designed to help: people experiencing bereavement.

How we experience grief may be influenced by a number of factors including age, cultural and religious/spiritual beliefs and our relationship with the deceased. Every bereavement experience is included in the remit of this framework. Whether we have a support network of family and friends, or feel isolated and are having to deal with family tensions, we recognise that all can have a major impact on our wellbeing in the medium to long term.

Bereavement can severely impact a person's overall health and behaviour. It can trigger a range of emotions and physical symptoms which we may never have experienced before which leave us feeling lost and unable to function. It is known there are costs, often long term, associated with allowing grief to remain hidden and unsupported. Everyone at any age can suffer from these negative impacts from very young children to the oldest members of our society. Bereavement care is part of health and social care's core work.

There are examples of good bereavement care in parts of Wales. But there are gaps and limitations in its provision. More is provided in some parts of Wales than in others, and some groups of people experiencing bereavement in particular contexts or at particular stages of life have not been able to get the right support at the right time. This framework seeks to address the inequity of the response to bereavement in Wales and will support the development of networks of services and other responses to help people regardless of where they are in Wales and across the whole range of experiences of bereavement.

People in Wales have always sought to care for those who are facing the death of someone close to them. The urgent goal is to do this better and more fairly across Wales so more people get what they need.

2. Strategic Context

A Healthier Wales (2018)[1] sets out the long-term future vision of a 'whole system approach to Health and Social Care' and called for bold new models of seamless local health and social care at the local and regional level. It challenged us to work differently, not just across portfolios within Government, but also with our partners and stakeholders.

Our third and independent sector stakeholders make an important contribution and the Welsh Government values the contribution which these sectors make to the long-term economic, social, environmental and cultural well-being of Wales, its people and its communities. In line with the principles of the Well-being of Future Generations Act[2] this framework requires the Welsh Government and other public bodies to think about the long-term impacts of the decisions we make today for a better tomorrow. This legislation is fundamental to developing a coherent, holistic and long-term response to bereavement care in Wales.

The Social Services and Well-being (Wales) Act 2014[3] established the Regional Partnership Boards (RPBs), to *improve the well-being of the population* and to *improve how health and care services are delivered*. The RPBs are key to ensuring that proposals are co-produced with third and independent sector organisations, local authorities and the NHS to best meet the needs of the local population.

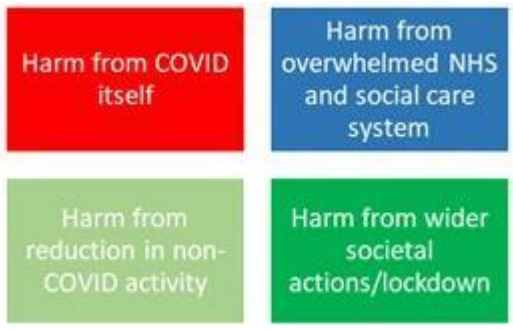
The NHS Planning Framework[4] , which is also the Minister's Direction to the NHS, always seeks to align with the Wellbeing of Future Generations Act and to continue to strengthen how organisations work to deliver their plans using the five ways of working (long term, prevention, integration, collaboration, involvement).

Covid-19 has had a profound effect upon the delivery of NHS and social care services, as well as changing the behaviour of the general public in the way they access healthcare. However, the vision we set out in A Healthier Wales for seamless health and social care remains sound, with many of the new ways of working and innovative approaches introduced in response to the pandemic accelerating progress. Welsh Government remains committed to delivering the transformation needed. However, since the beginning of the Coronavirus pandemic there has also been a strong focus on avoiding the four harms (see fig 1 below) that have been the key quality context within which services and care must be provided.

[1] https://gov.wales/sites/default/files/publications/2019-10/a-healthier-wales-action-plan.pdf
[2] https://gov.wales/well-being-future-generations-wales-act-2015-guidance
[3] https://gov.wales/sites/default/files/publications/2019-05/social-services-and-well-being-wales-act-2014-the-essentials.pdf
[4] https://gov.wales/nhs-wales-planning-framework-2020-2023

All four harms are relevant to the well-being of future generations but the need to prevent harm “from wider societal actions/lockdown” also provides a broader and longer term context to planning and investment in health and social care.

Figure 1: The four harms



Firstly, through direct harm to individuals and families from Covid-19 and complications including for those who develop severe disease and in some cases sadly die or experience bereavement as a result.

Secondly, the harm caused if services including the NHS became overwhelmed due to any sudden large spike in demand from patients with Covid-19 on hospitals, critical care facilities and other key services.

Thirdly, harms from non-Covid illness, for example if individuals do not seek medical attention for their illness early and their condition worsens, or more broadly from the necessary changes in NHS service delivery made during and following the pandemic in Wales as a result of the pause to non-essential activity.

Fourthly, socioeconomic and other societal harms such as the economic impact on certain socioeconomic groups of not being able to work, impacts on businesses of being closed or facing falling customer demand, psychological harms to the public of social distancing and many others.

The NHS Planning Framework sets an expectation of a broad approach to prevention to be applied in all aspects of planning. This is supported by Welsh Government policy that is set out from a perspective of prevention.

Preventative approaches to all physical and mental health challenges and support for well-being will ultimately avoid escalation of conditions and illness. Health and social care providers should consider opportunities that will support future generations and inform future service provision.

Our aim is to take significant steps to shift our approach from treatment to prevention. The vision we have established in A Healthier Wales is to place a greater focus on prevention and early intervention. For bereavement this means providing people with appropriate bereavement care and support, as delays can contribute to the development of more complex grief.

The priorities that will be delivered through the bereavement framework continue to support principles of prudent and value based healthcare[5] with its focus on integrated, co-produced, person centred care delivered in a way that has been informed by service users and carers.

3. Scope

Bereavement is experienced in relation to the death of a person wherever and whenever it happens. For the purpose of this framework it includes pre-bereavement (a grief reaction before someone dies, sometimes referred to as anticipatory grief) and includes bereavement experience of anyone, whatever their relationship to the person who dies. It includes bereavement due to the death of any person, including those who die before birth.

All types of bereavement and pre-bereavement are included, wherever and whenever they occurred, and whatever the circumstances around the death.

Support will be provided to children, young people, and adults of all ages without restriction, and must be accommodating of the needs of people of all communities and backgrounds.

Every effort should be made to ensure that the support offered recognises the culture and beliefs of the bereaved person, including recognising the significance of the faith, religious or spiritual beliefs that the individual or family hold.

4. Principles

Wales should be a place where:

- People who are bereaved will be treated with compassion, empathy, and kindness, have their wishes, choices and beliefs listened to, considered and respected by all. Pre-bereavement will also be recognised, to offer support before the death wherever possible.
- People's needs and grief reactions are recognised and acknowledged as being different at different times, (e.g. the need for practical help and / or emotional

[5] https://vbhc.nhs.wales/

support). People may need to return several times for these different types of support following a bereavement.

- There is help to know where to turn for additional support when it is needed, this should be available for bereaved people affected by any cause of death, at a time and place when they can access it easily.

- The needs of bereaved people with protected characteristics, as outlined in the Equality Act 2010, of the Public Sector Equality Duty (age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation) are recognised;

5. The Need for Bereavement Support

Every person's bereavement experience is different but for some the extreme emotions which we can feel when grieving, including shock, anger, guilt, emptiness and lack of purpose, coupled with physical sensations including fluctuating appetite, weight loss or gain, sleep deprivation, and emotional episodes can be overwhelming. It is known that for some people, unresolved grief issues can lead to serious mental health difficulties and is a risk factor for suicide. Helping bereaved people to understand these feelings and learning how to cope with them on a day to day basis is an important part of supporting them at the most difficult time in their lives.

Many people find that the support of family and friends or colleagues may be sufficient to enable them to overcome, over time, the devastating sense of loss. For some, additional and / or more specialist bereavement support may be necessary. There may be identifiable reasons for this need, such as the circumstances of the bereavement, the nature of their relationship with the person who has died, or strains in their social or economic environment caused by family tensions or feelings of isolation and loneliness. For some families, particularly those with children and young people, it may be because the family struggle to communicate about what has happened and understand how children cope with grief. For some, there will be no clearly identifiable reason but the need will be no less real.

Everyone should be aware of and be able to access the support which they need, at a time and in a manner which is best for them. For some, the consequences of being unable to access this support in a timely manner may include prolonged grief and other mental health disorders, including depression, anxiety, substance misuse (including alcohol), self-harm and increased risk of suicide. For children and young people it can present in risky behaviour, behaviour problems, school refusal, eating disorders and poor mental health outcomes.

The impact on a bereaved person's family life and relationships can also be devastating, and it is recognised that the whole family, all those who are affected, including close friends or personal carers, should have access to support as and when

they need it. We must also consider how we support individuals who experience death or bereavement as part of their work such as health and social care staff, police officers and funeral staff.

6. Models of Bereavement Support

There are a number of adult and children bereavement frameworks/models that set out a range of approaches to providing bereavement care and support. The Bereavement Scoping Survey[6] undertaken by the Marie Curie Palliative Care Research Centre, Cardiff University, and the Wales Cancer Research Centre used the National Institute for Health and Clinical Excellence (NICE) three component model below.

The Three Component Model

NICE outlines a three component model of bereavement support, complemented by a public health approach of universal / selective or targeted / intervention:

- Component 1 (universal): where information is offered regarding the experience of bereavement and people are sign-posted towards further support can be provided as part of a conversation, in written form (leaflets / factsheets) or via on-line resources. Intended to help bereaved people understand that, whilst everyone's grief journey is unique, that there are certain emotions and physical characteristics which are an entirely normal reaction to the loss which they have experienced. These resources should help awareness and assist a person identify when to seek further support.

- Component 2 (selective or targeted): which makes provision for people to access more formal opportunities to reflect upon their grief, and may involve individual or group sessions, peer support, friendship groups, and / or specific groups relating to the type of bereavement, e.g. suicide

- Component 3 (indicated): which encompasses specialist interventions that may involve mental health services, psychological support and specialist counselling.

This framework encompasses all of these components in the care required by bereaved people in Wales. It is important to note the inter-dependencies between each category – without adequate capacity being available in each component, subsequent components could become overwhelmed.

[6] https://gov.wales/sites/default/files/publications/2019-12/scoping-survey-of-bereavement-services-in-wales-report.pdf

Other Models or Programmes of Support

Similar programmes or models of support exist, particularly in relation to the needs of bereaved children, young people and their families/carers. A number of these evidenced based examples can be found in Annex 3.

7. Bereavement Care to meet the needs of our population

While the informal care of friends, families and members of communities are invaluable, we recognise that there are those who live and are bereaved in situations where these supports are not available to them or are unable to meet their needs. One aspect of a public health approach to better supporting bereavement in Wales is provided by the encouragement of compassionate community values and principles.

The care received by those at the end of their lives and the people caring for them are key foci of Compassionate Cymru[7] and supporting those who are bereaved is an important aspect of this work.

The Welsh Government's *Connected Communities – A strategy for tackling loneliness and social isolation and building stronger social connections (2020)*[8] further supports the Welsh Government's ambition, working with statutory and third sector partners, to *make Wales the world's first Compassionate Country*.

It recognises the need, as one of its Priorities for Action, to raise the profile of loneliness and social isolation as part of a £1.4 million Loneliness and Social Isolation Fund over the next three years. It also identifies how bereavement can be one of the life events which result in people feeling lonely or becoming socially isolated.

The *Compassionate Cymru Steering Group*, comprising a variety of statutory and third sector organisations is engaging with a range of key initiatives including Communities of Practice, social prescribers, community connectors and work by the Regional Partnership Boards, Public Service Boards, and other organisations to develop compassionate community models.

There are clear linkages between the establishment of Compassionate Cymru and the provision of community support to bereaved people in Wales. The role of the Social Value Forums, supported by the Regional Partnership Boards, will be key in working to identify, enhance and sustain the support communities are able to offer their residents during bereavement. The importance of supporting informal responses in

[7] https://www.dyingmatters.org/wales
[8] https://gov.wales/loneliness-and-social-isolation-connected-communities

this way is clear in the evidence already available around the ways in which well-being is enhanced by social connectedness. The benefits of this work will include the ability to target and make best use of the resources available from statutory and specialist services.

Person centred care should be holistic and include a spiritual, pastoral and religious dimension where this is required by the person (Health and Care Standards Wales 2015[9], p.8). Spiritual care addresses the dimension of illness, disability, suffering and importantly bereavement that go beyond the immediate and the physical. Chaplaincy provides specialist spiritual care (Standards for Spiritual Care Services in the NHS in Wales 2010) but importantly must link into or connect services between health care organisations and the multiple faith/pastoral communities within Wales.

8. Existing Provision - Scoping Survey of Bereavement Services in Wales

In 2019, a Bereavement Scoping Survey in Wales was undertaken by the Marie Curie Palliative Care Research Centre, Cardiff University, and the Wales Cancer Research Centre, funded by the End of Life Care Board in Wales.

The survey identified that the amount of bereavement support available varied significantly across Wales. The findings identified gaps in the provision of adult and children and young people bereavement services, in particular following the loss of children, infants and in pregnancy, pregnancy loss and stillbirth. There are also gaps in provision of support in each of the NICE components above, including access to specialist support.

Its key considerations were as follows:

A National Framework: the development of a national framework for the delivery of bereavement care in Wales. This would in turn facilitate:

Prioritisation of Bereavement Care: the prioritisation of bereavement support at organisational and regional levels.

Equity and access to appropriate support: availability of appropriate types and levels of support which are responsive to local needs and comprise an effective balance of non-specialist community based provision and specialist professional intervention

Referral and Risk Assessment: The establishment of clear referral pathways and approaches to risk / needs assessment. The development and maintenance of a

[9] http://gov.wales/sites/default/files/publications/2019-05/health-and-care-standards-april-2015.pdf

directory of available bereavement provision could improve signposting, referrals and access to appropriate local support.

Training and Learning: Improved access to training for staff and volunteers and sharing of expertise and good practice between local service providers

Evaluation and Assessment: Improvements in how services are evaluated and assessed, with implications identifiable for service improvement and investment. Appropriate sets of standards could be considered for use as audit and quality improvement tools, and suitable measures and methods identified for evaluating the impact of services on service users.

9. Learning from Covid-19

The impact of Covid-19, with shielding of "at risk" groups which occurred during the first wave, the introduction of local lockdowns and necessary restrictions on meeting friends and family, has caused heightened levels of anxiety. Additionally, changes to visiting policies across inpatient and care settings have limited contact with loved ones before and during death, complicating end of life care and contributing to the trauma of the bereaved. Restrictions have also affected how bereavement care is delivered, including across perinatal services. Sadly, there have already been many deaths. At the time of writing we do not know what the full effect will be but we know something of what we can learn from this era.

Cardiff University are leading on a UK wide '*Supporting People Bereaved during Covid-19* Study', which is investigating bereavement experiences, support needs and support provision during the pandemic. Interim results have demonstrated the exceptionally difficult nature of pandemic bereavement and the unique sets of challenges experienced by people grieving at this time. Not being able to spend time with loved ones in their final illness, restrictions on numbers able to attend a funeral and the inability to console someone with a hug can be heart breaking for a bereaved person and their family. Grieving, already a lonely process, is increasingly occurring in isolation without that contact from friends and family. For many communities, mutual social contact is an essential element of bereavement rituals which allow for expression of grief and support of those bereaved, this has been especially difficult during the pandemic.

There is the sense from some bereaved people that their loved one's death was avoidable. This, coupled with a range of emotions including anger and frustration, with guilt in some cases that they themselves may have been complicit in transmitting the disease to their loved ones, is causing increasing distress.

All of these factors are having a lasting impact on people's grief and there is a risk that this isolation which many people are experiencing in the current environment, may lead to chronic loneliness. Just over half of participants in this study demonstrated

"severe" (28%), or "high" (24%) levels of vulnerability in grief, as well as high / fairly high needs for support in six psycho-emotional domains. These included; dealing with feelings about being without loved ones (51%) and the way in which they died (62%); feelings of anxiety and depression (55%); expressing feelings and being understood by others (55%); feeling comforted and reassured (53%) and loneliness and social isolation (53%).

These phenomena have illuminated the need for bereavement support perhaps more than ever, however, we know that people are also experiencing difficulties accessing support, for reasons such as long waiting lists, lack of appropriate support, and feeling uncomfortable asking for or not knowing how to access help. In seeking to improve bereavement care we must learn from these experiences.

Many providers of bereavement support during the pandemic have moved to providing support by telephone or online rather than in person or in groups. This may not be the model preferred by bereaved people, but it is the prevailing model of support for the foreseeable future due to infection, prevention and control considerations for the bereaved person and the provider of support.

The National Bereavement Alliance Report, *Covid19: the response of voluntary sector bereavement services* similarly highlights the impact of the pandemic on grief and bereavement. Key findings include the increased complexity of deaths, and subsequent increase in the levels of distress suffered by bereaved people, difficulties in accessing normal levels of support (e.g. family and friends) due to social distancing requirements resulting in increased isolation and loneliness, and lack of capacity in bereavement services.

We have learned during the pandemic that those with underlying conditions and those living in areas with high levels of social and economic deprivation have suffered disproportionately. Learning from Covid-19 should provide foundations for the implementation of preventative initiatives that can make an impact on reducing all four harms. Bereavement support needs to be a core component in a national co-ordinated strategy on the response to a pandemic.

10. Black, Asian and Minority Ethnic Communities

The report of the BAME Covid-19 Socioeconomic Subgroup[10] chaired by Professor Emmanuel Ogbonna found that although the coronavirus pandemic has created widespread fears and risks to lives and livelihoods across communities in Wales and around the world, the impacts on Black, Asian and Minority Ethnic groups have been especially profound. Members from ethnic minority communities are disproportionately contracting and dying from the Covid-19 disease, with available statistics suggesting that British Black, Asian and Minority Ethnic groups are up to two times more likely to die from the disease than their white counterparts.

[10] https://gov.wales/sites/default/files/publications/2020-06/first-ministers-bame-covid-19-advisory-group-report-of-the-socioeconomic-subgroup.pdf

These losses have been exacerbated by the disruption caused by Covid-19 restrictions to the community resources which would normally be available to them for informal support. Many families have not been able to visit dying loved ones, have had to grieve alone during lockdown and have experienced painful disruptions to funerals and traditional death rites.

The Cross Party Group on hospices and palliative care heard directly from bereavement service providers and leaders from Black, Asian and Minority Ethnic communities across Wales at their meeting on 20 January 2021. The message from community leaders was clear: bereavement services are not always experienced as accessible to people from diverse communities, despite the efforts of bereavement services to ensure their services are open to all. Community leaders advised that tailored bereavement and mental health services are often needed to support people from ethnic minority communities and that people from ethnic minority communities should be involved in bereavement service design, taking a co-productive approach.

Similar views and experiences are described in a recent publication by *BAMEStream*, which reports results from a survey of Black, Asian and Minority Ethnic mental health services in the UK during the pandemic. The report identifies increased demand for bereavement support provided by Black, Asian and minority ethnic led organisations, as well as a need for mainstream Bereavement therapists and service providers to have quality assured cultural competency training. A need for research and good-practice sharing relating to ethnicity, bereavement and bereavement support provision is also identified.

The UK wide 'Supporting People Bereaved during Covid-19 Study' referenced in section 9 above aims to understand more about the bereavement experiences and support needs of people from minority ethnic backgrounds. Forty participants from minority ethnic backgrounds took part in the survey, with follow up interviews planned to explore experiences in more depth. Research with voluntary sector bereavement services will also explore support provision relating to minority groups. A key goal of the study is to identify recommendations to ensure that equitable bereavement support is provided across the UK.

Providers and Commissioners of bereavement services need to engage with ethnic minority communities to address this inequity of care and to discuss what level of bereavement support is needed.

11. Training, Learning and Supervision for Individuals Providing Bereavement Support

All formal volunteers and staff who come into contact with bereaved people should have the relevant training and experience for the level of support they offer (see Annex 1, section 1.2 for more detail on the types of support and the standards required). This will include initial training in listening skills, supporting the bereaved, identifying and providing the correct level of support at that time, identifying where further and more specialist support may be necessary, e.g. for more complex grief and other mental

health conditions such as Post Traumatic Stress Disorder. Safeguarding training must be provided to all staff and volunteers.

Training needs should be established to ensure that staff and volunteers are equipped with the necessary skills and expertise, recognising that this may require training in other skills not just relating to counselling. All training should be monitored to ensure that it meets the requisite quality standard.

All providers should have mechanisms in place to review on a regular basis, the skills and competence of their staff and volunteers, and have a regular programme of Continuing Professional Development to equip them with new skills, developments in the provision of bereavement support, and identifying where further training is required.

The *Bereavement Care Service Standards*[11] (statement 4) also highlight the need to provide access to support and supervision to ensure safe working practice and afford staff and volunteers the opportunity to recognise the impact of this work on them. Depending on the level of service provision, and the skill set of the provider, supervision should be undertaken in line with regulatory bodies, and in line with the Bereavement Care Service Standards.

As part of the implementation and ongoing support of the Bereavement Framework, a forum will be established to share experiences, ideas, best practice, and learnings.

12. Accessing Bereavement Support - the need for Clear Referral Pathways

Bereaved people and their families looking for support at a time of distress need to be able to access up to date information concerning the range of support available, in a format that works for them. Individual providers may be providing one or more levels of support but commissioners should ensure that all three levels are available and clearly sign posted for professionals and the public.

On making contact with an organisation, the means of referral into the service needs to be clear with an understanding of the range of services available, including an estimate of the waiting time for that support, where a waiting list exists.

The provider needs to ensure that the process of assessment for referral into their service is clear and comprehensible, collecting only the information needed to ensure a full assessment of the needs of the bereaved person. If after collecting this information and discussing the outcome of the assessment with the person, it becomes clear that their needs would be better served by another provider (in terms of complexity of need, specialism, type of service provision available, or more timely support), then onward referral to the alternative organisation should be offered to the bereaved person.

[11] Bereavement Care Service Standards : Bereavement services Association & Cruse Bereavement Care, 2014

This onward referral could occur at the start of the bereavement support or during its initial stages, for example, after the bereaved person has been seen for the first time or first few sessions following a referral into the service.

Where, for example, a need for more specialist mental health provision has been identified then the referral into that service should be facilitated by primary care, although additional clinical information may be required including a mental health assessment by the Primary Mental Health team. (See Annex 1. Section 1.2 in relation to commissioners' and providers' responsibilities).

It will be important in any cases of onward referral for both organisations (both referring and receiving) to ensure that the process is properly managed, that the bereaved person does not feel "forgotten", and that they are still able to access support in the intervening period.

There will also be times (such as throughout the pandemic or following mass bereavement) when services should proactively reach out to communities to offer bereavement care and support.

13. Self- Management/Care

Health, social care, third sector partners and service users are central to the planning, design and delivery of bereavement services.

Approaches which empower people to manage their own bereavement such as self-help guides can be highly effective. Health and care staff will need to adopt these approaches to increase quality of outcomes and experience for individuals and to maximise access to resources and reduce variation across services. Services will need to assess and plan to prioritise those in most urgent need and to consider meeting potential increased demand. Ensuring that bereavement is "everyone's business" will support the use of self-management and wider community resources to increase general health and well-being. Signposting to sources of support should be part of all bereavement after care.

14. Securing Outcomes

Although grief can be complex whatever the last stage of the person's life has been like, we know that experiences and perceptions of poor communication, of poor care, or of uncontrolled distress can make bereavement much harder. Mitigating the distress of the bereaved is only one reason to provide good end of life care, most of which is beyond the scope of this framework, but the approach to bereavement has to be matched by attention to the care of those with chronic and progressive life shortening illnesses and the care of the dying.' Family involvement and memory making during all parts of the care pathway, as well as during end-of-life care, is particularly important.

In order to optimise outcomes, bereavement resources will be required throughout all parts of the system. Strong inter-professional and partnership working throughout

health, social care, third and independent sectors will maximise the resource available to support better outcomes.

There is much variation in the timely provision of quality bereavement support across Wales. Adopting evidence-based person reported outcome measures will ensure that care is provided equitably according to need. This has the added benefit of identifying health inequalities in access to timely, effective bereavement support. It will also afford health and care planners the opportunity to deliver equity in bereavement responsiveness across Wales.

15. Links to other Work/Programmes

This framework should be read and implemented in conjunction with a number of other related work programmes. A number of these programmes are listed at Annex 4.

16. Action Required

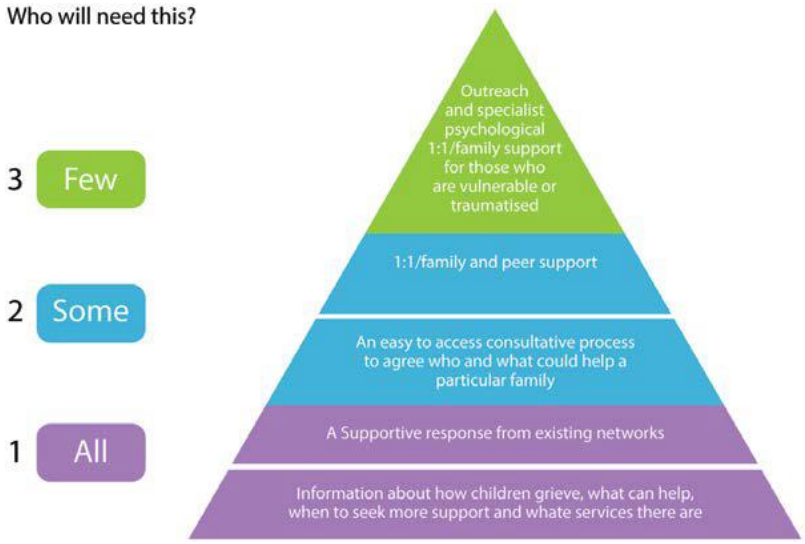
In order for Wales to meet the bereavement needs of the population, action is needed at national, regional and local level.

The End of Life Care Board has overall responsibility for bereavement care and support in Wales and through the National Bereavement Steering Group will provide the ongoing leadership and oversight that is needed to implement this framework and to support regional and local planning. This will include:

- Monitoring implementation of the bereavement standards (Annex 1) and advising the Welsh Government on further action/resources needed;
- Working with health boards to identify an executive lead for bereavement care and support;
- Considering the specific bereavement needs of Black, Asian and Minority Ethnic communities and other disadvantaged groups.
- Supporting the development and / or implementation of clear referral pathways for specific client groups:
- Supporting bereavement providers to deliver identified national bereavement outcome measures for adults and children/young people;
- Developing quality standards for the design and delivery of national training programmes to ensure bereavement is “everyone’s business”, promoting an empowering, person-centred approach that is adopted by all;
- Embedding advances in technology and smarter ways of working to support the increased demand for bereavement support and improve access, outcomes and experience;
- Training and up-skilling the wider multidisciplinary and multiagency teams, promoting self-management and the co-production of care alongside access to a range of specialist bereavement provision.
- Framework implementation and monitoring; and evaluation.

Annex 1 – Standards

The need for bereavement support (including anticipatory grief / pre-bereavement) has already been identified. It is important for those commissioning bereavement services, those providing the service, and for bereaved people who will ultimately receive that service to have confidence that there are measures in place to ensure that (a) support is available to them and (b) that it meets the required standard. The National Bereavement Alliance, in its document *A Guide to Commissioning Bereavement Services in England* gives a description of *what good local provision for bereaved children and their parents and carers looks like* (shown here to illustrate models of delivery):



1.1 Government

Government should ensure that a clear pathway exists for bereavement issues to be raised and addressed.

1.2 Commissioners

(a) Commissioners should ensure that the appropriate standard of care and support can be provided to children, young people and adults, so that their bereavement needs can be met taking into account their faith, culture, gender, economic status, and their location within Wales. This includes supporting bereaved people to understand how children grieve.

(b) Commissioners should ensure that anyone experiencing a bereavement is provided with up to date, relevant information on the support available to them. This will include those people who may find it difficult to access bereavement support (e.g. because of disability) or who are in groups who have historically been under represented (e.g. LGBTQ+).

(c) Commissioners should ensure that people have a bereavement risk assessment at the initial point of contact into a service.

(d) Commissioners should ensure that bereavement services which may already exist within their individual Health Board Directorates are properly co-ordinated to provide a consistent level of service to bereaved people.

(e) Commissioners should demonstrate that adequate support is available under each of the following categories:

Category	**Type of Support**	**Standard Required**
Available to all Bereaved people (NICE component 1 *Universal*)	**Commissioners' Responsibilities:** To ensure that sufficient informal care, support networks and information services are available, and that the information provided is always up to date, and in a range of formats and languages. **Providers' Responsibilities:** Information about bereavement and support available, outlined as part of a conversation with the bereaved person or a family member. Material provided via leaflets or details of on-line resources given. Ascertain what support can be provided through informal social networks. Some providers may also directly enable social/peer support by hosting social activities or groups.	Accurate and timely Information on how to deal with practical matters. Information on grief and coping with bereavement to be made available Sign-posting on how To access other types of support to be understood.
Available to some bereaved people (NICE component 2 *Selective / Targeted*)	**Commissioners' Responsibilities:** To ensure that capacity exists to support bereaved people who request it, especially for those people who may be at risk of developing more complex needs. **Providers' Responsibilities:** People supported to reflect upon their / their children's grief, individually or within a group environment. Support via befriending / faith /other community groups, as appropriate to the individual circumstances; trained bereavement support workers.	See core standards, s1.3 below and s1.4 detailed measures

Available to a small number of Bereaved people (NICE component 3 *Indicated*)	**Commissioners' Responsibilities:** To ensure that more specialist support is available, and accessible. To identify those people who may be at risk because of complex needs or from the effects of long term or complicated grief. This would include the effect of grief on a child/young person's emotional neuro psychological development). **Providers' Responsibilities:** To ensure that the appropriate level of expertise is in place to meet this high level of need, where specialist interventions are required.	See core standards, s1.3 below and s1.4 detailed measures

1.3 Core Standards for Providers of Bereavement Services

(a) The following are core standards which providers of bereavement support are expected to follow, and be able to demonstrate as part of a regular review of services. They are designed to be clear, concise and comprehensive and should be used for planning, provision and quality review of all bereavement care.

They are taken from the *Bereavement Care Service Standards, 2014* produced by the Bereavement Services Association and Cruse Bereavement Care, and endorsed by the National Bereavement Alliance, following funding from the Department of Health. They are the *Fundamental Principles* for the provision of bereavement care services:

Confidentiality: services should respect the confidentiality and privacy of each bereaved person and any information shared by them, with due regard to safeguarding, consent and data protection.

Respect: services should respect the individuality of each bereaved person's grief and needs, with each person treated with compassion and sensitivity.

Equality and Diversity: services should be non-discriminatory and delivered without prejudice, recognising and responding to personal beliefs and individual situations including (but not exclusive to) age, culture, disability, gender, sexuality, race, religion and spirituality (Equality Act 2010).

Quality: services should ensure that all those delivering support to bereaved people, whether in a paid or voluntary capacity, have the skills, knowledge, training, supervision and support relevant to their role, and that services work to improve what they offer.

Safety: services should have robust processes for recruitment, including appropriate levels of clearance with the Disclosure and Barring Service and ongoing staff/volunteer development. There needs to be due regard to safe and ethical practice in order to protect bereaved people and those who work with them. The necessary processes for safeguarding must be in place and accountability evidenced through an audit trail.

Bereavement support is underpinned by a variety of standards, including professional standards set by their own organisation, or professional body. In addition, there may be other standards and outcomes measurements to meet local requirements, or as required by funders or as part of service level agreements or other commissioning documents.

1.4 Detailed Measures for Bereavement Support Providers

Providers of bereavement support should consider adopting some or all of the following measures, or such other measures as agreed with their funders.

1.4.1 Access to the service

(a) Registration / Referral: Following an enquiry from a bereaved person, initial contact should be made within five working days.

(b) Risk Assessment: A comprehensive assessment of the needs of the bereaved person and a risk assessment must be undertaken by a trained individual with the required skills. This may include arranging higher priority support for those people deemed to be at the highest risk, or referring the client for more specialist support elsewhere.

(c) Waiting times for support: an estimate of the approximate waiting time should be provided on initial registration with the service. This is intended to give a general guideline only on the time it may take for support to be provided.

(d) Keeping in touch: where bereaved people are on a waiting list for support, regular contact should be maintained to provide re-assurance and check that their situation has not changed. This should occur at a minimum of four weekly intervals and if it is identified that more timely support could be provided by an alternative provider, then this should be discussed and an onward referral to the alternative service offered.

(e) Review: If after a period of twelve weeks support is still awaited, a discussion with the bereaved person should take place to discuss their current situation, their needs after three months and whether support can be provided from an alternative source.

1.4.2 Monitoring of the service provision

(a) Supervision and Monitoring: all services provided must be monitored to ensure the safety of the client and the provider of that support, and that they are operating ethically.

(b) End of support Evaluation: a process must be in place to monitor the quality of the service provided with both quantitative (e.g. using recognised evaluation tools such as the Clinical Outcomes in Routine Evaluation CORE-10) and qualitative (e.g. questionnaires for completion at the final session of support) measures.

There are other tools which may be used as required (CORE 10 is not appropriate for young children therefore other evaluation tools must be used).

(c) Evaluation Measures: These should include client perception of waiting times, ease of initial contact and or subsequent referral, understanding of client needs and level of empathy shown, adequacy of support given, understanding of next steps and / or referral to other support where appropriate.

1.4.3 Review

The needs of bereaved people, articulated by colleagues in Welsh Government's Patient Experience team, together with research from palliative and bereavement care will be included in the review and updating of these measures.

1.5 Using the Bereavement Standards

Commissioners will be responsible for implementing these standards at regional and/or local level. Providers of bereavement care will be responsible for implementing these standards at the organisational level.

ANNEX 2 - MEMBERSHIP OF THE NATIONAL BEREAVEMENT STEERING GROUP

Member	Title	Organisation
Dr Idris Baker (Chair)	National Clinical Lead Palliative/End of Life Care	Hywel Dda University Health Board
Gareth Hewitt	Head of Older People's Health	Welsh Government
Alison Lott	Senior Manager, Older People's Health	Welsh Government
John Moss	National Bereavement Lead	Welsh Government
Vivienne Collins	Policy Manager, Older People's Health	Welsh Government
Gareth Howells	Nursing Officer	Welsh Government
Professor Lesley Bethell	Chair	Compassionate Cymru Steering Group
Daisy Shale	Medical Examiner Officer Lead	Medical Examiners Service, Wales
Janette Bourne	Director	Cruse Bereavement Care Cymru
Anita Hicks	Clinical Lead	Sandy Bear's Children's Bereavement Charity
Helen French	Hospices Representative	City Hospice
Claire Cotter	National Co-ordinator for Suicide and Self-harm Prevention	NHS Wales Collaborative
Jessica Reeves	Public Affairs & Campaigns Manager	SANDS (Still birth and neonatal death society)
Jessica Evans	Patient experience representative	Fair Treatment for Wales
Sue Phelps	Director	Alzheimer's Society
Ian Stevenson	Chair & Senior Nurse	All Wales Spiritual Health and Well-being Group
Dr Emily Harrop	Research Associate. Marie Curie Palliative Care Research Centre.	Cardiff University
Dr Anthony Byrne	Clinical Director of the Marie Curie Palliative Care Research Centre.	Cardiff University
Josie Anderson	Campaigns and Policy Manager	Bliss
Alex Walsby	Senior Nurse Bereavement	Hywel Dda University Health board
Rocio Cifuentes	CEO	Ethnic Minorities and Youth Support team Wales
Melanie Lewis	End of Life Care Co-ordinator	NHS Wales Collaborative
Charity Garnett	Palliative Care Nurse for North Powys and Bereavement Project Co-ordinator	Powys Teaching Health Board
Jane Brewin	CEO	Tommy's
Rhian Mannings, MBE	Founder & CEO	2 Wish Upon a Star
Dr Anne Johnson	Consultant Clinical Psychologist General Paediatrics	Aneurin Bevan University Health Board
Dr Liz Gregory	Consultant Clinical Psychologist	Aneurin Bevan University Health Board
Sally Rees	National third Sector Health & Social Care Facilitator	WCVA
Marika Hills	Strategic Partnership Manager, Wales	Macmillan Cancer Support
Professor Stuart Todd	Life Science and Education Department	University of South Wales
Dr Karen Pardy	GP	Cardiff South West Cluster
Dr Rachel Lee	GP	Cardiff South West Cluster

Annex 3 – Bereavement Models

This annex provides examples of both bereavement models and frameworks currently operating within the UK.

2.1 Children's Bereavement

The following models outline the differing needs of "most" "some" and "few" children, and how these needs can best be met, and by whom.

The Childhood Bereavement Network, in conjunction with the National Children's Bureau, has published guidelines on *what good provision looks like*, as well as what constitutes *high quality support:*

http://www.childhoodbereavementnetwork.org.uk/media/96900/grief-matters-for-children-2017.pdf

The Irish Childhood Bereavement Framework: encourages adults who care for bereaved children to understand that, in most situations, children can be supported by providing accurate information and emotional support through their family and community:

https://www.childhoodbereavement.ie/professionals/standards-supporting-bereaved-children/

2.2 Pregnancy and Baby Loss Bereavement

The National Bereavement Care Pathway (NBCP) for Pregnancy and Baby Loss is a pathway to improve the bereavement care parents in England receive after pregnancy or baby loss. The nine NBCP bereavement care standards were launched during Baby Loss Awareness Week 2018. They form the basis on which the roll out programme in England is established.

https://nbcpathway.org.uk/

https://nbcpathway.org.uk/nbcp-standards

2.3 Bereavement by suicide

Developing and delivering local bereavement support services is a toolkit produced by the National Suicide Prevention Alliance and the Support after Suicide Partnership, supported by Public Health England. The documents provide guidance for developing and delivering local bereavement support services, and guidance on evaluating local bereavement services. A common resource used across the UK to support people bereaved by suicide is 'Help is at Hand' which is available in English and Welsh on the Dewis Cymru website.

https://www.nspa.org.uk/home/our-work/joint-work/support-after-a-suicide-providing-local-services/

Dewis Cymru Help is at Hand Cymru

Annex 4 - Links to other guidance/framework documents:

https://gov.wales/sites/default/files/publications/2019-01/palliative-and-end-of-life-care-delivery-plan-2017_0.pdf

https://gov.wales/guidance-funerals-covid-19-html

https://gov.wales/maternity-services-strategy-2019-2024

https://gov.wales/suicide-and-self-harm-prevention-strategy-2015-2020

https://www.nice.org.uk/guidance/qs189/chapter/Quality-statement-5-Supporting-people-bereaved-or-affected-by-a-suspected-suicide

https://gov.wales/mental-health-crisis-care-agreement-action-plan-2019-2022

https://gov.wales/loneliness-and-social-isolation-connected-communities

https://gov.wales/substance-misuse-delivery-plan-2019-2022-0

https://gov.wales/sites/default/files/publications/2018-03/statutory-guidance-to-welsh-local-authorities-on-the-provision-of-independent-counselling-services.pdf

https://www.wales.nhs.uk/researchandresources/publications/nhswalesadvancefuturecareplans

http://advancecareplan.org.uk/who-could-speak-for-you-if-you-were-unable-to/

https://nwssp.nhs.wales/ourservices/medical-examiner-service/about-medical-examiner-service/#:~:text=The%20Medical%20Examiner%20Service%20will%20have%20offices%20in,provided%20care%20to%20the%20person%20who%20has%20died.