

**Welsh Government Consultation – Summary of response
Number: WG43337**

Draft National Framework for the Delivery of Bereavement Care in Wales

Overview

This document provides a summary of the responses received by the Welsh Government to the consultation:

WG42168 - Draft National Framework for the Delivery of Bereavement Care in Wales

The consultation was published on 22 March 2021 and closed on 17 May 2021. 65 responses were received from a range of stakeholders and interested parties.

Action Required

For information only.

Further information

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Additional copies

Large print, Braille and alternate language versions of this document are available on request.

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1.1 Introduction

The national framework for the delivery of bereavement care in Wales seeks to set out how in Wales we can respond to those who are facing, or have experienced, a bereavement. It describes a vision for a Compassionate Wales where everyone has equitable access to high quality bereavement care and support when they need it. The framework includes core principles, minimum standards and a range of actions to support regional and local planning. It also recognises that there will be long lasting effects from the pandemic and includes a section about learning lessons from COVID-19.

1.2 The context for change

Bereavement can be defined as the sorrow you feel or the state you are in when a relative or close friend dies. Bereavement is associated with elevated risks to mental health, morbidity and mortality and services that provide bereavement support can be vital in managing these risks. Bereavement support can also reduce the emotional, physical and mental impact of grief.

A bereavement services scoping study was undertaken by Cardiff University in conjunction with Marie Curie and the Wales Cancer Research centre on behalf of the End of Life Care Board. The study mapped existing support, ranging from signposting through to specialist counselling and identified areas where further resourcing is needed. The study was published in December 2019 and can be accessed at:

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

The scope of the study covered the broad range of bereavement support, including that for children and young people. It highlighted the gaps and challenges in bereavement support, and raised a number of considerations for service development. These are centred on the need to develop a national framework for bereavement care in Wales.

A national framework would support the establishment of clear referral pathways, risk and needs assessments, training for staff and volunteers and a directory of available bereavement provision. It would also support improvements in how services are evaluated and assessed and enable standards for use as audit and quality improvement tools.

To address the gaps in bereavement service provision, the Welsh Government is making an additional £1.4m available for bereavement support from 2021-24.

1.3 This consultation

This consultation ran from 22 March 2021 and closed on 17 May 2021. 65 responses were received to the consultation from individuals and a wide variety of organisations, including Health Boards / Trusts, the Royal Colleges, General Medical Council, Children's Commissioner for Wales, Welsh Language Commissioner, Local Authorities and a variety of third sector organisations. All responses have been considered equally in terms of the comments received.

A list of respondents is attached at Annex A. A summary of the responses, together with the Welsh Government's analysis and conclusions, can be found at Section 2.

This document provides a summary of the responses received through the consultation.

2.1 Summary of responses received

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

The majority of responses agreed that the framework was clear, who it was for and why it had been developed. Many felt that this work is *timely*, and *good to see a co-production approach taken*, involving people with lived experience in this work. There were comments that the framework will assist in reducing inequalities across Wales, and that this will start to help address the stigma of talking about dying and end of life care.

Some felt that the document was not specific in terms of to whom it is addressed given that it seeks to address multiple audiences. It was felt that responsibilities, particularly the responsibility of Welsh Government, should be highlighted.

One comment highlighted that there are often issues in the acknowledgement that a bereavement has taken place, resulting in disenfranchised grief. An example was cited of loss during pregnancy, where in the case of an early miscarriage, the parents might not always feel that there has been an acknowledgement of the death, nor that they have been bereaved.

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

Many comments supported the need for better provision and access for bereavement services for those with protected characteristics but tended to focus on the 'who' rather than 'how' this could be improved.

Some responses suggested that there needs to be wide engagement with people who have protected characteristics, and to go out to these groups via positive outreach, as many groups may not otherwise come forward. Comments included *'need to engage, involve in service design / co-produce, and ensure active outreach with community groups, focus groups'*.

There was also a call for this communication to take place in different languages: *'Offer a range of ways to contact and communicate, and in formats which are easy to understand, and in different languages'*.

The need to recognise cultural norms and the experiences of particular groups in society was also highlighted, as were the needs of people with disabilities, including learning disabilities and children with Special Educational Needs and Disabilities (SEND).

Question 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?

Responses to question 3 highlighted the needs of people with dementia, mental health problems, the importance and implications of Adverse Childhood Experiences (ACEs), and the NEST Framework (which aims to ensure a 'whole system' approach for developing mental health, well-being and support services) were highlighted. One respondent asked whether the Regional Partnership Boards (RPBs) could consider bereavement support in their Population Needs Assessment work. Another respondent observed that it was necessary to *'Recognize the less equitable provision for deaths in the community'*.

The absence of a National Bereavement Care Pathway in Wales and the quality of care that bereaved families receive during pregnancy or baby loss was also highlighted.

Question 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?

Comments were received from a number of members of the public who described their personal experiences during the pandemic. One response described her experience as '*The isolation felt by the bereaved, support and understanding was truly lacking*'.

Another respondent spoke of the need to improve patient communication between relatives, patients and staff, particularly for those at end of life. An example was provided of the experiences of people who had lost a baby, with partners excluded from appointments, scans, and the general lack of support, which they felt during the pandemic.

Other comments mentioned the value of Advance Care Planning, which it was considered might have helped some families and possibly reduced more complex grief reactions.

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

Comments received included the need to gain the understanding of communities and to offer services, which are available in a variety of languages.

The need for more active engagement and information / awareness raising with local communities, co-producing services, tailoring them to local needs, and the need to forge stronger community links, was also highlighted: '*Ground services in the communities, provided by members of those communities where possible*'.

Question 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?

Comments were received about the need to train a variety of workers in bereavement awareness / support / end of life care, recognizing that individuals in many different roles may effectively be the "front line", e.g. staff in care homes, health and care, non-clinical staff in hospitals and GP surgeries etc.

The key contribution made by volunteers in providing bereavement support was highlighted, along with the need to ensure that those volunteers receive the training required to undertake this role.

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

Comments were received about the need for clear and concise referral pathways, with waiting times being kept to a minimum, regular reviews of clients waiting for support to be undertaken and for organisations to be clear on how people will be supported whilst they are waiting for that support. There were also calls for up to date information to be available on service provision, and the ability for referrals to be made electronically.

The importance of those clients who wished to access support in Welsh was also highlighted.

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

Respondents acknowledged the important role that self-management/care can play in bereavement support and referenced a wide variety of types of self-management packages available. These included on-line packages for CBT, mindfulness, social media platforms such as bereavement groups, local community groups, faith groups, spiritual retreats and grief retreats.

The need for individuals directed to self-management packages to be appropriately risk assessed was also mentioned.

Question 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?

The majority of responses to this question were around clarity as to who would be responsible for reviewing and monitoring compliance with the standards outlined in the framework. One respondent asked whether the standards were mandatory and what the implications would be for non-compliance.

Responses included '*What are the standards for providing bereavement support and care in Welsh?*' and '*Who will hold the Commissioners to account?*'

Question 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?

A number of responses suggested that there should be a feedback mechanism, to ensure that bereaved people were consulted about their experiences with bereavement support; '*Obtain feedback from bereaved people in Wales. Consult with service users about their experience of services delivered?*'

Another respondent indicated '*Quality assurance monitoring to take place across a random sample?*'

It was also suggested that there should be standard monitoring in place '*for all LHBs, Authorities, and third sector organisations across Wales?*' The link between the provision of end of life care and bereavement support was mentioned in one response, which called for '*A clear reporting mechanism through the End of Life Care Board and the Bereavement Steering Group with data from Commissioners and providers?*'

Question 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.

Question 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.

There were many comments received which highlighted the need to ensure that all bereavement support was offered in Welsh as a matter of course: *‘Provide equal availability of support in Welsh. Some people struggle to express their emotions in English if their first language is Welsh’*. The Active Offer was also referenced: *‘As part of the “Active Offer” conversations must be offered in Welsh or English’*.

Other comments referred to the needs of bereaved people living with dementia: *‘People with dementia may lose the ability to converse in a language which is not their first’*.

Question 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:

A variety of comments were received concerning representation on the bereavement steering group, bereavement support required in the case of certain types of bereavements, sudden deaths, and the needs of people with disabilities and vulnerable groups of people. One respondent mentioned the *‘Need to ensure information is available on how friends and relatives can help the bereaved’*.

2.2 Welsh Government response and way forward

The Welsh Government has considered all of the responses received from the consultation. Many thoughtful and considered responses were received, with considerable effort and research having been undertaken by many people who took the time to respond.

Some respondents outlined their personal experiences of bereavement in general, and bereavement during the pandemic. The Welsh Government would like to thank all respondents for sharing their views so openly on such a difficult subject.

One of the strengths of the framework has been the co-production approach taken, which addresses multiple audiences. However, there does need to be a primary audience and this has been clarified as commissioners and providers of bereavement services in the final framework, although the intention is that the framework has still been worded in a way that makes it understandable and relevant to others.

The link between receiving good end of life care, anticipatory grief, advance care planning and bereavement support has been added to the revised framework. Distinctions have also been made between support required for families where a bereavement can be anticipated, and those who suffer a sudden bereavement, where the circumstances of the death and the initial help that may be needed by bereaved people could be very different.

Welsh Government is supporting the work being undertaken by Compassionate Cymru, our NHS colleagues and many others across Wales to promote a wider conversation on caring for people at end of life, dying and bereavement. This framework is part of that overall activity.

The need for proactive outreach to take place, to communities who may find it difficult to access support, disabled people, and those with protected characteristics is outlined. There is a real need for commissioners and providers of bereavement services to ensure that such outreach takes place, and the resulting support co-produced with those communities and if possible, provided by them.

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Learning from COVID-19 highlighted by responses to the consultation has shown us there are impacts which arise from people being isolated from their normal support mechanisms including the lack of opportunities to visit people and obtain informal support, which is so important. The level of humanity shown in hospitals following a death, and allowing bereaved families time so they do not just feel as if they are being “moved on”, is important and has been included.

We have also added how bereavement standards will be monitored by the Welsh Government in the framework and set out the requirements for the establishment of baseline standards and ongoing monitoring, with commissioners being asked to report on their performance at regular intervals.

The National Bereavement Steering Group was responsible for initially developing the framework and met twice following the conclusion of the consultation process to discuss the responses and advise upon further changes. Subsequent changes were made to the document as deemed appropriate.

There were some consultation responses made which were felt to be beyond the remit of the framework. Where relevant these responses are being considered by the National Bereavement Steering Group as part of its ongoing work programme.

Annex A – List of Respondents

No.	Confidential Yes /No	Organisation/On behalf of
00001	Yes	Anonymous
00002	Yes	Anonymous
00003	Yes	Anonymous
00004	Yes	Anonymous
00005	Yes	Anonymous
00006	No	Antenatal Results & Choices
00007	Yes	Anonymous
00008	Yes	NHS Wales
00009	Yes	Anonymous
00010	No	NHS Wales
00011	No	NHS Wales
00012	No	Ceredigion School Services
00013	No	Royal College of Midwives
00014	No	Wales Council for Voluntary Action
00015	No	Royal College of General Practitioners Cymru
00016	No	Powys Teaching Health Board
00017	No	Welsh Ambulance Services NHS Trust
00018	No	Association for Palliative Medicine
00019	Yes	Anonymous
00020	No	Gwent Regional Partnership Team
00021	No	Swansea Bay University Health Board
00022	No	British Association for Counselling & Psychotherapy
00023	No	Wrexham County Borough Council
00024	No	Social Care Wales
00025	No	Carers Wales
00026	No	Cytun (Churches Together in Wales)
00027	No	Specialist Palliative Care Dept, Betsi Cadwaladr UHB
00028	No	Age Cymru
00029	No	Corporate Governance Dept, Hywel Dda UHB
00030	No	Marie Curie
00031	No	Tenovus Cancer Care
00032	No	Sands (Stillbirth and Neonatal Death Charity)
00033	Yes	Anonymous
00034	Yes	Anonymous
00035	Yes	Anonymous
00036	Yes	Anonymous
00037	No	Macmillan Cancer Support
00038	No	Pregnancy Crisis
00039	No	Hospice UK & Hospices Cymru
00040	No	Aneurin Bevan UHB
00041	No	Pembrokeshire Bereavement Forum
00042	No	Wales Safer Communities Network
00043	No	Powys Teaching Health Board
00044	No	University of Edinburgh
00046	No	General Medical Council Wales
00047	Yes	Anonymous
00048	No	Royal College of Paediatrics and Child Health
00049	No	Together for Short Lives
00050	No	NHS Collaborative & Aneurin Bevan UHB
00051	No	Children's Commissioner for Wales
00052	No	Royal College of Psychiatrists
00053	No	Welsh Language Commissioner

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No.	Confidential Yes /No	Organisation/On behalf of
00054	No	Board of Community Health Councils in Wales
00055	No	End of Life Care Group, Cwm Taf Morgannwg UHB
00056	No	Alzheimer's Society
00057	No	Learning Disability Wales
00058	No	Cardiff & Vale UHB
00059	No	Faculty of Intensive Care Medicine
00060	No	Royal College of Physicians
00061	No	Swansea Local Authority
00062	No	Cwm Taf Morgannwg UHB
00063	No	At a Loss
00064	No	Police Liaison Unit
00065	No	British Deaf Association