Llywodraeth Cymru
Welsh Government

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National bereavement care pathway

Improving access to bereavement care for people to reduce local and national inconsistencies.

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Contents

Its aim is to:

- provide information and guidance to promote a consistent approach for accessing bereavement support
- promote integrated partnership working
- develop consistent bereavement support pathways

1. Background

1.1 Purpose

The National Bereavement Care Pathway for Wales's model specification has been developed to improve access to high quality bereavement care for all bereaved people in Wales and to reduce local and national inconsistencies. The aim of the specification is to provide information and guidance to promote a consistent approach for accessing bereavement support, promote integrated partnership working and to develop consistent bereavement support pathways across Wales.

The National Framework for the Delivery of Bereavement Care in Wales sets out a vision for a compassionate Wales where everyone has equitable access to high quality bereavement care and support when they need it. The Framework sets out the responsibilities of commissioners to ensure that bereavement support is available to all, including people with protected characteristics and those who may find it difficult to access support. This may be because of a variety of reasons including language, ethnicity, disability, sexual orientation or other barriers people face and a consequent feeling that services 'aren't for them'. There will also be those groups who experience bereavement in the most traumatising of circumstances (e.g. war, those impacted by terrorism, or homicide).

This specification is designed to assist a range of partners, who are in contact with individuals who are bereaved, to work together to develop and implement integrated bereavement support pathways. As such integrated support pathways need to be tailored to address local need and context and build on good practice and experience.

1.2 Integrated support pathways

An integrated support pathway is a multi-disciplinary and multi-agency outline of the bereavement journey an individual can expect, mapping what will happen, where, when and by whom. The range of bereavement support in a locality is mapped to avoid duplication in services and to inform commissioning. Support pathways will support those bereaved to move through and / or across the three components of bereavement care depending on the level of support they need. Although integrated support pathways will be developed for specific types of bereavement, support should always be tailored to meet individual needs following an appropriate assessment, rather than assuming their needs only according to the 'type' of bereavement they have suffered.

1.3 Benefits of integrated support pathways

The benefits of integrated support pathways are multi-fold and are summarised below. They:

- Place those bereaved at the centre of the service and provide information and guidance (through a variety of methods e.g. face to face, phone, email, etc.) regarding what support and care is available and what progress and outcomes are expected at each stage of their journey
- Facilitate a seamless, whole system approach to bereavement by supporting continuity across different services and agencies
- Help to clarify roles, service offers and the availability of expertise and

encourage the development of new support services and new ways of working
- Ensure consistency and parity of approach across Wales
- Reduce duplication and identify gaps in services to facilitate better use of scarce resources and to prioritise the commissioning of multi-agency support and interventions
- Provide a means of continuous quality improvement, monitoring and audit

2. Effective joint working to deliver integrated support pathways

Implicit in the implementation of integrated support pathways is the requirement for effective joint working between all partner agencies. The key issues which have emerged from the evidence for integrated working that need to be considered, prior to, and during the planning stage are summarised in paragraphs 2.1 to 2.8.

2.1 The role of health boards

The overall aim of the health board is to improve and strengthen the arrangements for the planning, commissioning and performance management of bereavement services in Wales. Health boards should provide a forum, which will bring together representatives of all partner agencies involved in the planning, commissioning and delivery of bereavement services. It is intended that health boards and local authorities will work together with other relevant partners to discharge their statutory responsibility by providing a mechanism to pool scarce resources and expertise to deliver the National Framework for the Delivery of Bereavement Care in Wales. Health boards will also play a key role in ensuring the delivery of integrated services for individuals who are bereaved.

This includes developing appropriate systems and mechanisms to support integrated bereavement pathways including:

- service specifications
- information sharing protocols, working with information governance teams to facilitate this, ensuring internal and external governance
- performance management systems, including quality checks
- workforce development such as joint training initiatives
- protocols for accountability and responsibility.

2.2 Bereavement standards

The Welsh Government has published a high-level overview of the core standards that need to be in place for providers and commissioners of bereavement services as part of the National Framework for the Delivery of Bereavement Care in Wales. Minimum requirements of the bereavement standards need to be considered, when developing integrated support pathways.

2.3 Sharing information and resources

In order to plan, implement and achieve the aims of an integrated bereavement support pathway, there needs to be excellent communication processes within and between organisations and agencies. Protocols and information technology systems that support information sharing need to be developed through a joint working approach. Developing integrated bereavement support pathways also presents an opportunity for organisations and agencies to exchange skills and knowledge to facilitate the range of support across the three NICE components of bereavement care.

2.4 Roles and responsibility

A key priority when designing bereavement support pathways is to clarify and define the roles, service offer and responsibilities of each agency and organisation involved. Similarly, members of the workforce need to understand the service offer, roles and skills of their colleagues and how these contribute to the care of the bereaved. This will help to identify the availability of expertise and prevent misunderstandings from organisations and professionals with differing perspectives. Clarifying roles and responsibilities will promote mutual trust and respect between members of the workforce and allow them to realise the usefulness of their contribution and how this fits within, and around, the bereaved person's journey.

2.5 Management

In order to ensure effective joint working, members of the workforce require clear lines of responsibility and accountability, with clear governance and escalation/ feedback processes.

This needs to be clarified when individuals are identified to co-ordinate and manage bereavement support pathways. It is also necessary to identify appropriate sources of support for the workforce.

2.6 Education, training and supervision

Organisations and agencies need to ensure that their workforce are appropriately qualified and equipped to deliver the care specified in the bereavement support pathway. Joint education and training is beneficial and is strongly recommended as good practice. It can promote team building; keep staff informed throughout the process of developing the bereavement support

pathway; help staff to prepare for the implementation of the bereavement support pathway e.g. use of documentation; and provide a platform to agree aims and objectives of bereavement support pathways, access and referral processes, support and interventions and information sharing protocols. Each agency and organisation needs to ensure that there is adequate, ongoing supervision to support their staff to deliver care and to support their wellbeing and development. Where smaller agencies and organisations lack the skills and resources to supervise their staff, this responsibility could be shared.

2.7 Co-ordination of care/assessment

There should be clear and published access to bereavement support. The intention is to engage the bereaved as early as possible; hence, assessment should be proportionate to their needs. It may be more appropriate to carry out incremental assessments over a period of time rather than overload individuals with intensive assessment at their first contact. This, together with clear handovers between agencies, should help prevent duplication of assessment and unnecessary distress to bereaved people.

Assessment should be viewed as a collaborative exercise between the individual and the organisation, so that a plan of care is developed which builds on the strength and resilience of individuals, their needs, both immediate and in the short/longer term, and the support available from their family and community as appropriate. This will empower individuals to engage with services as they deem necessary during their bereavement journey. Staff undertaking this important task require the knowledge, skills, competence and professional judgement to identify the needs of each individual. This will help them to develop and agree support plans with individuals and identify salient issues and problems requiring immediate action and support. Individual's progress and needs should be reviewed on a regular basis to ensure that their support needs are being met.

2.8 Monitoring and governance

The health board will be responsible for ratifying bereavement support pathways including the monitoring and governance arrangements. A protocol needs to be developed at the outset outlining the lines of responsibility and accountability and expectations of service providers.

3. Developing integrated bereavement support pathways

3.1 General principles

The development of integrated bereavement support pathways in Wales must start from the understanding that they have to be agreed between and with local providers and built into both service specifications and service level agreements. Support pathways need to be developed within and between the three components of bereavement care. Prior to implementation, they need to be signed off by health boards. Each pathway needs to be sufficiently comprehensive and include all the necessary elements of care and support that an individual may need.

Bereavement support pathways should also clarify the expectations of the individual, the roles and responsibilities of staff in relation to the care they receive and the evidence based support interventions, treatments and outcomes the bereaved person can expect.

3.2 Identify and prioritise areas for integrated bereavement support pathways

In order to develop appropriate integrated bereavement support pathways, health boards and the providers of services need to map and identify local

needs, including faith and cultural requirements. This should take into account any additional services provided as a result of the Welsh Government's Bereavement Support Grant funding of £1m pa from 2021-24. A review of current local practice and processes of bereavement support is necessary along with feedback from key stakeholders, such as, individuals and carers, commissioners/planners, members of the bereavement workforce and all related services and individuals working in generic services. This will identify whether existing service provision is sufficient to develop comprehensive bereavement support pathways to meet local needs. Where gaps are identified, further services may need to be commissioned, or resources pooled where capacity exists.

There needs to be agreement between all stakeholders in terms of the areas where integrated bereavement support pathways are required and decisions made regarding the priorities. Due to the nature of bereavement and variance of needs for each individual, it is advisable to develop bereavement support pathways across the components of bereavement care. NICE Component 1 (Universal – available to all bereaved people) for the majority, initially, with a single point of access with information being provided by the care provider most closely involved with managing the death (hospital, hospice / community palliative care, GP as appropriate), before developing more specialised and complex pathways.

Identify who will develop the integrated bereavement support pathway. In order to foster ownership of integrated support pathways, operational staff from all organisations and agencies providing direct and indirect bereavement care need to be involved in the process of developing and implementing pathways. Some staff will be identified to develop the integrated support pathway whilst others will be consulted to give their expert opinion. Individuals and carers should be included in both activities.

3.3 Building a vision

The next step in the process is to develop a shared vision of the bereavement journey, which will form the basis of the integrated support pathway. All current and potential service providers within the locality can identify their role within, and what resources they can bring to, the pathway. This will require accurate and reliable information from all organisations and agencies who are directly and indirectly involved in supporting individuals who are bereaved to enable the team to identify gaps in the provision of care and support. Outreach work may be needed to tap into existing community support provision, e.g. faith or community groups.

3.4 Developing an integrated bereavement support pathway

There are a number of steps that should be undertaken when developing an integrated bereavement support pathway. These are set out in paragraphs 3.4.1 to 3.4.3.

3.4.1 Consult with individuals and organisation/providers who provide direct and indirect bereavement support to:

- discuss and agree any potential changes to current practice
- identify areas of expertise that could be shared
- identify who could provide care (but may not currently)
- identify gaps in services and resources

3.4.2 Draft the bereavement journey:

- define the purpose and objectives of the bereavement pathway
- ensure incremental and appropriate assessment depending on the needs of

the individual
- develop systems to support information sharing, for example, appropriate information technology systems
- identify baseline data that will be used to audit and evaluate the integrated support pathway
- ensure that ongoing support pathways are appropriate and in place to include, generic services, and other non-specific bereavement services such as housing and domestic violence
- identify desired outcomes and support outcomes treatment goals and how these will be measured
- ensure that services are accessible and tailored to meet the needs of individuals and are based on evidence and best practice
- identify how the integrated bereavement support pathway will be evaluated against the bereavement standards
- ensure there is a mechanism in place to report variances to the integrated support pathway
- identify who will undertake each task, intervention and assessment

3.4.3 Promote and advertise the integrated bereavement support pathway to:

- ensure that staff understand the concept of integrated bereavement support pathways and how to implement them
- ensure service users and partner agencies are aware of, and understand the, integrated bereavement support pathway
- ensure that support is always available in Welsh, and provision made (e.g. by commissioning access to interpretation and translation services) for other languages as required
- ensure that materials are available in a range of formats and different languages, and use inclusive language to meet the needs of those people with protected characteristics, as required

3.5 Implement the integrated bereavement support

pathway

The integrated bereavement support pathway, accompanying documentation and relevant protocols should be circulated to all organisations and agencies involved in supporting bereaved individuals. In order to ensure that all members of staff adhere to the philosophy and aims of the integrated bereavement support pathway, ongoing support, supervision and training may be required during the implementation period.

A mechanism/forum needs to be in place to report problems and queries, as it is essential that those who implement the pathway have their views heard and their concerns and questions addressed, and processes changed if necessary. Time needs to be allowed for this and for staff to develop an understanding of the potential benefits of using the pathway. It may be useful for neighbouring health boards to participate in these, to avoid duplication and provide mutual support.

3.6 Review of the integrated bereavement support pathways

Once implemented, integrated bereavement support pathways need to be continuously reviewed and modified as appropriate. It is important that data (including feedback from individuals and members of the workforce) are analysed and acted on. Reasons for variances need to be reviewed. In order to ensure quality, performance indicators and adherence to bereavement core standards needs to be monitored. This can be achieved through service level agreements.

3.7 Developing a user friendly version of support

pathways

A ‘user friendly’ version of the pathway can be used to inform individuals what will happen, where, when and by whom (for example, by means of a flowchart to outline the bereaved persons’ journey). It will give them a clear vision of the bereavement care and outline the support pathways available.

4. Integrated bereavement support pathways to be implemented by local health boards

Immediate support pathway for families with sudden and unexpected death in children and young adults.

Others pathways to be added as they are developed.

5. References

Welsh Government (2021) National Framework for Delivery of Bereavement Care in Wales.

NICE (2016) End of life care for infants, children and young people with life-limiting conditions: planning and management.

NICE (2018) Preventing suicide in community and custodial settings.

National Bereavement Care Pathway for Pregnancy and Baby Loss (2017)