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National Palliative and End
of Life Care Programme

Guidance For the Development of Regional Pathways for Supporting Bereaved Children and Young People up to 25 Years of Age

March 2025

Acknowledgements

We extend our sincere gratitude to colleagues and services across Wales and beyond who generously contributed their time, knowledge, and expertise to inform the development of this guidance. We would like to thank the members of the task and finish groups whose dedication and collaborative efforts were instrumental in shaping significant aspects of this work.

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Foreword

Grief is part of life, but for children and young people, it can be particularly isolating, complex, and often misunderstood. Whether it's the death of a parent, sibling, grandparent, friend, or trusted adult, bereavement can shape a young person's identity, health, and well-being far into adulthood.

In Wales and across the UK, bereavement among children is more common than many realise. Each year, an estimated 46,300 children lose a parent, over 127 every day, and by the age of 16, 1 in 20 young people will have experienced the death of a parent. Around 78% of 11–16-year-olds report having lost someone close to them. These figures represent not just statistics, but thousands of individual stories of loss and adaptation.

The impact of such experiences can be significant. Research shows that bereaved children are around 1.5 times more likely to be diagnosed with a mental health disorder. Many face challenges at school, including problems with concentration, attendance, and emotional regulation. Despite this, support for bereaved children and young people remains variable, and navigating services can be especially difficult during a time of grief.

This national guidance, developed by the National Bereavement Steering Group as part of the National Programme for Palliative & End of Life Care, sets out a shared ambition for how Wales can support children and young people experiencing loss. Grounded in compassion, evidence, and lived experience, it outlines the roles and responsibilities of Local Health Boards and partners in developing pathways that are inclusive, responsive, and person-centred.

This work has been shaped by the insight, experience, and dedication of bereaved children and young people, their families, voluntary organisations, and professionals from across Wales. Their voices have been instrumental in ensuring the guidance is not only practical and deliverable but also compassionate and rooted in what truly matters. We extend our heartfelt thanks to all who contributed to its development and to all those who will now bring it to life in practice.

By working together, we can ensure that no child or young person has to face bereavement without understanding, support, and care.



A handwritten signature in black ink, appearing to read 'Idris Baker'.

Dr Idris Baker
**Chair, National Bereavement
Steering Group**

Aim of the Guidance

This document provides an overview of the key issues for consideration by Local Health Boards (LHBs) and partners in the development of regional pathways to support bereaved children and young people (C&YP) up to 25 years of age in Wales. It sets out a collective vision for how Wales can better support C&YP through experiences of loss. Informed by compassion, evidence, and lived experience ([See Appendix 1](#)). Support includes both pre-bereavement (also known as anticipatory grief when the death is expected) and post-bereavement support. This document also provides guidance to anyone who encounters bereaved C&YP, and those who may meet them pre-bereavement.

Primary Responsibility: Local Health Boards (LHBs) are the lead partners and are responsible for the planning, commissioning and performance management of all bereavement services in Wales. They play a key role in ensuring the delivery of integrated services for individuals who are bereaved. LHBs should use this guidance to develop local pathways to support bereaved C&YP, tailored to the specific needs of their locality.

Partners: All partners should support the development of regional pathways and be able to provide some degree of immediate help and guidance to bereaved C&YP and know how to refer to other organisations where additional support is necessary.

Partners include but are not limited to; LHBs, Schools, higher education (e.g., universities) and further education institutions (FEIs) (e.g. sixth form, colleges), early years childcare settings, school nurses, Local Authorities, youth workers, Charities, community organisations, LHBs Child and Adolescent Mental Health Service (CAMHS), GP Practices, health visitors, National Youth Advocacy Service, palliative and end of life care providers, all those working directly in the community in a position of trust with C&YP, and all providers of support to bereaved C&YP and their families.

1.1 General Principles of Regional Pathways

Partners should always:

Recognise the provisions of the United Nations Convention on the Rights of the Child including that every child should be recognised, respected, and protected as a rights holder and as a unique and valuable human being, with the right to be listened to and the right to be heard.

Encourage a *culture of openness* where C&YP who have been bereaved or have someone close to them who is dying or very unwell feel able to share this information and be supported. This includes supporting parents and caregivers, when the time is right for them, to have open and honest conversations with C&YP around Palliative and End of Life care (PEoLC).

Recognise that there may be stigma attached to certain types of bereavement (e.g. suicide, substance misuse) meaning that C&YP may experience barriers to seeking or accepting support.

Take steps to identify bereaved C&YP, establish their needs and support them through their grief (pre and post bereavement) in the most appropriate way, including offering choices, however small, to empower them and help them feel valued and listened to.

Consider the impact of the bereavement on family and friends when considering support needs. Recognise that C&YP may respond well to support from a trusted adult, who may not be a "specialist", but someone they trust and feel comfortable with.

Recognise that support for bereaved C&YP is part of a network of services as part of the /NEST (Nurturing, Empowering, Safe, Trusted) Framework and Whole School Approach. Support for those bereaved should be part of a connected system of support across health, social care, third sector and wider, where people can access the right service, at the right time, and in the right place. Care and support should be person centred, compassionate and recovery-focused, with an emphasis on improving quality, safety, and access.

See <https://www.gov.wales/nest-framework-mental-health-and-wellbeing-core-principles>

Ensure that appropriate referral mechanisms are in place where emergency support is required.

Additional considerations to be considered by Partners are listed in [Appendix 2](#).

1.2 Providing Support When the Need is Identified:

Partners should:

Provide clear and honest information as outlined above which meets the needs of C&YP and / or those caring for them, at the time when the need for support is known. A range of support material including booklets and on-line information and resources are available.

Understand that age and developmental stage should be a guiding principle. For C&YP at some ages / developmental stages it will be appropriate to work with parents /care givers to provide them with information to help C&YP “normalise” grief, including guidance on talking truthfully and supporting them to deal with their circumstances. At other ages/ developmental stages it will be more appropriate to work directly with C&YP. Remember that some C&YP may not feel able to engage with support offered depending on their individual circumstances and stage in the grief / bereavement process. As a result of this, a variety of approaches may be necessary, on multiple occasions over time.

Consider the needs of C&YP where the diagnosis of a life-shortening illness has been received for a loved one, or the loved one is receiving palliative or end of life care, encouraging parents / guardians to involve them in these discussions where appropriate, and always ensuring that they are supported in doing so.

Encourage memory making on their bereavement journey as early as possible. Involve C&YP, siblings and family in the memory making process throughout their

bereavement / pre-bereavement journey, asking them what they would find most memorable.

Ensure that information and support is equitable and meets the needs of C&YP of different faiths, religions, and cultures, and those with protected characteristics or from deprived communities. This information and support should always be available in other languages including BSL, braille, depending on need.

Consider the needs and additional support requirements of bereaved C&YP who have existing mental health difficulties or other vulnerabilities. They may find bereavement particularly difficult because of these additional issues and the fact that their resilience is compromised because of them. Understand the importance of a strong support system for C&YP and provide support to parents and caregivers in acknowledgement of the impact the bereavement may have on them. Parents and caregivers can identify the impact the grief has on the family and should be supported to do so.

Recognise the wishes of parents and caregivers in supporting their C&YP according to their individual needs; with special consideration given to C&YP with disabilities / additional learning needs (ALN) and how they are affected by a bereavement. Where appropriate, provide connections to specialist support that is available, e.g. from C&YP's school or educational establishment, paediatric palliative care team and therapeutic play support to explore how everyone can best support them and help develop their understanding of death in an age and stage appropriate way.

Provide parents and caregivers with support, advice, and signposting services such as counselling, Children's Services teams in the Local Authority which could be for emotional, practical, or financial support.

Consider if signposting or referral to relevant charities or organisations is appropriate. Not all C&YP will need to have direct or immediate support from these organisations but will benefit from information and resources available from them.

2.1 Making a Referral for External Support:

Partners should:

Before making a referral for external support, consider the appropriateness of doing so, whether express consent to make such a referral has been provided by the parent or legal guardian, and any risks such a referral may pose to C&YP and the external organisation. For C&YP with complex issues and where bereavement is not in itself the presenting issue, proper consideration must be given as to where C&YP will be best supported, and appropriate liaison must be made with the external support organisation before any referral is made; to do otherwise increases the risk that the referral may not be accepted.

Make C&YP aware of any referrals taking place for support, along with relevant details about the referral e.g. type of support, provider, why this support may be beneficial, and anyone else their information is being shared with, to develop trust.

2.2 Responsibilities of External Organisations Receiving a Referral for Support

Organisations should aim to make contact following a referral between 24 and 48 hours of the referral being received, depending on resources available locally.

Organisations should consider their policies for the ability of C&YP to self-refer into bereavement support services; it is not widely known that C&YP aged 16+ may be able to self-refer, nor that those under 16 may be able to demonstrate their competency to consent (also referred to as "Gillick Competence"). C&YP may be unaware of or not understand this, so the ability to self-refer should be explained in accessible and age-appropriate language, with appropriate signposting to support, or materials provided to help them.

Where a referral for support from a bereavement support organisation is made, the organisation **receiving** the referral should:

- Complete a full assessment of current needs and circumstances (including risk assessment), consider any safeguarding concerns, and review any information which has been provided already and its effectiveness. Any care and support / wellbeing plans in place for C&YP should be shared with the organisation if possible.
- Undertake an assessment of their needs and what is most important to them in person with C&YP during the first session.
- Consider if there is a need for immediate support depending on the needs identified, e.g. sudden, or traumatic bereavement.
- Examine if there are specific considerations, e.g. care experienced / adopted C&YP, young carer, or where there is no surviving parent able to care for them.
- Understand that there may be geographic considerations on where services can be accessed. The location of C&YP will need to be considered since they may not be at their normal place of residence.
- Consider what further action should be taken to follow up the referral if unable to contact or there is no engagement, being mindful that such a lack of contact / engagement may be due to a variety of issues one of which may be safeguarding.

2.3 Planned & Short-Term Support

Partners should:

Provide C&YP with the ability to communicate and access support in a variety of different means. The choice of how they are supported and through which format should reside with C&YP as far as possible, with the resources available.

Assess on an ongoing basis the effectiveness of the support for C&YP (including the needs of the family in its widest sense).

Offer support (or signposting where the organisation may not be able to provide support) for other family members as required.

Take further appropriate action to follow up with parents or legal guardians, and other agencies as appropriate if engagement with C&YP stops without notice and is a cause for concern. C&YP under 16 years of age who have demonstrated their competency to consent and have been receiving support without the knowledge of their parents or legal guardians and cease to engage must be made aware that where there is a concern that the C&YP is at risk, then partners have a duty to disclose this to parents / legal guardians / others as appropriate.

2.4 Long term support

Partners should:

Provide appropriate self-help materials / sources of further information and support.

Consider where longer term support needs have been identified or more specialist support is necessary, and how this can be achieved.

Support C&YP with access to Specialist Children and Adolescent Mental Health Services (S-CAMHS) for Primary and Secondary mental health intervention if required.

Allow C&YP to make choices on where and how they access support

Consider referrals to Children's Services teams as the Local Authority's single point of contact for information / triage / signposting, and other external agencies and referring into Family Centres for ongoing support.

Consider Social Prescribers for parents and caregivers who require non-medical support for their health and well-being which long term helps C&YP, and family holistically.

3. Prevention / Wellbeing

Partners should:

Be aware that death is a normal part of life and that not all C&YP will require bereavement support, however all C&YP can be helped to understand the impact of bereavement and the importance of being kind to those who may be grieving.

Consider providing general support/information/training and informal bereavement support in community hubs/school/youth club settings etc to help normalise and understand death and the associated feelings around grieving.

Offer C&YP the opportunity to explore their grief journey, to tell their story and be assessed to ensure that risk factors are identified to prevent additional traumatic grief and risky behaviours in later life. Bereavement is one of several Adverse Childhood Experiences (ACEs) – traumatic events which may occur in the life of C&YP and have a significant and life changing impact on them.

4. Additional Requirements:

4.1 Welsh Language Provision: Bereavement support for C&YP and their families must always be available in Welsh and all referral information, assessments that may be carried out, leaflets, and support materials should similarly always be available in Welsh as part of the core offer to bereaved people in Wales.

4.2 Equity of Access: LHBs must ensure that support is provided to C&YP and adults of all ages without restriction and must be accommodating of the needs of people of all communities and backgrounds. The needs of Black, Asian and Minority Ethnic communities must be included in service provision. Partners should recognise that bereaved people from these communities may experience barriers in accessing support and as a result, may require specific adaptations and considerations to ensure that support meets their needs. The needs of people with all disabilities, including preparing for, and following, the death of a loved one, must also be supported.

4.3 Monitoring and Evaluation: Monitoring and evaluation of the support provided should be carried out by partners. NHS organisations will be required to report on their progress on developing a specific pathway to support bereaved C&YP as outlined in this guidance. The performance of other bereavement providers will be monitored by the LHB.

4.4 Training: Partners should ensure that anyone who may have contact with bereaved C&YP are provided with the appropriate training to provide support, and that appropriate governance and supervision arrangements are in place.

4.5 Other Considerations: Partners should consider this guidance in conjunction with other procedures and guidance including the All-Wales multi agency PRUDIC, the National Bereavement Care Pathway for Wales Model Specification, other bereavement specific pathways, and processes and guidance developed by the Palliative & End of Life Care (PEoLC) National Programme for C&YP and adults. Partners should also be aware of the guidance to support those affected by suicide: [Responding to people bereaved or affected by suicide | GOV.WALES](#) and the National Advisory and Liaison Service, which provides support to individuals and families, including children and young people affected or bereaved by suicide.

Appendix 1 : Case Story – Bereavement Support for a Young Person After Sibling Loss

The following case story from Tŷ Hafan Children’s Hospice illustrates the impact of bereavement support on a young person following the death of her 17 year old sister.

R is a lively, outgoing and insightful 17 year old. Her sister E died in early 2021, following a complex illness. E and her family were due to have their first stay at Tŷ Hafan in April 2020, but sadly due to lockdown E was not able to access a residential stay before she died.

That year R regularly attended our adolescent sibling group with other bereaved and non-bereaved siblings. It is a space where siblings are able to access fun opportunities and a safe space to bond with other siblings and let their hair down, away from any difficulties at home. R found these very beneficial as it provided opportunities to meet other young people in similar situations, where they can, ‘leave their problems at the doors and be themselves with no explanation’.

In the Autumn of 2021, R attended her bereaved sibling workshop. These therapist-led workshops are specifically for bereaved siblings, to make memory books and provide a safe space to talk to staff and other bereaved siblings about their brothers and sisters. During the memory book workshop, R was very tearful. R joined a member of staff outside to help R to regulate herself before rejoining the group. During her time outside, R told the staff member about all the loss she had experienced over the course of lockdown, all of it starting with her sister E. At the end of that day, the staff member, R and R’s mum agreed for a 1:1 therapy referral to go in. Although R had been receiving school counselling, R felt this support was not specialist enough or individual enough to meet her needs and experiences.

From the point that this referral was able to be picked up, R regularly attended therapy sessions at the hospice with the support of her parents to bring her each week. R feels that the therapy she has accessed has enabled her to learn new, creative ways of expressing herself, without needing to use words. This has

helped her unlock new emotions and understand her past and present self better. R continues to be a regular attendee at our sibling groups and has made very special and important friendships that span time and geography. R is grateful for all the support she has been given and feels that her connection with Tŷ Hafan has allowed her to grow and develop as a person and will support her going forward in the future.

"After my sister died I felt confused, sad and lonely. Tŷ Hafan were there to help me understand and process these feelings and I will always be grateful for the care and safe space they provided for me.

My sister died in early 2021 following a complex illness, she was 17 years old and I was a few years younger. Because of the Covid lockdown our family were even more isolated than usual and we had not been able to have our first stay at Tŷ Hafan before she died, which was really hard as we were all looking forward to it. Luckily by 2021 Tŷ Hafan had restarted all their face to face sibling groups again and I was able to go along to these events where I got to meet other young people who were either bereaved or experiencing the complicated feelings, emotions and worries that go hand in hand with being a sibling of a child with a life-shortening condition. These groups gave me an opportunity to have fun with other people who were not judging me, who understood my experiences; more than anything these groups gave me a safe space and somewhere away from the sadness and grief at home. A place where we could all leave our problems at the door and be ourselves with no explanation.

A few months after my sister died, Tŷ Hafan offered me the opportunity to attend some bereaved sibling workshops. These therapist-led workshops are specifically for bereaved siblings, to make memory books and provide a space to talk to staff and other bereaved siblings about their brothers and sisters. That first session was really difficult as I had experienced lots of bereavements since the death of my sister and it felt

overwhelming. The staff were brilliant, giving me time and a safe space with one-to one support to help regulate these overwhelming feelings. I had been getting some counselling support from school, but it was never able to meet my exact needs to help explore these overwhelming feelings, so I began some one-to one Therapy sessions with one of the Tŷ Hafan Play Therapists. These consistent weekly sessions were so important to me, and some sessions were even able to take place outside, which helped me feel more at ease to discuss hard feelings. It enabled me to learn new, creative ways of expressing myself, without needing to use words. This helped me unlock new emotions and understand myself better.

I continue to go to as many Tŷ Hafan sibling groups as I can. I have made some very special and important friendships that span time and geography. I feel so grateful for the support I received and my connection with Tŷ Hafan is so important to me. I know that they will be there for as long as I need them.”

- *Young person supported by Tŷ Hafan Children’s Hospice*

Appendix 2 – Additional Considerations

1. Neurodivergent C&YP

Consider the needs and support requirements of bereaved neurodivergent C&YP. C&YP who are neurodivergent may experience difficulties in expressing grief, however this does not mean that they are not impacted or having significant emotional distress. Appropriate therapy for C&YP who may struggle with talking therapies, (e.g. art, music, drama) should be offered.

2. Traumatic Incidents

Traumatic Incidents (e.g. following an accident, bereavement by suicide, criminal act, illness or natural disaster) can impact bereavement. Previous exposure to a traumatic incident is one of the issues that may make anyone more susceptible to developing heightened and more complex responses if they are subsequently traumatically bereaved. Traumatic incidents may specifically impact individuals but also the social group and families in which the person lives. Traumatic incidents can also affect whole groups of people such as incidents in school or natural disasters. Psychological responses may include anxiety and mood disorders as well as Post Traumatic Stress Disorder (PTSD). Repeated exposure to multiple traumas can lead to Complex PTSD.

[Trauma-Informed Wales \(traumainformedwales.com\)](https://traumainformedwales.com)

3. Complex Trauma

Children and young people who experience bereavement with pre-existing difficulties and experiences often develop more intense and complex bereavement responses. This is particularly true in children who experience complex trauma. Emotional responses can be extreme and labile, and regulation can be elusive. It is important that those supporting the young people in bereavement work alongside services providing specialist support for their trauma. This may include local authority staff, and the specialist trauma psychological therapy lead in each health board. They will be

accessible through the CAMHS in-reach or general CAMHS contacts.

Designing a clear patient centred care plan with clear responsibilities and roles is vital to ensure best outcomes are achieved. Further information and resources are available at <https://uktraumacouncil.org/>

4. Children Looked After (CLA)

The grief of looked after C&YP will be different and may be complex; they may have felt a type of grief following the removal from their birth families, however necessary the removal may have been. Consideration needs to be given to the needs of foster carers / adoptive parents to support care experienced children e.g., following the death of a birth parent from whom the child has been removed, and the complications around that grief.

5. Adopted C&YP

There are additional complexities for adopted C&YP who are aware of their birth parent(s) and where a birth parent dies. Consideration will need to be given to the support required and whether this is bereavement support, more specialist counselling related to the adoption, or both.

6 Corporate parenting duties for C&YP leaving care

It will be vital for corporate parents to ensure that children and young people leaving care have the correct access to pre and post bereavement support. Children and young people leaving care will already be suffering grief and loss, and may suffer multiple bereavements through life, of birth parents, foster parents, and a loss of services which have been their safe space. Transition into adult services will be vital, and introductions for specialist support and guidance if needed.

7. Children with additional support needs that may impact their understanding of death

It is important for partners to regard the role of additional support needs, including various diagnoses, additional learning needs and neurodiversity in

the understanding and processing of bereavement. While support should be accessible, bespoke and make use of condition-specific resources; in all cases, children and young people should be invited to comprehend and explore death, dying and grief as a part of day-to-day life. Partners may need to consider adaptations to the environment (e.g., accessibility), language used (simple, clear, concise) and communication needs (e.g., communication aids, behaviour-based communication rather than verbal).

8. Circumstances of the death

Many overlapping factors influence the impact of a particular bereavement on a child or young person, including the circumstances of the death. Sudden deaths are particularly associated with shock and the lack of ability to say goodbye, while deaths after a long illness may have exposed C&YP to a prolonged period of stress and witnessing of suffering, and potentially significant care-giving responsibilities. Some causes of death are associated with stigma and challenge. Partners should be aware of the differing needs of C&YP bereaved in different circumstances.

Deaths due to suicide may be particularly challenging for C&YP because of the complex feelings associated with grief in these circumstances, concerns from adults about how to manage information and risk, and the stigma that people bereaved by suicide can face. Further guidance in this area is being developed by the Childhood Bereavement Network and the Support After Suicide Partnership, supported by NHS Wales, which should be read in conjunction with this pathway.

9. Complexity of living circumstances and experiences

C&YP experiencing poverty and disadvantage are both more likely to experience bereavement and less likely to have the resources to mitigate or cushion its impact. Financial and practical support may be needed so that families have the breathing space to engage in emotional support. Even young children may be aware of the financial as well as emotional stresses

on their caregivers. Racism and other forms of discrimination and oppression impact on C&YP and their families' experiences of bereavement and on their use of services. Partners should work to dismantle barriers that exclude C&YP and families from accessing support and make services inclusive and responsive to diverse needs, also being aware of cultural differences and practices.

10. Significance of immediate caregiving environment

The family and other caregivers have a significant impact on C&YPs experiences and outcomes of bereavement. Studies have consistently found that stability, warmth, continued routines, and open communication support better outcomes. However, it can be a struggle for parents and carers to maintain the best environment for their children when they are grieving deeply themselves and facing practical challenges. Reassurance, support, and practical help can help to stabilise families.

Some C&YP will face significant additional changes, for example moving to live with a new main carer after the death of a lone parent. Parents and caregivers should be encouraged and supported to make plans about the future care of their children in case they die before they grow up, such as appointing guardians. C&YP moving to foster or residential care following a parent's death, and their new carers, may need specific support to promote an environment where grief can be expressed and supported.

11. Anticipatory Grief and Pre- Bereavement

The feelings and sense of loss experienced before the death of a loved one should be recognised. This may occur following diagnosis of a life-shortening illness, whether a terminal diagnosis has been received or not. Support will differ depending on the stage of the illness, e.g. if a terminal diagnosis or confirmation of a transition from palliative to end of life care has been received, then support should be provided to C&YP to help prepare them for

the impending death.

12. C&YP grieving their own mortality pre-death

C&YP with a life-shortening illness may experience grief for their own shortened lives and mortality. They may carry this grief with them and feel unable to discuss it with their parents and care givers / those closest to them for fear of compounding their loved one's grief. C&YP may wish to know what will happen when they have died and may wish to verbalise their own wishes for how they will be celebrated and remembered. While such conversations can be difficult and specialist, it is important to find a suitable professional who is able to give permission to the C&YP to discuss such topics, as this enables a sense of control, comfort, and empowerment.

13. C&YP Who Are Not in School

C&YP may not be in school due to emotional based school avoidance, with the consequent increased risk of self-harm and suicide. Partners should be mindful of their need for support and how this can be best achieved.