



Llywodraeth Cymru
Welsh Government

PUBLICATION

Sudden and unexpected death in children and young people up to 25 years of age: support pathway

What bereavement support individuals and families can expect.

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Aim

To provide immediate support to anyone affected by the sudden and unexpected death of a child or young person up to the age of 25 years.

Partners:

- Local Health Board (LHB), including Accident and Emergency Departments, Critical Care, Neo-natal Units, Paediatric Care, Primary Care, Community Nursing
- Welsh Ambulance Service (WAST)
- Police forces
- Fire & rescue services
- Medical Examiner Officers
- HM Coroner
- All providers of support to bereaved people
- Funeral Directors
- HM Coastguard
- Mountain Rescue
- Emergency Medical Retrieval and Transfer Service (EMRTS) Cymru/Wales Air Ambulance
- Organ Donation Team
- Local Resilience Groups (in the event of a multiple death incident)

Geographical area (All Wales)

Health board/regional partnership board contact

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What bereavement support can individuals and families expect?

Bereaved individuals and families can expect to be offered the following support:

1. Immediate response

Appropriate information should be provided, which meets the needs of the bereaved person at the time when the bereavement is known (NICE component 1 – universal), wherever the death occurs.

Bereaved individual's consent should be obtained for a referral to a co-ordinator within the LHB or to an appropriate partner bereavement service to speak to the bereaved person usually within 24 hours (but within a maximum 48 hours), guide them through the next steps, assess their immediate needs and offer further support if required, including a home visit.

LHBs and/or partners should:

- Consider this pathway in conjunction with the procedures contained within the All-Wales multi agency PRUDiC (Procedural Response to Unexpected Death in Childhood) for children and young people up to 18 years of age.
- Consider the development of a booklet and on-line information containing local information on the support available to bereaved families.
- Consider the provision of memory boxes: these can provide great comfort to bereaved families and demonstrate compassion at a very difficult time, as well as providing support to staff when sitting with families at such a difficult time. (It is important to understand the value behind memory making at this time, e.g., lock of hair, hand / foot prints and capturing pictures).
- Provide suitable facilities in hospitals for bereaved families to visit the

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deceased and ensure that there is a quiet space available for clinicians to meet with family members, away from a busy Emergency Department / ward, where the family can sit and support each other, recognising the needs of different faiths and religions.

- Be aware of the need for sensitive handling of the deceased property and returning this to the family as soon as practically possible, recognising that these items may well have great sentimental value to the bereaved.
- Consider the need for multi-faith / cultural training to ensure support provided meets the needs of families of different faiths and religions.
- Consider the need for training to ensure that spiritual needs and beliefs are being met.
- Ensure that support is always available in Welsh and provision made for other languages depending on local need.
- Ensure that materials are available in a range of formats to meet the needs of those people with protected characteristics, as required.
- Give bereaved people the ability to communicate in a variety of different means, e.g. text, email, recognising that they may not feel able to speak by telephone at this difficult time.

2. Planned/short term care

The LHB or partner agency co-ordinator should arrange a follow-up call to the bereaved person no later than ten days after their initial contact (or within this timescale if the bereaved family do not initially engage). This should assess their current needs and the support options available to them (and from whom) if required.

Where the family have engaged then support (including a home visit if applicable) may already be taking place.

Following the assessment, the co-ordinator will ask if they would like a referral

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for further support (NICE component 2 – selective / targeted) and/or need further assistance from the LHB. If further support is not requested at that point, the bereaved person should be advised that they can get back in touch with the co-ordinator at any stage in the future should they need further information, or if they feel that their needs have changed. Written information should be given so families can re-engage in the future should they wish to do so.

LHBs and/or partners should:

- Provide opportunities for peer support – virtually and in-person where possible.
- Consider play therapy e.g. for siblings / friends who have been bereaved.

3. Long-term care

Longer-term support requirements identified at stage (2) above, or subsequently from the bereaved person via a call to the LHB or other partner at any stage should be referred to a bereavement support provider for further assessment and support.

This may include more specialist support (NICE component 3 – indicated) for those people who may be at risk because of complex needs or from the effects of long term or complicated grief.

LHBs and/or partners should:

- offer bereavement counselling for the whole family, including siblings
- ensure the provision of other support as well as bereavement specific, eg. support due to risk of self-harm, suicide etc
- offer group support sessions
- consider alternative therapies, e.g. complementary therapy

4. Prevention/well-being

Timely and relevant support provided to bereaved people in the steps identified above should assist them in their grief journey at such a difficult time, hopefully reducing more traumatic grief support interventions later.

LHBs and/or partners should:

- Consider providing family social events.
- Consider residential weekends where a range of support is available, including play therapy, complementary therapies, creative workshops etc.
- Consider the provision of community events; these are important as they can prevent isolation and give freedom to bereaved families to be able to still talk about their bereavements no matter how long ago they occurred.
- Consider reaching back out to the bereaved at significant touch points, e.g. anniversary of death, birthday, Christmas etc.

Visualisation of the support pathway

1. Bereaved people offered immediate information and promised a referral call within 48 hours
2. Call made to bereaved person to assess their immediate needs, next steps, and offer further support as required
3. Follow-up call made 7-10 days later to check-in, advise further support options, answer any questions and offer the ability to call back at any time

Workforce

LHBs will need to assign a named bereavement co-ordinator (if this role does not exist already) who will work closely with all partners.

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Referring partners will need to be aware of their responsibilities in making inward referrals to the LHB co-ordinator and the service specification being offered.

Support partners must work closely with all parties to ensure that referrals into their services are properly assessed, monitored and evaluated.

Training needs will need to be analysed by all parties and the relevant training sourced and provided to staff and volunteers as applicable.

The role of the LHB co-ordinator in assessing the immediate and short-term needs of the bereaved person and the support that can be offered to the bereaved is key to this process and full training and ongoing support must be provided.

LHB staff who may be affected by the death can access support too. Debriefs should also occur following a traumatic event with partners facilitating this if appropriate.

Communication

An engagement and awareness campaign will need to be undertaken with all other providers of bereavement support/ partners. All LHB staff who may have contact with bereaved people will need to be aware of the service provided and the referral routes, as well as having access to accurate support information to provide to bereaved people (NICE component 1).

Technology

All partners must ensure that referrals take place in a timely and secure fashion and that technology is used in accordance with normal security protocols.

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Monitoring/evaluation

Qualitative and quantitative data should be collected by all partners to ensure adherence to the pathway contact requirements, onward referrals and experiences of bereaved people in relation to the support which they have received at all stages of the pathway. Specific measures should include:

- Information provided to bereaved people at the time when the bereavement is known.
- Initial call from the co-ordinator within 48 hours.
- Referral to bereavement support provider and their response within x days / provision of 'fast track' support where this is needed and monitoring that this has taken place.
- Follow up call from co-ordinator to bereaved person no later than 10 days following initial contact.
- Qualitative feedback from bereaved people on the support which they have received (it is acknowledged that such feedback may be difficult to elicit due to the traumatic nature of the bereavement suffered).

The pathway should be reviewed at annual intervals.

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