NATIONAL CHILDREN'S HOSPITALS BEREAVEMENT NETWORK

Bereavement support standards for children's hospitals within the UK or district general hospitals that offer services for children and families

Background

These standards are recommended as a minimum level of bereavement support and family follow-up provided by professionals working in acute children's hospitals in the UK. They are underpinned by the model of support recommended in the NICE guideline (End of life care for infants, children and young people with life-limiting conditions: planning and management, **2016** (**LINK**) in section 1.4 Care and support for parents, carers and healthcare professionals in relation to the death of any child or young person. These standards apply regardless of the circumstances of the death. In some cases liaison with the local police and/or Coroner will be required and local policy should be followed.

These standards are also based on the new Child Death Review statutory and operational guidance (England) 2018, which introduces the role of the key worker and the various processes that may occur after a child has died (LINK). Trusts should audit provision against these standards and improve the bereavement care they offer where gaps are identified in provision. A Trust that meets these standards is considered to be providing satisfactory bereavement care.

These standards were developed by the National Children's Hospitals Bereavement Network with key stakeholders from 16 paediatric in-patient units in the UK[1]. These standards recommend the level of bereavement support and follow-up provided by professionals working in an acute children's hospital through the early days and weeks following the death of a child. They

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[1] This document applies to both children's hospitals and DGH's that offer services to children and families

do not cover what may be termed ‘specialist bereavement support’ or interventions such as those delivered by a psychologist or counselling services.

We acknowledge that each death is unique and there are different levels of services that are currently offered. In some cases liaison will be needed with the police/Coroner especially if death is thought to be suspicious? Each area will have their own local policy and this should be followed

1. What do we mean by Bereavement support?

Bereavement support may include but is not limited to:

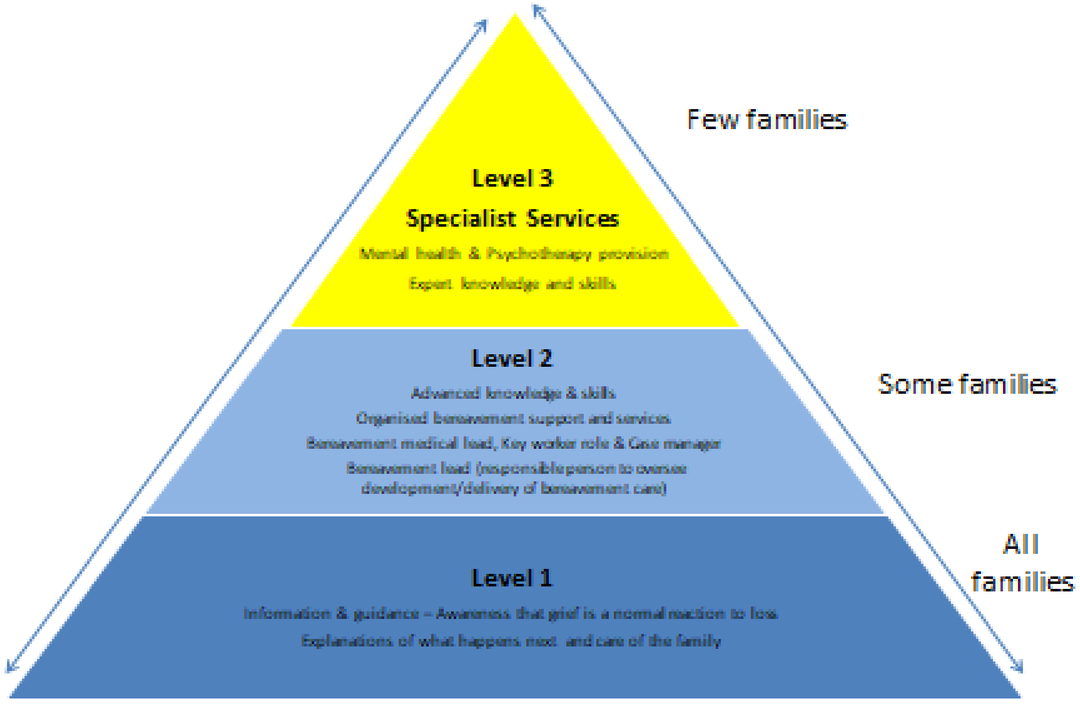
- practical support such as advice on arranging a funeral
- information on who to inform of the death
- information on what to do with equipment and medication
- supportive conversations with health and social care staff
- signposting to support from voluntary, community and faith sectors
- information about local support services, telephone helplines, national and online support organisations and, in some cases,
- referral to more specialist support from trained bereavement counsellors or mental health workers.

We recognise that grieving is a normal process. The loss of a child, however, would be considered complex or complicated in all normal grief theories and tends to hold greater risk factors than other bereavement situations. So whilst bereavement is a normal experience, following the loss of a child, it is more likely that specialist interventions may be required through specialist bereavement support services.

2. What do we mean by Family?

In this document, child/ children and young people' refers to those under 18 years old. This includes neonates and infants. We use a broad definition of ‘family’ to include parents, siblings and grandparents as well as step-parents/partners, adoptive-parents, foster carers and guardians, or those with a significant close relationship to the child who has died, such as teachers and friends. It is always important to clarify who has parental responsibility for the child.

3. The three-tiered model of bereavement service for families after the death of their child (adapted from Craft & Killen (2007):



- **Level 1** - The foundation of services that are offered to all families regardless of location of care or death
- **Level 2** - These form the majority of services required by families and include the role of the Key Worker
- **Level 3** - Support offer by specialist bereavement counselling services and mental health services

The Pyramid model outlines the levels support that should be available, who is likely to need it, and who should provide it. It sets out what good provision for bereaved children and young people and their parents and carers looks like. The Pyramid model identifies the needs of 'most', 'some' and 'few'. It suggests most people can be supported by providing accurate information and emotional support through their family and community. The Pyramid model further identifies the types of services appropriate for ‘some’ who have extended needs and may require support outside of their normal networks of support.

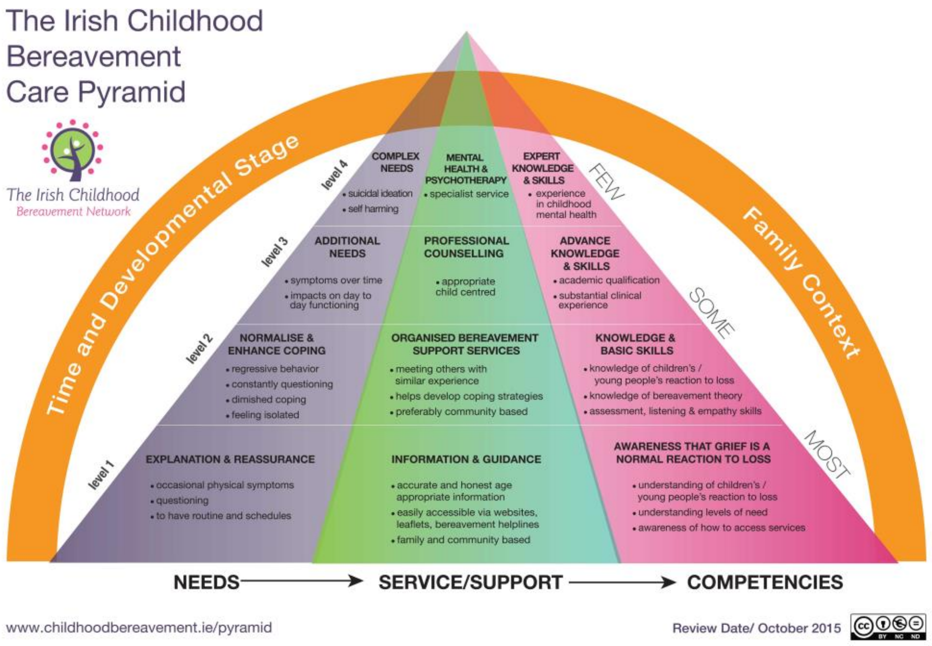
We would expect that all in-patient paediatric services should be able to provide level 1 support as a baseline offer to all families in the early hours following a death. We would hope that a tertiary children's hospital would be able to offer levels 1 & 2 support. There will be some hospitals that may well be able to offer level 1, 2 & 3.

We would expect there to be a **Bereavement lead professional** in each Trust who would be responsible for ensuring a joined-up and a co-ordinated service to all families and be responsible for the development of policies and procedures.

Siblings:

The care of siblings is of the upmost importance. In 2015 the Irish Childhood Bereavement Network (ICBN) developed the Bereavement Care Pyramid below. This Pyramid outlines a useful model of the support that should be available, who is likely to need it, and who should provide it. It sets out what good provision for bereaved children and young people and their parents and carers looks like. The Pyramid identifies the needs of ‘most’, ‘some’ and ‘few’. It suggests most people can be supported by providing accurate information and emotional support through their family and community. The Pyramid further identifies the types of services appropriate for ‘some’ and ‘few’ who have extended needs and may require support outside of their normal networks of support. This model mirrors the model above and again we would expect that all services should be able to offer level 1 as a baseline offer to all families. We would hope that a tertiary children's hospital would be able to offer levels 1 & 2 support. There will be some hospitals that may be able to offer level 3 & 4.

Irish Childhood Bereavement Network (2017) ‘Standards for Supporting Bereaved Children & Young People – A Framework for Development’ ICBN, Dublin (LINK)



4.0 What do we mean by a bereavement service?

4.1 All hospitals offering paediatric care should have:

- A Standard Operating Procedure (**SOP**) or guidelines for supporting families following the death of a child in their hospital. Families should be aware of what this offer is. It will vary across the UK given the different resources, demographic and types of services being offered. There must be information for families about the local offer and sources of ongoing bereavement support. As a minimum Level 1 must be provided.

4.2 A workforce consisting of:

- **An 'End of Life medical lead' for each child who dies -** this should be the most appropriate consultant to continue to support the family following the death of their child and is usually the child's designated lead consultant in life. The bereavement medical lead will offer follow up sessions to discuss any clinical issues with the family and ensure transition to local care, GPs/Local Paediatricians, as appropriate. The bereavement medical lead is responsible for going through the post mortem and any other peri-mortem results with the family

- **A bereavement 'Key Worker' for each child who dies**- the bereavement key worker will be the key point of contact for the family and for staff who are part of the "team around the family". They will have experience in managing the processes surrounding the death of a child, and be able to coordinate support for the family meetings, ensure the family are supported and know who they can contact. (See Chapter 6 & Appendix 5 in Child death review: statutory and operational guidance (England) LINK *(This is an England only document, but is very useful in developing services outside of England)*

  Once the family is at home, the main point of contact will be the bereavement key worker. This person will contact them as agreed, to offer support through their bereavement, make onward referrals to other agencies as required, provide an ongoing and open link to the hospital, and offer a supportive and information-gathering role.

Key Worker model: A trust may have a bereavement team and this team should include a key worker who will have a vital role for the majority of deaths when children die suddenly and unexpectedly in the community and are brought in via ED, or who are brought in and subsequently die in PICU.

In the case of children with known life limiting conditions, there will often be a specialist liaison nurse already involved (e.g. Oncology/Cardiac/Metabolic Clinical Nurse Specialist), or a similar professional involved with their care in the community. These individuals will know the family extremely well and may be better placed to take on the key worker role. It is important to work with the family to determine their preferences and ensure they are supported by someone they feel comfortable with to accompany them throughout the Child Death Review process.

- **A named 'Clinical Lead' for the Bereavement service.** This is a different role to the 'Key Worker' as set out in the Child Death Review Statutory and Operational Guidance (England) (Cabinet Office September 2018, page 7). This person should oversee and develop the service that is being offered to families. In some settings this may be a joint post - for example covering adult deaths as well. The post holder should always however have knowledge of the paediatric child death processes and be able to offer Level 1 support.

- **A 'Case manager' –** in cases where a formal complaint or patient safety investigation has been initiated after a child has died, a case manager should be appointed to have an oversight of procedures. (CDR 3.6.3) While local policy for the management of complaints should be followed it is good practice for the case manager to discuss and agree with the bereavement keyworker who should be the 'lead communicator' with the family regarding the investigatory processes.

4.3 A suitable environment Provide a suitably attired room where a family can spend time with their child in privacy.

5. Every family is entitled to compassionate communications

- All communication with parents/carers experiencing the death of their child must be empathic, honest, sensitive, non-judgemental and parent-led.
- Sensitive communication and bad news should be delivered in a quiet space and families given adequate time to process the information
- Ensure communications are: in plain, understandable language (free of jargon) with clarification of any technical terms, phrases, acronyms, processes, procedures, and organisations
- Staff should never assume that they can anticipate the needs of any individual with a sensory impairment, learning difficulties or who is experiencing a language barrier. Staff should ask parents if they need additional support and their preferences for bow this is received

- All bereaved parents should be informed about, and if requested referred for emotional support and specialist mental health support when needed

6. Care by the team at time of death and the hours following the death

6.1 The care team should;

- Respect the family's privacy and wishes at the time of their child's death and allow them, where possible, to spend time with their child. Support the family as best they can and help them with the immediate shock that they may experience.

- Treat bereaved families with compassion, dignity, respect, kindness, and empathy, regardless of the circumstances surrounding the death

- Clarify who has parental responsibility and arrangements for sharing information while also respecting family structures and treating parents as equal partners in accessing appropriate bereavement care and support.

- Provide opportunities for the family to view and have contact with their child (where appropriate) and give them the opportunity to wash their child.

- Offer opportunities to make-memories/keepsakes; this is best started, where possible, before the child has died, or soon after death, but in some cases of unexpected death this may need to wait until after the post mortem examination has been carried out (NB not all children will require post mortem)

- Ensure, wherever possible, that the values, culture, faith and beliefs of the family are followed and any needs that they may have in this respect are met. The hospital chaplaincy team may be able to help with this aspect of care.

- Give families time on the ward / department before moving the child to the hospital bereavement room / viewing room /mortuary. Viewing and time arrangements will be depend on local policy and facilities

- Consider what support the family need to get home safely. If they are not ready to leave, consider what space can be offered to allow them to stay longer in hospital.

- Help with temporary car parking arrangements to make collection of belongings and other family members easier

6.2 What the family should expect before they leave hospital

A family may be in a state of shock at this time; first and foremost they should be able to expect kindness and compassion from all the staff around them. Please refer to the prompts above regarding the environment, who supports them, and when and how they are getting home i.e. a s a minimum, find a quiet room for the family, help them think about how to get home safely and arrange who will be in contact with them and when.

The family should be:

- Allocated a dedicated and named key worker:

- Given their child's Medical Certificate of Cause of Death (MCCD), if issued. Check the certificate for accuracy before providing to a family.

- Provided practical information in relation to the registration of the child's death, arrangements for the collection of the death certificate, how to find and appoint the services of a funeral director and details about the Children's Funeral Fund for England (LINK) –(similar schemes are available in Wales and Scotland).

- Provided with information around informing government organisations such as the Child Benefit Office, Tax Office and Department for Work and Pensions, and details on using the Tell Us Once service (LINK) service (if available) to inform all government organisations in one go, so that any benefits paid in the child's name will stop.

- Informed of the local policy for the release of their child into the care of their nominated undertaker, or the necessary arrangements for the option of taking their child home themselves or to a local hospice.
- Informed about the various processes that happen after a child has died and how they will be supported during this time
- Informed about the Child Death Review Process (booklet in England only)
- Informed about the Coroners process (**if applicable**)
- Offered specific information if required on the post mortem process, be it a coroners or hospital post mortem.
- Provided with support around any decisions requiring consent with regard to a hospital post mortem.
- Provided with support when decisions are required to be made within short timeframes
- Provided with time and space to process information and not pressured into making decisions or to engage with services
- Informed of whom they can expect to be in contact with them from the hospital (end of life Bereavement Medical Lead & Bereavement key worker as set out in the national statutory CDR guidance) and when. This should be mutually agreed with the family.
- Given information on support groups
- Provided with information on the use of social media and support and advice around contact with the press if required – this becomes more of an issue in unexpected deaths
- Offered/signposted to bereavement support services for siblings and schools if required

Bear in mind that any information given before the family leave hospital may not be retained and therefore should be reiterated in subsequent meetings by the bereavement key worker and also given in writing if needed.

7. On-going bereavement support

Once the family are at home their main point of contact will be their bereavement key worker. This person will contact them as agreed to support them through their involvement with the hospital and the various processes that need to happen following the death. They will make onward referrals to other agencies as required, provide an ongoing and open link to the hospital, and offer a supportive and information-gathering role.

All bereaved parents should be informed about and, if requested, referred to emotional support services, and for specialist mental health support when needed.

7.1 The bereavement key worker or ‘point of contact’ will ensure that:

- A joined-up and co-ordinated response is provided to all families
- The family know how to make arrangements to view the child's body if this remains at the children’s hospital. Families will be encouraged to make an appointment within normal working hours but under exceptional circumstances flexibility can be offered.
- Where a post mortem is required, it is important that the family know when and where this is going to happen and why. They should be given the opportunity to spend time with their child’s body before the post mortem. In some areas children are transferred to another hospital and it is important that families know where this is and are informed when their child leaves the hospital.
- The family are informed via their preferred means of communication when their child's body leaves the hospital to go their appointed funeral

director (or receiving hospital, in the case of a post mortem). In the event of a coroner's case, it is the responsibility of the coroner's officer to keep the family informed of the whereabouts of the child's body.

- A meeting with relevant clinicians is offered to the family, to take place at a time and place of the family's choosing where possible. Subsequent meetings may be required and these should be offered flexibly, bringing in any relevant professionals necessary to provide information and discuss ongoing support needs.
- Letters containing unexpected information should not be sent without a preceding meeting or telephone call with the family. Where possible letters should be sent during the working week to ensure the family can contact someone if they have any questions or concerns. All contact with the family should be documented on the local IT system.

The bereavement key worker should;

- Consider appropriate venues and forums for proposed meetings and interactions and give families a choice where possible. Ensure bereaved families are represented and / or supported at key meetings
- Provide bereavement support in the aftermath of a child's death and for as long as is required as based on local policy – this local policy should be made very clear to all bereaved families, so as to avoid any distress
- Ensure that suitable and appropriate bereavement support is accessible and coordinated in a timely fashion and, when required, close to the family home
- Signpost bereaved families to sources of high quality advice and support services including: aftercare; chaplaincy; counselling; independent advocacy; legal; local charities, helplines, and family liaison service
- Ensure that families are aware of how to access 24 hour/7 days a week telephone support. This may be via the national NHS 111 Service, or Samaritan's Listening Service (116 123). Give advice to telephone local

24/7 Mental Health Services (provide contact details), or dial 999 or attend a local hospital Emergency department in the event of a mental health crisis.

- Liaise closely with the Coroner / pathologist in those children who have had a post mortem. Post mortem reports should not be sent directly to bereaved parents in the post. Best practice would suggest that such reports be sent to the family's end of life medical lead, and that a face to face meeting is arranged at which the post mortem report is explained. The family should then receive a copy of their child's post mortem report if they wish to receive it.

The bereavement key worker is responsible for ensuring that all elements of the local SOP/guidance are in place and/or available to the family. The bereavement key worker will also ensure the clinical team is aware of their responsibilities.

Specialist bereavement services: These are service(s) that may be offered by the hospital psychologist, psychiatrists, social worker, counsellors or pastoral care workers or services in the wider community. The hospital should employ(s) appropriately qualified staff or actively develop(s) links with other service providers or organisations that have relevant experience in providing this high level of support to specific social and cultural groups represented in their catchment area.

8. Individual Trust culture and values

Any NHS trust where children die should overtly acknowledge that this happens, and look for ways to honour death and improve the experience of families and staff alongside their bereavement services, which are different from the needs of adult services.

8.1 Each trust should;

- Have an executive with a responsibility for bereavement services
- Support bereaved families to provide feedback about the care of their child and their own bereavement care, if they wish to do so, and act on it
- Outline ways to raise concerns and welcome challenge positively
- Provide bereaved families with opportunities to evaluate any recommendations or action plans developed to improve services following the review of their child's death
- Provide bereaved families with opportunities to contribute to, shape and support local guidance, systems, processes, tools or staff training
- Inform bereaved families of any changes to the systems of care resulting from the review of their child's death
- Provide training on the principles of bereavement care to **all staff who come into contact with bereaved parents,** and ensure staff are supported by their Trust to access this.
- Demonstrate a willingness to provide/fund supervision and restorative experiences for staff members appropriate to their level of engagement with bereaved families.

Resources:

- The Childhood Bereavement Network (CBN) LINK
- Child Bereavement UK LINK
- Child death review: statutory and operational guidance (England) LINK
- Irish Childhood Bereavement Network LINK