LRI Children's Hospital

Child Bereavement Support Services

Staff relevant to:	All Leicester Hospital's staff involved in caring for a child aged 0 (not requiring specialist neonatal care) up until 18 years of age.
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Written by: Reviewed by:	K Sanger (Bereavement Support Nurse) K Sanger & Mathers
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1. Introduction and who this guideline applies to

Grief is a normal and very individual response to a loss. The death of a child is devastating and can hold greater bereavement risk.

The Child Bereavement Support Service model is underpinned by the standards of bereavement support recommended by the National Children's Hospital Bereavement Network (NCHBN V4.2 September 2020). These standards were influenced by the recommendations from NICE (End of life care for infants, children and young people with life-limiting conditions: planning and management, 2016) and the Child Death Review statutory operational guidance (DoH, 2018), which - acknowledging the support families need during the first days, weeks and months following their loss - introduced the role of the key worker.

This guideline will explain how members of the UHL Child Bereavement Team (CBT) work alongside the hospital and community multi-disciplinary teams to ensure that all families are offered and have the opportunity to access the support they may need.

The service is offered to bereaved families after a child has previously received care or has died in UHL.

The service does not cover neonatal or maternity deaths where support is provided by the Neonatal & Midwifery teams.

The guideline applies to all Leicester Hospital's staff involved in caring for a child aged 0 (not requiring specialist neonatal care) up until 18 years of age.

Support for those bereaved where the deceased was 18 years and over is covered by the Adult Bereavement Support Service**.**

All clinical staff involved in caring for a child will require awareness of this service. Their attendance may be requested at a ‘follow up’ meeting with the bereaved or they may be required to give information about the care provided if requested by the family.

Where UHL Specialist Nurses (e.g. Cardiac nurse specialist, Respiratory, Oncology / Teenage Young Adult/ Macmillan, Haematology etc.) have been providing care and formed a relationship with the child and their family, and as part of their role will have continued family contact post bereavement, this guideline explains how a joint approach with the Child Bereavement Team (CBT) will enable the Trust to ensure that all families are offered the immediate and ongoing bereavement support they may need.

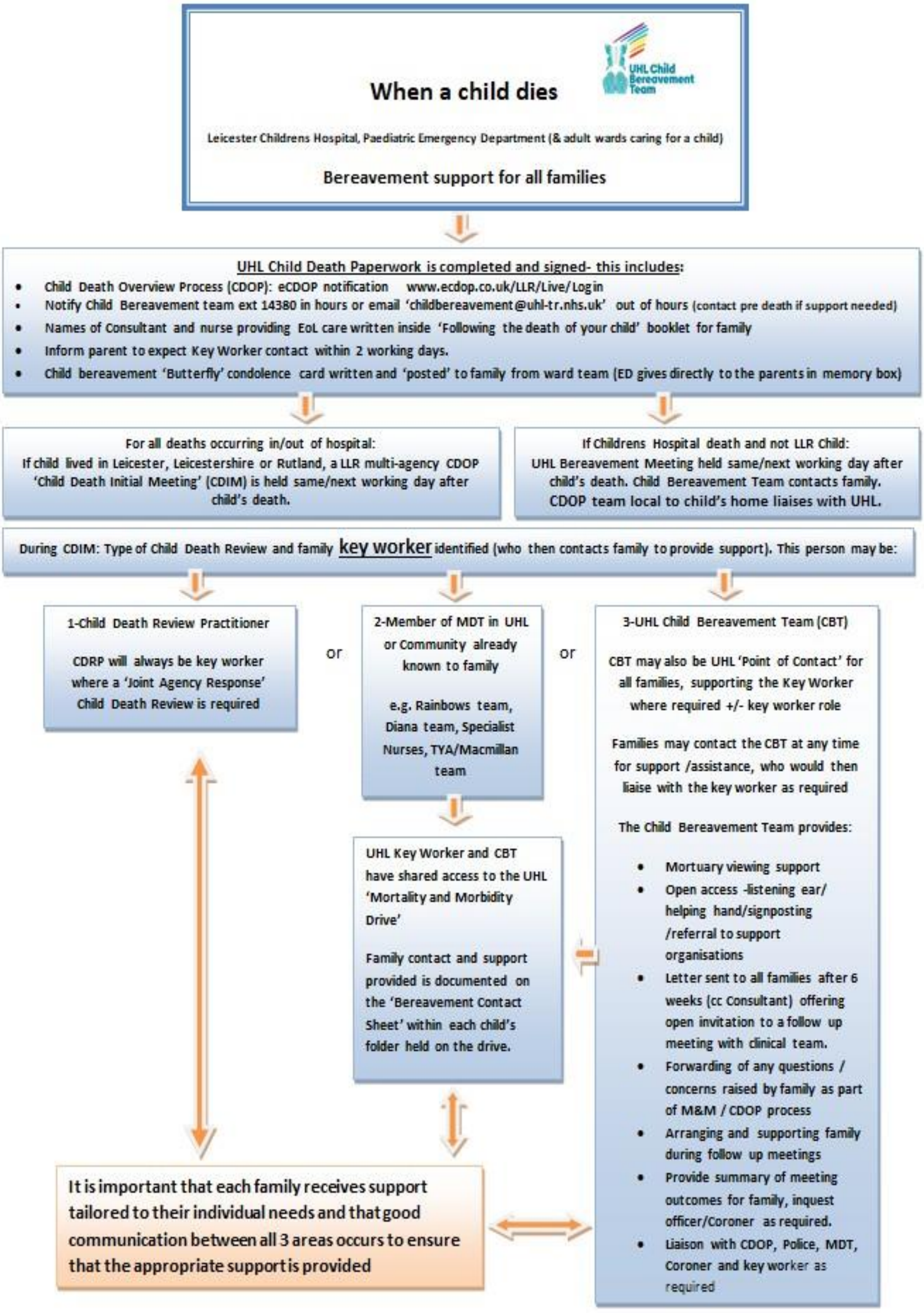
Contact details: Childbereavement@uhl-tr.nhs.uk Call: 0116 258 4380 / 6776 or 07590 868337. The service is available Mon - Friday (excluding Bank Holidays) within normal office hours. Any messages left on the answering machine will be responded to during the next working day.

Related Documents

- Child Death and CDOP Process (0-18 years) UHL Childrens Hospital Guideline – UHL ref: D3/2021
- Certification of Stillbirth and Neonatal Death on Labour Ward UHL Obstetric Guideline - UHL ref: C33/2021
- Bereavement Support Services UHL Guideline – UHL ref: B4/2016

Please see following diagram showing key worker role within the

UHL Child Bereavement Support Service Model.



When a child dies

UHL Child Bereavement Team

Leicester Childrens Hospital, Paediatric Emergency Department (& adult wards caring for a child)

Bereavement support for all families

UHL Child Death Paperwork is completed and signed- this includes:

- Child Death Overview Process (CDOP): eCDOP notification www.ecdop.co.uk/LLR/Live/Login
- Notify Child Bereavement team ext 14380 in hours or email 'childbereavement@uhl-tr.nhs.uk' out of hours (contact pre death if support needed)
- Names of Consultant and nurse providing EoL care written inside 'Following the death of your child' booklet for family
- Inform parent to expect Key Worker contact within 2 working days.
- Child bereavement 'Butterfly' condolence card written and 'posted' to family from ward team (ED gives directly to the parents in memory box)

For all deaths occurring in/out of hospital:
If child lived in Leicester, Leicestershire or Rutland, a LLR multi-agency CDOP 'Child Death Initial Meeting' (CDIM) is held same/next working day after child's death.

If Childrens Hospital death and not LLR Child:
UHL Bereavement Meeting held same/next working day after child's death. Child Bereavement Team contacts family.
CDOP team local to child's home liaises with UHL.

During CDIM: Type of Child Death Review and family key worker identified (who then contacts family to provide support). This person may be:

1-Child Death Review Practitioner

CDRP will always be key worker where a 'Joint Agency Response' Child Death Review is required

or

2-Member of MDT in UHL or Community already known to family

e.g. Rainbows team, Diana team, Specialist Nurses, TYA/Macmillan team

or

3-UHL Child Bereavement Team (CBT)

CBT may also be UHL 'Point of Contact' for all families, supporting the Key Worker where required +/- key worker role

Families may contact the CBT at any time for support /assistance, who would then liaise with the key worker as required

The Child Bereavement Team provides:

- Mortuary viewing support
- Open access -listening ear/ helping hand/signposting /referral to support organisations
- Letter sent to all families after 6 weeks (cc Consultant) offering open invitation to a follow up meeting with clinical team.
- Forwarding of any questions / concerns raised by family as part of M&M / CDOP process
- Arranging and supporting family during follow up meetings
- Provide summary of meeting outcomes for family, inquest officer/Coroner as required.
- Liaison with CDOP, Police, MDT, Coroner and key worker as required

UHL Key Worker and CBT have shared access to the UHL 'Mortality and Morbidity Drive'

Family contact and support provided is documented on the 'Bereavement Contact Sheet' within each child's folder held on the drive.

It is important that each family receives support tailored to their individual needs and that good communication between all 3 areas occurs to ensure that the appropriate support is provided

Abbreviations used within this guideline:

CBT	Child bereavement Team
CDOP	Child Death Overview Process
CDIM	Child Death Initial Meeting
CDR	Child Death Review
CDRP	Child Death Review Practitioner
MDT	Multidisciplinary Team
TYA	Teenage & Young Adults
M&M	Morbidity & Mortality

2. Standards and Procedures

The following standards and procedures include both those deaths where the CBT are acting as the Key Worker and also those where the CBT is purely providing a limited supportive role in close liaison with the Key Worker.

2.1 All bereaved families are made aware that they can contact and access support from the CBT at any point in time after the death of their child. Contact details are provided by means of:

a) The UHL 'Butterfly' condolence card sent from the ward/department where the child died.

b) The Clinical team verbally informing families of what happens next following the death of a child.

c) The UHL 'Following the death of your child' booklet. https://yourhealth.leicestershospitals.nhs.uk/library/women-s-children-s/children-s/children-s-hospital/1868-following-the-death-of-your-child/file

d) The UHL website

e) A letter sent to the family 6 weeks after the child's death inviting families to contact the CBT and also offering the opportunity to attend a follow up meeting with members of the clinical team who cared for their child.

f) Where family have not responded to the letter, a follow up call will be made around 2 weeks later (two attempts made leaving a voicemail messages where able). The reason for the follow-up call is:

- To establish whether the letter was received
- To establish if the family have any unmet bereavement needs and whether the family have engaged where support offered or require referral or signposting to ongoing support.
- To establish whether the family would like to offer feedback to the hospital regarding the End of Life Care they and their child received

Where the LLR Child Death Review Practitioner (CDRP) is the family's key worker, they will be informed when the 6 week letter has been sent. During their next follow up call with the family they will ask if this has been received and inform the CBT if it was not. Any feedback received regarding care will be forwarded via the Child Death Review Process.

2.2 The CBT offers the following support to all families (in collaboration with the Key Worker as applicable):

a) **Supporting the Clinical Team:** In collaboration with members of the Chaplaincy or Palliative Care teams, where requested, assist the clinical team in providing emotional or practical support for the family during the period leading up to a withdrawal of care or after a child has died.

b) **Mortuary visiting support:** To allow families to see their child following the death (includes deaths referred to the Coroner where Coronial permission given).

c) **Supporting Transfers:** Assist the clinical team as needed in facilitating a family's request to transfer a child following death to the Rainbows Hospice or home.

d) **Open access for the family:** To talk through whatever matters to them regarding their bereavement. Supporting and enabling the family to talk about their experiences and feelings, identifying where there may be difficulties and tailoring further contact and support to the family's or individual family member's needs and preferred method of contact.

e) **Signposting:** Offer signposting advice on bereavement services available where there appears to be difficulty in coping with the loss e.g. counselling or peer support services and making referrals where consent given, as appropriate. Support for siblings is also offered and signposted to the relevant agencies.

f) **Provide further information or support as required:** This may be related to social care and financial burdens experienced by the families.

g) **Feedback:** Offer families the opportunity to provide feedback to the hospital, raise questions and/or meet with members of the clinical team who cared for their child, sharing with the team the family's compliments, questions or any concerns regarding the care their child received. Feedback on the delivery of the bereavement service is also gained to ensure continual service review and improvement.

h) **Follow up support and UHL learning:** Coordinate a response from the clinical team to any questions raised or a meeting with members of the team as requested by the family, providing a meeting outcome summary letter for the bereaved family afterwards. Any identified learning will be shared with the CDOP and UHL Learning from Deaths teams.

i) **Tailored family support and liaison:** Where not identified as the family key worker, at the request or with the consent of the family, liaise with the family's key worker and /or members of the multi-disciplinary teams as needed, where it has been identified that the family may have unmet needs or where questions or concerns have been raised which would be more appropriate for the CBT to take forward.

2.3 Additional CBT roles and responsibilities:

a) **Debriefing:** A member of the CBT may be requested to support debrief sessions with the clinical team alongside members of the Chaplaincy and Palliative Care team after a child has died.

b) Supporting the Children's Hospital **Bereavement Champions:** (Key clinically based staff who are dedicated to and instrumental in promoting, supporting learning and leading their team to ensure appropriate bereavement support is offered to the family).

The CBT will provide update information, resources and support to the clinical areas and their Bereavement Champions to ensure that teams have the appropriate information, training and resources to support a family who are anticipating or have experienced the death of a child.

c) **Engaging with Child Death Overview Process Identifying key worker:** Following the death of any child a mandatory Child Death Review (CDR) is undertaken as part of the Child Death Overview Process (CDOP). This is to find out why the child died and identify whether there are any interventions that can be put in place to protect other children and prevent future deaths from occurring. A Child Death Initial Meeting (CDIM) is held either the same or the next working day and is a fact finding meeting to identify 1) what type of review is required, 2) whether there are any immediate family needs and who is best placed to support these, 3) the most appropriate person to be the family's key worker, who will undertake the responsibility of being the point of contact for the family and address their ongoing needs (see section 3.4).

(The above occurs where the child lives locally in Leicester, Leicestershire or Rutland (LLR). Where a child lives out of county, UHL is contacted by the regional CDOP team where the child lived for further information to support this process).

A member of the CBT will assist in identifying and inviting an appropriate UHL clinician who has been involved in caring for the child to attend the CDIM with them, provide initial meeting outcomes to the UHL Child Death lead doctor and update the UHL Child Death Spreadsheet.

Where it is identified during the CDIM that the criteria has been met for a Joint Agency Response Child Death Review to be undertaken (e.g. external or unnatural causes, sudden and no immediate apparent cause or a child or young person in custody or detained under Mental Health Act), the Child Death Review Practitioner will undertake the role of key worker for the family in LLR. Where the death does not meet the Joint Agency Response criteria, if a family already have a good working relationship with a member of a hospital or community multi-disciplinary team, they may be identified as the family's key worker. Where no previous links with such teams have been made, a member of the CBT will undertake the role of the key worker.

The key worker will liaise with the Child Bereavement, multi-disciplinary teams and support organisations as required to ensure that the needs of the family are met.

2.4 Key worker role and responsibilities: (National Children's Hospital Bereavement Network V4.2 September 2020):

The key worker will contact the bereaved family or carer 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.

The bereaved family's 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 to their appointed funeral (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 bereaved family's 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 Mental Health Services (0808 800 3302 2pm-9pm / 24hrs Sat, Sun and B/Hols), 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.

3. Education and Training

There are no specific education requirements to implement the guideline. Awareness raising and information for staff will be provided for all clinical areas by the Bereavement Support Nurse and ward Bereavement Champions. Information may also be given by education teams during staff 'End of Life Care' induction sessions for Registered Nurse and HCAs.

4. Monitoring and Audit Criteria

Key Performance Indicator	Method of Assessment	Frequency	Lead	Reporting arrangements
Key worker identified	Child Death Database	Quarterly	CBT lead nurse	Departmental audit group
6 week follow up letter sent	Child Death Database	Quarterly	CBT lead nurse	Departmental audit group
Family feedback shared with Clinical, LFD and CDOP teams	Child Death Database	Quarterly	CBT lead nurse	Departmental audit group

5. Supporting Documents and Key References

Bereavement support standards for children's hospitals: National Children's Hospital Bereavement Network V4.2 September 2020.

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

Child Death Review statutory operational guidance (DoH 2018).

UHL Child Death Paperwork & CDOP Process (0-18 years) Ref D3/2021

6. Key Words

Bereavement, Death, Condolence.

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.
As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

CONTACT AND REVIEW DETAILS	
Guideline Lead (Name and Title) David Mathers - Bereavement Support Lead Nurse	**Executive Lead** Head of Outcomes & Effectiveness
Details of Changes made during review: Terminology changes only; Cardiac liaison now cardiac nurse specialist Mortuary viewing changed to mortuary visiting	