Standard Operating Procedure

SUPPORT TO FAMILIES FOLLOWING THE DEATH OF A CHILD IN HOSPITAL; THE "CORE OFFER"

SETTING Division of Women's and Children's Services

FOR STAFF All Departments

PATIENTS Any parent/carer/family whose child dies whilst under the care of Bristol Royal Hospital for Children or St Michael's Hospital.

Standard Operating Procedure (SOP)

1. Introduction

When a child dies the pain and devastation of the loss can feel overwhelming for the family. This Standard Operating Procedure (SOP) is written with the understanding that the processes outlined are primarily in place to support the whole family, including extended family members, through their immediate loss, as well as fulfilling mandatory and statutory requirements.

The SOP details a "core offer" which describes the support the Division is expected to offer all bereaved families, and the roles and responsibilities of the various staff involved in the care of the child and their family.

Whilst it provides an outline of what families and staff can expect, it is recognised that the "core offer" will need to be adapted in partnership with each family and tailored to meet their individual needs, taking into account the other professionals involved in their care.

Most importantly, it is recognized that the success of this "core offer" in supporting a family through the early stages of bereavement is dependent on the compassion with which it is delivered. This cannot be described but is inherent within the way in which this SOP has been developed.

Key roles associated with the hospital (acknowledging that these individuals may join an existing team around the family provided by community child health, social care and specialist palliative care services in the community):

Bereavement medical lead – this is the most appropriate consultant to continue to support the family following the death of their child. 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.

This role might be undertaken by the person that they have had the most involvement with whilst the child was alive or it might be the consultant who was closest to the family at the time of death. Those involved in the child's care should agree who this will be as early as possible.

Bereavement key worker – this will be the professional most suitable to support the family after death. 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" (see below). They will have experience in managing and supporting the processes surrounding the death of a child and be able to coordinate support

for the family and ensure the core offer is delivered. They may be the key person offering emotional support and informational counselling unless this is to be provided by another member of the team around the family.

The default situation is that this role will be undertaken by a member of the Paediatric Palliative Care and Bereavement Support Team. However, where specialties have clinical nurse specialists and other multidisciplinary team (MDT) members, it may be that a member of the speciality MDT team provides this role. Again, those involved in the child's care should agree, in conjunction with the family, who this will be as early as possible. The bereavement key worker is also responsible for clearly documenting who the "Team around the family" (see below) are and for tracking communication with the family on the bereavement proforma and ongoing contact on the bereavement contact proforma on Medway.

Case manager – in cases where a formal complaint or patient safety investigation has been initiated, a case manager will be appointed. Where there is a formal complaint, the case manager will be a General or Assistant General Manager, in cases where there is no formal complaint only a patient safety investigation, the case manager will be the patient safety lead. It is the responsibility of the case manager to discuss and agree with the bereavement keyworker who should be the 'lead communicator' with the family regarding the investigatory processes. This decision should be documented on the complaint record, and the Medway paediatric mortality proforma.

Clinical Psychology support – Psychological Health Services will provide a clinical psychologist to consult with the team around a family whose child has died whilst under the care of our hospitals.

Where individual family needs indicate it is appropriate, they will also offer direct initial end of life and bereavement support for family members.

Team around the family – this will include the above three roles and will also bring in other health professionals such as other nursing staff (particularly relevant when the death occurs outside of Mon-Friday working hours), local paediatrician, community paediatrician, social worker, family support worker (LIAISE), midwife, health visitor, general practitioner, specialist palliative care team, chaplaincy and pastoral support team. As above, roles need to be made clear so as to ensure that the grieving family do not suffer from confusion or mixed messages about any aspect of their child's care. Communication between this team is of paramount importance. It is the responsibility of the bereavement key worker to ensure the team from the hospital know who they are and provide clarity on the roles they will play (within the usual professional boundaries).

2. The Core Offer

2.1 Planning prior to death (where death is expected)

The best time to start supporting a family for their child's death is whilst the child is still alive. The following should be considered by the clinical team:

- Do the family have an end of life care coordinator and will they continue to support the family as the bereavement key worker after the child has died?
- Who is the nominated medical lead for end of life care and who will be the bereavement key worker?
- Are there any other processes in operation that these people should be aware of, for example, a complaint (formal or informal), incident or other investigation, or child protection issues?

- Has the family come from Bristol or outside of Bristol? Are they known to local/community
- services and who is the local lead for the child's care?
- Have the "team around the child" been identified?
- Has an advanced care plan which reflects the wishes of the child and family been completed (e.g. Wishes document or similar)?
- Have there been a parallel planning/end of life care meetings?
- Do the family have any cultural, religious or spiritual needs that need to be considered prior to death?
- Has a Medway paediatric mortality proforma been started?

2.2 Transfer to hospice or home prior to death

If a child or family chooses to transfer their end of life care from the hospital to the hospice or to home the following additional considerations should be made:

- The end of life care medical lead for the child and family will not change but consideration should be given to the most appropriate bereavement key worker.
- The team around the child should be reconfirmed to ensure that all those involved continue to recognise and carry out their role accordingly; this should be clearly documented in the child's medical record

2.3 Immediately following the death of a child (while the family are still in hospital) – *applicable to expected death and to sudden and unexpected death*

2.3.1 Staff responsibilities

- To support the family as best they can and help them with the immediate shock that they may experience. The following might be considered:
    - What environment are the family in? Can they be offered somewhere quiet? Do they want time with their child's body?
    - Who from the ward is supporting them? This might need to be someone not involved in the child's care, as the death of a child can be distressing to staff involved and someone a little removed might be able to offer better support at this time.
    - What support do the family need to get home safely? If they are not ready to leave, what space can we offer to allow them to stay longer in hospital?
    - When the family are ready to leave, can the front desk help with temporary car parking arrangements at the front of the hospital to make collection of belongings and other family members easier?
    - Staff must follow the Child Death Check List or in the Children's Emergency Department, use the Unexpected Child Death in Bristol and the wider area: Checklist following the unexpected death of a child
    - Assurance of completion of this document, in a timely fashion (usually within two working days) will be the responsibility of the Paediatric Palliative Care and Bereavement Support Team.
    - The bereavement key worker will confirm the team around the family (see above) and clearly document those named on the bereavement proforma on Medway
    - The Rainbow Room (body store) operating process should be followed within normal working hours. This will be led by the Paediatric Palliative Care and Bereavement Support Team. Out of hours the clinical site manager will support all processes associated with the Rainbow Room.
    - The staff involved in the death of the child must ensure that they follow and respect any spiritual needs that the family may have. The hospital chaplaincy team can be

reached on 26799 during office hours and via switchboard outside of office hours. For additional information on how to access chaplains and faith representatives for patients approaching the end of life follow this link. You can also find further general information about Spiritual Care and Chaplaincy Support on the website.

- Ensure the family situation and contact details are known and are accurately recorded.

2.3.2 What the family can 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 in 2.3.1 above regarding the environment, who supports them, and when and how they get home in order to offer the best support possible. As 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.

During normal working hours, the Paediatric Palliative Care and Bereavement Support Team can be contacted to meet with the family. They will provide support and information, determine who will be the bereavement key worker, and arrange further contact with the family over the following few days.

Before the family leave the hospital, they should be given the following documents individualised to meet their families' needs by their ward nurse:

- Their child's death certificate (if issued)
- Family booklet – "When your child has died"
- Who they can expect to be in contact with them from the hospital (end of life Medical Lead & Bereavement key worker) and when – this should be mutually agreed with the family.
- Contact details for their bereavement key worker and end of life medical lead.
- Information on support groups
- Information on the Child Death Review Process
- Information on the Coroners process (if applicable)

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

2.4 What the family can expect after they have left hospital

Once the family are at home, their main point of contact will be the bereavement key worker. This person will contact them as agreed to support them 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.

The bereavement key worker will ensure that:

- 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 this is going to happen and why, and are given the opportunity to spend time with their child's body before transfer to the receiving hospital.
- The family are informed via their preferred means of communication when their child's body leaves the Rainbow Room 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 coroners officer to keep the family informed of the whereabouts of their 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. 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 in the 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 on the bereavement contact proforma on Medway.

It should be noted that the bereavement key worker is responsible for ensuring that all elements of the "core offer" are in place and/or available to the family.

The bereavement key worker will also ensure the clinical team is aware of their responsibilities.

2.5 Monitoring and support to specialty teams

- The Paediatric Palliative Care and Bereavement Support Team are available to attend any specialty MDT meetings, and will be regular attenders at key MDT integrated care Paediatric Palliative Care and End of Life Service Delivery Group. Finalised October 2016, updated and ratified September 2018 Pg.6 meetings, such as PICU and Oncology. Standardized paperwork for each child will be held and maintained by the Paediatric Palliative Care and Bereavement Support Team and uploaded directly to Medway so that all health professionals with access to this system can view the arrangements surrounding the child's death and ongoing support to the family.
- The Paediatric Palliative Care and Bereavement Support Team are responsible for assuring that the "core offer" described in this SOP is available to every family whose child dies whilst under the care of the Children's Hospital. This will be monitored by the Palliative Care and Bereavement Service Delivery Group.

3 When a previously well child dies in the emergency department or arrives at hospital having died in the community

When a child dies unexpectedly in the emergency department, or in the community and is brought to hospital to confirm the death, the hospital roles of bereavement key worker and bereavement medical lead apply regardless of multiagency rapid response process associated with an unexpected child death in the community - http://nww.avon.nhs.uk/dms/download.aspx?did=7330. The multiagency rapid response process considers the conditions leading up to the child's death and undertakes a detailed multiagency review of the situation. The immediate need to support the family from the hospital following the death of a child is still required.

- The bereavement key worker for this situation will default to the Palliative Care and Bereavement Support Team, unless the child is already known to one of the hospital specialties, in which case a specialist nurse that the family already know may undertake the Bereavement Key Worker role. Outside of the Palliative Care and Bereavement Support Team/Clinical Nurse Specialist's working hours, the nurse in charge of the Children's Emergency Department (CED) will allocate a nurse to support the family prior to the bereavement key worker becoming involved.

- When the child has a pre-existing medical condition and is known to a hospital consultant, that consultant should become the Bereavement Medical Lead. When the child is not known to a hospital specialty, the Bereavement Medical Lead will be the CED consultant most closely involved with the child's care.

- The Bereavement Medical Lead, working with the Bereavement Key Worker, is expected to offer the family a meeting at the earliest possible opportunity and in response to their needs. It should be noted, that when a child dies in the Emergency Department or before arrival there, the relationship with that family is much less established and follow up from the hospital is therefore likely to be confined to one meeting. Further follow up and review of the circumstances surrounding the child death is undertaken by the community paediatrician.

- The community paediatrician may attend the hospital-organised meeting but this element of bereavement support to the family falls outside of the multiagency rapid response and therefore the community paediatrician will not lead this component of care to the family. As stated above, they will take over any ongoing involvement with the family associated with the findings of the child death review process and/or multiagency rapid response.

- Where a death has occurred outside of hospital and the child and family been brought to the Children's Emergency Department there is a stronger expectation that the community paediatrician will be involved in any hospital-organised bereavement support meetings held Paediatric Palliative Care and End of Life Service Delivery Group. Finalised October 2016, updated and ratified September 2018 Pg.7 with the family, due to the limited information surrounding the child's death that the Emergency Department Paediatrician is likely to have.

4 When a child has died and an investigatory process is instigated

An investigatory process into the care of a child may be instigated for a number of reasons; these are the same whether or not the child has died. UH Bristol, as an NHS organization, has responsibility to investigate whenever an incident is thought to have occurred or whenever a complaint is brought against the organization, be that formally or informally. There is also a statutory responsibility to investigate every child death as part of the March 2010 legislation "Working together to Safeguard Children". These statutory processes can be seen below:

4.1 When there is a child death and incident investigation

When a clinical incident is thought to have had occurred the “Link between incidents and other investigatory procedures” standard operating procedure should be followed. This introduces the concept of a case manager who will be the Patient Safety Lead for the incident investigation and who will be responsible for coordinating the investigatory process(es) that have been instigated, whilst maintaining close links with the bereavement key worker. The bereavement key worker and case manager must agree and document who is the lead communicator with the family regarding the ongoing investigatory processes.

4.2 When there is child death and complaint investigation

A complaint from the family following bereavement will follow the Trust complaints process.

In these situations, a General Manager (or Assistant) will take on the role of case manager. He/she will be responsible for coordinating the investigatory process(es) whilst maintaining close links with the bereavement key worker. As above, the bereavement key worker and case manager must agree and document who is the lead communicator with the family regarding the ongoing investigatory processes.

When a complaint is received sometime after the death of a child and the case is fully closed, the normal complaints process will be followed. The Palliative Care and Bereavement Team can offer support to a family that have complained; their contact details should be provided to the complainant in case this is of support

4.3 When there is child death, complaint investigation and incident investigation

Where a clinical incident investigation has been instigated and a complaint from the family has been received, the “SOP for managing simultaneous investigatory processes” should also be followed. In this instance, the case manager is a General Manager, who supports the Patient Safety Manager with the incident investigation, provides a full complaint response, and works alongside the bereavement key worker to ensure that all communication with the family is coordinated and Trust deadlines are met. In this situation, as in 4.1 & 2 above, the case manager and the bereavement key worker must agree and document who is the lead communicator with the family regarding the ongoing investigatory processes.

Early communication must be made with the family to ensure that the family is aware of the incident investigation process, the child death review process and the interface between the two.

If there are likely to be any delays in providing a written response to a family's questions following a bereavement there should be explanatory communication with the family.

4.4 Independent review

The requirement to provide an independent review of a given case will be identified through either the Trust SI Policy or the Trust Complaints and Concerns Policy.

http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/patient-and-family-support-services/chaplaincy/

RELATED DOCUMENTS	Child Death Check List Unexpected Child Death in Bristol and the wider area: Checklist following the unexpected death of a child Rainbow Room (body store) operating process Access to chaplains and faith representatives for patients approaching the end of life Child death review process - information for professionals
AUTHORISING BODY	Paediatric Palliative Care & End of Life Service Delivery Group
SAFETY	None
QUERIES	Contact Bereavement Support team on 27293 Bleep 1061 or Francis Edwards on 07785333014‘