On the death of your Child
Children’s Community Nursing Team

“I wish that our dreams were frozen,
Then our hearts would not be broken
When we let each other go…
If I could steal this moment forever,
Paint a picture-perfect smile,
So our story stayed alive
We would never say goodbye.”

(M. Ravel & P. Sheyne)
This booklet is designed to help you with the practicalities following the death of your child.

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Introduction

Please accept our deepest sympathy on the death of your child. We understand what a tragic time this must be for you and your family. You may well have intense feelings of shock, disbelief, numbness, and inconsolable sadness. You may feel anger, guilt or even a sense of relief that your child is now free from their suffering. You may experience physical strain such as exhaustion, fatigue and a loss of appetite. These are all normal responses and are part of grieving. And yet, even at this difficult time when you are feeling so broken hearted, you as parents have to make some painful decisions. You may have made some decisions before your child died or you may have decided to leave them until now. There are many practical things that have to be done. However, you can take your time and it is important for you and your family to do so.

This booklet is designed to guide you through this process and offer you some practical advice on what you need to do following the death of your child.

The Children’s Community Nursing Team, a doctor, or a member of the Palliative Care Team will have informed Urgent Care service (the out of hours GP service) of your child’s details, so that if they need to be contacted out of hours, following the death of your child, they will be aware of your situation.
What to do when your child dies

• The death needs to be *confirmed* by a doctor. During working hours this is normally done by your G.P. Out of hours, this is done by Urgent Care (or its equivalent).

  Ideally, this needs to be done as soon as practically possible, but if your child dies during the night, then this can generally wait until the morning.

• The death also needs to be *certified* by a doctor who knew your child and the cause of death. This is essential before funeral arrangements can be made.

• You may want to wash and dress your child (and put on a nappy if age appropriate). Don’t be frightened to hold your child. Some parents take photographs as a memory, especially if there are younger siblings to consider, who may/may not wish to see their brother or sister after they have died, and may wish to see a photograph in the future.

• If there are tubes etc in place, these will need to be removed. The Children’s Community Nursing Team can help you with this and support you.

• A funeral director of your choice will need to be contacted to guide and assist you with your plans.

• If you choose for your child to remain at home (particularly in the summer), a coolant is required to keep your child’s body and room cool. Your children’s community nurse can help you with this. Alternatively you may want your child’s body to be taken to a chapel of rest/children’s hospice. Choose what feels most comfortable for you.

• There will be a change in your child’s skin: it will become blue, cold and mottled in appearance. This is normal. Sometimes it is necessary to preserve/embalm your child’s body. (The funeral directors undertake this).
Informing relevant people

You may want to inform those people close to you immediately, such as your family and friends. You may choose to inform others at a later time. If this is too painful a task for you to do, ask a close relative/friend to cascade the news for you.

You may want to telephone people or there may be some whom you wish to inform face-to-face, such as brothers and sisters.

The Children’s Community Nursing Team can inform ‘professional’ personnel such as hospital staff, GP or hospice for you.

Useful contact details

- Your family GP: .................................................................
- Urgent Care Cambridge (UCC): 0330 123 9131 (outside of normal G.P. working hours)
- Children’s Community Nursing Team: 01223 218061
- Addenbrooke’s Hospital: 01223 245151
  Wards C2: 01223-217534; C3: 01223 217450;
  D2: 01223-217250; PICU: 01223 217294;
  NICU: 217678; A&E: 01223 217118.
- East Anglia Children’s Hospice: 01223 860306
- Symptom Management Team (24 hr on call: 08454 501053)
- Registrar’s Office (Shire Hall): 03450 451363 (Mon-Fri 9am - 4pm) appointments can be booked online at www.cambridgeshire.gov.uk/bmd
- Coop Funeral Directors: 01223 357046
- Cambridge Crematorium: 01223 458000
- The Woodlands Cemetery
  (Barton): 01223 303874
  (Brinkley): 01638 600693
Legal requirements
As previously stated, your child’s death needs to be confirmed first by a doctor and then certified by a doctor who knew your child and the cause of death (e.g. GP or Paediatrician).

If you wish to have your child cremated, then two forms are required (called forms B & C): one can be obtained from your G.P. and another is required from a second doctor. Your funeral director can help you with this.

The death has to be registered by the Registrar of Births/ Marriages/Deths, in the district in which the child died. Again, this needs to be done as soon as practically possible, once the death has been certified, but within five days.

You will need:

- The death certificate (given to you by the doctor who certified your child’s death).
- Details of your child’s date and place of birth; details of your child’s place and time of death.
- The full name and occupation of both parents.
- To have decided whether you wish to bury or cremate your child.

You will need to make an appointment to do this and a charge is made for death certificates. In Cambridge this is done at Shire Hall (see useful contacts for details), which is open Mon – Fri 9am - 4pm.

You will then be given a green form that the funeral director requires in order to authorise them to proceed.

In some cases where the cause of the death is unknown or unexpected, a post mortem is legally required. Parents or carers understandably find this very difficult to bear. Following every paediatric death a letter is sent to parents from the Child Death Overview Panel. This is a formality and not intended to cause alarm. Every paediatric death is investigated and parental feedback is always welcome.

A referral to a Coroner may be made if further investigations for the cause of death are needed. This can unfortunately delay the registration of death and the funeral plans.
Planning the funeral

There is no hurry in planning a funeral. It is important to have the service you would like in order to say goodbye to your child, in a way that is special to you. It can reflect the uniqueness of your child.

Funeral directors can give you invaluable advice concerning burial, cremation or a ‘woodland’ burial. They can act on your behalf and contact local services for you. If there are brothers or sisters, they might want to be involved. You may wish to design the service sheet yourself, with special photographs of your child.

Music and words, which are special to you or were special to your child, have a significant part to play in saying goodbye. There are no rules and the choice of music and words is yours. You may want to ask people who were special to your child to read, pray, speak or take an active part in the service.

You may want a religious service in a place of worship or a ceremony at the crematorium. You can have a service of your choice. You may know a minister (or the equivalent) or you may ask someone local to officiate. However, if you do not know one, then the funeral director can advise you. You can choose a burial, a cremation or both (ashes interred).

Most funeral directors will not charge you for their basic services when a child dies and provide a hearse / hearsette; a child’s coffin; organise the funeral and liaise with third parties – all free of charge.

Some cemeteries charge for the burial and some ministers charge for their services.

From 1st April 2018 Cambridge Crematorium will not charge for paediatric cremations for under 16 year olds. There will however be a charge for graves.
The day of the funeral

This is likely to be very emotional and exhausting. For some parents, not only will they have their own grief to consider, but also the welfare of their other children. If it is possible, arrange for some relatives/friends to look after young siblings. (They will need to be prepared for the funeral and given explanations of what to expect).

Some parents have photographs of their child in the service. As there may be a considerable number of people at the service, some parents arrange to have a book in which names of attendees can be recorded.

Burial

You may choose to have the burial as part of the service with everybody attending or you may choose to have this part of the service for close family only.

Cremation

You can choose to have the coffin in view for the whole/part of the duration of the service or you may choose to have the curtain drawn around the coffin for the entire duration of the service. You can arrange to collect the ashes; to keep them with you at home; to have them buried or scattered in a place that was special to your child. You do not have to make a decision in a hurry.

After the funeral

Some parents choose to return home immediately. Others choose to talk to people following the funeral. It really depends on how you are feeling and what you can cope with. Some families choose to have folk back to their house for refreshments. (Bereaved parents have suggested that if friends/family offer to help with this, then agree to it as it can take the pressure off you).

You may consider nominating a friend or family member to be responsible to ask folk to leave when you feel that you need space/quiet/rest.

Other parents arrange for folk to meet in a designated place for refreshments such as a hotel/public house. You then have the option to attend if you choose.
Flowers

If you have had flowers at your child’s funeral, you may choose to leave them at the church/crematorium. Alternatively, you may wish to have them placed beside the grave, to take them home with you or distribute them. You may ask someone to remove the cards attached to the flowers so that you can read the messages.

Donations

Some parents choose to send donations to their chosen charity. This may be associated with the diagnosis of your child. Funeral attendees may like to contribute to this. It is your choice. You may choose to do something practical much later on.

Memories

Hair locks from your child can be taken and kept. Hand and foot prints are a very special memory. The Children’s Community Nursing Team can help you with this. Keeping a ‘memory box’ containing those items that were special to your child is a good way of preserving precious memories. (This could be a favourite toy/cuddly/book, a favourite item of clothing, a nappy, a piece of jewellery, works of art, a school work).

While it can be difficult to collect these following the time of your child’s death, they are so important for you to cherish later. Bereaved parents find memories an important part of their grief.

Siblings

Children need to be told the truth about their brother or sister who has died. They too need to grieve and say goodbye. Age-appropriate explanations are necessary. However, try not to be vague, as this can often be misunderstood and frightening for young children and may cause their imagination to run. The concept of death as something final may require repeated explanations to the very young. If you are struggling with this, the Children’s Community Nursing Team can help you; they have resources, which may be of benefit.

If possible, it is helpful to include brothers and sisters in the decision-making of your child’s funeral.
Cancelling benefits/equipment/supplies

All benefits will need to be cancelled as soon as possible, (to prevent you from having to pay any money back); such as: Child Benefit, Disability Living Allowance, and Carers’ Allowance. You will need to contact the appropriate office (see below for contact details). They will need your child’s name, date of birth, reference number and National Insurance number. If this is too painful for you to do, then ask someone to act on your behalf.

Any medical/nursing equipment will also need to be returned.

- Bereavement Services (to cancel benefits and report a child’s death) 0800 731 0299   Website: www.gov.uk
- Carer’s Allowance helpline: 0800 731 0299
- Disability Living/Attendance Allowance helpline: 08457 123456
- Nutricia Homeward (re. collecting feeding equipment): 08457 623671

And afterwards

You may experience feelings of grief: such as numbness, yearning, anger, guilt, and sadness for some time. Your emotions (and those of your other children) may also fluctuate. Missing your child and the loss of the role of being a parent can cause considerable pain. You may cry for a considerable length of time. You may find it difficult to function normally. Disorganisation, lack of motivation and despair are common.

Grieving is a natural response to loss. Grieving takes time and it might help to talk to someone about the feelings you may be experiencing. The Children’s Community Nursing Team would be happy to support you (or your other children) in your bereavement. Some families may want to contact bereavement groups, such as those listed below.

Useful bereavement groups

- Child Bereavement Trust: 01494 568900 (www.childbereavement.org.uk
- Compassionate Friends: 08451 232304
- Cambridge CRUSE Bereavement Care: 01223 302662
- SANDS (Stillbirth & Neonatal Death charity): 020 7436 5881
- Winston’s Wish: 0845 2030405

The Children’s Community Nursing Team is available to provide you and siblings with bereavement support/counselling or can direct your family. (Tel: 01223 218061).
And finally…

“Will you forgive me if I go on?
If you can’t make this earthly journey through time with me,
Will you then come along in my heart and wish me well?”

(Word of a bereaved mother).
Acknowledgements

Special thanks to the bereaved parents and their families whom I have had the privilege of supporting/counselling, and to those who have contributed to the writing of this leaflet.

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The Children’s Community Nursing Team was granted funding from the Diana Memorial Trust (Registered Charity No: TSC13) to support families with children who have life limiting/threatening conditions. We have a small supply of equipment that we lend to families in order to keep their child as comfortable as possible at home. If you would like to donate any monies to our charitable trust, we would be extremely grateful and use it for the care and comfort of future sick children.

Thank you.

If you require this information in a different format such as in large print or on audio tape, or in a different language please contact the service on the details above.

If you have any compliments about this service or suggestions for improvements, contact our Patient Advice and Liaison Service on 0300 131 1000 (charges may apply depending on your network) or email: ccs-tr.pals@nhs.net.

For free, confidential health advice and information 24 hours a day, 365 days a year please contact NHS 111.