



Choices

This document helps the child's medical and nursing team to explore and record the child and family wishes and choices for care of a child with a life limiting or life threatening condition in the event of significant deterioration

<p><u>Child Profile</u></p> <p>Name of Child:</p> <p>Preferred Name:</p> <p>Male/female:</p> <p>Address:</p>	<p>Date Of Birth:</p> <p>Hospital Number:</p> <p>Ethnicity:</p> <p>Spoken Language:</p> <p>Religion:</p>
<p><u>Family profile</u></p> <p>Mother's Name:</p> <p>Spoken Language:</p> <p>Is interpreter required: Yes/No</p> <p>Mother's Address / Telephone number:</p>	<p>Father's name:</p> <p>Spoken Language:</p> <p>Is interpreter required: Yes/No</p> <p>Father's Address / Telephone number</p>
<p>Are Parents: Married /Partners/ Single/Divorced/Separated</p> <p><i>(If living separately: Ensure both addresses for contacting parents are recorded)</i></p> <p>Child lives with:</p> <p>Person with legal responsibility for the child:</p> <p>Names and ages of siblings:</p> <p>Significant others e.g. Grandparents, Foster carers:</p>	



Role	Name	Contact Details
Named medical lead		
Named non-medical lead (Keyworker)		

Significant People – Family/Friends/Professionals/Carers

Name	Relationship	Contact details
	GP	
	Children's Community Nurse	
	Children's Hospice	
	Specialist Social worker	
	Family Support worker	
	Psychologist	
	Physiotherapist /Occupational	



	Therapist	
Name	Relationship	Contact details
	Charity/voluntary Organisation	

Is an Emergency Care Plan/Personal Resuscitation Plan in place?	Yes/No
Has 'out of hours' Emergency GP been notified?	Yes/No

**Family's Level of Understanding and Emotional Support Needs:**

Please give consideration to the family's emotional needs and how they are coping with the situation they find themselves in.

Please consider the support systems that the child and their family have in place and whether further referrals are required. Get child / family permission before sharing any information.

Agencies that may be able to help include:

Child Bereavement Team
Butterfly Project
Local Hospice
Specialist Social Worker
Specialist Nurse
Psychology team
Counselling services
Child/young person's school
Support organisation for child's specific condition
Child Bereavement Trust
Winston's Wish charity

There are many useful leaflets and workbooks available to help families.

Resources are available to assist in the completion of this document. These should be made available to professionals and families. All information has been chosen for being informative and accessible for professionals and families.



What is the child's understanding of their situation		Sign	Date
Discussion held with			
Give details of understanding wishes during life			
Action taken			
What do the parents understand about their child's situation?		Sign	Date
Discussion held with			
Give details of understanding, beliefs, wishes during life			
Action taken			



What do the sibling's understand about the situation? Please be aware each sibling knowledge and understanding may be different and should therefore be documented separately.		Sign	Date
Discussion held with			
Give details of understanding, beliefs, wishes during life			
Action taken			

What do extended family/support network understand about the situation? What are their support needs?		Sign	Date
Discussion with			
Give details of understanding, beliefs, wishes during life			
Action taken			



<p><u>Practical and support needs</u> - <i>If relevant to the choices they can make</i></p> <p>E.g. Housing, financial, employment, respite care, educational, play, complementary therapy or transport needs/issues etc?</p>		Sign	Date
Discussion with			
Action taken			

<p><u>Keepsakes and memory activities</u></p> <p>Have the family been offered the opportunity to obtain keepsakes whilst the child is well and still able to contribute themselves.</p> <p>The family may wish to consider compiling life/memory books/diaries/video diaries, as well as taking hand and foot prints, jewellery, castings, clay imprints.</p> <p>The family may also like keepsakes of all family members.</p>			
	Details	Sign	Date
Discussion with			
Action taken			



Specific choices around the time of death

It is important to take the child's wishes into account where possible.

Circumstances and events around the child's condition and death may cause these choices to change, so these should be revisited as often as necessary, according to child and family's needs.

	Name	Contact Details
Keyworker for pre and post bereavement Support		

Where would the family prefer their child's death to take place, if choice is a possibility at the time?

HOME

HOSPICE

HOSPITAL

OTHER;

	Details	Sign	Date
Discussion with			
Child and Family wishes			
Actions Taken			



If at home, who will certify death?	
Name:	Contact Details:
Who would the family like to be with them at the time of death? (Immediate family, extended family, community nurse, specialist nurse, support worker, GP, religious/cultural representative - <i>it is not always possible for professionals to be present</i>)	
Names:	Contact Details

Are these any specific Cultural/Religious or Spiritual needs that need to be considered/ performed during last few days of life? E.g. Would they like their child to be blessed / baptised, does the child need to be facing a certain direction, ambient lighting, and music?			
	Details	Sign	Date
Discussion with			
Discussion of families wishes			
Action taken			



Tissue Donation

Before & following a death some families may wish to consider donating organs or tissue for the purposes of transplantation or research. If this is requested by the family then the key worker should contact the On-call Donor co-ordinator (via Switchboard).

They will then give the family all the advice and information to help them reach an informed decision.

Corneas can be obtained up to 24 hours after death
Heart valves can be obtained up to 48 hours after death.

Unless the child is attached to a ventilator on PICU, it would not be possible to donate any organs for transplantation, although donation for research purposes may be possible.

Because of the short time frame whenever possible it is helpful to have explored this choice beforehand. Detailed information is best given on a family by family basis.

	Details	Sign	Date
Discussion with			
Family's choice			
Action Taken			



Would the family like help with planning the funeral before or after death?		Yes Before	Yes After	No
Do they wish to speak to a funeral director or religious support?			Yes	No
	Details	Sign	Date	
Discussion with				
Child and Family's wishes				
Action taken				
<p>Details of Funeral Directors – if already chosen by family</p> <p>Name:</p> <p>Contact details:</p> <p>Have the family decided on burial or cremation <input type="checkbox"/></p>				



Are there any specific Cultural/Religious or cultural need that need to be considered after death?		Sign	Date
Discussion with			
Details			
Action Taken			

Care of child after death - Family should be made aware of the choices for care of their child after death (Keep the child at home, collection by funeral director, hospice, embalmed and returned home, cultural or religious observances etc.)		Sign	Date
Discussion with			
Family's wishes			
Action taken			



Child Death Review Process

Parents and family members should be informed that their child's death will be reviewed anonymously through the Child Death Review process. This is to ensure that any lessons are learnt; improvements to services are made and appropriate support is provided for the family.

Parents should be informed on how they can contribute their views to the process.

The differences and implication for families regarding expected and unexpected deaths should be explained.

Parents should be provided with literature that explains the review process.

Please contact the Child Death Review Team for any further information

Parents informed on:.....

Post Mortem Examinations

Some families may express an interest in having a post mortem after the death of their child.

This may help answer questions and may help with the planning of any future pregnancies etc.

In this situation please contact the pathology team.

	Details	Sign	Date
Discussion with			
Families choice			

What arrangements would the family like for collection of equipment/drugs from for the home?	Immediately	
	After the funeral	
	Not sure	



Please document where copies of this document are held:	Tick
With child or young person with PRP	
Family held records	
Key worker	
Hospital Case Notes	
GP	
Community Nurses	
Hospice	
Other:	
Other:	

Signed:	Date:
Print name and designation:	
Contact details :	

If you would like any assistance in completing this form then please do not hesitate to contact the Child Bereavement Team or the Butterfly Team of specialist family support workers.



Any additional information or choices can be recorded here
(continue overleaf if necessary):

A large, empty rectangular box with a black border, intended for recording additional information or choices. The box is currently blank.

