

CHILD & FAMILY WISHES:

Discussion Record

Advance care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision making.*

This discussion record can be used by **any member of the Healthcare Team** in co-ordination with colleagues, to record a family's preferences and requests at all stages over the life course.

These are difficult but necessary conversations and guidance is offered in the accompanying 'Information for Health Professionals' and 'Information for Families' leaflet.

Name of child:

Date of birth:

NHS/patient ID number:

Date plan first discussed:

Date plan reviewed:

After discussion with the family, please ensure that a copy of the plan is included in all medical notes and give a copy to the family, the child's GP & all other relevant services.

To have completed records uploaded to the Bristol Children's Hospital database, email to ubh-tr.WishesDocument@nhs.net

*Ref: Fraser J, Harris N, Beringer AJ, Prescott H & Finlay F (2010) Advanced care planning in children with life-limiting conditions – the Wishes document. *Archives of Disease in Childhood* 95:79-82.

COORDINATION INFORMATION

Name of child:

Date of birth:

Name of parent/carer(s):*

Address:

Telephone No:

***Name/address of adult(s) with parental responsibility:
(if different from above)**

Diagnosis & background summary:

Framework for decision-making:

- ☐ Wishes of young person with capacity
- ☐ Wishes of parent(s) for child on 'best interests' basis
- ☐ Best interests basis (according to Mental Capacity Act 2005)
- ☐ Other (please specify)

Lead Consultant:

Name:

Post:

Organisation:

Tel no:

E-mail

Care Coordinator: (the person who works closely with the family to plan, coordinate and communicate between different members of the team)

Name:

Post:

Organisation:

Tel no:

E-mail

Key people involved in the care of the child & family: (NB check page 7 where there is space for more people to be included)

Name:

Post:

Organisation:

Tel no:

E-mail

WISHES DURING LIFE

Name of child:

Date of birth:

Child's wishes:

(consider in relation to 'everyday' quality of life as well as special treats)

Family wishes:

(consider how the family want to be supported to achieve 'everyday' quality of life)

Other's wishes: (e.g. school friends)

PLANS FOR WHEN CHILD BECOMES MORE UNWELL

Name of child:

Date of birth:

What may happen?

(e.g. deteriorating mobility, feeding, cognitive function, worsening seizures)

Preferred place of care: (may include hospice, home, local or regional hospital ward, HDU, PICU)

Preferred treatment options: (Indicate if not applicable or inappropriate)

- ☐ **Antibiotics** - e.g. Oral / IV / 'Portacath'

- ☐ **Feeding** - e.g. NG tube / gastrostomy

- ☐ **Respiratory Support** - e.g. Oxygen / non-invasive ventilation

- ☐ **Seizure Management Plan** (please provide summary and/or location of detailed plan)

- ☐ **Advanced Life Support Requiring PICU Admission** (might include inotropic drugs, invasive ventilation and advanced renal replacement therapy)

PLANS FOR CARE DURING AN ACUTE LIFE-THREATENING EVENT

Name of child:

Date of birth:

	YES	NO
Oxygen via face mask/nasal cannulae	<input type="checkbox"/>	<input type="checkbox"/>
Airway management using oral/ nasopharyngeal airway	<input type="checkbox"/>	<input type="checkbox"/>
Bag & mask ventilation	<input type="checkbox"/>	<input type="checkbox"/>
Endotracheal tube & ventilation	<input type="checkbox"/>	<input type="checkbox"/>
External cardiac compressions	<input type="checkbox"/>	<input type="checkbox"/>
Defibrillation & adrenaline to restart the heart following cardiac arrest	<input type="checkbox"/>	<input type="checkbox"/>

Please give further details, if required:

(e.g. continue 'bagging' until parents are present)

Next steps:

If child deteriorates further and end of life phase is recognised, identify from within the team an 'end-of-life care coordinator' and medical lead to facilitate and implement end of life care pathway. (Refer to 'Information for Health Professionals' leaflet p2, for guidance about these roles)

Name/contact details of end of life care coordinator:

Name/contact details of medical lead:

Preferred place of care:

Inform Ambulance Service if DNA CPR (do not attempt cardio-pulmonary resuscitation) has been agreed and child is going/at home (tick when done) ☐

For families living in the former Avon area (Bristol, Bath, North and North East Somerset and South Gloucestershire), Cornwall, Devon, Dorset, Gloucestershire, the Isles of Scilly, Somerset or Wiltshire email a copy of the record to swasnt.Clinical-Alerts@nhs.net

WISHES FOR AFTER DEATH

Name of child

Date of birth:

Organ & tissue donation: (See <https://www.organdonation.nhs.uk/> or <http://www.nhsbt.nhs.uk/tissuedonation/> or tel. 0800 432 0559 for additional guidance)

Preferred place of care of child after death:

Funeral preferences:

(Seek detailed information or further advice if needed)

Spiritual & cultural wishes:

Other child & family wishes:

COMMUNICATION INFORMATION

People involved in the care of the child & family (NB check also page 2 where Lead Clinician and Care Coordinator are named)

Name:	
Post:	
Organisation:	
Tel no:	E-mail

Name:	
Post:	
Organisation:	
Tel no:	E-mail

Name:	
Post:	
Organisation:	
Tel no:	E-mail

Name:	
Post:	
Organisation:	
Tel no:	E-mail

Name:	
Post:	
Organisation:	
Tel no:	E-mail

Communication notes: use this space to record any other information you think is important

This plan discussed by:	
Child / Parent / Carer	
Professional [Name & job title]	
Date	
Updated on (new date)	

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FURTHER INFORMATION & RESOURCES

'Information for Health Professionals' and **'Information for Families'** leaflets to support the use of the 'Child & Family Wishes: discussion record' are free to download from the Together for Short Lives website or request from;

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UWE Bristol
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antonia.beringer@uwe.ac.uk

End of life care planning - useful resources:

1. Together for Short Lives www.togetherforshortlives.org.uk
2. Child Bereavement Trust www.childbereavement.org.uk
3. Child Bereavement Network www.childhoodbereavementnetwork.org.uk
4. CLIC-Sargent (Cancer and leukaemia in childhood) www.clicsargent.org.uk
5. Children's cancer and leukaemia group (CCLG) www.cclg.org.uk
6. Winston's Wish child bereavement charity <http://www.winstonswish.org.uk/>
7. Department of Health guidance relating to child death:
www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview

The Child & Family Wishes: discussion record was developed by members of the Avon Children's Palliative Care Partnership Group, with the intention that it is freely available to support, and promote, end of life care planning for children with life-limiting conditions.

We update the record regularly and are always pleased to receive suggestions about how it can be improved. Please email these to childrenspalliativecare@uhbristol.nhs.uk

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