

## CHILD & FAMILY WISHES: advance care plan

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 advance care plan can be used by **any member of the Healthcare Team** in co-ordination with colleagues, to record a family's preferences and requests.

These are difficult but necessary discussions and guidance is offered in the accompanying 'Child & family Wishes - Information for Health Professionals' and 'Child & Family Wishes – Information for Families' leaflet.

Name of child:

Date of birth:

NHS/patient ID number:

Date(s) plan discussed:

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

\*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.

## CHILD & FAMILY WISHES

### COORDINATION INFORMATION

**Name of child:**

**Date of birth:**

**Name of parent(s):**

**Name and age of sibling(s):**

**Address:**

**Telephone No:**

**Diagnosis & background summary:**

**Lead Consultant:**

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

**Other professionals in the Team around the child:** (this should include the 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

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

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

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

## CHILD & FAMILY WISHES

### WISHES DURING LIFE

**Name:**

**Date of Birth:**

**Child's wishes during life:**

**Family wishes during life:**

**Other's wishes during life:** [e.g. school friends, siblings]

**This page discussed by:**

Child / Parent / Carer

Professional [Name & job title]

Date

Updated on (new date)

## CHILD & FAMILY WISHES

### PLANS FOR WHEN CHILD BECOMES MORE UNWELL

**Name:**

**Date of Birth:**

**What may happen?**

E.g. deteriorating mobility, feeding, cognitive function, worsening seizures.

**Preferred place of care:**

**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. mask ventilation**
  
- ☐ **Seizure Management Plan**

**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 regarding these roles)

**Inform Ambulance Service if DNA CPR has been agreed and child is going/at home.**

**This page discussed by:**

Child / Parent / Carer

Professional [Name & job title]

Date

Updated on (new date)

## CHILD & FAMILY WISHES

### PLANS FOR CARE DURING AN ACUTE LIFE-THREATENING EVENT

	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	<input type="checkbox"/>	<input type="checkbox"/>
Advanced life support requiring PICU admission (Including inotropic drugs and advanced renal replacement therapy)	<input type="checkbox"/>	<input type="checkbox"/>

**Please give further details, if required:**

**Other issues discussed:**

**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.**

**Inform Ambulance Service if DNA CPR has been agreed and child is going/at home.**

**This page discussed by:**

Child / Parent / Carer

Professional [Name & job title]

Date

Updated on (new date)

## CHILD & FAMILY WISHES

### WISHES FOR AFTER DEATH

**Preferred place of care of child's body:**

**Funeral preferences:**

(Seek detailed information or further advice if needed)

**Spiritual & cultural wishes:**

**Other child & family wishes:** e.g. what happens to possessions?

**Organ & tissue donation:**

**This page discussed by:**

Child / Parent / Carer	
Professional [Name & job title]	
Date	
Updated on (new date)	

## CHILD & FAMILY WISHES

**'Information for Health Professionals'** and **'Information for Families'** leaflets have been designed to support the use of the 'Child & family Wishes: advance care plan'. These are available on request from;

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[antonia.beringer@uwe.ac.uk](mailto:antonia.beringer@uwe.ac.uk)

...or for free download at the Together for Short Lives website.

### End of life care planning - useful resources:

1. Together for Short Lives (The Association for Children's Palliative Care and Children's Hospices UK [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk))
2. Child Bereavement Trust [www.childbereavement.org.uk](http://www.childbereavement.org.uk)
3. Department of Health guidance relating to child death:  
[www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview](http://www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview)  
Since April 1<sup>st</sup> 2008, there has been a statutory requirement to investigate **unexpected and unexplained** deaths of children. The website summarises these processes.
4. Child Bereavement Network [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)
5. CLIC-Sargent (Cancer and leukaemia in childhood) leaflets/booklets, including; 'When there is no Longer a Cure', 'When our Child Has Died', 'Living Without your Child', available at [www.clicsargent.org.uk](http://www.clicsargent.org.uk)
6. Children's cancer and leukaemia group (CCLG) leaflets, including; 'Choices: When it seems there are none', 'Facing the Death of Your Child', 'Bereavement: Where to go for help', available at [www.cclg.org.uk](http://www.cclg.org.uk)

**The Child & Family Wishes: advance care plan was developed by members of the Avon Children's Palliative Care Partnership Group and is freely available to support, and promote, End of Life planning for children with life-limiting conditions.**

**We update the plan regularly and are always pleased to receive suggestions about how it can be improved. Please email these to [antonia.beringer@uwe.ac.uk](mailto:antonia.beringer@uwe.ac.uk)**

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