

CHILD & FAMILY WISHES: Advance care plan

Information for Health Professionals

This guide is intended to support and guide you in using the 'Child* & Family Wishes' advance care plan, when supporting families in planning for end of life care, in your clinical practice.

“What is the ‘Child & Family Wishes’ advance care plan?”

It is a plan, designed to communicate the health-care preferences of children who have life-limiting conditions and their family. It sets out an agreed plan of care to be followed when a child's condition deteriorates. It provides a framework for both discussing and advance care planning the agreed wishes of a child and his or her parents, when the child develops potentially life-threatening complications of his or her condition. It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service. It can be used as a resuscitation plan or as an end-of-life care plan. It remains valid when parent(s) or next of kin cannot be contacted.

“Who should initiate a ‘Child & Family Wishes’ conversation?”

Any member of the multidisciplinary team who knows the child and family well can initiate a conversation and begin a 'Wishes' advance care plan. In practice, this is usually a senior clinician or experienced nurse. A 'Wishes' advance care plan is different from a DNACPR [Do Not Attempt Cardio-pulmonary Resuscitation] form in that it does not need to be authorised by a medical doctor.

The main **benefit** of the 'Wishes' advance care plan being initiated by anyone, is flexibility, as different people may know the child and family in different clinical circumstances. The main **drawback**, of the 'Wishes' advance care plan being initiated by anyone, is the risk that no-one may actually take it upon themselves to do it. For this reason, it may be useful to **designate someone in your own clinical area to be responsible** for checking that everyone who needs one has one, and setting up a system for reviewing this.

* for child please also read baby, child or young person

“Who plays what role in planning end of life care?”

We have recognised there two key phases to take into consideration when planning end of life care and suggest it might be helpful to identify the different roles associated with these. The first phase may go on for some time, perhaps years, during which a ‘Team around the Child’, including a number of different professionals and a lead consultant, will manage the child’s care.

The second phase is when the child becomes significantly more unwell and the end of life stage is recognised. This is when the plans made for end of life care need to be acted upon. At this stage, or in anticipation of it, you may find it useful to identify an ‘End of Life Care Coordinator’ and a medical lead, to facilitate and implement the end of life care pathway.

The purpose of the End of Life Care Coordinator is to facilitate the delivery of an individualised care package which has been drawn up to match the needs of the child with available resources of staff, knowledge and equipment. It will involve skilful coordination, across agencies, at a time-pressured and stressful period.

The End of Life medical lead role involves coordinating care with other medical colleagues and making sure arrangements are in place to allow the child to die in their preferred place, wherever possible.

We envisage that both these roles will be taken up by professionals who are already members of the ‘Team around the child’, but would emphasise the need for clear lines of communication and responsibility for implementing the end of life care plan once this phase is reached.

“Why should I initiate a ‘Child & Family Wishes’ conversation?”

A discussion about options for end of life care **offers choice** to families. The opportunity to plan ahead is related to better coping after bereavement and is also associated with people being more satisfied with the service they receive. Parents who have been in this situation report how having an end of life care plan, even if the details changed in the event, helped them come to terms with their child’s death.

“When is the right time to start planning for end of life care?”

Begin by asking yourself the following questions:

- Would you be surprised if this child died prematurely due to a life-limiting illness?
- Would you be surprised if this child died within a year?
- Would you be surprised if this child died during this episode of care?
- Do you know what the child’s and family’s wishes are for the end of life?

If the answer to any of these questions is “No”, then this might well be the right time to start planning for end of life care.

Another way of helping to decide when to start planning is to use a ‘traffic light’ approach, where the following questions act as triggers at different life stages.

A ‘traffic light’ approach:

- **Diagnosis or recognition**
 - Would you be surprised if this child died as a result of this condition or problem?
- **Death before adulthood**
 - Would you be surprised if this child died before adulthood?
- **Increasing instability**
 - Would you be surprised if this baby / child died in the next few months to years? Or
 - Would you be surprised if this child died in the next five years?
- **Critical illness or end of life**
 - Would you be surprised if this child was not alive in a few weeks’ time?

Again, if the answer to any of the above questions is “No”, then this may be the right time to start planning for end of life care.

The next steps are to:

- Find out who else is involved in the care of the child & family, e.g. Lifetime, Jessie May, children’s hospice or other services.
- Find out if the family have already discussed End of Life care and whether they have a resuscitation plan. (Prompt: *‘has anyone had a*

discussion with you about what you would like to happen if your child becomes seriously ill?)

“There never seems to be a good time to bring up the subject of end of life care...”

Initiating a conversation about end of life care is a difficult thing to do, even if you have had years of experience and training. Try not to let this natural apprehension hold you back from beginning the conversation.

Pick up on cues from families and **take opportunities** when they arise. These can often be **triggered** by a clinical event, for example an episode of acute illness or deterioration in an existing condition. Other things that may prompt a discussion are;

- following one or several 'acute episodes'
- if the child is very unwell or the potential for this is very present
- if you are concerned that it has not been done and needs doing
- if asked for by family
- if the family express anxieties about 'what might happen' at the end of life
- if there is disagreement amongst family members about their choices for end of life care
- if you don't know what the wishes of the family are...

“How shall I get the conversation started?”

You may find it helpful to talk (about something else) before 'the talk'. You could use recent experiences the family/child have had. Once you've started a conversation you could bring in the subject of end of life care by saying something such as...

'this is a difficult thing to bring up, but I wonder if you've had any thoughts about how you would like [child's name] to be cared for if they were to become even more unwell.'

If the family does not feel ready, let them know that they can talk to you or others when they do feel ready. Try to set them a time to have the conversation(s). You could also offer them the Information for Families about the 'Wishes' advance care plan leaflet (not the 'Wishes advance care plan' itself). This keeps the door to that conversation ajar, so it can be opened more easily next time.

Key point: If, for any reason, you do not feel able to begin the conversation with a family, even though you think it's the right time, tell someone else in the team so they can pick it up. Don't let the opportunity pass.

In summary:

- Think about why you are doing it, and be sensitively honest with the family about these reasons.
- Pick up on cues...
- Acknowledge the difficult feelings for yourself and family, but also the importance of the conversation and what is hoped to be gained by it.

Once the conversation has begun, parents often feel relieved to be able to talk openly about the choices available to them, and their wishes for end of life care for their child.

“What happens if I don't get to fill in all the boxes?”

- You shouldn't aim to fill them all in at one sitting. If you do that's fine, but it will often take more than one conversation.
- The advance care plan is not intended to be a 'tick box exercise', but rather to support a process and a conversation (the 'boxes' are only there to prompt and guide you)

- Do not feel under pressure to complete the form by a certain time - be **led by the needs of the family** as to which parts need to be discussed or reviewed – with whom, where and at what time.

If the family already have a plan, you may wish to review it with them, to ensure that it is still relevant and to update it if required. If there is no plan, you can use the Wishes advance care plan ‘template’ as a guide for the discussion.

	CHILD	FAMILY	OTHERS e.g. friends, school
WISHES DURING LIFE	special event or a goal to achieve	family holiday	fundraising
PLANS FOR WHEN CHILD BECOMES UNWELL	what may happen?	treatment options	visiting
ACUTE LIFE THREATENING EVENT	preferred place of care,	treatment options	
AFTER DEATH	wishes for pets, belongings	spiritual & cultural wishes	funeral plans

Table: examples of aspects of care the child & family may want to consider.

“What do I do if I feel unable to answer the families’ questions? For example, I know nothing about organ donation”

- Do not worry. No-one is an expert.
- This situation can be avoided by having a ‘talk before the talk’ that explores in advance the issues the family wishes to discuss. This gives you an opportunity to source information from the professionals with the specific knowledge.
- If there are things you don’t know, and haven’t anticipated, tell the family you will find out the information for them and provide this in a timely manner.

“What should I do with the ‘Wishes’ advance care plan after the discussion?”

Sign, print your name and date the form. Give a copy of the plan, even if it is incomplete, to the family. Put a copy of the plan at the front of the child’s health record (or copies in the medical notes and the nursing notes if these are held separately). Also, write in the notes that the ‘Wishes’ advance care plan has been started. Email a copy to the Emergency Department at BCH. Send, or arrange to

have sent, a copy to the child's GP and copies to other community based services who are involved in the child's care.

For any child going home with a 'Wishes' advance care plan, especially if the family have chosen to care for their child at home at the end of life, send a copy to GWAS (Great Western Ambulance Service) to notify them. This is important as it allows the paramedics to uphold the family's wishes. The default response to a call-out is to attempt resuscitation and bring the child to hospital.

The maximum time for review is no more than 12 months. When setting the review date the health care team should consider:

1. The nature of the child's condition or disability, and the likelihood of changes in prognosis or treatment options.
2. The child's developing maturity (competence) and how this will affect their need for involvement in the planning discussion.
3. Whether there are any planned procedures or interventions that have the potential to precipitate a collapse, such as major surgery. In such circumstances the potential complications should be discussed, and an appropriate level of intervention (or non-intervention) agreed and advance care planned. This may involve a temporary suspension of a DNACPR. The child's surgical and anaesthetic team must be consulted and kept informed of any decisions.
4. Families should be invited to take part in the review process but may choose not to if nothing has changed.

Health warning

It is recognised that this work can have a psychological and physical impact on you. Take steps to look after yourself by accessing support available, e.g. colleagues, psychologists, bereavement counsellors, as and when you feel it is appropriate.