



Child and  
Young Person's  
**Advance Care Plan**  
Collaborative

# Policy

## Child and Young Person's Advance Care Plan

### A unified collaborative approach

This document provides additional information for clinicians to help inform discussions related to the Child and Young Person's ACP (CYPACP) forms (Version 4).

Should you have any ethical, legal or clinical queries about the CYPACP please contact your local team for advice and training. The document should be used alongside local Trust policies and guidelines.

It is the responsibility of the clinician to keep abreast of relevant ethical, legal and professional guidelines and developments that may impact on the use of the CYPACP document.

#### **Guidance**

The Child and Young Person's Advance Care Plan (CYPACP) is a summary document that facilitates the clear and concise communication of the wishes of a

child or young person (and their families), who have chronic and life-limiting conditions:

- It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates.
- It provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents, when the child or young person 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 and emergency care.
- The CYPACP can be used as a resuscitation plan and as an end-of-life care plan.
- It remains valid when parent(s) or next of kin cannot be contacted.
- It incorporates the ReSPECT form as a summary for those geographical areas where ReSPECT has been adopted. A version with an original style page for the management of cardiopulmonary arrest is still available for areas that have not transitioned over to ReSPECT. (Legacy Version)

The CYPACP is intended to support and enhance the delivery of the best possible care to the child or young person and their family. The document can be used flexibly and is likely to change over time.

The CYPACP can be used for a person under the age of 18 years old. After the age of 18 years, the use of an Advance Care Plan and/or Lasting Power of Attorney for Health and Welfare can be considered. The CYPACP document can be used to plan and state the wishes of a child that is likely to need medical intervention at delivery and is known to have a life-limiting condition.

## Decision-making

A child or young person should be involved in the decision-making process where possible and reasonable; their wishes listened to and taken into account about issues that affect them.

It is important that clinicians using the CYPACP document are clear about the roles and responsibilities of parents in relation to decision-making on behalf of a child and, potentially, the developing ability of a child to be able to make decisions about their healthcare as they mature. Clinicians must be able to assess the capacity of a child or young person below the age of 16 years and adhere to the Mental Capacity Act (2005) relating to decisions for a young person that is 16 years old and older. Information about the consent and the roles of parents in this process can be found in GMC guidance or directly from statutory law, including the Children Act (1989).

The GMC document *0-18 years: guidance for doctors* provides valuable information about consent, confidentiality and parental responsibility which should be used in conjunction with the NICE guidance for end of life care for infants, children and young people with life limiting conditions (NG61, 2016 and QS160).

Parents and clinicians are required to act in the child's **best interests** when making decisions on behalf of or with a person under the age 18 years. This is described in the General Medical Council (GMC) ethical guidance for doctors working with 0-18 year old as follows:

An assessment of best interests will include what is ***clinically indicated*** in a *particular case*.

You should also consider:

- a. the views of the child or young person, so far as they can express them, including any previously expressed preferences
- b. the views of parents
- c. the views of others close to the child or young person
- d. the cultural, religious or other beliefs and values of the child or parents

- e. the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
- f. which choice, if there is more than one, will least restrict the child or young person's future options.

This list is not exhaustive. The weight you attach to each point will depend on the circumstances, and you should consider any other relevant information. You should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability (GMC 0-18 years).

When there is a divergence of opinion about the type of medical intervention that represents a child's best interests, parents and clinicians should work together to resolve the disagreement as far as possible, with the child's welfare considered of paramount importance. Parents and clinicians have a moral and legal duty to protect children from significant harm. If local resolution is not possible, it may be appropriate to seek a second opinion, consult a Clinical Ethics Committee and consider mediation. The Royal College of Paediatrics and Child Health (RCPCH) have published guidance on both Conflict Resolution and Withholding and Withdrawal of Life-sustaining treatment which can be found on the RCPCH website.

### **Do not attempt cardio-pulmonary resuscitation (DNACPR)**

Whatever the prognosis and advance decisions that may be in place, the child's comfort should always be a primary consideration. Every attempt should be made to minimise distress and to fulfil the child and the families' wishes wherever possible.

Attempted resuscitation should be the default action for all children, unless there is a valid DNACPR decision in place. If there is any doubt about the validity of a DNACPR decision, then resuscitation should be initiated.

Clinicians should adhere to a valid DNACPR in the event of a life-threatening change in the child's clinical condition, unless this is a potentially reversible cause such as

choking or anaphylaxis, or a person with parental responsibility changes their mind. The recorded DNACPR decision should, therefore, be considered in context. As the clinical picture of the child/young person evolves, DNACPR decisions should be reviewed appropriately.

DNACPR applies **only to CPR**. Other types of resuscitation can be described in the CYPACP document and considered independently of CPR decisions.

## **Summary**

The CYPACP documents the collaborative wishes and plans of decision-makers about children and young people with chronic or life-limiting conditions. The conversations and documentation of decisions should be considered within the ethical, legal and clinical frameworks that guide clinicians working with this group of children and young people.