

# Advanced Care Plan/ Emergency Health Care Plan Guidance for Professionals completing ACP/EHCP

## Introduction

### 1 Background

Children's palliative care is an active and total approach to care, from the point of diagnosis or recognition, throughout the child/young person's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement.

A child/young person with palliative care needs meets one of the following criteria as defined by 'Together for short lives' ([www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)).

#### Category 1

Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.

#### Category 2

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

#### Category 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, Mucopolysaccharidoses.

#### Category 4

Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.

One of the objectives in the 2016 Palliative Care Strategy NI is that families are informed and can contribute to the development of an appropriate and flexible end-of life plan.

- Advance care planning with families of children/young people 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 (Brook et al 2008).
- All professionals involved in the child/young person's care should be open and honest with parents and/or child young person.

- Advanced Care plans should be developed and reviewed with relevant members of the multidisciplinary team and in discussion with the child/young person and their parents or carers [those with parental responsibility] (NICE Guidelines 16, 2016).
- Families should be empowered through appropriate up-to-date information to make decisions, and their children, as appropriate should be integral to the decision making process (Together for short lives, 2012).
- A written plan of care is agreed and shared with relevant professionals and the parents and/or child / young person (as appropriate).
- Predicting the time when a child/young person is likely to move into the end of life phase of his/her illness is difficult, and the realization that death is inevitable and imminent can cause great distress to the family and the child/young person.
- It is vital that the family and child/young person should be allowed to plan for death. They should be able to exercise informed choices and receive full care and support in those choices.
- It is advisable that a plan is agreed in advance, based on the wishes of the family and/or child/young person (where relevant) with a proviso that the plan can be reviewed and updated/amended at any time in accordance with the parents and or child/young person's wishes.
- They may not be able to decide entirely about somethings until the death is a reality. (Together for short lives, 2012)
- Parents and child / young person must be made aware that the plan will be shared with other relevant professionals.

**The Plan is in two parts, the main Advanced Care Plan [ACP] and the Emergency Health Care Plan [EHCP] which contains a summary of the ACP discussions but focusses on emergency care including resuscitation requests.**

The EHCP is an agreed plan designed to make communication easier in the event of a health care emergency for children with life limiting conditions.

The core principles are: The Emergency Health Care Plan

- Is a clear plan previously agreed with the child and/or family for when the child's condition deteriorates
- Is to be used in all environments which the child encounters such as hospital, home, hospice, school and for use by the Northern Ireland Ambulance Service.
- Provides a framework for discussing and documenting the agreed wishes of the child and/or family when the child develops potentially life-threatening complications associated with his/her condition.
- Remains valid for an institution formally acting for parents, if parents or next of kin cannot be contacted.
- Shows clearly at the front of the document what action should be taken with regards resuscitation so that this can be immediately understood in times of crisis.
- Aims to prevent the situation where health workers unfamiliar with the child and what they are like at their best when well, may make judgments based on poorly informed or unfounded assumptions about the impact of the child's condition or disability on their quality of life
- Is brief so that information can quickly be communicated in an emergency
- Unlike an advanced directive, the document has no legal standing but the plan should be followed unless parents request different management.

- 

## 2 Purpose

This is a guideline to ensure ACPs and EHCPs are completed correctly at an appropriate time by the most appropriate person in partnership with the child and family.

## 3. Completing an Advanced Care Plan/ EHCP

### Starting the process

- **The child's best interest should be the focus at all times**
- Professionals should offer all families the opportunity to talk about issues regarding advanced care planning and end of life concerns. The ACP should be initiated by a Health care professional who knows the child well eg CCN, Hospice nurse, The EHCP should be completed by a senior doctor (e.g. Consultant, Associate Specialist) who knows the child and family well. both documents in conjunction with members of the multidisciplinary team
- The discussions can occur at many different times during the patient's journey, e.g. after a recent intensive care admission, after recovery from recurrent chest infections, if the child/young person and/or family enquire about an advanced plan
- The first step is open and sensitive discussions with child/family /parents and carers. This process may take several discussions over a period of time.
- A young person who has capacity should be involved in formulating their own plan.
- The child/young person and family must be allowed time to understand and question the information given
- The discussion may include issues of organ or tissue donation
- The child/young person and family must be reassured that they have the right to ask for a review and that their wishes during a medical emergency will be respected
- A written plan of care should be completed with the parents and/or child /young person (where relevant)
- The plan will include the preferred treatment options, special wishes, spiritual and cultural needs and preferred place of death. Decisions about withdrawal of non-essential drugs and other invasive interventions may be addressed at any time but should be further discussed and documented when the approach to end of life is recognized.
- The plan should be signed by a parent/guardian[ those with parental responsibility [+or the young person]to indicate that discussions have been held; that they understand the plan and understand that they may ask for a review
- All plans will be reviewed on an annual basis or as and when required to take account of any changes in the management of care or the child/young person's and family's wishes.
- It is essential that professionals ensure parents are aware of this and that changes can be made at any time.
- The family, child/young person should be supported in their choices and goals in planning for deterioration and the end of life phase of the child/young person's illness.
- Professionals should be open and honest with the child/young person and the family when the approach to end of life is recognized.

## Roles and Responsibilities

Advanced care plan can be completed by medical staff/Community nurse or Children's Hospice Nurse Specialist or nominated key worker for the child/ young person  
Once the advanced care plan is completed it is vital that it is circulated to the relevant professionals

### Dissemination

To all Paediatric Staff and Paediatric Clinical Areas,  
All Places where child spends time,  
School,  
Respite facilities,  
Grandparent **etc.**

Also a copy to NIAS

Medical Director:

[David.mcmanus@nias.hscni.net](mailto:David.mcmanus@nias.hscni.net)

Assistant Medical Director:

[Nigel.ruddell@nias.hscni.net](mailto:Nigel.ruddell@nias.hscni.net)

PA:

[Jane.mcswiggan@nias.hscni.net](mailto:Jane.mcswiggan@nias.hscni.net)

CCN team,  
NICH.

The doctor who signs the EHCP has responsibility to circulate the plan to relevant medical colleagues including /GP/NIAS and parents [those with parental responsibility]/ young person

The key worker within the trust has responsibility to ensure that completed plan is forwarded to school /NICH/respite facilities /trust care plan etc.

Each time the Advanced Care plan is updated/changed the professionals as mentioned above should ensure that the updated plan is circulated to professionals. Each professional has a responsibility to ensure that old plans are removed and retained as per trust policy .The original paper copies of older versions must be clearly scored out on both sides, if not destroyed.

**This is not the responsibility of the family**

## The Advanced Care Plan Form

### Section 1: Recognition of Need for Advanced care Plan.

Through their own understanding or following discussion with key professionals, the parents/child/young person (where relevant) recognize that there has been deterioration in their condition or that they are approaching end of life. Within this section a detailed record of the discussion with parents/child/young person should be completed and the following clinical aspects of care detailed:

- Decisions regarding the continued use of monitors and other equipment
- Continued use of regular medications, the introduction of palliative medication and possible routes of administering these
- Resuscitation - Parents and/or the child/young person (where relevant) must have full information regarding Cardio Pulmonary Resuscitation (CPR). Information should include description of CPR available (basic in community, advanced in hospital), the

consequence of intubation and possible ventilation, alternatives and possible outcomes of not attempting resuscitation.

## **Section 2: Equipment**

The child / young person may have medical equipment / monitors in their home as part of their existing care plan. As the child / young person's condition deteriorates towards the end of life, professionals should discuss the appropriateness of continued use of this equipment.

## **Section 3: Medication**

- (1) Parents or child / young person should be given the opportunity to discuss their treatment choices in the event of the development of infection i.e. oral or intravenous antibiotics.
- (2) Professionals should provide information on alternative routes of administration of medication e.g. (trans-dermal and subcutaneous) should the child / young person become unable to tolerate these by the usual route.
- (3) As the child approaches end of life, professionals should review the need for non-essential medication.

## **Section 4: Resuscitation**

Professionals should document the parent or child / young person's decisions regarding resuscitation and intensive care treatment. **This should include parent's wishes if they are absent at the time of the life threatening event.**

Within the Resuscitation section of the Advanced Care Plan ten issues are highlighted for individual discussion and decision. This is to ensure all relevant areas are discussed and that there is clarity about what are the wishes or parents /children. Decisions about resuscitation must be made on a highly individualized assessment of each child/young person's case.

## **Section 5: Family**

Families should be encouraged to focus on short term achievable goals in order to avoid distress of failure of achievement due to deterioration in child/young person's physical ability. They should be supported in their choices and in their endeavors to achieve their goals. Parents and/or child/young person should be advised that they have the choice to discuss and change any plans/goals that they may have made.

Siblings: It is important to recognize the impact of life limiting illness on siblings and the need for support should be discussed with siblings/parents. Determine key supportive adults and networks (e.g. teacher, friend, activities)

## **Section 6: Preferred place of care**

Discuss possible options for place of care at the end of life giving consideration to available resources and practical and clinical issues.

Where possible family wishes should be facilitated and these may change as the child/young person's condition changes or the family's need for support increases.

## **Section 7: Spiritual and Cultural Needs**

Discuss parental or child/young person's spiritual or cultural needs to ensure that these are considered and addressed, currently, at impending death or after death. NB: Be aware that parents may have different beliefs.

## **Section 8: Care at the Time of Death and After Death**

Discussing funeral arrangements etc. prior to a child/young person's death can ensure the parents and/or child/young person's (where relevant) wishes are followed at a time when shock and emotional stress may affect their ability to make their wishes known.

Discussions should include advice, support and their options regarding issues such as:

- Privacy and time with their child/young person after death.
- Having a member of staff with them after the child/young person dies
- Being given the opportunity to perform caring tasks for their child/young person if they wish. Some parents may derive comfort from washing and dressing their child/young person. Some families may wish to stay with their child/young person's body others may choose to leave after a short while.
- Having the opportunity to engage in memory making activities e.g. photos, hand or footprints.
- Individual cultural or religious needs and wishes will be considered and respected.
- Sibling support.
- Organ Donation

## **The Emergency Health Care Plan /summary of ACP discussions**

### Filling in the form

The form should be completed by the appropriate doctor after the discussions with family. It should then be reviewed by the family before signing and final copies being made.

**The form is designed to be A4 double sided and laminated.**

Side one is for use by paramedical staff or Emergency department staff to deal with the very acute situation.

Side two is designed to inform care/ subsequent to treatment in the Emergency Department/ward when further clinical information is vital to ongoing care.

### **Side 1**

#### Patient information

This should include full name, current address, date of birth, Health and Care number and the patient's most recent weight, with the date the weight was taken.

#### Clinical information section

This section should include diagnosis and relevant information about the patient's situation as well as the name of person(s) with parental responsibility, contact number and address, if different from patient.

#### Types of Emergency treatment required

This section should be tailored to the specific child/young person, depending on their condition.

This may include for example

- clearing upper airway
- using suction,
- oxygen by facemask,

- bag and mask ventilation,
- non-invasive ventilation,
- antibiotics (oral or intravenous should be documented),
- intravenous fluids,
- intraosseous fluids
- blood products,
- elective/emergency surgery.

Other management plans such as seizure control, management of metabolic emergencies, ITB pumps etc may be too big to include on the front page but should be attached to the plan.

### Management to be avoided

Include any allergies or actions that should be avoided eg. IV dextrose for a child on a ketogenic diet.

### Cardio-pulmonary Resuscitation requests

**This is not a tick box** as each child and/or their parents may have different opinions regarding actions which are and are not appropriate. **There needs to be clear and concise documentation of what the child and/or their family wants.**

This may vary from full resuscitation,

- bag and mask ventilation only,
- rescue breaths only,
- 20 minutes of CPR but no intubation
- or no cardio-pulmonary resuscitation.

The following list may be helpful when considering your wording

- No active resuscitation beyond comfort and support
- Suction to upper airways and airway clearance
- Oro or nasopharyngeal airway
- Oxygen by face mask or nasal cannulae for comfort
- Mouth to mouth or bag and mask ventilation/rescue breaths
- Full CPR
- IV or IO access
- ET tube and ventilation/admission to PICU

### Preferred place of death

If the child/young person and/or family have a preferred place for death to occur, this should be clearly documented, e.g. Home, Northern Ireland Children's Hospice, Children's ward.

### Contact details of Doctor who knows child

This section should clearly document name, address and emergency contact details of the doctor who knows the child. Please note there should be contact names and numbers of more than one person.

### Signatures

The child/young person and/or parents [those with parental responsibility] sign to confirm what has been discussed and agreed.

The signature of the doctor who had the discussion with the child/young person and/or the family.

The date should be completed to indicate when the discussion occurred.

The child/young person or those with parental responsibility can change their mind at any point including during resuscitation

## **Side 2**

### Clinical Summary

A very brief description of patient's condition, prognosis, and treatments given.

Technologies in use, eg PEG, trachea, Baclofen pump

### Salient points

Also, how the patient communicates, what they like, dislike, distresses them etc.

### Medication with weight at time of completion

All medications but particularly Anti-Epileptic, Anti dystonics etc

### Medication with special instructions

eg, dissolve in water

Baclofen pump needs to be deactivated by the neurodisability service

## **Rescue medications should be highlighted in bold**

### Main contact list

eg.

- GP
- Specialist nurses
- Specialist centre outside of NI, eg GOSH etc

### Dissemination list

List all people and institutions where there is a copy this plan.

**Please note that an EHCP does not expire**, but should be updated if the child's condition changes, or if the parent's change their request regarding treatment option.

A yearly review is recommended but the plan does not need to be rewritten if there are no changes. A reviewed date should be signed and posted on ECR so that people know they are looking at the latest version

## **3 IMPLEMENTATION**

Guideline should be available in all clinical areas where children with life-limiting conditions will be managed, e.g. Children's Ward and Neonatal Intensive Care Units in District and Regional Hospitals, Paediatric Outpatient Departments, and Community Paediatric Clinics. NICH

Agreed by the NI Special Interest Group Paediatric Palliative Care May 2017/ Reviewed and Updated October 2018