



Child and Young Person's Advance Care Plan Collaborative

Endorsed by NICE

This plan could begin antenatally

ALLERGIES

| | | | |
|---------|--|--------------|--|
| Name | | DOB | |
| Address | | | |
| | | Post code | |
| NHS No. | | Hospital No. | |

| | | | | | |
|--|-------------------------------------|-------------------------------|---------------------------------|-----------------------------------|----------------------------------|
| For use <small>(indicate as appropriate)</small> | Everywhere <input type="checkbox"/> | Home <input type="checkbox"/> | School <input type="checkbox"/> | Hospital <input type="checkbox"/> | Hospice <input type="checkbox"/> |
|--|-------------------------------------|-------------------------------|---------------------------------|-----------------------------------|----------------------------------|

| | | | |
|----------------------------|--|---|--|
| Date plan initiated | | Date review due (if appropriate) | |
|----------------------------|--|---|--|

| Date reviewed | Designation (grade/speciality) | Clinician name | GMC/NMC/ HCPC number | Signature |
|---------------|-----------------------------------|----------------|-------------------------|-----------|
| | | | | |
| | | | | |
| | | | | |



Child and Young Person's Advance Care Plan

This document is a tool for discussing and communicating the wishes of an infant, child, young person and/or their parent or carer. It is a collaborative document for shared decision-making between families and clinicians.

In addition to recording a concise record of the advance plans, this document is designed to provide a rapid overview of key decisions to the attending carers, should an emergency situation arise when the individual cannot give informed consent for themselves. This is particularly helpful if next of kin / parent(s) are not present immediately. It now incorporates ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) at the end of this document, including decisions around resuscitation.

The document has had input and support from English regions including: South Central and Wessex, South West, West Midlands, East Anglia, Kent and Sussex, London, North West, and the North East. The content of this care plan accurately reflects the NICE guideline on end of life care for infants, children and young people with life-limiting conditions. (NG61, 2016 and QS160). It also supports statement 1 in the NICE quality standard for end of life care for infants, children and young people. Version 4 is endorsed by NICE (E193) (2018).

For electronic copies of this form, information leaflets and associated guidance, see the CYPACP website: <http://cypacp.uk/>

Also see the ReSPECT website for further resources: <https://www.respectprocess.org.uk/>

| | |
|--|--|
| Lead Clinician | |
| Contact details | |
| 24 hr contact phone number (if available) | |
| What is this number? e.g. Ward, community nursing team, on call team or hospice? | |



Child & Young Person's Advance Care Plan (CYPACP)

INDEX

Section 1: Contacts, Demographics and Decision-making

Contacts and who has agreed and supports this plan 4

Diagnosis and Decision-making 5

Distribution list (Key Contacts) 6

Section 2: Wishes

Wishes during Life 7

Wishes around End of Life (Optional) 8

Section 3: Emergency Medical Management

Management of Anticipated Complications 9

Additional Notes 9

Management of an Acute Significant Deterioration (non-arrest) 10

ReSPECT (Recommended Summary Plan for Emergency Care & Treatment) including *Management of Cardiorespiratory Arrest* 11



Contacts and who has agreed and supports this plan

| | | | |
|--------------------|--|---------------------|--|
| Name | | Date of Birth | |
| Known as | | Interpreter needed? | |
| First Language | | Interpreter contact | |
| Telephone Numbers: | | | |

Name and emergency contact number of person/people with parental responsibility (and address if different from front page)

Other key family members and carers (optional):

Who has agreed and supports the plan?

| | | | |
|-----------------------|--|-------------------------------|--|
| Lead Clinician | | | |
| Name | | | |
| Role | | Professional registration no. | |
| Signature | | Date: | |

Young Person and person/people with parental responsibility

Please note that in recording names below, this indicates that the person/ people with parental responsibility, and the young person where appropriate, are aware of the plan and in agreement with it. (The signatures below are optional but help ensure their opinions have been included in the decision-making).

Young Person (where appropriate; signature optional)

| Name | Signature | Date |
|------|-----------|------|
| | | |

Person/ People with parental responsibility (signature optional)

| Name | Signature | Role | Date |
|------|-----------|------|------|
| 1 | | | |
| 2 | | | |

Others involved in decision-making, for example Multi-Disciplinary Team (MDT)

The young person or parents /carer can change their mind about any of the preferences on the care plan at any time. If a parent /person with parental responsibility is present at the time of their child's collapse, they may wish to deviate from the previously agreed plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person.



Diagnosis and Decision-making

Diagnoses

Main problems and background information

Social issues (Include if looked-after child)

Decision-making process

(Select at least one and please ensure this is consistent with Sections 5 & 6 of ReSPECT)

Basis of discussion / decision-making? (Indicate as appropriate) [X]

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Wishes of child/young person with capacity |
| <input type="checkbox"/> | Wishes of parent(s) for child on "best interests" basis |
| <input type="checkbox"/> | Best interests basis (as in Mental Capacity Act 2005) |
| <input type="checkbox"/> | Other (please state) |

Comment

Clinicians have a duty to act in a patient's best interests at all times.



Distribution list (Key Contacts)

Who is responsible for the distribution of the CYPACP, bringing it to the attention of professionals, and circulating any updates to it?

| Name and/or Role | Contact Details |
|------------------|-----------------|
| | |

NB: The child and family will hold a full copy of their plan
A full photocopy of the plan also to: (include date sent and by whom)

| | Full copy= Aware of plan= | FC/ A | Name and contact details | Date sent and by whom |
|--------------------------|------------------------------|----------|-------------------------------------|-----------------------|
| <input type="checkbox"/> | | | Local Emergency Department | |
| <input type="checkbox"/> | | | Children's Community Nursing Team | |
| <input type="checkbox"/> | | | Hospice | |
| <input type="checkbox"/> | | | Lead Paediatrician | |
| <input type="checkbox"/> | | | GP | |
| <input type="checkbox"/> | | | Hospital (ward or assessment unit) | |
| <input type="checkbox"/> | | | Respite / Short Break Care provider | |
| <input type="checkbox"/> | | | GP Out of Hours | |
| <input type="checkbox"/> | | | Ambulance Control | |
| <input type="checkbox"/> | | | School Nurse / Head Teacher | |
| <input type="checkbox"/> | | | Social Services | |
| <input type="checkbox"/> | | | Other (e.g. Hospital Specialists) | |
| <input type="checkbox"/> | | | Other | |
| <input type="checkbox"/> | | | Other | |
| <input type="checkbox"/> | | | Other | |
| <input type="checkbox"/> | | | Other | |

Comments



Wishes during Life

WISHES DURING LIFE

Child's / Young Person's wishes e.g. Place of care, symptom management, people to be involved (professional/ non-professional), activities to be continued (including spiritual and cultural) and goal-directed outcomes.

Family wishes e.g. Where you want to be as a family, who you would like to be involved, sibling needs (e.g medical, spiritual or cultural backgrounds).

Others' wishes (e.g. siblings, school friends)



Wishes around End of Life (Optional)

WISHES AROUND THE END OF LIFE

Organ & tissue donation (see separate guidance on web link <http://www.organdonation.nhs.uk>)

National contact numbers. 0300 123 2323

Regional contact numbers.

Priorities for care, including preferred place of care of child /young person

Spiritual and cultural wishes

Other child/ young person & family wishes, e.g. what happens to possessions?

Funeral preferences

Seek detailed information or further advice if needed

If page not completed please comment



Management of Anticipated Complications (Allergies recorded on Front Cover)

| Date of Weight | Weight (Kg) | This section should be used to record plans for specific circumstances which might be encountered e.g. management of chest infections. Where a management plan already exists (e.g. seizure management plan) it should be signposted |
|----------------|-------------|--|
| | | |

Instructions for specific circumstances

For example seizures: manage as per Advanced Paediatric Life Support (APLS) Guidelines, or may require a personalised seizure plan as signposted here.

Include below as to if, or when, to call 999 and transfer to hospital.

| Name | Signature | Professional Role | Date |
|------|-----------|-------------------|------|
| | | | |

Additional Notes

Management of an Acute Significant Deterioration (non-arrest)

Prompt: allergies recorded on Front Cover | Prompt: Review with ReSPECT form

In the event of a likely *reversible* cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis please intervene and treat actively.**
Please also treat the following possible problems actively e.g. bleeding (**please state**):

An acute deterioration may lead to a cardiorespiratory arrest. If a decision about CPR has not been made then the default is to attempt resuscitation unless this would be futile, unlikely to be successful or not in the child's best interests.

In the event of life threatening event provide the following care (Add patient-specific detail below)

| | | |
|-------------------------------------|--|--|
| <input checked="" type="checkbox"/> | Support transfer to preferred place of care if known and possible | |
| <input checked="" type="checkbox"/> | Maintain comfort and symptom management, and support child / young person and family | |
| <input checked="" type="checkbox"/> | Clear upper; airway / mouthcare | |

| | |
|--|---|
| <input type="radio"/> Yes <input type="radio"/> No | Facemask oxygen if available. |
| <input type="radio"/> Yes <input type="radio"/> No | Bag and mask ventilation or mouth to mouth ventilation. |
| <input type="radio"/> Yes <input type="radio"/> No | Emergency transfer to hospital if considered appropriate. |
| <input type="radio"/> Yes <input type="radio"/> No | Intravenous access |
| <input type="radio"/> Yes <input type="radio"/> No | Intraosseous access. |
| <input type="radio"/> Yes <input type="radio"/> No | Non-invasive ventilation/Optiflow. |
| <input type="radio"/> Yes <input type="radio"/> No | Intubation |
| <input type="radio"/> Yes <input type="radio"/> No | Admission to Intensive Care (where medically appropriate) |
| <input type="radio"/> Yes <input type="radio"/> No | Other: |

Comments about feeds and fluids

Other (please state): (e.g. may include specific information if a life-threatening emergency happens at school)

ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) including Management of Cardiorespiratory Arrest (may include DNACPR)

| | | |
|--|--|---|
| 1 | Preferred Name: | Date completed: |
| 2 | Summary of relevant information for this plan (see also section 6) | |
| Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded. | | |
| Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation. | | |
| 3 | Personal preferences to guide this plan (when the person has capacity) | |
| How would you balance the priorities for your care (you may mark along the scale, if you wish): | | |
| <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | |
| Prioritise sustaining life, even at the expense of some comfort | | Prioritise comfort, even at the expense of sustaining life |
| Considering the above priorities, what is most important to you is (optional): | | |
| 4 | Clinical recommendations for emergency care and treatment | |
| <input type="checkbox"/> | Focus on life-sustaining treatment as per guidance below (Clinician signature) | Focus on symptom control as per guidance below <input type="checkbox"/> (Clinician signature) |
| Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support: | | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| CPR attempts recommended <small>(Clinician signature)</small> | For modified CPR (as detailed above) <small>(Clinician signature)</small> | CPR attempts NOT recommended <small>(Clinician signature)</small> |



| 5 Capacity and representation at time of completion | | | |
|---|---------------------------------|--------------------------------|-------------------------------------|
| Does the person have sufficient capacity to participate in making the recommendations on this plan? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | |
| Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? If so, document details in emergency contact section below. | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Unknown <input type="checkbox"/> |

| 6 Involvement in making this plan | |
|---|--|
| The clinician(s) signing this plan is/are confirming that: (select A, B or C, OR complete section D below): | |
| A <input type="checkbox"/> | This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan. |
| B <input type="checkbox"/> | This person does not have the mental capacity to participate in making these recommendations. This plan has been made in accordance with capacity law, including, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends. |
| C <input type="checkbox"/> | This person is less than 18 (UK except Scotland) / 16 (Scotland) years old and (please select 1 or 2, and also 3 as applicable or explain in section D below): |
| <input type="checkbox"/> | 1 They have sufficient maturity and understanding to participate in making this plan |
| <input type="checkbox"/> | 2 They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account |
| <input type="checkbox"/> | 3 Those holding parental responsibility have been fully involved in discussing and making this plan |
| D | If no other option has been selected, valid reasons must be stated here. Document full explanation in the clinical record. |
| Record date, names and roles of those involved in decision making, and where records of discussions can be found: | |

| 7 Clinicians' signatures | | | | |
|-----------------------------------|----------------|--------------------------|-----------|-------------|
| Designation (grade/speciality) | Clinician name | GMC/ NMC/ HCPC Number | Signature | Date & time |
| | | | | |
| Senior responsible clinician: | | | | |
| | | | | |

| 8 Emergency contacts | | | |
|-----------------------|------|-----------|---------------|
| Role | Name | Telephone | Other details |
| Legal proxy/ parent | | | |
| Family/ friend/ other | | | |
| GP | | | |
| Lead Consultant | | | |

| 9 Confirmation of validity (e.g. for change of condition) | | | | |
|---|--------------------------------|----------------|--------------------|-----------|
| Review date | Designation (grade/speciality) | Clinician name | GMC/ NMC/ HCPC No. | Signature |
| | | | | |
| | | | | |
| | | | | |