

|  |  |
| --- | --- |
| Endorsed by NICE | This plan could begin antenatally |

|  |
| --- |
| **ALLERGIES** |
| *Enter details here* |

|  |  |  |  |
| --- | --- | --- | --- |
|  Name | Patient’s full name |  DOB | DOB |
|  Address |   |
|  |
|   |  Post code |   |
|  NHS No. | NHS number |  Hospital No. |   |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **For use** (indicate as appropriate) | Everywhere [ ]  | Home [ ]  | School [ ]  | Hospital [ ]  | Hospice [ ]  |

|  |  |  |  |
| --- | --- | --- | --- |
| **Date plan initiated** | *dd/mm/yyyy* | **Date review due** (if appropriate) | *dd/mm/yyyy* |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Date reviewed | Designation(grade/speciality) | Clinician name | GMC/NMC/ HCPC number  | Signature |
| *dd/mm/yyyy* | Designation | *Name* | *GMC/NMC/HCPC* | *Signature* |
| *dd/mm/yyyy* | Designation | *Name* | *GMC/NMC/HCPC* | *Signature* |
| *dd/mm/yyyy* | Designation | *Name* | *GMC/NMC/HCPC* | *Signature* |

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|  | http://cypacp.uk/https://www.respectprocess.org.uk/ | Version 4Incorporating ReSPECT |

**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 | **­**  *Lead clinician*  |
| Contact details |  *Contact details*  |

|  |  |
| --- | --- |
| 24 hr contact phone number(if available) |  ***Enter 24 hr contact phone number***  |
| What is this number? e.g. Ward, community nursing team, on call team or hospice? | *Details* |

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](#_Toc535487238)

[Diagnosis and Decision-making 5](#_Toc535487239)

[Distribution list (Key Contacts) 6](#_Toc535487240)

**Section 2: Wishes**

[Wishes during Life 7](#_Toc535487241)

[Wishes around End of Life (Optional) 8](#_Toc535487242)

**Section 3: Emergency Medical Management**

[Management of Anticipated Complications 9](#_Toc535487244)

Additional Note 9

[*Management of an Acute Significant Deterioration* (non-arrest) 10](#_Toc535487245)

*ReSPECT* (Recommended Summary Plan for Emergency Care & Treatment) [including *Management of Cardiorespiratory Arrest* 11](#_Toc535487246)

# Contacts and who has agreed and supports this plan

|  |  |  |  |
| --- | --- | --- | --- |
| Name  | Patient’s full name | Date of Birth | DOB |
| Known as |  | Interpreter needed? | *Yes/No* |
| First Language | *1st Language* | Interpreter contact | *Contact* |
| Telephone Numbers: | *Telephone* |

|  |
| --- |
| **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 | *Name* |
| Role | *Role* | Professional registration no.  |   |
| Signature | *Signature* | Date: | *dd/mm/yyyy* |

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| **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 |
| *Name* | *Signature* | *dd/mm/yyyy* |
| **Person/ People with parental responsibility (signature optional)**  |
| Name | Signature | Role | Date |
| 1 | *Name* | *Signature* | *Role* | *dd/mm/yyyy* |
| 2 | *Name* | *Signature* | *Role* | *dd/mm/yyyy* |
| **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] |
| [ ]  | Wishes of child/young person with capacity  |
| [ ]  | Wishes of parent(s) for child on “best interests” basis  |
| [ ]  | Best interests basis (as in Mental Capacity Act 2005)  |
| [ ]  | Other (please state) | *Other* |
| **Comment** |
|  |
| **Clinicians have a duty to act in a patient’s best interests at all times.** |

# Distribution list (Key Contacts)

|  |
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| 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 |
| *Name & Role* | *Contact detail* |

|  |
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| **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 |
| [ ]  | Local Emergency Department | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Children’s Community Nursing Team | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Hospice | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Lead Paediatrician | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | GP | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Hospital (ward or assessment unit) | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Respite / Short Break Care provider | *FC/A* | *Name and contact details* | *By* *dd/mm/yyyy**By* |
| [ ]  | GP Out of Hours | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Ambulance Control | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | School Nurse / Head Teacher | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Social Services | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Other (e.g. Hospital Specialists ) | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Other | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Other | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Other | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |
| [ ]  | Other | *FC/A* | *Name and contact details* | *dd/mm/yyyy**By* |

|  |
| --- |
| **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 number**s**. 0300 123 2323Regional 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 |
|  |

|  |
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| 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 |
| *dd/mm/yyyy* | *weight* |  |

|  |
| --- |
| **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 |
| *Name* | *Signature* | *Role* | *dd/mm/yyyy* |

#

# Additional Notes

|  |
| --- |
|  |

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

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

|  |
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| 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. |

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| --- |
|  **In the event of life threatening event provide the following care** (Add patient-specific detail below) |
| **🗸** | Support transfer to preferred place of care if known and possible | *Specify* |
| **🗸** | Maintain comfort and symptom management, and support child / young person and family | *Specify* |
| **🗸** | Clear upper; airway / mouthcare | *Specify* |

|  |
| --- |
|  |
| [ ]  | Yes | [ ]  | No | Facemask oxygen if available. *any comment* |
| [ ]  | Yes | [ ]  | No | Bag and mask ventilation or mouth to mouth ventilation. *any comment*  |
| [ ]  | Yes | [ ]  | No | Emergency transfer to hospital if considered appropriate. *any comment* |
| [ ]  | Yes | [ ]  | No | Intravenous access. *any comment* |
| [ ]  | Yes | [ ]  | No | Intraosseous access. *any comment* |
| [ ]  | Yes | [ ]  | No | Non-invasive ventilation/Optiflow. *any comment* |
| [ ]  | Yes | [ ]  | No | Intubation *any comment* |
| [ ]  | Yes | [ ]  | No | Admission to Intensive Care (where medically appropriate) *any comment* |
| [ ]  | Yes | [ ]  | No | Other: *any comment* |
| **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**)

# Management of Cardiorespiratory Arrest

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **1** | **Preferred Name**: | ***Name*** | **Date completed**: | *dd/mm/yyyy* |
| **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. |

|  |  |
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| **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): |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| [ ]  |  | [ ]  |  | [ ]  |  | [ ]  |  | [ ]  |  | [ ]  |  | [ ]  |
|  |
| Considering the above priorities, what is most important to you is (optional): |

|  |  |
| --- | --- |
| **4** | Clinical recommendations for emergency care and treatment |
| [ ]  | **Focus on life-sustaining treatment as per guidance below**(Clinician signature) |  | **Focus on symptom control as per guidance below**(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**:** |

|  |  |  |
| --- | --- | --- |
| [ ]  | [ ]  | [ ]  |
| CPR attempts recommended | For modified CPR(as detailed above) | CPR attempts NOT recommended |
| *Clinician signature* | *Clinician signature* | *Clinician signature* |

|  |  |
| --- | --- |
| **5** | Capacity and representation at time of completion |
| Does the person have sufficient capacity to participate in making the recommendations on this plan?  | Yes[ ]  | No[ ]  |   |
| 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[ ]  | No[ ]  | Unknown[ ]  |

|  |  |
| --- | --- |
| **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 | [ ]  | This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.  |
| B | [ ]  | 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 | [ ]  | 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): |
|  | [ ]  | 1 | They have sufficient maturity and understanding to participate in making this plan |
|  | [ ]  | 2 | They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account |
|  | [ ]  | 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 of discussions can be found: |

|  |  |
| --- | --- |
| **7** | Clinicians’ signatures |
| Designation(grade/speciality) | Clinician name | GMC/ NMC/ HCPC number | Signature | Date & time |
| *Designation* | *Name* | *GMC/NMC/HCPC* | *Signature* | *dd/mm/yyyy**time*  |
| *Designation* | *Name* | *GMC/NMC/HCPC* | *Signature* | *dd/mm/yyyy**time*  |
| Senior responsible clinician:  |
| *Designation* | *Name* | *GMC/NMC/HCPC* | *Signature* | *dd/mm/yyyy**time*  |

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

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