

**ALLERGIES**

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



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



# Child and Young Person's Advance Care Plan

This document is a tool for discussing and communicating the wishes of a child, young person, parent(s) and/or their family. The plan is also designed to record the wishes of families for their baby (neonate or infant).

In addition to recording a concise record of the advance plans it 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 and / or next of kin / parent(s) cannot be contacted.

It is a collaborative document with representation including the South Central and Wessex, West Midlands, North West, Kent and the South West for shared decision making between families and clinicians.



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

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## Contacts

|                    |  |  |                     |  |
|--------------------|--|--|---------------------|--|
| Name               |  |  | Date of Birth       |  |
| Known as           |  |  | Interpreter needed  | <input type="radio"/> Yes <input type="radio"/> No |
| First Language     |  |  | Interpreter contact |  |
| Home Address       |  |  |                     |  |
|                    |  |  |                     | Postcode:  |
| Telephone Numbers: |  |  |                     |  |

### Family Tree

**Name of person/people with parental responsibility (and address if different from above):**

**Emergency contact number for person/s with parental responsibility:**

Other emergency contact No.

**Others** (e.g. family and friends)

| Name | Relationship | Telephone numbers |
|------|--------------|-------------------|
|      |              |                   |
|      |              |                   |
|      |              |                   |

**Emergency contact for professional who knows child:**

**For use** please tick [x]    Everywhere     Home     School     Hospital

**Date Plan Initiated**

**Date Review due**

| Date reviewed/amended: | Name & title of lead reviewer | Expected review date (if appropriate) |
|------------------------|-------------------------------|---------------------------------------|
|                        |                               |                                       |
|                        |                               |                                       |
|                        |                               |                                       |

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## Wishes during Life

| <b>WISHES DURING LIFE</b>  |  |
|--|--|
| <b>Child's / Young Person's wishes</b> e.g. Place of care, symptom management, people to be involved (professional/non-professional), activities to be continued (spiritual and cultural). |  |
| <b>Family wishes</b> e.g. Where you want to be as a family, who you would like to be involved (e.g. medical, spiritual or cultural backgrounds).   |  |
| <b>Others' wishes</b> (e.g. school friends, siblings)  |  |

|   |  |
|---|--|
| This page discussed by:   |  |
| <b>Child /Young Person / Parent / Carer</b><br>Professional (full name and job title/ initials)<br>(Initials only may be used if this page is filled out by the lead clinician) |  |
| Date:   |  |

|              |  |         |  |
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## Diagnosis and Decision Making

### Diagnosis

### Main problems and Background information

### Social issues (Include if Looked after Child)

### Decision Making Process

#### Basis of discussion / decision-making? (Tick 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

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
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## Specific Treatment Plans

(Prompt: allergies recorded on Front Cover)

| Management of seizures <i>(Please select one option only)</i>    | Date of Weight | Weight (Kg) |
|--|----------------|-------------|
| <input type="radio"/> Manage using APLS guidelines               |                |             |
| <input type="radio"/> Requires a personalised seizure plan below |                |             |

**Personalised Seizure plan:** (drug name, dose and route) please add patient weight used to calculate drug doses

|             |  |               |      |
|-------------|--|---------------|------|
| First Line  |  | after         | mins |
| Second Line |  | after further | mins |
| Third Line  |  | after further | mins |

Call **999** for emergency transfer to hospital?  Yes  No

If yes, at what stage

Description of usual seizure pattern/ types

Other instructions for seizures

### Management of infection

This section is for community use and may involve instructions to transfer to hospital.

Contact specialist team and microbiology

Please record if likely to be neutropaenic or have an immune deficiency

Preferred antibiotic or regime for recurrent infections – drug dose, route, duration:

### Instructions for other specific circumstances

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

|              |  |         |  |
|--------------|--|---------|--|
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## Management of a Life Threatening Event

Prompt: allergies recorded on Front Cover

### Symptoms and signs to expect (NB Information about diagnosis is on p6)

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**):

A life threatening event may lead to a cardiac or respiratory arrest (cardiorespiratory arrest). If p15 has not been completed, decisions about resuscitation would normally be made on a 'best interests' basis. The presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.

### In the event of life threatening event (Add comments to clarify wishes)

- |                                     |  |  |
|-------------------------------------|--|--|
| <input checked="" type="checkbox"/> | Support transfer to preferred place of care if 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.                                 |
| <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 or Intraosseous access.                |
| <input type="radio"/> Yes <input type="radio"/> No | Non-invasive ventilation.                                 |
| <input type="radio"/> Yes <input type="radio"/> No | Intubation.   |

### Comments about feeds and fluids

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

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



|              |  |         |  |
|--------------|--|---------|--|
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## Wishes during End of Life

| WISHES AROUND THE END OF LIFE   |
|---|
| <p><b>Priorities of care including preferred place for care of child /young person</b></p><br><br><br>  |
| <p><b>Spiritual and cultural wishes</b></p><br><br><br>   |
| <p><b>Other child/ young person &amp; family wishes, e.g. what happens to possessions?</b></p><br><br><br>  |
| <p><b>Organ &amp; tissue donation</b> (see separate guidance on web link <a href="http://www.organdonation.nhs.uk">http://www.organdonation.nhs.uk</a>)<br/>National contact numbers. 0300 123 2323<br/>Regional contact numbers.</p><br><br><br> |
| <p><b>Funeral preferences</b><br/>Seek detailed information or further advice if needed</p><br><br><br>   |

| This page has been discussed with child / young person/ parent/ carer: | Professional:<br>(full name and job title/initials) | Date |
|--|---|------|
|  |   |      |

If page not completed please comment on reasons

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
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## Signature Page

Note the signatures apply to pages 4 - 9 only

### Who has agreed and supports the plan?

(Doctors must add GMC number after the signature)

| Lead Clinician                   |  |       |  |
|----------------------------------|--|-------|--|
| Name                             |  |       |  |
| Professional Registration Number |  | Role: |  |
| Signature                        |  | Date: |  |

| Others included in the decision making. (also see p 14)   |           |      |
|---|-----------|------|
|   |           |      |
| Young Person<br>(if appropriate; optional) (to ensure their opinions have been included in the decision making) |           |      |
| Name  | Signature | Date |
|   |           |      |

| Person/ Persons with parental responsibility (see page 4)<br>(to ensure their opinions have been included in the decision making) |           |      |      |
|---|-----------|------|------|
| Name  | Signature | Role | Date |
| 1   |           |      |      |
| 2   |           |      |      |
| 3   |           |      |      |
| 4   |           |      |      |
| Other   |           |      |      |
| 1   |           |      |      |
| 2   |           |      |      |
| 3   |           |      |      |

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

If a parent or legal guardian 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. The child/young person or parents /guardian can change their mind about any of the preferences on the care plan at any time.

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
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## Additional Notes

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
| DOB:         |  |         |  |
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## Additional Notes

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
| DOB:         |  |         |  |
| Hospital No. |  | NHS No. |  |

## Distribution List (Key Contacts)

The co-ordinator is responsible for the distribution of the CYPACP, for bringing it to the attention of professionals, and for circulating any updates to it:

| Name of Co-ordinator | Contact Details |
|----------------------|-----------------|
|                      |                 |

**24 hour contact number available:** (record p14)  Yes  No

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

|                          | 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<br>(refer to p14 for specialists involved) |                       |
| <input type="checkbox"/> | GP  |                       |
| <input type="checkbox"/> | Other   |                       |
| <input type="checkbox"/> | Other   |                       |

**Other professionals who require either a full photocopy, or need to be made aware that the child has a plan (please state which):**

|   | Full photocopy=<br>Aware of plan= | FP /<br>A | Name and contact details | Date sent and by whom |
|---|-----------------------------------|-----------|--------------------------|-----------------------|
| Hospital (ward or assessment unit)  |                                   |           |                          |                       |
| Respite /Short Break Care provider  |                                   |           |                          |                       |
| GP Out of Hours   |                                   |           |                          |                       |
| Ambulance Control   |                                   |           |                          |                       |
| School Nurse  |                                   |           |                          |                       |
| School  |                                   |           |                          |                       |
| Transition  |                                   |           |                          |                       |
| Social Services   |                                   |           |                          |                       |
| Other<br>(e.g. CDOP, Coroner, or EOL Register)  |                                   |           |                          |                       |
| Other (e.g. Hospital Specialists see p14 for contact details; list specialties only here) |                                   |           |                          |                       |

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
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| Hospital No. |  | NHS No. |  |

## If the child / young person dies (Please contact the following people)

Co-ordinator responsible for the distribution of the CYPACP and bringing to the attention of professionals that the child has a plan.

|  |                           |                          |                  |
|--|---------------------------|--------------------------|------------------|
|  |                           |                          |                  |
| <b>24 hour contact number available:</b> | <input type="radio"/> Yes | <input type="radio"/> No | <b>Phone No.</b> |

|                          |                                | Name and contact details |
|--------------------------|--------------------------------|--------------------------|
| <input type="checkbox"/> | Parents/Guardians              |                          |
| <input type="checkbox"/> | General Practitioner           |                          |
| <input type="checkbox"/> | Lead Paediatrician             |                          |
| <input type="checkbox"/> | Hospice                        |                          |
| <input type="checkbox"/> | Organ and Tissue Donation team |                          |
| <input type="checkbox"/> | Other (Rapid Response Team)    |                          |
| <input type="checkbox"/> | Other (ED/ Childrens Ward)     |                          |
| <input type="checkbox"/> | Other                          |                          |
| <input type="checkbox"/> | Other                          |                          |

**Other professionals who have either a full photocopy (FP), or are aware (A) that the child has a plan (please see page 13 and below).**

**NB Where multiple hospital specialists are involved in care it is the responsibility of the lead paediatrician/ lead clinician to inform them of the death; please list names and speciality below and name of person who will inform them.**

|  |
|--|
|  |
|--|

|              |  |         |  |
|--------------|--|---------|--|
| Name:        |  |         |  |
| DOB:         |  |         |  |
| Hospital No. |  | NHS No. |  |

## Management of Cardiorespiratory Arrest

(Including DNACPR)\*

\*Delete if not appropriate

|  |   |                |  |
|--|---|----------------|--|
| <b>Child's Name</b>                                |   | <b>NHS No.</b> |  |
| <input type="checkbox"/>                           | <b>Cardiopulmonary Resuscitation status (CPR) has not been discussed</b><br>attempt CPR unless clearly not in the best interest of the child/ young person (Only a senior clinician may make this decision) |                |  |
| <input type="checkbox"/>                           | <b>Cardiopulmonary Resuscitation status has been discussed and the following has been agreed:</b>   |                |  |
| Diagnosis and reason(s) for decision (also see p6) |   |                |  |
|  |   |                |  |
| Ambulance Directive                                |   |                |  |
|  |   |                |  |

Clearly strike through unused boxes in dark ink as appropriate (only 1 box to be active)

|   |   |  |  |                      |  |             |  |      |  |   |
|---|---|--|--|----------------------|--|-------------|--|------|--|---|
| <b>Attempt full<br/>Cardiopulmonary<br/>Resuscitation</b> | <b>Attempt Cardiopulmonary Resuscitation with<br/>modifications below:</b>  | <b>DO NOT attempt<br/>Cardiopulmonary<br/>Resuscitation<br/>DNACPR</b> |  |                      |  |             |  |      |  |   |
| <b>OR</b>   |   | <b>OR</b>  |  |                      |  |             |  |      |  |   |
| <input type="radio"/> Select                              | <input type="radio"/> Select  | <input type="radio"/> Select   |  |                      |  |             |  |      |  |   |
| Attempt CPR as per Resuscitation Council (UK) guidelines. | <table border="1" style="width: 100%;"> <tr> <td style="width: 30%;">INTUBATION</td> <td><input type="radio"/> Yes <input type="radio"/> No</td> </tr> <tr> <td>AIRWAY AND BREATHING</td> <td></td> </tr> <tr> <td>CIRCULATION</td> <td></td> </tr> <tr> <td>PICU</td> <td><input type="radio"/> Yes <input type="radio"/> No</td> </tr> </table> | INTUBATION   | <input type="radio"/> Yes <input type="radio"/> No | AIRWAY AND BREATHING |  | CIRCULATION |  | PICU | <input type="radio"/> Yes <input type="radio"/> No | <b>DNACPR</b><br>Patient-specific supportive care is documented on pages 7, 8 and 9 |
| INTUBATION  | <input type="radio"/> Yes <input type="radio"/> No  |  |  |                      |  |             |  |      |  |   |
| AIRWAY AND BREATHING                                      |   |  |  |                      |  |             |  |      |  |   |
| CIRCULATION   |   |  |  |                      |  |             |  |      |  |   |
| PICU  | <input type="radio"/> Yes <input type="radio"/> No  |  |  |                      |  |             |  |      |  |   |

|  |  |  |  |
|--|--|--|--|
| <b>Clinician</b><br>(usually lead clinician) |  | <b>2<sup>nd</sup> Clinician</b><br>(2 <sup>nd</sup> Signature may be required if lead clinician has not signed above and countersigns at a later date) |  |
| Clinician Name                               |  | Clinician Name   |  |
| Professional Role/ Grade                     |  | Professional Role/ Grade   |  |
| GMC/ (NMC) No.                               |  | GMC/ (NMC) No.   |  |
| Signature                                    |  | Signature  |  |
| Date   |  | Date   |  |

|              |  |         |  |
|--------------|--|---------|--|
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**Version 1.1**

**Review date: December 2018**

**Please note exceeding this date does not invalidate the information contained in this proforma.**

**However this version should not be used to record a new CYPACP after this date.**

