Name:		DOB:		NHS No:	

Child and Young Person's Advance Care Plan

ID photo

QR code

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

Plans can begin antenatally (using ante-natal version of this document) and are suitable for infants, children and young people

Name (baby, infant, child or young person):		**EDD** (if relevant)**:**	
Known as (if different):		**DOB:**	
Address including postcode:			
NHS no:		**Gender** (optional)	

ALLERGIES:

For Child/Young Person or Carers' Use – Who to call in emergency (eg 999 or 111, or Hospice, etc)

In emergency call:	
Other situations:	

See also Emergency Contacts on last page

This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

Not every page/section needs to be completed.

Date of Plan/Last review	

Irrespective of the 'Date of plan' it is good practice to check this still reflects current decisions / views, and to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see http://cypacp.uk/

ReSPECT

http://cypacp.uk/
https://www.respectprocess.org.uk/

Version 5
Incorporating ReSPECT

Out of hours support and emergency contacts can be found on the last page

Name:		DOB:		NHS No:	

Decision-making (additional to the ReSPECT document at the back)

First language		Interpreter required?	Yes ☐ No ☐

Information to help improve communication / support capacity:

Decision-making details/preferences: For example - details of those involved if "looked after" child; others involved key family members/carers; how do child/family wish to be involved in decision-making?

Important information relating to capacity and where further information can be found.
Further guidance will be available on the CYPACP website. See also last page

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

Distribution list / Key contacts (*where available, please include out of hours numbers)

Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate)

Name/Role/Department/Organisation and contact details:

		Name and contact details			Name and contact details
☐	Is there a regional central database?	Upload and note where this can be found:	☐	Respite/Short Break Care provider	
☐	Ambulance service		☐	School Nurse/Head Teacher	
☐	Lead Paediatrician/ Obstetrician		☐	Social Services	
☐	Palliative Team*		☐	Midwife	
☐	Hospice*		☐	Health Visitor	
☐	GP		☐	Other (eg Hospital Specialists)	
☐	GP out of hours (if different)		☐	Other	
☐	Children's Community Nursing*		☐	Other	
☐	Hospital (ward/ Assessment unit)		☐	Other	
☐	Local Emergency Department		☐	Other	

It is good practice to keep a copy of the Care Plan with the infant/child/young person at all times

Out of hours support and emergency contacts can be found on the last page

Name:		DOB:		NHS No:	

Medical Background

Summary diagnoses / current situation:
Medical problems and background information (inc antenatal scans): Medical history, key moments in journey; previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan)

Personal Background

Personality/Quality of life when well: May help others recognise deterioration, targets for recovery. May also wish to document concerns about your/your child/s health now and for the future?
Tips to make infant/child/young person/yourself more comfortable: eg communication methods; particular likes; music; stories; play, etc. Please note where to find more detailed, separate care plans if relevant
Social/Psychological/Spiritual/Education support: (if felt to be helpful)
Family details: please include details of siblings, include family tree if helpful; other important family/friends/carers

Priorities/Goals/Values

Baby/infant/child/young person's wishes: Consider support to achieve everyday quality of life as well as special goals, eg place of care; spiritual wishes; goal-directed outcomes; what I most value/wish to avoid; legacy and memory-making during life
Family (including siblings) wishes: Consider how you as a family wish to be supported to achieve everyday quality of life as well as any special goals, eg where you want to be as a family; who to involve; sibling support and needs (eg medical, spiritual or cultural backgrounds); legacy and memory-making during life; what is most valued/wish to avoid.
Others' wishes: Wider family, school friends, carers

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Name:		DOB:		NHS No:	

Wishes around End of Life

If it is recognised that your child/young person is nearing the end of their life, is there anything that would be important for us to know to provide the best care possible?

Priorities for care, including preferred place of care at the end of life and after death: Specify if preferred place of care at end of life is different to place of care after death.
Organ and tissue donation: See separate guidance on web link: https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/ National contact numbers: Referral line 0300 20 30 40 / General advice line: 0300 123 2323 Organ and tissue donation may be possible, but it depends on several factors. Specialists can guide on specifics should this option be considered
Spiritual and cultural wishes around death and dying: to include faith, beliefs and personal wishes such as music, family traditions and rituals
Memory and legacy making wishes (include family/siblings/friends if relevant) Consider how you/your child wish/es to be remembered which may include wishes for possessions and/or digital legacy.
Preparation/communication of process for management after death: 1. Consider referrals (including sudden death and automatic referrals (eg HIE (hypoxic ischaemic encephalopathy); **2**. Need for regular medical review; **3**. In-dwelling devices and removal
Funeral preferences and bereavement support and other family preferences: eg preferred timing for removal of equipment from home. Seek detailed information or further advice if needed
If not discussed, it may be helpful to put specific reasons/context of why not: Note: No need to explain, but record if helpful to be aware of certain situations/circumstances

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Name:		DOB:		NHS No:	

Management of Anticipated Complications/Deteriorating Health

Include reference to separate documents (and where to find) eg symptom management plan, specialty care plan(s).
Please balance the risk (version control risk) of duplicating information already detailed in separate management plans whilst recognising this section can be very helpful for quick access in emergencies.
NOTE: For antenatal care plans – this section may be deferred (if desired) until assessment after birth.

General Management

Current course of medical treatment: eg disease directed therapy; clinical trials, etc
Notes on likely deterioration (if known and relevant): Consider likely cause(s) of deterioration, including signs, symptoms and red flags
Management of progressive deterioration (if different to general deterioration detailed below): It may be appropriate to refer to other sections such as priorities of care if end of life is recognised

Systems approach to managing deterioration

Airway: Tracheostomy (also note if patent upper airway) and airway adjuncts
Breathing: Oxygen, pressure and ventilation support
Circulation/cardiac: Access; diuretics; blood pressure support; implants – what patient has, when and how to change or turn off
Neurology: State if VP shunt or reservoir present and action if blocked; role of pulsed steroids in neurological decline; acute seizure management
Management of commonly occurring infections: Including central line and stated temperatures for individual child
Nutrition and hydration: Including presence of, or discussion about NG, NJ PEG and JEJ, TPN
Blood tests: Consider frequency, indication and specific tests or stop routine tests
Blood products: Consider type, frequency and indication eg blood test or clinical symptoms
IV/SC access: Portacath; Hickman; Midline; other; and discussions about subcutaneous access
Condition specific interventions/general: not previously mentioned, may include when to call 999, transfer to hospital
Other patient plans/where to find: symptom management plans; specialty care plans (eg respiratory care plans), etc

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Name:		DOB:		NHS No:	

Management of an Acute Significant Deterioration/Emergency

For review with **"Management of Anticipated Complications"/"ReSPECT"**
If end of life recognised, see **"Wishes around End of Life"** and consider transfer to preferred place. Allergies listed at front

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 (irrespective of resuscitation wishes)**

Note any differences to plan detailed below if parents/carers are not present
If none recorded, assumption will be made to follow plan detailed below, even in absences of parent/carer

In the event of life-threatening event, provide the following care: add patient-specific detail below

				Comments (patient-specific decisions eg duration)
Basic Life Support	**Yes ☐**	**No ☐**	**Airway repositioning**	
	Yes ☐	**No ☐**	**Airway adjuncts**	
	Yes ☐	**No ☐**	**Bag and mask/tracheostomy** (also note if upper airway patent)/mouth to mouth ventilation	
	Yes ☐	**No ☐**	**Chest compressions**	
	Yes ☐	**No ☐**	**Defibrillation**	
Airway	Yes ☐	No ☐	Suction	
	Yes ☐	No ☐	Intubation/Supraglottic airway insertion (eg LMA)	
Breathing	Yes ☐	No ☐	Supplementary oxygen if available	
	Yes ☐	No ☐	Highflow (eg Optiflow/Vapotherm)	
	Yes ☐	No ☐	Non-invasive ventilation	
Circulation	Yes ☐	No ☐	Intravenous access	
	Yes ☐	No ☐	Intraosseous access	
	Yes ☐	No ☐	Cardiac/ALS drugs (usually in conjunction with chest compressions)	
Other	Yes ☐	No ☐	Emergency transfer to hospital	
	Yes ☐	No ☐	Consider Intensive Care admission	

Additional comments about the above decision or relevant other decisions

Please record details of implantable devices eg VNS/pacemaker/defibrillator, and management at end of life of these devices; long-term IV access; respiratory support (further details may be in separate care plans or "Anticipated Complications" page (eg may include specific information if a life-threatening emergency happens at school).
Consider revoking ACP for planned surgery, etc
Include preferences of transfer, eg local hospital or specialist centre if more suitable (**Note:** preferences may not be possible depending upon situation and local policies.
Consider how interventions will be carried out for emergency clinicians and on-going management plans

Out of hours support and emergency contacts can be found on the last page

Name:		DOB:		NHS No:	

(as part of the CYPACP [Child and Young Person's Advance Care Plan]**)**
(Recommended Summary Plan for Emergency Care and Treatment Version 3)

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

1	**Preferred name:**		**Date completed:**	

2 Shared understanding of my health and current condition:

Summary of relevant information for this plan including **diagnosis** and **relevant personal circumstances:**

Details of other relevant planning documents and where to find them (eg Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency Plan for the carer):

I have a legal welfare proxy in place (eg registered welfare attorney; person with parental responsibility). If "yes" provide details in Section 8 Yes ☐ No ☐

3 What matters to me in decisions about my treatment and care in an emergency:

Prioritise sustaining life, even at the expense of some comfort | **Prioritise comfort,** even at the expense of sustaining life

How would you balance the priorities for your care?

What I most value:	What I most fear/wish to avoid:

4 Clinical recommendations for emergency care and treatment:

Prioritise extending life	OR	Balance extending life with comfort and valued outcomes	OR	Prioritise comfort
Clinician's signature		Clinician's signature		Clinician's signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended	For modified CPR (Child and Young Person)	CPR attempts **NOT** recommended
Clinician's signature	Clinician's signature	Clinician's signature

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Name:		DOB:		NHS No:	

5	**Capacity and representation at time of completion** (see also "Decision Making" section)		
Does the person have sufficient capacity to participate in making the recommendations on this plan?	☐ Yes ☐ No	→	If "no" in what way does this person lack capacity? If the person lacks capacity, a ReSPECT conversation must take place with the family and/or legal welfare proxy
Document the full capacity assessment in the clinical record			

6	**Involvement in making this plan**		
The clinician(s) signing this plan is/are confirmation 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, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.
C	☐		This person is less than 18 years old (16 in Scotland) 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 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/specialty)	**Clinician name**	**GMC/NMC/HCPC Number**	**Signature/image**	**Date/Time**

Senior responsible clinician:				
Designation (grade/specialty)	**Clinician name**	**GMC/NMC/HCPC Number**	**Signature**	**Date/Time**

8	**Emergency contacts and those involved in discussing this plan**			
Emergency contact name (Primary contacts in purple)	**Role/Relationship**	**24 hr contact** Tick if Yes	**Emergency contact number**	**Signature** (optional)
Patient/family:		☐		
Patient/family:		☐		
Professional:		☐		
Professional:		☐		
Professional:		☐		

9	**Form reviewed (eg for change of care setting) and remains relevant**			
Review date	**Designation** (grade/specialty)	**Clinician name**	**GMC/NMC/HCPC Number**	**Signature**

Out of hours support and emergency contacts can be found on the last page