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What does an Advance Care Plan include?

July 2025

wellchild.org.uk

Introduction

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This booklet is designed to help you understand what an Advance Care Plan might look like, and what it can include. Each double page features:

- **On the right:** A example template of each section of the Advance Care Plan.
- **On the left:** Clear explanations, helpful guidance, and comments from Stacey, a parent carer who has navigated the ACP process with her child.

Please note: This is just an example of what an Advance Care Plan might look like. Every child is unique, and your child's plan may differ to reflect their individual needs and circumstances.

We would like to thank the Child and Young Person's Advance Care Plan Collaborative for providing the materials used in this booklet. The images on the right are purely for illustrative purposes and you cannot click on the links. To access the original document please visit **CYPACP-Version-5-Standard-all-ages-with-ReSPECT.docx**

You can access the Child and Young Person's Advanced Care Plan website for more materials and information at: **https://cypacp.uk/about-us/**

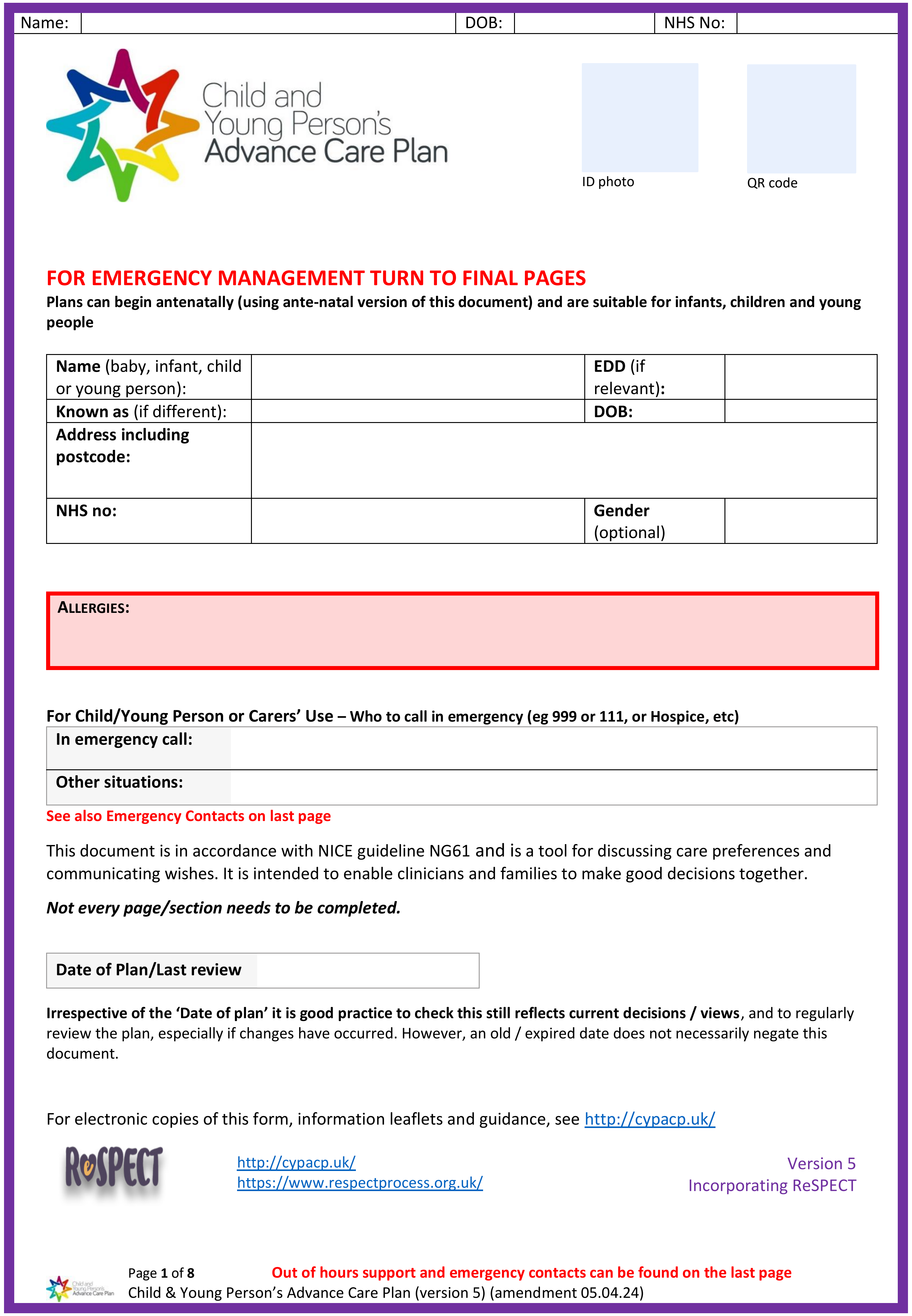
We hope you find this resource useful. If you've been through the Advance Care Plan process and would like to share your experiences or tips (anonymously if you prefer) for other parent carers to benefit from, we'd love to hear from you.

Please get in touch at **familynetworks@wellchild.org.uk**

1. Important Information For Your Family

This section gives you information about who to call if something happens to your child. For example, this may be a 24 hour number for the hospice.

(There is also a section for emergency contacts for all the professionals later on in the document).



Name:		DOB:		NHS No:	

Child and Young Person's Advance Care Plan

ID photo

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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

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Child & Young Person's Advance Care Plan (version 5) (amendment 05.04.24)

2. Decision Making and Distribution List

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Decision Making

This is not meant to be a full capacity assessment. Instead, it helps inform professionals about how best to communicate with the patient and their family, and how the family prefers to be involved in decision-making.

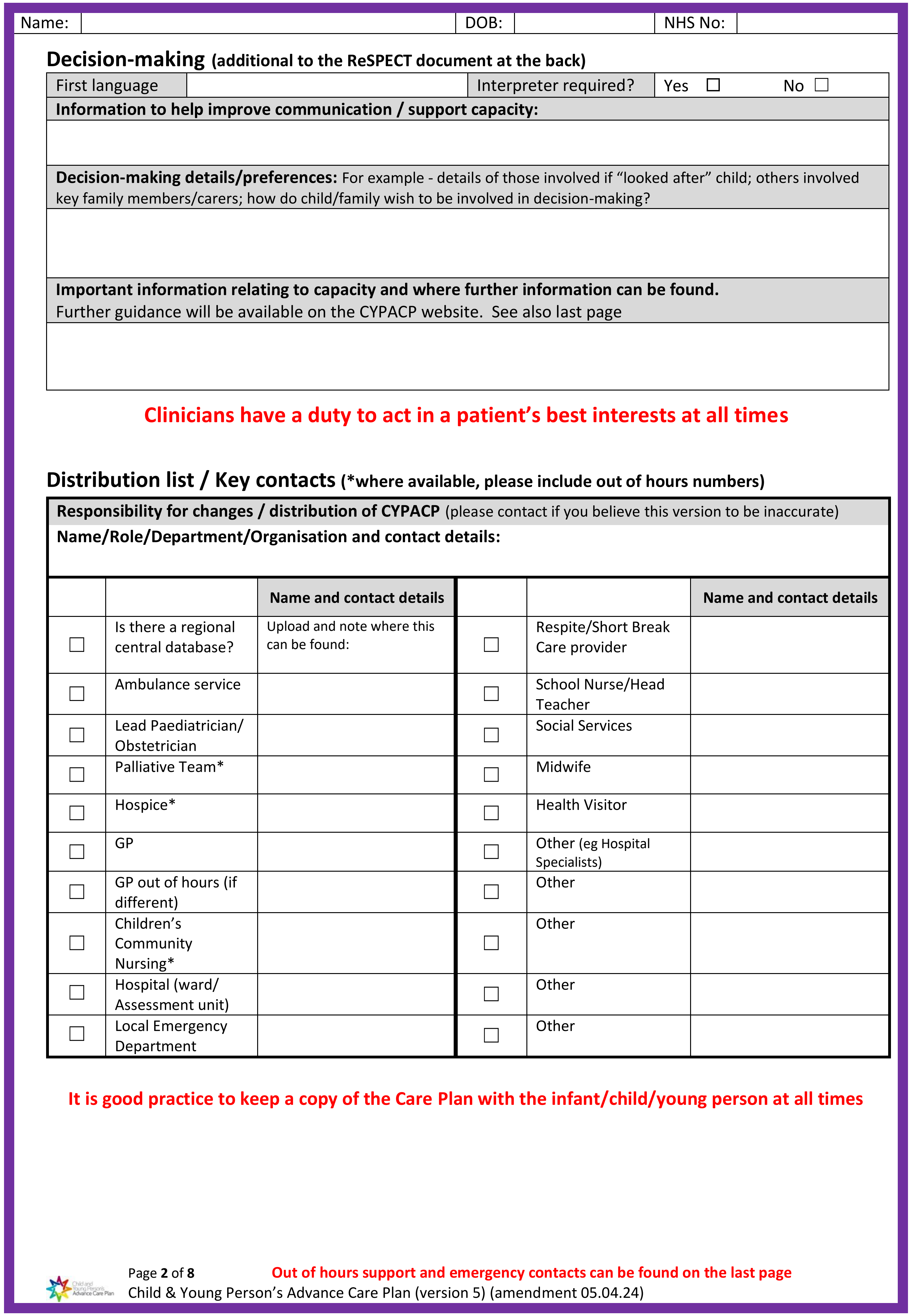
Healthcare professionals should note whether a mental capacity assessment has been completed, and if so, include the date it was carried out.

Distribution List/ Key Contacts

This section helps identify who is responsible for managing the Advance Care Plan. If any part of the ACP changes, professionals will know who to contact, as that person holds the most up-to-date version of the document.

It is your healthcare professional's responsibility to inform anyone who has a copy of the plan about any updates. You do not need to do this yourself.

However, the contact list is included for your reference, and there is space to add 24-hour contact numbers if needed. It may be helpful for you to know who has a copy of your child's Advance Care Plan.



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

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3. Medical Background; Personal Background; Priorities, Goals and Values

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Medical Background

This section provides a summary of your child's medical background and condition. It is not intended to cover every detail extensively. This section helps someone who has never met your family to quickly understand the issues that they need to be aware of.

Personal Background

This section allows the care plan to be personalised to your family. It helps someone working with your child to quickly understand what your child likes and dislikes.

For example, you might include that your child doesn't like loud noises. This allows professionals to adapt their approach to better support your child.

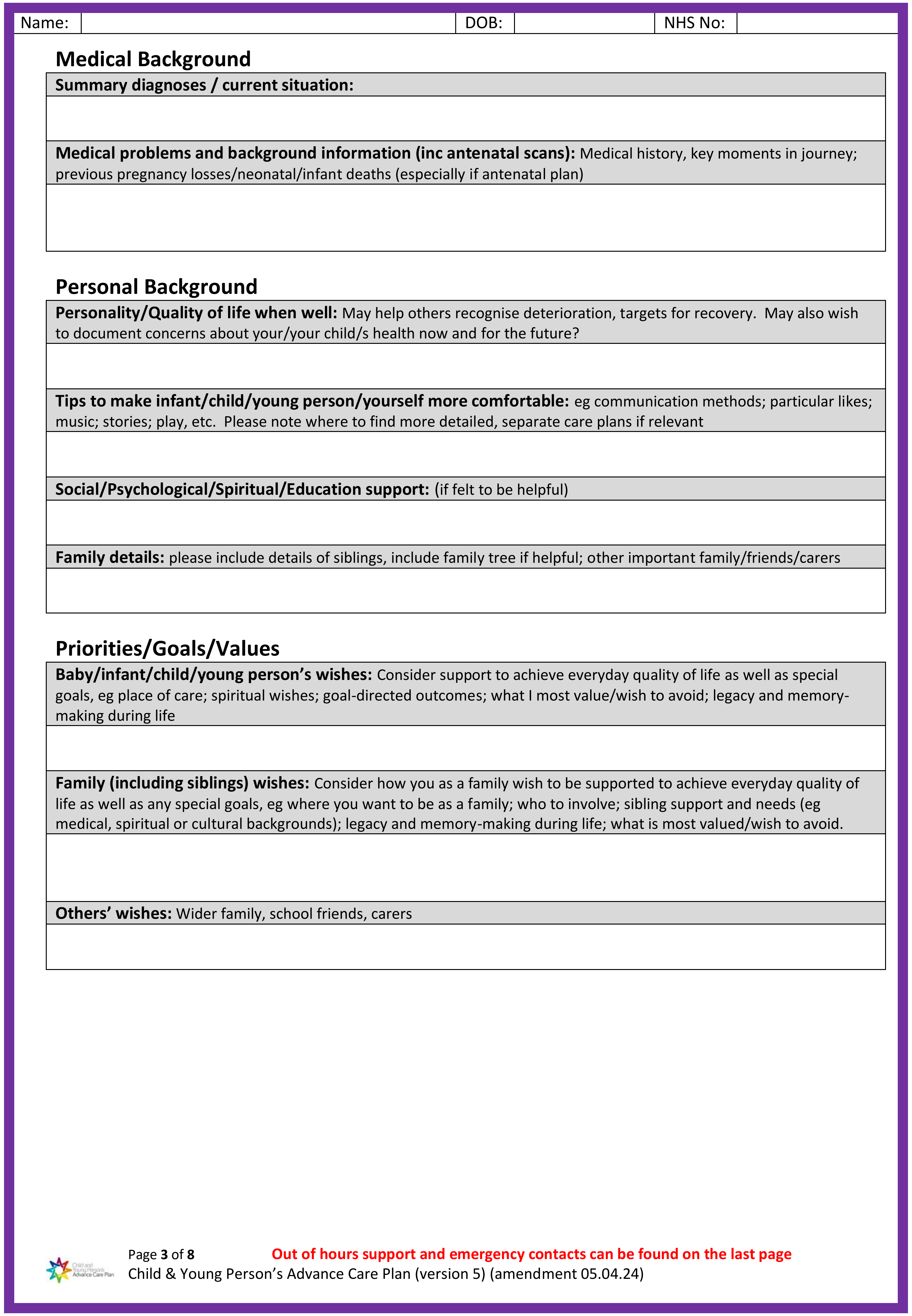
It also gives your healthcare professional the opportunity to advocate for your child. Some professionals may only see your child when they are very unwell. This section gives you a chance to say who they are and what they enjoy.

> "The Advance Care Plan gave me the opportunity to say, "This is who my child is, and this is what matters to us." It's about making sure their care reflects your priorities - not just in medical crises, but in daily life too."
>
> **– Stacey, Parent Carer**

Priorities, Goal and Values

This section gives you the opportunity to highlight your values. You can say what you would like in an ideal situation and what you want to avoid.

> "It's not just a medical document - it's a way to capture what matters most to your child and your family. That's what made me finally come around to the idea."
>
> **– Stacey, Parent Carer**



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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4. Wishes around End of Life

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This section offers a space to record your thoughts and values regarding your wishes around end-of-life care.

This section also provides an opportunity for healthcare professionals to explain what may happen, what end-of-life care might look like, and some of the things you may need to consider.

Depending on your situation, this may or may not be discussed in detail, but it gives your healthcare professional a prompt to begin those important conversations when the time is right.

> "Take your time, ask questions, and be honest about what matters to your family because at the end of the day that's what matters the most."
>
> **– Stacey, Parent Carer**

Top Tip

Remember, you **do not** have to complete the entire Advance Care Plan at once.

If there are decisions you're not yet ready to make, or discussions you're not yet ready to have, you can return to them when you feel ready, or not fill in this section at all.

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 020 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 required referrals (including sudden death and automatic Coroner referrals (eg HIE (hypoxic ischaemic encephalopathy); **2**. Need for regular medical review; **3.** Consider discussion and explanation of SUDIC process; **4**. 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

5. Management of Anticipated Complications/ Deteriorating Health

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Not all of the boxes in this section may be relevant, and you don't need to complete every one.

However, this section can be a helpful way to encourage you and your healthcare professional to consider all the different elements involved in your child's care.

It also allows you to distinguish between what to do in the case of an acute deterioration versus a more gradual decline.

> "It's about making sure your child receives the kind of care you'd want, even when you're not there to explain it. We had numerous discussions before finalising our wishes which really helped us in completing the ACP. We weren't always in agreement either but speaking to the professionals and discussing more in depth definitely helped us to all get on the same page once we understood further."
>
> **– Stacey, Parent Carer**

Thinking About End-Of-Life Care Can Be Incredibly Difficult

You don't have to face it alone. Connecting with others who are going through similar experiences can offer comfort, understanding, and practical support.

You could consider joining the **WellChild Family Tree**, our dedicated parent carer community, or explore other peer support networks, to share, listen, and find help within in a community that understands. You could also try using our **In Your Area platform** to find local support groups near you.

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

6. Management of an Acute Significant Deterioration/ Emergency

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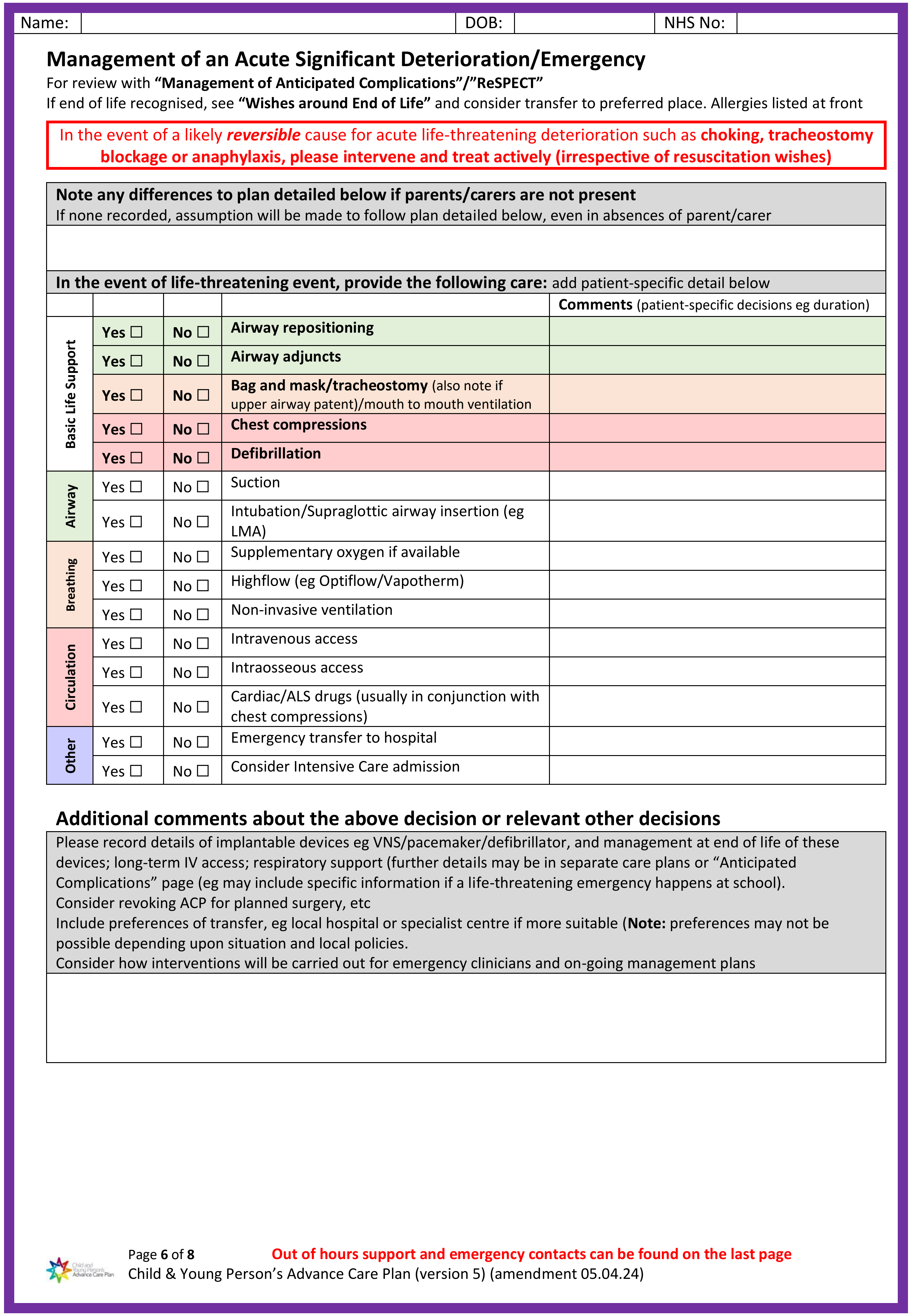
This section is primarily for emergency services, so they know what to do first in accordance with your wishes.

Completing this section prompts a conversation between you and your healthcare professional about the different types of care, how each one might apply to your child, and why certain interventions may or may not be appropriate, including their potential implications.

The final part of this section, titled **"Additional Comments"**, offers prompts for various scenarios that may arise. It gives you the opportunity to consider and record how the care you want for your child might change depending on the situation. For example, if your child is at respite care or school, would you want an intervention to be carried out in your absence?

> "For us, it was reassuring to know that in situations where we might not be there to advocate directly, there's a clear guide in place that reflects who our daughter is, how she communicates, what helps her feel safe, and what kind of interventions we feel are or aren't appropriate."
>
> **– Stacey, Parent Carer**



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

7. The ReSPECT Document

It's important to note that the ReSPECT document is not a Do Not Resuscitate order, it is a nuanced plan tailored specifically to your child's needs. It is also **not** a legally binding document.

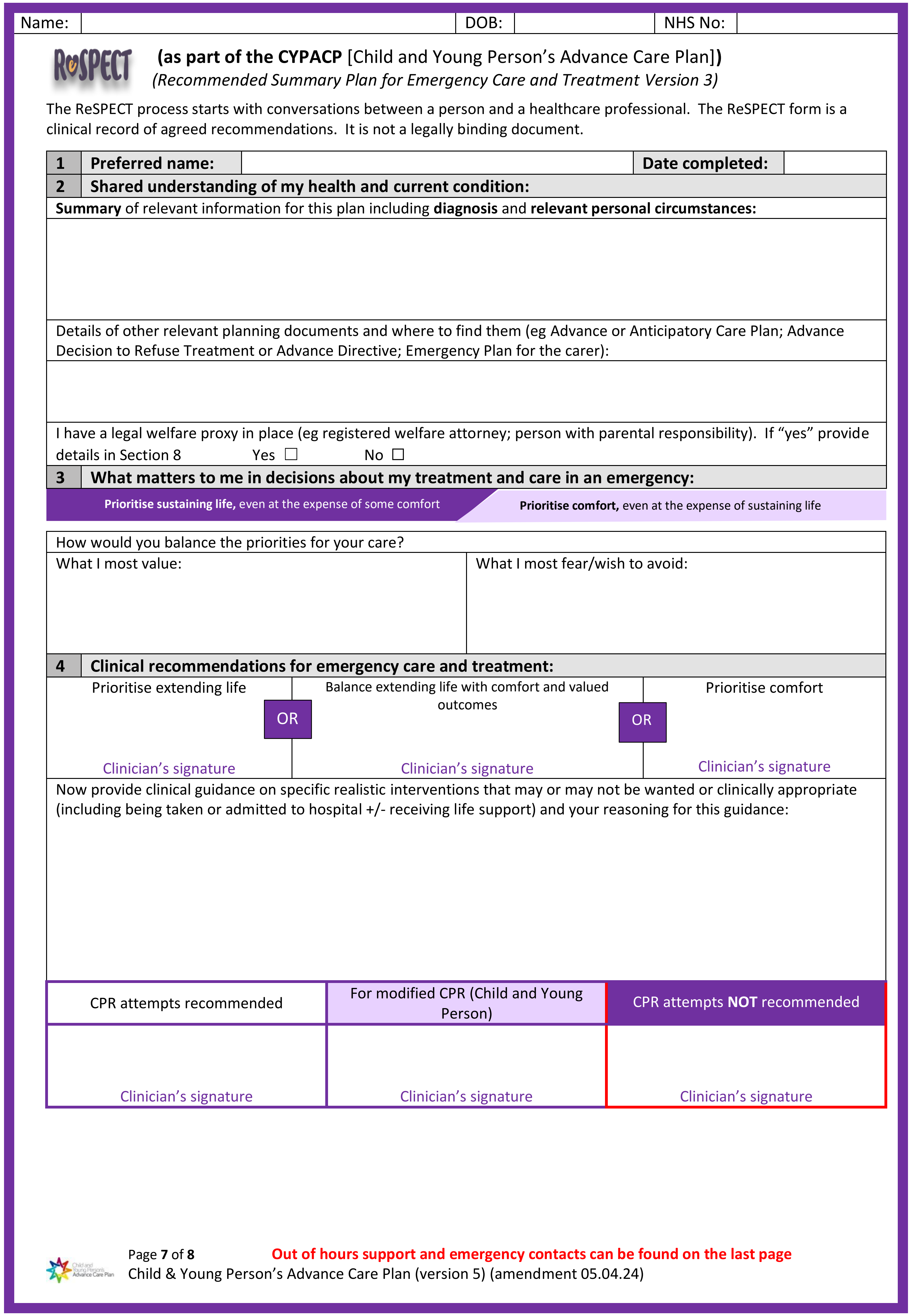
This is the part of the Advance Care Plan which brings together your wishes and thoughts with medical expertise. Therefore, it should be completed by a medical professional to confirm their recommendation. Usually, this should be completed by **your child's lead consultant** but may also be completed by other professionals with appropriate expertise (and knowledge of your child's condition).

> "I think having supportive professionals who understand your child and can help you work through it makes all the difference. We would have been lost without the teams we have had around us during the process."
>
> **– Stacey, Parent Carer**

The ReSPECT summarises the rest of the Advance Care Plan, but concentrates on management in an emergency situation.

Where there is no agreement between you and the clinical team, it can still be helpful to highlight views of both professionals and yourself to help decision making at the time.

It is important to note that ReSPECT is not a legal document, and any clinician must do what they feel is appropriate at the time. However, part of that decision making process should include appropriate consideration of your thoughts and values.



Name:		DOB:		NHS No:	

ReSPECT **(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 Clinician's signature	OR	Balance extending life with comfort and valued outcomes Clinician's signature	OR	Prioritise comfort 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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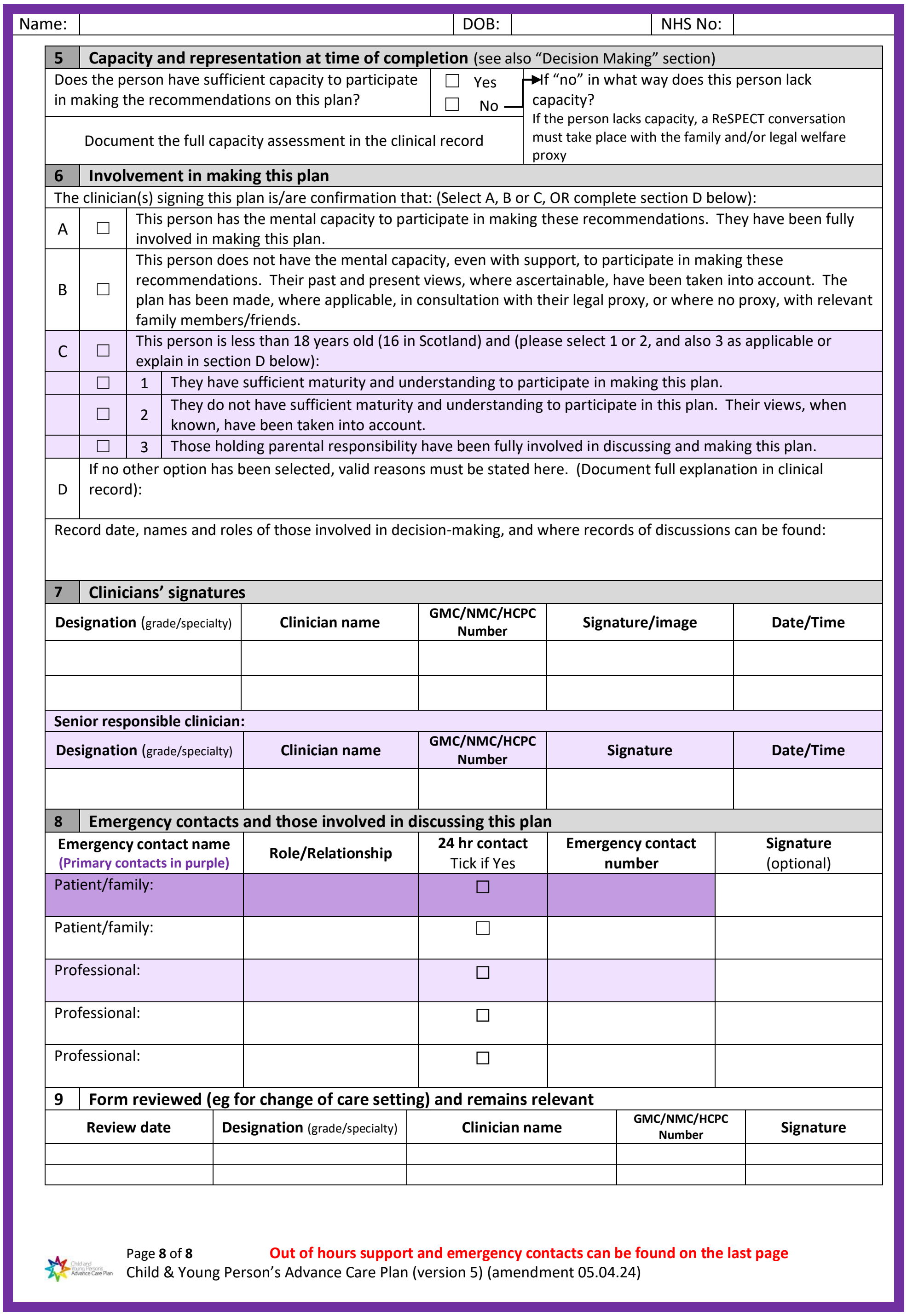
8. Capacity and Signature

The final page is for recording who was involved in the document.

There is the space to sign the document, however this is optional as this is not a legal document. **You do not have to do this if you don't wish to** and your healthcare professional may not even ask you to sign.



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**

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