University Hospitals of Leicester NHS
NHS Trust

Advance Care Planning for Children's and Young People [including Recommended Summary Plan for Emergency Care and Treatment, ReSPECT and Do Not Attempt Cardiopulmonary Resuscitation, DNACPR orders]

Policy for Infants, Children and Young People aged less than 16 years

Approved By:	Policy and Guideline Committee
Date Approved:	May 2016
Trust Reference:	**B25/2016**
Version:	5
Supersedes:	V4 – March 2020
Trust lead: **Policy reviewed by:**	Bedangshu Saikia, Consultant Intensivist, Paediatric Intensive Care and Retrieval Medicine
Board Director lead:	Medical Director
Date of latest approval:	21 June 2024 – Policy and Guideline Committee
Next Review Date:	**June 2027**

Contents

KEY WORDS

CPR, Resuscitation, Cardiopulmonary Resuscitation, ACP, Advanced Care Plan, CYPACP, ReSPECT, DNACPR, DNAR, Do Not Attempt CPR, Paediatric DNACPR, Under 16 yrs.

NB: for the purpose of this document, ACP means CYPACP unless specified.

SUMMARY

1. This policy applies to all patients aged less than 16 years, and patients from 16 years to less than 18 years who have a valid CYPACP/ReSPECT in place that has not been revoked or reviewed since the sixteenth birthday.

2. All patients are presumed to be "for Cardiopulmonary Resuscitation (CPR)" **unless:**
   - A decision excluding CPR has been made and recorded on a CYPACP **or**
   - A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision has been made and recorded on a ReSPECT form or,
   - For infants with severe congenital anomalies, a DNACPR decision has been clearly documented in the clinical notes or the antenatal care plan.

3. All decisions about CPR should:
   - Be made after consultation and in a transparent and fair manner that is free from any element of discrimination on the grounds of gender, religion, sexuality, ethnic group or age.
   - Reflect the best interests of the child.
   - Be taken within a supportive partnership involving the child where appropriate, their parent/guardian(s), and the healthcare team.
   - Respect the wishes of the child and the family, where possible.
   - Provide benefits that are not outweighed by burdens.

4. DNACPR decisions refer only to CPR and not to any other aspect of the individual's care or treatment options.

5. All discussion around CPR decisions must be clearly documented in the patient's contemporaneous notes including identification of those involved in the discussion and responsible for the decision.

6. Where a decision has been made that a child should not receive CPR as part of a wider advanced care plan, the relevant sections of an Advanced Care Plan should be completed (see appendix 2)

7. Where a decision has been made that a child should not receive CPR, and the completion of anACP is either not necessary or not appropriate, a ReSPECT form should be completed (see appendix 1).

8. ACP and ReSPECT forms should be filed at the front of the medical notes.

9. CPR decisions are clinical decisions. Whilst clinical decisions remain the responsibility of the medical professional, the clinician has a duty to involve those with parental responsibility in the CPR decision making process unless this would cause actual psychological or physiological harm. In this situation, the reasons why the parents were not involved should be clearly recorded in the contemporaneous notes.

10. Those with 'parental responsibility' for the child make decisions on the child's behalf. This 'parental responsibility' bestows on parents the responsibility of making decisions for, and acting in the *best interests of the child*, until he or she is old enough to make their own decisions

11. Parents hand over the responsibility for making decisions to their child when a child is old enough to make his or her own decisions affecting their care. As a child develops and matures so will his or her understanding of their illness or disability. They will come to understand their condition, the reasons for their treatment, and the consequences of not having that treatment. This maturity or competence has been referred to as 'Gillick' (or 'Fraser') competence. Such competence is both time and decision specific and may not apply when a child wishes to refuse life-saving interventions and their parents disagree.

12. The child who understands the nature of his or her illness and the likely outcomes of treatment options should be involved wherever possible in the decision-making process.

13. Parents should be offered a second opinion if they disagree with a decision to not attempt or to limit CPR.

14. CPR decisions will normally be made by the consultant with clinical responsibility for the child. They may rarely be made by doctors at ST4 level and above or by an Advanced Clinical Practitioner where this role is included in their job plan. This decision should be endorsed by the clinician with overall responsibility for the patient's care (usually Consultant/Associate Specialist) at the earliest opportunity, at the latest within 24 hours. The person/persons in charge of the patient's daily care is/are responsible for communicating the CPR decision to colleagues involved in the patient's care (for example on handover, including documenting this in electronic handover systems)On discharge or transfer, the person/persons in charge of the patient's daily care is/are responsible for ensuring that the ACP /ReSPECT accompanies the patient to the new care setting (e.g. an alternative ward, hospital or home). A record of the CPR decision should also be included on the discharge letter.

15. Do not keep photocopied version in notes. Follow plan with the child as hospital and community teams may have to update as necessary.

16.

17. Make sure to ask families to always carry the ACP with them and bring in the event of needing to come to Emergency Department or to Hospital for any medical reason including attendance in the clinics etc.

    Complete the "alert on Nervecentre" when the patient has an ACP / ReSPECT / CPR decision completed to prompt when arrival to ED (representation following discharge).

18. **NB: Just to be aware that a RAPID transfer policy being drafted if End of Life Care demands and parent's wishes to be at home / hospice**

CHANGES MADE TO THE POLICY

- Whole policy reviewed and terminology updated.
- Policy brought into concordance with UHL policy on the use of 'ReSPECT' to record DNACPR in adults.
- Change to use the Children's and Young Person's Advanced Care Plan (which includes ReSPECT) instead of all other available means e.g EHCP, PRP etc.
- Policy checked to conform with recommendations from NICE guideline NG61, 'End of life care for infants, children and young people with life-limiting conditions: planning and management' and the associated Quality Standard QS160. National Institute for Health and Care Excellence 2016.

ABBREVIATIONS

ReSPECT = Recommended Summary Plan for Emergency Care and Treatment

CYPACP = Child & Young Person's Advance Care Plan

LPT = Leicester Partnership Trust

GMC = General Medical Council (UK)

NMC = Nursing and Midwifery Council

1 INTRODUCTION[1] AND OVERVIEW

1.1 This document sets out the University Hospitals of Leicester (UHL) NHS Trusts Policy and Procedures for making decisions about advanced care planning and cardiopulmonary resuscitation (CPR) for infants, children and young people (under the age of 16 years) with chronic and life-limiting conditions, or those without previous chronic conditions but who suffer from a severe acute illness, such that cardiopulmonary arrest represents a terminal event in their illness and in whom attempted CPR is inappropriate.

1.2 The process of Advance Care Planning involves discussions with children and young people and their parents or carers about the goals and desired direction of their care, particularly with regard to end of life care. This comprises personalised as well as parallel planning for important stages when changes may occur.

1.3 Personalised, parallel and advance care planning are processes that involve considering, discussing and documenting the wishes of a child or young person, and their parents or carers, for their future care. Where a child or young person lacks capacity, their parents' wishes should drive this process, taking into account the best interests of their child.

---

[1] Parts of this introduction are taken from NICE guideline NG61, 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. National Institute for Health and Care Excellence 2016.

1.4 Parallel planning refers to the development of plans that allow for unpredictability in the course of the condition. Thinking about a care plan should take place in anticipation of a change in the progression of the condition in the future.

1.5 Advance care planning typically covers the concerns and wishes of children and young people about their care, including what should be done, where, how, when and by whom. Importantly, Advance Care Plans also consider what should not be done.

1.6 An effective care plan allows care to be delivered according to the wishes of the child or young person and their parents or carers, allowing them to retain autonomy and to influence how they are looked after and what is done to them.

1.7 The discussion around an Advance Care Plan provides a forum for honest and direct communication between members of the multidisciplinary team, the child or young person and their parents or carers. People can talk about their fears and uncertainties, ask questions and regain some control over what happens to them.

1.8 Currently, however, too often discussions about CPR and Advance Care Plans happen late in a person's illness, and may focus principally on medical issues, such as the withdrawal or limitation of life-sustaining therapies, rather than taking a more individualised view of their care.

1.9 The aims of this policy are to ensure that:

a) All children (under the age of 16 years) are presumed to be for Cardiopulmonary Resuscitation (CPR) **unless** a ReSPECT form (stand-alone or as part of an Advanced Care Plan) that excludes the use of CPR has been completed.

b) All decisions concerning resuscitation are made in accordance with the latest legislation and guidance from regulatory authorities, such as the GMC and NMC, and professional bodies, such as the medical and nursing Royal Colleges.

c) Sensitive communication concerning a child's care and resuscitation occurs between appropriately trained professionals making the decision, the child and the child's family and/or guardians/carers where appropriate, and the results of this decision are communicated to all members of the multidisciplinary healthcare team involved in the child's care and across the range of care settings.

d) The decision-making processes for resuscitation are measured, monitored and evaluated to ensure a robust governance framework

2. POLICY SCOPE

2.1. This policy applies to all infants, children and young people aged less than 16 years

2.2. The policy applies to all staff involved in caring for children aged less than 16 years.

2.3. The UHL "DNACPR Policy (16 years and above)" applies to young people aged 16 years and above.

2.4. For young people who have a valid Advanced Care Plan started before their 16th birthday, this will remain valid until the next review, which should normally happen at their next appointment or contact with their lead clinician (See section 5.14)

3. DEFINITIONS

An Advance Care Plan (ACP) is a structured documented discussion with child or young person or/ and their families or carers about their wishes and thoughts for the future; this includes details about the child or young person's clinical condition too. It is a means of improving care for people, usually those nearing the end of life, and of enabling better planning and provision of care, to help them live and die in the place and the manner of their choosing. An ACP is likely to contain information about personal preferences (e.g. place of care preferences, understanding prognosis).

Cardiopulmonary Arrest: The cessation of breathing and loss of cardiac output.

Cardiopulmonary Resuscitation (CPR) includes all the procedures, from basic first aid to advanced medical interventions, that can be used to try to restore the circulation and breathing in someone whose heart and breathing have stopped. The initial procedures usually include repeated, vigorous compression of the chest, and blowing air or oxygen into the lungs to try to achieve some circulation and breathing until an attempt can be made to restart the heart; may also include administration of drugs and an electric shock (defibrillation).

Children and Young People

In law, a child is anyone under the age of 18 years. Parental responsibility persists until a child is 18, but a child can attain competence to make decisions for themselves (Gillick competence) according to their age and maturity and, once they are 16 years old, are assumed to have capacity to make their own decisions like an adult. In this document the term “children and young people” is used to refer to anyone under the age of 18, but the law in this area is complex, particularly with regards to those who are 16 and 17. Please refer to 1.5.8 Mental Capacity Act (MCA) as refers to the same policy

Child and Young Person’s Advanced Care Plan (CYPACP): A template document for recording both the **resuscitation plan** in the event of a respiratory or cardiac arrest and the plan in the event of a more **gradual deterioration** which may be due to an intercurrent illness. This is now widely used throughout the United Kingdom. a

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Refers to not making efforts to re-start breathing and / or the heart in cases of respiratory / cardiac arrest. It does not refer to any other interventions / treatment / care such as analgesia, fluid replacement, feeding, antibiotics and basic care etc.

DNACPR Decision: The agreed decision on whether it is appropriate, and in the child’s best interest, to attempt cardiopulmonary resuscitation. The purpose of a DNACPR decision is to provide immediate guidance to those present (mostly healthcare professionals) on the best action to take (or not take) should the person suffer cardiopulmonary arrest or die suddenly.

DNACPR Discussion: The discussion leading to the DNACPR Decision, involving health care professionals, the parents and, where appropriate the child or young person.

End of life care: In this policy, end of life care includes the care and support given in the final days, weeks and months of life, and the planning and preparation for this.

Life-limiting condition: Conditions that are expected to result in an early death, either for everyone with the condition or for a specific person.

Parallel planning: Planning for end of life care while taking account of the often unpredictable course of life-limiting conditions. It involves making multiple plans for care, and using the one that best fits the child or young person's circumstances at the time.

Parent: For the purposes of this policy, when the word parent is used it can be read as referring to parents, guardians or others with parental responsibility.

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT): Nationwide approach to discussing and agreeing care and treatment recommendations to guide decision-making in the event of an emergency in which the person has lost capacity to make or express choices. This process can be used by patients and people of all ages.

NB: **Emergency Healthcare Plan / Personal Resuscitation Plan (EHCP/PRP)**
The Emergency Healthcare Plan / Personal Resuscitation Plan is a medical care plan and is the responsibility of the child / young person’s consultant. It is their plan of best care for their patient. **EHCP/PRP still valid if written prior to 01/01/2020 with an expectation they will be reviewed and transferred to CYPACP with ReSPECT when the child or young person has their next medical review.**

4. ROLES AND RESPONSIBILITIES

4.1 Chief Executive

The Chief Executive has overall responsibility for Trust compliance with this Policy and Procedures.

4.2 Medical Director

The Medical Director is responsible for making arrangements to support the safe and effective implementation, monitoring and review of this policy. This is delegated to the Chair of the UHL Resuscitation Committee.

4.3 Chair of the Resuscitation Committee (Deputy Medical Director)

The Resuscitation Committee Chair, supported by members of the Committee, and the Senior Resuscitation Officer, is responsible for:

a) Continuing to develop this policy.
b) Consideration of educational needs.

c) Monitoring compliance with this policy, including:
    a. The completion of CYPACP in compliance with NICE Guideline NG61 and Quality Standard QS160.
    b. Completion of ReSPECT forms.
d) Review of this policy and identifying the appropriate reviewer(s).

4.4 The Resuscitation Committee

The Resuscitation Committee acts as a decision-making body for development, implementation and monitoring of operational policies relating to resuscitation.

4.5 Senior Resuscitation Officer

In addition to supporting the Resuscitation Committee Chair with 4.3, the Senior Resuscitation Officer has a responsibility for co-ordinating educational programmes relating to DNACPR.

4.6 CMG Clinical Directors and Heads of Nursing/ Midwifery, with services providing care for children under the age of 16 years, are responsible for:

a) Making sure that all staff in their CMG are made aware of the policy and procedure for completion of CYPACPs and ReSPECT forms as appropriate.

b) Making sure that staff groups and individuals are given appropriate training to complete and assess the validity of CYPACPs and ReSPECT forms as appropriate to their role (see Section 6).

c) Managing the effectiveness of this policy through a robust system of reporting, investigating and recording incidents and report any concerns / issues to the CMG Quality and Safety Boards.

d) Ensuring processes are in place to undertake audits of compliance, results reviewed and actions taken to address any areas of non-compliance

e} Act on the results of audits pertaining to this policy

4.7 Ward Managers and Heads of Services caring for children under the age of 16 years, to include the Emergency Department, are responsible for ensuring:

a) Staff and trainees are aware of this policy and related documentation.

b) Staff and trainees have had the opportunity to undertake the appropriate level of training as part of their contract of employment. (See section 6).

c) Review of audit results and actions taken where applicable.

4.8 Consultants/Associate Specialists caring for children under the age of 16 years are responsible for ensuring that:

a) CPR decisions are considered as part of overall patient care in a timely way and form part of the consultant ward round as part of escalation planning.

b) CYPACP / ReSPECT / DNACPR decisions (as appropriate) are considered, dependent upon a child's individual circumstances and preferences

c) CYPACP / ReSPECT / DNACPR discussions with children (where appropriate) and parents/guardians are undertaken in line with this policy and documented accordingly in the child's records.

d) CYPACP and ReSPECT forms are correctly completed, are filed at the front of the patient's medical notes and decisions are reviewed, as appropriate.

e) Effective communication of a DNACPR decision to the rest of the clinical team occurs, including when the patients' care is transferred to the care of another team (both internally and externally).

f) Any decisions relating to CYPACP and DNACPR that are not made by either a Consultant or Associate Specialist are verified within 24 hours.

g) Delegated decision making, associated discussions and records are in accordance with this policy.

h) CYPACP and ReSPECT forms are reviewed as appropriate.

4.9 **Healthcare professionals completing a CYPACP or ReSPECT forms must be consultants, senior medical trainees (ST4 level and above) or appropriately trained Advanced Clinical Practitioners, and must:**

a) Have undertaken appropriate training and education in communication and resuscitation decision making, in line with this policy. See Section 6.

b) Involve parents/guardians, and children where applicable, in CYPACP and DNACPR discussions and decision making.

c) Document discussions with the child and parents/guardians or provide the rationale if no discussion has taken place.

d) Document the discussion and decision on the CYPACP or ReSPECT form as appropriate and in the child's notes.

e) Effectively communicate the decision to the rest of the clinical team and when the patients' care is transferred to the care of another team (both internally and externally).

f) Ensure that any CYPACPs or ReSPECT forms not made by either a Consultant or Associate Specialist are endorsed at the earliest opportunity and within 24 hours at the most. This might involve consulting with the on-call consultant out of hours.

4.10 **All staff caring for children under 16 years of age are responsible for:**

a) Adhering to this policy and supporting procedures

b) Notifying their line manager of any training needs and for undertaking relevant training

c) Ensuring they are aware of the existence of a CYPACP or ReSPECT form.

d) Checking the validity of a CYPACP or ReSPECT form and escalating concerns appropriately.

e) Communicating the existence of a CYPACP or ReSPECT form at handover.

f) Notifying other services of the CYPACP or ReSPECT form on the transfer of the patient – both internally and externally.

g) Participating in the audit process and acting on the results accordingly.

h) Being aware of their responsibilities in relation to the legal framework concerning resuscitation decisions in children, such as the Children Act (1989 & 2004), the Human Rights Act (1998), and the Mental Capacity Act (2005).

5. POLICY STATEMENTS

5.1 Cardiopulmonary Resuscitation (CPR)

a) All children are presumed to be for CPR unless a valid ReSPECT form (stand alone or as part of a CYPACP) **excluding CPR** is presented.

b) All decisions about CPR should:

Be made after appropriate consultation and in a transparent and fair manner that is free from any element of discrimination on the grounds of gender, religion, sexuality, ethnic group or age.

- Reflect the best interests of the child.
- Be taken within a supportive partnership involving the child, where appropriate, their parent/guardian(s) and the healthcare team.
- Respect the wishes of the child and the family, where possible.
- Provide benefits that are not outweighed by burden.

c) Children, including neonates, and young people are individuals with rights that must be respected. If they are able to express a view and take part in decision making, they must be listened to and taken into account, respecting their decisions and confidentiality.

5.2 Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

a) When considering limitation of CPR as part of a CYPACP, or making a DNACPR decision in the absence of a CYPACP, it is important to bear in mind guidance from the RCPCH[2], which describes three sets of circumstances when treatment limitation can be considered, as treatments cannot provide overall benefit and it is no longer in the child's best interests to continue:

i. When life is limited in quantity.

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

- Brain stem death, as determined by agreed professional criteria appropriately applied.
- Imminent death, where physiological deterioration is occurring irrespective of treatment.

---

[2] Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A Framework for Practice.

- Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by life-sustaining treatment confers no overall benefit.

ii. When life is limited in quality.

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits.
- Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life.
- Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

iii. Informed competent refusal of treatment

Adults, who have the capacity to make their own decisions, have the right to refuse life-sustaining treatment and to have that refusal respected. An older child with extensive experience of illness may ask for the withdrawal or withholding of life-sustaining treatment. In these circumstances and where the child is supported by his or her parents and by the clinical team, there is no ethical obligation to provide life-sustaining treatment. See section 5.14 for more details.

5.3 ReSPECT Forms

a) The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. Such emergencies may include death or cardiac arrest but are not limited to those events. The process is intended to respect both patient and family preferences and clinical judgement. The agreed realistic clinical recommendations that are recorded include a recommendation on whether or not CPR should be attempted if the person's heart and breathing stop.

b) In children who have an Advanced Care Plan, the ReSPECT form is incorporated into the Children and Young People's Advanced Care Plan (see section 5.4).

5.4 Advanced Care Plans

UHL Children's Services have adopted the 'Child and Young Person's Advanced Care Plan' (CYPACP - See Appendix 2 and https://cypacp.uk). This is now widely used throughout the United Kingdom. ACPs should be considered for all children who have life-limiting conditions on recognition of diagnosis.

An ACP is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service.

a) A valid ACP should be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse.

AN ACP provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents.

AN ACP is designed to be a holistic, summary document that facilitates the clear and concise communication of the wishes of children or young people (and their families), who have chronic and life-limiting conditions**. The original signed copy of the ACP will be kept in the front of the child's notes whilst an inpatient and <u>must</u> be given to the parent / guardian(s) at discharge**

b) All staffs, Drs and nurses caring for a patient, with an ACP / ReSPECT should read/be aware of wishes/management plans prior to reviewing.

c) Complete the "alert on Nervecentre" when the patient has an ACP / ReSPECT completed to prompt when arrival to ED (representation following discharge).

d) Alert Palliative care team once an ACP / ReSPECT implemented if not involved already.

e) On discharge or transfer, the person / persons in charge of the patient's daily care is / are responsible for ensuring that the ACP / ReSPECT accompanies the patient to the new care setting (e.g. an alternative ward, hospital or home). A record of the CPR decision should also be included on the discharge letter.

f) Do not keep photocopied version in notes. Follow plan with the child as hospital and community teams may have updated

5.5 Recording DNACPR decisions and the ReSPECT form

a) Children who do not have an ACP, but in whom cardiopulmonary resuscitation would not be appropriate (such as the child who suffers from a severe illness, where cardiopulmonary arrest represents a terminal event in their illness and attempted CPR would be inappropriate), and in whom a decision is made not to attempt cardiopulmonary resuscitation in the event of cardiopulmonary arrest, should have this decision recorded using the (standalone) ReSPECT form (See appendix 3).

c) The recording of a decision not to attempt cardiopulmonary resuscitation refers only to CPR and not to any other aspect of the individual's care or treatment options

e) The DNACPR decision must be shared with the multidisciplinary team and other professionals involved the care of the child at the next opportunity

f) The following should be taken into account when completing the ReSPECT form or the 'resuscitation' section of the CYPACP:

    i. The decision should be made by the patient's consultant and should be part of consultant ward round. Ideally the patient's consultant should lead the discussions with the parents / guardian and child / young person (if appropriate).

    ii. Rarely, DNACPR decisions may be made by a senior middle grade doctor (ST4 or above) or appropriately trained Advanced Clinical Practitioner but must be reviewed by a consultant within 24 hours. The healthcare professional making the DNACPR decision must sign and date the completed resuscitation planning section of the ACP or ReSPECT form. If this is not the consultant, then this must be countersigned by the consultant as soon as possible and within 24 hours at the most.

    iii. The parents and child do not have to sign the ACP or ReSPECT form, as this may place an unnecessary burden on families. It is sufficient for the healthcare professional to document and endorse the DNACPR decision to confirm that this has been discussed and agreed with the family.

g) The Trust has a legal duty to consult with and inform the parent/guardian(s) before a DNACPR decision is made as part of an ACP or ReSPECT form, and to ensure that this is recorded in the child's notes.

h) The existence of a current ACP or ReSPECT form must be documented in the child's clinical notes, along with a record of discussions with the child (if applicable) and the parent/guardian(s).

5.6 Completing the Advanced Care Plan and/or the ReSPECT form

a) Supporting information about ACPs and the ReSPECT form are available from the relevant websites (http://cypacp.uk/ and https://www.resus.org.uk/respect/).

b) The ACP may be most effective when drawn up by the child/young person and their parents/guardian, and with a doctor who they know and who has known the child. ACPs should be completed in advance of any life-threatening event if possible. See Appendix 5 for guidance on when to consider completing an ACP

c) The ACP should not normally be the first thing mentioned when meeting the child/family for the first time.

d) The ACP is the responsibility of the child / young person's lead consultant or GP and ideally it is that doctor who leads the discussions with the parents / guardian and child / young person if appropriate. The responsibility for competing an ACP should not be left to the community paediatrician or the consultant 'on take' who happens to be looking after the child at the time of an acute admission.

e) The child / young person's community nurse should usually be part of the discussions to ensure that the care plan will work in the community setting.

f) Discussions should usually include other professional's central to the care of the child (i.e. GP, system specific specialist nurses, hospice staff etc.).

g) The process of completing an ACP may involve several different discussions over a period of time as it is essential that all concerned in the decision-making process are allowed enough time for information to be given and understood, to consider, to ask questions and to express their opinion.

h) The blank CYPACP template can be used to discuss options with families in a positive way as soon as a life-threatening event or deterioration can be predicted as a possibility in the future.

i) There are information leaflets for families and for young people about personal resuscitation plans and DNACPR decisions. PDFs of the leaflets are available from https://www.resus.org.uk/respect/respect-resources and http://cypacp.uk/.

j) The consultant must sign and date the completed form.

k) The child / young person and or parents / guardian can also sign, but do not have to, as they can over-ride this written plan at any time for any reason, i.e. they can change their minds and verbally ask for a different action or more or less intervention.

5.7 Communicating the presence of an ACP or ReSPECT form

a) The clinician making a DNACPR decision is responsible for communicating the decision to colleagues within the same care setting;

b) The presence of a valid ACP or ReSPECT form must be part of clinical handover, both internally and on transferring or discharging the child out of UHL

c) If a child with an ACP or ReSPECT form is admitted as an in-patient, the ACP or ReSPECT form will be secured in the front of the patient's notes.

d) Where an ACP or ReSPECT form is completed or revised by UHL, this should be filed at the front of the child's notes whilst in hospital.

e) The parent/guardian(s) must be given the original signed copy of an ACP at discharge.

f) On transfer from UHL, the ACP or ReSPECT form must be sent with the child.

g) The presence of the ACP or DNACPR decision must also be documented in the discharge summary.

5.8 ACP & DNACPR decision review.

a) Review timescales should be based on the child's individual circumstances and should be sufficiently frequent to allow a change of decision (in either direction) in response to the person's clinical progress or lack thereof.

b) Where a child is receiving end-of-life care for a progressive, irreversible condition there may be little or no need for review of the decision. This should be determined by the health professional in charge of the individual's care at the time of the initial decision and documented on the form and in the contemporaneous medical notes.

c) There is no fixed expiry time on an ACP or ReSPECT form.

d) ACPs and DNACPR decisions should normally be reviewed at least annually, but do not have to be discussed with the family at each appointment or hospital admission.

e) A review date, or 'no review required', for an ACP or DNACPR decision should be specified by the senior clinician at the time of completing the documentation and must be documented on the ACP or ReSPECT form and in the patient's clinical record.

f) The ACP ReSPECT form must specify a named health care professional who is responsible for keeping the plan up-to-date.

g) Review meetings need to be organised well ahead of time to ensure there is always a current valid plan.

h) The parents/child can ask for a review of the ACP or ReSPECT form at any time. For example, they may wish to consider different treatment options. This discussion should preferably be with their lead Consultant.

i) The DNACPR decision must be reviewed when there is a change in care setting. If a DNACPR decision is not cancelled on transfer, then the previous DNACPR decision (recorded on an ACP or a ReSPECT form) remains in effect until reviewed.

j) If the ACP or ReSPECT form has a review date but is not reviewed at the stated date, the ACP or ReSPECT form becomes invalid

5.9 Unexpected Cardiac Arrest and ACP/DNACPR.

a) In the event of an unexpected cardiac arrest, every attempt to resuscitate the individual will take place in accordance with the advice given by the Resuscitation Council (UK) unless:

  i. a valid ACP or valid ReSPECT form which excludes CPR is presented.
  or
  ii. irreversible death is confirmed by an appropriately qualified healthcare professional (i.e. qualified to certify death)
  or
  iii. the arrest team determine that CPR is not in the patient's best interests.

b) Professional judgement must be exercised at all times in any decision making. Provided a rational process in decision making can be demonstrated, and is recorded, UHL will support staff if this decision is challenged

c) Consideration of the following will help to inform a decision:

  i. what is the likely expected outcome of undertaking CPR?

  ii. is the undertaking of CPR contravening the Human Rights Act (1998) where the practice could be inhuman and degrading if futile?

5.10 Situations where there is lack of agreement.

a) The health care team should ideally be in agreement about the proposed plan. Although unanimity for the final decision is not required, it is clearly beneficial for all if consensus is obtained. The consultant/senior clinician in charge of the child's care has final responsibility for the decision.

b) If agreement regarding an ACP or DNACPR decision cannot be reached between the health care team and the parents, those with parental responsibility, or the child, where appropriate, then full resuscitation and CPR should be commenced in the event of a cardiopulmonary arrest. Decisions to stop CPR should be made in line with current best practice and professional guidance.

c) If the clinician in charge wishes to proceed with a DNACPR decision or an ACP, and agreement cannot be reached with the family, then a second opinion must be sought. The nature of all discussions, concerns and referrals must be comprehensively documented in the patient notes.

d) It is usually sufficient to have consent from one parent, but if more than one person holds parental responsibility, they should be encouraged to reach a consensus.

e) A child under 16 may consent to treatment (in their best interests) if they are capable of fully understand the implications of their decision. They may refuse treatment (including life sustaining treatment such as CPR) where parents and clinicians agree with that refusal. However, where there is no such agreement, the child's refusal may be overridden by those with parental responsibility or by the Court if it is considered in their best interests to do so. The Children Act and the UN Convention on the Rights of the Child place emphasis on involving individual children, in accordance with their age and capacity, and giving due weight to their views in making informed determination of what is in the child's best interests.

f) A verbal refusal of CPR, by either the child or their parents, should not be ignored and does need to be taken into account when making a best interest decision. The verbal refusal of CPR needs to be documented by the person to whom it is directed and any decision by a clinician to take actions contrary to it must be robust, accounted for and documented

g) Parent/Guardian(s) may state that they do not agree with a DNACPR decision being made even if the clinical evidence suggests that CPR will not succeed. Sensitive discussion with the parent/guardian(s) should aim to secure their understanding and acceptance of the DNACPR decision.

h) Professionals should also be aware of the possibility of disagreements between the child and their parents about decisions regarding their care. This would need careful consideration by the healthcare professional to support them to reach an agreement.

i) Although individuals do not have a right to demand that doctors carry out treatment against their clinical judgement, the person's wishes to receive treatment should be respected if possible. It is best practice to seek a second opinion if there are differing views that cannot be resolved.

j) Where the clinical decision is seriously challenged and agreement cannot be reached, legal advice should be sought from the Head of Legal Affairs – 0116 502 7079

5.11 Cancellation of an ACP or ReSPECT form.

a) In some circumstances, a decision may be made to cancel or revoke an ACP or ReSPECT form. If this is cancelled, the form should be crossed through with two diagonal lines in black ballpoint ink and the word 'CANCELLED' written clearly between them, dated and signed by the responsible healthcare professional.

b) It is the responsibility of the healthcare professional cancelling the ACP or ReSPECT form to communicate this to all parties informed of the original decision, to retrieve old versions, mark them as 'cancelled', to file these and document changes in the clinical notes.

c) Electronic versions of the ACP or ReSPECT form decision must be cancelled as per the guidance above.

5.12 Suspension of an ACP or ReSPECT form

a) In some circumstances, there are reversible causes of a cardiopulmonary arrest. These are either pre-planned or occur during acute care, and the individual should receive treatment, unless intervention in these circumstances has been specified.

   i. Pre-planned: Some procedures could precipitate a cardiopulmonary arrest, for example, induction of anaesthesia, cardiac catheterisation, pacemaker insertion or surgical operations etc. Under these circumstances, the decision not to commence CPR (if needed) should be reviewed prior to the procedure and a decision made as to whether the ACP or ReSPECT form should be suspended. Discussion with key people, including the child if appropriate, will need to take place.

   ii. Acute injury or emergency situation: Where the person suffers an acute, unforeseen, but immediately life-threatening situation, such as anaphylaxis or choking. CPR may be appropriate in this instance even if an ACP or ReSPECT form is in place. Some emergency situations may be explicitly covered by the Advanced Care Plan, in which case the measures outlined in the ACP should be completed

5.13 Patients with a non-standard ACP or DNACPR form

a) The ACP in this policy is based on the Child and Young Person's Advanced Care Plan (http://cypacp.uk/).

b) When a patient is admitted or transferred into the Trust who is subject to an ACP or DNACPR order from a different authority, then the form will be considered valid as long as it has an original signature, is dated, and not been cancelled and is not past its review date.

c) However, it is essential that the admitting team review the order at the earliest opportunity and document their decision in the patient's notes and on to a Trust recognised ACP.

5.14 ReSPECT forms for Young People (16 and 17 years)

a) There is a presumption that 16- and 17-year olds have the capacity to make decisions for themselves. Young people of this age can consent to treatment and may be able to refuse treatment in some circumstances. However, the young person's refusal may be overridden by those with parental responsibility or by the Court if it is considered in the young person's best interests to do so. The Children Act and the UN Convention on the Rights of the Child place emphasis on involving individual children, in accordance with their age and capacity, and giving due weight to their views in making informed determination of what is in the child's best interests. Legal advice should be obtained in this situation.

b) For young people who have an ACP started before their 16th birthday, this will remain valid until the next review, which should normally happen at their next appointment or contact with their lead clinician.

c) Young people who do **not** have an Advanced Care Plan started before their 16th birthday should preferably be managed in accordance with the policy 'UHL Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Policy (16 years and above)'

d) As with adults, decisions about CPR must be made on the basis of an individual assessment of a young person's current situation.

e) DNACPR decisions relating to young people should be taken within a supportive partnership involving patients, parents and the healthcare team.

f) If a 16 or 17 year old is thought to lack capacity for a decision there is no requirement to consult an IMCA where there is a parent available for consultation and there are no safeguarding concerns arising in connection with that parent. The parents are able to provide consent under the normal arrangements of the Children Act.

g) There is no provision in the Mental Capacity Act (2005) for young people aged 16 and 17 to appoint Lasting Powers of Attorney, or to make an Advance Decision to Refuse Treatment (ADRT).

h) The Mental Capacity Act (2005) runs 'parallel' with the Children Act (1989), and the two statutes are drawn up in such a way as to co-exist, rather than provide contradictory advice. There will be times when it is not clear whether a clinical problem should be approached via the children Act or the Mental Capacity Act. If there is any uncertainty, or if it is not possible to reach agreement between the patient, the individuals with parental responsibility and the healthcare team, legal advice should be obtained from the Head of Legal Affairs – 0116 502 7079

i) Children over 16 years of age, still transitioning to adult care or transition not started at all, potentially might fall in this category.

6. EDUCATION AND TRAINING REQUIREMENTS

To support implementation of this policy, DNACPR teaching is included in the resuscitation training programme and forms part of annual statutory and mandatory training.

This will take the form of both e-learning and videos and discussion in all UHL resuscitation face to face sessions.

All staff who have clinical responsibility for children and young people should undertake statutory and mandatory training and supplement this with further training appropriate to their role.

7. PROCESS FOR MONITORING COMPLIANCE

7.1 Compliance with this policy will be overseen by the UHL Resuscitation Committee using the Key Performance Indicators below:

Element to be monitored	**Lead**	**Tool**	**Frequency**	**Reporting arrangements**	**Lead(s) for acting on recommendations**
Completion of ACP and ReSPECT form	Resuscitation Lead and Children's Quality & Safety Lead	Case Notes and ACP	6 monthly	Resus Cttee and W&C CMG Q&S Board	W&C CMG Clinical Director / Heads of Nursing/Midwifery
Resus Team called where DNACPR decision not followed	Resuscitation Lead and Children's Quality & Safety Lead	Resus Audit forms	6 monthly	Resus Cttee and W&C CMG Q&S Board	W&C CMG Clinical Director / Heads of Nursing/Midwifery

7.2 NICE Quality Standard.

Data will be collected to monitor compliance with NICE Quality Standard QS160; Quality statement 1: Advance care plan[3].

Process

a) Proportion of parents or carers of infants with a life-limiting condition who are involved in developing an advance care plan.

Numerator – the number in the denominator who are involved in developing an advance care plan.

Denominator – the number of parents or carers of infants with a life-limiting condition.

Data source: Local data collection based on audits of patient care records.

b) Proportion of children and young people with a life-limiting condition who are involved in developing their advance care plan.

---

[3] https://www.nice.org.uk/guidance/qs160/chapter/Quality-statement-1-Advance-care-plan

Numerator – the number in the denominator who are involved in developing their advance care plan.

Denominator – the number of children and young people with a life-limiting condition.

Data source: Local data collection based on audits of patient care records.

Outcome

Level of satisfaction with care in infants, children and young people with a life-limiting condition and their parents and carers.

Data source: Local data collection based on feedback from children and young people with a life-limiting condition and their parents and carers, and parents or carers of infants with a life-limiting condition.

8. EQUALITY IMPACT ASSESSMENT

8.1 The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.

8.2 As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

9. SUPPORTING REFERENCES, EVIDENCE BASE AND RELATED POLICIES

6

UHL Policies

Combined UHL/LPT/LLR Alliance Cardiopulmonary Resuscitation Policy E4/2015

UHL Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Policy (16 years and above) B25/2014

Legislation

Clinicians using this policy should be familiar and act in compliance with the following legislation: (http://www.opsi.gov.uk/acts):

Children Act (1989 & 2004)
Clinicians are expected to understand how the Act works in practice. The key consideration is to make decisions consistent with the best interests of the child.

Adoption and Children Act (2002) (2006) addendum 2014
Clinicians are expected to understand who has parental responsibility to consent to treatment in a child

Mental Capacity Act (2005)
Applicable to 16 and 17 year old patients and adults (see point 6.13)
The Mental Capacity Act (MCA) 2005 is specific to a particular decision being considered: so a person may lack capacity for a DNACPR decision but have capacity for another e.g. preferred place of care.

Clinicians facilitating an ACP for 16 and 17 year old young people must be familiar with, and fully comply with the MCA.

Working Together to Safeguard Children (2006 & 2013) revisions Jan 2015.
This details the responsibilities to report child deaths to the Child Death Overview Panel (CDOP) and the role of the local Rapid Response Team.
https://assets.publishing.service.gov.uk/media/Working_together_to_safeguard_children_2023

Human Rights Act (1998)
The following sections of the Act are relevant to this policy:

- Failure to provide CPR could be a breach of the individual's right to life (article 2)
- To be free from inhumane or degrading treatment (article 3)
- Respect for privacy and family life (article 8)
- Freedom of expression, which includes the right to hold opinions and receive information (article 10)
- To be free from discriminatory practices in respect to those rights (Article 14)

Coroners Act (1988) new guidance updated 2012
Clinicians are expected to know the circumstances when a death must be discussed with the District Coroner.
http://www.medicalprotection.org/uk/resources/factsheets/england/england-factsheets/uk-eng-reporting-deaths-to-the-coroner
https://www.gov.uk/government/publications/update-for-coroners-on-death-certification-reforms

Guidance
Additional guidance may be drawn from the following sources:

NICE guideline NG61, 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. National Institute for Health and Care Excellence 2016.

Together For Short Lives – Standards Framework for Childrens Palliative Care (https://www.togetherforshortlives.org.uk/resource/standards-framework-childrens-palliative-care/)

Ambitionsfor Palliative and End of Life Care – A National Framework for Local Action 2021 – 2026 (https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/)

http://cypacp.uk/

Resuscitation Council (UK) Guidelines https://www.resus.org.uk/

Advanced Paediatric Life Support Group Guidelines http://www.alsg.org/uk/apls.

Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A Framework for Practice. http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html.

Resuscitation Council (UK) Recommended standards for recording "Do not attempt resuscitation" (DNAR) decisions (2009)
http://www.resus.org.uk/siteindx.htm.

Decisions relating to Cardiopulmonary Resuscitation (3rd edition) Guidance from the British Medical Association (BMA), the Resuscitation Council (UK), and the Royal College of Nursing (previously known as the "Joint Statement") Oct 2014
https://www.resus.org.uk/pages/dnacpr.htm.

BMA (2006) Parental Responsibility: Guidance from the BMA. https://www.bma.org.uk/practical-support-at-work/ethics/children

General Medical Council (2007) 0-18 years: guidance for all doctors http://www.gmc-uk.org/publications/standards_guidance_for_doctors.asp#0-18

DNAR decisions in the Perioperative Period; Association of Anaesthetists of Great Britain and Ireland May 2009 https://anaesthetists.org/Home/Resources-publications/Guidelines

Reconsideration of ACP for surgery or procedures, GOS protocol
http://www.togetherforshortlives.org.uk/assets/0000/8555/Great_Ormond_St_policy_required_reconsideration.pdf.

General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making. https://www.gmc-uk.org/-/media/documents/Treatment_and_care_towards_the_end_of_life___English_1015.pdf_48902105.pdf

10. PROCESS FOR VERSION CONTROL, DOCUMENT ARCHIVING AND REVIEW

This document will be uploaded onto SharePoint and available for access by Staff through INsite. It will be stored and archived through this system.

The latest version of the ACP will be uploaded onto SharePoint and available for access by Staff through Insite and is also available at http://cypacp.uk/

The policy will be reviewed on a 3-yearly basis or earlier if new guidance is published

Appendix1: Child and Young Person’s Advance Care Plan Collaborative (CYPACP)

Child and
Young Person’s
Advance Care Plan
Collaborative

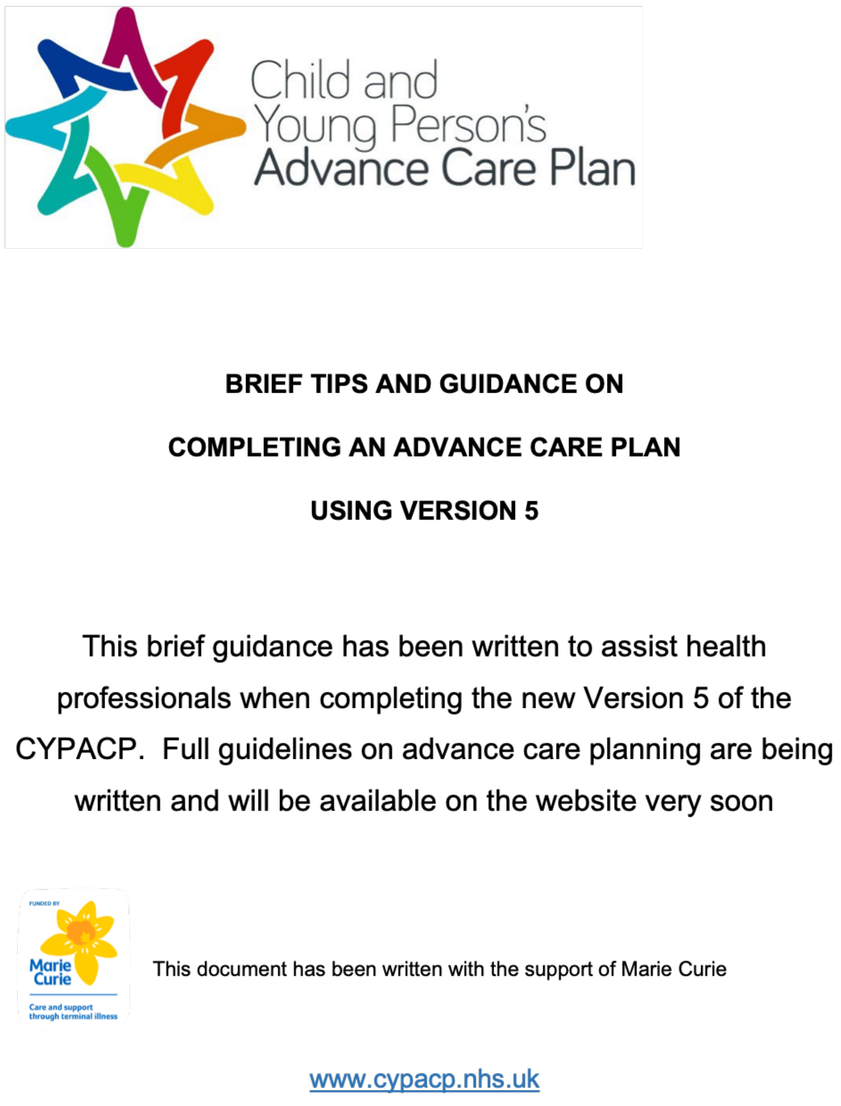
Welcome to the CYPACP Website (Click on the link below)

[CYPACP – Child & Young Persons Advance Care Plan]

Appendix 2: How to complete the CYPACP form

(please see the attachment for details or click on the link below for details)

How-to-complete-the-CYPACP-form.pdf



Child and
Young Person's
Advance Care Plan

BRIEF TIPS AND GUIDANCE ON

COMPLETING AN ADVANCE CARE PLAN

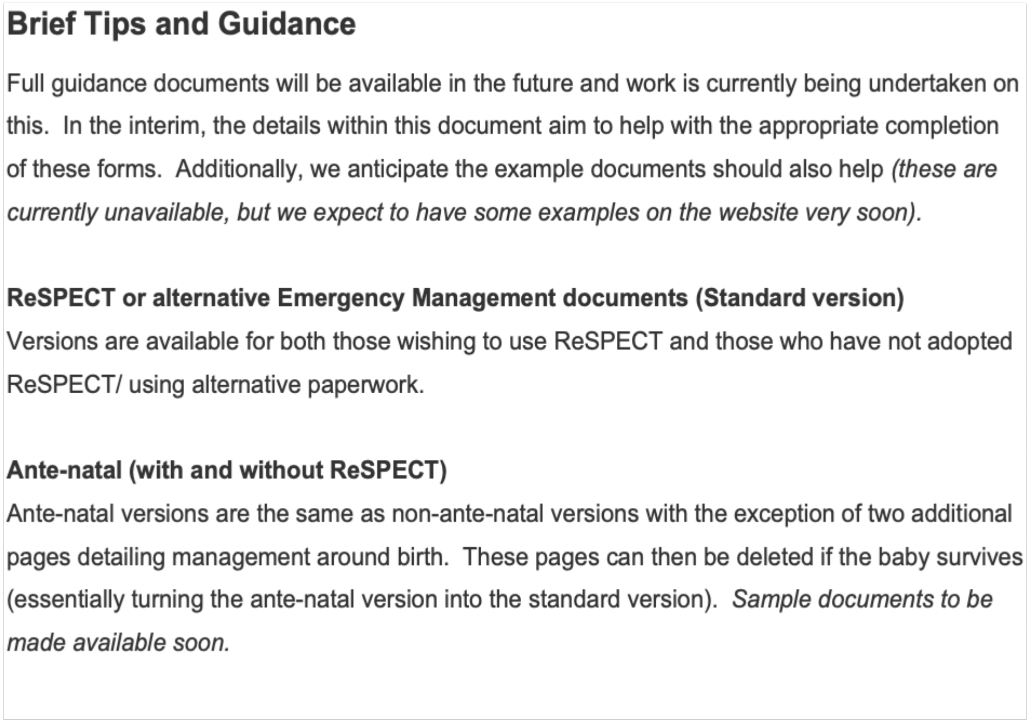
USING VERSION 5

This brief guidance has been written to assist health professionals when completing the new Version 5 of the CYPACP. Full guidelines on advance care planning are being written and will be available on the website very soon

FUNDED BY
Marie Curie
Care and support through terminal illness

This document has been written with the support of Marie Curie

www.cypacp.nhs.uk



Brief Tips and Guidance

Full guidance documents will be available in the future and work is currently being undertaken on this. In the interim, the details within this document aim to help with the appropriate completion of these forms. Additionally, we anticipate the example documents should also help *(these are currently unavailable, but we expect to have some examples on the website very soon).*

ReSPECT or alternative Emergency Management documents (Standard version)
Versions are available for both those wishing to use ReSPECT and those who have not adopted ReSPECT/ using alternative paperwork.

Ante-natal (with and without ReSPECT)
Ante-natal versions are the same as non-ante-natal versions with the exception of two additional pages detailing management around birth. These pages can then be deleted if the baby survives (essentially turning the ante-natal version into the standard version). *Sample documents to be made available soon.*

HOW TO COMPLETE AN ADVANCE CARE PLAN

Make an assessment of the child's clinical situation:
The process of advance care planning should begin at a time that best suits the family, ideally during a period of stability in the child's condition and not at a time of acute illness. Natural triggers for starting the conversation may be a recent admission to hospital or intensive care, or deterioration in their underlying condition. In children with complex neurodisablity, there may be increasing frequency of acute illnesses, paired with a failure for the child to return to their previous state of health in between.

Facilitate discussion/s with all healthcare professionals (multi-disciplinary team (MDT) involved in the child's care:
Secure their opinions regarding the appropriateness of preparing and the content of an ACP.

Discuss the child's status with the child's parents/guardians and child (if appropriate) Also include other significant family members or others invited by the family where appropriate. Establish their feelings regarding the need for an ACP. Consider involving a professional interpreter if they are not fluent in English.

Allow plenty of time to discuss and complete the document with the parents/guardians (and child as appropriate):
Allow a minimum of 1–2 hours. Consider the best setting for these conversations (home, hospital, hospice or elsewhere). Completion of the plan may require several

consultations/discussions, which may take place over several days or weeks. The amount of input into this process by the child depends on their capacity for these decisions.

Completing the ACP:

This document has been devised by a wide range of users and ALL sections are useful. They are also recognised within NICE guidance.

The CYPACP should ideally be completed within Microsoft Word and then printed out for signing and circulation. It can be handwritten but must be completed in writing that is legible, using black ink. Some families/professionals may not wish to complete all sections initially (it is not compulsory to fill in all sections). However, they should be left in the document in case discussion around these areas occurs at a later stage.

The only pages that should be deleted if not appropriate are in the neonatal section. The name, date of birth and NHS number of the child, or the mother of the child if the form is completed ante-natally, should appear on every page (NB: Please double click in the header to enter these details – the header is not automatically populated from elsewhere).. If the ACP remains in place post-natally, don't forget to change the name, date of birth and NHS number in the header from the mother's to the child's.

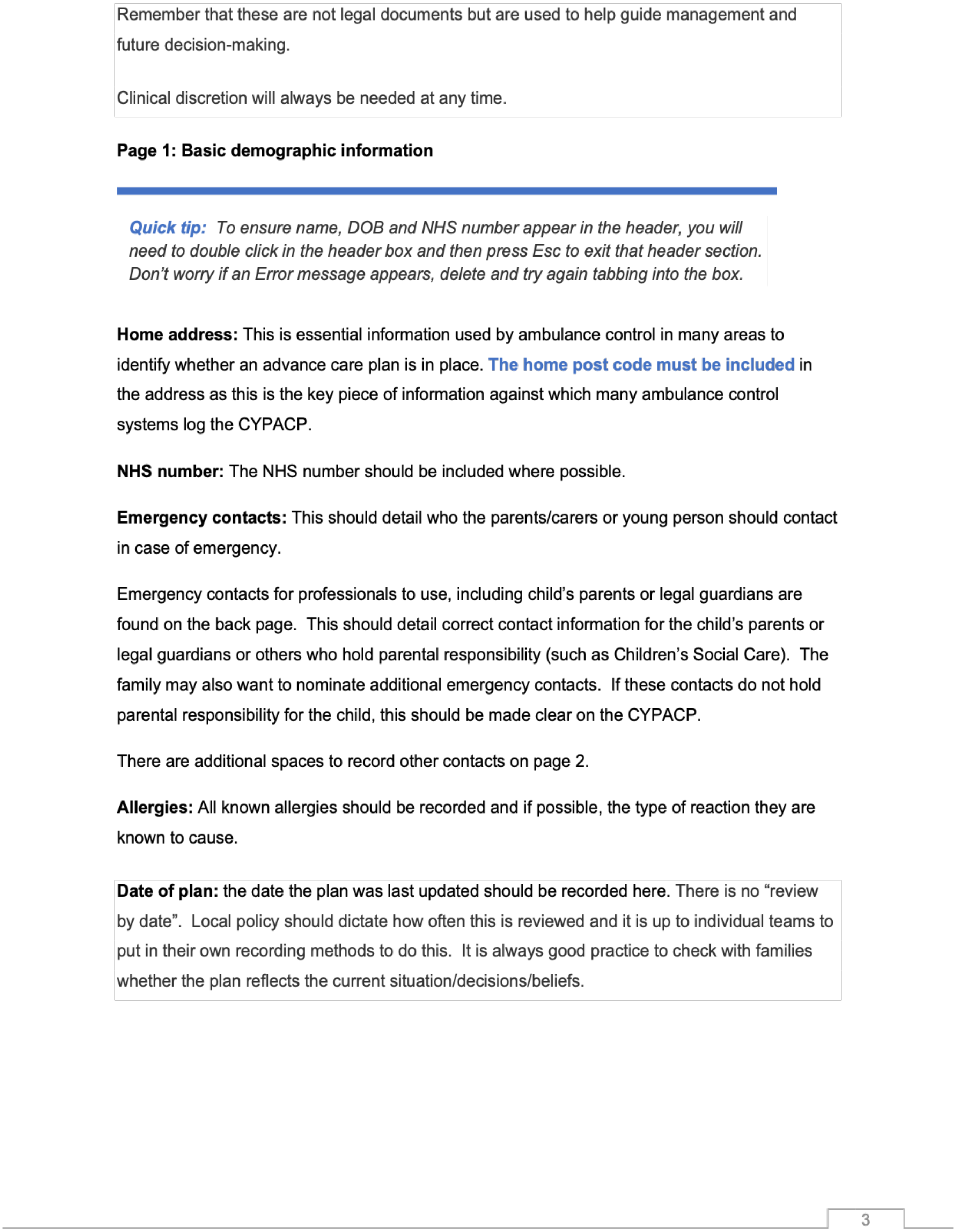
The documents are in Word and the formatting can change and move about as the text is not "protected". Don't worry about this – it can be rectified as with any Word document. You are able to use formatting to make the document easier to read eg bold, bullet points, etc and it is possible to paste into the boxes, although again be aware the formatting may change but can be easily put right.

Boxes will expand downwards as you write more, and this may mean the number of pages increases as each section has a section break to keep them separate. However, always think of the users, particularly on the emergency pages, and try to keep instructions/information succinct.

It is recommended that you use this website and download your chosen ACP when creating a new care plan (rather than storing it as a template and working from that). This will ensure that you are always using the latest version.

Ideally, the CYPACP should be circulated electronically, but where this is not possible, physical copies can be circulated. Some organisations (such as the ambulance service) may require only part of the CYPACP but including the ReSPECT / Emergency Management Section for ease of use.

The original copy of the CYPACP should stay with the child. The family may require additional copies for different family members.



Remember that these are not legal documents but are used to help guide management and future decision-making.

Clinical discretion will always be needed at any time.

Page 1: Basic demographic information

Quick tip: *To ensure name, DOB and NHS number appear in the header, you will need to double click in the header box and then press Esc to exit that header section. Don't worry if an Error message appears, delete and try again tabbing into the box.*

Home address: This is essential information used by ambulance control in many areas to identify whether an advance care plan is in place. **The home post code must be included** in the address as this is the key piece of information against which many ambulance control systems log the CYPACP.

NHS number: The NHS number should be included where possible.

Emergency contacts: This should detail who the parents/carers or young person should contact in case of emergency.

Emergency contacts for professionals to use, including child's parents or legal guardians are found on the back page. This should detail correct contact information for the child's parents or legal guardians or others who hold parental responsibility (such as Children's Social Care). The family may also want to nominate additional emergency contacts. If these contacts do not hold parental responsibility for the child, this should be made clear on the CYPACP.

There are additional spaces to record other contacts on page 2.

Allergies: All known allergies should be recorded and if possible, the type of reaction they are known to cause.

Date of plan: the date the plan was last updated should be recorded here. There is no "review by date". Local policy should dictate how often this is reviewed and it is up to individual teams to put in their own recording methods to do this. It is always good practice to check with families whether the plan reflects the current situation/decisions/beliefs.

Page 2:

> **Quick tip:** ***Please be careful with Yes/No tick boxes.*** *Ideally, we would like to have been able to make it that only one could be ticked when given a choice. However, this was not possible, therefore, please pay particular attention to this.*

Interpreter: This is important to record for any family where English is not their first language, even if they speak it fluently. They may prefer to have an interpreter present when having discussions around advance care planning.

Communication: Consider if the child or their parent/carer requires support with communication including electronic communication aids, use of sign language, interpreter, particular communication techniques enabling yes/no answers or a description of how the child/young person communication. Information about this should be included on the CYPACP.

Mental Capacity: (see also last page of ACP) The Mental Capacity Act (2005) applies to all people over the age of 16 years. Young people aged 16/17 are assumed to have capacity to make their own decisions under the MCA. If the young person lacks capacity to make specific treatment decisions, the person with parental responsibility can consent or the care staff providing care can carry out treatment or care with protection from liability. The MCA code of practice must be followed. Young people may have had an MCA assessment, and details of where to find this should be included in the CYPACP rather than including the actual assessment.

Parents making decisions for their child under 16, and who hold parental responsibility are assumed to have mental capacity unless it can be established that they lack capacity. They can make decisions on behalf of their child either to prioritise life-sustaining treatment or prioritising comfort care, although it should be noted that clinicians must always act in the best interests of the child/young person. The decisions and this document will help guide “best interest” decision-making, but it cannot be guaranteed that the decisions detailed in this care plan will be followed to the letter.

Pages 3-4:

There is a lot of information that children and families may wish to share with professionals completing the CYPACP. These are the pages for recording that information. It is important that the person completing the CYPACP is familiar with the topics included and are aware of local policies which may be relevant to the conversation. No information is deemed too trivial or too small.

Page 3: Summary diagnosis, background information and personal background information

Completing these sections is useful, particularly for clinical encounters where the child is not known to the clinician. It provides useful context and goes some way to ensuring that parents do not need to tell their story repeatedly.

In addition to the information suggested, it is helpful to also include safeguarding issues, if the child is subject to a safeguarding plan, a Child in Need plan, is a 'looked after child' or there is shared parental responsibility with the local authority.

Page 4: Priorities of care when nearing the end of life

Children and families may have very specific thoughts around their priorities of care including specific spiritual or religious practices they would like to observe. It is important to document these especially for those professionals present who may not know about specific observances.

Organ donation: it is important to understand if children and families have wishes around organ donation and to be able to answer their questions. Often it is necessary to have the conversation in two stages, first to understand what the children or family would like to do and secondly to give them information about what might be possible according to local policy. Transplant co-ordinators in hospital settings are generally willing to talk directly with children and families, but they may prefer to share information with the person writing the CYPACP and for them to share the information with the parents/carers or young person.

Coroner / Post-mortem/ medical examiner referrals: From April 2023 it will be a requirement that all child deaths in hospital are discussed with the medical examiner. This should be explained to children and families, as in some cases this can delay the issuing of

the Medical Certificate of Cause of Death (MCCD) and may affect family decisions/wishes for after their child has died.

In some areas, the Child Death Overview Panel (CDOP) or the Rapid Response Team should be made aware and/or sent a copy of the CYPACP, particularly if the child is not for resuscitation or for modified resuscitation. This sharing of information in advance can help reduce the chance of a disproportionate Rapid Response if the child dies suddenly.

It is important, if the information is available, that families are informed about the need for their child to be referred to the coroner after they have died. If possible, it should be agreed prior to the child's death, who should inform the coroner once the child has died. In some areas, Coronial teams prefer to be informed of the imminent death of a child who may be referred to them, but this will vary according to region.

Families may wish to consider a voluntary hospital post-mortem and it may be appropriate to share this information with them.

An unexpected death is defined as the death of an infant or child which was not anticipated as a significant possibility 24 hours prior to their death, or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death The coroner will need to be contacted and a Rapid Response Team will also need to be informed.

The coroner will also need to be contacted (as an emergency or electively as appropriate) if:

- The cause of death appears to be related to a medical procedure, medical treatment or equipment failure
- The cause of death appears to be related to drug use, overdose, alcohol or neglect
- There are any suspicious circumstances or a history of violence
- The cause of death appears to be suicide
- The death is linked to an unnatural event or accident (Coroners Act 1988)
- The death has occurred while the patient was in police custody or any state detention

Children and families may not want to discuss certain aspects of their child's life and death, their reasons for this can be documented at the bottom of page 4.

Pages 5-6: Neonatal section

This section is for use with families who are known to be expecting a life-limited or life-threatened child. It can be completed with a family at any point during the pregnancy with the support of the obstetric and midwifery teams.

Quick tip: *These ante-natal pages can then be deleted if the baby survives (essentially turning the ante-natal version into the standard version*

Page 5: Plan for delivery and plans for after delivery/birth

Quick tip: *Please be cautious when completing Yes/No tick boxes.*

This is to record the family's wishes around the pregnancy and birth. It is important to know the types of information that can be recorded on this form and the local policies (for example access to side rooms, birthing pools, etc) prior to the conversation with the family. It can be filled in in conjunction with an existing birth plan the family may have.

It is often helpful to have these meetings with the midwife and or obstetrician present.

Page 6: Management of baby at birth

This page is to record the medical interventions and management of the baby after their birth. This may vary from full resuscitation to prioritising comfort care. There may also be a symptom management plan written for the baby. This should be documented on the CYPACP and kept with it.

If the baby survives beyond the immediate newborn period, then the rest of the CYPACP should be referred to, including 'Management of Anticipated Complications/Deteriorating Health' and 'Management of an Acute Significant Deterioration/Emergency'. These additional pages should be completed for the majority of families prior to the birth of their baby.

Pages 7-10: Medical management of deteriorating or acute conditions, ReSPECT or alternative Emergency Management documents (Standard version)

Versions are available for both those wishing to use ReSPECT and those who have not adopted ReSPECT.

Please note: ReSPECT section should be kept to **TWO** pages in total as the emergency services will be expecting this

Page 7: Management of Anticipated Complications/Deteriorating Health

This is the page of the CYPACP document to discuss and record ceilings of treatment with children and families. There may be specific actions that families do or do not want to undertake if their child deteriorates (for example intravenous antibiotics that might require admission to hospital and cannulation, but they would be willing to give oral antibiotics at home). For some children, this page will be expanded to include detailed and specific information about them, their condition and their or their family's wishes. It can be difficult to convey very nuanced situations on paper and it is important to include the information in a succinct way that can be understood by any professional using the document, who may not know the child, and if necessary, refer to a specific separate treatment document.

- General management: this is to document current treatment and specific vulnerabilities of the child.
- Many children will have separate specific treatment plan documents such as for dystonia or seizures and these can be referred to and a note of where to find them included in this section.
- There may be specific aspects of deterioration that can occur with the child's condition. These can be highlighted here, with the specific management response or wishes documented; for example, metabolic emergencies.

- A systems approach to the documentation has been developed to reflect the complexity of some children's conditions and multi-system involvement. Some sections will not be relevant to individual children and should have some indication that this is the case (either a written 'not appropriate' or a line in the box). This can prevent potentially unnecessary and distressing conversations with families.

Page 8: Management of an Acute Significant Deterioration/Emergency.

This page is separate from but linked to the ReSPECT or Emergency Management Summary section of the document. It is for documenting whether a family or child wish for ceilings of care should they have a life-threatening event. It is supported by the ReSPECT or Emergency Management Summary section of the document but allows for more detail of specific situations to be recorded.

- All reversible causes of acute deterioration (such as anaphylaxis) should be treated in the absence of instructions to the contrary. This position should be made clear to all parties involved in the decision-making process.
- In the absence of instructions to the contrary, standard APLS guidelines should be followed.
- The discussions around medical interventions in the event of an acute deterioration or cardio-respiratory arrest may not always be appropriate, especially where there is no perceived risk of the child sustaining a cardiopulmonary arrest. However, it is important to consider having this discussion at the time of writing the CYPACP, as it is much better discussed at a time separated from an acute event, than in a time pressured situation around resuscitation or in intensive care.
- If the child and their family decide that they do not wish to have any life sustaining treatment in the event of a life-threatening event, it is good practice to record the reasons for the decision according to The Royal College of Paediatrics and Child Health (RCPCH) guidance on 'Making a decision to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice' (2015).

These are categorised as the following:

- **When life is limited in quantity:** If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:
    - Brain stem death, as determined by agreed professional criteria appropriately applied
    - Imminent death, where physiological deterioration is occurring irrespective of treatment
    - Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by life-sustaining treatment confers no overall benefit.

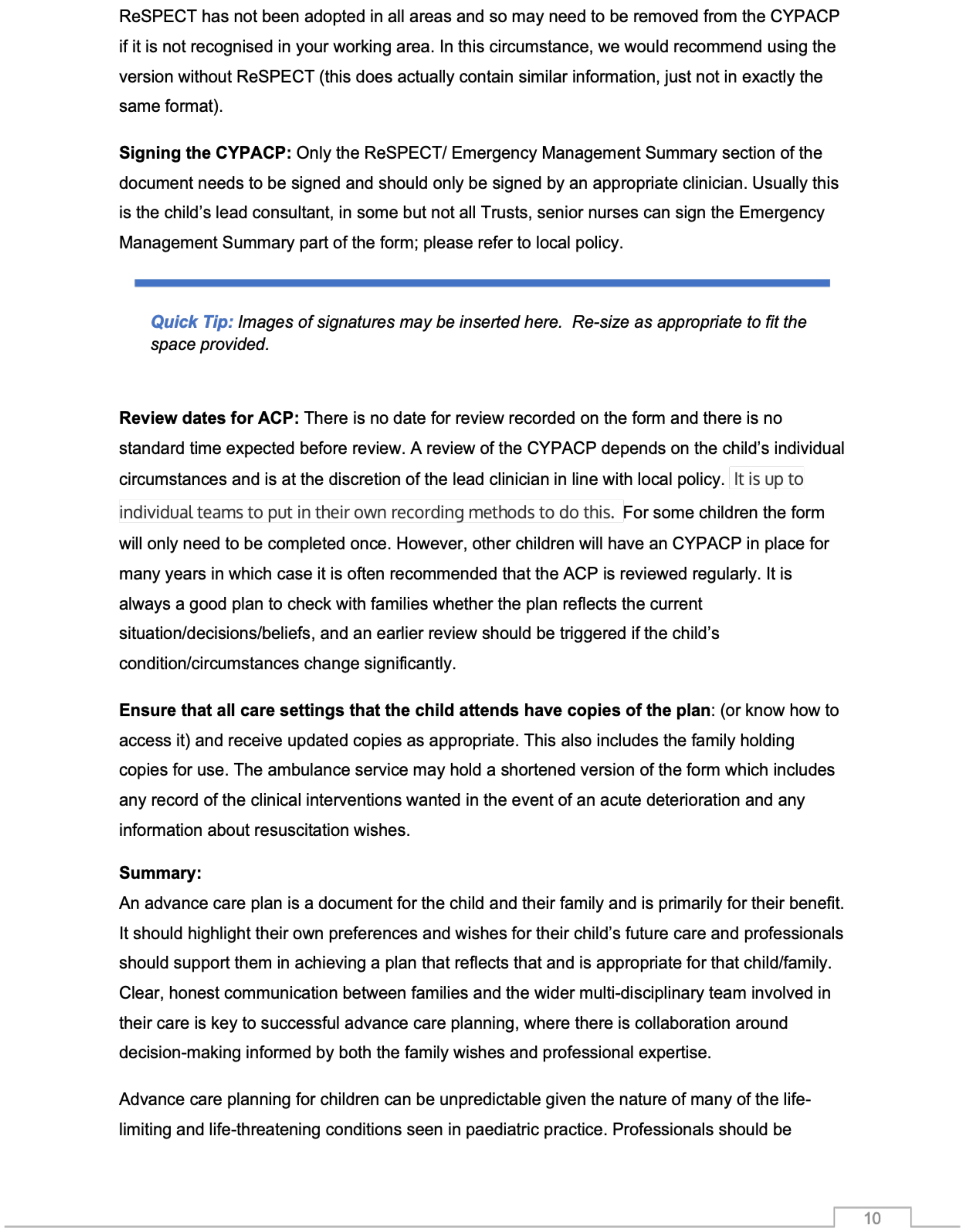
- **When life is limited in quality:** This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:
    - Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
    - Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
    - Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.
- **Informed competent refusal of treatment:**
    - Adults, who have the capacity to make their own decisions, have the right to refuse life-sustaining treatment and to have that refusal respected. So, an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of life-sustaining treatment. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide life-sustaining treatment.
    - It is still assumed that all rapidly reversible causes of cardiorespiratory arrest (such as choking) are to be treated actively and this should be made clear to the parties involved in the decision-making process.
    - The last box is to record other information to be conveyed to health care and other professionals in this event. It may also include ambulance directives for transfer of care to other institutions. If families have specific wishes about the transfer to a different setting (eg to go straight to the hospice), it should be conveyed, that although it is documented, that this may not always be possible.

Pages 9 and 10: **ReSPECT form**

The ReSPECT process and form are complementary to the CYPACP document. ReSPECT presents the key emergency information that may be required in an Emergency Department, or wherever the child or young person first presents, without needing to read the whole of the CYPACP.

There are many organisations/regions nationally now using the ReSPECT form for both children and adults. Please check with local guidelines and information about its use. Information about the completion of the ReSPECT part of the CYPACP will not be included in this document and referral should be made to the following document

https://learning.respectprocess.org.uk/wp-content/uploads/2017/06/What-is-ReSPECT-download.pdf



ReSPECT has not been adopted in all areas and so may need to be removed from the CYPACP if it is not recognised in your working area. In this circumstance, we would recommend using the version without ReSPECT (this does actually contain similar information, just not in exactly the same format).

Signing the CYPACP: Only the ReSPECT/ Emergency Management Summary section of the document needs to be signed and should only be signed by an appropriate clinician. Usually this is the child's lead consultant, in some but not all Trusts, senior nurses can sign the Emergency Management Summary part of the form; please refer to local policy.

> ***Quick Tip:*** *Images of signatures may be inserted here. Re-size as appropriate to fit the space provided.*

Review dates for ACP: There is no date for review recorded on the form and there is no standard time expected before review. A review of the CYPACP depends on the child's individual circumstances and is at the discretion of the lead clinician in line with local policy. It is up to individual teams to put in their own recording methods to do this. For some children the form will only need to be completed once. However, other children will have an CYPACP in place for many years in which case it is often recommended that the ACP is reviewed regularly. It is always a good plan to check with families whether the plan reflects the current situation/decisions/beliefs, and an earlier review should be triggered if the child's condition/circumstances change significantly.

Ensure that all care settings that the child attends have copies of the plan: (or know how to access it) and receive updated copies as appropriate. This also includes the family holding copies for use. The ambulance service may hold a shortened version of the form which includes any record of the clinical interventions wanted in the event of an acute deterioration and any information about resuscitation wishes.

Summary:

An advance care plan is a document for the child and their family and is primarily for their benefit. It should highlight their own preferences and wishes for their child's future care and professionals should support them in achieving a plan that reflects that and is appropriate for that child/family. Clear, honest communication between families and the wider multi-disciplinary team involved in their care is key to successful advance care planning, where there is collaboration around decision-making informed by both the family wishes and professional expertise.

Advance care planning for children can be unpredictable given the nature of many of the life-limiting and life-threatening conditions seen in paediatric practice. Professionals should be prepared for this and remain flexible and responsive during the process of writing the CYPACP, not only in response to disease related change but for the changes in parental or child expectations and wishes as a result. Given the importance of such a document, time spent in preparation and writing it well, will enable children and families to effectively communicate difficult decisions and important information with the medical teams they encounter.

Appendix 3: CYPACP Version 5 for all ages with ReSPECT

(Click on the links as required)

Example of CYPACP with Respect, as shown below.

CYPACP-Version-5-Standard-all-ages-with-ReSPECT.docx

Pleae click on the links to access:

CYPACP Version 5 for all ages generic without ReSPECT CYPACP-Version-5-Standard-all-ages-Generic-without-ReSPECT.docx

CYPACP Version 5 Antenatal with ReSPECT CYPACP-Version-5-Antenatal-with-ReSPECT.docx

CYPACP Version 5 Antenatal Generic without ReSPECT CYPACP-Version-5-Antenatal-Generic-without-ReSPECT.docx

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/

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)

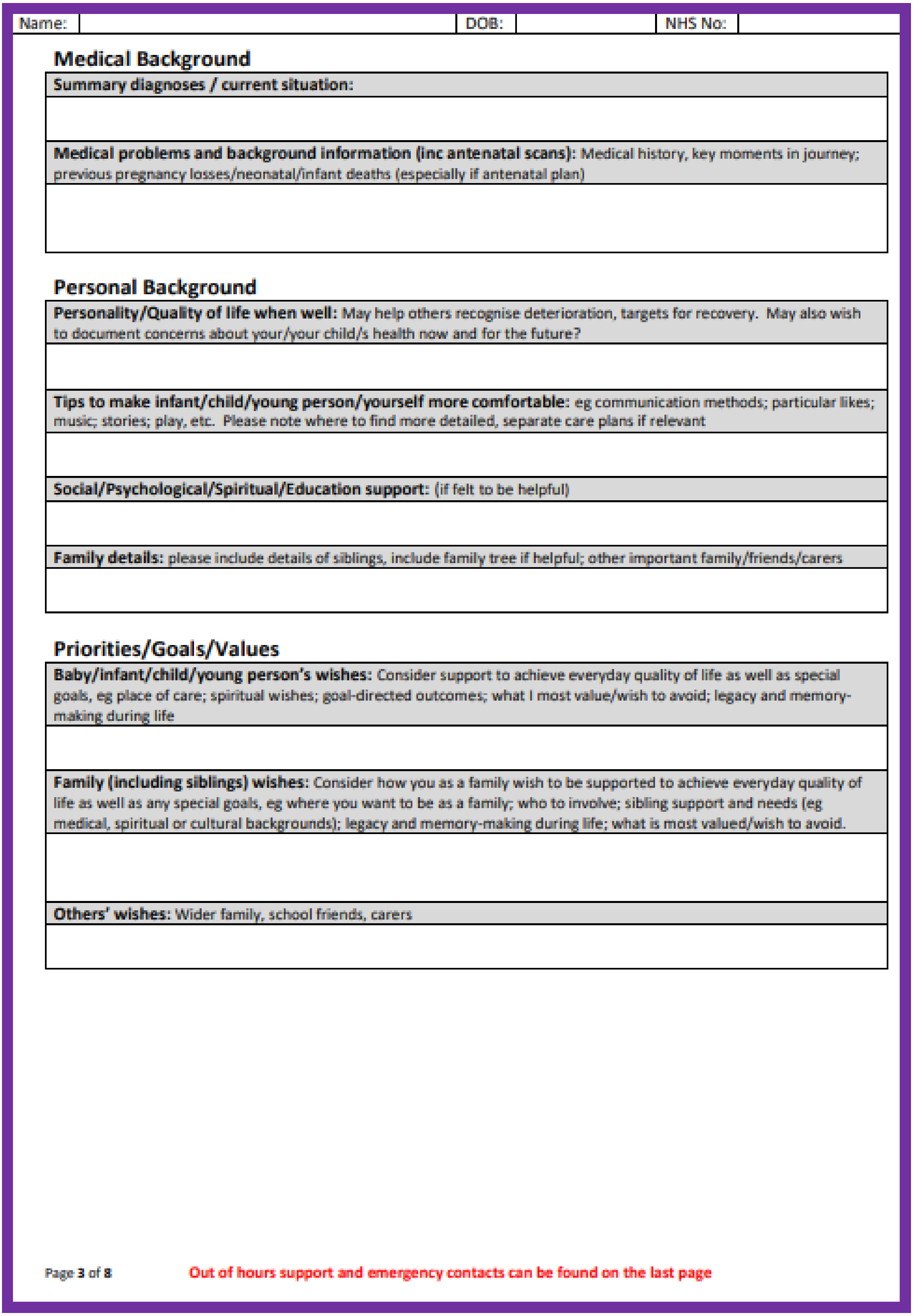
Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate)

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

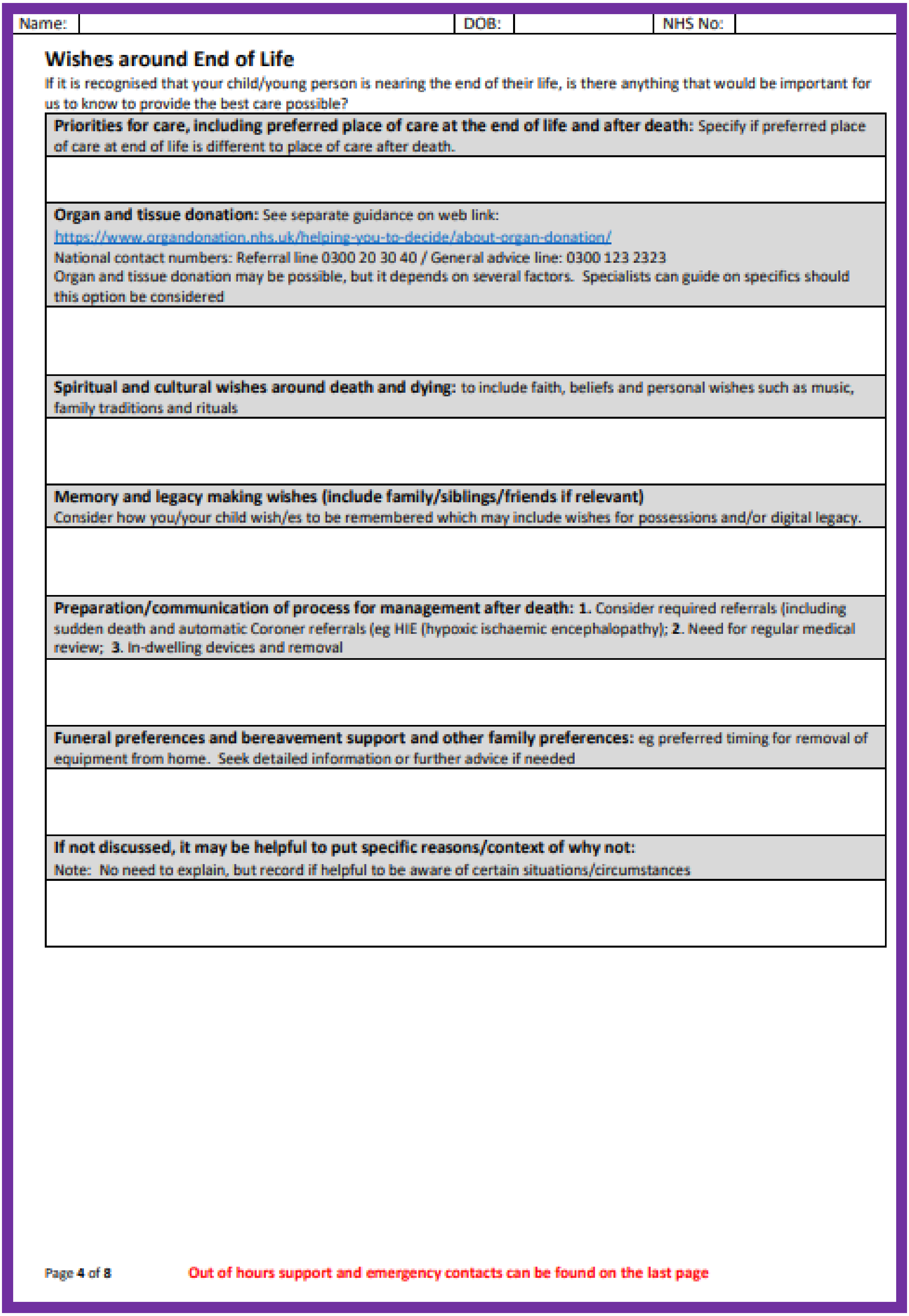
Priorities/Goals/Values

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

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



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.

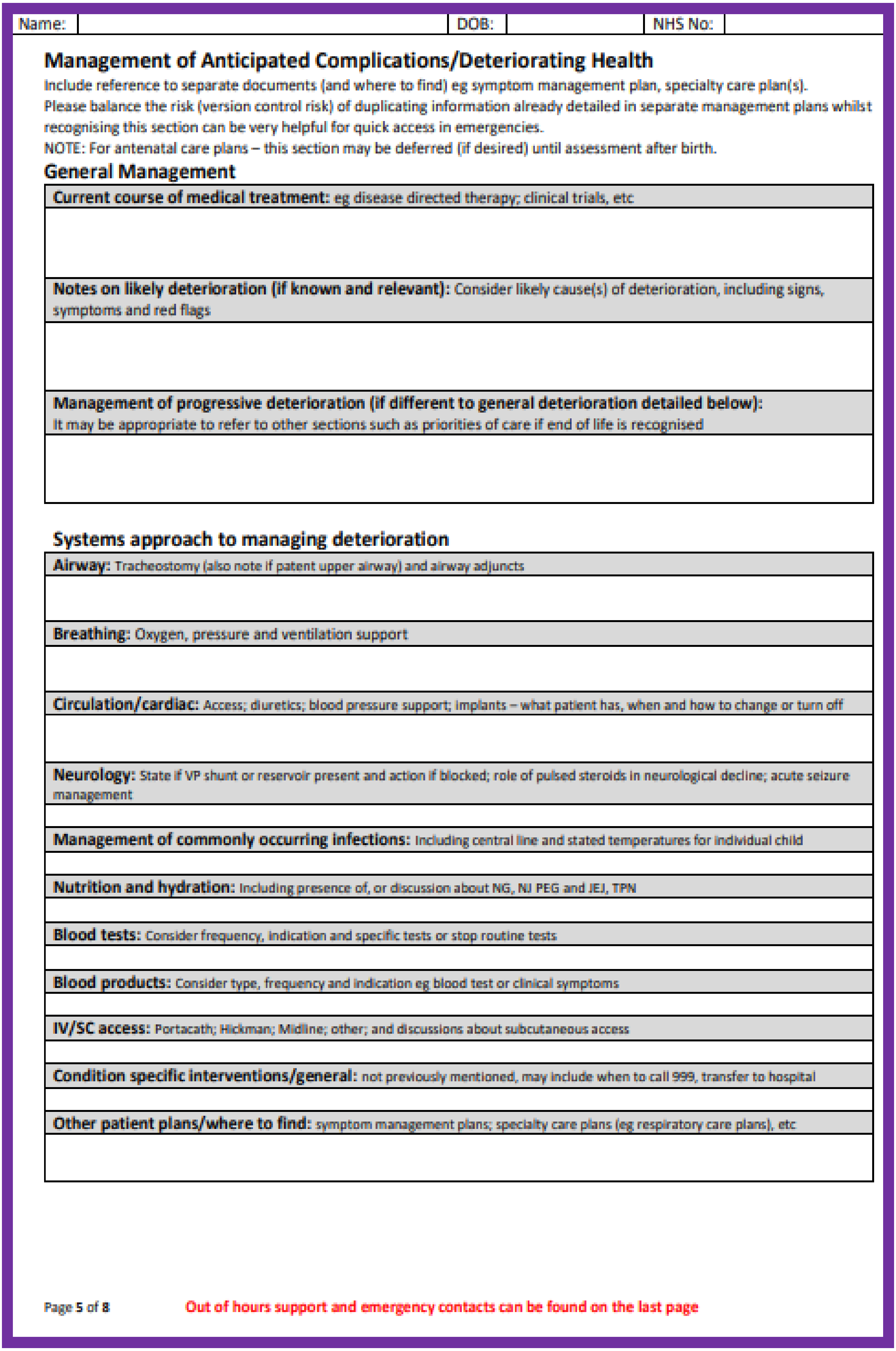
Preparation/communication of process for management after death: 1. Consider required referrals (including sudden death and automatic Coroner referrals (eg HIE (hypoxic ischaemic encephalopathy); **2.** Need for regular medical review; **3.** In-dwelling devices and removal

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

Page 4 of 8

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



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

Page 5 of 8

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

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

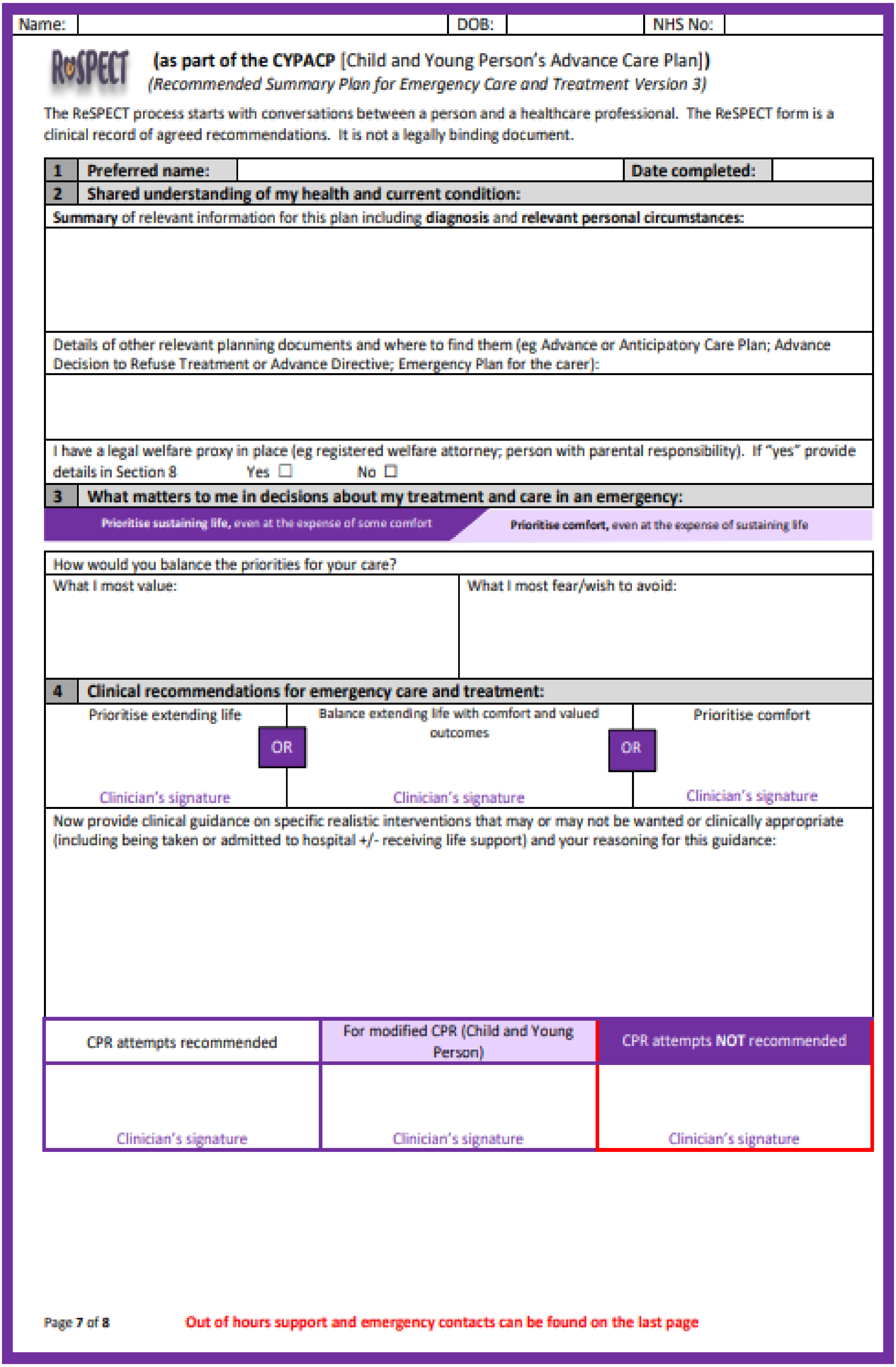
In the event of life-threatening event, provide the following care: add patient-specific detail below

				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:	

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:

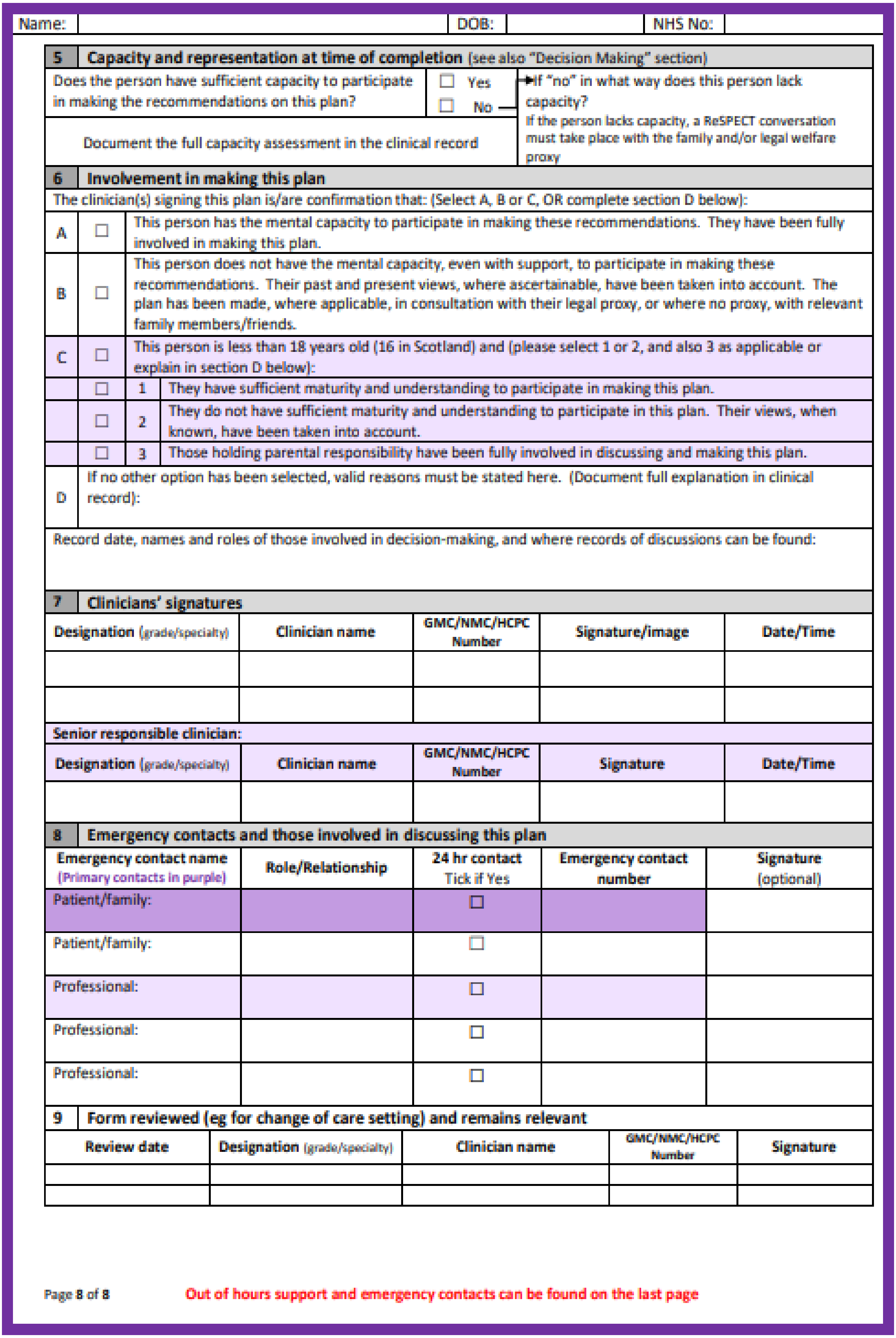
Prioritise extending life	OR	Balance extending life with comfort and valued outcomes	OR	Prioritise comfort
Clinician's signature		Clinician's signature		Clinician's signature

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

Page 7 of 8

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



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**

Page 8 of 8

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

Appendix 4 – Suggested framework for completing an Advanced Care Plan

Step	Action	By
1	Make an assessment of the child’s clinical situation: Has there been a new diagnosis or recent change in the prognosis or clinical condition that should prompt the formulation (or revision) of an ACP?	Any professional involved with the child’s care
2	Facilitate discussion/s with all health care professionals involved in the child’s care and secure their opinions regarding the appropriateness of preparing an ACP. Consider if it is appropriate to discuss the ‘resuscitation plan’ section of the form.	Senior clinician
3	Discuss the child’s status with the child’s parents/ guardians and child (if appropriate). Also include other significant family members where appropriate. Establish their feelings regarding the need for an ACP. Consider involving an interpreter if they are not fluent in English.	Senior clinician
4	Allow plenty of time to discuss and complete the document with the parents/guardians (and child as appropriate). Allow a minimum of 1–2 hours. Consider the best setting for this conversation or conversations (home, hospital or elsewhere). Completion of the plan may require several consultations and discussions, which may take place over several days or weeks. The amount of input into this process by the child depends on their capacity for this decision	Senior Clinician, Senior Children’s Community Nurse, Palliative Care Specialist Nurse, specialty specific Specialist Nurse
5	Once the ACP is completed, ensure it is dated and signed by clinician and/or specialist nurse. Parents or legal guardians may wish to sign the form to indicate their agreement, but this is not essential. Where parents prefer not to sign, the notes should record that the discussion has taken place, and that agreement has been reached.	Senior specialist nurse and/or senior clinician
6	Consider whether a review date should be set for the ACP. There is no standard maximum time before review: this depends on the child’s individual circumstances and is at the discretion of the lead clinician. An earlier review should be triggered should the child’s condition change significantly.	Senior specialist nurse or senior clinician
7	Ensure that all care settings that the child attends are aware of the plan and receive updated details as appropriate.	Consultant (delegated accordingly)

Amended from ‘Guide to using the Advance Care Plan v1.6’, CYPACP Collaboration, 2015: http://cypacp.uk/.

APPENDIX 5 – Suggested Advanced Care Plan Decision Making Framework

NICE recommends[4] that professionals should develop and record an Advance Care Plan at an appropriate time for the current and future care of each child or young person with a life-limiting condition. Yet Advanced Care Plans are commonly discussed very late in a child's illness, or not discussed at all. Reasons for this include difficulty in identifying when an ACP should be considered; professionals reluctance to take responsibility for discussing an ACP; a lack of understanding of the role of parallel planning; and the distressing nature of having to consider end of life care, for patients, families and professionals.

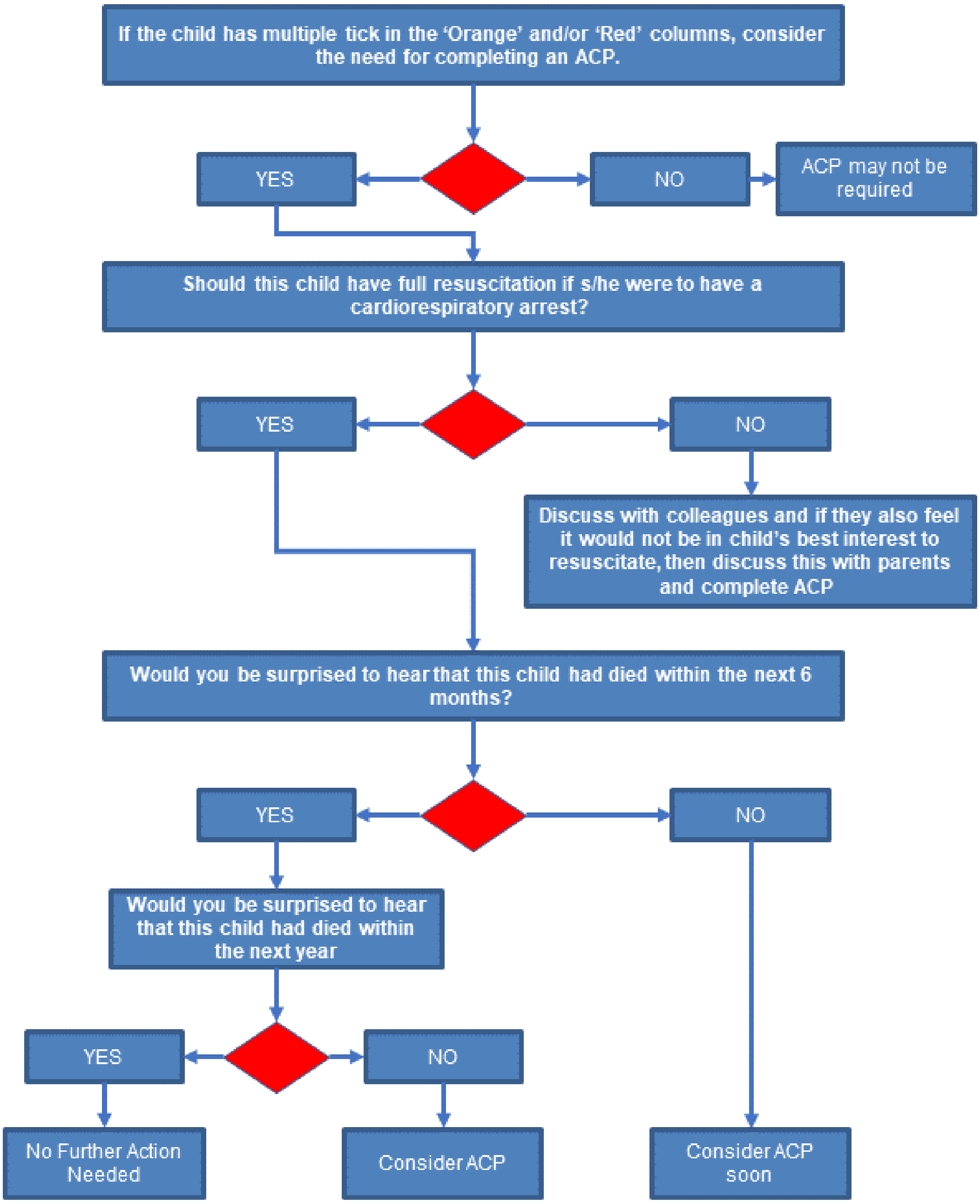
The flow charts and tables in this appendix, developed by Dr Annette Shawcross, give guidance on when to consider introducing an ACP; when to complete it, and who it should be completed by.

Identifying children who might benefit from an ACP – a guide to vulnerability factors for a child with a static neurological condition

	Green	Yellow	Orange	Red
Respiratory	Frequent or increasing No. LRTI	PICU admission for LRTI	Home: long term Oxygen or non-invasive ventilation	Tracheostomy +/- 24-hour ventilation
Feeding	PEG	Jejunostomy Severe GOR despite max treatment	Weight loss due to feeding diff	Pain/ distress with feeds --> progressive feed reduction
Seizures	Epilepsy requiring treatment	Poor seizure control despite numerous Rx	Daily use of rescue Rx	Episodes of status needing IVI / PICU
Locomotor	Spastic quadriplegia / total body involvement	Poor head control/ fixed spinal curve	Depends on carer / propelled wheelchair	Difficulty maintaining sitting (GMFCS level V)
Other Evidence of sever bulbar involvement (worsening swallow, cough, gag reflex) Baclofen pump (as a marker for severe hypertonia/ very difficult spasms) VP shunt (especially if there is a frequent need for review) severe sensory impairment				
If the child has multiple tick in the 'Orange' and/or 'Red' columns, consider the need for completing an ACP.				

---

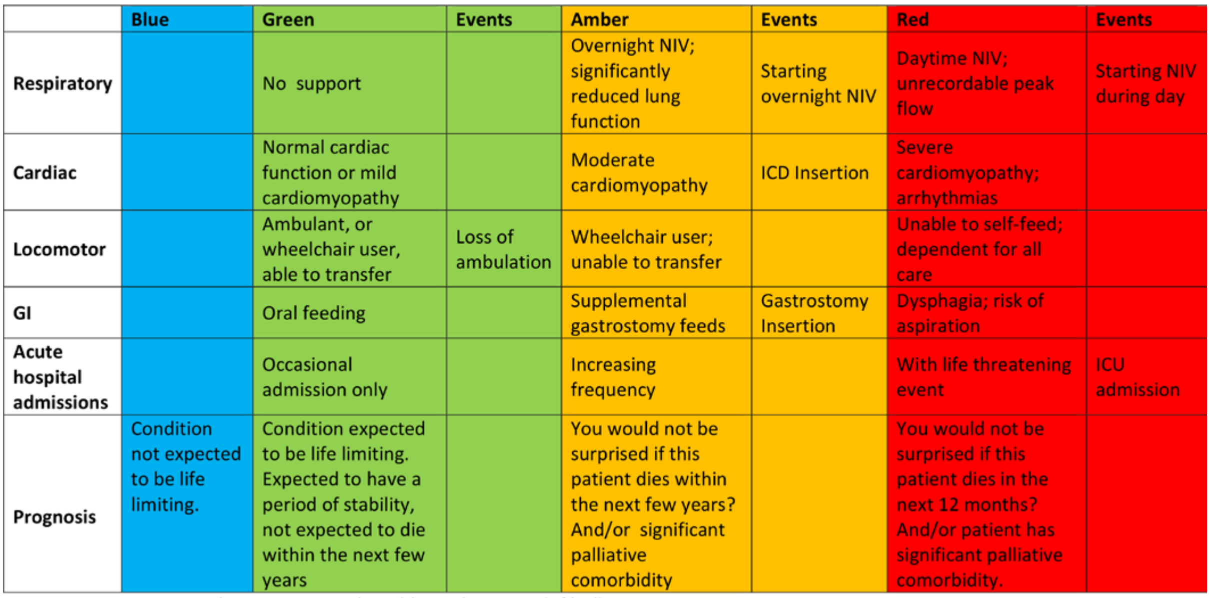
[4] NICE guideline NG61, 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. National Institute for Health and Care Excellence 2016.



The flow chart above is intended for broad guidance only, and individual patient and family circumstances may mean that an ACP is needed earlier in the process than indicated here.

There is unpredictability in the course of a life-limiting condition, and hence planning that covers times when the child or young person is well and times when the condition may deteriorate is particularly important in end of life care (Parallel Planning).

A similar 'traffic light system' has been developed and being used by Dr Tracey Willis and colleagues for their children with Neuromuscular diseases to identify and prioritise those who might benefit from Advance Care Planning and integration into the joint palliative/neuromuscular clinic.



	Blue	Green	Events	Amber	Events	Red	Events
Respiratory		No support		Overnight NIV; significantly reduced lung function	Starting overnight NIV	Daytime NIV; unrecordable peak flow	Starting NIV during day
Cardiac		Normal cardiac function or mild cardiomyopathy		Moderate cardiomyopathy	ICD Insertion	Severe cardiomyopathy; arrhythmias	
Locomotor		Ambulant, or wheelchair user, able to transfer	Loss of ambulation	Wheelchair user; unable to transfer		Unable to self-feed; dependent for all care	
GI		Oral feeding		Supplemental gastrostomy feeds	Gastrostomy Insertion	Dysphagia; risk of aspiration	
Acute hospital admissions		Occasional admission only		Increasing frequency		With life threatening event	ICU admission
Prognosis	Condition not expected to be life limiting.	Condition expected to be life limiting. Expected to have a period of stability, not expected to die within the next few years		You would not be surprised if this patient dies within the next few years? And/or significant palliative comorbidity		You would not be surprised if this patient dies in the next 12 months? And/or patient has significant palliative comorbidity.	

NIV = Non-invasive ventilation; ICD = implantable cardioverter defibrillator; ICU = intensive care unit

If it is decided that it is appropriate to complete an ACP or ReSPECT form

1. When should it be done?

1.1. In the next few days: If the child has multiple factors, is unwell and medical team feel that resuscitation would not be in the child's best interests.

1.2. Before the child leaves hospital: If it is felt that resuscitation would not be appropriate if the child arrested.

1.3. Within next few weeks: If, when the child is seen in clinic, it is considered that the answer to the question "Would you be surprised to hear that this child had died within the next 6 months" is 'no'.

1.4. Within the next month: If, when the child is seen in clinic, it is considered that the answer to the question "Would you be surprised to hear that this child had died within the next 12 months" is 'no'.

2. Who should do it? For options above:

2.1. Needs to be done in next few days /before the child leaves hospital: The consultant who knows the child best in hospital regarding the condition that is likely to cause their death (e.g. respiratory or seizures), along with a key nurse from the ward or specialist respiratory/cardiac/neurology nurse as appropriate.

2.2. Needs to be done within next few weeks: The consultant who knows the child and their condition best. In general, the doctor or nurse who made the decision that the child needs to discuss having an ACP is best placed to do this. If the child is well known to a community paediatrician then clinicians should liaise with them about this discussion.

2.3. Needs to be done within the next month: The consultant most closely involved with child and their family – this could be a hospital paediatrician or a community paediatrician if they are already closely involved with the family.

2.4. Although patients with life limiting conditions often have more than one specialist consultant involved in their care, it is best to avoid having more than one doctor speaking to the parents about ACPs if possible (excluding trainees for learning). The health care team should instead discuss and come to a consensus on specific issues to be addressed in the ACP, regarding, for instance what would be in the child's best interest with respect to DNACPR, invasive ventilation, admission to PICU etc.

2.5. Completion of the ACP should not be left automatically for the community paediatrician or forgotten about until the next time the child becomes unwell and is admitted to PICU.

Appendix 6: Children's and Young Persons Advanced Care Plan process

Children's and Young Persons Advanced Care Plan process for

Medical/Nursing Staffs (Based on EMCYPPCN Process)

In the event of change in a child's condition triggering the need for an ACP, a senior member of the child's medical team and ideally the child's keyworker should develop the plan with the family and sometimes the child/young person themselves. Document the plan with the help of the template which aids its recognition by emergency staff.

↓

A copy of the plan is produced that can be given to the family as a temporary record and for their further consideration at their leisure. A copy of that should be filed in the child's main medical record

↓

The Consultant needs to sign originals of the final plan printed in colour.

Consultant or senior member of medical/nursing team needs to meet with the family for the parent/carer signature, if applicable.

If amendments are made at this point, return back to secretary to make changes.

↓

If the plan states that the child should be transferred to the hospice it must also state that the hospice needs to be contacted prior to transfer.

↓

If no amendments required, a final version of the plan should be printed off in colour and signed and filed in the patient's notes (if an inpatient) or given to the child's parent/guardian (s)

Ambulance staff will follow the plan that is with the child

Consultant:

Ensure that the final copy of the ACP is filed at the front of the child's main medical record.

Date plan created and Consultant responsible plus 24 hour contact number for any queries about the plan needs to be on the front page.

Arranges for final version of Plan to be typed.

Secretary:

If the copy has been signed by Consultant and parent/carer with no changes proceed to distribution.

If amendments are made following signing by Consultant, the Consultant makes amendments and puts an amended date on the front of the plan.

There may be several drafts before the final version is agreed and each amended copy should be kept in the notes (not at the front).

All amended copies should be crossed through with 2 diagonal lines to show that this plan has been amended and is not the up to date copy.

Appendix: 7 Paediatric End of Life Care Transport Checklist

Often these children are transferred to home or hospice and sometimes specialised transport service/s are required. Below is a checklist developed by the CoMET, East Midland's Paediatric Critical Care Transport team to facilitate these transfers. This checklist could be extremely helpful for anyone undertaking these transfers.

Paediatric End of Life Care (EoLC) Transport Checklist

Children's Medical Emergency Treatmnet (CoMET)

Before the transport:	**Notes, if any**
Clear handover of relevant palliative care issues between referring hospital and transport team in collaboration with Nurses in Community Paediatrics Team, Primary Care Team, Palliative Care Nurses if any	
Clear and concise communication about Advanced Health Care Olan (AHCP) ensuring the parents/carers are fully aware of it and on-board	
Ensure all important documents are being taken with the child on transfer (discharge letter, AHCP, nursing care plans, symptom control plans, parent competency forms for equipment, drug chart/TTO, information leaflets and contact details of community team, bereavement team, others as applicable)	
Ensure appropriate facilities and healthcare staff support available at the time of arrival when going to family home (including extubation if applicable) (equipment as applicable – portable oxygen, airway and breathing equipment, tracheostomy box, suction machine, drugs listed in TTO with consumables for administering, syringe driver, feeding plan and feeding equipment)	
Ensure appropriate facilities as well as appropriate healthcare staff support available when going to hospice (including extubation if applicable) (equipment as above)	
Ensure who takes responsibility if the child dies after extubation, if applicable (? Referring Team/Primary Care Team)	
Ensure emotional, psychological and bereavement support are in place	
Ensure religious/chaplain support has been provided	
Ensure organ donation discussed with parents/carers and plan documented	
During the transport:	
Ensure family well supported by transport team	
Ensure the child stays comfortable with necessary medications on-board (as agreed and planned by the referring team members)	
Ensure who takes responsibility if the child dies while in transport (? Referring Team/primary Care Team)	
Ensure the PICTS team have an up to date list of contacts for the healthcare groups involved in the care of these children	

Saikia, Sep 2018 I UHL