



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



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www.cypacp.nhs.uk

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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 neurodisability, 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 communicates. 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.