Child and Young Person's Advance Care Plan

www.cypacp.uk

Collaborative planning for end-of-life decisions

Best practice guidance to enhance the process of advance care planning for a child or young person

November 2023

FUNDED BY Marie Curie

This document has been made possible by the Marie Curie Research Impact Fund

Focus group and contributors

Margot Armstrong, Parent representative

Dr Helen Bennett, RSCN, MSc, PhD, Director of Care Alexander Devine Children's Hospice Service

Dr Peta Coulson-Smith MA MRCPCH SFHEA, Subject Lead Medical Ethics and Law, University of Southampton

Alison Cramp, Parent representative

Caroline Dew, Parent representative

Sheila Docherty, Counsellor, Alexander Devine Children's Hospice Service

Nikki Essex, Children's Community Clinical Nurse Specialist, Keech Hospice Care

Dr Emily Harrop MBBS BSc DCH FRCPCS PhD Dip Pal Med, Medical Director, Helen & Douglas House

Katherine Hedges, Clinical Nurse Specialist, Royal Marsden Hospital

Liz Hopper, Independent Facilitator

Lisa Iacniofano, Children's Community Clinical Nurse Specialist, Keech Hospice Care

Dr Susie Lapwood, former member of the Medical Team at Helen & Douglas House and member of the CYPACP Network

Juliette Lee, Paediatric Nurse, Addenbrooke's Hospital, Cambridge, PPI Lead in the CYPACP Network and sibling of Beatrice

Tracy Lewin-Taylor, Head of Specialist Palliative Care Team at Shooting Stars Hospice and SE of England CYP PEoLC Programme Lead

Dr Abigail Macleod BSc, MBChB, MRCPCH, Dip Pall Med (Paeds)
Deputy Medical Director, Children's Hospice South-West

Abbie Mason Clinical Practice Education Facilitator, Birmingham Community Healthcare NHS Foundation Trust

Dr Linda Maynard, Consultant Nurse Children's Palliative Care, Assistant Director Specialist Services, East Anglia's Children's Hospices (EACH)

Dr Hannah Parks, Associate Specialist in Paediatric Palliative Care, Helen & Douglas House and Oxford University Hospitals NHS Foundation Trust

Tracy Rennie, Independent Adviser, Children’s Palliative Care Programme, Heard

Ellie Romer-Lee, Parent representative

Dr Karen Shaw, PhD, BSc (Hons), PG Cert. Research Fellow/Psychologist, Institute of Applied Health Research, University of Birmingham

Nicky Smallwood, Chaplain, Naomi House/Jack’sPlace

Dr Ross Smith, MBChB, MRCPCH, Dip Pall Med (Paeds), Consultant in Paediatric Palliative Medicine, Martin House Children’s Hospice and Leeds Teaching Hospitals Trust.

Chiara Varè, Programme Manager, Children’s Palliative Care programme, Heard

Amanda Whateley, Head of Clinical & Family Services, Together for Short Lives

Natalie Whitby-Lear, Family Support Manager (Reading), Rainbow Trust Children’s Charity

Contents

Note: For the purposes of this document, when the word ‘child’ is used it can be read as ‘baby, infant, child or young person’ and CYPACP refers to the child and young person advance care plan.

Foreword

Perhaps there is no greater heartache than planning end of life care for a child. Yet bereaved families tell us that accompanying their beloved child through a life-limiting illness until their death, and their bereavement afterwards, is made very much worse when they don’t understand what is happening; when different care teams have different ideas about the best care to offer; when crises occur and there is no clear plan in place to deal with it; when the important conversations between child and family, family and professionals, and amongst different professional teams have not taken place. That’s why planning ahead matters.

It’s in the spirit of planning ahead, ensuring all options have been considered, all opinions have been voiced, and as many concerns as possible have been addressed, that Advance Care Planning takes place. This best practice guidance calls upon the wisdom of parents and practitioners together, to provide an explanation of the process and a template to guide it. This guidance is a unique piece of joint working that draws on expertise in nursing and medicine, ethics and law, chaplaincy and social work, children’s hospice teams and bereavement organisations, and above all those expert parents who have lived through the process of parenting a dying child.

Planning ahead is a process, not a single event or a one-off conversation. It requires all contributors to pool their expertise and to listen to each other, putting the wishes of the child (when we can know them) and their wellbeing at the very centre of every plan. These are tender conversations that enable parents and families, and the young person if they wish, to talk about the possible ways in which a condition might progress, about the foreseeable crises that may happen along the way, so that the best interests of this young, beloved person, can remain central throughout their shortened life.

Above all, an Advance Care Plan is always a work in progress. Each time a Plan is agreed, it must be accessible to all services that might care for this child and their family both for routine care and in a crisis. All service providers should know how to access it and should use it to guide the care they provide. Particularly towards the end of life, it is vital to respect any boundaries that have been agreed and summarised in the plan, to avoid treatments and interventions that are no longer useful or not wanted by the child; to ensure that the child and family are helped in the ways they find acceptable and useful to them; and to ensure that any special requests like place of care or cultural traditions are taken into consideration. As the child’s condition changes, or their wishes alter, or their ability to join in conversations grows, their Advance Care Plan will need review and perhaps modification, so that it is constantly a reflection of their current needs and understanding.

And so I commend this carefully-crafted guidance to you, as colleagues who are and who will be engaged in the precious task of supporting and caring for children reaching the end of their lives and for the people who love them. Whether you are working to develop, to update, or to follow a child’s Advance Care Plan, this is a vital component of teamwork between professionals, families and the children we serve.

May this guidance serve you well.

Kathryn Mannix
Former palliative care doctor
Writer and End of Life Care campaigner

November 2023

Executive summary

Advance care planning

Children's palliative care provides all-encompassing care to children with life-limiting and life-threatening conditions and their families. It is delivered by a multi-professional team who offer care when and where the family need it.

Advance care planning is a central part of this vital care. It ensures that support continues throughout the child's life, and into death and bereavement if needed. It is recommended as a core standard of best practice (NICE 2016, NHS 2021).

A collaborative process

Advance care planning is a process where professionals, parents and children (where able) work together to discuss, agree, and document priorities for care. This helps them talk about what matters most to them, including important values, hopes, goals and options for current and future treatment. It is an ongoing, supportive process that takes place through a series of conversations that are documented in an Advance Care Plan (ACP).

Making an ACP requires collaborative working. Services and clinicians need to share information, engage in advance care planning processes in a timely manner, and maintain open, honest dialogue with children and families. It also requires an individualised and all-encompassing approach that centres on the wishes of families. Understanding these goals and preferences will guide future treatment and interventions as the child's condition deteriorates or in emergency situations. This helps families and clinicians feel better prepared and make the best possible decisions together.

- Advance care planning for children and young people holds similar principles to advance care planning for adults – but has important differences.
- Parents value advance care planning when it addresses their hopes and goals, with shared information about future options for treatment and care.
- Children and young people's advance care planning is a collaborative process involving a multi-professional team. It is a series of ongoing conversations, not a single event.
- Children and young people's advance care planning is a complex intervention that requires skilled communication.
- Advance care planning for infants, children and young people can be used across all settings.

The value of planning ahead

Growing evidence shows that advance care planning can empower parents when planning for their child’s care and death (Shaw & Spry 2020, Bennett et al 2022), where parents describe feeling more prepared and having more control. Advance care planning conversations can facilitate professionals and families to have important discussion about current and future options for treatment and care. It helps to make plans for a range of scenarios when the child’s or young person’s condition deteriorates. Having an advance care plan can additionally enable and also encourage wider conversations between the child, parents, siblings, carers, and teams of professionals. However, advance care planning is a complex intervention that needs the right support, resources, and skilled staff for it to be meaningful (Shaw & Spry 2020).

Best practice guidance

This guidance is primarily written for professionals and those working with families in advance care planning. It covers best practice for the process of advance care planning that includes both the conversation and written tool - the CYPACP document - a specific advance care plan document for children and young people (http://cypacp.uk). The CYPACP document captures the wider issues of advance care planning as well as emergency care and treatment and ‘Do Not Attempt Cardiopulmonary Resuscitation’ decisions and/or ReSPECT.

The guidance establishes key principles for advance care planning, including how to initiate conversations, support decision-making, and complete the advance care plan document.

This guidance is based on the latest available evidence and was co-produced by parents and professionals as part of a stakeholder event.

1. Purpose and scope

This guide has been developed by the Child and Young Person's Advance Care Plan Network; a group of NHS and non-NHS organisations and professionals who aim to unify the approach to advance care planning for children with palliative and end-of-life care needs.

It is for professionals and those working with families who may be involved in advance care planning for a child and has been co-produced by stakeholders, including parents.

This was made possible by a grant from the Marie Curie Research Impact Fund.

The guidance aligns with the fifth edition of the Child and Young Person's Advance Care Plan (CYPACP) and is informed by the NHS Universal Principles for Advance Care Planning (NHS 2022) and the Specialist Palliative and End-of-Life Care Services for Children and Young People (NHS 2023). It builds on recommendations that advance care planning should include a personalised plan, focus on what matters most to the individual and family, be based on shared decision-making, and offer opportunities for review and revision.

The guidance also addresses key recommendations from the Marie Curie funded study; Evaluating Advance Care Plans; Listening to Families and Professionals (Shaw & Spry 2020). This study showed that advance care planning is a valuable component of high-quality care, but families need more choice and support. It also acknowledged that advance care planning is a complex intervention that requires support to implement and greater societal awareness.

The guidance also highlights important distinctions between adult and children's advance care planning.

2. What is advance care planning

Advance care planning is designed to communicate the priorities and goals of care for a baby, child or young person who has a chronic, life-threatening or life-limiting condition. It involves children and young people (where they are able to contribute), their parents and carers and teams of professionals caring for them.

Advance care planning is a collaborative process rather than a single event. It involves a series of honest conversations and a written document that sets out agreed plans to manage symptoms throughout the child's care, including at the end of life. It aims to empower children and families to share their values, hopes, and goals.

The following definition is adapted from the Association for Paediatric Palliative Medicine (APPM 2023):

Advance care planning for children and young people with life-limiting and life-threatening conditions will help CYP and their families plan for and receive care at the end of their life that is in line with their wishes. Talking with the child or young person, and their parents or carers, at appropriate stages gives them the opportunity to influence the care that they receive and improves their experience of care. Advance care plans should be appropriate to the circumstances and continuously updated throughout the delivery of care and support. Alongside family wishes and preferences, the information within the plans will include individualised treatment plans for a range of medical scenarios, as well as specific information about cardiopulmonary resuscitation.

Advance care planning involves working with children, young people and their families to make a future plan that includes important details about their condition, prognosis, choices for care, wishes and personal values. It encompasses choices about life and death that can be difficult, such as withdrawal and ceilings of treatment.

This formal ACP document includes decisions to support emergency care and treatment and resuscitation decisions, however it is important to note that the presence of an ACP document does not equate to a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decision and covers a wide breadth and scope of choices about future planning and end of life care. The advance care plan document although not legally binding, provides recommendations that care teams should consider when deciding what clinical interventions are in the child's best interests. Advance care planning for children is guided by key recommendations for practice, including NICE guidance (See NG61 Guidance below).

Statement 1: Infants, children, and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

1. 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.
2. Begin discussing an advance care plan with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition. For each individual think about who should take part in the discussion.
3. Develop and regularly review advance care plans.
4. When developing the advance care plan, take account of the beliefs and values of the child or young person and their parents or carers.
5. Explain to children and young people and their parents and carers that advance care planning should help them be involved in planning care, help them to understand the life-limiting condition. Prepare for possible future difficulties and support continuity of care.
6. Share the advance care plan with the child or young person and their parents or carers (as appropriate) and think about which professionals and services involved in the individual child or young person's care should also see it.
7. Update the advance care plan when needed.
8. Share the advance care plan with everyone involved when it is updated.
9. When making an advance care plan, discuss with the child or young person and their parents and carers the nature of the life-limiting condition, its likely consequences and prognosis and the expected benefits and possible harms of the management of options.
10. Be aware that all children and young people with life-limiting conditions should have an advance care plan in their medical record, and that this should not be confused with a do-not-attempt-resuscitation order.
11. Be aware that any existing resuscitation plan for a child or young person may need to be changed in some circumstances, for example, if they are undergoing general anaesthesia.

3. Principles of advance care planning for children and young people

Advance care planning for children and young people has unique features. characterised by complex decision-making that requires consideration of a child's changing capacity alongside parental rights. Life-limiting conditions in childhood are also complicated by high prognostic uncertainty and increasing options for treatment. It is important, therefore, that advance care planning adheres to the following principles to ensure that all relevant perspectives are included, including those of children (see section 9).

Key principles for advance care planning for children and young people and their families:

- Advance care planning is a dynamic and ongoing process, for which the child/young person and their family should be actively involved.
- To understand the child's/young persons and their parent's preferred role and approach to decision making and what matters most to them about current and future care.
- To develop and record discussions of advance care planning with the child/young person where they are able and their parents/carers.
- The advance care plan can be shared across all environments that the child encounters: home, hospital, school, hospice and respite care, and remains valid when parent(s) or next of kin cannot be contacted.
- Some parents may not wish to have an advance care plan or sign any documents. They are communication tools not legal documents.
- The child/young person and their parents can change their minds and revise their advance care plan.

4. Who can initiate and when is the best time

Advance care plans are designed to establish clear goals of care where there is a possibility that children may die or experience life-threatening complications. However, practice can vary and there is limited evidence about when to initiate advance care planning (Carr et al 2022). It is a complex process influenced by diagnosis, prognosis, family readiness to engage, family situations, and professional responsibilities.

Advance care planning can begin soon after diagnosis or recognition of a life-limiting condition. Some children will have an advance care plan for many years before they reach the end of their life and it can be applicable as part of parallel planning.

Where possible, advance care planning should be initiated by someone who:

- Knows the family, has experience and confidence and has the time to lead on advance care planning conversations.
- Understands the emotional impact of conversations and has the ability to provide support.
- Is sensitive to the parents, child's and family's needs.
- Understands the complexity of initiating a conversation and that this should not act as a barrier to meaningful conversation (Carr et al. 2022; Bennett et al.2022).
- Is able to harness and respond to uncertainty and supports families to cope with these uncertainties.
- Is able to consider all possible treatment and care options and addresses them in terms of the benefit for the child.
- Is able to include members of the family and key members of the multi-disciplinary team
- Understands that the process may involve several different discussions over a period of time.
- Understands that all concerned in the decision-making process are allowed enough time for information to be given and understood, to consider, ask questions and express their opinion.

The advance care plan can be used as a communication tool to initiate conversations when the child’s condition is stable. Where multiple teams are involved in a child’s care the family can use the advance care plan as a way to share their wishes without having to repeat conversations.

5. Key considerations in working with families

No one wants to think about their child being in pain or dying. However, families in this situation want experienced professionals to provide the best experience of advance care planning, comfort and support.

Parents, like everyone else, want to feel heard, held and prepared. Advance care planning enables them to communicate their needs and hopes for their child's care.

Research, and our stakeholder work, has revealed how many families experience advance care planning.

This information has been used to co-design a framework that promotes supportive conversations about advance care planning and recommends that professionals consider the following:

- **Parents use the advance care planning process to share their values and wishes to provide the 'best care' for their child.** Talking about end of life can be distressing. However, parents do not want professionals to avoid conversations with them and want to talk about their thoughts, hopes and fears. They want professionals to understand the day-to-day demands of family life and to recognise the importance of their family values, culture and beliefs. They may wish to discuss options of care, as well as end of life choices, including, care after death, funeral planning and bereavement support.

- **Parents want professionals to share information about options for treatment and care. They look to balance the management of symptoms with not wanting their child to suffer.** They want their child to have the highest quality of life with the remaining time they have.

- **Sensitive communication and relationships with professionals who have the skills and knowledge to guide parents are central in supporting parents to make the 'right' decisions.** A non-judgemental and caring approach helps parents to address difficult and painful issues and navigate the process of advance care planning, including choices at the end-of-life. Understanding that each child and family is different and that they will need time and space to adjust to the changing situation is essential in planning when to talk.

- **Parents look for clear explanations and expectations, with opportunity to talk and be prepared for their child deteriorating.** Parents value honesty and transparency. They do not want 'false hope'. Making decisions at a time of crisis is not helpful. Instead, parents call for joined-up decision-making that includes everyone involved in their child's care - before a crisis situation occurs. Parents recognise the profound emotional impact of discussing end-of-life care for their child and need to feel held in this space, comforted and supported. If done well, families feel heard and respected, and advance care planning offers a sense of safety and control. This can offer therapeutic benefit and time to build precious memories.

- **Children and young people want to be included in their own advance care planning and want their opinions to be heard.** Children and young people and their parents emphasise the importance of the child and young person's perspective. Despite their age children and young people may be in the best possible position to discuss their own wishes and what is important to them. Children and young people may be concerned about practical issues and the anxiety for people who are left behind after their death. Thus, all professionals should consider the timing of advance care planning conversations to support children and young people to participate. Conversations can often occur too late for them to be involved.

- **Professionals can facilitate a positive experience for children and young people around advance care planning by supporting trusting relationships and fostering effective communication**. Professionals should use an approach that can empower children and young people and facilitate their engagement in the advance care planning process. This will help children and young people understand about the care they need and develop the skills to convey their wishes.

- **Children and young people should be supported in their choices and goals for quality end of life care.** Overcoming barriers and assumptions about children and young people's understanding of advance care planning can support more open conversations that allows for discussions about wishes and values for the future. It is important to facilitate flexible and clear compassionate conversations using language that is both age and developmentally focused. In addition, openness and honesty, sharing information at a desired pace will support children and young people to discuss wishes openly.

6. Communication

Advance care planning needs sensitive and skilled communication. This is best done in a series of conversations, as part of a compassionate and caring approach that promotes choice and shared decision-making.

Talking to a child and family about advance care planning

- Create opportunities to have conversations and to listen to families.
- Plant a seed or warning shot to families.
- Be adequately prepared and use an appropriate safe space.
- Consider who else should be present and the need for an interpreter.
- Both parents (where possible) should be present with a trusted advocate. alongside the family if they wish where possible/appropriate.
- Consider the level at which a child or young person may wish to be involved.
- Be mindful of pace and timing.
- Start by exploring parents' understanding of their child's condition.
- Be honest and transparent and state clearly what advance care planning is.
- Use clear, non-medical language, open questions and prompts – 'how are you feeling?', 'what do you think is happening?'
- Listen.
- Acknowledge the sadness and distress .
- Don't be afraid of silence, give families space and time to gather their thoughts and process information.
- Manage expectations, use open directive questions – 'what is most important to you now?'
- Consider goals of care.
- Prepare for the worst and plan for the best.
- Reflect and clarify what you have understood.
- Summarise what you have heard and if you have missed anything.
- Ask families how they want to move on.
- Close and let them know what actions you will take and when you will come back to them.
- Ask for guidance if you need more help.
- Record and share appropriately.

Conversations may include talking to the affected child, siblings, parents, and friends. Discussions will cover complex and difficult issues around options for treatment and care, as well as values and beliefs, hopes and fears. It will also involve talking time to understand how families process information, make choices and comprehend the implications of their decisions. There are several tools and frameworks for supporting effective communication and managing difficult conversations (see Resources).

7. Decision making: best interests, mental capacity and parental responsibility

It is important that clinicians using the CYPACP document are clear about the roles and responsibilities of parents in relation to decision-making on behalf of a child. This includes recognising the ability of a child (or the developing ability) to make decisions about their own healthcare. Clinicians must be able to assess the competence of a child or young person below the age of 16 years and adhere to the Mental Capacity Act (2005) relating to decisions for a young person who is 16 years old or older.

A child or young person should be involved in the decision-making process where possible and reasonable. Their wishes should always be listened to and taken into account. Young people aged 16- and 17-years old can, in principle, make decisions relating to their own medical treatment, but need parental agreement to withhold or withdraw treatments sustaining life. If a young person refuses treatment which may lead to their death or a severe permanent injury, their case may be referred to Court for consideration.

Information about consent and the role of parents in this process can be found in GMC guidance or directly from statutory law, including the Children Act (1989). The General Medical Council (GMC) document ‘0-18 years: Guidance for Doctors’ (2018) provides valuable information about consent, confidentiality, and parental responsibility. This should be used in conjunction with the NICE guidance for end-of-life care for infants, children and young people with life-limiting conditions (NG61, 2016 and QS160, 2017) and the RCPCH document, ‘Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice’ (RCPCH 2022).

Parents and clinicians are required to act in the child’s best interests when making decisions on behalf of, or with a person under the age 18 years. This is described in the GMC ethical guidance below.

This list is not exhaustive. The weight attached to each point will depend on the circumstances and all relevant information should be considered. No unjustified assumptions about a child or young person’s best interests should ever be based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

Assessment of best interests

An assessment of best interests will include what is clinically indicated in a particular case.

You should also consider:

a) the views of the child or young person, so far as they can express them, including any previously expressed preferences.
b) the views of parents.
c) the views of others close to the child or young person.
d) the cultural, religious or other beliefs and values of the child or parents
e) the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare.
f) which choice, if there is more than one, will least restrict the child or young person's future options.

When there is a divergence of opinion about the type of medical intervention that represents a child's best interests, parents and clinicians should work together to resolve the disagreement as far as possible, with the child's welfare considered of paramount importance (Gillam 2016). Parents and clinicians have a moral and legal duty to protect children from significant harm. Clinicians should understand the 'zone of parental discretion' and recognise that professionals' preferences are not always synonymous with best interests. Those supporting the writing of CYPACPs should be able to support families in a course of action that is considered reasonable, even though it might not be the one that they personally prefer. There is often more than one ethically permissible way forward (Larcher et al 2015). Professionals should, however, be willing to respectfully challenge parental preferences that would not be of overall benefit.

If local resolution is not possible, it may be appropriate to seek a second opinion, consult a Clinical Ethics Committee and consider mediation. The Royal College of Paediatrics and Child Health (RCPCH) has published guidance on both conflict resolution and withholding and withdrawal of life-sustaining treatment which can be found on the RCPCH website (See resources section).

The CYPACP is a vehicle for discussion and documentation of wishes and preferences. As such, parents and clinicians are not rigidly bound by the statements and wishes within the document; wishes and values may change over time or in an emergency situation which might override the stated preferences in the CYPACP. The documentation of signatures indicates involvement in the creation of the document and awareness of the information contained.

8. How to use 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, this should be soon after diagnosis, or during a period of stability in the child's condition. Natural triggers for starting the conversation may be a new life-limiting or life- threatening diagnosis, recent admission to hospital or intensive care, increased frequency of acute illness 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: Seek their opinions regarding the appropriateness of preparing an advance care plan and who might be best placed to complete this.

Discuss the child's status with the child's parents/guardians (person with parental responsibility) 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 advance care plan. If families are not fluent in English, ensure all parents have the same opportunities to be involved and consider a professional interpreter.

Time and setting - 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 who the family want to be involved in conversations and the best setting (home, hospital, hospice or elsewhere). Completion of the plan may require several consultations/ discussions, which may take place over several days or weeks. Involve the child at an appropriate level. The amount of input into this process by the child depends on their capacity for these decisions.

Completing the advance care plan: The CYPACP should ideally be completed online and then printed out for signing and circulation. It can be handwritten but must be completed in writing that is legible, using black ink. Sections within the core document should not be deleted. The only pages that can be deleted, if not appropriate, are in the perinatal sections in the antenatal version. The name, date of birth and NHS number of the child, or the mother of the child if the form is completed ante-natally, will appear at the top of every page.

Ideally, the CYPACP should be circulated electronically. Physical copies can be circulated where this is not possible. Some organisations (such as the ambulance service) may require. only part of the CYPACP but always including the ReSPECT / DNACPR form 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.

Basic demographic information

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 for the child should be included where possible.

Emergency contacts: The emergency contacts should document who the family wish to be informed in an emergency

Allergies: All known allergies should be recorded and if possible, the type of reaction caused.

Date of plan: The date the plan was initiated or last reviewed can be recorded here. There is no requirement to set and record a review date. Locally agreed policy may guide this. In all circumstances professionals should check with families that the plan still represents the current situation and reflects their values - irrespective of when it was last reviewed.

Decision making

Interpreter: This is important to record if English is not a family’s 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/young person or their parent/carer requires support with communication including electronic communication aids, use of sign language interpreter etc. Information about this should be included in the CYPACP. (See section six of full guidance)

Mental capacity: (See section seven of full guidance) The Mental Capacity Act (2005) applies to all people over the age of 16 years. Young people aged 16/17 years 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; offering staff with protection against liability for actions done to provide treatment or care. The MCA code of practice must be followed. Young people may have had an MCA assessment, and the details of where to find this should be included in the CYPACP.

Parents making decisions for their child under 16 years, 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 to either prioritise life-sustaining treatment or comfort care.

Key contacts: The contact details of those that need to be aware of, or hold a copy of the plan, should be recorded. Those listed will need to be informed of any changes on review.

Medical and personal background

Completing these sections is useful, particularly for clinical encounters where the child is not known to the clinician or care team. It provides useful context and minimise the need for parent to tell their story repeatedly.

It is helpful to also include safeguarding issues. This is particularly important if the child is subject to a safeguarding plan, or a Child in Need plan, is a ‘looked after child’ or parental responsibility is shared with the local authority.

Children and families may wish to share a lot of personal information with professionals completing the CYPACP. These pages can be used for that purpose.

Wishes around end-of-life

Children and families may have specific thoughts around their priorities of care, including spiritual or religious practices they would like to observe. It is important to document these with meaningful and actionable levels of detail, especially for those professionals who may be required to implement the plan, but have insufficient knowledge or experience to enact 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. It can be helpful to have the conversation in two stages to (i) understand what the children or family would like to do and (ii) give them information about what might be possible within 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 professional writing the CYPACP so they can share the information with the parents/carers or young person.

Coroner / post-mortem/ medical examiner referrals: From April 2023 (England) 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 this can sometimes delay the issuing of the Medical Certificate of Cause of Death (MCCD) and affect family decisions/wishes for care after death.

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

Families should be informed about the need for their child to be referred to the coroner after they have died. If possible, the decision about who should inform the coroner should be made prior to the child's death. 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. (Working Together to Safeguard Children 2018). In such a situation 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 (Coroner's Act 1988)
- The death has occurred while the patient was in police custody or any state detention

Perinatal section

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

Plan for delivery and plans for after delivery/birth

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. This section 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.

Management of baby at birth

This section 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 many families prior to the birth of their baby.

It is likely the later pages of the CYPACP will not need to be completed before birth, and only if the baby survives beyond the immediate newborn period.

Management of anticipated complications / deteriorating health

This section helps to detail what sort of complications and difficulties to expect. There may be specific actions that families want, or do not want, to be undertaken if their child deteriorates. For example, the family may be willing to give oral antibiotics at home, but not want intravenous antibiotics that require hospital admission and cannulation. For some children, this will be expanded to include specific information about them, their condition, wishes, or family’s wishes. It can be difficult to convey nuanced situations on paper. However, 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. 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. These can be referred to in this section, with information about where to find them.

- There may be specific aspects of deterioration that can occur with the child's condition. These can be highlighted here, with the specific management or wishes documented; for example, for 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. This should be indicated by writing 'not appropriate' or putting a line through the box. This can prevent potentially unnecessary and distressing conversations with families.

Management of an acute significant deterioration / emergency

This section is supported by the ReSPECT or DNACPR part of the document - but separate from it. It is for documenting whether a family or child wishes to have a treatment ceiling, should the child or young person have a life-threatening event. It is supported by the ReSPECT or DNACPR document but allows for recording of more detail about specific situations.

- 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 (or NLS) should be followed.
- Discussions around medical interventions in the event of an acute deterioration or cardio-respiratory arrest are much better discussed at a time separated from an acute event, than in a time pressured situation around resuscitation or in intensive care.
- It is good practice to record the reasons for a DNACPR decision, if the child and their family decide against life-sustaining treatment during life-threatening events. See 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' *(*2022).

These are categorised as the following:

- **When life is limited in quantity:**
  It may not be in the child's best interests to provide treatment that is unable or unlikely to prolong life significantly. 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 that should be conveyed to health care and other professionals in these events. It may also include ambulance directives for transfer of care to other institutions. If families have specific wishes about transfer to different settings (eg hospice), it is important to clarify why their documented wishes may not always be possible.

ReSPECT form

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process and form are complementary to the CYPACP document as a whole. 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 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 section in the CYPACP will not be included in this document. Instead please refer to the following document:

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

However, ReSPECT has not been adopted in all areas. As such, there are two versions of the CYPACP document. One that includes a ReSPECT section and one that does not.

Emergency contacts of professionals: This should detail information of 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.

Signing the CYPACP: The ReSPECT/DNACPR section needs to be signed. This should only be signed by an appropriate clinician. Usually, this is the child's lead consultant. However, senior nurses can sign the DNACPR section in some Trusts.

Signing the ReSPECT form can also represent confirmation for the overall CYPACP document where signing refers to the discussion and involvement in the completion of the document and awareness of the information contained.

When signing ReSPECT and the CYPACP, please refer to local policy.

Review dates for advance care plan: Appropriate timing for review of the CYPACP depends on the child's individual circumstances but should be at the discretion of the lead clinician. For some children, the form will only need to be completed once. However, other children will have a CYPACP in place for many years in which case it is often recommended that the advance care plan is reviewed annually. An earlier review should be triggered if the child's condition changes significantly. Parents or professionals may request a review.

Ensure that all care settings that the child attends have a copy of the plan (or know how to access it) and receive updated copies as appropriate. This also includes the family's own copy. Some ambulance services 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 preferences and wishes for the child's future care and management. Professionals should support them in achieving a plan that reflects that. 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 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. This involves responding to disease-related changes, as well as shifts in families decision-making.

Time spent in preparation, discussion and writing the CYPACP will enable children and families to effectively participate in communicating important information and making difficult decisions. The resulting CYPACP should help ensure this information is shared with relevant professionals to inform treatment and care.

9. Resuscitation

‘CPR’ refers to ‘Cardiopulmonary Resuscitation’ and incorporates all elements of resuscitation. (Care needs to be taken with the use of the term CPR as it can be interpreted in different ways).

In children’s services, there are usually three broad categories of recommendations around resuscitation:

- **Full resuscitation**
- **Modified resuscitation**
- **Do Not Resuscitate**

It is important to note that the presence of an advance care plan and /or ReSPECT document does **not** mean that there is a limitation of treatment. Instead forms should be read carefully to understand the specific details of any limitation that is considered appropriate or recommended.

Full Resuscitation

It will be appropriate for many children and young people with advance care plans to be offered attempted ‘Full’ (without limitation) resuscitation should they become unwell. Unjustified assumptions should not be made based on the fact they have a life-limiting condition or an advance care plan.

Modified resuscitation

Recommendations for resuscitation, in the face of life-threatening events, should use evidence-based predictions to gauge the success of different interventions. These algorithms change from time to time. Pathophysiological differences between adults and children have resulted in separate protocols. Most notably that most adult cardiac arrests are primarily cardiac in nature whilst paediatric cardiac arrests are often secondary to a primary respiratory arrest.

It is also reasonable to discuss options of appropriate interventions for resuscitation that may be described as ‘modified resuscitation’. Modified resuscitation essentially means that differing levels of resuscitative measures can be considered for patients according to their condition. For example, a young adult with Duchene Muscular Dystrophy may have deteriorating respiratory function due to their underlying muscle weakness, often with a reduced ability to clear secretions, potentially leading to a respiratory arrest. It is reasonable therefore, to support these young adults in a request for bag and mask ventilation, even if they would not want cardiac compressions.

Modified resuscitation may therefore be appropriate for children and young adults with palliative care needs where it may be appropriate to intervene with respiratory based resuscitative measures without proceeding to cardiac compression. It is better when discussing modified resuscitation (and in general) to avoid any ambiguity and be precise about what respiratory and/or cardiac measures are recommended. We do not recommend using the term ‘CPR’ in documentation as this can be interpreted differently.

Do Not Attempt Cardiopulmonary Resuscitation

> “There are circumstances in which treatments that merely sustain ‘life’ neither restore health nor confer other benefit and hence are no longer in the child’s best interests.”
> RCPCH *(1997, 2004, 2015)*

A child with a valid ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR) decision in place should not have any attempt made to resuscitate them in the event of a cardiorespiratory arrest. (This will exclude cardiorespiratory arrest due to rapidly reversible causes such as choking or anaphylaxis, or situations specific to the individual child as specified in the advance care plan).

If there is a valid ‘Do Not Attempt Cardiopulmonary Resuscitation’ decision in place, in hospital a clinical emergency (crash 2222) call will not usually be made, and no resuscitative interventions (such as ventilation and chest compressions) will be made to assist the child’s failing respiratory or circulatory function.

If an ambulance is called, then Ambulance Control should be told of the existence of an advance care plan and/or ReSPECT containing a completed DNACPR decision.

A DNACPR decision does **NOT** mean a withdrawal of care. Every attempt should always be made to make the child as comfortable as possible, and to fulfil the child’s and the family’s wishes.

DNACPR orders do not override clinical judgement or discretion. For example, they may not be followed if a child suffers a cardiac or respiratory arrest from a reversible cause, (e.g. acute aspiration, choking or anaphylaxis or one not envisaged when the original order was made).

All children must be assumed to be for attempted resuscitation unless there is a valid, documented DNACPR decision in place. If there is any doubt about the validity or applicability of a DNACPR decision, then resuscitation should usually be initiated.

Irrespective of previously documented recommendations or decisions, if a clinical decision is made by a senior clinician that resuscitation is futile, all attempts at resuscitation may be ceased. This should be discussed, if possible, with the family or person with parental responsibility at the time the decision is made. For example, if a child is already on full maximal intensive care medical management and the child continues to deteriorate and their heart stops,’ despite the highest levels of intervention, then it is unlikely that there is a reversible element to their decline and thus commencing chest compressions would be unlikely to bring benefit to the child.

A valid DNACPR decision:

Reflects the agreed wishes of the child (where appropriate), those with parental responsibility for the child, and the health care professionals caring for the child. Is clearly recorded, signed and dated in the DNACPR section of the ACP and still reflects the current situation/wishes.

Some parents may request that their child receive attempted resuscitation, despite a small chance of success or a high risk of adverse outcomes. Parental understanding about resuscitation and outcomes, and the reasons for their request, should be explored. This includes reasons for allowing a natural death. It may be possible to reach an agreement on the extent to which treatment should be limited. However, clinicians cannot be compelled to provide treatment they feel is not in the child's best interests. If a parent or legal guardian wishes to deviate from the care plan at any point, including DNACPR, then wishes should be respected, as long as they are still felt to be in the best interests of the child.

Cancellation of a Do Not Attempt Cardiopulmonary Resuscitation Decision

In some circumstances, a decision may be made to cancel or revoke the CYPACP or DNACPR decision. Should this occur, the CYPACP or DNACPR documentation should be crossed through on printed copies, on every page, with 2 diagonal lines in dark ball-point ink and the word **“CANCELLED”** written clearly between them, dated and signed by the senior clinician. Reasons for the change should also be clearly documented. Comments should also be made on any electronic copy. It is the responsibility of the CYPACP Co-ordinator or lead clinician (in the absence of a co-ordinator) to inform all parties and arrange an urgent review so that a new CYPACP can be completed.

Exclusions from and suspension of Do Not Attempt Cardiopulmonary Resuscitation decisions

A DNACPR decision does not apply to immediately remediable and acutely life-threatening clinical emergencies such as choking and anaphylaxis. Appropriate emergency interventions should be attempted, which may include resuscitation. Wherever possible, the lead consultant should be contacted as a matter of urgency for ongoing management advice.

An applicable DNACPR decision may be temporarily suspended. For example, it may be suspended during specific interventions such as anaesthesia or surgery that have an associated increased risk of cardiorespiratory arrest. If such procedures are planned, then the CYPACP should be reviewed, and any decision made should be documented and communicated accordingly. The surgeon performing the procedure and anaesthetist should be included in the decision-making. This documentation should clearly specify the beginning and end date of the suspension.

Useful guidance on this can be found in the Great Ormond Street Hospital policy on required reconsideration of DNACPR decisions. http://www.togetherforshortlives.org.uk/assets/0000/8555/GreatOrmondStpolicyrequiredreco nsideration.pdf

10. Implementation and review

Where available, the local CYPACP co-ordinator is responsible for distributing the latest version of the advance care plan. In areas without a co-ordinator, this task falls to the child’s lead clinician or lead professional. The role of the coordinator or lead clinician is to ensure all parties agree to the content of the document (child or young person as appropriate, parent, or person with parental responsibility, professionals), that signatures have been completed and distributed to the wider team caring for the child or young person. Care should be taken with printed hard copies or un-signed electronic copies that the most current version is used.

It is recommended to regularly review the document with review meetings organised at an appropriate time. The frequency of review will depend upon the situation (age / diagnosis / stability of the condition and situation) and local guidance. Irrespective of regular reviews, the care plan should be reviewed if there is any known change in circumstances, need, prognosis or significant event. It should also be communicated to families that if their thoughts change, they should inform those holding the advance care plan. There is purposefully not a review date on the CYPACP document to avoid people assuming it is 'out of date' when it may still reflect the current situation. In any situation, it should be checked that the care plan reflects the current situation, wishes, decisions, and views on treatment. Additionally, it is worth noting that local policies may have more specific time frames for review and where possible these should be adhered to with a process adopted to ensure this occurs. It is vital that every contact documented on the CYPACP document receives the updated version. When a plan is revised, there should be agreed local systems to ensure that old plans are crossed through/or deleted/superseded electronically and recirculated.

11. Advance care planning for different specialities

A. Perinatal and Neonatal

Every year there are over 1,000 neonatal deaths (Draper et al 2022) in the UK. Advance care planning in this population is vital as parents have limited opportunity to make and share memories of their baby. Many babies may die in a very short time, and it is essential to talk to parents and family members, giving them choices in a timely manner.

For babies with a life-limiting illness, some medical treatments may do more harm than good and may not be beneficial. Decisions and treatment options should be made with parents and family members and adjusted as the baby's condition changes. The baby's mother will also need care and support and it is important to understand which professional is best placed to provide ongoing support. The mother may find it comforting to receive continuity of care from the midwife or, it may be too upsetting to work with the same midwife.

In addition, whilst there are many situations where there is reasonable certainty of death during the fetal and neonatal life, there are babies where prognosis is less clear. Babies may survive longer than expected and conversations around continued and parallel planning can be helpful.

Thus, advance care planning may cover antenatal care, birth, and postnatal care and should be co-ordinated and involve a multi-professional team. Parents should be offered the opportunity to discuss care with the obstetrician, neonatal and palliative care team. Conversations may address life expectancy, whether to continue with the pregnancy and parallel planning. These conversations can be documented in the perinatal advance care plan and filed in the mothers' maternal records.

B. PICU

Annually, around 15% of child deaths in the UK occur in Paediatric Intensive Care Units (PICA net annual report 2020). Long stay patients (≥28 days) account for an increasing number of PICU admissions and bed-days and have a significantly higher mortality rate (23% vs 6%).

Children and young people with life-limiting illnesses may already have an advance care plan at the time of admission to PICU, as admission to critical care may well be felt to fit well with their best interests. This would state an agreed treatment escalation plan and a decision about resuscitation.

If a child in PICU does not have an advance care plan in place and has had repeated admissions or is experiencing a prolonged stay, this presents an opportunity for opening conversations about advance care planning. This can be undertaken by appropriately trained PICU staff/lead acute clinicians and/or supported by a local palliative care team (if available). If the child is known to community paediatrics, children's community nursing, or a local hospice it would be sensible to involve them in the decision-making process alongside the acute team, remembering that these teams often know the child and family well.

Key messages

- Children who have been admitted to paediatric critical care are more than ten times more likely to die than those who have not (Fraser et al 2011).
- Palliative care input has been associated with more children dying outside the hospital; a national study from England and Wales of children who died after being discharged from paediatric intensive care units showed that children who had palliative care plans recorded at the time of discharge were eight times more likely to die in the community than children who were not referred to palliative care (Fraser et al 2018).
- ACP discussion can occur at any time (even in complete health) but may be prompted by major crossroads like repeated or prolonged admission to PICU.
- Many children in critical care will lack capacity. Healthcare professionals should discuss with parents and carers what the views of a child or young person might be and ask for the views of the parents and carers themselves.
- At critical care discharge plans for future treatment should be documented along with patients' & families' wishes, values and preferences and included in discharge summaries to GPs and local paediatric services.

C. Oncology

Annually in the UK there are between 1800 – 1900 new cases of childhood cancer (<14 years), and around 250 of these may die of their disease each year (CCLG, Cancer research). Palliative care improves quality of life and is recommended as a standard of care for all children with advanced cancer. Data from adult metastatic non-small cell lung cancer, suggests that early palliative care referral improves mood and quality of life. The palliative care cohort received less aggressive treatment and lived longer (Temel, 2010).

In practice, oncology referrals to the paediatric palliative care team are often late, leading to untreated symptoms, distress, and unnecessary aggressive treatment at the end of life (Jordan et al 2020). Barriers to referring include families associating palliative care with ‘giving up and hopelessness’, stopping treatment and impending death. Oncologists may find addressing the need for palliative care difficult in terms of treatment failure and doctor/patient relationships.

Referral to palliative care for vulnerable oncology patients can be seen as ‘the umbrella, not the rain’. In the face of uncertainty, the storm may never come but if it does early access to an umbrella prevents the patient from being drenched (Zimmerman 2022). Early referral and parallel planning, with palliative care running alongside active treatment, provides families with appropriate symptom management, physical and emotional support, and guidance for decision-making.

Key messages

- Referral to the palliative care team can provide enhanced supportive care for children who still have active treatment options available and are likely to benefit from resuscitation.
- Having an advance care plan is a passport to accessing the right care in a timely way, usually involving palliative care teams working collaboratively with other teams involved.
- ACP discussions are important for guiding medical staff and families to achieve the maximum support and can be initiated by any trained healthcare professional.
- ACP discussion can occur at any time but may be prompted by an initial poor prognosis, or crossroads in care, such as relapse and progression of disease despite treatment.
- Some children with cancer will lack capacity.
- Healthcare professionals should discuss with parents and carers what their, and their child’s or young person’s views might be.
- Advance care plans must be distributed to all member of the team looking after the family including the principle treatment centre, and the local shared care centre.

D. Complex neurological conditions

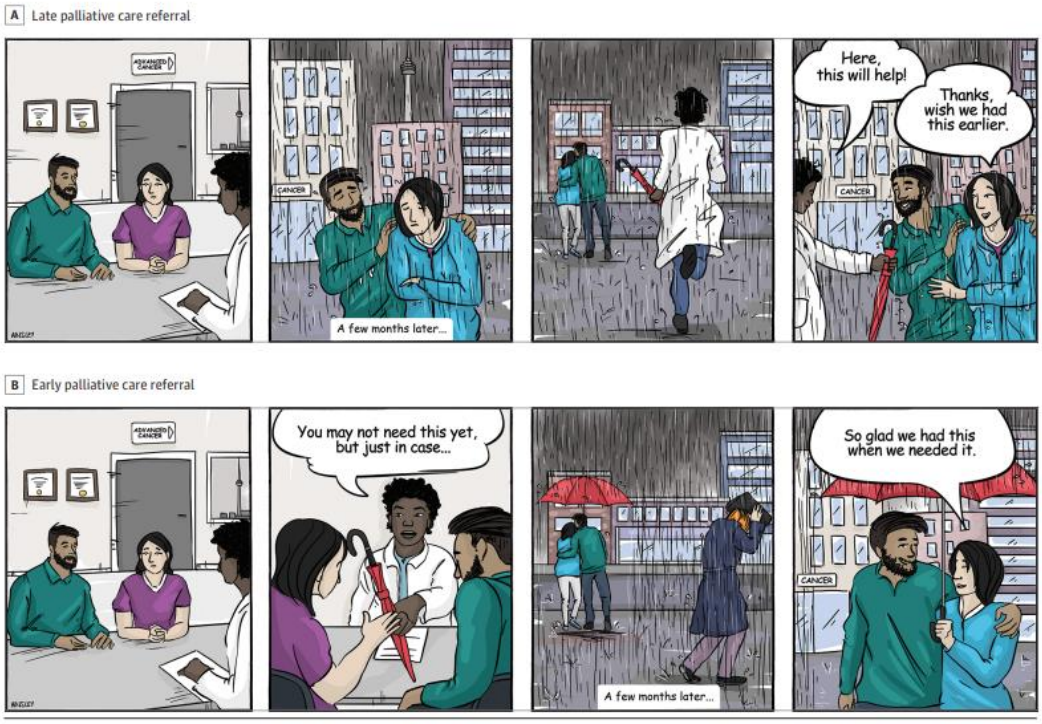
Children and young people who have underlying complex neurological conditions will often have a large and multi-disciplinary team of professionals around them and their families.

It is important to capture the following information in relation to any complex neurological symptoms and conditions the child or young person may have:

- How does the child or young person communicate?
- How does the child or young person show distress or agitation?
- A record of baseline observations.
- Are there any escalation plans?
- What is their level of consciousness and are they presenting any confusion?
- What is their alertness/responsiveness?
- An understanding of the child and young person’s seizures and medications,
- Are there non-pharmacological methods used?
- An understanding of the child or young person’s dystonia/muscles spasms/involuntary movements?
- An understanding of other symptoms that may include muscle weakness or paralysis, muscle pain/sensitivity; dysphagia; Ventriculoperitoneal (VP) shunt in situ.

Other important considerations will include the families understanding and choices for admission to hospital for exacerbation of symptoms.

Figure. Illustrated Metaphor of Late vs Early Palliative Care



12. Young people and transition to adult services

Whilst young people requiring an advance care plan are a small discrete group of patients (relative to the whole population), they are an important group and should be given due consideration and respect.

The pathophysiology of young adults with life-limiting illnesses is typically more similar to children rather than the older population, and therefore this group of patients may die of a primary respiratory arrest. Thus, it is appropriate for young people to use and maintain their advance care plan and decisions for modified resuscitation.

Once a child reaches the age of 18, the CYPACP should be used to inform ongoing advance care planning discussions with them as a young adult, their family and professionals involved in their care.

13. Governance

Each organisation is responsible for the implementation and governance of advance care planning, including the provision of appropriate training for relevant staff groups

The advance care planning document aims to support best interests decision-making and although not legally binding, the recommendations must be considered to inform the child’s care. In all cases clinical judgments must be made in the child’s best interests.

The document is transferable across settings and should be kept with the child.

14. Training

It is beneficial for all professionals working with children or young people to have relevant training for advance care planning. This should include support to understand the concepts and outcomes relevant to advance care planning, and develop the skill to implement the CYPACP appropriately (see www.cypacp.uk). Core components will include how to initiate advance care planning conversations and how to record and document these accurately.

Training to develop advanced communication skills will be particularly important (accessed via the E-Learning for Health website www.e-lfh.org.uk). Training to understand the ethical and legal issues associated with advance care planning will help support shared decision making.

Indeed, the CYPACP is more likely to optimise care when it meaningfully reflects the conversation with a family; providing more understanding about their wishes and preferences than clinical information alone.

15. Resources

- Together for Short Lives: Caring for a Child at the End of Life – a guide for professionals on the care of children and young people
  Together for Short Lives: End of Life Guide

- Dying Matters
  http:/www.dyingmatters.org

- Effective communication for health care
  http://www.ec4h.org.uk

- Mental Capacity Act (2005)
  Mental Capacity Act 2005 (legislation.gov.uk)

  https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/

- NHS (2022) Universal Principles
  universal-principles-for-advance-care-planning.pdf (england.nhs.uk)

- Resuscitation Council
  https:/resus.org.uk

- RCPCH Making decisions to limit treatment in Making decisions to limit treatment in life- limiting and life-threatening conditions in children: a framework for practice
  https://www.rcpch.ac.uk/resources/making-decisions-limit-treatment-life-limiting-life-threatening-conditions-children

- Children Act (1989)
  Children Act 1989 (legislation.gov.uk)

- Human Rights Act (1998) Sections 2 and 3
  Human Rights Act 1998 (legislation.gov.uk)

- GMC: Ethical guidance for doctors working with 0–18-year-olds (updated 2018)
  https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years

- GMC: treatment and care towards the end of life: good practice in decision making (updated 2022)
  Treatment and care towards the end of life - ethical guidance summary - GMC (gmc-uk.org)

- The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child, Gillam L (2016) Clinical Ethics 11(1): 1-8
  The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child - Lynn Gillam, 2016 (sagepub.com)

- RCPCH: Making decisions to limit treatment in life-limiting and life-threatening conditions in children (2014)
  Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (DtLT) | RCPCH

- RCPCH: Achieving consensus: advice for paediatricians and other healthcare professionals on prevention, recognition and management of conflict in paediatric practice (2019)
  Achieving consensus - on prevention, recognition and management of conflict in paediatric practice | RCPCH

- RCPCH: Seeking and providing external second opinions in paediatrics (2022)
  https://www.rcpch.ac.uk/resources/external-second-opinions

- Conflict Management: https://www.e-lfh.org.uk/programmes/recognising- and-managing-conflict-between-children’s-families-and-healthcare-providers/

- NICE NG61 (2016)
  Overview | End of life care for infants, children and young people with life-limiting conditions: planning and management | Guidance | NICE

- NICE QS160 (2017)
  Overview | End of life care for infants, children and young people | Quality standards | NICE

- Larcher V, Craig F, Bhogal K, et al Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, Archives of Disease in Childhood 2015;100:s1-s23.

- Children's cancer statistics | Cancer Research UK

- Childhood cancer facts and statistics 2021 | Children with Cancer UK

16. Glossary

Advance Care Planning: Advance Care Planning (usually called anticipatory care planning in Scotland) is a process of discussion between an individual and their care provider and often those close to them. Advance Care Planning may lead to actions such as advance statements about wishes and preferences, preferred place of care, withdrawal of treatment and resuscitation status. For families this will include decisions relating to treatment options and choices of care in the case of acute deterioration and gradual deterioration of their child's condition. It may also address preferences for organ and tissue donation.

Child and Young Person's Advance Care Plan (CYPACP): is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different Advance Care Plan should normally be used for those over 18, see local guidelines. A CYPACP will include whether the cardiopulmonary resuscitation status has been discussed, and the outcome of that discussion should a cardiorespiratory arrest occur.

Cardiorespiratory Arrest: is specifically the cessation of breathing and loss of cardiac output. This definition is strict and should not be extrapolated to include any other circumstances. The terminology 'Cardiopulmonary Arrest' is also used in some documents. In children, a particular arrest is sometimes documented as a respiratory arrest where there is still cardiac output but cessation of breathing, or as a cardiac arrest where there is cessation of breathing and loss of cardiac output. A respiratory arrest is much more common in children than in adults.

Cardiopulmonary Resuscitation (CPR): Interventions delivered with the intention ofrestarting the heart and breathing. These will include chest compressions and manualventilation via mouth, bag and mask or endotracheal tube, and may include attempteddefibrillation and the administration of drugs.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): refers to a specific, agreeddecision to refrain from making efforts to restart breathing and/or the heart following a cardiorespiratory arrest.

Valid DNACPR: A Do Not Attempt Cardiopulmonary Resuscitation decision is only valid if the form is appropriately completed, signed and dated and applicable to the situation.

Modification to DNACPRR: Differing levels of resuscitative measures can be considered for patients according to their condition.

ReSPECT: The ReSPECT process creates personalised recommendations for a person’s clinical care and treatment in a future emergency in which they are unable to make or express choices.

Child Death Overview Panel (CDOP): This group monitors and reviews all deaths ofchildren.

Rapid Response team: When there is a sudden and unexpected death in childhood (SUDIC/SUDC) a Rapid Response occurs. Police and Health work together to understandwhy the death occurred at that time. If the death of a child with a CYPACP occurs at an unexpected time, a rapid response may be triggered.

Perinatal / Neonatal: The period of time up to delivery and up to 4 weeks after delivery

Child: Anyone under the age of 18

Adult: A person aged 18 years or over

Young person: A person aged 16 or 17. Anyone under this age is legally regarded as abay, infant or child.

Parental responsibility: the rights and duties relating to those in relation to the child.

17. References

Bennett HE, Duke S & Richardson A (2022) Paediatric advance care planning in life-limiting conditions: scoping review of parents experience. BMJ supportive and palliative care. Doi:10.1136/bmjspcare-2022-003544.

Carr K, Hasson F, Mcllfatrick & Downing J (2022) Initiation of paediatric advance care planning: Cross sectional survey of health care professionals reported behaviours. Child Care Health and Development. May 48(3). 423-434. Doi: 10.1111/cch.12943.

DH (1989) Children Act Children Act 1989 (legislation.gov.uk)

DH (2005) Mental Capacity Act.

Draper ES, Gallimore ID, Smith LK, Matthews RJ, Fenton AC, Kurinczuk JJ, Smith PW, Manktelow BN, on behalf of the MBRRACE-UK Collaboration. MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2020. Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester. 2022.

Fraser LK et al. (2011) Place of death and palliative care following discharge from paediatric intensive care units. Archives of Diseases in Childhood. Short Report.

Fraser LK et al. (2018) Changing place of death in children who died after discharge from paediatric intensive care units: A national, data linkage study. Palliative Medicine.32(2).

Gillam L (2016) The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. Clinical Ethics. 11(1): 1- 8.

GMC (2018) Ethical guidance for doctors working with 0–18-year-olds (updated 2018). https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years

GMC (2022) Treatment and care towards the end of life: good practice in decision making (updated 2022). https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/guidance

HM Government (2018) Working Together to Safeguard Children. https://www.workingtogetheronline.co.uk/chapters/chapter_five.html

Jordan et al. (2020) Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. BMC Medicine. 18:368.

Larcher V, Craig F, Bhogal K, et al. (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, Archives of Disease in Childhood.100:s1-s23.

NHS (2021) Ambitions for palliative and end of life care. https://www.nice.org.uk/guidance/qs160/chapter/Quality-statements

NHS 2023 Service specifications for palliative and end of life care: Children and young people (CYP). https://www.england.nhs.uk/publication/service-specifications-for-palliative-and-end-of-life-care-children-and-young-people-cyp/

NHS (2022) Universal principles for advance care planning. https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf

NICE NG61 (2016) End of life care for infants, children and young people with life-limiting conditions: planning and management. https://www.nice.org.uk/guidance/ng61

NICE QS160 (2017) End of life care for infants, children and young people. https://www.nice.org.uk/guidance/qs160/chapter/Quality-statements

RCPCH (2023) A framework for practice. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. http://dx.doi.org/10.1136/archdischild-2014-306666

Shaw K & Spry J (2020) Evaluating Advance Care Plans. Listening to Families and Professionals. University of Birmingham.

Temel JS et al. (2010) Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. N Engl J Med 2010; 363:733-742. DOI: 10.1056/NEJMoa1000678.

Zimmermann C & Matthews J (2022) Palliative Care Is the Umbrella, Not the Rain-A Metaphor to Guide Conversations in Advanced Cancer. JAMA Oncol 1;8(5):681-682. doi: 10.1001/jamaoncol.2021.8210.