Quality Statements to Support Paediatric Advance Care Planning in Southwest England 2025

Content

Introduction

These are quality statements which describe recommended best practice in advance care planning for babies, children and young people and their families (BCYPF). They have been developed collaboratively with input from professionals engaged in advance care planning, and with input from those with lived experience.

These standards should inform, complement, and not replace relevant guidelines and policies that exist within individual organisations.

Definitions used in this document

Babies: babies and unborn babies under the age of 1 year

Children: children and young people aged 1 year and older, who are under the age of 18 years

Parent(s): people with parental responsibility

Purpose of quality statements

1. To develop a consistent approach to the process of paediatric advance care planning in the Southwest of England
2. To raise awareness of paediatric advance care planning for professionals
3. To define the process around what is expected for paediatric advance care planning
4. To improve the quality of experience of paediatric advance care planning for both families and professionals
5. To enable cross-organisational clinical governance practice including audit

This document is NOT a ‘how to’ guide. Please see resources section for training materials.

What is Advance Care Planning?

- Advance care planning communicates 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 can contribute), their parent(s) 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 for future care. It aims to empower children and families to share their values, hopes, and goals. It is not limited to a discussion about resuscitation.
- An advance care plan is **not** equivalent to a legal document such as an ‘Advance Decision to Refuse Treatment’ in adults.
- An advance care plan is a vehicle for discussion and documentation of wishes and preferences. As such, parent(s) 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, which might override the stated preferences in the advance care plan.
- Parent(s) 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 of 18 years.[1]
- Some parent(s) may not wish to have an advance care plan or sign any documents.

Which children? Which professional? When?

- **Which children?**
    - All children who are recognised to have a life-limiting or life-threatening condition should be given the opportunity to develop an advance care plan

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[1] General Medical Council. 0-18 years: Guidance for all doctors. In effect: 15 October 2007. Updated 25 May 2018

    - When there is uncertainty about survival antenatally or on the neonatal unit the offer of advance care planning should be made
- **Which professional?**
    - Where possible, advance care planning should be initiated by someone who:
        - Knows the family and has experience, confidence, and time to lead on advance care planning conversations
        - Can consider all possible treatment and care options and considers them in terms of the benefit and burden for the child
- **When?**
    - It is a complex process influenced by diagnosis, prognosis, family readiness to engage, family situations, and professional responsibilities
    - It can begin soon after diagnosis or recognition of a life-limiting condition, or during a period of stability in the child's condition
    - Natural triggers for starting the conversation: 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
    - Ideally, the need for advance care planning should be identified during a stable phase and introduced by familiar professionals. It is recognised that sometimes this is not possible, and it is necessary to undertake advance care planning during a hospital admission
    - Some children will have an ACP for many years before they reach the end of their life

Quality Statements

1. Preparation for ACP discussions		
1.1	Use CYPACP – Standard (all ages) – with ReSPECT care plan. (Or CYPACP – Antenatal with ReSPECT for antenatal plans). Use most up to date version In localities where ReSPECT has not been adopted for use, the CYPACP care plan without ReSPECT should be used along with other local documentation to support the delivery of care across all settings Access these forms from cypacp.uk/care-plan	
1.2	Ensure family have information about advance care planning prior to discussions (information can be accessed from cypacp.uk/parent(s)-and-families/)	
1.3	Prior to meeting the family there is a need to gather information from the multidisciplinary team around the child so that conversations are fully informed. Identify who needs to agree the CYPACP before it is signed off	
1.4	For each patient, identify a CYPACP co-ordinator to lead on the process. Examples of CYPACP co-ordinators are Community	

	Children's Nurses, Hospice Nurses, or hospital based Clinical Nurse Specialists. The co-ordinator's details should be written on CYPACP page 2, under 'Responsibility for changes'	
1.5	Identify all the professionals who need to be inputting to agree the content of the plan prior to sign-off. (This may well be from more than one team)	
1.6	Identify a 'lead clinician for CYPACP' to sign off the care plan when it is finalised. The lead clinician could be any of patient's consultants who knows them well	
1.7	All professionals who participate in advance care planning should be able to access the training and support they require to work confidently and competently	
1.8	Take all necessary steps to ensure that the child/young person is appropriately involved in CYPACP discussions. The voice of the child may well be best represented by the parent(s), but it is important to involve others who may be able to support this e.g. school teams	
1.9	Liaise with family regarding the best setting for CYPACP conversations (hospital/home/hospice or elsewhere). Ensure privacy and minimal disturbance as much as is possible	
1.10	Be prepared to go at the pace of the family in these discussions, and prepare the family that the discussions may need to take place over more than more session	
1.11	Ensure parent(s) know that the CYPACP will be revisited at intervals in the future, this can also be done at their request	
1.12	Include both parent(s) if possible, in advance care planning conversations and consider how best to include the voice of the child or young person	
1.13	Give parent(s) the option of inviting other individuals to join the ACP conversation if they would find their presence supportive e.g. family members/friends, faith leader, familiar professional	
1.14	Consider how best to meet the child & parent's communication needs. For example, using communication aids or if child/parent(s) are not fluent in English use a professional interpreter for these discussions. Take time to explain the nature of the conversation to the interpreter before starting	
2. Having ACP conversations		
2.1	ACP discussions should be done in collaboration with lead clinician and can be supported by hospital, community or hospice-	

	based teams, according to local arrangements. Consider involving the child's school (particularly special school) or respite care provider	
2.2	Good advance care planning involves really listening to and understanding a family's and young person's perspective to summarise it succinctly in the document and tailor our communication to their needs accordingly	
2.3	Professionals should remember the sensitive nature of advance care planning conversations and the impact it may have on the family. The messaging needs to be both clear and kind	
2.4	The CYPACP document does not need to be completed in one sitting. For example, families may be able to speak about wishes in life, but not yet able to talk about wishes around death and after death. A family wish to defer completion of some sections of the CYPACP should be respected. It is better to have a partially completed CYPACP than no CYPACP at all	
2.5	Consider the emotional impact of ACP discussions on families. Help families explicitly to consider their support needs, particularly later that day. Acknowledge the possible impact having these conversations may have on them. They may benefit from being asked what their plans are later that day and helping them to identify sources of support as appropriate	
2.6	Consider the emotional impact of CYPACP discussions on professionals and whether a few minutes away from clinical work might be useful following discussions. Staff regularly involved in CYPACP discussions may benefit from access to facilitated reflective practice	
3. Clinical decision making		
3.1	If YP < 16 years old – clinician must assess the competence of YP to be able to make decisions about their own healthcare and contribute to ACP discussions	
3.2	If YP is 16 or 17 years old they are assumed to have capacity to make their own decisions under the Mental Capacity Act. However, it should be acknowledged that the court can override patient consent/refusal up to the age of 18 years. If YP lacks capacity to make specific treatment decisions, this should be documented and the person with parental responsibility can consent	
3.3	The lead clinician needs to take responsibility for the decisions in the ACP, and confirm they agree that they are in the child's best interests. Sometimes when advance care planning begins it reveals differences of opinion around recommendations for future clinical	

	care. To reach agreement about future care you may need to follow additional organisation policies to achieve consensus between professionals themselves, professionals and parent(s), or child/YP and parent(s). This may include but not be limited to an external second opinion, referral to clinical ethics advisory group, and legal advice	
3.4	When families find it hard to engage with ACP discussions take all possible steps to provide as much support as possible to enable patients and parent(s) to engage in these conversations, including seeking advice from clinical psychology if available	
4. Completion and circulation of CYPACP		
4.1	Once ACP discussions have taken place, documentation should be completed on a CYPACP template within a time frame that is appropriate to the clinical scenario, and sent to the lead clinician and other key professionals for comments	
4.2	The CYPACP should then be reviewed and content agreed by parent(s). Their signature is optional	
4.3	For CYP who spend significant periods of time not in the care of their parents (e.g. at school or with a respite care provider) the CYPACP coordinator or CCN should offer a conversation with those teams about the ACP so that they understand the decision making that underpins the plan and can be supported to implement it. This is particularly important when the ACP does not recommend full resuscitation. Confirmation that the plan should (or should not) be followed if parents are not present should be documented on page 6 of the CYPACP It may be appropriate to support the parent to have a direct conversation with the care provider, so they have a chance to hear parent's wishes directly and be in the best position to follow through on this plan should the child deteriorate while in their care	
4.4	The family and ACP coordinator will work together to agree who receives a copy of the ACP	
4.5	CYPACP should NOT be circulated, printed for notes, or uploaded to electronic records until agreed with lead clinician and parent(s)	
4.6	The CYPACP should then be circulated to all relevant professionals electronically as soon as possible. Parent(s) should be provided with a printed copy (or copies) as well being offered an electronic copy (pdf version).	
4.7	Receiving professionals must commit to ensuring the CYPACP is accessible within their organisation as per local procedures in a timely manner given the clinical context	

4.8	CYPACPs should no longer be sent to the ambulance service (SWAST). Parent(s)/carers (and schools/respite care providers) should be told that attending ambulance crews will not be aware of the existence of the CYPACP. It is therefore important that a copy of the CYPACP remains with the child in all settings and those supporting the child show the CYPACP to the attending ambulance crew	
4.9	It is extremely important that parent(s) understand that a copy of the most up to date version of a child's CYPACP should always be with/near the child - so that it can be shared as needed at points of care with paramedics, out of hours teams, Emergency Department staff etc. Parent(s) should feel confident to share the document with professionals who may otherwise be unaware of its contents	
4.10	Each person with parental responsibility should hold a copy of the CYPACP and, particularly when they do not share a home address, this should be explicit on the distribution list	
4.11	When saving the CYPACP, electronically label in the format below: Name – CYPACP – Month Year of creation or review (eg Joe Bloggs – CYPACP – Jun 24)	
5. Review of CYPACP		
5.1	Annually, CYPACP co-ordinator should review the CYPACP to ensure the contact details are up to date, and consideration should be given as to whether the CYPACP content needs updating with the family (and young person), depending on clinical context	
5.2	CYPACP should be reviewed sooner if there is any known change in circumstances (including change of address/contact details), clinical need, prognosis, or significant event, by whoever is best placed to do so	
5.3	If any changes to the CYPACP have been made, the amended CYPACP should be re-dated (pg. 1 and pg. 8) and recirculated If the CYPACP has been reviewed, confirmed as still 'current' with the family and there are no changes it should still be re-dated (pg. 1 and pg. 8) and recirculated	
5.4	When a child/YP who has a CYPACP presents to a new care setting (e.g. hospital) the treating professionals should confirm with the family that the CYPACP is up to date and still representative of their views and wishes, and this should be documented in the child's notes. Professionals should recognise that this should be done sensitively. Reviewing the document in detail is only required when the clinical scenario dictates or the family wishes to	
5.5	When a CYPACP is revised all old plans should be crossed through and disposed of according to individual organisations' processes	

5.6	At each CYPACP recirculation the family should be reminded that the handheld paper copy is the most important to share information with urgent care professionals at point of care	
	6. Using CYPACPs when delivering patient care	
6.1	It is the responsibility of professionals who look after children to be aware of whether they have an advance care plan and if they do, what it says	
6.2	When a child/YP who has a CYPACP presents to a new care setting (e.g. hospital) the treating professionals should confirm with the family that the CYPACP is up to date and still representative of their ideas and wishes, and this should be documented in the child's notes	
6.3	The treating team should review the contents of the CYPACP and assess whether the existing plan for care is still deliverable considering the situation the child is in at that moment	
6.4	Following initial confirmation of the CYPACP avoid repeated unnecessary conversations about advance care planning unless there is a clear clinical need to make changes. If possible, involve lead clinicians	
	7. ReSPECT form / DNACPR	
7.1	If the ReSPECT form is agreed for use in the child's locality: When opinions have been sought from all relevant professionals (including lead clinician) and they agree with resuscitation decisions any responsible consultant can sign section 4 of the ReSPECT form (as part of the CYPACP form with ReSPECT)	
	8. Preparing for surgery/procedures	
8.1	It is the responsibility of professionals who look after children to be aware of whether they have an ACP and if they do, what it says	
8.2	If a child/YP who has a CYPACP with a modified resuscitation plan is coming into hospital for a procedure requiring an anaesthetic, the family should have an opportunity to discuss with their responsible clinician for that admission, surgeon and anaesthetist any changes in resuscitation plans peri-operatively e.g. temporary suspension of DNACPR decision	
8.3	Any decision as per standard 8.2 should be documented and communicated in healthcare records and handover accordingly. Documentation should clearly specify the beginning and end date of any changes	
	9. Antenatal plans	

9.1	Use the CYPACP Antenatal Advance Care Plan for families who are known to be expecting a baby with a life-limiting or life-threatening condition	
9.2	Parent(s) of unborn baby should have copy of CYPACP, and copy should be uploaded to maternity notes on BadgerNet, and mother's electronic record	
9.3	Advance care plans made antenatally should be reviewed in a sensitive, compassionate, and timely manner following delivery of the baby to ensure that documentation is still in line with the family's wishes and treating team's recommendations	
9.4	If indicated following discussions, consideration should be given to appropriateness of redevelopment of the advance care plan for the baby using standard CYPACP	
10. Critical Care		
10.1	Consider starting CYPACP discussions if a child in PICU does not have an advance care plan in place and has: - Repeated unplanned admissions or - Prolonged stay (>28 days)	
11. Transition to adult services		
11.1	Advance care planning should be considered as part of the transition pathway which would normally begin at age 14 years old	
11.2	When an ACP is being developed for a young person older than 14 years old it is important to involve relevant professionals from adult settings to ensure that any plans made are deliverable beyond transition	
11.3	During transition to adult services a young person's up to date CYPACP should be passed on appropriately to adult services. This could include, but not be limited to GP, adult hospice, and learning disability team	

Resources

- CYPACP best practice guidance. https://cypacp.uk/guidance/
- '0-18 years: Guidance for all Doctors' (2018) GMC document. https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years
- 'Making decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice' RCPCH 2022
- 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
- NICE NG61 (2016) Overview | End of life care for infants, children, and young people with life-limiting conditions: planning and management

- NICE QS160 (2017) Overview | End of life care for infants, children, and young people | Quality standards
- PPCEducate – Digital platform supporting learning across the breadth of Paediatric Palliative Care. (https://ppceducate.co.uk/)
- Recognising uncertainty: an integrated framework for palliative care in perinatal medicine. A BAPM Framework for practice. BAPM 2024

Quality Statements Working Group

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The working group are grateful to colleagues working across the region for their contributions to the development of these statements and to the following organisations who have committed to using them to support their delivery of care.

For more information about the ACP Quality Statements please contact childrenspalliativecare@uhbw.nhs.uk

Please provide feedback on these Quality Statements here or by using the QR code below

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