

Advance Care Planning (ACP) in Pediatrics

Explanations and suggestions for professionals



Introduction

This document provides you with an explanation of what Advance Care Planning (ACP) is and also offers you suggestions for conducting ACP discussions with children and parents. ACP discussions are different from regular consultations or conversations. ACP discussions explore how a child and his/her parents approach life and what they consider to be important. The purpose of this exploration is to better align decisions about the child's care and treatment with the values, preferences and needs of the child and family.

NB: where the term parents is used, it can also mean parent or guardian(s)

NB: the role of the child depends on his/her age and developmental level

Summary of key points related to ACP

Key points for Advance Care Planning in Paediatric Medicine:

- ACP is a communicative process that enables children and parents to formulate their values, goals and preferences for future care and treatment and to discuss these goals and preferences with caregivers and relatives.
- This process can be adjusted according to the child and parents' willingness to talk about the future.
- ACP is relevant for all children with a life-limiting or life-threatening condition and can happen at any time. The need and motivation for ACP increases when the condition of the child deteriorates or as the end of life approaches.
- The child's primary treating physician is involved in the ACP process.
- The fundamental question in ACP is: what is truly important to this child, to these parents and to this family?
- The next question is: what does care and treatment that is aligned to the values and preferences of the child and family look like?
- During ACP discussions, experiences with illness, values, hopes, fears and worries, are explored at medical, psychosocial and spiritual levels.
- ACP discussions explore the child's preferences and aims regarding future care and treatment, as well as those of the parents and family.
- The health care professional can share his/her perspectives regarding the child's future as necessary.
- The health care professional can provide information about additional care and treatment options as necessary.
- During an ACP discussion, the health care professional will ask who makes decisions about the care and treatment of the child and how the child is to be involved.
- Preferably, the child participates in conversations in a manner that is appropriate for his/her age and competence.
- If the child is unable to participate in the discussions, parents and caregivers consciously describe the child's perspective and interests.
- A summary of ACP discussions is documented in the medical record. Specified treatment directives are shared with other care professionals involved.
- Aims and preferences for care and treatment may change over time. ACP discussions can therefore be held repeatedly and care directives can always be amended or revised.

What is Advance Care Planning?

Advance Care Planning (ACP) is a process that enables children and parents to formulate their values, goals and preferences for future care and treatment and to discuss these goals and preferences with caregivers and relatives.

ACP encourages children and parents to reflect on the significance and consequences of a serious illness. ACP deals with the needs of children and parents in physical, psychological, social and spiritual terms.

Care professionals talk to children and parents about their expectations regarding the child's development and the progress of the disease. The caregiver asks what the child and parents see as truly important in the child's care and treatment, now and in the future. ACP invites children with a serious illness and their families to discuss any care preferences, to document them and to revise them if necessary. During this process, the child is involved in a way that is appropriate for his/her age and level of development.

Why is ACP important?

Every child and family has his/her own unique needs. Every child goes through their own process of development. For a child with a life-limiting or life-threatening condition, ongoing development is closely linked to the course of the disease and to the corresponding care and treatment required. Care and treatment should match the needs, values, preferences and aims of the child and family and should contribute to a 'good' life for the child.

In ACP conversations, children and parents are asked how they perceive the future and what they consider to be important in regarding care and treatment. This is assessed by asking them questions about their values, preferences and goals with a view to the future. In this process, the individual child's needs, desires and wishes form the starting-point of the discussions. These discussions are necessary to reinforce the autonomy of the child and parents and to promote shared decision-making.

Thus, they form the basis for decisions about the child's future care and treatment. By participating in an ACP process, care professionals develop more insight into the perspectives of the child and parents in relation to living with an illness, living a good life and the quality of life.

ACP can contribute to proper alignment of care and treatment with the family's preferences. It also prepares families for situations that may arise in the future and thus reduces uncertainty and fear if a critical situation occurs.

ACP can prevent unexpected acute hospitalizations and invasive procedures. In addition, careful documentation of an ACP conversation provides clarity in acute situations for care professionals who are not familiar with the child.

What are the aims of ACP discussions?

The aim of ACP is to ensure that the child receives care and treatment that corresponds to his/her values, goals and preferences and to those of the family. The following principles form the foundation of an ACP conversation and help achieve this aim:

- 1.1) Exploration of the perspectives of the child and parents about themselves, about living with illness and about the future.
- 1.2) Support for the child and parents in identifying their values and sharing these values with other care professionals.
- 1.3) Exploration and documentation of the aims of the child and parents for future care and treatment.
behandeling verkennen en documenteren
- 1.4) Support for the child and parents when translating preferences into goals about future care and treatment.
- 1.5) Help parents articulate and define their role as parents and decision-makers for the child.
- 1.6) Keep the child's perspective central, whether this be in direct communication with the child or via the parents or significant others.

For whom is ACP relevant?

ACP is relevant for all children with a life-limiting or life-threatening condition. In principle, ACP can be conducted at any age and at any time during the course of an illness. The necessity and focus increase when the condition of the child deteriorates due to his/her illness.

The questions below can assist in identifying children with a serious illness who might be eligible for ACP:

- Would I be surprised if the child were to die from this illness?
- Would I be surprised if the child were to die from this condition before reaching adulthood?
- Would I be surprised if the child were to die from this condition within the next twelve months?

If the answer to any one of the above questions is 'no', ACP might be relevant for the child, the family and health care professionals involved.

When are ACP discussions held?

ACP discussions preferably take place during a stable stage of the disease process and not during a time of crisis. This gives the people involved space to reflect on the conversation and to think about it without immediately needing to make decisions.

Who initiates an ACP discussion?

In principle, everyone can initiate an ACP conversation. In practice, children and parents rely on their care professionals to take the initiative. Care professionals involved can be pediatricians, general practitioners, palliative care physicians, (specialist) nurses, psychologists, social workers or child life specialists.

Preferably, the child's primary medical care provider should be involved in the discussions. This ensures congruence between the ACP discussions and the child's future care and treatment. The conversation can be led by the primary physician him/herself or by another healthcare provider who is able to effectively facilitate ACP discussions. Involving various disciplines or areas of expertise in the discussions can lead to a broader, more nuanced

perspective. For this reason, the child, family or primary physician can consider inviting other relevant healthcare professionals to take part in the discussion.

How does an ACP discussion affect the child, parent and professional?

Talking about the future with children who have a serious illness can be difficult. These conversations confront the child, parents and care providers with the child's possible deterioration, and this can be emotionally challenging. However, parents want open and honest information. They want to be involved in the decision-making process regarding their child's care and treatment. After an ACP conversation is initiated, parents often feel more enabled to think about various options and to talk about them. These discussions help families maintain hope and find meaning during a child's illness. Healthcare professionals need these conversations so they can harmonize their medical expertise with the preferences and goals of the child and his/her parents. By discovering the family's preferences and goals, care can be optimally aligned to the family's needs.

How do I prepare for an ACP discussion?

An ACP discussion requires preparation. It is necessary to be well informed about the condition of the child, the care and treatment options, his/her expected prognosis and who is involved in the child's care. It is important to consider the child's current and prospective developmental levels. It is also important to think about the ACP topics prior to the discussion; be well versed in the issues that will be addressed and practice how to discuss these topics. The IMPACT conversation guide and training will assist in this preparation.

How do I prepare parents for an ACP discussion?

ACP discussions should be a regular aspect of medical care. Given the special nature of these discussions, they should preferably be planned separately from other consultations. Make sure to reserve sufficient time to conduct an ACP conversation.

Parents and children are not always ready for an ACP conversation. When inviting a child and parents to an ACP conversation, their needs are central. If parents or children are reluctant to engage in an ACP conversation, clarify these reasons in order to leave the possibility open for having the discussion at a later time.

The preparation chart of IMPACT contains instructions and sample phrases for inviting parents to an ACP discussion. The following points form part of preparation:

- Ask if the child will be present during the ACP discussion.
- Book a separate appointment for the ACP discussion and set aside enough of time for this meeting (at least 60 minutes).
- Before the appointment, ask the parents if they would like other care professionals (family doctor, nurse, home care professional) or family members to participate as well.
- Before the appointment, give the parents a copy of the information letter about the discussion.

How is an ACP discussion structured?

An ACP discussion is primarily an explorative conversation or a listening conversation; during the conversation the child's and parents' perspectives are the central focus. The child and parents have the opportunity to tell about how they live with an illness, what they consider to be important in the child's care and treatment, why they consider these things important, as well as their hopes and worries. Goals of care and, if necessary, concrete treatment directives are determined together with the care professional. During the conversation, the care professional may provide additional information about prognosis and different options for care and treatment. This information can pertain to either the broader process of care and treatment or specific treatment options, such as the insertion of a PEG tube, ventilator support or ICU-admission.

An ACP discussion is structured around four steps. The IMPACT conversation guide lays out the topics for each step with sample phrases.

The IMPACT conversation guide is not meant to be used as a questionnaire. Rather, it should help support and structure the dialogue. It will always be necessary to adapt the conversation to the individual children and their parents and to specific situations.

The four steps of an ACP conversation:

Step 1 Introduction	Introduction to the discussion Aim of the discussion
Step 2 Assessment	Child Illness Parenting Future Care and treatment
Step 3 Decision making	Role of decision makers Goals of care Documentation
Step 4 Conclusion	Summary Other issues Follow-up

The discussion should form one coherent whole. It's possible that all the steps cannot be discussed during one meeting because some topics require more elaboration or because the child or parents need more time. If this is the case, the different steps can be divided over several conversations. Not all discussion topics may be relevant for every child. Therefore, agreement with the child and parents should be repeatedly assessed during the conversation.

A subsequent conversation about future care can be arranged at the conclusion of the ACP conversation. It is important for ACP discussions to be planned separately from regular appointments in order to underline their overarching character. These discussions can also be emotionally draining for the child and parents; this is why it's important for the child and parents to know beforehand when the ACP discussion will take place so they can properly prepare.

It takes time to determine the preferences and aims for care and treatment. Preferences and aims can also change over time. As the child's illness or condition changes, the nature of ACP directives can also change. Therefore, discussions should be held frequently; the timing and frequency depends on the nature and the course of the child's illness.

What is the role of the child in ACP?

Ideally, the child will participate in the discussions, depending on his/her age and level of development. Before and ACP appointment, the child and parents are asked whether or not the child will be present. In addition, the parents are asked to talk to their child about the planned discussion.

The IMPACT conversation guide provides suggestions for asking the right questions with children and teenagers. Questions used with children should always be adapted to their age and level of development.

If a child is too young or has a developmental disability and cannot express his/her wishes and preferences, the parents can explore the ACP topics with the child's perspective and best interests in mind.

How is an ACP discussion documented?

A summary of the ACP conversation is documented in the medical records at the conclusion of the process. The IMPACT documentation form can be used to structure the report; it contains a summary of the conversation and describes the care and treatment objectives. If specific treatment directives are defined, they will also be documented on the form and included in the medical records according to the procedures for the relevant care institution. Care and treatment directives must be obvious and clear to all care professionals involved. Discuss with the parents whether external healthcare professionals will also receive a copy of the documentation.

Parents receive a copy of the ACP documentation in the medical record. In addition, they will receive their own form to fill in with their

personal summary of the conversation, which they can reflect upon at home. The conversation and to be able to reflect on this at home.

What communication skills are helpful in ACP discussions?

ACP is a communicative process in which the care provider primarily takes the role of the listener. Questions about what the child and parents consider important are the central focus of the conversation. This requires probing and open questions. Adapt the questions to the child's and parents' responses. Summarise what the child or parents are saying and clarify where necessary. Acknowledge and explore emotions. Name the emotions and do not react to them with factual information.

I can see how this is making you sad/angry/worried. Please tell me more about what is making you feel like this.

Use silence during the conversation; let there be times of silence. Give open and honest information rather than false reassurances. And remember, don't give more information than seems to be needed. Do not use the computer during the discussion. If you want to take notes, please do so on the discussion form. Always maintain eye contact with the child and parents.

If child or parents don't seem to be open to discussing certain topics, explore the reasons for this reluctance.

You don't seem to want to talk about this today. That's okay, you don't need to. Can you help me understand why you prefer not to talk about this? What do you think may help you to think about this?

I know that it is hard to talk to about this, and I would like to see if I can help you to become clearer about what exactly is worrying you about the future. Can you tell me more about that?

When some questions or topics are difficult or emotional for parents, the 'wish/worry/wonder'-approach may be helpful.

I also **wish** that things keep going well for your child, but **I am afraid** that we may not be properly prepared if things turn out to be different and so, **I am wondering** if we can discuss ... together.

To clarify the relevance of looking ahead for the parents, it can be helpful to talk about 'what-if' scenarios.

At the moment, your daughter's airway problems are under control, but what if she gets a serious respiratory tract infection in the coming winter season? What do you think would be important for her then?

If the child is not present during the meeting, try to focus on the child's perspective.

How do you think your child feels about this? What is important to him/her at the moment?

Go through the discussion on your own; think about what parents may say and how you would react.

How do I apply ACP in my daily activities?

The aim is for ACP to become part of all standard care. Create an overview of children in the population you serve who might be eligible for an ACP discussion. Approach the parents of these children for a special appointment. An unexpected hospitalization, a major operation or an urgent treatment decision may be good reasons to arrange for an ACP discussion with parents, even if there was no previous need for such a conversation. At the organisational level, it is necessary to consider if ACP discussions can be integrated into care plans in your daily practice.

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Implementing Pediatric Advance Care Planning Toolkit

IMPACT is the result of a collaboration between the UMC Utrecht, the Erasmus MC and the Knowledge Center for Child Palliative Care; it was developed with the cooperation of children, parents, and professionals working in childcare and children's hospitals.

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