

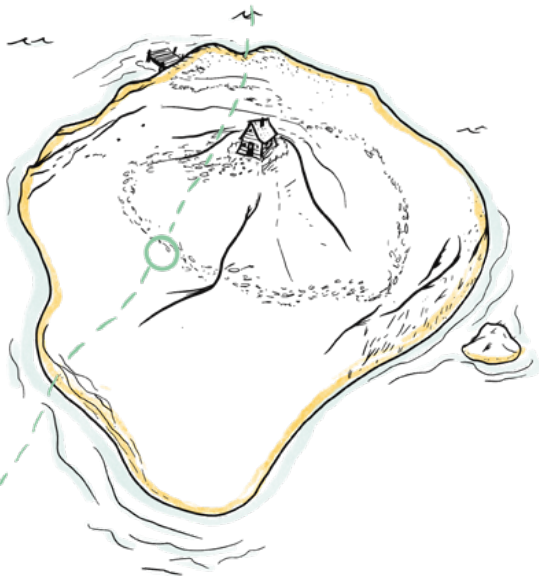


My Map

Advance Care Planning

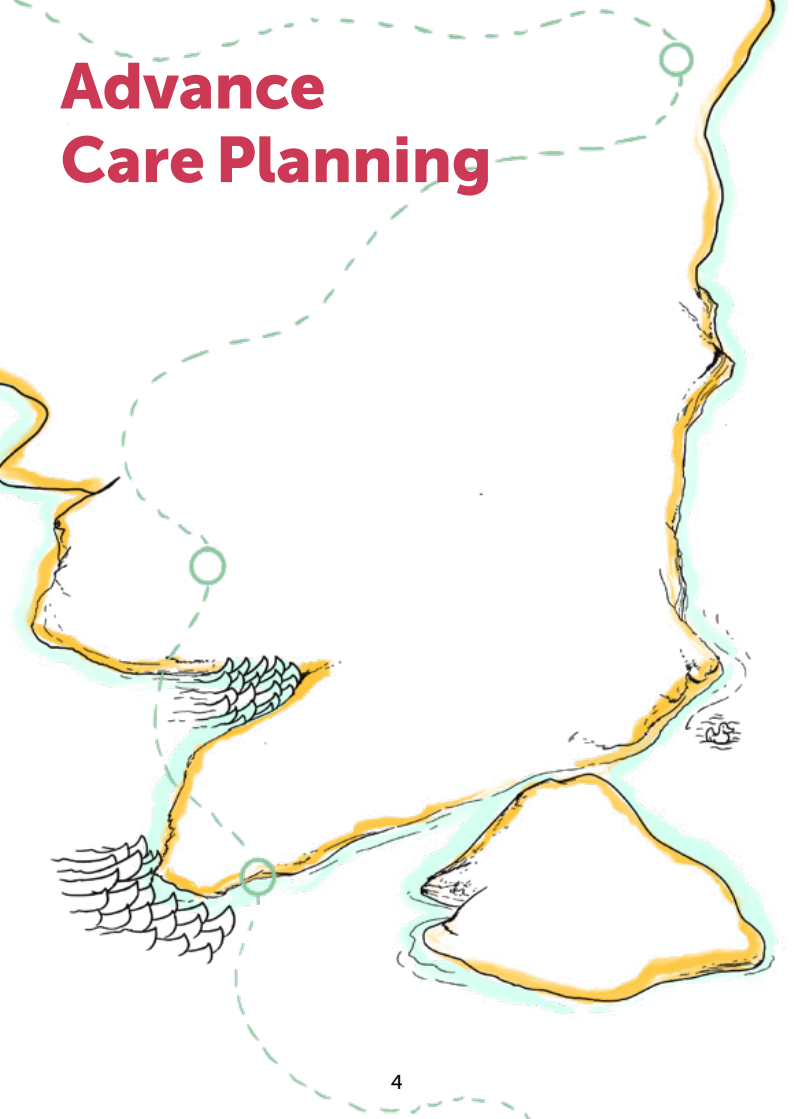
Conversation Guide And
Background Information For
Healthcare Providers In Paediatrics

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Advance Care Planning

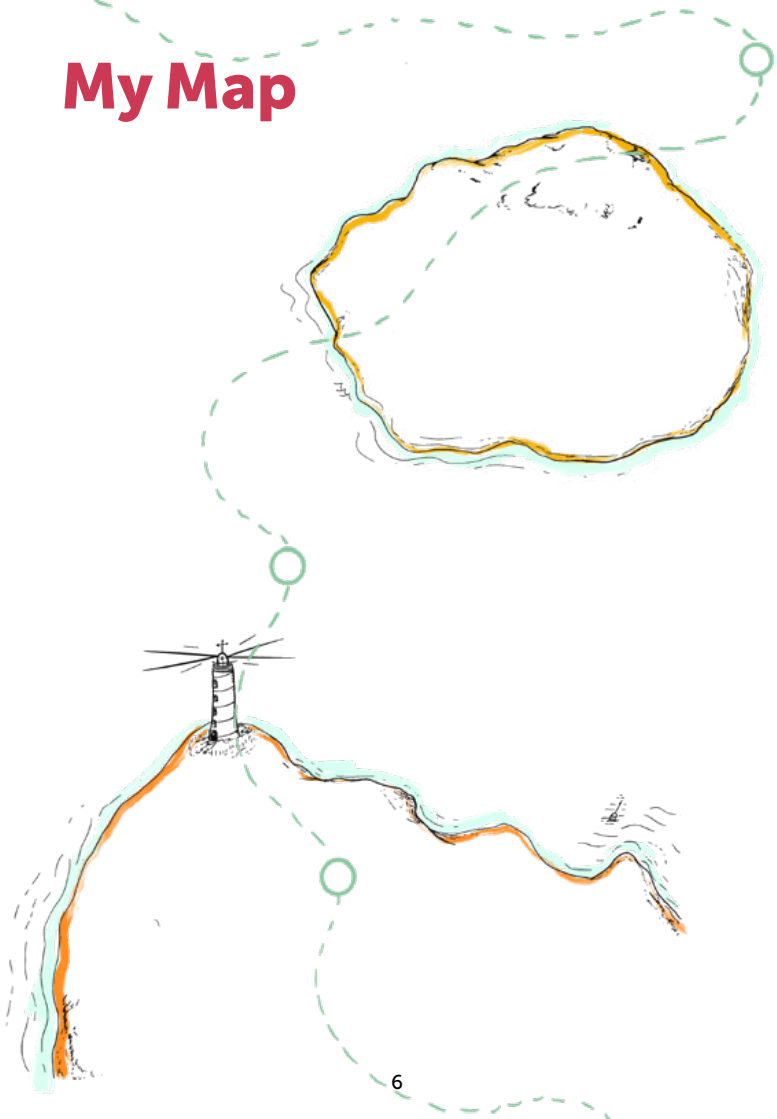


Discover, Discuss, Document And Share

In advance care planning, values, goals and preferences for future care and treatment are discussed with the child and their family. These are (1) repeatedly explored over time, (2) discussed with healthcare providers and (3) documented in the child's medical records and shared with healthcare providers in the network around the child and their family.

- Advance care planning is considered standard practice for children receiving long-term and/or intensive care.
- Advance care planning takes place in separate, consecutive meetings in addition to regular appointments and requires preparation time for the child, family and healthcare provider.
- The responsibility for initiating and organising advance care planning for an individual child lies with the primary care provider. The child, family and other healthcare providers involved can also initiate the advance care planning process themselves.
- A change in the child's condition makes it necessary to re-discuss goals and preferences for care and treatment, based on underlying values of the family and the healthcare team.

My Map



A Conversation Guide For Advance Care Planning In Paediatrics

My Map is a method for having a meaningful conversation (Figure 1). Goals and preferences for future care and treatment can be formulated together with the child and family based on the values of both the family and the healthcare team.



Figure 1. The subsequent steps in an advance care planning conversation.

Invitation for a conversation

To the child and/or parent*: We would like to invite you to discuss the things you consider important in your or [child's name]'s care and treatment. We call this 'advance care planning'. During the meeting, everyone is welcome to share what they feel is important.

General invitation

To the child and/or parent:

When you receive long-term care or a lot of care, it can change your life. All children and/or their parents who experience this are invited in for a chat. We would like to talk to you about what you find important in your/your child's care and treatment. We will talk about what is important now and in the future.

At the end of the conversation, we will decide together what we consider important and what needs to be done to achieve this.

Tailored invitation

To the parent and/or child:

We have noticed that **you/ [child's name]** has shown signs of **[medical symptoms]**. This means that over the coming **period [prognosis]**.

Pause

For this reason we would like to invite you to discuss what is important over the coming period in terms of **your/[child's name]'s** care and treatment.

At the end of the conversation, we will decide together what we consider important and what needs to be done to achieve this.

*Wherever the term "parent" is used, it can also be read as "parents" or "guardian(s)".

For the child: How would you like to be involved in the conversation about who you are, what you are going through and what you wish for?

For the parent: How can we ensure your child's voice is heard? How would you prefer to have this conversation with us? Who or what would help make that possible?

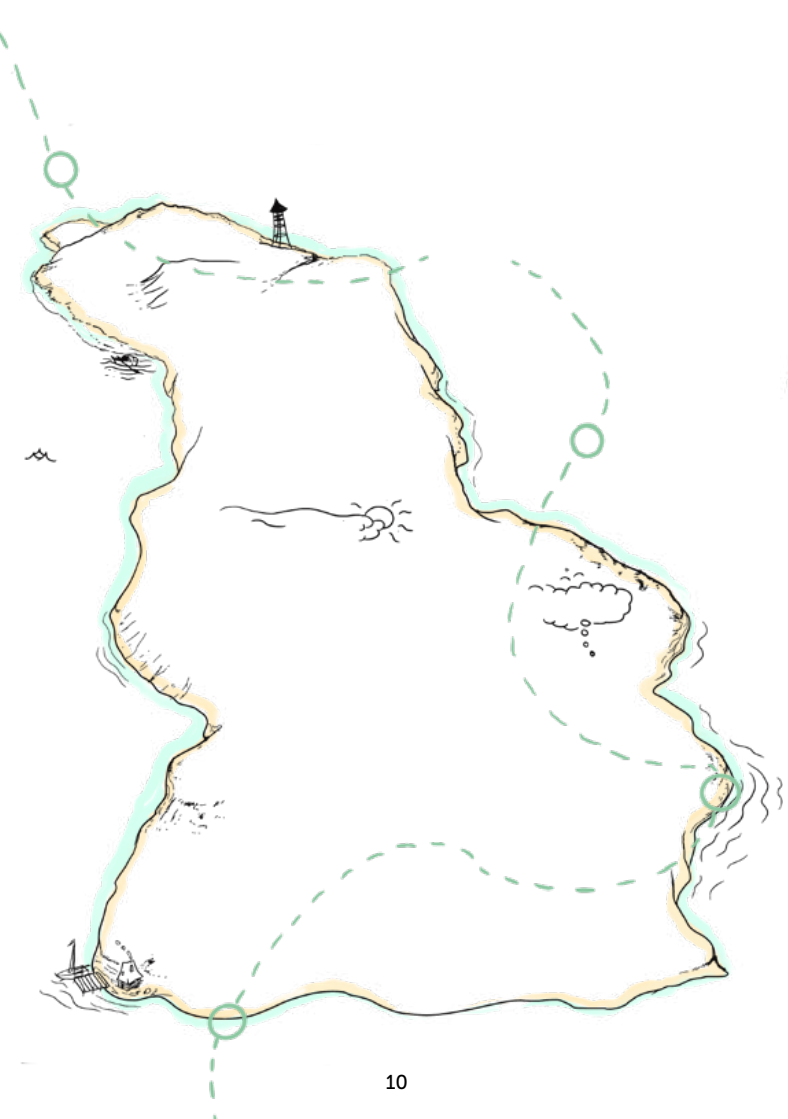
To the child and/or parent:

- We are going to talk about who you are, what you are going through and what your wishes are. This will all be discussed during the meeting. If more time is needed we will continue the conversation during a follow-up meeting.
- This conversation card, "My Map", will help you think about this beforehand. One side is for **you/[child's name]** and the other side is for you as a family. We will fill in the "Moving forward" section together. Bring the card with you to the meeting.
- What do you think about this? Sometimes children or parents prefer to talk separately, which is fine. With whom, where and when would you like to talk?

Preparation

As a healthcare provider, what do you consider to be good care and treatment for and in the best interests of the child?

If the child and/or family are not willing to have a conversation, respect that. Explore their thoughts on having a meeting to discuss matters. How do they view the meeting? What could happen during the meeting? How could it help them? What makes it difficult? What would enable them to have the chat? Offer to come back to it at a later stage.



The conversation

General introduction

To the child and/or parent:

Today we're going to talk about the things you find important in **your/ [child's name]'s** care and treatment, now and in the future.

Tailored introduction

To the parent and/or child:

Today we're going to talk about what you consider important in **your/ [name of child]'s** care and treatment. We have noticed that **you/[child's name]** has shown signs of **[medical symptoms]**. This means that over the coming period **[prognosis]**.

Pause

Together we will look at what is important for **your/[child's name]'s** care and treatment over the coming period.

We will talk about:

1. Who you are
2. What you are going through
3. What your wishes are
4. Then we will determine what you consider important for **your/[child's name]'s** care and treatment, and which things need to be done to to achieve this. We'll be talking more often. Sometimes we may want or need to change direction, in which case we will look for alternatives together. Are you comfortable with this? Do you have any questions? I will now ask you a few questions.

To the child (if possible): I will always ask you each question first and then your parents can say something afterwards.

1. Who you are

1. If I asked you to describe yourself/[child's name]?, what would you say?

To the child: What do you like to do? What is it like to be you?

To the parent: What makes [child's name] so special? What makes you proud to be their parent?

2. Can you tell me about your family?

To the child: What do you like to do with your family? What makes your mum/dad/brother/sister special?

To the parent: What do you enjoy doing together? How would you describe your family? When do you feel like a good parent?

3. What does a good day/good moment look like?

To the child: What are you doing? What makes it so enjoyable?

To the parent: What are you doing? How can you tell when [child's name] is feeling happy?

4. What is your biggest dream?

To the child: What do you want to be when you grow up? What are your other wishes for the future?

To the parent: What are your dreams for your family? What are your dreams for your child?

5. What happens on a difficult day?

To the child: How do you feel then? What helps you on a difficult day? Who or what can comfort you? What do you do then?

To the parent: How do you feel then? What helps you on a day like that?

6. What gives you strength or support?

To the child: Do you have any religious beliefs? Is there a place you go to, or someone you go to, when you need support?

To the parent: Do you have any religious beliefs? What gives you strength? Who or what gives you support?

2. What you are going through

1. Which words would you use to describe what you are going through?

To the child/parent: How do you explain what you are going through?

2. When you think about what you are going through, how do you feel?

To the child: Do you feel sad, angry, happy or afraid? What thoughts go through your mind?

To the parent: What thoughts go through your mind?

What has changed in your lives? How are you dealing with it?

3. Which things are going well in this? **To the child:**

What are your hopes for yourself? What do you hope will change?

To the parent: What are your hopes for your child? What are your hopes as a family? What are your hopes for yourself as a person?

4. What have your family and friends noticed about what you are experiencing?

To the child: What do family and friends do for you at home or elsewhere? How do you feel about that?

To the parent: To what extent do you feel supported by others? Can you share your story with others and talk to each other?

5. What keeps you awake at night?

To the child: Are you worried about anything? How do you deal with it?

To the parent: What are your concerns? What are you doing about them?

6. Do you ever think about death?

To the child: What would you like to say about this?

Who do you talk about it with?

To the parent: What would you like to say about this?

Who do you talk about it with?

7. Which questions are in your head that you have never dared to ask anyone?

To the child: Would you like to say something about this?

Who or what can help you?

To the parent: When would you like to talk about this?

Who or what can help you?

8. How do you make decisions together?

To the child: What do you think about that? Would you like to be more involved, or involved in a different way? How do you make it clear what is important to you?

To the parent: As parents, how do you experience your role in decision-making and working together? Are there others who play an important role in this? Would you like to change anything?

9. Are there any other things you would like to discuss?

To the child: Is there anything else you would like to say?

Is there anything else you would like to ask me?

To the parent: Is there anything else you would like to add?

Do you have any questions?

3. What you wish for

1. What are your wishes for today?

2. What are your wishes for the future? What would you like if things go well, and what would you like if things don't go well?

To the child and parent:

- In terms of yourself
- In terms of your family
- In terms of your care and treatment/the care and treatment of [child's name]

4. Moving forward together

1. Summary of family values, goals and preferences

To the child and parent: To clarify what is important for the coming period, I will summarise what you have just told me. I understand that you consider [values] important and that's why we are aiming for [goals, preferences]. Is that correct?

2. Summary of the healthcare provider's values, goals and preferences

To the child and parent: I know that for other children with [diagnosis], it has been important to think about [values, other treatment goals/limitations, preferences]. I would like to tell you a little about that. I would also like to tell you how I see this for you/ [child's name]. Is that okay with you?

3. Next steps

To the child and parent: We now know that you consider [values, goals, preferences] important. As the care team, we consider it important that [values, goals, preferences]. This means that we're working together towards care and treatment for you/[child's name] that focuses on [summary of shared values, goals and preferences]. To achieve this, we can outline the following: [specific follow-up actions] to be carried out by [people].

Closing the conversation

1. Documenting and sharing

We will make a report of the conversation to record our thoughts and action points as discussed today. We will send you a summary of the conversation. You can then add to or amend the summary. We will agree together what information should be shared with other healthcare providers.

2. Planning the next conversation

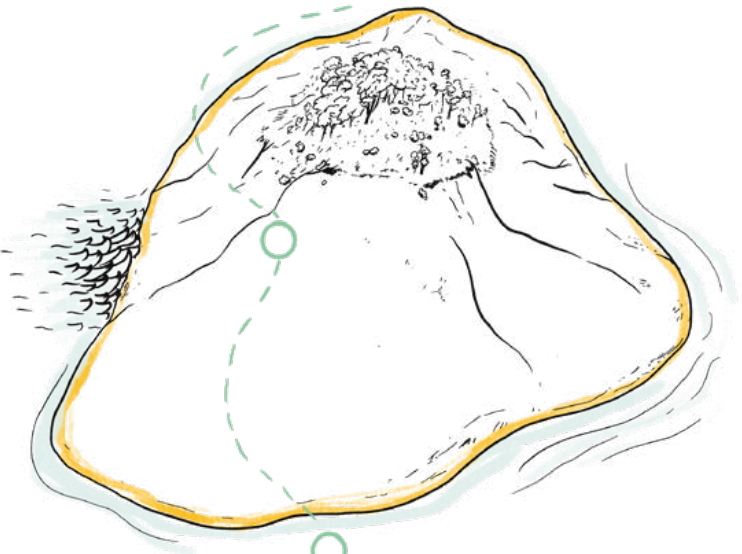
Sometimes we may want or need to change direction. That's why we will continue to have these conversations. What do you think about that? When would you like that to be? In the next conversation about [term], we will discuss [content] further.

The report consists of 1) a description of the different perspectives and underlying values of the child, family and care provider, 2) a summary of the goals and preferences for care and treatment, and 3) the specific follow-up points associated with these. Include the contents of this conversation in the Individual Care Plan.

Notes:

A series of horizontal dotted lines for writing notes.

Conversation Skills



Core Skills For Clear Communication In Advance Care Planning

Advance care planning is a communicative process and requires specific communication skills (Table 1): the ability to formulate a clear reflection of the shared understanding of the child's condition and the purpose of the conversation; responding appropriately to emotions; exploring and acknowledging the different perspectives; and figuring out a common ground for working out follow-up steps (Figure 2). The training course "Advance care planning using the IMPACT method" focuses on these communication skills.

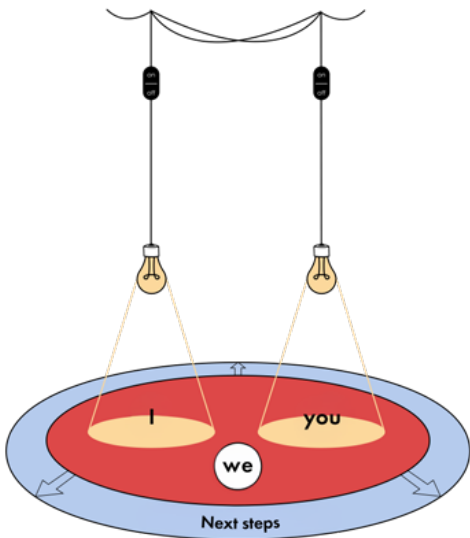


Figure 2
In the I YOU WE method, developed by Wilde Kastanje Training & Opleiding, we highlight the different perspectives of the conversation partners in the advance care planning conversation so that appropriate follow-up steps can be formulated that everyone agrees with.

Skill	Aim	Strategy	
Framing the situation	Formulating a shared understanding of the child's situation, the relevance of the conversation and the purpose of the conversation	<ul style="list-style-type: none"> • General invitation and formulation of objectives early in the illness • Tailored invitation and formulation of objectives in case of progression of the illness 	
Responding to emotions	Exploring the nature of the emotion and outlining the emotion in order to be able to continue the conversation	<ul style="list-style-type: none"> • Silence • Listening and affirming • Paraphrasing • Expressing support • Exploring 	
Exploring perspectives	Exploring the other person's perspective	<ul style="list-style-type: none"> • Open, neutral questions • Follow-up questions • Reiterating and checking the information obtained 	
Giving legitimacy to different perspectives	Recognising the perspectives of all conversation partners	<ul style="list-style-type: none"> • Summarising different perspectives and allowing them to coexist • Contributing your own expertise as one of these perspectives 	
Formulating next steps based on common ground	Based on all the information obtained during the conversation, determining the next steps together	<ul style="list-style-type: none"> • Summarising how the different perspectives relate to each other • Formulating joint goals • Specifying the next steps 	

Table 1. Core skills in advance care planning.

Examples

- “We talk to all children who receive long-term or intensive care about what is important to them.”
- “We have noticed that [child’s name] [objective findings from recent observations]. This means that [consequences for the coming period]. (Pause) That’s why we would like to talk to you about what may be important over the coming period.”

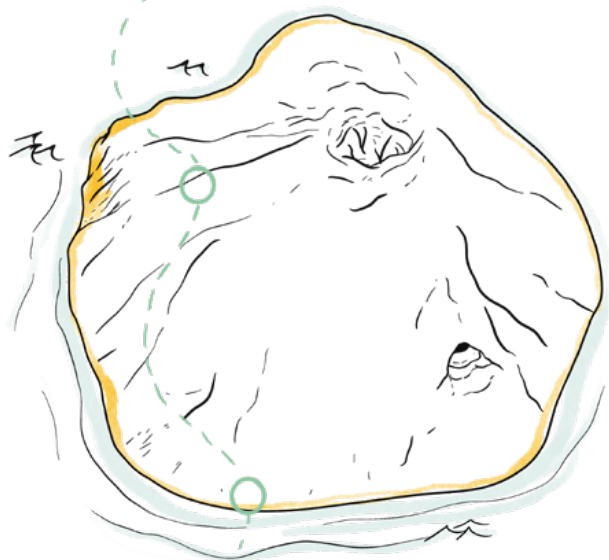
- “I see that [state objective observation or repeat words spoken].”
- “You said: [paraphrase what has just been said].”
- “I can’t imagine what this is like for you.”
- “That’s awful...”
- “[Repeat what has just been said]. Tell me more.”

- “How does this affect you? How are you feeling?”
- “Tell me more about [repeat what has been said].”
- “You said: [summarise what has been said]. Is that right?”

- “[Child’s name], you said: I think that...”
- “[Name of mother], you said: for me, it’s...”
- “[Name of father], you said: my idea about...is...”
- “As the doctor/nurse of [child’s name]/children with [child’s diagnosis] I believe/know that...”

- “[Child’s name] thinks it’s important that...”
- “For you as a parent, it’s important that...”
- “We, as the medical team, believe that...”
- “Together, we will focus on...”
- “That’s why we are going to...”

Implementation

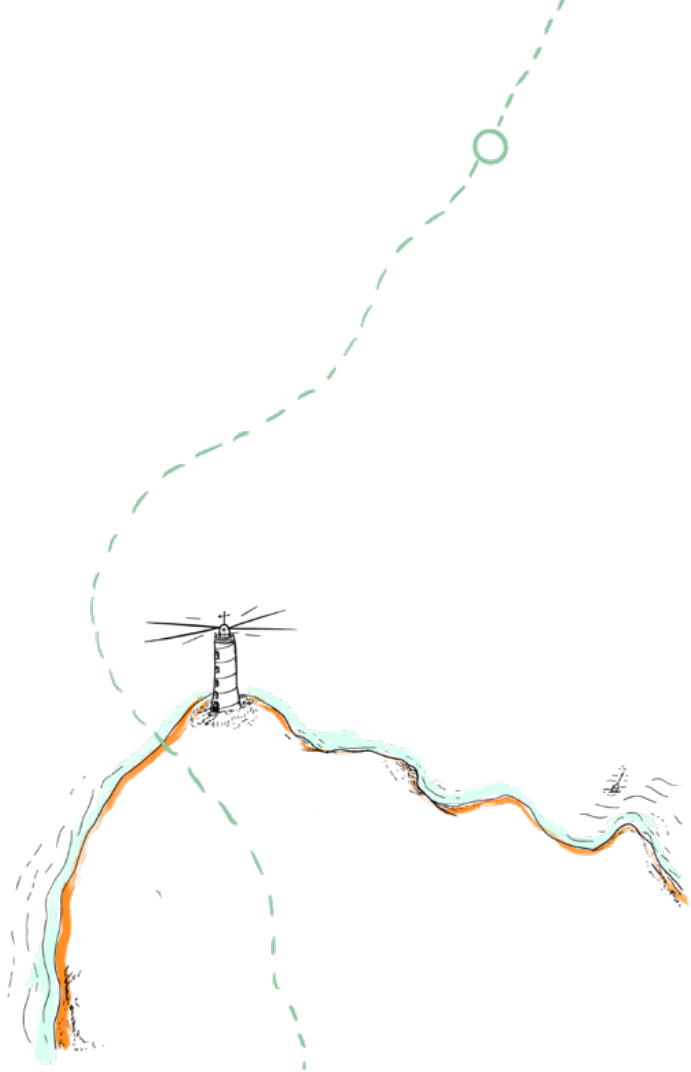


Putting Advance Care Planning Into Practice

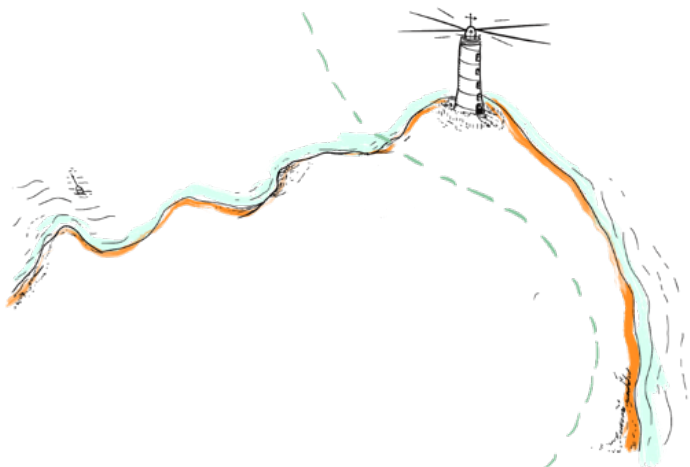
Putting advance care planning into practice can be challenging. Work with your team to decide how you want to organise this in your work setting.

- Which patients in your daily practice are eligible?
- When is a good time to invite your patients for advance care planning?
- Who will conduct the advance care planning conversations?
- How will the outcomes of advance care planning conversations be documented and shared within the care network around the patient?





Background Information



Advance Care Planning As The Foundation For Child- And Family-Centred Care

Advance care planning is an approach to child- and family-centred care. This conversation will explore the perspectives of the child, family and healthcare provider, along with their underlying values. Values are our inner motivations and determine what we consider important. Values provide guidance in making decisions. Based on our values, we can formulate goals and preferences for future care and treatment.

Concrete follow-up plans will enable us to achieve our goals and thus live according to our values. In this way, values give direction to what quality of life and quality of dying mean to each individual (Figure 3).

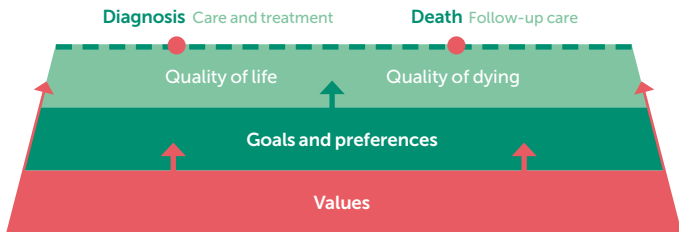


Figure 3. Values guide goals and preferences for future care and treatment.

Every individual has their own values, which may differ from or correspond with those of others. In advance care planning conversations, all perspectives are explored and acknowledged. All perspectives are valid and have a right to exist. By making all perspectives transparent, similarities and differences can be accepted by the child, family and healthcare provider. From there, follow-up steps can be taken.

By maintaining an honest and open attitude, everyone can share their perspective in confidence.

Perspectives can be shaped by hope and loss. Moving back and forth between feelings of hope and loss is a familiar process for children who receive long-term and/or intensive care and their families. Having hope does not mean that the child and family are unaware of the reality. Repeatedly checking this sense of reality with the child and family is unnecessary.

Hope keeps us going...

By integrating all perspectives into advance care planning, child- and family-centred care takes shape, from diagnosis to the end of life (Figure 4).

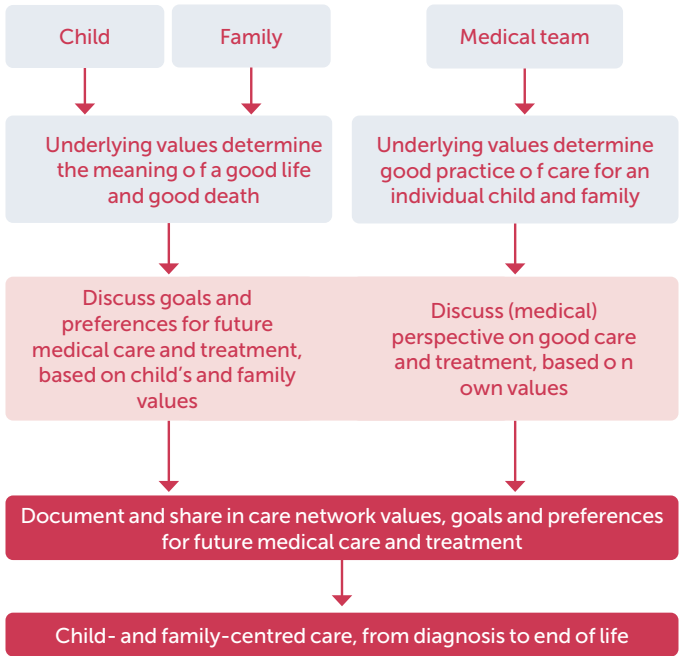
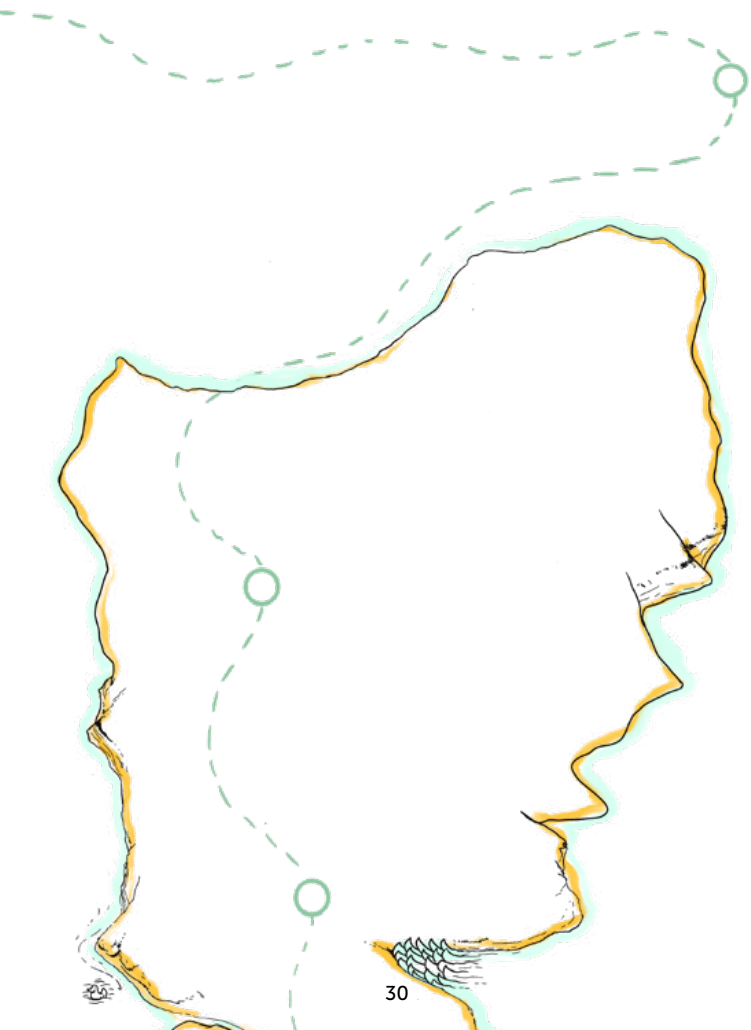


Figure 4. The perspectives of the child, family and healthcare providers form the basis for a shared understanding of goals and preferences for future care and treatment.



Want to know more?

Background information, training, literature, guidelines and materials on advance care planning can be found on these websites:



www.hetbelangrijk.nl



www.kinderpalliatief.nl/impact/over-impact



www.palliaweb.nl/richtlijnen-palliatieve-zorg/richtlijn-palliatieve-zorg-voor-kinderen

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My Map