

Conversation guide for healthcare professionals in the home situation

# A conversation with parents about meaning and existential questions



**CONNECT**

Attention to meaning and  
existential questions

# Appropriate attention for each moment

Paying attention to meaning and existential questions is part of good care and it is important that parents know that they are supported. But parents do not always have the time and energy for an in-depth conversation about meaning. Ask parents what they need. To make sure that parents feel supported, even if they have

no time for an extended conversation, the phase model below can be used. The questions in this guide can be applied to each phase. For the in-depth conversation, use the conversation structure of this guide.

## Phase 1. Offering space

### For all parents with a seriously ill child

Within the care setting, pay attention to meaning in an easily accessible manner. This normalizes the topic and allows parents to see that there is concern for their questions and needs.

*Respect the boundaries of parents; do not introduce distressing topics unless parents themselves indicate their willingness to discuss them.*

*"We often talk about how [child] is doing, but how are you doing right now?"*

## Phase 2. Informal conversation opener

### In connection with signals given by the parents themselves

It is possible to use signals that parents themselves give to initiate a conversation with them in an informal setting.

*Keep it low-threshold with respect to time and subject matter. Be aware that this conversation is probably unexpected for parents.*

*"You recently said .... How do you actually view that?"*

## Phase 3. An invitation to talk

### For parents who feel there is time for a conversation

A set time for a conversation gives you the room to go into more depth.

*Give parents as much control as possible in the conversation.*

*The objective is not to gain as much information as possible from the parents but to give the parents room to think by offering them a listening ear.*

*"Would you like to take the time to talk about what it means for you to be a part of this?"*

# 1. Preparation: prior to the conversation

## Step 1. Introduction

Explain to the parents why you would like to start a conversation with them about meaning and existential questions. Use everyday terms when doing so.

*Your child has a serious condition. This has a great impact on the life of your child but, as a parent, much in your life has changed as well. I would like to spend some time with you about what it means for you to go through this. In this talk, we could examine what the illness does to you as a person, the things that are important for you, or maybe you would like to reflect on what the illness and the future of your child means to you and your life.*

## Step 2. Explore the needs of the parents

Check whether the parents are open to a conversation. If not, agree on a time with the parents as to when you may ask them again for a talk (for example, in a month).

*Are you open to talking about what the illness of your child means for you and how you give meaning to the changes in your life?*

## Step 4. People present at the conversation

*Would you be comfortable if others were present at this conversation, such as your partner or a neighbour?*

## Step 3. Plan an appointment

Make sure you plan an adequate amount of time to have the conversation with the parents (a minimum of 60 minutes). Explore the possibilities for a location in which the parents can talk undisturbed.

*I suggest that we take enough time for this talk so that we have all the time we need to focus on what is important to you. What would be a good time and place for us to have a quiet conversation?*

## Step 5. Preparing the parents

Give the parents the conversation cards.

*The conversation cards can be used to help you prepare yourself for this conversation on your own or with a neighbour as to what the illness of your child means for you and which questions this raises for you.*

## 2. Assume a good form of listening



### Good for the conversation

Make sure that both of you are comfortable, on the same level. Make sure that there are no objects between the two of you that could distract either one of you. You could also choose to talk with the parents during a quiet activity, such as a walk.



### Calm

Make sure that you are calm and that the nearby vicinity is peaceful; speak calmly, take your time, and restrict distractions during the conversation.



### Dealing with emotions

Do not be afraid of the parents' emotions but try not to provoke them unnecessarily either.



### Silence

Do not be afraid of moments of silence. Sometimes parents need time to think about a question.



### No solutions

Do not offer solutions or suggestions. Let the parents decide for themselves whether they are willing to work on a solution at this time.



### No assumptions

Do not tell parents how they will feel about something but ask them openly what something means to them.



### Comfort

Avoid physical contact. Rather, comfort the parents by giving them room for emotions. Only if it is truly necessary, you could put your hand on a shoulder.



### Seek support

If you have doubts about the conversation, or are affected by the conversation, seek support from colleagues, the regional manager of your Regional Network Integrated Childcare (NIK) or a spiritual counsellor in your region.

### 3. Opening the conversation

#### Step 1. Introduction

Make the purpose of the conversation clear. Emphasize that the parents are free to express their thoughts, fears and concerns and that this conversation is separate from the conversations about the treatment of their child.

*Today we will talk about what it means for you as a parent to deal with your child's serious illness or uncertain future.*

*We are doing this because we want to take good care of not only your child but you as a parent as well. We want to support you so you can keep going, and to help you with existential questions.*

*This is an open conversation where you can share your experiences, cares and questions. This conversation has no direct impact on the care of your child.*

#### Step 2. Getting to know one another

##### Assessing the state of the parents

*How are you doing right now?  
Do you ever talk with people about how you are doing? What does that do for you?  
Do you feel you have the time to discuss this with me today?*

#### Step 3. Giving attention to questions that parents have

##### Questions parents already have

*To prepare for this conversation, you received a set of conversation cards to go through on your own. Were there any questions that made you pause, or that you would like to look at more closely in this conversation?*

##### Priorities

*There are many different topics to discuss regarding meaning. There is a list of themes on the following page. Discuss with the parents which topics will be dealt with.*

- **Restrict the conversation to a few themes.**
- **Give the parents as much control as possible and stress that it is up to them to answer questions.**

## Parenthood

What does it mean to be a father or mother?



## Identity

Who are you?  
Who do you want to be?



## Objectives & expectations

What do you want to achieve?



## Those around you and the outside world

Who are around you?



## Being in control & letting go

What do you hold on to, what do you let go of?



## Meaning & existential questions

## Convictions & uncertainties

What is it like to (not) know?



## Healthcare needs

What do you need?



## Decisions & the future

What do care decisions mean to you?



## 4. Having the conversation: going into depth

### 4.1 Identity

#### Self-reflection

*Do you often reflect on how the illness of [name of child] has changed you as a person? Are you the person you would like to be right now? Why or why not?  
How do you hope others see you?  
What gives you and your life value?*

#### Room for self-development

*Right now, is there enough room for you to be yourself?  
What would you need to get more attention for who you are or want to be?*

#### Relationship with family

*Has the relationship with your partner/family changed? Do you experience enough room for being together as a family? What do you need to make that possible?*

### 4.2 Parenthood

#### Being a father/mother

*What does it mean for you to be a father/mother?  
Is it different than you had expected?  
What are the great or difficult moments?  
Does the way you are a parent of [name of child] fit you?*

#### Relationship with child

*What kind of child is [name of child]?  
What makes you proud of [name of child]?  
What have you learned from [name of child]?*

#### Caring for the child

*What is it like to be responsible for the (medical) care of [name of child]?  
Do you feel able you to keep up with those tasks? What do you need to be able to fulfil this role?*

### 4.3 Objectives & expectations

#### Values

*What is important to you?  
What is it that makes you get out of bed?*

#### Embracing objectives and expectations

*Do you have goals, expectations or dreams for yourself and your family?  
What do you hope to learn yet in your lifetime? What would you look back on with fond memories at the end of your life?*

#### Letting go of objectives and expectations

*Which expectations have you been forced to let go?  
Which goals have you been forced to let go?  
How did that make you feel?  
What do you need to deal with letting go of goals and expectations?*

## 4.4 Those around you

### Explore the network

*Do you feel supported by those around you, or do you often feel lonely? Who can you count on? Can you share your concerns? Who do you miss when sharing your concerns?*

### Dealing with the outside world

*Do you ever feel different from those around you? What is it like to encounter families with healthy children? How do you deal with those emotions?*

### Using support

*What question would you like to hear from those around you?  
What do you need to receive more support from those around you?*

## 4.5 Being in control & powerlessness

### Being in control

*What gives you something to hold on to? Do you feel you are in control of your life? Why or why not?*

### Losing control

*What have you been forced to let go? Do you ever feel you are losing control? When? What is it feel like for you not to be in control? Do you ever feel powerless?*

### Regaining control

*What helps you to conquer the feeling of powerlessness? Are there other things that you feel you have control over and have added value?*

## 4.6 Convictions & uncertainties

### Existential questions

*Are there questions that concern you? Which question would you like an answer to? What place do these questions have in your life?*

### Dealing with (un)certainties

*What is it like to deal with what you know or do not know about the future of [name of child]? How important is it for you to know or not know what the future is like?*

### Philosophies of life

*Do you have a life vision or faith that is important to you? How does this play a role in dealing with the illness of your child? What helps you or does not help you in this?*



## 4.7 Decisions

### Exploring values

*What do you feel is important for [name of child]? What do you feel is important for the time that you have together? Do you feel that there are enough people listening to what you feel is important for [name of child]?*

### Uncertain future

*Do you often think about the future of [name of child]? When you think about the future of [name of child], what does that do to you? Are you ever concerned that [name of child] will not get better or could die? How does it feel to talk about this? Do you feel a need to share your concerns about the future? If so, what would be helpful for you?*

### Healthcare decisions

*Do the choices that have been made up until now for [name of child] fit in with what is important to you? At which times would you have liked to make a different decision?*

## 4.8 Healthcare needs

### Cares

*What are you concerned about?  
What makes you lie awake at night?  
Do you dare to express your concerns to others? What do you need at this time?*

### Support

*Do you feel that you reflect enough on your own needs?  
What would help you at this time?  
What would make you feel supported?  
Who or what kind of person do you need for this?*

## 5. Concluding the conversation

### 5.1 Summarizing the conversation

#### Feedback from the caregiver

*Thank you for this valuable conversation and your openness in talking about this. What I mainly take away from this conversation is [mention about 3 key points]*

#### Ask about the parents' experiences

*What was it like to talk about this? Are there things from this conversation that you will take with you?*

### 5.2 Inventory needs

Ask whether the parents, based on this conversation, feel a need for a follow-up conversation with you or with a professional.

*Would you like to talk about this again, or would you like to speak with someone who could counsel you professionally in what it means for you to experience this?*

#### Make appointments

Plan a possible follow-up conversation or help the parents to find a good conversation partner by putting them in contact with the network leader of the NIK in your region.

#### Follow-up

Ask the parents again several days or weeks after the conversation what the conversation did for them and whether there are needs that must be addressed.

*How did you feel about our talk? Are there still questions or topics that are troubling you or that you would like to talk about?*

## Colophon

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