

Explanation and assistance for healthcare professionals

# Supporting parents in finding meaning and with their existential questions



**CONNECT**

Attention to meaning and  
existential questions

## Introduction

This information folder contains an explanation and handouts about supporting parents in finding meaning and with existential questions when they are confronted with a serious illness and/or the possible death of their child. This is based on four central questions.

1. What is meaning?
2. What are the signs that parents need assistance regarding meaning and existential questions?
3. How do I have a conversation with parents about meaning?
4. How do I make sure that parents are given appropriate support?

This information folder is part of the CONNECT toolkit on meaning and existential questions by parents of seriously ill children in the home situation and is intended for healthcare professionals who provide medical/nursing care in the home situation.

## Summary

### 1. What is meaning?

- Meaning and existential questions are related to who we are as people, what is important to us, what motivates us and how we relate to the world around us.
- Meaning becomes visible at a time of major changes, such as a confrontation with a serious illness.

### 2. What are the signs that parents need assistance with respect to meaning and existential questions?

- Parents will not be so quick to raise questions about meaning.
- Use the procedure (p. 8) as a tool for determining if an exploratory conversation and/or structural support is desired.
- Meaning often focuses on parents' experiences with parenthood, identity, objectives, control, dealing with the world, dealing with (un)certainities about the future and healthcare decisions.

### 3. Making it a subject of conversation

- In a conversation about meaning, it is essential that you remain calm and listen without offering solutions or being prejudiced.
- A conversation can consist of an introduction, prioritising topics for the conversation, going into more detail on several topics, making an inventory of further support and rounding off the conversation.

### 4. Referrals

- If you suspect more support for the parents is needed, please contact the coordinator of your regional NIK for appropriate counselling.

## 1. What is meaning?

*We discuss 'meaning' in this folder. However, the terms meaning, existential questions and spirituality may all be used interchangeably.*

Meaning can be described as the process in which people give meaning to who they themselves are, life and important events that they undergo. It is a process that is always present; all of our actions, the decisions we take and the way we experience the world – all contribute to developing an interpretation or meaning, whether or not we are aware of it.

This has to do with questions such as: Who are you? Who or what is important to you? What drives you? How do you look at the world around you? What gives you and your life value?

*“Giving meaning often becomes visible when something happens to you. This could be something beautiful or something bad, but it comes to the surface at turning points in your life. And, of course, there is everyday meaning as well. The things that make you happy, such as going running or walking or reading a book..”*

*(Conversation with a spiritual counsellor)*

## Why is giving meaning important to parents of seriously ill children?

When parents are faced with a child's serious illness or death, their world can be turned upside down in such a way that they are faced with questions dealing with meaning.

*After the diagnosis, I felt as though I was living in another world. You know, time just goes on, but it's as if you yourself are standing still.*

*(Conversation with a parent)*

The future that they saw for themselves and their child changes completely. It may feel as though all meaning has disappeared from their lives, and it takes a long time and a lot of trouble to give their lives new meaning again.

Because many parents play a major role in the medical care of their child, their lives change in many different ways.

Their work, their social lives and personal development change because of the care for their child. This may lead to existential questions.

At the same time, the illness could also contribute to meaning in a positive way. Spending valuable time with their child, or the development that parents go through during the illness, finding new purpose for their lives and their child – all of this may empower parents.

### Why is providing parents with support in meaning important?

Paying attention to meaning belongs with caring for seriously ill children with an uncertain future. The objective of paediatric palliative care is to offer children and their relatives as much quality of life as possible and to ease their physical, psychosocial and spiritual suffering. This means that healthcare professionals have a responsibility to guide not only children but the family around the child as well through this difficult time as best they can.

### Paying attention to meaning may:

- help parents to make the period during and after the illness of their child as valuable as possible;
- prevent parents from breaking down because they are no longer able to provide the care for their child;
- prevent conflicts between parents and/ or between parents and healthcare professionals.

### For whom is this conversation intended?

A conversation about meaning is an added value to all parents who are dealing with a child with a serious illness and an uncertain future, even if the child's life expectancy is not immediately restricted.

### Where can I find more information about meaning?

For adult patients, there is the Guideline “*Existential & spiritual aspects in palliative care.*” This is available through Palliaweb.nl. You could also search for questions about meaning by parents of seriously ill children with a spiritual counsellor affiliated with your Regional Network Integrated Childcare (NIK) region.

*“It would have helped so much if someone had asked us: How are you doing? And what does going through this do to you?”*

*(Conversation with a parent)*

## 2. What are the signs that parents need assistance regarding meaning and existential questions?

### Who starts the conversation about meaning?

Parents will not be so quick to raise questions about meaning. Often they are so busy with caring for their child that they lose sight of their own needs. Furthermore, parents do not always know that they can raise questions about meaning. And yet, the way which parents experience their child's illness and give meaning to it is very important for the way in which they keep going. This is why it is important that you as healthcare professional pay attention to meaning but also always check with them whether or not they feel there is room to discuss this.

### What do parents' questions about meaning and existential questions look like in practice?

Parents' questions about meaning or existential questions often occur around a number of themes. These are discussed briefly in order to give you ways on how to recognize them in practice.

#### Identity

When parents provide medical care over a longer period of time, they often scale back their personal, social and professional lives. In the long term, this may lead to existential questions. Supporting parents in continuing to develop themselves in addition to their role of parent/caretaker without failing either of the parties may help them.

*"I put my own life on hold so that I could take care of him. But now I am wondering who I am besides that care. I no longer want to live after him but next to him."*

#### Parenthood

The way in which parents fill their role as father or mother changes because of the illness of their child. For many parents, parenthood consists of a double role in which they are father or mother as well as caregiver for their child. Sometimes this causes parents to look for a way that they can combine these roles and enjoy the nearness of their child.

*"I just want to be a father and for him to be a child, a teenager who does teenage things, but the fear of the illness goes so deep that it is really hard at times. I still get stuck in that role of protector."*

#### Objectives and expectations

If families are confronted with a serious illness or possible death, old dreams and expectations about the future must often be let go. Concern that a possible death will remove any future that their child may have plays a major role although parents often find it difficult to express this. However, after a period of loss and letting go, many parents (sometimes with counselling) are able to find new purpose and new meaning for themselves and their family that usually

focus on the here and now and experiencing valuable moments within their family.

*“I danced with her then, in the room. And I cried my heart out because she would never be able to walk. But then I said: we are going to give you the best life there is.”*

### Being in control and letting go

Many parents feel that they are forced to give up control during the course of the illness. They feel powerless because the illness has invaded their lives without being able to control it. They also feel that they are not always involved enough in decisions that are taken.

*“You just have no control. I put a perfectly healthy child to bed with her rucksack all ready for her in the hallway, and the next day she was in a coma. You can plan as much as you want, but life goes its own way.”*

### Those around you and the outside world

While caring for a seriously ill child, a major part of the world the parents experience is focused on the sick child. But parents are also a part of the world around them. Sometimes they can draw support from this, but it can also lead to a feeling of loneliness

or lack of understanding because they get the feeling that the world around them no longer connects with what they are going through. In addition, the confrontation with ‘healthy’ families may emphasise their own ‘otherness’.

*“Sometimes I sit in the park with friends who are all occupied with their healthy children and then I feel alone. They have no idea what it is like for us to be going through this.”*

### Dealing with (un)certainities and convictions

During the illness, parents must deal with a lot of certainties as well as uncertainties about the illness and future perspective of their child. They must adapt to this. Would you rather know or not know? Are you still able to hope if the illness is so serious? What does it mean if you must deal with a possible death? Some parents find their philosophy of life important.

*“The knowledge is always in the back of your mind. You see blue skies but there is always a dark cloud on the horizon, so you always feel there is something coming but you don’t know when. And that becomes very tense. So that tenseness becomes a part of you.”*

## Healthcare decisions

What parents see as meaningful for themselves and for their child can have a major influence on the decisions that they make during the illness of their child. This is why, when making well-considered choices about the treatment of their child, it is very important to know what is important for the parents.

*“As parents, you continue to struggle with questions. The first question: why is this happening? And then: did I do the right thing? And I think that, as a parent, I have found my peace with this, because I know that my child has made me a better mother. And we have done our best for him.”*

### What are the signals that parents have questions about meaning?

Given the way in which the lives of families change due to the serious illness of their child, almost all parents will have questions about meaning to some degree.

For some parents, these questions will play a small role and will not lead to immediate problems and, in other cases, questions about meaning can lead to care needs that require structural support.

For the identification of signals, you can use the indications in the adjoining box.

A conversation with an involved healthcare professional is an important first step to allow parents to reflect on their own

meaning. In many cases, this alone provides some relief and parents are better able to find their way. But in some cases parents benefit from support by a professional who has the knowledge and resources to provide parents with proper support.

If you suspect that more support for the parents is needed, please contact the coordinator of your regional NIK for appropriate counselling.

**It is advisable to begin an exploratory conversation about meaning if one of the following situations applies ...**

- If one or both parents have scaled back long-term on their working lives;
- If the child cannot communicate well;
- If the care intensity for parents is more than two hours daily;
- If parents have asked questions about the future perspective of the child;
- If participation in daily life has significantly altered for parents because of the care process;
- If parents have no safety net for transferring the care for the child if the care load becomes too much for them;
- If the course of the illness is erratic with unpredictable crises.

### 3. How do I have a conversation with parents about meaning?

#### An appropriate conversation for any moment

Paying attention to meaning and existential questions is part of good care and it is important that parents know that they are supported. Throughout the course of the illness, parents go through different periods in which they, to a greater or lesser degree, experience space to consider their own needs and reflect on what the illness of their child means for them.

To make sure that parents feel supported, even if they have no time for an extended conversation, it is important to connect with the needs that parents have at that time.

The phase model to the right helps us to pay attention to parents' meaning, from very low-threshold attention to structural support. By paying attention to meaning in an early stage, parents know that you as a healthcare professional are concerned for their needs and that they can talk about them.

In this, it is important to coordinate with the multi-disciplinary teams and parents who opens the conversation about meaning.

#### Phase 1. Offering space

*For all parents with a seriously ill child*

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

*We often talk about [child], 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.

*You recently said ... how do you actually see that?*

#### Phase 3. An invitation to talk

*For parents who feel there is room for a conversation*

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

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

#### Phase 4. Referrals

When structural support is desired.



### What is the purpose of a conversation about meaning and existential questions?

A conversation about meaning is meant to offer parents the opportunity to contemplate the questions and thoughts they have about meaning and to explore with them whether they have care needs that concern meaning. By listening – and listening without judgement – you give them room to explore for themselves what is important to them.

As a healthcare professional, you do not assume the role of a therapist. This is why a referral for more complex questions is important.

### Proper attention to meaning, for you, means:



Focusing on the needs of parents. The purpose is to offer a listening ear.



Normalizing meaning as a subject in your care relationship, so that parents feel there is room to discuss their needs.



Give parents as much control as possible in the conversation. Emphasise that it is up to them if they want to answer questions and respect the parents' boundaries.



Coordinate within the team who will keep an eye on the parents' needs with respect to meaning.

### How do I invite parents for a conversation?

Use the phase model to make meaning a subject of conversation in an appropriate manner.

Let the parent know that you would like to take the time to discuss how the parents are doing, and what the illness and the care tasks do to them.

Always ask if the parents are open to a conversation about this and ask them if they feel you are the right conversation partner for this.

The conversation guide by CONNECT provides example sentences to make this a topic for conversation.

### How can I prepare parents for a conversation?

Prepare parents by providing them with the conversation cards so that they, if they so desire, can already think about the topics before the conversation.

### How can I prepare myself for a conversation?

It is important to be well-prepared before starting the conversation. Read the conversation guide beforehand and consider which wording best suits the parents with whom you want to converse, and how you can make sure that there are as few distractions as possible during the conversation.

### Where and how can I let the conversation take place?

Ask the parents where they would like to meet and at which times they could have a conversation with as few disturbances as possible. Many parents will choose their home, but other locations are also possible. It is important that the parents are comfortable and that you are equal partners in the conversation.

### Which communication skills help with a conversation about meaning?

In a conversation about meaning, it is important that you as healthcare professional assume a chiefly listening attitude. You need not give answers or solutions to the parents but should be there for them mainly by listening and continuing to ask questions. The following tips can help create a constructive atmosphere for a conversation.



#### Calm

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 themselves decide whether they are willing to collaborate 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.

### How will the conversation go?

The conversation consists of the following parts. The conversation guide will help you to fill in the details.

- Introduction
- Explore the parents' existing questions
- Prioritize themes for the conversation
- Detail a selection of meaning themes:
  - Identity
  - Parenthood
  - Objectives and expectations
  - Those around you
  - Being in control and powerlessness
  - Convictions and uncertainties
  - Healthcare decisions
- Inventory needs for further support
- Conclusion and agreements

## 4. After the conversation

When you have spoken with the parents about meaning, it is important to ensure that the parents feel supported after the conversation as well, and to assess whether any follow-up is needed.

Ask the parents again several days or even weeks after the conversation about how the conversation went for them and whether they feel the need to speak with you or someone else about it.

### How do I refer conversations with parents?

Within the framework of the domains of a child's life in the Medical Child Care Collaboration (in Dutch MKS) and the Individual Care Plan (in Dutch IZP), there are possibilities for having these conversations with parents. Having a conversation about meaning is part of the inventory of care or the assessment that a paediatric nurse tends to do. This is a part of the nursing process. It also questions the domain of spirituality. The care plan details which existential questions are current for the family and which support could be helpful in this. In the file, the paediatric nurse keeps track of how much time the questioning has taken and which parts required extra time, for example, having a conversation about meaning. Discuss what the possibilities are within your organization with your team leader. Additionally, follow the developments within the toolbox Assistance with the Referral Process for Paediatric Care (Handreiking Indicatieproces Kindzorg, HIK).

### Which support is available?

In some cases, a single conversation with you or a fellow healthcare professional is sufficient. Sometimes it is advisable to plan one or more follow-up conversations in which you further explore the topics that were left unexplored in the first conversation, but it is also possible that the parents' questions take so much time in the conversation or are so complex that a referral to a professional supporter is advisable. Various options are available for this.

**Spiritual counsellors** focus mainly on conversations about meaning and spirituality. They try to be a good listener and help parents to reflect on their own life story.

**Grief and loss counsellors** can engage with parents in a conversation about experiences of hope, loss and grief during the illness and after death. They support parents in searching for an appropriate way to deal with it and to be able to bear the loss better.

**Psychologists** can offer psychosocial support. They differ from spiritual counsellors and grief/loss counsellors in that they offer support with a therapeutic objective and are therefore less focused on meaning and more on the psychosocial functioning of the parents.

### When should I refer?

Determine together with your team or the coordinator of your regional NIK whether referral to a professional counsellor or psychologist is required.

### How do I know to whom I should refer a parent?

The support that is most appropriate depends on the individual parent(s).

The network coordinator of the Network Integrated Childcare (Netwerk Integrale Kindzorg, NIK) in your region knows the various professionals that work in your neighbourhood and, together with the parent, can search for a support person. The most recent information and contact details of the network coordinator in your region can be found at:

<https://www.kinderpalliatief.nl/ondersteuning/regionale-netwerken-nik>

## Colophon

CONNECT Information Flyer, August 2022 version

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CONNECT is a project by Centre of Expertise in Palliative Care Utrecht (in Dutch: Expertisecentrum Palliatieve Zorg Utrecht), UMC Utrecht, in collaboration with the Dutch Centre of Expertise for Children's Palliative Care (Kenniscentrum Kinderpalliatieve Zorg) and the Regional Network Integrated Childcare – for families with a seriously ill child (Netwerk Integrale Kindzorg (NIK)) – Limburg and Southeast Brabant.

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*The development of this product was financed by ZonMw*