

Conversation guide for professionals:

conversation with child and parents



Step 1: Introduction

1.1 Make the goal of the conversation clear

To the child: Today we are going to talk about what you think is important in your life and for your future. Because when you have a serious illness, it affects your daily life. That's why we – the doctors and nurses – want to talk with you and your parents to make sure that the care and treatment that you get is right for you. During our conversation, I will first ask you some questions. And then your parents can say something if they want to. Is that alright with you?

Step 2: Exploration

To the child: To get to know you better, I would like to get a better idea about how you think about all sorts of things. To help me to do this, I would like to ask you and your parents a series of questions. Is this alright with you?

2.1 Exploring identity

To the child: If I were to ask you 'who is [child's name],' what would you say? What sort of things do you like doing? Do you have brothers and sisters? Do you have friends or nice classmates at school? What is your favourite subject at school? And what do you do at the weekend / on vacation?

To the parents: As a parent, how would you describe [child's name]? What do you think is important in [child's name]'s life?

2.2 Exploring illness experience

To the child: What do you notice about your illness? Is there anything that you think about a lot? What do you think the illness does to you? Does it mean you have to do some things differently, or can you do everything normally? Do you know any other children who have the same illness? What do you think about the things these children tell you? Who do you talk to about your illness? Would you like to tell me something about it, or would you rather only talk about it with this person?

To the parents: What does [child's name]'s disease or condition mean to you as parents? What does it mean for your family?

2.3 Exploring expectations for the future

To the child: What do you think your future/the next few weeks/months will be like? What do you want to be when you are grown up? What do you dream about? What do you hope for? What else do you hope for? And if that doesn't work out, what else would you hope for?

To the parents: As parents, what are your expectations for [child's name]'s future? What are your goals? As parents, what do you hope for? And what else do you hope for?

Step 2: Exploration

2.4 Exploring role of the parents

To the child: Do you get along well with your parents? What do your parents do for you? When are they the nicest to you? Do you and your parents usually agree, or do you sometimes argue? When do you need your parents most? What do you like doing with your parents?

To the parents: What sort of a parent are you to [child's name]? What sort of a parent would you like to be to [child's name]?

2.5 Exploring views on life

To the child: What do you do when you want to be comforted? Do you speak to someone or go to a special place? Do you believe in God? Do you ever go to church or to the mosque? Do you like it there?

To the parents: As parents, do you have a particular believe system? What makes you feel supported in your life?

2.6 Exploring fears and worries about the future

To the child: Do you worry about things that could happen in the future? What are you afraid of? Do you ever get angry?

To the parents: As parents, do you have concerns about {child's name}'s future? And what about yourselves/yourself? Are you afraid of anything?

2.7 Further information about expectations for the future (if necessary)

To the child: From my experience as a doctor for children with [name of disease], I know that [state expectation for future] could play a role. What do you think about this information?

To the parents: As parents, what are your thoughts about this?

2.8 Exploring goals and preferences for care

To the child: What would you like us to do for you? What should we do for you when you are with us in the hospital? And what shouldn't we do? What do you think is important about the care and treatment that you are getting?

To the parents: In your opinion, as parents, what is the goal of the care and treatment of [child's name]?

2.9 Exploring goals and preferences for care at differing stages of illness (if necessary)

To the child: We hope it won't happen, but just say things started to get slowly worse with you, what would you like to do then? What would you hope for in that case? If things suddenly got much worse with you, what would you like to do then? What would you hope for if that happened? Have you ever thought about the types of treatment that you would like to have, or wouldn't like to have? Do you ever talk about this with other people? Can you tell me what you would say to them? The time could come when we think or we notice that you haven't got much longer to live. What would you like us to do then? Where would you like to be then? And who would you like to be with you?

To the parents: As parents, what would you consider important if [child's name] became very ill? What would you hope for in that case? What would you consider important if [child's name] became acutely ill? And what about yourselves/yourself? What would you consider to be important if we thought that your child did not have long to live? What would you hope for in that case?

2.10 Summary of exploration

To the child: From what you are saying, I can hear that you think [summarize desired care goals] is/are important. And that is why I think that the doctors and nurses should aim to [goals of care]. That means that [explain care]. What do you think about it?

To the parents: And you, as parents?

Step 3: Decision-making

To the child: From what you have just told me, I now know better what you and your parents think is important. We have now come to the part of the conversation, where we look at the sort of medical goals that fit your goals and preferences. If necessary, we can also make the decisions about your care and treatment. In any case, we can make an agreement about what the main goals of your care and treatment should be.

3.1 Designate decision-making roles

To the child: Who decides what sort of care and treatment you should get? What do you think about it? Who would you like to make the decisions about your care and treatment?

To the parents: As parents, what is your role in making decisions about the care and treatment of [child's name]

3.2 Establish care goals

To the child: What do you think would be the best thing that our care and treatment could do for you?

To the parents: And in your opinion, as parents? What steps do you think should be taken?

3.3 Further information about goals of care (if necessary)

To the child: I know that other children with the same disease thought it was important that.... I would like to explain to you why I think that it would be good if we thought about.... Is that alright with you?

3.4 Documenting

To the child: What would you like to write in your medical record? What sort of things should other people know? And who should know?

To the parents: As parents, what do you think should be put down in your child's case notes?

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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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