

PEDIATRIC SERIOUS ILLNESS CONVERSATION GUIDE

Parent Version

OPEN THE CONVERSATION

I'd like to talk with you today about where things are with your child's illness and do some thinking in advance about what is important to you and your family. **Would this be ok**?

ASSESS ILLNESS UNDERSTANDING

What is your **understanding** of where things are now with your child's illness? Looking to the future, what are your **hopes** about your child's health? What are your biggest **worries**?

SHARE UNDERSTANDING

Would it be okay if I share my understanding of where things are with your child's illness?
Uncertainty: It can be difficult to predict what will happen and when. I hope that

will continue to live well for a long time and I worry that he/she could get sick quickly

OR
 Function: I hear you are hoping for _____ and I worry that the decline we have seen is going to continue.

ALIGN AND ASSESS SUPPORTS

I wish we didn't have to think/worry about this.

and think it's important to prepare for that possibility.

In times of difficulty (or when making decisions), where do you find your support?

EXPLORE WHAT'S IMPORTANT

If your child's health worsens, what is most **important** for your child and for your family?

What **abilities** are so important to your child's life that you can't imagine your child living without them?

Are there any conditions or states that you would **not find acceptable** for your child? How much have you talked about these issues with your **family or clinicians**?

CLOSE THE CONVERSATION

I've heard you say that _____ is very **important** to your family. Keeping that in mind, and what we know about your child's illness, **I recommend** that we_____.

How does this plan **seem** to you?

DOCUMENT YOUR CONVERSATION AND COMMUNICATE WITH KEY CLINICIANS

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PEDIATRIC SERIOUS ILLNESS CONVERSATION GUIDE

Adolescent/Young Adult Version

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I'd like to talk with you today about where things are with your illness and do some thinking in advance about what is important to you. **Would this be ok**?

ASSESS ILLNESS UNDERSTANDING

What is **your sense** of where things are now with your illness?

Looking to the future, what are your **hopes** about your health?

What are your biggest **worries**?

SHARE UNDERSTANDING

Would it be okay if I share my understanding of where things are with your illness?

 <u>Uncertainty:</u> It can be difficult to predict what will happen with your illness and when. I hope you will continue to live well for a long time and I worry that you could get sick quickly and think it's important to prepare for that possibility.

OR

• **Function:** I hear you are **hoping** for ______ and I **worry** that the decline we have seen is going to continue.

ALIGN AND ASSESS SUPPORTS

I **wish** we didn't have to think/worry about this.

Who (or what) **helps** you when life feels hard?

EXPLORE WHAT'S IMPORTANT

If you get sicker, what is **most important** to you?

How much do your **family or clinicians** know about your priorities and wishes?

Have you thought about **who you would want** to make medical decisions for you if you could not?

CLOSE THE CONVERSATION

I've heard you say that ______is really **important to you**. Keeping that in mind, and what we know about your illness, **I recommend** that we_____.

How does this plan **seem** to you?

DOCUMENT YOUR CONVERSATION AND COMMUNICATE WITH KEY CLINICIANS

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