

Guidelines for the Conversations(s)

With Your Child's Palliative Care Team and/or

Your Child's Most Trusted Medical Provider

who you want to have help you with decision-making and understanding what it is you want for your child

I. The first meeting with the palliative care provider

Questions from you to them. *You ask, they respond, you listen –*

Here are some things you may wish to ask at your first palliative care meeting”

So, what is palliative care anyway?

How is palliative care different than social work or child life specialist work?”

When is it appropriate for me to ask you for help?

When I need to get a hold of you, how do I do that?

How will you work with my child's other specialists?

II. In the first meeting and/or over subsequent meetings with the team

Things to discuss with them: *You share, they listen.*

Here are some things that the palliative care team will be interested in hearing from you about you and your child.

Here is what we want you to know about my child and my family, in order for you to help us make the best plan of care.

Here is how my child communicates with me, how I know what s/he is feeling and thinking.

Here is how my child communicates with *others*, to let them know what s/he is feeling and thinking.

Here is how *I* like to communicate about my child's care (directly, practically, sensitively, etc.

Here is what I understand about my child's illness ...

Here is what I think may happen in the future ...

Given what I understand and know, here is what I HOPE FOR for my child and my family. ...

Given what I understand and know, here is what matters most to me for my child and my family. . . .

Here is how much information I would like about what is likely ahead with the illness. ...

If my child's health condition worsens, here is what are our most important goals for my child and my family. ...

My biggest fears and worries about the future, given my child's condition are

If difficult medical decisions lie ahead, these are the people that I think can help me and that I would like to involve (friends? Family members? Spiritual leader? Therapist?)....

To me, quality of life for my child means

These are the abilities that are so important to my child and make up her quality of life. If s/he can't do them anymore because of the illness, then it may influence how I think about medical decisions.

These are the specific conditions or physical states that I would not find acceptable for my child to be in.