Talking about death

Talking with family and friends

Family and friends are part of all big life events and passages. They can be a great comfort and support. Some are better at it than others. Sometimes family and friends disappear when you would like them to be there. At times they are too much involved. They may make you sad or mad when they say the wrong things. Not everyone will know how to behave with you or your child. Some people feel helpless and afraid.

Family & friends may not know how to give emotional support

You can't do this alone and really, people want to support you. When they are clumsy it is because they don't know what to say or do. It is sad, but true, that how you talk to others about your child can make a difference in the emotional support you get.

The scripts below, like those in other sections, are just ideas to start you thinking.

* When you are asked about your child

You can say honestly that:

"______'s condition is getting worse There seems little anyone can do to improve her condition. We are focussing our attention now on giving as much quality as we can to the rest of her life. We have decided to... Our plans are..."

You may not want to answer questions about your child. It is O.K. to say: "Thanks for asking but I don't want to talk about it now."

* If family or friends challenge your decisions

You can say something like:

"It will help me most if you accept what I say and can support us in what we are doing." You may not want to have to give the same hard message over and over. You can ask a family member or friend to be the contact person for your family. Let it be known that anyone can call that person for updates.

If people give unwanted advice about what you should do

You can say:

"I know you care about me. Thank you for that. I don't have energy for "shoulds". I am doing what I can and what we feel is best".

Or, "Thank you for caring. You have been great. Remember, though, we are at the bedside all of everyday. We talk to the health team all the time. We trust them and are quite sure we are doing what is best. It just adds to our stress to feel that you don't trust our judgement."

If people are strained with you

People often feel that they mustn't show emotions. They want to cry but stop themselves. They are about to tell you something funny but stop themselves. Explain how you feel about this. Most people are afraid to upset you:

"Don't stop your tears. It allows me to cry with you... and don't feel that you have to say some magic words to make me feel better – there aren't any. We can just cry and hug each other."

"I don't want you to stop yourself from telling me funny stories. We always laugh together. A laugh is as healing as a cry."

"Please don't avoid mentioning _____, you know it helps me to talk about _____ and her friends. Please let's do that."

• Sometimes friends and family disappear if they think they have upset you by saying the wrong thing. Reassure that you feel comforted and supported by them. "I know my crying made you feel bad. I just want you to know, I cried because you made me feel comfortable enough to do it. Thanks for your visit."

Friends and family will certainly want to help

Let them help – it makes them feel a whole lot better.

They will ask about things they can do for you. The more help you get, the easier it is to be your best for your children.

* Keep a list of specific things people can do that will be helpful.

If you have a contact person give her the list too so she can make suggestions. For example:

- Please can you do my grocery shop this week? I will have a list for you.
- Please can you cut the grass.
- Please take my other kids to see the movie all the other kids are going to see.
- Could you be here for a few hours so I can go and get school supplies for my other kids?
- Can you take my son to soccer each week when you go.
- Can you find a tactful way to tell my sister I don't want her to talk about God's role in this when she visits?
- It would be lovely to have a batch of homemade cookies.
- Bring dinner and join us on Thursday it would be so nice to have an evening with our good friends.
- Please help me organize a birthday party for

* Guidelines for asking for help:

- You don't have to explain why you need what you are asking for.
- Give a few options from which people can choose.
- Be specific and give clear instructions, e.g., "keep the dog on the leash, even in the open field".
- Try to ask people for something they can do. Aunt J. may be useless at childminding, but wonderful on casseroles.
- Be ready for some people to say no when you ask. This has something to do with their life rather than with you.

* Be aware that you may be expecting more than some members of your family can give

- If you don't usually talk about feelings in your family, you may not be able to share important things now.
- When we are on edge and needy we want those closest to understand and support us. This understanding may not happen, even between close partners.

Parent Voice:

Every time my partner (my sick child's stepfather) saw me cry he would say the same thing 'What? What's it now?' So what was it now? It wasn't what was now. It was what was yesterday and the day before and forever. I just had to accept that he couldn't help with talk or touch when I was upset. He was showing his love and support by taking over all the household chores, carpools and pet care. He did this without me asking it of him. That was what he could do, and he did it, every day for two months. But it took a friend to point this out to me!

End note:

An Agency of the Provincial Health Services Authority

Keep talking to family and friends so that they learn how to support you. But don't judge others badly if they just can't be there in the way you want them to. So few people can do this just right! You may all have to love each other and forgive each other as best you can.

This pamphlet is the result of a collaboration between British Columbia's Children's Hospital and Canuck Place Children's Hospice

Canuck Place Children's Hospice

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Some people do not cope at all well with stress. They are not at their best when you need them most.

Try not to judge those you love too harshly. "If he really cared for me he would know" He may really care for you and still not know when you need holding or when you need to be alone.