

**YOU HAVE
CANCER.**

Now you have to
tell your children.



Helping Children Cope when a Parent has Terminal Cancer



wellspring family programming
**When a Parent
Has Cancer**



Having cancer as a parent can leave people feeling overwhelmed and frightened, more so if the cancer is terminal (not curable). End-of-life realities are difficult for everyone, and can feel almost impossible to comprehend when you are a parent who has young children who depend on you.

Parents often are faced with many questions and concerns about how to talk about the nature of their cancer with their children, and the possibility of them dying from it.

Please note that the purpose of this booklet is to give you some starting points in thinking about how to communicate with, and provide support to, children on the very difficult topic of a parent's pending or likely death. The content is meant to complement, but not replace, expert advisement you may need from your medical team or health care professionals such as WellSpring's Family Counsellor. It also does not include information about children grief and bereavement, which is a specialty health care area and for which most communities have experts and special programming.

In addition to the general information on communication with children provided here, please call your Wellspring centre for more information about programs or professionals within Wellspring, or in the community, that may support you and your children.

Here are some questions that might arise for you:



“I am still hopeful that some kind of cure will be found or even for a miracle. Why would I want to share with my child that my cancer is not expected to be cured?”

Many parents fear that explaining that they have a cancer that cannot be cured means giving up hope. The idea is not to give up hope but, rather, to reframe hope. Rather than focusing on cure, a child can begin to understand that the cancer remains with their parent and they are hoping to live with it as long and as well as they can. Parents even may say that they are still hoping for a miracle or a cure but not that they are planning on it.

Sharing the reality of the illness with your child ensures that they are kept up-to-date and are better prepared when you become more ill. It also allows them to feel trust as they move forward because they are being told the truth.

Open communication allows children to explore their feelings about a parent’s illness and ask questions about end of life. For many children, that supports healthy expression of feelings and less anxiety because their questions are answered and they are informed of what to expect.

“Why should I talk to my children about dying?”

Children who are informed know better what to expect, feel more prepared, and have less chance of having “unfinished business” such as not getting to talk to you about something or do something for you.

They may feel upset and confused if they are not informed ahead of time that a parent’s death is a possibility.

Parents are guides for children as they go through life. Although it is perfectly natural to want to protect them from such a difficult experience, the reality that death will, or is likely to, happen cannot be changed.

If the possibility of death is not talked about, it sends a message that death is too terrible a topic to speak about and that we are not open to hearing their concerns or answering their questions.

Without open communication, children can even be left with the thought that they were not told because they themselves were to blame. Children may be prone to “magical thinking” which is imagining that something they did or said caused the parent to have cancer or to die from it. This is a worrisome possibility for children to bear, and communicating with children can help to avoid it.

“When should I start talking to my child about the nature of my illness and about dying?”

Ideally, children are informed right from the initial diagnosis about their parents' cancer, and what is expected. This allows them to digest the information slowly over time.

Sometimes children have been protected from this information until a parent's illness has progressed and is terminal. That can reduce the amount of time children have to understand the circumstance and be supported in their reactions.

Parents can start by explaining about the cancer, what type it is and what goals are of treatment.

In some cases, parents are already involved with Palliative Care and it can be explained that the goals of any treatment are for comfort and to help the parent cope with the cancer, but not to cure it or shrink it.

“When should a child be told that their parent will die?”

Children will need to be prepared for their parent dying when things are changing and when a parent is showing signs that the illness is progressing.

Parents often wait for the “right time” to talk about this. But, there really isn't a right time. The timing often needs to be created by the parent as opposed to waiting for the “right time” to emerge.

“How do I talk to my child about the fact that I am dying?”

Find a quiet time for you to meet with your children. Include your partner or another close adult.

Ask the children what they understand about your cancer. Ask them what they have noticed or what they understand about how you have been acting or how you look. Their responses will give you a good sense of where you need to start sharing additional information.

Help them understand the current status of your cancer and treatment, and if the goals of treatment have changed. For example, “You know how before I was having chemotherapy and hoping it would get rid of the cancer? Now, we have found out that it didn't work and that the cancer is growing. We don't have another way to keep it from growing.”

You can explain that lots of people do survive cancer but that although you tried very hard, that isn't going to be possible for you and that you expect that you will die from this.



Especially for younger children, you can explain your circumstance in simple terms. For example, “No one knows exactly when people will die. Usually, with cancer, as the cancer gets worse it makes it hard for your body to work. After a while, it will stop working. When my body stops working that will mean that I will die.”

Try to use the words “die” or “death” rather than “pass on” “go to sleep” or “go home” or other phrases that are used to describe death and dying. It is often used in attempt to “soften” the news but is often confusing especially to young children.

Babies, toddlers and young children do not understand that death is permanent. Although you may have explained a parent will die, they might still indicate that they believe a parent is getting better. As children get older (school age and teens) they are better able to understand that death is permanent.

You can explain to children that when someone dies it means . . .

- The person is no longer with us in our lives because their body has stopped working.
- Their heart doesn't beat and they don't breathe anymore. They don't feel anything.
- We will no longer see someone after they have died.
- When someone dies it is not like going away or going on vacation nor is it like sleeping.
- We can still have memories about the person or imagine them in our head or feel love for them. We might even dream about them.
- We don't have to stop loving them when they die.

If your family holds a religious belief about what happens to people after they die, it would be at this point you can have a discussion about what you believe.

“How should I expect my child to react to the news that I am dying and how can we best support them?”

It is normal for children to initially be shocked or not believe that a parent will really die.

They might act or say things that indicate they still believe the parent is going to get better in spite of being told otherwise.

Children may be angry -- angry at the doctors, angry at you, angry at the world. It may be directed at you and it might be very hard to manage this since you are likely having such an emotional time yourself. Make sure you have support to help you process what is happening. Both anger and disbelief are very normal reactions to the news that a parent will die.

They may become very sad, cry and become “clingy”, showing signs that they do not want to be separated from those that they love. Other children may get quiet, retreat and keep to themselves.

Give children time to process the news and sort through their feelings. Later, double check what they heard by asking “What did you understand about what Mommy told you about earlier?” You may need to go over it many times, before you feel like it has really been absorbed. Children will frequently ask the same questions again, often hoping for a different answer or to find out that they have misunderstood and that you really will be ok.

Children may be worried about who will help to take care of them. This is especially so if the ill parent is a single parent. Talk to them about who will take care of them and involve that person in the conversation. Let the children talk, if they are able, about the feelings they have about being cared for by someone other than you.

They may wonder about what happens if their well parent (or designated caregiver) gets sick too. It helps if you have discussed secondary arrangements about what would happen so you can best address this with your child.

There are some things that children need regardless of how old they are. All children benefit from:

- Opportunities to spend time with the ill parent when desired
- Reassurance that they are still loved even if their parent can't spend as much time or be with them as much
- Maintenance of routines and rules as much as possible
- Explanation of what is happening and what to expect
- Encouragement to talk about feelings and ask questions
- Knowing who they can talk with at home, at school and in the community.



When a parent is actively dying

- Children can be given the option to be present or not.
- Explain what to expect to see before they go in.
- Explain what is happening to the parent's body. It may be beneficial to ask a doctor or nurse to help with the explanation.
- Ask your child if there is anything they would like to say or do before their parent dies.
- If your child is reluctant to see their parent, tell them that you can bring a picture to them or say something on their behalf.
- If your child has chosen to not attend and the ill parent is away from home, try to keep your children with a trusted adult at home where they are most comfortable and safe.
- It is not advised that children "keep vigil" 24 hours a day at their parents' side but, rather, visit with breaks in between.

After a parent has died

- When a parent dies, children may cry, become angry or even laugh. There is no right way to react.
- Children may benefit from having a moment with the parent after they have died. Often children will decline to do this if they have not seen the parent during the process of dying.
- Children will vary in the needs following the death – some may need to be alone, others may feel clingy and in need of physical closeness.
- Encourage their connection with friends.
- Children should be given every opportunity to be involved in rituals following death such as funeral or religious rites.
- Children are known to "re-grieve" as they mature in a way that they were unable to when they were younger.

Support for both child and family is available in every community. The Family Counsellor at Wellspring can facilitate referral to appropriate agencies to help. Please call your local Wellspring centre.



wellspring.ca/familyprogramming

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