

cancer answers

Cancer Answers is a series of free public lectures, presented by *Cancer Care Nova Scotia*, on a variety of cancer-related topics. The lectures, delivered by cancer experts, are designed to raise awareness and educate participants about issues related to prevention, screening, early diagnosis, treatment, survivorship and palliative care.

Following each lecture, the presentations are posted on the *Cancer Care Nova Scotia* website.



Talking to Children about Cancer: When a Parent or Grandparent is Sick

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Cancer Answers Public Lecture

What are we going to discuss?

- Review a few research findings
- **Questions Parents Often Need Help With**
 - Why do I need to tell my children?
 - What do I need to consider when talking to them?
 - What do I actually say?
 - Should my child be seeing a health professional?
- Example

What we Know

- Parents struggle with having to tell their children about the cancer.

(Helseth et al 2005, Barnes et al 2003)

- Parents want help with the timing of telling their children, wording & the amount of information they should provide.

(Stiffler et al 2008, Helseth et al 2005, Barnes 2003)

- Even if children are not told of the illness they soon become aware of changes in atmosphere at home & in their parent's health. (Semple & McCance 2010)
- Children suspect that something is wrong even before they are told the diagnosis. (Forrest et al 2006)

- Parent perspectives are different from the child's or adolescent's, particularly if the child is young.
- Adolescents rate themselves as being more distressed than how their parents rated them.
- Adolescents may have more difficulty coping than younger children.

- Children & adolescents report that their distress declines over time. (parents not aware).
- Awareness of cancer as a life threatening illness existed even among the youngest children interviewed. (age 6)
- Children have more potential to understand complex concepts of illness than we ever thought.

Ways to Improve Learning about the Breast Cancer Diagnosis

- Being able to talk to the doctor directly
- Knowing ASAP that something is wrong
- Being treated as an adult
- Not having the information sugar coated
- Being able to talk with other teens in the same situation

(Adolescents girls) Fitch & Abrasmson 07

Providing children & teens with information about the cancer situation actually helped lower anxiety.

(Eaton, 2008, Beal et al, 2004)

Why do I need to tell my children?

Why don't Parents want to tell their Children?

- want to protect their kids from worry
- causes a lot of anxiety & stress
- don't have all the information
- can't give definite answers
- don't think they will understand
- **afraid they will ask the hard question**
 'Are you going to die?'

Why tell the Children?

- they pick up that something is not right
- uncertainty & the unknown can cause great anxiety
- **informing children of what is going on (at a level they can understand) decreases their anxiety**
- not 'if' they hear from someone else, but 'when'

Why tell the Children?

- If you are usually open & honest with your children, shouldn't change how you do things now.
- Cancer is a family affair. Children can feel betrayed, excluded & lose trust when they learn that you have been keeping information from them. Can create far more distress & mistrust.

Why tell the Children?

- Younger kids may not understand what is happening, but we are learning that it can be important to the children when they get older to know that they were aware & involved in their parent's or grandparent's illness.

What do I need to consider when talking to my children?

What to consider ...

- Tell your children as soon as you are able, before they hear from someone else.
- Tell all your children together.

What to consider ...

- If possible parents/guardians should be the ones telling their children what is happening.
- Don't forget the phone.

What to consider ...

- There is never going to be a right time, a good time to talk about things. Need to just do it.
- You don't have to have everything figured out....
 - ‘I don't know but I will try to find out’
 - ‘I don't really understand that myself’

What to consider ...

- Use time frames that are meaningful to your children.
 - ...finish the strong medicine by Xmas
 - ...probably won't be feeling better until you are ready to grade

What to consider ...

- Use the word 'cancer'.
- Address the 'die' question.

What to consider ...

- Explain treatment.
- Use the medical words.
- Tell children the plan for all: sick parent, healthy parent & the children.
- Keep conversations with children short.

What to consider ...

- Younger kids may become glued to you for a while.
- Older kids will probably need to escape to some of their normal.
- Tell them who else you are going to tell & who they can go to for questions.

What to consider ...

- ‘Mommy (Grammy) is feeling sad about all this right now, so if you have questions, come & ask me. I will tell you when it is OK to talk to her about things.’
- Give direction to the children as to whether the cancer is a secret in the family or can be shared.

What to consider ...

- Give your child 'permission' to talk to another adult.

'Some kids find it helpful to talk to an adult other than their parent about how things are going, how they are feeling. If you do, & they have any questions, I would be happy to explain what is happening. We would not talk about what you talk about.'

What to consider ...

- Don't provide new info just before kids are to go to bed or school.
- Don't whisper (implies secrets).

What to consider ...

- Inform school. Provide guidance. 'If you see changes, if you have any concerns, please call me. I don't want anyone talking with my children without checking with us first.'
- Surprises can generate fear. Try to eliminate them as much as possible.

What to consider ...

- Remind children that nothing they or anyone else said, did or felt made Daddy have cancer. It isn't anyone's fault.
- Remind your children that you can't catch cancer.
- Always offer your child options of what they could do.

What to consider ...

- ‘If you hear anything different than what we have told you, come talk to us, we know best what is going on’.
- ‘We will have a check-in every few weeks or so just to see how everyone is doing. If you have questions before that, be sure and ask them.’

What to consider ...

- ‘If anything changes, we will let you know’
(But then, you need to keep that promise).
- Keep you children up to date when things change.
- Include your child, even when young, it seems to be important as they get older.

What to consider ...teens

- Hard to get them all together to talk. Keep explanations similar.
- Don't force them to listen to or have to keep hearing information over & over.
- May want specifics of the disease. May want to learn about it (helps them feel in control).

What to consider ...teens

- Respect their bedroom as a private place.
- Teens will usually cope with parent illness as they usually cope with other stress.
- Don't force them to share their feelings with you.

What to consider ...teens

- If you have discussed the dying issue openly, more likely to trust that you are not keeping things from them.
- Don't put expectations on them to explain things to others.
- They will go to the net. Find some respectable websites you can suggest.

What to consider ...teens

- Your teens will understand the impact of a cancer diagnosis better than other age groups.
- Don't expect your children to be able to concentrate as well as before.

What do you actually say?

Explaining Cancer to Children Under <2

- Infant/toddler may understand that something is amiss, but no matter what you say, they can't understand or grasp what is happening.
- keep their routine
- give them extra loving
- try to keep different caregivers to a minimum

Explaining to Toddlers (2½-5)

‘Part of mommy’s body is sick. It is called cancer. The doctors have to get the sick part out of Mommy to get her better again.’

‘Cancer is a kind of sick. There are bad cells (little pieces) in the body that aren’t supposed to be there & it can make you (very) sick if you don’t get it out’.

Young School Age (5-8)

‘The body is made up of cells. Cells work to help keep the body working.

Sometimes the good cells become sick (or bad) & they begin to hurt the good cells & hurt the body.

The cells that turn bad are called cancer. If you have cancer you need to stop the bad cells from growing or they will hurt your body’.

Explaining Cancer

‘Often the cancer cells stick together & form a lump called a tumor.

Mommy has a lump of these cells, a tumor, in her breast’.

Explaining Cancer

Older School Age (9 & up)

‘The body is made up of millions of tiny cells, so small you need a microscope to see them. When healthy, they work hard & well to keep your body running smoothly. When they get old, they die & are replaced with new cells to do the same job.

Sometimes something goes wrong & the cells start growing too quickly or they

Explaining Cancer

Older School age (9 & up)

change & stop working like they should.

They can crowd out good cells.

When cells don't work like they are suppose to, it is called cancer. Cancer can lead to big problems for the body. It can stop the body from working properly. If you don't stop the cancer it can cause so much harm that you can die'.

Explaining to Teens

- certainly use all the medical words
- Do they want to speak to a health professional to better understand the disease?
- Keep discussions short for those who don't want to talk about it.

'If we need to update you because something has changed, I will keep it short & to the point'.

Explaining Cancer

‘There are lots of different kinds of cancers. Even if 2 people have the same kind of cancer, it doesn’t mean it will act the same in both people. So you can’t compare one person’s cancer to another.’

Explaining Cancer

‘Daddy has cancer in his blood. Cancer in the blood is called leukemia. There are different kinds of leukemia. Daddy’s is called acute myeloid leukemia or AML. There are different categories of AML. I wanted you to know that because they are all lumped together when you read about them & some of the information may not apply to Daddy’s cancer’.

Explaining Cancer

‘Mommy has cancer in the place near her tummy where the food turns into things that she needs for her body. It is called colon cancer. If you forget the name of that you can just say she has cancer in her tummy.’

Addressing the Dying Question

‘There is no reason to think that I am going to die. The doctors think I am going to be fine. No one is thinking that I am going to die.

If anything ever changes, I will let you know.’

Addressing the Dying Question

‘There are different kinds of cancers. As you know, some are bad & people do die from them. But for many people, treatment (medicine) kills the cancer & the cancer gets cured or it goes away for many years. Right now, we are not sure exactly where things stand for me. When we know, we will tell you.’

Explaining Recurrence

‘Sometimes a person gets cancer & it goes away & then it comes back. This is what has happened to me. For some people, they get more treatment & they get better & never get sick again. Sometimes, even though the person has tried everything, the cancer doesn’t go away. If this happens, some people can live with the cancer for years, but you don’t get better ’.

Explaining Treatment

‘It is not good for the cancer to stay in the body. It can grow & cause problems.’

‘There are different kinds of ways to get the cancer out or to kill the cancer.’

‘The best way for the doctors to get my kind of cancer out is for them to cut it out. This is called surgery.’

Explaining Treatment

‘The best way to kill the cancer in me is to have a very strong medicine called chemotherapy. It will kill the cancer. Because it is so strong it will likely also make me feel sick or tired, or have a sore mouth. These might happen for a while & it may be uncomfortable, but it is more important that I get the cancer out of me.’

Explaining Treatment

‘The best way to kill the cancer in me is to have radiation. This is a way to kill the cancer. Radiation is like a laser beam going thru my skin. It goes in & kills the cancer. It can make me tired and but I need to have this to kill the cancer.’

Explaining Treatment

‘With the kind of cancer I have, I have to have surgery. The doctors will cut off part of my breast. Then to make sure the cancer doesn’t come back, I am going to get radiation. I probably won’t be finished all this until after Christmas, maybe not until your birthday.’

**Should my child be seeing a
health professional?**

Should my child be seeing a health professional?

- Parents can underestimate distress.
- Children may not necessarily express their distress.
- Many children experience a lot of distress.
- Parents sometimes believe that younger children don't 'get' what is going on.
- Children report that their distress declines over time.

Should my child be seeing a health professional?

- Are you noticing changes?
 - sleeping
 - bad nightmares
 - eating
 - school
 - socializing
 - anger
 - anxiety
 - physical
- Pre-existing issues, challenges

Seeing a health professional?

- Are you talking openly & honestly about what is happening (including the 'die' discussion), so child feels informed & would be comfortable asking questions?
- Have you got worries that your child is struggling?
- Is your child asking to see someone?
- Have you asked them if they want to talk to someone?

Should my child be seeing a health professional?

- Majority of children do not see a counselor when their parent is sick.
- If you have any concerns or gut feelings, would encourage you to have them assessed.
- Resources

Example of Possible Discussion

You know daddy hasn't been feeling well & that he has been having some problems. Well, we have found out what is wrong with daddy.

Daddy has something in his head (brain) that shouldn't be there. We are hoping very much that it isn't serious, but it could be serious. We won't know until daddy has an operation to see what it is.

We have found out about Daddy's operation & what is wrong. Daddy is very sick. Daddy has an illness called cancer. Cancer means that Daddy has something in his body that has mutated or morphed into something bad & it needs to come out so it doesn't get bigger & cause problems.

The cancer is in Daddy's brain (head). When someone has cancer in their brain, it is called a brain tumor.

Daddy is doing OK after his operation. He is a bit sleepy and has a big bandage on his head but he is talking and feeling better all the time. He is getting better all the time. You can come & see him tonight, or stay here with Aunt Sue...or maybe call him in the morning?

When we know more about the operation & the cancer, we will talk to you.

We have found out more about Dad's cancer.

The doctors took out as much of the cancer as they could without hurting daddy's brain.

Now daddy is going to get some more treatment to try to keep the cancer from coming back.

In a few sleeps Daddy is going to start to get some very strong medicine called chemotherapy.

OR

In a few sleeps Daddy is going to start to have a treatment called radiation. Radiation is like a laser beam that goes in the head & goes to the exact place where the cancer was, & the radiation will zap the cancer.

The doctors hope the chemotherapy, the strong medicine (RT) will kill any cancer that may be left in daddy's head.

Option 1

- The doctors feel that Daddy is going to do fine.
- There is no reason to think that Daddy is not going to get better. No one is thinking that Daddy is going to die.
- If anything changes, we will let you know.

Option 2

Cancer is serious & some people do die from cancer & some people do die of brain tumors.

The doctors have told us that the chemotherapy (the radiation therapy) should kill any little bits of cancer that may be left.

Option 2

Sometimes a cancer like daddy's does come back a long time later, months or years later. We are really hoping that that isn't going to happen.

So right now there is no reason to think that daddy is going to die. We are not thinking that. We are expecting Daddy to do fine.

Option 2

If anything changes, (if we find out in months or years) that the cancer has come back, we will tell you.

If you hear anything from other people that is different from what we have told you, come & talk to us, we know best what is going on.

The medicine that Daddy is going to get can make him feel sick & tired. He may not be able to play with you like he usually does. When Daddy gets sick because of the medicine, it has nothing to do with the Cancer, it is because the medicine is strong.

- This is not a secret, you can tell people if you want to.
- I am going to tell your teachers that Daddy is sick...so they know.
- Things will probably change a bit around the house for a while. We are both going to stop working for a while & we will be home. Daddy will probably feel tired for a while & he may feel sick sometimes.

- We will tell you what is happening with Daddy unless there is something unexpected that happens that is a surprise to us as well.
- Daddy wants things to be normal around here. He doesn't want us to talk about his cancer all the time so we just need to talk to Daddy as we usually do, about hockey and school and things.

- If anything changes, we will talk to you.
- If **you** want to talk about Daddy's cancer or have questions, just ask us.
- If you are feeling kind of scared, that is OK, Daddy & Mommy are feeling a bit scared too.

...a few months later.....

Remember when we told you that we would tell you if things changed with Daddy. Well, things have changed.

We have found out that Daddy's cancer has come back. The RT/CT did work for a while but it seems like the cancer is really strong and it has come back.

The doctors say that there is another chemotherapy, another medicine that Daddy can try to see if it will help the cancer from growing. We hope very much that it will work. We are going to have to wait & see if it helps. This is all kind of scary right now for all of us. We will tell you when we find out if it is working.

Daddy went to see the doctor. The medicine has not worked. The doctors say there is no more medicine or treatment that will kill the cancer or keep it from growing. Daddy has tried everything there is to try. This probably means that Daddy is not going to get better & that gradually Daddy is going to get sicker.

Nobody knows how long Daddy is going to live. He could live for weeks, for months, maybe even a couple of years, we just don't know.

That means that sometime down the road, Daddy is going to die.

We hope that that won't be for a long long time.

We will talk every couple of weeks about how Daddy is doing & if anything has changed.

Right now Daddy is feeling really sad about things and he just couldn't talk to you about this today. But we want to talk about things together in a few days so that everything is out in the open.

If you have any questions in the next few days, maybe you should come and ask me...until Daddy is feeling a bit better.

Right now the plan is for Daddy to stay at home. I am going to take time off work again so I will be home as well.

When Daddy gets sicker, Daddy will go in to hospital. Daddy doesn't want to die at home. You can go & visit Daddy if you want.

Aunt Sue will come & stay with us so that you will still go to school and soccer and . . .

Although we hope that Daddy is not going to die for a long time, there is always a chance that something could go wrong that we don't know about & he could die very quickly.

We don't expect that to happen, but I wanted you to know that there is always a chance that it could.

You may be feeling a bunch of different things (feelings) right now. I know that I am feeling scared, mad, really sad & ripped off.

Have you got any questions about things that I have or haven't talked about?

a couple of months later...

Daddy is getting weaker & weaker.

He is getting more confused.

We think that it is time for Daddy to go to the hospital.

This means that Daddy won't be coming home.

The nurses are thinking that Daddy may die soon. It still could be weeks, it could be days, we just don't know.

- Daddy is a bit more confused because of his brain tumor but he is on a medicine now that makes him calmer.
- Daddy is sleeping most of the time now. It is a different kind of sleep than we have. It is because of his brain tumor.
- I am going in to see Daddy. Wondered if you wanted to come see him or if you want to stay here with Aunt Sue?

I have decided that I am going to stay in the hospital now with Daddy until he dies.

I know this is going to be hard for all of us. I want to be with Daddy because he needs me, but I also want to be with you & I know you need me.

Aunt Sue will be here and if you want to come & see Dad or me, she will bring you any time.

The nurses have told me that Daddy is probably only going to live for a few more days. This means that Daddy is going to die very soon.

So every time you visit Daddy & say good-bye it could be the last time.

If the doctors & nurses get an idea when that will be, I will tell you, but it may be that we won't know. Something could change quickly & he could even die tonight.

- If Daddy dies in the middle of the night, do you want me to wake you up and tell you, or tell you in the morning?
- Do you want to come to the hospital when Daddy dies, or, will you say your good-byes in your own way?

Summary

- Address the 'die' issue/question
- 'If anything changes, we will let you know.'
- Keep promise, **keep children up to date.**
- 'If you hear something different than what we have told you come and ask us, we know best what is going on.'
- Please ask if you have questions.
- Eliminate surprises.

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