



In the News:

Kudos and congratulations:



PMP Pals is very proud that Treasurer Adele Jasion was recognized this year by UPMC & the Society of Surgical Oncology for her work as a patient advocate. The annual Gabriella Graham award, named for our founder, is given to an individual or organization that most represents Gabriella's tireless work for patients. Congratulations Adele and thanks for all you've done for so many!

Our Featured Article:

Information source - Laura Crutchlow, Licenced Clinical Social Worker, San Jose, California
www.CancerCAREpoint.org and The Cancer Council, New South Wales

Talking to Children about your Cancer or Advanced Cancer Recurrence

Why Children need to know:

When you were first diagnosed, your first worries may have been for your children. How will they cope if you get really sick? What will you tell them? How will it affect their lives?

You are not alone, each year thousands of people are diagnosed with cancer and one quarter of these have children less than 18 years of age.

It can seem overwhelming but there is strong evidence that being open and honest with your children is the best way to help them cope with cancer.

We look at the reasons for telling your children about your cancer and include general tips to help your family.

There are several reasons why it is best to be honest with your children about your cancer.

Secrecy makes it worse:

Some parents avoid talking about their cancer because they want to protect their children. However, there is strong evidence that children who are told about their parent's cancer have lower levels of anxiety than children that are kept in the dark. The problem with secrets is that they are very hard to keep.





When to tell:

Deciding when to tell, and how much to tell initially, can be difficult, depending on the type of cancer you have and how much is known about your case. Parents sometimes decide to hold off telling their children until they know more about their prognosis, such as if they're waiting on test results to see if the cancer has spread.

Keeping a secret while you're waiting for results will increase your stress and your children will probably sense that something is wrong. So try to tell your kids the truth as soon as you feel able to. If you don't know how serious it is, just say so.

Getting Started:

In the blur of the first few days after a cancer diagnosis, these things can help you prepare for the first conversation with your children.

Make sure you understand the facts: If there are things you don't understand about your cancer, make an appointment with your doctor so you can check on any grey areas. It can help to take a relative or partner with you to take notes, or bring a small voice recorder.

Talk through your feelings with a trusted adult: This can help you to deal with your emotions before talking to your kids. You may choose to talk to a close friend, family member or spiritual advisor.

Practice what you want to say. Parents often doubt their ability to find the right words and to answer tricky questions from their children. Role-playing the conversation with your partner, friend, relative or oncology social worker can show that you can do it. It means you've spoken the words and perhaps dealt with some of the anxiety attached to those words before you talk with your kids.

How to tell:

The choice of who tells the kids may depend on how the family already communicates. In most two-parent families, one parent usually does most of the talking, so it is best if that parent breaks the news, ideally with the other parent present.

If possible, the key thing is that you tell your children before they start to worry.

Depending on the ages and temperaments of your children, you may decide to tell them separately or together.

Ideally, you should tell them at the time and in a place where they are most likely to listen and take it all in.

Have a plan of what to say but be prepared for anything. If your plan falls over and you end up blurting out the bad news, don't panic. You'll have many conversations ahead of you and your children won't be damaged by one discussion that doesn't go according to plan.

What to Say:

Tell them the basics in words that they can understand. Breaking the news in the beginning can be just a few short sentences explaining what you know so far and what will happen next. You can use children's cancer books to help explain cancer terms.

- *Find out what they already know.* Ask them what they know about cancer and then deal with any myths and rumors (e.g. you can catch cancer).
- *Ask them what they want to know.* Only answer questions that the kids ask, and don't assume they have the same fears as you. Avoid giving too much information.
- *Be honest and open.* Don't be afraid to say you don't know the answer to a question. Say you'll try to find out the answer from the doctor and let them know as soon as possible. Make sure you follow through.



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- *Tell them what to expect.* Let them know about changes to their routine that may happen, (e.g. Mom won't be able pick them up from school like normal)
- *Ask them who they want to tell.* They may want to tell their best friend, the teacher, the whole class or perhaps no one.
- *Open the door.* Your Children may say very little when you first tell them and not have any questions. Some kids need time to absorb the information, but it doesn't mean they don't understand. Let them know they can come back to you anytime with questions or worries.
- *Balance hope with reality.* Tell your children that although cancer can be serious, many people get better and you are doing everything you can to be well.
- *Listen.* Let them know they can talk to you about anything, even scary and awful feelings. You can't always take away those feelings, but you will be understand and help them cope.

Words you can use:

For younger children-

"I have an illness called cancer. The doctor is giving me some medicine to help me get well. The medicine might also make me feel sick or tired some days, but other days I will feel fine."

"I have an illness called cancer. It means something is growing inside my body that shouldn't be there. I am going to have an operation to have the cancer taken out and some other treatment to make sure it doesn't grow back."

For Older children and teens-

"We've had some bad news. I've got cancer. We don't know what we're dealing with yet, but I'm going to have surgery so that the doctor can have a look and find out."

"You know I've been sick a lot lately. The doctors told me today that the tests show that I have cancer. The good news is that I have a chance of beating this."

Answering key questions:

Here are some ways to deal with the most common questions that kids raise at diagnosis.

1) Are you going to die?

Words you can use:

"Some people die from the type of cancer I have but I plan to do everything that my doctor recommends to get better."

"We're not planning on that but I'll probably be sick for a while"

2) Am I to blame?

Some children may ask you directly if they are to blame for your cancer while others worry in silence. It is best to confront the issue.

Words you can use:

"It's no one's fault that I have cancer. Nothing you did or said made me get sick."

"You can't make my cancer better or worse but you can make me laugh with a funny story"

"Don't ever think that you caused this cancer or that your behavior can make the cancer better or worse."

3) Can I catch cancer too?



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A common misconception for many kids and some adults is that cancer is contagious. This belief can be reinforced after chemotherapy when a patient has to avoid contact with people who are sick because of the risk of infection.

Words you can use:

"You can't really catch cancer like you can catch a cold so it's okay to be close to me when I'm sick."

"No, even though cancer can spread through a person's body, it can't spread to another person."

4) Who will look after me?

When a parent has cancer, the most important thing for children so what will happen to them and how will it affect their lives. Children need to know the basics: who will look after them,... who will pick them up from school,... how roles will change. Try to give them as much detail about changes as possible so they know what to expect

Words you can use:

"We will try to keep things as normal as possible but there may be times when I have to ask Dad/Mom/Grandpa to help out."

5) Do I have to tell other people about it?

Your Children may not know who to tell about your cancer and how much to say. They may not want to say anything at all. So it helps to explore their feeling about talking to other people (this can trigger a discussion)

Words you can use:

"You don't have to tell anyone if you don't want to but would you like to speak to someone?"

"You don't have to tell anyone if you don't want to but if you feel comfortable, it might help

"What comes into your mind when you think about talking to other people about cancer?"

How parents react-

When cancer becomes advanced, you confront difficult emotional issues and the possibility of death perhaps more than at any other times of your illness.

Many people say the news that the cancer is advanced is more devastating than the original diagnosis. Significant anxiety and depression are common and it can be harder to cope emotionally. However, people with advanced cancer who express their emotions and communicate may find it easier to cope.

For some people, faith and spiritual beliefs can help them get through tough times. For others, cancer can test their beliefs. Either way, you may find it helpful to talk to a spiritual advisor.

How children react-

How to react to advanced cancer can affect the adjustment of the whole family. If you are anxious and depressed, the family may be too. Some studies of people with advanced cancer show that family members often feel more distressed than the person with cancer. This seems to be more common where there is a lack of communications. Some people avoid talking about the advanced cancer because they don't know what to say. When cancer is advanced, your children may have similar but more intense reactions than when you were first diagnosed.

- Children (12 and under)
They may worry about the well parent
They may think that they or their behavior caused the cancer to become advanced
- Teenagers



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One of the biggest issues is that teenagers are striving for independence while feeling drawing back into the family. They may hide their feelings to protect you. They struggle with not being able to do their normal social activities (this is a significant loss for teens).

Keep the door Open



If cancer becomes advanced, it is more important than ever to keep talking with your children. Again, just as with diagnosis, children may sense that something is happening and not telling them can add to their anxiety and distress.

Show them that they can talk about it and ask questions. You can say to them: *"It's okay to talk about this; you don't have to protect me from scary feelings because you're worried about me."*

Facing a parent's death: how different ages react

In preparing children for the possible loss of a parent, it can be helpful to understand what death means to kids of different ages.

Toddlers- Very young children have a sense that something is happening. They often confuse death with sleep. While they don't understand the permanence of death, children as young as three can grieve.

Ages 3 to 5- Preschoolers understand the concept of death but they struggle with the permanence of it (e.g. they may ask when a dead parent is coming home). Also, death can be hard to explain to young children because they have no adult concept of time. They can only understand what's happening now. For example, a six-year-old can understand what it means to have five sleeps until her birthday but will not be able to understand the meaning of a reduced life expectancy. Try to avoid explaining death to young children as sleeping because it can cause distress about sleep.

Ages 6 to 12- Primary school children know about death but often don't have the emotional maturity to deal with it so their behavior may change.

Ages 13 to 18- Teenagers understand death as much as an adult but may not have an adult's emotional capacity to deal with its impact.

Facing questions about death

Honest communication

If death is likely in the short term, it is best to be as honest as possible. This is an incredibly hard thing to do and you don't need to do it on your own. Social workers and other health professions and palliative care services can help you tell children.

Being open about the possibility of death gives you and your family the chance to show and say how much you care for each other and the opportunity to resolve conflicts. The chance to talk through old arguments and make amends seems to be particularly important for older children.

Another advantage of being open about death is that it allows you to develop strategies to help your kids. For example, when a child's parent dies, an important factor that helps them cope is a link with the dead parent. This could be a material reminder of the parent such as a piece of jewelry, an article of clothing with dad's scent, etc. We



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don't know how much those links can be established before death, but parents can help their child talk about those things if there is open communication.

Explore the question

When kids ask a parent if they are going to die, sometime they are really asking: "Am I going to be okay?" A key concern for kids is who will look after them if a parent dies. This is particularly important for single parent families.

It is normal for a young child to worry about themselves in this situation. If you can, stop and explore the question before answering by saying something like, "Do you feel scared sometimes?" or "Have you been thinking about that a lot?" When your child asks questions, sometimes there won't be a hidden meaning, but other times there will. Exploring the question is a great chance to identify the feelings behind the question.

Balancing hope and reality

Parents worry that if they talk about the possibility of death they take away their children's hope. YOU can still be honest and offer hope.

Words you can use:

"The treatments can't take all the cancer away. Now I am working to live with the cancer as long as possible."

"It's possible I will die from the cancer but I am doing my best to survive."

"Some people with cancer get better and some don't. I am trying my best to get better"

Being together

When Cancer becomes advanced and life even more uncertain, many families find new ways to make the most of every minute. Here is what some people have done to maximize their time with their families:

- Accept any offers of help from family and friends. It not only allows them to feel that they are contributing, it frees up your time and energy for your kids.
- Save your energy for what matters most to you. If you want, let the housework slide and spend more time with the kids.
- Sift through old photos and make a scrapbook of your lives together as a way to establish memories.
- Make an audio recording for each child. You can make one for special occasions like 21st birthdays and weddings.

Survivor Happenings:

Are you interested in meeting some of those who share your PMP experiences in your local area? Start a Regional PMP Pals Survivors Group in your area. Perhaps a discussion with a fellow caregiver or patient could give you new insights and coping skills. If you belong or have started a PMP Pals Survivors Group, please let us know what you're up to so that we can feature your event(s) in our Newsletter. Just e-mail us at:

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Information for the Newly Diagnosed

PMP Pals- Simply by reading this newsletter you are well on your way to staying informed. We believe knowledge is power and hope follows close behind. Did you know that PMP Pals has both a Facebook page as well as a Website where lots more information can be found.

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PMP Appendix Cancer Support Group – On this Facebook page, you'll be able to connect with fellow patients and caregiver throughout the globe. This private (closed) group is ONLY for individuals and their caregivers/advocates, who have, or have had, Pseudomyxoma Peritonei (PMP) and/or any other form of Appendix Cancer, including Adenocarcinoma, Goblet Cell, Signet Ring Cell and others. To join, just navigate to the "ADD MEMBERS" column of the homepage.

<https://www.facebook.com/groups/PMPAppendixCancerSupportGroup/>

ACPMP – (Appendix Cancer Pseudomyxoma Peritonei-Research Foundation) is dedicated to:

- **Funding research to find a cure** for (PMP), Appendix Cancer, and related Peritoneal Surface Malignancies (PSM),
- **Funding educational programs** to educate physicians and patients about these diseases.

<https://acpmp.org/>



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<http://pmppals.net/become-a-donor-2/>

We do **NOT** want patients or their families donating—they have more than enough on their plates and must concentrate on getting better. But we are open to donations from past patients and their families if they've found us to be helpful and would like to help us continue this work. Businesses or organizations are also welcome to donate to help us defray cost.

PMP Pals is a global volunteer-run organization that gives hope to patients and caregivers fighting appendix cancer, also known as Pseudomyxoma Peritonei or PMP, and other cancers of the abdominal cavity. We provide information through our web site and personalized support through our programs.

We want to hear how PMP Pals' Network has helped you and your family. Write to us and share your story of hope with new patients as well as long-time PMP Pals. We look forward to hearing from you! E-mail:

info@pmppals.com