

First Steps for the Newly Diagnosed: The Cancer Survival Toolbox

[TRACK 1: INTRODUCTION]

[TRACK 2: SURVIVOR STORIES: GATHERING INFORMATION]

[TRACK 3: SURVIVOR STORIES: YOUR CANCER CARE TEAM]

[TRACK 4: SURVIVOR STORIES: YOUR CANCER CARE PLAN/SECOND OPINIONS]

[TRACK 5: SURVIVOR STORIES: OTHER RESOURCES AND HOW TO FIND THEM]

[TRACK 6: SURVIVOR STORIES: REVIEWING YOUR HEALTHCARE POLICY]

[TRACK 7: SURVIVOR STORIES: ASKING FOR HELP]

[TRACK 8: SURVIVOR STORIES: WHO TO TELL]

[TRACK 9: SURVIVOR STORIES: TELLING YOUR EMPLOYER]

[TRACK 10: SURVIVORSHIP CARE PLANNING]

[TRACK 8: SURVIVOR STORIES: WHO TO TELL]

[Michael]

After my diagnosis, it was difficult to say the word “cancer.” I wanted to tell my family and friends who knew I’d had a biopsy. When I called them, I said, “What we feared has happened.” They immediately knew what I meant.

[Narrator]

Announcing good news is simple. But, sharing bad news is hard to do. It’s okay to take your time and wait to tell others until you’re ready. And, it is entirely your decision who to tell and how much information to share. The *Cancer Survival Toolbox* program entitled “Communicating” includes many suggestions to improve communication that may be useful both now and in the future.

Linda offers these thoughts about talking to others about your cancer.

[Linda]

Deciding who to tell and what to tell can be difficult. If this is an issue for you, ask yourself this question: “Would I want to know if one of my family members or close friends was diagnosed with cancer?” This might help you decide who to tell.

Often, people are curious about next steps. Will you have radiation? Chemotherapy? Both? They may wonder where and when you’ll have surgery. If the time is right for you, answer their questions as best you can, but keep in mind that “I don’t know right now” or “I’m still in too much shock to think about that” are good answers, too. And of course, there will be people who ask questions, but whom you don’t feel obliged to answer. People who care about your well-being will respect an answer such as: “You know, Greg, I really appreciate your concern, but right now, I’m just not ready to talk about this. I’ll let you know when I’m ready.”

[Claire]

Telling family, friends and co-workers about my diagnosis and planned treatment wasn’t as tough as I thought. But keeping up with phone calls from friends and family members who wanted to know how I was doing was really tiring. My friend Jan offered to send e-mails once a week to keep everyone posted and would include pictures too, if I wanted. Accepting Jan’s offer was a great decision! Once a week I give her an update on how I’m feeling, how treatment is going, the highs and the lows and anything else I want to share. Then, Jan sends the next chapter of my journey with cancer to everyone on the e-mail list.

Jamie, a young man in my support group, said he was getting annoyed by so many calls, even though he knew people meant well and just wanted to express their concern. He created a web page to keep everyone informed. You can give your friends and family the web address, and they can read what you write or send a message. You can even include photos, which everyone seems to enjoy. In addition to his webpage, Jamie also assured his friends and family he’d call if he needed help or wanted company, and was able to keep the telephone calls to a minimum.

[Narrator]

There is a list of websites that can be used to help keep your family and friends updated in the online Resource Booklet. Before you create a webpage, you may want to discuss with your family how much and what types of information you are comfortable sharing with others.

[Narrator]

Most families find being honest and open about their cancer and feelings helps them handle changes that occur. Telling your children about your cancer is another aspect of cancer that is not easy for many people. Of course, the age of the children makes a difference, although even adult children might be quite distressed by the news of a parent's cancer.

[Joan]

The National Cancer Institute booklet called "*When Somebody in Your Family Has Cancer*" provides guidance and suggestions that can help families cope with a loved one's illness. Likewise, the American Society of Clinical Oncology has a web site devoted to the needs of patients and survivors and their families –cancer.net – that also offers educational information, guidance, and support to people who are affected by cancer.

One resource I use a lot is the book *When a Parent Has Cancer* by Dr. Wendy Harpham, a cancer survivor, wife, and parent of three young children. In this book, Dr. Harpham describes how she and her family have dealt with her illness in ways that didn't rob the kids of their childhood AND helped the entire family learn and use positive coping skills. Dr. Harpham suggests that families work towards making a "new normal" for family life, including looking at the cancer as a manageable part of daily life.

I know too, it's really crucial to be honest: tell your children you have a serious illness, and doctors and nurses are working to help you get better. Depending on your situation, some honest talk about the possibility of death might also be in order. Give children time to ask questions, and to express their feelings and fears. Make it a point to let your children know their basic needs will always be met. Children should also know they did nothing to cause your cancer.

Share books about cancer that are written for children. *Becky and the Worry Cup* comes with *When a Parent Has Cancer*. Other books that may be helpful include *Our Mom Has Cancer* by Abigail and Adrienne Ackermann (American Cancer Society, 2001), *When Mommy Had a Mastectomy* by Nancy Greenfield (Bartleby Press, 2005), *Our Dad is Getting Better* by Alex, Emily and Ann Rose Silver (American Cancer Society, 2007), and *Let My Colors Out* by Courtney Filigenzi (American Cancer Society, 2009). As time goes on, and more families are facing cancer, more books will appear. Bookstore customer service people and librarians often have information about new and useful books.

Children need to know that although things are different, your love for them has not changed. It's also important to let other adults in your children's lives know about your cancer – teachers, coaches, neighbors, and parents of your children's friends. That way, these adults may be better prepared to hear and help with concerns you child brings to them or shares with his or her friends.

All children, but especially teenagers, should continue to spend time with friends and take part in their normal activities. Teenagers should be told as much as they want to know about your diagnosis, treatment, and prognosis. A good response to the question, "Are you going to die?" is "I hope not. I'm getting treatment and doing everything I can to get better." Encourage them to

talk about their feelings and concerns. It's helpful if you are honest about your feelings and your fears.

Suggest ways children can help. Maybe there are things on your "friends and family list" that kids can do. Today's teens are so at ease with computers – asking them to help share your news by way of e-mail or setting up and maintaining a web page for you might be a good way they can help lighten your daily burdens.

Talk with your adult children about your cancer, even if you expect they'll be upset or worry. Tell them about your feelings and wishes in case you don't recover. Here are some things you may want to consider:

- Ask your adult children to help you make decisions about your healthcare.
- Ask your children to go with you to doctor's visits so they can hear what the doctor is telling you.
- Talk with your children about what you need from them, whether it is emotional support, help with paying bills, or taking care of the house.
- Make the most of the time you have with your children. Share your feelings – not just love, but also your concerns, your fears, your sadness, and your hopes.