

First Steps for the Newly Diagnosed: The Cancer Survival Toolbox

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[Pam]

After the doctor said, “I’m sorry, you have cancer”, I didn’t hear anything else. My heart started pounding and I couldn’t breathe. All I could think was, “I’m going to die.” But I didn’t. It took a few days, but I decided I was going to beat the cancer. And I was going to need help to do that.

[Narrator]

When you first learned you had cancer, you may have felt frightened, angry, or alone. These feelings are very common. But no one needs to face cancer alone. When people with cancer ask for help from others, they often find it easier to cope.

Let’s hear how Pam found help and support in her community.

[Pam]

When I saw my doctor for my annual checkup, he wanted me to have a colonoscopy. When he told me the polyp they found in my colon was cancer, I didn’t believe it. He told me I needed to see a surgeon, and the surgeon said I needed to have part of my colon removed.

After surgery, my surgeon said I would need a medical oncologist. My cancer had spread to two lymph nodes and I would need chemotherapy. When I heard chemotherapy, all I could think of was how sick my father was when he had chemotherapy for lung cancer. That really scared me.

While I was still in the hospital, Linda, an oncology social worker, came to see me. She helped me realize my fear and anger are normal. Together, we developed a list of resources available in our community that could help me. I’ve never been one to ask for help, so I did need this gentle push to just ask. Linda explained that my family and friends will want to help, but they may also need ideas about what I’ll need and what they can do.

[Narrator]

Knowing what resources are available can be very helpful. To help you get started in putting your list together, Linda shares the list of resources she and Pam developed.

[Linda]

Family is how you define it. It can include your spouse or partner, siblings, children, parents, grandparents, aunts, uncles, cousins, and friends.

Other Friends may include co-workers, people in your faith community or church, and your neighbors. These are people who love and support you.

Cancer support groups are meetings for people with cancer and their families and friends. These groups let you talk about what it’s like to have cancer and how to cope. There are different types of groups: face-to-face groups, telephone groups, and online groups. Groups like the “I Can Cope” online program sponsored by the American Cancer Society (www.cancer.org) provide information related to cancer treatment and other issues. Other groups, like those offered by the Cancer Support Community (www.cancersupportcommunity.org), provide emotional support to help members cope with common concerns. Some groups are for family members and other caregivers. Find out what groups are available in your community. You might try to attend more than one group if more than one exists to see which seems most helpful. Hospitals, doctors’

offices, newspapers, and telephone directories often list contact and schedule information for support groups in the community.

You can connect with services that offer telephone, online, and even talk-radio-based support programs. I'll mention just a few examples here, and more are listed in the online Resource Booklet. *CancerCare*, an organization based in New York that offers many types of services including educational programs, individual counseling, and facilitated support groups. CancerCare can be accessed by a toll-free number (1-800-813-4674 – 1-800-813-HOPE) or online at www.cancercares.org.

The Cancer Support Community (CSC) (www.cancersupportcommunity.org) is an international non-profit organization that provides free support and education to people with cancer and their loved ones. There are more than 40 local CSC affiliates in the U.S., as well as satellite off-site programs and online cancer support services, which include support groups, a resource library, and discussion boards.

Some grassroots advocacy groups also facilitate support. For example, the Pancreatic Cancer Action Network – PanCAN™ – helps connect pancreatic cancer survivors with others who are more recently diagnosed. Check with an advocacy group that offers services to people with your form of cancer to see if they help connect survivors with one another. You will find a list of advocacy groups in the online Resource Booklet. You can also find links to advocacy groups at the National Coalition for Cancer Survivorship web site, www.canceradvocacy.org

Spiritual support often involves finding meaning in our lives, and now, finding meaning in having cancer. Many people find support and meaning through prayer or with the guidance of a chaplain, pastor, rabbi, other spiritual leader, or a social worker, oncology nurse, or psychologist.

Organizations, such as the National Cancer Institute's Cancer Information Service, the American Cancer Society, and cancer type-specific organizations like the Leukemia and Lymphoma Society, the National Colorectal Cancer Alliance, the National Prostate Cancer Coalition, and the Susan G. Komen Foundation, can provide up-to-date information and connections to other people with the same kind of cancer. A good place to start is the National Coalition for Cancer Survivorship's web site – www.canceradvocacy.org. Many NCI-designated cancer centers also provide information and help connect patients and survivors to one another.

Another list Pam and I made included ideas about ways family and friends could help. This way, when people ask what they can do, there is a ready-made list to choose from. I usually suggest one person in your circle of friends and family be asked to be the main contact person and in charge of the list.

[Pam]

This was a good idea for me. Having this list eliminated a lot of confusion. Most importantly, I think it helped to spread the tasks that had to be done more evenly among everyone. That way, no one felt over-burdened, yet I felt good knowing things would not be forgotten. Here are some things I put on my list:

- Pick up my children from school on days I have treatment.
- Take my son to soccer practice or my daughter to dance lessons.
- Put my name on the prayer list at your church.
- Cook a meal for my family and bring it in disposable containers.
- Visit for coffee, to share stories and laugh, but call before you visit.
- Help with the housecleaning or yard work when my husband is out of town.
- Send a card or letter.
- Drive me to my doctor's appointment or treatment if my husband is working.

It's been several months since I learned I had cancer. I started attending a support group and it's been so helpful to hear others talk about their fears, to be able to talk about my experience, and to find support and hope. I also went to a weekend-long retreat for people with cancer. It was amazing to find so many other people were going through the same physical and emotional things I was! The support group meetings and the retreat helped me realize I'm not alone, and gave me so many new ideas for coping with my cancer and treatment in really simple and useful ways. I also put my help list into action. It was difficult at first accepting help. But the list made it easier for me. I also think it made it easier for my friends. I could tell they appreciated the suggestions and I'm so grateful for their help.