

[TRACK 4: SURVIVOR STORIES: FINDING INFORMATION]

Elena, Part I

[Narrator]

Now, let's talk about another basic, skill for caregivers, as well as cancer survivors: information seeking. Let's hear from Elena. 33.

Elena: I'll never forget that day in the doctor's office at the cancer center. The doctor told Salvador, my husband, and me there was nothing more he or anyone could do for us. What do we do now? Where do we go from here? I needed information.

[Narrator]

As a caregiver of someone with cancer, you are always needing information in order to make decisions, solve problems, get help, and move forward. The need for information goes on throughout treatment and even after treatment ends. When cancer progresses, family members may need to assume more and more of their loved one's physical care. They may also need to assume more of the information-seeking role. In the example of Elena and Salvador, when their health-care team had no more treatment options to provide, where could they turn for information on what to do next?

[Elena]

I knew after that visit with the doctor that I needed help to deal with Salvador's physical needs. I needed a plan for Salvador's care. I needed information in order to decide what was best for Salvador, our children, and me. The doctor mentioned hospice. I didn't know what hospice was. It turns out that hospice is a special kind of care designed to provide support for people in the final phase of a terminal illness. Hospice would offer my husband and me care that would focus on quality, rather than length of life.

[Elena]

I also knew I needed to call my insurance company. I remembered that I had worked with a case manager in the past in order to get Salvador's experimental therapy covered by insurance.

[Elena]

Lifting Salvador on my own at home was really hurting my back. His physical care, like bathing, was becoming more than I could do by myself. I didn't dare fall asleep at night for fear Salvador would wake up and try to get out of bed on his own. He was getting more and more confused at times, especially at night. I was exhausted and sad. I wasn't taking care of myself like I should. If this were to go on, I would be in bed next to Salvador. I knew that I didn't want to end up sick also. Our children live away from us. Our girls are busy working and raising their own young children. Our sons are busy with their jobs and families. I was concerned about Salvador and me becoming a burden on our children.

[Elena]

The case manager at the insurance company was able to explain Salvador's coverage to me. I asked about hospice, nursing homes, and attendant or live-in care coverage. She was helpful, but I still needed more information.

[Elena]

The oncology social worker was able to provide more information about hospice. She gave me information on nursing homes and agencies that provide in-home help and assistance. She answered my questions and helped me understand the different kinds of services that are available. We looked at the options and what effect they would have on Salvador and me. She helped me to give permission to myself to think of my needs as well as the needs of Salvador and my children. I don't honestly think that I had ever considered my own needs until this time, at least not without feeling guilty. This brought up other questions we needed to have answered. How could I give Salvador the best care and the care that he wanted, while still taking care of myself? Maybe, I should let my children tell me what is a burden for them and what might be easy for them to do to help. What did they feel that they could do to help in this situation? What could I do with all the stress that I was feeling?

Elena, Part II

[Elena]

Well, my son, who loves the Internet, got me more information about hospice. He also found a chat room on the Internet where I could talk with other caregivers. A couple of the people in the chat room gave me suggestions that I was able to talk about with our social worker. Soon, all my children were exploring options and getting information together.

[Elena]

I visited my local library. The librarian showed me how to use the computer there. I also visited my local senior center. The people there were very helpful with information on local nursing homes and even had a list of private-duty attendants who had been screened and other resources. They also had an exercise program and some other activities that sounded interesting to me.

[Elena]

One of the best things I did for myself was to attend a local support group for caregivers like me. People shared with me their firsthand experiences. I also got some training in stress management from the local wellness center. This helped me a lot. I knew that I needed to make sure to get some exercise and do other outside activities every day to get my life back in balance.

[Elena]

With each place I went for information, I had to judge how good the information was and if the information really fit my own situation. Hearing some of the same information from several sources helped me feel good about that information. The social worker was one of the experts I chose to help me go through it all to pick out what I needed.

[Elena]

Salvador and I met with our children to talk about this next phase of our lives with cancer. We discussed Salvador's needs. We discussed his insurance coverage. We then laid out all the options on the table with all the information I had gathered. My children had many questions. I was surprised, and I think they were too, at how much I knew. Making these decisions was not easy, but it felt like we were going into things with our eyes wide open. I think our expectations were more real than they might have been without the information we had gathered. We also felt that we weren't locked into any one thing. I was very proud of my children and myself for how we were able to handle this new situation. I'm sure Salvador could see how much we all loved him and treasured every day with him.

[Narrator]

Let's review what Elena was able to do that helped Salvador, their children, and herself. · She took the time she needed to get important information. · She put together a good team to help her. This team included the nurse, case manager at the insurance company, social worker, children, support group members, and librarian. · She was willing to ask questions and explore options. · She checked the value of information she was getting by looking for more than one opinion. She looked at information from different sources and checked to see if it agreed. She chose a reliable expert - her social worker - a person she trusted and with whom she could discuss information and receive feedback. · She was creative in her approach and used all resources available to her. · And, she didn't do it alone. Elena sought help through her team and her family. The family benefited from the information that Elena was able to gather. They made their decisions as a team.

[Narrator]

As you know, a diagnosis of cancer requires a lot of important decisions. Making decisions about treatment options and life choices is a major challenge for caregivers and cancer survivors. But, a growing number of people who get cancer are without family members - either family is at great distance away - or families have grown apart so no family member is close by to provide care. This is when friends and neighbors can step in to fill caregiving roles that might otherwise be provided by family. Let's listen to two long-time friends, Sandra and Jean, talk about how they managed this kind of situation.