

[TRACK 5: SURVIVOR STORIES: DEALING WITH FAMILY ISSUES]

Kathleen, 70 years old

[Kathleen]

My husband, Michael, comes from a large Irish-American family that prides itself on looking out for each other. When Michael was diagnosed with advanced lung cancer after he turned 71, all of the relatives got together to talk about how to handle this family crisis. Some of them were determined to act like everything would be all right. Others felt like there was nothing they could do for him. There was a great feeling of sadness throughout our house.

[Kathleen]

But, I looked at it another way. I believed that Michael's future was in God's hands, and so I would make the best of whatever time he had left. I realized that there were things to be hopeful for. While he still felt well enough, I could hope that we'd enjoy our daily walks together. When he didn't feel up to going outside, I could hope that he'd still enjoy his favorite meals. If he does become bedridden, I could hope that he'd still be able to enjoy visits from our children and grandchildren. And when his end is near, I hope that he will be free of pain and at peace.

[Narrator]

As a family member, Kathleen did not feel hopeless or helpless. You may never have thought much about what role hope plays in your life, or about how you hope, or even about how you learned to hope. Yet research tells us that people hope very differently, and that the way we hope is affected by family experiences. We learned how to hope from our family of origin -- that is, parents, brothers and sisters -- and from our current families as well.

[Narrator]

Families have well-established ways of hoping, which are called family-hope patterns. They contain your family's values and standards regarding hope, and ways to maintain hope. For example, some families use a religious or spiritual basis for their hope. As a result, statistics and medical facts may not be as important to those families because they believe God will determine the outcome. These family members may draw great strength from attending religious services, from prayer, and from talking with their clergy.

[Narrator]

Another family may use information as the basis for their hope. Their hoping leans more toward fact gathering. They use cancer information services and medical libraries. Information gives them a sense of control and hope.

[Narrator]

No one family pattern of hoping is the best or most useful. What is important is that you think about your own way of hoping, and that you be direct with family, friends, and your health-care team about what is most helpful to you about using and maintaining hope. You don't have to accept it if someone tells you there is nothing to hope for or that there is no hope. As we heard from Kathleen, there is always something to hope for, and you and your family have the right to determine for what, when, and how you hope.

[Narrator]

Try to think about something someone said or did in the past week that increased your hope. Go back even further and try to think of the most helpful thing someone said to you since you were diagnosed with cancer. What made the statement so helpful? Did it have anything to do with your maintaining hope?

[Narrator]

Another useful exercise is to keep a journal of hope. All you need is a notebook or several sheets of paper. Your hope journal should have several headings:

- The date,
- A column for people's names or the source of your hope entry, and
- A section for writing what was said or what you found that was hopeful and helpful to you.

[Narrator]

Hope comes in different forms. It may be something someone says. It may be a passage you read in a book or in the Bible, or it may be something you hear on television or the radio or at a support group. Or it may simply be some thought or memory that makes you feel more positive. The most important part of keeping your hope journal is to review it often.

[Narrator]

In cancer survivorship, advocacy does not stop with standing up for yourself. While it begins with you, it may broaden to include advocacy on behalf of others. As you become a "veteran" cancer survivor, you may find that you want to give something back, to share some of the wisdom that you have gained from your experience to help other cancer survivors.

[Narrator]

For example, when people find out you have had cancer, they may call you and ask you to speak to a family member or friend who has been diagnosed recently. If you are comfortable speaking on a personal level, talking with the newly diagnosed person can be an act of advocacy.

[Narrator]

Other ways that you may want to use your personal experience to help others include: Starting a support group in your community. Speaking about your cancer experience to community groups. Making sure your library has up-to-date resources on cancer. Speaking to medical, nursing and social work students and to employers and employees about your cancer experience. Telling your story publicly to the media or your congressional representatives to help change public opinion and policy about cancer.

[Narrator]

While the cancer experience is not unique, your individual experience with it is. Your age, your previous experience with illness, your cultural background, your job and resources, and many other circumstances affect how you respond to having cancer. As a cancer survivor, you need to become your own best advocate, even if this means having a loved one or friend advocate for you. In order to do that, you can develop survival skills that will help you maintain the highest quality of life possible after your cancer diagnosis.