

[TRACK 4: SURVIVOR STORIES: COMMUNICATION]

[Narrator]

Mark is 50 years old and was diagnosed with kidney cancer about a year and a half ago. He is married and has two teenage sons and a teenage daughter. Let's hear what he says about the impact of his diagnosis on his family.

[Mark]

Since my cancer surgery, some things have had to change permanently in our family. Before, we all knew what our jobs around the house were. Everything went pretty smoothly. My wife and I both work outside the house, and at home, we had different things to take care of. I kept up with the cars and things that needed to be done around the house. I also paid the bills and managed the finances. My wife took care of all the shopping and kept everybody organized. Our teenage kids concentrated on their school work, sports, and summer jobs. Since I've had cancer, my wife and our kids have had to do a lot of my share. My sons take turns cutting the grass and doing the yard work. But, they can't really handle the harder maintenance jobs. My daughter is now in charge of getting the cars serviced on schedule and has to drive me to doctor appointments sometimes. My wife is working overtime to help make ends meet. I feel so dependent...almost useless. Sometimes, when I'm really frustrated, I get mad at them for no reason. I don't mean to. I just want to get back to normal.

[Narrator]

A family is a social system. Change in one part of the system causes change in the other parts. A cancer diagnosis for one family member can change the ways the entire family communicates and gets along. Sometimes, the change can have long-lasting effects on all family members. Many researchers have found that some of the most difficult problems that cancer survivors face are the reactions of the people closest to them—their family members, friends, and co-workers. To learn more about communication skills, you can listen to the *Cancer Survival Toolbox* program entitled "Communicating." Linda, the social worker, sees how a cancer diagnosis affects individuals and their families.

[Linda]

Families can take all different forms. They don't have to be bound by blood or legal relationships. In times of trouble, we usually think of families as a refuge...a place of support. Even the word "home" has special significance for most people in times of stress. Stress is an expected part of family life, but cancer puts extraordinary stress on families. For some families, the challenge of cancer can offer the chance for personal growth and can actually strengthen bonds within the family. But extreme and prolonged stress can have a negative effect on even the strongest and closest families.

[Linda]

It is not only during the initial cancer crisis that families face new and tough challenges. Once treatment ends, family members continue to need information that will help with recovery of their loved one and readjustment for the entire family. As we heard from Mark, family members may need to take on new responsibilities, at least for a while. They may also have to make tough financial decisions. They have to

find ways to continue supporting one another emotionally while they manage a new set of fears and uncertainties. Each of these changes requires family communication.

[Linda]

Open communication and the expression of feelings within the family are crucial to creating a healing environment and for helping each other gain the strength necessary to deal with the long-term effects of cancer. Remember that, while separate cancer crises may come and go, cancer itself is a long-term illness. You will need to maintain or develop good communication skills so your family can adapt over the long haul. And, you need an understanding of what kinds of factors create communication barriers, so you can overcome them.

[Linda]

For example, family members may have differing views about cancer and its treatment. They, too, are frightened and concerned for their loved ones: Is the cancer really gone? Will it come back? Was the treatment aggressive enough—or was it too aggressive? Sometimes, they may disagree with the doctor's recommendations about follow-up care. Good communication continues to be important after treatment ends, and getting answers to their questions can help family members feel more secure. But, the cancer survivor has to have the final word about health-related issues. Family disagreements and undue pressure about follow-up care and about the health habits of the cancer survivor only add to the stress level of the whole family.

[Linda]

Serious illness can often intensify the strong relationships that already exist within a family. It also may intensify existing family problems. For example, if a child is not doing well in school, his or her grades are not likely to improve when an additional family problem, like cancer, comes up. Likewise, marital or financial problems often get worse when someone in the family develops a serious illness. Substance abuse, including excessive use of alcohol, use of illegal drugs, misuse of prescription drugs, as well as eating disorders, may also become more severe for a family member or the cancer survivor when new problems arise. This can be especially hard these days, since so many families are already stretched by the demands of taking care of both young children and elderly relatives.

[Linda]

Sometimes, existing problems do seem to “self-correct” for a short time as everyone focuses on an immediate cancer crisis. Eventually, however, the increased stress will probably take its toll. If someone in your family has a personal problem or is caught up in destructive behavior, do all you can to get them to seek counseling or go together for family therapy so that your family doesn't get overwhelmed. If a loved one will not seek help, seek counseling without them so you can get help in managing your own responses to the ongoing family problem and to any new crisis.

[Linda]

I always talk with cancer survivors about specific ways to avoid common barriers to family communication. First, keep cancer in perspective. Cancer can be treated, controlled, or managed. Don't let the negative myths and fears about cancer get in the way of family communication. The cancer

survivor and his or her family members need accurate and honest information about cancer, its treatment, cancer recovery, as well as long-term survival, including recurrences and possible second cancers.

[Linda]

Second, periodically review the ways in which family roles and activities have changed or may need to change. For example, will you need to delay or cancel a vacation or family event this year? Have finances changed, and, if so, what does that mean for your family? On the other hand, talk about things that have remained the same or don't need to be changed. It's important to remind each other of the love you have for one another, the value of family time, and the need to continue special activities and celebrations that keep you together as a family.

[Linda]

If family roles have changed, are the changes temporary or more permanent? One suggestion I often make is to change assignments or responsibilities among family members, when possible, every few months. This way, nobody becomes too burdened by any one task or responsibility. It usually helps to avoid having all of the personal care tasks fall on only one person. Consider asking a teenager in the family and close family friends to share the care. For example, a teenager who drives could take you to follow-up appointments with your doctor or help with other errands. This will enable the teenager to learn more about your progress or your continuing recovery, and will also provide an opportunity for private and meaningful conversation between the two of you.

[Linda]

If you worked before your cancer diagnosis and treatment, talking with your boss about your employment situation every few weeks or months can be very important. Will your employer need to make changes so you can return to work? Or, will you need to find a different type of work that is better suited to your energy level and recovery process? Keep in mind that you have rights in the workplace.

[Linda]

Some people use their experience with cancer as an opportunity to evaluate many fundamental aspects of their lives. Some will be eager to return to their original jobs and activities, but others will want to explore new options.

[Linda]

A third suggestion for avoiding barriers to communication—think about and plan exactly how you are going to go back to work and other outside activities. Many friends, neighbors, and co-workers will be curious about your illness and prognosis. Most will ask questions because they care about you and want to be supportive. Some people, however, are simply interested in the drama of a serious illness, or they like to gossip. Don't feel like you have to share the details of your health with everyone who asks. You and your family may want to practice answers to difficult questions so that when other people ask, you will have your answers ready.

[Narrator]

Keeping lines of communication open between you and your family, friends, and your boss, are all important for helping you discover your life beyond cancer. Listen to Mark's experience on an issue that might seem relatively minor, but can be a continual stumbling block for many survivors.

[Mark]

What I find most difficult in communicating with some acquaintances is that they think things are actually worse than they are, especially since I haven't had been able to return to work yet. This one woman from work always asks me how I am. When I say "I'm fine," it's like it's never a good enough answer for her. She'll lean in close, lower her voice, and ask, "How are you, really?" You know what? I'm really not interested in sharing a lot of details with her. I resent her being so nosy.

[Narrator]

Discussing and even practicing different kinds of responses with close family members might help Mark come up with a simple statement that will stop people from asking these kinds of questions. Sometimes, you just have to be blunt.

[Linda]

You might simply ask, "Why don't you believe me when I tell you 'I'm fine'?" Or sometimes, humor does the trick. You could ask, "What are you doing, writing a book about me?" Or, you may need to be clear that you are beyond discussing the cancer. What you want to talk about is the future or how things are going at work. The responses should be ones that you are comfortable saying. Take time to think about and talk through responses to these kinds of questions, so that you are prepared when you need to be.

[Linda]

A fourth suggestion for avoiding barriers to communications—avoid family burnout. We usually think of burnout affecting an individual person who's been under a lot of stress coping with a physically or emotionally difficult situation over a long time. Burnout sets in when that person finally reaches the point at which he or she is completely wiped out... drained of the energy and motivation needed to keep on coping. The same thing can happen to a family that's been coping with a stressful situation, like caring for a family member with cancer, over a long time. Family burnout can occur during the initial cancer crisis and over the duration of treatment that may extend for many months or even years. The signs of burnout range from physical symptoms, like fatigue and exhaustion, frequent headaches, or sleeplessness, to behavioral and psychological symptoms, such as being quick to anger, feelings of being unappreciated, and being unable to make decisions. Sometimes symptoms lead to "escapist" behavior, and an individual may start using alcohol or drugs to avoid the overwhelming feelings of stress. Sometimes, stress can lead to domestic violence. Problems like this demand professional help.

[Linda]

Two major clues to burnout are increased cynicism and feelings of being indispensable. You or your loved ones may become cynical about the slowness of your recovery after treatment, or about the accessibility of your health-care team. Or, you may start feeling despair that the situation will never get better. This cynicism may be linked to anger, and you may be directing your angry feelings about the situation or your sense of hopelessness at family members, your friends, or your doctor. On the other

hand, family members may direct their anger and frustration at the family member with cancer. If this is happening, it needs to be addressed directly. Your social worker is a good resource for issues like this.

[Linda]

Feeling indispensable is another sign of burnout. A family member who believes that he or she always has to be involved in caregiving – no matter how tired or stressed out they are. They may set aside their own personal goals, gratification, or even health so that they can always be around to help their loved one. Some people call this the “martyr” complex when one person sacrifices personal well-being for the family’s sake. It is very important that all family members take care of their own health. This means eating right, exercising, and taking time to relax and get enough rest. If not, the “martyr” may suffer burnout and could become resentful. And you may begin to feel smothered by a loved one who is so worried about you that they want to do everything for you – even after you have finished your treatments. They need to know that part of your survivorship involves getting back to being independent.

[Linda]

The entire family, including the family member with cancer, should try to continue outside interests, hobbies, sports, and exercise programs as much as possible. If not, this can be an area of family conflict. Sometimes family members feel like the individual who had cancer isn’t trying hard enough to get back to normal, or that they should be getting on with life, not dwelling on the illness.

[Linda]

On the other hand, family members can become overprotective, and some even have difficulty giving up the caretaker role. You may feel you’re ready to return to work... that it would be helpful to feel productive again. Your spouse or partner may worry that it will be too much for you, or that you’ll have a setback if you return to work or other activities too soon. If this creates a conflict, you may want to meet jointly with your doctor, oncology nurse, or physical therapist to discuss what level of activity might be optimal for you.

[Linda]

A final suggestion for avoiding barriers to communication—work at becoming better at asking for what you need. This applies to you, the survivor, as well as to family members who need to ask assertively for what they need. At times of serious illness and increased tension, many people put their own needs on hold and feel that it would be selfish to ask for something they personally want, or that it would be wrong to keep up with their own personal interests. After a while, this denial of personal needs can become the family norm, and resentment builds up. **Do not** assume that other family members know what you think, feel, or need. They are involved in the same situation and may not have taken your needs into account. Similarly, you may have overlooked their needs and concerns. Eventually, you and your family will return to normal, but it will be a “new normal.” Living with a diagnosis and history of cancer does change some things, but not all change is bad.

[Linda]

In fact, managing a serious medical condition over an extended period of time frequently leads to a higher level of functioning for the entire family. Families often draw closer together and can handle minor

problems and stresses more easily. They may be able to communicate with each other more directly. They may get to know one another better and be able to recognize and acknowledge one another's strengths and weaknesses and provide support as needed.

[Linda]

Good family communication skills can be learned, but you may need to get some specific training for dealing with cancer-related communication issues. If your family doesn't have the communication skills it needs, help is available. Talk with someone from your health-care team, attend mutual support groups or community programs specific to cancer-related problem-solving, or seek some individual or family counseling.

[Narrator]

We've covered a lot of ground in this section. To learn more about communication skills, listen the *Cancer Survival Toolbox* program entitled "Communicating." You can find more information on workplace discrimination in the Toolbox program entitled "Negotiating," or in the free booklet called *Working it Out: Your Employment Rights as a Cancer Survivor*. Information on ordering this booklet can be found in the resource booklet that accompanies the *Cancer Survival Toolbox*, or online at www.canceradvocacy.org.