

## [TRACK 6: SURVIVOR STORIES: PROBLEM SOLVING]

### Sandra and Jean, Part II

[Jean]

Of course, other issues came up. Part of my treatment did make me pretty sick. And, I was so afraid. I was afraid of becoming a burden on my family and friends. My parents came out and, of course, I worried that taking care of me would affect their health, too. I worried that my relationship with Hal would suffer. I've heard stories about how some marriages fall apart because of the stresses of dealing with cancer. I worried about the costs of my care - all of the medicines, the special equipment that we used in our home, and things like that.

[Sandra]

You know, it was a help to know that Jean's worries were pretty typical for people facing cancer. So common, in fact, that I could guess what would happen - what Jean was going through, her physical needs, her worries and concerns - before they actually happened. Being able to think of likely problems - and solving them before they became problems - would be key to how everyone would cope. What I know about Jean's kind of cancer and her treatment, and our discussions with her health-care team, helped us plan for her physical and emotional needs. One of our friends, Bonnie, is a social worker. She helped Jean, Hal, and Erin talk with each other about things that really matter to them.

[Sandra]

Bonnie reminded us - Jean's caregivers - to take care of ourselves, too, so that no one would get burned out or feel overwhelmed. Jean agreed to be honest with us about her needs and that helped us come up with a schedule of shifts, so that a caregiver would be with Jean whenever she needed it. This allowed everybody to be a part-time caregiver when it fit into their schedules best. Caregivers' lives were disrupted as little as possible - while at the same time, allowing us to help our friend in this very special way.

[Sandra]

We also arranged time for Jean just to be with her family - which gave the caregivers a break, too. Jean, Hal, and I talked about how to make time when they could just be husband and wife - not patient and caregiver. I showed Erin how to do some of the nursing tasks for Jean. I know Erin took great pride in developing these skills and in being able to help her mother in important ways.

[Jean]

Oh yeah, Erin also loved learning how to cook from our friend, Tom, who's a really good cook. Hal was very patient with some of the recipes Erin made especially for him. Some of her early cooking "experiments" have become great family stories. You know, Erin really grew as a person through it all.

[Sandra]

Jean's cancer is under control, and she has gone back to work. The roles in her family continue to change as everyone's needs have changed over time. Erin cooks dinner for the family pretty often now - and our whole caregiving group gets together a lot with Jean, Hal, and Erin, just to have fun. Our friendships are so strong now. While I know that caregiving can be an emotionally and physically draining experience, I found it to be a very special thing that I could give to my friend. Taking care of people with cancer is the profession I love, and having the knowledge and

skills to care for my friend has really given me some of my most rewarding caregiving experiences.

[Narrator]

In this situation, a circle of friends came together to help one of their own. Each friend had something special to contribute - one, her nursing abilities, another, her knowledge of emotional and social needs, and yet another, his cooking skills. From this example, we can pick out elements that lead to the success of any caregiving experience. · First, potential problems were identified, and caregiving plans were carefully thought out. · Second, the person with cancer was very involved in developing caregiving plans. · Third, no one person was left to assume all caregiving duties. Instead, tasks were shared, and caregivers were expected to pay attention to their own needs as well. · Fourth, caregivers were invited to contribute in ways that used any unique skills they have. · And, fifth, each family member's needs were very much a part of the total caregiving plan.

[Narrator]

Cancer creates a crisis of some measure for almost all families. We know that when people are living through a crisis such as cancer, their usual ways of solving problems and their normal ways of coping might not work as well as they did with past problems. They sometimes don't even know how to think about the problem, how to decide what should be done, or even what they can do to get the problem under control. In short, for a while at least, the family may feel too overwhelmed to put a workable plan in place.

[Narrator]

Most of the time, a crisis has a time limit - usually about 4 to 6 weeks. By then, people have adapted to the problem and have started finding ways to deal with it. Sometimes, though, the burden seems too great and families get stuck. They can't seem to find a way through the crisis, and they may need some outside help to get them moving forward. Listen to the problem that Bob and Mary faced when Bob needed surgery that would change the way he looked. Bob became so depressed about his cancer that he stopped going out. Mary didn't know how to help her husband and they became isolated - alone with the cancer.

### **Mary, Part I**

[Mary]

Last year, right after we celebrated our 45th wedding anniversary, my husband began having severe pain in his left jaw. We were shocked to learn that he had a cancerous tumor in his jawbone. The doctors explained that the only treatment was surgery. It was very hard for us to take it all in, and things seemed to happen so fast. I was surprised at how short a time Bob was in the hospital after surgery, and I didn't get very much training about his care before he came home.

[Mary]

Even with the home nurse coming by to change his dressings, there was so much to do. Preparing his special food took a long time each day, and we had a hard time keeping his pain under control. But most of all, it was hard dealing with Bob's moods. At first, he seemed angry at everyone, me included. He didn't want any visitors, and he refused to go out. He said he felt like a freak - that he didn't want people staring at him. The doctors had suggested reconstructive surgery, but Bob was having none of it. He said they had already put him through enough. Every time I tried to bring the subject up, he would get angry and more withdrawn.

[Mary]

Another hard part was that Bob wanted me with him all the time. We have always been very close. We never had children and our relatives all live some distance away. But we had an active social life here and I thought we had lots of friends. Yet, after a few weeks the friends just seemed to fade away. I guess I can't blame them - Bob didn't make them feel welcome when they stopped in after his surgery, so soon they just stopped coming altogether. I began to feel more and more isolated, and sometimes I was even mad at Bob too. Sometimes, whole weeks would go by and I didn't see anyone other than Bob, and he seemed more and more depressed. Some days he hardly talked to me.

[Mary]

Through it all, my minister kept coming to visit, and he kept encouraging me to get out more. He even offered to help arrange for some people to come by and stay with Bob while I went out, but Bob didn't want that. Finally, my minister told me right out that he thought I needed some help. He suggested I call my younger sister and ask her to come for a visit. I knew Bob wouldn't like it, but I was feeling pretty desperate. Well, Judy's visit was a turning point. When my sister got here, she was shocked to see us both. She had expected Bob to look different, but she said I, too, looked sick and exhausted. I guess I did look a sight, I hadn't had my hair done in months and I had lost a lot of weight. I just felt worn out.

[Mary]

My sister just took charge. First thing she did was make a doctor appointment for me! I had a physical, and the doctor said my blood pressure was a little high, and I was anemic. Most of all, he said I needed some rest. I told him how worried I was about Bob, how he seemed so withdrawn and depressed. Dr. Morris has been our family doctor for more than 20 years. He called Bob right on the spot and told him he wanted the home care nurse to stop by again. To my surprise, Bob agreed.

[Mary]

When the nurse came, she spent a lot of time talking with both Bob and me about our feelings. She called Dr. Morris, who ordered an antidepressant for Bob's depression. Again, I was surprised that Bob agreed to take the medicine. I could see a difference in Bob's attitude over the next couple of weeks.

[Mary]

Meanwhile, Judy took me to the beauty shop and we went together to my Bible class. She also took me to the cancer resource center at our local hospital. There was a social worker there who suggested I might want to join a family caregiver group. My sister went with me to my first meeting. It was so good just to see that others there had had problems like mine. After the second meeting, I began to understand how important it was to take care of myself and to feel connected to others. I made an effort to call up some of our old friends and get together.

[Mary]

One of the best things that happened was that the husband of a woman in our group also had gone through head and neck surgery for cancer. And he had had the reconstruction work done. I invited this couple, Jim and Betty, to our home for dinner. Jim and Bob really hit it off. They liked many of the same things - especially golf. Bob said he hadn't played golf in almost a year - that he couldn't stand the thought of people staring at him. Jim said he felt the same way at first after his surgery, but he refused to let cancer rob him of the joy of golfing.

[Mary]

About a week later Jim stopped by early one Saturday morning, and he actually talked Bob into going out to hit a few golf balls. And just yesterday, Bob told me that he had been thinking about going to see that plastic surgeon that his cancer doctor recommended.

[Mary]

It seemed like we had both gotten so far down after the cancer, that we couldn't get out of the situation by ourselves. I just stopped realizing that there were people who cared about us and who wanted to help - my minister, my family doctor, my sister, and many others. I go to the caregiver support group every week. It helps me to realize that I'm not the only one with problems, and it helps me put my problems in perspective.

## **Mary, Part II**

[Narrator]

Bob and Mary had been overwhelmed by Bob's cancer and his surgery. They had no immediate family in the area, and Bob's anger and depression made it hard for friends to help. When Mary stopped going out, too, there was no one left to help them. When two people are involved in the same crisis, it becomes almost impossible for them to support one another equally because all of their emotional energy is going into managing the crisis. When this happens, outside help is needed, and families need to be aware that there are many people and resources to support them.

[Narrator]

Let's try a short exercise. Take out a sheet of paper and a pencil. Make a list of all possible resources that you know about - ones that you can take advantage of if you need help. You might start with the nurse in your cancer doctor's office. Add your place of worship, the American Cancer Society, or the cancer resource center of your hospital. Go through the yellow pages of the phone book. Reread all of the materials you received when you were discharged from the hospital. The next time you visit your cancer doctor's office, pick up any brochures that are on display in the waiting room. Add these resources to your list. Then, make a second list with the heading of "People I Can Count On." Put their names and what they could help you with if you needed assistance.

[Narrator]

Whenever someone asks if there is anything he or she can do for you, add their names to the list. People genuinely want to help others who are having a hard time. Sometimes, we let pride, shyness, or exhaustion get in the way of asking for help. Or, we become so overwhelmed that we can't think where or to whom to turn. You'll find that there are probably many resources and many people out there to support you.

[Narrator]

Oncology social workers, like Linda, will have specific suggestions for families who are in the midst of a crisis.

[Linda]

Based on the work I've done with many families in crisis over the years, I have several recommendations that might help you when your family is struggling with managing a problem as big as cancer. These suggestions are especially geared toward caregivers. · First, keep to your

usual activities and routines as much as possible. This includes your hobbies, sports and exercise programs, and spending time with friends and other family members. · Take routine breaks from discussing and living the cancer crisis. Vacations, even if only for a day or two, can help you take a much needed break and come back better able to do your caregiving role. · Even if your loved one is extremely ill, try not to exclude him or her from your family decision-making process. While some family roles may need to shift, all family members, including the cancer survivor, need to feel that they are a valued part of the family system. · Don't assume that other people know what you think, feel, or need. Ask directly for what you need. · Ask for assistance from extended family and friends for help with things like picking up a prescription, grocery shopping, or helping get your loved one to a doctor's appointment. They'll be glad they can be useful. · Don't cut yourself off from people and groups who can support you. For example, if you have always gone to religious services on a regular basis, keep on going. Or, you can ask your clergy-person to stop by when you can't attend services. · Likewise, don't put your own needs on hold. Keep appointments for medical and dental checkups, and for personal care. Being a caregiver can be exhausting and it can take a toll on your health. Eat a healthy diet, exercise, and get as much rest as you can. Remember, if you get sick, it will only make the situation worse. · Don't allow yourself to feel you have to do everything. While you may want and need to be the main caregiver for your loved one, keep in mind that others can help, too. You don't have to be present all the time. In fact, if you never leave your loved one with anyone else or if you never go out, you may be contributing to making him or her overly dependent on you. · Finally, find a strong support network. Talking with people with similar experiences or those in similar situations can be very helpful, and you realize you are not alone.

[Narrator]

There's no question - being the caregiver for a loved one who has cancer is a hard job. No matter how much you love that person, there are times when you will feel burdened and exhausted. The most important things you can do are take care of yourself and reach out to others. Don't let cancer isolate you from those who are there to help.

[Narrator]

At some point after you first face a crisis, things seem to settle into a new routine. The cancer treatment may end or become more manageable. The immediate crisis is over and perhaps your loved one may be able to resume the life that was put on hold. This is a positive change, but it creates the need for a change in family roles again. If these changes become difficult for you, you may benefit by talking to a social worker, oncology nurse, or support group about the situation.

[Narrator] As a caregiver, you've got so many roles and responsibilities. You've got at least two lives to think about, yours and the person you are caring for, so many decisions to make, and problems to solve. Negotiating is a crucial skill for you, as Mei Ling's situation shows.