

[TRACK 7: SURVIVOR STORIES: NEGOTIATING]

Mei Ling, Part I

[Mei Ling]

My husband had just been diagnosed with lymphoma. We have two young children, who are four and six. I have a full-time job. I also take care of my husband's mother. She needs to have someone checking on her daily. I take her shopping, prepare her meals, take her to the doctor, and on and on.

[Narrator]

Negotiation is a process through which two or more people exchange their viewpoints on an issue, clearly state their needs and desires, and try to reach an agreement they can both live with. Caregivers often may need to negotiate not only for themselves, but also for their loved ones- at the same time. Negotiation requires good communication, the ability to identify and express your needs, knowing and setting your personal limits, setting aside your emotions, and showing a willingness to look for more than one solution to any problem. These skills often lead to what we call a win-win situation.

[Mei Ling]

After the shock of my husband's diagnosis, I realized that I would need to quickly make some changes in our current situation. I was already stretched in my ability to care for my family and my mother-in-law. My husband's physical situation became bad overnight, it seemed. The lymphoma affected his ability to work, drive, walk, and care for himself. After his surgery, his doctors told us that he needed six weeks of daily radiation therapy and chemotherapy. They also said that we might not see a lot of improvement in his physical condition until toward the middle or end of the treatment.

[Mei Ling]

We don't have any other family in this country except my husband's mother. How was I going to take on even more? What was I going to do without my husband to take charge and make decisions? He needed me to take some of the responsibilities that he had always done, you know, paying the bills, managing the finances, handling the car service and repairs. The list of responsibilities I would need to take over was getting bigger and bigger. I was scared. I didn't know what to do.

[Mei Ling]

The doctors and nurses called the oncology social worker. I spoke with her about my situation and resources available to me. We looked at some options for my husband, my children, and me. One option I definitely needed to learn about was the Family Medical Leave Act. The social worker was able to help me understand the law which says that family members can have unpaid time away from work to take care of other family members without being afraid that their job won't be there when they can return to work. This law applied to my situation because I worked for a company that had more than 50 employees.

[Mei Ling]

With good information, a plan, and having practiced what I would say, I met with my boss about taking the next six weeks off to care for my husband and take him to daily radiation treatments. I knew this was not a great time to be taking time away from my job. Yet, I also knew that I needed the time to take care of my husband and work on additional plans for the rest of my responsibilities. My boss and I were able to negotiate the time off to my satisfaction.

[Mei Ling]

Looking at the whole situation, I knew that I needed to fix some other areas in my life that take a great deal of my time. I had found the social worker to be very helpful, so I met with her again to discuss the care of my mother-in-law. I had recently read an article in a ladies magazine that talked about the "sandwich generation." I could really identify with this. I was not only raising two children, but also taking care of an elderly parent. I felt like I was pulled in all directions. Sometimes in the past, I had felt like I didn't have time for myself. I felt I didn't really have a life. Now with my husband's cancer diagnosis, I knew, more than ever, that I needed to deal with some of these feelings and the issues involved.

[Mei Ling]

I know Mother and my husband have strong feelings about my involvement in her care. In our culture, this is very important to them and to me. The social worker did help me think about ways that someone else might manage my mother-in-law's actual physical needs, yet I could remain in charge and oversee that care. This helped me look at my concerns in a way that did not mean that I wasn't doing the things that I thought were important. We talked about the people who could do this care. We thought about other family members for support even though they lived far away.

Mei Ling, Part II

[Narrator]

Again, Mei Ling sought information. She took time to set and understand values and limits. She tried to step outside her emotions and look for more than one solution to her problem.

[Mei Ling]

The other concern that I had at this time was with my husband. He very much wanted to continue in his role as provider and decision maker for the family. This was becoming harder for him to do especially with the treatment to come. The doctors were telling me that he would get more tired and sicker before he would get better. Already we were struggling with this change that was happening to us. I felt isolated and alone. My husband felt I wasn't telling him about everything. I felt he didn't want to talk about things that needed to be talked about. We needed help.

[Mei Ling]

It felt really good to talk to the social worker about these feelings and get some support. She had me attend a caregiver group that met while my husband was receiving treatment. The program was called Strength for Caring. I got a lot of help from the materials passed out at the meeting and from the group members themselves. I also got the strength I needed to negotiate with my husband on the changes in our roles and responsibilities. I was able to put aside my feelings and look for what the social worker called a "win-win situation" for the both of us. I asked my husband to meet with the social worker and me once he started into treatment, and I felt he could handle the time and energy that this would take. We found ourselves negotiating our roles right there with the social worker. It helped to have someone in the discussion who could be very objective for both of us.

[Linda]

Here's a recommendation I make to all caregivers I work with. If you are able take a few moments now, listen to the instructions and then stop this audio program and sit in front of a mirror. Pretend that you are talking with the person or persons with whom you need to negotiate. Rehearse what you would say to them. How do you look in the mirror? Are your emotions showing clearly on your

face and in your body language? Try it again. This time try not to let your face and body language show your emotions as clearly as the first time. This exercise may seem silly and awkward at first, but you will find that rehearsal will help you think about questions or stumbling blocks to the negotiation and will help you feel more confident. Mei Ling rehearsed her negotiation with her social worker. Some people feel more comfortable practicing with a friend or family member than with the mirror. Do what works for you.

[Linda]

Important tips to remember include: get good information, know your values, set your personal limits, control your emotions, and be willing to look at more than one solution to a problem. Create a win-win solution. Rehearse, rehearse, and rehearse.

[Narrator] When a child is diagnosed with cancer, it can cause overwhelming feelings in parents. Depending on the age of the child, it may be important for the parents to make sure that any special needs, whether they are related to culture, a school situation, or other concerns in the family, are communicated to the health-care team. Let's hear from Brian, who is 16 years old and his parents.