

Track 7: Role of the Caregiver

Narrator

A cancer diagnosis affects the whole family and it's important to talk about the stress and problems affecting family members. Many families find the uncertainty of chronic leukemia is one of the hardest aspects. In addition to the sources of support mentioned already, talking to an oncology social worker or counselor who understands cancer can be most helpful. In counseling, cancer survivors and their caregivers can learn strategies for anxiety management and stress reduction to use before, during and after treatment..

If you're helping a family member or friend through cancer treatment, you're a caregiver. Caregiving activities differ depending on the situation and need. Helping with daily activities, personal care, coordinating care and services, and giving emotional and spiritual support are just a few of the ways you can give care.

What comes naturally for most of us is to put our own feelings and needs on hold and to focus on the person with cancer. This may work for a short time, but it can be hard to keep up.

Julie

I'm Julie. My husband Bruce and I were talking with his doctor about treatments scheduled for the next few weeks, and my husband laughingly said, "I guess I'm ready to turn everything over to Julie for the next month. She has a hard time letting me do anything because I get so tired. I wish she'd let me push myself to do some things. I wouldn't feel like such a big lump."

I laughed along with him, but it got me to thinking and a little upset. The social worker noticed and said several women were having coffee next door, while their partners got chemo. She suggested I join them, said it might help to talk to other caregivers.

One of the people there was Susan. We had a lot in common. Our husbands were both being treated for CML. We both struggled between hovering over them and backing off when they pushed

themselves to go to work or to get out in the yard. We didn't want to take away the feeling they were doing what needs to be done.

Susan helps me to not feel so alone. We talk about our feelings, traded stories and advice. We're there for each other. When I'm struggling, I give Susan a call. It helps me get through the hard times.

Narrator

Taking care of yourself can help you be a better caregiver, and give you strength to do what needs to be done. Consider:

- Giving yourself an outlet for thoughts and feelings.
- Finding comfort by doing what makes you happy or relaxed.
- Joining a support group or finding a "buddy" going through a similar situation.
- Talking to a counselor.
- Finding time for special moments with your loved ones.
- Looking for positive moments every day.
- Laughing.
- Being grateful.
- Writing in a journal.
- Maintaining your regular activities as much as possible.
- Learning as much as you can about your loved one's medical condition. Knowledge increases understanding.
- Listening to the *Cancer Survival Toolbox*[®] program, "Caring for the Caregiver."

Julie

One thing Susan did was ask me each week if I'd done something to take care of myself. Susan encouraged me to think about myself while still focusing on my husband.

Narrator

As a caregiver, remember to care for yourself too. Your loved one will appreciate it. It will provide balance that will help keep your relationship strong during this difficult time.

Many caregivers find the experience changes them. Each is affected in a unique way. Each shows great courage.

Julie

Caregiving also means we have to be problem solvers. Susan has a five-step approach. I've tried it and it helped me find better ways to care for my husband when he was dealing with a lot of fatigue. The steps are:

1. Identify and define the problem
2. Gather information
3. Plan your action
4. Carry out your plan
5. Evaluate your plan and make necessary changes.

With the fatigue, one action idea for my husband was a daily nap. We nap together, and it gives us both energy to complete things we might have had to miss.

I suggest looking at caregiving as problem solving. It's a positive approach.