

[Track 5: Concerns of Caregivers]

The decision to have a transplant has an impact on your family and caregivers. Let's listen to some of the issues caregivers face when supporting their loved ones.

Support Group #2: The blood and marrow transplant center

As this caregivers' group illustrates, uncertainty as well as distressing side effects are often part of the blood and marrow transplant experience.

Emily: Welcome to tonight's group. We offer this drop-in group for those of you caring for friends or family undergoing transplants here at our center, because we know this experience can be very stressful for both the patient and the caregiver. We invite you each to talk about whatever you wish to talk about, since everyone's experience is unique as you support your loved one through this.

Ron: Well I'd like to go first since I've got three little kids at home and I'll have to step out early to call them before they go to sleep tonight. This has probably been the hardest on my wife, Patrice, who's still here in the hospital with her blood counts coming back up. It's been really rough. She's had all kinds of stomach trouble and has lost a lot of weight. Now she's getting this rash on her legs, which could be what they call graft-versus-host-disease. I'm not sure how much more she can take.

Dora: I hear you Ron, but hang in there. My husband went through a transplant two years ago and I remember thinking after the chemotherapy he had that he wouldn't ever be the same, but he came through it and he's been great for two years. I've been sicker than he has with my heart problems. He had an autologous transplant so he didn't have to be in the hospital for as long as Patrice, but he went through a lot. We've said many times it was worth it because it got rid of his Multiple Myeloma. Now they think it's coming back, so he's going to have another transplant using his own cells again. We're hoping this one goes as well as the first. Your wife's young and she's got a lot to live for. You can get through this and get her through it, too.

Blanca: Listening to all of you, I'm feeling the same way. I'm Blanca. My mother has Mantle Cell Lymphoma and is receiving an autologous transplant right now. She'll need to be here at the hospital at least three to four more weeks. Her blood counts are down to nothing. She has no immunity right now. It's only been one week but I'm already exhausted. My mom just wants to go home. I'm afraid to leave her alone here. She gets confused and scared. I want to be here for her. I run back and forth from the hospital to home and work, but I don't know how I can do everything. I wasn't going to come to this group. I'm glad I did though. Being here and listening to all of you helps me to not feel so alone.

Randy: Wow, Blanca, I can relate to you. My name's Randy. My partner Lee has lymphoma. We've been together for nearly 20 years. Lee's currently having chemotherapy. He's been getting weaker with each chemo treatment. I also think he's having what the Nurses call "chemo brain." He forgets everything. He has trouble thinking of the words he wants to say. He even gets confused. I feel like I need to be with him all the time, to interpret and make sure he's safe and calm. The good thing is the Nurses have told us "chemo brain" usually improves the further from

the transplant Lee gets. We're trying to complete some legal paperwork right now. Something we never got around to before. We need to do it now, before the additional stresses of the transplant, and while he's able to make these decisions clearly. I hope we haven't waited too long at this point in the event I have to make important decisions on my own down the line. We discussed his wishes when he was diagnosed and Lee said he didn't want me to run into health and financial legal problems during this crisis.

Diane: My brother has leukemia and I'm the donor. I felt so good that my stem cells were a match for him, but now he's got this awful reaction where my stem cells are attacking his body and I feel so guilty. I'm taking turns through the day and night in his isolation room with my parents since my brother's so weak so we don't dare leave him for long. Everyone tells me not to feel guilty because giving him my stem cells is his best hope for a cure and he's determined. But it's hard to watch him go through this. I just keep praying he'll start feeling better.

Nancy: We know that transplants can be very stressful for caregivers. There's a great deal of uncertainty watching the people you love go through some difficult times. The symptoms and side effects you've mentioned are expected—some more than others—and it's important to accept support for yourselves because this is more like an endurance race than a sprint. You've got to get enough sleep and nutrition and respite to get through the long haul.

I want to mention a few resources that can help caregivers. The National Family Caregivers Association—NFCA—has so many resources for education and support for caregivers. Just quickly – they have a list of six steps caregivers can use to get help:

1. Recognize caregiving is like any job, made up of lots of tasks.

2. Recognize that asking for help is a sign of strength and not weakness.
3. Create a list of tasks that need to get done in any given week.
4. Group your tasks into categories – like personal care, transportation, household chores, groceries...
5. Write down your caregiving worries: you'll find seeing them in black and white can help diffuse some of the emotion and help the caregiver to think more rationally.
6. Share your lists with someone you trust before reaching out for help – this helps to get comfortable with the idea of talking about the need for help.

Now, another wonderful resource for caregivers comes from the National Bone Marrow Transplant Link – *The Caregivers' Guide for Bone Marrow/Stem Cell Transplant*.

And, CancerCare has a podcast, “Helping Children and Teens Understand When a Parent or Loved One has Cancer” and other publications on similar topics. The Leukemia and Lymphomas Society also has caregiver resources and support on their website. Last, I will just reiterate that many social workers are experts in family and child-life issues. I want to remind you, too, that I'm available to talk privately with you about these normal feelings you're experiencing.