

[Track 3: Common Concerns]

Support Group #1: Patients and Caregivers

Narrator: To get a sense of what some cancer survivors experience with transplants, let's listen in on a meeting of a patient and family support group.

Emily: Welcome, everyone. Tonight, we're talking about blood and marrow transplants. For the benefit of those new to the group, let's have each member tell us a bit about yourself and what your questions and concerns are.

Winston: Hello, everyone. I'm Winston and this is my wife Dora. I've been coming to this group for a long time I had an autologous transplant two years ago for multiple myeloma and I've been doing great. In fact Dora's health has been more of a problem than mine this past year—she has respiratory problems. I'm a minister and I had to retire to help take care of her, but I was really feeling blessed. I had a transplant that worked. But, my protein levels have been rising and I'm going to have a second transplant. I have Social Security now and so Medicare is going to pay for the second. But I have to admit I'm really frustrated. It's a lot to go through once, never mind twice. I just hope this one goes as well as the first.

John: Hi, my name's John. Three months ago I graduated from the University. I'd just started my first job at this amazing company in their software development division when I became sick. The Doctors say I have Hodgkin lymphoma. They say I need a blood or marrow transplant, the kind where they take my own stem cells from the blood or marrow. I don't need a donor. They're

going to give me high doses of drugs to kill my immune system and this may make me pretty sick. I'll have to be in the hospital for possibly a month. I don't have time for all this right now. I may lose my job. I'm living with my parents again. I feel like my whole life has been turned upside down. It doesn't seem real. It feels like I'm in a bad dream and I can't wake up. On top of all of this my parents want me to donate sperm to a sperm bank. I don't know if I can even think about sperm banking right now. I don't want to think about having babies. I just want my old life back. I can't believe I just told everyone all this.

Bill: I'll go next. I'm Bill. Thanks for being so brave, John. I can't imagine how you must feel, but I think it's great you've been so honest with us. I have chronic lymphocytic leukemia. I have several other medical problems—diabetes and a heart problem. I suffered a heart attack a year ago. The Doctors are talking to me about a non-myeloablative transplant. They keep calling it a reduced intensity transplant. Because of all my medical problems, they feel this is my best option. I'm not sure about any of this. What will this do to the rest of my problems? Will I be able to make it through even the reduced intensity transplant? I worry they'll do more testing and this option won't even be available any longer. I thought I was going to get more chemotherapy, but they don't think I can handle more of that right now. I also worry about my wife and what this means for her. We aren't prepared for me to not be able to do my share, or, worse yet, die. I've said it. I'm afraid of dying. That was pretty hard. My wife is a great support, but I can tell she's scared, too, and I know she thinks about me dying. I came to this group to get information to help me make some decisions. I guess it's already helped me face the fact I'm scared of dying.

Patrice: Well I'll go next since I'm terrified and I came to this group so I can meet other people who know what it's like to have leukemia. I have acute myelogenous leukemia, and my hematologist said an allogeneic transplant—a transplant from a donor—is the best way to achieve a remission for my kind of leukemia. I have three sisters and a brother. My brother, it turns out, is the only match but he can't do it for his own health reasons. So, through the registry they found an unrelated donor.

This is my husband, Ron, and I know this is really stressful for him—the medical expenses are piling up and the transplant center is two hours from where we live. The kids are only 4, 7, and 9 and I'm going to be away for so long. We never expected to have to deal with anything like this.

Lourdes: Buenos noches. I'm Lourdes, and this is my daughter, Blanca. Two months ago they told me I have a disease in my lymph system called Mantle cell lymphoma. I'd never heard of it before, and the cancer Doctor at the medical center told me it is not the most common. She said there are many types of lymphoma. At first the Doctor told me the best treatment is a transplant where they take bone marrow from a donor and give it to me. My family and friends all signed up to be tested, but no one was a good enough match. Then they looked in the Registry for a donor for me but they still couldn't find a good match. I don't understand it, but they told me that there are just not enough Latino donors in the program. So now they're going to take my own stem cells, give me other treatments to get rid of the cancer and then give me my own marrow back—something called an autologous transplant. I'm very scared but I think I have to try for it.

Kay: Hello everyone. My name's Kay, and I'm here with my husband, Dale. It's hard for me to know what to say—how to describe what my situation is. I don't really have a blood cancer, but my bone marrow has stopped making blood cells. It's called a *myelodysplastic syndrome*, or MDS. No one knows for sure, but it's possible the MDS developed because of the chemotherapy I had years ago for breast cancer. I was told sometimes MDS can turn into a form of acute leukemia. Anyway, I usually have very low white and red blood cell counts, and low platelet counts. I have to have red blood cell and platelet transfusions, and I get medicines called “colony-stimulating factors” that boost up my marrow production of white blood cells. I worry about how many transfusions I've had, and how long I can keep getting transfusions.

We live out on the family farm—not close to any cancer center. Several months ago, we made the day-long drive to the University Medical Center to see the transplant specialist team. They don't think my body could handle a stem cell transplant. A few months ago, after the transfusions I needed got closer and closer together, we saw another transplant specialist out of state. This visit came out more or less the same way. I'm not a good candidate for having any kind of transplant because of other medical conditions I have. I always thought of transplant as a last ditch effort, something to do when you've run out of other options. But, now I understand that the best time to have a transplant is not when you're really sick—but instead, when you're in a fairly healthy state despite the condition of your marrow. I'm just not there. So, what's left for me is, basically, supportive care. I'm not giving up hope—and I don't feel my Doctors and Nurses have given up hope either. But, I'm trying to look at the reality of my health and condition—to hope for and work towards things that are, well, realistic for me.

Dale: Hi – I’m Dale, Kay’s husband. We’ve been together nearly 40 years. I don’t want to just give up—and I don’t want Kay to give up either. I can’t help but wonder if the Doctors in our area just don’t know as much about treating Kay’s illness as Doctors in university cancer centers. I feel guilty—like maybe we waited too long to go to see the people who really specialize in this disease. Maybe I should have insisted we go to the University Center in the very beginning. Maybe then, Kay might have been able to get a transplant.

Kay: It’s hard to say. But, living where we do, and how we live, I guess I’m not sure I’d opt for the transplant even if it were offered. As I’ve learned more about transplants, my condition and my other health concerns, I know my chances of making it through the aggressive therapy would be low. I don’t want to spend so much of this part of my life being in the hospital that’s so far from home, from our kids and grandkids, from my friends. As it is now, I get my blood counts tested often, and I have transfusions. I take care not to be around crowds, and when my low white blood cell counts make me susceptible to infection, I stay away from the grandkids. That’s maybe the hardest part for me. But, otherwise, I can’t say I’m real uncomfortable. I don’t have pain. I’m able to do other things that don’t involve a lot of physical energy. One very special and enjoyable thing I’m doing—I’m going through stacks and stacks of old photographs—noting locations, dates, names of people in them—that sort of thing: I know my kids and their kids will appreciate this—at least someday. It’s sort of my way of leaving a legacy. It’s kind of a bittersweet thing to be doing, but it’s something I very much want to do.