

[Track 7: Longer-term Considerations]

Narrator: You can see that while both John and Patrice are doing fairly well, they both have some side effects from their transplants. Let's also listen in on our support group one year later. Tonight there's a special guest, Daniel, the long-term transplant survivor, who we heard from previously.

Support Group #3: Patients and Caregivers one year later

Emily: We'll open our group tonight with our usual check-in before our guest, Daniel, speaks to us about his experiences since his transplant 14 years ago. Patrice, we haven't heard from you in a while. How are you doing?

Patrice: (Sigh and in quiet voice). Well, as you can see by my skin, I'm still dealing with this horrible GVHD. I guess it's the chronic type. It's still a shock when I look in the mirror, but I am seeing improvements. I'm taking an antidepressant, because my mood was affected by the steroids. Our daughter is also still dealing with the effects of my being in the hospital, so our family is seeing a Social Worker to help us work through everything we've experienced.

Transplant has brought some challenges, but I am feeling better.

Lourdes: I'm seeing a Social Worker, too. I don't have that graft problem because they never did find a donor match for me and I had the transplant with my own marrow. But now the Doctors say my one chance is to go with a donor that doesn't match as well as they'd like, and I have to decide if it's worth trying it. There's more chance my body will react like yours, Patrice.

This is the hardest decision I've ever had to make, so I'm taking time to think it over very carefully with my family.

Winston: I never thought I'd outlive my wife, but I got through my second transplant and here I am, without her. You remember she had serious heart problems. When they got really bad, she didn't want to be resuscitated and she died peacefully at home. After her death, I wasn't so sure I should try for my second transplant, but I did it and here I am—back feeling pretty well again. I've slowed down but it was worth it. I've got more time to see my grandson graduate from college—the first in our whole family—and that's a big goal for me. I'm so sorry it's been rough for you, Patrice, and Lourdes, I'm going to pray that if you try this second transplant, it goes real well.

Emily: John, we haven't heard from you yet.

John: Well, it has been quite the year for me. I'm back to work, I met a wonderful woman, and we got married. I hate to admit it but I'm glad my parents pushed me to do sperm-banking. I'm going to need that sperm to start a family. I'm also seeing a Social Worker for depression. My Doctor and everyone say that after the year I've been through it's normal to have some depression. My wife is very supportive and she's going to therapy with me. This is just another reason why I love her so much.

Emily: Bill, what's been happening with you?

Bill: The first few months of treatment I did well. My heart disease and diabetes didn't give me any problems. But once I started tapering off the medicines, I had really bad problems with GVHD. I had a lot of stomach problems. I lost weight. I couldn't eat what I was used to eating. It was pretty bad. Then finally I realized this was a wakeup call. My Doctors had been talking to me all along about the way I ate, my lifestyle, my habits, my lack of exercise. Today I no longer smoke or drink more than a glass of wine a day. I eat fruits and vegetables now and I don't even crave the fried foods and sweets any more. My wife and I are walking. I try and focus on these things I can control, because so much of what went on was out of my control. I hope to get to a point where I feel better than I have felt in a long time. I appreciate this group and everyone's help over this past year. I want to continue to help others like I've been helped.

Dale: I'm Dale. Some of you might not know me. My wife, Kay, and I used to come to this support group when she was living with MDS. Well...she passed about 6 months ago. At the end of her life she seemed satisfied that she'd fought the good fight with her illness, that she'd done what she needed and wanted to do, and was prepared to die. I kept hoping for a miracle. That didn't happen. But, I do get peace of mind knowing that we did the best that we could do given the cards we were dealt. I was able to take her to two of the best treatment centers in the country—with Doctors who specialize in this disease. I don't have to live with the "what ifs" – I have no second guessing or regrets about the decisions we made about her illness. I'm not saying it's easy to be without her. I miss her. I get lonesome. At least I get lonesome when my kids let me! (chuckles softly) They, and the grandkids, do keep me occupied. I came here tonight, though, for the first time without Kay. Being here with you, people who really understand what Kay and I went through, helps me and I want each of you to know how much you've helped us.

It's hard to be a caregiver—that time is so intense—and now, there's just a big empty hole in my life. But, I'm not just sitting around feeling sad. I keep busy. Best of all, I found out there's going to be a new grandchild in another few months. I just want you all to know how much you meant to Kay and thank you for being one of the good things to come out of Kay's illness.

Emily: Thank you for that, Dale, and thank you all for the updates. I hope we'll be able to address many of your issues tonight, especially when we hear from our special guest, Daniel. In addition to being a survivor, Daniel has also become an Oncology Nurse Practitioner. So he can give us two perspectives.

It may seem discouraging to some of you that it's been over a year since you were treated, yet you're not fully recovered. You may wonder if you'll ever feel normal again. So let's spend a little time talking about what "normal" means to someone who's had a transplant.. I can't think of anyone more qualified to lead this discussion than Daniel. So, Daniel, I'm going to let you first introduce yourself by telling us your story and then have you talk about what "normal" now means to you.

Daniel: Thank you so much for the invitation to speak to you all. It was well over a decade ago when I was in the very same situation you are in today. I was diagnosed with chronic myeloid leukemia—or CML—at the age of 28. After undergoing high dose chemotherapy and total body radiation, I underwent a transplant from an unrelated donor..I also suffered from graft-versus-host-disease, along with a long list of other lingering and late effects. Early after the transplant, walking up a flight of stairs was my exercise for the day. To say that my body felt "beat up" or

like I was “run over by a truck” is a true understatement. The toll therapies take on our bodies can last for years, and I’m still dealing with some medical issues. But even more than that, I never expected the huge impact this disease and treatment would have on my emotions and mental health. And – just like the typical male in our society – I felt it was a sign of weakness to ask for help. At some point I realized I couldn’t handle the stress of being told I have a life-threatening illness, and I saw both a Social Worker and a Psychiatrist. I realized it’s a sign of strength, not weakness, to be able to ask for help. I was anxious and depressed, which is normal for people who are going to have a transplant. It felt like a roller coaster. I would have OK days and then I would have really, really bad days when I didn’t even get out of bed. My Psychiatrist prescribed some medication that smoothed out my moods. So my good days were better and I didn’t have as many really bad days. I really applaud you all for participating in this group so that you can both “give and get” continuing support for you and your family members.

So let’s talk about this idea of returning to normal. First of all, how many of you have had family members or friends say you can get back to normal now that your transplant is over? Or that you should just forget about the past and move forward? I see a few hands going up.

John: Yeah, all my friends are congratulating me for getting through this ordeal, and they think I can party with them like I used to. But I really don’t even want to do the crazy stuff I used to do, like drinking a lot or staying up all night. My priorities have definitely changed.

Daniel: Isn’t that the truth. Since a transplant is probably the most difficult treatment for cancer, it has a much longer recovery period than do other cancer treatments. We live for months or

years with GVHD, sometimes a visible and painful reminder of treatment. We may experience early onset organ problems, such as heart or lung damage. So the chance of feeling “normal” again is pretty far-fetched...that is, feeling the same as we did before we got sick. But that doesn’t mean that we can’t find our “new normal.”

Lourdes: I don’t understand. What you mean “new normal?”

Daniel: Actually, there are many ways to describe this concept. Our “new normal” will mean something different to each of us. Just go online and search “new normal and cancer” and see all the sites that have information about this topic. It certainly is being recognized now as a major part of cancer recovery. Here are just a few descriptions I’ve found. Some are negative descriptions, but there are just as many positive ones. It just goes to show you that we still have ups and downs, good days and not-so-good days. Sounds to me like this could describe just about anyone’s sense of what a normal life is. So ... a “new normal” could mean:

- Adapting to life after treatment
- Learning to live with uncertainty and risk
- Knowing more about our health
- Continuing Doctor visits and medical tests
- Living in a constant state of “watchful waiting” or worrying that it will happen again
- Feeling anxious and fearful about the cancer coming back
- Living with less energy
- Deciding what is now most important to us
- Appreciating new beginnings. This list could go on and on.

There's a really good essay on this topic at the end of the online Livestrong Care Plan entitled *The New Normal – Life as a Cancer Survivor*. I especially like the sentence: “Many survivors say they look at life differently, they don't take things for granted, and they don't sweat the small stuff.” So, I would say that there are just about as many ways to define this “new normal” as there are numbers of us living through transplants.

At this point, I want to switch gears and talk like the Oncology Nurse that I am. I want to emphasize the importance of follow-up care after your transplant. As you heard during the check-ins this evening, you all have a number of different challenges even though you had similar treatments. Some of you are still dealing with GVHD. You continue to be fatigued. Some of you are still concerned about your image and appearance due to the GVHD skin changes. Sexual problems are often ignored. Relationships may be strained. Post traumatic stress is often unrecognized. You all deal with the fear of recurrence in your own way. You may have taken a big hit financially and wonder how you'll be able to afford any more out-of-pocket expenses. And some of you are probably wondering if it's been worth all the trouble. I'm not here to tell you everything will get better with time. But I can assure you there are ways to make the best of your current situation by finding the right support and using the right tools. Let's talk about some of these tools, specifically a “Survivorship Care Plan” that guides long-term follow-up.

I can't say this enough: routine follow-up is important. Please do not ignore your scheduled visits to your health care team. We now have good guidelines to help us get the screening tests that are

needed to monitor our health. Unfortunately, we're at risk for any number of health-related problems after transplants. On the other hand, we have methods to identify symptoms early so we can prevent or reduce possible problems. Benjamin Franklin had it right when he said, "An ounce of prevention is worth a pound of cure." I practice what I preach, and it's so worth the time. I saw my dermatologist for a total body check because of the radiation. He found a spot that he removed on my leg that turned out to be precancerous. It was because I had a screening echocardiogram that I found out that my heart muscle was not working as well as it should have. I was started on some medication and my heart function has returned to normal. If I'd waited, it probably would have gotten worse and less likely to improve.

The following information I want to share with you is adapted from the module *Living Beyond Cancer* in the Cancer Survival Toolbox. This module includes a discussion about Survivorship Care Planning, along with information about what life might be like as a longer-term survivor. You can listen to the entire module for much more information. It can be accessed online or ordered as CDs.

The section about care planning starts with this paragraph: "Surviving cancer is more complicated than simply being sick or well, or having cancer or being cancer-free. Rather it's a continual process of survival and is constantly changing." OK, so you may ask, "What can we do to stay as well as we can after being treated for cancer?" Since little is known about preventing some of the fall-out after cancer, it's extremely important that we learn how to monitor our health and have regular check-ups. Meanwhile, here are a few suggestions from this module that may help you develop your own personal plan for life after cancer.

- Request an exit or transition interview with your Physician and Nurse if you're just completing your treatments, or make a separate appointment if you're a longer-term survivor. Have them help you create a monthly or yearly follow-up plan. How often do you need to be seen and by whom? What medical or diagnostic tests need to be done and how often? What are the possible risk factors specific to your case?
- Next, request copies of medical records if you have not been getting these reports already. These would include surgery, pathology, x-ray and other reports. Also include details of all cancer treatments: the names and doses of all chemotherapy drugs, and the amount and location of radiation therapy. Make sure that all treatments related to your transplant are included. Have them list any problems that may have occurred during treatment, and what to expect now that you're finished. Make sure you have all medical summaries from your healthcare team.
- Get the name and phone number of someone you can call if you become anxious or have questions. Besides the numbers of all your Doctors—and this would include Nurse Practitioners and Physician Assistants—you will want the number for your Oncology Nurse or Social Worker. They are often much easier to contact than your Doctor. They can often answer many of your questions, and can help point out symptoms that may need further attention. They also can refer you to support groups or other community resources that offer continuing support to survivors and their family members when you are no longer receiving treatment or are on maintenance therapy.
- And finally, if a long-term follow-up clinic (sometimes called a late effects or survivor clinic) is available, do try to be seen there if possible.

Your follow-up care after a blood or marrow transplant is usually more rigorous than other survivors receive, so you'll most likely have regular check-ups with your health care team for many years, and possibly for the remainder of your life. Your transplant team cares passionately about you as a long-term survivor. They also understand the specific issues you will face and will be there to support you.

Narrator: The information Daniel just discussed is really only the first part of a survivorship care plan. It's the historical summary of what happened to you during treatment. To help you collect this information and create this part of your care plan, you may want to use a ready-made outline available to both you and your medical team. You may want to look at both *Journey Forward* and the *Livestrong Care Plan* for examples. Be The Match also offers post-transplant guideline booklets—one for autologous transplants and one for allogeneic transplants. These are noted in the booklet that comes with this module. Or, you may already have a plan that was created by your own clinic or hospital team.

Once this part is complete, you can move on to developing the second part of the plan, which helps you move forward and look more to the future. This can also be seen as a wellness plan and will change over time. With the growing number of survivors, we're learning more each year from them about the value of exercise, healthy nutrition, and stress reduction to improve recovery and quality of life after cancer treatments.

An interesting thing to keep in mind is that not everything that happens to your body post transplant has to do with the transplant. While any illness will trigger fears related to the

transplant and your cancer, especially in the first few years, the further you get from transplant, the more likely you'll once again be dealing with general illness issues like everyone else, as well as the natural aging process. In other words, at some point the "new normal" and the old realities merge, and you'll begin to realize that not every health issue has to be related to the transplant.