

[Track 4: Before the Transplant]

Narrator: From this conversation, you can see members of the support group are at various stages regarding transplants. Let's follow two of our support group members as they go through a consult with their medical oncologist. First, let's join John.

Doctor Griffin: John, good to see you today. How have you been feeling since your last chemotherapy treatment?

John: Other than being a little more tired than usual, I've been feeling good. Is my last round of chemo still a go today?

Doctor Griffin: You bet. The scans you had two days ago are clear—there's no evidence of your cancer. But before you head to the infusion room, I want to talk with you again about the next step, transplant.

John: Do I still get to be my own donor? I remember you saying that was the plan.

Doctor Griffin: Yes. Your own stem cells will be collected and frozen until the transplant.

John: So, when will all this start—collecting my stem cells and getting the chemotherapy?

Doctor Griffin: That decision's made by the transplant Doctor. He'll likely order some tests to get a good idea how your health is after chemotherapy. It will also be important that you're

feeling good. I'm going to schedule an appointment for you to meet with him in the next few weeks. Do you have any questions?

John: I do, but I guess I'll wait until I meet with the transplant Doctor. I'll make a list of my questions. Becky—my favorite Oncology Nurse—always reminds me to write my questions down so I don't forget!

Doctor Griffin: I always appreciate it when someone brings their list of questions—it helps me know what's important to them. One other suggestion, have someone close to you go with you to the appointment. I'd suggest whoever will be your primary caregiver during the transplant, so they can also hear the information.

Narrator: Before the transplant begins, the transplant Doctor orders tests such as an EKG and an echocardiogram to assess cardiac function, pulmonary function tests to examine the health of lungs and breathing, a chest x-ray, a dental exam, and infectious disease blood work to make sure there are no infections that would prevent the transplant. You'll also have Human Leukocyte Antigen (HLA) tissue typing for allogeneic transplantation. It's part of the process to identify potential donors, and also gives your Doctors guidance about what kind of transplant they can use. In addition, the Doctor may encourage you to meet with a psychosocial provider, such as a Social Worker, to discuss the emotional impact of the transplant and to ensure that you have enough support after the transplant.

Let's now join Patrice.

Doctor Griffin: Patrice, I'm glad you and Ron could come in today to discuss your upcoming transplant. How was your appointment with Dr. Lewis, the transplant Doctor?

Patrice: He had good news. He told us my pre-transplant evaluation went well—I passed all the tests to check out my heart, liver and kidneys. It also sounds like they found a donor. But, I have to be honest, I'm scared. I know I can do the chemotherapy, even though it's a higher dose than what I've had. I'm scared about how long I'll be away from home and my children. Dr. Lewis said I may need to stay near the transplant center for about 100 days after the transplant—that's over three months! Thankfully, I don't have to be in the hospital all that time.

Doctor Griffin: What suggestions did Dr. Lewis have when you brought up your concerns?

Ron (husband): He made sure we visited with the Oncology Social Worker at the transplant center. She gave us some suggestions about what to tell the children and ways Patrice can still feel connected. We also decided I'm going to stay home and take care of the children while Patrice is having the transplant. Her oldest sister is going to be her major caregiver during the transplant, and she will rotate with other family members.

Patrice: I'm so thankful my sister can be with me. But, I'm still worried about being gone so long. And I'm scared about all the possible complications. What scares me the most is “graft-versus-host-disease.”

Doctor Griffin: Patrice, you're right, all the information can be overwhelming and frightening. It's normal to be worried and scared about your disease and complications from treatment.

It may help to break down the transplant process into three parts or phases: the conditioning treatment, the infusion of stem cells, and the recovery. During conditioning, depending on the type of transplant and disease, patients get high doses of chemotherapy, total body radiation therapy or a combination of both. Side effects of the conditioning treatment can include nausea and vomiting, diarrhea, mouth sores, hair loss, infection, fatigue and others.

The second phase is the actual infusion of the stem cells. A day or two after the conditioning treatment, stem cells are given through an IV, much like a blood transfusion. For many people, the day when stem cells are infused seems like a second birthday: it's a chance at a second life. If donated stem cells were frozen, the preserving agent used can cause the recipient to have a strong taste of garlic or creamed corn. The recipient's body could also have the same odor. Both the taste and smell slowly fade away in a few days.

Recovery, the last and longest phase, begins when the stem cell infusion is finished. During recovery, recipients and family members wait for transplanted stem cells to move into the bone marrow. This process, called "homing," is likened to homing pigeons finding their way back home. After a few weeks, engraftment begins and stem cells begin to produce normal blood cells. During the first weeks after stem cells are infused, recipients have low numbers of red and white blood cells and platelets. Antibiotics are given to prevent or treat infections that occur because of reduced white blood cell levels. Red blood cells and platelets are transfused until

bone marrow produces enough healthy, functional blood cells. Other possible side effects include heart, lung, liver, and kidney problems.

Patrice, you said you think you'll have an allogeneic transplant, and you're worried about Graft-versus-host-disease, or GVHD. Many allogeneic transplant recipients go through GVHD.

Estimates are that as many as 70% of all allogeneic transplants develop GVHD. With GVHD, transplanted donor cells – or “the graft” - attack the recipient's body – the host - causing skin changes, damage to the digestive tract such as diarrhea and liver injury, and other problems.

Acute GVHD occurs soon after transplanted cells begin to produce new cells – usually within the first 100 days after the infusion of transplanted cells. GVHD that begins after the first 100 days is called Chronic GVHD. The effects can range from mild to severe. Medications are used to help prevent acute and chronic GVHD. It's important to know that transplant physicians and other members of the transplant team will help you and your caregivers to be as prepared as possible for any side effects that can occur.

Narrator:

As we noted earlier, decisions about if and when and what type of transplant are based on many factors. Some are physical such as age, type and stage of cancer, medical condition, illnesses and previous treatments. Other factors are personal such as emotional status, willingness and ability to be away from home, insurance coverage, financial resources and social support.

Your Doctor will discuss your transplant treatment options with you and answer questions you may have. This requires an open and frank discussion. It's often useful to take a family member or close friend with you when trying to gather the information you need to make your decision.

There are many questions you will want to ask, including:

- what type of transplant is recommended and why that type
- will they need to find a donor or will they use your own stem cells
- the goals of treatment (cure or long term remission)
- best timing of the transplant and why
- how to prepare for the transplant
- what to expect
- how they will know if the transplant's working
- what choices will you have if the transplant doesn't work
- what will the plan be if you don't get a transplant
- concerns related to future fertility, if applicable
- will additional treatment be needed/planned after transplant

In addition to getting your medical questions answered, you'll need to talk to your insurance carrier and your employer if you're employed. You'll also need to talk with family and friends about how they can help and support you.

Once you have answers to all of these questions, you'll need to make your decision regarding undergoing a transplant. We know people make decisions in different ways. You may want to

listen to the Toolbox module on "Making Decisions." It can help you identify your pattern for making decisions, and may help you develop some new skills.