

Myeloma Matters: A Podcast Series from the Multiple Myeloma Research Foundation

Episode 4: Autologous Stem Cell Transplantation

Transcript

Narrator: Welcome to the *Myeloma Matters* podcast, hosted by the Multiple Myeloma Research Foundation and focusing on patients' experiences with and perspectives on multiple myeloma topics that matter to anyone affected by this blood cancer.

In this episode, you'll learn about autologous stem cell transplantation and why it's considered the standard of care for eligible newly diagnosed patients. You'll also hear from four patients who have undergone stem cell transplantation—sometimes even twice!

Please note that every myeloma patient is unique; the information in this podcast is not intended to replace the services or advice of trained health care professionals. Please consult with your health care team or contact the MMRF Patient Navigation Center at 1-888-841-6673 if you have specific questions about your health.

An autologous stem cell transplant is a procedure in which a patient's own stem cells are used to help restore their blood counts and immune system after receiving a high dose of melphalan. Melphalan is a chemotherapy drug that is effective in killing myeloma cells. Unfortunately, in the process, it also kills normal cells. In a stem cell transplant, healthy stem cells—that is, the cells that mature into blood cells—are removed from a patient before he or she receives melphalan. Later, after the melphalan treatment is complete, these stem cells are re-infused back into the patient, where they mature into blood cells.

For many patients, studies have shown that a stem cell transplant used after initial therapy offers the best chance at a deep, long-lasting remission.

In the past, a person's eligibility for transplant was based primarily on age. Nowadays, age is not a barrier to stem cell transplant. Rather, eligibility is based on the patient's overall health and any co-existing conditions. Because of this, more patients than ever before are considered to be candidates for transplant.

All four of our guests today—Alesia Wiggs, Jennifer Ansier, Lynn Cella, and Suzanne Wolfrom—received an autologous stem cell transplant as part of their myeloma treatment journey. Like most patients, Jennifer, Lynn, and Suzanne received transplants as part of their initial therapy.

Suzanne was diagnosed with multiple myeloma in 2018 after routine bloodwork revealed some abnormalities. She was surprised, because she didn't have any symptoms.

Suzanne Wolfrom: And I was in the best physical shape that I had been in 'cause I quit my job to move, and so I was focused on exercise and, you know, cooking and all that. So, cancer was the furthest thing from my mind. And lo and behold, he sent me to the lab four times, and I kept thinking, "The lab can't get this right, you know, there's something wrong."

After additional testing and a bone marrow biopsy, Suzanne was told that she had cancer—and that it may be aggressive. Her oncologist recommended a stem cell transplant.

Suzanne Wolfrom: my doctor had said, "Well, this is the gold-standard treatment: we do immunotherapy and then a stem cell transplant." And I said, "Well, I wanna get another opinion," and he said, "Absolutely."

Suzanne went to MD Anderson Cancer Center for a second opinion, where a myeloma specialist confirmed that a stem cell transplant was her best option.

Suzanne Wolfrom: I was fully confirmed I'd say late March-beginning of April of 2018. I started, I did May, June, July of the immunotherapy, which brought my levels down, thank god, and then I was ready. Then they tested me and I was ready for an autologous stem cell transplant. So I did that in September, and that was that. And ever since then, I've been on Revlimid.

For Lynn, the experience was similar: her doctor recommended that she undergo a stem cell transplant as part of her initial treatment. After several years of testing and consultations for extreme fatigue—and a misdiagnosis of immune-related conditions—Lynn finally learned that she had multiple myeloma.

Lynn Cella: Towards Thanksgiving I started having tremendous amount of neck and back pain out of nowhere. I was going to physical therapist and it wasn't getting better, and I finally went and had some x-rays done on my spine and they had noticed that I had compression fractures to my spine and that my T1 vertebrae was in bad shape and went through the tests and then I was diagnosed.

Lynn's bone disease was so advanced, her oncology team wanted to be aggressive with her treatment. They started her on immunotherapy right away.

Lynn Cella: And then at that same time, he discussed with me the stem cell transplant, and he said this really the first line of treatment. As I recall,

that was really where they were going. So, there was not, I was not given another option.

Jennifer's case was unusual: she was just 31 years old when she got her myeloma diagnosis. Like Lynn, Jennifer was diagnosed after her doctor found abnormal results during routine bloodwork, which led her to an endocrinologist and ultimately an oncologist. And, like both Lynn and Suzanne, Jennifer received a recommendation from her health care team to get a stem cell transplant up front in her therapy. Jennifer's doctors wanted to be aggressive with her therapy, given her age.

Jennifer Ansier: And when I went to Texas Oncology for my appointment, the oncologist came out and said, "Your numbers really got my attention", which is something you never want to hear from a doctor.

But not everyone receives a stem cell transplant as part of their initial treatment. Improved response rates to new myeloma therapies have led to differing opinions about the role of stem cell transplant and when it is best to perform the procedure. Stem cell transplant after initial therapy—otherwise known as induction therapy—remains the standard option for eligible patients, but some patients may choose to delay transplant until after they have relapsed from initial therapy.

Our fourth guest, Alesia, was diagnosed with multiple myeloma after experiencing dizziness and fatigue for several years. Initially, these symptoms were incorrectly attributed to menopause. Ultimately, her myeloma diagnosis came after doctors performed x-rays and found a large lesion on her hip. Alesia consulted with multiple oncologists to weigh her options. She decided to take advantage of the new advances in immunotherapy that were available and opted to delay her stem cell transplant. After receiving 6 weeks of a Darzalex-based treatment, Alesia experienced pain in her legs. A PET scan revealed that her myeloma was continuing to progress. At that point, Alesia decided to pursue a transplant.

Alesia Wiggs: looking back on it it's like the initial diagnosis and the overload of fears and anxiety and looking for a specialist. I mean if you listen to the specialist that I saw, I saw three of the top in the world. Each one of them had a different opinion. And each one of them had a different guidance, except for they all agreed on I need a stem cell.

Alesia was hesitant about her stem cell transplant but ultimately decided it was the right choice for her.

Alesia Wiggs: And I already was having so many bone lesions and issues that I wanted to stop it in its track and be in remission for as long as

I could, so stem cell was my—it wasn't that I asked for other choices. Well, I did ask for another choice, right, I tried immunotherapy. And I really wanted that to work, right? But it didn't, so...

To determine a patient's eligibility for transplant, the health care team conducts a number of tests to ensure that the patient can handle the transplant process. Alesia received a full-body x-ray and an echocardiogram, and she underwent tests on her lungs, heart, and kidneys.

Patients should talk with a myeloma specialist regarding their eligibility for transplant, as well as the potential risks and benefits of the procedure, when deciding whether to include a transplant as part of their treatment plan.

An autologous stem cell transplant is a multi-step process. In the first step, patients receive 4 to 6 cycles of induction therapy, typically a 3- or 4-drug regimen, to reduce the number of myeloma cells in the body. Patients then undergo extensive evaluation to make sure they can tolerate the procedure. This involves assessment of their heart and lung function, as well as screening for active infections. Once a patient is confirmed to be a candidate for the transplant, his or her stem cells are collected, a process known as apheresis. Before apheresis is started, patients receive injections to ensure that a sufficient number of stem cells can be collected. During apheresis, a catheter is used to collect the stem cells from the bloodstream. The collection is done over the course of 1 to 5 days. Some patients, like Jennifer, only need one session of apheresis to collect enough stem cells for transplant. Others require multiple sessions.

Alesia Wiggs: I didn't even collect enough for one, what a panic. And then they gave me a shot that night and then I have enough for five.

Some people have side effects after treatment with these types of medications—these can include bone pain, headaches, nausea, and diarrhea.

After the stem cells are collected, they are frozen and stored until the patient is ready to have them re-infused. Even patients who choose not to have a transplant right away can have stem cells collected early to ensure that they have enough when they are ready.

Before stem cells are re-infused, patients receive a chemotherapy drug known as melphalan. Melphalan kills most of the myeloma cells left in the body after induction therapy, making way for the collected stem cells to be infused. The day after melphalan is given, the patient's stem cells are thawed and re-infused into the bloodstream. This is done relatively quickly over the course of 30 minutes, depending on how many bags of stem cells are being reinfused. These re-infused cells migrate to the bone marrow, where they begin reproducing new blood cells, typically beginning within 2 weeks of transplant.

A stem cell transplant can be performed as either an inpatient or outpatient procedure. When conducted as an inpatient procedure, the patient stays in the hospital throughout the process. When it is performed as an outpatient procedure, the patient stays nearby and makes daily visits to the clinic. Many centers provide housing that is set up specifically to meet the needs of transplant patients.

Alesia needed to have her procedure done inpatient, because she was part of a clinical trial. Being inpatient also ensured that both she and her husband had the support they needed, which was especially important because of the higher toxicity of the drugs used in the clinical trial.

Alesia Wiggs: But just the mental, physical responsibilities like you're saying are a lot on a caretaker. And even though I really wanted outpatient, we now talk about it, and he did not want, it was kind of a back and forth. Because my desire of having the place to relax and get away from two four hour vital signs and all of that, he was very happy to have those things and to have the support of the medical staff there.

Jennifer, on the other hand, chose to have her transplant done as an outpatient procedure.

Jennifer Ansier: I actually, having talked to other people that have had it, really appreciated that it was outpatient because I feel like it got me up every morning and out of bed and in the shower and walking there, and I don't know that I would have done that as much if I had been in the hospital where I didn't have to do those things.

Both Lynn and Suzanne also opted for outpatient procedures. However, after their chemotherapy, both experienced significant side effects that required them to be hospitalized. Suzanne was also hospitalized for dehydration resulting from nausea and vomiting.

Lynn Cella: I was pretty uncomfortable. I was very, very, very nauseous and to the point where it was intractable nausea. So, I wasn't able to eat well and I had, the chemo changes your taste buds, but I was extremely nauseated and to the point that they finally put me in the hospital so they could do better control. And I had some back pain associated, but it really wasn't for the back pain. They put me in for that, for the nausea, just so they could give me IVs.

Side effects following stem cell transplant are common due to the high-dose chemotherapy, which kills many of the remaining myeloma cells but also kills healthy cells in the gastrointestinal tract. This can lead to nausea and vomiting.

Some patients, like Alesia, experience mucositis, or painful sores in the mouth. These symptoms can make it difficult to eat, which can lead to weight loss. Other possible side effects of transplant are diarrhea, low blood counts, hair loss, and fatigue.

Lynn Cella: I expected to be tired. I didn't expect to be quite that tired, but your bone marrow had been wiped out, so building back your blood cells and everything. So, it didn't surprise me and it was manageable.

Patients are also at increased risk for infection following a stem cell transplant, because the high-dose chemotherapy kills healthy disease-fighting cells as well as cancerous cells. It is important for transplant recipients and their caregivers to carefully follow their health care team's instructions on minimizing infection risk.

Suzanne Wolfrom: so we had to totally clean, sterilize the apartment, and then they also have you eat—your diet is very important. You can't eat fresh vegetables or fruit and all of that. It all has to come in cans and be very well cooked, you know, because of organisms and infections and all of that. So you had to—you basically—you know, we had to clean the sheets—no one could be in my room with me. I had to be by myself, when I slept, and the bathroom, and all of that.

Avoiding infection risks can be challenging during the months immediately following the transplant. Friends and family may want to visit after an important medical procedure.

Jennifer Ansier: my dad really wanted to come, but got a cold and was really scared he was gonna give me something. So, anybody that felt a little off or not as healthy, that was a challenge for them because you wanna see your daughter, but you also don't wanna give her a cold that could end up in the hospital. So, everybody was super careful about how they felt, washing hands a lot.

Alesia Wiggs: So my husband and I laugh about it now, but sometimes he would take my temperature three to four times a day. And I had no temperature. But again, he was my caretaker and he—that was a fear for him.

Ten to fourteen days after the transplant, newly formed blood cells can be found within the patient's blood as the infused stem cells begin replacing those that were lost. This process is known as engraftment. Over time, the blood counts will continue to increase as new healthy red blood cells, white blood cells, and platelets are produced.

The road to recovery after a stem cell transplant takes time. Some patients take longer than others, depending on their underlying health and the side effects they experience.

Alesia Wiggs: I know I went to a wedding let's see, March, April, May, four months later. I went to my nephew's wedding. I still wore my wig because I still did not have significant hair growth. I was still very thin, but I was able to go to the wedding, have a good time. So I'm going to say at about four months I actually felt like putting makeup on, putting a dress on, going out into a crowd. And I was smart about handwashing and food safety and that type of thing. But I went out into the public and everything, I felt good. And then probably two months after that, my hair started to really grow in, and I stopped wearing the wig.

Many patients experience meaningful and long-lasting responses after autologous stem cell transplant. Alesia was found to be minimal residual disease—or MRD—negative after her transplant and has enjoyed more than 3 and a half years of MRD negativity with continued Revlimid maintenance therapy alone.

For Lynn, the M protein levels continued to drop with Revlimid maintenance therapy. After a year and a half, her oncologist recommended she stop taking Revlimid, and her disease has remained undetectable for 8 years.

Ongoing monitoring—which includes blood tests, imaging, and bone marrow biopsies—is recommended to determine the number of myeloma cells that remain after transplant and how these levels change over time.

Jennifer's initial biopsy 6 months after her transplant showed that she was in remission, with no cancer cells detected. But she continued regular monitoring, and nearly 3 years after her first transplant, her M protein values started to increase.

Jennifer Ansier: My doctor at the time kind of threw out a couple options. I want to say that we tried thalidomide again with the new version of steroids, which is once a week, and that wasn't really doing a whole lot. So, he wanted to be a little more aggressive, and we talked about a second transplant since the first one worked so well.

Jennifer's transplant team had collected enough stem cells during her first transplant for another procedure, so she did not have to undergo apheresis a second time. She had a second transplant 4 years after undergoing her first. This was followed by 2 years of maintenance therapy. She currently sees a myeloma specialist every 3 to 4 months, but she has maintained disease control for more than 11 years at this point.

Jennifer Ansier: So, my myeloma since the second one has been extremely slow moving. I joke with everyone and I say that we have been coexisting peacefully in my body.

Whether they are performed up front or later in treatment, stem cell transplants provide durable and meaningful responses for many people with multiple myeloma. Studies suggest that when transplants are performed early—that is, right after initial induction therapy—patients can expect longer periods of remission than if transplant is delayed. But the view of transplant timing in myeloma is evolving, and many patients choose to delay a stem cell transplant for personal reasons.

Lynn Cella: it's the anticipation of not knowing how you're gonna feel and what's gonna happen. And then once you're in the throes of it, you deal with it. And it's not anything that I couldn't handle that I think most people can handle and probably some people handle a lot better than me.

All of our guests emphasized that the decision of if and when to pursue a transplant should include a discussion with your oncologist but should ultimately be dependent on your own personal preferences and priorities.

Jennifer Ansier: be educated first and foremost. Ask questions, advocate for yourself. Trust your gut is one of my biggest ones. There's so many times that a doctor wants to do something and you just have this horrible feeling about it. And I would say just go with your gut. I have some friends that have done the transplant and others that are like, “Nope, I don't wanna do it. It's the last thing I wanna do.” And I completely understand. But I personally have had crazy good response from it, and it's given me a lot of time that I honestly didn't think that I would have. Like I just never thought I was, at 31 I didn't think I would've hit 40 with this, and here I am 47.

Alesia Wiggs: Would I have chosen to have a stem cell, would I have chosen to have chemotherapy, would I choose to have myeloma? No, I don't choose any of those things. I don't want any of them. But when you see what will give you the longest remission time, will give you the most significant remission, that's what I needed and what I wanted.

Let's hear more now from Alesia, Jennifer, Lynn, and Suzanne, as they join the MMRF's Mary DeRome in a roundtable discussion on their perspectives on what the transplant process is like and how it has shaped their myeloma journey.

Mary DeRome (MMRF): Hi, everyone. First, how did the topic of stem cell transplant come up as a treatment option? And what tests did you have to undergo to determine whether you were a good candidate for this procedure?

Lynn, let's start with you.

Lynn Cella: The stem cell transplant came up right away. It was one of the first things my oncologist said would be part of [my] treatment. At the time I was diagnosed, it was the standard, so there wasn't much decision-making there, and I felt very comfortable with him. I was diagnosed when I was 59, so they had to make sure that my heart and lungs were strong enough. They did a the general physical, but I had a pulmonary function test to make sure that my lungs were working properly, and I had good lung capacity. They also did an echocardiogram, or possibly a multigated acquisition (MUGA) scan, I don't remember exactly, for more extensive testing of the heart. And I was good to go, so I was cleared.

Mary DeRome (MMRF): Does anybody else want to talk about their experience when they were first diagnosed and how stem cell transplant came into the picture? Jenn, how about you?

Jennifer Ansier: Since I was diagnosed in 2006, there weren't as many drugs out as there are now for myeloma, so it truly was standard of care. They not only pushed an autologous stem cell transplant, they were also trying to talk me into doing an autologous [stem cell transplant] immediately followed by an allogeneic stem cell transplant, kind of in tandem. I ended up doing a ton of research and talking to people who had had them. Honestly, it came down to a gut feeling where I decided not to do the allogeneic stem cell transplant. So, I just did the autologous transplant. It was very common, even then, for people to do two autologous transplants back-to-back or autologous-allogeneic transplants back-to-back, because of the lack of other resources. But eventually, I came to the decision that we would try the autologous transplant. Since I had such a good response to the thalidomide and Velcade I was on, we were hoping I would have an excellent response to the transplant – which is what happened.

Lynn Cella: I would add to that, Jenn, in 2014, after I had my workup, they said I was a good candidate for a donor transplant and worked me up for that. I was told that the donor would give me 7 years, if I had the donor after the autologous transplant, and that could be possibly a 25% chance of cure. They did not really discuss with me the other issues of donor transplants. I discussed it with my family and my sister who's in the medical field. My sister discussed it with some people she knew, including an oncologist, and he was not on board. He recommended that I have some second opinions, which I did, and I decided against the donor. I am now 8 years out without the donor. I was happy I made the decision I did. And as a matter of fact, I have been told that multiple myeloma

patients do not do as well as other patients with donor transplants. If that is an option that you have to have, you do what you have to do, but that happened to me, as well. And this is still in 2014.

Mary DeRome (MMRF): The allogeneic and autologous stem cell transplants were among the only treatments available back when you were diagnosed in 2006. And starting in 2015, that's when many drugs began to be approved for multiple myeloma. So now there are many more options that are actually safer than an allogeneic transplant, and allogeneic transplants can be pretty debilitating and not so great. They've really fallen out of favor in the medical community in myeloma because now there are many better options available for people. You were all diagnosed relatively young. None of you were diagnosed when you were in your 80s, or even in your 70s, when transplant begins to be not an option due to the frailty of patients. That's usually what they look at, the frailty index, or how healthy the person is overall and how well can they tolerate a stem cell transplant. They can be a little bit overwhelming, and we'll talk a little bit more about that.

As you guys know, because you've all been through this, patients who undergo a transplant usually require a lot of help and support just to get through the procedure. So, Suzanne, tell me a bit about the level of help you needed. How long of a commitment is it for a care partner, and who have you relied on for help throughout your transplant?

Suzanne Wolfrom: I was very fortunate. I had a sister who was a diligent researcher, and I consulted with two oncologists. I'm in Austin, I went to one here, and then I also went to MD Anderson Cancer Center. I'm also a breast cancer survivor, so I was already a patient and familiar with that. In talking to both of them, they laid out the pros and cons and the journey. One of the doctors explained to me, and it's still the case, that multiple myeloma is not a curable cancer, but it is a treatable cancer. So, it's a lifelong journey with myeloma. Once I researched the stem cell transplant, fortunately, there was a unit here in my town that had only opened 3 years prior. So I met with those doctors and became very confident in their ability, and I was going at it with outpatient, believe it or not. I was in great health, otherwise, going into it, but they said I would need help. So I did immunotherapy for 3 months leading up to my stem cell transplant, and I did great through that. I had a little nausea, a little tiredness, but it wasn't much of a lifestyle change. I drove myself and was able to take care of myself the whole time, so I was really fortunate. I think going into it being so healthy and not having other underlying conditions really served me well.

Once I knew that I was going to have the stem cell transplant and I was ready, I did the whole process, collection and whatnot, outpatient, just in case I had issues. Particularly after, once they collect your stem cells, they hit you with the

chemo, the hard chemo. I called on my sister, who generously flew down, because my husband was still working.

And he's the breadwinner, and he needed to keep our insurance and keep things going. So, we were secluded in an apartment at the time, as we were between homes, and it worked out beautifully. They stripped down when he came in the house, and they had to use a separate bathroom, and we sterilized the whole apartment and cleaned.

And then you could only eat certain foods, and they gave lots of instruction, and we just managed through that. I had friends drop off meals that would meet the stringent requirements during that time. And then beyond the stem cell transplant, I got sick and ended up in the hospital for 10 days. I tried to do it all outpatient, but my sodium levels dropped to an alarming rate. So, I went to the hospital. There's a 100-day isolation period following that, which now that we've been through Covid, everyone understands isolation.

Anyway, I was blessed. For me, I rallied fairly quickly after the stem cell transplant. I would gradually walk and start to get my physical activity built up. Once I was about another 3 weeks after, my sister left, and my husband and I were able to handle it on our own. I think it really helps, because particularly if something goes awry, as in my case I needed to go to the hospital, my sister had to be my advocate. Because I went to the emergency room (ER) and was in pretty dire straits, and I wasn't getting the attention that I would on the VIP myeloma floor yet, it's really helpful to have someone who can help. – You could tag-team different people, but they all have to be healthy and willing to stay in a confined environment with you. But there are a lot of blessings that come from that, too. Sometimes, I was thankful that I had the isolation; I didn't really want to go back to the real-world, because you're totally focused on yourself, and it gives you time to reflect inward. There are a lot of blessings that come from that.

Mary DeRome (MMRF): That's a great take, to really think of it, at least parts of it, as a blessing.

Lynn Cella: Thank God for sisters. My sister was my caretaker when I had my transplant. The center that I had it at in Hackensack, New Jersey, you can choose to be in the hospital or they had apartments set up. I chose the apartment. My sister also flew in from Portland, Oregon, and she stayed with me throughout. She would transport me during the day when I had the chemo, and then they gave me my stem cells they engrafted during that period. In the evening, we would go back to the apartment and she made sure that I had all of my medications, and she forced me to eat. And she made sure I had a mouthwash that helped me from getting sores in my mouth that I had to do diligently, about six or eight times a day. It tasted terrible and she forced it on me,

but I'm glad that she did, because I didn't have any mouth sores. They also had me chew ice during my infusion, so that was not a problem. I had another problem called engraftment syndrome, but we can discuss that later, if you like.

Mary DeRome (MMRF): We do have a section where we want to talk about side effects and the things that you went through. Alesia, you were diagnosed when you were 54, and you were on a clinical trial when you were first diagnosed. So, when you did your stem cell transplant, you had to do it inpatient in the hospital because of the trial that you were on. Tell us more about that.

Alesia Wiggs: There was no choice. I had mine done at MD Anderson Cancer Center, and they did not do outpatient. I think if you really fought for it, you could have outpatient, but you had to do just a typical transplant, and they had recommended a clinical trial for me, and the clinical trial was not an option of doing outpatient. I really wanted the outpatient experience. I just feel like going home to my own bed, my own apartment, and having my own space. I was inpatient for 21 days. During that 21 days, getting my vital signs checked every 4 hours around the clock really got old. I asked to space them out, and that did not happen.

So for me, inpatient, that was a little challenging in that way, and you were not allowed to leave the floor. So, when you did walk, the only walking you could do would be around the halls, mile after mile of walking in the halls, day after day. Once I was released, I still needed to stay in Houston for another 14 days, and then I could get out and walk with the mask on. The mask is routine for so many people these days, but that was a little odd back then. But you could walk in nature, and that sure was nice to be outside. In my mind, an outpatient was where you could go out and outside, but the clinical trial required being in the hospital.

It was a rigorous protocol, multiple drugs, and they caused lots of mouth sores. I lost a lot of weight, but no one was real concerned. I did gain the weight back, as they knew I would. When I left, I felt so thin and hungry and really worried that my appetite would never return, but the transplant team was not concerned. I went home and was slowly able to think of strange things that I could eat and would be hungry for, such as Fritos and bean dip. I don't even know where that came from, but it was something I could eat. I began to eat and gain my strength again from getting out in nature and eating different things.

But being in the hospital, it seemed like forever for me. You don't feel great, so I slept a lot, watched some TV, and there wasn't a lot to do.

Mary DeRome (MMRF): So it was 21 days that you were in the hospital, and then you had to stay in the area for another 14 days after that?

Alesia Wiggs: Correct, I had to stay in the area for another 14. I live a 5-hour drive away. So I was able to go back home to my rural area after the 14 days. We found an Airbnb-type apartment, because Houston did not have an apartment complex for you to stay in. So, a lot like Suzanne, we had to wash and clean everything. My husband was my main caretaker, but again, he was working, so I had several friends who came and stayed to relieve him at different periods of time. We made sure they were well, and if they felt the slightest tickle in their throat, they wore a mask.

For me, it was interesting how a lot of the friends really showed up and were very helpful even though I hadn't seen some of them in years. My husband put out a post on CaringBridge that he needed some help, and these friends stepped right up and gave of themselves and their time and were very, very helpful.

Mary DeRome (MMRF): You have to really take some very strong chemotherapy in order to have a stem cell transplant. As you mentioned, Alesia, there are other drugs that you take, as well. Have any of you experienced any long-term complications from having undergone your stem cell transplant? What are some of the things that you've gone through since the stem cell transplant that might have happened because of that treatment?

Jennifer Ansier: I had a short-term problem that resolved but no long-term problems.

Alesia Wiggs: I don't have any long-term problems from the stem cell transplant. I take a maintenance drug, and I do have some long-term side effects from my maintenance drug. But after my stem cell transplant, my hair grew back, my weight came back on, and there have been no known long-term side effects from the stem cell transplant.

Lynn Cella: I did a different immunotherapy leading up to my stem cell transplant. They checked out my heart, because one of the therapeutics I had was known to impact the heart. After the stem cell transplant, I started to develop heart palpitations. I did have an episode that took me to the ER, and I thought I was having a heart attack. I met with the cardiologist and everything checked out fine.

Now that I'm starting new treatment, because I'm coming out of remission, that was a factor, and I'm not using that particular drug. I've responded really well, but one of the oncologists said, "You know, if you had an episode, let's use another treatment." I was on maintenance, and I've been on Revlimid, as well. I'm assuming it was from the chemo and the Revlimid, but I've had gut issues ever since. I've always been a good eater and always could drink dairy, but I have had ongoing gut issues and diarrhea. So, I do feel like that was probably part of the stem cell transplant, the chemo that I undertook, and the treatments beyond.

Mary DeRome (MMRF): Maintenance could definitely [contribute side effects], especially with Revlimid, as it has pretty well-known gastrointestinal (GI) toxicity.

Alesia Wiggs: I'll add to that. I did not attribute it to the transplant, but I have had stomach issues as well. I get intermittent nausea. My stomach definitely has changed, and I get full faster. I eat small meals to overcome that.

Mary DeRome (MMRF): Everybody's on different medications, and it's hard to really pin down exactly where these symptoms come from based on what you happen to be taking at the time. Jenn, let's talk about your case, because you were diagnosed fairly young with multiple myeloma at 31 years of age. And that was back in 2006 when there really weren't a lot of effective therapies for people with multiple myeloma. When you were diagnosed, did your doctor talk about treatments that you were going to go on? Anything about fertility issues with you regarding that?

Jennifer Ansier: It was very matter-of-fact what I was going to go on, because there just weren't a lot of options at the time. They were really excited that Velcade had come out, so I could do this cocktail of three drugs instead of two, but we did talk about fertility issues. I had never, desperately wanted children. When I was diagnosed, the statistics then were way worse than they are now. You had a 40% chance, I think, of living for 5 years and a 20% chance of living for 10 years.

I just couldn't think about having a child who I would have to leave within 10 years. The statistics were just so bad, so I just refused it.

I just didn't even think I was going to hit 40. Do I want to throw a child in there? So, I refused any of the fertility, because they did talk about harvesting my eggs.

Mary DeRome (MMRF): That must've been a very difficult time. On top of everything else, you have to worry about fertility, along with your own survival.

Let's talk about the process of stem cell transplant. I'm sure that you all had conversations with many doctors about what you were going to be undergoing. Was there anything about stem cell transplant that was very scary to you? My mother was diagnosed with multiple myeloma when she turned 80 years old, and the only thing that she would ever talk about was, "I'm not going to have something done that I'm going to lose my hair." And I said, "Ma, you're 80. They're not going to give you a transplant." Thinking about things like that, was there anything in particular that you just had a lot of trepidation thinking about?

Lynn Cella: Losing my hair was a very frightening prospect, because my hair was my pride and joy. What am I going to look like bald? How are my children going to perceive me? How are other people going to perceive me? They're

going to see that I have cancer. Will I be attractive to my husband? I think focusing on that maybe helps you not focus on some of the other things that are equally scary or maybe scarier.

The other thing was how sick would I be from the medications and nausea? Am I going to be nauseous? You see things depicted in movies or on TV, and those were my fears. Dying from it just did not cross my mind, but in the back of my mind, there was potential. They did a very good full-day training at the center I was at where they had a doctor, nurse, nutritionists, and a pharmacist come in. And you brought your family members, and they went over everything. The best part of it was the pharmacist, when he talked about how they we're going to control nausea. There were many things in the arsenal, so that helped tremendously and prepared me for the process.

Mary DeRome (MMRF): That's good that they brought in your entire family and many specialists, and talked about everything, so there weren't any surprises. Alesia, does anything stand out for you that you were not looking forward to?

Alesia Wiggs: The anxiety and the buildup and just the fears of what it would be. Again, finding out that I would need to be inpatient instead of outpatient, which I preferred, [increased my anxiety]. I really do think that by the time it was over, I thought, "Wow, I did it. I was able to do this." And even though I had a lot of extra things, such as the nausea, the mouth sores, the diarrhea, and I had a workup for a secondary infection, many things, I came out and said, "Oh, I didn't die, and it wasn't as bad as I thought it would be."

For me, it was not as bad as the anxiety had worked it up in my head. And then getting my cells back that day, I had a birthday party, we brought in cupcakes, and the priest blessed my cells, and it was done. It just was almost anticlimactic, and then once the transplant was done, it was time to heal. I even worked with a therapist for a little while, working through my thoughts and my trauma from the time, and like you said, I spent a lot of time on myself, it was a lot of inner self-care time. And then I was cleared and Covid came along. We've all been in that isolation time, learning to take care of yourself and in quarantine.

Mary DeRome (MMRF): We've talked already about maintenance therapy, so I think that all of you are familiar with Revlimid and being on that for maintenance, which a lot of people go on after they have their stem cell transplant. At the recent American Society of Hematology (ASH) Annual Meeting in New Orleans. I saw a couple of talks about what they call secondary cancers or second primary malignancies, which can be a relatively rare offshoot in people who are on Revlimid for a long period of time.

Suzanne, when you were on Revlimid, did your doctors talk to you about that at all? And what did you think about that?

Suzanne Wolfrom: They did mention that it was a risk, and I had already survived breast cancer. Interestingly, a year after my stem cell transplant, they did find basal cell carcinoma on my nose and forehead. So, I underwent nose surgery for skin cancer, pre-skin cancers, and I've been careful ever since on that. But quite honestly, having gone through breast cancer and then through myeloma, I thought, "I'm gonna handle whatever's thrown my way." Going back to the question regarding the stem cell transplant, my biggest fear was collecting enough stem cells.

You work all up to it, and it's out of your control, you don't know how many they're going to be able to collect. As Alesia pointed out, you anticipate this big, process. It's like a blood transfusion, and they actually took my cells and spun it. And then your stem cells rise to the top, and they collect those. Then they put your white blood cells and red blood cells back in you. I was fascinated by the whole thing. I thought it was amazing that we have this available to us. And then I had to pray for the guy that carried my stem cells, since they had to carry them to another town. He literally put them in a canister, in a car. I was talking to the nurse who handles all of this, and I said, "Well, is he a good driver? What if it gets caught on the road and my stem cells are all over the highway?"

We prayed for him to deliver them there, and prayed for them to get back to put back in me. That was my biggest fear of the whole event, but it all worked out great.

Mary DeRome (MMRF): And if you don't have your cells, then you don't have the transplant, so that's arguably the most important part of the whole thing.

Lynn, you were also on Revlimid, right?

Lynn Cella: Yes, I was on Revlimid for 1.5 years.

It started to affect my bone marrow. My blood cell counts were going down, so I was taken off of it. For 5 years, I have not had any medication.

Jennifer Ansier: I did 1.5 years also, Lynn. They did not talk to me about secondary cancers, but I had been doing a lot of research and saw that was an option. That was after my second transplant, and I didn't want to have another cancer. I had had two transplants, and I just said I wanted a break. My doctor wasn't very happy about it, but it's lasted 10 years.

Lynn Cella: Certain doctors have certain approaches. There are a lot of different drugs and clinical trials out there. As a patient, it's very hard to decide. It's almost too much. It's wonderful that there are so many options now, but it's very difficult to decide. Sometimes, you have to just go with your gut, and you

have to take control and make a decision. I admire you that you did that. And I also was not told about the Revlimid and the side effect of possible secondary cancer.

Suzanne Wolfrom: I'm on Revlimid now and have been on it for about 3.5 years. I've gone down in dose. I'll begin to feel more frequent diarrhea, mood swings, some of the other GI issues with nausea and that type of thing. And when I go back in, I say, "This is terrible, it's affecting my daily life. What can I do?" and he just drops the dose, drops it a little bit more, drops it a little bit more, so I'm going down another little dose now. But for my physician, it makes him feel better, and myself, too, to know that I am on some type of maintenance, even though it's such a low dose at this point.

But secondary cancers are not focused on. When I do a yearly physical, they look a little closer for both melanoma or breast cancer. Those are really the only two types that I've been checked further for the cancers, and they've watched my bloodwork for anything else they might see.

Lynn Cella: There are many drugs that treat cancer and have side effects. You weigh whether the benefit is worth the risk. For me, the benefit outweighs the risk. There is no perfect drug, and these drugs have side effects, so, that's something that we all live with. There is no perfect medicine.

Mary DeRome (MMRF): Speaking about risks and benefits, all of you have undergone at least one stem cell transplant, right? Jenn, you have undergone more than one. Thinking about your experience in having a stem cell transplant and what you think the gain that you may have gotten from a stem cell transplant, if you were to talk to another myeloma patient, what would be your advice? If they were trying to decide whether to have a transplant, what would you say? Alesia, let's start with you.

Alesia Wiggs: I see that there are new and upcoming things, and I think in 5 years, it would be a totally different story. I was diagnosed 3 years ago, and I heard yesterday, "That's the olden days." Things are changing rapidly, but I do still think the tried-and-true stem cell transplant got me the longest-term remission to allow the time for these drugs to catch up with my disease. I'm almost 4 years in remission, and it is because of the stem cell transplant, I feel. It gave me a longer term of being disease-free, so I can hopefully be here as more drugs are discovered. The next treatment that comes along could be the cure.

I saw world-renowned doctors, and they all agreed that the stem cell transplant was the thing to do, especially 3 years ago. It was successful for me, so I'm happy that I did it. I know it's a big choice, and I think that people have a few more choices these days, but there's no magic combination yet. The stem cell transplant is still the gold standard and gives you a longer promise. CAR T-cell

therapy and bispecific antibodies are wonderful, and I'm ready for them to work. This gave me more hope and more time to get to those.

Mary DeRome (MMRF): Suzanne, how about you?

Suzanne Wolfrom: I had high hopes for the stem cell transplant. I really thought I was going to be in remission longer, and like I mentioned earlier, I'm climbing out of remission. I've reflected on that, because I'm going to be entering immunotherapy. After discussing with three different oncologists, we talked about another stem cell transplant. From what I understand, after you've had one, your hope for remission or your amount of time in remission is reduced almost in half the second time around. I was 4 years out, and it started climbing.

I've talked to other patients who have done just the immunotherapy, and it brought my levels to less than 1%. However, I've come to find out that I may have a more aggressive type of myeloma. I think each patient needs to look at their health and where they are. There are benefits having gone through it when I was younger and stronger. I think it would become more difficult to do a stem cell transplant if I had other health issues going on or been older. In that regard, I think youth is on your side with the stem cell transplant. Every therapy you just make the best decision you can, and you weigh all the pros and cons. Just know that there are more therapeutics on the horizon. It's really just trying to buy more time until we get that magic combination that works for each of us.

Lynn Cella: I would not want to advise someone on doing one treatment or another. Each person's myeloma is different. There are 12 different subtypes, and people are in different stages of their life. Get as many opinions as you can, and then make a decision from there. It seems like all of us have access to good healthcare. It makes me think of other people who may not. Some people may not have the choice to have two or three opinions.

I was able to travel to a center in New York for one of my opinions, and I went in to New York City from New Jersey. I was lucky to see some very good people. It's a tough one, because there are so many options. We've been lucky from that standpoint.

Mary DeRome (MMRF): Jenn, let's talk about your case, a little bit. Among all of you, you alone have had two stem cell transplants, and that is probably partially because you were diagnosed so early on, when there really wasn't that much else that you could do, aside from having a transplant. How far apart were your transplants? Was the second transplant different from the first? Was it harder? Was it easier?

Jennifer Ansier: My first one was in 2007. I didn't do any maintenance after. They specifically said, "We'll give you a break." In 2009-2010, my numbers

started slowly rising again. We thought about going back on thalidomide, and my numbers still were slowly going up. It truly wasn't very aggressive, but I did find an expert, and he said if I had such good success with the first transplant, it had almost been four years, to go ahead and do a second one. Again, that's when tandem was kind of a big deal. They definitely weren't tandem, because people were doing them literally back-to-back, but they were pretty close together. I definitely don't regret doing the second one.

It was interesting, a few years later, I went to see another expert who wasn't sure if I should've had that second one then. It really threw me off for a while, because I thought, "Wait, did I waste that one? Should I not have done that one?" It truly messed with my head for about a year. My husband reminded me how I had such previous success with it. I've had 10 years of – I wouldn't call it remission, because my M protein spike is still there – but no medication. For me, it was totally worth it. It's personal for everyone, and I would do another one, if I had the opportunity, because I've had such success.

I would rather be hit hard for a few months, and then have a few years without medication. I have friends who would rather take the meds for years, so it's a personal choice. I was a little older for the second one, so the recovery time was a bit longer. With the first one, I was probably back to work halftime in about 2 months. I was pretty young, and I didn't have any complications. I was super lucky with both transplants. They were both outpatient, and I didn't have to stay in the hospital for either of them.

For the second transplant, it took me a little bit longer to recover. I probably was off for about 3 months before I started going back to work. Luckily, I had friends who were there. And then, July of that year, we went to Peru. I was definitely ready to go after that.

Mary DeRome (MMRF): We've talked about how much the field of myeloma therapeutics has advanced over the past 10 years, and there are so many more choices available to patients now. Some of these really effective medications, like Darzalex, have really moved up into the frontline, so even newly diagnosed patients are getting a quad therapy, which is really very effective for many patients in bringing their disease down. There's also been some recent trials that have been following patients who have been on RVd (Revlimid, Velcade, and dexamethasone) for long periods of time. They started off on that therapy, and then some were transplanted right away. And then, some people just stayed on the Revlimid-Velcade and dex for a long period of time.

And perhaps when their numbers started going back up, then they were given a transplant. They looked at the length of time that patients were able to stay off of their therapy or just stay on maintenance after having their transplant. We had the DETERMINATION trial that came out in June at ASCO (the American Society

of Clinical Oncology). There was a big presentation in a room that seated probably 15,000 people, and they were talking about this study. They found that early transplant and late transplant, for most patients, did not change their overall survival at all, but it reinforces the idea that early transplant is the standard of care for the longest period of time that patients stay disease-free. And that's true for pretty much all patients, unless you're an African American patient, they didn't really see as much of a benefit of having an early stem cell transplant versus a later one. Thinking about that and all the choices that are available now to patients, if you were to be newly diagnosed now, do you think that you would still have a transplant now? Or do you think that you might put it off until later, and see what else might come along therapeutically? I think a lot of people think that transplant may not be the standard of care in just a few years, although we'll have to see what the data says from the trials that are ongoing.

Lynn, what do you think about that? Do you think that you would still have it upfront if you were diagnosed now, or would you wait?

Lynn Cella: I'd really have to think about it and research the information. I rely a lot on my hematologist-oncologist. He's been the quarterback for me, and his recommendations would [influence whether I] consider having the transplant. It's hard to say, knowing what I know now, and I'm 8 years out. There's been a lot of new drugs, and there'll be a lot of treatments as my numbers climb again. But I think I would probably opt again for a transplant.

Mary DeRome (MMRF): Suzanne, what about you?

Suzanne Wolfrom: I think if you're young, you don't have other underlying conditions, and your doctors are telling you that you're a good candidate for a stem cell transplant, I would encourage you to do it. It's a detour in life, but it's not a be-all and end-all I think it depends on the individual, the state of your health, and your support group. If I was surrounded by people I can rely on to help me through during those tough times, I think I would do it again, if I were posed that question and in good health.

I think as you get older and you have more health issues to consider, your doctors certainly should take that into consideration and would not recommend it if it wasn't a good option for you. But it is very encouraging that all these therapeutics are out there, and I'm hearing more and more people who are delaying the stem cell transplant based on that. It's a hard call.

Mary DeRome (MMRF): It's still new information for the community, and people are trying to digest it. It can make the decision a little harder, taking everything into consideration that's known now.

Suzanne Wolfrom: I have a question for Jenn about her second transplant. Once you have your stem cell transplant, it takes another 2 years to get through all your vaccines. Did you have to go through all your vaccines again?

Jennifer Ansier: I did, yes. It was a day of shots. They brought a handful of shots out.

Suzanne Wolfrom: That's another consideration, because I thought when I was done with my stem cell transplant, I wouldn't see the doctors for a long while. But I had to come back and get all my vaccines scheduled over 2 years.

Jennifer Ansier: I actually [got my vaccines] at my oncology office here in Austin; I didn't have to go back down to the transplant [center] in San Antonio.

Mary DeRome (MMRF): Alesia, what about you?

Alesia Wiggs: When I was first diagnosed, the first expert I spoke with told me to go look around: There are so many new things out there, so many new pathways, so many clinical trials. I tried immunotherapy first, and I did not want all the other stuff. I only wanted immunotherapy. Unfortunately, my myeloma continued to progress, and my numbers continued to progress. So, as I saw the next specialist and the next specialist said I needed a transplant.

I didn't want to hear it. I do think you have to listen to what the specialists are saying. We all want the cure, and we want it all spelled out. And like you said, it is a blip in your life — you get it done, and you can move on in a lot of positive ways. But if you delay it, they can always go back to it. Everyone has a different story, a different time to treatment. Sometimes you delay it or even get one right away, and then your myeloma decides on how it will go.

It's a very sneaky disease and works differently for all of us. I have never met someone who has the same story that I have.

Mary DeRome (MMRF): Very true, it's a complex disease and it's different in every single patient. No two patients have the same experience, that's for sure.

Alesia Wiggs: I think you have to go and get your consults and speak to people. Look at your caretakers in your life, look at your situation and your place in life, your time in life, your strength, and your physical ability. There's so much that goes into the picture of choosing to have it now or to delay.

Mary DeRome (MMRF): Jenn, let's wrap up with you. I know your case is a bit different than everybody's, because you've had two of them and you were diagnosed a long time ago. If you were diagnosed today, what do you think you would do?

Jennifer Ansier: I think I would do another one. Again, I'm one of those people if I can hit it hard in the beginning and knock it out as much as possible, then I would totally do that again. I would much rather not drag it out over years of medication, if I can help it, but again, that's just my choice, and everybody has to go with their gut and do their research. You know your body better than anybody else.

Mary DeRome (MMRF): It's so important to really determine upfront what your goals are for therapy. Jenn, there are people who are like you and say, "Hit me with everything you got. I want to get rid of this thing, so just give it to me." And then there are other people who say, "I don't know if I want to do that and be really sick for a really long period of time. I have some other things happening, like my daughter's getting married and my kids are going off to college." People may have things that they really need to have a little space before they become incapacitated for a period of time from something like this. It really comes down to thinking about what your options are and making your needs known to your healthcare teams, so that you can decide together. You know the best path for you, and that's really what it comes down to.

I want to thank my guests today, Lynn, Jenn, Alesia, and Suzanne, for sharing their amazing experience in myeloma and with their stem cell transplants. I think this is going to be a great way for other myeloma patients to understand the transplant process and the decision-making thought process. You've done a great service to the myeloma community through this podcast, and I thank you for being on with me today. I wish you all the best of luck and the best of health moving forward.

Narrator: Thank you for listening to this episode of the *Myeloma Matters* podcast on autologous stem cell transplant in multiple myeloma, hosted by the Multiple Myeloma Research Foundation. The MMRF thanks Alesia Wiggs, Jennifer Ansier, Lynn Cella, and Suzanne Wolfrom for sharing their stories and unique perspectives on autologous stem cell transplantation. The MMRF also thanks AbbVie, Adaptive Biotechnologies, Amgen, Bristol Myers Squibb, GSK, and Janssen for their generous support of this podcast. If you have additional questions about anything you have heard today, please call the MMRF Patient Navigation Center at 1-888-841-6673 for more information.