

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

Episode 7: Maintenance Therapy

Transcript

Narrator: Welcome to the *Myeloma Matters* podcast, hosted by the Multiple Myeloma Research Foundation—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 hear myeloma patients providing first-hand accounts on the importance of continuing treatment after induction therapy and autologous stem cell transplant—and about what to expect with this type of ongoing treatment.

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 M-M-R-F Patient Navigation Center at 1-888-841-6673 if you have specific questions about your health.

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Most patients begin treatment for multiple myeloma with a course of induction therapy, which aims to reduce the number of myeloma cells in the body. This is followed by consolidation therapy, which involves either more medication or an autologous stem cell transplant, if the patient is eligible. But treatment doesn’t stop there.

Myeloma patients require additional long-term treatment, known as *maintenance therapy*, because there is a high likelihood that the myeloma will come back—which can occur for a number of reasons, such as myeloma cells remaining in the body after induction and consolidation therapies. The goal of maintenance therapy is to prevent or delay myeloma from returning.

Our three guests today—Elizabeth Bohannon, Linda Lane, and Kathryn Mohorn—are all currently receiving maintenance therapy after their initial induction and consolidation therapies. They all received induction therapy with a 3- or 4-drug regimen. Both Kathryn and Elizabeth received induction therapy followed by a stem cell transplant, but Linda chose to wait for her transplant: she’s hoping that the steady advances in myeloma treatments will soon reach a point where transplants are obsolete. For all three of our guests, maintenance therapy is especially important, because there are features of their myeloma that make it more aggressive or more likely to relapse.

Maintenance therapy offers several benefits. It helps delay disease progression for longer periods and reduces the risk for early relapse. Studies have shown that it also helps prolong survival.

As Linda's doctor explained to her, an aggressive approach to maintenance therapy was best for her given her high-risk disease.

Linda Lane: So, because of being light chain, because of the translocation, because of how I had that spike very quickly, he wants my maintenance plan. He said, "I'm going to treat this with a heavy hand." He said, "We can always pull back, but my tendency with you is going to be over-medicate and then pull back as we see fit."

With this additional therapy, all of our guests today have maintained their responses for at least 1 to 2 years, despite their high-risk disease. This prolonged window of disease control gives Elizabeth hope. She knows her disease is likely to return, but she's optimistic about the myeloma treatment options that will be available when that happens.

Elizabeth Bohannon: It's the feeling I have right now, my current mantra for—it might make some people squeamish, but I say to myself when I have a bad day, not dead yet. And what that triggers for me isn't, oh my God I'm going to die. Because we all are, but it's like I'm here today. So how do I want to choose to live this day. And that's really important to me. And I'm able to do that because I have such knowledge about all the research that's going on and all the drugs that are being developed and what's happening with CAR T therapy where it's advancing every month. And so I feel better that by the time I'm ready for CAR T, that it will be ready for me. That it'll be a better, even better treatment than it is today.

Maintenance therapy not only extends responses, it also deepens responses. This extra treatment helps by reducing the number of myeloma cells left in the body and slowing the recurrence of new myeloma cells. Many people who receive maintenance therapy achieve a much deeper response than they would have without it. The deepest response a patient can have is called minimal residual disease—or MRD—negativity.

This was the case for Kathryn, who was initially treated with an induction regimen of Kyprolis, Revlimid, and dexamethasone—commonly known as KRD—before her stem cell transplant in September 2021.

Kathryn Mohorn: I responded well to the KRD. And when I had the stem cell transplant, I was still responding. I mean you don't take anything for a while after that. You're off of all the medications. But when they started looking at things again, they were seeing like the light band in the blood that made them think that there was still a little something there.

Kathryn's doctors put her back on the KRd regimen for her maintenance therapy, and she was found to be MRD negative in October of last year.

For most patients with standard-risk myeloma—as opposed to the high-risk myeloma our guests had to contend with—the standard maintenance therapy is Revlimid given at a dose of 10 or 15 milligrams per day for 21 days, usually beginning 100 days after a transplant for patients who receive one or right after completing induction therapy for patients who don't receive a transplant. This gives the patient's blood cells a chance to recover and repopulate.

Patients with myeloma that has genetic or clinical features indicating that it is more aggressive are said to have high-risk disease, which means that they are less likely to achieve long periods of remission. These patients are more likely to relapse quickly after their initial treatment than patients without high-risk disease. There is no standard treatment approach for high-risk myeloma, but most myeloma experts prefer to pursue an intensive treatment plan, as Linda's doctor did. This typically involves using a combination maintenance therapy regimen consisting of Revlimid and at least one other agent. This regimen is sometimes started sooner after transplant—such as after 60 days rather than after 100 days. All of our guests are receiving a combination maintenance therapy regimen—Elizabeth and Kathryn are both receiving KRd, whereas Linda is receiving Velcade, Revlimid, dexamethasone, and Darzalex.

According to multiple myeloma treatment guidelines, maintenance therapy should continue until the myeloma progresses or until the patient develops unacceptable side effects or asks to stop treatment.

Revlimid is a pill that can be taken at home. Patients on combination regimens, however, often need to make regular visits to a clinic, as some parts of their treatment need to be given as infusions or injections. As Kathryn explained, it can be difficult making a maintenance therapy schedule fit into your busy life.

Kathryn Mohorn: But I would say that we've had to just juggle our lives around it, which can be a real pain trying to make travel plans. But you make it work. You just do what you have to do.

Fortunately, her care team is willing to work with her to make sure she still gets the treatment she needs.

Kathryn Mohorn: So because of travel, because of traveling and stuff, I've gotten off track a little bit. Like I had to take a month off when we went to the east coast for a month. But they feel good enough about the way I've responded that they don't, they told me I need to live my life and if I want to take a trip, we'll just skip a treatment. But they want to get the 24 cycles in even if it takes a little longer.

Though Linda understands why her frequent clinic visits are so important for controlling her disease, it can be difficult to cope with emotionally.

Linda Lane: And I will say it was, it wouldn't have changed my decision, but I did not expect to have to go in every other week. I really, as I was sitting in the treatment room each time, you spend a lot of time there. And every once in a while, someone would be able to ring the bell and you know that they were done with treatment, and you'd be so excited for them, and they make a big deal the doctors and the nurses....And then it was like, I'm never gonna ring that bell. I'm never gonna be done, and that really, I can be, I'm a very faith-centered person and a lot of things, I can weather a lot, but that really did bother me for some time because it was very heavy. It was like I'm never going to be done and I'm going every other week, that precipitates another trip to the lab, so I just felt so tethered. And then, that little voice in my head says the longer you're going every other week, the longer it means those meds are working, that you're still in that response. And that turned things for me for the positive like okay, all right, this is what it is.

Elizabeth agrees that living with myeloma—both the disease and the treatment—can be overwhelming. But she says that introspection and self-care can go a long way in helping build resilience through all the treatments and tests, and she hopes they can help other patients cope with these realities.

Elizabeth Bohannon: So it's part of the dance of this disease I've found is I don't know how this will land with other people, but for me it's about making friends with myeloma. Because it's never going to leave me. Maybe some day there'll be a cure, but until then just like every myeloma patient even when you're in remission, it's not gone and everything knows that. So you have to find a way to live with it. And so my view of living with it is to support my body as much as I can, do mindfulness work, learn how to breathe properly, and to self-soothe, to calm myself. Because when I get scared, that's when things can come unraveled so easily.

Doctors encourage patients to stay on maintenance therapy for a minimum of 2 years. Studies are ongoing to determine whether Revlimid can be safely stopped without compromising potential benefits, especially in patients with deep and sustained responses.

If a patient is having trouble tolerating maintenance therapy, their doctor may first try to adjust the dose to eliminate or minimize side effects before considering stopping treatment.

Kathryn has discussed dose adjustment with her doctors, who are considering reducing the amount of medication she is having to manage her side effects.

Kathryn Mohorn: And I mean, I'll be honest, it makes me nervous to be completely, done with the Kyprolis because I don't know. I just. I just worry that it's going to make it come back faster. But at the same time I'm kind of ready to get this poison out of my body. I feel like I'm taking poison every two weeks, so. I'll just listen to them as usual, and if whatever they recommend that's what I'll do.

The most common side effects of Revlimid are fatigue, rash, or gastrointestinal problems such as constipation or diarrhea. Revlimid can also cause low blood counts, which may increase the likelihood of developing certain infections.

Linda deals with frequent fatigue and occasional GI issues as a result of her Revlimid treatment, which have forced her to make adjustments to her daily routine.

Linda Lane: I live like a toddler, right? Take a nap in the morning or in the afternoons, and I go to bed at 8:30 at night. That's not so bad when you look at what other people deal with, but that was a little bit of a tougher transition than I had anticipated. And a lot of it was just kinda like okay, all right, let's just get in the groove again.

Because of her side effects, Linda also recently had to make the difficult decision to stay home from an overseas trip with her husband and sons.

Linda Lane: My husband has always wanted to go to Ireland. That's one place we didn't get to yet. I was like, "Take the boys." And they planned this wonderful trip to Dublin and Edinburgh, and they were really sad that I wasn't going. And I was like, I would be back at the hotel, and you would be worried about me. And plus, too, with the occasional GI issue, I just, yeah. So, I went vicariously. They sent me plenty of pictures.

Elizabeth experienced a short episode of changes in her blood counts, which fortunately resolved quickly on their own. However, as she explains, the constant unknown of what to expect can be challenging.

Elizabeth Bohannon: They did a CBC and all of my blood counts had plummeted. I don't know, even my platelets were like 128. Everything had plummeted and I was saying what is going on? And then a few days later I got some sort of stomach bug and was flat for a week. And when you have myeloma, one of those things you have to get used to when you get a cold you think, oh my God, I'm going to die. Or oh my God, my disease is roaring back. Or you don't feel like you're in the world with everyone else anymore. And so I probably just had a little norovirus or some stomach bug. But to me, it was a scary week because I didn't know what was wrong. And that combined with my counts dropping, but then I went in for chemo on Friday and all my counts had rebounded. So I don't understand it and I don't think my doctors do. And that's

just the way it is sometimes. You just have to get used to not understanding everything that goes on in your body.

Maintenance therapy is given indefinitely, and some patients may find that its side effects become intolerable over time. Again, if you experience problematic side effects while taking Revlimid, your doctor may want to first try lowering the dose of Revlimid before considering stopping treatment all together.

This was the case with Kathryn, who developed a rash while taking Revlimid. Adjusting her dose after talking with her doctor helped her tolerate these effects.

Kathryn Mohorn: And like if I was out in the heat, that's when it would kind of affect me. Underneath my clothes I would get like a rash and kind of itchy and everything, and so they reduced me. Now I'm on 5 milligrams and I'm not really seeing a rash on my body. But like we play golf a lot and I wear a cap, you know, to keep the sun off of me and like around the band, like where the hat fits I get a little rash in my hair, like my scalp. But if that's what I have to deal with that's not the end of the world. It's a lot better than having a rash all over my whole body.

Medications that can help you manage treatment-related side effects are usually available, such as Imodium to help with diarrhea. Other medications can help target the underlying causes of the side effects. Changes in diet may also be helpful to address or avoid some of the potential side effects.

In rare cases, Revlimid and other immunomodulatory drugs have been linked to the development of new cancers, also known as second primary malignancies. In studies where this was observed, Revlimid was used with melphalan, the main chemotherapy used during autologous stem cell transplants. The secondary cancers seen in these studies included blood cancers such as myelodysplastic syndromes and acute leukemia. Skin cancer is also of concern; however, with appropriate monitoring, this type of cancer can be caught early and managed. There have been very few second primary malignancies seen in studies of Revlimid where melphalan was not part of the treatment. The information available to date indicates that therapy with Revlimid significantly decreases the risk of myeloma progression, and most doctors believe that the benefits of Revlimid outweigh the risk of secondary cancers. As always, it's important to discuss any concerns you have about treatment with your doctor.

If a patient does need to discontinue Revlimid, their doctor may switch them to a different type of drug—such as a proteasome inhibitor like Kyprolis, Velcade, or Ninlaro or a monoclonal antibody like Darzalex. If the patient is already on two drugs, the other agent may be continued and the Revlimid discontinued. Ultimately, it is important for patients to receive and stay on maintenance therapy as long as possible, as studies have shown that patients are at greater risk of

relapse if maintenance therapy is discontinued. If you are having any issues with your treatment, no matter how insignificant they might feel, it is important to talk with your care team and discuss your options.

To learn more about what to expect with long-term myeloma treatment, let's hear more from Linda, Kathryn, and Elizabeth, who join the MMRF's Mary DeRome to discuss their experiences with maintenance therapy and share the challenges they've faced, the adjustments they've made, and what their extended responses have meant to them.

Mary DeRome (MMRF): My guests today have gone through the traditional steps of initial treatment for myeloma, which includes induction therapy with a triplet regimen, with or without a stem cell transplant.

Currently, you are all on some form of maintenance therapy. The standard of care for maintenance is single-agent Revlimid. Elizabeth and Kathryn, you are both on a triplet maintenance regimen, and Linda, you're on a quadruplet regimen. This says something about the subtype of your disease, which—at least in the case of Elizabeth and Kathryn—is probably somewhere on the high-risk spectrum. Linda, you're on a quadruplet. Is that because you have not yet had a transplant?

Linda Lane: Correct. I'm also in the high-risk category, as well.

Mary DeRome (MMRF): Let's talk about how you came to be on three or four drugs instead of one.

Linda, let's start with you.

Linda Lane: I was diagnosed in May of '21 as a result of long Covid; that's how they found it. My local doctor was going to do standard Revlimid-Velcade-dexamethasone and then go to stem cell transplant. We also brought in a specialist at Dana-Farber. I had been doing some research, as well, and I had been finding some things about daratumumab, and I had asked him about it and he said, "Yes, absolutely, we can add that on, if you'd like." He did that and said, "Hey, we'll see how you do. Maybe you'll get to the point where we can ask if it makes sense to do the stem cell transplant soon after or if it's something that you can defer." We opted to defer, but the agreement was that I to have the stem cells collected.

So we paused treatment for the few weeks that it takes to collect the stem cells, and during that time, my kappa spiked. I quickly went right back down as soon as I got back on treatment. My doctor at Dana-Farber just felt that, "Okay, for maintenance, let's keep a very heavy hand," based on, one, my profile, with it being light chain and with translocation, but also because of how I reacted during that short period where I was off.

That's how it's come to be that I've continued with the four drugs.

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

Kathryn Mohorn: It was November of 2020. I was just in for my regular routine physical, and my doctor's always really good about all the bloodwork, and my proteins came back elevated. They were at 9.5, and the range was 6.5 or 6 to 8.5, something like that. He said, "Well, you look like the picture of health, but if you were my wife, I would just want to check it a little further." So they did the urine test and they saw the Bence-Jones proteins. Initially, I was actually diagnosed with smoldering myeloma, and we were living in North Carolina at the time. We moved to Park City, Utah, and within 4 months, I went from 18% plasma cell to 80%, so I became active in 4 months. I immediately started the induction therapy. They found an extra leg on chromosome 1, which isn't textbook high-risk, but they think that it has the potential to be one of the high-risk categories.

They put me on Kyprolis, Revlimid, and dex. They chose Kyprolis because they feel like it's better for that particular abnormality and also because I'm a super-active person and I would be less likely to have neuropathy from that than with Velcade.

In September of 2021, I had a stem cell transplant. I continued going in for the same triplet therapy—you have the break, right after the stem cell transplant, for 90 days or whatever it was, then they put me back on the same regimen. I am still currently on that. I get intravenous (IV) chemotherapy every 2 weeks, and then I take Revlimid. They are only making me take the dex when I have the treatment, just to avoid some side effects.

But anyway, that's the plan. It took about a year for me to be minimal residual (MRD) negative. If it continues, by the end of this year they're hoping to have me just on the Revlimid. I'm hoping that, too, because it would make my life a lot easier. I'm sick of having to make my travel plans around that.

Mary DeRome (MMRF): Elizabeth, how about you? You're taking the same maintenance as Kathryn?

Elizabeth Bohannon: Yes, I am. I was diagnosed in February of 2021. Interestingly, it was a brand-new chiropractor who saw the classic lytic lesions of multiple myeloma on a set of head and neck x-rays that he did before initiating chiropractic care. I'd been having a lot of rib pain for over a year. I thought it was intercostal muscles.

Like Kathryn, I'm very active. I am an equestrian, so I was riding. I kept blaming myself, saying, "you're clearly not doing enough core workouts, so therefore,

you're pulling your intercostal muscles." That was the story I had. But it had gotten very debilitating; it was hard for me to sit, it was hard for me to move, it was hard for me to sleep. I thought, "I'll go to a chiropractor and see if I can get an adjustment," and that's where he saw the lesions. That began my journey. I'm being treated at the University of California here in the San Francisco Bay area. I also have intermediate- to high-risk disease: I have a 1q deletion, 11;14 translocation, and extensive lytic lesions in every bone in my body. I also have the problem of having non-secretory disease. The PET scans don't pick anything up, the bloodwork doesn't show anything—nothing in the urine. If you didn't look at my bone marrow biopsies, you wouldn't know I have this disease, which makes it really challenging when it comes to treatment and monitoring. The first round of induction therapy, my doctor wanted to put me on carfilzomib, but my insurance company refused. I had to go on traditional Velcade, Revlimid, and dex, and we elected to do a 6-month induction instead of 4 months, because the only way we would be able to measure my body's response was by bone marrow biopsies, and my doctor didn't want to expose me to more of those than absolutely necessary.

We did 6 months of that, then my bone marrow biopsy showed that, while we had gotten some response—I started out with 40% to 45% plasma cells, and we brought it down to maybe 20% or 25%.—it wasn't enough for me to be transplant-eligible at that time.

We switched to another regimen, and then I went on daratumumab, because I'm also CD38-positive, and daratumumab targets the CD38 protein. I had high hopes for daratumumab plus two other drugs—it was a triplet, including high-dose of dex, it was weekly daratumumab injections. That went on until December of 2021, then we did another biopsy and my plasma cells had actually increased while on daratumumab. I said, "I'm done for a while," and I took a break, I took 6 weeks off and went to Mexico to celebrate my 60th birthday, my husband's 70th birthday, on the beach with the whales, and just not think about it.

Then I came back, and we decided to use big guns. I was admitted for high-dose Cytoxan. I did high-dose Cytoxan and high-dose dex and, after that, my counts came down to transplant-eligible levels. I will say, at the time, I thought, "There's no way I can go through a transplant after this." But I rallied and I did. I went into the hospital in May of 2022 and started maintenance therapy with carfilzomib and Revlimid, and a very tiny dose of dex. I hate it, just like everyone. We're down to 8 mg of dex, only on carfilzomib days. That's because we tried to do carfilzomib without anything, but I get these terrible shaking chills from the carfilzomib, so we do it with as small a dose of dex to manage the side effects. I've been on that maintenance therapy ever since.

I've never achieved MRD negativity, but on biopsy my counts have stayed at a low roar for that whole time.

Mary DeRome (MMRF): Your insurance wouldn't approve Kyprolis for your induction therapy, but they approved it for your maintenance therapy?

Elizabeth Bohannon: They insisted that I was like everyone else and needed to go on the standard of care for my initial induction. I tried everything, I wrote letters, I had friends at Blue Shield try to advocate, but it didn't work.

Mary DeRome (MMRF): You also said that you have a t(11:14), right? Did you have venetoclax?

Elizabeth Bohannon: Venetoclax and dex was my second induction regimen. It was miserable, because my doctor said to me, "Elizabeth, I just feel like every time we meet it's with bad news," and I said, "Yeah, I feel that way, too."

Mary DeRome (MMRF): Kathryn, you said that you're ongoing with your maintenance therapy and that you have reached MRD negativity, so your response to the therapy has deepened. You said it took you about a year to get to the point where you went from being MRD positive to being MRD negative, correct?

Kathryn Mohorn: They kept seeing a slight band in the bloodwork, and they just wanted that to go away, and it took a year for that to go away.

Mary DeRome (MMRF): Linda, do you have any date or have you heard anything from your doctors about whether or not your response to therapy is actually deepening on your maintenance or if it's staying the same?

Linda Lane: They have not retested me for MRD negativity, so I've only had two biopsies, one at diagnosis and the other in October of '21, in preparation for the collection. My doctor essentially said, "You know what, the only reason we're doing another bone marrow biopsy is just to see MRD negativity. We want to continue with the plan anyway, so we can hold off on that." I was fine with that, quite honestly.

Mary DeRome (MMRF): Let's talk about side effects of all of these drugs. These are some pretty serious drug cocktails to take on a long-term basis. Normally, people are taking only one drug, they're taking Revlimid and then dexamethasone for maintenance. But you guys are on these very serious and strong maintenance therapies. Let's talk about how those are impacting your day-to-day life.

Elizabeth, how are you dealing with your therapies, as time goes on?

Elizabeth Bohannon: In all honesty, I mean, I've changed my life because of multiple myeloma, and it's served me well. I eat a plant-based diet now, I'm religious about my sleep, I work out with weights, I hike, I ride my horse, I do

yoga, so I'm super active, and that's served me well in terms of side effects. I have a tiny bit of neuropathy, but it only really shows up when I'm in bed at night and I feel it like a burning sensation on my feet. But that's about it, so I've been pretty well.

I will say, though, I took another holiday from drugs to go hike in Alaska to raise money for the Multiple Myeloma Research Foundation, but I trained for 3 months for that, and then I went on this trip and was about 6 weeks off from all the drugs. I came back and had to get my last set of five vaccines, because you have to get revaccinated after transplant. So I had my last set of vaccines plus Xgeva for bone hardening, plus carfilzomib, and that hit me like a rock. I cried a bit. I really missed that feeling of living in a well body, and I didn't realize how much I was putting up with in terms of fatigue and energy reduction until I was off the drugs for a while. I have more fatigue than I would otherwise, but you can get used to it. You know, already, since I've been on, now, what, two cycles, I'm okay.

Mary DeRome (MMRF): How often do you find yourself going to the clinic?

Elizabeth Bohannon: Every other week.

Mary DeRome (MMRF): Does that impact your schedule, as well?

Elizabeth Bohannon: I go on Fridays, and I try to go on Friday afternoons. What gets me through—because I really don't like being a patient or being so connected to a hospital and an institution like that—is just thinking of it as another appointment. I go in and usually carve out Fridays and consider them “me” days. I try to do fun things on Friday as well as chemo, and that helps.

Mary DeRome (MMRF): Kathryn, how are you doing with your maintenance therapy?

Kathryn Mohorn: Like Elizabeth, I just try really hard to be positive and keep on going. I don't let anything stop me. I was on 40 mg of dex, and I've been trying to wean off of it. I had gotten down to where I was just taking three pills versus ten, and the last two times I've gone, I've gotten fairly sick afterwards. I got shaking chills and high fever, so I'm going to have to bump it back up, at least to five, and see how that goes. But I am more tired than I used to be, because I never even knew I was sick. It was completely picked up on a routine physical. The only thing that was going on with me was that I was dizzy. They told me that that could've been the myeloma cells crowding out the healthy cells.

I'm doing okay; I just try to stay positive. I go every 2 weeks, as well, but we plan trips around that and that keeps me happy. Getting ready to go to Alaska on a cruise next week, so looking forward to that. But, overall, I'm doing okay.

Mary DeRome (MMRF): Linda, how was your experience? Now, you're on four drugs. Are you getting dara as an infusion or are you getting it subcutaneously?

Linda Lane: Subcutaneously. It was always subcutaneous. Like Kathryn and Elizabeth, fatigue is my biggest issue. I go back to bed every day. I'm fine in the morning, but I feel like I have to budget my activity—do what I want to get accomplished in the morning, and then when I get up from my nap it depends upon what I feel, what I accomplish for the rest of the day. And logistically, it's an issue; psychologically, it takes a lot to go from being very active and doing things and doing for others. Not being able to do that is very hard. But in the mornings, I always try to check the box for my physical health, my mental health, my spiritual health. If I can do that each day, I consider that successful. But it is tough. Also, like the others, I'm in every other week, which precipitates a trip to the lab for bloodwork every other week. It's just in induction therapy, you really were in the battle rhythm, and that extends into maintenance, that routine. And it's okay, because it can shape your week and your activities. But other times, it feels like, "Man, this is really getting in the way, this is frustrating."

Mary DeRome (MMRF): When you were talking to your care team, before you were making decisions about whether you were going to have a stem cell transplant and, if you weren't, how that was going to work out, did your care team talk to you about the drugs you were going to be on and what you might expect for side effects?

Kathryn Mohorn: We knew, we had the laundry list of what to expect. They tell you fatigue, they tell you nausea, they tell you vomiting, they tell you constipation, diarrhea. I do deal with GI issues, although I've been able to manage that. But sometimes it's, "Okay I need to make sure that I'm close to a bathroom," and sometimes you just hang at home if you're not feeling too confident. You know, sometimes, you don't wander too far on those days. But, yes, they give you the laundry list of side effects, and it's just "All right, well, see what hits you." Sometimes others hit you, and other cycles, maybe it's not so bad.

Mary DeRome (MMRF): Kathryn, was it like that for you? Did your care team prepare you for what you could expect as far as side effects when you started your maintenance?

Kathryn Mohorn: They did, and every time you go in and—at least for Revlimid—you get that packet that tells you everything that could happen. For the most part, it is the fatigue. I have also had bathroom issues—walking my dog and it's, "Okay, I'm going to have to stop and run home, now..." "It just comes on like that. I forgot to say that I haven't had severe neuropathy, but I've been having cramping in my hand, almost like a charley horse, and I started taking potassium and magnesium, and that seems to have helped.

But, they've been very helpful, and I feel like they're family. I know all their names; there are so many of them. They've been great.

Mary DeRome (MMRF): Elizabeth, did your care team prepare you for what you were facing with your maintenance therapies?

Elizabeth Bohannon: I don't really remember those conversations. I remember what I want to remember, and most of the time, I want to believe everything's going to be just fine. That's my mindset. The plus side of that is that I don't spend a lot of time being anxious. The downside of that is when these side effects show up, it's, "Wait, what is that?" You know, I'm a little shocked.

Like the others, I have had all kinds of GI issues, primarily diarrhea. It is okay as long as I'm home, as the others said. But when I was training for Alaska, it was scary, because the thought of having to hike these long hikes in Alaska and have diarrhea was terrifying.

But it's interesting, it comes and goes, it's not all the time. When I went back on drugs, after taking that holiday, my scalp was itching like crazy, and my doctor said, "Oh, that's Revlimid. Start taking Claritin," and don't you know that the itching improved. So, some itching and GI issues and fatigue, and I will say, of all of the drugs—aside from the high-dose chemotherapy drugs, which are in another class by themselves—the dex is far and away the worst.

Mary DeRome (MMRF): Elizabeth, you've gone on a couple of drug holidays since you've been diagnosed. What did your care team think about these drug holidays? Did they just say, "Okay?" Or did they try to talk you out of it?

Elizabeth Bohannon: I've been really lucky in that regard. My care team, Dr. Wong has been my doctor up until just now, and she always said, "Your life is the most important thing to me, your choices are the most important thing to me. As long as you're informed, you get to choose." So I always see it as I've got the keys to my car and I drive. When I need a break, I need a break. I couldn't have hiked in Alaska on those drugs, so I knew I needed a break. When nothing was getting me to be transplant ready, I needed a psychological break to celebrate my birthday. I just did it because I needed it, and I can see doing it again. I mean, it will depend on what happens with this most recent biopsy, but I could see doing it regularly, for my mental and physical health.

Mary DeRome (MMRF): People have different ways that they approach that what they need for themselves.

Elizabeth Bohannon: There was a woman on my hike who was diagnosed when she was 30 years old and she's now 48, and she did two transplants and never achieved remission, even, much less MRD negativity. She decided to take the keys to her car, after that, and she's been off all drugs ever since. Her way of

referring to it is, “My myeloma and I coexist quite nicely.” She monitors her counts, so she will know when they start to rise, but they haven’t, and that’s awfully lucky.

But that was her choice, and I found that very empowering for me, personally, to hear her story.

Mary DeRome (MMRF): It’s something that patients do need to hear, that that is an option, and care teams will respect that.

Kathryn, let’s talk about how your caregiver can help with the side effects that you’re having while you’re on maintenance.

Kathryn Mohorn: I see my doctor, Dr. McClune, I see him about every 3 months, and then there’s a PA named Mary that I see whenever I need to. She pops by probably every 2 months or so. Primarily, I just go in and have my bloodwork done, then I go into the infusion room and there are probably 20 nurses in there. They always ask, “Has anything changed since last time? Any more side effects?” I haven’t had to do anything special for the side effects. They did reduce the Revlimid. I’m down to 5 mg; I was on 25 mg. That was primarily because I was getting really bad rashes. Fortunately, not on my face, but anywhere that I would sweat—my stomach, and I’ve had an itchy head, too. I just started using medicated shampoo and that helped some, but it’s still itchy. If I have any questions, they answer them. I’m a rule-follower. I just listen to what they say and trust that they have my best interests at heart. They say the same thing to me about traveling: “You need to live your life. That’s more important than anything else.” So I have taken a couple of breaks, for a month we went and drove cross-country. I was going to fly back for treatment, and Dr. McClune said, “Absolutely not. You just go have fun. Everything’s looking good. We’ll just check when you get back.” So far, so good.

Mary DeRome (MMRF): Linda, is your caregiver—your husband—helpful when you’re having your side effects?

Linda Lane: My husband and—at the time I was diagnosed, my boys were in college, and they were in and out, and honestly, they could not have been sweeter. It was really wonderful. People were trying to get a meal train going for that, and one of my boys loves to cook and he just took over. Honestly, I feel like I did something right, you know? So that was wonderful.

But, like the others, I do see either my doctor or the nurse practitioner, a little bit more regularly than they do. I see either one in the beginning of each cycle, as just a check-in, and this is where I have my treatment done locally. Then I go into Dana-Farber in Boston—well, probably down to every 5 months, at this point. But all of my bloodwork goes and they’re always monitoring it, too, so I feel lucky to have an extra set of eyes.

Mary DeRome (MMRF): Elizabeth, how about you? Does your husband play a big role to help you through what's going on?

Elizabeth Bohannon: Let me give some background on my attitude toward the keys to my car.

I started off my adult life as an oncology nurse back in the '80s when inpatient oncology patients pretty much all died. Cancer was a different beast back then—myeloma, for sure. I mean, you pretty much had a year. I have some of that. My husband is also a retired transplant physician. Together, we have a lot of—it's not so much knowledge, because that background doesn't really help you when it's your body and your disease. But the attitude of exploration and pushing the boundaries, it might just be how I was born, but I also think that my background informs some of that. But my husband has been my thought partner, so when we have to make decisions we talk it through together. I also have children, I have two daughters, one is 31 and one is 29, and they've just been incredible, just powerful resources for us, almost as much, if not more, than my husband. We've been married for 33 years and you have habits, you know? Whereas, your daughters, at least my daughters, have just really stepped up. Then I have a pretty extensive friend group. Of course, when you get sick like this, you quickly learn who are the ones that you can really depend on to be there for you when you really need them. So I get support when I need it, and when I don't, I literally try to pretend that I don't have this.

Kathryn Mohorn: When you asked me, I was the first, so I thought you were talking about my caregivers at the hospital, but my husband has been so awesome. He actually retired in July of 2020, before I was diagnosed, and he is a retired endodontist, and he has come with me to every single appointment and has just been so great. I just can't thank him enough, but, he's been great.

My kids, I have three kids, they've all been very supportive, too. Elizabeth is so right about friends, you really know who your friends are.

Mary DeRome (MMRF): You guys are on at least three drugs, and some of you are on four.

Linda, have you ever had a discussion with your care team about whether they might want to drop one or two drugs or just change your maintenance, based on what's happening with you?

Linda Lane: The last time I was in at Dana-Farber, which was May, Dr. Nadeem suggested that, "All right, we'll revisit whether or not we pull back on the dose of something or eliminate something altogether." I'll see him next in October. The end of January will be 2 years on maintenance, so he was saying most likely then.

I don't know what will happen. My kappa number, which is my primary marker, is trending upwards a little bit, still in the normal range, so my guess is he won't do anything like that in October, and perhaps revisit in January. But each time, he says, "All right, maybe we'll tweak things." I started my maintenance on 15 mg of Revlimid. In induction, I was at 25, and they brought me down to 10 just to try to help with the fatigue. He has tweaked things up until this point, so he'll say, "All right, this is what we're going to do, and then down the road, maybe this is what—we'll try to let you know what the next step might be."

Mary DeRome (MMRF): Kathryn, have your doctors talked to you about tweaking your maintenance therapy?

Kathryn Mohorn: At the end of November, it will have been 2 years since the transplant, and they said that they're going to hopefully take me off the carfilzomib infusions—maybe entirely, or I may have to just do it once a month. But I am sure I'll still be taking Revlimid, I don't know what dosage, and I don't know about that dex—we'll see.

Mary DeRome (MMRF): Elizabeth, have you ever talked to your care team about whether they're going to tweak your therapies?

Elizabeth Bohannon: Funny you should mention that. My new doctor is Dr. Wolf at the University of California, San Francisco. I chose him after Dr. Wong left because he's gone on record saying that he believes there's a cure for myeloma within the next 5 years, and he's not going to retire until there is one. I'm always thinking about that, because as much as I'd love to live a long life, I'd far rather live a good life. I'm very attached to the idea of being able to do what I want to do, so I'm always thinking about what's possible. I think about CAR T, but I also recognize that, when you're able to live your life and it's pretty good, I'm not eager to change things up. Because while we are getting more and more drugs approved and more and more options, I don't want to run out of options. So I'm a little calmer about that than I was in the beginning when I was really hellbent on achieving MRD negativity and I had this idea of a long-lasting remission. I'm aware, now, that that may never be the case for me, so it's about that balance. What gives me the best quality of life for the longest period of time is really my goal.

Mary DeRome (MMRF): Thinking about if and when your myeloma decides to reassert itself and your labs start to go up, do you think about what therapy you might go on next? Or if you're having this resurgence of your multiple myeloma and you get an opinion from your doctor about what they think your next therapy should be, would you consider getting a second opinion from another doctor? Linda, how would that work?

Linda Lane: I do already have two doctors, but, yes, if I needed a tiebreaker, maybe I would. We do have a very dear friend who is an oncologist, so I would run things by her. Knowledge is power. I would just keep seeking information until I was comfortable with whatever decision we made.

I liked Elizabeth's analogy of we have the keys to our car. If I were to relapse soon, the thought was, okay, if you relapse within a certain amount of time you'd go to stem cell transplant. I've been reading a lot about all these other great things, so if there are newer technologies—bispecifics and CAR T—I might push for something like that.

Mary DeRome (MMRF): Kathryn, how would you go about that type of decision?

Kathryn Mohorn: I would want to get another opinion. I'm very lucky that I actually have a myeloma doctor that lives in my neighborhood, and she said I can always come to her with questions. She works for the other hospital, there's Intermountain Healthcare at University of Utah, but she said, "That doesn't matter. Any time you have a question, feel free to ask me." But I feel encouraged that there is so much going on with the research, and Todd from the Multiple Myeloma Research Foundation comes to see me once a year when he's in Utah, and he was here a month ago or so, and he said that it's a possibility that they'll be able to just use bloodwork instead of having to have a bone marrow biopsy in the future. That would be great. But I would want to get another opinion if it was a significant change. I don't think that I want to be part of a trial, because of being high-risk. It wasn't even an option for me this time around. I hope these medications that they're coming up with are going to be the key to our future, and I sure hope that there is a cure in the next 5 years. That would be awesome.

Mary DeRome (MMRF): There is a lot of work going on in high-risk myeloma right now, because that's a huge area of unmet need. Approximately 25% of myeloma patients are high risk. The whole field is moving more towards risk-adapted therapies, and there needs to be more work in that area. The MMRF is starting a number of programs to look at that, and also trials to look at risk-adapted therapy based on chromosomal abnormalities. It's an active area of research.

Elizabeth, how are you thinking about what's going to happen with you if and when you get to the point of relapse and you need to go on some other therapy?

Elizabeth Bohannon: I have done a second opinion, once, and I would be interested in hearing other people's experiences with second opinions. But I did it before I went Cytoxan, and I did my second opinion through the Mayo Clinic program. I found it unsatisfactory, to be honest, because even though I consider myself someone who stays on top of the research and is pretty educated about my disease, when its patient talking to doctor, so much gets lost in translation. So I came back to my doctor with the Mayo doctor's opinion, and my doctor said,

“did you ask him this? Did you tell him that? What about this?” and I said, “No, I didn’t ask any of those questions and I didn’t tell him that, because I’m the patient.”

I would love to get a second opinion, but properly. For me, a second opinion could be valuable for doctors talking to doctors, or at least institution to institution. I’m not able to communicate about my disease at the same level as my provider could, so I would totally want to do it, but not as it’s set up now. They take thousands of dollars for something that doesn’t get you very far.

Mary DeRome (MMRF): Kathryn has already said that she’s not interested in a clinical study, because she’s a high-risk patient. Elizabeth, if your doctor suggested to you to go on to a clinical study, would you consider that?

Elizabeth Bohannon: Oh, in a heartbeat. When I was a nurse, I ran clinical trials, so I have experience with them. I’m also very much champing at the bit to get into a clinical trial down at the Hogue Research Center, looking at alternatives to bone marrow biopsy. Immune PET scans are what I’m looking at, but I can’t get into the trial until I officially relapse, and that’s a whole definitional thing. But I would for sure do a clinical trial, maybe not a phase 1 for the reasons that Kathryn mentioned. If you’re looking at an option that might buy you more time or better quality of life, I wouldn’t want to be in a phase 1 trial, but I don’t think that’s really what most of us are talking about anyway. It’s really about earlier access to some of these novel drugs, and that has a lot of appeal to me.

Mary DeRome (MMRF): There are some interesting things in phase 3 right now—immunomodulatory drugs that are analogs of Revlimid and Pomalyst, so, iberdomide and mezigdomide—so they might be the next ones that are going to be approved.

Linda, would you consider going on a clinical study, if your doctor thought it might be your best choice?

Linda Lane: I would consider anything. Whether or not I do it depends on where I am, what it is, how badly I’m feeling at the time, what my history has been. I will definitely keep my options open.

Mary DeRome (MMRF): You still haven’t had a transplant, so that’s still an option, right?

Linda Lane: It is a big option, although it’s an option I’m hoping not to have to do.

Mary DeRome (MMRF): I’d like to close by asking each of you what you would say if you were talking to a patient who was in the same boat as you were in.

Maybe they have been diagnosed and they've had a transplant, and now they're on maintenance therapy.

Kathryn, let's start with you.

Kathryn Mohorn: Number one, be positive. Eat right. Exercise is key. It keeps me feeling better physically and mentally. Don't give up. You can live with this. I compare it to having AIDS: you can live for a long time, you just have to take the medication, but you can live a very fulfilling life.

Mary DeRome (MMRF): As we go through the years, people have started talking about a possible cure for myeloma. We certainly have progressed to the point where it's become almost a chronic disease. Many people can stay alive for quite a long time. As long as they keep on top of things and they're on maintenance therapy and their labs are watched, if they start to have a recurrence, they can go on something different. Newer drugs are coming to the market all the time for patients that are in later stages, and these later-stage drugs are becoming more and more effective.

In the old days, you couldn't expect more than a 20% or 30% response from these drugs, for patients who had seen 4 or 5 lines of therapy. But things are getting much better.

Linda, what would your advice to other patients be?

Linda Lane: I would start with, life certainly is very different than we imagined, but it can still be great. Similar to what Kathryn said, activity is so incredibly important. I work with a trainer twice a week—weight-based training, which is so good for the bones. I'm out walking year-round. Physical activity is so important. That old commercial "a body in motion stays in motion" is so important, and in my prior session, my father-in-law passed away from multiple myeloma, so we were very familiar with what it was. When he lost his mobility, it was the beginning of the end. Granted, he passed in 2002 when there was very little that could be offered to him, but I really do think that his lack of mobility really accelerated things.

Mary DeRome (MMRF): Elizabeth, you have the last word.

Elizabeth Bohannon: I would say a few things. One is that, while staying positive has been really important to me, it's a hard journey. It's not easy. It's lonely. People look at you and they say, "You look great," and then they think you are great, and it's not great. It's okay for it not to be great and for you to get the help and support you deserve, because it's not great. Get a therapist, join a support group, talk to your loved ones, whatever it takes to get the support you need, do that. Because no matter how great you look, it's not great; it's hard. So I would definitely say that.

I would also echo the others: there are things that are within our control. We can't control what our myeloma cells are doing, but we can control our diet, our sleep, our exercise. Take care of your body as best you can. That's been a real key to my experience.

Also, stay informed. The more you know, the better you can advocate for yourself. For me, it's really important to stay on top of the research, to attend MMRF webinars, to learn as much as possible, because it makes me a more informed consumer, and I can ask those tough questions.

Mary DeRome (MMRF): Thank you, ladies, for the wisdom you have imparted during our podcast.

I'd like to thank my panelists today, Elizabeth Bohannon, Kathryn Mohorn, and Linda Lane, for answering all these questions and just being such great partners in this discussion.

Narrator: Thank you for listening to this episode of the *Myeloma Matters* podcast on myeloma maintenance therapy, hosted by the Multiple Myeloma Research Foundation. The M-M-R-F thanks Elizabeth Bohannon, Kathryn Mohorn, and Linda Lane for sharing what it's like to live with myeloma and be on some form of treatment indefinitely. The MMRF also thanks AbbVie, Amgen, B-M-S, CURE, Genentech, GSK, Janssen, Karyopharm, Sanofi, and Takeda Oncology for their generous support of this podcast. If you have additional questions about what you heard today, call the MMRF Patient Navigation Center at 1-888-841-6673.

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