

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

## Episode 1: Bone Health

### 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 how and why multiple myeloma affects the bones, as well as how patients can maintain their bone health. You'll also hear from two patients who experienced drastically different complications from bone disease and learn what they've done and continue to do to maintain the strength and health of their bones.

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.

Many patients first learn that they have multiple myeloma after experiencing an issue with their bones, such as bone pain or a fracture. Multiple myeloma is a disease of the bone marrow, which is the soft tissue inside the bones where blood cells are made. The bone marrow helps regulate bone health by controlling a process known as bone remodeling. In healthy individuals, old bone is replaced with new bone in a constant cycle. In people with multiple myeloma, myeloma cells develop and accumulate, disrupting the balance between bone removal and bone growth, which can lead to bone loss.

Up to 85% of people with multiple myeloma experience bone disease. In some people, myeloma may cause thinning and weakening of the bones to the point where holes are formed in the bone, which can lead to pain or fractures. These most commonly occur in the bones of the spine, pelvis, and rib cage. If bone weakening occurs in the spine, it can also lead to a condition known as spinal cord compression. This occurs when bones in the spine collapse and put pressure on the nerves in the spinal column, which can cause sudden and severe back pain, numbness in the legs, and muscle weakness. Spinal cord compression is a serious condition that requires emergency medical attention.

Bone loss can also cause levels of calcium in the blood to increase. This is called hypercalcemia, and it can lead to complications like kidney stones, nausea, vomiting, constipation, fatigue, and dehydration. In very severe cases, it can lead to kidney failure or coma.

For some people, it may be obvious that something is wrong with their bones, even if it isn't immediately recognized as an effect of multiple myeloma. This was the case for our first guest, Mike Mankowich, who was diagnosed with multiple myeloma in 2017.

**Mike Mankowich:** I was diagnosed probably a little over five years ago. Part of having been diagnosed, I was having back pains probably for, you know, maybe 8 to 12 months prior to being diagnosed. And my first thing I did was I went to a chiropractor, which was probably the worst thing I could've possibly done.

Mike left the chiropractor in more pain than he had when he went in. After another painful visit with a chiropractor, he went to a doctor, who prescribed him anti-inflammatory medications for a suspected muscle tear. When the pain kept coming back, Mike knew it was time to see an orthopedic specialist. The orthopedist ordered an MRI, which revealed fractures and bone lesions in his spine.

**Mike Mankowich:** I'm sitting in my office at work and I pull this report off the fax and in the report it basically provides a conclusion, that conclusion being it's either metastasized cancer or multiple myeloma. So we all know what I was pulling for. But it was a rough day, at least.

For other patients, bone issues may be more subtle and can be dismissed as regular aches or pains that are related to normal activities—until they lead to a medical emergency. This was the case for our second guest, Jamie Alamillo.

**Jamie Alamillo:** I do work outside and I had just, I had simply bent over to pick up something that was in a path of travel and move it off to the side. And as I came back up, I felt this feeling in my back and I'm like, okay, I must have pulled something. Of course, I was 43 at the time and I figured, hey, it'll heal up in about a week.

The pain didn't get better, though. Jamie would rest and relax until his back felt better, only to be met with severe pain once he tried to return to regular activities. After a month of this cycle, Jamie had another episode of back pain that felt different. He says he told his wife he was going to stay home from work because he wasn't sure what was going to happen.

**Jamie Alamillo:** I took a shower and got back out of the shower and then I immediately went paralyzed from the waist down. After that it's kind of a blur, but I do remember going to the emergency room and my doctor that was trying to figure out what was my diagnosis or what was going on, she was able to get us to the front of the line because of course it was packed and I had no movement.

Two days later, Jamie returned to the hospital for emergency surgery as a trauma patient.

**Jamie Alamillo:** I was considered trauma, and the myeloma had broke my back at T7 and L4. And then also, I had lesions all along my spinal cord. And actually,

I wasn't the first one to find out. My wife was the first one to find out that I had multiple myeloma.

Bone damage in multiple myeloma is serious, but the good news is that it is treatable. Treating the underlying myeloma is one way to help prevent further bone damage, as reducing the number of myeloma cells in the bone marrow can help restore the balance between bone growth and removal.

In addition to providing regular myeloma treatment, a myeloma patient's health care team may also prescribe medication to help with bone issues. These medications work by blocking the activity of the cells in the bone marrow that are responsible for breaking down bone tissue, which can help lower bone pain, reduce the likelihood of fractures, and prevent bone disease from getting worse.

Two types of medicines are typically used to manage bone disease in multiple myeloma: bisphosphonates, such as Zometa, which are given intravenously; and the monoclonal antibody Xgeva, which is similar to Zometa but is given as an injection under the skin. Xgeva is typically considered an alternative treatment option for patients who are not able to take bisphosphonates—for example, patients who have kidney problems.

The goal of treatment with either of these medications is to stop or slow the pace of bone loss. Neither is able to rebuild bones that have already been damaged. The health care team may provide other recommendations for maintaining bone health, such as eating calcium-rich foods, taking calcium or vitamin D supplements, and staying active.

Indeed, staying active has been an important part of the recovery process for both Mike and Jamie. And they both understand just how hard it is to stay active at the start of the process.

For Jamie, staying active meant starting from square one. With the fractures in his spine, Jamie was completely paralyzed from the waist down before he even knew he *had* multiple myeloma. It took a lot of physical therapy, medication, and perseverance to recover after his spinal surgery.

**Jamie Alamillo:** It took about a year of therapy. I had months and months of therapy, just teaching myself how to walk again and stand up and just able to function. But I was mainly in a wheelchair. Then I kinda graduated into the Canadian crutch, the loft strands double. And then after that I went to double cane and then it was a single cane. And then one day I just told my wife, "Let's go to the mall and I'm ditching the cane."

Jamie has also received several rounds of radiation therapy to help manage his bone pain. Low-dose radiation therapy is sometimes used to help manage specific bone lesions that cause recurring pain.

**Jamie Alamillo:** It was like a proton therapy, so it was a targeted radiation therapy. It was more targeted, which now is the choice of treatment for a lot of

cancer patients because they can target the actual lesion or tumor. And then also, the areas in the bones where of course our disease is in the bones. So, it's able to target those specific areas. I think it truly helped me quite a bit.

Jamie still experiences bone pain and stiffness, mostly as a result of his spinal surgery, but he has learned to live with his bone disease. He knows what to expect from his pain and is quick to alert his health care team if anything changes. But staying active has made a world of difference, and Jamie now regularly participates in group bike rides with the MMRF across the country. Roughly 9 years after starting his recovery journey, Jamie recently completed a 550-mile ride from Santa Clarita, California to Lake Tahoe.

Both Jamie and Mike have come a long way since receiving their myeloma diagnoses and encourage others to stay active to help their recovery, as well. Activity will look different for everyone.

**Jamie Alamillo:** Even for the myeloma patients that can't do much, there's stuff to do that you could sit down. There's a sitting down, a recumbent bike. There's of course, dumbbells that you can do at home just to keep strong, because you need to be strong, 'cause if the myeloma ever comes back, you're strong enough to handle it and you're in good shape versus sitting at home in a corner and not doing much and woe is me. No, you can't do that.

Although there are many effective options for management of bone disease in multiple myeloma, the risk to bone health is constant and requires careful ongoing management. Episodes of disease recurrence can lead to new or worsening bone disease. When there are changes in bone pain or if new fractures develop, it's important for patients to let their care team know about it.

Long-term use of bisphosphonates or Xgeva is also potentially associated with a rare but serious condition known as osteonecrosis of the jaw, or ONJ. In ONJ, the bones in the mouth and jaw become eroded or die, leaving a painful open sore along the inside of the jawbone.

Although it is recommended that bisphosphonates only be used for no more than 2 years, many patients stay on them for longer periods than intended. Both Mike and Jamie received Zometa for several years. Jamie never experienced any complications from his treatment, even after 6 years on Zometa. Mike, on the other hand, was not so lucky.

**Mike Mankowich:** There's only one thing out there that had me more scared than multiple myeloma, and that was the specter of necrosis of the jaw.

Mike's doctors had explained to him that the risk for ONJ was very low, but internet searches still left him worried. He made sure to set up care with a dental specialist who had experience with ONJ and multiple myeloma and was diligent about getting regular dental care. But after about 3 years on Zometa, Mike felt a sore on the inside of his mouth that wouldn't heal. He knew something was wrong.

**Mike Mankowich:** But I tell you, I didn't really – and everything I was reading about necrosis, I had a real hard time getting a handle on it. I kind of assumed that it started and it would just continue to progress with time and eventually you had to have your face replaced, or something like that. I didn't realize that with a lot of people it kind of would start and stop, and you know, some people have very minor forms of it.

Mike's health care team confirmed that he had ONJ. They immediately stopped his Zometa treatment but preferred to take a "wait-and-watch" approach before rushing to surgery.

Fortunately, Mike was able to connect with an oral surgeon who suggested trying a different approach to managing his ONJ...

**Mike Mankowich:** he's in his jeans and a t-shirt, you know, I get in the chair it's totally casz. And he looks in there, he goes, "Okay, I like it. I have a lot of success when it's in that particular location." He goes and he pulls out one of his probes or whatever and he goes, "Sometimes I can just go in there and just kind of flick it off." I'm like, "really?"

Mike returned one more time to remove some remaining bone from his jaw that was diseased. In all, the amount of bone removed was so small, he says he doesn't even notice or feel a difference in his jaw.

Like many people, Mike worried about ONJ more than his multiple myeloma. But ONJ is treatable when caught early and preventable with good oral hygiene and regular dental care.

For both Mike and Jamie, experiencing bone disease led them to their multiple myeloma diagnosis. Both had to overcome pain and—in Jamie's case—recover from debilitating fractures that led to paralysis.

**Jamie Alamillo:** I still experience bone pain daily. Takes me a while to roll up and get out of bed. I have stiffness in my bones, and that's because of the spinal surgery that I had. And yeah, it's a long going effect. I think it'll be with me for the rest of my life. Wish it wouldn't be, but I'm used to it now. It's like drinking coffee in the morning.

Like many patients with multiple myeloma, Mike and Jamie continue to be vigilant about their bone health. They encourage everyone with multiple myeloma to take the steps needed to keep their bones from weakening, and emphasize the need to stay active, in whatever form that may take. Whether that means walking or biking, or even just getting up to cook a meal every day, they encourage everyone with multiple myeloma and their caregivers to keep moving as much as they can.

Let's now hear more from Mike and Jamie, who are joined by Mary DeRome from the MMRF, who'll share more about their challenges and the ways that their bone disease has shaped their myeloma experience.

**Mary DeRome (MMRF):** Jamie and Mike, thank you for joining me today to talk about bone health, which is a really important topic in multiple myeloma.

Let's talk about your journeys. We'll start by talking about who on your care teams is responsible for managing your bone health? Is it your multiple myeloma specialist or is it the nurses, nurse practitioners, or physician assistants that you work with? Where's the best place for patients to turn if they have concerns about their bone health?

**Jamie Alamillo:** It's primarily my oncologist, Dr. Alexander Black, with UCLA. Every quarter, he checks in with me regarding my bloodwork and how I feel overall. Because my cancer was in my spine, and my back had broken at T7 and L4—the bones broke in those areas—they really monitor that, along with your own analysis of how you feel. If something feels different, my oncologist is always on call.

I also think that my internal medicine doctor with UCLA also has a big responsibility, too. Your oncologist is there to take care of your cancer, keep it away, and give you the cocktails you need to keep it away—whether you still have the myeloma or if you're in remission.

I find myself going to both. To answer your question best, the internal medicine doctor does a lot more for me as far as prescriptions and what to do if I need some type of a therapy or a different type of medication.

**Mary DeRome (MMRF):** Mike?

**Mike Mankowich:** As far as my situation goes, I deal primarily with my oncologist. As far as bone health goes, when I was first examined, I had a number of lesions on my spine—some stress fractures, but nothing that was so bad that I needed any treatment specifically for my bone or my spine. It's been the oncologist and when I develop problems with my jaw, I had a maxilla facial specialist get involved. But that was not an ongoing situation.

**Mary DeRome (MMRF):** When you began to have problems, was it your oncologist that you first brought the problems to?

**Mike Mankowich:** When I first had problems, I thought I had pulled a muscle in my back, and it became rather chronic, and I saw a few specialists. As a matter of fact, I went to a chiropractor first, which was not the best choice given the fact that I was in far more pain leaving his office than I was going into it. I went and I saw a spinal specialist for lack of a better term, and he sent me in for an MRI. Within 12 hours, I got a phone call during which I was asked if I knew anybody at Sloan Kettering. Which led me to believe that I might be dealing with something that was a little worse than I had anticipated. At that point, I was introduced to some folks from Sloan Kettering—an orthopedic specialist who then introduced me to an oncologist that specialized in multiple myeloma.

**Mary DeRome (MMRF):** Jamie, let's talk about when you started taking Zometa. You had some really serious bone problems; what did you expect when you started taking Zometa? Did you expect it to help you as much as it did?

**Jamie Alamillo:** No, I really didn't. As a cancer patient, when you see these infusions going into you, you're just like, okay, wow...here we go again.

I was told by Dr. Black, the UCLA physician, that this was just to strengthen my whole skeletal system—that way, if I did have some type of a fall, it would be a rarity that something would break. I said, "Okay, well, then let's just keep doing this." Because we did do it for an extended time. I didn't think it would work, because of how I felt.

But feeling it now, I think that's gone a long way. My bones do feel better. Of course, I'm achy in the mornings, during the days just in my joints. I mean, I still feel bone pain, but I truly believe that if it wasn't for the Zometa, my bone pain probably would have been more extreme than it is now.

**Mary DeRome (MMRF):** Mike, did you have a similar experience with Zometa when you started taking it?

**Mike Mankowich:** I had a totally different mindset than Jamie. Before I take anything, I research it, probably like everybody else out there. When I read about Zometa, the one thing that stuck out to me was the side effect, the possibility of getting osteonecrosis of the jaw, which reading about people who had experienced this side effect was rather unsettling.

The thought of your jawbone starting to die, and that spreading throughout the jawbone and your jawbone basically decomposing in your face—man, that scared the hell out of me. I never ever stopped thinking about that. I was like, "Well, I'm good, I understand I need this." I've got issues with my spine, I had stress or compression fractures and lots of lesions, and there was not a day that passed that I wasn't concerned. In the end, it turned out, rightly so.

Because maybe about 3 years down the road, I felt a little something inside my mouth, and it didn't go away over the course of a couple weeks. My gut told me that this might be a problem. I saw the dentist at Sloan Kettering and, sure enough, it was the start of osteonecrosis.

I was upset, but fortunately, there was a happy ending. I went to see this maxillofacial specialist who used to wrestle for Cornell. He was part of the program that I was part of, so that put me somewhat at ease.

When I went to see him, he took a look at it, and he said he had a lot of experience with it. He had his own way of dealing with it that perhaps wasn't aligned with the way Sloan Kettering would have dealt with it. But he went in there, took a probe, and said that often he had luck in just flicking it off. And that's what he did. He just reached in, stuck a

pointy thing in my jaw, and flicked it. He said you'll probably be good. I went back 2 weeks later, and he cleaned up a little bit more. I never looked back, it's fine.

**Jamie Alamillo:** I agree with Michael on that: yeah, I did my research. But multiple myeloma is deadly enough and I was willing—despite reading some of the reviews of the side effects of Zometa.

But the one thing for us multiple myeloma patients—it's your body. If this is going to keep you alive, then why not do it.

I always called it [osteonecrosis of the jaw] lockjaw. Me and my wife always called it that, because I cannot pronounce the actual name. We knew all about it, the oncologist knew all about it, and, again, multiple myeloma patients should do the research on it. But you've got a deadly disease: do anything and everything that will help you. If you do have some type of a side effect, that's why there's doctors. They're professionals, there are specialists out there that will take care of it just like they took care of Michael.

It scares me that I read that a lot of not only multiple myeloma patients, but patients with other type of cancers, stay away from something that could have helped them. But it's a chance we've got to take: we have a deadly disease, we have to take that chance. Just do what's best for us and the family, just know the side effects, and just keep moving forward.

**Mary DeRome (MMRF):** Mike, you told us about how your osteonecrosis of the jaw was treated and how you detected it. Have you had any recurrence of ONJ?

**Mike Mankowich:** No, he treated it maybe a year ago. I've been fine ever since.

**Mary DeRome (MMRF):** Jamie, when you were talking to your oncologist, what did you learn about the medications that prevent bone damage that you were receiving? Did you have any concerns about the long-term side effects?

Were you as concerned about osteonecrosis of the jaw as Mike was after researching it on Google?

**Jamie Alamillo:** That's the first thing my oncologist said when I was diagnosed. He told my wife that, because she was Googling "multiple myeloma." All she kept seeing on there was survival rate of 2 to 3 years, which is old information. My oncologist told us do not read that anymore, because multiple myeloma patients are living for 20 years.

My wife works for UCLA, so she was into doing the research. We were requesting literature on multiple myeloma, which was better. But it seems like the web is only going to give you the worst-case scenario. That was one thing he told us—just stay away from looking at longevity with multiple myeloma. Stay away from that; we're going to take care of you here. We have new drugs that are coming out, this is what's happening. Initially when I was diagnosed, he did say that life expectancy was 3 to 7 years and that

my regimen was going to be the RVD, which we all know: Revlimid, Velcade, and dexamethasone along with Revlimid and Zometa.

The jaw thing was in the back of our minds. My thought was, if it happens, it happens—then we deal with it. I wasn't going to shy away from anything that was going to help me with my cancer. I only read a little bit of information, just a few side effects. That was pretty much it. I mean, there's side effects with everything.

Videos also helped. I watched the progress of different multiple myeloma patients, that's all I wanted to see. I wanted to see the success stories versus what could happen. But, of course, it's always in the back of our minds and the family's minds: what if this happens? This type of side effect? So it's always there. But, again, my thought about this whole disease is, just combat it with anything and everything that you have. I was 43 at the time, I'm 52 now, but I was willing to do anything, because I had a one-year-old and a three-year-old at home. I wanted to live for them. I told them, throw everything at me, I'm young, I'm strong, let's do this.

**Mary DeRome (MMRF):** Do you feel like this treatment has helped your bones remain strong, and are you still concerned about getting more fractures?

**Jamie Alamillo:** I'm pretty confident, because I've had some falls while washing my car. I had my Crocs on, and I'd slip and fall down, and I pop right back up and I'm like, I'm fine. I feel sore, I felt that the treatment has done me well.

I hope I never fall. I'm an avid cyclist, and I raise money for MM, for the Multiple Myeloma Research Foundation. The funny thing is that my oncologist is also a cyclist, and he tells me, "Jamie, if you ever were to fall off your bike, you're not going to break your bones, you'll be totally fine. You'll jump right back up." I know that if I did have a fall, the Zometa is—in some way, shape, or form—protecting my bones and bone health.

**Mary DeRome (MMRF):** Do you feel the same way, Mike?

**Mike Mankowich:** I do, I feel great. Like Jamie, I go out and I raise money for MMRF, I've gone on a couple of these crazy treks. One was to Patagonia and the other was to Alaska. My body held up fairly well; I made it, I finished it. I feel good, but I will say that, every once in a while, if I feel a little twinge or any little pain in any of my bones, it makes me nervous. I'm questioning, is it coming back? Because I'm fortunate in the fact that I'm MRD negative at this point. They can't locate it [myeloma cells], they can't see it in my system. We know it's still there, but at a very low level.

**Mary DeRome (MMRF):** You've had some serious bone issues. You broke your back because of the myeloma that was there. You got radiation treatment for your myeloma. You're not still getting those, are you?

**Jamie Alamillo:** No. I had ten rounds of radiation and then I had 37 rounds of chemotherapy. Then a successful stem cell transplant at UCLA, where I harvested my own stem cells, five million, and then they gave me back two and a half million. That's what put me in remission.

**Mary DeRome (MMRF):** That must have been very painful when you had those back issues. What steps did your health care team take to help you with your pain management when you were going through that? Did you have certain drugs that worked, and maybe some that didn't work? Do you still have pain today, or is it mostly stiffness?

**Jamie Alamillo:** Stiffness. And, yeah, I do have bone pain. Now I develop some type of a tennis elbow, and I think it's all attributed to myeloma. It's really hard to grip with my right hand, but we're treating that with the medication that relaxes all the tendons in that area.

When they knew I had broken my back at T7 and L4, first I had to heal. Because on T7, I had some cadaver bones and then I also had a cage installed in that area. My lower back is still damaged, but they felt that that can fuse itself.

The main therapy, not just drugs, is physical therapy and occupational therapy, and they are what helped. Because I had to learn how to walk again. I could not walk. My mind knew I could walk, but my legs were not moving. What really helped was when the therapy team put me in close to a sitting position. Sitting was a big thing, especially with the back pain in the wheelchair—sitting, adjusting, moving, laying down. It's positions like lying down that helped me, as far as relieving some of the pain and pressure. A lot of pillows; my physical therapy team was amazing.

It was through Henry Mayo Newhall Hospital, here in Santa Clarita, California. The only drug I took was oxycodone, which is not the best. It's very addicting, because it's a narcotic. I still take that today, but I take it to a minimum. Only when I come home and my bones are sore, my back is sore; I'll take one pill and be okay. Oxycodone is just the blanket to hide the pain.

But it wasn't any type of medication that was most helpful; it was my therapy team putting me in the right positions at night, during the day, when I'm sitting, when I'm walking, just making the right movements, just to help with the pain.

**Mary DeRome (MMRF):** Let's talk about what you are doing to keep your bones healthy.

**Mike Mankowich:** I'm not really doing anything. I started out taking Zometa, and I ran into some problems with that. That was pulled, and now other than some exercise and some light lifting, I'm not doing anything. If there was a problem, my doctor tells me it would show up in my blood tests; they'd see elevated levels of calcium, and that's not been the case. All is well, knock on wood.

**Mary DeRome (MMRF):** Jamie, how are you doing with your bones?

**Jamie Alamillo:** Same as Mike. I was on Zometa for an extended time, about 4 years. I feel that that has helped me out tremendously.

What I do about it on a personal aspect is I do a lot of stretching because my back is stiff, as you can imagine by having your back broken in upper and lower locations. Stretching is good. Exercise is probably one of the best things that I think any multiple myeloma patient could do; keep yourself on a good exercise regimen. That way, you know that if cancer ever does come back, at least you're strong enough.

But every morning when I get up, I'm stiff. My back is stiff, my bones are achy, it takes me a few steps to walk normally. Stretching is huge. Medically, what my oncologist or internal medicine doctor has done for me, it seems like the gabapentin that I take really helps a lot. I take three gabapentin at night, because that makes you extremely drowsy. That does help; it relaxes my body, relaxes the bones, so I'm not tossing and turning. It keeps me in one position. That has helped tremendously, as well.

I believe Zometa is probably the best thing that I could have received. Because my bone health was not good, I was prone to any type of fractures if I didn't receive that Zometa. I know some people just can't combat Zometa and its side effects. But I was lucky that the Zometa had literally no side effects.

There isn't a study past, I think, one year of taking Zometa, but the UCLA doctors felt that was the best thing that I could do. Because I had lesions all over my body and they wanted to make absolutely sure that I did not have any stress fractures or a major break. Yeah, that's what helped me out.

As far as diets—hey, I'm a cancer survivor; I'm going to eat whatever I want to eat. I'm alive right now. I'm not changing my diet, because I'm going to live. I'm not going to sit there and have a salad while everybody's having a double cheeseburger, I'm going to have a double cheeseburger with you.

**Mary DeRome (MMRF):** Mike, it sounds like you're really active and going on all these treks and hikes for multiple myeloma, and I know that these weight-bearing exercises are great for your bones no matter who you are. What would you tell older patients whose ability to be active may be more limited? Are there exercises or activities they can do that would help their bone strength?

**Mike Mankowich:** Absolutely. Walking is an activity that helps keep us healthy. Any physical activity can benefit your bone strength, even for people who are older and limited in what they can do. They can push themselves to walk or ride recumbent bikes. There are very few people who can't deal with either of those two activities.

**Mary DeRome (MMRF):** I have one more question to ask, and I'm going to ask this to both of you.

Mike, you can start, but when you were first diagnosed with multiple myeloma, do you feel like you learned from your care team about the issues about bone health and what the treatment options were? Did they give you the information you needed, or was there anything that you felt like you didn't learn until it was much later that you wished you had known when you were first diagnosed?

**Mike Mankowich:** No, I had an excellent care team at Sloan Kettering. They laid it all out for me; they were fantastic. They explained what they saw, what was wrong with my bones, what damage had been done. They laid out a plan as to how they were going to go about treating it. Along with that, they were kind enough to provide details related to the risks that came with that treatment.

**Mary DeRome (MMRF):** Jamie, you had a different experience, where your initial diagnosis came with broken bones. I imagine that you were aware of the issues with your bones right away and that you received all the information you needed up front.

**Jamie Alamillo:** I was considered a trauma case, so the information that was given was given to my poor wife. She was by herself, and family was en route to get to her with two little kids. She received all the information and immediately, being a well-educated woman, she got online and started doing research, which every time I saw her she would come in and be crying. I'm like, "What's the matter?" She's like, "Nothing." I'm just, "We need to get through this."

Later, of course, she told me everything that she was reading, and she expressed that to my doctor, Dr. Black, and to Dr. Gary Schiller— they're both myeloma specialists. That's when they said, "Stop reading, this is what's going to happen." Then they told me about the cocktail RVD, what was going to happen. They told me the side effects of it and said that if there's any side effects, we'll try something different. We'll find the cocktails that suit you for what has happened to you. They're really responsive. When I started to get my radiation, I felt nauseated and just not good. One phone call later, medicine was prescribed that helped me get rid of that.

They give me prescriptions to help combat the bone pain as I was healing and going through physical therapy. They laid it all on the line. There was very little research we— well, I—had to do.

My theory was, let's just do whatever. My wife was more behind the literature of it, just to make sure what they were doing suited me. Of course, we didn't know. The doctors just are phenomenal. I'm glad I had the team that I had behind me. Because you hear horror stories and I'm just glad that the team that I had behind me was complete and thorough. My oncologist is straightforward, he doesn't beat around the bush. He'll tell it to you like it is, which I love.

**Mary DeRome (MMRF):** As a parting message to myeloma patients and caregivers, what is the best advice that you can give about how to deal with it?

**Mike Mankowich:** I don't know if it's necessarily good advice, but what works for me is not thinking about it a lot. I live my life as I would live my life had I not had the disease. I take it one day at a time. I'm blessed in the fact that I'm doing as well as I am, that it is in remission, that it's been in remission for some time. The damage that's been done for the most part is and has been reversible. Thinking about it, worrying about it, that's not going to do me any good. I'm just moving forward.

**Mary DeRome (MMRF):** Jamie, any last words?

**Jamie Alamillo:** We often forget about the caregiver, because it's always about the patient. The caregiver is probably the most important person that you can have on your side. Without a caregiver, doing this by yourself is virtually impossible. You guys are an important backbone in a cancer patient's recovery. Listen to your patient, or listen to your loved one, listen to what is going on with their body. Help them out, that's just the most important thing.

You try not to think about it, but it's always there. You think about it. I think the motivation is these if you have small ones or you want to walk your daughter down the aisle. You think about it, like, "What if I'm not here to do that?"

I don't think about it a lot, but there are moments where I think, "I want to be there for her, I want to be there for him." Now I have little grandkids. I want them to remember who I am, remember grandpa.

But my best advice is to remember that the caregiver is number one, the cancer is number two. Caregivers, just listen to your patient. Listen to your loved one. Do what they want you to do. Don't argue with them when the steroids are taking them through the roof. The treatments, the dexamethasone, it's putting them in a different state of mind. It's just patience, and my wife had probably the most patience of anybody. Because I was a pretty ornery dude.

**Mary DeRome (MMRF):** Thank you, Mike and Jamie, for being with us today and telling us about your patient journey as it related to bone health.

**Narrator:** Thank you for listening to this episode of the *Myeloma Matters* podcast on bone health in multiple myeloma, hosted by the Multiple Myeloma Research Foundation. The MMRF would like to thank Mike Mankowich and Jamie Alamillo for sharing their stories and unique perspectives on bone health. The MMRF also thanks 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.