

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

### Episode 8: Caregivers

#### 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 today’s podcast, we’ll be discussing caregivers—the spouses, partners, family members, and friends who play such an important role in helping myeloma patients manage everything from health care visits to the activities of everyday living.

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.

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Caregivers play a vital role in helping myeloma patients manage their disease, providing assistance with managing symptoms, coordinating health care, supporting dietary and exercise needs, helping with daily activities, and—through it all—providing emotional support.

Helping the patient navigate treatment options is a particularly important part of the caregiver’s role. The fast-growing number of therapies available for multiple myeloma makes this part of the caregiver role especially challenging.

In general, being a caregiver requires considerable personal sacrifice, potentially involving a commitment of many years. The emotional and physical toll can be difficult for some caregivers to bear.

To provide a deeper look into what it means to be a myeloma patient caregiver, we are joined today by Ben Dey and Vickie Avara—both of whom have taken on the caregiver role for a myeloma patient in their immediate family.

One of the earliest—and biggest—hurdles a multiple myeloma caregiver faces is getting up to speed on what multiple myeloma is, what symptoms it produces, how it is treated, and what patients can expect at different stages of the treatment process.

Vickie is the caregiver for her husband, Gary, who was diagnosed with multiple myeloma in 2020 after blood tests during a routine checkup revealed anemia. When Gary got the diagnosis, Vickie wanted to dive in and educate herself on everything right away.

**Vickie Avara:** I fall on the very extreme of wanting to know everything and plan and prepare as much as possible. [...] So as soon as we talked to the first multiple myeloma specialist, I was all over the Internet at night after Gary would go to sleep and just researching and just trying to learn as much as I could.

For Ben, it was the options available for myeloma treatment—and the need to make informed decisions about how to proceed with therapy—that were particularly overwhelming. Ben is the caregiver to his husband, Mike, whose myeloma diagnosis was—like Gary’s—the eventual result of a routine blood test that showed anemia.

**Ben Dey:** we quickly realized [...] no one was going to tell us the right thing to do anywhere. Everyone was gonna be like my opinion this, my opinion that. So, I was like, we're gonna have a bunch of decision tree moments here where we're gonna have to decide stuff. So, I had to be to like educate ourselves about each particular decision.

For some myeloma patients, a clinical study is a good treatment option. In addition to providing hope for myeloma patients, clinical studies can be an important source of information and support for caregivers.

Caregivers are an integral part of the health care team and play a crucial role in the myeloma management process. They ensure that the patient attends appointments, and they can also serve as another set of ears for information relayed during these health care visits.

Ben not only ensured that Mike made it to his appointments, he attended them, as well, which positioned him to serve as an effective sounding board for Mike.

**Mike Smith:** [...] Ben was extraordinarily supportive whenever I was going to especially like my early treatments. He was always there. When I was going to all of my doctor appointments, he was always at every one [...] it's really important to have somebody in those appointments with you, because some of it's like Charlie Brown's teacher, like you don't really understand what they're saying. And so, it was really important for us to debrief after those early visits, or even just visits in general, to say, "This is what I heard" and Ben could say, "Well, that's not really what I heard" [...] And because of that, Ben has a relationship with both of my doctors

Vickie did the same for Gary's appointments, even taking notes to help her research key details at home. Gary was diagnosed with a specific type of high-risk myeloma, and Vickie's efforts helped them make sense of what that meant for Gary's treatment.

**Gary Avara:** So Doctor Anderson did have the FISH test done, and it was determined that I have P17 deletion with 1Q add.

**Vickie Avara:** I take a lot of notes and then I go home and I go, "What did he mean by this?" [...] I just did Doctor Google to begin with and was reading up on – I had to learn what chromosomes – how they were built. [...] So then I figured out it was 17. "And why was that important?" well, I read Doctor Anderson's notes because they had them in my chart. [...] So that's the kind of stuff I would do to...after every meeting.

Caregivers are in a good position to note symptoms and side effects and to be able to report them to the health care team. They are also able to ensure that the patient takes any prescribed medications in the correct dosages at the appropriate time.

The caregiver also helps the patient optimize nutrition, self-care, sleep, and exercise. For Vickie, this latter point was particularly important, and she made sure Gary kept moving.

**Vickie Avara:** I noticed that he would say, “Well, I’m going to get up and go walk,” but then the day would go by and the walk from happened. And so, I just said, “Hey, Gary. I’m going to go for a walk with you.” And so, we started in the early morning hours getting up and going and walking. And that has been very helpful. [...] And it was a great bonding time for Gary and I to go on those morning walks.

The caregiver also often takes the lead in providing emotional support, a point to which Ben can readily attest.

**Ben Dey:** [...] I tried to keep it like as much of normal as possible. So, when you're sitting in the hospital room all day, every day, it's like you're not just talking about the hospital. [...] You're talking about everything else that's going on. You're like having the regular conversation that you would have if you were at home [...]

Learning about multiple myeloma and its management not only empowers the caregiver to help the patient make decisions about his or her care, it can provide comfort during a difficult, stressful time. Additionally, caregivers often find that their newfound knowledge about multiple myeloma can help educate other people in the patient’s life about what to expect.

Vickie, for instance, found herself needing to explain why Gary’s diagnosis sometimes limited how he could engage in social situations.

**Vickie Avara:** [...] I've learned that, people, they don't understand [...] why his immune system is down and that he can't go into a small room and talk and hug them.

When you’re a multiple myeloma patient caregiver, it can be easy to ignore your own well-being while focusing on the needs of the patient. But caring for yourself is important: it recharges you and enables you to provide steady, strong support to the patient. A key aspect of this is establishing and maintaining a strong support system for yourself.

For Ben and Mike, enlisting friends and family to help share the responsibilities of such things as attending doctor visits helped Ben minimize the time he needed to take off from work.

**Ben Dey:** [...] Mike has a lot of great friends. [...] He had friends who would come out from New York and New York primarily, but also L.A. would come out and be with him for a period of time and they all rotated out. And then there were a couple of friends in L.A. that, there were the odd appointment here or there that I couldn't make, especially trips to Duarte every once in a while that I couldn't go on that he would have someone go.

Being comfortable with receiving help can be a challenge, but Ben recognized quickly that accepting help was as beneficial to their friends as it was to Mike and him.

**Ben Dey:** [...] our plan was just to like always have somebody and most of the time that was me, but the other friends picked it up easily and in an amazing way. [...] they all reached out and said, “What can we do?” [...]

It's like, take them up on that and say, “Here's what you can do. You can take Mike to this appointment, you can do this, you can do that.” And be specific about how they can actually help, and then most of the time people want to do that. They want to be feel, they want to feel helpful...

Vickie was thankful that her children could offer support.

**Vickie Avara:** I have some wonderful adult children. And, boy, they were all Papa Gand his diagnosis. And so, they were constantly telling me things that you know, do with food and with water. So I really can give a lot of credit to my children for letting me godown that path

Seeing to your own needs is an essential component of being an effective caregiver. Support groups provide an opportunity to meet and speak with other caregivers. It's also important to stay on top of your own health needs, including your mental and spiritual health.

Vickie found support in a variety of places, and she cites her faith in God as a major source of strength that helped see her through tough times.

**Vickie Avara:** ...I am in different groups on Facebook with multiple myeloma people. But the one that – I asked one of the groups [...] “If you were a newly diagnosed patient not knowing what you know now, what – and if you were only able to do one thing, what would you change in your environment?” [...] And the number-one change was stress [...] I rely on God. His Spirit is within me and he directs me and he gives me the strength.

To the extent that it's possible, keeping to your routine in terms of work, relationships, and social activities—both with and without the patient—can help provide a sense of normalcy and keep you connected to others.

Recognizing the importance of maintaining normalcy, Ben and Mike made sure to watch their favorite shows together.

**Ben Dey:** So yeah, we watched Love Island and then talked about Love Island for two hours. That was so different than being like, “How was treatment today? Do you need anything?”

Vickie and Gary make sure to set aside bonding time where myeloma isn't the focus.

**Vickie Avara:** Unfortunately I think I'm more of Nurse Ratchet as Gary said than, you know, beautiful, wonderful wife. But at the same time we're very open with each other and we try to make time to be not Nurse Ratchet. Like, we love to do Friday night movies. So just setting up special times to do things that myeloma isn't even in the mindset, it really helps.

The hard work of being a caregiver, and the challenges it entails, have not been lost on Mike.

**Mike Smith:** [...] we walked past a conference room at a hospital and outside there was a big sort of cardboard thing on a stand that said they were doing a forum or a talk and the title of the talk said, caregivers need care too. [...] it's actually, it's very true. And so, as much as this is about me, it's also very much about Ben, as the caregiver. And I think it is very important for us as the patient to extend that like grace and space for the caregiver

To learn more about the roles, challenges, and rewards of being a multiple myeloma patient caregiver, let's now join our guests as they discuss their experiences and perspectives with the MMRF's Mary DeRome.

**Mary DeRome (MMRF):** Let's start with Vickie and Gary. So, how quickly did you realize that finding and securing a myeloma specialist was the best first step to take in your case? And how easy or difficult was it to find a specialist?

**Vickie Avara:** It was easy for us. We recognized right away how much the myeloma specialist was needed. We were in the emergency room, and they told us he had multiple myeloma. The oncologist that Gary had seen briefly, a month or so before, didn't know what it was. She suspected multiple myeloma but didn't know for certain. When we found out he had multiple myeloma, our grandchildren at university, had some friends in medical school. We used those connections and asked, "Hey, would you please find out who they would recommend here in the Dallas-Fort Worth area?" They came back and gave us three names. Gary and I separately went off and researched each one ourselves. We both came up with the same person we thought would be our first shot.

I called UT Southwestern to set up an appointment with Dr Larry Anderson. The lady taking the appointment said, "Oh, I'm so sorry but we will not be able to see you." I think she said, not until four months out. I was like "Okay, he was our number one choice." I was thinking "Okay, let me go to the phone and start with number two." And I was about to hang up and she said, "Oh, wait a minute, we have an opening." I think it was Thursday or Monday, she said "That just popped up. Somebody has canceled. New patient. Would you like it?" I was like, "Yes?"

He's been awesome. He speaks at a lot of these conferences. And every treatment he has had Gary on, as we see through our studies, is what the latest and greatest should be, so we're happy.

**Mary DeRome (MMRF):** So, Ben and Mike, you guys ended up switching from where you received care. First you were at UC San Francisco and then you went to City of Hope. What happened with that? And why did you feel like you needed to make that transition?

**Mike Smith:** We didn't know much about City of Hope. For whatever reason, they didn't necessarily come up in our first list we put together. I can't really remember why we chose UCFS. I think we were there with Tom Martin. We had one initial meeting with Dr Martin, and he was incredible. I will message him questions and he'll still answer, so there's a great relationship there.

I have a local doctor in Santa Monica who's a hematologist. He's not a myeloma specialist, but he specializes in all sorts of hematological cancers and stuff, so he's incredibly knowledgeable and fantastic. But just the coordination of the travel, and while it's pretty easy to get from L.A. to San Francisco, the first couple of times actually planning the logistics, with life and the anxieties of being newly diagnosed and all of that stuff, it became clear that it would be easier to find someone locally.

We reached out to the MMRF and had a conversation with them and they introduced us to City of Hope. I think we had gone to a couple of myeloma conferences or seminars, and locally there were several different people talking about Dr Amrita Krishnan. Specifically one woman who had a very, very difficult, severe disease that was super complicated and she was talking about

just how amazing Dr Krishnan was and my ears perked up and I think that that's how we added her to the list. So, we went to City of Hope and were incredibly happy there.

**Mary DeRome (MMRF):** Good choices, both, I have to say.

**Ben Dey:** I remember when we were thinking about where to go, and finding the best choice was obviously our main focus. I remember we went to Little Rock, we went all over the place, and I remember us thinking "We're going to get the best no matter what and it doesn't matter where it is." We're lucky because we live in Los Angeles where we have a bunch of options. But a couple months later there was a little bit of an issue Mike had right before his transplant.

There were other things along the way that were last-minute emergencies and I do remember being very, very grateful that ultimately, we chose a Los Angeles place. We have friends in L.A. who get treated other places and I remember feeling "Gosh, I am so happy we're not doing what they've done now because Mike had this emergency and we'd be in the emergency room with a new doctor, with people who did not understand what we were specifically going through." So, we stumbled into it. But just because you feel like you're going to a specialty somewhere else, that doesn't make it better. There is real life stuff about being close to home.

**Mary DeRome (MMRF):** I think that the point that you make is a very good one about having an emergency and ending up in the emergency room with a doctor who is totally unfamiliar, potentially totally unfamiliar with myeloma and certainly unfamiliar with you guys, Mike as a patient and you as the caregiver. I think that's a super, super good point. That it's good to have a care team that you trust nearby. You guys were lucky that you happened to have some choices near you.

Not everybody is so lucky, unfortunately, but it's certainly something to consider.

Let's talk about some of the biggest challenges with being a myeloma caregiver, like the steep learning curve when you're trying to figure out "What is this disease and how are people treated and what should be our treatment plan? Who should we be going to as a doctor?" And on the flipside, what has been the biggest help to you? So, is it having a good team or having resources available?

**Vickie Avara:** The biggest challenge to begin with was just understanding what is this word, "multiple myeloma," and what does it mean? Gary's L1 vertebrae had collapsed, and he had a four-vertebrae spinal fusion. So, as a caregiver you must be there for them, and you have to remain calm while you're in the hospital.

You must take copious notes and notice every medicine they're giving them and just really stay on top of it; try to get some sleep when you can. Then when you get home, you must be the nurse too. And if you've never been a nurse – I'm a math major, so it's like you have to learn how to take their blood pressure, how to take their temperature. What time do you call if his temperature goes above a certain number? What do I do on the weekends when his blood pressure bottoms out? Do you call 911? And there's a big learning curve there, but you do it. It just comes when you need it. It's there.

**Mary DeRome (MMRF):** Myeloma is incredibly complicated, right? I've been working in this field for ten years and I remember when I first started it took me two years to totally wrap my head around the disease and the treatments.

And it's changing all the time, which is one of the things that I find most fascinating about myeloma. There's always new treatments coming on board and new knowledge. While for me it's super interesting to have all these advancements happen, for patients and caregivers it can be really daunting to try to keep up with all of it, especially if you're not people who have a research background or a medical background.

**Vickie Avara:** I was already on X (formerly Twitter). So, I knew the platform and I immediately recognized that for all these myeloma specialists and doctors, X was their platform. That's where they shared information. Since I am a mathematician, I understand math science and so I understood their lingo. I learned a lot just from that study on X to begin.

But then I, of course, signed up for MMRF and any organization I could think of that dealt with multiple myeloma.

**Mary DeRome (MMRF):** How about you guys, Ben and Mike? What is the biggest challenge about being a myeloma caregiver for you?

**Ben Dey:** Mike is definitely a researcher and a person who was going to get diagnosed and discover everything he possibly could about the disease, so it wasn't as if I felt like I had to be the primary knowledge center. What we quickly discovered was that myeloma, like you said, is very complicated. I don't have a lot of experience with a ton of types of diseases, but it felt, with myeloma especially, that we had to be active participants in deciding what our treatment plans were going to be, and it wasn't just going to be someone telling us.

And so, for me I had two sorts of targets. Looking back on it, I realized number one was, I wanted to know enough and be present enough in all the appointments and just be physically there, but also to witness and hear everything that Mike heard. I wanted him to feel like I was part of it and that I could be helpful in deciding so that it didn't feel like it all would end up on him.

I could only do that if I was actually there and I got to see the doctor and I got to understand how things were being laid out. Obviously, with my own research and going through MMRF and X (formerly Twitter). I think X was super helpful for all of us. Emotionally, the other part of being a caregiver beyond just the knowledge stuff, I think I was trying to be a source of calm. And part of that is understanding what's going on enough to be helpful in making decisions and feel confident in making those decisions. You kind of have to be the source; I don't know how effective I was. But if we made a choice, I was trying to pretend like I was sure or that I understood enough to be sure enough so that Mike could hopefully take some confidence in that.

I tried to be a calm source. I tried to find the right balance of understanding how enormous and sad and scary the diagnosis was but also try to be a source of optimism and lessen anxiety. But you can only do that if you dip in and understand it a little bit. You have to find the right target of not being unrealistic but being realistic, and also trying to provide hope.

I also tried to keep it light and that was difficult sometimes. You're in scary, serious situations and in tough conversations. When we'd go to conferences and see people in really scary situations or feel like "Oh, that's going to be us in a little bit" and it all started to feel really true, I would try to, not disrespectfully, but I would try to make jokes and just try to keep all of it light.

**Mike Smith:** It's a really scary situation. That's an obvious thing to say. I always like to speak to younger patients too because I was 38 when I was diagnosed and Ben was, what, 34, I think? We would leave these rooms and Ben and I would look around. Ben said "I look around and I'm like 'Where are the adults in the room?'" And it's like all of a sudden, we realized "Oh, shoot. It's us" The doctors even look to you to lead them in a lot of ways.

I don't want to speak for Ben as to what was difficult, but I think that just generally we really grew up throughout the process.

**Mary DeRome (MMRF):** Yes, I think it can be a little bit more challenging when you're diagnosed earlier, and not only because your disease is a little bit different than people who get it when they're in their 60s and 70s. But also it's hard to find that relationship because that's not really your demographic. You're much younger than a lot of people who have been diagnosed. It can be hard to come across somebody who can act as a resource and really understand what you guys are going through at a much younger age compared to people who are having their kids take care of them. So, it can be very different.

As a caregiver, what are some of the resources that you have or that you rely on to give you help and support when you feel like you need something?

**Ben Dey:** I think it was most impactful for me to feel like I had somebody else I could dump on. You have to have an outlet yourself, and Mike couldn't be that person. I remember having very hard conversations with my parents, with my friends, with other people in our life who knew our situation very well. And in those conversations, I was able to really address some of my scarier fears and some of the things that I didn't think would be helpful to talk with Mike about. So, that was a resource to me, an outlet, people to talk to, people to engage with.

I think X (formerly Twitter) truly is a fantastic source. I would go there. The thing about the internet is you can find whatever you want, so sometimes when you want to find the bad news and really address it, you can find that, and then sometimes when you want to feel hope, you can find that too. And so, I would certainly do that.

I think the MMRF in general or having somebody you felt was in the fight with you that you could rely on and ask questions. It sounds corny, but just to know that they were there, that is really meaningful. At the hospital when we were there for the transplant and for some of the actual procedures, I found being there all the time or as much as you possibly can and getting to know the nurses yourself as the caregiver and getting to know the people who were caring for Mike allowed me to have conversations with them outside of Mike or allowed me to be part of the process, and that was really helpful to me.

**Mary DeRome (MMRF):** I can see how that would be very calming that you could have these conversations with other people and offload your anxiety on someone other than Mike who didn't really need more anxiety.

**Ben Dey:** I'm sure that they deal with a lot of people who are with their patients who kind of flit in, flit out. I think you have to earn their respect through consistency and by asking smart questions and by being curious. You have to let them know that you're in this too, and they'll treat you differently than somebody who flits in and out or is unformed.

**Mary DeRome (MMRF):** I totally agree. Definitely, if you're talking to the care team and the questions you ask them come across as being educated and informed, they will realize they



need to give you an educated and informed answer, which means you're going to get more information.

So, Vickie and Gary, how about the resources you have relied on for help and support over the course of this journey?

**Vickie Avara:** Well, for me, I relied on my family, my sisters, and Gary's family, his sister and mother. They were first. And then, we're very tight with our Bible study group, and so they were on top of it. I set up a text message to everybody so I could tell everyone at one time what was going on.

With Gary's multiple myeloma, it was somewhat of a horrific beginning with the back breaking. Other people with myeloma may be diagnosed with blood tests and they may have smoldering myeloma or monoclonal gammopathy of undetermined significance (MGUS). But no, we went into double-hit, high-risk multiple myeloma from the get-go. I actually went on Facebook and started a "Praying for Gary Avara" group and I would post there. We felt the prayers of all those people, and that was a lot of the emotional support that Gary and I both had.

When your back is broken there's not much you can do. Gary got so much out of everybody reaching out to him.

They would call him on the phone. I loved every one of those people when they would call him. He worked at T-Mobile. His bosses were just amazing. They would call him as well. We had really good resources.

And of course our children; we have two adult children, They were supposed to come to our house for Christmas. And this happened, Gary was diagnosed on December the 14th and it was our year to have Christmas. Well, they jumped in and researched as well. Even though I'm capable but the children helped us. It's just like we all bonded so well in coming together to learn about this disease. And it has stayed that way to this day.

**Gary Avara:** From a technical standpoint, the kids did do a lot of research for us.

They researched foods and how to improve nutrition for a cancer patient. They did a great job with that. Vickie did a wonderful job researching everything from the best doctors and what they were saying, and the clinical trials. MMRF and other entities had that information available.

And then, even though it was double-hit, high-risk MM, there's a whole other level of research that needed to go on. And we found the information with Dr Anderson. He was really fantastic at answering questions. I've never met a doctor ever, even the ones I personally know, that would answer questions so quickly and so thoroughly. And then, we'd find out later through research everything that he said so far has been correct.

**Mary DeRome (MMRF):** Speaking from somebody who's in the myeloma community, every single myeloma specialist is so dedicated to their patients. Certainly Dr Anderson is a great example of that and Dr Krishnan as well. They're very, very attentive to patients, happy to answer questions, very dedicated to the work that they do. And many of them are involved in clinical trials, which is so super important for patients to get involved with – to move forward to the next therapy once things are taking a turn for the worse.

Let's talk about how easy or hard it is to be a caregiver. I'm sure that you must have good days and bad days. Ben, does it ever get easy? For example, Mike is undergoing treatments and maybe there's a response obtained to the treatment, like after stem cell transplant or something like that.

Do you get to a point sometimes when you actually can enjoy life a little bit better without these routine appointments with a doctor and therapies and side effects and stuff interfering with your quality of life?

**Ben Dey:** Yes, for sure. Recently, for instance, Mike made the decision to stop taking lenalidomide (Revlimid) or maintenance therapy after four and a half years. I've noticed a difference in him being off that for a couple of months, his general energy levels and mood. That's fun to see. But earlier in the process when Mike would be on dexamethasone and steroids, those days would be hard. He would talk a lot and drive everyone crazy.

I remember some days were harder than others. Mike and I were talking about this the other day because we knew that we were going to be talking about this and part of us we're like "Gosh, it's kind of hard to remember some of the specifics." And it's not like it was all that long ago. We kind of thought maybe it's a little bit like childbirth where it's painful but then your body just knows to forget how painful it was and you move on, because we look back and I'm like "It wasn't that bad."

I remember being in it; it was very, very scary and there would be times that felt very, very dark. But then there'd be little wins along the way, or you'd have a funny nurse, or you'd have a bad meal or you'd have a good meal. Mike and I, when we were going back and forth to our rental house out by City of Hope during the transplant procedure we got obsessed with Love Island and every night we'd look forward to Love Island, and that's what kept me going through the day. We were going to have a new episode that night. And things like that, that are silly, but were able to keep us going.

I also just tried to be very grateful all the time because we would meet other people who were not in our same situation. And my job was so flexible to allow me to spend so much time with him. Even when it was hard, I would try, not to be too corny, but I would try to sort of lean into the gratitude of "Oh, my gosh, this appointment just got rescheduled. I'm so happy." Or I'm so grateful that

I don't have to miss this because my work situation is tough and I won't be able to get that time off at the last minute or whatever. So, I tried to just remain grateful. But yes, you have to celebrate the wins and sit in the bad for a little bit and then try to keep it moving. That was my process.

**Mary DeRome (MMRF):** Do you feel that same way, Vickie, that there's the good times and the bad times?

**Vickie Avara:** Absolutely. You're going to have your good days and your bad days. You learn the medications and what they're going to do. Like, Ben mentioned dexamethasone and Gary's on daratumumab (Darzalex), which lowers the red blood cell count, and he's on lenalidomide (Revlimid) and you all, Ben and Mike, you know about lenalidomide (Revlimid) side effects. And, Gary to start with was on bortezomib (Velcade). So, it's just a rollercoaster.

I think Gary's primary care physician at the very beginning told Gary, "Gary, it's going to be a rollercoaster.

You're going to have your good days and your bad days."

**Mary DeRome (MMRF):** So, Ben and Vicki, do you still feel that you need to continually educate yourself about the disease? Ben, do you talk to Mike and, Vicki, do you talk to Gary about joining a clinical trial that might be a good option for you, depending on where you are in your disease course?

**Vickie Avara:** Yes, I feel like I should educate myself constantly. Now, I've got to be honest, we're at the end of year three with multiple myeloma. The very first year, I was just spending every second of my time when I wasn't cooking or caring for Gary, trying to learn more. You just must. Nobody can do that for you. You must get in there and figure it out. Year two, things started getting better. Now, year three, Gary's in maintenance mode.

He's in maintenance mode, but he still takes three out of the four medicines, because he's a double-hit, high-risk patient and he's never reached minimal residual disease (MRD) negativity. But he's stable. Dr Anderson is doing a great job of keeping myeloma under control.

Anyway, this last year I've kind of laxed off. And there's been so many things that have been announced. I've got guilt, to be quite honest. I've got to get in there and understand things, so I'll be ahead of the curve when he does relapse so they'll know what to do next.

**Mary DeRome (MMRF):** Exactly. It sounds like he's doing pretty good right now. I think that patients coming off maintenance therapy is becoming a thing. People are on it for a couple of years or three years.

If they stay MRD negative, they request coming off maintenance therapy from their care teams. But you must be a little bit more careful about that when you're a high-risk patient. Not to say that Gary will never get there. He may get there at some point where he'll be able to get off maintenance, especially if he does something like chimeric antigen receptor T-cell therapy (CAR T), which is a one-and-done type of thing. So that might be in your future, Gary. You never know.

**Ben Dey:** I don't think you need to feel that guilt, honestly. When he was diagnosed, I bet you figured it out very quickly and you're working on it and your life is affected enough by it. You don't need to spend every day doing that. That's my feeling because I know I certainly don't. And Mike knows.

But I do know when we made the choice to go off of lenalidomide (Revlimid), that wasn't something that we took lightly or that we didn't research or ask our doctor about and have real conversations about. I am not and I do not think Mike is everyday trolling on X (formerly Twitter) like we used to, but we'll know about new options when we need to know about them.

For now we're just trying to live life. And we'll be quick studies like we were last time if something comes up. I don't think we're missing anything.

**Mike Smith:** I always tell people when I was first diagnosed, I made two X (formerly Twitter) accounts. I had my own personal one where I would keep up with dumb interest and gossip and stupid things that I just generally enjoy, and then I separated out myeloma information, to a

separate myeloma X account so I could really focus and be in that mode when I wanted to or needed to. That is where I followed doctors, caregivers, patients, and organizations. I rarely look at that X account now.

Like Vickie, I think part of this journey is knowing when to step back and come back in and step back and come back in, because I do think that it's incredibly important not to have this take over your life. You can get sucked into the fear of it.

I remember this pressure that I put on myself to understand everything as if I were a doctor and went to med school. And to all the patients and caregivers that haven't gone to med school and aren't doctors, take that pressure off yourself. There are some people that can pick it up quickly. There are some people that never will, but it's really about who you surround yourself with to help you understand. And some things you'll pick up quickly; some things you don't even need to understand, it's just good to have an awareness.

I do think there's an ebb and a flow of how much Ben and I are in it. And like he said, I just recently came off maintenance and that was a huge decision and one that I agonized over.

I went back on X (formerly Twitter) and I started direct messaging (DM'ing) doctors and asking questions.

I think that it's just important to allow your life to come back and do the things that you enjoy because that's really going to be what gets the patient and the caregiver through the difficult times.

**Vickie Avara:** Mike and Ben, you are so right. I want to say that on Facebook, I'm part of a "Beating multiple myeloma with naturopathic methods" group but I just do that just to see what foods and supplements they recommend. I asked the group, "If you only could make one choice knowing now what you knew then, what would it be? If you could only do one thing, what would it be?" And I thought they were going to say food or no sugar or water and something like that. You know what the number one answer was? Just what you two guys just said: It's stress.

One step, as a caregiver now with Gary, is for us to be not as stressed out about things. I'm trying to do more of that. We have made a habit now of going out and walking every day. It is so enjoyable just to get out into nature, into the weather. People in our neighborhood will stop and talk to us. And it's really great to have that stress gone.

**Ben Dey:** By the way, Mike and I do that every day when we walk our dogs which normally takes about 20 or 30 minutes. And a classic story that we tell is, one of the first times Mike was on steroids and dexamethasone. From the time we walked out the door until the time we got back, which was 30 minutes, I did not say a single word and it was a monologue of him just fast talking at me about nothing.

And we're like "Oh, that's what steroids are. We just experienced it for the first time."

**Vickie Avara:** Gary jokes and says I've learned on his dexamethasone days to put my "honey do" list out, because that's when he has a lot of energy and he stays up, so I get a lot done.

**Mary DeRome (MMRF):** Okay. So, let's talk a little bit, without getting too incredibly personal, about relationships. Both of you, you've got a patient and your partner is the caregiver. So, how

does that dynamic work? And how do you maintain your relationship without it feeling like it's a nurse and a patient as opposed to being partners in life? Ben, how do you guys deal with that?

**Ben Dey:** I think it's about trying to focus on, not to go back to the Love Island example, something other than the disease and trying to find ways to do that. I think we still do it, obviously, because we don't talk about myeloma every day, certainly.

Even when you're at the most intense stage going through treatment or in the scariest moments, focusing on and talking about other things, staying involved in your friends' lives and each other's life and work and things that are out there in pop culture or whatever you care about, sports, whatever it is, is important. You just can't talk about myeloma all the time or else that's the dynamic, then you'll be nurse and patient. You've got to have some of the things that you used to do, even if it's just talking about them, because you can't go to dinner or you can't go to a movie or you can't go to a game. We spent a lot of time thinking about what we were going to watch, because there was so much time when we were just in the hospital in bed. So it's like "Okay, how do we find a show or a movie or a book or something that we can watch and talk about or get into a different world?"

I don't know, Mike, do you agree with that? That's kind of how I thought we did it. It's just like having some other life.

**Mike Smith:** Yes, I think that's right. And I think we were in a very great time in our life but also odd time to be diagnosed.

We had just gotten engaged. I think we were engaged for two or three months or something crazy. So, for me, I was really nervous. I mean, I was just nervous. It was like "Oh here I am, this invalid that Ben's now stuck with." There was so much guilt, I think, on my part. And it's not what you sign up for when you're just getting married, but I think it also is to a certain extent.

We are navigating that. I think for me, a big part of it is I also had to release a little bit of control, which is very hard for me, and allow Ben to be there for me and know that he wanted to support me and figure out ways to be there for me, and allow that love in.

As cheesy as that sounds, I think it's really true. And recognize that it is more than a nurse-patient relationship. There's so much more to it than that.

But yes, we tried to continue our life as best as we could. And I was lucky that I didn't have any skeletal involvement, so I was able to go to work and keep up my life that way. And we were able to travel. We went to Hawaii and Japan in the midst of it because I was stubborn and wanted to do it, even though parts of those trips were incredibly difficult. Ultimately, I think we were happy we did it. But I think it was keeping up with our lives.

**Ben Dey:** I also think it takes effort to not be a resentful caretaker or a demanding patient.

You can have your moments, and everyone can have a sad, sorry for yourself moment. I remember I had to check myself a couple times and be like "Oh, no, you're going to complain about having to be in the hospital right now? Mike's in the bed; you can go leave." And I'm sure Mike probably had moments where he felt like "Woe was me" and wanted to be a brat or wanted to be demanding. You still must remember that you're a person and you want to be the best possible version of that. A diagnosis is not a "get out of jail free" card for bad behavior. And being a caretaker, you can't be a jerk to your patient or show that you're resentful or you're

having a hard time or you're upset about it all the time. It takes effort. You must make the choice to do it in a respectful, loving way.

**Mike Smith:** And I think it's relying on that larger network around you, not just one person.

It would have been really unfair of me to only rely on Ben. While he's my caretaker, primary caretaker you could say, I think that we were really blessed and lucky to have a village of people around us, whether that be friends or family. I was still recovering from my transplant and there was a huge work opportunity for Ben to go to London and it was really important for me to say, "Go. Please don't worry about me. Please go do this." And my parents came in and took the baton from him. It's just really important to have an awareness of that.

**Mary DeRome (MMRF):** How about you guys, Vickie and Gary? How do you keep your relationship semi-normal in the face of this diagnosis?

**Gary Avara:** One of the things that we've done – and we did even when the kids got older, we had date night. And then, of course with COVID-19 and everything we couldn't go out, but what we have done is maintain movie night.

We each pick a movie of our choice and we alternate. We will occasionally order special food and have it brought in and just make it a date night as best as we can. Or schedule time for the spa or the pool or whatever. That has really helped. And Vicki has pushed to maintain it even when I was a little bit blah. She was "Nah, let's do this." And it's been good.

**Vickie Avara:** Gary and I have been married over 40 years. Friday movie nights, we look forward to it. "We don't do movies every night. No, Friday is movie night." We get involved in a lot of series. It just helps to take your mind off those words, "multiple myeloma."

We stay isolated a lot. Now, I know a lot of multiple myeloma patients don't, but with respiratory syncytial virus (RSV), COVID-19, flu, and colds, we avoid being around people a lot. So, we have really enjoyed all the TV series that you can get involved in and sometimes we'll watch three or four at one time. We really like that.

We have a miniature Schnauzer that we got as a puppy three or four months before Gary was diagnosed. I had just gotten her trained and she has been so wonderful for us as well. She's just a wonderful dog. She was a gift as well.

We asked our financial manager about affording a pool, because we really weren't expecting to retire and be disabled this quickly in life.

He said, "Yes, you can do that." We've really enjoyed that too.

As Ben said, you find ways to not talk about myeloma.. We love to eat. I'm into organic foods. I do believe that you can help your immune system by making healthy choices. I do a lot of the cooking, so it's really nice for me when we do order out. I look forward to that.

**Mary DeRome (MMRF):** So, tell me some other ways, Vickie. It's really important for the caregiver to take care of not only the person that they're caring for, but also take care of themselves. What are the kinds of things that you do to try to take care of yourself and make sure that you're prepared for whatever challenges might come your way?

**Vickie Avara:** I'm just going to talk about this year, the third year into it. I realized that "You know, I've got to be happy and healthy in order for Gary to be happy and healthy." My son got me interested in podcasts. So I have started taking a step back, and I do a stretching routine every day and I listen to podcasts. I've really learned so much and I'm really enjoying that.

Also, I decided I've got to have some me time. In the morning, and Gary's wonderful about this, I have the door closed and I'll do my meditation, my prayers and play a little game.

I'm a game kind of person, so I need that time. It works. And Gary, he'll get away from me, and that's how I'm taking it. And we walk. What else am I doing, Gary? I'm really doing a lot right now. I'm about to get into resistance training. I know I need to do that.

**Gary Avara:** Yes.

**Vickie Avara:** I try to do at least 30 minutes of cardio three times a week. I have an Apple Fitness account and watch, I can bike and do a cardio program.

**Mary DeRome (MMRF):** So, Ben, how do you take care of yourself? What's your self-care routine?

**Ben Dey:** Like Vickie, exercise is the biggest thing for me. I think that's the most important thing. I found a way that that works for me and that's my own time.

Also back to your other question about how to do something separately and feel productive together. Exercise is something that we do a lot together.

But also for me, I still am pretty career-focused. Being able to go to work and Mike not making me feel guilty about working and allowing me that time keeps me sane. I still feel productive and I still feel like part of the world. That has been helpful to me because I enjoy work and that's a big focus of mine. So, those two, I think, are good.

I also think just seeing friends. Even when Mike was in treatment, going over, taking a break and seeing some of my friends or having conversations with people, or even just Face Timing, trying to maintain the relationships that were not work relationships was also really helpful to me.

**Mike Smith:** Can I ask Vickie a question?

I'm very curious about this from the caretaker standpoint., I've seen Ben take better care of himself over the last couple of years than at any point in our relationship, and I've been really excited and proud of him for that. And I don't know, if that's a result of being a caretaker. I don't know if that's from taking care of Gary and myself. We're obviously in distress or in poor health. Does that put a focus on your own health or your own wellness? I don't know how active you were prior to this. It popped into my head as something that might be a result of being a caretaker.

**Vickie Avara:** Absolutely. I realized that everything that I have done to help Gary and be a partner with him, not just caregiver but friend and the love of my life, all that I have done to help him in return has helped me, because I wasn't really wanting to go out and walk but now, I look forward to it. Gary's like, "Do you want to go walk with me?" I'm like, "Of course. Let's go. Let's do this."

I've lost weight now helping him because I'm trying to stay away from sugar and be more mindful of the foods we eat as well as adding in exercise. Yes, everything is better for me because of the situation that was given to us. We didn't choose it. Right?

**Mary DeRome (MMRF):** Do you see it, Vicki and Ben, as something that you can do for yourself that you can control versus what's happening with the myeloma, which is something that's not really under your control?

**Ben Dey:** There's just stuff you can't do. I work at a career where it would be drinks with colleagues or clients or something every night as well as work events. Mike would allow me to work and do all that stuff and I wanted to do all that stuff, but there's all the other stuff that I just wouldn't have been able to do and been a good caretaker. So, you start eliminating that stuff and then you're like "Oh, I don't necessarily need to be out until late every night." So then, you're like "Oh then, that's a healthier thing."

When Mike was getting his transplant I was so focused on myself and not bringing illness to him. So, of course you're going to choose healthier options and you're going to be prepared. You can't take care of someone else if you're not taking care of yourself.

You have to be in a good position to care for others. So, yes, I think it only helps you make healthier decisions, or else you're just going to completely implode and be a terrible caregiver, right? You have to make the choice.

**Mary DeRome (MMRF):** I just wanted to ask one more question of our caregivers. What would be your best piece of advice to a person going into caregiving for a partner with myeloma?

**Ben Dey:** My best piece of advice would be whatever you can do to not be resentful and lean towards gratitude will be helpful to you. And to fully step into it, because that allows you to do everything else and it doesn't feel like you're taking things away. You have to make the conscious decision to go all in, not be resentful and think about the things that you have in your life that allow you to do that or that you're grateful for, and that will allow you to have a positive attitude.

**Mary DeRome (MMRF):** Vickie, what's your advice?

**Vickie Avara:** I would say just put one foot in front of the other, take one step at a time. It's not something that you'll be able to achieve overnight. And don't get discouraged. You can do it. Just take one step at a time.

**Mary DeRome (MMRF):** That was an excellent conversation. You have been so enlightening and I think what you've conveyed here, is going to be so helpful to other patients and caregivers who listen to this podcast. I'd like to thank Gary and Vickie Avara and Ben Day and Mike Smith for sharing challenges and optimism in dealing with caring for a loved one with multiple myeloma. You guys really have all these pearls of wisdom.

**Narrator:** Thank you for joining us for this episode of Myeloma Matters on being a multiple myeloma caregiver, hosted by the Multiple Myeloma Research Foundation. The MMRF thanks Ben Dey, Mike Smith, and Gary and Vickie Avara for sharing their experiences and perspectives on being a caregiver for a loved one with myeloma. The MMRF would also like to thank AbbVie, Amgen, BMS, CURE, Genentech, GSK, Janssen, Karyopharm, Sanofi, and Takeda Oncology



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