



Inspiration and Encouragement From a Myeloma Survivor

Sean Murray

Myeloma Survivor and Advocate

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr. I'm sitting with a man who knows myeloma all too well, but has gone on with his life and also to help others. That's Sean Murray from Branson, Missouri.

Sean Murray:

Branson, Missouri.

Andrew Schorr:

Thank you for being with us, Sean.

Sean Murray:

Thank you. Good to be with you.

Andrew Schorr:

So we're doing this interview sitting here at the University of Arkansas for Medical Sciences, where they have a world-renowned myeloma institute. You know this place very well, because you've gone through months and months of therapy over the years since 2008.

Sean Murray:

That's right.

Andrew Schorr:

I want to go back to 2008 when you were diagnosed. Terrible back pain, and then you get the news that basically bones are falling apart, right?

Sean Murray:

That's right. Vertebrae had collapsed, pieces of bone and tumor were pushing on the spinal cord, and that's why aspirin and heating pads weren't taking care of the pain. So it took this diagnosis to answer that question for me, that it was not just a simple thing that I could endure on my own, that I needed treatment.

Andrew Schorr:

Now, back pain is pretty common, and people, say, well, maybe I need surgery, but maybe there are other approaches that can happen. But when you're told that it's cancer, and many people don't really understand multiple myeloma and then the effects on the bones, became very real for you, you began to learn about it.

Sean Murray:

Yes.

Andrew Schorr:

But wasn't it terrifying?

Sean Murray:

Oh, of course, it was terrifying. I was in a whole new space that I had never been in before, had never gone through a chronic or acute illness like that. And with myeloma, there's a very steep learning curve. It's a confusing disease, especially for patients, lots of different opinions about treatment out there in what I call myelomaville. And so I had the job to figure out where the best place that I should go would be, and I settled on UAMS.

Andrew Schorr:

That worked out for you, but treatment for you was very aggressive. Now, we've come a long way in myeloma treatment. There are many more options that have been happening now, but transplant for you, double transplant was part of it and lots of chemo...

Sean Murray:

Yes.

Andrew Schorr:

...that's tough stuff. Tell us about how you got through that and also your image with your wife and your two adopted daughters...

Sean Murray:

Right.

Andrew Schorr:

...of wanting to be with them.

Sean Murray:

Well, I determined fairly early on that I wanted them to be proud of me and proud of how I handled this disease. I wanted to approach this with dignity. I began to adopt the thought that I was going to begin with the end in mind, and I knew where I wanted to go. I knew it was a very real possibility that cure wasn't going to happen, so I wanted to do the very best that I could.

To me—I was young, I was 49, I was in relatively good health and just seemed to fit the profile of a patient that could be treated well here, and so I looked into this clinical trial. And, yes, it was very aggressive. Lots of chemotherapy, two autologous stem cell transplants, more chemotherapy, and then back home for three years of weekly chemotherapy, so there were four years of just this chemical blitzkrieg.

But I felt that I could handle it, and I learned to take it a day at a time, sometimes a minute at a time, frankly. There was lots of nausea, lots of pain, but we addressed the issues as they came. They explained things to me very well, and I'm still here eight years later.

Andrew Schorr:

How are you doing?

Sean Murray:

I'm not doing too bad. I was laughing with somebody earlier that this is the first time coming back in seven years that I don't have to have a bone biopsy and stick myself into a CAT scan or an MRI.

Andrew Schorr:

You're a guest.

Sean Murray:

I'm a guest, and so I'm actually doing very well.

Andrew Schorr:

Now, are you taking any maintenance therapy?

Sean Murray:

I had three years of maintenance, bortezomib (Velcade), lenalidomide (Revlimid) and dex[amethasone] (Decadron), weekly infusions. I stopped that in December of 2012, so since then I have had no myeloma medications.

Andrew Schorr:

Wow.

Sean Murray:

I had blood clots in the interim, so I'm on anticoagulant medication. I had some support meds, vitamin D and those kinds of things, but no myeloma meds for almost four years.

Andrew Schorr:

Now, we're in the age where there are increasing number of oral medicines that come into play for myeloma and others in development as well, so what do you say to people now about whether it's infused therapy or transplant or now oral therapy, about playing an active role in their care, because it's a lot of responsibility the patient has increasingly?

Sean Murray:

Oh, absolutely. I think it's vital that you have—that you understand the lay of the land. If you want to be a decision-maker in your own life, you certainly have to educate yourself about this. I would have welcomed not having so many needle punches. My three years of maintenance, I actually had an IV every time. I didn't need a port. I was fortunate that way. But if there was a way to take some of these meds in pill form versus through a vein, I would welcome that.

I've also learned that people have a strength, an inner strength in them that they don't really know that they have. So when you're faced with these kind of conditions, even getting stuck with a needle, even having bone biopsies—I've had about 20 since I've been through this process here—you can get through almost anything with the right attitude. Faith helps, too, and I lean on that.

Andrew Schorr:

Right. Sean, you've been writing. You are a writer...

Sean Murray:

I am a writer.

Andrew Schorr:

...and you've been writing with a publication that many people are familiar with, the Myeloma Beacon...

Sean Murray:

Yes.

Andrew Schorr:

...for years.

Sean Murray:

Yes.

Andrew Schorr:

What propels you to write and speak out to the community, and what would you say is your underlying message?

Sean Murray:

My underlying message is that every myeloma patient, every myeloma caregiver has a voice, and they have a story. And all those stories should be shared. My particular story is no more inspiring than anyone else's. So when I write, I write to inspire, to create enthusiasm, to educate. I write to entertain, to make people laugh.

When I was first going through this, I promised my wife that I was not going to let myeloma blot out the sun. There are lots of things that drive our lives, there are passions and joys and faith and family and those kinds of things. And when you're faced with this kind of illness, all those things come out of focus. You know, you're concentrating on your illness, and things get dark and stormy.

Live it out. Ride it out. Things will get better, and so I try to create enthusiasm and momentum for people to continue to enjoy those things that they enjoy. Maybe you enjoy them differently. Maybe you can't go out on the links and shoot 18 holes of golf—doesn't mean you have to divorce yourself from golf completely. There are things that you love, things that you do.

It's also an opportunity to practice your faith. You can walk around all you want and talk all you want, but until you walk your faith, it doesn't mean that much.

Andrew Schorr:

And happy there's been so much progress in myeloma where more people have that opportunity to live longer lives.

Sean Murray:

Absolutely. I'm very encouraged by all the new things that are coming down the pike. I should say, I was treated from December of 2008 until November of 2009 here in Little Rock and then three years back at home. But I found complete remission in June of 2009, and I've been in remission since then.

Andrew Schorr:

Amen.

Sean Murray:

It's absolutely fantastic, and I am the most fortunate guy that I know even given these circumstances.

Andrew Schorr:

One last thing. You and your wife adopted two girls from China.

Sean Murray:

We did.

Andrew Schorr:

You were very worried about whether they were going to see Dad die.

Sean Murray:

Yeah.

Andrew Schorr:

And now they see Dad living and thriving. Just the family must take great faith from this.

Sean Murray:

Absolutely. Of course, my wife was very scared. Who wouldn't be when faced with this? I'm the man that she loves, and the thought of her potentially losing me was very scary. Likewise, I didn't want to leave my family. We adopted our oldest daughter when she was just a year old, and she knew me as a show producer. And she used to come to the theater and play in the rafters and do all sorts of fun things, and she got to see the transition of me turning into a sick dad.

And so—and she was 11 when I was diagnosed, so she was old enough to know that there was really something afoot, and there was no hiding it. I was in such, such desperate shape. My youngest was 2 when we adopted her, and I was diagnosed a couple years after we adopted her, so she basically knew me as a sick dad. But—so they both have reacted differently, but they both have just taken this in stride.

Kids are wonderful. We can learn a lot from these kids. We just take it a day at a time the way that they do. They find the joy where they can find it, and we all keep going. And God willing, I have a lot more years.

Andrew Schorr:

I hope so with your wife and with your kids.

Sean Murray:

Absolutely.

Andrew Schorr:

And writing with us, thank you for sharing your story.

Sean Murray:

My pleasure.

Andrew Schorr:

Sean Murray, I'm really glad to see you and doing so well.

Sean Murray:

Thank you very much. Great to be with you.

Andrew Schorr:

Andrew Schorr on location in Little Rock at the University of Arkansas for Medical Sciences and the Myeloma Institute where it's made a big difference for Sean, and him sharing his story makes a big difference for us. Remember, knowledge can be the best medicine of all.

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