

Scott

My name is Scott, and I'm living with multiple myeloma for seven years now.

Ruthee-Lu Bayer, MD

Multiple myeloma is a form of blood cancer. In patients that have multiple myeloma, the cell that is problematic is the plasma cell. These cells in patients with this disease are dividing rapidly in the bone marrow and can crowd out the healthy cells in the bone marrow. Patients with multiple myeloma can also have issues with their bones and with the kidneys. These patients also have abnormal protein in their blood and their urine.

Scott

I was hospitalized twice with pneumonia and then one day, I was playing basketball with my youngest daughter, Hanna, and all I did was bend over and I cracked a rib. I didn't think anything of it, but luckily my doctor, who is also my cardiologist, due to my past history did an extra lab test without me knowing it, and that's where I got the diagnosis of multiple myeloma.

Dr. Bayer

So I often tell my patients who are initially diagnosed with multiple myeloma, this is a chronic disease. We can treat the disease but it's difficult and it's not curable at this time. And the way that we are able to keep people alive, keep them going with this disease is by using all of the treatment modalities that we have in our arsenal.

Dr. Bayer

The initial treatment often includes three drugs and patients will receive those medications over a period of 4 to 6 to 8 months. The goal of that treatment is to get their disease under control.

Scott

We got ourselves the top doctor in the area, and he sat down with me the first time, and he drew pictures of what is multiple myeloma. He drew pictures of exactly what was happening to me. Then, we discussed all the different treatments that we could do. Once he went over all that, just because of my personality, I told him I wanted to go aggressive. Ten minutes later, I went in to get my first treatment because I just wanted this thing, whatever it was that was eating away at my body, I just wanted it out of me.

Dr. Bayer

Many of these patients after induction treatment will then be considered for a stem cell transplant. An autologous stem cell transplant. In some of our younger patients where they have progressed after an autologous transplant, they might be considered for an allogeneic transplant. An allogeneic transplant is where we are utilizing a donor and we are literally trying to grow the donor's bone marrow and ultimately, the donor's immune system, in the patient.

The process of the stem cell transplant for many patients can give them disease control for quite some time.

The essential idea behind the autologous transplant is more is better. So if standard doses of chemotherapy are beneficial for a patient, the idea is if we can escalate the amount of chemotherapy we give a person we can take their disease control to the next level. The issue arises when we give these more intensive cycles of chemotherapy, that we not only destroy abnormal cells, but we will destroy healthy cells. We will shut down their bone marrow with these more intensive sessions of chemotherapy. So before we can give a patient this more intensive session of chemotherapy, we have to first collect from them their stem cells. The stem cell is essentially the seed that can regrow the patient's bone marrow after they receive this more intensive cycle of chemotherapy.

There is a second benefit from the process of the autologous stem cell transplant and that is a resetting of the immune system. The more intensive cycle of chemotherapy knocks down the patients' immune system and when the marrow recovers, we can actually see that the immune system can be heightened or can actually be reset against the disease.

Unfortunately, most patients at some point after the autologous transplant will have progression of their disease and this is why we are monitoring them. We will do 24-hour urine evaluations once or twice a year. They should be having blood worked to monitor their myeloma approximately 3 or 4 times a year. Patients also need to have their bones monitored. Often we will use a skeletal survey and sometimes we use a CT PET scan to assess the patient's bones.

There are now second and third line and fourth line drugs available to us for these patients. And some of these drugs include new proteasome inhibitors and several different antibody treatments. It does seem that most of these drugs work better together, so people often focus on using doublets, two drugs, or triplets, three drugs.

Scott

The infusions themselves of the treatments, they weren't scary at all. I think probably the hardest part was not what it was doing to me, but it was my family. What was it doing to my wife; what was it doing to my daughters? That was probably the most, we could call it, scary and most concerning thing that was happening to me at the time.

Karen Kell Hartman, LCSW-R, OSW-C

We talk a lot about multiple myeloma - in particular, in some other cancers – as being, treated like a chronic illness and the medical community sees that as a tremendous advance – which it really is because years ago people didn't live very long with those illnesses because they weren't treatable. From a patients' perspective, they hear “treatable, not curable,” which is a phrase that comes up all the time, and that can be kind of devastating to a patient who wants to have a cancer that is cut out of the body and then gone. Most of the blood cancers, certainly multiple myeloma, doesn't work that way. So it's very challenging for patients to cope with it; to think, “I'm always going to be on some kind of treatment. This is never going away. Cancer is my life.” To help them figure out a way for cancer to become a part of their lives, but not all of it – to put it in its own compartment – which takes time to work toward that. That's a lot of talking with a social worker like me or the medical team or just getting through weeks and months of treatment and feeling that, “You know; I actually – I can manage this. I can take a vacation. I can raise my children. I can walk the dog even though I have cancer.”

Scott

Before multiple myeloma I was a workaholic, I was a control freak. Beforehand, my job was to earn a living for my family. When I developed multiple myeloma, my wife said to me, “Your job now is to live,” and that's what I'm doing. I'm living my life the way I want to live it and I'm really enjoying it. It's a much more fulfilling life.