

My Experience Undergoing a Stem Cell Transplant

I recently completed an autologous stem cell transplant at New York-Presbyterian Hospital, under the supervision of Dr. Tomer Mark, an Assistant Professor of Medicine in the Division of Hematology/Oncology. The transplant process was a very physically and psychologically challenging procedure, both in the hospital and during the at-home recovery. After recovering from my successful transplant, I concluded that it would have been very helpful in preparing me for the procedure if I had had the benefit of a detailed description from another patient of their experience in going through the operation and the recovery process.

In order to assist other cancer patients in preparing for a stem cell transplant, and to give them one patient's granular view of what to expect during their hospitalization and the recovery process at home, I have written this article in collaboration with Dr. Tomer Mark and the medical staff of the Division of Hematology/Oncology. In preparing for a stem cell transplant, the prospect of which is fairly intimidating, I think you will find this summary of my experience as a transplant patient to be informative and helpful.

I was initially diagnosed with multiple myeloma, a form of bone marrow cancer, in late June 2009, as I was training for the New York City Triathlon. When I found myself without sufficient stamina to run more than a short distance, I finally visited my internist, who ordered a CT scan. The results disclosed a large tumor in my left abdomen, which was rapidly growing, and appeared to be lymphoma. As an athletically active 58 year old, I was shocked and dismayed by the disclosure that I had cancer. I was immediately referred to Dr. Morton Coleman, a senior physician at New York-Presbyterian Hospital who is a leading specialist in lymphoma and myeloma. Once a biopsy confirmed that I had myeloma, I spent approximately five months undergoing chemotherapy, administered intravenously twice a week in Dr. Coleman's office, which was successful in shrinking (and eventually eliminating) my tumor, and dramatically reducing the level of cancer in my blood.

Dr. Coleman informed my wife and me that, once my cancer level was reduced to a level that reflected effective remission, the next recommended step to achieve long-term remission would be a stem cell transplant, using my own stem cells. After my initial intravenous chemotherapy, by which time my "blood markers" reflected a rapidly diminishing level of myeloma, I transitioned to Revlimid, a form of maintenance chemotherapy in pill format which is taken in 21-day cycles, typically in combination with Decadron, a steroid. I elected to postpone having a transplant for several months, to accommodate my work schedule, while continuing to take Revlimid, which was effective in keeping my cancer in remission.

I was referred to Dr. Mark and his nursing staff, who scheduled my hospitalization and prepared me for the stem cell extraction process, which precedes hospitalization. They described for my benefit, day-by-day, what I could expect during the period of my hospitalization, which was expected to last approximately 18 days, depending on my response to the high-dose chemotherapy I would receive, and the success of my transplant. He also advised me that the hardest aspect of the transplant process would be the recovery at home, when the patient experiences extreme fatigue for a number of weeks. He also noted the risk of infection post-transplant, when the patient's immune system remained compromised, arising from exposure to bacteria and viruses from others, requiring the patient to minimize contact with non-family members during the recovery process. Finally, he told me that I would feel fairly sick during the second week of my hospitalization, and that I could expect to lose ten or more pounds while hospitalized.

In order to facilitate extraction of the patient's stem cells, and the later infusion of chemotherapy, stem cells, periodic blood transfusions, and intravenous administration of antibiotics, a venous catheter was placed in the upper chest by an interventional radiologist, below the collarbone. This process required a short surgical procedure done under general anesthetic. I had the catheter implanted the day before I was scheduled to begin the stem cell extraction process.

The transplant unit of New York-Presbyterian Hospital seeks to collect sufficient stem cells from the patient to support two transplants, since the patient will likely be unable to produce a sufficient volume of stem cells for a second transplant after undergoing high-dose chemotherapy. If your cancer recurs after achieving remission, certain patients with myeloma will benefit from a second transplant. A successful transplant requires a minimum of 2 million stem cells per kilogram of body weight, but more cells are usually infused, since more cells usually speed the transplant recovery process and minimize time of exposure to severe side effects.

Since I had gone through extensive chemotherapy prior to my transplant, I had to go through four consecutive extraction sessions at New York-Presbyterian Hospital in order to obtain a sufficient number of stem cells for two transplants. However, most patients will only need to attend one or two sessions, in all likelihood. Extraction involves spending approximately seven hours connected to a device that circulates the patient's blood, while collecting the patient's stem cells. You sit in a comfortable chair throughout the process, during which you can read or watch television. For several days prior to extraction, the patient is required to give themselves injections of Neupogen, a myeloid growth factor which stimulates bone marrow production of white blood cells and therefore enhances the patient's production of stem cells. The nursing staff instructs you in the use of the syringes, which are given to you by the nursing staff during your orientation meeting. The needles used are almost identical to the standard ones used for diabetes insulin management. I found injecting myself to be unpleasant, but manageable.

I completed the extraction process on a Saturday, and was admitted to the hospital on the following Monday morning. Patients undergoing transplants are resident on the tenth floor of the Greenberg Pavilion. Most patients undergoing stem cell transplant are placed in private rooms; however, given the relatively low infection risk with an autologous stem cell transplant, some patients have roommates. Once you are admitted, the nursing staff start the routine of measuring your blood pressure, your pulse and your temperature, which they do multiple times each day. On the first and second day of my hospitalization I received, intravenously, high dosages of Melphalan - a powerful chemotherapy drug that is related to nitrogen mustard. For the five or six days following receipt of this chemotherapy, you do not experience any adverse effects. On the third day (which is referred to as "Day 0" by the medical staff), you receive your stem cells intravenously, which takes anywhere from 30 minutes to 2 hours, depending on the volume of the stem cell solution. Before the stem cell infusion, the patient is given benadryl to minimize the risks of any infusion reaction, such as rash.

For the first six days of my hospitalization I did not feel ill or experience any of the unpleasant side effects customary from chemotherapy. I had regular visitors, read, and used the stationary bike in my hospital room. However, by the seventh day, I began to feel fairly ill: I lost most of my appetite, started to have diarrhea, and felt quite fatigued. Most food quickly became unpalatable, so I looked for food that I could eat, which in my case consisted of mashed potatoes, scrambled eggs, applesauce, and ice cream. My white blood cell count started to decline rapidly, reaching nearly zero on the eighth day following my chemotherapy.

For the next seven days I felt quite ill. I was chronically fatigued, suffered regular diarrhea, had no appetite (and started to lose weight rapidly), and generally felt lousy. That week was very unpleasant and dispiriting. I was taking various medications several times daily to reduce the risk of infection, and

on several occasions received transfusions of red blood cells to combat anemia. However, after several days my white blood cell count started to rise, reflecting the success of my transplant, and as it did so I started to feel less fatigued, and generally less ill. By the end of the second week, I had lost more than ten pounds.

The nursing staff looked in on me regularly, and did an excellent job. My wife kept me company every day and evening, and I had regular visits from family members, which helped to keep my spirits up. Every morning I was visited by the resident in charge, and later in the day by Dr. Mark.

By the 15th day I was feeling less ill and less fatigued. I was encouraged by the steady increase in my white blood cell count, knowing that it would be instrumental in the decision concerning my discharge. I also noticed that my hair was beginning to thin.

I was discharged on the 18th day, after receiving instructions from the nursing staff about precautions I needed to take to avoid infection, and after meeting with Dr. Mark, who warned me about the level of fatigue I could expect to experience once home. I was naturally skeptical concerning the warning, and assumed -- incorrectly -- that I would quickly regain my strength and stamina. On leaving the hospital I felt liberated, and was thrilled to be back in my own home. I was feeling less sick, with less severe diarrhea, although my appetite had not returned, and most food continued to be inedible.

However, within a day I began to feel extremely fatigued and lethargic, on a level much more intense than anything I had previously experienced. Slight physical exertion, like simply taking a shower, left me panting and feeling exhausted. I discovered that I needed to take one or more naps during the day, and on most days I was especially fatigued in the morning.

My wife prepared all of my meals, which continued to consist of only a few food items I found edible. I continued to lose weight for the first week at home, although thereafter my weight stabilized.

Within several days my hair began to fall out in large clumps, which I found very disconcerting, not to mention unsightly. I had my longtime barber come to our home on a Sunday and shave off all of my remaining hair, which was a big improvement. Now, I looked like Yul Brenner. It was a very strange sensation, and I had to adjust to my new appearance.

I continued to feel extremely fatigued for the next three weeks, reading, staying in touch with my office by phone, and sleeping. I did not have the strength or stamina for even short walks, and I was very mindful of the risk of infection if I went outside. When I went outside, I wore a mask, as advised. I was determined not to become sick, knowing that a simple infection could easily escalate into a major infection that would require re-hospitalization, which I knew was common among many transplant patients.

By the fourth week, I began to gradually regain some strength and energy. I began to take walks in Central Park (despite the presence of heavy snow from multiple snow storms), although on some days I would need to take a nap after returning from a walk in the park.

My appetite began to return, but very slowly. I discovered that I could begin to eat certain foods (like chicken), but could not eat others (including meat, fish, fresh fruit and vegetables). In addition, alcohol tasted very acidic, and I gave up all forms of alcohol, including wine, until fairly recently.

During the next four weeks, my strength and stamina levels steadily improved, although I remained far weaker than I had been before the procedure. I remained very tired upon waking up, but within an hour or so my energy level increased significantly, allowing me to work from home several

hours each day. I made several visits to the hospital during this recovery period for a blood test, and to meet with Dr. Mark and his staff, who were very encouraged by my progress.

I discovered that simple cardiovascular exercise, like walking, quickly elevated my energy level, and made me feel much better. I began to take walks everyday, and soon bought a stationary recumbent bike, which I began to use daily. The favorable effect was very noticeable, and helped to accelerate my recovery.

With the approval of Dr. Mark, I returned to work on a part-time basis after eight weeks, and started to work a full schedule after ten weeks, by which time my strength and stamina levels had increased dramatically. However, I also contracted a cold after being home for eight weeks, which developed into bronchitis and a chronic cough that required that I take Zithromax for several weeks. It was a humbling reminder of my vulnerability to infection, and the fact that my immune system was limited in its ability to successfully fight an infection, once I became sick.

I also experienced an unpleasant resurgence in the neuropathy I had suffered when going through my earlier chemotherapy treatments. I had a pervasive numbness in both feet for many months when I was taking Velcade, which began to slowly fade after going off that chemotherapy. Within a week of being discharged, however, my neuropathy was even more pronounced than it had been while I was on Velcade, and it remains quite unpleasant. However, I have been assured that the condition will start to fade within several months. I came to learn that most patients with myeloma with neuropathy experience a transient surge in unpleasant symptoms 1-2 months after transplant, but this fades with time.

A key benchmark in the recovery of transplant patients is the date 100 days after the patient's transplant. Prior to that date, the patient's immune system is considered too compromised to travel, or to have any surgical or dental procedure. In my case, my wife and I took a short vacation in the Caribbean on Day 100, which was enormously therapeutic for both of us. I also underwent a cataract lens replacement operation one week later, since my many months of taking steroids had generated cataracts in both eyes.

Fourteen weeks after my discharge, my energy level is now fully restored, although my stamina level remains reduced from what it was before the procedure, and I have started to go back to the gym on a daily basis in a concerted effort to regain my previous cardiovascular and physical condition.

It has been a long and rough road, but well worth the physical hardship, suffering and inconvenience. I am now cancer free, and hope to keep my cancer in long-term remission as a result of this procedure.