Lucie Martineau's Journey to Stem Cell Transplant

My story begins in 2011, when I was 55 years old. I had been a professional ballerina, blessed with good health and good eating habits. Even after I had to quit dancing because of lower back problems, I remained active – running, biking, hiking, kayaking, and going to the gym. When I was told I had Waldenström's, I was stunned. More than that, I was insulted that I was hit with cancer despite my healthful lifestyle. The good thing, I was told, was that my constant training and good eating habits helped me through what were to become two very tough years.

I met my husband when I was fifteen years old. We went through this journey together, and we succeeded as a team. Needless to say, my WM diagnosis was also very hard on him. In the turmoil that sometimes follows such a diagnosis, caregivers often are left to watch from the sidelines, feeling powerless and losing control of their own lives as well.

While daunted at first, I want to add that I never thought of not making it. That said, despite the love surrounding me, it proved to be a very hard and lonely journey. Fear and anxiety were there at every turn, and fatigue was at times so severe I wondered how I would make it through the next hour, let alone all the way to recovery. There was also the behind-the-scenes activity with its load of appointments, antibiotics, medical follow-ups at home, sleepless nights with pain, PICC lines, hair loss, the weird feeling of not recognizing myself in the mirror, losing friends, and being stared at or avoided.

In the end, my intense period of treatment led to a significant recovery. Throughout, my husband and I supported one another, which was not always easy. We were sustained in the process, however, by knowing of other patients' treatment experiences. So that others may profit from mine,

here is my story.

2011:

From a routine blood test by my then-new primary care physician, I was found to have an IgM kappa monoclonal peak in the spring of 2011. As a result, I was referred to a haematologist for more testing.

2013:

In November it became clear that what had been MGUS until that point, had evolved into full-on WM. Symptoms included fatigue, a material increase in IgM to 8750 mg/dL, and haemoglobin decreasing to 10.2 g/dL. The situation began feeling scary, especially as a bone marrow biopsy was called for.

Dec. 6: Bone marrow involvement was found to be 65%; viscosity was 5.8; and haemoglobin had fallen further, to 9.7 g/dL. My haematologist recommended treatment with RCP (Rituxan, cyclophosphamide, prednisone or prednisolone), 6X, at three-week intervals. To begin, however, I underwent two sessions of plasmapheresis to bring my IgM down prior to treatment and to avoid Rituxan flare. My IgM decreased to 300 mg/dL.

Dec. 11: I had my first treatment, which included a strong reaction to Rituxan that had me jumping on my chair from chills and tremors.

2014:

Jan 3: IgM rose back up to 5850 mg/dL.

March 4: With no response in IgM, monoclonal peak, and viscosity levels, my therapy was put on hold for two weeks. My haematologist consulted with Dr. Treon on other courses of action. As bendamustine was not then covered by Quebec health insurance, the new plan was to treat with Velcade + dexamethasone on days 1, 4, 8, and 11 for six cycles.

March 28: Velcade + dex cycle 1.

April 18: Velcade + dex cycle 2.

May 9: Velcade + dex cycle 3 on days 1 and 4 only, since I was going to the Ed Forum (May 16-18) in Tampa – my first one!!!

May 26: I returned from Tampa with neuropathy in my legs. The pain was severe and was interfering with my sleep. This side effect, plus no apparent response to the therapy, led to my Velcade treatment being discontinued. Instead we transitioned to watch-and-wait, to see if my condition improved from the treatment I already had. The good news was that I became asymptomatic and felt quite well. Over the next few months, my numbers began to trend slowly downward: IgM 4334 mg/dL; monoclonal peak 1810 mg/dL; and haemoglobin up at 12.6 g/dL.

LucieIn October we decided to go to Italy for three weeks. PN was controlled with Lyrica and Tramadol. We had a wonderful trip and celebrated Christmas and the New Year with friends and family. Life was great! Our thoughts turned quickly to planning for a trip to Bali in spring 2015 – a dream destination for me – to celebrate my 60th birthday, my husband's 65th, and our 30th wedding anniversary.

2015:

In mid-January I started to notice a lack of energy and loss of appetite. Three days in a row I woke up totally drenched in sweat and noticed that I had a growing stomach.

Jan. 30: Results of a blood test included an above-normal lactate dehydrogenase (LDH) reading of 500. A subsequent CT scan did not explain this reading.

Feb.13: LDH rose to 729, and a bone marrow biopsy diagnosed a transformation from WM to diffuse large B-cell lymphoma (DLBCL).

Feb. 18: I was admitted to hospital with systolic blood pressure of 70, severely neutropenic (0.0), and completely dehydrated.

Feb. 19: Ultrasonography diagnosed acalculous cholecystitis, an inflammatory disease of the gallbladder. A percutaneous biliary tube was inserted by interventional radiology.

Given the aggressive nature of the malignancy, it was decided to start chemo while I was still neutropenic, and with the biliary tube in place. The treatment plan called for R-EPOCH (Rituxan-etoposide, prednisolone, oncovin, cyclophosphamide, hydroxydaunorubicin), 6X. Each cycle was to be for five consecutive days, 24 hrs/day.

Feb. 20: Start of 1st cycle R-EPOCH.

March 2: The biliary tube was removed, and I instantly experienced severe abdominal pain accompanied by nausea and vomiting. X-rays and CT scan showed no signs of peritonitis or colitis, but constipation was diagnosed as secondary to opioid medication I was receiving. I was given laxatives and discharged March 6, with neutrophils at 4.7.

March 8: The pain got so severe that I was rushed back to hospital by ambulance. This time ultrasound showed peritonitis and acute cholecystitis.

March 9: Laparoscopy was performed to remove gallbladder and clean abdominal cavity.

March 12: Discharged home.

March 23-27: 2nd cycle R-EPOCH.

March 28: I suffered severe chills overnight, with 102.2°F fever, and terrible abdominal pain again. I fell unconscious, was taken to the ER, diagnosed with septic shock and hypotension refractory to volume resuscitation, and transferred to ICU. I received roughly a total of 72 hours of levophed. CT

scan showed severe proctitis, colitis, and enteritis. E-coli grew on the blood cultures, I received loads of antibiotics and was put in isolation in ICU.

April 5: I was transferred from ICU to haematology department for further management where I was closely monitored since there was still presence of bowel inflammation and proctitis. Pain and fever remained an issue over the ensuing days. Another CT scan was repeated an April 14 and a 1.5 inch small rim-enhancing collection was reported anterior to the bladder suspicious for and abscess. I underwent a drainage in interventional radiology the following day, a small quantity was eliminated and grew E-coli sensitve to tazocin on culture. Despite the drainage fever persisted until April 21

April 22: PET scan showed complete response in DLBCL but extensive pelvic peritonitis and retroperitoneal extension. My situation improved significantly from that point and I did not spike any more fevers. I was also able to come off TPN (total parental nutrition) and start eating light food.

May 1: I was discharged home with a month of intravenous antibiotics (tazocin) to be administered 3 times a day.

June: With a complete response but mindful of the aggressive nature of the lymphoma, my haematologist decided to give me two R-CHOP (Rituxan-cyclosphosphamide, oncovin, prednisone or prednisolone) cycles (June 11 and July 2), with an autologous stem cell transplant scheduled for September.

July 20: I started having lower back pain, worse at night and preventing me from sleeping. I started to worry when no pain medication helped, and the feeling was not like my regular back pain.

August 10: I went to hospital to undergo a PET scan, hopeful it would confirm remission and would green-light the transplant procedure scheduled for September. While I was in the hospital, I went to see my pivot

nurse to tell her about my severe back pain. She had me see a haematologist who requested the PET scan results on the spot. The scan showed DLBCL had relapsed with T12-L4 leptomeningeal involvement.

The haematologist immediately referred me to the ER for an MRI. I was readmitted once more and could detect the serious emergency nature of my situation based on the medical staff's reactions. I was given a dose of intrathecal dexamethasone and methotrexate, which gave me immediate relief. The stem cell transplant was postponed pending my re-establishment of remission.

Later that day (Aug. 10), I was informed that I urgently needed a new treatment plan and was prescribed high-dose methotrexate and cytarabine. I do not remember for how many cycles. This time I was in complete shock, very fearful, and depressed. This new treatment normally is given in hospital over five days. It is quite potent, and I developed a C. difficile infection, fever, febrile neutropenia, and "red man syndrome" because of the vancomycin, an antibiotic I was taking to treat my diarrhea. My PN was so severe I could hardly walk, and stairs became completely unmanageable.

Aug. 30: My neutropenia resolved and I was discharged.

Sept. 15: My chemo was modified to five cycles of ARA-C (cytosine arabinoside) and intrathecal methotrexate injections because of my severe PN. The first cycle was administered in hospital over four days, and all went well. I went home on Sept. 18.

Sept. 25: I went back to the ER with 102.6°F fever, and was found to be again in septic shock with febrile neutropenia and systolic blood pressure of 70. I was transferred to the ICU for two nights, and subsequently to the haematology department. I had pneumonia, which explained the fever. I received blood and platelet transfusions.

Oct. 1: I underwent a PET scan to determine whether I was still a candidate

for stem cell transplant therapy. It was confirmed that I was eligible, the procedure was set for November, and I was discharged home.

After many tests, the transplant procedure was begun. I felt in such great shape both physically and mentally that I even asked my doctor if I really had to go ahead with this! Yes, of course I had to, and my stem cells were collected at the end of October.

Nov. 12: I was admitted for transplant. It consisted of BEAM chemotherapy (BCNU carmustine, etoposide, ARA-C, melphalan) given over six days, followed by the actual autologous transplant of the stem cells collected at the end of October, which is like a blood transfusion. It took four minutes.

Nov. 20: I was so weak I could not get out of bed. I had terrible nausea – ginger ale was the only thing I could consider putting into my stomach. I understood at that point what the medical staff

meant by “very tough” chemo. I did not want to talk to or see anyone!

Nov. 24: As had been foreseen, I experienced febrile neutropenia. I became hypotensive and was sent to ICU where a blood culture showed an E. coli infection.

Nov. 27: I was transferred to the haematology department where I remained febrile until Dec. 1.

Dec. 2: I was discharged home with a prescription for two weeks of antibiotics. I was very weak, and my mind seemed to be in la la land!

2016:

In January, I slowly regained strength and was able to focus again, but that recovery took until the end of the month.

All told, 2016 was a challenging year, having to deal with the realization of

all that had happened, fear of the lymphoma coming back, contending with my physical weakness, and my desire to forget it all and to get back to being my normal self. April saw me back in hospital with gastritis, which I managed to get over. At other times during the year I suffered diverse infections. Psychological help became necessary and was generously provided by my husband, family and friends, all of whom pulled out many stops in order to support and guide me. I learned to be patient and nice to myself, and to relax. I started understanding what “convalescence” means.

Jan 2017: Haemoglobin: 13.3 g/dL; IgM: 848 mg/dL; monoclonal peak: 290 mg/dL.

Postscript

By February 2017, as this memoire is being written, I have recovered so much that – unless they notice my now-different hair –I believe no one (with the exception of me) can tell what I went through during the last couple of years. Most importantly, I can now think of leading a normal life and of travelling again.

But let me be very candid – I also have learned that being this sick can be terrifying. The cycles of treatment, relapse, anxiety, and recovery can be very taxing. But one must sustain belief in oneself. The body and the mind make up a wonderful machine. And listening to them can be most instructive, as they guide us to finding ourselves again and unlock the opportunity to enjoy every single second that we are blessed to live.

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