
FIELD NOTES | SPRING 2013

Poetic Therapy

By Elaine Benton

I was born with Gaucher disease, a rare disorder, caused by a genetic mutation from both of my parents, resulting in a deficiency of a specific enzyme (glucocerebrosidase). The missing enzyme affects the liver, spleen, and bone marrow, causing severe bone pain, bone deterioration, in particular damaging joints, and various additional symptoms such as bleeding and anemia.

I was diagnosed at the age of five and as soon as I could read and write, I began writing stories and poems; expressing myself on paper was a form of therapy. Despite adversity I was given the ability to enjoy every moment I have. I grab life with both hands and make the most out of each day.

As if suffering a rare chronic disease was not enough, at the age of 44, I was diagnosed with Parkinson's disease. My life became very difficult struggling with two chronic debilitating degenerative diseases. A year ago, I wrote a book that is a collection of poems about living with Gaucher and Parkinson's. For me it was very therapeutic in a cathartic sense, but what was even more astounding; I found others suffering chronic disease could relate to my poems. From personal experience I've written with stark honesty and humor, giving a fresh perspective from the patient's point of view.

Through my poetry, doctors have the opportunity to see the entire picture, not merely medical facts but the emotional side of suffering disease and how a patient really feels. Encouraging empathy, and understanding those who suffer disease, ultimately benefits both doctor and patient. Today we realize there is a strong link between physical medical issues and the emotional attitude. What started as merely a few poems has spiraled into an entire project, resulting in me writing a blog <http://elainebenton.blogspot.com/> on wide-ranging topics that sufferers can relate to and letting them know they're not alone in their daily struggles. People around the world are reading my blog and contacting me, and I reply personally to each one. I speak at various organizations, to student doctors, and gave an oral presentation about "Writing as Therapy" at The First International Congress for Narrative Medicine and Rare Diseases in Rome in June 2012. I believe there is need for education and greater awareness heard directly from patients. This project has given my life purpose, keeping me busy and making me feel I have something of value to contribute to society, which is highly important in sustaining me.

Putting into practice "narrative medicine" may sound an impossible feat, and although understandably a doctor has time restraints regarding how long he spends with each patient, narrative medicine can still be applied. A doctor, who is aware of narrative medicine being a valuable additional tool, not only can improve diagnosis and ultimately treatment, but also provide a feeling of empathy that patients need and deserve. Simply applying the powers of observation can make a difference.

When a patient enters a doctor's office, he or she sends a message. By looking and observing how the patient walks into the room—posture, gait, facial expression, how he or she sits down—can within a few seconds summon up a rough picture indicating the patient's condition both physical and emotional. Every detail, no matter how small, if observed and noted can be of tremendous help, possibly filling in information or details, like missing pieces of a jigsaw puzzle; a larger, clearer picture comes into view. Eye to eye contact is another very important feature of a good consultation, and using the patient's first name immediately makes even the shortest of visits more personal, leaving the patient satisfied he/she has been seen as a person, an individual, not merely another case in the endless stream of patients a doctor generally sees each day.

These practices require little additional time or effort, during a doctor's regular appointment slot, and yet can vastly improve the outcome for both doctor and patient. The patient can also help to get the most out of a doctor's relatively short consultation by arriving on time and prepared; making a list of questions in advance, any new symptoms and additional information that may be pertinent, giving the doctor a complete story with the maximum of information. A list ensures nothing is forgotten and no precious time is wasted, which again helps doctor and patient with a joint goal, working as a team. I sincerely hope more doctors will begin to adopt narrative medicine as an additional valuable tool, helping patients cope better with ill health and that it becomes an integral part of medical care.

I consider myself very lucky to receive good medical care and am grateful to be in good hands. Suffering a rare disease, or any chronic condition, a patient's case can become quite complex and the need for input from doctors in various different fields may be required. Having a multi-disciplinary team comprised of several doctors looking at a patient through their own field of expertise, working together as a team, I am convinced is the best healthcare for the patient, portraying a comprehensive view of the case being presented ultimately ensuring that the correct diagnosis and treatment plan are set in place. I am very fortunate to be taken care of in this manner, and the Professor who looks after me, being one of the leading doctors in the world specializing in Gaucher disease, has a complete team of doctors, nurses, and technicians that he works with, all of whom are familiar with and trained to spot the unusual abnormalities that manifest in Gaucher disease and unusual patients like myself who also suffer a secondary disease.

Although it's not easy suffering Gaucher and Parkinson's, I keep smiling and have a strong fighting spirit. No matter what disease a patient may have, it's the state of mind that counts. It's very easy to fall into depression and wallow in self-pity, but having a positive attitude and a sense of humor is vital in keeping me going even when circumstances are tough.

Elaine Benton was born with Gaucher, a rare inherited disease, for which there is no cure. At age 44, she was diagnosed with Parkinson's, so now battles two diseases. In 2011 she wrote a collection of poems about living with the two diseases. It was therapeutic in a cathartic sense, writing from personal experience with stark honesty and humor, giving a fresh perspective from the patient's view. "Narrative medicine is an important tool for understanding a patient's entire story, not medical facts alone, but realizing the link between physical and emotional issues," she says. "Poetic Therapy" appeared in the Fall 2012 issue.
