Imagine

Category: Stories
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Linda Koebner

“Her vitals are fine,” the nurse told Besarta’s mother during a rare visit to the family’s basement apartment in the Bronx.

Besarta’s mind is also fine—sharp and clear. She asked me to use her real name in this story.

Her twenty-five-year-old face is beautiful and flawless, despite the howls of frustration, rage and pain she directs at her family, at fate and especially at Friedreich’s ataxia, the disease that controls her.

When I come for our weekly visit, Besarta’s blue-green eyes smile at me from where she sits in her wheelchair. Then her head suddenly wobbles sideways. Her face smashes against the chair’s headrest—first the right side, then the left.

I can only watch helplessly. Much worse than my impotence is the knowledge that modern medicine can do nothing to stop this disease. There is no cure—not even a way to slow its progress.

A rare hereditary illness, Friedreich’s ataxia usually begins in childhood. It attacks the central nervous system, thinning the spinal cord and peripheral nerves. Patients suffer from impaired balance and coordination, slurred speech and spinal curvature. They can also develop heart disease, diabetes and loss of vision and hearing. Their lives are usually short.

Since Besarta’s diagnosis, at age eleven, her mobility has steadily eroded. She has lost the use of her arms and legs; she can’t wiggle her toes, which are always icy cold. With each passing week her tongue seems to grow thicker, muffling her speech.

Like a sadistic jailer, her disease is pushing her further and further into the prison of her body, until one day she will be locked in, motionless and speechless—a dead weight, but not dead; aware, but unable to do anything but think.

She can still use her right hand to press an iPad touchscreen, but it takes moments of agonizing concentration to send the signals from brain to finger. To write this sentence would take her hours.

This is why I come to sit with her each week.

These past two years, while studying for a master’s degree in health advocacy, I interned at a children’s rehabilitation hospital. A member of the board asked whether, “as a *mature* person,” I’d be willing to help one of the hospital’s past residents write her story.

It sounded like a great opportunity, and so Besarta and I began weekly dictation sessions.

Because it took her hours to speak even a few sentences, we decided that she would talk into a recorder during the week, and that I would transcribe her words.

Now her story—her book—is 200 pages long. There’s much more to go. But will there be enough time?

“We must finish my book by January, because I probably won’t be able to talk after that,” she told me not long ago.

Besarta’s urgency is understandable. She will never have children, a husband or a profession; she can leave only her experiences. Her story will be her legacy.

She wants to be a voice for other young people who face her fate. She wants their parents and the medical community that cares for them to understand a child’s point of view.

There may also be another reason. Besarta’s younger sister shows symptoms of Friedreich’s. Although Besarta never says so, I believe this story is for her sister.

Besarta was born in Kosovo. Her early childhood was spent on the family farm with her parents and many siblings.

“When she was a little girl, Besarta climbed trees so fast! High in the branches, she tossed baskets full of cherries down to me,” her mother once told me with pride.

Hearing this, Besarta tried to smile.

On my next visit, I brought a bag of cherries, but quickly realized my blunder.

Grabbing them from me, her mother yelled, “Not for Besarta! She might choke—only soft food now!”

In Kosovo the family led a simple rural life until gunfire, bombs and carnage began to tear their country apart. When Besarta was ten, they fled to the U.S.

Around that time, her symptoms started: she felt weak and unsteady and listed to one side when she walked.

It was a year before the family got sufficiently settled to seek medical care for Besarta. But when they took her to the doctor, he had no clue as to what was wrong.

Only when Besarta could barely walk did her school’s social worker step in, finding a physician at a research hospital; he saw Besarta and handed down the diagnosis.

Besarta’s parents were stunned—and frantic. Speaking almost no English, they could neither ask questions nor truly understand the doctors’ advice about treatment options.

For Besarta, both diagnosis and treatment were hellish.

Imagine you’re a young girl who speaks and understands very little English. The doctor says you are going to have “pictures” taken. For days ahead, you plan what to wear and how to braid your hair. Before going for the pictures, you put on your mother’s lip gloss, “to look pretty.”

Imagine, then, the shock, fear and humiliation as a man yells incomprehensible words and motions for you to take off your clothes and earrings and stand in front of a huge machine. Once you’re there, he pushes you into postures you cannot physically hold—if you could stand as he wishes, you wouldn’t be here.

Imagine a doctor’s asking you to hop, bend over, crawl and then walk a straight line, wearing only your underpants and a paper hospital gown, in front of a roomful of strangers—medical students.

Now imagine doing this as a twelve-year-old Muslim girl.

Imagine a doctor’s telling you that surgery for your scoliosis will make you walk normally. Imagine awaking in agony after the operation, but doing your best to bear it, believing that once you can walk again, people will no longer laugh and stare.

Imagine learning, after weeks of grueling rehab, that the night before the surgery was, as you put it, “The last time I could brush my teeth by myself.” Because now you can’t do anything by yourself.

Imagine studying hard so you can graduate high school, despite your disabilities, and earn your American citizenship.

Finally, imagine aging out of your rehab program—reduced to minimal services and suffering a series of bureaucratic snafus, year after year, until all you have left are days spent sitting in a manual wheelchair in a basement apartment, waiting.

After more than two years and many Medicaid applications, Besarta still has none of the equipment—a power wheelchair, a special bath—that would make her life so much easier. She’s been unable to enter a day program; they’re not accepting new enrollees.

So she sits and waits.

This is the bare outline of the story I’ve promised to help Besarta tell. I don’t know if we will finish it before she is silenced by her illness, so I offer the medical community two vital truths she wishes to share.

First, if you want to give compassionate care, communicate openly and truthfully.

“Be absolutely clear in what you tell a patient, even if she is ten years old,” Besarta urges. “Take time, no matter how difficult, to be honest. Say the truth so patients understand, so their families understand.”

Second, treat your patients as people, not just cases.

Besarta knows that the doctors did what they could, and that they must sometimes use patients as teaching tools. But she wishes they’d also known how to reassure a scared young girl.

“What I wanted more than anything,” she says, “was for the doctors to know *me*, not just my sickness.”

Now I, too, am impatient to tell Besarta’s story. I want her to know, before she dies, that her story will be heard.

I want this mostly because she wants it, but also because I have come to care so deeply for her.

Besarta has shown me what true bravery looks like. She has opened my eyes to the plight of the countless young people who inhabit the chasm of “aged out” and who deserve more, much more.

And she reminds me, and will do so every day for the rest of my life, to be grateful that I can pick a cherry, put it into my mouth, and savor the flesh and juice without thinking twice.

About the author:

Linda Koebner has been a lifelong advocate for human and nonhuman animals. In her early twenties she created a sanctuary for chimpanzees retired from biomedical research; this became the National Institute of Health’s Chimpanzee Sanctuary System. She recently received a master’s degree in health advocacy from Sarah Lawrence College. In addition to serving private clients, she works as a patient advocate and patient representative at Westchester Medical Center in Valhalla, NY. She has also initiated a pet-therapy program for hospice patients with one of her dogs, Spirit. While at Sarah Lawrence, she became interested in the power of medical narrative. “Writing has always brought me comfort and leaves me amazed at what appears on paper if I just let go. I love hearing people’s stories and exploring the breadth and depth of experiences in medicine’s complex world.”

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