

TALIA WOOLDRIDGE || 1-88 Oxford St., Toronto, ON, M5T 1P3 || Talia.wooldridge@gmail.com
+1.416.856.6459

On February 6, 2016 at 3:20 pm, Gail Benshabet sent a quick text to her 27-year-old daughter, Lisa, inquiring if she wanted to catch an early movie. Benshabet was wrapping up her workday at the quiet special needs school where she works in the north end of Toronto, forty minutes from her home.

Lisa never texted back.

“I knew something was wrong,” Gail says to me a few months later on a warm Sunday afternoon. Her calm blue eyes look straight into mine as she explains how she bounded up the three flights of stairs at her home, calling her daughter’s name, “only to find Lisa hanging lifeless from the ceiling fan in her room.”

Lisa left three letters: one to her mother, one to her sister, and one to her extended family and friends.

“Mom,” Lisa wrote, “you went way beyond what any Mom did but I couldn’t imagine living a life where I didn’t have any control over my body.”

Lisa suffered from interstitial cystitis (IC), a little known medical condition also known as bladder pain syndrome (BPS), painful bladder syndrome (PBS), and hypersensitive bladder syndrome (HBS). The statistics list 4 to 12 million people who are *believed* to suffer from IC, with 90% being women (roughly 3 per cent to 6 percent of women in the United States are affected). Symptoms can start to develop at any age in men and women; however, many are diagnosed with IC, after countless failed treatments for urinary tract infections, between the ages 20 to 40 years old. Presently, there is no known cure, just symptom management, although Dr. Curtis Nickel, an urologist based in Kingston, Ontario who no longer accepts new patients is seeing some success with trial studies. Interstitial cystitis often accompanies other conditions such as irritable bowel syndrome, chronic fatigue syndrome, and fibromyalgia. Lisa was diagnosed at the age of sixteen after having what was believed to be recurrent bladder infections since she was twelve. By her 24th birthday, Lisa had seen the inside of nearly forty specialists’ offices across North America.

On the night of Lisa’s funeral, Benshabet woke up at 3 a.m. and started writing emails and letters to the doctors who cared for Lisa. One psychiatrist replied with his condolences but still suggested that the entire diagnosis of interstitial cystitis was in Lisa’s head, something that is frequently heard by many sufferers.

Today Gail is carrying on her daughter’s legacy. Benshabet’s mission, since losing Lisa, is to create more awareness surrounding this disease so as to avoid blank stares in the doctor’s offices. While she is having some success, sadly, many other women are suffering from a host of other physical pains that doctors dismiss as being imaginary. To be told, while suffering from crippling pain, that “it’s all in your head; there’s nothing wrong” is devastating.

Abigail, a young woman and musician from Kingston, Ontario suffered debilitating menstrual cramps since the age of fourteen. Her family doctor, along with a host of specialists, told her to take pain medication to deal with having painful periods. One doctor dismissed Abigail’s suggestion of it being endometriosis because Abigail was not overweight. After doubling over in pain and having to cancel music concerts and a prestigious tour in her twenties, Abigail began what would become a harrowing, decade-long search for answers in the medical system, including misdiagnoses of yeast and bladder infections both in Canada and abroad in France. By the age of 33, Dr. Cleve Ziegler, the Director of Gynecology at Jewish General Hospital in Montreal, discovered cysts on Abigail’s ovary and

scheduled surgery. Post surgery, Abigail's pain returned with her menses. After emailing detailed dates and pain recurrence since the surgery, along with a rational fear it could be ovarian cancer, Dr. Cleves wrote back Abigail, "Blah, blah, blah. There will be a requisition for an MRI available for pick up in my office on Tuesday."

Such dismissal is hardly reassuring or helpful, let alone professional. Abigail descended into a deep depression and sense of despair saying, "I thought I was going mad because no doctor could explain what was causing the pain." Unable to find compassionate help from her doctors for intense pain she knew was not imaginary, Abigail turned to personal research on the Internet. After six months, she stumbled across the Endometriosis Network of Canada. While the specialists she saw denied she had the disease, Abigail took refuge in multiple online forums and blogs where others, with similar symptoms, swapped tales and tips about this misdiagnosed disease. After reading countless suicidal posts, something commonly heard in chronic pain forums, Abigail stopped reading. At the age of 41, Abigail has endured three surgeries, lost substantial income from not being able to work and faced the possibility that she will never have children. The last surgery, performed by Dr. Tessier in Kingston, was effective for three months until Abigail's symptoms, a heavy bladder, not being able to void and extreme pain on her lower tailbone, recurred. She is now worried it is Interstitial Cystitis. Why this was never considered is upsetting to Abigail. When asked how the doctors came to diagnose her, she said there was "always a lack of information" – all of her doctors would consult a "massive tome of pharmacology to diagnose the symptoms but none of the medications they prescribed cured her."

Abigail and Lisa's story is, sadly, echoed in countless other women's stories, such as Vanessa, who was told by doctors to "just not have sex" as a means to cure troubling uterine pain that various doctors could not successfully treat. Vanessa's sentiment of feeling belittled was also heard in mainstream media last year, when Canadian pop star, Avril Lavigne, who has been diagnosed with Lyme Disease, broke down during an on-camera interview as she talked about the dismissive treatment she experienced from countless doctors. "It was awful," she sobbed. "The doctor just kept saying 'it's in your head.' But I knew it wasn't. It was shocking to not be taken seriously."

The gender bias in the western medical system is not new. But why does it still exist? And why, in an increasingly connected world, is there such a large gap for doctors in finding the appropriate information to help patients with chronic pain?

Dr. James Maskalyk, an emergency medical doctor at St. Michael's Hospital in Toronto who travels annually to Ethiopia to train African ER doctors, explains how despite numerous conferences, newsletters and medical journals available to keep doctors in the loop surrounding medical diagnoses and available treatments, there is no guarantee the specialists are always up-to-date. Doctors, like any professional, are saddled by shifting burdens in their professional and personal lives. Plus many new diseases are cropping up. There also exists a funding bias in medical research. Maskalyk, along with other family doctors, have also confirmed to me that there is no central database or online forum where doctors can look to for puzzling seemingly incurable symptoms. Having medical knowledge and research exist in such a vacuum is baffling.

Imagine how shattering it would be, to be told by a medical specialist you've waited to see for nine months that there is nothing they can do because it's all in your head? Many Canadians, frustrated by chronic pain, are turning to Dr. Google to expedite a way out of their own personal hell. In Benshabet's case, she was able to locate a specialist for Lisa but only after years of searching off and online. Unfortunately, Lisa took her life the time by the time Benshabet received the appointment date. Further, the average Canadian, visiting specialists abroad is not always feasible. For Abigail, the specialist she managed to locate in Quebec was dismissive and unprofessional. Sadly, these reports are growing at an alarming rate. ...