

Move it or lose it

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I wear a low-back, sparkly dress, revealing my spinal-fusion scar. With legs braced and arms akimbo, I raise my head and address myself in the mirror. “You are awesome.” My daughters convinced me that low-back was the way to go and taught me the power stance to show my confidence about my scar. This generation of young women is a new breed of feisty. They are armed with more information, determined to show their brilliance and promote women’s resilience.

Remarrying at 70, I am exposing my idiopathic scoliosis, a condition that bonds three generations of women in my family. Mum had a severe case that was left untreated. Her approach was to put on some lipstick and carry on, which she did as a single mum during World War II — while Dad served overseas as an army surgeon — and for the rest of her very active life. Her motto was “move it or lose it,” which has served me as well through scoliosis and other medical conditions. It also fed my obsession with fitness, to prove I could do anything. It served my daughter, too, as she strengthened her mild curve with years of ballet and yoga.

It is disturbing that, although Hippocrates diagnosed scoliosis around 430 BCE, real progress in treatments was made only in the last 60 of 2000 years. Perhaps this is because it is a female-predominant condition. Those of us with scoliosis make up 3% of the population. In some African countries, the percentage is 5.5%. Around the world, the female-to-male ratio ranges from 3:1 to 10:1. Hippocrates had mixed results with his treatments. First, he instructed four grown men to stand on the back of the person with scoliosis, which did not fix the curve and probably squashed a few organs. Then, no surprise, his stretching rack caused extreme pain. The rack was later

used for torture in medieval times, although a variation on his gentler inverted table is still used today.

From the 1500s to the 1900s, people with scoliosis wore versions of the iron corset, which mostly resulted in compressed lungs. Then followed the bizarre fashion of rigid corsets and rib resections to ensure a nineteen-inch waist; women suffered unnecessarily for their beauty. In the 1930s, Mum’s doctor told her to simply hang from a tree. Perhaps he was trying to avoid squashing her lungs, but a bit more imagination might have been useful. Our family doctor checked my sisters and me for scoliosis during our adolescence because of Mum’s condition. I had X-rays and met with an orthopedic surgeon who told me that surgery was the only option. I trusted him completely.

I am grateful for my 1960s Harrington rod fusion, and for the surgeon’s skill. Compared with current practice, though, recovery was very constricting. I spent two weeks strapped to a kind of ironing board, which the nurses flipped every four hours. Then, four months of immobility in a plaster body cast in a hospital bed at home, where I faced the ceiling. My friends visited me with homework and grade 10 news, which all seemed so far away and irrelevant. I spent the next four months in a plaster walking body cast, semihuman, and wrote a few exams, acing the English but flunking the math. At a dance, as I shuffled to the beat, trying to feel normal, a boy’s elbow knocked my plaster torso, invisible beneath my minidress. He recoiled in horror as I smiled at my secret power. Finally, I spent four months in a body brace. Then, no physiotherapy whatsoever for my flaccid muscles. It took me 12 months to recover, but I was taller (I grew two inches with the straightening) and stronger.

Today, patients are walking one day post-op without brace or cast. They are in pain, but their back and leg muscles do not atrophy from months of disuse, as mine did. The teen years were challenging enough, but having scoliosis in the groovy 1960s and wearing the contraptions that I did was not great for self-image. Somehow, Mum made me feel smart and full of personality.

Today, there are excellent support groups for teen girls with scoliosis, such as Curvy Girls. Books written by and movies featuring people with scoliosis normalize the condition. That is a far cry from my day, when it was all a mystery: no discussion, let alone T-shirts, online support groups, or reading material. We have come a long way since then, but when I meet online with other people with scoliosis I am humbled by their stories of multiple surgeries, broken hardware, depression, anxiety attacks, and medication challenges. They are champions of endurance, shattered by pain.

For seemingly healthy patients with scoliosis, there is no follow-up. Now dealing with several comorbidities related to scoliosis, as so many of us are, I need reassurance that my spine will continue to support me as I age and rage. I feel it curving and torquing more each day. My GP’s referral to an orthopedic surgeon last year was returned because of a two-year wait-list. I didn’t care how long the wait was — I wanted to know what was going on with my spine.

Magically, my referral was reinstated and after 18 months of waiting, I finally saw the specialist recently. He confirmed the extreme Cobb angles in my aging scoliotic spine and suggested surgery with two new rods in the lower lumbar area if I continue to experience deep pain. He also confirmed that my routine of

stretching, walking, lifting hand weights, and taking bone-strengthening injections is excellent and said, “We should be asking you for advice.” That made my 18-month wait worth it. He said to keep in touch about my treatment, and I was relieved to be welcomed into his practice.

But I wish all patients with and without scoliosis, young and old, and especially women, could also feel seen, heard, respected, and cared for, in a timely fashion. All too often, we older adults and the essential continuity of our care are overlooked. We need a system where everyone is treated regularly and for life, with a

swifter connection between our GPs and specialists when needed.

I continue to stretch and keep fit despite pain. My new motivators are my grandchildren, who share their drooly kisses as I lift them in the air, and my husband, whose Parkinson diagnosis has shaken our little world but has pushed us to treasure each day. I have to keep being strong — and I want to be, for my family and for me, and for Mum.

I am ready for what’s next. I continue to put on some lipstick, to move it or lose it, and to embrace life. I slip on my low-back, sparkly dress and practise my power stance in front of the mirror. Then I

twirl and twirl, watching my scar wink and disappear, wink and disappear. Now you see it, now you don’t — my secret power.

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