

## People with arthritis are “heroes”

Arthritis presents many challenges to everyday activities that most people take for granted, like getting dressed or cooking a meal. Adversity can foster great strength too. People who live with arthritis are “heroes” because in spite of their pain, disability, and fatigue, they still go to work, raise their children, care for elderly parents, maintain relationships with friends and spouses, and for the sake of emotional and physical health continue to participate in hobbies and exercise.

Sharing the challenges—and triumphs—of living with arthritis can help empower others with the disease, so Arthritis Consumer Experts (ACE) asked people to submit their story of living with arthritis.

*Courage is to feel the daily daggers of relentless steel and keep on living.*  
~Douglas Malloch

Linda  
Olbort,  
Saskatoon  
SK

It was a warm, sunny day when I dove into the bottom of a swimming pool and snapped both my wrists back. It didn't really hurt, just kind of stunned me that I was that close to the bottom. I was six years old. Six months later, I was in the hospital getting all kinds of tests each day so the doctors could find out what was causing the mysterious swelling on my hands and ankles. The first time they came at me with a needle, I ran as fast as I could from them. It took seven nurses holding me down to take my blood.

While my family and I waited for a diagnosis, the swelling rapidly progressed to the point I could no longer walk. Finally, after a month and a half, the doctors determined I had juvenile rheumatoid arthritis (also known as juvenile idiopathic arthritis). Aspirin and oral gold were my main treatments, which made me dizzy most of the time. I endured the teasing of bullies because of the visible joint damage, but I got their respect when it came to artwork. I was put in a special class because the regular class wasn't challenging.

The disease raged until I was eleven and then went into remission. In my twenties, I had a heavy lifting factory job in the early daytime and a confectionery job at nights and weekends. I was earning money and feeling good. I took karate every night I could.

Then one day, my fingers started to hurt. At first, I thought I had sprained them, but then my shoulders and knees started to hurt. I went to see my family doctor and one blood test confirmed it: I had full blown rheumatoid arthritis (RA). My life as I knew it was over at age twenty-four. My doctor quickly referred me to a specialist.

[bit.ly/ArthritisStories](http://bit.ly/ArthritisStories)

Some of the stories did not fit within a single JoinHealth™ monthly, so we have made them available online. To read Linda's full story, along with more stories, please visit: [bit.ly/ArthritisStories](http://bit.ly/ArthritisStories)



Linda in Hawaii



read  
more...

  
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**Fran  
Halter,  
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QC**

**At age 23, life was good:** I was recently married with a rewarding career as a radio journalist and an exciting life. So when I developed a sharp pain in my upper left leg and it began to radiate downward, the medical diagnosis from my family GP was sciatica and bed rest. Little did I know that this was just the beginning of a medical journey that would nearly destroy my marriage, change my career, and put me on a path of countless medical appointments over the next dozen years as I sought relief and answers for my pain.

The initial pain intensified and traveled from my left leg down to my toes, then ping-ponged from one side to the other. My family urged me to find a solution to the GP's diagnosis, which was revised to a "non-specific lower back issue", likely a compressed disc. I walked with a distinct limp when the pain was acute, I slept with a heating pad, I wore a brace that wrapped around my middle for extra lumbar support, and I lived on acetaminophen (Tylenol®).

In the pre-Google age, the available research on spinal issues was limited, even though I lived in a large Canadian city. So my quest for information led me to consultations with dozens of medical specialists:



back care doctors, neurologists, orthopedic surgeons, physiotherapists, radiologists, sport medicine doctors, rehabilitation services, and yes, even a psychiatrist. Perhaps the pain was really just in my head? Twice I was hospitalized and received cortisone shots in my lower spine and twice, I left the treatment room still in unrelenting pain.

Like so many who live with arthritis, I soldiered along. I learned to live with the pain, but there were countless nights when sleeping in an easy chair was the only way to get temporary relief and countless days when the pain would hit without warning in a stabbing attack that lasted for days. There were no big strategies for coping, just the will to keep going, discover the source of the pain, and get relief.

I was almost 30 years old when a prominent back care specialist told me: "a pregnancy will cripple you." I decided that option was preferable to remaining childless. During my pregnancy, for the first time in seven years, I was almost pain-free. Four months after the birth of my daughter, the pain returned. A year later, I was pregnant again and the pain disappeared. Again, only a few months after the birth of my son, the pain came back – with a vengeance. Neither my husband nor I had family nearby, so paid help was our only alternative. A full-time nanny and a cleaning lady provided the much-needed support on days when my parenting abilities were curtailed. I left my full-time job in journalism and began a freelance career working out of the house with a more manageable and downsized career, and less stress.

The cycle of pain – and then no pain – was mentally and physically debilitating with its highs and lows, and the unexplained suddenness

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**Bonnie  
McClung,  
Ontario**

**Bonnie was first diagnosed with psoriatic arthritis** at the age of thirty-four and has been living with the disease for thirteen years. Early on, her family doctor ordered a blood test, which showed no rheumatoid arthritis, so the possibility of another type of arthritis was not considered. Bonnie, however, with swollen toes and knee pain was sure she had arthritis. Frustrated by knowing that she needed treatment, but was being denied access to it, she asked her dermatologist to insist the family doctor provide a referral to a rheumatologist. The rheumatologist told Bonnie she had arthritis in every joint in her body.

After a year long process, it was a relief to finally have a diagnosis, but she also found the news depressing. Because there is no cure, she knew she would be living with the disease for the rest of her life. Knowing that it could debilitate her and take away some of the small pleasures of her life, she shut down a little. After being told that exercise was hard on her knees, she stopped. She gained weight, but that made her arthritis worse. It took her four years to come out of that, and start exercising again. She began by walking, and walking, and walking some more. She lost 35 pounds and was feeling good about herself again.

During this time, she was put on arthritis medications and started taking dietary supplements. The medications helped her get back



*Bonnie after finishing the Disney Marathon.*

with which an episode would begin. One day at a client's office, I was faced with the prospect of climbing a steep flight of stairs, which had become a challenge. My client offered me the name of yet another physiotherapist as a possible solution to my back "problem". After working with this practitioner for many weeks without any improvement, she recognized that her treatments were not alleviating my situation. She wisely recommended that I seek an opinion from a rheumatologist (the one medical specialty I had not yet seen). I had been suffering for nearly 12 years; I went with low expectations as I had nothing to lose and everything to gain.

The rheumatologist listened to my tale of despair and sent me for a single x-ray of my lower pelvis, the first time that any medical doctor had requested this image. He told me to "wait for the result and bring it back to me." In less than an hour, he confirmed his initial diagnosis: ankylosing spondylitis (AS). You could have blown me away with a feather! Typically AS is found in males with onset usually in one's early 20s; I was female and the disease had raged – uncontrolled – for nearly 12 years, which gave it ample opportunity to eat away at my sacroiliac joints and ligaments. He gave me literature to read and a prescription for an anti-inflammatory medication. He asked that I return in a few weeks to report on my progress, which he reassured me would be infinitely better. The diagnosis (and anti-inflammatories) provided more than relief: there was a label for my pain and it was not "crazy". And most importantly, there was a real solution.

In the 20 years since that day, with careful medical monitoring and a treatment plan, the episodic pain has gradually ebbed and faded from

**Biologics, also known as biologic response modifiers, are arthritis medications that treat symptoms and the underlying disease process in inflammatory forms of arthritis, such as rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis.**

the forefront of my daily life. At age 55, nonsteroidal anti-inflammatory medications have stabilized me and I no longer watch life unfold from the sidelines. My AS is in remission, but I am aware that as I age I must take care to always be on the lookout for other symptoms of this disease. I monitor my food to see if anything in particular sparks an "attack" (it doesn't), I never wear heels (well, almost never), I try to get eight hours of sleep each night (five nights out of seven) and I watch my posture (no shoulder slouching for me).

I don't consider myself a hero. I walk the dog every day, although a flare up in recurrent plantar fasciitis, linked to my AS, slows me down occasionally. I travel, but still bring along a heating pad – just in case. I'm looking forward to the start of a yoga class to ensure that I remain flexible over time. I pray that my grown children dodge the genetic bullet and the destruction to body and soul that undiagnosed AS creates in its wake. I take my anti-inflammatory medications religiously and have added a herbal supplement (with my doc's blessing) to the mix to combat inflammation. I know that in the future I will likely need to migrate to the new array of biologic treatments to fight the disease. Mine is not a hero-like existence, but I am back to the business of enjoying life. ◀

into exercise. Though she wishes she did not have to take medications – she hates the constant blood tests to make sure there is no kidney damage – they keep her mobile. Physiotherapy and acupuncture also help, and yoga has been improving her flexibility.

When she lost the weight, she decided to do something bigger to fight arthritis . . . on a bigger scale than her personal fight. She started fundraising for arthritis by running. First she completed the half-marathon at Disney World, which she loved so much it spurred her to do more. She did a full marathon in Athens, Greece and then the Goofy Challenge at Disney World (a two day event with the first day being a half-marathon and the following day a full-marathon). What's next for her? She has registered for a five day cycling event in Provence to raise more money for arthritis. Bonnie is very proud of herself, with good reason.

She takes one day at a time. Some days are worse than others. Bonnie walks her dog every day, which helps take most of the stiffness out of her joints in the morning. Until a few months ago she had two dogs but her older dog, Honey, died. Honey also had arthritis, and though she could not go very far in her final six months, she was always excited to go for walks. Bonnie misses Honey every day: "She was my arthritis hero. It didn't matter how much she hurt, she never lost her sweet disposition." ◀



Bonnie with her dogs.

*I think a hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles  
~ Christopher Reeve*

Would you like to share your story?  
Please feel free to post something at [www.facebook.com/ACEJointHealth](http://www.facebook.com/ACEJointHealth) or [www.facebook.com/ArthritisIsCured](http://www.facebook.com/ArthritisIsCured), send us an email at [feedback@jointhealth.org](mailto:feedback@jointhealth.org) or write to: JointHealth™ monthly  
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## Arthritis Consumer Experts

### Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit [www.jointhehealth.org](http://www.jointhehealth.org)

### Guiding principles and acknowledgement

#### Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a

practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities, and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and healthcare providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.

### Thanks

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ACE thanks these private and public organizations and individuals.

### Disclaimer

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