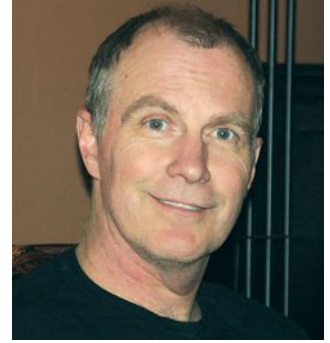


Dr. Shane Inlow Looks at Chronic Disease from the Inside



Dr. Shane Inlow:
"I have always been diligent
about managing my disease."

Dr. Shane Inlow was a practicing physician and is a past medical director of the Geriatric and High Risk Foot Clinic in Calgary and a founding member of the CAWC. He spoke recently with Heather Orsted, RN, director of the CAWC Institute of Wound Management and Prevention and a clinical and educational consultant, about living with multiple sclerosis.

Q When did you first discover you had multiple sclerosis (MS)?

I was first diagnosed with multiple sclerosis in 1986, back in the days before MRI. My main symptom was that I was losing my co-ordination. As an athletic person, I noticed that I was not serving well in tennis and was falling while skiing—things that had come naturally to me before. I had a numb patch on my left chest and I had ringing in my ears.

At that time I had been in my medical practice for six years, married for 12 years and my kids were one, three and six years of age.

Q What was your reaction when you heard the diagnosis?

It was devastating, because I knew the wheels were going to fall off my future. My biggest concern was that I had just spent 11 years getting my MD and I had only practiced for six years. I refused to quit practicing medicine, as I wanted to use my medical training as much as I could.

Q What lifestyle changes did you make in the first five years?

I had to retire from certain areas of clinical practice, such as obstetrics and performing minor surgical procedures. Then, in 1987, an opportunity was presented to me to become medical director of a foot and wound care clinic. This met my criteria, in that I did not have to do any manual work due to the availability of highly trained staff in the clinic.

The biggest problem in the early years was non-stop fatigue, which was manageable initially because the clinic was only two days a week. As the clinic became more successful, the demands on me increased. Although work gave me a sense of purpose, academic stimulation and interpersonal interaction, it was taking a toll on my personal life, leaving me exhausted not only after work but for days later, with my family bearing much of these problems.

As time passed, having MS required an explanation to my

patients in the clinic. Some had expressed concerns to staff regarding my staggering gait and slurred speech, thinking I was drunk. Writing skills were a challenge and charting became increasingly difficult. I started using a cane to help others identify my disability.

I really missed sports, but found there was one that I could still play and so I took up golf. I managed to play for more than 10 years.

Q What have the last 10 years been like?

Due to increasing fatigue, I have had to completely retire from practice. I have always been in a slow decline, with primary progressive disease for the first 15 years and secondary progressive disease for the last 10 years. Walking became increasingly difficult, so I used a scooter for long "walks" and outdoor activities. Five years ago I progressed to a full-time wheelchair. I remain independent with my personal care but need support

with every other aspect of my life, including travelling, cooking, shopping and housework.

Socially, I spend more time in my home than outside my home. I get to the gym often, which is located close to my house, to exercise and swim. I rely on family and friends for most of my social life, as I get too tired in the evenings to go out.

The fatigue tends to be the most difficult complication and wears on your ability to control your emotions. Unfortunately, family and friends have often been the recipients of raw emotions that I was no longer able to buffer.

Q What are your complications related to MS?

With decreased sensation and mobility, I have found out how vulnerable I really am. A minor bang on my shin led to months of monitoring and wound management, and if I did not know what I was doing I would really get into trouble. I get onto treating injuries right away, no matter

how minor. My risk for pressure ulcers is scary—fortunately, pain sensation in my butt is still relatively intact and I get off my butt when I feel significant discomfort. But it really lets me know how difficult it must be for people who don't have sensation to get things done. I find I can't even sit on my butt for an hour without feeling discomfort. However, if I am up too long, I pay for it for days afterward.

My feet are neuropathic and I wore a new pair of shoes to the gym that I thought fit well. I did not realize how stiff the lateral aspect of the shoe was and after 10 minutes I had trauma that caused my leg to be black and blue from my knee to my toes for a month.

I have recurring painful neuropathy of my left leg so, like a person with diabetes, I need to manage my neuropathy. I have tried all sorts of drugs and treatments, but it seems a warm bath or several minutes on a Whole Body Vibration machine (www.wbv-md.ca) help more than anything.

My autonomic neuropathy has also led to really cold feet. I use an electric heating pad that has low voltage and a restricted heat limit. I know this is a risk, but when my feet are cold my whole body spasms, including my bladder, and I can't sleep.

How do you manage your MS?

I have always been diligent about managing my disease—from exercise, diet, drugs and lifestyle changes to managing stress, fatigue and anxiety. I have kept on top of the research and think I have managed my disease well, in part because I am a medical doctor.

I am aware of the impact of controlling my body, my lifestyle and my environment.

I frequently get calls from others who have just been newly diagnosed with MS. I feel I have helped them just by talking to them about the basics of managing the disease. I find most people with MS try and ignore it and hope it goes away—I am pretty certain it will not! Living with, not fighting against MS—in my opinion—is the key.

What do you think your future holds?

Well, I guess that is part of the management of the disease. I try not to think too far into the future, because that might affect my ability to stay strong and do as much as I can in the present. The big problem is depression when you think of long-term consequences. I try to think in days and weeks, instead of months and years. If I thought that in 10 years I might be in a nursing home, that might depress me and prevent me from being as active as I try to be. My biggest challenge is getting through the day—I need to be very flexible with what I do in a day based on what is happening with my body and my mind.

I know the stats and know the prognosis for people with a disease like mine, and I don't focus on them because I know I am doing a better job managing my MS in part because of my medical knowledge.

I am also reassured by new research in the field of MS that gives me hope. Chronic cerebral spinal vascular insufficiency has been shown to be present in

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many people with MS and the treatment for it is a simple balloon angioplasty. Unfortunately, it is currently only available in Phase II trials in Europe.

What would you like to share with healthcare professionals to help them better help their patients with chronic diseases?

I think, first of all, focusing on the entire living process rather than just on drug therapies. Many doctors think that if there is not a drug available for a particular disease then there is nothing they can do to help you. And I would have been one of them—but I think differently now.

Recognize the importance of exercise, nutrition and lifestyle management for any chronic disease. Embrace alternative medicine as an option, because it may make your patients feel better and that may be all that matters. Unfortunately it is often dismissed by medical practitioners. Listen to and try to embrace total care, putting aside the limited current treatments. Know local medical assistance within the community, such as AADL [the Alberta Aids to Daily Living program], home care and even disability tax programs. Encourage spousal support programs, as the strain to the able-bodied spouse needs TLC. All these little things can make a huge difference in the management of chronic diseases. 🙌