

# Weighing the risks and benefits of drug tapering—two patients, two perspectives

June 20 2018, by Nancy Whelan

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Rheumatoid arthritis (RA) is a chronic autoimmune disease that causes fatigue, joint pain and swelling, and can have long-term, devastating effects. Fortunately, treatment for rheumatoid arthritis has advanced, and most patients can now control their disease with medications.

The usual practice is to continue with these medications for life, but emerging evidence suggests some patients may be able to reduce their [medication](#) once their [disease](#) has been under control for some time. But before treatment guidelines can change, more research needs to be done on the risks and benefits of reducing medication; otherwise known as drug tapering.

Dr. Glen Hazlewood, MD, Ph.D., a rheumatologist and a member of the Cumming School of Medicine's McCaig Institute for Bone and Joint Health, has received funding from the Canadian Institutes of Health Research to evaluate the safety and effectiveness of a patient-centred approach to treatment reduction in patients with RA.

"When a patient has been doing really well with their treatment, they often ask their rheumatologist, 'When can I stop or reduce my medication?'," says Hazlewood. "It's very rare that people can stop treatment completely, but we think that many may be able to successfully reduce their medications."

Hazlewood and a colleague from the University of Toronto, Dr. Vivian Bykerk, MD, have designed a trial with 200 patients who are part of a

larger national study that follows patients with RA. They will identify patients whose disease has been well controlled for at least six months, and ask if they would like to participate.

Interested patients will be randomized to either continue with their usual care or start a structured but flexible approach to reduce (not stop) treatment, in a shared decision with their physician. Patients will be followed for 18 months and the benefits and harms will be compared.

A unique aspect of the study is that researchers will also measure patient preferences for the benefits and harms of reducing treatment. "No two patients are the same; they have different experiences with their disease," says Hazlewood. "Some may not want to reduce their medications because they don't want to risk a flare-up. For other patients, the benefits may outweigh the risks."

Before embarking on the study's design, Hazlewood sought the guidance of RA patients Laurie Proulx and Dawn Richards. Both members of the Canadian Arthritis Patient Alliance, a national grassroots organization that advocates for people with arthritis, they represent very different views on the topic of drug tapering.

## **Laurie's story**

Proulx was diagnosed with juvenile idiopathic arthritis/[rheumatoid arthritis](#) when she was 14 years old. Since then, her world has consisted of doctor's appointments, surgeries and medications.

For seven years she took increasing doses of methotrexate, a powerful drug also used to treat cancer, in an attempt to get her disease under control. The drug was moderately effective but the side effects, mainly nausea, were unpleasant. During that time, the arthritis ravaged her joints and caused breathing and cardiovascular issues. "Things weren't

looking so good for me," she says.

But then things changed. When she was 21, Proulx was one of the first Canadians to access a new class of drugs called biologics. "For the first time, my disease was under control," she says. For her, the thought of reducing her medication is scary.

"Because it took so long to get my disease under control, and because I have a life-threatening complication of the disease (airway issues), I would say that I would not consider it or proceed with extreme caution."

## **Dawn's story**

"As a person who has lived with rheumatoid arthritis for over a decade, I can tell you that the one thing a patient wishes for on a daily basis is simply to no longer be a patient," says Richards. She was diagnosed with RA 12 years ago. Once she became clinically stable and reached a state of remission (based on criteria that her rheumatologist measured), she began considering reducing her medication.

Richards advocates for patients to be given the opportunity to take control of their disease treatment, and wants to make decisions based on her own preferences and desires. Through her own experiences, and in consultation with her rheumatologist, Richards has chosen to take significantly less medication than when she was first diagnosed.

"I now have one to two days per week that I call my RA 'drug holidays.' These are days that are blissfully medication free," she says. "It's as close to not having [arthritis](#) as I will ever be."

**The goal: Informing treatment decisions with the individual always in mind**

This four-year study will try to measure everyone's different perspectives, while simultaneously looking at the effectiveness of drug tapering. "We first want to make sure that reducing medication is safe and effective," says Hazlewood. "But beyond this, we want to understand patient preferences for the risk and benefit trade-offs. Hopefully, this will help provide guidance in terms of how rheumatologists can best advise their [patients](#) to choose the [treatment](#) that's best for them."

Provided by University of Calgary

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