Living with Chronic Pain: Tips for Patients by Patients

One unintended consequence of the opioid crisis has been the neglect of the needs of people living with chronic pain. People who live with chronic pain often rely on opioids, along with other forms of treatment, to manage their quality of life and to allow them to contribute to society.

The Canadian Arthritis Patient Alliance (CAPA) is a grassroots, patient-driven, not for profit organization of people who live with arthritis. CAPA uses the power of information, research, and communication to help people living with arthritis find their voice and support others. CAPA developed this document based on the results of an online survey hosted in 2018. The survey aimed to understand the unintended consequences of opioid policy, directly from people living with chronic pain. Based on the survey results, we’ve created tips for people who live with chronic pain and resources to help you.

A Summary of the Survey

- 264 responses
- 92% Canada, 8% International
- Most respondents were diagnosed over 10 years ago
- 75% of respondents have taken or take an opioid medication for pain
- Most respondents (88%) were female
- 30% of respondents have been taking an opioid for >10 years
- Most respondents (75%) were between 40-69 years old (22% 40-49 years; 29% 50-59 years; 23% 60-69 years)
- 30% of respondents live with rheumatoid arthritis, 42% of respondents live with osteoarthritis

What People With Chronic Pain Told Us

- 11% of respondents are no longer on opioids.
- Over half (53%) of respondents’ doctors had talked to them about or tapered their opioid medication.
- Just over two thirds (69%) said that tapering or stopping their opioid medication affected their pain:

  - “Tapering does not necessarily help manage my pain. It does help me feel clearer overall, more clear minded.”
  - “If I do not take an opioid at night to take the edge off the pain, I can’t sleep which just makes my pain worse. It is an endless cycle.”
  - “My overall daily pain has increased.”
Find a pain clinic (if possible). These clinics often have many different types of healthcare providers including pain specialists and many types of approaches to treating pain. Wait times for these clinics may be long and you may need to advocate for a referral.

Develop a relationship with one healthcare provider and ask for advice. This person might be a pharmacist, your family doctor, or a specialist. By developing this relationship, this healthcare provider will know you and your needs better than others.

Make a plan so you feel in better control. Experiencing pain often makes you feel out of control, while coming up with your plan and approach to dealing with your pain can empower you.

Use your opioid pain medication only when you need it, try changing your medication, or changing the dose of your medications. Talk to your healthcare provider if you are considering changing medications or would like to reduce or get off opioids.

You may wish to consider mindfulness, physiotherapy, medical cannabis, and other therapies to help you. You may need to try different treatments to see which one(s) work best for you.

Do your own research and advocate for yourself. Make sure that you seek evidence-based resources to help you, for example, those from or associated with a credible organization such as an academic centre. Use this knowledge to help communicate your needs to your healthcare providers.

Tips from People who Live with Chronic Pain

Dealing with Barriers

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Coping with Stigma

- Don’t share information about opioids or other pain medications outside of close family/friends.

- Don’t be concerned with others’ perceptions.

- Read trustworthy references and materials.

- Provide your insights to government initiatives and committees.

- Volunteer for advocacy or support groups to feel a sense of control.

- If you take opioids for your chronic pain, you might wish to try a different medication.
Evidence-based, Free Resources

These are credible, free Canadian resources to help you cope with and manage your pain. This is not an exhaustive list and you may also want to ask your healthcare provider for other resources.

- **Arthritis Consumer Experts.** Arthritis Consumer Experts is a national organization that provides free, science-based information and education programs in both official languages to people with arthritis. The ‘Pain of Arthritis’ JointHealth™ insight highlights what causes arthritis pain and provides tips on pain management.

- **The Arthritis Society.** The Arthritis Society is a national health charity, fueled by donors and volunteers, with a vision to live in a world where people are free from the devastating effects that arthritis has on lives. The Arthritis Society has resources on Pain Management (this links to different resources on their site) and a Managing Chronic Pain Online Module.

- **Canadian Agency for Drugs and Technologies in Health.** Called CADTH for short, this is an independent, not-for-profit organization responsible for providing health care decision-makers with evidence to help make informed decisions about the optimal use of health technologies, including: drugs, diagnostic tests, and medical, dental, and surgical devices and procedures. This link is for their pain resources.

- **Canadian Spondylitis Association.** The Canadian Spondylitis Association is a national, non-profit, patient association that supports and advocates for those suffering from spondyloarthritis diseases. Their resource page has information about non-drug approaches to deal with pain.

- **National Pain Centre: 2017 Canadian Guidelines for Chronic Non-Cancer Pain.** These are the most up to date Canadian guidelines for opioids for chronic non-cancer pain. Clinical and medical experts and people who live with chronic pain were part of the guideline development.

- **PainBC resources.** PainBC is a not for profit organization that works with and for health professionals and people who live with pain to better support, educate, and empower people who live with pain.

- **Dr. Andrea Furlan’s YouTube channel.** Dr. Furlan is an Assistant Professor in the Department of Medicine at the University of Toronto, staff physician and scientist at the Toronto Rehabilitation Institute, and Associate Scientist at the Institute for Work & Health.

- **Living Engaged and Actively with Pain (LEAP) YouTube Channel.** LEAP is a team of occupational therapists and physiotherapists in the Brain and Spinal Cord Rehab Program and Toronto Rehab, University Health Network.

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*This resource has been reviewed by a medical expert, Dr. Norm Buckley, BA (Psych), MD, FRCPC (Professor Emeritus, Department of Anesthesia Michael G DeGroote School of Medicine, McMaster University) for general purposes. Please consult your doctor about your specific situation.*