

## Background

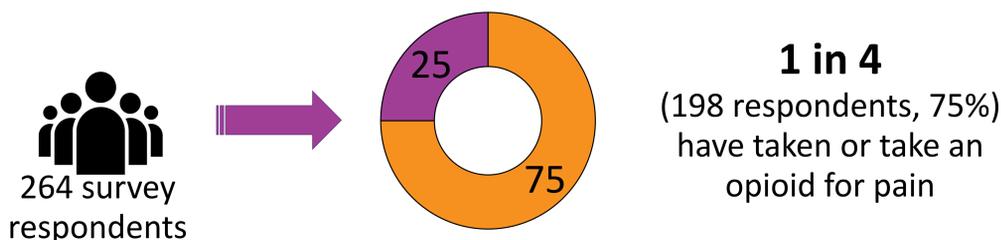
- The Canadian Arthritis Patient Alliance is a grass-roots, patient-driven, independent, national organization that advocates for people living with arthritis on a range of health care and other policy issues
- A key component of CAPA's mandate is to support people living with arthritis through education and awareness
- People living with pain reported additional stigma and challenges accessing treatments due to the government response to the opioid crisis
- CAPA has developed a number of evidence-based resources and we believed there was a need for information for both patients and policy makers
- Patient-centred educational resources and social support are needed to live with the day-to-day realities of arthritis and may also improve the dialogue with primary care, rheumatologists and allied health care professionals.

## Methods

- Unmet patient needs are identified through the lived experiences of CAPA Board members and members at large
- Typically, surveys are developed to further examine the topic
- Results are then analyzed and a resource is developed to meet the needs of individuals living with arthritis and promoted through CAPA newsletters, social media and partner networks
- Survey results are then analyzed and prioritized for content
- The CAPA board worked in partnership with a leading pain specialist to review the resource and ensure it reflects the most current, evidence-based knowledge
- The final educational resources were made available in both English and French

## Results & Discussion

- CAPA heard from our patient networks that there were unintended consequences for chronic pain patients as a result of policies being implemented in response to the opioid crisis
- We communicated our concerns to Health Canada at a number of levels and conducted a survey of our patient network on the impact of changing opioid policy on their lives



- The resource developed from our survey is **for patients and policy makers from the real world experience of patients.**

### Living with Chronic Pain: Tips for Patients by Patients

This resource and one for policymakers can be found at: <http://arthritispatient.ca/living-with-chronic-pain-resources/>

**CAPA Canadian Arthritis Patient Alliance**

**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."

**Tips from People who Live with Chronic Pain**

**Dealing with Barriers**

- 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.

**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.

## Conclusion

- CAPA developed this educational resource to help support patients when they are making the decision whether to take an opioid medication for their pain and to help policy makers better understand the needs of people living with pain
- The use of educational resources increases patient knowledge and management of their condition
- It also encourages effective dialogue with primary care physicians, rheumatologists and allied healthcare professionals which can lead to better decision-making and reduce stress for people living with arthritis and their families

## Acknowledgements

- CAPA acknowledges industry for ongoing support of its operations
- We also acknowledge Dr. Norm Buckley for reviewing materials for this project for medical accuracy