

2026

# Broken Chains: Drug Supply Disruptions Impact Patient Lives



# Introduction

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People living with arthritis have experienced significant challenges due to drug shortages since 2017. The COVID-19 pandemic compounded the existing drug supply system challenges – in the early stages of the pandemic, the arthritis community was among the first to be affected by shortages. Hydroxychloroquine, commonly used to treat autoimmune arthritis such as systemic lupus erythematosus and rheumatoid arthritis, became scarce after it was speculated to help treat COVID-19. Later in the pandemic, tocilizumab (Actemra), which is another drug used to treat inflammatory arthritis, was shown to benefit people with severe COVID-19. This resulted in many people taking tocilizumab having to switch from the infusion to self-injectable forms to maintain access to treatment.

Disruptions in the supply of medications continue to occur. People living with arthritis have been affected by shortages of pain-relieving medications, such as [acetaminophen with codeine or oxycodone](#), as these medications are used to treat various types of pain associated with conditions such as inflammatory arthritis and osteoarthritis. In the most extreme situations, Health Canada has allowed the importation of medications from outside of Canada to ensure an adequate drug supply; one example of this was abatacept (Orencia) in 2024. This medication is used to manage different types of arthritis, including rheumatoid arthritis, juvenile idiopathic arthritis, and psoriatic arthritis.

People living with disabilities and chronic illnesses, like arthritis, are often the first to feel the effects of these shortages. As a result, the Board of Directors of the Canadian Arthritis Patient Alliance (CAPA) identified drug supply issues as a top priority. As global trade tensions, tariffs, and industrial policy shifts continue to dominate headlines, our community and many others remain vulnerable to these systemic challenges.

This report summarizes experiences of people living with arthritis and caregivers in Canada related to medication supply disruptions. It offers recommendations to improve communication, continuity of care, and system accountability. We use the terms “patients” and “people with arthritis” interchangeably, and include caregivers and people who support someone living with arthritis.

# Project Approach

From June to December 2025, CAPA conducted interviews with people living with arthritis and caregivers to understand how they learned about medication disruptions, how they responded, what support they received, and what information would help them manage future shortages.

Interview participants represent diverse perspectives from Ontario, Quebec, and Western, and Atlantic Canada. Those interviewed came from various cultural and linguistic backgrounds and disease experiences, such as rheumatoid and juvenile idiopathic arthritis. These interviews have shown that shortages have affected multiple drug classes, including:

- Analgesics and pain management medications such as opioids (Percocet, Tylenol 3) and hydromorphone
- Disease-modifying antirheumatic drugs (DMARDs) like methotrexate, sulfasalazine, leflunomide and hydroxychloroquine have also been impacted
- Biologics and biosimilars, including etanercept (Enbrel) and abatacept (Orencia)
- Adjunct therapies such as cholestyramine and JAK inhibitors, and over-the-counter medications, such as muscle relaxants and acetaminophen.

Insights from these interviews will inform the development of educational resources to help patients better understand how to mitigate the effects of shortages, both when they happen and before they occur.

This following section summarizes the key themes that emerged from the interviews with people living with arthritis.

# 1 Uncertainty and Stress Associated with Drug Shortages

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“I remember the powerless feeling that it brought to me... The dismissiveness of it all was so difficult to manage. Sometimes I think they (healthcare providers) forget that we are real people counting on these medications to function.”

When medications become unavailable, patients describe profound disruptions to their physical and mental well-being, impacting their daily lives. Many only discover shortages at the pharmacy counter or when medication deliveries fail, leaving them scrambling for solutions. One participant noted how they had to call fifteen pharmacies to find the medication they needed. Another highlighted how they had issues with receiving a medication delivery at home and a situation when the medication was not delivered at the required temperature, resulting in spoilage.

The uncertainty surrounding these situations creates emotional distress, including feelings of anxiety and helplessness. Practical challenges such as rationing doses, stockpiling, or travelling to multiple pharmacies were reported. These shortages can often have cascading effects, including interference with work, mental health, independence and mobility challenges, issues with sleep, delays with vaccinations and lower overall quality of life. Difficulties also extend to caregivers or others who support those living with arthritis. In some interactions, healthcare providers were dismissive of the person's concerns about the shortage.



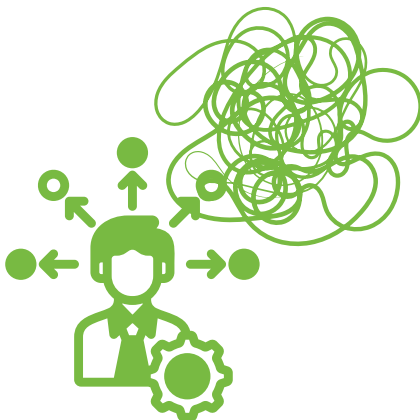
**Policy/System Barrier:** There is no proactive communication or coordinated response between pharmacies and prescribers, forcing patients to self-advocate.

# 2 Drug Shortages Cause Long-Term Behavioural Changes

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“Fool me once, shame on you - fool me twice, shame on me.”

Reflecting on their experiences, many patients reported that supply interruptions have a significant impact on how they manage their personal supply of medications. Some people reported the fear it caused led them to create their own stockpile of medication, while others skipped doses to keep an adequate supply on hand “just in case.” Additional stress surrounds this behaviour because it takes people a long time to find a medication or combination of medications that works, and that efficacy is limited because no combination of medications works for a lifetime. Finding the right combination always brings a certain precarity to life, which is put at risk when a shortage happens.



**Policy/System Barrier:** Drug shortages can create a feedback loop of anxiety and mistrust of systems. Additionally, they can cause systemic and psychological responses to uncertainty based on a lack of timely access to information, which can force patients to self-manage.

# 3 Bridging the Gap: Inconsistent Support in Dealing with the Drug Shortage

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“We feel like a burden, but we can’t help it. I feel like a burden to my doctors, but I can’t change what I need. It’s my job to advocate for the best thing I require to live life well with the years I have.”

Participants described inconsistent experiences when seeking support during a shortage. In some cases, physicians were proactive and went above and beyond, quickly identifying alternative medications, adjusting prescriptions, and staying closely involved to help patients maintain their treatment. In other situations, however, patients were left to manage the crisis on their own, navigating pharmacies, substitutions, and insurance issues without meaningful guidance. This variation highlights a gap in coordinated care and communication between physicians, pharmacists, and Patient Support Programs.

*“I contacted my rheumatologist and the secretary at the office said, ‘Well what do you want me to do?’ **I was not given any options of other medications.**”*

*“**What happens to people who don’t have someone to support them through this?** Would they just be waiting in the pharmacy while in immense pain – I would hate for my mom to be stuck in a situation like this on her own.”*

# 4

## Switching to Alternative Medications Is Difficult and Sometimes Not Possible



*“I’ve had a lot of health trauma because I’ve had no choice but to speak up. My spouse often picks up my medication because I can be bed-bound.”*



Finding the right combination of medications is already a long and difficult process for arthritis patients. When shortages occur, switching to an alternative is often not clinically recommended or possible due to a variety of factors. For some individuals, clinical options may be limited or unsafe, e.g. contraindications or allergies.

During recent opioid shortages, some patients were forced to try alternative medications, restarting the difficult trial-and-error process to find something that offered equivalent relief. Others made the difficult decision to taper themselves off opioids entirely because no suitable alternative was available. For many, this caused unnecessary suffering, disruption to daily life, loss of and increased anxiety about their future stability.

Several people also described the stigma they experienced when trying to fill prescriptions during shortages. Calling multiple pharmacies to locate medication often led to suspicion or added scrutiny, even when the individual had taken the medication safely and appropriately for years.



**Policy/System Barrier:** People who use pain medications face persistent stigma. They are often treated with suspicion, seen as potential ‘drug seekers’, regardless of their medical history, stability, or years of appropriate use. This stigma becomes even more acute during shortages, when people must advocate for themselves more frequently and may seem/sound more desperate to acquire the medication.

# 5

## Coordinated and Honest Communication During Drug Shortages

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*“This is a world of able-bodied people who don’t know how it is to depend on medication to survive or thrive. All human beings are allowed to thrive; people don’t understand the context and impacts of their miscommunication.”*

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Communication around shortages is typically reactive and inconsistent. Arthritis patients want clear, timely updates from pharmacies, prescribers, and manufacturers, but often rely on social media, traditional media, or peer networks for information. Existing tools, such as the [Drug Shortages Canada website](#), that healthcare providers rely on, are poorly publicized, underused, and delays may cause dates to fluctuate.

Communication and advice provided by Patient Support Programs vary widely, leaving gaps in communication to people with arthritis. One interviewee living in a rural area said that they travelled 30 minutes to their local pharmacy only to be told upon arrival that there was a shortage of their medication.

Patients consistently emphasized the importance of honesty in communication. They said they would rather be informed well in advance about a potential shortage, even if it never happens, than be caught off guard once the shortage occurs: *“I was told: ‘We don’t know about next month’. It’s not knowing that is challenging.”*



**Policy/System Barrier:** Fragmented communication and a lack of standardized protocols for notifying patients create confusion and mistrust.

# 6

## Lack of Monitoring and Reporting Drug Shortages to People with Arthritis

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*“It has to go to this person, this person, this person... like nine different organizations before it can hit the market.”*

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Currently, there is no standardized mechanism for people with arthritis to report shortages they experience. Existing systems focus on manufacturers and distributors rather than patient experiences, despite patients being the first to be impacted. People living with arthritis bear the most significant impact of the supply interruptions with direct impacts on their health, mobility, mental health, stress, and more. Some people with arthritis suggested a traffic-light system (green/yellow/red) to indicate supply status and the expected duration of shortage to help with planning. Incorporating community-reported data into policy-making and responses could improve real-time monitoring and resource allocation.



**Policy/System Barrier:** Complex regulatory approval processes delay responses and prevent timely updates to people with arthritis.

# 7 Compounded Challenges: Drug Shortages and Policy Constraints

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*"Patients shouldn't carry the burden of continuity. Systems need to step up."*

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Supply interruptions do not occur in isolation; they intersect with other healthcare policies, creating compounded challenges for patients. For example, opioid tapering mandates and biosimilar switching policies coincided to create a situation where people were experiencing both policies simultaneously along with a shortage. This created significant stress for people living with arthritis.

Arthritis patients taking opioid medications that were in a shortage situation faced heightened vulnerability when effective alternative therapies are scarce or non-existent. Given the scrutiny around opioid dispensing and regulations around controlled substances, this meant that patients faced additional scrutiny and stigma when calling around to different pharmacies to find a supply of their opioid medications.

Inflexible insurance and reimbursement policies made switching to alternative medications difficult. Some arthritis patients reported that they had difficulties in accessing alternative medications because of lengthy prior authorization processes. Strict 30-day dispensing limits and prior authorization requirements prevent arthritis patients from maintaining emergency reserves, forcing repeated pharmacy visits and increasing anxiety during shortages. One person insured under Blue Cross illustrates this barrier: despite managing rheumatoid arthritis and fibromyalgia as a chronic condition, they could not access more than a 30-day supply of critical medications. Some insurers offer patients the opportunity to access up to a 3 month supply of a medication for maintenance medications.

These systemic constraints influence the behaviour of people with arthritis. Fear of future shortages drives stress, rationing, stockpiling, and guilt, which, while understandable, can impact current symptom management and result in inequitable access. Arthritis patients emphasized the need for clear guidance on safe coping strategies and systemic solutions, such as allowing emergency reserves for high-risk medications, to reduce the burden on patients. Many people noted that they experience stress and guilt from rationing medications, and reported not communicating this rationing to their rheumatologist or other healthcare providers for fear of judgment.



**Policy/System Barrier:** Rigid insurance policies and overlapping mandates compound the impact of shortages, leaving patients with limited options and heightened stress.

# What do Arthritis Patients Want to Know about Drug Shortages?

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People with arthritis need resources that explain why shortages occur and what steps they can take. Interviewees noted that these resources should include coping strategies for maintaining a sufficient supply of medications, advice on alternatives, and tips for advocating with pharmacies and prescribers. Transition guidance outlining the pros and cons of alternative medications and insurance considerations is essential. Trusted sources, such as official government portals and patient organizations, should also be highlighted.

Patients discussed how they want to know about strategies to where they can build up a buffer or reserve of their medications. For example, patients who take immunosuppressants often need to stop taking their medications during an active infection or when receiving certain vaccines. Patients use these opportunities to ensure that they have a sufficient supply of medication to safeguard against potential drug shortages and give them peace of mind.

“Even when it’s approved, and you’re prescribed it, you still have all these hoops to go through.”

“You’re going to be your best advocate. Make a call to a prescribing doctor right away, follow up with the nurse and office regularly.”



**Policy/System Barrier:** Insurance and administrative hurdles make switching or accessing alternatives difficult, adding to stress during shortages.

# Recommendations

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To address the challenges identified by patients, recommendations were intentionally designed to address drug shortages across multiple levels—process, policy, and system—while aligning with five core action areas: proactive communication, patient-centred risk management, insurance flexibility, centralized resources, and patient reporting and engagement. This multi-level approach reflects the complex, intersecting nature of drug shortages and ensures that solutions reduce patient burden while strengthening system resilience.

Within each recommendation area, actions are presented in order of their direct impact on patients, while recognizing the importance of system and policy measures for long-term resilience.

## ***Implement Proactive Communication Protocols***

***“If the pharmacy can call or text me when my medication is ready, then why not where there is a shortage?”***

- Require pharmacies and prescribers to provide timely alerts to patients through phone, SMS, email, and app notifications. This is particularly relevant for those living in rural and remote areas where pharmacy access is limited. Communication protocols should account for delivery failures and travel burden, particularly for rural and remote patients, to prevent unnecessary travel and medication loss.
- Enhance communication about potential drug supply issues, even before a shortage is confirmed. Patients need sufficient time to prepare and adjust their treatment plans and should not be the last to receive this information. Ensure all communications are accessible, clear, and easy to understand so that patients feel confident discussing next steps with their healthcare providers.

- Develop patient guidance on safe coping strategies including plain language guidance on safe buffer strategies, what not to do, and when to contact a healthcare provider. This patient guidance should be led by a patient leader and/or patient organization.
- Develop a standard drug shortage response pathway for prescribers, pharmacies, and Patient Support Programs outlining roles, patient messaging, and escalation steps. These protocols should clearly outline the roles of prescribers, pharmacists, and Patient Support Programs in supporting patients during shortages, including clinical guidance, coordination, and follow-up.
- Improve patient engagement and outreach to the [Multi-Stakeholder Steering Committee \(MSSC\)](#) as a centralized platform for drug shortage reporting, for early notification and communication of shortages.

## 2

## *Create Proactive, Patient-Centred Risk Management Strategies*

- Stigma-reducing protocols should be developed for controlled medications during shortages (standard scripts, verification processes that don't penalize patients, and escalation routes for complex cases). Shortage response measures should be implemented in ways that avoid stigmatizing patients who rely on pain medications, particularly when patients are required to contact multiple pharmacies or seek alternative access.
- Risk management strategies should explicitly recognize situations in which therapeutic switching is not clinically appropriate or safe, and should prioritize continuity of effective treatment whenever possible.
- Develop a plan for essential medicines in rheumatic diseases and other similar disease areas (e.g. Crohn's, psoriasis) to proactively understand what drugs are essential and create practical back-up plans for patients when one or several medications are in a shortage situation.
- Support Health Canada's proposed amendments requiring Market Authorization Holders (MAHs) to maintain drug-specific prevention and mitigation plans tailored to disease areas, including safety stock requirements.

- Engage patient communities in detailed risk assessments and contingency planning for potential supply chain disruptions. These assessments should identify medications most vulnerable to shortages, proactively consider alternative treatment options where appropriate (e.g., when a medication is frequently in shortage), and account for the seriousness of arthritis and the potential impact on patients' quality of life.
- Expand domestic manufacturing capacity by supporting federal initiatives under the [Biomufacturing and Life Sciences Strategy](#) to reduce reliance on imports and strengthen Canada's pharmaceutical supply chain.

3

## *Enhance Insurance Flexibility and Policy Coordination During Shortages*

- Coordinate with provincial drug plans and private insurers to allow temporary coverage for brand-name drugs or alternative therapies when generics are unavailable.
- Create simplified reimbursement approval processes and streamline prior authorization processes (e.g. enable temporary exceptions to provide broader access to medications) during shortages to avoid treatment delays.
- Review Health Canada's 30-day dispensing policy for opioids and other controlled substances, which can exacerbate shortages and increase patient stress.
- During active shortages, policymakers and payers should consider the combined impact of overlapping policies (e.g., opioid tapering, biosimilar switching, dispensing limits) to avoid compounding patient harm.

4

## *Create a Centralized Patient Resource Hub*

- Build on [Health Canada's "Building Resilience" plan](#) by developing a national patient portal with real-time supply status, guidance on coping strategies and alternative therapies, and links to existing resources such as the Drug Shortages Canada portal for real-time updates.

- Communications should clearly distinguish between confirmed shortages, anticipated risks, and uncertain supply timelines, and be transparent about what is known and unknown.
- Ensure all communications and the patient portal are accessible (plain language, bilingual, mobile-friendly) and include equity considerations for rural/remote, marginalized, and unsupported patients.

## 5

## *Patient Reporting and Engagement*

- Introduce a patient-facing reporting tool integrated with Drug Shortages Canada would help to capture real-world impacts and inform policy decisions.
- Consider patient and patient group reports of shortages to inform the work of Health Canada's regulatory provisions for faster importation of medication during critical shortages to maintain continuity of care.
- Expand the engagement of patient partners and patient organizations in the [Multi-Stakeholder Steering Committee \(MSSC\)](#) to reflect the perspectives of those experiencing shortages and their effects.



**Policy/System Barrier:** Lack of policy flexibility and prioritization for patient needs.

# Acknowledgements

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