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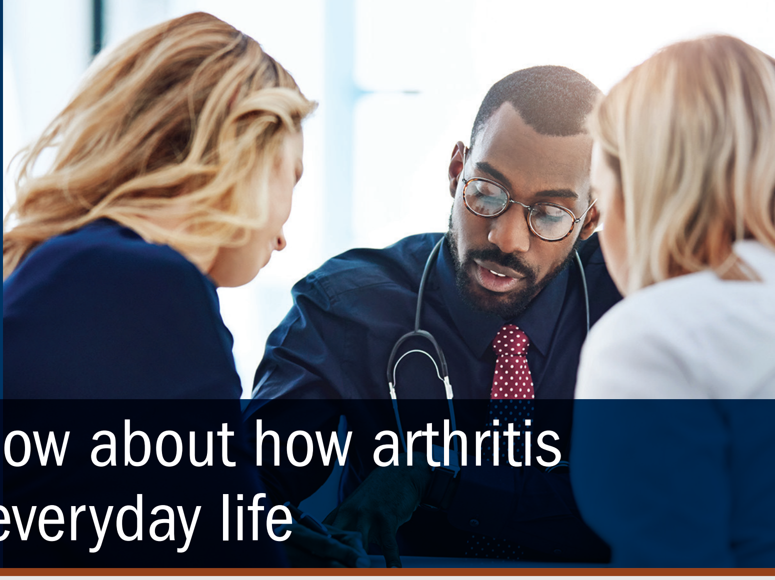

What I want my doctor to know about how arthritis and chronic pain affect my everyday life

For many people, living with arthritis means coping with chronic pain and living with disability. Everyday activities, such as climbing stairs, carrying groceries, washing dishes, or brushing teeth, can become hard to do. When living with chronic pain and loss of function, a person's doctor can be an important source of support and medical advice. Doctors may prescribe nonopioid medications, steroid injections, low-impact exercise, physical therapy, and occupational therapy and may recommend surgery. But these treatments may not work as arthritis gets worse over time. When this happens, doctors may prescribe opioids. Opioids are drugs such as tramadol, hydrocodone, or oxycodone.

Opioids may help some people control their pain and participate more fully in life. But opioids can have negative effects too. Some people may take opioids for years without a problem. Other people may find opioids to be harmful and develop a condition called opioid use disorder (OUD). OUD occurs when people lose control over opioids. They may develop behaviors that can be harmful to them. OUD affects their relationships and ability to carry out their responsibilities. Some people may even overdose on opioids.

People with disability due to arthritis may face barriers to good care when taking opioids, including getting an accurate assessment of their opioid use and accessing treatment options for OUD when needed.[1]

In this brief, you can learn what matters most to people living with disability and coping with chronic pain. You can learn what people want their doctors to know and how doctors can improve the care they provide.

We wanted to hear directly from people with disability due to arthritis to get a better understanding of what they want doctors—or any clinician prescribing a chronic pain treatment plan—to know about their healthcare needs.

We interviewed 24 people who have chronic pain (pain that lasts more than 3 months) due to rheumatoid arthritis, osteoarthritis, spinal stenosis, or severe osteoporosis of the spine. They all have trouble with mobility—for example, climbing stairs, lifting and carrying objects such as a grocery bag, or using their fingers.

The people we spoke with currently take opioids or have stopped taking opioids after developing an OUD.

From the interviews, we learned that people with disability due to arthritis want doctors to:

- talk with people in detail about how they can treat chronic pain and improve function;
- treat the whole person, thinking beyond their health condition to who they are as a person;
- describe what happens if medication does not control their pain or improve function;
- explain the signs and symptoms of OUD and the treatment plan should they develop OUD; and
- outline other options for managing pain if they develop OUD and cannot take opioids anymore.

Take the time to have a clear and comprehensive discussion about treating chronic pain

Many people with disability due to arthritis want their doctors to clearly discuss a pain management plan that includes all treatment options and their potential risks and benefits early on in their care. The people we interviewed understand that this plan may include treatment options such as surgery, cortisone injections, physical therapy, pool therapy, and acupuncture.

People wished they had known from the beginning of their care that it may take some time to find pain treatments that work for them.

People shared that their doctors typically explained the side effects and risks of opioids such as developing OUD. Their doctors also discussed the need to monitor opioid use. They knew to expect regular visits and tests, such as urine drug screening tests, while taking an opioid.

Although this information is helpful, many people wanted their doctors to be more open about the limits of what the opioids might do, or fail to do, to control their pain. *Will my pain completely go away? When do we need to talk about changing my pain medication?*

People explained that a franker discussion about treatment would help them play an active role in their care. It would help them manage their expectations and have a better sense of how treatment options may help manage their pain.

A patient is a person: Thinking beyond a health condition

People with disability due to arthritis want their doctors to:

- take a holistic approach to their care;
- spend time discussing their overall life goals; and
- help them think through how the treatment options may help them achieve those goals, not just control pain.

People shared how their pain affects their quality of life—when their pain is not managed and they are having a bad day, they miss time and sometimes important milestone events with family, friends, and colleagues. Even when they are with loved ones, the psychological effects from their pain, such as mood swings, depression, or feelings of isolation, affect their relationships with others.

Many people with disability due to arthritis also have other health conditions. They want their doctors to consider all their healthcare needs when addressing their chronic pain.

People with disability due to arthritis want their doctors to understand how chronic pain affects their whole lives. People may struggle to communicate with their doctors. They feel as though their doctors do not understand the effect of chronic pain on their daily lives.

What if the medication does not help my pain?

People with disabilities due to arthritis know that the pain is long term and that they will need to manage it for the rest of their lives. So, from their doctors, they want to know:

- details about the treatment plan;
- reasons why it is the best option;
- why the treatment plan may change; and
- what options they have if pain medication does not reduce their pain and improve their function.

People are concerned about increasing their opioid dosage. *What will happen if the higher dosage does not work?*

They are also concerned about decreasing their dosage. *If I think the medication is helping, why would my doctor decrease the dosage?*

What happens if I develop an opioid use disorder?

Many people with disability due to arthritis who are taking opioids are aware of the risks of opioid use. Doctors describe warning signs and the risk of developing OUD. They advise people to be careful and not to take more medication than they are prescribed.

People understand that opioids may be addictive. They want their doctors to tell them what will happen if they develop OUD. Doctors tell many people that they will stop prescribing opioids, but the conversation ends there. *If I develop OUD, will my doctor continue working with me to treat my pain?*

People want their doctors to talk through the signs of OUD. They want to know how doctors treat OUD and what their treatment options are. People are concerned about how treatment will impact their pain management.

What resources are available if I develop an opioid use disorder?

People with disability due to arthritis who take opioids want the conversation to go beyond the risks and benefits of opioids. They urge doctors to understand that it is not enough to say that some people become addicted to or misuse opioids. People want to know—*what should I do when things go wrong?*

People want their doctors to discuss the details of treatment options for OUD. *Do I need to enroll in a detox program? Should I enter inpatient drug rehabilitation? What medications can I take to treat OUD, and does my doctor prescribe these medications? Do these medications work for someone with chronic pain? How will my pain be addressed during treatment and throughout recovery?*


How can people with disability due to arthritis talk with their doctors to improve the care they receive?

- Tell your doctor how your condition affects your daily life and function.
- Talk with your doctor about what your goals are for pain treatment.
- Ask your doctor what options are available to treat your pain and why the current option is the best option.
- If you are seeing a new doctor, bring a list of tests, past procedures, and surgeries, including dates, to your appointment.
- Provide the doctor with a medication list. Be sure to include medications that you have tried in the past.
- Be sure to ask your doctor to clearly explain the signs and symptoms of OUD and your options for treatment if you develop OUD.

How can doctors talk with people with disability due to arthritis to help improve their care?

- Make time to have a dedicated, clear, and comprehensive discussion with people about their treatment options to manage chronic pain and improve function. Help people set clear expectations about their treatment and how they can expect to feel.
- Take the time to discuss how the health condition affects a person's entire life and the person's goals when recommending treatment. Consider their goals when describing treatment options.
- In lay terms, discuss the signs and symptoms of OUD *and* the treatment plan if OUD occurs. Clearly explain how the treatment plan will address both OUD and the person's chronic pain.

Resources and References

Addressing the Opioid Crisis (Administration for Community Living)

Understanding Pain and Treating Pain (Arthritis Foundation)

[1] Lauer, E. A., Henly, M., & Brucker, D. L. (2019). Prescription opioid behaviors among adults with and without disabilities—United States, 2015–2016. *Disability and Health Journal, 12*(3), 519–522. https://doi.org/10.1016/j.dhjo.2018.12.001

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