

What Quality of Life Really Means When You Have Chronic Illness

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Learn some common myths about quality of life – and why it's key to discuss whether you're living well despite your illness at your next rheumatology visit.



(<https://creakyjoints.org/wp-content/uploads/2022/01/Questions-to-Ask-Yourself-and-Your-Doctor-to-Ensure-Your-Quality-of-Life-logo-1024x683.jpg>)

Credit: Tatiana Ayazo

“Good quality of life” might seem like a throwaway phrase that doesn’t mean much of anything, or maybe you assume it refers to a standard of living you’ll never attain given your chronic illness. Neither of those things are true.

Quality of life may be subjective, but it's still incredibly important and worth discussing with your doctor. That's because, broadly speaking, [^] it's really about making sure you're mentally and physically well enough to do the things that you want to do.

"Every patient has their own wants, desires, self-image, and ideas about what they want to accomplish in life," says rheumatologist Joseph Huffstutter, MD (<https://www.arthritisassociateschatt.com/our-providers/j-eugene-huffstutter-md/>), Partner with Arthritis Associates in Hixson, Tennessee. "I want patients to tell me about everything that's going on with them so I can help them reach their goals. I don't want your disease to define who you are."

Unfortunately, there are many misconceptions about what quality of life means and what you can do to improve it. Here, we aim to dispel a few of the most common myths and shed some clarity on how to live well in spite of your illness.

Myth: "Good quality of life" means you don't have any symptoms

Quality of life does not equal lack of symptoms. Rather, it's a subjective measure of how well you're functioning. It's based on your own perception of how you're doing, your goals, and your expectations, says Bonita Libman, MD (<https://www.uvmhealth.org/medcenter/provider/bonita-s-libman-md>), Chief of Rheumatology at the University of Vermont Medical Center. In other words, quality of life means how well you are actually faring as compared to how you think you should be doing.

Take pain, for instance. "Some people have an expectation of having no pain at all," says Dr. Libman. If that sounds like you, and you're experiencing any physical discomfort, you might rate your quality of life as poor. Yet another person might find that their pain is manageable and doesn't interfere with them doing whatever is most important to them.

Quality of life is often an evolving concept, depending on where you are in your patient journey.

"Before my symptoms of multiple sclerosis, 'quality of life' meant improving my financial, familial, and employment status," says Wisconsin-based psychotherapist [Shelley DeJongh, LPC](#)

(<https://shelleyramseydejongh.com/about>). “When my symptoms of optic neuritis started and eventually led to my diagnosis of MS and other pain disorders, I ^ fixated on my symptoms.”

Once DeJongh accepted the fact that she’d always have symptoms from multiple chronic illnesses, she reframed how she saw her role in the world: “My quality of life has been to honor all of my accomplishments as a psychotherapist, mother, wife, sister, daughter, and volunteer,” she says. “Those roles allow me to feel how purposeful my life has been. For me, that purpose is no longer trying to fix the symptoms or will them away. Instead, my intention is to live a quality life with the symptoms.”

Myth: Quality of life is about only physical functioning

Good health, according to the World Health Organization

(https://www.who.int/mental_health/media/68.pdf) (WHO), encompasses complete physical, mental, and social well-being. If you have a chronic disease, you might find that it impacts several of these domains. For example, research (https://erar.springeropen.com/articles/10.4103/err.err_39_19) has shown that rheumatoid arthritis (RA) patients often deal with physical limitations (including disability and pain) and mental disorders (such as anxiety and depression (<https://creakyjoints.org/living-with-arthritis/depression-arthritis-tips/>)). It’s also natural for the condition to impact how you function socially and in your career.

“It can impact your energy level, your mobility, and your intimate relationships,” says Dr. Huffstutter. “There’s no aspect of your life it doesn’t touch.”

And that’s exactly why there’s no one-size-fits-all solution for improving quality of life. If issues like pain or physical disability are what’s bothering you most, your rheumatologist might be able to make changes to your medication regimen, suggest supportive tools (like a cane or physical therapy), or even refer you for surgery. But you might also need help coping emotionally; in that case, working with a therapist who specializes in seeing people with chronic diseases might be beneficial.

“My clients present with fear, sadness, doubt, shame, guilt, anger, helplessness, and anxiety (<https://creakyjoints.org/about-arthritis/rheumatoid-arthritis/ra-patient-perspectives/arthritis-flare-fear-anxiety/>),” says DeJongh. “I help my clients identify their emotions associated with their diagnosis through using

acceptance and mindfulness strategies along with commitment and behavior-change strategies. My approach is to help my clients find hope and increase ^ psychological flexibility around their long-term health challenges.”

Myth: Everyone who reaches remission has a good quality of life

If your C-reactive protein (a measure of inflammation) is low and you don't have any tender or swollen joints, that's certainly good news, but it doesn't always correlate to great quality of life. “Disease activity is an objective measurement of how much inflammation is present, and we certainly have to take that into account,” says Dr. Libman. But since quality of life has to do with your personal assessment of how you're doing, it may or may not correlate to your disease activity score.

“Some people [in remission or with low disease activity (<https://creakyjoints.org/symptoms/how-rheumatoid-arthritis-disease-activity-improvements-compare-with-symptoms/>)] feel that whatever symptoms or limitations they have impact their quality of life significantly,” says Dr. Libman, noting that a patient might have developed permanent joint damage that will impact them indefinitely. Another person in remission might find that having to get regular medication infusions is substantially disruptive or distressing.

On the other hand, someone with very active disease might feel their quality of life is pretty good. “It may sound odd,” she says, “but some people are not that bothered by their symptoms.”

Myth: Your doctor doesn't want to hear about quality of life

When your doctor asks, “How are you?” they're not just making polite conversation. They want to know whether you're having trouble sleeping (<https://creakyjoints.org/living-with-arthritis/how-to-sleep-better-with-arthritis/>), are in too much pain to play your favorite sport, or are struggling to care for yourself or your family. These are the kinds of issues your provider needs to know about in order to help you improve and achieve your personal goals.

To make sure you don't forget something important or run out of time, make a list of any issues you want to discuss before you head to your checkup, advises Dr. Libman, who uses the RAPID3

(<https://www.rheumatology.org/Portals/0/Files/RAPID3%20Form.pdf>) index to assess patient's quality of life at each visit and track it over time. ^

This questionnaire is just one of several patient-reported outcome tools that your doctor might use. Some are general health surveys, whereas others focus on a singular condition, such as the Rheumatoid Arthritis Quality of Life (<https://link.springer.com/article/10.1007/s00296-014-3138-4>) questionnaire. (You can also keep track of your symptoms and help advance research by joining ArthritisPower, (<https://arthritispower.creakyjoints.org/>) the first-ever patient-led, patient-centered research registry for joint, bone, and inflammatory skin conditions.

Some rheumatologists, such as Dr. Huffstutter, don't use a formal survey but are still very invested in understanding how your condition is impacting you and your daily life. He and other providers may ask such questions as these, which assess how you're doing with everyday activities and issues.

- Can you dress yourself easily, including doing buttons?
- Are you having any trouble walking, showering, or driving?
- Are you frequently having to turn down invitations with friends and family due to flares?
- How are you sleeping?
- Are you struggling with anxiety or depression?

A recent study, published in the journal *ACR Open Rheumatology* (<https://onlinelibrary.wiley.com/doi/full/10.1002/acr2.11335>), found that 63 percent of RA patients have not discussed treatment goals with their provider. While your doctor should be broaching the subject, consider this a reminder that sometimes the onus may be on you to speak up — whether you're prompted or not.

“Many patients' coping mechanism is to try to ignore symptoms as much as they can,” says Dr. Huffstutter. “I'm okay with that as long as it doesn't interfere with daily living — but when it does, I need to know about it.”

Don't wait — promise yourself today to address quality of life at your next rheumatology visit.

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