

From Practical Tips to Heartfelt Encouragement: How Social Media Can Improve Quality of Life With Rheumatic Disease

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Background & Purpose



Cheryl: Diagnosed with rheumatoid arthritis in 2003 at age 20. Today she is on her fourth biologic medication along with methotrexate and enjoys a good quality of life despite moderate to severe RA.



Zoe: Diagnosed with Crohn's disease in 2015 at the age of 20, followed by diagnosis of spondyloarthritis in early 2016. Zoe would try and fail on multiple treatments before finding the right combination of medications.

We have learned new ways to manage our autoimmune conditions and experienced greater support through online patient communities.

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Intervention

- After sharing evidence-based information, heartfelt support and practical tips for coping with chronic illnesses on social media, we discovered that the comments section of our posts were full of helpful information as well.
- While we initially looked to social media to share tips, it's become a place for us to learn others' tools and strategies as well, many of which we have implemented in our own lives.

Table: Example of Quality-of-Life Improvements from Social Media Conversations

Improvement Type	Content	Impact	Platform and Date
Tips for daily activities	"Adaptive knife" demonstration (Cheryl); commenters shared more arthritis-friendly knife styles and tips for alternate ways to grasp the knife. They also shared insights into the importance of selecting the right knife for the right task.	Cheryl tried a rocker knife for the first time, which has a different style than the adaptive "handle knife" she originally posted a demonstration of. She found it helpful for cutting items with even less knuckle pain than the adaptive knife.	TikTok April 2022
Disease and medication management	"Methotrexate" post (Zoe); commenter suggestion to take leucovorin calcium after methotrexate to help with side effects.	Zoe mentioned this to her doctor and now takes leucovorin; her side MTX effects have greatly diminished.	Instagram May 2020
Emotional support	"Second guessing pain" (Zoe); shared about second guessing her pain and others commented with similar stories.	Zoe felt validated and felt it easier to bring her symptoms up to her doctor after knowing others feel the same way.	Instagram March 2022
Tips for daily activities	"Opening containers" (Cheryl); Zoe saw post about life hacks for gripping and opening containers.	Zoe purchased an automatic jar opener which has relieved a lot of stress in cooking.	TikTok March 2021
Disease and medication management	"COVID-19 vaccine" (Zoe); commenters shared how they were adjusting their medications and working with their doctor to get the vaccine.	Zoe had an informed conversation with her doctor about medications and vaccines.	Instagram March 2021
Emotional support	"When people say you're too young for arthritis" (Cheryl); video post about what it's like to hear invalidating comments; commenters shared similar stories and what others have said to them and how they responded.	Cheryl learned she wasn't alone in dealing with insensitive remarks and felt a sense of release from reading humorous responses from others living with chronic disease.	TikTok March 2022

Maintenance

- Zoe shares daily CreakyJoints articles filled with education, support and firsthand stories from patients.
- Cheryl shares regular updates from her Arthritis Life Podcast, which features interviews with others living with rheumatic disease. Cheryl also shares frequently on her Arthritis Life TikTok and Global Healthy Living Foundation TikTok accounts and benefits from hearing others' feedback about her life hacks.



Quality of Life

- Social media has changed the way we approach our health.
- Cheryl has tried new techniques and gadgets to make daily living with rheumatoid arthritis easier. She has also felt less alone and more open to addressing the ways her condition has affected her mental health, through seeing others open up and share their coping tools and emotional journeys.
- Social media has helped Zoe normalize her symptoms. Zoe feels empowered to advocate for herself and speak up at doctor's appointments and is able to better manage her conditions because of the social media community.