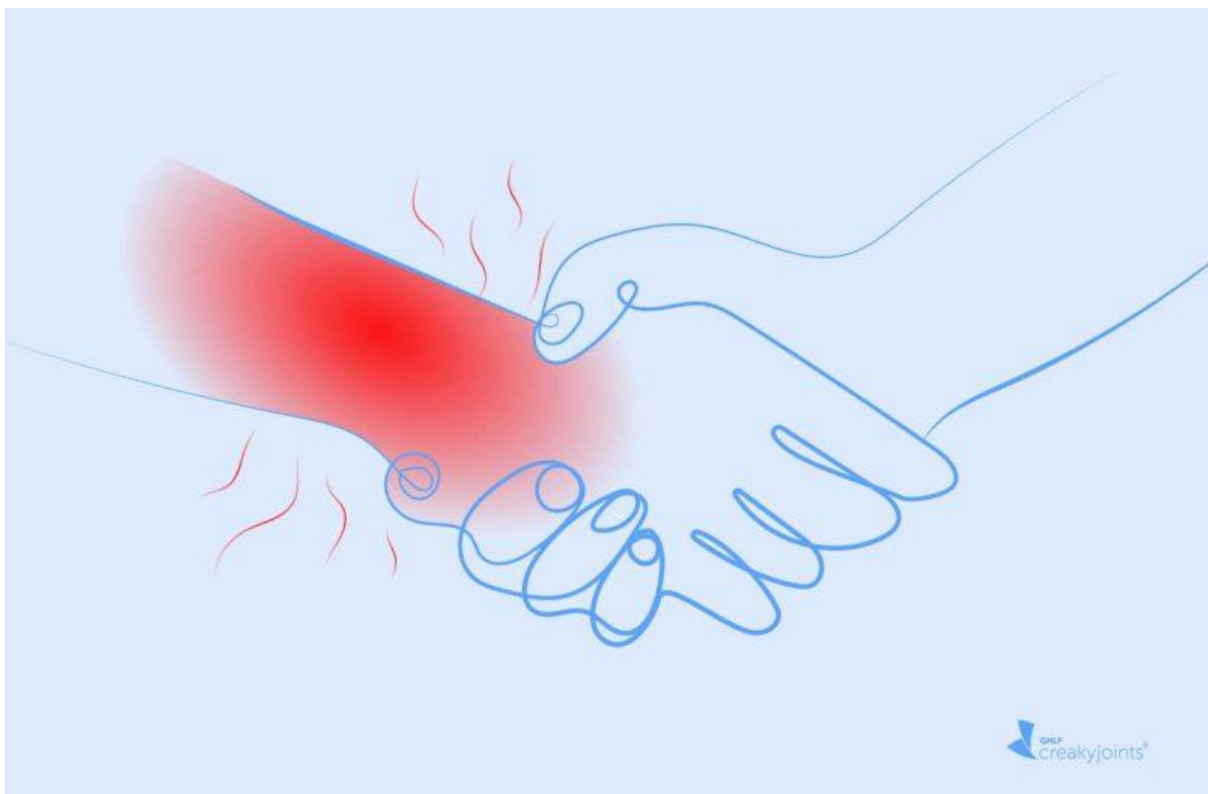


How You Can Support Someone with a Chronic Illness (and Some Real Advice on How *Not* To)

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Start by avoiding ableism and toxic positivity.



When I think back to my life before I had rheumatoid arthritis (RA), I realize I probably said some inflammatory things (no pun intended) to people living with chronic illnesses because I didn't know what it was like to be in their shoes. I didn't mean to, but I also didn't really understand much about how chronic illnesses affect those they afflict.

When you have a chronic illness — be it an autoimmune condition like RA or something else — having good support from others is key.

People who have strong social support networks tend to do better long-term.

But how should others know how to support someone going through a challenge with their health when they don't know much about it?

Many of us chronic illness patients routinely hear bad advice or hurtful comments, even from the people closest to us. The world is full of all sorts of opinions, personalities, and attitudes. Sometimes we can't choose who's around us and sometimes we definitely don't jive. We can, however, choose to learn. We can ask ourselves, how would I want to be treated if that were happening to me?

So if you're reading this article and you have a chronic illness, well, I'm preaching to the choir. But my real hope is that chronic illness patients share this with caregivers and loved ones who genuinely want to be more involved, but maybe aren't sure what to say or do.

There are two main things you must know to best support someone with a chronic illness.

First, Understand Ableism and Disablism

- **Ableism:** The practices and dominant attitudes in society that devalue and limit the potential of persons with disabilities. A set of practices and beliefs that assign inferior value (worth) to people who have developmental, emotional, physical, or psychiatric disabilities.
- **Disablism:** A set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities.

Both describe forms of discrimination, but disablism is more about discriminating against people with disabilities while ableism is more about discriminating in favor of non-disabled people.

Many people would swear that they're not disablist, but ableism can be more subtle and sometimes harder to recognize.

Examples of common ableist remarks:

- You're too young for that
- Just push through it
- If you just ate better / exercised more / lost weight
- You're sick because you are not positive enough
- Everyone gets tired
- Everyone gets aches and pains
- But you don't look sick

Whatever you do, don't be an ableist. Everyone's story, abilities, and limitations are different.

Second, Watch Out for 'Toxic Positivity'

What is toxic positivity, exactly? Have you ever spewed some positive, fake, happy verbal diarrhea because you didn't know what else to say – and you didn't listen to what the other person was really saying? Have you ever shamed or chastised others for expressing frustration or anything other than good vibes 24/7? If so, you might be unknowingly throwing around some toxic positivity.

Examples of toxic positivity include saying things like:

- Everything happens for a reason
- What doesn't kill you makes you stronger
- You just have to think or be more positive
- You'll be fine
- You'll get over it or get used to it
- Positive vibes only
- Everything works out in the end
- Don't worry, be happy
- It could be worse
- It is what it is

I'm not saying I never look for silver linings, but there's a huge spectrum between being a Debbie Downer and a Pollyanna. Having toxic positivity as your default response to someone's situation can cause minimization, invalidation, and denial of their experiences.

By disallowing the existence of certain feelings, people with chronic illness can fall into a dark state of denial and repressed emotions. This breeds stress — and stress is not good for anyone, especially those with chronic illness.

Hint: stress = flare.

Some Real Advice on How to Support Someone with a Chronic Illness

1. Show us compassion and empathy

Researchers have defined compassion as the feeling that arises when you are confronted with another person's suffering and feel motivated to relieve that suffering — a desire to help.

- **Compassion is not:** Telling people to try turmeric, lose weight, exercise more, or any other unsolicited advice. Just don't — even if it comes from the goodness of your heart.
- **Compassion is:** Getting ice packs for someone, doing a difficult task that might put someone into a flare, or going out of your way to do anything that could “save some spoons.” In other words, real compassion is helping and letting your actions speak louder than words. And it's OK to ask how to help if you don't know how but want to.

Also, it's OK if you can't help physically offer help. Empathy refers more generally to the ability to take the perspective of and feel the emotions of another person. When others are empathetic, it just helps us feel a little less alone.

- **Empathy is not:** Saying “everyone experiences aches and pains” or “everyone gets tired” or “it is what it is.”
- **Empathy is:** Saying “I am sorry” or “I imagine that must be difficult to manage” or “I am here for you.”

2. Reflect what we say and do your own research

By this, I mean listen to what we tell you about how we’re doing. Show us that you’ve heard how our illness impacts our lives. Look, showing you can pronounce the name of our disease correctly can sometimes go a long way. (Ankylosing spondylitis friends – am I right?)

Go one step further and research a little about our disease – a Google entry or two can go a long way in giving you a good overview. This helps because we don’t have to start at square one explaining everything. Chances are, we’re already exhausted and don’t want to have to explain our disability over and over.

Try using our language with us:

- Do you have enough spoons for that today?
- How is your battery level today?
- What level is your pain at today?
- Did [painsomnia](#) keep you awake last night?

Read some articles on what it’s like to live with the condition from people living with the condition. You can learn a lot from the patient perspective. (Here’s my POV on what it’s like to [live with RA](#) and [with fatigue in particular](#).)

3. Give us validation and believe in us

Validating and believing our needs, feelings, concerns, and wants as someone with a chronic illness can help us feel a little less alone and misunderstood. Keep in mind that we often have invisible illnesses that some with stigma and misconceptions. A top issue with RA, for example, is people thinking that arthritis affects only older adults.

- **Validation is not:** Saying “you’ll be fine” or “at least you’re young” or “it can’t be that bad” or “but you don’t look sick.”
- **Validation is:** Saying “I understand that *insert chronic illness* can be debilitating. I can’t imagine what it’s like, but I am here to support you in your journey” or “I notice how hard you work toward your health! I am proud of you.”

Recognize our achievements, but please note that we are not your inspiration porn. Please do not tell me that my misfortune in life inspires you to live a better life because you never know when or if your health will take a turn for the worse. Instead, tell me it inspires you to help others with misfortune in their lives to live a better life.

4. Show interest and support in our journey

I had to say goodbye to a lot of my friends when I was diagnosed with rheumatoid arthritis. I’ve learned that it’s easier for some people to be around when things are going well; when the going gets tough, people ghost you. I felt extremely isolated and alone. But the people who were willing to stick by me and take part in my new life made things so much better.

To show support in our patient journey, come to our doctor appointments. Exercise with us. Cook healthy recipes by our side (and help with cleaning up!). Join us for disease awareness events. Donate to charity in our honor. There are many ways you can engage in our journey to make it seem like normal life for us and help us feel less lonely.

5. Let us know that it’s OK to not be OK

Understand that many people living with a physical chronic illness also live with anxiety and depression. We are going to have dark days – with both our physical and mental health.

You can ask us what we like to do when we’re in a funk. Take note of what makes us happy or just give us space if that’s what we need (but

don't be insulted if that's the case). Sometimes rest and personal space is just what we need.

- **Don't say:** "Get over it" or "just push through it" or "everyone has bad days" or "Yeah, I have pain too."
- **Do say:** "This is really hard" or "I'm thinking of you" or "I'm here for you." Curse at our disease with us. Cry with us or let us cry to you. Help us be comfortable with you so we can be real with you.

6. If you are able-bodied, offer help (but do not question why help is needed)

It drives me nuts to have to explain to someone who already knows that I live with a debilitating condition why I am asking for physical help with something. Ummm, I'm asking for help because my arthritic joints and my fatigue-ridden body can't do it. Or if I do attempt it, I'll go into a flare and be out of commission for days (or longer). It sucks having to explain over and over why I can't do something at the ripe young age of 34.

For example, if you see something in our environment that we haven't done yet, don't ask us

continuously why. You can ask yourself, "Would this task make me break a sweat?" or "Would I have to watch my posture with that load?" If you answered yes, chances are, the task would put someone with a chronic illness into a painful flare – and that's why we are putting it off.

So instead of asking why we haven't done something, offer to help us. Sometimes we are just too stubborn to actually ask for help.

Some great ways to help someone with a chronic illness: grocery shopping, meal prep, house cleaning, running errands for them, yard work, or driving them around. (Plus: simply being their friend or loved one who listens.)

7. Let go of expectations

Don't expect someone with a chronic illness to always be there. Life is rocky, especially when health is unpredictable. If we don't answer text messages, emails, or phone calls right away, we're probably not ghosting you on purpose. If we can't commit to a party (or these days, a Zoom get-together), it's not because we're being flaky.

The best support you can give is continued love and understanding. And trust that we're doing our best and will be back in the picture when we're feeling a little better.

8. Let us rest

Most importantly, when we need it, just let us rest.

Want to Get More Involved with Patient Advocacy?

The 50-State Network is the grassroots advocacy arm of CreakyJoints and the Global Healthy Living Foundation, comprised of patients with chronic illness who are trained as health care activists to proactively connect with local, state, and federal health policy stakeholders to share their perspective and influence change. If you want to effect change and make health care more affordable and accessible to patients with chronic illness, [learn more here](#).

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