

Cope: Managing relationships

Relationships and post-COVID fatigue

Illness can impact relationships in small and large ways. It can strengthen relationships, and also create challenges. You may have less capacity for socializing due to your illness. People in your life might not know what to say to support you, so they might say nothing. This might feel like they are not acknowledging what you are going through. It can be hard for people to relate to what you are experiencing if they haven't been through something similar. You might get advice from others about treatments and cures – and that advice can be upsetting if it makes you feel like they think you are not doing enough.

The invisible nature of post-COVID fatigue may mean that you are constantly navigating what it means to not “look sick”. You're also able to choose what you share with people about your illness, if they can't tell that you're sick just by looking at you.

If you look good will people believe you? If you are honest, will people see you as complaining? The decision of what to tell people when they ask how you are doing can be exhausting.

The relationships with the people you live with may be impacted as you redistribute household labour and if your illness affects your finances. It can be hard to understand that taking rest means that chores must go undone and that your contribution to the household will be different than it was before you became ill. It can be hard to understand that you don't have the energy to explain that you have no energy.

8 WAYS TO IMPROVE YOUR RELATIONSHIPS

This section is adapted from “[8 Ways to Improve Relationships](#)” by Bruce Campbell

1. Assess and triage

You might think of your relationships as a series of concentric rings. The inner ring contains the most important people in your life. People on the outer ring are casual acquaintances. In between there may be one or two other rings of people with varying levels of importance.

As you navigate your illness you can make this a deliberate choice to concentrate on the relationships that enrich your life. Dr. David Spiegel studies the impact of relationships on illness: “Save your energy and use the illness as an excuse to disengage from unwanted social obligations. Simplify the relationships that are necessary but unrewarding and eliminate the ones that are unnecessary and unrewarding.”

2. Adapt how you socialize

You may be able to preserve important relationships by adapting how you socialize. For example:

- Connect virtually. If you cannot get out of the house, you may be able to stay in touch with people using phone calls and emails. Perhaps text a picture of a small moment of your day to a friend.
- Plan short visits. Knowing that the visit will only be for a short time might make it easier for you to commit, because you don't have to worry about being exhausted.
- Change the places and times that you socialize. Asking a friend to come to you, or going to a restaurant when you know it will be quiet and not busy, might help you preserve your energy.
- Limit the number of people you socialize with and take rest breaks. For example, if you have a large family, you could ask that only one couple visit at a time.



3. Change expectations and set boundaries

Sometimes pressure from others can push you to do more than your body can tolerate. Socializing uses emotional/social and cognitive energy and can be just as taxing as say going for a walk or cleaning the house. Our "*Plan: How to Pace*" handout outlines different types of energy, and how to stay within your energy envelope.

It can be hard to change expectations, but it is important to learn your limits so that you can find a "new normal." You might feel acceptance, grief, sadness, anger, and frustration as you go through this process.

Setting boundaries can be challenging but it will help you to teach others about your limits. Here are some tools to help you set boundaries:

- Be very specific in the requests you make or limits you set.
- Showing empathy for how your illness has impacted the people in your life can help them to accept your new limits. that you understand the ways that your illness has impacted the people in your life. As an example, if you're feeling too tired for an activity, you could say, "I need to take things easy and rest more right now and I know this has been frustrating and scary for you."
- Start your request with a statement of appreciation, such as by telling the person you're speaking to that you appreciate them.
- Practice saying your request to yourself or someone you trust before making it to the person who you are setting the boundary with. This can help you to feel more calm and assertive when you speak to them.



4. Educate others (or not)

It is very common for people with invisible illness to not feel understood and believed when they say they are ill. It can also be tiring to feel the need to educate people about your illness.

It can be helpful to give the people in your life resources and educational materials so that they can learn about your illness. You may want to share materials with the people in your life to educate them, like this booklet.

It's also okay to put limits on your efforts to educate others. Sometimes you will need to focus on the relationships that are most important. You might also learn that some people may never be willing to understand or accept your illness.

5. Build new sources of support

Building new relationships can help you to manage frustration in your current relationships and can also help you to rebuild your community if there are relationships you lost because of your illness. One good place to meet others who understand what you're going through is the many online supports for people with post-viral fatigue, i.e. Facebook, Instagram hashtags, and Reddit. We've outlined some of these sources in the "Connecting with Peers" section of this handout.

It can also be helpful to put together a group of people who can help you with your practical, social, or emotional needs. It's wise to have several people to fill these various needs, so that one or two people don't feel overburdened and burn out.

Others living with invisible illnesses or disabilities may be especially understanding when it comes to living with post-viral fatigue.

6. Do your part

One step toward easing strains in your relationships is to acknowledge the ways that your illness impacts the people close to you. Talking about impacts won't make them worse, but it can help your loved ones to feel like you understand what they are going through too.

For example, if your illness affects your ability to follow through with plans, warn people ahead of time that you may need to cancel on short notice. Tell them that you value them and that that canceling your plans together does not mean you don't like them.

Take responsibility for the problems your illness creates for others. For example, if your illness makes you moody, make a list of things you can do to help yourself feel better. When you are feeling irritable, you might listen to music, take a walk or have a rest.



7. Help others and ask for help

Your illness might make people in your life feel helpless and they may not know how to support you. Asking them for help in clear, practical ways can help them to feel involved in your life. Helping others is a way that people find value in their relationships.

At the same time, it's important to maintain balance. Check in with the people you are asking for help to see if they need a break. Do your best to ask multiple people for help so that one person doesn't feel overwhelmed.

8. Embrace solitude

A final strategy for responding to limits and the loss of relationships is to embrace solitude. Serious illness often forces people to spend much more time alone than before. Solitude can provide an opportunity to develop new solitary interests. This might include activities that are devoted to learning new things, personal development or spiritual growth, and creative pursuits.

COMMUNICATION RESOURCES

For further exploration regarding communication in relationships, Marshall Rosenberg's Non-violent Communication is one model for communicating with loved ones. There are many books out there on this technique. If you search for "Non-violent Communication PDF" online, you can find some free resources.

[Here is one example.](#)

You could also check out the [BC Network for Compassionate Communication.](#)



CONNECTING WITH PEERS

You may find that you need to take a break from social media to enable more time for rest and recovery. If you notice that your mood or energy is adversely affected by the time you spend online, this may not be a good place to look to for support. But if you feel the need to connect with people who are going through similar experiences, you could try one or some of the following. Just remember to use social media with moderation and don't forget to pace online activity.

Reddit

Reddit is composed of “subreddits” – smaller communities that are public. Please note you will come across a variety of information and communication ranging from helpful to harmful. Things to remember:

- For most subreddits, what you post is publicly accessible. You can withhold identifying information from your account when you sign up
- It is a good idea to read the guidelines for a subreddit before posting – they vary by subreddit
- It is also a good idea to scan recent posts and comments to get a sense of the community – how supportive it is, etc.

Two such subreddits are the [/covidlonghaulers](#) and [/covidpositive](#).

Instagram

There is a thriving post-COVID community on Instagram. If you decide to post about your experiences, use hashtags so that others can find and comment on your posts. The sky is the limit with hashtags – some examples to start with are #longCOVID and #longCOVIDrecovery

Facebook

There are some wonderful online communities in Facebook groups. Here is one example [from the National ME/FM Action Network](#).

The Mighty

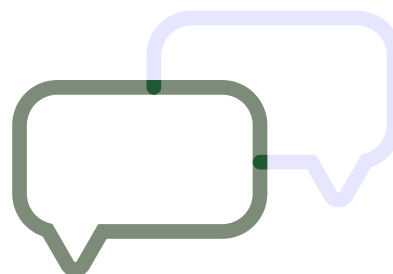
The Mighty is a digital health community created to empower and connect people facing health challenges and disabilities. You can read stories from others, contribute your story, and connect with others [on their digital platform](#).

“These are the stories that the world needs. We're all struggling, and the more that we recognize ourselves in the stories of others, the more compassion we have for others & for ourselves.” @DrGinnyGrimsley via The Mighty website.

Body Politic COVID-19 Support Group

The Body Politic seeks to destigmatize issues facing the [COVID-19 community](#) and people with related chronic illnesses and disabilities by offering alternative narratives that get to the root of what it's like to live with a novel or chronic illness. Their support group is on Slack and [Facebook](#), and consists of people from all over the world who have tested positive, are experiencing symptoms, or are recovering from COVID-19.

Their discussion groups include 50+ channels based around different communities and topics, including one for those symptomatic for 30+ days or 90+ days, caretakers of sick friends or relatives, those who have recovered from being on ventilators, those experiencing known and lesser known symptom groups such as respiratory, neurological, GI, and others, and forums to discuss mental health, financial and employment concerns, medical advocacy, along with many others.



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