

Relationships with family and friends

With family and close friends what problems have you had in having them understand and accept that you have a real, serious physical illness?

What ways have you found to help them understand? Which approaches are most effective, and which ones are less effective?

Does giving them medical information on the illness help?

Do you appreciate them when they understand and help? How do you cope when they become frustrated?

With others whose minds are closed, and just tell you to “get on with it” - how do you deal with/cope with them? Do you waste your energy on a losing battle?

What are self-positive ways to deal with these persons?

<https://www.massmecfs.org/living-with-me-cfs/137-coping-and-hoping>

Article Coping and Hoping – Priscilla Larson

What are the most hurtful ways persons have related to you?

- *"Comparing their tiredness to ME/CFS showing that they really don't get it."*
- *"Ignoring what I said about hurting and then going right into long descriptions of their temporary pain."*
- *"Saying, 'You're not sick, you're lazy. Snap out of it!' "*
- *"Are you sick again?"*
- *"The attitude that since I'm disabled I'm worthless. My accrued knowledge doesn't count."*
- *"Come on! You can go! Think positively!"*
- *"I wish I could lie around all day like you and watch TV."*
- *"We need an able-bodied person here."*
- *"You can't do anything!"*
- *"You should be ashamed of yourself parking in that handicap space. You don't look handicapped to me."*

What would you like well persons to know?

- *"Realize that we have feelings!"*
- *"We want well people to know that we want to socialize but sometimes we can't even handle a phone call. Please don't take it personally but call again. If we don't return your call right away it's not because we don't want to but because we can't think clearly right then."*
- *"Give us credit for what we do."*
- *"Understand that our symptoms vary from hour to hour as different systems in our bodies become affected. What is happening today might be superseded by other symptoms tomorrow"*
- *"When our memory shuts down it doesn't mean that what you said isn't important to us, our brains just didn't register at that moment."*
- *"I'm still the same person—I just don't have the abilities I used to have."*
- *"I wish that well persons understood the difference between ME/CFS and temporary fatigue due to overwork. So many compare their tiredness to our fatigue and think it is the same."*
- *"When you see us out on an errand and say, 'You look wonderful, you must be all better now,' we feel like you don't realize that we may have just used up our entire energy quotient for the day and will probably drop into bed when we get home."*
- *"I'm able to do a lot if I can do it at my own pace. Others can't do that, so just ask."*
- *"It means a lot when you include us in your social events and you don't get offended if we can't do it all."*

<https://www.massmecfs.org/living-with-fibromyalgia?start=4>

“Chronic illness cannot be hidden from the family...

Your family may not say much but it does see the effects of your chronic illness.

When people are newly diagnosed, there is an enthusiasm and willingness by other family members to set aside their personal agendas for a while and help the patient rise above the problem. But when the problem appears to be ongoing, it can often drive people apart.

The family members may not share the physical symptoms, but they may suffer fear, anger and grief from what has happened.

Due to the disruption caused by the illness, there could also be feelings of resentment. Often problems prior to illness can escalate.

"Words can sting, but silence breaks the heart" as Sefra Kobrin Pitzele reminds us in her book, *We Are Not Alone: Learning to Live with Chronic Illness*.

Spouses/other family members may avoid asking how the patient is doing for fear of having to hear about it and deal with feelings. It is important to share and acknowledge each other's feelings, exercise common courtesy, and come up with a new definition of "normal" in order to keep the relationship alive.

It is also important not to allow illness to always be at the center of attention and to build upon the common interests/experiences that hopefully still exist. Some families may benefit from counseling by professionals with an expertise in dealing with the impact/effects that chronic illness can have on the whole household.”

<https://www.massmecfs.org/long-covid-lessons-learned-from-me-cfs?start=4>

“Family members, friends, and even health care providers may question or not understand your illness, especially if your symptoms vary over time. They need to learn you are really sick and can’t do everything you used to do. You should not be blamed, nor should you blame yourself – no one wishes to get sick. Instead, seek treatment and support from those who care for you, tell them how you are feeling and how they can help. Seek any potential outside support. You may need to educate others as well as yourself, as you learn more.”

<https://www.massmecfs.org/living-with-fibromyalgia?start=5>

Walk away from stressful situations that are not yours, and try to avoid toxic people.

<https://www.massmecfs.org/more-resources-for-me-cfs/472-tips-for-living-with-cfs-and-fmin-real-life-and-online-communities?start=4>

“Pick your battles

Nowadays, many people don't think twice about making snap judgments or remarks that are inappropriate or impolite—sometimes, even compliments are meted out without discretion or understanding.

There is a difference between telling someone that they look nice today or they are glad to see them and putting undue emphasis on "but you look so great" or "you don't look sick." It may be easier and better to overlook these sorts of remarks from strangers, by chalking it up to their ignorance or ill manners; however, people who are closer to a patient might do the same thing.

Anyone who bears the burden of illness on a daily basis will need to pick their battles wisely and not feed more energy or emotions into situations than they warrant. A simple honest reply may do, or using a little humor or creating a couple of clever quips can help patients end the situation in a way that can also let the other person know they made a faux pas.”

<https://www.massmecfs.org/more-resources-for-me-cfs/472-tips-for-living-with-cfs-and-fmin-real-life-and-online-communities?start=5>

But there will be times when what is said by another person will be unacceptable, totally unfair or inaccurate—these should be addressed, to the best of the patient's ability.

People who are ill will typically become flabbergasted by these unexpected remarks and many won't be able to say anything on the spur of the moment. Depending on the individual, this can be turned into an opportunity to educate the other person, by responding in an honest and unapologetic way that speaks to the heart of the matter.

If the other person still does not get it, then it would be reasonable for the patient to remove themselves. Sometimes the other person could be someone's doctor whose remarks or conduct was very dismissive or in some way, offensive.

One option is to send a letter to the doctor about the incident after the patient has had a chance to quietly digest and reflect over the details of the incident. [But the patient should be aware that the letter will be made part of his/her record.]

The worst thing that patients or anyone can do is to respond by lashing out with their offensive remarks and/or stooping to the level of the offender.

<https://www.massmecfs.org/living-with-me-cfs/102-a-view-from-outside-how-to-help-a-pwc>

“A View from the Outside, How to Help a Person with ME/CFS” by Jean Mosher

How Friends and Family can help a person with ME by providing needed help and by also understanding the day-to-day limitations posed by the illness.

These are not dispensable people, but rather people who cannot be dispensed with. The spirit of a person never really leaves them, whatever their physical condition, and if the friendship is built on that and on love, you've got a winner.