

Friends, Family, Life & ME/CFS/FM

Prepared by Charlotte Kelp

People with ME/CFS and FM experience many frustrations in their relationships, including:

- **Loss of Relationships:** The unpredictability of symptoms, together with our limitations, can make it difficult to maintain relationships. Some relationships may be lost, while others are redefined
- **Feeling Misunderstood:** Other people may not believe we are ill or may not understand the seriousness of our condition
- **Guilt:** You may blame yourself for getting sick or for not contributing to family or society
- **Feeling Unreliable:** The unpredictability of symptoms often leads to cancelling out of commitments, creating misunderstanding and threatening some relationships
- **Isolation:** You may feel a sense of isolation, either from spending more time alone or because of feeling different from other people
- **Fears of Dependency and Abandonment:** You may worry about losing your ability to care for yourself or fear that others upon whom you depend will leave you

Try some of the following, they may help to improve your relationships:

Assess & Triage

If you have ME/CFS or FM, it likely that many relationships will be redefined and some will end. We suggest you make this transition a conscious and deliberate process by using *relationship triage*.

The general idea is to concentrate on the more valuable or necessary relationships. In the words of Dr. David Spiegel of Stanford: "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."

Adapt How You Socialize

You may be able to preserve a good number of relationships by adapting how you socialize. For example, if you have severe limits and cannot often get out of the house, you may be able to stay in touch with people using phone calls and emails, plus having them make occasional visits.

Be aware of how much time you devote to being with others and if it is using too much energy adapt e.g. set a timer on phone calls, set a limit on time at gatherings, only invite 2 people around at the time etc.

Change Expectations, Use Assertiveness, Create Boundaries

Because of guilt or pressure from others, you may do more than your body can tolerate. A solution is the combination of changing your expectations and being more assertive. Changing expectations is a gradual process by which we come to accept that we have limits and need to adapt to a "new normal".

Learning assertiveness or setting boundaries, can also be a gradual process, as you educate others about your limits. Here are four ideas to consider: First, be very specific in the requests you make or limits you set. Second, show that you understand the other person's situation. You might say something like, "I know my illness makes your life more difficult and that some things I say and do may be frustrating." Third, preface your request with a statement of appreciation, such as "I appreciate all you do for me." Fourth, if you find it difficult to be assertive, practice saying your request to yourself or someone you trust before making it to the person whose help you want. Remember, "no" is a complete sentence.

Accept Help and Help Others

Other people often feel helpless about our illness. By giving them something specific to do, you can do them a service while helping yourself. As one person in our program said, "People are often thrilled when I ask for help in clear, practical ways." A caution: asking too much of others in total or of one person can risk caregiver burnout.

Helping others aids self-esteem and also gives others an incentive to stay in the relationship. As someone in our groups said, "I ask myself what I am doing to make a relationship valuable to the other person."

Nourishing Relationships *Adapted from Elena Rosen*

Behaviour and Attitudes around relationships may need to change.

- **Feeling understood**

Feeling understood in a relationship can often be a challenge, but even more so after a diagnosis of ME/CFS. One way of dealing with this can be letting go of the expectations that friends and family will understand all aspects of your illness. Others that have experienced health challenges may be able to relate more. It may not be realistic for family and friends to understand ME/CFS, but it is OK to ask them to respect the complexity and limitations that come with living with a chronic illness.

- **Boundaries with love**

Sometimes loved ones may not want to understand how exactly how you are feeling as it is too painful for them to see you in pain and struggling with exhaustion. This can create pressure to act well and upbeat even when feeling terrible. Being more honest about how you are feeling can help to take the pressure off and maintain good boundaries by letting them take responsibility for their own emotions.

- Handling casual relationships and social situations

It can be difficult to hold a conversation with someone who doesn't understand ME/CFS so give yourself permission to only share what you are comfortable with.

"You're looking well"

This statement can be hard to hear, especially when you are not feeling well. People that do not have ME/CFS may not see the doubt and judgement that those words carry to someone with an invisible illness. It can be useful to try to take this at face value and the judgement that can be felt from others is coming from within.

"What have you been up to?"

Another seemingly innocuous statement to others can be tricky to navigate for someone with ME/CFS. The honest answer may be 'I have a full time job looking after someone with a chronic illness (me!)'. However our health is something we may choose to keep private, so it can be helpful to have some pre thought out answers.

The bottom line

Release relationships that are no longer suitable, set good emotional boundaries, let go of negative self-talk and protect yourself in social situations.

References; Rosan, E. (n.d). Nourishing relationships. ME/CFS & Fibromyalgia Self-Help. Retrieved from [Nourishing Relationships | ME/CFS & Fibromyalgia Self-Help \(cfsselfhelp.org\)](https://cfsselfhelp.org/Nourishing-Relationships-|_ME-CFS-&-Fibromyalgia-Self-Help)