

Advice to a New Patient

by Bruce Campbell

from the **CFIDS/Fibromyalgia Self-Help Website (Offering self-help resources)**

www.cfidselfhelp.org/artcl_advice.htm

What are the most important things to remember in coping with
Chronic Fatigue Syndrome (ME) or Fibromyalgia?

We asked that question of several groups of people participating in our programme. Specifically, we asked them to imagine that a newly-diagnosed CFIDS or fibromyalgia patient approached them for advice, asking what three or four things they had found most helpful in coping with their illness.

Their responses clustered into six themes. About two-thirds of people mentioned one or more aspects of the following three ideas:

1. Accept Your Illness

Whether you have CFIDS or fibromyalgia, your illness is real, physical, and long-term. Getting it was not your fault. While you should accept that your illness is long-term, you should also be hopeful because there is much you can do to improve your life. Rather than fighting your condition, be compassionate toward yourself as someone with a serious illness.

As one student said “the single thing that has probably helped me most with living with my disease is accepting that I have a chronic illness. Since I started to plan my life around my illness, my life seems to have improved. For a long time, I was in denial of my disease and lived in hope for the day it would just go away. My life seems better since I accepted that I have to adapt to the illness.”

Another student emphasized the challenge of adjusting to loss. She said that a new patient is likely to go through a grieving process before reaching acceptance. “We grieve the losses this disease has caused in our lives. Our lives are drastically changed by our illness.”

2. Live within the Limits of the Illness

Adjusting your activity level to the limits imposed by the illness is one of the most helpful coping strategies you can use.

In our course, we call it “living within the energy envelope.” The idea is that we have less energy than before. If we try to do too much, we usually trigger an intensification of symptoms that forces us to rest.

In contrast to living life on this roller coaster, we can gain some stability if we learn to live within our limits.

To do this, you need to learn to listen to your body and respect its needs. Having limited energy imposes the need to simplify and to prioritize. By pacing yourself (balancing activity with rest) you can gain some control over your illness and bring stability to your life.

One student summarized the idea of accepting limits by saying she would advise “setting priorities, really getting down to basics and saying no to activities that do not fall within our personal agendas.

It is essential to preserve our energies for activities that help us get better. This becomes most difficult when we hate to disappoint special people in our lives, but we must remember that if we do one thing, we can't do another.”

Another said that she believes the key to living successfully with chronic illness is to adapt life to the illness, and not just as a short term strategy. Looking back, she believes she clung to the idea of getting better too long. “I really needed to be told, life will not be the same. I needed to learn to manage my life from that point on, very carefully, much as diabetics and others with chronic conditions do.”

3. Get Support

Chronic illness can be isolating and demoralizing. Others may not always understand or sympathize. Having people in your life who acknowledge your suffering and offer support can be crucial.

Seek out support from fellow patients, who understand because they share your situation. Stay connected to family and friends to the extent possible, but be realistic in your expectations. Some people may never understand.

A third to half of those responding mentioned three other themes:

4. Keep a Positive Focus

Though there is as yet no cure for either illness, improvement is a real possibility. Through your efforts, you can gain some control over your illness.

Regardless of your situation, it is possible to lead a meaningful life, so value and take care of yourself. In the words of one student: You have a choice in every situation. You can be defeated by it or learn and grow from it.

5. Educate Yourself

Many treatments are used for the two illnesses, with new developments occurring all the time. No cure has been found to date for either illness and no treatment has proven widely helpful. Seek out information and options about the illness. Experiment to find what works in your individual situation.

6. Rest Daily

Integrate regular periods of rest into your day, regardless of how you feel. (In the course, we call this “pre-emptive resting” or resting as a preventive measure.)

By taking scheduled rests - lying down with your eyes closed in a quiet place - you may be able to prevent flare-ups or reduce their intensity. Such rests can help lower symptom levels and increase a sense of control.

Other themes

Other themes mentioned included getting exercise and avoiding stress. A surprising result was that only about one person in ten mentioned medical care as being important to their coping.

Summary

In summary, members of our groups think that the foundation for coping with CFIDS and fibromyalgia lies in the combination of accepting the long-term nature of the illnesses, adjusting one’s life to live within the limits imposed by illnesses, and having supportive relationships.

They also believe that a hopeful attitude is both realistic and effective, and that self-management includes education about the illness and experimentation to find what works in an individual situation.