

Coping with chronic illness

In coping with the illness, what have you found to be un-useful or unhelpful coping methods?

What have you found to be helpful coping methods in terms of everyday life?

Have you learned how to say “No” when you need to?

Also, when you are in a relapse, how do you care for yourself? What are the best ways to “ride-out” a relapse? How do you get help during a relapse?

Have you found things to do that give you pleasure and “take you away from the illness?”

Coping and Hoping - Priscilla Larson - Coping Tips

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

- “Respect yourself enough to explore what affects you beneficially as well as adversely. Watch yourself. Analyze your needs.”
- "Don't stop doing the things you love but do them on a different level. Have a windowsill garden instead of a yard one, listen to music instead of performing."
 - "Keep a list of things you like to do and do them according to your energy level."
 - "Do what gives you satisfaction and pleasure."
 - "I listen to my body when it calls out with a need."
 - "I've learned to rest before I'm totally drained. "
 - "I give myself plenty of time to prepare for anything, rest time."
 - "I gave up on trying to be perfect."
 - "I try to learn or enjoy every moment that I can."
 - "I don't waste energy on negative thoughts."
 - "I've learned to let people help me."
 - "I plan an enjoyable activity every day."
 - "I keep a journal."
 - "I bought an answering machine."
 - "I stay involved in my health care seeing a doctor regularly."
 - "I disconnect the phone whenever I need an uninterrupted nap."
 - **"I have simplified my life by learning to say 'No.' "**

- "I accept myself as I am now, not as I was before."

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

- *Change your outlook*—ME/CFS, FM or any other chronic illness will bring people to a fork in the road: one path can lead to bitterness, anger and despair; and the other can bring peace, acceptance, hope, and courage. When you cannot change your circumstances, then the only choice is to change your reaction and attitude. Moreover, changing how you get through daily activities should not take away from your intellect, sense of humor, and overall value. Do not measure your worth by how much can be accomplished. Sometimes your opinion of yourself may be based on inaccurate information or unreasonable expectations.
- *Reduce stress*—organize your day so that you can be in control of your time and activities, allow a "cushion" of extra time to minimize rushing. Evaluate if a particular situation warrants the kind of reaction or attention that you're giving it. Walk away from stressful situations that are not yours, and try to avoid toxic people.
 - *Seek a support system*—when you find that you are becoming more isolated and lonely due to the illness, seek and develop outside sources of support with people who can relate to your situation.

<https://www.massmecfs.org/living-with-fibromyalgia?start=6>

Incorporate play and laughter

An important part of pacing in the work/rest routine is to have a little pleasure and not when all the work is done!

Don't postpone fun until when you feel better or new medicine is found for a cure. You need it now!

It is crucial to find ways to escape or distract yourself from the illness. There is more than one way to have fun and it doesn't have to be what you did before.

Read uplifting/inspirational material, chat with friends, get some fresh air by taking a brief walk or sitting on a porch, or watch a funny tape or TV show.

Look out for new things to try like container-gardening that can be done on a balcony or deck; attend a class or presentation (many local libraries offer free programs or lectures on various topics); treat yourself to a cup of tea at Barnes & Noble while you browse through magazines; listen to soothing music; and/or consider getting involved with a little volunteer or advocacy work.

Look for small pleasures and things that still bring you joy and comfort. Every so often, it is important to put the "what if's" aside (with regards to what might happen if I go and participate in this activity) and take an occasional gamble at trying something different or going out somewhere.

The outcome could turn out to be a very positive experience, the dreaded consequences may not be as bad as feared, and even if they are, it just may be worth it psychologically for the chance to break away from the drudgery of the daily grind.

<https://www.massmecfs.org/living-with-me-cfs/104-steps-to-happiness>

Everybody Knows:

You can't be all things to all people.
You can't do all things at once.
You can't do all things equally well.
You can't do all things better than everyone else.
Your humanity is showing just like everyone else's.

So:

You have to find out who you are, and be that.
You have to decide what comes first, and do that.
You have to discover your strengths, and use them.
You have to learn not to compete with others, because no one else is in the contest of being you.

Then:

You will have learned to set priorities and make decisions.
You will have learned to live with your limitations.
You will have learned to give yourself the respect that is due.

<https://www.massmecfs.org/more-resources-for-me-cfs/472-tips-for-living-with-cfs-and-fmin-real-life-and-online-communities?start=1>

Realistic Expectations according to the stage of the illness - When it comes to expectations, patients need to consider the role of outside sources on their own expectations and personal assumptions, fears or beliefs which they themselves could be attaching to these. For instance, patients might be trying to live up to their pre-illness level or they might be doing more than they can realistically handle, for the sake of gaining approval.

It is important to remember that *no one can be everything to everyone*; people who push themselves and attempt to do this will only further jeopardize their health and self-esteem.

Realistic expectations are linked to time—the period of time when a patient tends to feel or function at their best. This window of time should be spent on high priority tasks or something meaningful to the patient—time is a precious commodity which needs to be used judiciously.

<https://www.massmecfs.org/living-with-me-cfs/41-the-joy-box>

A Project for Those Non-Day Days

Something to prepare for those days when you're feeling especially sick or blue is your own personal "joy box." Take a large old shoe-box or other container and wrap it (and the lid separately) in brightly colored paper or whatever pleases you (stickers, rubber-stamp images, decoupage, paint, glitter glues, clips from magazines, photos of places you'd like to travel, etc.).

Fill the box only with items that bring joy to you: seashells, photos of your family and best friends, pictures of favorite places, treasured letters and notes from friends, small toys, anything that uplifts your spirit—be creative and fill the box! Then, when you're having a particularly rough day, close your eyes and reach into the box (shake first!) to see which particular joy you've selected. Spend time letting your mind wander about what the "joy item" brings to mind—take a mental vacation and relax, thinking about dear friends, happy memories, favorite places, the joys you still have in your life.

(Idea adapted from *Gypsy's Words of Wisdom* Online Newsletter)