



Solve M.E. Patient and Caregiver Resource Guide: Mental Health and Chronic Disease

ME/CFS and Long Covid are not psychiatric illnesses. However, it is common for people with serious medical issues to experience secondary anxiety and depression, and patients with ME/CFS or Long Covid are no exception. Feelings of anger, grief, hopelessness and guilt are common as well.

It is important to address the issues of loss – multiple areas of loss in one’s life can be directly attributed to ME/CFS or Long Covid. Such as, loss of professional identity, loss of income and financial security, loss of driving, which can lead to loss of independence, and most importantly, loss of overall health and well-being.

Other losses yet to be named, are no less important. They may be more subtle, often unspoken losses, but are just as devastating as those previously mentioned. The loss of self-confidence, loss of friends, loss of ability to maintain intimacy, loss of ability to parent adequately, loss of ability to express one’s creativity; and after multiple hospitalizations, testing and doctor’s examinations, modesty can even be taken away.

If you’re having anxiety or depression, counseling and complementary therapies (mindfulness techniques such as yoga and meditation) may be of help. Be aware that “cognitive behavioral therapy” has not actually shown significant long-term improvement in patients with this disease despite the fact that it is often recommended by physicians.

Antidepressants and anti-anxiety medication have been found to help some patients, while others report no benefit and/or harmful side effects. If you are considering a trial of medication, talk through the options with your healthcare provider.

Also, keep in mind that stress is a type of mental exertion and can potentially trigger PEM. While easier said than done, do what you can to reduce, minimize or avoid stressors whenever possible. Support groups exist to help patients share their experience and learn from others who truly understand the disease.

Online Support Groups:

1. [ME/CFS Weekly Phone Support Group](#)
2. [Bateman Horne Center Crisis Support](#)
3. [ME Action Support Groups](#)
4. [Center for Chronic Illness](#)

ME/CFS WEEKLY PHONE SUPPORT GROUP

ME/CFS Weekly Phone Support Group – Saturdays at 8 pm EST

(609) 746-1155; 915110#

OVERVIEW:

This is a peer-to-peer ME/CFS support group. This call is designed to support one another through the hardships of this illness by listening and sharing experiences. Join us from the comfort of your own bed, with others who understand. Most participants have ME/CFS, but family & friends are very welcome to join the dialogue, so we can all benefit from sharing different perspectives and information.

Each call is different, focusing on the topics that participants want to talk about that evening. Discussions can cover a wide range of matters, including symptoms, socializing, research, treatments, diet, the isolation and stigma of this disease and advocacy efforts. A typical call runs 1-1.5 hours, but you can join for a shorter period.

Click on the 'EVENTS' section for this group to RSVP for a call. If you RSVP, that call will be added to your Facebook calendar as a helpful reminder. We prefer you to RSVP, but you can still join the call without an RSVP.

Please be respectful of others' opinions and journeys. No solicitation for any business or product will be tolerated, as this is for social support only. If you have any questions, feel free to ask.

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INSTRUCTIONS FOR JOINING:

Participant Instructions

Dial-In Number: (712) 770-4700

Enter your Access Code: 915110 followed by # sign.

TIP: Add the dial-in to your mobile phone's contacts or calendar reminder for easier dialing

Blackberry Friendly: 712-770-4700×915110#

iPhone Friendly: 712-770-4700; 915110#

All are welcome to join this free conference call (U.S. based phone #). International participants can download "Free Conference Call" in the app store and connect via the Internet for free. For information on the app, go to <https://www.freeconferencecall.com/apps>. Certain local in-country dial-in numbers may be available – reach out to the group admins to check.

Pay Attention to Mental Health as Physical Health Declines

Written by Susan Rebecca Culbertson, MSW LISW

How do we manage our mental healthiness when we expend so much energy by simply bathing, getting dressed, brushing hair, arranging transportation to go out, walk to our destination (already feeling exhausted) and are told by the first person we bump into, “You don’t look sick!”. How do you hold onto your self confidence, and not just want to go home and climb back into bed? How do you control your anger and hurt feelings? How do you go on? There are no easy answers, but there are ways of managing internal thoughts that can help prevent any further decline of mental health.

It is vastly more important what you tell yourself, than what another person says to you. You can actually translate, “Well you don’t look sick!” into “That person really doesn’t understand ME/CFS, and how hurtful that comment is”. You can always say “Thank you!”, and move on quickly. You can send a blessing out to the universe mentally, saying “May this person never know a chronic illness”.

Thoughts travel through your mind on the same neural pathways as the spoken word, so therefore you do have control over what you allow to enter your consciousness.

Although it is very important to stay positive and “future think”, it is also important to be realistic with your internal thoughts. It is easy after a stretch of nine or ten good days, especially if consecutive, to know that you are feeling stronger and you have the desire to make future plans, (i.e., tomorrow I will do

laundry; let's meet on Tuesday for lunch; yard work on Friday). Then the ME/ CFS reminds you of it's presence - crushing fatigue, mental disruption, pain in every joint, etc., etc., etc.

It is your job to learn to ride the roller coaster with as little emotional disruption as possible. The energy you do have is best used toward recovery, not wasted on anger and frustration. It is a mindset change, not an easy thing to accomplish, but also not impossible!

The ups-and-downs and wild turns create not only a "roller coaster" for you, but also for your close family and friends. I am not suggesting an emotional shut-down; what I am suggesting is an opportunity to learn to redirect your energy only toward positive thoughts. Research has shown the best predictor of any type of success has a direct correlation to the degree of positive attitude exhibited by the person being tested.

As you begin this transformation from your usual negative thought, such as "Oh no! Here it comes again!", to a new more positive thought, "I better rest now so I can get through this smoother and faster!". This can be the beginning of your transition to a more positive outlook. Again I remind you, I am not suggesting an emotional shutdown. I am, however, suggesting that you pass through the frustration and pain as quickly as possible.

There are several options included for Negative Release Exercises at the conclusion of this section. Over time you may be able to shorten your negative frustration time, and find your return to positive energy smoother and more fluid with practice. Just a precautionary note: we all advance in our own time. No two fingerprints are the same, and no two negative transformation times are the same.

We all have our own unique path and method to recovery. We must be kind to ourselves during the times of frustration and personal anguish – sometimes will be more difficult than others, and that's ok! The important thing is to just keep trying, and doing the best of which you are capable.

NEGATIVE RELEASE EXERCISES

1. Journaling - Writing down your thoughts, negative or positive, can be a valuable tool in your daily effort to release negative emotional content. It can be surprisingly useful to keep a daily “Appreciation Log” where you record at least three things: people, circumstances, abilities, etc. that you sincerely appreciate. Research has shown that we have the same thoughts day after day. In fact, as high as 98% of our thoughts may be repeated daily. Change your thoughts, change your life!
2. Emotional Release - Do not ignore or stifle your body’s natural response to stress. It is not a weakness, but a strength, to recognize when your body desires to release stress through tears, verbal expression, or even screaming. Preferably not screaming AT another person, but productive screaming as an outlet of emotion, directed mentally at your chronic illness in a private place where your inhibitions are not in check.
3. Music - Yes, music can soothe the soul. Passive listening can be achieved even on your most physically limiting days. Active participation, if you are so gifted or so bold, can be an ultimate spirit lifting experience even on your most “down” day. Select your genre carefully, find what is right for you, from rock to classic, this is a very personally tailored emotional release that anyone can achieve in the privacy of their own home.
4. Candles - Lighting one candle or more can help pull me out of a “dark” day. If you are bedfast, keep a candle on a bedside table within easy reach. Unscented candles may be best for you, as scented ones can sometimes affect persons with Fragrance Sensitivities. However, if you have a favorite scent, indulge in the olfactory pleasure until your spirits are lifted! Battery powered candles are a nice worry-free choice.
5. Tailor a Plan for yourself - list other negativity releasers that you find personally cleanse both your negativity and repetitive self-defeating thoughts. While you may not be able to change your illness (at least at this

very instant), with determination and practice you can get pretty good at changing your mood. Aim for soothing, not final solutions. Often there is a significant satisfaction in achieving some relief, even when you know you can't totally resolve an issue. Relief and soothing, "Ah, that's better".

CHRONIC ILLNESS FORMULA FOR REALISTIC GOAL SETTING

Your goals should be rewritten as many times as you desire. Short term goals can be rewritten weekly or monthly, and long terms goals could be rewritten once or twice a year. You will find that your goals change as your health changes. They may go backwards or forwards, depending on your physical gains or losses. I encourage you to take breaks away from any pressure you may experience if goal setting feels overwhelming at any point. And, you must continue to remind yourself, that is ok! It is more than ok, it is normal for a chronic illness.

Don't forget, be flexible! It is useful to make all of your goals flexible and open to change at any point in time. But don't give up your future goals just because you have been unfortunate enough to have a chronic illness. The lack of goals, plus a lack of hope can lead to anger. Anger and frustration can quickly consume the energy otherwise available for hope.

At times you may vacillate between feeling hopeful about a treatment and a cure for this frustrating illness, to feeling hopeless about ever having your body return to normal. It is best to learn to quickly shift your thoughts back to hopeful ones!

Stay realistic and hopeful!

Date:

Setting mini steps that can be attained, what I name "chunking down" is the first focus of this exercise. The second focus is to never lose sight of your idealized fantasy goals.

Let us begin with a small plan:

Today my goal is

Small steps to accomplish this are

By next week I want to have accomplished

Small steps to accomplish this are

Let us move to a larger plan:

In six months I will have accomplished

Small steps to accomplish this are

In one year I will have accomplished

Small steps to accomplish this are

Let us move to my idealized fantasy goal:

In five years, I will have accomplished

Small steps to accomplish this are