



Fatigue

Everyone experiences fatigue—a feeling of low energy and tiredness—from time to time. Fatigue after exertion or a period of hard work, or when it is time to sleep, is normal and improves after resting, sleeping, or engaging in another activity that restores energy. Some people, however, experience fatigue that does not disappear after these restorative activities. This type of fatigue is distressing and makes it difficult to enjoy a good quality of life.

Persistent fatigue that responds poorly to rest is a frequent symptom for people with cystic fibrosis (CF). It can have a negative impact on physical and emotional well-being, making it harder to keep up with CF treatment, do activities you previously enjoyed, perform your best at work or school, or maintain relationships.

What Are Some Signs and Symptoms of Fatigue in CF?

A person with CF may describe persistent fatigue in different ways. If any of these experiences become chronic or distressing, discuss them with your CF care team, as treatment may be needed.

Physical fatigue: Your body feels weak and becomes exhausted even after little or no activity. This weakness can discourage you from starting or continuing activities.

Mental fatigue: You have difficulty concentrating, a short attention span, memory problems, or feel less alert than before.

Emotional or mood-related fatigue: You feel too tired to cope with problems, and your stress may feel overwhelming. Your mood may be sad, and you may be irritable or impatient with others.

What Can Cause Fatigue in CF?

Persistent fatigue may be directly related to problems caused by CF or it may be related to other conditions—physical or emotional. Sometimes, the cause of persistent fatigue cannot be found. If a cause of persistent fatigue can be identified and treated, the fatigue is likely to improve. Describing your fatigue symptoms to your CF care team will help them look for treatable causes.

When a person with CF develops a pulmonary exacerbation or a chronic infection in the lungs or sinuses, or if lung disease becomes advanced, fatigue is very likely to occur. Other CF-related problems that lead to fatigue include malnutrition, poorly controlled diabetes, or conditions like anemia, depression, anxiety, or chronic abdominal pain.

Some medications, like antidepressants, can cause fatigue as a side effect, and some people develop fatigue as a result of using alcohol or drugs like cannabis.

Sometimes, fatigue occurs because a person has been spending most of the day in bed or in a chair. Even just a week or two of very limited activity can lead to fatigue that persists.

What Can I Do to Help?

There are a variety of strategies for coping with fatigue. Self-management approaches that you can do on your own are extremely important.

Physical Activity

Although it may be surprising, physical activity, which might normally produce tiredness, is actually an effective treatment for persistent fatigue. Activity needs to be planned, however. Before starting an exercise program, discuss it with your CF care team. The usual approach is to start exercise at a very low intensity, such as walking for 10 minutes 3 times per week, then slowly increase. There should be specific goals for progress. Sometimes it is helpful to find someone who will support you in starting and keeping with your goals (see the Goal Setting Form below for tips).

If fatigue is particularly bad, such as after a period in the hospital, you might start physical activity with the help of a physical therapist. A physical therapist can help make a plan for conditioning and exercises that can help with effective breathing.

Improving Sleep

Some people with CF have fatigue because of poor sleep. Self-management of sleep problems may be helpful, sometimes combined with treatments suggested by your care team. Try to improve your sleep by doing the following:

- Go to bed at the same time every night and set an alarm for the same time every morning.
- Limit your intake of caffeine (coffee, tea, and cola beverages). Avoid drinking caffeine-containing beverages after mid-afternoon.
- Avoid meals and alcohol late in the evening.
- When it's time for sleep, turn off the lights, television, and mobile devices. If sleep does not come after an hour, it is fine to get up, but sit quietly in a chair and try to return to bed after a short time. If you feel that stress or thoughts from the day are intruding, use one of the self-management approaches described below, like a relaxation approach or meditation.

Activity Pacing

Activity pacing includes ways to spread out activities throughout the day to allow yourself time to recover your energy. For example, you may consider scheduling important tasks, like chest physiotherapy, when you have more energy or when you will have time to rest afterwards. Consider simplifying your schedule by dropping some tasks that are not necessary or cause excessive fatigue, or delegating these to others. Think about planning and spacing out activities—not just throughout the day, but also throughout the week.

Psychosocial Approaches

Cognitive behavior therapy (CBT) and other psychosocial approaches may help to reduce fatigue. CBT is a type of psychotherapy that can improve emotional distress and teach coping by helping people change unhelpful thoughts and behaviors. Members of the CF care team, or a mental health professional, may be able to help you start using a CBT approach and provide access to a fatigue-focused CBT program.

Mindfulness-based stress reduction, meditation, passive and progressive muscle relaxation can be done on your own as part of a self-management program.

Among the relaxation approaches that are easily learned are deep breathing and guided imagery. See the examples below.

Family and friends can be enlisted to help you cope with fatigue. Remaining active without overdoing it may be much easier if there is a group of family or friends who can assist with tasks while encouraging the activity program that you have planned. Receiving emotional support from loved ones can also help reduce stress and emotional fatigue.

Integrative Medicine Approaches

Many integrative medicine approaches are well accepted by medical providers, and some involve self-management techniques that you can learn to do on your own. You may try massage or acupuncture, if available, as part of a program to address persistent fatigue. Music or art therapy, can be done on your own or with others.

Relaxation Approaches

• Deep breathing

- Make yourself comfortable.
- Breathe in through your nose (or mouth if your nose is congested).
- Lay your hands over your abdomen (**not your chest**) and feel your hands gently rise and fall.
- Relax your abdominal muscles.
- Take slow, deep breaths.
- As you gently breathe out, release your tensions and feel these flow out.

• Guided imagery

- Find a quiet place to yourself.
- Comfortably pace your breathing—slowly and deeply.
- Close your eyes and imagine a peaceful or happy scene in which you feel relaxed and safe. Include the sounds, smells, and colors.
- Repeat this every day for 5 minutes.

Progressive muscle relaxation also can be learned.

Progressive Muscle Relaxation

Progressive muscle relaxation involves gradually tensing, and then relaxing one area of the body at a time, eventually bringing relaxation to your entire body. This involves tensing groups of muscles, then releasing the tension and focusing on the relaxation you experience. Do not tense to the point of feeling pain, and be careful about tensing areas where you may have an injury.

Preparation:

Find a comfortable, quiet place where you will not be disturbed for 15-20 minutes. Sit or lie down, wear comfortable clothes, and make sure you are comfortably warm before starting the technique.

Instructions:

1. Focus your attention on one part of the body at a time.
2. Breathe in as you tense the muscles of that body part.
3. Hold the tension for 5-7 seconds.



4. Release the tension and relax the muscles.



5. Focus on the muscles relaxing for 10-20 seconds before moving to the next body part.
6. You can start by tensing and relaxing your facial muscles, followed by your neck and throat, shoulders and back, arms, hands, chest, abdomen, thighs, legs, and finally feet.

Medication Management

You may want to speak with your CF care team about your medications. Sometimes a drug is contributing to fatigue, and changing it or reducing the dose may help. Occasionally, a drug treatment is tried specifically to improve fatigue.

What Can My CF Care Team Do to Help?

Your CF care team will investigate your symptoms of fatigue. Treatments may focus on the underlying cause of your fatigue, such as CF lung disease, anemia, malnutrition, pain, sleep disturbance, or substance use. Your CF team may suggest changes in your medications, or other treatments that directly address the fatigue, such as training in self-management approaches or exercise.

What Else May Help?

Joining a support group or talking about it with others could help. You can find another person with CF who has had similar experiences like yours through the CF Foundation Peer Connect (cfpeerconnect.com).

What Should I Tell My CF Care Team at My Office Visit?

If fatigue is keeping you from completing your CF treatments or preventing you from enjoying your daily activities, speak to your care team. Sudden onset of fatigue should be brought up sooner. Describe your symptoms and possible triggers. Your team may want to know about your sleep pattern, diet, activities, and stressors. Using a symptom tracker or log may help (see the handout, *Stress Among Adults with Cystic Fibrosis (CF) and Their Loved Ones*, included in this series).

Your CF team's expertise, when combined with your expertise, has a greater chance of solving the problem of your fatigue than working on it alone. Don't hesitate to ask for your team's collaboration and help to tackle this together!

What Can I Expect if I Use Highly Effective CFTR Modulators?

If you use highly effective CFTR modulators, you may experience increased energy levels, increased physical endurance, or little or no impact on fatigue at all. Everyone is different and may be affected by CFTR modulators differently.

Goal Setting Form

Goal Setting: What does it require?

A goal should be:

- measurable
- realistic
- specific
- behavioral
- “I” centered (something you can do)
- desirable

List the goals that you would like to accomplish in the next month. Use the above suggestions to help develop your goals. Choose the one goal that is most important to you and identify the steps that you feel are reasonable to reach that goal. Create a weekly action plan and identify possible obstacles along the way, as well as solutions for dealing with them. Remember to focus on the benefits you will experience, and celebrate each success...it’s the best part!

Goal: To increase my physical activity.

This week, I will walk around the block twice before lunch on three days.

This week I will walk around the block (what)
twice (how much)
before lunch (when)
3 days this week (how many)

WEEKLY PLAN		
	TIME OF DAY	COMMENTS
Monday	At 10:00 a.m.	Started off slowly. Felt a little tired, but good.
Tuesday		
Wednesday	At 11:00 a.m.	Rained. Didn’t walk today.
Thursday		
Friday	At 10:00 a.m.	Walked an extra block to make up for Wednesday. Felt less tired.
Saturday		
Sunday		

Adapted from Margaret Caudill, PhD (1995) *Managing Pain before it Manages You*; and Lara Dhingra, PhD 5/18/2020.