

Fatigue can have both physical and mental aspects. People with fatigue may have reduced stamina and energy levels, and many also experience problems with concentration and memory. Fatigue can have a significant effect on quality of life, especially when it's severe.^{1,3,4}

Want to find out more about Fabry disease?

Visit www.fabryfacts.com for more information about Fabry disease. Topics include genotypes, phenotypes, diagnosis, prognosis, and why mutations matter in Fabry disease.

A guide for people living with Fabry disease

Many people who live with Fabry disease suffer from fatigue—a deep feeling of tiredness that rarely goes away completely, even after rest or sleep.^{1,2}

UNDERSTANDING AND MANAGING

FATIGUE

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Possible effects of fatigue in Fabry disease

Daily activities

Reduced energy and stamina can make it hard for adults with Fabry to keep up with necessary daily tasks, such as cooking, housekeeping, and grocery shopping. Children with Fabry may have too little energy to participate in after-school activities.

Work and school

Memory and concentration problems can make the demands of academic or professional work difficult to meet. Attending school or having a job may be virtually impossible for Fabry patients whose fatigue is especially severe.

Social life

People with fatigue may lack the energy to socialize and may feel isolated and lonely as a result. Adults may worry about the impact of fatigue on their relationships with their partners, other family members, or colleagues, and children may struggle to make friends.

Causes of fatigue in Fabry disease

Although fatigue is common in Fabry disease and in many other chronic diseases, its exact causes are often unknown.^{1,2} In Fabry disease, some evidence suggests that serious complications such as heart, kidney, or lung problems may contribute to fatigue in various ways. For example, certain problems with the kidneys or heart can lead to anemia, which may reduce energy levels, and lung or central nervous system problems can cause disordered breathing which makes it hard to get a restful night's sleep.^{1,5,6} However, exactly how these and other complications of Fabry disease contribute to fatigue is not fully understood. Additionally, many patients with Fabry disease who don't have serious complications still suffer from fatigue.¹

It's important to discuss your fatigue with your healthcare provider to see if any specific cause can be identified and to decide how best to manage your symptoms. You should also keep in mind that fatigue does NOT necessarily mean that you've developed a complication or any other serious problem.

Curling up with a (non-electronic!) book can be a good way to wind down for the night. **Cut off this chart at the perforation and fold it into a handy bookmark** that you can use to mark your place and to remind yourself to give these suggestions a try.

Managing fatigue: some suggestions and reminders

There's no specific medical treatment for fatigue, but there are actions that may help. The chart below suggests some simple changes to your habits and routines that might make a noticeable difference in your energy level, especially if you stick with them consistently. Consider giving them a try to see if they work for you.

Budgeting energy⁴



- Try breaking your daily chores and activities into short periods balanced with periods of rest.
- Planning each week in advance can help ensure that no one day is excessively busy.
- Although it may be tempting to overexert yourself when you're feeling well, remember that doing too much might exhaust you and cause you to crash.⁴

Reducing stress^{2,4}



- Stress drains mental energy. Learning to say no without guilt can help.
- Building time to relax into your daily schedule helps you make regular rest a priority.
- Reducing stress can be enjoyable as well as rewarding. Explore stress reduction techniques to find one that you enjoy. Consider taking a gentle yoga class, trying out a guided meditation app, or taking walks in a local park.

Working smarter⁴



- Making lists and using calendars or schedulers may help you stay organized and work more efficiently (especially if you have problems with memory or concentration).
- Grouping similar tasks together can help you conserve energy. For example, grouping household chores by room can reduce the need to walk and climb stairs.

Exercising (gently!)^{3,4}



- Daily light exercise, such as gentle stretches and strengthening exercises, may help you feel better.
- It's important to break exercise sessions into short intervals followed by periods of rest.
- It's also important to listen to your body. If exercise makes you feel more fatigued, it's not helping!
- Be sure to talk to your healthcare provider before starting any exercise routine.

Establishing good sleep habits^{2,3,7}



- Following a consistent bedtime routine every night can help you wind down.
- Avoiding bright light and the use of electronics (including computers, handheld devices, and TVs) before bed may help you fall asleep more easily.
- Controlling noise, light, and temperature in your bedroom can create a more comfortable environment for sleep.
- Caffeine (found in coffee, tea, chocolate, and some headache remedies) and alcohol can disrupt sleep. Reducing your intake of both may help you sleep better.

Staying cool⁴



- Dressing in layers helps keep you prepared for changes in temperature.
- Carrying a reusable water bottle (and refilling it regularly) makes it easier to stay hydrated.
- Staying in the shade can help you stay cool. Consider limiting activities that require spending too much time in direct sun.
- A cooling vest (a thin garment that holds cooling packs next to your body) can be helpful on especially hot days.