

FitFacts®

Exercise and Systemic Exertional Intolerance Disease (SEID)

IN FEBRUARY 2015, THE INSTITUTE OF MEDICINE RELEASED A [REPORT](#) RECOMMENDING A NEW NAME FOR THE DISABLING MEDICAL CONDITION COMMONLY KNOWN AS CHRONIC FATIGUE SYNDROME (CFS) AND MYALGIC ENCEPHALOMYELITIS (ME). *SYSTEMIC EXERTIONAL INTOLERANCE DISEASE (SEID)* IS A MORE ACCURATE NAME, THE IOM EXPLAINS, BECAUSE EXERTION OF ANY TYPE—PHYSICAL, COGNITIVE, OR EMOTIONAL— *“CAN ADVERSELY AFFECT PATIENTS IN MANY ORGAN SYSTEMS AND IN MANY ASPECTS OF THEIR LIVES.”*

ARE THERE EXERCISE GUIDELINES I SHOULD FOLLOW?

If you're living with SEID, you may be wondering what type and how much exercise you can do without making your symptoms worse. Because everyone experiences SEID differently, and a great deal of research is still needed, there are no standardized exercise guidelines for people with SEID.

It is clear, however, that a traditional exercise program of cardio and strength training is *not* appropriate for people with SEID because of the nature of the disease. High—and even moderate—levels of physical activity are generally not tolerated well and often exacerbate symptoms.

The good news is that you can find a level of activity that works for you; talking with your health care provider is the best place to start. Whether you begin with gentle stretching, light walking, or other activities will largely depend on your current symptoms and fitness level, and knowing the triggers that make you feel worse.

ARE THERE ANY BENEFITS OF PHYSICAL ACTIVITY FOR ME?

Because of reduced activity due to disabling symptoms, people with SEID tend to have lower fitness levels, including low levels of endurance, strength, and flexibility. Regular exercise at a level you can tolerate can help prevent further deconditioning and enable you to maintain the strength, flexibility, and energy you need for everyday activities.

Being as active as you can also contributes to cardiovascular health, brain health, emotional wellness, an enhanced sense of well-being, and a better overall quality of life.

WHAT PRECAUTIONS SHOULD I TAKE?

Ask your healthcare provider about specific dos and don'ts based on your health status. The following are general precautions and tips for people with SEID interested in becoming more active:

- Get evaluated for any muscle strength imbalances, joint issues and deconditioning. Addressing these issues before beginning an exercise program will help reduce your risk of injury.
- Keep an exercise and symptom log to discover what kinds and how much exercise you can tolerate without triggering a relapse.
- Start low and go slow. Many people mistakenly engage in a push-crash cycle of activity in which they go hard and soon after experience debilitating post-exercise fatigue. It's better to do less than you think you can than to do too much.
- You may want to start with activities of daily living—such as getting out of bed, taking care of personal hygiene, cleaning the house or checking the mail. Back off and rest before your symptoms get worse.

- For most people, everyday life involves walking—or rolling, for those using wheelchairs. Some people find walking in the shallow end of a pool more comfortable. Consider trying a 2–3 minute walk or roll at an easy pace. Rest for at least three times as long as you exercise. If this doesn't make your symptoms worse, try it again tomorrow, or the next day, or whatever feels right for you.
- Focus on increasing exercise duration, not intensity. Gradually increase your exercise time as long as your symptoms don't flare up. Pace yourself according to the other physical, cognitive, and emotional challenges you face on any given day and make sure you get the rest you need.
- For strength exercise, start with resistance bands, tubing or weight machines with light workloads. The National Center on Healthy, Physical Activity, and Disability recommends holding each contraction for 3–5 seconds each, for 3–6 repetitions and strength-training three times a week according to your ability. For best results, work with a certified fitness professional for a program tailored to your needs.
- Gentle stretching exercises help maintain a normal range of motion around your joints. Stretch to the point of tension and hold for 10–60 seconds. Repeat each stretch 2–4 times as you are able. Perform stretching exercises two to three times a week or more, as long as your symptoms do not worsen.

EXERCISE MATTERS

When you're living with SEI, sometimes just getting through the day can be difficult. Getting started with exercise and getting to know what level you can tolerate will take patience and persistence. But you may be surprised at how the right level of physical activity can help you feel better and perform daily activities with less effort.

If you want to begin an activity program but don't know how or where to start, a registered physical therapist or [certified fitness professional](#) with experience and training in SEID can help.

ADDITIONAL RESOURCES

[National Center for Health, Physical Activity, and Disability](#)

[Centers for Disease Control and Prevention](#)

American Council on Exercise® is a nonprofit organization dedicated to empowering people to live their most fit lives. In addition to offering quality certifications and education for health and fitness professionals, ACE also protects the public against ineffective products, programs and trends by arming them with unbiased, science-based health and fitness information. To learn more about ACE, or how you can use or purchase Fit Facts, visit ACEfit.com/FitFacts.