

SCLERODERMA – MANAGING FATIGUE

An information guide to managing fatigue
with scleroderma



scleroderma **australia**

What is fatigue?

People describe fatigue as feeling tired, mentally exhausted, or physically overwhelmed day after day, no matter how much sleep they've had or what they've been doing, even if it's just everyday tasks.

Fatigue is a common challenge for people living with chronic conditions, including scleroderma. In fact, people with scleroderma in clinical studies have listed fatigue as one of the top 3 symptoms that bother them.¹

With 9 out of 10 scleroderma people rating their fatigue as moderate or higher,² and almost half experiencing 'severe fatigue',³ it is a concerning symptom that isn't talked about enough – especially given how much it can impact daily life and wellbeing.⁴

Why do people with scleroderma get fatigued?

It's important to recognise that experiencing chronic fatigue is not the same as simply "feeling tired", something which may be hard to appreciate for someone who does not live with a chronic condition.

For people with scleroderma, unmanaged fatigue can be a disabling symptom and is known to be a key factor affecting quality of life, as well as being related to other symptoms, such as pain, joint and pulmonary (lung) involvement, and disability.²

Additionally, there are different types of fatigue that can affect people with scleroderma, which feel different from one another, but can all be described as fatigue, such as:

- **'Needing sleep'**, which can be due to medication side effects, sleep deprivation from pain or poor sleep quality
- **'Reduced energy'** as a result of the effects of disease, malnutrition, or the emotional impact of living with scleroderma
- **'Reduced exercise capacity'** or feeling out of breath, which can be caused by the physical effects of scleroderma, such as heart or lung involvement through pulmonary arterial hypertension (PAH), or muscle weakness

Do people experience fatigue all the time?

People who experience fatigue don't necessarily have it all the time. Symptoms of fatigue can come and go in cycles over the course of days or weeks and some people may describe having 'good days' and 'bad days'. Unfortunately, what often happens is that someone will have a good day and use it as an opportunity to do lots of things they have been wanting to do for a while, or 'doing too much', leading to more pain and fatigue the next day, or 'a bad day'.

When to talk to your doctor

Fatigue can be caused by many things, but if you suddenly notice that you are more fatigued than usual or have a change in your energy levels, make an appointment with your doctor.



Although most of the time, fatigue can be managed by things you can do yourself, there are

instances where you should talk to your doctor about how you're affected in case it's due to something other than your scleroderma.

Lung involvement, mainly pulmonary arterial hypertension (PAH), is the most severe condition associated with fatigue.⁴ The symptoms of PAH can be vague, but if you start feeling more and more like you're becoming short of breath, fatigued and faint or dizzy, you should talk to your doctor about being checked for PAH.⁵

Active skin disease, gastrointestinal involvement, diarrhoea and abdominal pain can also contribute to fatigue, as can mental health problems such as anxiety and depression – even the medication you take may have an impact on fatigue.⁴

This is why it's so important to stay in close contact with your healthcare team and let them know if you have been feeling unusually tired for a long period, and in some instances, they may recommend specific treatments that can help.⁴

Make an appointment to see your doctor if you are concerned about fatigue.

Tackling fatigue and energy levels

Breaking this cycle to give yourself more energy throughout the day and being able to better manage your daily activities is important, as it will allow you to take control of your fatigue and minimise its negative impacts.

Some positive steps you can take include:

- Practising healthy sleep habits
- Pacing your day and taking breaks
- Exercising and ensuring healthy nutrition
- Managing stress in your life.

Tips for better sleep

Healthy sleep habits, also called good 'sleep hygiene', include things you can do to help yourself get better and more consistent sleep. While you cannot make yourself sleep, you can increase your chances of a good night's rest.



Time: try to be consistent with when you go to bed and when you wake up.



Light: having a dark room to sleep in is important, but so is getting some daylight to regulate your body clock. Try and be out or near a window during the day to get some light and avoid wearing sunglasses all day. It's also important to stop looking at screens and devices an hour before going to bed.



Sound: if you're easily disturbed, try sleeping with earplugs. Alternatively, many people find 'white noise' comforting and helpful when going to sleep. You can buy dedicated white noise machines or just use an app on your phone.



Caffeine: a bit of coffee or tea is great in the morning, but caffeine is best avoided after lunch. Watch out for hidden sources of caffeine, such as green tea, herbal teas based around black tea, soft drinks and sports nutrition.



Alcohol: although it may help you get to sleep, alcohol can cause you to have poor sleep.

A word on napping...

Napping during the day is ok, but you should try to limit sleeping to 45 minutes or less and avoid doing it in the late afternoon or evening, as this can affect your sleep rhythm may reduce your ability to sleep well at night.



Pacing your day

Pacing is relevant not only when you are experiencing fatigue, but also when you feel like you have plenty of energy. It's important that you plan your day so that you don't cram too much into it, spreading your tasks evenly throughout the day to include time to rest. Also, when it comes to strenuous tasks, make sure to seek help where necessary.

Like with any task management, break up bigger tasks into smaller more achievable tasks. Ticking lots of little things off your list will give you more of a positive boost than slogging away at one big task and perhaps not finishing it in a day.

It's also a good idea to do the hardest activities in the morning so you can ensure enough time for rest, and always stop before you become fatigued.

Exercising

It is well known that exercise, even when relatively light, can increase energy levels and reduce fatigue. There are many benefits to exercise for people living with scleroderma, such as increased cardiovascular fitness, overall wellbeing, strength and flexibility, and even improved sleep. For example, Tai Chi has been shown to have a positive effect on endurance, balance, sleep quality, anxiety, depression and fatigue in people with systemic sclerosis, and has been recommended in rehabilitation programs as a result.⁶



Although the value of exercise can't be understated, it's important to talk with your doctor, a physiotherapist or personal trainer before you start any exercise to make sure you avoid injury.

The right food

Nutrition is an important consideration when it comes to fatigue since the food you eat is what fuels your body, but for people with scleroderma, there are also other factors to consider. People living with scleroderma may be at risk of weight loss due to chronic inflammation, bowel involvement and

malabsorption caused by their condition, so it's important to always keep your doctor informed of any changes to your diet, even if you are making them for positive reasons.⁷

It's important to ensure that you are getting enough protein, carbohydrates, and fats, as well as fruits and vegetables. If you experience malabsorption, it may be necessary to add supplements to your diet as well.

You can read more tips about managing nutrition and scleroderma in our dedicated brochure, here: <https://www.sclerodermaaustralia.com.au/resources/>.

Alternatively, you may find it helpful to talk to a dietician about personalised nutritional counselling.⁷

Some useful tips on reducing fatigue with your diet include:⁸

- Drink plenty of water – being mildly dehydrated can make you feel fatigued.
- Reduce or eliminate caffeine – try to cut out tea and coffee for a month to see how you feel.
- Don't skip meals – especially breakfast; you don't want your sugar levels to dip.
- Eat healthily – increase your fruit, vegetable, wholegrain, low-fat dairy, and lean meat consumption; reduce high-fat, high-sugar and high-salt foods.
- Keep meals small – large meals take energy to break down. Keeping meals small and frequent will spread your energy intake more evenly.
- Supplement where needed – consult your doctor about any supplements you may need.

Staying stress-free

Stress can be a major influencing factor leading to fatigue. It uses up a lot of energy and can take you into a negative cycle where you become stressed because you're fatigued and then more fatigued due to the stress! There are many ways to help limit or reduce stress, including exercise, meditation, listening to music, reading or socialising with friends.⁸

Where you can, try to limit the number of things in your life that cause you stress and instead make more time for activities and situations that you find relaxing. There is a lot of pressure in modern life to drive ourselves to bigger and better heights 24/7, but it's actually ok to just do nothing sometimes. Don't worry about it – just sit back, relax and hang out.⁸

Talking about things with friends, a counsellor or a psychologist might help to reduce stress and fight fatigue. See your doctor about a referral for 'talking' treatment.⁸

Getting support with fatigue

Your doctor is generally the best person to contact for support with fighting fatigue; however, there are also other places to turn to if you need help with specific strategies for fighting fatigue.

- The Sleep Health Foundation is Australia's leading advocate for healthy sleep. They offer resources, fact sheets and help with getting better sleep and fighting fatigue. Visit their website at:
<https://www.sleephealthfoundation.org.au>

- Headspace is a mobile app on Android and Apple iOS that provides guided meditation and mindfulness techniques, which can help to manage anxiety and stress:
<https://www.headspace.com>
- Scleroderma Australia are a national association dedicated to helping people with scleroderma in Australia:
<https://www.sclerodermaaustralia.com.au>
- Friends and family – never underestimate the support that can be provided by those closest to you, whether physical or emotional, healthy relationships go a long way to improving happiness and energy levels.

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