

A close-up photograph of two hands held palm-up. The fingers of both hands are pale and appear numb, characteristic of Raynaud's phenomenon. The skin on the fingers has a slightly waxy or translucent appearance. The background is softly blurred, showing what appears to be a wooden table and a white plate.

COLD HANDS AND FEET

INCLUDING RAYNAUD'S PHENOMENON

AUGUST 2022



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INTRODUCTION

Cold hands and feet/toes are a fairly common and sometimes very disabling symptom of ME/CFS – especially during the cold winter months.

WHAT CAUSES COLD HANDS AND FEET IN ME/CFS?

The answer probably lies in a disorder of the autonomic nervous system (ANS).

This is a part of the nervous system that helps to control the size of blood vessels, and then the blood flow, to key parts of the body such as the brain. It also controls the size of small blood vessels that supply the skin and diverts blood away from skin when the external temperature drops.

So any disturbance in the ANS control centres in the brain, or in the messages that are being sent to control blood flow, can make people over-sensitive to cold weather. This causes the tiny blood vessels to shut down even more and produces cold hands or feet/toes. The ears and nose are also sometimes affected.

During a more severe attack, the fingers become white and then turn blue due to lack of oxygen. They finally turn red when blood flow returns to normal. In addition, there may be pain, numbness or tingling/pins and needles-type sensations.

WHY DO PEOPLE WITH ME/CFS HAVE PROBLEMS WITH TEMPERATURE CONTROL?

Problems with temperature control (also called disturbed thermoregulation in medical language) are very common in ME/CFS and include sensitivity to both heat and cold. So people with ME/CFS are often unable to tolerate either hot weather or cold weather and often experience very cold hands and feet when the temperature drops. They may also feel very fatigued after a hot bath or shower.

Poor temperature control is a symptom that is probably caused by a problem with the hypothalamus. This is a small gland in the brain that acts as a thermostat for a range of normal body functions, including helping to maintain a normal and stable body temperature, and the way in which the autonomic nervous



Cold Hands and Feet, including Raynaud's Phenomenon was written by Dr Charles Shepherd (pictured above), Trustee and Hon. Medical Adviser to The ME Association.

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.



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system controls the size of blood vessels in response to changes in temperature. As a result, there is over-constriction of small blood vessels in the skin in response to cold weather and this causes cold hands and feet.

A more persistent feeling of low body temperature is something that you should see your doctor about because there are other medical explanations for this type of temperature control problem – poor thyroid function (hypothyroidism) for example.

If you have a raised body temperature, without any obvious symptoms of an infection, this should also be discussed with your doctor. This is because there may be some form of 'hidden infection'. There are also some non-infectious medical conditions that can cause a raised body temperature.

It is always useful to use a thermometer to keep a diary of temperature recordings that can be shown to the doctor, along with notes about any symptoms that coincide with changes in temperature, if you feel that you have a persisting low body temperature, or a high body temperature.

OVERALL TREATMENT

Various treatments are available for Raynaud's phenomenon - depending on how severe it is.

For milder symptoms, simple self-help measures such as hand warmers, thermal gloves and hats may be sufficient. But it's also important to keep the whole body warm – and wearing several layers of loose clothing is important here.

An even background temperature is also important because even a small change can bring on an attack. Cold draughty places should be avoided where possible and care taken with any air conditioning as this can also trigger an attack.

If the condition is more severe you should see your GP, who will want to exclude other possible explanations and advise on management. This will include taking a detailed history to see if there are any symptoms or signs that suggest you may have another medical condition sometimes linked to Raynaud's – auto-immune conditions such as lupus, rheumatoid arthritis, scleroderma and Sjögren's syndrome. Raynaud's is also more common in people who have chronic infections such as hepatitis B and C.

Your doctor may want to check some blood tests – ESR, full blood count, antinuclear antibodies, cold agglutinins, thyroid function, blood glucose (for diabetes), etc. to see if there are



COMMUNITY COMMENT

“I wear buffalo wool socks in various weights, from Buffalo Wool Company. Their bed socks are amazing. For my hands, fingerless gloves made from wool, or wool and silk, help. I have now realised that if I avoid cold beverages and drink warm water my extremities seem to do better”

KRIS



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any signs of another medical condition or an overactive immune system, as can also occur in ME/CFS.

A number of drugs can also cause or exacerbate Raynaud's because they constrict blood vessels as a side-effect. These include anti-migraine drugs such as sumatriptan, beta blockers (for high blood pressure and angina), decongestants in cold remedies, the contraceptive pill, HRT and ACE inhibitors (for high blood pressure).

For more severe symptoms, there are a number of prescription-only drugs available. These include vasodilator drugs such as nifedipine that open up the small blood vessels. However, it may be necessary to try more than one drug before finding one that works.

Natural products such as vitamins, fish oil, evening primrose oil, Ginkgo biloba and ginger are used by some people. But there is only very limited evidence for their effectiveness.

More information: NHS Raynaud's:

<https://www.nhs.uk/conditions/raynauds/>

WHAT SORT OF SELF-HELP MEASURES ARE HELPFUL?

- Keep warm by wearing several layers of loose-fitting clothing – as well as gloves, warm socks and a hat, because a great deal of heat is lost through the scalp.
- Small heating pouches can be added to socks and gloves. Some people find electrically-heated gloves helpful.
- Avoid touching cold surfaces and objects such as milk bottles.
- Wear insulated gloves when taking food from the fridge or freezer. Don't have ice-cold drinks straight from the fridge.
- After a bath, leave the water in while you dress – this will give off heat to keep you warm.
- If you are out in the snow wear plastic disposable gloves over woollen ones – as getting wet makes the cold worse.
- Use a hair dryer to warm clothes and shoes before going out.
- Cigarette smoking is harmful for everyone and smoking can reduce the temperature by one degree over a 20-minute period.
- Use warm-air hand dryers in public places to warm your hands when shopping.



COMMUNITY COMMENT

“I was told, when diagnosed with Raynaud's, to wear two pairs of sock and use natural fibres if possible. Around the house I wear thin bamboo socks and then thick heat-holder socks over the top. I also wear heat-holder leather gloves whilst driving ”

DEDE



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- Keep your clothes and shoes for the next day in the airing cupboard overnight or use a radiator to warm clothing before going outdoors.
- Alcohol in moderation can help to open up the circulation but do not mix alcohol with medication.
- Keep doors closed – leaving a door open can drastically reduce the temperature in your house.
- Use shoulder bags for shopping where possible rather than ones with handles as these can cause restriction of blood to the fingers.
- Do not try to rapidly warm up cold hands or feet by placing them directly on a hot radiator or in hot water.

TAKING CARE OF HANDS AND FEET

SRUK (Scleroderma and Raynaud's UK) website has detailed information on shoes, nail care, skin care, ulcers, chilblains and callus (hard skin) formation.

Skin care is very important if blood supply to the hands or feet is reduced. If there is any sign of ulceration, or an open sore, you must see your doctor as soon as possible because this could lead to tissue death and even gangrene.

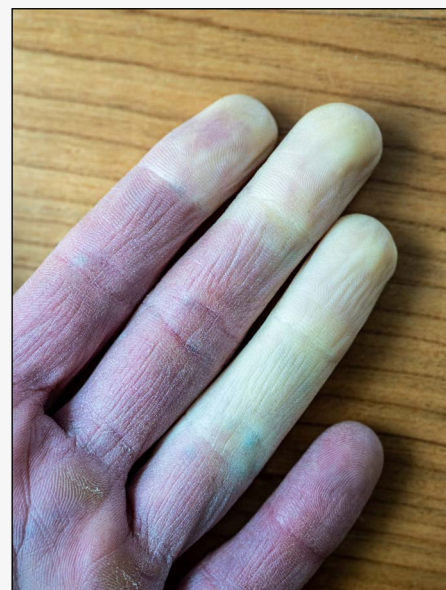
TAKING CARE OF DRY SKIN

Advice from SRUK (Scleroderma and Raynaud's UK):

Raynaud's can cause dry and cracked skin. Ulcers may then develop, especially on the fingers and toes. Dryness and irritation of the skin on the rest of the body can also occur.

Normal skin has a large amount of moisture (water), which is prevented from evaporation and drying out by a film of oil over the surface of the skin. Dry skin usually results from a failure to produce adequate levels of oil. This can be exaggerated by frequent washing which removes the oil. Care should therefore be taken when using detergents and soap as they have a de-greasing effect on the skin.

Replenishing protective oils can be achieved by adding moisturiser to the bath or applying it directly to the skin, either when the skin is wet or dry. Bath moisturisers are emulsions of oil in water, which can be added to the bath. Care should be taken when getting out of the bath as it can be slippery. Use a non-scratch bath cleanser to remove the oil film.



COMMUNITY COMMENT

“I have microwaveable slippers, cosy socks and gloves and I always sit with a blanket over me, but I get both overly-hot and overly-cold so I also use gel packs, cold flannels and a fan with ice packs in to deal the the opposing symptoms.”

KERRY



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During the day, creams or ointments will replenish natural oil and help keep the skin more supple, preventing drying out and cracking.

Creams are cosmetically more acceptable but their moisturising effect tends to be short-lived. Simple petroleum jelly is effective and can be thinned down by mixing it in a tub placed in a basin of hot water and mixing in an equal amount of liquid paraffin.

There are two ways to rehydrate:

- Take a bath containing a moisturising bath oil and sit in it for 20 minutes.
- Use moisturising creams. Creams which contain lactic acid, urea or lanolin are most effective. A small number of people are sensitive to lanolin but this is quite rare.

Read more from SRUK (Scleroderma and Raynaud's UK):

<https://www.sruk.co.uk/>

The Raynaud's Association have tried and tested a variety of heating aids and warm clothing that help keep people warm. It really is a matter of finding which is most suitable for your own circumstances.

You can have a browse by visiting their online shop here:

<https://srukshop.co.uk/>



COMMUNITY COMMENT

“My feet get so cold. I have a heated blanket across the foot of the bed. It works really well and doesn't overheat the rest of me”

HELEN

BECOME A MEMBER



For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/ CFS and with stories from other members of the charity.

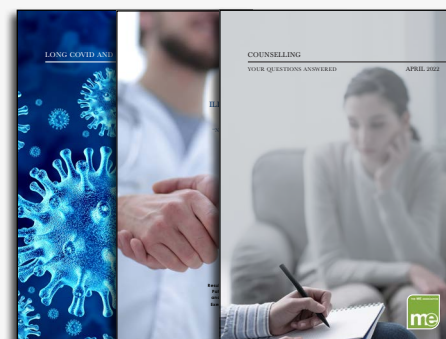
You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family members, and anyone with a professional interest in the condition.

Visit our website to find out more:

<https://meassociation.org.uk/8cjm>

The MEA website shop:

The ME Association has the largest selection of ME/CFS advice leaflets in the UK on: **Medical Management; Mental Health; Diet & Nutrition; General Information; Fundraising Leaflets; Benefits & Social Care; 'To Whom It May Concern' letters; and leaflets written by ME Connect:** <https://meassociation.org.uk/shop>





ME CONNECT

The Support and
Information Service for
people affected
by ME/CFS/PVFS
and Long Covid



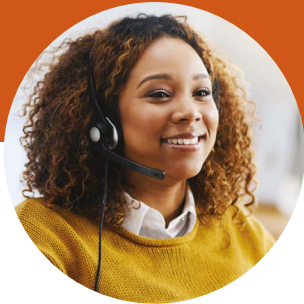
Freephone

0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)

Saturday & Sunday
10am - 12 noon & 7pm - 9pm

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT

We are here to help you reach an informed decision.



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



MEConnect@meassociation.org.uk



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