

Raynaud's phenomenon



**VERSUS
ARTHRITIS**

WE ARE VERSUS ARTHRITIS

We're the 10 million people living with arthritis. We're the carers, researchers, health professionals, friends and parents all united in our ambition to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes.

We understand that every day is different. We know that what works for one person may not help someone else. Our information is a collaboration of experiences, research and facts. We aim to give you everything you need to know about your condition, the treatments available and the many options you can try, so you can make the best and most informed choices for your lifestyle.

We're always happy to hear from you whether it's with feedback on our information, to share your story, or just to find out more about the work of Versus Arthritis. Contact us at content@versusarthritis.org

Contents

Sarah's story	4
What is Raynaud's phenomenon?	6
Symptoms	7
Causes	9
How will Raynaud's phenomenon affect me?	10
Diagnosis	11
Treatment	12
Living with Raynaud's phenomenon	14
Research and new developments	20
Glossary	21
Useful addresses	21
Where can I find out more?	22
Talk to us	23



SARAH'S STORY

I first noticed symptoms of Raynaud's in my teens. My hands would change colour in the cold, and I'd get really bad pain in my fingers.

I hadn't had a diagnosis, until I had operations on my shoulder and hand recently. The operations weren't related to Raynaud's.

I told the surgeon I always had cold hands, and I was referred to a rheumatologist.

I'm a nurse, and the air conditioning at the hospital where I work can make my symptoms worse. I like to have two or three layers of clothes on. At work, I wear scrubs, and you can only put so much under those.

My Mum laughs at me for wearing my 'Nanny's vest'. I'm always wearing gloves and scarves in the summer. Even in the middle of summer, I can have an attack. I always keep clothes like fleeces, hats and scarves in my bag and car.

My daughter does horse riding, so I spend lots of time outside when she is going to and from the farm. It's important to keep my core temperature warm, so I'm always wrapped up well. But if I'm stressed in any way, I can get attacks even when I'm wrapped up.

When I go to the supermarket, I tend to whizz round the fridge and freezer aisles because I can feel it starting.

It's important to keep moving and to keep the circulation going. I'm always wiggling my fingers, just to keep the blood moving. I think healthy eating helps too.

I describe it as sparklers going off at the ends of my fingers and it can be debilitating. A full-on attack can last a couple of hours. My fingers go white and then blue or even purple. They can go cold and numb. A couple of times they've gone a dark grey, almost black. That was scary.

Because the feeling is not there, there can be a tendency to put my fingers in hot water, but I know I could burn myself.

And then when the blood comes back it can be painful. Sometimes I won't be able to drive home until the pain has stopped in my hands and the feeling has come back. It can take a few minutes for feeling to come back once I'm in the warm, or it can take half an hour.

They're very frequent in the winter. It doesn't have to be going out into the cold that does it. Even going from my living room to the kitchen can trigger one, if the temperature is different. In the winter, it can happen every day. I don't let it stop me doing things though.

What is Raynaud's phenomenon?

Raynaud's phenomenon (Ray-nodes fen-om-e-non) causes blood to stop flowing properly to the outer parts of the body. This happens mainly when you get cold, and it can also happen because of stressful situations.

It most commonly affects fingers and toes, but can sometimes also affect lips, noses, ears and nipples.

The most common thing to happen is for fingers, and slightly less commonly toes, to change colour. Usually they will go white, then blue, sometimes black, and then red.

You may not experience all four stages every time. For example, your hands may just go blue then red.

These colour changes often happen alongside pain or a tingling feeling.

Going out on a cold day, or even reaching into the freezer to take out some frozen food, can bring on an attack of Raynaud's. As can emotionally stressful situations.

Raynaud's phenomenon often occurs on its own. This is called primary Raynaud's phenomenon. Primary Raynaud's is a fairly common condition. It affects more women than men. Most people with primary Raynaud's won't go on to develop any further problems.

Raynaud's can also be linked with other conditions, such as **scleroderma**, and less commonly **lupus**. When this happens, it's called secondary Raynaud's phenomenon.

For more information, see the Versus Arthritis booklets:
Systemic sclerosis; Lupus (SLE)



You can also view our information online at:
www.versusarthritis.org



Primary Raynaud's phenomenon usually affects young women and teenage girls. But men, babies, children and older people can also be affected. It sometimes runs in families.

Symptoms

Raynaud's phenomenon mainly affects hands and feet.

If you have Raynaud's phenomenon, your hands may change colour in cold weather and there may be pain, tingling and numbness.

These attacks often only last a few minutes, but they can last two to three hours. You may find that moving into a warmer environment often stops the attack.



Causes

We don't fully understand why some people develop Raynaud's phenomenon. However, we do know that the colour changes and pain of Raynaud's are due to a short-term reduction in blood supply.

The blood supply to the fingers and toes is controlled partly by nerves connected to the blood vessels. The nerves can reduce the blood supply in response to certain situations, one of which is extreme cold temperatures. This is a natural reaction, to prevent a loss of heat from the body.

People with Raynaud's phenomenon probably respond too much to cold temperatures and shut off the blood supply more quickly than normal. The blood vessels reduce in size, and so less blood can flow through them.

Emotional changes, such as feeling worried, can also cause an attack of Raynaud's by triggering the nerves to shut down the blood supply.

Raynaud's phenomenon can occur as a result of using vibrating machinery, for example pneumatic drills, hammer drills, hedge cutters and other power tools. This is called hand-arm vibration syndrome (or vibration white finger).

Raynaud's may also develop as a side effect of some drugs such as beta blockers, which are used in the treatment of high blood pressure and angina.

With primary Raynaud's phenomenon your fingers usually go back to normal after each attack. Attacks of primary Raynaud's phenomenon can be unpleasant and a nuisance, but they don't usually damage your fingers.

Secondary Raynaud's phenomenon can be severe and can cause ulcers on the fingertips and loss of tissue at the fingertip. However, this is very rare.

Some people find that their feet are also affected so that they become very cold and change colour. The ears, lips, nose and nipples can also be affected. Women who are breastfeeding can have Raynaud's in the nipples, especially when they expose them to cold air.

How will Raynaud's phenomenon affect me?

Although primary Raynaud's phenomenon can be very uncomfortable, it's not usually severe. Look for ways to keep warm and avoid sudden changes in temperature.

If you've recently developed any symptoms of Raynaud's, it's best to visit a GP to get checked out. It may well be primary Raynaud's phenomenon, especially if you're a young woman. If your doctor is in any doubt, then they'll arrange some tests. These may need to be done at the hospital.

Most people with Raynaud's phenomenon will always have the condition, although it can improve with time. If there's an underlying cause of the condition, then it's sometimes possible to remove or treat this.

For example, Raynaud's caused by taking beta blockers can be 'cured' by stopping this medication. However, you must ask your doctor before stopping any regular medication.



Diagnosis

Your doctor will be able to make a diagnosis based on your symptoms and the results of any tests. These tests are carried out to tell apart the primary and secondary forms of the condition.

What tests are there?

There are various tests your doctor can carry out if they suspect you have Raynaud's phenomenon.

- Blood tests can show how many white and red blood cells you have, as well as other information that will help a doctor decide if you have Raynaud's. Blood tests can also help to show if you have primary or secondary Raynaud's.
- An x-ray can look for an extra rib at the base of the neck, called a cervical rib. This can cause Raynaud's phenomenon by putting pressure on the blood vessels that supply blood to your arms.
- There is a test that involves looking at the tissue from a fingernail under a microscope. It will help doctors look closely at the small blood vessels in your fingers. This test is called a nailfold microscopy, or a capillaroscopy (cap-ill-er-os-copy).
- A cold stress test, or thermography, is used in some hospitals to find out how you react to cold. It involves using cold water and recording how long it takes for part of the feet or hands to return to their normal temperature.

If you have scleroderma, it's likely that you'll get Raynaud's symptoms at some stage. However, having Raynaud's doesn't mean that you'll go on to develop scleroderma or another connective tissue disease.

Try to get a diagnosis early to find out if you have primary or secondary Raynaud's.

Treatment

There are several ways to help ease the symptoms of Raynaud's phenomenon. Many of these are things you can do in your day-to-day life, but there are also a number of medications that may help.

Drugs

A number of drugs can be prescribed for Raynaud's phenomenon. Most of these work by making the blood vessels wider.

Examples include nifedipine and amlodipine. These are in groups of drugs known as calcium channel blockers.

Unfortunately, there's no drug that will act only on the blood vessels in the fingers and toes, so these medications may also cause side effects such as **skin flushing** of the face, headaches or dizziness. This is because the drugs increase blood flow elsewhere. However, many people experience no side effects from the drugs and find them very useful.

Drinking grapefruit juice and eating grapefruits can increase the risk of side effects from nifedipine.

Losartan and ACE inhibitors are more commonly used to treat high blood pressure, but they can also help control symptoms of Raynaud's. These drugs also relax blood vessels and stop them from narrowing.

A drug called fluoxetine can help improve circulation. Fluoxetine can also be used to treat depression. This is an entirely different use and if you've been prescribed it for Raynaud's, it doesn't mean your doctor thinks you're depressed.

In severe cases – almost always in cases of secondary Raynaud's – some treatments may be given as a drip directly into a vein, otherwise known as an intravenous injection. These intravenous drugs act directly on the blood vessels and cause them to open up. The most commonly used intravenous drug for this condition is iloprost.



Another family of drugs used to treat severe Raynaud's are the phosphodiesterase inhibitors (foss-fo-dye-ess-tur-aze in-hib-e-turs), which include sildenafil – trade name Viagra. These are drugs that can treat a number of conditions, including high blood pressure in the blood vessels supplying the lungs and erectile dysfunction. They can help with Raynaud's because they improve blood flow around the body.

It's important you talk to your doctor if you're planning for a baby, if you become pregnant, or if you want to breastfeed when on any of these drugs.

Living with Raynaud's phenomenon

When you have Raynaud's, there are things you can do to reduce the risks and control the number of attacks. As well as medication, the following may help.

Keeping warm

It's important to keep your core temperature warm, as well as your hands and feet in particular.

Wearing several layers of clothing works better at trapping the heat than fewer layers of thicker clothes. Wearing warm socks and a hat can really help you.

You should wear warm gloves when outdoors in cold weather and warm your hands before you put the gloves on. It can help to keep the gloves in an airing cupboard or on a radiator, before putting them on.

You may find that so called 'silver fibre' products and self-heating gloves and socks are helpful. Your local **occupational therapy** department will be able to provide further information.

You can also look out for the many small portable heating aids and hand warmers available online and from outdoor shops.

If you do get cold, you should get out of the cold environment as soon as possible. However, you should avoid warming back up too quickly, especially if your fingers or toes have changed colour and are painful. If blood goes back to a part of the body affected by Raynaud's too quickly, this can be painful. Moving your fingers or toes around can help.

It can be difficult to completely avoid situations that may trigger attacks. But planning ahead as much as possible can help.

If trips to the supermarket makes your Raynaud's worse, particularly in the fridge or freezer aisles, could you take someone with you to do this part of the shopping? Alternatively, could you ask a member of staff for help? Wearing warm gloves may also help.

Looking after your hands

Having wet hands can lead to the development of cracks on your hands. To help look after your hands, put a moisturising cream on whenever you've had them in water, making sure first that they are properly dry.

You can either use a short-acting water-based cream, such as E45 or aqueous cream, or an oil-based cream that is thicker and longer lasting, such as emulsifying ointment. Older people or children should use a pH neutral unscented cream to avoid allergic reactions. Wearing protective gloves when you put your hands in water can help you look after your hands.

If you have to use vibratory tools, then make sure that you use these correctly and do not use them for longer than necessary. Use any necessary protective clothing and equipment.



Advice for breastfeeding women who have Raynaud's phenomenon

Raynaud's phenomenon can affect women's nipples, especially when breastfeeding. It can occur during or immediately after breastfeeding.

This often gets misdiagnosed as a fungal infection.

If Raynaud's is affecting your nipples, and you'd like to continue breastfeeding, there are steps you can take:

- It helps if you're able to warm your nipples up before breastfeeding, talk to your midwife or health visitor about the best way to do this.
- Try to reduce the amount of time your nipple is exposed to the air before and after your baby latches on.
- After a feed, never let the nipple dry naturally in the air, as soon as your baby comes off your nipple, cover it with a clean breast pad and dry it gently.
- Use lanolin or a moisture barrier cream, to take care of your nipples. Warm the cream in your hands before applying it.
- Ensure your bathroom is warm before you undress for a shower or bath.

Nifedipine can be prescribed to take when you're breastfeeding. Talk to your doctor if you have any concerns. And talk to your health visitor for further advice.

Keep an attack diary

You may wish to use a diary to keep track of your Raynaud's attacks. This could show a pattern to help you control symptoms and reduce the risk.

If something is causing you stress, there will often be ways to reduce or avoid the stress in the first place, and to manage it better. Talking to people and good planning can often help deal with stress.

Exercise

Regular exercise will improve your circulation, and if you're outside on a cold day keeping active will improve the blood flow to your hands and feet and help you stay warm.

If you're new to exercise or haven't exercised for a while, start gradually and build up the amount you do. Doing something you enjoy, will help you do it regularly.

For more information see the **Versus Arthritis** booklet: **Keep moving**



You can view all our information online at: www.versusarthritis.org





Complementary medicine

Some people find that vitamin supplements, evening primrose oil, fish oils, ginger or Ginkgo biloba help their Raynaud's. However, there is no good evidence to support the use of these.

What else should I know about Raynaud's phenomenon?

In some rare cases, your Raynaud's may suddenly become more severe. This may need urgent attention.

Look out for:

- ulcers or black areas on the fingers or toes
- a colour change in fingers or toes that doesn't go away as quickly as usual
- symptoms, particularly numbness, only affecting one side of the body
- joint pain
- skin rashes
- muscle weakness.

If you develop one of these symptoms, see your doctor or contact your nurse specialist, if you have one, as soon as possible.

These problems are uncommon, and they aren't usually experienced by people with primary Raynaud's phenomenon.

Stop smoking

Smoking can damage your circulation, so if you have Raynaud's phenomenon you shouldn't smoke.

Quitting smoking can be tough, but there is plenty of help and support out there. Your doctor can provide advice and support, and put you in touch with groups who can help further.

Diet

There's no particular food or diet that has been proven to help Raynaud's phenomenon. However, it's still very important to eat a healthy, balanced diet.

Research and new developments

We're currently funding a number of research projects investigating Raynaud's phenomenon.

Professor Ariane Herrick at the University of Manchester is investigating the use of a mobile phone application to monitor Raynaud's phenomenon. It is currently difficult to monitor the impact of Raynaud's phenomenon on patients going about their everyday lives, which has made it difficult to run clinical trials and has slowed the development of new treatments. The app will monitor symptoms such as changes in colour to the fingers in cold weather, captured using the camera on a mobile phone, providing patients with a simple and fast way to record their symptoms.

Dr Andrea Murray, also at the University of Manchester, is examining two different imaging techniques to measure Raynaud's phenomenon in patients with scleroderma. Much of the pain and disability in scleroderma comes from the fingers, but at the moment there is no reliable measure of changes in blood flow or skin temperature in the hands. This makes it hard to evaluate the effectiveness of treatments. This research will test two imaging techniques, laser Doppler imaging and thermography, to check that these methods are reliable and can pick up clinically important differences in response to treatment.

Glossary

Lupus is a condition where the body's immune system attacks healthy cells instead of infections. Lupus can affect the skin, hair and joints, and can sometimes affect the internal organs, such as the heart or kidneys.

Occupational therapy aims to help you stay independent by showing you how to work around your condition. They can also recommend useful equipment that you can use to make life easier.

Scleroderma is a condition that causes hard, thickened areas of skin on the body. It might also cause problems in your internal organs and blood vessels.

Skin flushing, also known as blushing, is when the face, ears, neck or chest become red and may feel hot. It happens when extra blood rushes to the area and is usually triggered by feelings of embarrassment or stress, but some medical conditions and drugs can also cause it.

Useful addresses

Scleroderma and Raynaud's UK

A UK charity dedicated to improving the lives of people with scleroderma and Raynaud's.

Phone: 020 3893 5998

Helpline: 0800 311 2756

Email: info@sruk.co.uk

www.sruk.co.uk

Where can I find out more?

If you've found this information useful, you might be interested in other titles from our range. You can download all of our booklets from our website www.versusarthritis.org or order them by contacting our Helpline. If you wish to order by post, our address can be found on the back of this booklet.

Bulk orders

For bulk orders, please contact our warehouse, APS, directly to place an order:

Phone: 0800 515 209

Email: info@versusarthritis.org

Tell us what you think

All of our information is created with you in mind. And we want to know if we are getting it right. If you have any thoughts or suggestions on how we could improve our information, we would love to hear from you.

Please send your views to bookletfeedback@versusarthritis.org or write to us at: **Versus Arthritis, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD.**

Thank you!

A team of people helped us create this booklet. We would like to thank Ariane Herrick for writing the original text and Connor Duckworth, Debbie Bond, Lorraine Croot and Anisur Rahman for helping us review this booklet.

We would also like to give a special thank you to the people who shared their stories, opinions and thoughts on the booklet. Your contributions make sure the information we provide is relevant and suitable for everyone.

Talk to us

Helpline

You don't need to face arthritis alone. Our advisors aim to bring all of the information and advice about arthritis into one place to provide tailored support for you.

Helpline: 0800 5200 520

Email: helpline@versusarthritis.org

Our offices

We have offices in each country of the UK. Please get in touch to find out what services and support we offer in your area:

England

Tel: 0300 790 0400

Email: enquiries@versusarthritis.org

Scotland

Tel: 0141 954 7776

Email: scotland@versusarthritis.org

Northern Ireland

Tel: 028 9078 2940

Email: nireland@versusarthritis.org

Wales

Tel: 0800 756 3970

Email: cymru@versusarthritis.org

Raynaud's phenomenon

Raynaud's phenomenon causes the outer parts of the body, mainly fingers and toes, to change colour and become painful in the cold. In this booklet we explain what Raynaud's is, how it develops and how it's treated. We also give some hints and tips on managing your condition in daily life.

For information please visit our website:

versusarthritis.org

0300 790 0400

 **/VersusArthritis**

 **@VersusArthritis**

 **@VersusArthritis**

FAMILIES
FRIENDS
DOCTORS
RESEARCHERS
SUPPORTERS
FUNDRAISERS
VOLUNTEERS
VERSUS
ARTHRITIS

© Versus Arthritis 2020



VA2052