

### UNDERSTANDING LOCALISED SCLERODERMA



**WE ARE DEDICATED TO IMPROVING THE LIVES**OF PEOPLE AFFECTED BY SCLERODERMA AND RAYNAUD'S

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#### **ABOUT THIS INFORMATION**

Localised scleroderma (also known as morphoea), is a complex condition that affects people in different ways. Localised scleroderma primarily affects the skin and soft tissues and is separate from systemic sclerosis, that also impacts upon other parts of the body.

This information is designed to provide an overview. It is written for adults with localised scleroderma and is also useful for family and friends. This guide is backed up by reliable sources and evidence. It has been reviewed by healthcare professionals and people who are living with this condition themselves. You will also find some real-life quotes. When you have a rare condition like localised scleroderma, you may have to become something of an expert yourself. That way, you can make informed choices about your treatment. This guide can get you started, and we are here to give you more details and support along the way.

### UNDERSTANDING LOCALISED SCLERODERMA

#### What is localised scleroderma?

Localised scleroderma (also known as morphoea), is an inflammatory autoimmune condition, where the immune system is overactivated and leads to inflammation and changes in the skin. There are different types and each sub-type of this condition is characterised by the shape and amount of affected skin.

#### These are:

- · Limited plaque morphoea
- Generalised or disseminated plague morphoea
- Pansclerotic morphoea
- Linear morphoea
- En coup de sabre

For more information on each of the sub-types, please turn to page 8.

With localised scleroderma, the affected skin usually begins to appear red and a bit swollen (oedematous), sometimes looking purplish and 'bruise-like.' Then it becomes yellowish-white, waxy, thickened and harder than usual because of excessive collagen deposition. Collagen is a protein normally present in our skin that provides structural support. However, when too much collagen is produced, the skin becomes stiff and hard. The area of yellowish-waxy, thickened skin may have a pink-to-lilac edge or 'ring,' which is said to reflect active, spreading disease. With time, the skin softens and becomes darker and thinner. This can happen within weeks, but most often takes months or even years. In some cases, the skin goes straight from being pink and inflamed to being thinned and darker without going through a paler, thickened (sclerotic) phase.







Red and a bit swollen





Thickened, waxy and brown

Thinned and brown (visible veins)



## WHAT CAUSES LOCALISED SCLERODERMA?

The cause is not clear. What is known is that in the early stages, there are increased numbers of white blood cells (lymphocytes and plasma cells), causing inflammation in the skin. In the next stage, cells called fibroblasts make too much of the protein called collagen. The collagen gets deposited in the skin, causing hardening and thickening (sclerosis).

It is not known why the fibroblasts produce too much collagen in these affected areas. Localised scleroderma usually starts without any apparent trigger, but it has been noted to occur after a skin injury such as an insect bite or a burn, or sometimes viral infections or immunisations. It may start at any age, including in childhood as well as in adults.

In adulthood, localised scleroderma usually appears between the ages of 20 and 50 years, most often in people in their 40s. It is more common in women than in men and can appear for the first time during pregnancy. The condition usually affects white-skinned people and is rare in people of African American origin. It is also sometimes seen in association with other autoimmune conditions, such as lichen sclerosus, lichen planus, autoimmune thyroid disease, psoriasis, rheumatoid arthritis and systemic lupus erythematosus.

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"I think what helped me more than anything else was the knowledge that I had strong support from family and friends. They were eager to help me get through it and gave me safe space to feel afraid and expel any emotions I felt. Their support helped me stand up to the challenge of managing a long-term condition."

# WHAT ARE THE SYMPTOMS OF LOCALISED SCLERODERMA?

Localised scleroderma can come on gradually over months, or more quickly over a period of a few weeks. For many people there are no symptoms at all. Everyone's experience of localised scleroderma is different. It depends on what type you have, how severe it is and what parts of your body are affected.

### Skin changes

- Sometimes the skin can be itchy, burning, or sore.
- Thickened skin may become fixed and 'stuck down' across a joint such as the wrists, ankles, knees or elbows. This can restrict growth and mobility.

### **Deep tissue involvement**

- Involvement of deeper tissues on the face can lead to distortion of the natural facial contour and altered facial appearance.
- Fatigue, joint pain and muscle aches.
- Hair loss over the affected area, headaches and more rarely, epilepsy can occur.
- The eyes and teeth can occasionally be affected, so it is important to have both a dental and an eye assessment.





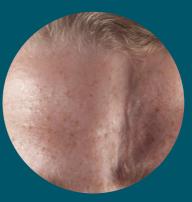
**Superficial dermis** 

Deep dermis and fat



Fascia (faciitis)

**Muscle and bone** 



# WHAT ARE THE DIFFERENT TYPES OF LOCALISED SCLERODERMA?

**Localised scleroderma (morphoea),** covers a wide spectrum of different types, which vary significantly in terms of their severity, depending on how much of the skin is involved, whether any structures beneath the skin such as fat, fascia, muscle and bone are affected; and whether the disease is active and progressing. Each sub-type of this condition is characterised by the shape and amount of affected skin and underlying tissues.





### Disseminated plaque morphoea:

This occurs at more than two anatomical sites. Plaques may join together and can be "isomorphic" (occurring at sites of friction including the waistband, bra-line, over the shoulders, under the breasts and in the groin). This type is seen more often in middle-aged women. Plaques can also be "non isomorphic," (scattered plaques at any site). In most cases, the morphoea is confined to the skin and does not involve the deeper tissues such as muscle or fascia.









Limited plaque morphoea: Limited plaque morphoea is the most common type of morphoea occurring in adults and is characterised by discrete plaques occurring at one or two "anatomical sites" of the body. Plaques are usually superficial and may be pale, waxy and thickened, or thinned and darker. The affected areas usually range from two to 15 cm in diameter and are often oval in shape (like a thumb print or palm print).

Pansclerotic morphoea: This is very rare and involves circumferential involvement in most body sites. It can occur in adults or children, begin on the trunk or limbs and spread quickly over a period of weeks or months. If the chest or trunk become "encased" (affected circumferentially), this can cause restriction of skin movement and difficulty with expansion of the chest when breathing. It is more likely to affect deeper tissues (such as fascia, muscle and bone), and affect mobility as well as day-to-day activities. It is the most severe form of morphoea.

There is an overlap between pansclerotic morphoea and a condition called **eosinophilic fasciitis**, which can also be very extensive and tends to involve the deeper tissues (fascia) first, causing swelling and pain. Within weeks or sometimes months this may cause skin thickening as well.

Sometimes, the term 'generalised morphoea' is used to include both disseminated plaque morphoea and pansclerotic morphoea. Since these sub-types are very different in terms of severity and the need for treatment, we avoid using the term 'generalised morphoea,' simply to avoid confusion.



Linear left lower hemiface



En coup de sabre



Linear morphoea of the left leg



Muscle and bone

Linear morphoea: This occurs in a line. It can involve the head and neck or the trunk and limbs, and occasionally both. In adults it can cause asymmetry of the limb girth because of loss of muscle and soft tissue bulk. If the morphoea crosses joints, this can lead to stiffening and reduced mobility (contractures).

Linear morphoea involving the head and neck can cause a change in skin texture or a groove, which runs vertically up the forehead into the hairline. This type is called morphoea 'en coup de sabre'. It may also involve the cheek, or the chin and the side of the neck. In this case it may be referred to as 'progressive hemifacial atrophy', or 'Parry Romberg Syndrome'. In some cases, this may lead to changes to the shape of the face, hair loss at the affected site, eye and dental problems and neurological complications including migraine and epilepsy.

Whilst all subtypes described above can have superficial or deep involvement, the linear and pansclerotic forms are most likely to involve structures below the skin such as fat, fascia, muscle and bone. They should be monitored closely and are more likely to need treatment.



Deep dermis and subcutis



Superficial

# WHAT ARE THE POSSIBLE COMPLICATIONS OF LOCALISED SCLERODERMA?

In most cases, localised scleroderma does not cause any life-threatening complications. However, the psychological impact of developing changes to the colour of the skin and to the shape of a limb or the face can alter self-confidence, cause anxiety and be very challenging. Emotional support is important and talking about your feelings to your family, GP, hospital consultant or clinical nurse specialist can help. We can also help you to access psychological help such as talking therapies if needed.

Severe linear disease can have an impact on mobility if it crosses joints and or causes muscle loss and limb asymmetry. In some cases, pansclerotic disease can result in significant disabilities requiring a wheelchair or modifications to the home.

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"Yes, the information leaflets were useful, as were the websites provided."

Shanta

Please visit: sruk.co.uk/publications/

# HOW IS LOCALISED SCLERODERMA DIAGNOSED?

Localised scleroderma can usually be recognised by its appearance without the need for any tests. Your doctor will examine the affected skin and ask you about how and when the skin changes occurred, and whether you have any symptoms.

It is important to distinguish localised scleroderma from systemic sclerosis, especially in cases of rapidly progressing widespread or circumferential skin thickening. So, if you have localised scleroderma, your doctor is likely to refer you to a specialist in skin disorders (dermatologist) or diseases of the joints, bones and muscles (rheumatologist).

Over time, you will probably have several tests, which might include:

### **Skin biopsy**

This is a procedure in which a small sample of affected skin, subcutaneous fat (and sometimes fascia) is removed under local anaesthetic and examined under the microscope.

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"Upon finally receiving a diagnosis approximately 18 months after my symptoms first appeared, I was incredibly relieved. Understanding what was happening to my body helped to alleviate some of the stress associated with the condition. Acquiring a diagnosis brought clarity and understanding that I sorely needed."

Hannah

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"Morphoea can usually be diagnosed clinically, i.e. from the appearance of the skin changes and the area(s) of the body which are affected. Sometimes a biopsy is needed if there is uncertainty or in order to establish whether the process is just involving the skin or deeper tissues such as fascia or muscle (depth of involvement). Blood tests, MRI and thermography can sometimes also be helpful in determining whether the condition is active or affecting deeper tissues."

Dr Cate Orteu

### **Blood tests**

- Eosinophils (eosinophilia), a type of white blood cell count (may be raised).
- Inflammatory markers. The erythrocyte sedimentation rate (ESR), or C-reactive protein (CRP), may be raised.
- Anti-nuclear antibody (may be raised, but systemic sclerosis specific ENA antibodies such as anti-Sc70 are negative).
- Thyroid function tests (may be abnormal, and the risk of associated autoimmune thyroid disease should be considered).
- Rheumatoid factor or anti-CCP antibodies if arthralgia/arthritis may be positive. This is more likely to occur in people with arthritis and joint pains.

### **Imaging**

- Magnetic Resonance Imaging (MRI).
- Ultrasound.
- Serial thermography, which measures the temperature of the skin, can also be used to assess extent and progression of disease.
- Electroencephalogram (EEG), a test that detects electrical activity in your brain using small, metal discs (electrodes) attached to your scalp, may be used to diagnose epilepsy.
- X-rays are also occasionally used to check that children's bones are growing properly.

### **TREATMENTS**

### **Making treatment decisions**

The aim of treatment is to stop progression, shorten the duration of disease and avoid tissue damage. Several courses of treatment may be needed over a lifetime, especially when localised scleroderma begins in childhood. There is no "cure" for localised scleroderma, but in most cases, it is not a serious condition. It is generally thought to get better by itself, but this may take many years. There are several treatment options available, that will vary depending on the type, extent and depth of involvement, the activity of your condition and your wish (or not) to be treated.

Before any treatment decisions are made, you will be assessed by your dermatologist and/or a rheumatologist. They will ask you questions about your medical history and whether you have been a smoker, as well as carry out a physical examination and a range of tests. Your doctor will then discuss a treatment plan with you, and there may be several options available.

### **Consent to treatment**

Before treatment starts, your doctor will talk to you about the potential benefits, as well as the possible side effects and any associated risks. You will have the opportunity to discuss anything that you do not understand or any concerns you may have. It is important to understand exactly what the treatment involves before you decide to go ahead, and to feel as confident as possible that you have made the right decision, so do ask for more time to consider the options if necessary.

Having high-quality information will help you feel more confident about your treatment decisions, so always ask for clarification if there is something that you do not understand.

### The following questions may be helpful at the time:

- What do you think is the best type of treatment for me?
- What may happen after I start this particular treatment?
- How will this affect my everyday life?
- What are the side effects?
- What clinical trials are available to me?

For consent to treatment to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision. Consent should be given to the healthcare professional responsible for the person's treatment. Consent is sometimes given in writing, e.g., by signing a consent form for a medical procedure, or it may be verbal, such as confirming to the doctor that you are happy to have an X-ray. It could also be implied, for example, by holding out your arm to have blood pressure taken.

When it comes to giving consent to taking medications, verbal rather than written consent is often used.

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"Yes, from the beginning my doctor made the pros and cons of each treatment clear to me, and I essentially chose the treatment which would stop the scleroderma spreading the quickest."

### Treating localised scleroderma

This section will help you think about what you want to do next and introduces some of the treatments that may be available to you. The treatment for morphoea depends on the type (linear, plaque or generalised), the person's age and whether it has spread deeper underneath the skin

Limited plaque morphoea does not always need treatment, as it may not cause too many problems.

### **Topical treatments**

- Strong steroid creams or ointments are often used and may help to reduce inflammation and speed up the resolution of the plaques. They are applied once or twice a day and can be used safely for between four and 12 weeks, depending on the steroid strength.
- Vitamin D analogues, which are usually used twice-aday for several months.
   Combinations of vitamin
   D analogues and steroids are available as ointments or foams and can also be effective.

- Immunosuppressive ointments including tacrolimus and pimecrolimus used twice daily.
- Imiquimod cream are also sometimes recommended.

If you have superficial but disseminated plaque morphoea, especially if the plaques are inflamed or waxy and thickened, light treatment may be recommended

### **Light therapy**

- Ultraviolet A1 (UVA1) is the most effective form of light therapy as it penetrates deep into the skin and can lead to improvement. However, it is not widely available in the UK.
- PUVA light treatment,
   where you soak in a bath of
   psoralen, have psoralen gel
   painted on to the affected
   areas, or take a psoralen
   tablet prior to exposure to
   UVA light, is a much more
   widely available form of light
   therapy, which can also give
   good results.

Light treatment may also be recommended in some cases of superficial linear morphoea or as an additional treatment in pansclerotic morphoea.

### **Tablet treatment**

In most cases of active linear morphoea and pansclerotic morphoea, especially if there is involvement of muscles (myositis), or fascia (fasciitis), tablet treatments and/or steroid infusions are recommended. These treatments can also be offered if you have disseminated plaque morphoea if cream or light treatments have not been helpful.

- Infusions of steroids (methylprednisolone) are sometimes given at the start, or monthly for the first threeto-six months.
- **Steroid tablets** may also be given over the first few months and may be needed for longer (e.g., 18 months), if you have fasciitis.

### The main tablet treatments used are immunosuppressants.

- Methotrexate is used "first line" as there is the most evidence for its effectiveness in morphoea (in adults and children).
- Mycophenolate mofetil is used if methotrexate is contraindicated or not tolerated. In some cases, ciclosporin can be added and more recently hydroxychloroquine, an anti-inflammatory, has been found to have some beneficial effects.

Your doctor's recommendations will be based on the type of morphoea that you have and how it is affecting your body. You can read more detailed information about many of these medicines on our website:

sruk.co.uk

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"Initially I went on methotrexate and steroids to manage the condition. During later reappearances of the condition, I underwent phototherapy, steroid infusions, methotrexate injections and I used a multitude of topical treatments."

Hannah

### **Non-drug treatments**

- Physiotherapy to maintain mobility.
- Manual lymphatic drainage massage may be beneficial.
- Stem cell fat transfer and fillers may be helpful to reduce asymmetry, especially in head and neck disease
- Orthopaedic and plastic surgeons may also need to be involved in the treatment of joint contractures and limb asymmetry.

### Side effects during treatment

All forms of treatments can have side effects. The type and extent of these will vary from personto-person and will be dependent on factors such as the type and dosage of treatment. It is

important that you are informed so that you understand how to deal with them if they happen and to help you decide about agreeing to treatment.

Steroids do not tend to cause significant side effects if they are taken for a short time at a low dose, however they may sometimes have some unpleasant effects, such as increased appetite, mood changes and difficulty sleeping. This is more common with higher doses of steroids.

Longer term use of oral and/or intravenous steroids can be associated with bone thinning, high blood pressure and diabetes

Some side effects may develop during treatment and continue for a short time, whereas others can appear later and may be longer-lasting. This can be unpleasant and uncomfortable,

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"Yes, I was made aware of the risk associated with taking the methotrexate pills and from having frequent phototherapy sessions."

but it is critical that you do not stop taking your treatment without first discussing this with your medical team. Stopping a prescribed course of medicine can cause further unpleasant side effects such as a flare-up or worsening of your condition.

Your dermatologist or nurse specialist will see you regularly throughout your treatment and be available to answer any questions you may have.

The MHRA Yellow Card reporting scheme allows members of the public to report suspected side effects of any medical treatment.

### Follow up care

Your doctor will work with you to develop a personal, follow up care plan. This will tell you how your health will be monitored over the coming months and years and will involve regular check-ups at your hospital or with your GP or community nurse. How often these check-ups occur will depend on the treatment you have had and how well it has worked.

Follow up is also important because it gives you an opportunity to discuss any long-term side affects you are experiencing. Your doctor may be able to help, or they may refer you to a service that can. In addition, you will be able to ask any questions you may have. Getting answers from a professional who understands your individual circumstances can provide reassurance and help you feel more in control of your situation.

### Difficulties between appointments

Your healthcare team can provide details of whom to contact if you have any problems with your treatment or notice any new symptoms between appointments. It is important to get in touch if you have any serious concerns, if you are struggling with side effects or if you notice worsening symptoms.

Remember the first port of call is often your GP or nurse specialist, who can then directly discuss the situation with your doctor.

## MANAGING YOUR WELLBEING

Treatments will work best when you play an active role alongside your healthcare team. It takes time and persistence, but you should feel the benefits if you can:

- Learn about your medicines and how to take them.
- Talk to your doctor about medication side effects. They
  might be able to change your prescription or help you
  feel more comfortable.
- Keep up with the exercises recommended by your physiotherapist and ask for advice if they are too hard or not working for you.

#### Skin care

Routine skin care is essential when you have localised scleroderma. Moisturisers containing 10% urea such as Eucerin, or with a high ceramide content such as Cerave, may be helpful. Keep your skin well-moisturised and avoid highly fragranced soaps. Itchy skin can also be treated with creams containing anti-itch ingredients such as crotamiton (Eurax,) and lauromacrogols (E45 itch-relief, Balneum Plus). Antihistamines may sometimes also help.

### **Keep warm**

A small proportion of people with localised scleroderma may also have Raynaud's Phenomenon, meaning that the small blood vessels in the extremities such as the hands and feet are over-sensitive to even the slightest changes in temperature. If this is the case then planning ahead and following a few simple rules, such as wearing suitable clothing and having heating aids readily available, you will be in a better position to keep warm in fluctuating temperatures. This should help to minimise the problems which may otherwise cause you pain or discomfort.

### **Heating aids**

A selection of heating aids and gadgets are available, these include disposable, rechargeable and microwaveable heat packs and silver socks and gloves.

### At night

Take the chill off the bed with a hot water bottle or use an electric blanket. Make sure to turn your blanket off before getting into bed unless you have an all night model. Wear flannelette night clothes, bed socks, gloves etc. Duvets are warm without being too heavy but keep extra blankets at hand during a cold spell. Thermal under blankets add extra warmth.

### Air conditioning

It is advisable to have a headscarf to wear, especially when in air conditioned buildings and on aircraft when the cold air circulates around your neck.



### **Physical activity**

Try to learn a few basic exercises that are within your own physical limitations. Gentle exercise such as walking or moving your arms and legs, even when sitting, will help to stimulate the circulation. Should the cold cause you to lose feeling in your fingers and toes, reheat them slowly.

#### **Exercise can help you to:**

- Manage fatigue
- Reduce stress and anxiety
- Boost your mood and energy level
- Help you relax
- Improve your sleep

Physical activity can also reduce the risk of depression, increase appetite and boost confidence; and keeping active during treatment is generally safe as well. Whilst it is natural to feel a little nervous about overexerting yourself and getting out of breath, light exercise can have real benefits to your wellbeing. There is no specific exercise that is guaranteed to help, so start with something you enjoy so that you are more likely to stick to it. This can include daily activities such as walking your dog or gardening, or simply moving about more. Examples of aerobic and strengthening exercises can be found on our website, as well as breathing techniques.

### Other impacts of localised scleroderma

Localised scleroderma can affect various parts of your life and may mean that you must spend more time thinking about certain areas, to ensure that all actions and potential outcomes are well-considered.

#### For example:

- **EMOTIONAL WELLBEING:** changes to your lifestyle can be stressful, due to limitations in what you can do daily or simply due to taking medications. This can take a toll on your mental and emotional wellbeing, and it is important that you have someone to talk to, be that friend, family or the SRUK Helpline.
- EMPLOYMENT: by law, you do not have to tell your employer about being diagnosed with localised scleroderma. Some of our community report that it was more practical for them to do so, and that their employer was able to better support them after being informed, however everyone's circumstances and preferences are different.

### With thanks to our clinical reviewers:

#### **Dr Cate Orteu**

Consultant Dermatologist at the Royal Free Hospital and Honorary Associate Professor, UCL Medical School.

#### **Professor Chris Denton**

Professor of Experimental Rheumatology at UCL Medical School and Consultant Rheumatologist and Joint Director of the Centre for Rheumatology, Royal Free Hospital.

We would like to acknowledge Shanta Keshwala, who features on the front cover and has provided quotes. We would also like to thank Hannah Stevens for her quotes and her support in helping us to produce this booklet.

> For more detailed information and for further advice on managing localised scleroderma, please visit: sruk.co.uk/scleroderma/managing-scleroderma/

### HOW SRUK CAN HELP

We are the only UK charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's. We exist to improve awareness and understanding of these conditions, to support those affected, and ultimately to find a cure. We understand that being diagnosed with a condition can be a scary and uncertain time. But don't worry, we are here for you, every step of the way. We provide trusted, reliable and evidence-based information on Scleroderma and Raynaud's. We want you to be able to learn more about your condition, feel confident in working with your health professionals and receive the right care for you.

### **Access to support services**

Our online community is a friendly space where you can exchange advice, information and support with others who are affected by Scleroderma and Raynaud's. Many of our community members are living with these conditions themselves, but friends, family and partners are also welcome. We can connect you with your local Scleroderma and Raynaud's Support Group, to connect with others in a similar situation.

## You can contact our free Helpline 365-days-a-year on 0800 311 2756.

To find out more and receive all the latest information, please join our community on social media and start building a network of supportive friends today:



### Research

We fund scientific and medical research to better understand the causes and progression of these conditions and enable us to find better treatments as we work towards a cure. Our community is at the heart of our research programme. We are committed to addressing your needs to improve life in the here and now, alongside focussing on our long-term aim of discovering a cure. Through our investment in research, we have increased life expectancy for people living with scleroderma and have brought more treatments into clinics.

To find out more about current studies, please visit the central register at **www.clinicaltrials.gov** and search for 'scleroderma'.



### HOW TO GET INVOLVED

The work of the charity is funded entirely through donations, fundraising and memberships. We would like to ask you to support our work so we can continue to improve lives.

#### Become a member

As a member of SRUK, you will be entitled to all the following:

- Four issues of our magazine, received quarterly
- Priority booking for all patient educational events
- Regular member-only discounts in our online shop, where you will find products that are tailored to these conditions
- Invitations to sign up for observation and/or product trials we may be running throughout the year, with key product partners and market research partners

Visit our website to find out more: www.sruk.co.uk/membership or call our team on 020 3893 5998



### **Donate to us**

Donating to SRUK will help support our life-changing work. There are many ways you can do this, including one-off or monthly donations, leaving a gift to us in your Will or nominating us as Charity of the Year at your company.

Make a donation today by texting SRUK05 £5 to 70070

### Sources used

We rely on several sources to gather evidence for our information.

All our information is in line with accepted national or international clinical guidelines where possible. Where no guidelines exist, we rely on systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals, and government publications.

If you would like further information on the sources we use on a particular publication, please contact the Information and Support Services team at

### Valuing your feedback

As someone who has received a copy of this booklet, we would very much value your opinion on whether it meets the needs of people affected by Scleroderma and Raynaud's. Please complete the survey online at

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