

SCLERODERMA: A GUIDE FOR EMPLOYERS

How to support an employee
living with scleroderma



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ABOUT THIS INFORMATION

Scleroderma is a complex condition that affects different people in different ways. The symptoms can be mild, severe or anything in between, and no one is affected in exactly the same way.

This guide was created to help business owners, line managers and HR professionals provide effective support to employees with Scleroderma. It covers what the condition is, how a person may be affected by it, and the range of help an employer can provide.

The guide is backed up by reliable sources and evidence, and has been reviewed by healthcare professionals, HR consultants and people who are living with Scleroderma.

If you need more details and support, please visit us at sruk.co.uk or call our free Helpline on **0800 311 2756**.

WHAT IS SCLERODERMA?

Scleroderma is a rare condition that affects people of all ages. It occurs when the body produces too much collagen.

It is an autoimmune condition, meaning that the immune system becomes overactive and attacks healthy tissue within the body. When the extra collagen builds up, it can make your skin stiff, tight, thick or scarred. It may also affect your blood vessels, joints, muscles and internal organs, such as the heart and lungs. The name comes from the Greek words 'sclero,' meaning hard, and 'derma', meaning skin.

Currently, we don't fully understand why some people develop scleroderma, and there's no cure for this condition. But the good news is that effective treatments are available to help with the symptoms, and many affected people can lead full and active lives.

Two types of Scleroderma

There are two different types of scleroderma:

Localised scleroderma (also known as morphea)

The condition primarily affects the skin, but in some rare cases it can also affect soft tissue, muscle and bone. This can cause changes to the shape of limbs and other body parts.

Systemic sclerosis
(also known as scleroderma)

Systemic sclerosis is the more severe form of Scleroderma and can affect internal organs as well as the skin. For example, scar tissue may form inside the lungs, gut or kidneys.

**Up to 19,000
people are living
with Scleroderma
in the UK.**

**Up to 1,000 people
are diagnosed
with Scleroderma
each year.**

HOW SCLERODERMA MAY AFFECT PHYSICAL HEALTH

Every person's experience of scleroderma will be different. It depends on what type of scleroderma they have and how their condition affects them.

In this section, we look at a range of symptoms and how they may affect a person's everyday life.

Skin changes

For most people, scleroderma causes problems with the skin. This may mean a person diagnosed with scleroderma experiences one or more of the following symptoms:

- Patches of thick, hard skin that may become discoloured.
- Itchy and tight skin.
- Hard lumps under their skin called calcinosis (in systemic sclerosis).
- Tiny blood vessels (spider veins) appearing just beneath their skin (in systemic sclerosis).

At work, this may lead to an employee feeling uncomfortable and self-conscious about their appearance.



Reduced movement

Thickened skin may become fixed and 'stuck down' across a joint such as the fingers, wrists, ankles, knees or elbows. This may restrict a person's movement.

As a result, they may struggle to do everyday tasks such as typing with a keyboard, lifting equipment or walking long distances.

Tiredness (fatigue)

Scleroderma is an autoimmune condition, which means it causes the body to attack normal cells. As a result, a person with scleroderma may sometimes experience extreme tiredness (fatigue) from doing physical or mental activities.

Nausea and vomiting

The medications an individual takes to treat their scleroderma may lead to a range of side effects, including nausea and vomiting. If they do experience these symptoms, their healthcare team will review their medications.

Weakened immune system

Common treatments for scleroderma include medication to reduce the activity of the immune system, meaning that a person may become more susceptible to infection in some cases.



“People need to understand how Scleroderma can really affect your mobility. It's not always just a skin thing. Even for me, it took a long time for me to admit that I have a disability.”

Pain

Pain can be one of the most challenging symptoms of scleroderma. Thickening of the skin can prevent people from straightening their joints, leading to stiffness and pain.

Chronic pain can be difficult to manage, but it can be treated. Early management of symptoms can drastically improve quality of life and reduce the risk of a person developing depression.

With scleroderma, pain can flare up quickly and at any time. This may mean an employee will suddenly not be able to complete a task or need time out.

Changes to the body

In some cases, scleroderma can affect structures under the skin, such as fat, muscle and bone. This may lead to a physical disability and an employee needing support to move around your workplace or carry out certain tasks.

Changes to the face

Scleroderma can affect the head and neck and cause a change in skin texture or a groove which runs vertically up the forehead into the hairline. It may also involve the cheek, chin and the side of the neck.



A groove in the forehead caused by scleroderma, often referred to as 'en coup de sabre'.

Raynaud's Phenomenon

People with systemic sclerosis are also likely to be affected by a condition called Raynaud's. It causes reduced blood flow to the body's extremities and typically affects the fingers and toes.

A person may experience what's called a Raynaud's attack if they are exposed to the cold or become stressed. This may lead to numbness, tingling or pain in their fingers and toes, which can make everyday tasks extremely difficult.



Credit: NHS

In some people, Raynaud's can lead to changes in colour in their hands and feet.

Digital ulcers

Systemic sclerosis may lead to an individual developing painful sores on their fingers and toes (called digital ulcers). These must be treated straightaway to protect the affected tissue and prevent an infection.

If an employee develops digital ulcers, it may be difficult for them to complete certain tasks that involve them using their hands or feet. They may need to visit their GP or hospital regularly and a period of planned sick leave may be required until the ulcers have been treated effectively.

The gastrointestinal (GI) tract

Systemic sclerosis can affect any area of the GI tract, including the mouth, oesophagus (gullet), stomach, small and large intestines and the rectum.

This means that an individual may be affected by a wide range of digestive issues, including acid reflux, swallowing difficulties, nausea and vomiting, pain, bloating, weight loss, diarrhoea and constipation.

Lung involvement

Systemic sclerosis can affect the lungs. This may mean that a person experiences a range of symptoms, including shortness of breath, a cough, chest pain and dizziness. They may be particularly affected by these symptoms when they exert themselves, such as going up stairs or lifting heavy objects.

High blood pressure

If systemic sclerosis does affect internal organs such as the heart, kidneys and lungs, this can lead to an increase in blood pressure. This may lead to a person experiencing dizziness, headaches and blurred vision.

HOW SCLERODERMA MAY AFFECT MENTAL HEALTH

The impact that scleroderma and its treatment has on the mood and mental health of a person can vary greatly.

Some people cope really well and don't require further emotional support, while others can be affected considerably and might need support on an ongoing basis.

As an employer, line manager or HR professional, one of the most important ways you can support a person with scleroderma is to regularly check in with them and ask how they're doing physically and mentally.

Feelings after a diagnosis

Following a diagnosis of scleroderma, an employee may feel many different emotions. These include:

- Worries they may die.
- Anxiety about their health and the impact on their future.
- Sadness or anger in relation to their diagnosis and what it means for their health.
- Struggling to accept their condition, and as a result, struggling to talk about it.

Taking time off work

Having to miss work for treatment or other medical appointments may cause a person with scleroderma to worry and feel anxious. They may feel concerned that having time off draws attention to themselves, worry they're letting their colleagues down, or stress about not being able to complete tasks.

Pain and mood

Some people with scleroderma may struggle with pain a lot of the time, while others may be affected by flare ups that can happen suddenly and without warning.

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“The fatigue can really strike you hard. Work would say take time out in the staff room. But it wasn't like I could take 10 minutes and I'd be alright.”

If a person is affected by pain, it can understandably have an impact on their mood. They may feel low, anxious or irritable, or struggle with mood swings. Pain can also result in fatigue and difficulty concentrating.

Body image

Physical changes caused by scleroderma may have a significant impact on a person's mood and mental health. They may feel:

- Less confident about themselves because of their condition.
- Anxious about the reactions of other people to them.
- Worried about attending work.
- Sad or angry about the physical changes affecting them.

Physical struggles

A person with scleroderma may feel embarrassed, frustrated or isolated if they can't do physical tasks they previously could, or which other employees can do.

They may also feel similar emotions if they struggle with everyday tasks such as using a pen, fastening up a zip, or making a cup of tea.

If this is the case, it's important not to draw attention to this. And there are lots of simple things an employer can do to help a person complete tasks and remain a valued team member.

Impact of medication

An individual's mood may be affected by unpleasant side effects caused by medication. These include nausea, fatigue, mood swings and problems concentrating (brain fog).

WHY WORK IS IMPORTANT

It's understandable to be concerned about the possible impact a long-term condition such as scleroderma will have on an employee's performance and reliability.

But the reality is there are often simple and inexpensive things you can do to minimise the effects of scleroderma on a person's work life. Support that will not only benefit the employee but also your organisation.

It's also good to remember as a business owner, manager or HR professional that work is often extremely important to people with a medical condition. This is because:

- After diagnosis, a job can provide a sense of normality, routine and stability.
- Work can help an employee retain self-confidence and give them a sense of purpose.
- Work may provide money that's vital to a person paying their bills and buying essential items.
- A job may be important to a person's sense of worth and make them feel like they're contributing to society.
- Work may offer a person social contact that's good for their mental health.

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“My area manager kept saying, ‘How are you doing? You don't look well.’ That really didn't help, as I was already self-conscious about the patches on my skin.”

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“I felt like I was too much of a headache for my employer, so they weren't interested in supporting me. I felt really sad about that, because when I got the job I didn't have the condition.”

THE BENEFITS OF BEING A SUPPORTIVE EMPLOYER

Supporting an employee diagnosed with scleroderma will help them cope with what may be a difficult time in their life. But it can also lead to clear benefits for your organisation too.



Retain knowledge and skills – By helping a person overcome physical and emotional difficulties, you can keep hold of vital knowledge, skills and experience that has a positive impact on your organisation's productivity.



Save time and money – Retaining an employee ensures you avoid the cost and time of recruiting, inducting and training a new member of staff. The Chartered Institute of Personnel and Development estimates the average cost of recruitment is £5,000 for senior managers and directors, and £2,000 for other employees.



Increase staff loyalty – By supporting a person with Scleroderma, you may benefit from greater loyalty from them and their colleagues, and increase overall employee engagement.



Boost employer image – Effectively supporting people with medical conditions such as Scleroderma may have a positive impact on how a range of audiences see your organisation, including customers and job applicants.



Reduce team pressure – If an employee isn't supported and has to leave their role, this may mean their colleagues have to take on extra work in the short or long-term. This can lead to poor morale and reduced productivity.



Fulfil legal obligations – By law, an employer cannot discriminate against an employee with a condition that's classed as a disability. If you do, you may have to pay compensation and legal costs, and your reputation may be damaged. See page 13 for more information.

THE IMPORTANCE OF LINE MANAGERS

If you're a line manager, you're likely to be an important source of support for a person diagnosed with scleroderma.

As a result, it's important you speak to your HR manager, an internal occupational health (OH) professional or external OH professional.

They should be able to give you helpful information and support. This could be guidance about the employee's scleroderma, advice on reasonable adjustments (see page 19), or details about a return-to-work plan.

You could also speak to your HR manager or an OH professional about any worries you have about providing the right support.

However, it's important to note that no one should pass on confidential information to you that an employee wants to keep private.

WHY A WELL-INFORMED AND SUPPORTED LINE MANAGER IS IMPORTANT

- You're usually the person an employee contacts first when they're feeling ill at work or cannot go to work.
- You're likely to play a key role in implementing reasonable adjustments for an employee.
- You may be the person an employee contacts first if they wish to speak to HR or occupational health.
- You'll probably manage the workload of the employee, so you can determine how much pressure or demand is placed on them.
- You can support a person so they don't feel anxious about returning to work after time off.

YOUR LEGAL OBLIGATIONS

Many people with scleroderma will not consider themselves to be disabled. But an employee with the condition may meet the definition of disabled as outlined by the Equality Act 2010.

The definition set out in Section 6 of the Equality Act states you're disabled if:

- You have a physical or mental impairment.
- Your impairment has a substantial and long-term adverse effect on your ability to do normal day-to-day activities.

If an employee is classed as disabled, it's unlawful for an employer to discriminate against them. Discrimination occurs where:

- A disabled person is treated less favourably than someone else because of their disability.
- There is a failure to make reasonable adjustments for a disabled person (see page 19).
- A disabled person is victimised or harassed by colleagues or an employer.

Under the Equality Act, a disabled person is not only protected against discrimination while in employment. The act also protects people when they're applying for a job and when their employment is terminated.

If you'd like further information about your responsibilities under the Equality Act 2010, the Equality and Human Rights Commission (EHRC) offers extensive guidance on its website.

If you're based in Northern Ireland, the Equality Commission for Northern Ireland can give you advice about your responsibilities as an employer.

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“I didn't know my rights at work. I just felt like I was pushed out because of my Raynaud's and Scleroderma.”

FIRST STEPS

If an employee is diagnosed with scleroderma, they may or may not decide to tell you about their condition. This is likely to depend on the type of Scleroderma they have, how severe it is and their treatment plan.

If a staff member does disclose their diagnosis, we suggest they have an initial meeting or meetings with one or more of the following people:

- Their line manager.
- Their HR manager.
- An occupational health professional.

However, it should be the employee that decides who attends the meeting or meetings. For example, they may not feel comfortable speaking about their condition with their line manager. Or they may want other people to be present, such as a colleague, family member, friend or trade union representative.

Before the meeting, it may be helpful if the person's line manager and HR manager, and any other relevant people, increase their knowledge of Scleroderma. This is something they can do at **sruk.co.uk**

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“A good thing my work did was to arrange a meeting with my whole team to discuss how they could support me.”

Topics you may wish to cover in an initial meeting about a person's scleroderma

- The best way to communicate with the employee about their condition and if any issues arise.
- Who they should contact if they want to discuss anything concerning their condition.
- How regularly the employee will meet someone to review their condition, work life and the support they need.
- How wide a circle of colleagues should be informed about their diagnosis.
- What reasonable adjustments would immediately help the employee, for example, time off work for medical appointments, which may be paid or unpaid; different or reduced working hours.
- Your organisation's policies on taking time off work, reasonable adjustments and coming back to work after time off.
- The person's legal rights with regards to discrimination.

At the end of this initial meeting, it's reassuring to let your employee know they can speak to you, or a designated key contact, if they ever need any help.

Establishing good two-way communication is critical to positive outcomes being achieved for a person with a medical condition and the organisation employing them.

TELLING COLLEAGUES

It usually helps to talk to an employee early on about who should be informed about their diagnosis and what information should be passed on.

If the person decides they want to keep their situation confidential, you must respect their decision. However, colleagues may be more understanding about time off and changes to how they work if they know what's happening.

If your employee agrees they would like to inform others about their diagnosis and its impact, it's important to clearly establish with them:

- What information they want to share and what should remain confidential.
- Who should be informed – colleagues from their team or department, all managers, your whole organisation.
- How the information should be passed on – by the person themselves; by their line manager, with or without them present; by another colleague.
- How colleagues should be told – by telling one person at a time; in a meeting; via email.

At your workplace, you may also want to provide advice to the person's colleagues about how they can support and be a good friend to someone diagnosed with Scleroderma. This may involve you directing them to **srुक.co.uk** so they can find out more about the condition.



“I had colleagues tease me about my weight loss and that I couldn't open my mouth wide. I think that's because they had no knowledge about Scleroderma and the impact it can have on someone's life.”

LEARNING WHAT YOUR EMPLOYEE NEEDS

With the right support and adjustments, a person with scleroderma can usually continue in employment. However, it's important to regularly speak to them about any issues they're facing and possible solutions to these problems.

This is something you may wish to do by using the checklist below. Or your organisation and the employee may benefit from the help of an external occupational health professional (see page 23), if your organisation doesn't have an internal OH professional.

Checklist for identifying needs and potential solutions

- Identify with your employee the parts of their role they can complete without any problems.
- Identify with your employee the parts of their job they know or think they may struggle with.
- Establish what could be done differently to help them perform their role to the best of their ability. For example, would certain technology help them perform their role better, such as speech recognition software?
- Examine their working environment – Is it easy for them to move around it? Are there any accessibility issues?
- Discuss with your employee if they feel they can continue in their current role. Would a different role in your organisation be a better option for them? Look at potential retraining options.
- After discussing their needs and potential solutions, clearly outline what actions will be taken, when they'll be taken and who will be responsible for them.



“Despite my condition, I could have done 70% of my job. But it felt like my employer wanted me to do my full role or I had to go.”

TIME OFF WORK

A person with scleroderma is likely to need time off for treatment, check-ups and blood tests, and especially following their diagnosis.

How much time off they need will depend on the type of Scleroderma they have, how severe it is and their treatment plan.

For example, someone with mild localised scleroderma may not require treatment and just see their GP when issues arise. While a person with systemic sclerosis and severe Raynaud's may need to attend hospital every three to six months for a course of treatment that last five days.

An employee may be able to arrange their medical appointments outside of work hours. But if this isn't possible, they may request time off from work to attend them.

It's a good idea to discuss your organisation's policy on medical appointments shortly after your employee's diagnosis and what time off they may need.

It's also important to note that your employee may be classed as disabled by law. As a result, you may be viewed as discriminating against them if you don't let them have time off for a medical appointment.

Fit notes

If a person needs time off because of their scleroderma, they can self-certify they are unable to work for seven days. After this time a doctor may issue them with a fit note (previously sick note).

If the fit note says the person is fit to work, it may include information from their doctor about what you could do to help them return to work. This is something you should discuss with your employee.

REASONABLE ADJUSTMENTS FOR AN EMPLOYEE

The Equality Act 2010 states that employers must make reasonable adjustments to any elements of a job which place a disabled person at a substantial disadvantage compared to a non-disabled person.

There is no fixed description of what a reasonable adjustment should be. It will depend on:

- How much the adjustment will help the person.
- How practical it is to make the adjustment.
- The cost of making the adjustment.
- How the adjustment will affect the company or organisation.
- The size of the company or organisation employing the disabled person and the resources it has.

If an employee has scleroderma and they meet the legal definition of a disabled person, it's important to talk to them about what would help them in their role before making any adjustments.

Your organisation and the person may also find it helpful to speak to an occupational health professional (see page 23). They can provide advice about reasonable adjustments based on their clinical expertise and an understanding of the employee's role at your organisation.

It's also worth noting that reasonable adjustments are often easy to implement and usually don't cause disruption to a workplace.

Many adjustments are also free or inexpensive. Grants from Access to Work schemes (see page 24) can also sometimes cover a percentage or the whole cost of an adjustment.

POTENTIAL ADJUSTMENTS FOR A PERSON WITH SCLERODERMA

On this page and opposite, we've suggested adjustments you could make to help an employee with scleroderma remain in or return to work.

You can also find more extensive guidance on workplace adjustments on the websites of the Equality and Human Rights Commission and Equality Commission for Northern Ireland.

equalityhumanrights.com/en/multipage-guide/employing-people-workplace-adjustments

equalityni.org/reasonableadjustments

- Give your employee time off for regular medical appointments, which may be paid or unpaid. You may have information about this in your existing policies.
- Change your employee's job description to remove tasks that are particularly difficult for them.
- Temporarily give some of the person's duties to a colleague, for example, lifting heavy items.
- Allow them to temporarily or permanently work part-time hours or have a flexible start or finish time.
- Allow your employee to work from home all the time or a number of days per week. Make sure their home is a suitable work environment and they have the right equipment to do their job.
- If the person does start to work from home permanently, help them to stay in touch with colleagues so they don't become isolated.
- Give them extra breaks and access to a quiet room if they're affected by fatigue.
- Allow your employee to take regular breaks to stretch and move about, as sitting still for a long time can lead to pain and stiffness.
- Make it easy for them to notify you if they're affected by pain or fatigue while at work and need to go home. Try to do this in a way that doesn't draw attention to them.

- Change your employee's performance targets so they take into account their condition and the time off they need for medical appointments.
 - If the person with scleroderma agrees to it, transfer them to a job with more suitable tasks for their situation.
 - If they have mobility issues, give them a parking space closer to the entrance of your premises.
 - Change where the person works in your premises, for example, a move to the ground floor may be preferable if they find it difficult to go up and down stairs.
 - Provide equipment or technology that will help them in the role, for example, a supportive chair, a keyboard and mouse that supports their wrists, or voice-recognition software if they struggle to type.
 - If your employee struggles with gastrointestinal or mobility problems, make sure they can get to a toilet easily.
 - Modify workplace policies so they don't put a person with a disability at a disadvantage. The policies you look at might focus on sick leave or disciplinary procedures.
 - If a person is affected by scleroderma and Raynaud's, ensure their work area is warm and they're not sitting in a draught or near open windows.
 - Allow a person to dress warmly if they're affected by Raynaud's. This may mean they wear gloves, a hat or scarf at any time of the year.
 - Allow your employee to have a phased return to work if they've had a long time off.
- Please remember these are just suggestions. The support each individual needs will differ. Regularly speak to your employee about what adjustments will help them in their role.**

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“I didn't know my legal rights, so I ended up paying for a lot of equipment myself: a supportive chair, a rest for my feet, a special upright mouse I could use with my thumb.”

OCCUPATIONAL HEALTH ADVICE

An employee with scleroderma and your organisation may benefit from the support of an occupational health professional.

They can help you understand what you need to do to support the person in relation to employment and health and safety laws.

An occupational health professional can also help to:

- **Identify reasonable adjustments**, such as changing how a job is performed, modifying the work environment, adapting equipment, providing assistive technology or other equipment such as wrist supports.
- **Create a return-to-work plan** that ensures a person returns to work in a way that helps them stay well and do their job to the best of their ability.
- **Carry out a risk assessment** to make sure an employee is doing work that's right for them from a health and safety point of view.

If you don't have access to an internal OH professional, there are many companies that offer occupational health consultancy to businesses of all shapes and sizes.

Important:

It's often helpful to speak to an occupational health professional shortly after an employee tells you about their diagnosis. This is so you benefit from their expertise before making important changes to your workplace, a job description or your policies.

ACCESS TO WORK SCHEME

Government Access to Work schemes offer grants and advice to employers and employees to help people with a disability or long-term health condition stay in work.

An Access to Work adviser can give you support and information to help tackle practical obstacles in the workplace. They might do this by reviewing an existing report from an occupational health professional, or they may arrange for a workplace assessment to take place to determine what type of help an employee needs.

The Access to Work scheme may also pay for the following support if your employee is classed as disabled and needs help beyond the reasonable adjustments you're legally obliged to carry out.

- Special aids and equipment needed in your workplace.
- Adaptations to your premises and equipment.
- Extra travel costs to and from work if the person can't use available public transport.
- Extra travel costs a person must pay for while carrying out their work duties.
- A support worker for an employee.

If you're based in England, Scotland or Wales, visit [gov.uk/government/publications/access-to-work-guide-for-employers](https://www.gov.uk/government/publications/access-to-work-guide-for-employers) for an Access to Work guide for employers.

If you're based in Northern Ireland, visit [nidirect.gov.uk/articles/access-work-practical-help-work](https://www.nidirect.gov.uk/articles/access-work-practical-help-work) for further information.

HELPING AN EMPLOYEE RETURN TO WORK

If a person has had a long period off work because of their Scleroderma or treatment, they may feel anxious about returning to your workplace and their role.

To help make this return as comfortable as possible, it may be a good idea for you and them to meet one or two weeks before their first day back. At this meeting, you may want to discuss:

- How the person is currently feeling, their concerns and whether they're definitely ready to return to work.
- Work developments that have happened during the time they were away.
- Any recommendations made by members of the person's care team with regards to their role.
- Reasonable adjustments that may need to be implemented in the workplace to remove or reduce any disadvantages. For example, changes to working hours, equipment or duties.
- Whether a referral to an occupational health professional would be helpful.
- Your organisation's employee assistance programme, if it has one, and how it may help boost your employee's wellbeing and improve performance.
- How the person wants to return to work, for example, a phased return involving reduced hours or lighter duties may be preferable.
- How much information they want to pass on to their team and the rest of your organisation about their condition.

HELPFUL ORGANISATIONS AND RESOURCES

AbilityNet

National charity and provider of advice on technology and disability.

abilitynet.org.uk

ACAS

Provides independent advice and information to solve work problems and improve performance.

acas.org.uk

Access to Work

Government scheme helping people with a disability remain in work.

gov.uk/access-to-work

Business Disability Forum

Provides information and advice on disability to its members.

businessdisabilityforum.org.uk

Chartered Institute of Personnel and Development (CIPD)

Supports employers to improve their HR and people development practices.

cipd.co.uk

Employment Tribunal

Website content includes guidance on how to respond to a tribunal claim.

gov.uk/courts-tribunals/employment-tribunal

Equality Advice and Support Service

Assists individuals on issues relating to equality and human rights.

equalityadvisoryservice.com

Equality and Human Rights Commission

Provides advice and guidance on a range of equality and diversity issues.

equalityhumanrights.com

Health and Safety Executive

Practical advice for small businesses in England, including employer responsibilities.

hse.gov.uk

Healthy Working Lives

Practical workplace advice for small businesses in Scotland.

healthyworkinglives.scot

Healthy Working Wales

Supporting employers in Wales to improve the health and wellbeing of their staff.

phw.nhs.wales/services-and-teams/healthy-working-wales

Labour Relations Agency

Provides advice and support to employees and employers in Northern Ireland.

lra.org.uk

NHS Health at Work

Provides a gateway for businesses who seek occupational health advice and support.

nhshealthatwork.co.uk

Thank you to our clinical reviewers

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HOW SRUK CAN HELP

Scleroderma & Raynaud's UK is the only 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.

If you'd like to find out more about Scleroderma, the impact it has on people's lives and available support, please make use of the following resources.

We'd also appreciate it if you passed on this information to an employee, if you think this is appropriate.

SRUK website

Our website features a wealth of high-quality information about Scleroderma and Raynaud's, details about our services and research, and personal stories from people affected by these conditions.

Visit **sruk.co.uk** today.

Our free publications

You can download a wide range of publications about Scleroderma and Raynaud's at **sruk.co.uk/publications**

You can also order printed copies of our guides and fact sheets by calling **020 3893 5998**.

Our titles include:

- *Understanding Scleroderma*
- *Understanding Raynaud's*
- *Understanding localised scleroderma*
- *Systemic sclerosis (SSc) and lung involvement*
- *Systemic sclerosis (SSc) and the Gastrointestinal Tract*

Our Helpline

Our Helpline offers support to people affected by Scleroderma and Raynaud's. Please call **0800 311 2756** to speak to a trained volunteer. The Helpline is open 9am to 7pm, every day of the year.

Our online community

Our online community is a friendly space where people affected by Scleroderma and Raynaud's can exchange advice, information and support. It's available at **healthunlocked.com/sruk**

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

We rely entirely on the support of our community to continue our vital work in supporting everyone affected by Scleroderma and Raynaud's.

Fundraising for SRUK will help support our life-changing work and can be a great team building and morale boosting experience.

You can set up your own events, take part in one of ours, set your team a challenge and a fundraising target and we will be there to support you every step of the way.

Please email fundraising@sruk.co.uk for more information and a fundraising pack to get you started.

You can even 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 to produce our publications, please contact our Information and Support Services team at info@sruk.co.uk

Valuing your feedback

As someone who has received a copy of this booklet, we would very much value your opinion on whether it meets your needs. Please complete our survey at sruk.co.uk/publications

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