SCLERODERMA & RAYNAUD'S UK

SCLERODERMA: A GUIDE FOR SCHOOLS

Supporting students living with scleroderma

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

WHAT'S INSIDE

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 head teachers, primary and secondary school teachers, teaching assistants, school nurses and other school staff provide effective support to students with scleroderma and their families. It covers what the condition is, how a student may be affected by it, and the range of help a school can provide.

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

For further information and support, please get in touch with us at SRUK – we're here to help.

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 the skin stiff, tight, thick or scarred. It may also affect the 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 morphoea)

The condition primarily affects the skin, but in some rare cases it can also affect soft tissue, muscle and bone. In children, this can affect the growth and shape of limbs and the face.

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.

Typically, out of 100 children with scleroderma, 93 will have localised scleroderma and seven have systemic sclerosis.

HOW SCLERODERMA MAY AFFECT PHYSICAL HEALTH

Every child's or young person's experience of scleroderma will be different. It depends on what type they have, how severe it is, and how their condition affects them.

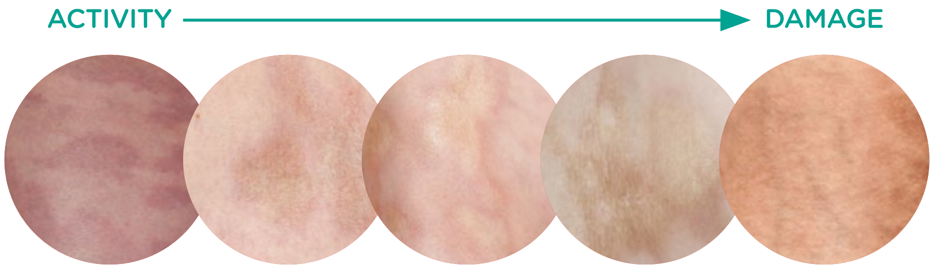
In this section, we look at a range of symptoms and how they may affect a student's everyday life.

Skin changes

For most people, scleroderma will affect the skin. This may mean a child or young person experiences one or more of the following symptoms:

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

At school, this may lead to a child or young person feeling uncomfortable, because they look different to their peers.



Red and a bit swollen

Shiny and bruise-like

Thick and waxy, inflammatory red border

Thickened, waxy and brown

Thinned and brown (visible veins)

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 child or young person's movement.

As a result, they may struggle to write or draw, take part in physical activities, or sit down on the floor.

Tiredness (fatigue)

Scleroderma is an autoimmune condition, meaning that the immune system is overactive, causing the body to attack healthy tissues. As a result, a child or young person may experience extreme tiredness (fatigue) from doing simple physical or mental activities.

Sickness

The medication a child might be prescribed to treat their symptoms could lead to a range of side effects. Two of the main issues they may experience are nausea and vomiting.

Weakened immune system

Common treatments for scleroderma include medication to reduce the activity of the immune system. This means in some cases a child may become more susceptible to infection.

> **"You can't predict who's going to struggle with scleroderma, that's why it's so important that schools offer reassurance and support to every child or young person and their family."**
>
> **Dr Clare Pain, Consultant in Paediatric Rheumatology**

Pain

Pain can be one of the most challenging symptoms of scleroderma. Thickening of the skin can prevent a child 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 child or young person developing depression.

Changes to limbs

In some cases, scleroderma can also affect structures under the skin, such as fat, muscle and bone. This may result in a child's limbs not fully developing, leading to a physical disability.

This may mean a student needs additional support to take part in some activities or move around a school setting.

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.

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.

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

Raynaud's Phenomenon

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

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

Credit: NHS

Raynaud's can lead to changes in colour to the child's hands and feet.

Digital ulcers

In a rare number of cases, systemic sclerosis leads to a child or young person developing painful sores on their fingers and toes (called digital ulcers). These must be treated by their medical team straightaway to protect the affected tissue and prevent infection.

If a student does develop digital ulcers, they are likely to struggle to take part in activities that involve them using their hands or feet, for example, PE, writing and drawing, fastening buttons or zips.

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 a student 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 also affect the lungs. This can lead to a range of symptoms, including shortness of breath, a cough, chest pain and dizziness.

A child or young person may be particularly affected by these symptoms when they exert themselves, such as taking part in PE, walking uphill or going up stairs.

Scleroderma is…

- ☑ linked to your immune system
- ☑ sometimes difficult to diagnose
- ☑ variable from mild to severe

Scleroderma is not…

- ☒ contagious
- ☒ confirmed with a single test
- ☒ the same for everyone

ALISON'S STORY

Alison is mum to Eliza, 12, and Eleanor, 9, who are both living with localised scleroderma. Here, Alison talks about how the condition and its treatment has affected her daughters' lives.

Eliza has what I'd class as generalised morphoea, which means she has multiple patches of discoloured, thickened skin around her body. Eleanor's patches are much smaller and mainly appear on her ankles, legs, torso and arms.

Compared to other children with scleroderma, the girls haven't been affected too badly. They both often feel tired, because it's an autoimmune disease, and Eliza's started to complain more about pain travelling from her hips, down her thighs and into her knees.

But for both the girls, the condition itself rarely stops them from doing anything. It's mainly been the medication and travelling to hospital appointments that have caused the main issues.

When Eliza was diagnosed, we had to miss quite a bit of school to go to appointments and treatment. But now she typically misses one day every three months to see her consultant.

Eliza also initially struggled with her medication. She was on methotrexate, which made her feel really grotty and tired. Now she's on a drug which agrees with her more, but we do have issues with Eleanor. She often refuses her medication and misbehaves in the lead up to taking it.

HOW SCLERODERMA MAY AFFECT MENTAL HEALTH

The impact of scleroderma and its treatment upon the mood and mental health of a child or young person can vary greatly.

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

Feelings after diagnosis

Following a diagnosis of scleroderma, a student may feel a range of emotions which affect the way they behave and potentially their schoolwork. These feelings include:

- Anxiety about their health and the impact on their future.
- Low mood and sadness that they're different from their peers.
- Anger in relation to their diagnosis and what this means for their health.
- Finding it hard to accept their condition, and as a result, struggling to talk about it.

In contrast, some children may feel relief when they're told they have scleroderma, because it may have taken a long time for them to get their diagnosis.

Taking time off school

Having to miss school for treatment or other medical appointments can cause a child or young person with scleroderma to worry and feel anxious.

They may feel concerned that being away from school draws attention to themselves. Or they may feel upset about missing out on parts of their education or being away from their school friends.

Body image

Children and young people may have worries about their appearance. As a result, physical changes caused by scleroderma can have a significant impact on their mood and mental health.

They may feel:

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

Because of this potential impact, it's important to find out what support a student needs to help them feel more confident in themselves and around their peers.

Physical limitations

A student may feel embarrassed, frustrated or isolated if they can't take part in PE or another physical activity because of their scleroderma.

They may also feel similar emotions if they struggle with everyday tasks such as using a pen or pencil, fastening buttons or using a zip, or tying their shoe laces.

If this is the case, it's important not to draw attention to this. There are lots of simple things a school can do to help a child or young person take part in activities and complete tasks, such as providing a laptop or tablet in class.

Pain and mood

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

If a child or young 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.

Impact of medication

If a child or young person has to regularly take tablets or have injections, this may impact on how they feel towards their condition. They may dislike how medication can disrupt their life, or feel angry or sad that having to take medication makes them feel different from their peers.

A child or young person's mood may also be affected by unpleasant side effects caused by medication such as methotrexate or steroids. These include nausea, fatigue, mood swings and problems concentrating (brain fog).

Anticipatory anxiety

If a student, and especially a younger child, knows they have to attend a hospital appointment or take their medication, they may be affected by increased levels of anxiety as this event approaches.

In turn, this anxiety may lead to disruptive behaviour, irritability or tearfulness at school, as the child tries to cope with multiple emotions.

THE ROLE OF YOUR SCHOOL

As a head teacher, class teacher or other member of school staff, there may be a great deal you can do to help and support a student diagnosed with scleroderma and their family.

However, it may be difficult to determine the appropriate level of contact and how much support is needed and welcomed by the family.

Their views and your perception of the situation may keep changing, depending on the individual affected, the type of scleroderma they have and the nature of their treatment.

As a result, you should try to put in place good, open lines of communication with the student and their family.

This will help to ensure the physical and mental health of the child or young person is supported so they can play a full and active role in school life, remain healthy and achieve their full academic potential.

Your school should also have in place a policy that outlines its approach to students with medical needs and provide suitable training to school staff.

> **"I think the bottom line is there's nothing a school can't do or adapt to help a child with scleroderma have a happy, fulfilling school life."**
>
> Katie Dobson,
> Occupational Therapist

FIRST STEPS

If a child or young person with scleroderma attends your school, their parents or carers 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 the treatment plan for their child.

If a family does get in touch, it will be helpful to speak to the parents about the diagnosis, how it's affecting their child, and what your school can do to support the child and their family.

It's also important to include the child or young person in this conversation, if they wish to be involved in it and have reached an age where they can make decisions on their own behalf.

Increase your understanding

Before your initial conversation with a family, it may be helpful to find out more about scleroderma. This guide is a good place to start, but you'll find more comprehensive information at **sruk.co.uk**

> **"For some young people, their scleroderma might not be immediately visible to others, like teachers and pupils. It's therefore important, regardless of how visible a child's condition is to us, to always consider what emotional and physical needs a young person might have."**
>
> Dr Marilena Hadjittofi, Clinical Psychologist

Topics you may wish to cover in an initial conversation

How often does the family want to be contacted to discuss their child's condition?

Who should the student and family speak to if they want to discuss anything concerning the condition?

What support would the student and family like to receive from the school?

Would it be helpful for the school to speak to the student's consultant and other members of their healthcare team to discuss the potential physical and emotional needs of the child or young person at school?

What is the best way to communicate with the student and the family if an issue arises or the school has a question or concern?

How wide a circle of teachers, other school staff members and students should be informed about the diagnosis?

Would it be helpful for a community occupational therapist to visit the school to assess what support the child or young person may need to take part in everyday school activities?

Does the family want an individual healthcare plan to be developed by the school for the student? Typically, most children and young people with a medical condition do have a plan, where it's felt appropriate and proportionate to their condition.

SUPPORTING A STUDENT WITH SCLERODERMA

Teachers and other school support staff often play a key role in the lives of their students.

They may be the only trusted adult that a child knows outside their immediate family, and they are experts in talking to young people and maintaining their welfare.

Because of this, it may be helpful to a student with scleroderma if your school identifies several members of staff they can talk to if they have any difficulties while in school.

If your school decides to do this, it's important that staff who take on this role are appropriately supported by the school.

We also suggest that these members of staff look beyond this guide and increase their knowledge of scleroderma further.

Visit sruk.co.uk and look at our wide range of content.

Download or order some of our other publications, which include a comprehensive guide called *Understanding Scleroderma* (see page 29).

Call our Helpline on 0800 311 2756 to ask a question.

WeAreSRUK

PASSING ON INFORMATION TO SCHOOL STAFF

Once your school has a clear indication from a family about who should be informed about their child's scleroderma, it's important to pass on information appropriately.

It may not be essential for every member of staff to receive all the information about a student's diagnosis, their needs and the practical and emotional support they will receive at school.

However, it may be helpful to tell all staff if a school rule needs to be compromised to accommodate the needs of an individual child. But, as always, the student and their family should be involved and supported when decisions are made.

Topics that may need to be discussed with teachers and other school staff

- Time off school for medical appointments.
- Relaxing of uniform rules to cover up skin changes or avoid discomfort.
- Support aids in the classroom, such as a laptop.
- A student's reduced ability to take part in PE or other physical activities.
- A student leaving the classroom if they suddenly feel unwell or experience pain.
- A student sitting near a radiator or away from draughts if they feel the cold more.
- Extended homework and coursework deadlines because of medical appointments or symptoms.
- Providing emotional support through a school counsellor, if available, or referring a student to other mental health support services.

Important:
Please remember to pass on appropriate information to supply teachers about a child or young person with scleroderma.

SPEAKING TO A STUDENT'S PEER GROUP

Most children and young people simply want to fit in and be like everyone else.

But being diagnosed with scleroderma may set them apart from their peers, depending on the type they have, how severe it is, and how it affects their daily life.

As a result, some children may decide they want to keep their experience of scleroderma completely private and not draw attention to themselves.

Other young people with scleroderma may welcome the opportunity to talk about their condition and let other students know why they need to take time off school and can't do certain activities.

If a child or young person and their family decide they would like to inform other students about the condition, it's important to clearly establish with them:

- What information they want to pass on.
- Who should be informed – a group of close friends, their form class, students in all their classes, their year group.
- How the information should be passed on – by the student themselves; by a teacher, with or without the student present; by a school nurse or a member of the child's or young person's healthcare team.

At your school, you may also want to provide advice to students about how they can support and be a good friend to someone diagnosed with scleroderma.

YOUR SCHOOL'S LEGAL OBLIGATIONS

By law, schools in the UK must ensure that a condition like scleroderma doesn't put a child at any disadvantage to their peers in terms of accessing their school or learning.

UK governments have published a range of statutory and non-statutory guidance to ensure that you properly support young people with medical conditions so they can play a full and active role in school life, remain healthy, and achieve their academic potential.

Wherever you are in the UK, we believe it's good practice for schools to follow key statutory requirements outlined in the Children and Families Act 2014 for England, the Children and Young People (Scotland) Act 2014 and Children's Services Co-operation Act (Northern Ireland) 2015.

Non-Statutory Guidance

School policy – Schools have in place a policy that outlines its approach to students with medical needs. This should be reviewed regularly and be accessible to staff, parents and carers.

Individual healthcare plans – Schools develop individual healthcare plans for students with medical conditions, where it's felt to be appropriate and proportionate in the circumstances.

Training – Any member of school staff providing support to a student with medical needs receives suitable training.

INDIVIDUAL HEALTHCARE PLAN

Most families will probably not request an individual healthcare plan for a child or young person with scleroderma. But if a family does decide they'd like one to be developed, it should look to feature the following:

- Details about the child or young person's medical condition.
- Any symptoms the student experiences.
- The impact scleroderma has on the student's life, both physically and emotionally.
- Information about any medication needs.
- Information about the adjustments made by the school to support the child or young person physically and emotionally.

You can find templates for individual healthcare plans at **gov.uk**

Ideally, an individual healthcare plan should be developed by your school with:

- The student, if this is felt to be appropriate.
- The student's parents or carers.
- Members of the child's or young person's healthcare team, which may include:

Consultant

Specialist nurse

Occupational therapist

Physiotherapist

Clinical psychologist

- A community paediatric occupational therapist (every local authority in the UK should have one).

After the healthcare plan is developed, it should be:

- Signed off by the family and the healthcare professionals involved.
- Provided to the family for their records.
- Easily accessible to anyone in your school who may support the student and is permitted by the family to view this information.
- Shared with a child's or young person's new school, if they leave your school and the family agrees for this information to be passed on.
- Reviewed every year with the student, their parents or carers, and, ideally, their healthcare team.

ADJUSTMENTS YOUR SCHOOL CAN MAKE

Having scleroderma may make some parts of school life very difficult. But there are often easy changes a school can make to help a student greatly.

As a teacher or other member of school staff, you can be absolutely key to ensuring a young person with scleroderma has a happy time at school and fulfils all their potential.

Good communication

More than anything, it's important to establish good two-way communication with a child or young person with scleroderma and their family to identify the support they need and any issues they're worried about. This could involve you:

- Regularly checking in with the student, if they want this.
- Setting up regular meetings with the family.
- Identifying teachers or other staff members the student can approach if they have any issues.
- Creating an individual healthcare plan.

Mood and mental health

It's good practice to let a student know they can always talk to someone about how they're feeling and any emotions they're struggling with. This could be with a school counsellor, a pastoral care teacher, SENCO or other member of staff.

It can also help a child or young person cope better with their condition if they have a supportive and understanding friendship group. Something you could regularly keep an eye on.

If a child is affected by Raynaud's as well as scleroderma, it may be helpful to explain to classmates what this condition is and how the colour of child's hands may change when they have a Raynaud's attack. Get the permission of the student and their family before disclosing this information.

Keeping warm

If a child or young person has Scleroderma and Raynaud's, they may struggle to keep warm and sometimes have cold or numb fingers. It is important to ensure that their core temperature and extremities remain warm, and that they're not exposed to sudden changes in temperature.

The following suggestions may be helpful:

- Allowing thin, insulating layers to be worn under uniform. This may involve them wearing leggings or running tights under a skirt.
- Allowing them to wear trousers rather than a skirt or shorts.
- Allowing them to wear gloves in and out of class.
- Allowing extra layers, gloves and tracksuit bottoms or running leggings when doing PE or another physical activity outdoors (see more about PE on page 27).
- Seating a student away from draughts or open windows in the classroom and when they're having lunch or attending assembly. You could also try to seat them next to a radiator when it's on.
- Allowing a younger child to sit on their coat or a cushion rather than a cold floor. They could alternatively sit on a chair, but try to do this without drawing attention to them.
- When it's particularly cold, allowing a student to stay indoors at break time or lunch, or when PE is taking place outside.

Time off school and keeping up with work

Due to medical appointments, a child or young person with scleroderma may miss some time at school. This could lead to them worrying about falling behind in their schoolwork.

To help them, a teacher could:

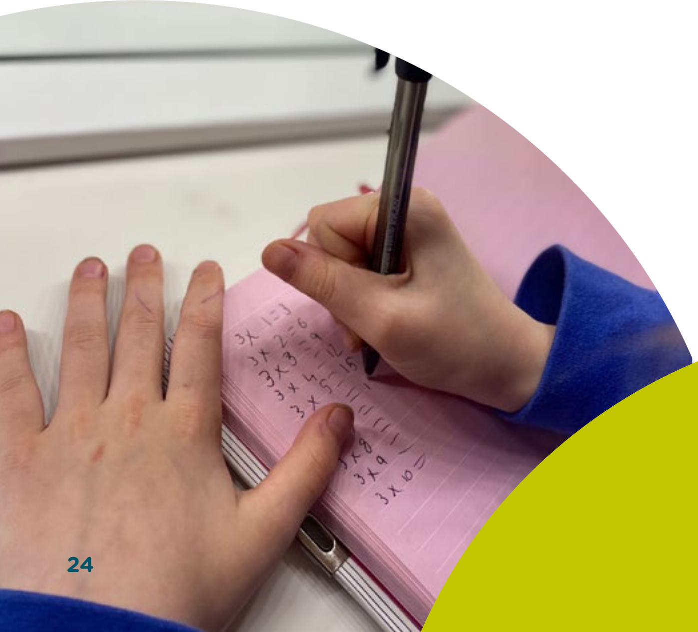
- Speak to the student individually about the work they've missed.
- Communicate with parents regarding absence and catching up.
- Make sure the student has all the lesson notes they need.
- Extend internal schoolwork deadlines, if possible.

Changes to uniform

If a student has patches of discoloured or thickened skin on their legs, they may prefer to wear trousers rather than a skirt or shorts, or leggings under a skirt. If their feet are affected, the child may need to wear soft shoes or trainers, rather than more traditional school shoes.

Applying make-up

Being able to use camouflage make-up to cover up changes to their skin can be incredibly important to a young person with scleroderma. Consider letting a student with the condition leave your class to top up their make-up if they ever start to feel uncomfortable about their appearance.



Eating and drinking

A student may need to eat and drink at unusual times of the day to coincide with the taking of medication or to ease problematic gastrointestinal symptoms.

As a result, you may need to allow the student to be excused from school activities to eat a snack or possibly a small meal.

Getting around school

Scleroderma may affect a student's ability to walk and get around school. If this is the case, it's a good idea to speak to them about potential solutions. These could include:

- A student leaving class a few minutes before the end of a lesson, so they can get to their next class on time.
- A student using a lift to get to different floors, if there is one in school.
- Friends accompanying them around school to give practical support, for example, carrying their bags.

Writing and other fine motor skills

Scleroderma can make it difficult and painful for a child or young person to write, draw and do other tasks with their hands. Support you can provide includes:

- A laptop, tablet or a similar device for them to work on.
- Being allowed to take photos of notes on a board.
- Providing chunky pens or pencils, or special pen or pencil grips.
- Providing chunky cutlery at lunchtime that a pupil can easily grip.

Important:
If a student comes to a class straight after being outdoors, it may take time for their fine motor skills to warm up.

Seating arrangements

Because a student may struggle to twist their head and body, it may help them if they're always facing the front of the class.

If a child or young person has scleroderma, it's important to seat them away from draughts and open windows, which may make them cold. Instead, look to position them near radiators when they're turned on.

Toilet breaks

A child or young person affected by systemic sclerosis may need the toilet urgently or more often. If the student agrees, make teachers aware of this and put a system in place that allows them to leave a lesson immediately and walk through corridors to a toilet during class time.

Pain and stiffness

Sitting still for a long time may lead to pain and stiffness for a young person with scleroderma. This means it can help a student if they're given regular opportunities to get up and walk around.

Speak to a student about how best they'd like to do this.

Potential solutions include:

- Giving the student errands to do, such as being the book monitor or taking something to the school office.
- Getting a whole class to move around regularly so attention is not drawn to the individual.

Some school chairs and sitting crossed legged on the floor can also be painful for a child with scleroderma. Speak to a student and their family about potential solutions. An occupational therapist can also provide expert advice.

Fatigue and brainfog

A child or young person with scleroderma may often experience overwhelming tiredness and times when they're unable to concentrate (brainfog). To support them, consider doing the following:

- Providing a quiet room where they can take rest breaks during the day.
- Putting a system in place that discreetly alerts you when they need to leave your class because of fatigue, pain or another difficult symptom. For example, they could show a 'time out' card to make you aware of an issue.
- Having a system that supports the child and their family if they need to return home because they feel unwell or very tired.

PE and sports

A student with scleroderma may struggle to do everything their classmates can in a PE lesson or when playing a sport. But there are usually ways you can support a child or young person so they get involved to a level they're happy with and without drawing attention to themselves.

To make this happen, it's best to initially speak to them about what is and isn't possible for them. It's also good to think outside the box about how physical activities or equipment could be adapted to make them more inclusive.

School trips

When arranging a day trip or residential visit, carefully consider the needs of a child or young person with scleroderma. Speak to them and their parents or guardian about what's planned and what they'd like to get involved with. Once you know that, be creative and work out how you can include the student in those activities.

Exams and coursework

A student may need additional support for exams, such as extra time or the use of a computer or scribe. Speak to them about this and request any special arrangements well in advance of an exam.

If writing or typing is difficult, a student may struggle with coursework. Talk to them about any issues and ask what your school can provide to help them, such as speech recognition software.

Important: Because stress can trigger Raynaud's in some people, a student affected by this condition as well as scleroderma may experience worsening symptoms when coursework is due or around exam time. As a result, they may require more support than usual.

With thanks 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 a student with scleroderma and their parents or carers, 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 localised Scleroderma*
- *Systemic sclerosis (SSc) and Lung Involvement*
- *Systemic sclerosis (SSc) and The Gastrointestinal Tract*
- *Understanding Raynaud's*

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.

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 way to teach and learn teamwork.

You can set up your own events or projects or take part in one of our initiatives. However, you decide to do it, we are here to support you and your school community every step of the way.

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

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