

RAYNAUD'S: A GUIDE FOR SCHOOLS

Supporting students living
with Raynaud's



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ABOUT THIS INFORMATION

Each person has their own individual experience of Raynaud's. 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 to provide effective support to students with Raynaud's 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 Raynaud's.

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 RAYNAUD'S?

Raynaud's is a common condition that affects adults and young people, and more frequently teenagers than younger children.

Raynaud's means that small blood vessels in the extremities such as the hands, feet, fingers or toes are over-sensitive to even the slightest changes in temperature, cold conditions and sometimes emotional stress.

When our bodies are exposed to the cold, a normal response is for the blood vessels to become narrower. However, with Raynaud's this reaction may be much more extreme.

It will sometimes cause a noticeable colour change to the affected areas, with the skin turning white, then blue and finally to red as the circulation returns. This is known as a Raynaud's attack and the symptoms can have a major impact on a person's ability to do everyday tasks.

Currently, there's no cure for Raynaud's. But the good news is that most people can manage the condition with practical steps and medication and lead a full and active life.

Two types of Raynaud's

Primary Raynaud's occurs on its own and is not linked to any other condition. Currently, we don't fully understand what causes it, but research is taking place to find out.

Secondary Raynaud's happens because of a medical condition such as scleroderma. It can also be caused by certain medications. Typically, someone with secondary Raynaud's needs more support and possibly medical treatment to manage their condition.

10 million
people in the UK are
affected by Raynaud's

WHAT CAUSES A RAYNAUD'S ATTACK?

The two main things that may cause a Raynaud's attack are exposure to the cold and stress.

Exposure to the cold

Being exposed to cold temperatures is one of the main triggers of a Raynaud's attack.

This means a child or young person living with Raynaud's is more likely to experience symptoms during the winter months. However, just a slight change in temperature can cause an attack, so even during the summer, Raynaud's can still impact considerably upon daily life.

It's also worth noting that attacks are not just triggered by exposure to the cold outdoors. Simply washing hands in cold water, sitting in a draught in class or holding a cold can of drink can suddenly lead to an attack.

Feeling stressed

Stress, anxiety and emotional distress can all lead to some people experiencing a Raynaud's attack.

As a result, it may be important for a child or young person affected by the condition to recognise highly stressful situations and ask for support to help them manage these.

It may also be important that a school does its best to help a student with Raynaud's manage their stress levels throughout the year.

Of course, this can be difficult, given that a child or young person often experiences highs and lows throughout a typical school day. They may also feel particularly stressed when coursework is due or exams are taking place.

HOW RAYNAUD'S MAY AFFECT PHYSICAL HEALTH

Every child's or young person's experience of Raynaud's will be different. It depends on what type of Raynaud's 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.

Symptoms caused by a Raynaud's attack

On different days, the physical symptoms of Raynaud's may be mild, severe or anything in between.

Symptoms are not constant and can come and go quickly, hence the name Raynaud's attack.

The number of attacks a child or young person experiences can be anything from a few a day, to one a week, to even less frequently. And an attack can be as short as a few minutes or last a number of hours.

The most common parts of the body affected are the hands and feet, but an attack can also affect the ears, nose, lips and tongue.

When a Raynaud's attack does occur, the main symptoms are:

- Cold fingers and toes.
- Colour changes to the skin, often from white, to blue, to red (see page 6).
- Numbness.
- Tingling (pins and needles)
- Pain.

At the end of an attack, a child may experience a stinging or throbbing pain as an affected area begins to warm up.

Reduced movement

Raynaud's may also cause pain in the feet and toes. As a result, an affected child may struggle to comfortably walk around school or take part in PE or other physical activities.

When Raynaud's affects the fingers and hands, they may also struggle to do tasks that involve fine motor skills, such as writing and drawing, fastening buttons and doing up zips, tying shoelaces and using standard cutlery.

Colour changes to affected areas

During a Raynaud's attack, the hands or feet may take on a white, waxy like appearance and initially become numb. They may then turn blue/purple in colour and finally red when the blood starts to flow back. This stage may also be quite painful.



1. Skin goes white when the blood supply is cut off.
2. The affected area turns blue when the blood trapped in the skin loses its oxygen.
3. The area turns red when blood flow returns to normal.

Sores on fingers and toes

If a student has a severe form of Raynaud's, repeated attacks may damage body tissues starved of blood flow. This can cause sores on the fingers and sometimes the toes (known as digital ulcers). The ulcers can be very painful and affect daily tasks. This is very rare in childhood.

Issues caused by medication

Most children can manage Raynaud's by wrapping up warm. In a small number of cases, doctors may prescribe medications to reduce symptoms from Raynaud's. The medication a student takes to treat their Raynaud's may lead to a range of side effects that affect them physically. Potential side effects include:

- Headaches (migraines).
- Dizziness.
- Feeling or being sick.
- The skin or face becoming red and hot (flushing).
- Feeling weak or tired.
- Swollen hands and feet.



“Normally, we’re trying to get children and young people to manage their Raynaud’s, and they tend to do this quite well. But sometimes their coping strategies can be tricky to use because of things like uniform rules.”

Dr Clare Pain, Consultant in Paediatric Rheumatology

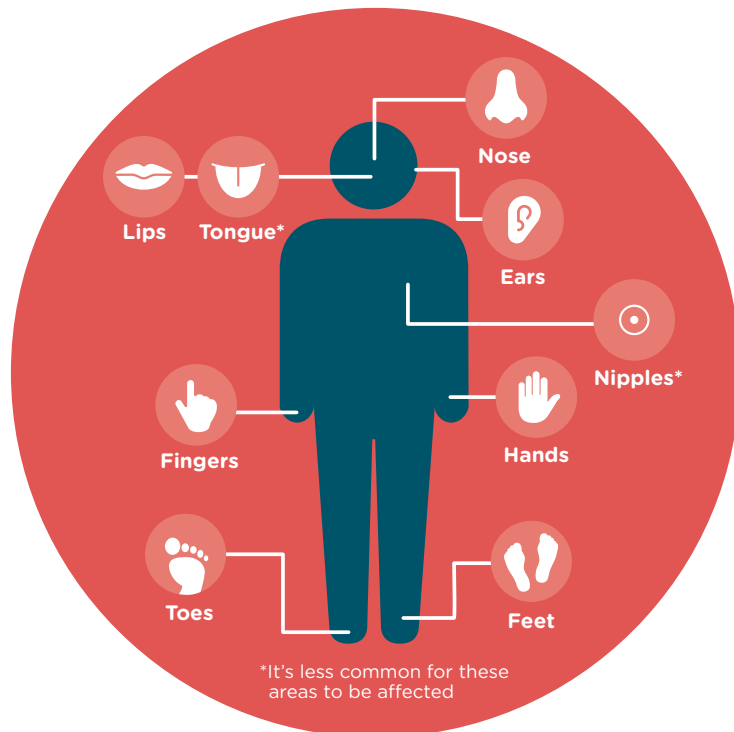
Secondary Raynaud's and associated health conditions

Secondary Raynaud's is closely linked to underlying conditions such as scleroderma, lupus and Sjogren's syndrome. These are autoimmune conditions, meaning that the immune system is overactive and attacks healthy tissues within the body.

If a child or young person is affected by another autoimmune disease, common treatments include medication to reduce the activity of their immune system. This may make them more susceptible to infection.

Individuals may also experience extreme tiredness (fatigue) during the school day, although it is also worth noting that medication for Raynaud's can lead to a child or young person feeling tired or weak.

Parts of the body affected by Raynaud's



LIFE WITH RAYNAUD'S

Amy is able to manage her Raynaud's with practical steps and medication. But before her diagnosis, she struggled to cope with symptoms caused by her condition.

My first set of Raynaud's symptoms occurred when I was a teenager. I constantly felt cold and numbness in my hands and feet.

The only way that I would feel better was to sit in the bath, but even then my feet would turn black, white and purple. I did not know what it was, and it started to worry me.

School was a real struggle, as my feet were so painful, and it hurt to walk around all day. I would never know what to say to people when they asked why my hands looked so 'weird'.

I began to wear long sleeved thermal tops that would cover my hands as much as possible. The pain was excruciating and I dreaded the every day.

The pain was getting worse and I really started to struggle. I went to my GP, who didn't see anything wrong with me. I was so upset that they couldn't see what I was seeing.

It took a few times of me going to the doctors before they finally referred me to a rheumatologist in children's outpatients.



HOW RAYNAUD'S MAY AFFECT MENTAL HEALTH

The impact Raynaud's and its treatment may have on 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 a diagnosis

Following a diagnosis of Raynaud's, a student may feel a range of different emotions which affect the way they behave and potentially their schoolwork. These may 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.
- Struggling to accept their condition, and as a result, struggling to talk about it.

Taking time off school

Having to miss school for medical appointments may cause a child or young person with Raynaud's 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 Raynaud's may cause them distress and greatly affect their mental health.

Changes to the colour of their hands or feet may be noticeable to others, who may then offer unwanted comments.

As a result, a student with Raynaud's 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 they experience.

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 struggles

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

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 shoelaces.

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

A student may feel pain during a Raynaud's attack, as an affected area begins to warm up, or because of sores on their fingers or toes.

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.

Anticipatory anxiety

Because a Raynaud's attack can happen suddenly and without warning, a child or young person may be anxious and worried that an attack is going to occur again.

If a student, and especially a younger child, knows they have to attend a hospital appointment or take their medication, they may also 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.

Impact of medication

The fact a student has to regularly take medication may have an 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 common Raynaud's medication, including headaches (migraines) and dizziness.

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 Raynaud's 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 Raynaud's they have and the severity of their condition.

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 individual 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.

“

“For teachers, it's understanding that things can change very quickly for a pupil with Raynaud's. They might be having a good day and can do everything, and then an hour later they may be affected by pain and numbness and need a lot of support.”

Lindsey Clarke, Occupational Therapist

FIRST STEPS

If a child or young person with Raynaud's 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 Raynaud's 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 take part in any decision-making.

Increase your understanding

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



“There are instances where a pupil might get comments from others about how they look or how they do things differently. In those cases, we know that helping other children understand what Raynaud's is and the impact it can have can significantly reduce these incidents.”



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?



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?



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



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



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



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?



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?



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 RAYNAUD'S

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 Raynaud's 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 Raynaud's further.

This will help staff to feel more confident when discussing issues, develop a better understanding of what a student may be experiencing, and show that they are making a concerted effort to offer support.

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 Raynaud's* (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 Raynaud's, 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 keep warm.
- 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 experience pain or feel unwell.
- Seating the child near a radiator or away from draughts to keep up their core temperature.
- A student not being able to tell the difference between hot and cold because of numbness in their hands. Something a home economics, metalwork or science teacher will need to know.

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

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 Raynaud's may set them apart from their peers, depending on the type of Raynaud's 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 Raynaud's completely private and not draw attention to themselves.

While others 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 care 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 Raynaud's.

YOUR SCHOOL'S LEGAL OBLIGATIONS

By law, schools in the UK must ensure that a condition like Raynaud's 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 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 the 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 Raynaud's. 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 Raynaud's 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](https://www.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 Raynaud's 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 Raynaud's has a happy time at school and fulfils all their potential.

Good communication Mood and mental health

More than anything, it's important to establish good two-way communication with a child or young person with Raynaud's 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.

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.

With the permission of a student and their family, it may also be helpful to explain to classmates what Raynaud's is and that changes to the colour of the child or young person's hands is part of their condition.

Keeping a student warm

Key to preventing a Raynaud's attack is ensuring a student's core temperature and extremities remain warm and they're not exposed to sudden changes in temperature. It's always better to be proactive than reactive to help to stop Raynaud's attacks occurring in the first place.

Ways a school can help to do this include:

- Allowing a student to wear thin, insulating layers under their 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 to be worn when doing PE or another physical activity outdoors (see more about PE on page 26).
- 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 Raynaud's 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.

Getting around school

Raynaud's 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

Raynaud's 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.

Pain and stiffness

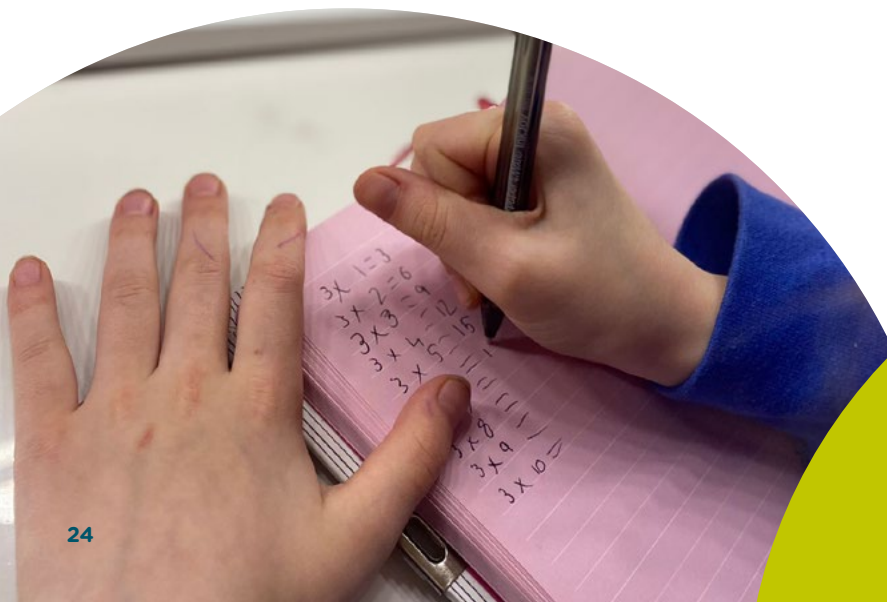
Sitting still for a long time may lead to stiffness and pain for a child or young person with Raynaud's. As a result, it may help them physically if they're given regular opportunities to get up and walk around.

Speak to the student about how best they'd like to do this. Potential solutions include:

- Giving them 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.

Sitting crossed legged on the floor can also be painful for younger children with Raynaud's. Speak to a pupil and their family about potential solutions. An occupational therapist can also provide expert advice.

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



Leaving class and school premises

A student with Raynaud's may experience overwhelming pain or tiredness during the school day. To support them, consider doing the following:

- Letting them leave class so they can go and sit in a quiet room and rest.
- Putting a system in place that discreetly alerts you when they need to leave your class. For example, by issuing a 'time out' card.
- Having a process that supports the child and their family if they need to return home because they feel so tired or unwell.

PE and sports

A student with Raynaud's 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.

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 Raynaud's. 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 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 Raynaud's*
- *Raynaud's in teenagers and youngsters*
- *Handy hints on keeping warm*
- *Understanding Scleroderma*

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.

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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