

SYSTEMIC SCLEROSIS (SSc) AND THE GASTROINTESTINAL TRACT



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

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ABOUT THIS INFORMATION

Systemic sclerosis (SSc), is a complex condition that affects people in different ways, and the information in this booklet is designed to provide an overview. It is written for people who are living with systemic sclerosis and gastro-intestinal tract involvement and is also useful for family and friends. This guide is backed up by reliable sources and evidence and has been reviewed by healthcare professionals as well as people living with these conditions themselves.

Living with a rare condition means that you may need to become something of an expert yourself, so that you can make informed choices about your treatment. This guide can get you started, and we are here to provide information and support along the way.

What is systemic sclerosis?

Systemic sclerosis (also referred to as scleroderma) (SSc), is a chronic disease associated with skin thickening and changes to blood vessels, particularly those supplying your fingers and toes. The hardening of the skin is caused by the formation of scar tissue. This occurs because of an increase in collagen, a normal component of tissues that is produced in excess. In SSc, scar tissue or 'fibrosis' can also form within the internal organs including the gastro-intestinal (GI) tract. The condition can also affect the lungs, the heart and the kidneys.

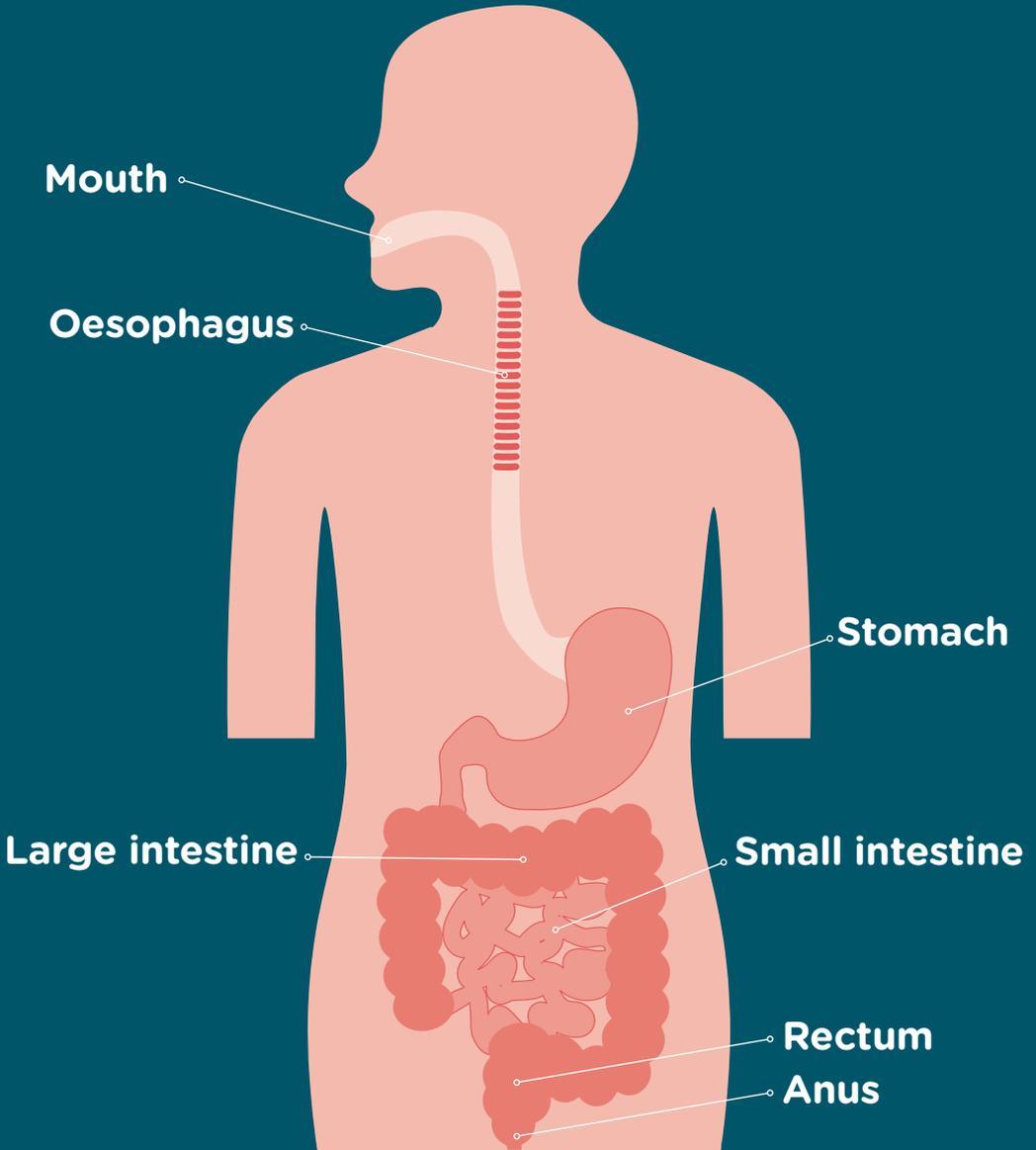
Excessive scarring is due to the overreaction of the immune system, whereby it attacks the body itself. Why this overactivity of the immune system occurs in individuals with SSc is unknown. One of the important ways that the immune system deals with injury or infection is by causing inflammation. Normally, following an injury (e.g., a bad cut), or infection (e.g., pneumonia), inflammation helps the body repair itself by triggering the process that leads to healing. A necessary part of the healing process is scarring. In people living with SSc, the immune system remains continuously 'switched on,' and is therefore overactive. This means that inflammation is constant, leading to damage to the body through fibrosis (scarring).

About the gastrointestinal tract

Gastrointestinal (GI) tract involvement (or gut involvement), is common in people living with systemic sclerosis; and is thought to affect around 90% of people diagnosed. Any segment of the GI tract from the mouth to the anus may be involved, which can occur in varying degrees and affect different people in very different ways. If left unmanaged and untreated, the condition may become severe, eventually leading to malnutrition and even the need for intravenous nutritional support.

The GI tract runs from top (mouth) to tail (anus). Its function is to allow the intake, digestion and absorption of food and the disposal of waste in the form of faeces. Food is propelled along the gut through co-ordinated contractions of the muscles in the gut wall (peristalsis). In systemic sclerosis, thickening of the gut wall and atrophy (thinning) of the muscles of the digestive system can lead to these muscles not working as well as they should. This is known as dysmotility. For example, when food moves more slowly through the gut, people may feel full after eating only a small amount. Gut involvement can occur at any point following the initial onset of SSc, and may progress over time.

THE GASTRO-INTESTINAL TRACT



SSc and the GI tract

Although most people diagnosed with SSc will develop some form of GI tract involvement, the type and extent will vary from person-to-person, and different people can be affected in very different ways.

The mouth and oral cavity

Thinning of the upper lips and reduction in mouth opening may restrict food intake and oral function. Dry mouth symptoms can impair chewing and swallowing and may also increase the risk of cavities. Telangiectasia (red vascular mucosal lesions), may occur and occasionally bleed.

The oesophagus

The oesophagus (gullet) is the tube that runs from the mouth to the stomach. It is affected in most patients with SSc (80-90%), although this will not always cause symptoms. The main features are dysmotility and a lack of peristalsis. You may also experience a cough.

Gastro-oesophageal reflux (acid from the stomach slipping back into the oesophagus), will be an early symptom of GI tract involvement for many people. This can lead to other complications such as oesophagitis (inflammation in the oesophagus), strictures (an abnormal narrowing of the oesophagus), and Barrett's oesophagitis (mucosal changes that can increase the risk of developing cancer). Typical symptoms include difficulty swallowing (dysphagia), heartburn, water brash and reflux.

The stomach

The stomach is less commonly involved in SSc.

The two main features are:

- Mucosal vascular lesions (eg gastric antral vascular ectasia), which can lead to bleeding, both acute and chronic. This is often accompanied by chronic anaemia and individuals may also experience fatigue because of this.
- Delayed emptying of the stomach with bloating due to dysmotility. People often report early satiety and in severe cases may even develop an aversion to eating, due to nausea and vomiting afterwards.

The small and large intestines

The small intestine is the part of the body that absorbs most of the nutrients from food that is digested. The large intestine (the colon) reabsorbs water and salts that have been secreted by the rest of the gut, and disposes of waste in the form of faeces. This can also be affected by dysmotility. In SSc, both the small and the large intestines may be affected in several ways that can lead to reduced movement, reduced absorption (of various minerals/vitamins/iron/fatty acids), and the overgrowth of bacteria (normally the small intestine has a very small number of bacteria). When there is reduced absorption, patients can experience significant weight loss and fatigue that are difficult to treat.

The anorectum

The rectum has the capacity to hold a volume of faeces until the bowels are emptied. Continence is maintained with the help of the anal sphincters. If anorectal involvement is not managed effectively, this may lead to rectal prolapse and the thinning of the anal sphincter. There may also be a loss of control over bowel movements when the rectum is involved.



“One of the worst things I have is the acid reflux. I wake up in the early hours and then I am awake, more or less until it is time to get up. I am supposed to eat little and often, but my stomach always feels full. This is the worst thing for me. I can feel food going down and it feels like it is sticking in my oesophagus.”

Patricia

SYMPTOMS OF GI TRACT INVOLVEMENT

Symptoms will vary greatly from person-to-person and will depend upon which part of the GI tract is affected, and to what extent. Early signs may seem quite non-specific, such as acid reflux, a reduced appetite and weight loss. It is important to be aware of any changes and to report any new symptoms as soon as you can, since early detection and treatment will often lead to better outcomes.

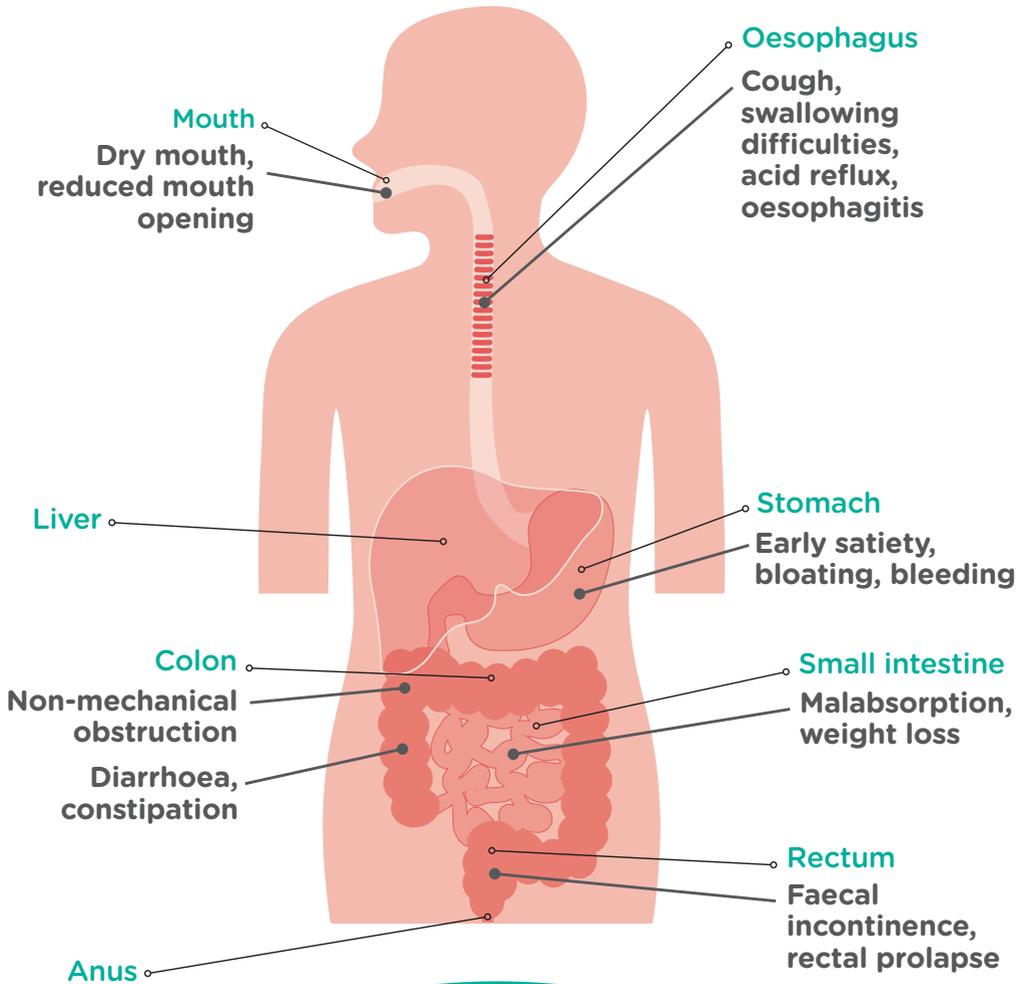
If your intestines are affected, specific symptoms may be:

- Nausea and vomiting
- Bloating
- Increased flatus (wind)
- Pain
- Weight loss
- Diarrhoea
- Constipation (colonic involvement)

If your anorectum is affected, specific symptoms may be:

- Increased bowel frequency
- Constipation
- Difficulty in emptying
- Sense of incomplete evacuation when emptying the bowels
- Faecal incontinence

SYMPTOMS OF GI TRACT INVOLVEMENT



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“When something happens, having somewhere to share our struggles can be very helpful, and the SRUK Support Group is ideal for this. For example, I was having trouble swallowing and ended up having an endoscopy, I reached out to the group to see if anyone else had the same experience, and this was very useful.”

HOW IS GI TRACT INVOLVEMENT IN SSC DIAGNOSED?

Your doctor may diagnose GI tract involvement in SSC by asking about your medical history to learn about signs and symptoms, as well as possible risk factors. The following tests may also be used to assess whether the GI tract is affected, and to what extent:

Oesophageal physiology studies (pH probe monitoring)

The amount of acid reflux can be measured by a 24-hour study. Again, this involves a small tube being passed from the nose into the oesophagus.

Oesophageal manometry

Oesophageal manometry is a test used to measure the pressure and functioning of the muscles of the oesophagus and the sphincter leading to the stomach. This indicates how well these muscles are performing as food and liquids pass from the mouth into the stomach.

Barium swallow

A barium swallow is an examination of the oesophagus and the stomach. This test will be conducted by a radiologist (a doctor who uses X-rays to diagnose and treat illnesses), and a radiographer (a health professional trained in producing these images).

The procedure uses a type of X-ray called fluoroscopic imaging to view images in real time. These areas of your body cannot normally be seen on X-ray images, so you will be asked to swallow some contrast material, that enables your doctors to evaluate the surface changes as it passes through the oesophagus and stomach. The images are taken as you swallow the liquid and as it passes into your stomach, and the radiologist will assess how well the liquid moves through.

Endoscopy

An endoscopy is a procedure that enables doctors to examine organs inside the body, using an instrument called an endoscope. This is a long, thin, flexible tube that has a light and camera at one end. This procedure is usually carried out under sedation. Images from inside the body are shown on a television screen. This test can also detect and help manage strictures (meaning a narrowing of the oesophagus). For example, **gastroscopy** involves passing the tube through the mouth and down into the stomach. A paediatric scope, which is smaller, may be used to minimise discomfort caused by a smaller mouth opening. A biopsy (extraction of some cells) of the mucosal surfaces may be taken to evaluate any changes. Gastroscopy can also detect and help manage strictures (meaning a narrowing of the oesophagus) and treat any actively bleeding mucosal lesions (eg gastric antral vascular lesions).

MRI (magnetic resonance imaging) scan

This test uses magnetism to create a detailed image of areas inside the body and can be used to assess the presence and extent of GI tract involvement in SSc. Sometimes, you may be given an injection of a dye (a contrast medium), to help make the images clearer. The procedure will be carried out by a radiographer and is painless, however you may find it a little uncomfortable as you will have to lie in a long tube for about 30 minutes. Importantly, you can only have this scan if you do not have any metal within your body, (i.e., dental wires or metal plates). There is no exposure to radiation with an MRI scan.

Hydrogen or lactulose breath test

This involves ingesting a sugary solution followed by the testing of serial breath samples over several hours. This may be considered in cases of suspected bacterial overgrowth.

Anorectal physiology studies

These are tests that will check the function and structure of the anal sphincters and rectum. Testing will involve a small probe being inserted at the tail end.

TREATMENTS

Making treatment decisions

Although GI tract involvement is common in SSc, its manifestations will vary greatly in terms of both extent and severity. If you do have GI tract involvement, it is important that this is diagnosed and treated as early as possible, since this is likely to lead to a better prognosis in the long-term.

There are several treatment options available, which will depend upon a range of factors, including the type and severity of symptoms. The best approach will always depend on your own individual situation, and before any decisions are made, you will be assessed by a gastroenterologist and/or a rheumatologist. This will include a discussion about your medical history, a physical examination and some diagnostic tests. Your doctor will then discuss the best treatment for you, and there may be more than one option to consider. It is important to feel confident that you have made the right decision for you, so do ask for more time if necessary. Seeing a gastroenterologist and a rheumatologist who have experience in SSc is ideal, and it is also important to make sure that your specialists are talking to each other about your care.

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“I have GI tract involvement and I have a narrowed oesophagus, so I have to take a lot of liquids and I can’t eat certain things. It can affect swallowing medications as well. I take a medication which, as a proton pump inhibitor, greatly reduces the acid in my stomach and so protects it.”

Celia



Consent to treatment

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

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

The following questions may be helpful at the time:

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

For consent to treatment to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision.

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

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

Types of treatment

There are a number of treatment approaches that can be effective, however the best option will always depend on your own, individual circumstances.

If you are affected by **poor oral intake and weight loss**, consuming small but frequent meals as well as nutritional and vitamin supplements can be helpful.

If you have **severe weight loss and malnutrition** and are unable to eat adequately by mouth, another, more invasive approach may sometimes be necessary.

These may include:

- having a small tube passed into the stomach
- a nasogastric tube (where a tube is inserted through the nose and throat into the stomach)
- a percutaneous endoscopic gastrostomy (PEG, where a flexible feeding tube is placed through the abdominal wall and into the stomach)
- intravenous feeding (via a tube inserted into veins)

Reflux can be treated with anti-reflux medications including proton pump inhibitors and antacids e.g. Gaviscon Advance or Rennies. Practical changes, such as raising the head of the bed, can be helpful to give some relief.

If you have dysmotility causing symptoms such as **swallowing difficulties, nausea and vomiting**, this can be helped by prokinetic medications, such as domperidone, metoclopramide, and prucalopride.

Gastric antral vascular ectasia (GAVE or bleeding from stomach), can be alleviated with iron supplements (tablets or intravenous formulation), or endoscopic treatment with thermal/radiofrequency methods to stem the bleeding points.

Small bowel bacterial overgrowth can be managed with antibiotics. Either a single course or cyclical courses may be required, and this largely depends on the frequency and severity of your symptoms. Adjusting your diet can also help to alleviate symptoms of bacterial overgrowth.

Constipation and diarrhoea can be managed symptomatically, but this must be done very carefully as some people may experience both symptoms.

Bowel rest may be required on occasion for severe cases of non-mechanical **bowel obstruction**. This often requires medical evaluation with inpatient admission.

Treatment for the anorectum is tailored to your individual symptoms and the abnormalities found. **Faecal incontinence** is often a challenge that requires careful evaluation with your gastroenterologist. Obstetric history with forceps delivery may be relevant for some people. In some selected cases, nerve stimulation to the anorectal apparatus can be considered. Many different treatments can be used and are often very effective. Pelvic floor physiotherapy can also be helpful.

If you suffer from diarrhoea and incontinence, treatment options may include loperamide and opiates. Sometimes, more specialised interventions will be required such as trans-anal irrigation or surgery (e.g., rectal prolapse repair).

Side effects during treatment

All forms of treatment may have side effects. The type and extent of these will vary from person-to-person and are dependent on factors such as the type and dosage of treatment. It is important that you are informed, so that you understand how to deal with them if they happen and to help you in making treatment decisions.

Medicines do not tend to cause significant side effects if they are taken for a short time at a low dose. However, there may sometimes be unpleasant effects, such as an increased appetite, mood changes and difficulty sleeping. These symptoms occur most commonly with steroid tablets.

Some side effects may develop during treatment and continue for a short time, whereas others can appear later and may be longer-term. Whilst these can be unpleasant and uncomfortable, it is critical that you do not stop taking your treatment without first discussing this with your medical team. Stopping a prescribed medication suddenly may cause further unpleasant side effects in the form of withdrawal symptoms.

Your doctor or nurse specialist will see you regularly and can answer any questions about managing and reducing the impact of medication side effects.

Follow-up care

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

Follow-up also provides the opportunity to ask questions and discuss any long-term side effects. Your doctor may help you to manage these, or they may refer you to a service that can. Getting these answers from a professional who understands your individual circumstances can provide reassurance and help you feel more in control of your situation.

Your rheumatologist / gastroenterologist or nurse specialist will see you regularly throughout your treatment and be available to answer any questions you may have about managing and reducing the impact of any side effects.

Difficulties between appointments

Your healthcare team can provide details of whom to contact if you have any problems with your treatment or notice any new symptoms between appointments. It is important to get in touch if you have any serious concerns, if you are struggling with side effects or if you notice worsening symptoms. Remember that the first port of call is often your GP or nurse specialist, who can then directly discuss the situation with your doctor.

MANAGING YOUR WELLBEING

Treatments for GI tract involvement in SSc will work best when you play an active role alongside your healthcare team.

It can take time and persistence, but you may feel additional benefits if you:

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

Nutrition

Because the gut is affected in up to 90% of people with SSc, nutritional awareness is especially important. Whether or not you have gastro-intestinal symptoms, eating a balanced diet can help you to manage your condition and stay healthy. People are often keen to avoid prescription medications if possible and may wish to try natural therapies first. These are available from many pharmacies and supermarkets as well as from health food stores. It is important to speak to your doctor before starting anything new, just to ensure that it is safe for you to take.



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“Through guiding my patients through the process of making connections between how they feel in relation to what they eat, I have found that patients begin to develop more insight into their bodies and more awareness of how outside factors (work, stress, relationships) can also affect their health.”

Dr Elizabeth Volkmann, MD, MS

Keeping a food diary

For some people, a trial of dietary modifications may be helpful. Whilst there is no single diet regime that works for everyone, keeping a food diary to help identify any problematic foods can help you to understand the relationship between your body and what you eat. Begin a new page every day and write everything down, to show how certain foods may be affecting how you feel, for better or for worse, as well as what agrees with you and what probably does not.

Track your symptoms daily, and record how you feel whilst you eat, as well as afterwards and even a day or so later, since any reactions may be delayed. Consider noting not only your GI symptoms, but also your energy and mood that day, along with how you slept during the night. Although this may seem a little time-consuming, maintaining the food diary for four weeks will help to highlight any connections between what you eat and how you feel.

Working with a dietician is important if you are considering an elimination diet; as this will help to ensure that you are getting all the vitamins and nutrients you need to stay healthy and to maintain a steady weight during this period.

You may need to try using a combination of methods, either together or separately and at different times of the year, to find a regime that works for you. Your doctor or specialist nurse can refer you to a dietician who can offer more personalised help in this area. For further information, please visit,

sruk.co.uk/scleroderma/managing-scleroderma/nutrition/

Self-managing your symptoms

Dry mouth

A dry mouth can cause difficulties with tasting, chewing and swallowing foods.

- Sip fluids regularly throughout the day and have a soft, moist diet.
- Chew sugar-free gum and suck ice or sweets to help stimulate saliva.
- Try sugar-free sharp lemon / lime / orange flavour squashes.
- Use artificial saliva from your chemist or doctor.
- Maintaining good dental health with regular dental checks is helpful.
- Review your medication list with your doctor to ensure that you are not taking something that lists dry mouth as a side effect.



Difficulty swallowing

Muscles in your throat can slow down causing swallowing difficulties, and you may need a referral to a speech and language therapist.

- Allow plenty of time for meals.
- Eat slowly and chew your food well.
- Always eat sitting upright.
- Choose soft foods or purée your foods in a blender to help you swallow safely.
- Avoid tough meats, stringy vegetables, raw nuts and seeds.
- Add extra sauce/gravy /milk to your foods to create a consistency that is easier to swallow.
- Fortify your foods if you begin to lose weight.

Heartburn (reflux)

This is a very common symptom for people living with GI tract involvement.

- Sit upright during meals and for ideally two-to-three hours afterwards.
- Eat little and often.
- Avoid very fatty/fried foods as they stay in the stomach longer.
- Cut down on caffeine, chocolate, alcohol and fizzy drinks.
- Eat your main meal at lunchtime rather than in the evening.
- Elevate the top end of your bed by six-to-eight inches.
- Avoid eating and drinking before bed.

Gastroparesis (slow stomach emptying)

You may find that your stomach empties very slowly, causing you to feel full and uncomfortable.

- Chew food well.
- Sit upright during and after meals.
- Eat little and often.
- Take a gentle digestive walk after eating.
- Avoid alcohol and fizzy drinks.
- Softer foods (e.g., tender/puréed meat/fish, well-cooked vegetables, eggs, dairy), and liquids (e.g., blended soups, smoothies, milky drinks), may be better tolerated.
- Avoid having solid meals with a lot of fat or protein as these empty more slowly.

Diarrhoea, constipation and bloating

Whatever your symptoms are, it is important to:

- Eat meals regularly each day, taking time to sit down and relax while you eat.
- Avoid skipping meals or leaving long gaps between meals.
- Avoid chewing gum, fizzy drinks, caffeine and alcohol.

Diarrhoea (with or without alternating constipation)

- Reduce fibre (avoid raw vegetables, raw fruits, raw nuts and seeds).
- Avoid skins, pips and pith from fruit and vegetables.
- Avoid sorbitol (a sweetener found in sugar-free sweets/drinks) as this has a laxative effect.
- Avoid fatty, spicy and processed foods.

Diarrhoea with wind and bloating

- Limit fruit to three portions per day, including fruit juice.
- Eat fruit on its own (do not combine with foods that are high in fats and/or proteins).

Constipation

- Gradually increase high-fibre foods (choose wholegrain breads/pasta/rice/cereals, nuts and seeds, fruit and vegetables).
- Increase your fluid intake as you increase fibre: a minimum of eight glasses (approximately two litres) per day.

Constipation with wind and bloating

- Try oats or golden linseeds (one tablespoon per day), to help soften the stool. Golden linseeds should be ground and not consumed whole. Ensure that fluid is taken with these to help them to work.

Immobility or pain in the hands

This can make preparing and cooking foods more difficult.

- Buy pre-cut/ready-packaged foods such as frozen or tinned fruit and vegetables or ready chopped, re-sealable portions.
- Cook more than you need, then freeze the remainder in portions for another day.
- Try online shopping.
- An occupational therapist can provide you with cooking and feeding aids if necessary.

Difficulty maintaining weight

Weight loss and poor appetite can be a common issue for many people with scleroderma.

- Try to eat little and often. Aim to have three smaller but regular meals with nutritious snacks in-between.
- Drink plenty of milk and milky drinks such as hot chocolate, malted drinks and milkshakes. Aim for at least one pint of whole (full cream or full fat) milk a day. If you cannot tolerate cow's milk, consider non-dairy milks made from nuts, oats or soy.
- Fortify your meals and drinks to increase the energy and protein in each mouthful.

Examples of how to fortify your meals include:

- Add flaxseed oil/olive oil /avocado oil to savoury foods such as potatoes, vegetables, soups and sauces.
- Add a nut or seed butter to your smoothie (almond butter or pumpkin seed butter).
- Add double cream to both sweet and savoury foods and drinks such as porridge, cereal milk, coffee, custard, soups and sauces.

Some people may require oral nutritional supplements, prescribed by a doctor or dietician, if they continue to lose weight. For more information, talk to your gastroenterologist or nurse specialist.



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“Whilst I am lucky to be well, digestive problems have been a significant issue over the years and I have had to make significant changes to my diet, for example I became a vegetarian four years ago but also have to avoid yeast/sugary foods.”

Jane

Living with GI tract involvement in SSc

GI tract involvement in SSc can affect various parts of your life and may mean that you have to spend more time thinking about certain areas, to ensure that that you have as much information as possible.

- **PREGNANCY:** pregnancy can be more complicated if you have SSc. The majority of affected women will have normal fertility, however younger women may have a higher risk of infertility than those who have already had children. It is vital to speak to your rheumatologist or gastroenterologist if you are considering trying to conceive, as they will assess your health and any associated risks. In addition, some of the medications commonly used in the treatment of SSc may affect fertility and pregnancy development.
- **EMOTIONAL WELLBEING:** changes to your lifestyle can be stressful, especially if you are living with limitations in what you can do on a daily basis or restrictions in what you are able to eat. This can take a toll on your mental and emotional wellbeing, so it is important that you have support when you need it: from your friends, family or the SRUK Helpline.
- **EMPLOYMENT:** by law, you do not have to tell your employer about being diagnosed with SSc or that you have GI tract involvement. Some of our community have said that it was more practical for them to do so, and that their employer was able to better support them after being informed, however everyone's circumstances and preferences are different.

For more detailed information on each of these areas and for further advice on living well with SSc, please visit:

sruk.co.uk/scleroderma/managing-scleroderma/

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“It is difficult to work as you did in the past as you have so many hospital appointments etc., and you can be off sick more than others. This is where I have been very lucky with my employers, they have been very accommodating to my situation.”

Diane

With thanks to our clinical reviewers:

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Consultant Rheumatologist at the Royal Free Hospital and Senior Clinical Lecturer at UCL.

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HOW SRUK CAN HELP

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

Access to support services

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

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

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



Research

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

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



HOW TO GET INVOLVED

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

Become a member

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

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

Visit our website to find out more:

sruk.co.uk/membership or call our team on 020 3893 5998



Donate to us

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

**Make a donation today by
texting SRUK05 £5 to 70070**

Sources used

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

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

If you would like further information on the sources we use on a particular publication, please contact the Information and Support Services team at 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 the needs of people affected by Scleroderma and Raynaud's. Please complete the survey online at sruk.co.uk/publications

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