

# APPOINTMENT PLANNER

GETTING THE MOST FROM  
YOUR SPECIALIST  
APPOINTMENT



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

# ABOUT YOUR APPOINTMENT

**Your appointment is your time to talk to your doctor about your condition. This could include any new test results, anything that has changed or any new concerns you may have. You can also ask questions and discuss the next steps in your care plan. Appointments may take place face-to-face with the doctor or nurse, over the telephone or video call.**

Scleroderma is a complex condition. It affects people in different ways so you may see different specialists as part of your care. This will depend on the type of scleroderma you have and how it affects you.

You should also be offered regular, annual tests to monitor your condition. These will include:

- Heart function
- Lung function
- Kidney function
- Blood pressure

These tests are vital for monitoring your condition, so do not be afraid to ask if they are due. Before each appointment, think about what you want to talk about and the questions you want to ask. You can use the space at the end of this leaflet to make any notes that will be helpful at the time.

**REGULAR TESTS ARE A VITAL PART OF YOUR CARE.**

## Before your appointment

**It may be useful to think about some of the following before your appointment:**

- **Has anything changed since last time?** This might be health-related, or it could be about your lifestyle, e.g., if you have had to reduce your working hours.
- **How your condition affects you**, and what this means for you. Keeping a diary of your symptoms can help you keep track of any changes in-between appointments.
- **Any questions** about your care and treatment. It is helpful to make a list to bring with you to the appointment.
- **If your appointment is for a review** it could take up to two hours. You can request a time to fit in around your work and caring responsibilities.

You should receive a letter, email or text message confirming the details of your appointment.

**MAKE A LIST OF THE QUESTIONS YOU WANT TO ASK DURING THE APPOINTMENT.**



**“Always be prepared for an appointment, take notes and ask your doctor or nurse specialist to speak slowly and explain anything that is not clear. Ask and keep on asking, there is no such thing as a silly question. We are here to help provide as many answers as we can. Find out who to contact in between appointments, and don’t be shy about calling.”**

Rachel Ochiel, Lead Research Nurse at the Royal Free Hospital, London.

**IT MAY BE HELPFUL TO HAVE SOMEONE WITH YOU FOR EXTRA SUPPORT.**

## Preparing for your appointment

- Check whether the appointment will take place by phone, video or at the hospital or clinic.
- If the appointment is face-to-face, ensure you know exactly where to go.
- Bring a list of your medications and the dosages you are prescribed.
- Check whether any tests have been booked to take place during your appointment.
- Remember to bring your hospital letter as well as any letters or messages received from other specialists or hospital departments.
- If you need any extra assistance, let the department know as soon as possible. For example, if you have hearing loss or if you need an interpreter.
- Remember that many people find it helpful to have somebody with them for some extra support.
- Check whether any tests are due, so that you can remind the doctor during your appointment.

## Preparing for a remote consultation

- Ask for a telephone call instead of a video appointment if this is more comfortable.
- You will usually be given a timeslot for a remote appointment, that could be a window of several hours. It is important that you can talk and be heard during this time.
- Try to use a quiet, comfortable area with a good connection where you will not be disturbed during the call.
- You may have to ‘sit’ in a virtual waiting room for a video call.
- A phone call may appear as “No Caller ID” or ‘number withheld’.
- The doctor or nurse may ask questions to confirm your identity.
- Make sure the clinic has your correct contact details. It sounds simple, but always worth checking!
- Ask a friend or relative to sit with you if you feel you need support.
- If you worry about remembering information, ask to record the call so you can listen back.

**Remember: A remote consultation is not suitable for all situations. Do not be afraid to say if you need to see someone face-to-face.**

**YOU CAN CALL OUR FREE HELPLINE TO TALK TO ONE OF OUR TRAINED VOLUNTEERS, SEVEN DAYS A WEEK.**  
**0800 311 2756**



## During your appointment

- Start by asking how much time you have. Then tell them what you would like to cover, e.g., ***'there are three things I would like to discuss today..'***
- Talk honestly about your condition and concerns. Try to raise these in order of priority, so you do not end up mentioning the biggest concern right at the end.
- Do not be afraid to ask questions and ask the doctor or nurse specialist to repeat or explain anything that is unclear.
- Repeat information back to make sure you have understood. Phrases like ***'it sounds as if you are saying....'*** may be helpful.
- Make notes to help you remember. You may need to ask them to slow down whilst you write.
- Ask about any tests that may be due to take place.
- If you have had any new tests, you can ask about the results and what they mean.
- Note down any medication changes and do not be afraid to ask for an explanation. You may also have questions around possible risks or side effects.
- If you need a moment to take in a piece of information, tell your healthcare professional.
- Ask the doctor to summarise what has been said and the next steps, before the appointment ends.
- Ask them to confirm when you will have a follow up appointment and if this will be remote or face-to-face. This should also be confirmed in any follow up letters or emails.
- If you are not already under the care of a specialist scleroderma centre, you can ask for a referral within the specialist centres network. Visit **sruk.co.uk** for more information.
- Remember to ask about new or embarrassing symptoms even if you do not think these are scleroderma related.
- Keep a journal of your symptoms and your health so you can share a summary in an appointment.
- If your annual tests are due, remind the doctor or nurse before the appointment ends.
- Find out if the rheumatology service has a nurse support line for questions about your care.

## Summary information

Use the space below to note down the questions you need to ask during your appointment.

1.

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2.

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3.

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NOTES:

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## About SRUK

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.

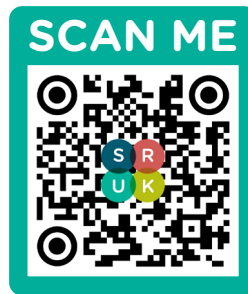
**Free Helpline:**  
**0800 311 2756**  
**sruk.co.uk**  
**info@sruk.co.uk**

**This appointment planner is designed to help you get the most from specialist appointments. It has been developed by SRUK with the help of leading healthcare professionals along with members of our patient community.**

## We value your feedback

We very much value your opinion on whether this leaflet meets the needs of people affected by Scleroderma. Please complete our short survey via this link: [bit.ly/SRUKsurvey](https://bit.ly/SRUKsurvey)

Or please scan the following QR code:



Alternatively, you can call us on **0203 893 5998**.

## Thank you for your support!

Published: August 2023  
Next review: August 2026



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