Caring for someone with scleroderma

Looking after yourself and those you care for

“The most important person in my life is my wife, Alison. She has been fantastic. She’s my nurse, my doctor, my friend, but above all, she’s my partner. And, I don’t know what I’d do without her. Let people support you, let your family support you. Don’t be afraid.”

Mike, a person living with scleroderma

morethanscleroderma.com
If you have someone in your life who has scleroderma, you’ll know that it can cause uncertainty. It can also sometimes feel like things are out of your hands.

But there are many ways to adapt. Learning to manage the symptoms can help people with scleroderma to get on with their lives. But it’s also important to find ways to look after yourself too.

This booklet is designed to help you do just that. You will also find lots more information and handy resources at morethanscleroderma.com

Your health and wellbeing is just as important as the person you are helping with scleroderma. Finding ways to look after yourself, as well as the person you’re helping, will ultimately benefit both of you.
Defining your role in someone’s care

You may be supporting a husband or wife with scleroderma. Or perhaps a parent or a child. You may be a relative, a friend, or neighbour who helps out with the shopping or a few jobs around the house.

Everyone’s role is different. The variety of symptoms scleroderma can cause means that everyone will need different types and levels of help.

Whatever you do and whatever your role, how you define it is up to you. Some people don’t see it as anything extraordinary. They think they’re simply sons, daughters, friends, husbands, wives and parents who are showing their love through support. They may not want to be defined by the idea of one person being a ‘giver’ of care and the other as the ‘receiver’ of it.

If you are supporting someone with scleroderma, then the chances are you will be classed as a ‘caregiver’ in the eyes of healthcare providers. Being labelled as a caregiver in this setting is important to ensure you gain access to any support you might need.

A caregiver is anyone who cares (unpaid) for a friend or family member, who due to illness, disability, a mental health problem or an addiction, cannot cope without support.

3 in 5 of us will be caregivers.

“I think it’s in my nature just to be there and be supportive to Mike. He’s my husband, and that’s what I want to do. We are a team and we do everything together and we talk about everything, the good and the bad.”

Alison, supporting a person living with scleroderma
By helping someone with scleroderma, you can have an incredible impact on their life and happiness. Your time and input really does make a difference.

You may not realise it, but not only do you provide emotional and practical support, you can also have a positive impact on:

- **Outcomes – how the disease affects someone and their future**
- **Helping patients to stick to their medications and healthcare advice**

It doesn’t have to be a one-way relationship either. In many cases, sharing the responsibilities can have a positive effect on you and the person you’re helping.

A study led by Associate Professor Margaret Sebern, at the College of Nursing at Marquette University in Milwaukee, United States, evaluated 75 pairs of caregivers/people needing care to assess the impact of ‘shared care’ or ‘partnership’ approaches. The findings suggested that adopting these ‘shared care’ or ‘partnership’ approaches helped people with a chronic condition to take better care of themselves. It meant they both shared the responsibilities and had a say in key decisions.

Adopting these ‘shared care’ or ‘partnership’ approaches helped people with a chronic condition to take better care of themselves.
You are an expert by experience

The wealth of knowledge and experience you gather providing support for someone else is enormous. Doctors and nurses may have all the medical background about the disease and its treatment, but you know the details of your personal situation.

A scientific survey found that people who had lived with scleroderma for longer didn’t feel as negative about it as those whose symptoms had started more recently. When Dr. Frantz from the Rheumatology Department at the Cochin Hospital, Paris, France, and her team of colleagues from Europe and the United States looked at the data, they concluded that this was because those living with the disease for longer had probably found ways to adapt and work around many of their symptoms.

With scleroderma, experience is important. You get through the challenges together, and know what works for you. As time goes on, you’ll get better and better at it.

This is why it is so important to make taking care of yourself as much of a priority as taking care of someone else.

A large international survey was completed by more than 1,900 people with scleroderma from 60 countries.

People were asked by their patient association or by their doctor if they would like to complete a survey online about which symptoms of scleroderma they had; how long they had had them; what they understood and felt about the disease, and its impact on their lives.

“"We had experts who had been treating patients for many, many years with this disease. And they said, as long as she just doesn’t do the things that she’s not supposed to do, she’ll be fine. She’ll live until she’s ninety’. It was great. Her mindset changed, our mindset changed.”

Sharon, supporting a person living with scleroderma
Taking care of yourself

First things first, you have to look after yourself. This is not selfish. You simply won’t be able to help the person that you care for if you don’t.

It’s important that you look after your own wellbeing and manage any stress, particularly long-term stress. While taking care of somebody else could have an effect on your physical and mental health, it does not have to.

In a recent survey of over 1,400 caregivers in the United States, an overwhelming majority (83%) said that providing care is a positive experience in their life. Some studies even suggest that caring can have health benefits.

Your quality of life is an important aspect of your health. A happy, healthy you is important for everyone.

Research has found that people who are surrounded by many happy people, are more likely to become happy. This means that if you feel happier, the chances are the person you care for will feel happier too.

The information and advice on the following pages will help you ensure your needs are met, as well as those of the person you care for.

“I see my daughter trying to deal with the problems that I have and she finds the balance to help me and then to study. She’s doing very well and I’m very proud of her.”

Maria, a person living with scleroderma

Professor Fowler and Professor Christakis from Harvard University in the United States measured happiness in 4,739 people over a 20-year period. During that time, they found that people who are surrounded by many happy people are more likely to become happy in the future - in other words, happiness spreads.
Taking care of yourself
A healthy body

Eating well
It is important that everyone eats a healthy balanced diet. The energy and nutrients that make your body work well come from your food and drink. A healthy diet is one which is full of vegetables, proteins, whole grains and water, while remaining low in sugar and salt.13

Staying active
There’s strong scientific evidence that being physically active can help you lead a healthier and happier life.14 In the United States, physical activity guidelines have been developed by the Office of Disease Prevention and Health Promotion, based on medical research results that demonstrate health benefits seem to begin with as little as 60 minutes (1 hour) a week. Also, moderate-intensity aerobic activity, such as brisk walking, for a total of 150 minutes (2 hours and 30 minutes) a week consistently reduces the risk of many chronic diseases and other adverse health outcomes.15

Emotional benefits
As a caregiver, you may find it hard to fit exercise into your already busy life, but it is important for you to stay as active as you can. Not only will you benefit physically, but there are a lot of emotional benefits linked to exercise and activity too.

Research shows that physical activity can help:14

- Boost your self-esteem and mood
- Improve your sleep quality and energy
- Reduce your risk of stress and depression
- Lessen the risk of diseases
Caring for someone with scleroderma is different for everyone and there’s no right or wrong way to feel.

It can also be stressful at times. That’s understandable.

- Someone you love is experiencing pain, discomfort or distress
- Illnesses like scleroderma are often unpredictable and uncontrollable. You will have to stay vigilant – keeping a careful look-out for any new symptoms or problems
- If you take on extra responsibilities, your day-to-day life may have to be adapted. This may put some strain on your personal relationships and finances

Here are some practical ways that may help you to manage your stress and wellbeing. These simple changes don’t take a lot of time, but may make a big difference to how you feel.

**Expressing yourself**

Writing a personal diary for just 20 minutes each day reduces stress. People who use expressive writing like this often find it helps to put some structure to anxious feelings.

The biggest benefits seem to be in people who focus on the cause and meaning of stressful events when writing in their diary. What you choose to write about should be important to you (whether related to scleroderma or not).

**Try including the following phrases:**

- I feel like this because... / This happened because...
- I realise now that... / This has made me understand that...

You might feel a bit emotional at first after expressive writing, but this feeling should go away. If not, just stop writing.

"When Michael was diagnosed with scleroderma, I was devastated. I think it affected me more than it affected him, because Michael is a really positive, upbeat person. And, he’s really strong, and he’s been strong through all of this, which I haven’t been all the way, and I’ve, kind of, taken my strength from him in the end."

Alison, supporting a person living with scleroderma
Mindfulness is an awareness of what’s happening in the present moment in your mind, body and the world around you, coupled with an attitude of curiosity and kindness. More and more evidence suggests that being mindful not only reduces stress and anxiety, but also builds resilience, so that you feel more able to cope with problems in the future.

There are many ways you can learn how to practice mindfulness in your daily life. You can learn in person (either in a group or one-to-one) or teach yourself from library books, or information online. You can also download apps on your mobile phone or tablet.

How you choose to be mindful is up to you. Some people might prefer to listen to music, others to go for a short walk. Another popular option is mindful meditation.

Typically, mindful meditation will require you to:

- Sit on a chair with your feet on the floor. Close your eyes and place your hands in your lap.
- Focus your attention on what your body is feeling. For example, a breeze against your skin, or your feet pressed against the floor.
- Your mind will start to wander and think about other things. Allow this natural curiosity but don’t get caught up in it. Bring your attention back to your body in the present moment, whenever you find yourself wandering.

“This we end up living ‘in our heads’ – caught up in our thoughts without stopping to notice how those thoughts are driving our emotions... Gradually, we can train ourselves to notice when our thoughts are taking over and realise that thoughts are simply ‘mental events’ that do not control us.”

Mark Williams, Former Director of the Oxford Mindfulness Centre
Focusing on you

While much of the focus might be on the person you care for, or the scleroderma that affects your lives, it's worth taking the time to pause and consider what you want and need for yourself.

When you’re supporting someone with scleroderma, it can be hard to find a balance between your caregiving routine and other interests or hobbies. But you can still work towards your own goals, and achieve the things that are of value to you.

Just as the person you care for might have personal goals, so can you.

Setting personal goals

When setting goals, a good place to start is to think SMART:

- **S**pecific: Be clear about what you want to achieve
- **M**easurable: Know when you’ve been successful
- **A**chievable: You want a challenge, but nothing too difficult
- **R**ealistic: Don’t pick something impossible
- **T**imely: Make new goals frequently, i.e. weekly or monthly
Setting personal goals

**We all have basic human needs that we try to achieve.**

Goals can help us meet those needs. It’s worth spending a little time to give them some thought and structure. Don’t just say you want to do something and then forget about it. Use the SMART criteria. What exactly is it you want and how are you going to get there?

Think about the following areas of your life and whether there are any areas where you would like to set goals for your own health and happiness.

1. **Wellbeing and taking care of yourself**

   As a caregiver, you will recognise the importance of achieving the needs of the human body. Things like nutrition, sleep and exercise are important. Stress and a lack of sleep can really alter your health. How have you considered your own needs recently?

2. **Belonging and relationships**

   If you care for a loved one with scleroderma, it might have changed the nature of your relationship. The new circumstances might have altered other relationships you have, or brought new people into your life.

   Looking after both old and new relationships can help you feel supported and fulfilled.

   "You just have to adjust your life to do the things that you can do. Embrace the things that she can do and just enjoy them together."

   Sharon, supporting a person living with scleroderma
3. Safety, security and stability
Helping someone out can be a rewarding experience but it might have added some financial, time, and emotional pressures on your life. Some goals might help you to address these aspects.
Scleroderma is an unpredictable disease and, understandably, this can cause worry and uncertainty. Understanding what it is can help, as can talking to patient or caregiver organisations. Visit ‘Extra support’ at morethanscleroderma.com to find an organisation to suit your needs.

4. Building on your self-esteem
As a caregiver, it’s likely you have developed many valuable new skills. Maybe these were learnt with experience, or maybe you actively sought some training.
Knowing that you are doing a great job and actively making a difference can be a boost for your self-esteem. Take some time to reflect on the difference you make to the person you care for.

5. Ambitions
Is there something you have always wanted to do? Goals can be both long and short term, so you can use this opportunity to think about your ambitions both now and in the future.

“With scleroderma, it is really very important to surround yourself with people that will support you, because they don’t see this scleroderma, but they see you, as the person. And that is good, that keeps me going.”

Doris, a person living with scleroderma
Setting shared goals will give you something to work towards together. For example, it could be something that the person you care for can do for you. This might be an opportunity to bring you closer together and switch the roles on who is looking after whom.

“I get up at 5:30 every morning when Alison goes to work. You know, we make each other a cup of tea or whatever, and my day starts then. I am, you know, a bit of a house-husband these days. I go shopping on a Wednesday, and I do ironing on a Thursday and a Tuesday and I push the hoover around on a Monday and a Friday. Routine is important, that motivates me.”

Mike, a person living with scleroderma

“I’ve got a lot of support from my family and my church. My daughter and I try and do things together, because she knows I struggle with little basic things. Just getting dressed, she’s happy to do it. Sometimes she even helps me to take a bath. You know, she’s just wonderful.”

Doris, a person living with scleroderma
Develop your skills

Providing care for another person uses lots of different skills. Some of these you might have had already, but others you might have developed through experience.

The great thing is that many of these skills and qualities also have value in your personal or professional life.

Examples of skills and qualities that may be useful include:\(^{21,22}\)

- Communication skills, both verbal and written
- Problem solving
- Patience
- Observation skills
- Empathy and compassion
- Understanding the healthcare system and medical terms
- Time management and organisational skills
- Financial management
- Responsibility
- Positivity

Consider making a list of the skills you have, and those you’ve gained. You might want to think about any skills you would like to learn in the future as well.
Maintaining relationships

With the person you care for

In surveys in the United States, of more than 1,400 adults aged over 40, the vast majority of people who provide care (83%) said that it is a positive experience in their life. About 8 in every 10 people say that it has strengthened their relationship with the person they care for. It may not be easy at first. Your relationship dynamics with the person you care for may change. Whether they are your husband, wife, grandparent, child, friend or neighbour, what you can give and receive from one another may change.

With others

Many caregivers report feeling isolated. With so many other responsibilities it can be difficult to make time to see other people. But this may be very important to you. Make time for that cup of coffee!

To enable you to make time to see friends, try asking other friends or family members for a small amount of help – e.g. taking the kids to school, cooking dinner, etc.– and tell them what a difference it has made. It might mean they’ll offer to help out again.

Dr Powell Lawton and his colleagues, who interviewed 285 spouse caregivers and 244 grown-up son and daughter caregivers of people with Alzheimer’s, suggest that whilst caregivers experience emotional distress, they also gain great satisfaction from the care they provide and their personal growth.
A survey of 2,100 caregivers in the UK found that 75% felt unprepared for their caring role and 81% didn’t feel that they were aware of the support available.

There are lots of different types of support. The key is to find what works for you and the person you’re supporting.

**Connecting with other caregivers**

Sharing experiences and finding someone who understands your experience can be very helpful.

**You could find support from:**

- **Regional, national, or international support organisations**, who often provide support via their websites or organise meet-ups. You might find these through your local health services. Ask the doctor or nurse for information or a recommendation about whom to contact. Some clinics that specialise in treating scleroderma have support groups or meetings for caregivers.

- **Advice helplines** are run by several caregiver organisations. They can be a great place to get one-to-one advice.

- **Caregiver conferences**. Search online or ask the doctor/nurse for information on any conferences near you.

- **Online support forums** can be a source of more personalised, real-life discussion. Some of these forums can be specific to a particular health problem. Those related to connective tissue diseases are most relevant for scleroderma.

- **Groups for caregivers, or talking about scleroderma on social media**, like Facebook or Twitter. These can be a great source of uplifting and motivational messages.

**In all cases, be careful about disclosing any personal details online.**

If you know other caregivers, perhaps you could consider setting up your own support network. You could use messaging apps to create group conversations to share tips and support.

The website [morethanscleroderma.com](http://morethanscleroderma.com) has helpful links to patient associations that may be able to provide additional information on setting up caregiver groups.
You might be able to get extra financial, practical or emotional support from certain organisations and government departments.

- Check with your local government
- Contact national and regional charities to see if they can point you in the right direction
- Ask the medical team who look after the person you care for. Or even your own doctor or nurse. They might be able to give you more specific types of support, such as counselling.

Support is available. Don't hesitate to ask for help if you need it. There will be someone there to listen.
Working while supporting

Work life

There is no ‘one size fits all’ solution for caring for someone while working at the same time. Everyone has different needs and will need different support. Take time to think about the right decision for you.

If you are helping someone who has scleroderma, you may find it helpful to explain the issues you face to your employer. This will mean they are aware of the situation if you experience problems or need some time off work. You may also be able to discuss flexible working practices.

Examples of flexibility that you may be able to discuss with your employer include:

- Making changes to your working pattern, such as flexible hours or working from home - Employers who support such arrangements report increased loyalty and goodwill in their staff as well as greater work productivity

- Recognising that you may need time out from work to take the person you care for to doctor’s appointments or deal with emergencies - Make a plan for who will cover your work during those times. Make sure it’s clear who you need to contact and how your colleagues can get the information they need to cover you

Of course, every employer is different, and every country has different employment legislation. You should seek advice from your local employment advisory service to find out what you could be entitled to in the workplace.

A report commissioned by the Department for Work and Pensions in the UK, concluded that, as well as the financial advantage, there is evidence that caregivers who stay in work experience important social and health benefits e.g. social interaction outside your home
The symptoms of scleroderma can present some challenges for people living with the condition and those supporting them. However, you can find ways to adjust and work around these challenges. It might take some time and a little trial and error. But it’s worth the effort to find things that work, so that you and the person you’re helping don’t have to miss out on the things that matter to you.

You will also find more information and handy resources at morethanscleroderma.com

“I have a very good family. They’ve been there for me throughout. They take turns to attend appointments with me. My mum, she’s great at helping me with things in the house, just everyday things that I can get quite breathless doing. My dad’s always keen on doing the Hoovering. They’re very supportive.”

Mandy, a person living with scleroderma
Symptoms related to the digestive system are common for people with scleroderma.

When the food you eat reaches your stomach, the muscles in the wall of the gut move the food along, allowing it to be digested and the nutrients absorbed.

In some people with scleroderma, fibrosis (scarring) makes the walls of the digestive system a bit thicker and the muscles don’t work as effectively.27 This causes many of the digestive symptoms that some people experience.

These symptoms can be uncomfortable. As a result, the person you care for might not want to eat as much. Alternatively, you might find that they eat just as much, but are losing weight. This could mean their body is finding it harder to absorb nutrients because of the scarring.

You could encourage the person you care for to weigh themselves at least once a month, and to make a note of their weight so that they can let their doctor know if there are any changes.28 If necessary, the doctor can assess their nutrition and suggest a diet plan.

There are also a few simple things people can do to reduce the effects of digestive symptoms. See next section.
If the person you care for has difficulty swallowing, encourage them to:

• Eat foods that are soft and moist or purée them
• Use lemons or other sharp tastes, so that they produce more saliva
• Allow plenty of time for their meals

If they experience heartburn or indigestion, it may mean the muscle at the top of their stomach doesn’t work very well any more. Acid in their stomach may be travelling up their oesophagus (food pipe). If you eat together, some small changes to your mealtime habits might help, for example:

• Eating little and often, rather than a lot all at once
• Make lunch the main meal rather than dinner, and avoid eating and drinking just before bedtime, so that they aren’t uncomfortable during the night
• Encourage them to sit straight during and after meals, to let gravity help their digestion
• You may also find it helpful to raise the top end of their bed by 15 to 20cm so that gravity helps to keep any acid down in their stomach

If they experience diarrhoea or constipation, they may need to change the balance of fibre and fluids in their diet. Advise them to:

• Avoid insoluble fibre (such as the skins on fruit and vegetables), if they have diarrhoea. This simply passes through the system without absorbing any water
• Drink plenty of fluids so they don’t become dehydrated
• Speak to the doctor or nurse about any diarrhoea or constipation, in case the symptoms are serious or due to other causes, particularly if symptoms do not improve

If they have a poor appetite or have lost a lot of weight, suggest that they check with the doctor/nurse in case they need to add some supplements to their meals and drinks in order to get extra protein and energy. Ways in which they can do this include:

• Adding dried milk powder to full fat milk
• Adding butter/margarine or olive oil to potatoes and vegetables, soups and sauces
• Sprinkling extra cheese over food

If they find it hard to cook, perhaps because they are tired, or their fingers are stiff:

• Buy pre-chopped food – these could be fresh, frozen or tinned
• Try cooking together. Take over the tasks that they struggle with (e.g. opening jars, rearranging the freezer) and make cooking a joint effort. You may even learn new recipes in the process!
• Buy cooking equipment that is specially designed for people with hand problems. Consider investing in lightweight cutlery or knives that have a comfort grip
Practical ways to help someone with scleroderma

Staying active

Scleroderma can make it more difficult to stay active and exercise. When you’re tired or in pain, it’s tempting to stay in bed.

But there is strong scientific evidence that being physically active can help people with scleroderma to lead a healthier and happier life.31

The doctor, nurse or physiotherapist can advise on an exercise plan that will help them to take active control of their health.

There are also some light exercises the person you care for can do at home to help with specific symptoms.

A team of researchers from Brazil and Sweden looked at all the published literature on the benefits of exercise in people with scleroderma. They found that when lungs were not affected by the disease, aerobic exercise alone, and combined with resistance exercises, improved: aerobic capacity; muscle function and muscle strength; exercise tolerance (the ability to keep going); walking distance; and health-related quality of life. When there were some lung symptoms, health-related quality of life was still improved, as were muscle strength and physical and aerobic capacity.31

The person you care for may have bad days but try to encourage them to be active on the good ones. The more they move, the easier moving will become.

“I used to be, very active, very sporty. I cannot jog anymore, but I find different things to do.”

Maria, a person living with scleroderma
Practical ways to help someone with scleroderma

Finger exercises

When fingers feel stiff, even everyday tasks like using cutlery or typing on a keyboard can prove difficult. Performing regular finger stretches may help to improve grip and allow the person you care for to move their fingers more freely.

Here are some exercises that can be tried at home:

1. The finger stretch
   - Put the tip of your right index finger, against the tip of your left thumb
   - Put the tip of the left index finger just above the knuckle of your right index finger
   - Push your right index finger backwards with your thumb, until it feels stretched. The position of your left index finger should help stabilise the stretch
   - Hold for 10 seconds
   - Repeat this stretch for each finger on your right hand 3 times, then change hands

2. The starfish
   - Make a tight fist
   - Stretch all your fingers out, so that your hand looks like a star
   - Hold for 5 seconds, and repeat 3 times

3. The thumb slide
   - Touch the tip of your little finger to your thumb tip (on the same hand)
   - Slide your thumb tip down the length of your little finger
   - Repeat for your other fingers, starting with your ring finger and thumb

In Japan, 45 people with scleroderma agreed to do some finger stretching every day for a year. The total passive range of movement (when someone else moved the joint for them) was measured at the start, both after one month and after one year. Finger movement was found to improve in everybody after one month, and either maintained the same level of improvement or improved further, after one year.
Scleroderma can cause the skin to get tighter around the face. If this happens to the person you care for, they may find it harder to open their mouth fully.

Exercises can help. After performing mouth-stretching exercises for 18 weeks, people find it noticeably easier to eat, speak and clean their teeth.34

Here are some exercises you can try together at home:
Always warm up facial muscles by massaging the skin around the mouth, before trying any exercise.

1. The smile34
   • Put your right thumb in the right-hand corner of your mouth and your left thumb in the left-hand corner
   • Gently pull your thumbs to the side. Stretch your mouth as far as you comfortably can
   • Hold the stretch for 15 seconds
   • Rest for 10 seconds and then repeat 2 more times

2. The sideways shuffle35
   • An easier one! With your mouth closed, move your jaw from left to right
   • Repeat 3 times

In this study at the Department of Oral Sciences, University of Palermo, Italy, 10 people with scleroderma whose maximum mouth opening was less than or equal to 30mm undertook a series of mouth-stretching exercises for 18 weeks. The results were so positive that even though they were asked to stop to see if the benefits were maintained, all of the participants decided to continue with the exercises since these had made such an improvement to their quality of life.34
Before the person you care for starts any exercise programme, they should talk to their doctor/nurse or physiotherapist. Together, they will help you to plan the exercises that will help them the most.

Helpful exercises tend to fall into two categories:

1. **Moderate aerobic exercises** (also known as ‘cardio’): increases your heart and breathing rate. This gets your blood pumping and improves your circulation.

2. **Resistance exercises**: cause your muscles to contract, like yoga. This makes you more flexible.

Yoga is thought to improve digestion, so if the person you care for suffers from heartburn, diarrhoea or constipation, they may want to discuss doing this with their doctor.

Encourage the person you care for to give their body the best chance it has to fight scleroderma. The doctor/nurse can provide information about ways to stop smoking or cut down.36

If they’re a smoker...

Smoking can make it harder to exercise. It can also make the symptoms of scleroderma worse.

A scientific study showed that people with scleroderma who stopped smoking had an improvement in some of their symptoms, such as Raynaud’s phenomenon.

The Canadian Scleroderma Research Group undertook a study of 606 people with scleroderma of whom 16% were smokers, 42% were past smokers and 42% had never smoked in their life. The study provided strong evidence that smoking has a negative effect on scleroderma, and that these effects can be long-lasting (for example, in terms of effects on lung function). It also showed that giving up smoking can improve symptoms such as Raynaud’s phenomenon and finger ulcers.36
Living with a life-long condition that can’t be cured, can take its toll on a person’s emotional wellbeing. Adjusting to life with a new set of limits can be hard, and the person you care for may struggle with changes to how they see themselves and their relationships.

It is important that the person you care for talks about their feelings. Try and be a good listener. You can also support them if they want to try the same practical stress-management techniques that might help you, such as yoga, mindfulness or expressive writing.

If you have concerns that the person you are supporting has more serious mental health issues, such as severe depression or suicidal thoughts, talk to your nurse or doctor, or get in touch with a patient organisation.

More information on the extra support available can be found at morethanscleroderma.com

"If you've just been diagnosed with scleroderma, I would say just take one day at a time. Don't worry. There's loads of support around. In fact, I feel more positive now, than when I was first diagnosed."

Mandy, a person living with scleroderma
Some people with scleroderma may experience mental health problems, such as depression. Friends and family are often the first people to recognise the early signs of mental health problems—those small changes in how someone’s behaving or feeling.

If the person you care for is experiencing several of the following symptoms at the same time, they should be seen by a doctor or mental health professional, e.g. psychologist, psychiatrist:

- Rapid or extreme shifts in moods
- Big changes in sleeping or appetite
- Loss of interest or enthusiasm in activities e.g. quitting clubs
- Recent social withdrawal and loss of interest in other people
- Nervousness
- An unusual drop in functioning at work or socially—finding it difficult to do normal things
- Finding it hard to concentrate, remember or explain things
- Increased sensitivity to light, sounds, smells or touch
- Feeling disconnected from themselves or their surroundings
- Uncharacteristic behaviour or illogical thinking

If they are having suicidal thoughts they will need immediate attention.
Frequently asked questions

How might being a caregiver change my life?

We know that caring does have an impact on relationships, careers, finances and a person’s health and wellbeing both positively and negatively.2,9,23 But the answer is that every caregiver’s experience will be unique. You may be a spouse, a child or a friend caring for someone with scleroderma. And given the variety of symptoms scleroderma can cause,1 everyone will need different types and levels of help.

Whatever you do and whatever your role, how you define it is up to you.

Where can I find support for myself as a caregiver?

See the section ‘Finding the right support’. Support varies from area to area and country to country. A good place to start is to ask the doctor or nurse at the clinic the person you care for attends. You could also look online to find either a local or national scleroderma organisation.

You don’t need just to look for other scleroderma caregivers. There is a lot of general support available for caregivers as well.

There are so many medicines that I need to co-ordinate. How do I know which ones to give, and when?

The doctors/nurses should be able to provide a general outline of when it is best to take the medicines. Your local pharmacist can also help with this too. They may give you a pill box to help you keep the medicine in order and remember when each has been taken. It can also help to keep a list of the current medicines, as they may change every now and then.

I am worried about the future. Where can I find reliable information and advice?

The ‘Learning what scleroderma means’ booklet provides information about what scleroderma is, and explains what symptoms may appear. You can also find more information at morethanscleroderma.com

Who can I talk to about my work and benefits that may be available?

See the section ‘Working while supporting’. Contact your local authority/office who will be able to advise you not only what the person you care for is entitled to, but also if there are any benefits you may be able to claim.
References

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