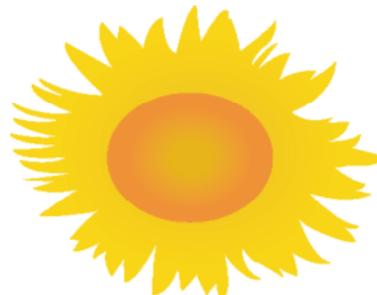


Tips on self-management

Kim Fligelstone

Scleroderma Society

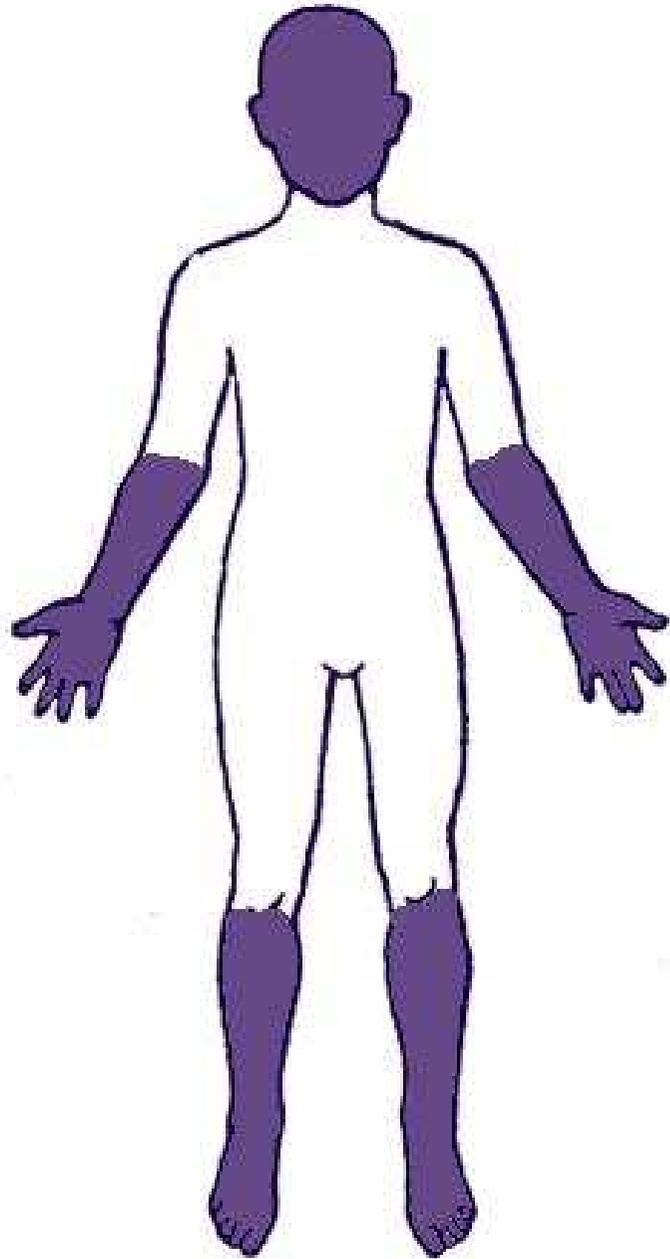
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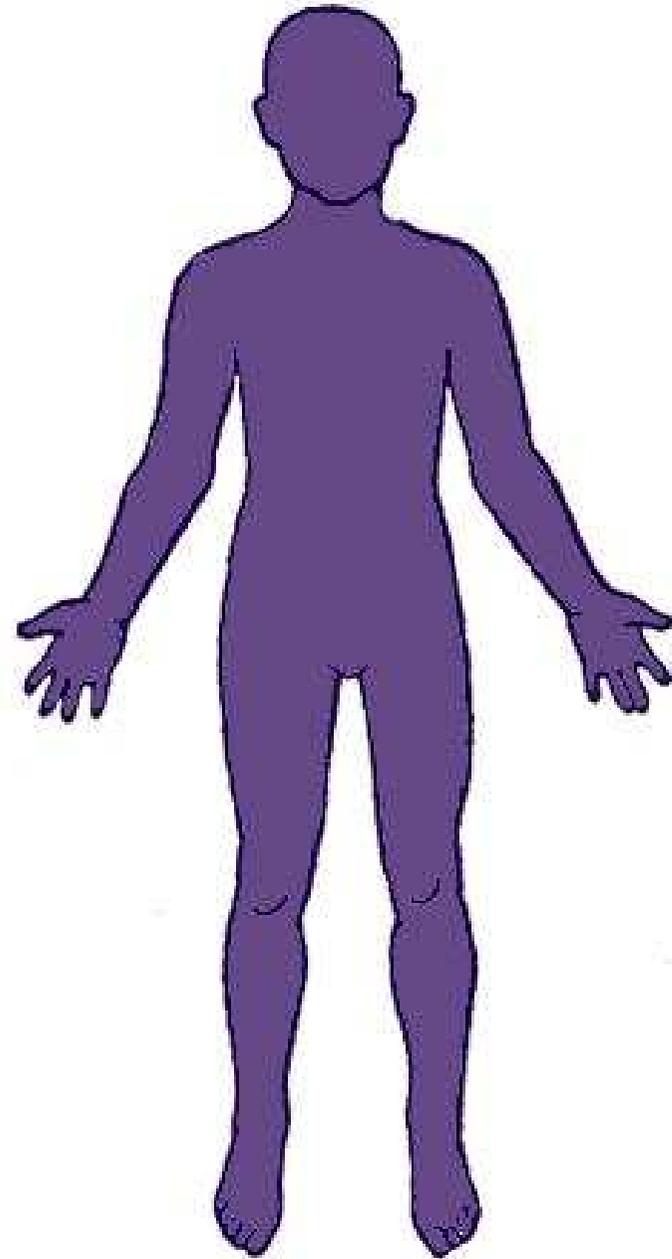
Disclaimer

- Most of these tips have come from people with scleroderma who have experienced many different symptoms some you may know about and others may not be relevant
- If unsure of any thing you hear during this talk please check with your physician to make sure it is suitable for you to try and above all use your common sense

I have had diffuse systemic sclerosis since 1988 and will have a completely different experience to another person with diffuse and the same applies to people with limited systemic sclerosis and the diff types of localised scleroderma. There are lots of overlap between the two systemic sub sets the reason for the two names diffuse and limited applies only to how the skin affects the body



Limited cutaneous SSc



Diffuse cutaneous SSc

Initial Shock

- First awareness of the implications
 - Incurable disease
 - Impact on appearance
 - Fear of what's to come
-
- This is all completely normal just mentioning because there is a session on Saturday afternoon on coping with ssc

Symptoms we may share

- We share the need to protect our largest organ, the Skin – moisturise, moisturise, moisturise
- People with SSc share poor circulation and or secondary Raynaud's and the need to stay warm
- Some may share poor mobility
- We will all share pain at some time during the disease for some this is chronic!
- Oesophagus, any part of the gut and bowel
- Other complications (organs) to medical for talk

Tips for living with scleroderma

From a user perspective

Hands

- Keep warm: be careful not to touch radiators and hot water when hands are cold as could be numb and burn
- Gloves: whatever material suits (for inside and outside) Woollen, cotton, rubber, gloves with silver, gloves for cleaning and cooking, to protect from cold, water, trauma
“avoid trauma by avoiding doing things that might break skin” Or find a way to protect them
- Hand warmers (huge variety find one that suits you)
- “Carry shopping on arm not fingers”, use plastic carrier bag holders if available
- Moisturise, moisturise, moisturise: *“Carry moisturiser for my hands everywhere in winter and put it on hands a lot to minimise dryness, which can cause cracks, ulceration”*
- Hand Wax

Hands continued

- Calcinosis
- Ulcers “ulcer management: learnt from the hospital, have a kit of bandage at home, learn to use it, care about your digital ulcers.
- If you travel you should always use hand cleaners- ant-bacterial liquid.”

Feet

- Moisturise (use plastic bag if can't reach feet)
- Keep warm
- Ensure good podiatry care
- Insoles (not evidence-based yet)
- Turn socks inside out so seams don't cut of circulation
- Use aid for socks and tights

Head and Face

- Wear hoodies, hats and scarves *“Wear as many hats and scarves as necessary to cover every open bit of skin in winter”*
- Protect skin with moisturiser - this applies to whole body
- Protect lips with lip balm or Lip Gloss
- If nose feels the cold cover with scarf etc
- Hide telangiectasia with foundation and make up
- Good dental hygiene/mouth care
- Electric toothbrush
- Receding gums: always carry dental floss picks

Body & Mobility

- Keep warm
- Moisturise
- Dance and Exercise to ability including physio, breathing, face, hands
- Sleep “*I make sure I get enough sleep as I can get over-tired, not the same as proper fatigue that some people get, but I over-tire easily without enough sleep*”
- Pace yourself “*sometimes it is better not to participate in an event in the evening and feel better the next day*” Or if you know your going to be busy make time before and afterwards to recharge batteries – *listen to your body*
- Massage - light

Personal Hygiene/Bathing

- Getting in and out of the bath
- Bath chair, blow up air bag
- Shower chair
- Restricted mobility: long handled brush or sponge
- Use emollients if soap & drying
- Oral hygiene – electric toothbrush

Gut and Bowels

- To help reflux heighten back of the bed so gravity can help
- Control reflux *“by eating little and often”*
- May help to eat before a certain time (i.e. early evening)
- Weight loss, eat little and often
- Learn what foods may affect you *“have them as a treat now and then if you like. I eat Melon as a treat when it is most ripe and in small pieces, and enjoy it”*
- **Incontinence** be prepared to take a change of underwear and pads

Eating/Food Preparation

- Thicker handles for cutlery
- Eat slowly and chew thoroughly *“do not be embarrassed with your slow eating”*
- Cut food into small pieces
- Ask for help if you need it
- Use Aids (never feel guilty) separate presentation

General tips

- Looking Good *“I try to make myself look nice in any way I can, doing my hair, wearing something that suits me, and makes me feel good, and generally live my life as happily as I can!”*
- Move about *“I try to move about as much as possible, especially in winter, as it helps to keep the whole body warm the more you can move about, even if not doing extensive exercise”*
- Don't forget to have fun, enjoy life!
- Adapt to new situations (doesn't mean giving in)
- Take water or drink when going out (helps if coughing and dry mouth)

Visiting the Physician

- Write down any new symptoms and questions you want to discuss in clinic
- Patient Passport, a PERMANENT notebook with all doctor visits, medications, dates etc. *“How I wish I had followed this advice”*
- Ask for help when needed
- Compliance: Tests and medications

WORK

- If appropriate, inform employer and colleagues about your situation
- Ask for help when needed
- PACE yourself
- Consider all options: May have to adapt to new job within same organisation or reducing hours

Travel

- Take medications with hand luggage
- May require fitness to travel
- May require dr's letter if liquids
- Hot water bottle
- Pillow – under mattress to raise level
- Warm clothes for plane/conferences (air con)

Three Main Considerations for People with Scleroderma *by Bianca Podesta*

1. Keep in mind that SSc is an autoimmune disease
2. Be careful to follow medication recommendations
3. Do not underestimate your sensitivities to stress and cold

Keep in mind that SSc is an autoimmune disease

1. SSc is an autoimmune disease. It has a number of things in common with other autoimmune diseases. Lifestyle changes can be most helpful in managing symptoms, and even eliminating some symptoms. Diet: there is some new research to support our trying to eat gluten-free and lactose free foods, for instance. Appropriate exercise can help maintain flexibility and reduce joint pain.

by Bianca Podesta

Medication

2. Medication: Follow the advice of your doctor and the printed inserts about how to take your medication. Take note of any side effects, and report them to your doctor. Some meds take time to get used to. If there are continued problems with side effects, ask your doctor if a different dosage or a substitute drug would work as well. Remember, that even while taking medication, positive lifestyle changes are still important.

by Bianca Podesta

Do not underestimate your sensitivities to stress and cold

3. Cold and Stress: Keep your whole body warm and comfortable. Stay inside on bitter cold or rainy days, if possible. Reduce stress by learning meditation and maintaining healthy loving relationships with relatives and friends. Belong to a group of people - a congregation or organisation - who are working together to make the world a better place. Do what you can to make your world a better place.

- Scleroderma Coping Strategies by B. Bianca Podesta available from www.sclerodermacoping.com

Attitude

- Don't beat yourself up if you have a bad day
- “Thinking: positive thinking is essential, although we know sometimes it is not always possible
- Importance of communication with family, friends and colleagues, going out if capable, go out in the fresh air if not too cold”

Summing Up

- Incredible amount of similarity in ideas from people with scleroderma
- Use common sense regarding implementation; remember what suits one person may not suit another
- Remember you're not alone
- Join a group
- Adapt as much as possible to make everyday living easier, but do not let scleroderma become your only focus
- Learn to say NO

Thanks for listening
Enjoy the rest of the congress
And your LIFE!

Kim

