Members Stories –

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Scleroderma

New Zealand support group

Spring 2025

Greetings to you all...

Welcome to the Spring edition of our Scleroderma Newsletter

Kia ora koutou, nau mai haere mai, greetings to you all.

Spring is upon us. It is wonderful to see the spring bulbs flowering, blossoms out and the colour replacing the dull shades of Winter. It is still very important to dress appropriately as Spring does still throw us many a chilly day. Last Spring was actually worse than our Winter down in Southland so keep those gloves and hats handy by the door but also your sun block to protect your skin.

If you are new to our newsletter, Welcome. We have quite a few new members so we wish you well on your Scleroderma Journey. Not the journey you had planned for but hopefully we can be of some support to you as you come to terms with your diagnosis.

Firstly we have the Presidents Report. Then the second half of my holiday. Strange to think we have been home for longer than we were away and I am still catching up.

We have a memorial for Elle Bray. The life and times of Perry piece. Some advice on stretching exercises for our hands and face.

Heather gives us some advice on what we can do to help with those zips that are on everything. I have some sunflower seeds to share that were originally from Betty.

We have Scleroderma Australia's pamphlet on Scleroderma and Fatigue. It was a good read. It is wonderful to be able to join forces with our neighbours.

Susil shares her blanket that she has put lots of hard work into and has organised a raffle which will be donated to the seminar in Te Awamutu. Thank you Susil that is very generous.

We have the flyer for the seminar which has the registration details. Get your registration in so the team has an idea of numbers. It is going to be a great day out.

Please feel free to send us any news, stories, jokes or anything you would like to share with us at any time. Our contacts are listed on the last page of this newsletter.

Take care everyone.

Nga mihi,

Tina, **Helene** and **Jenny**

Presidents Report:

Hi All,

By now everyone should have had their flu vaccines and you are all welcoming the spring colour in our gardens and the sunshine in the days. A big thank you to Tina and Helene for getting the last newsletter sent out to you all. With everything happening before we left I forgot to send in a report to Tina, hence it was written while I was away. Good old dictation onto my phone. What would we do without this technology that we are so used to now. Everything is instant these days. And I hear since I have been away that our local medical centre has finally changed the way they do things which I think means we will also be able to see our results etc on our phone. I was very envious of all those who could already as we were still having to phone in and ask and it takes such a long time now to get to talk to someone. So yay to Winton Medical.

Keep an eye on the website as it is quietly being updated in the background by Alumie with the help of Gordon. I was having a look around it and it was nice to be reminded of our seminar in Invercargill which was such a great day, as I look forward to seeing all those who will be making the trip to Te Awamutu in October for our next one. What a fabulous job the Waikato/Waipa team are doing with the organising of this. We really appreciate all the work you are all putting into a day of education and friendship for us. If you haven't already, get your registration in (actually I just left this for a minute and have just registered myself. It was too easy, Southlanders are shocking for leaving things like that to the last minute. All Done) Also get your flights and accommodation booked so you don't miss out.

We are getting more and more members all the time and it is great to see so many groups getting together to support each other. Remember if there is not a group near you, feel free to get in touch with me and I may be able to put you in touch with someone close to you. But failing that we do have the online support meetings, normally run by Perry Bray which are amazing. Thank you Perry for doing this for our members who may not otherwise be able to meet others in their areas or are unable to leave their homes.

It must be time for us to organise another wee fundraiser, so if anyone has any ideas of what we could do, for example Scleroderma NZ tea towels or such like then get in touch with one of the committee and we can take it to the next meeting.

I had a strange thing happen to me while I was on holiday and I wonder if anyone else has encountered this. I boarded a flight in Houston to come back to Auckland and due to having a chesty cough I was advised by a doctor in Luxemburg to wear a mask at the airports and on the planes when there would be a lot of people around me. This not only helped me, as I was run down with one lot of bugs he didn't want me catching any other strain – but also helped others around me to prevent them from getting what I had. I sat in my seat and a woman across the aisle from me, but 3 seats away in a row to herself kept looking at me. And looking at me, and then looking at me some more. Finally she asked if I was sick. I said yes I have a cold. She then said she had an autoimmune condition and would ask if she could be shifted away from me. I did tell her that yes I also had an autoimmune condition and that maybe she should really be wearing a mask to keep herself safe if she was so worried about it. Gosh it made me feel so uncomfortable and unloved. So if you are going to be around a lot of people and you are worried about bugs and air conditioning and the close quarters of a flight then do consider wearing a mask yourself rather than making someone else feel bad for wearing one. Only we are responsible for our own bodies and need to do what we can to keep ourselves safe. Take care all. **Jenny**

Memorial

In memory of Eleanor Bray – Member of the New Plymouth Scleroderma Support Group

Eleanor BRAY Obituary – Taranaki Daily Times

On Wednesday, 13 August 2025, our beautiful Mum passed away after a short illness at Taranaki Base Hospital, New Plymouth. She was a treasured great-grandmother to Bonnie, Luca, Arlo, Neco, Cleo, Thao, Rhylan, Sayla, Solace, Theodore, Lani, Kaumoana, and Waerea, and a much-loved nana to Tyson, Bianca, Luke, Tayla, Jack, Dylan, Jamie, Evelyn, Elijah, Lilliah, Avalee, Ethan, and Ezra. Beloved Mum of Marie, Michelle, Rodney, Hadley, and Angela. Our hearts ache with her passing, yet overflow with gratitude for the love, warmth, and guidance she gave so freely. Mum touched every life with her kindness, leaving us with memories we will hold close forever. We will see you in the sunset, Mum - forever loved, forever missed. As she wished, a private ceremony was held on Saturday, 16 August 2025.

I didn't know Elle personally, but I did speak to her a number of times on the phone and I found her to be such a lovely lady. She was looking after the New Plymouth group until she had to pass it on when she became sicker. She did enjoy meeting up with the ladies up there and she will be very sadly missed by all who knew her.

A gentle soul has gone to rest,
A life well-lived, a heart so blessed.
Through trials faced with quiet grace,
She left her light in every place.

Though scleroderma marked her days,
Her spirit shone in countless ways.
Now free from pain, her song takes flight,
A star now burning soft and bright.

We hold her memory, pure and true,
In every bloom, in skies of blue.
Her love remains, it does not part—
She lives forever in each heart.

Members Stories:

The second half of our European holiday… Jenny

I thought I would share a little bit more about our holiday as we had only just started it at the time of the last newsletter. I must say one of the highlights was definitely catching up with Jane and John Sainsbury, even if it was only for 10 minutes before we all had to leave. It was so fun seeing a familiar face all the way over in Germany.

Above - Cesky Kromlov

We had spent the day in Cesky Kromlov, Czech republic, so had started the day in Austria, travelled to Czech and then met back up with the boat and Jane in Passau in Germany. We visited lots of Burgs on our trip:

Bamburg

Below - Nuremburg

Regensburg, Nuremburg, Bamburg, Miltenburg and Warzburg. Such beautiful places.

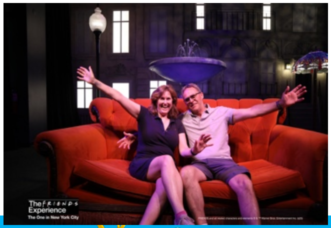
Miltenburg - below

We attended Opera, a couple of classical music concerts, we had musicians come aboard to play for us and then onto Cologne and Amsterdam. We had a small mishap on the boat where it was giving way to another boat going upstream and we scraped along the bottom of the river damaging the rudder. It was fixed in dry dock while they looked after us in Amsterdam. Jeff and I decided to do a biking excursion while in Amsterdam. Wow, I have never seen so many bikes in one place.

Us at Warzburg Residence

It wasn't the cars that you were worried about being run over by, but the bikes. There were about 17 of us that headed off on bikes. Went about 200 metres to then catch the ferry across the river, by that stage I had jelly legs. Oh my goodness I thought how am I going to do this.? Rested for 5 minutes on the ferry and I was freaking out, then we were off again. I lost the group in front of me, only Jeff and tail end Charlie behind me. Jeff kept telling me to keep up with the bunch, ah yes, that is what I was trying to do, lol. They stopped to look at a windmill and we were able to catch up. There were nearly tears but not quite. Luckily for me they did slow down enough that I didn't get left behind. It was very intense and we did about 18 kms. We left the city behind and got into the countryside, riding over dykes and past golf courses which looked more appealing than the bike, then she lead us to a wee gem of a church and through some gorgeous wee villages. One we stopped in and had a taste of the local Beef Bitterballen. Very nice indeed. Once we left the boat we met Scottish friends who came over to Amsterdam to meet us. So a very busy couple of days with them before Jeff and I spent the next 2 weeks on our own again and at our own pace of bedtime by 7.30pm and exploring all day. We travelled by train then and visited Rotterdam, Antwerp, Brussels, Ypres, Passchendaele and Luxembourg before making our way to Frankfurt to fly out to New York. We loved Netherlands and Luxembourg. Spent a day doing the World War I sites which was very sobering. Amazed at how close the Germans and Allies were to each other on a number of occasions. In New York we saw Harry Potter and Cursed Child on Broadway. Went to the top of the Rockefeller Centre. Watched a Pride Parade take over the bulk of the Manhattan streets, saw Statue of Liberty, visited the 911 memorial and went to the Friends Experience. It was fantastic. But we are pleased to be home safe.

In Flanders Fields Poem



Us in the opening scene of Friends Sitcom

Members Stories:

Heather Milligan on zips …

Heather shares her helpful hints on using zip pullers.

Zips that I use every day are problematic. I find my pincer grip is rubbish when trying to grip the zip puller that come on the garment as I find they are so hard to grasp.
There has to be an easier way!
I did find there are zip pullers, the best ones were from AliExpress, alas I could not find any New Zealand stockist.
They have been attached to many things and certainly make my life easier; as in the photos I have attached them to the chiller bags and jackets. The zips on jackets can be challenging when you are outdoors and getting cold, the zip pullers give me some extra leverage.
Heather Milligan

Betty's Sunflowers …

Sunflower seeds to give away.

In 2023 Betty Wilson planted sunflowers in her garden. Then she spent many an hour collecting the seeds and bagging them up to then give out to our members, schools for the children to grow and anyone else that wanted some sunflower seeds. Sadly then Betty passed away in October 2024. The seeds were even more special then. I planted 108 of them in my old potato patch. They grew beautifully and I planted them so they would be flowering at the time that would have been Betty's birthday. Sadly they did get a bit of a thrashing with torrential rain and gustily winds. But still made for a great show. I then collected the seeds and have bagged them up and have them for anyone who would like them. They are free but if you want some I would please just ask for the postage to get them to you. If you would like some of Betty's sunflower seeds please get in touch with me. At jennyred@xtra.co.nz or give me a call on 0273 166124.

Jenny

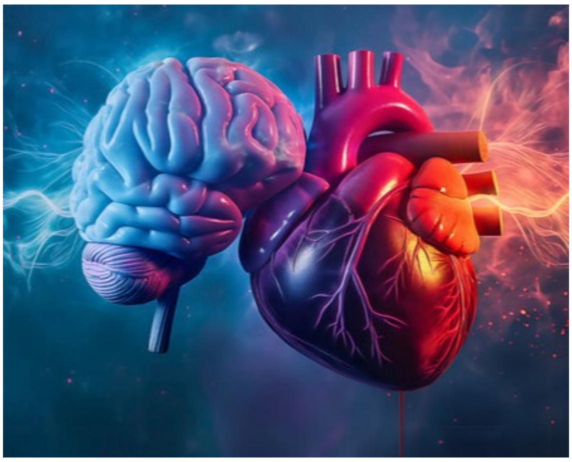
Members Stories

The life and times of Perry…

Are you in the game or are you watching from the sidelines…

Managing Your Emotions Can Save Your Heart

June 27, 2025 by Perry



We often think of the heart and brain as being completely separate from each other. After all, our heart and brain are located in different regions of our body, and cardiology and neurology are separate disciplines.

They are typically around 12-15 inches, or roughly 30-38 centimetres apart and are however in constant communication influencing each other through the autonomic nervous system and the vagus nerve.

This bidirectional communication, often referred to as the heart-brain connection, impacts not only our physical health, and cognitive function, but also our emotions, and overall well-being.

You see, these two organs are intimately connected, and when our emotions adversely affect our brain, our heart is affected as well. And many Scleroderma patients experience bouts of depression and struggle emotionally every day, with stress, anger, anxiety, worry, and problems with self-esteem.

Depression along with these strong emotions are caused by, among other things, challenging home and work routines, due to the toll that Scleroderma can take on one's body, unsupportive family and friends, and a lack of supportive social interaction.

There may well be a link between stress and scleroderma as "Physical and psychological stress has been implicated in the development of autoimmune disease." https://pubmed.ncbi.nlm.nih.gov/18190880/ "Chronic stress can make the immune system less effective at regulating itself, leading to misdirected attacks on healthy tissues." https://www.mysanitas.com/en/blog/link-between-stress-and-autoimmune-flare-ups

Stress is the body's response to any experience that causes tension, whether physical, psychological, or emotional. It is a survival mechanism that helps us react quickly in dangerous situations.

The thing is, there are two kinds of stress that impact our brain. Helpful stress (also known as eustress) can assist us with getting things done by helping us to focus our attention. Unhelpful stress (distress), on the other hand, can be so severe that it can lead to fatigue and heart disease.

Therefore it is important to control our worry and stress, not just because we'll worry less and feel better, but because less worry means less stress for our heart.

This applies to the entire range of stressors, from a small episode of acute panic to a larger context such as living through a natural disaster.

The majority of people generally adapt well over time to life-changing situations and stressful conditions.

But what enables them to do so? It involves resilience, an ongoing process that requires time and effort and engages people in taking a number of steps.

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems, serious health problems or workplace and financial stressors. It means "bouncing back" from difficult experiences.

Research has shown that resilience is ordinary, not extraordinary. People commonly demonstrate resilience. One example is the response of many Americans to the September 11, 2001 terrorist attacks and individuals' efforts to rebuild their lives.

Being resilient does not mean that a person doesn't experience difficulty or distress. Emotional pain and sadness are common in people who have suffered major adversity or trauma in their lives. In fact, the road to resilience is likely to involve considerable emotional distress.

Resilience is not a trait that people either have or do not have. It involves behaviours, thoughts and actions that can be learned and developed in anyone.

So, here are 10 Ways to help Build Resilience

1.Make connections.

Good relationships with close family members, friends or others are important. Accepting help and support from those who care about you and will listen to you strengthens resilience.

Some people find that being active in civic groups, faith-based organisations, or other local groups provides social support and can help with reclaiming hope. Assisting others in their time of need also can benefit the helper.

2. Avoid seeing crises as insurmountable problems.

You can't change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. Try looking beyond the present to how future circumstances may be a little better. Note any subtle ways in which you might already feel somewhat better as you deal with difficult situations.

3. Accept that change is a part of living.

Certain goals may no longer be attainable as a result of adverse situations. Accepting circumstances that cannot be changed can help you focus on circumstances that you can alter.

4. Move toward your goals.

Develop some realistic goals.

Do something regularly — even if it seems like a small accomplishment — that enables you to move toward your goals. Instead of focusing on tasks that seem unachievable, ask yourself, "What's one thing I know I can accomplish today that helps me move in the direction I want to go?"

5. Take decisive actions.

Act on adverse situations as much as you can. Take decisive actions, rather than detaching completely from problems and stresses and wishing they would just go away.

6. Look for opportunities for self-discovery.

People often learn something about themselves and may find that they have grown in some respect as a result of their struggle with loss. Many people who have experienced tragedies and hardship have reported better relationships, greater sense of strength even while feeling vulnerable, increased sense of self-worth, a more developed spirituality and heightened appreciation for life.

7. Nurture a positive view of yourself.

Developing confidence in your ability to solve problems and trusting your instincts helps build resilience.

8. Keep things in perspective.

Even when facing very painful events, try to consider the stressful situation in a broader context and keep a long-term perspective.

We need to avoid blowing the event out of proportion and remain positive.

9. Maintain a hopeful outlook.

An optimistic outlook enables you to expect that good things will happen in your life. Try visualizing what you want, rather than worrying about what you fear.

10. Take care of yourself.

Pay attention to your own needs and feelings. Engage in activities that you enjoy and find relaxing. Exercise regularly. Taking care of yourself helps to keep your mind and body primed to deal with situations that require resilience.

Additional ways of strengthening resilience may be helpful. For example, some people write about their deepest thoughts and feelings related to trauma or other stressful events in their life. Meditation and spiritual practices help some people build connections and restore hope.

The key is to identify ways that are likely to work well for you as part of your own personal strategy for fostering resilience.

Staying Flexible

Resilience involves maintaining flexibility and balance in your life as you deal with stressful circumstances and traumatic events.
This happens in several ways, including:

- Letting yourself experience strong emotions, and also realizing when you may need to avoid experiencing them at times in order to continue functioning.

- Stepping forward and taking action to deal with your problems and meet the demands of daily living, and also stepping back to rest and reenergize yourself.

- Spending time with loved ones to gain support and encouragement, and also nurturing yourself.

- Relying on others, and also relying on yourself.

Much of the above information came from an article entitled "Managing Your Emotions Can Save Your Heart" which appeared on the Harvard Health Blog, and excerpts from 'The Road to Resilience' by the American Psychological Association.
The American Psychological Association has a range of articles exploring resilience that you may also find helpful.

Blessings 'til next time 🙂

Medical Report

National
Scleroderma
Foundation

Stretching Exercises for the Hand and Face - by Janet Poole, Ph.D., OTR./L

What are the benefits of stretching for people living with scleroderma?

- In scleroderma, your body's collagen, part of the connective tissue of your skin and tendons, builds up. This causes your skin to tighten. Skin can't stretch easily over joints, so it's difficult to move them.
- Over time, your joints may stiffen up. Your skin feels tight. You may not be able to form a fist, straighten your fingers, bend your knees and elbows, or open your mouth wide enough to floss or brush your teeth. When you go to the dentist, it's hard for your hygienist to clean your teeth or examine your gums.
- You may have worse stiffness in certain joints in your arms and hands, leading to joint contracture, or loss of motion.
- Your large knuckles (metacarpophalangeal phalangeal or MCP joints) can be hard to bend or flex. (See Figure 1.)
- Smaller joints, like the proximal interphalangeal or PIP joints in Figure 1, can be hard to fully straighten.
- If you try to wrap your hand around a cup or glass, you may find it hard to bend your thumb or flex your thumb away from your hand.

Stretching Can Help: Daily range-of-motion stretches can prevent or slow down the loss of motion in your joints. You can do these exercises on your own at home or work to keep your joints from getting stiffer.

First, talk with your doctor. They can refer you to an occupational therapist (OT) or physical therapist (PT) who will show you how to properly do each stretch, give you a plan, monitor your progress, and answer any questions you have.

HELPFUL HINTS: STRETCHING/JOINT RANGE OF MOTION EXERCISES

- Get in the habit of doing stretching or range-of-motion exercises as early as possible, even before you notice reduced flexibility in your fingers.
- Warmth can relax tight tissues: paraffin wax baths for hands or feet (instructions at bottom of page), electric moist heating pad, microwaveable hot packs, warm showers or baths.
- Make sure you apply warm, moist heat for 15-20 minutes, but not hot! You could burn your skin.
- Do your range-of-motion exercises about two to three times each day.
- Stretch beyond the point where you feel some tightness and until you feel your muscle stretching.
- Once you feel your muscle relax, hold the stretch for about 5-10 seconds. You may feel

NAMES OF THE JOINTS IN THE FINGERS

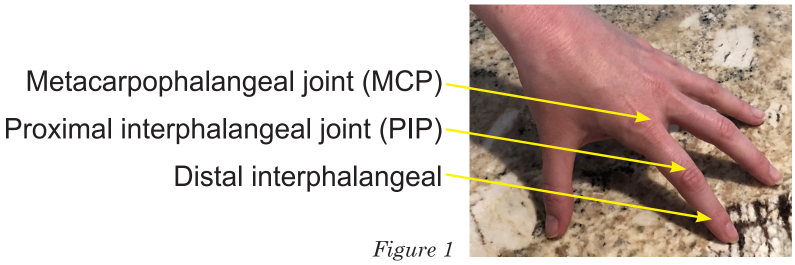


Figure 1

your skin and muscle stretching. Hold it even if your skin turns white.

- Remember to breathe during each stretch!
- Repeat each stretch 5 to 10 times for a “set.”

Stretching is helpful even if you have finger ulcers. Ulcers are very painful, so you may not be able to do as many repetitions. Stretching helps finger joints stay mobile while your ulcer heals.

Specific hand stretches:

Do each exercise 5 to 10 times, and hold to a count of 3 to 5 seconds.

EXERCISES FOR LARGE JOINTS ON YOUR FINGERS (MCP)

Exercise 1

Exercise 1 helps you bend large knuckle joints farther. Make a fist emphasizing flexion (bending) of the MCP joints. Use the palm of the other hand to press down on the back of the fingers close to the joint, as shown in the picture.

EXERCISES FOR BENDING ALL FINGER JOINTS

Exercise 2

Exercise 2 helps you bend and flex your middle and upper finger joints. Make a fist and try to touch the tips of all fingers to the palm of the hand. Use your other hand to push and try to bend the finger joints (see picture above).

EXERCISES TO STRAIGHTEN MIDDLE (PIP) FINGER JOINTS

If you can almost straighten the middle joints of your fingers, Exercises 3 and 4 are good choices for you.

Exercise 3

Exercise 3. Push your hand flat on a hard surface, like a table. Try to place the entire surface of your fingers and palm on the table. Use one palm to push down on the backs of your fingers.

Exercise 4

Exercise 4. Place both hands and fingers flat against each other in a “prayer” position. Try to place the insides (palm sides) of all fingers together, until they touch at the length of each finger.

If your fingers cannot straighten, or if the middle joint of one finger is bent more than the others, try Exercises 5 and 6 instead to stretch just one finger at a time.

Exercise 5

Exercise 5. Place your hand flat on the table. Use one thumb to press down on the back of the middle joint of one finger. Use your index finger to lift up underneath the tip of the finger, as shown in the picture, to try to straighten the middle joint. The finger you’re stretching may turn white. If this happens, repeat the stretch with another finger, and keep repeating the stretches until you have stretched all fingers. Then, start again with the first finger and keep repeating until you have done about 3 to 5 stretches with each finger.

Exercise 6

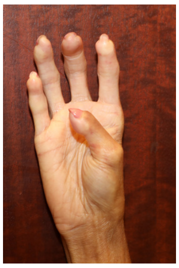
Exercise 6. Here’s another way to stretch your PIP joints. Use three points of pressure (see picture).
The first point of pressure is the pad (inside or palm side) of the index finger just above the joint. The second point of pressure is the pad of the third finger, on the palm side of the contracted finger below the PIP joint. The third point of pressure is the thumb against the back of the contracted PIP joint. Your thumb pushes against the joint, while your index and middle fingers apply counter-pressure to attempt to

straighten your joint. Repeat until you have done 3 to 5 stretches per finger.

THUMB EXERCISES

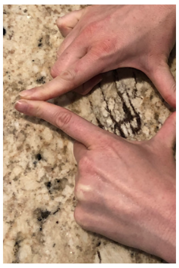
In some people, the space between the thumb and index finger, or webspace, becomes tight. This makes it hard to grasp a glass or other large objects. Try Exercises 7 and 8 to stretch your webspace and make it more flexible. Do each exercise 5 to 10 times.

Exercise 7. Try to bend your thumb so the tip touches the bottom of your little finger. Hold for 3 to 5 seconds. If the tip of your thumb cannot reach that far, keeping up with this stretch may help you reach that goal in time.



Exercise 7

Exercise 8. Place the pads of the thumb and index fingers of both hands together and push the thumbs away from your index fingers. Hold for 3 to 5 seconds.



Exercise 8

Exercise 9. Here's another way to stretch the webspace: Find a large, round object like a water bottle, tumbler, or soda can. Fit it snugly in the webspace of your hand. If there is a gap, the object is too big. Try a smaller object. Hold for 3 to 5 seconds, and do each stretch 5 to 10 times. If you keep up these stretches, your webspace may become flexible enough to switch to a larger cup or bottle.

Exercise 9

EXERCISES TO STRETCH THE SPACE BETWEEN YOUR FINGERS

You also have webspaces between your fingers, and these can tighten in people living with scleroderma. Exercises 10 and 11 can stretch these spaces to make it easier to use a computer keyboard, play the piano, or put on gloves.

Exercise 10

Exercise 10. Interlace your fingers. Try to slide the fingers all the way down so that the webspaces are touching, like in the picture. Hold for 3 to 5 seconds.

Exercise 11. Place the top of a water bottle between two of your fingers. Slide it down as far as the bottle will go. Hold for 5 to 10 seconds. Then, slide the bottle in between the next two fingers and repeat.

Exercise 11

WRIST EXERCISES

Exercise 12 can help you straighten your wrist. Turn one hand so your palm is facing up. Then, straighten your wrist so the fingers point down to the floor. Take your other hand and try to push on the palm to get the wrist to straighten more. Hold for 3 to 5 seconds. Repeat. Then stretch your other wrist.

Exercise 12

Exercise 13 increases the motion to bend your wrist. Turn one hand so the palm is facing down. Bend your wrist so your fingers point down to the floor. Use the other hand to push, very gently, on the back of the hand for 3 to 5 seconds. Don't force it, or push hard or for very long. Repeat with the other wrist.

Exercise 13

FACE & MOUTH EXERCISES

Scleroderma's skin tightening can decrease your ability to open your mouth. Stretching can help you improve flexibility for facial expressions and oral care.

Exercises 14-17 stretch the skin on your face. They look like exaggerated facial movements. Do these exercises in the shower, so warm water relaxes your skin. Hold each stretch for 3 to 5 seconds, and do each one 5 to 10 times.


Exercise 14

Exercise 14. Pucker up your lips like you're kissing or blowing out a candle. Hold the pucker. Count to 5, then relax and repeat.


Exercise 15

Exercise 15. Puff out your cheeks with air and hold. Count to 5, relax and repeat.


Exercise 16

Exercise 16. Smile! Give yourself a cheesy smile in the mirror. Show off all your teeth. Hold and count to 5, relax and repeat.


Exercise 17

Exercise 17. Open your mouth as wide as you can and hold. Count to 5, relax and repeat.


Exercise 18

Exercise 18. You can also use your fingers to manually stretch your mouth. Place your right thumb in the corner of the left side of your mouth, and your left thumb in the other corner of your mouth. Stretch your mouth with your the thumbs. Hold for 5 seconds, relax and repeat.

Exercise 19. Oral augmentation exercises use tongue depressors. Insert the depressors between the teeth from the left premolar area to the right molar region. Hold for several seconds. You can add more tongue depressors as your range of motion increases.


Exercise 19

INSTRUCTIONS FOR PARAFFIN WAX

Paraffin wax baths provide warm, moist, soothing heat to stiff joints. Paraffin units can be purchased from pharmacies, discount stores, beauty supply stores, or online retailers.

What you'll need:

- Paraffin wax unit
- Plastic wrap or bags
- Soft, terrycloth towels

Preparation:

- After you have followed the manufacturer's instructions to melt the paraffin, insert the thermometer; the temperature should read 125/126 degrees F.
- If it is too hot, turn temperature down to LOW and test again with thermometer.
- When temperature is 125-126 degree F, you're ready.

Treatment:

- Roll up shirt sleeves, remove all jewelry, wash & dry hands.
- Spread your fingers apart, and slowly put your hands in the wax.
- DO NOT TOUCH THE SIDES OR BOTTOM OF THE PARAFFIN UNIT.
- Gently remove your hand.
- Count to 5, and then dip hand back in the wax. Repeat 5 times.
- After you remove your hands, cover them with plastic bags, then wrap in a towel.
- Wait 20 minutes.
- Remove towels.
- Remove plastic bags and toss them out.
- Peel the paraffin wax from your hands. You can return used paraffin to the unit so it melts for future uses.
- TURN OFF UNIT.
- Do hand exercises while your hands are still warm.

NOTE: DO NOT use paraffin if you have open wounds or cuts on your hands. If you forget, call your health professional. Change the wax in the unit when it starts to look dirty or no longer white. Dump old wax, clean the unit, and put in new wax.

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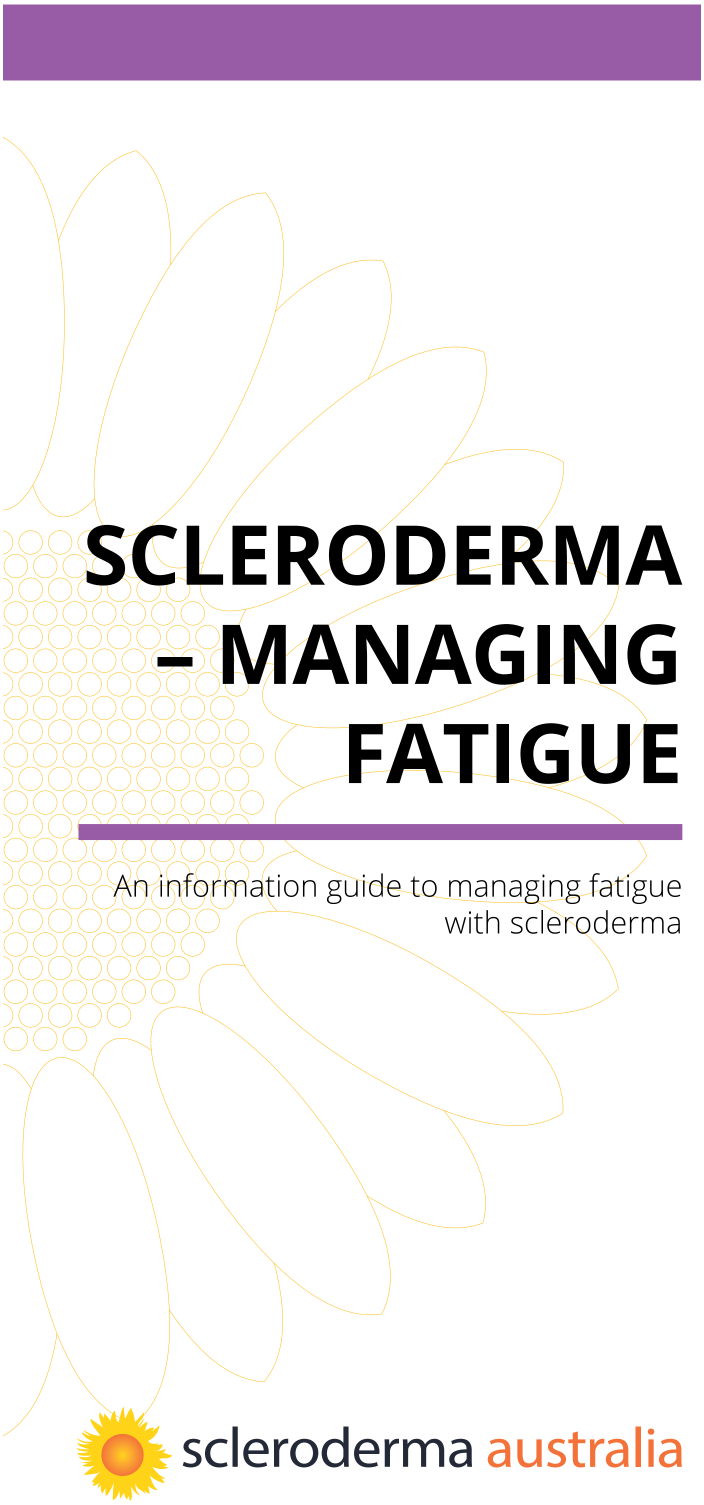
scleroderma australia



SCLERODERMA – MANAGING FATIGUE

An information guide to managing fatigue with scleroderma

scleroderma australia

What is fatigue?

People describe fatigue as feeling tired, mentally exhausted, or physically overwhelmed day after day, no matter how much sleep they've had or what they've been doing, even if it's just everyday tasks.

Fatigue is a common challenge for people living with chronic conditions, including scleroderma. In fact, people with scleroderma in clinical studies have listed fatigue as one of the top 3 symptoms that bother them.

With 9 out of 10 scleroderma people rating their fatigue as moderate or higher, and almost half experiencing 'severe fatigue', it is a concerning symptom that isn't talked about enough – especially given how much it can impact daily life and wellbeing.

Why do people with scleroderma get fatigued?

It's important to recognise that experiencing chronic fatigue is not the same as simply "feeling tired", something which may be hard to appreciate for someone who does not live with a chronic condition.

For people with scleroderma, unmanaged fatigue can be a disabling symptom and is known to be a key factor affecting quality of life, as well as being related to other symptoms, such as pain, joint and pulmonary (lung) involvement, and disability.

Additionally, there are different types of fatigue that can affect people with scleroderma, which feel different from one another, but can all be described as fatigue, such as:

- **'Needing sleep',** which can be due to medication side effects, sleep deprivation from pain or poor sleep quality
- '**Reduced energy**' as a result of the effects of disease, malnutrition, or the emotional impact of living with scleroderma
- '**Reduced exercise capacity**' or feeling out of breath, which can be caused by the physical effects of scleroderma, such as heart or lung involvement through pulmonary arterial hypertension (PAH), or muscle weakness

Do people experience fatigue all the time?

People who experience fatigue don’t necessarily have it all the time. Symptoms of fatigue can come and go in cycles over the course of days or weeks and some people may describe having ‘good days’ and ‘bad days’. Unfortunately, what often happens is that someone will have a good day and use it as an opportunity to do lots of things they have been wanting to do for a while, or ‘doing too much’, leading to more pain and fatigue the next day, or ‘a bad day’.

When to talk to your doctor

Fatigue can be caused by many things, but if you suddenly notice that you are more fatigued than usual or have a change in your energy levels, make an appointment with your doctor.

Although most of the time, fatigue can be managed by things you can do yourself, there are instances where you should talk to your doctor about how you’re affected incase it’s due to something other than your scleroderma.

Lung involvement, mainly pulmonary arterial hypertension (PAH), is the most severe condition associated with fatigue. The symptoms of PAH can be vague, but if you start feeling more and more like you’re becoming short of breath, fatigued and faint or dizzy, you should talk to your doctor about being checked for PAH.

Active skin disease, gastrointestinal involvement, diarrhoea and abdominal pain can also contribute to fatigue, as can mental health problems such as anxiety and depression – even the medication you take may have an impact on fatigue.

This is why it’s so important to stay in close contact with your healthcare team and let them know if you have been feeling unusually tired for a long period, and in some instances, they may recommend specific treatments that can help.

Make an appointment to see your doctor if you are concerned about fatigue.

Tackling fatigue and energy levels

Breaking this cycle to give yourself more energy throughout the day and being able to better manage your daily activities is important, as it will allow you to take control of your fatigue and minimise its negative impacts.

Some positive steps you can take include:

- Practising healthy sleep habits
- Pacing your day and taking breaks
- Exercising and ensuring healthy nutrition
- Managing stress in your life.

Tips for better sleep

Healthy sleep habits, also called good ‘sleep hygiene’, include things you can do to help yourself get better and more consistent sleep. While you cannot make yourself sleep, you can increase your chances of a good night’s rest.

Time: try to be consistent with when you go to bed and when you wake up.

Light: having a dark room to sleep in is important, but so is getting some daylight to regulate your body clock. Try and be out or near a window during the day to get some light and avoid wearing sunglasses all day. It’s also important to stop looking at screens and devices an hour before going to bed.

Sound: if you’re easily disturbed, try sleeping with earplugs. Alternatively, many people find ‘white noise’ comforting and helpful when going to sleep. You can buy dedicated white noise machines or just use an app on your phone.

Caffeine: a bit of coffee or tea is great in the morning, but caffeine is best avoided after lunch. Watch out for hidden sources of caffeine, such as green tea, herbal teas based around black tea, soft drinks and sports nutrition.

Alcohol: although it may help you get to sleep, alcohol can cause you to have poor sleep.

A word on napping…

Napping during the day is ok, but you should try to limit sleeping to 45 minutes or less and avoid doing it in the late afternoon or evening, as this can affect your sleep rhythm and may reduce your ability to sleep well at night.

Adobe Stock | #229161678

Pacing your day

Pacing is relevant not only when you are experiencing fatigue, but also when you feel like you have plenty of energy. It's important that you plan your day so that you don't cram too much into it, spreading your tasks evenly throughout the day to include time to rest. Also, when it comes to strenuous tasks, make sure to seek help where necessary.

Like with any task management, break up bigger tasks into smaller more achievable tasks. Ticking lots of little things off your list will give you more of a positive boost than slogging away at one big task and perhaps not finishing it in a day.

It's also a good idea to do the hardest activities in the morning so you can ensure enough time for rest, and always stop before you become fatigued.

Exercising

It is well known that exercise, even when relatively light, can increase energy levels and reduce fatigue. There are many benefits to exercise for people living with scleroderma, such as increased cardiovascular fitness, overall wellbeing, strength and flexibility, and even improved sleep. For example, Tai Chi has been shown to have a positive effect on endurance, balance, sleep quality, anxiety, depression and fatigue in people with systemic sclerosis, and has been recommended in rehabilitation programs as a result.

Although the value of exercise can't be understated, it's important to talk with your doctor, a physiotherapist or personal trainer before you start any exercise to make sure you avoid injury.

The right food

Nutrition is an important consideration when it comes to fatigue since the food you eat is what fuels your body, but for people with scleroderma, there are also other factors to consider. People living with scleroderma may be at risk of weight loss due to chronic inflammation, bowel involvement and malabsorption caused by their condition, so it's important to always keep your doctor informed of any changes to your diet, even if you are making them for positive reasons.

It's important to ensure that you are getting enough protein, carbohydrates, and fats, as well as fruits and vegetables. If you experience malabsorption, it may be necessary to add supplements to your diet as well.

You can read more tips about managing nutrition and scleroderma in our dedicated brochure, here: https://www.sclerodermaaustralia.com.au/resources/. Alternatively, you may find it helpful to talk to a dietician about personalised nutritional counselling.

Some useful tips on reducing fatigue with your diet include:

- Drink plenty of water – being mildly dehydrated can make you feel fatigued.
- Reduce or eliminate caffeine – try to cut out tea and coffee for a month to see how you feel.
- Don't skip meals – especially breakfast; you don't want your sugar levels to dip.
- Eat healthily – increase your fruit, vegetable, wholegrain, low-fat dairy, and lean meat consumption; reduce high-fat, high-sugar and high-salt foods.
- Keep meals small – large meals take energy to break down. Keeping meals small and frequent will spread your energy intake more evenly.
- Supplement where needed – consult your doctor about any supplements you may need.

Staying stress-free

Stress can be a major influencing factor leading to fatigue. It uses up a lot of energy and can take you into a negative cycle where you become stressed because you're fatigued and then more fatigued due to the stress! There are many ways to help limit or reduce stress, including exercise, meditation, listening to music, reading or socialising with friends.

Where you can, try to limit the number of things in your life that cause you stress and instead make more time for activities and situations that you find relaxing. There is a lot of pressure in modern life to drive ourselves to bigger and better heights 24/7, but it's actually ok to just do nothing sometimes. Don't worry about it – just sit back, relax and hang out.

Talking about things with friends, a counsellor or a psychologist might help to reduce stress and fight fatigue. See your doctor about a referral for 'talking' treatment.

Getting support with fatigue

Your doctor is generally the best person to contact for support with fighting fatigue; however, there are also other places to turn to if you need help with specific strategies for fighting fatigue.

- The Sleep Health Foundation is Australia's leading advocate for healthy sleep. They offer resources, fact sheets and help with getting better sleep and fighting fatigue. Visit their website at: https://www.sleephealthfoundation.org.au
- Headspace is a mobile app on Android and Apple iOS that provides guided meditation and mindfulness techniques, which can help to manage anxiety and stress: https://www.headspace.com
- Scleroderma Australia are a national association dedicated to helping people with scleroderma in Australia: https://www.sclerodermaaustralia.com.au
- Friends and family – never underestimate the support that can be provided by those closest to you, whether physical or emotional, healthy relationships go a long way to improving happiness and energy levels.

References: 1. Richards HL, Herrick AL, Griffin K et al 2003 Systemic sclerosis: patients' perceptions of their condition. Arthritis Rheum. 2. Yacoub Y, Amine B, Bensabbah R, Hajjai-Hassouni N. 2012 Assessment of fatigue and its relationships with disease related parameters in patients with systemic sclerosis. Clin Rheumatol. 3. Overman CL, Kool MB, Da Silva JA, Geenra R. 2016. The prevalence of severe fatigue in rheumatic diseases: an international study. Clin Rheumatol. 4. Basta F et al. Fatigue in systemic sclerosis: a systematic review. Clin Exp Rheumatol. 2017;36 Suppl 113(4):150–160. 5. Ferry O et al. Diagnostic approach to chronic dyspnoea in adults. J Thorac Dis. 2019;11(Suppl 17):S2117–S2128. 6. Cetin SY et al. Investigation of the effectiveness of Tai Chi exercise program in patients with scleroderma: A randomized controlled study. Complement Ther Clin Pract. 2020 Aug;40:101181. 7. Burlui AM et al. Diet in scleroderma: is there a need for intervention? Diagnostics (Basel). 2021 Nov 15;11(11):2118. 8. Fatigue Fighting Tips. Better Health Victoria. Victoria State Government Department of Health. Available from: https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/ fatiguefighting-tips. Accessed April 2022.

https://www.sclerodermaaustralia**.com.au/**

Waikato Team Sharing for Seminar…

Susil's beautiful blanket.

In July this year after maybe two and a half - three months our very own Susil (pronounced Sue-seal) Pereiri completed a NZ creation of a blanket in black, red and white. Traditionally the black for the unknown All the sacredness practices and knowledge of forefathers, lineage, links to lunar space, to our natural world and how to live in harmony. The white for the purity of human nature, vulnerability, the humanity, the spirituality of oneself in connection with elements of air, water and earth. Finally the red blood ties that connect our living bodies to family links from the four winds.

This was an initiative that Susil did of her own accord to fundraise for Waikato Seminar in October. She then advertised and listed the blanket as a raffle.
From start to finish drawing the winning tickets online a very kind and generous contribution.

It is one of a few contributions our team has gratuitously provided, especially for the Seminar. As a Waikato group the meetings monthly to progress on organizing as a group, has been what has made us motivated to build rapport and genuine friendships with our condition. Definitely a positive for having Scleroderma.

Thank you Susil, thank you team.

Ngà mihi
Mahana
Erena

Spring Poem..

"Spring Knows Our Name"

When winter winds have had their say,
And shadows stretch at end of day,
A softer voice begins to sing—
The gentle, healing breath of spring.

She paints the sky in brighter hues,
And warms the world with morning dews.
The crocus dares to rise again,
A promise blooming after pain.

For those whose days feel stiff and slow,
Where skin and joints forget to flow,
Spring whispers not of what is gone,
But all the strength to carry on.

Each petal, tender in the breeze,
Each dancing leaf upon the trees,
Reminds the soul it still can feel—
That beauty walks beside the real.

Though hands may ache and feet may tire,
The heart still holds a quiet fire.
And in the sun's forgiving light,
We find the will, we find the fight.

Let laughter bloom like daffodils,
Let hope run wild in greening hills.
Though Scleroderma marks the way,
It does not steal the gift of day.

So here's to spring—her boundless grace,
The smile she brings to every face.
She does not cure, but she can mend—
A season, like a faithful friend.

Scleroderma Seminar 2025 A holistic View

Date: 18 October 2025, 9am-3pm
Venue: Te Awamutu Bible Chapel Seminar room
110 Chapel Drive, Te Awamutu

We are excited to have speakers knowledgeable in their field of:
Rheumatology
Gastroenterologist - Melissa Haines
Nutritionist - Delwyn Mackenzie
Hand Therapist - Brittany Vincent
Alison Storey - Personal Trainer of the Year
Vibroacoustic Therapy - Karen Moratti

$30 registration
Payable to :
38-9017-0107454-00
Scleroderma new Zealand Incorporated
please include your name and the reference 'seminar'
Email Janine at: jobrearley12@gmail.com to let her know you have paid.

Seminar news from the Waikato Team:

Kia ora tatou,

Event: Scleroderma Seminar 2025 – A holistic View.
Date: **18th October 2025**
Venue: **Te Awamutu Bible Chapel, Chapel Drive Te Awamutu**

Registration: **$30.00**
Start Time: **9am registrations**
End Time: **3.30pm**

Friends and Family are welcome to attend the seminar.

Spring

It is the Spring time here and we have a real mix of weather cool mornings and evenings. Nice and warm during the day when wind is absent. The beautiful pink Tree blossoms are out and they line the streets, the town of Te Awamutu known for its roses (called Town of Roses) and of course the paddocks of daffodils are obvious it is also the season of pollen.

Raffles Raffles Raffles

A big massive Thank You to Helene Sunitsch, for her cosy merino ear muff raffle donation. This is much appreciated. We have talented crafts persons in our midst who have donated blankets as well.
Ideally, if people could support raffles cash is easier.

Accommodation

We have hosts here in Cambridge and te Awamutu that would be happy to accommodate those who are travelling long distances. Please make contact with me Erena 0211869680 .
Campers and Motor homes are able to stay on site. We ask that hey vacate Sunday morning early.

Transfers

If folk are flying and require transfers to accommodation again please advise and we have drivers available.

Dietary Requirements

If certain foods are required please advise Janine when you register online, we are able to plan ahead.

Janine Brearley

In closing I would like to thank Jenny Andrews in advance for making the trip up from Invercargill. Also Tina Mclean for attending, bringing her family to make the most of another adventure here in the Waikato.

If you have questions or queries, please email and our ladies will discuss.

Ngaa mihi maioha thank you with sincere regards, **Linda, Erena, Jill, Lea, Maree, Susil, Rachel Janine, Katie, Paula**

PROPOSED TIMETABLE

8.10am	Arrive - Register
9am - 10ish	Welcome & Rheumatology speaker/s
10.10 - 10.30 am	Karen Moratti - Vibroacoustic Therapy
10.30am	Morning Tea
10.50am - 11.50am	Delwyn Mackenzie - Nutritionist
12 noon	LUNCH
1pm - 1.45pm	Mellissa Haines - Gastrologist
1. 50 - 2.15pm	Brittany Vincient - Hand Therapist
2.20 - 2.45pm	Alison Storey - Personal Trainer of the Year
2.50pm to close	Cake

Members Update:

Podiatrists and Fingernail cutting

Please see below a list of Podiatrists who also work with our finger nails.

Jessica Dobbs Podiatry, Hamilton
Clinic is a Hamilton based Podiatry clinic in Flagstaff, Hamilton and also specialize in mobile podiatry across the Waikato.
Our Podiatrist are trained in fingernail cutting and are happy to assist your members
2 Endeavour Avenue, Flagstaff, Hamilton 3210.
Mobile: 0274 242 442

Dr Althea Page-Carruth, Central Otago
Dr Carruth does this only as part of general foot care.
To get in touch with her, her contact details are:
Mobile: 020 41785262
Clinics are in Cromwell and Alexandra

Elaine Yelland, Kapiti Coast
Podiatrist & Business Owner
Foot Focus Podiatry Ltd, Kapiti Coast
Mobile: 021 578 601

Saf Kear, Tauranga
Write: hello@thegoodpodiatrist.co.nz
Phone: (07) 219 7811, Mobile: 021 121 0435

Simon Speight, Auckland
www.speightspodiatry.co.nz
https://www.facebook.com/Speights-Podiatry
https://www.instagram.com/speightspodiatry
2nd floor, 43 High Street, Auckland Central
Phone: (09) 306 4006, Mobile: 021-535511

Greig Price, Home Visits from Takaka to Blenheim
Email info@mobilepod.nz
Mobile: 022 419 0205

Catie Rowe Podiatry, Timaru
17 Dee St, Seaview, Timaru
Phone: (03) 683-1448, Mobile: 027 6882036

Give a little: Scleroderma NZ Inc.

From Scleroderma New Zealand Incorporated - Givealittle

Scleroderma New Zealand Incorporated

Scleroderma NZ is a national support group which helps patients and their families to cope with this rare and difficult disease.

An example of what our give a little website page is shown below:
Scleroderma New Zealand Incorporated - Givealittle

Our give a little URL link address is shown below: -
https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPHtXV7UFf9KIAnAzM

If you are donating or you are circulating the givealittle link, please make sure you use the above address link, thank you.

Many General Practitioners have not had experience with this disease and Scleroderma NZ aims to help promote knowledge among our medical professionals and patients, by supplying them with educational booklets and hospital checklists for special requirements.

Events Happening:

Our next Scleroderma Zoom meeting:

Dear Members,

All welcome to the next online Scleroderma NZ support group meeting on the **6th** of **December** at **1.30pm**

A great opportunity to have a great catch up and to share with our Scleroderma friends.

Zoom meeting details:

Date: **Saturday December 6,** 2025
Time: **01:30 PM** Auckland, Wellington

Join from PC, Mac, iOS or Android:
https://otago.zoom.us/j/96432664870?pwd=Mvf7CpNxkjmqKod5fV7GoiC95sb81v.1
Meeting ID: **964 3266 4870**
Password: **712759**
Look forward to seeing you then. **Perry Bray**

Online Scleroderma Support Group Meeting
Saturday 6 December
@ 1:30pm
Check the Scleroderma Website
or Facebook page for the Zoom link

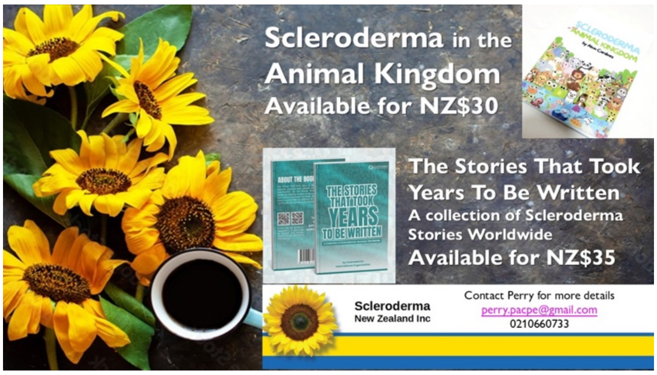
Scleroderma
New Zealand Inc
https://scleroderma.org.nz/
https://www.facebook.com/SclerodermaNewZealand

Thank you so much to Perry for organising the Scleroderma Support Zoom meeting on Saturday 30th August. There were 10 of us in total, from Auckland down to Southland attending.
It was indeed a very constructive and valuable hour and a half. The participants frankness and sincerity in how they are dealing with Scleroderma was so much appreciated.
I am still learning through these discussions, such as something so simple as there is such an ointment as Urea cream ! (is a non-greasy emollient or moisturiser . Always consult a doctor or pharmacist to determine if urea cream is an appropriate treatment for your specific case of scleroderma and to discuss proper usage and potential side effects.). Being rural I thought urea was a grass fertiliser!!!!
Looking forward to the next Zoom meeting.

Heather Milligan

Perry Bray has been in communication with Alvin Cardinez, a young man from the Philippines who wrote a children's book Scleroderma in the Animal Kingdom. Perry is hoping to source some to have them available at the seminar in Te Awamutu in October.

Thanks Perry, looking forward to having a read.



Scleroderma in the Animal Kingdom
Available for NZ$30

The Stories That Took Years To Be Written
A collection of Scleroderma Stories Worldwide
Available for NZ$35

Scleroderma
New Zealand Inc
Contact Perry for more details
perry.pacpe@gmail.com
0210660733

Auckland Scleroderma coffee group:

It's been suggested that I should explain how you can find our small coffee group at Daily Bread, the Kings Garden Café in Takapuna. We always try to sit at the first outdoor (but covered) long table. We spread these badges, booklets and crocheted sunflowers over the table. I've also popped in a photo of me – for recognition purpose.

Our next Auckland coffee group is:-

Date: **Monday, 22nd September** at **10.00am**
Venue: **Daily Bread Cafe,** Kings Plant Barn, 11 Porana Road, Takapuna 0627, **Auckland**

Do come. Brings friends and family. We're a small friendly group. Contact: **Helen Parsons**
HelenParsons@artcardsandposters.co.nz
Mobile: **021 248 3869**

Members News

Hawkes Bay Scleroderma Group

We had a get-together in June. Natania asked us all to talk about our families as we usually talk about ourselves. She wanted a rounded picture of us. It was a lovely meeting. Lorraine put together some advertising material to put by our table. Our July meeting was quieter with several members having other commitments.

Auckland Scleroderma Group

Our July meeting was rather fun because two of the people attending found that they had a family link. And another two people found they had a work link. So unexpected. And many stories were told.

We are becoming a regular meetup for our small group.

Helen Parsons
helenparsons@artcardsandposters.co.nz
021 248 3869

Helen Parsons, Kelly Donnelly, Fadi Kayed, Liz George, Mary Daniel

From left:-Mary Daniels, Kelly Donnelly, Nicole Bos

Peter Bos and Roger Parsons

Bay of Plenty Scleroderma Group

The Bay of Plenty Group continue to meet up so if you would like to join them get in touch with Alumie Nguyen: alumie.uow@gmail.com

Members News continued...

Southland Scleroderma Group

We had our Southland Scleroderma lunch on Sunday 17th August.

It was great to catch up with the other 18 attending and to see how we got through the winter. Three of us had the giggles when we ordered from the "kids menu', as our scleroderma appetites are almost nil, and then supping water with our meals to help the food go down!!!, Scleroderma is hard work.

Thank you so much Jenny for your kindness and thoughtfulness in organizing these occasions for us. It does feel we are part of a rather unique group of people in which we are supporting and learning from each other.

Looking forward already to our lunch at the end of November.

Heather

Wellington / Kapiti and Wairarapa Scleroderma Group

The Wellington / Kapiti and Wairarapa support group meet in Greytown recently. They were having such a good time and great food that they completely forgot about taking a photo. Maybe next time ☺ If you would like to join in with the group get in touch with **Cushla Marsters:** cushlam@outlook.com

New Plymouth Scleroderma Group

Sadly we lost our wonderful member Elle Bray. Elle was such a lovely lady. The New Plymouth group met recently for a chat and friendship. If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell:** **kelsitidswell@gmail.com**

Otago Scleroderma Group

We had a lovely morning tea at the Village Green in Dunedin. A small group but a wonderful discussion on all things Scleroderma and the odd sneak off to see what was happening with the All Blacks game. Thank you Murray for keeping Quinn occupied with the golf chat. If you would like to join in with the Otago group please contact **Gaynor:** gaymeddings@gmail.com

Murray and Lorna Elliot, Gaynor and Rowan Meddings and myself and Quinn

Members News continued…

Christchurch Scleroderma Group

The Christchurch group had a lovely meet up at our midwinter lunch. Very enjoyable lunch with 8 of us including new member Hannah. Was nice to see how everyone enveloped her with support.
If you would like to attend the Christchurch Support Group please get in contact with **Nicky Moore:** nicky.moore@xtra.co.nz

Palmerston North Scleroderma Group

The Palmerston North group had their lunch on the **9th of August** at the **Palmerston North Golf Club.** It was a cold day but lovely to meet up with new friends.
If you would like to join the Palmerston North group please get in contact with **Dianne Purdie**: diannepurdie@xtra.co.nz Phone: **04 4795548**

Waipa and Waikato Scleroderma Group

This wonderful group are flat out organising the seminar for us in October. See pages 16,17 and 18.

Waipa, Hamilton, Putaruru, Morrinsville,
Please contact **Erena Bruce** if you wish to join them. bruceerena@gmail.com

The Waikato welcomes those attending the Scleroderma Seminar 2025. Our small group of volunteers of (group photo Erena Bruce, Maree Meredith, Shirley Maclean, Leah Hunt, Jill Davies). Absent Pauline & John Groenedaal, Linda Bell, Katie Leeve.

Northland/Auckland Scleroderma Group

Lisa Cato and Helen Parsons decided to have coffee together. But notified the various Scleroderma groups so that others could join too. We met at Silverdale. Midway between our respective homes. Forty-five minutes north of Auckland central.
Here are Kelly Donnelly, one of our Auckland stalwarts. Kathy McEwan, who is now living just north of Auckland. She has returned to New Zealand after living in Canada more recently. Then Daphne Hiett, whom we met about a year ago. Great to see you here. Then Lisa Cato, very recently returned from Queensland. So she's having to change medical systems. And to choose new doctors.
And on the very right hand side is Anthony Hiett, Daphne's husband.
We had a long, very warm, friendly, and informative catchup.

Group Meeting Dates 2025: Regional

Wellington/Kapiti/Wairarapa support group meets:

We welcome any new members to come along. If you would like to join us, please contact:

Cushla Marsters:	cushlam@outlook.com
Tina McLean:	tinaoaisamclean@outlook.com
Fiona Yaxley:	fiona.gilloch@xtra.co.nz

Date and Time:	Venue:
Sat 20th September **@ 12:30pm**	**Chocolate Fish Café** 100 Shelly Bay Road, **Miramar**
Sat 22nd November **@ 12:30pm**	**The Farm Café & Bar** 33 Military Road, Boulcott, **Lower Hutt**

Palmerston North support group:

We welcome any new members to come along. If you would like to join us, please contact Dianne Purdie:
diannepurdie@xtra.co.nz **Phone: 04 4795548**

Date and Time:	Venue:
Saturday 8th November **@ 11:30am**	**Esplanade Cafe** 1 Palm Drive, **Palmerston North**

Christchurch support group meets:

We welcome any new members to come along.
Please contact **Nicky Moore** if you would like to join in:
nicky.moore@xtra.co.nz **Phone: 021 110 6123**

Date and Time	Venue
Saturday 20 September **@ 2.00 - 4.00pm**	**Urban Eatery Café,** Oderings, **Cashmere**
Tuesday 25 November **@ 2.00 - 4.00pm**	**Travis Courtyard Café** **Burwood Hospital**

Waimate/Oamaru support group:

We have members meeting up in these areas so if you are interested in joining them please get in touch with **Helene Sunitsch** at: hkjsunitsch@gmail.com

Bay of Plenty support group meets:

Come join us for more informative discussions and good company! Can't wait to see you there!
Please contact one of us for information.

Jane: janepuckey99@gmail.com
Mary: marybestrd3@gmail.com
Alumie: alumie.uow@gmail.com

Otago support group:

Please contact **Gaynor** if you wish to join us.
gaymeddings@gmail.com

Date and Time	Venue
Sunday 26th October **@ 11:00am**	**Village Green,** **Dunedin**

Auckland support group meets:

We welcome any new members to come along. Also, do contact me if you would us to meet at another time, day, or place. Please contact **Helen Parsons:**
HelenParsons@artcardsandposters.co.nz
021 248 3869

Date and Time:	Venue:
Monday 22nd September **@ 10.00am**	**Daily Bread, Kings Plant Barn** 11 Porana Road, Takapuna, **Auckland**
Monday 27th October **@ 10.00am**	**Daily Bread, Kings Plant Barn** 11 Porana Road, Takapuna, **Auckland**

Waikato/Waipa support group meets:

If you would like to join in with the Waikato/Waipa Group, please contact: -
Erena Bruce, Mobile: **021 186 9680**

Date and Time:	Venue:
Saturday 27th September **@ 1:00pm**	**Robert Harris** 39 Arawata Street, **Te Awamutu**

New Plymouth support group:

If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell: -**
kelsitidswell@gmail.com

Date and Time:	Venue:
Saturday 6th September **@ 11:00am**	**Locals Café** 11 Wallath Road, Westown, **New Plymouth**

Hawkes Bay support group meets:

If you would like to join in with the Hawkes Bay Group, please get in touch with Gail.
Gail Neilson: gail_neilson@hotmail.com

Date and Time:	Venue:
Third Saturday of the month **@ 11:30am**	**Serendipity Cafe** Pakowhai Road, **Hastings**

Southland support group meets:

Please contact **Heather** if you wish to join us.
milliganseeds@xtra.co.nz

Date and Time	Venue
Sunday 30th November **@ 12:00pm**	**Croydon Lodge** 100 Waimea Street, **Gore**

Welcome to Scleroderma New Zealand Inc.

To all our new members, who have recently joined us – Welcome….

Scleroderma New Zealand Inc. is for people with scleroderma and their families and friends. As there are not too many of us, we would like to be able to provide support, friendship, exchange of ideas & information.

Link to our **Website** address below: -

http://scleroderma.org.nz/

Link to our **Scleroderma NZ Facebook** page: -
https://www.facebook.com/SclerodermaNewZealand/

Link to our **Auckland Facebook** page: -
https://www.facebook.com/groups/sclero.akl/

Scleroderma New Zealand

President:	**Jenny Andrews** jennyred@xtra.co.nz
Vice President:	**Tina McLean** tinaoaisamclean@outlook.com
Secretary:	**Jane Sainsbury** jsainsbury@xtra.co.nz
Treasurer:	**Gordon Purdie** gordon.purdie@xtra.co.nz
Newsletter:	**Tina McLean** tinaoaisamclean@outlook.com **Jenny Andrews** jennyred@xtra.co.nz **Helene Sunitsch** hkjsunitsch@gmail.com

Committee Members:

Alumie Nguyen, Cushla Marsters, Dianne Purdie, Erena Bruce, Frances Tod, Heather Milligan, Helen Parsons, Helene Sunitsch, Perry Bray and Rachel Burgoyne

Contacts:

Find a Scleroderma a Support Group near You:

Auckland:	**Helen Parsons,** Email: helenparsons@artcardsandposters.co.nz
Bay of Plenty:	**Alumie Nguyen**, Email: alumie.uow@gmail.com
Waikato / Waipa:	**Erena Bruce,** Email: bruceerena@gmail.com
Hawkes Bay:	**Gail Neilson,** Email: neilson_gail@hotmail.co.nz
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