NUMBER: 63 MARCH 2025

Scleroderma

New Zealand support group

Autumn 2025

Greetings to you …

Welcome to the Autumn edition of our Scleroderma Newsletter…

Kia ora koutou, we hope everyone is well and looking after themselves.

We warmly welcome all our new members who have recently been diagnosed with scleroderma, we hope you will find some of the articles in this newsletter useful and informative.

As we come into autumn we say goodbye to the warmer weather and start gearing up for the colder months. It's also time to start thinking about getting our warmer clothes (gloves, hats, scarves) out of storage and plan for our flu injection ready for the winter season.

We hear from our President, Jenny Andrews with her report. Jenny keeps us up to date with what's happening in our community.

We revisit some very useful information written in our previous newsletters, such as Scleroderma Hospital Care Plan and How to Manage Work When You Have a Chronic illness.

We have our regular Members News and Updates from our different support groups.

Don't forget daylight saving ends on **Sunday 6th April** this year, and Easter and ANZAC will soon be here too.

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.

Remember, this newsletter is for you and there will be other members in similar situations who would like to hear about your experiences or activities.

Take care everyone.
Tina and **Jenny**

Presidents Report:

Hello all. I would like to welcome all our new members to Scleroderma NZ. We have had quite a few in the last few months. I'm sure we can all relate to how you will be feeling right now. Lots of confusing thoughts will be going through your heads. It is quite an emotional time after diagnosis. It can be a relief to know that you are not actually going crazy and there is a name for how you are feeling.

We have a fantastic group of people on our committee. We don't meet too often and work well as a team. We will be having our Annual General Meeting in May and we welcome anyone along who would be interested in joining us. Either get in touch with myself or Tina McLean (Vice President) or Jane Sainsbury (Secretary). The link to our meeting is as follows https://meet.google.com/tgw-bjxd-noh It will be held at 10am on the 3rd of May via online. Many hands make light work so come along and join in. We have received Linda Bell's resignation from the committee. Linda has served on the committee since the beginning of Scleroderma NZ and has been the instigator of seminars and education sessions in the Waikato Area. Linda has been such an active part of our committee and the wider Scleroderma Community for many years. She will be missed on our zoom meetings and especially by the community in the Waikato area. Thank you Linda for all your commitment to Scleroderma New Zealand. It has been very much appreciated.

I would like to thank all the members of the committee for their continued support. An especially big thank you to Committee members Erena Bruce, Linda Bell and their team in the Waikato area who are busy organising our next seminar. This will be held on the 18th October at the Te Awamutu Bible Chapel Seminar Room. Please see Page 7 & 8 for more details. This is open to anyone. All members, support people and medical professionals. It is a fabulous opportunity to attend the seminar, especially to those in the North Island, while it is in your region. We like to spread them around the country so everyone gets an opportunity to attend.

I have enjoyed what summer we have had down South here. When it has been hot it has been really hot. But when it was miserable it certainly was miserable. On the 1st March, Autumn hit with vengeance. Cooler mornings and darker mornings and evenings. While I write this though we have had 4 lovely days. I have spent each of them in the garden preparing it for the winter. It has been lots of hard work but feeling great to be able to do it. We head on holiday in 7 weeks' time so the more I can get done now the better. It does blow my mind that we are through March already. Where are the days going? I will be away for Scleroderma Day this year and the writing of the June newsletter so Helene Sunitsch as agreed to help Tina with getting this out to your all. I'm sure they will be more organised and get it out earlier in the month of the correct month. My next report might just be me on holiday ☺ Due to having such a great team working on Scleroderma NZ I have no worries about leaving it in their hands. Think about what you could light up for Scleroderma Day on the 29th June in your towns etc. Contact the council and see if they will light up with Yellow, orange and blue for Scleroderma Day. It's always awesome to get photos in of the lit up places.

The support groups are going great and we really appreciate the leaders who do the organising for these. It is so awesome to meet new people who understand. And it is a great excuse for a lunch or morning or afternoon tea out. I really enjoyed joining in to the Otago Group Morning tea. What a wonderful bunch of people to chat to. Thank you for coming along. Photo on page 15.

Now is the time to be getting your flu injections and making sure your homes are warm enough and you have those layers ready to go when heading outside in preparation for Winter coming. It is very important to stay in touch with family and friends during the colder seasons as it can get lonely if we don't want to go out in the cold and just stay home. Phone calls and video calls are a fantastic way to stay in touch as you can do that from the comfort of home. Technology is wonderful for that.

Take care everyone.
Kindest Regards
Jenny

Members Stories:

Heather Milligan shares about her Glass Jug Collection and also her sunflowers with her Granddaughter

Since I was diagnosed with Scleroderma 10 years ago, my collection of glass jugs, with most importantly handles, for use in the microwave has grown. I do feel safer grabbing the handles, usually with an oven cloth than grabbling a bowl with an oven cloth.

My favourite is the jug I cook my porridge in and then eat out of.....yes I am unsophisticated. 😊
Heather

Granddaughter Isla and our dog Jack admiring the sunflowers I grew from the seeds that the late Betty Wilson had collected and given out to us.
(See page 3 of the 2024 Summer newsletter about Betty's gift).

A Poem about living with Scleroderma

A Silent Strength

In the quiet of the morning,
When the world begins to stir,
There's a strength that rises softly,
In hearts that never blur.

A struggle hidden from the eyes,
A battle fought within,
With hands that clasp with trembling grace,
And faces worn with sin.

But still, the soul, it presses on,
Through days both dark and bright,
For courage is a flame that burns,
A beacon in the night.

The skin may stretch, the joints may ache,
But there's a spirit free—
In every step, in every breath,
There's boundless dignity.

So here's to those who walk the path,
With hands and hearts so strong,
You teach the world that even when,
It's hard, you still belong.

Through every trial, every tear,
You stand with love, not fear—
A living testament of hope,
That shines forever clear.

This poem is a tribute to the resilience, courage, and beauty of those living with Scleroderma. I hope it resonates with the strength and grace of those who navigate this condition every day.

Members Stories:

Health and Disability:

Thank you so much to Jenny and Jeff for opening your home to us for Kristie-Anne Scott, who is the Southland Advocate, contracted by The Health and Disability Commissioner to support people, New Zealand wide to speak to us.

The Nationwide Health and Disability Advocacy Service can help you with your concerns about a provider or service.

If you were like me and had seen articles in the news that the Commission was involved such as:
The care provided by a dentist to a patient has fallen "well below the standard" of competency, after they carried out a crown procedure on the wrong tooth, the Health and Disability Commission has found.
And…..
A woman in her 60s died of cancer after doctors at a Waikato hospital emergency department failed to tell her and her medical centre about a worrying chest X-ray that showed nodules on both lungs. Deputy Health and Disability Commissioner Vanessa Caldwell found Te Whatu Ora Waikato breached the woman's right to information about her condition and as a result her diagnosis of metastasised lung cancer was delayed. Although Caldwell said an earlier diagnosis may not have changed the trajectory of the disease, the patient would have been able to manage her condition and treatment.

I had looked at commission's leaflet up on the notice board whilst waiting for an appointment at medical facilities and thought that is for 'high powered' medical problems, these thoughts were transformed by Kristie-Anne. Yes, they do deal with the 'high powered' but also deal with individuals and can counsel you through the following in any area of the medical services.

- Help you understand your rights when using health or disability services
- Listen to your concerns
- Talk through your options
- Help you to formulate your complaint and make a complaint
- Support you while you resolve your issue.

It is a free service, and advocates are independent of all health and disability service providers and agencies

Kristie-Anne was very clear that she is unable to get you 'up a waiting list', but she will be able to talk both with you and the medical staff you are dealing with to understand what is happening.

She also is only able to speak to you as an individual and is unable to help family member/friends etc of yours only if you have the legal conditions to speak for them.

Kristie-Anne than presented several case studies that she had overseen.
One was that a patient had developed a serious infection after an operation and felt it should not have happened. She was able to meet the surgeon who explained the procedures they undertook for infection control up to, during the operation and afterwards. It appeared to be sadly ' it was one of those things that happened' . The patient did appreciate the input and explanations.
Another
A patient at a medical centre felt she was not being 'listening to'. Again Kristie-Anne facilitated a meeting with the staff at the medical centre and was able to support the patient with her concerns.

Afterwards one of our members let a friend know about this service. The friend (with a non-scleroderma health difficulty) is having problems with communicating with the hospital for an appointment. It is now being worked through with a positive conclusion in sight.

Kristie-Anne is more than happy to receive phone calls and if it was outside her jurisdiction she had many contacts for other organisations for people to follow up with.

Thank you, Kristie-Anne, for giving up you Sunday afternoon to speak to us. It was an eye-opener.

Contacts for the Health and Disabilities Commission
https://www.hdc.org.nz/
If you want to contact an advocate
a https://www.hdc.org.nz/advocacy/
Case Studies. https://www.hdc.org.nz/decisions/case-studies-nga-matai-take/

Members Update:

Podiatrists and Fingernail cutting

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

***Jessica Dobbs Podiatry** 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
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
02041785262
Clinics are in Cromwell and Alexandra

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

Tauranga
Saf Kear
Write: hello@thegoodpodiatrist.co.nz
Phone: 07 219 7811
Mobile: 021121 0435

Auckland
Simon Speight
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 Mob 021535511

Home Visits from Takaka to Blenheim
Greig Price
Contact Number
022 419 0205
Email info@mobilepod.nz

Timaru
Catie Rowe Podiatry
0276882036
17 Dee St
Seaview,
Timaru

Ph 03 683-1448

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.

UNIVERSITY of
BRADFORD

COLD HANDS, WARM HEART

PARTICIPANTS NEEDED FOR A STUDY ON RAYNAUD'S

We are conducting a research study to explore how Raynaud's disease affects quality of life and overall well-being. Your insights will help us improve support and awareness for those living with Raynaud's.

You Can Participate If:

- You are over 18+ years of age
- You speak English
- You have or think you have Raynaud's

What's Involved?

- You will be asked to complete a brief online survey that entails demographic questions (e.g., age, gender, ethnicity), questions related to Raynaud's (e.g., severity), and questionnaires that assess quality of life, depression, anxiety and stress.

How to Get Involved

If you're interested, have questions or prefer a hardcopy, contact us at:

✉ e.vaportzis@bradford.ac.uk
☎ 012742 35554

Please scan the QR code or use the link to find out more and complete the survey
https://is.gd/pCsGpt

Ethics approval has been granted by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 12/03/25 (E1301).

Scleroderma Seminar 2025 A holistic View

Date: 18 October 2025
Venue: Te Awamutu Bible Chapel Seminar room
110 Chapel Drive, Te Awamutu

You are warmly invited to the 2025 Annual Scleroderma Seminar. This event is hosted by the Waikato Scleroderma Group, with support from the Rheumatology team who will be present.

For any enquiries please reach out to:
Erena Bruce 021 186 9680
Maree Meredith 027 291 5297

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

Firstly, we would like to acknowledge the support of one of our guest speakers above, Delwyn. Gratefully, clarity in communication has resulted in Delwyn with her husband being able to attend to share her passion and interest in helping with Nutritional knowledge. While many of us may share food issues specific nutrition to is individualised and Delwyn is one that has gone the extra mile with clients.

<u>A Holistic View</u>

Our group of Waikato ladies have been pacing ourselves to the finish line of Saturday October 18th. Not only have we been able to enjoy each other's company our journey with Scleroderma but also a range of skills. It is a collaborative effort with lovely energy.

Our venue the Te Awamutu Bible Chapel in Te Awamutu has a rural outlook, it has a number of suitable rooms depending on numbers that can cater for our Seminar. Rooms are well lit, comfortable and warm, plenty of car parking, Campers or RV overnight stay welcome.

<u>Accommodation</u>

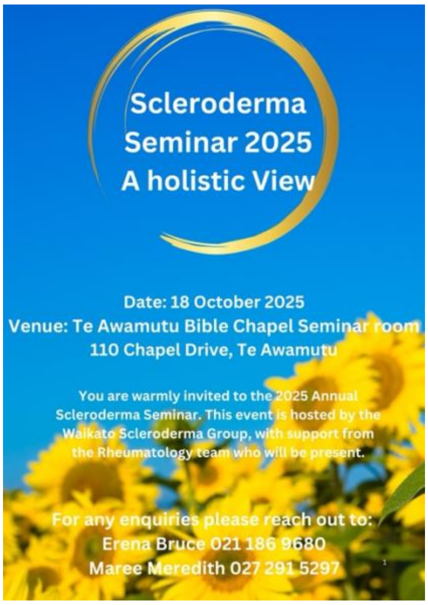
For those who are undertaking the hikoi (travel) and looking to stay, there are a few options. Te Awamutu has 3 motels in various places Around Te Awamutu, less than a kilometre away is Matariki Motor Lodge. If your preference is Hamilton or Cambridge time frames of travel are 25 minutes to Te Awamutu. Jetpark Hamilton Hotel is walking distance from the terminal.

Our ladies (whanau) are able to provide transport if needed to and from accommodation sites, Hamilton, Cambridge or Te Awamutu. We are also able to billet a handful of attendees, flick me an email let's see how we can manaakitia kia koutou (accommodate you).

In the next month or so more information will be forwarded including how to register. If you have questions or queries, please email and our ladies will discuss.

Our next meeting 7th May.

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



Scleroderma
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Erena Bruce 021 186 9680
Maree Meredith 027 291 5297

Events to note in your calendar:

Sun, 6 Apr 2025 - Daylight Saving Time Ends.
In New Zealand for 2025, Daylight saving time ends every year at 3am on the first Sunday in April. That means this year it ends at 3am on Sunday 6 April, so clocks will go back one hour at 3 a.m.

Sun, 20 Apr 2025

Fri, 25 Apr 2025

Webinar

Moving with arthritis: Unlocking the power of exercise

7-8pm, Wednesday 16 April 2025

GUEST SPEAKER Sasha Douglas Exercise Physiologist

Join Exercise Physiologist Sasha Douglas for an informative presentation on how exercise can be a powerful tool for managing arthritis.
Discover how different types of movement – resistance training, mobility, aerobic exercise and balance – can benefit those living with arthritis. Presented by Arthritis NZ.

Moving with arthritis:	Unlocking the power of exercise
Guest speaker:	Sasha Douglas
Date:	Wednesday 16 April 2025
Time:	7 - 8pm

Register to attend:
https://us02web.zoom.us/.../WN_vc16xZmnSD6HzwYOxaP2dw...

Scleroderma
New Zealand Inc

Scleroderma NZ AGM & meeting on 3rd May 2025 at 10.00am

An Invitation from **ANCA Vasulitis NZ** to people with Sclerodrma to listen to Professor Basu talk about fatigue.

Date:	Wednesday 21 May 2025
Time:	8pm via zoom.

Please email me with your registration:
diannepurdie@xtra.co.nz

ANCA Vasculitis NZ Presents

Professor Neil Basu
Professor of Musculoskeletal Medicine & Vasculitis
University of Glasgow

Professor Basu will talk on Fatigue
Professor Basu has done a lot of research on fatigue in ANCA associated vasculitis and other conditions

When:- Wednesday 21st of May 2025
8pm NZ time Via Zoom:- link in write up.
Please contact Dianne Purdie to register.
diannepurdie@xtra.co.nz

Time:	May 21, 2025 07:30 PM Auckland, Wellington. Join from PC, Mac, iOS or Android.
Zoom Link:	https://otago.zoom.us/j/94454781484
Meeting ID:	944 5478 1484
Password:	329927

Professor Basu's research programmes are inspired by his clinical practice where he is drawn to particular areas of considerable need:

Central Nervous System Determined Behaviours in Inflammatory Disease -

Despite the recent therapeutic revolution among inflammatory diseases such as rheumatoid arthritis, patients remain disabled by symptoms such as pain and fatigue. This multi-disciplinary translational portfolio aims to decipher these commanding symptoms by evaluating the roles of neurobiological and inflammatory factors.

Epidemiology of Systemic Vasculitis -

Inflammatory diseases such as systemic vasculitis are frequently overlooked due to their low prevalence. Patients feel marginalised and their true disease burden remains to be fully quantified. This programme of work seeks to apply descriptive, analytical and translational epidemiological methods to better quantify the burden and determinants of systemic vasculitis with view to informing and executing clinical trials.

Link to his page:
https://www.gla.ac.uk/.../infectionimm.../staff/neilbasu/

Kind Regards
Dianne and **Gordon Purdie**

Some Useful Information:-

Mobility Parking Permit Card

If you have Scleroderma you may be eligible for a mobility parking card, see below for details:

Applying for a permit

Having a medical condition or disability does not automatically entitle you to a mobility parking permit.

You are eligible if you meet the following criteria:

- You are unable to walk and always require the use of a wheelchair, or
- Your ability to walk distances is severely restricted by a medical condition or disability. If for example, you require the use of mobility aids, experience severe pain, or breathlessness, or
- You have a medical condition or disability that requires you to have physical contact or close supervision to safely get around and cannot be left unattended. For example, if you experience disorientation, confusion, or severe anxiety.

Your doctor needs to confirm your eligibility, unless you are renewing a long-term permit.

There are two types of permit: -

Long-term permit:

You can apply for a long-term permit if you have a permanent medical condition that affects your mobility. A long-term permit is valid for five years. You will need to renew it every five years

Short-term permit:

You can apply for a short-term permit if you have a temporary medical condition that affects your mobility. These are issued for a minimum of three months and a maximum of 12 months. Three month, six month or nine month permit may be extended to a maximum of 12 months from the date of issue. This requires confirmation from your doctor that your mobility is still affected.

You can apply by filling in the form by clicking on the button below. Please ensure your medical practitioner completes the medical page of the form.

Download the application form:
https://www.ccsdisabilityaction.org.nz/s/Mobility-Parking-Application-Form_January2024-FILLABLE.pdf

Fill in the application form electronically or by hand and take it to your doctor to complete the medical section (Page 2 of the form). A permit will be sent to you within ten working days from the date that we receive your application

Alternative ways to apply:

Email ***MobilityParking@ccsDisabilityAction.org.nz*** and they will post a form to you.

Source: Mobility Parking Support — CCS Disability Action — CCS Disability Action

Mobility Parking Permit Scheme renewal:

Online Permit Renewal: Mobility Parking Permit Renewal

How to Manage Work when you have a Chronic illness

Chronic illness can shake your world. One moment you're perfectly healthy, enjoying life. Then, the next moment, you're seriously ill and struggling to do the simplest tasks. Activities that used to come easily now require careful thought and planning. Life activities you once took for granted, such as breathing, eating, or walking, are now difficult. You once worried about work-life balance, but now your primary concern is making it from one day to the next without experiencing a serious health crisis.

Here's how to help you stay at work.

Be honest with your boss:

You don't have to tell your supervisor about your illness if you don't want to. However, if your illness is beginning to affect your work, you'll need to speak up at some point. If your work quality or production level starts to slide, the last thing you want is for your boss to think you're being lazy or you don't care about your work.
In this case, it's a good idea to meet with your boss and let him or her know you have a chronic illness. It's up to you how much detail you give.

Talk to human resources:

Although your boss might respond with concern and empathy, you should also have a chat with your human resources representative. It's important to make sure someone else in authority is aware of your illness — this way, you'll have an easier time defending yourself if a misunderstanding arises, and your job is suddenly on the line.
Ask for accommodations

Is your work schedule wearing you down?

If the way you're working right now seems to be negatively impacting your health, it's time to make a change. Ask your supervisor if he or she could make adjustments that would help keep you healthy and get your work done.
Perhaps you could request to work from home a few days a week. If doctor's appointments have become difficult to schedule because of strict office hours, ask whether you could change your work schedule, so you can get all your appointments in.

Know your rights:

Although many employers would do their best to accommodate a chronically ill employee, you could run into resistance. Some bosses will not be eager to assist you, especially if you don't look visibly ill. If you've been denied an accommodation that is necessary to do your job, speak with your human resources manager. Tell him or her about your situation and why you need the accommodation. Some illnesses are considered disabilities, so it might be your legal right to receive the adjustment. If you're unsure, consult with an employment lawyer.

Take care of yourself

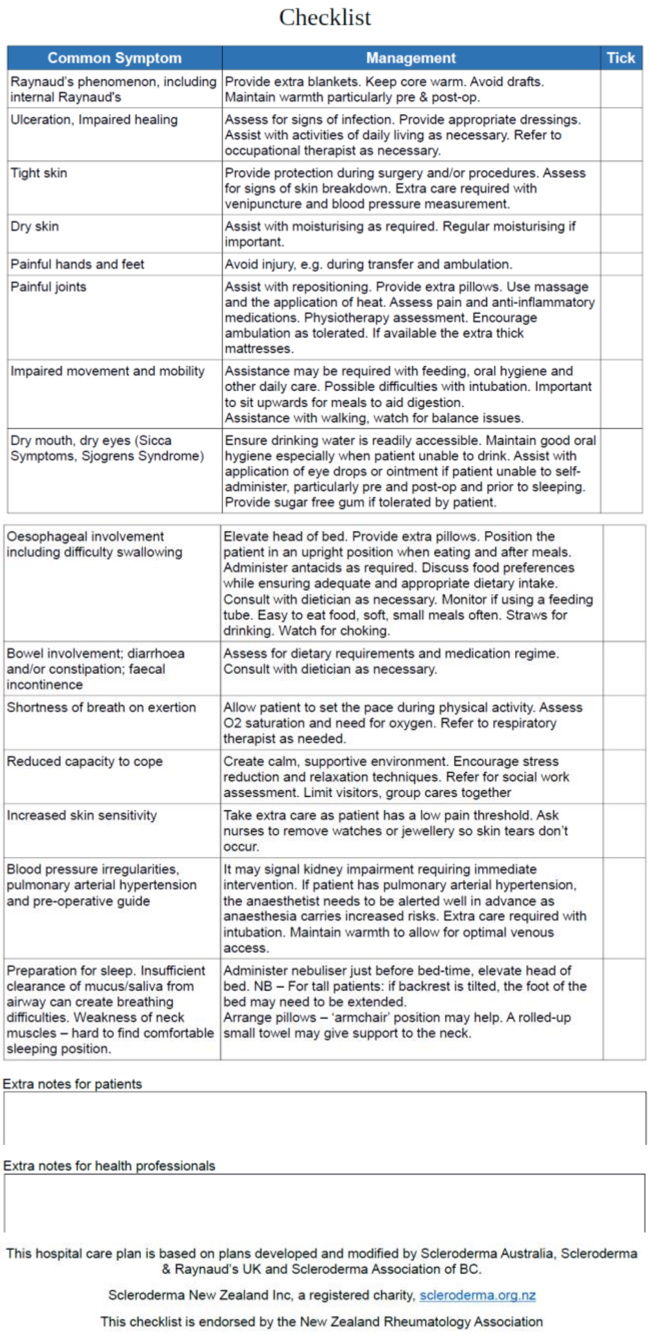
You won't perform at your best level if you don't take good care of yourself. Eat a balanced diet, get enough sleep, and follow your doctor's orders. Also keep track of how you're feeling from day to day, and make sure to keep in regular contact with your health team. Don't ignore any nagging symptoms in favour of getting a work assignment done. As soon as you start to feel sick, address the issue, and get the treatment you need. Delaying care could cause complications at work. Waiting to see a doctor could mean more days out of work and a longer recovery time.

Some Useful Information: continued....

Scleroderma Hospital Care Plan

Scleroderma (systemic sclerosis) is a rare condition. Often health professionals have had little experience with this disease. This leaflet has been developed to help nurses and other health professionals manage patients in hospital with scleroderma. It is a check-list of some of the main problems a person with scleroderma may experience and how to manage these problems.

For you as a person with scleroderma, the below check-list is where you can tick all of the problems that apply to you. This may help nursing staff know how they should help you manage these problems as they may not have looked after someone with scleroderma before. You can hand it to the nursing staff on admission to a ward. You might wish to take an extra copy with you.



Checklist

Common Symptom	Management	Tick
Raynaud's phenomenon, including internal Raynaud's	Provide extra blankets. Keep core warm. Avoid drafts. Maintain warmth particularly pre & post-op.	
Ulceration, Impaired healing	Assess for signs of infection. Provide appropriate dressings. Assist with activities of daily living as necessary. Refer to occupational therapist as necessary.	
Tight skin	Provide protection during surgery and/or procedures. Assess for signs of skin breakdown. Extra care required with venipuncture and blood pressure measurement.	
Dry skin	Assist with moisturising as required. Regular moisturising if important.	
Painful hands and feet	Avoid injury, e.g. during transfer and ambulation.	
Painful joints	Assist with repositioning. Provide extra pillows. Use massage and the application of heat. Assess pain and anti-inflammatory medications. Physiotherapy assessment. Encourage ambulation as tolerated. If available the extra thick mattresses.	
Impaired movement and mobility	Assistance may be required with feeding, oral hygiene and other daily care. Possible difficulties with intubation. Important to sit upwards for meals to aid digestion. Assistance with walking, watch for balance issues.	
Dry mouth, dry eyes (Sicca Symptoms, Sjogrens Syndrome)	Ensure drinking water is readily accessible. Maintain good oral hygiene especially when patient unable to drink. Assist with application of eye drops or ointment if patient unable to self-administer, particularly pre and post-op and prior to sleeping. Provide sugar free gum if tolerated by patient.	
Oesophageal involvement including difficulty swallowing	Elevate head of bed. Provide extra pillows. Position the patient in an upright position when eating and after meals. Administer antacids as required. Discuss food preferences while ensuring adequate and appropriate dietary intake. Consult with dietician as necessary. Monitor if using a feeding tube. Easy to eat food, soft, small meals often. Straws for drinking. Watch for choking.	
Bowel involvement; diarrhoea and/or constipation; faecal incontinence	Assess for dietary requirements and medication regime. Consult with dietician as necessary.	
Shortness of breath on exertion	Allow patient to set the pace during physical activity. Assess O2 saturation and need for oxygen. Refer to respiratory therapist as needed.	
Reduced capacity to cope	Create calm, supportive environment. Encourage stress reduction and relaxation techniques. Refer for social work assessment. Limit visitors, group cares together	
Increased skin sensitivity	Take extra care as patient has a low pain threshold. Ask nurses to remove watches or jewellery so skin tears don't occur.	
Blood pressure irregularities, pulmonary arterial hypertension and pre-operative guide	It may signal kidney impairment requiring immediate intervention. If patient has pulmonary arterial hypertension, the anaesthetist needs to be alerted well in advance as anaesthesia carries increased risks. Extra care required with intubation. Maintain warmth to allow for optimal venous access.	
Preparation for sleep. Insufficient clearance of mucus/saliva from airway can create breathing difficulties. Weakness of neck muscles – hard to find comfortable sleeping position.	Administer nebuliser just before bed-time, elevate head of bed. NB – For tall patients: if backrest is tilted, the foot of the bed may need to be extended. Arrange pillows – 'armchair' position may help. A rolled-up small towel may give support to the neck.	

Extra notes for patients

Extra notes for health professionals

This hospital care plan is based on plans developed and modified by Scleroderma Australia, Scleroderma & Raynaud's UK and Scleroderma Association of BC.

Scleroderma New Zealand Inc, a registered charity, scleroderma.org.nz

This checklist is endorsed by the New Zealand Rheumatology Association

Travelling with the Hidden Disabilities Sunflower lanyard

Several airlines, including Air New Zealand, Jetstar, Qantas, Emirates, British Airways, and Turkish Airlines, recognise the Hidden Disabilities Sunflower scheme, a program that allows people with non-visible disabilities to discreetly indicate their need for assistance.

Here's a more detailed explanation:

Hidden Disabilities Sunflower Scheme:

This international program allows individuals with hidden disabilities to wear a sunflower lanyard or similar item to discreetly signal their need for extra support or understanding to staff at participating organizations.

Airlines that Participate:

- Air New Zealand: Recognizes the Hidden Disabilities Sunflower scheme, with staff trained to provide assistance to passengers wearing the lanyard.
- Jetstar: Encourages passengers with hidden disabilities to wear a Sunflower lanyard or similar item, or to share this information when booking their trip.
- Qantas: Recognizes that each individual experiences disability differently and provides assistance to passengers with hidden disabilities.
- Emirates: Is the world's first Autism Certified Airline.
- British Airways: Officially partnered with Hidden Disabilities Sunflower as part of its initiative for customers and passengers with hidden disabilities.
- Turkish Airlines: Welcomes passengers with invisible disabilities with kindness, understanding, and care.

How it works:

Passengers with hidden disabilities can obtain a Sunflower lanyard from participating organizations, such as airports.

Wearing the lanyard allows staff to recognize that the passenger may need extra support or assistance.

Staff are trained to provide appropriate help, which may include slowing down the process, keeping things quiet, or offering extra assurance.

How to get a Hidden Disability Sunflower lanyard

If you're travelling throughout New Zealand, the airports at Auckland, Christchurch, Dunedin, Hamilton, Invercargill, New Plymouth, Palmerston North, Queenstown and Wellington have adopted the Hidden Disabilities Sunflower. Prior to your travel, you can request a free lanyard from the airport company, which you can collect at the airport to keep and use on future trips.

If you're departing from other international airports, or would like to know more, visit the Hidden Disabilities website.

Source: Hidden Disabilities Sunflower - Flying with a disability - Flying when you need special assistance - Plan | Air New Zealand

Members News

Southland Scleroderma Group

Sunday 16th February was a pleasant summer day when the Southland Group met for lunch in Winton. It was lovely and warm and so great to see all of us in our 'summer garb'.

We welcomed several new members and their supporters; it was so good that they had contacted Jenny and then were happy to come and meet us. We all wished them well on this daunting Scleroderma journey.

Thank you to all those who were able to attend and thank you Jenny for organising this.

Heather Milligan

Wellington / Kapiti and Wairarapa Scleroderma Group

On the 15th February on a lovely sunny Saturday the Wellington and the lower north island support group gathered for friendship, support, advice and yummy food. We had a good crew and a couple of newbies (Mother & Daughter) We even had some travel from the Wairapa which we very much appreciated. The cutest of us all was Frodo the dog and he was a big hit.

We always enjoy the gatherings, and we all get something out of them. We are looking forward to seeing you at the next one. The dates and venues are in the newsletter.

Cushla

Hawkes Bay Scleroderma Group

The Hawkes Bay group have continued to meet once a month this year. We were able to meet with Jane twice while she was in Hawkes Bay this time.

Our group has six members plus Jane. We usually meet on the third Saturday of the month for coffee. Our venue varies between Napier and Hastings. The following meeting date falls on Easter Saturday so we will discuss what we want to do on Saturday.

Sorry there are no photos, somehow it has slipped our minds. I'll try to remember this week.

Members News continued:

Auckland Scleroderma Group

Mary Daniel, Liz George & Roger Parsons

We had a delightful March Coffee Meetup. And we all look forward to the next time.
Helen Parsons
helenparsons@artcardsandposters.co.nz
021 248 3869

Peter Jones

Liz George

Helen Parsons

Mary Daniel

Christchurch Scleroderma Group

A small group of us met at the London Canteen in Oderings Garden Centre on Tuesday 25th March. We enjoyed catching up and sharing aspects of our Scleroderma journey with one another. It often astounds us each how every person's journey to diagnosis, symptoms and treatments can vary so significantly for each person.

I'm looking forward to the next gathering (Saturday 24 May @ 2pm) which will be at the Travis Courtyard Café in Burwood Hospital. Be great to see you there!

Blessings
Perry

New Plymouth Scleroderma Group

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

Members News continued:

Waipa and Waikato Scleroderma Group

This wonderful group are in full on mood organising the seminar for us in October. Page 8 is where you would have found all their information regarding this.
Waipa, Hamilton, Putaruru, Morrinsville,
Please contact Erena Bruce if you wish to join them. bruceerena@gmail.com

Otago Scleroderma Group

We had a wonderful morning tea on Sunday 30th March at the Village Green, Green Island. It was an interesting place to have it. After walking in past the cricket grounds then inside through the squash courts thinking we had gone the wrong way, then up the stairs and we came out at a lovely café. Thank you so much to Gaynor for booking this for us. It was an awesome venue. We had a great turn out. 11 of us. What a variety of places we all came from. With Helen, Roger and Daughter Emma who come from Auckland (but spend a lot of time in Dunedin), Lorna and Murray from Oamaru, Sandra from Lake Hawea, Gaynor and Rowan from Mosgiel, Terry from Gore, Myself from Winton and the lovely Jessica from Dunedin. It was so nice meeting Jessica, Lorna and Murray. And wonderful for the others to support the local group. That is how friendships are made and I saw a number of people exchanging contact details which was awesome. The 2 hours flew by and I was very surprised when my hubby rang to see if I was coming to lunch or not. All in all a very enjoying morning. Thank you all.
Jenny

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

Online Meeting coming up with Perry Bray

Join from PC, Mac, iOS or Android:
https://otago.zoom.us/j/96512441217?pwd=4EDIPSu99YtpoarCjDJeQ4UNSXNrVR.1

Meeting ID: 965 1244 1217
Password: 737177

Blessings

Online
Scleroderma
Support Group
Meeting
Saturday 26 April
@ 1:30pm

Check the Scleroderma Website
or Facebook page for the Zoom link

Scleroderma
New Zealand Inc

https://scleroderma.org.nz/

Group Meetings Dates 2025: Regional

Wellington / Kapiti and Wairarapa support group meets:

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

Cushla Masters: cushlam@outlook.com
Tina McLean: tinaoaisamclean@outlook.com

Date and Time	Venue
Sat 19th April @ 12:30pm	**The Farm Café & Bar** 33 Military Road, Boulcott, L/H
Sat 19th July @ 12:30pm	The Fisherman's Table (To be confirmed)
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, L/H

Palmerston North support group:

See Wellington Support group.

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
Sat 24 May 2-4pm	**Travis Courtyard Café,** Burwood Hospital
Sat 19 July 12pm Midwinter Lunch	**Koji, 257 Lincoln Rd**
Sat 20 Sep	**London Canteen, 92** Stourbridge, Spreydon
Tues 25 Nov	**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

Otago support group:

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

Southland support group meets:

2025 Meeting Dates, Venues to be confirmed
May 4th, Gore at 12pm, Croydon Lodge
August 17th, Invercargill at 12pm
November 30th, in Gore at 12pm

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

Waikato/Waipa support group meets:

Our next meeting: **7th May 2025**

If you would like to join in with the Waikato/Waipa Group, please contact: -

Erena Bruce, Mobile: **021 186 9680**
Rachel Burgoyne, Mobile: **027 3661881**

Auckland support group:

Venue: ***Daily Bread, Kings Plant Barn***
11 Porana Road, Takapuna, Auckland
Time: **Monday 14th April, 10am**

If you would like added to this email list contact Helen.
For any enquires please contact:-
Helen Parsons: 021 248 3869
helenparsons@artcardsandposters.co.nz

New Plymouth support group:

Venue: ***Locals Café, 11 Wallath Road, Westown, New Plymouth***
Time: Saturday, 7th June, 2025 at 11am

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

Hawkes Bay support group meets:

Venue: ***Frances' Home, Villa 147, Willowbank, Retirement Village, Napier***
Time: **Third Saturday of the month**

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

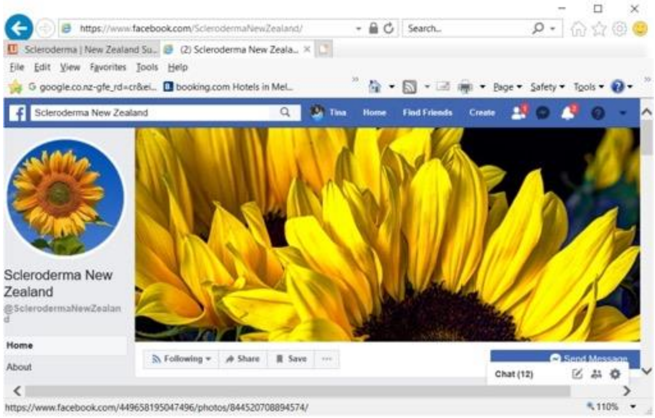
Welcome to Scleroderma New Zealand Inc.

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

Committee Members:

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

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:	**Rachel Burgoyne,** Email: rachieb1981@gmail.com **Erena Bruce**, Email: glenanderena@xtra.co.nz
Hawkes Bay:	**Gail Neilson, Email:** neilson_gail@hotmail.co.nz
New Plymouth:	**Kelsi Tidswell,** Email: kelsitidswell@gmail.com
Wellington	**Cushla Marsters** cushlam@outlook.com **Tina McLean** tinaoaisamclean@outlook.com
Christchurch:	**Nicky Moore,** Email: Nicky.moore@xtra.co.nz
Blenheim/Nelson:	**Jen Soane,** Email: jennasoane@gmail.com
Waimate/Oamaru:	**Helene Sunitsch,** Email hkjsunitsch@gmail.com
Otago:	**Gaynor Meddings,** Email: gaymeddings@gmail.com
Southland:	**Heather Milligan,** Email: milliganseeds@xtra.co.nz