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Scleroderma

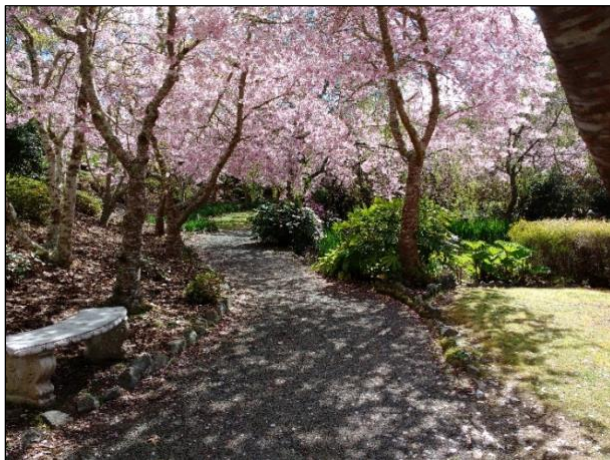
New Zealand support group

SPRING 2022

Greetings to you all.

Welcome to our spring edition of the Scleroderma Newsletter...

We hope everyone is well and keeping safe.



We hope everyone is well and have recovered from the winter flus, bugs, colds and covid. As we move into the spring season we hope the weather improves and everyone is able to get out and enjoy the warmer days.

We acknowledge the sad news of the passing of Queen Elizabeth II, who served a very long reign. The Queen was 96-years old, and died peacefully at Balmoral early on Friday 9th September, NZT. She was the longest-serving monarch in the history of Britain and the Commonwealth, having acceded the throne in 1952. The Queen is probably the most constant person in many people's lives. The morning the Queen's death was announced was the same day that we remembered and celebrated the life of Adrienne Burleigh, a

wonderful and supportive member of our Wellington Scleroderma group. Adrienne was always very positive and will be very much missed by us all. We have a memorial page for Adrienne in this newsletter.

We hear first from Jenny Andrews with the Presidents report. Jenny gives us good advice and keeps us up to date with what's going on in our Scleroderma community around New Zealand.

We have stories to share from our members, with one on Aroha by Erena Bruce, and we also have some interesting articles. Training sessions and toolkits in SPIN SSLED are introduced by Dianne Purdie.

We have our regular Members News from our different support groups, a small section on our fundraising efforts, with how to purchase our fundraising note cards and how to shop via the Rewardhub website for those online shoppers amongst us.

Be safe and take care everyone.
Warmest regards,

Tina and Jenny



Presidents Report:

Spring 2022



Hello Spring!! Welcome to our new members who have become part of our Scleroderma Family in the last few months. I'm sure Scleroderma is not the journey you would have chosen for yourself, but with our small tight nit community hopefully we can make it a little more bearable for you all.

My condolences go out to everyone who has lost someone special to them recently. It has been an emotional time with the passing of our wonderful Queen. Life will take a bit of getting used to now with us having a King for the first time in 75 years and for quite some time to come. I do wish King Charles III all the best in filling his Mum's shoes. Then we had a loss closer to home with the passing of Adrienne Burleigh. Adrienne was a committee member for a long time and her knowledge, kindness and huge personality will be sadly missed. We also had the passing of Rachel Pearce. Sadly Rachel never made it to any of our support group meetings due to her illness but she had phone and text friendships with our members.

It is lovely to see our support groups back meeting up in person. I personally missed seeing the wonderful faces of our Southland Group. A huge appreciation goes out to all those who organise the different groups, without you they would not happen. So please support your leaders as they support you. We would love to see some Christmas themed group pics for our Christmas Newsletter, so get your thinking hat on.

Thank you to our committee for all their continued support which goes on in the background. After our AGM in June, we gained a couple of new members. So welcome to Alumie and Frances. Thank you for putting your hands up to help. Thank you so much to our team who have agreed to stay on for another year, Tina as Vice President, Jane our Secretary and Gordon as Treasurer. Then on the committee we have the continued support of Maureen, Linda, Erena, Cushla, Heather, Dianne, and Catherine.

Thank you to Gordon for his continue hard work on the website. Catherine, Cushla and Dianne for keeping the Facebook page up to date, and as always a very big thank you to Tina for all you hours of work on the newsletter. You are truly all such superstars. 😊

Our card fundraiser is about to head back to the printers for the final print. They are looking great, so get an order in for your own or think about gifting them as a special Christmas pressie. We will have examples of them further through the newsletter. Thank you so much to all those wonderful artists and photographers who submitted their work for them. You are such a talented bunch.

If anyone has any ideas on how we can further raise awareness for Scleroderma, please get in touch. We are always open to new ideas and it is wonderful to get any feedback from you all.

Please go out and enjoy the sunshine now that spring is here. It is such a great mood booster. Enjoy mucking around in your garden, *without over doing it* and always remember though, to put on a hat and sunblock for that protection we all need.

Take care and look out for one another 😊
All the best

Jenny



Memorial for Adrienne Burleigh

ADRIENNE BURLEIGH OBITUARY



Scleroderma New Zealand Member

Adrienne Robin Burleigh



On 1st September 2022, aged 82 years

BURLEIGH, Adrienne Robin:

Of Paraparaumu. Died September 1st 2022 at Mary Potter Hospice with her family at her side. Aged 82 years. Wife of the late Colin J Burleigh, she is survived by her children Joanna, Fiona and Craig, their children and grandchildren. The funeral service will be held at Kapiti Uniting Parish Raumati Church, 10 Weka Road, Raumati Beach, at 1.00pm on Friday, September 9th. In lieu of flowers, Adrienne would have loved donations going to Scleroderma New Zealand Inc to help further research into this condition. Donations can be made using the Give-a-Little tab at www.scleroderma.org.nz. Adrienne's children would like to thank her Access carers, who enabled her to stay in her own home right to the end, and the Mary Potter Hospice staff who supported both her and the family. We are also indebted to our supportive spouses who carried us through these hard times.

Source:

<https://deaths.dompost.co.nz/nz/obituaries/dominion-post-nz/name/adrienne-burleigh-obituary?pid=202719137>



Adrienne and Colin on their wedding day



Adrienne and Colin



Memorial for Adrienne Burleigh

Scleroderma New Zealand Member

Adrienne Burleigh



Adrienne from her trip to the UK



Adrienne on her 80th Birthday



Adrienne last year at our Levin group lunch

It is with great sadness that we bring the news of Adrienne Burleigh passing on 1st September 2022

It comes with sadness to say goodbye to Adrienne, she has been with us for quite some time now and always a strong colourful and caring personality.

Adrienne reached a good age of 82 and has been involved with Scleroderma NZ from the beginning, she was a strong supporter of our society being made an incorporated society and a registered charity. Adrienne was on the Scleroderma NZ committee until recently.

Adrienne was always willing to share her knowledge with others and encourage people with scleroderma to keep going no matter what.

Adrienne attended a Scleroderma conference in the USA one year and brought back lots of helpful information for the group. Adrienne was always willing to speak with anyone who needed information and support from anywhere around New Zealand.

Over the last two or three years Adrienne attended education sessions and worked with SPIN (Scleroderma Patient Intervention Network) in Canada and naturally enjoyed it. She was very well respected by many at the organisation.

Adrienne suffered a lot with pain and mobility issues for many years, but during that time she spent a lot of time doing things for other people. As an example, every year she knitted a good 200 plus angels for the parents who had still born babies here in Wellington. She said the angels were there, to hang on their Christmas tree every year to remember their child. She also made countless tiny teddy bears for people. Always knitting, especially for her grandchildren. She enjoyed many crafts, her painting, cards and all sorts of happy colourful items. She also contributed to a number of our art exhibitions here in Wellington and Palmerston North.

Adrienne came from a teaching background and spent a lot of time teaching English to students in her retirement. Adrienne also did a lot for the local floral art society and was the President there for many years.

Adrienne was a strong backbone to our group in Wellington, and always very colourful and welcoming our members to her home, where we spent special times together as a group.

Adrienne will be sadly missed by us all. Our sympathy goes out to her family and many friends.



Dianne Purdie



Memorial for Rachel Pearce



"It is sadness that I record the death of a Southland member Rachel Pearce in Invercargill in July 2022.

I had phone and text contact with Rachel from mid 2021. She had hoped to get to our get togethers, but alas her ill health, both with Scleroderma and other serious health problems was not able to. Because of Covid concerns I was not able to visit her.

My sympathies to her family and friends."

Heather Milligan



**LIFE HAS TO END,
LOVE DOESN'T**

MITCH ALBOM

A Grief Plan for Support Groups

By Dianne Purdie



Creating a grief plan within a support group, can be very helpful. Below is some text from

SPIN (Scleroderma Patient Centered Intervention Network) with some helpful points.

It is best to start a conversation about how the group would like to handle these situations.

It may be a good idea to have the conversation at a time when the group hasn't experienced a recent loss. This helps take some anxiety out of the situation.

The membership should agree on how they would like to celebrate lives that have been lost, if they want to grieve as a group, and, if so, how they want to grieve as a group.

For some, grief is a private experience and some members may need to do this outside of the group. Being respectful and accommodating the desires of the group members will be key.

Some things you might want to decide on include:

If the group would like to send a collective message to the family (e.g. send a card or flowers)

How members would like to be notified of the loss (e.g. by email, during the next meeting)

If the group would like to attend rites or ceremonies related to the loss together.

By creating a support plan, leaders will know what the expectations of members are and be better prepared to meet them.



Members Stories:

Erena Bruce – “Aroha”



AROHA /Love is not self-seeking, it is not easily angered and is not provoked.

People have often asked me what Aroha means? My response was simply 'Love'. On reflection I kinda feel, how unfair.... to te reo Māori and to those who have the courage to ask to give such a simplistic response.

AROHA forgives; and keeps no record of wrong doings.

Since our last newsletter we have manoeuvred around the Mental Public Health system quite intimately in the under 18 area with our baby girl. In these covid 19, post Covid 19, and constant changes for our Youth, what is normal anymore? What does that look like around eating, acceptable behaviours, friendships, real life? Gosh even as adults who have strategies in place to manage stress, anxiety or even depression struggle! Unbelievably I passed a very modern vehicle parked in a driveway with spray paint on the side the word 'cheater', yup here in Cambridge! Then there's a group of 4 Youths walking, being followed by a mother in a car, she stops then starts yelling at these youths at the Cemetery gates whilst a Service was taking place, a neighbour pipes up after 5 minutes yells out for her to go home doesn't want to hear about her son being bullied by these Youths.

Aroha does not rejoice in inequity, but rejoices in the truth, Aroha does not envy, it is not jealous.

It is no wonder our Youth embark on a mirade of what their future may look like with so much uncertainty presently. For those of us who see Mental Health as part of a model that includes (Physical wellbeing, Emotional wellbeing, Spiritual Wellbeing and Family wellbeing, the Mason Durie Model of an Individuals Wellbeing) will internalise the balance of all these elements are necessary for each person's Ying and Yang to prosper. For our Whanau, I have only praise and so much admiration for our Kaitiaki, including Doctors, Advocates, Nurses, Families, Psychologist, Ministers, Spiritual practitioners, Administrators, Starship Hospital, it is that village of supporters that come together to contribute to the wellbeing of one who is in

need. This is AROHA/Love.... my fellow Scleroderma friends.

For AROHA is kind, it does not envy, it is not jealous.

Our Journey, is on going, we have used the skill of written clarity with our day to day planning, we Trust in the process to guide us and the practised logical skills of Certificated strangers to fill gaps of what pills to take, Therapy for rebuilding resilience and confidence, communication to parent through tricky teenage years and prayer for strength and for wisdom.

Again in reflection, with Queen Elizabeth's passing the New King what does the future hold for us, who knows! We are only guaranteed of one thing in life and that's when it's our time to pass it's our time. We in the present have to learn or continue to take what we have and enjoy the moments, live through the challenges reaching out to those who need levels of support and take time to LOVE.

My baby girl has said to me from time to time when we have a moment, 'Mum am I burden', (after our experiences this last year), my response with no lies, our Youth are intelligent people, always with a tear Honey **AROHA / LOVE is PATIENT which suffers long**, I am not perfect but you teach me such valuable things then 1 Corinthians 13 becomes our 'in the' moment of joy.

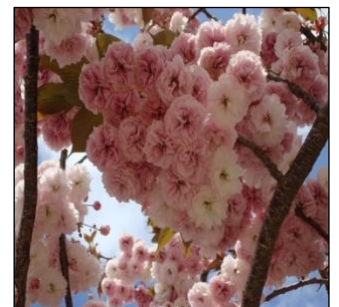
This is Mental Health Week starting 27th September, and with Te Reo Māori Month here a prime time to share. We live our Scleroderma journey of Mental Wellbeing how do we manage? Hopefully by helping someone else with LOVE it makes our Journey a little more tolerable.

All references to Aroha (Love is to 1 Corinthians 13)

Take care fellow Scleroderma friends

Ngaa Manaakitanga

Erena





Scleroderma Patient - Centered Intervention Network SPIN SSLED training sessions and toolkits.

By Dianne Purdie

Recently I signed up to attend the group leadership course (SPIN SSLED) through SPIN (Scleroderma Patient – centered Intervention Network) in Canada.

I wished that I had, had the opportunity to do this course earlier and this is why I am writing this little piece for the newsletter.

I think if you are a group leader, co leader or a member of a group, it would be helpful for you to attend. The course is free and you receive excellent information which is led by a very professional and sincere tutor/facilitator.

There are up to 8 students in the group which is run through 'group meet' which is similar to a zoom meeting.

The only thing you have to do outside of the group each week, is think about a couple of related questions which refer to the next week's session.

The course goes for 13 weeks, and if you can't make your session that week, there may be another time within the same week where you can join in, on another group to make up the time.

If you complete the 13 weeks you will receive a certificate of completion.

You receive lots of helpful resources, the list of modules are below, each session goes for 1 1/2 hours once a week. You get to choose your time slot.

Module 1- The Support Group Leader's Role

Module 2- Starting a Support Group

Module 3- Structuring Support Group Meetings

Module 4- Scleroderma 101

Module 5- Successful Support Group Culture

Module 6- Managing Group Dynamics

Module 7- Grief and Loss: The Support Group Leader

Module 8- Grief and Loss: Supporting Group Members

Module 9- Advertising and Recruiting for the Support Group

Module 10- Continuity of the Group

Module 11- Supporting Yourself as a Leader

Module 12- Remote Support Groups

Module 13- Transitions in Support Groups

After completing the course, you can attend a graduate session once a month if you wish.

This course is well worth the commitment of only 1 1/2 hours a week, you get to meet some lovely people from all over the world. We have members from a number of different states in the USA including Hawaii. My tutor is excellent, you couldn't have a more talented person teaching our course.





Scleroderma Patient - Centered Intervention Network SPIN SSLED training sessions and toolkits continued...

By Dianne Purdie

SPIN TOOL KITS

Also through SPIN you have the following resources through their website <https://www.spinsclero.com/en/about> and <https://www.spinsclero.com/en/toolkits>

I have mentioned the SPIN - HAND toolkit before, it is well worth looking at if you have hand problems. The upcoming tool kits are also listed



SPIN-HAND for hand function

The SPIN Hand Function (SPIN-HAND) toolkit provides exercises to improve hand function with sections to help you develop a personalized program, set goals, and track your progress. Instructional videos demonstrate how to perform each exercise properly with pictures to illustrate common mistakes.

[Open the SPIN-HAND toolkit](#)

Upcoming Toolkits



SPIN-SELF for self-management

The SPIN Self-Management (SPIN-SELF) toolkit provides essential knowledge and coping skills to help better manage day-to-day problems in scleroderma. Each of the 9 modules provides information about a different area (pain, fatigue, sleep, etc.) and teaches self-management techniques that you can implement at home.



SPIN-COACH for appearance changes

The SPIN Coping with Appearance CHanges (SPIN-COACH) Toolkit focuses on the impact of appearance changes in scleroderma, with two modules that help (1) manage negative appearance-related thinking and (2) build confidence in social situations. Additional modules focus on intimacy, as well as makeup and clothing in scleroderma.



SPIN-COPE for emotions

The SPIN COping with Positive Emotions (SPIN-COPE) toolkit consists of 7 modules, each addressing a different aspect of coping with the emotional impact of scleroderma, such as managing anger, worry, and depressive thinking.

All The Best Dianne



My Top 7 Scleroderma Self-care Items:

From Scleroderma News website

By [Amy Baker](#) | February 7, 2022



When dealing with scleroderma, some things are necessities. Following are the seven must-have items that best help me to manage symptoms and practice the best self-care possible.

1. Heating pad

I need my heating pad. I keep one on the couch. Yes, old lady business right here, but the body wants what the body wants. My body aches an awful lot. The heat helps to penetrate my muscles and joints and relieve the throbbing, painful feeling. Here's a piece of fantastic information: Heating pads can also come with an attachment for your vehicle. You can plug it right in. They are excellent on long trips and keep you warm if the other passengers want it cooler.

2. Gel ice pack

I just discussed the heat, but let's get into the cold for a moment. Scleroderma patients are prone to different skin manifestations. For example, chronic hives are my nemesis. To say I despise these exasperating things is an understatement. I have tried everything to find relief — antihistamines, topical creams, prescribed medication — and comfort still eluded me. Ice packs provided the relief I was seeking. They took away the heat from those troublesome eruptions and relieved the itching and the swelling.

A quick tip: Use a towel as a barrier to keep the ice pack from directly touching the skin.

3. Heating blanket

I keep this on my bed. Yes, even in the summer. The worst thing for a scleroderma patient with Raynaud's phenomenon is cold, and air conditioning will cause this painful occurrence to rear its ugly head.

I have neuropathy in my hands and feet — thanks, scleroderma! I don't know about you, but the cold causes me to experience severe foot and leg cramps. And there is nothing more jarring than waking up in the middle of the night to excruciating cramps. Heating blankets allow my legs and feet to stay warm.

If you don't have a heating blanket and are unceremoniously awakened with a vicious cramp, run it under hot water. I cannot tell you how many times I've hobbled to the bathroom, run the water, and sat with my feet submerged until the cramps subsided.

4. Hot hands/warm hands

If you have scleroderma, you probably also suffer from Raynaud's phenomenon. My hands get so cold it makes even

the slightest movement painful. Air conditioning or any level of cold air tends to kick my Raynaud's into gear. Stress also does it for me.

I keep hand warmers in my purse, in my vehicle, and stashed around the house. I've found it's best to be prepared to stave off any flares. These are not to be used in place of your prescribed medication. They can be used in addition to your meds to offer you the most comfort possible.

5. Thick, fluffy socks

In my humble opinion, the more ridiculous the socks, the better. I love colorful, funny ones. Why? When you feel icky and need a smile, you can look down at your feet!

Nonskid works best if you want to wear them around the house. Keeping your tootsies warm is essential. Mine get ice cold. When they are cold, they cramp. And I'm not too fond of cramping.

A quick tip: Although a tad more expensive, getting sherpa-lined socks is without a doubt worth it.

6. Lotion

Anyone with scleroderma knows that itching can drive you up a wall. There are several topical ointments and creams you may be prescribed. However, I use Eucerin Skin Calming Itch Relief Treatment.

I've tried different types of lotion. Oh my goodness, the money I've spent on finding a suitable cream has been ridiculous. If you read this column, you know the trials of having itchy skin.

The extreme dryness of your skin is often seen during active inflammation. It's one of my telltale signs. To respond to this, stay moisturized. But contact your physician if over-the-counter methods aren't working for you.

7. Jar, can lid opener

This adaptive tool is genuinely something all scleroderma patients need in their arsenal. My hands have arthritis, and my grip strength is nowhere near what it used to be. These little tools have allowed me to maintain my independence.

Here's my question for the folks who package products: Who tightens them up? The Hulk? I had a hard time allowing myself to buy these items. If I bought them, I was admitting my inability to do something as simple as opening a jar.

But I'm glad I did. And my hands are happy I did, too.

A quick tip: If you find you cannot open something that has been vacuum-sealed — you know, the thing that pops up when you open it? — take something sharp and stab it. It will release the pressure, and you can open the jar! Easy peasy.

This list is not all-inclusive. Find your comfort items and make them work for you. You will be happy you did.

Source: <https://sclerodermanews.com/2022/02/07/my-top-7-scleroderma-self-care-items>



What annual tests are available for scleroderma?

From the SRUK – Scleroderma & Raynaud's UK website

Empower Yourself

Annual tests are essential to monitor the progression of scleroderma and something you are entitled to as a patient.

Although scleroderma does not yet have a cure, symptoms can be treated and annual check-ups are critical to inform your doctor which treatments you need.

If any of these tests are not being performed and you feel they should be, tell your doctor. Some doctors will have more expertise than others and if you need to, take this booklet with you when requesting a particular test.

Don't be afraid to ask – all of these tests should be performed regularly.

Pulmonary function tests



Scarring and inflammation can cause the air sacs inside the lungs (alveoli) to become thicker than normal. Sometimes, these changes can increase pressure in

the blood vessels between the lungs and heart. This is pulmonary arterial hypertension (PAH), a serious condition which may cause shortness of breath, chest pain and lead to heart failure.

PAH is a rare condition but more common in people with scleroderma than the general population; early identification and treatment can slow progression.

What is it?

A pulmonary function test will assess how well your lungs work, mainly by testing your breathing.

How is it performed?

A spirometry test will measure the volume of your lungs. The maximum volume of your lungs will decrease if there is significant scarring.

A clearance test assesses how well your lungs take in oxygen and then passes into your bloodstream.

Your doctor will measure a 'gas transfer factor', which decreases if there is significant scar tissue on the lungs or if the blood vessels in the lungs are affected. Measuring this annually can tell your doctor whether your disease is stable or worsening.

What do the results mean?

Even if you don't have symptoms, it's important to get your lung function checked each year. If you do notice any changes, such as coughing or shortness of breath, inform your doctor who can arrange an earlier assessment.

Cardiac Function Tests



The heart is one of the organs directly affected by scleroderma. It's important to check heart function annually, as cardiac changes can develop without

noticeable symptoms. Irregular heartbeats frequently present with no symptoms and can go undetected for years.

What is it?

Alongside common tests such as blood pressure monitoring and cholesterol blood tests, an electrocardiogram (ECG) can detect slower contractions of the heart, which may indicate scarred heart muscle.

Echocardiograms provide information about the structure and working of your heart and enable assessment of wall thickness. It can also assess the likelihood of PAH. Other tests of heart structure and function may be performed, such as a cardiac magnetic resonance imaging (MRI) scan.

How is it performed?

In an ECG, sensors are attached to your chest to detect the electrical signals generated by your heart. In echocardiograms, gel is applied to your chest and the cardiologist scans over your chest using a small probe.

A cardiac MRI uses magnets to produce detailed images of the heart that can assess muscle damage, scarring and cardiac function.

What do the results mean?

If signs of heart disease are found, your doctor may wish to start treatment such as beta-blockers, blood thinners or statins.

If you notice any symptoms before your scheduled test – such as chest discomfort, palpitations or swollen ankles – make sure you tell your doctor, who can plan a test early.

Kidney Function Tests



Kidney damage is unlikely to be noticed by the patient because symptoms are not obvious. This means kidney damage is easy to miss, making regular tests

essential. People with scleroderma can develop very high blood pressure due to changes to the blood vessels in the kidneys. The kidneys may become starved of oxygen and dangerously high blood pressure could damage other vital organs. If this goes undetected it can lead to 'renal crisis', which requires immediate hospital admission and may need dialysis or a kidney transplant.

What is it?

Blood tests can check how much of a waste substance called creatinine is in the blood. Creatinine is usually removed from the body by the kidneys, so high levels in the blood may indicate that the kidneys aren't working properly. This value is used to calculate your glomerular filtration rate (GFR), which estimates how many millilitres of waste your kidney filters in one minute.

How is it performed?

These simple tests usually only require a blood sample.



What annual tests are available for scleroderma?

From the SRUK – Scleroderma & Raynaud's UK website

What do the results mean?

If your GFR is less than 90 millilitres per minute, your doctor may perform other tests, including a urine sample to check for protein. An ultrasound or MRI may also be done to assess kidney structure.

Based on the results, your doctor may prescribe commonly prescribed medication to lower your blood pressure.

Blood Pressure Measurements



Blood pressure tests are another way to detect a scleroderma renal crisis.

Regular blood pressure checks are important for all scleroderma

patients, but especially recommended for people with antibodies to RNA Polymerase III or Scl-70, or those being treated with high doses of corticosteroid drugs.

What is it?

Blood pressure tests estimate how hard blood is being pushed against the sides of arteries as it's being pumped around your body.

How is it performed?

In a standard blood pressure test, a cuff is placed around your upper arm and inflated to restrict blood flow. The cuff is then slowly released, and the pressure recorded as the blood flow returns to your arm.

What do the results mean?

Blood pressure is measured in two ways: systolic (first reading, the pressure when the blood is pushed out of your heart) and diastolic (second reading, the pressure when your heart is resting).

'Normal' blood pressure is between 90/60 mmHg and 120/80 mmHg. If it is above 140/90 mmHg your doctor may wish to consider extra tests, such as those described in the kidney function tests section to determine the cause of your high blood pressure.

It's possible to measure blood pressure at home, which you may wish to consider if you have a higher risk variant of scleroderma. Your doctor will explain if you are in this group.

Pain Assessments



Pain can be one of the most challenging symptoms of scleroderma. Thickening of the skin can prevent patients from straightening their joints, leading to

stiffness and pain.

Chronic pain can be difficult to manage, but it can be treated. Early management of symptoms can drastically improve quality of life and reduce your risk of developing depression.

What is it?

Pain assessments aim to evaluate the severity of your pain, to identify its source and identify how best you can manage it.

How is it performed?

Pain is difficult for a clinician to measure objectively, so is typically assessed by questionnaire. Your doctor may ask you to rate your pain on a scale of 1 to 10 and how much it interferes with your daily activities.

Your answers may be used in conjunction with more quantitative assessments, such as tests of mobility or ultrasound assessments of skin thickening.

What do the results mean?

If your results indicate pain is affecting your daily life or getting worse, your doctor will discuss the options for treatment. There are various medications available, such as anti-inflammatory drugs to reduce inflammation and analgesics to relieve pain.

Medications can be used in conjunction with other treatments including physical therapy and psychological therapies such as mindfulness.

Additional Things to Discuss with Your Doctor



Sexual Wellbeing

Closely linked to the psychological effects of scleroderma are the impacts on sexual function, which affect

both men and women.

Men with scleroderma may experience erectile dysfunction and women can experience physical symptoms that make sex difficult, such as pain, stiffness and vaginal dryness. All patients can experience fatigue, lack of sexual desire and changes to your body which may make you feel less confident in the bedroom.

There are solutions to all of these problems, including the use of special lubricants and referral to psychosexual counselling. Even if your doctor doesn't ask directly, don't be afraid to tell them if you have concerns or questions.

Mental health and emotional distress

The effects of scleroderma are not only physical. Living with a chronic disease can be challenging and it's important to address the psychological side too.

It is estimated that at least 30% of people with a long-term health problem also have a mental health condition. Mental health discussions with your doctor should therefore be routine and there are a range of options available including counselling and CBT. In some cases, medications, such as anti-depressants, may also be useful.

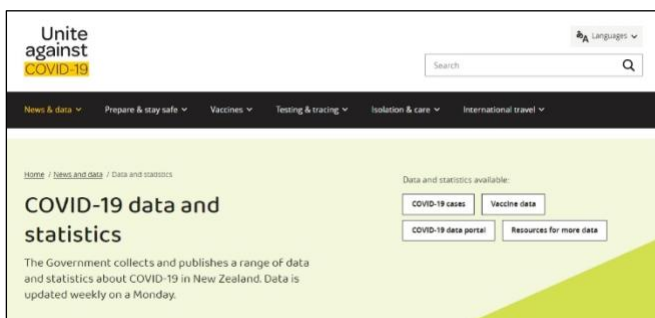
If you are struggling to cope, speak up.

Source: <https://www.sruk.co.uk/scleroderma/annual-tests-scleroderma/>



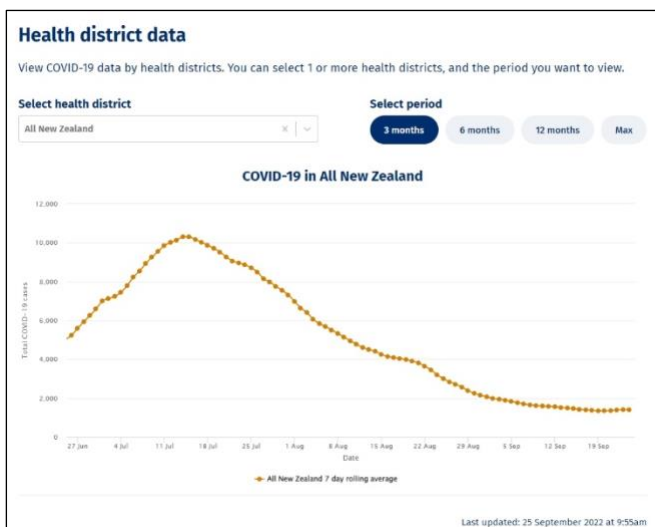
Covid-19: Update

The government has removed the Traffic Light system, here is the latest update on Covid-19 cases..

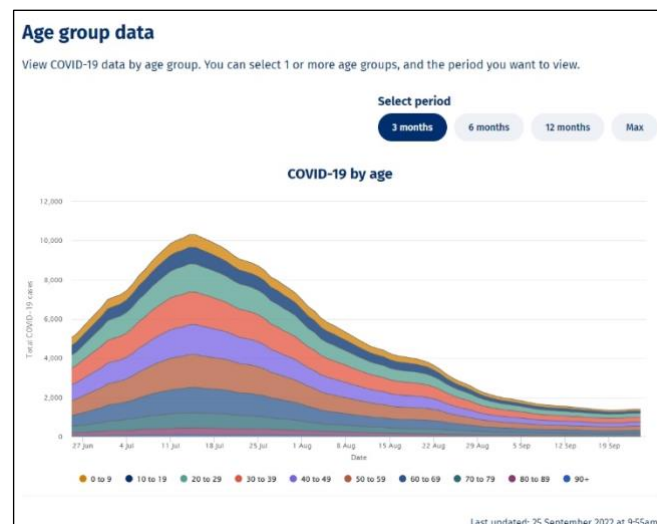


Some statistics from Ministry of Health:

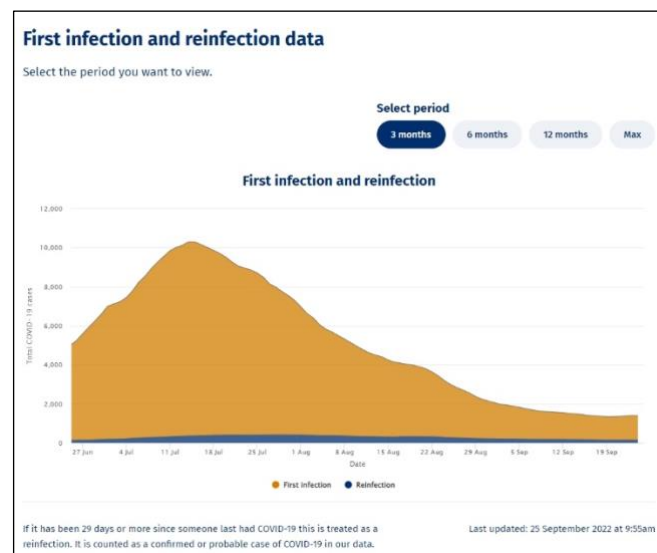
Graph showing the trend of Covid19 over 3 months from Health district data for all of NZ



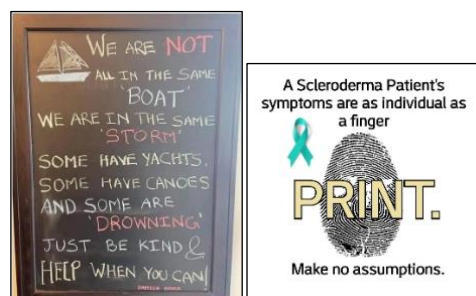
Graph showing Covid19 by Age group over 3 months



Graph showing first infection and reinfection of Covid19 over 3 months



Source: https://covid19.health.nz/advice/covid-19-data?_ga=2.173483687.528433941.1664078775-1614682841.1587286561



Members News



Hawkes Bay Scleroderma Group

The Hawkes Bay group regularly meet up. Last time we had a knitting meeting which was fun. Francis is a good knitter and gave Gail lots of hints.



Southland Scleroderma Group

Gore - 3rd of July.

So pleased to catch up with our Southland members at the Connected Eastern Southland Building in Gore with a Potluck Finger lunch. We had a delicious choice of food and seeing we hadn't caught up since our last meeting in November 2021, there was lots to talk about.

Lovely to meet our new member, Helen Parsons. We hope our future meetings work with your Auckland/Dunedin schedule Helen.

We also had Southern Mobility coming along showing us what is available at their business. Betty went away with a sleek, red aluminium walking stick, a fitting replacement for her wooden one which has served her well.

Thanks so much to Terry and Jenny for organising our day. Heather Milligan



Hedgehope - September 11th 2022

Thanks, Jenny, for our September meeting in a lovely rural setting at the Hedgehope Hall.

This time Jenny organised a friend who is starting her catering business to prepare our lunch, and it was delicious, even better for including Southland swede.

A delightful interlude where some of us talked about a personal item that is really special to us, enjoyed listening to Bettys watch that her husband presented to her after the birth of their first child many years ago, through to Jenny and Jeff showing us their daughter Maddy's Graduation Certificate, the first university graduate in the extended family.

A few of us commented that we had not had our yearly checks at the Rheumatology clinic at Southland Hospital. Subsequent Jenny contacted the Rheumatology department who are following this up, thanks Jenny.

Another bonus Jeff put a bowling mat out in the main hall, that was unexpected, playing bowls at a Scleroderma meeting.



Now Kimberley, you have missed out on our last two get togethers due to illness, hopefully we will see you all at the Saucy Chef in Invercargill on the 27th November.



New Plymouth Scleroderma Group

We had such a lovely catch up with Jenny Johansen, Judy Monk and myself out at the winery. These get togethers are wonderful and gives a chance to air concerns we have about scleroderma.



Jenny, Judy and Elle



Wellington Scleroderma Group

The Wellington Scleroderma group has new meeting dates. See table below: -

Wellington Scleroderma Support Group Get Together October 2022 – July 2023



Christchurch Scleroderma Group

We wish to thank Carolyn Barkhausen for all her hard work and friendship to the Christchurch group. Sadly Carolyn is not well and will not be organising this anymore. We send huge hugs and love to Carolyn at this time. Thank you Dianne Purdie for taking this over.



Waikato Scleroderma Group

It has been awhile since the Waikato Group were able to meet. Their Christmas luncheon is on December 3rd, venue to be advised nearer the time. It will be a fantastic way to finish off the year.

Date & Time	Venue	Address
Saturday 22nd October 2022 12.30pm	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 19 November 2022 1.30pm	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link https://otago.zoom.us/j/91651114858?pwd=ZkgzTzBXtmhrUk43czRKN2M5UTRldz09
Saturday 21st January 2023 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 22nd April 2023 12.30pm	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 27 May 2023 1.30pm	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link https://otago.zoom.us/j/92333389235?pwd=YnhUZk56ekc5c3BUUnM3WINnempXUT09
Saturday 22nd July 2023 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar



Members News continued.



Bay of Plenty Scleroderma Group

We had a small but cosy catch-up on Saturday morning at Nourish. So lovely to get together to share issues and ideas. I certainly went home with some contacts and more questions to ask my specialists. Thanks so much to Barb for organising and also to Vicki and Mary for listening and being supportive - so much good help and advice from the group!

We made a group decision that we liked Nourish so much we will meet there again on Saturday 12 November at 10am. Hope to see you again then. I'll send out a reminder nearer the time. Until then, take care and stay warm!

Cheers,
Millie



Waipa Scleroderma Group

Our ladies here in Waipa are all managing their own ups and downs, needless to say we haven't all been able to a catch up yet. But keeping hopeful in the Spring as the weather becomes warmer for longer that we will engage in face to face conversation again. We meet through Text messaging as sometimes details change at last minute, ideally once or twice a month. Three of us are in our mid 50s, two of us have young families. Three have no children at home therefore fill time up with work or play. Always keen to have anyone pop along share a story or check in with their own health Journey.



Palmerston North Scleroderma Group

There will not be meetings in the Palmerston North area at this stage as we have no one up there to organise them. If you would like to have a meeting in Palmerston North, please get in touch with me and we will see what we can do.

Jenny Andrews, 0273166124, jennyred@xtra.co.nz

In the mean time you have been invited to join in with the Wellington group. See Wellington dates on page 14

Support Groups:

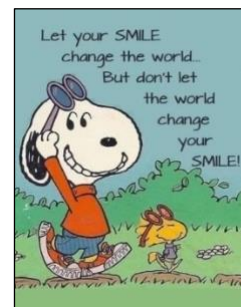
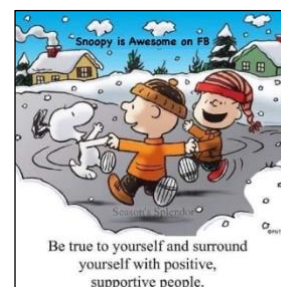
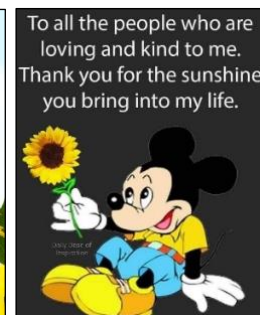
Support Groups are a wonderful source of friendship, information and fun.....

**Please do be mindful though that everyone is respected and has a chance to have their say.*

**It is also important to have some confidentiality within the meeting, (what is said in the meeting stays in the meeting)*

**Members should not give out medical advice but may share an experience - just advise that what you do may not be helpful to others. This is your own experience and emphasise this is what 'I do'.*

** And lastly it is important that there is no speaking negatively about medical professionals...*



Scleroderma NZ Inc.

Fundraising

Note Cards



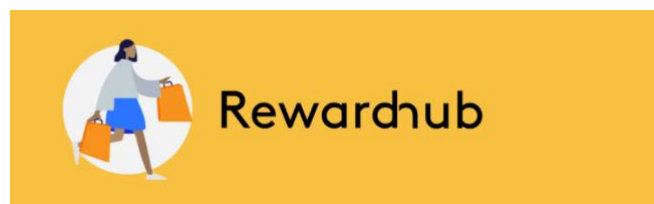
Thank you so much for submitting all your fantastic artwork for the fundraising note cards. The cards are now at the printers. They are looking fabulous. We have a set of 6 cards with envelopes that we are selling for \$10 a pack. *See the artwork in the photo above.* Each card has a blurb about Scleroderma NZ and who the artist/photographer was. *See Below photos.* They are a great way to make a donation to Scleroderma NZ and even better idea as an awesome Christmas gift. Get your order in today.

To order your own card pack, please email:
Jenny Andrews at jennyred@xtra.co.nz



Scleroderma NZ Inc.

Christmas Shopping



REWARDHUB

The thought of Christmas Shopping a little daunting? Why not do it from the comfort of home. Rewardhub is a website where more than 100 leading brands will Reward us with free donations, at no extra cost to you, when you shop online and are signed up to support us.

It's an easy place to shop and includes special discount codes on big brands in fashion, beauty, entertainment, travel, utilities, money, homeware, food, drink and more.

To learn more and sign up to our page, please visit:
<https://rewardhub.co.nz/scleroderma-new-zealand-incorporated?q=scleroderma>

Below are some examples of where you can shop through rewardhub

Countdown
Life Pharmacy
Paper Plus
Ezibuy
Mighty Ape
Cotton On
Bargain Box
My Food Bag
Hello Fresh
Rodd & Gunn
Lego
Bras N Things
Hallensteins
Skechers
Equipo
Vans
Uggs.com.au
Vistaprint
Wotif
Booking.com
Forever New
Converse
Bedpost
Contiki
Airbnb
Fishpond
Specsavers
Tarocash



Noticeboard:

Wellington support group meets:

Wellington meetings have re-started and new dates for the remaining year of 2022 and the new year of 2023 are published above on page 14.

For any enquiries please contact Dianne:

diannepurdie@xtra.co.nz,

Christchurch support group meets:

Venue: *The Great Escape Café, Burwood Hospital, 300 Burwood Road, Burwood, Christchurch*

Saturday 26th November 2022, 2:00pm to 4:00pm

Saturday March 25th, 2023, 2.00pm to 4.00pm

Saturday May 27th, 2023, 2:00pm to 4:00pm

Mid-Year lunch Saturday 22nd July 2023, 12pm, **Venue tba**

Saturday September 23rd, 2023, 2:00pm to 4:00pm

Saturday November 25th, 2023, 2:00pm to 4:00pm

We welcome any new members to come along too.

Please contact Dianne Purdie if you would like to join in;

diannepurdie@xtra.co.nz, 04 479 5548

Southland support group meets:

Sunday November 27th, 2022, **12pm**

Venue: *The Saucy Chef, Corner St Andrew and Sydney Streets, Invercargill* ☺ Please come along in your Christmas colours, **Green/Red** etc, you are also

welcome to wear a Christmas hat.

Please contact Heather if you wish to join us.

milliganseeds@xtra.co.nz

Sunday February 26th, 2023. This will be held in **Gore**.

Sunday April 30th, 2023. **Winton/Hedgehope**

Sunday June 25th, 2023. This will be in **Invercargill**

Sunday September 10th, 2023. This will be in **Gore**

Sunday November 19th, 2023.

Venue: Will decide as a group at the previous meeting

Waikato support group meets:

Venue: **To be advised nearer the time by Linda.**

We will be meeting again in 3rd December for our Christmas Luncheon. Linda will be in touch with the details. If you would like to join in with the Waikato

Group, please contact Linda Bell. linda.bell@hotmail.co.nz

Phone: **07 8535434**

Mobile: **027 548 1214**



Waipa support group:

Our group are looking to meet mid-October for lunch.

Venue: To be confirmed in Cambridge, picnic or cafe depends closer to the date on weather. Erena will text you the details.

All welcome, in case of changes please contact

Erena Bruce, Mobile: 021 186 9680.

Palmerston North support group:

See Wellington dates on page 14.

New Plymouth support group meets:

This group meets regularly, to attend the New Plymouth Support Group please get in contact Elle Bray

1elle@xtra.co.nz

Blenheim/Nelson support group:

Jen Soane is organising the Blenheim/Nelson support group so if you would like to attend please get in touch with Jen.

jennasoane@gmail.com

Hawkes Bay support group:

Tuesday 11th October, 2022, 10.30am

Venue: Co-op Café, Pakowhai Road

To join in with the Hawkes Bay Support group please get in touch with Gail Neilson, gail_neilson@hotmail.com

Bay of Plenty support group meets:

Saturday 12th November 2022, 10.00am to 11am

Venue: *Nourish Café, Te Puna*

Everyone stopping by Tauranga is welcome to join us, just let someone know. Please contact either:

Jane: janepuckey99@gmail.com

Mary: marybestrd3@gmail.com

Alumie: alumie.uow@gmail.com

Otago support group:

Please contact Vanessa if you wish to join us.

Nessie332@gmail.com



Welcome to Scleroderma New Zealand Inc.

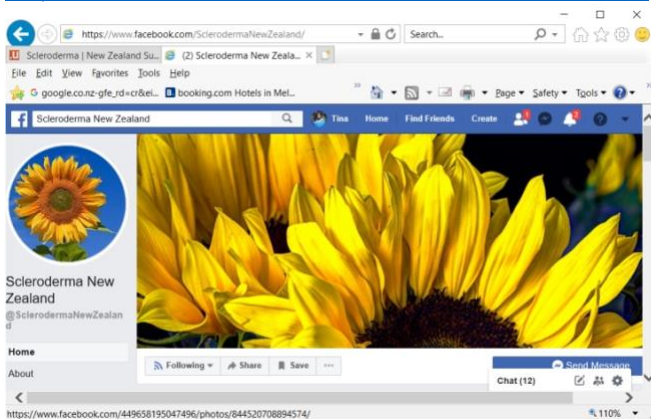
To all our new members, who have recently joined us – Welcome....

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.

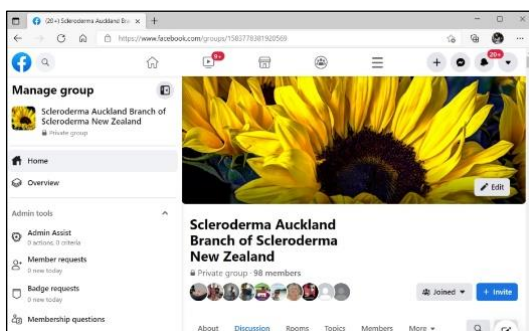
Link to our Website address below: -
<http://scleroderma.org.nz/>



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 altinamclean@xtra.co.nz
Secretary:	Jane Sainsbury jsainsbury@xtra.co.nz
Treasurer:	Gordon Purdie gordon.purdie@xtra.co.nz
Newsletter:	Tina McLean altinamclean@xtra.co.nz Jenny Andrews jennyred@xtra.co.nz

Contacts:

Find a Scleroderma a Support Group near You:

Bay of Plenty:	Alumie Nguyen, Email: alumie.uow@gmail.com
Waikato:	Linda Bell, Email: linda.bell@hotmail.co.nz
Hawkes Bay:	Gail Neilson, Email: gail_neilson@hotmail.com
Waipa:	Erena Bruce, Email: glenanderena@xtra.co.nz
New Plymouth:	Elle Bray, Email: 1elle@xtra.co.nz
Wellington:	Dianne Purdie, Email: diannepurdie@xtra.co.nz
Blenheim/Nelson:	Jen Soane, Email: jennasoane@gmail.com
Christchurch:	Dianne Purdie, Email: diannepurdie@xtra.co.nz
Otago:	Vanessa Gray, Email: Nessie332@gmail.com
Southland:	Heather Milligan, Email: milliganseeds@xtra.co.nz

