

Welcome.....	1
President's Report.....	2
Memorials	3
Coping with Grief.....	4
Members Stories.....	7
Scleroderma and the Ordinary Girl...	11
Coping with Scleroderma.....	12
How to manage work when you have a chronic illness.....	14
Nature Study.....	15
Mobility Parking.....	16
Members News.....	17
Events & Happening	20
Upcoming.....	21
Helpful Hints/Jokes.....	22
Notice Board.....	23
Contacts	23

Scleroderma

New Zealand support group

Spring 2019

Greetings to you all.

Welcome to our Spring edition of our Scleroderma Newsletter. We hope everyone is well.



We have a lot of stories from our members and a wealth of information to share.

Thank you to Dianne and Gordon for organising a very enjoyable and delicious afternoon High Tea during our Wellington Group meeting in August. A great time was had by all and we enjoyed catching up with each other.

We hear first from Dianne with her presidents report. She keeps us up to date with what's going on around New Zealand.

We have a Memorial to Terry Horne, Allison O'Sullivan and Lorraine Holbrook

We also have lots of news and events happening from our members. Heather found the following information about sunflowers. ***I reckon we change the words 'nutrient-rich soil' to 'encouragement and support' and we have what Scleroderma NZ is all about. – Heather***

Sunflowers found to share nutrient-rich soil with others of their kind

The natural world is sometimes portrayed as a vicious gladiatorial arena in which only the fittest, most selfish specimens survive.

Not so for the sunflower: a study has shown that the plants co-operate below the surface, sharing nutrients and demonstrating the kind of collaborative behaviour once believed to be restricted to the animal kingdom.

The research looked at how the common sunflower, *Helianthus annuus*, deploys its roots to forage for sources of nutrition. Each plant has a main tap root off which smaller, hairy tributaries grow. Unsurprisingly, a lone plant will send out more of these secondary roots when it encounters a patch of nutrient-rich soil.

This behaviour changes when it has a neighbour that is as well placed to benefit from the same fertile patch. In such cases, each sunflower sends out fewer roots, as if they have agreed not to compete. Declining to fight for nutrients, they effectively share resources.

The paper, which is published in Proceedings of the Royal Society B, suggests that each plant is responding to its "social environment". Sunflowers, in other words, seem to demonstrate a kind of vegetative egalitarianism.

Presidents Report:

September 2019



Dear All, time has flown by this past three months and our society has had some difficult times with the very sad loss of another three dearly loved and appreciated members of our society. Allison, Lorraine and Terry.

We will be feeling the grief especially the support group members from

Invercargill, Nelson and South Auckland.

We all need to be kind to ourselves over this difficult time, and understand that we all will grieve differently. Please remember to reach out to one another within your groups for support over this time. We have included a section on how to cope with grief. I hope that it will help.

I would also like to extend our sincere kindest wishes to Barbara and John Spavin. John is going through a difficult time with his health and our love and support are extended to them both.

Also a huge thank you to those of you who have written in with your personal stories, they are very heartening and inspiring and will encourage us all. I look forward to reading more stories of your journeys with Scleroderma, they are much valued. You are all very brave and show a lot of courage, thank you so very much.

It is nice to see Spring, it has been long awaited, but a fairly mild winter all up. But the Raynaud's still liked to make itself sincerely known!

A huge thank you to Tina Mclean and Jenny Andrews for taking over the newsletter from Barbara and John. They had some big boots to fill, and they came through with full marks!. A big thank-you, it isn't easy putting a National newsletter together, and they will rely on you all, out there to fill them in on your recent activities and helpful information.

We had a nice surprise back in July, When Scleroderma New Zealand and the Scleroderma Patient Intervention Network from Canada, formed a formal partnership.

Currently we have five group leaders who have applied to go into the randomised trial for the SPIN leadership program. If any of us are in luck, at being picked, the trial will go for 13 weeks as follows:-

13 weekly sessions of 60-90 minutes led by a trained instructor

Each week tackles one aspect of leading a support group, including structuring a group meeting, recruiting new members, fostering a positive group culture, supporting yourself as a leader, and many other topics

Participants can attend the online videoconference sessions from the comfort of their own homes

Supplementary resources include:

1. A workbook that summarizes all modules.
2. An online forum where participants can discuss what they've learned with other participants.
3. An online Resource Centre with educational videos and support group activity ideas.

At the end of 13 weeks, participants receive a certificate attesting that they have successfully completed the program

Next in line we are currently organising a full day seminar in Christchurch for the 23rd of November at Burwood Hospital.

This is a combined effort of the members in the Christchurch group.

We are currently getting a few speakers together. We will look forward to sending out the program in the near future, so if you are in Christchurch at the time please go along, you will be made most welcome.

Next on the agenda is a seminar in Invercargill which is being organised by Jenny Andrews for September 2020, which is terrific and then another great seminar in Hamilton organised by Linda Bell, a date to be finalised. Great efforts and I hope as many people as possible will be able to attend.

I hope you are all as well as can be, take time for yourselves, to look after your well-being, it is most important to help you through your Scleroderma journey. All the best,

Dianne



Memorials

It is with great sadness that we bring the news of three of our members who have passed away.

Memorial for Terry Horne – 7th of September aged 66 years Nelson.

Our Sympathy goes out to Terry's wife Maggie and family for the great loss of Terry on Saturday the 7th of September 2019.

We had great pleasure meeting Terry and Maggie a few years ago and recently at the beginning of this year in Nelson. Terry had a very difficult struggle with Scleroderma for a few years, he showed great courage and determination and kept going with all the loving support from Maggie.

Terry was very generous in supporting Scleroderma New Zealand over the years. He was a very helpful and kind person and will be sadly missed.

Dianne Purdie



Memorial for Allison O'Sullivan - 21st of July aged 64 Waiuku.

Our Sympathy goes out to Allison's husband Ken and family for the great loss of Allison on the 21st of July 2019.

We had a lovely time meeting Allison and Ken at Linda's seminar in Hamilton in 2018. Allison wasn't very well at the time, but she was extremely cheerful and positive and full of life.

It came as a big shock to us that Allison had passed away. Her scleroderma and PAH took hold unusually very rapidly. Allison gave the people she met lots of cheerful and positive caring help. Allison was very much lovingly supported by Ken.

We will miss Allison's happy personality and support.

Dianne Purdie



Memorial for Lorraine Holbrook – 6th September aged 43 years Gore.

Lorraine Holbrook, passed away peacefully at home in Gore.

I do remember attending our first get together that Maureen Anderson organised about 6 years ago in Southland. A young lady 'bounced' up to me, introduced herself as Lorraine and made me feel very welcome. I thought that's great, Lorraine has come to support her Mum or Dad. When we sat down and introduced ourselves as a group, I was stunned that it was that not only Lorraine but another young woman, Rachael, had Scleroderma.

Over the years it was a delight to catch up with Lorraine, she was so positive and had a caring and enquiring mind. She had no qualms about showing us her amputated finger and talking about flouncing behind the hospital curtains and not reappearing until she had completed an infusion. Her candour in making happenings which we may in the future have to deal with, a normal event.

I was shocked when Jenny let me know of Lorraine's death, I had heard she was ill but thought in typical Lorraine fashion she would bounce back as she had in the past. She lived for 43 years and packed so much into those years. She loved talking about her 2 children, Erica and Tegan. We all were delighted to see the photos when she married Shane, sunflowers were everywhere. She will be so missed by her family, friends and her 'Scleroderma family'

Heather Milligan



Grief and how to handle it

Health Navigator NZ

Grief is our reaction to loss. It includes the emotional, physical and mental responses we experience when we lose someone, or something, that we love or value.

Key points

Grief can be painful. When you are grieving, you may feel a range of emotions such as sadness, shock, anger and distress.

There is no 'correct way' to deal with grief. Be kind to yourself. Allow yourself time. Rest.

You may find it helps to talk to someone, or to express how you are feeling in some other way.

Some people find they need moments of distraction from their grief, to stop it becoming too overwhelming.

If you have ongoing feelings of grief that become overwhelming and heavy, seek advice and support from a trusted friend or your doctor.

What causes grief?

Everybody experiences grief in their lives. It helps you to distinguish what you value in your life; what you find important. You may experience grief when you lose things you love, such as:

- Locations – through changing schools, moving houses or cities.
- Your sense of place – from losing your spot in a sports team or being made redundant in your job, or because you feel that you yourself have changed.
- Pets – losing a long-term companion can be traumatic and sad.
- People – due to death or a relationship ending or experiencing a relationship changing for the worse.
- Good health – due to accident or sickness.
- Things you own – by mistake or from theft.

What does grief feel like?

Grief is our body's natural reaction to sadness and loss. Everyone experiences grief differently, but common feelings include:

- **Grief feelings:** These will come in waves, you might experience some feelings, but not others.
- **Shock/disbelief:** You might feel in denial, as if you've woken from a nightmare. You may feel jaded, disoriented, emotionless or vacant. Reality

may take a while to come to terms with.

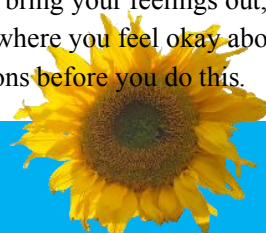
Sometimes an event can be so terrible you won't want to accept it as reality.

- **Sadness/ wanting to cry:** This can help to release emotions when you experience them, rather than suppressing them. After crying you tend to feel clearer and relieved.
- **Anger/blaming:** You might feel mad. You may want to blame a specific person for the event. Or you might feel guilt and feel that you caused the event.
- **Yearning:** There is a space in your life where that thing or person used to be. You know that you can't have things how they were again, but you dream about it, discuss with friends and family and think about it very often.
- **Out of control:** You might not be able to stop crying. You might feel anxiety because you have lost control of your emotions – tears want to escape without warning. This will stop in time.
- **Physical changes:** Your body grieves as well. You might feel unwell overall with stomach pains or headaches, you may become more susceptible to colds for a period. You may have an appetite shift or feel fatigued and run down.

How to cope with grief

There is no 'correct way' to deal with grief. We all grieve differently and in our own time. There are many ways to deal with grief in your life:

- Be kind to yourself. Allow yourself time. Rest.
- Chat with somebody you trust about how you feel – friends, family, minister, school counsellor, phone helpline such as Whatsup, Youthline or Lifeline. Talking won't change things, but it can feel good to vent and get things off your chest.
- Draw or write out your mood. You may want to do this a few times because your feelings will come and go.
- If you have them – browse over pictures of the person or thing you have lost. This may increase your feeling of loss quite intensely. It may help you to bring your feelings out, ensure you're in a place where you feel okay about exposing your emotions before you do this.



- Say farewell to the person or thing you have lost by writing a letter. You can write whatever you like because it's only for you. You can write about that person, what you loved about them, what used to frustrate you about them, the things you enjoyed together.
- Escape from your grieving for a while by doing something leisurely – watching TV, going for a walk, reading, seeing friends, playing a sport. Something that gives you a break.

Caring for others

If you have a friend who is grieving:

- Let your friend/family member understand that you realise that they're having a difficult time and that you are there for them if they need to chat or want to go out somewhere.
- Remember that your presence is enough, just be there for him/her.
- Discuss with them the tips you've read on this page about methods to cope with their grief.

Ongoing grief

If you have lost somebody or a thing that you loved dearly, you might experience grief over a longer period of time. If these feelings are overwhelming, severe, or you feel like you need help to cope with your grief, its important you consider talking with someone you trust and visiting your doctor.

Prolonged grief can sometimes lead to depression. Signs of depression include:

- ongoing feelings of hopelessness, anger or unhappiness lasting 2 weeks or more
- trouble focusing and making choices
- no longer excited about things that usually would excite you
- thoughts about suicide and dying.

Grief is our reaction to loss. It includes the emotional, physical and mental responses we experience when we lose someone, or something, that we love or value.

Key points

1. Grief can be painful. When you are grieving, you may feel a range of emotions such as sadness, shock, anger and distress.
2. There is no 'correct way' to deal with grief. Be kind to yourself. Allow yourself time. Rest.

3. You may find it helps to talk to someone, or to express how you are feeling in some other way.
4. Some people find they need moments of distraction from their grief, to stop it becoming too overwhelming.
5. If you have ongoing feelings of grief that become overwhelming and heavy, seek advice and support from a trusted friend or your doctor.

What causes grief?

Everybody experiences grief in their lives. It helps you to distinguish what you value in your life; what you find important. You may experience grief when you lose things you love, such as:

- Locations – through changing schools, moving houses or cities.
- Your sense of place – from losing your spot in a sports team or being made redundant in your job, or because you feel that you yourself have changed.
- Pets – losing a long-term companion can be traumatic and sad.
- People – due to death or a relationship ending or experiencing a relationship changing for the worse.
- Good health – due to accident or sickness.
- Things you own – by mistake or from theft.

What does grief feel like?

Grief is our body's natural reaction to sadness and loss. Everyone experiences grief differently, but common feelings include:

- **Grief feelings:** These will come in waves, you might experience some feelings, but not others.
- **Shock/disbelief:** You might feel in denial, as if you've woken from a nightmare. You may feel jaded, disoriented, emotionless or vacant. Reality may take a while to come to terms with. Sometimes an event can be so terrible you won't want to accept it as reality.
- **Sadness/ wanting to cry:** This can help to release emotions when you experience them, rather than suppressing them. After crying you tend to feel clearer and relieved.
- **Anger/blaming:** You might feel mad. You may want to blame a specific person for the event. Or you might feel guilt and feel that you caused the



event.

- **Yearning:** There is a space in your life where that thing or person used to be. You know that you can't have things how they were again, but you dream about it, discuss with friends and family and think about it very often.
- **Out of control:** You might not be able to stop crying. You might feel anxiety because you have lost control of your emotions – tears want to escape without warning. This will stop in time.
- **Physical changes:** Your body grieves as well. You might feel unwell overall with stomach pains or headaches, you may become more susceptible to colds for a period. You may have an appetite shift or feel fatigued and run down.

How to cope with grief

There is no 'correct way' to deal with grief. We all grieve differently and in our own time. There are many ways to deal with grief in your life:

- Be kind to yourself. Allow yourself time. Rest.
- Chat with somebody you trust about how you feel – friends, family, minister, school counsellor, phone helpline such as Whatsup, Youthline or Lifeline. Talking won't change things, but it can feel good to vent and get things off your chest.
- Draw or write out your mood. You may want to do this a few times because your feelings will come and go.
- If you have them – browse over pictures of the person or thing you have lost. This may increase your feeling of loss quite intensely. It may help you to bring your feelings out, ensure you're in a place where you feel okay about exposing your emotions before you do this.
- Say farewell to the person or thing you have lost by writing a letter. You can write whatever you like because it's only for you. You can write about that person, what you loved about them, what used to frustrate you about them, the things you enjoyed together.
- Escape from your grieving for a while by doing something leisurely – watching TV, going for a walk, reading, seeing friends, playing a sport. Something that gives you a break.

Caring for others

If you have a friend who is grieving:

- Let your friend/family member understand that you realise that they're having a difficult time and that you are there for them if they need to chat or want to go out somewhere.
- Remember that your presence is enough, just be there for him/her.
- Discuss with them the tips you've read on this page about methods to cope with their grief.

Ongoing grief

If you have lost somebody or a thing that you loved dearly, you might experience grief over a longer period of time. If these feelings are overwhelming, severe, or you feel like you need help to cope with your grief, its important you consider talking with someone you trust and visiting your doctor.

Prolonged grief can sometimes lead to depression. Signs of depression include:

- ongoing feelings of hopelessness, anger or unhappiness lasting 2 weeks or more
- trouble focusing and making choices
- no longer excited about things that usually would excite you
- thoughts about suicide and dying.

If you are concerned about depression, seek support and advice from a trusted friend, your doctor or by calling one of the support groups listed below.

Support

There are many organisations in New Zealand which provide support, advice & counselling to help those affected by loss and grief, including:

The Grief Centre provides counselling, support groups, information, resources and training. Auckland based. Phone 09 418 1457.

Skylight NZ information, education, professional services and support. Wellington-based. Freephone 0800 299 100
List of counselling helplines Mental Health Foundation



Members Stories:

Martine Fremaux - How the healing power of horses helps me live positively and successfully despite having Scleroderma...



I felt I would like to tell everyone the things Martine has achieved after her Scleroderma diagnosis including her riding, because her news is inspiring and positive. Setting goals which require confidence, strong motivation and hard work have assisted her to overcome the pains, fears, trials and tribulations of living with Scleroderma.

Martine was diagnosed with Scleroderma 5 years ago. At the time of diagnosis, she was not working. She lives on a life-style block with her husband Neil, her son Zane, 4 horses, 8 chickens, 2 dogs and 2 cats! Martine has a life-long love of horses. An integral part of her journey towards recovery was walking down to the horses to feed them every day. That gradually lead to her riding them, for 10 minutes a week.

Having managed the challenges of looking after horses and starting riding again, led to Martine starting a Mātauranga Māori degree. This was no mean feat in itself because a component of this intense degree involved seven-day courses which started at 6am and finished at 9pm. Several sleeps were needed during those courses, but a stubborn determination ensured she finished the degree, after three years of blood, sweat and tears!

She then returned to work as an Early Childhood Teacher, where despite several work challenges, her health took a turn for the better. "Chris, one of the reasons my health improved so drastically was, as an ECE teacher you are on the move all day." Martine is now a Mentor Teacher for a major educational provider in Auckland. She flies to Auckland every two months for two weeks at a time, as mentoring for all the teachers of six ECE centres keeps her busy.

At the beginning of 2019, Martine returned to long distance horse riding. Martine's first trek was a 17-kilometre fund-raiser trek at Stormy Point. Stormy Point is a working sheep and beef hill country farm, so the terrain is steep, very steep.

On her Facebook page, Martine wrote: "Survived a 5-hour, 17- kilometre horse trek. Not a gentle stroll in the countryside as anticipated. More like a high-speed horse chase UP HILLS and DOWN HILLS - VERY, VERY STEEP HILLS WITH 'NO' PATHS. Thank you to Tag, my faithful steed who; jumped thistle bushes somewhat higher than needed, fell down a hole, cantered (e.g. fast) scaled precipices, and oh walked (yeah, nah). Thank you to Neil for being my support person!" She now regularly rides up to 3 hours and 20 kilometres without stopping (other than for a quick breather).

Her passions, such as horse-riding and teaching, inter-linked with a positive attitude and the ability to keep physically moving despite pain, has enabled Martine to seize all she can get out of life. "Every day I get fitter and stronger" was her comment to me. Taking the time to rest has reduced from 2-3 days on the sofa to soaking in the hot-tub and a few hours rest.

Surrounding herself with positive friends and a very supportive husband, has enabled Martine to overcome her challenges with Scleroderma. Her life is her family, horses, friends (new and old), farm and mentoring of other truly exceptional people, all encouraging her to strive to make the most out of her life. "I will not allow Scleroderma to be my life" was her parting comment to me.

By Chris Carlyon



Members Stories:

Adriana's Journey With Diffuse Scleroderma - I've been living with my scleroderma for thirty three years now..

Adriana Nicholls

In 1986, I was 29 years old and living in Britain, when my scleroderma struck. Despite the dreadful prognosis then, I've been living with my scleroderma for thirty three years now. I was more fortunate than most scleroderma patients in England at that time, because I was given an opportunity to be cared for by an extraordinary lady, called Carol Black. This is my story.



The onset of my scleroderma followed the breakdown of my first marriage. In February 1986, having never had a serious illness in my life, I went down with a massively debilitating dose of 'flu. It was probably at this time, that the tips of two fingers started going white occasionally, but because I was grappling with bigger issues, I assumed it was due to the severity of the English winter. Having booked a much-needed trip to N.Z. in March, I focused on getting well enough to make the long-haul flight to Auckland.

Time spent with my family, in the warmer weather was very restorative and I felt good on my return to the U.K. in April. But all was not well. Throughout May, my face and fingers became increasingly puffy and a simultaneous outbreak of severe tenosynovitis developed in both shins and both forearms. I struggled through work, wearing splints and bandages whilst also taking an array of non-steroidal anti-inflammatory tablets, which did nothing for my worsening problems! Come September, my G.P. signed me off for a month and realizing I was developing an auto-immune condition, referred me to a rheumatologist. My specialist was sure I was developing rheumatoid arthritis, so started me on his best medications and guess what - they didn't work either!

Knowing that my health problems were stress-related, I needed to move out of my marital home. Good friends offered me a tiny granny flat, built on to their property and I moved in at Christmas. By now, I'd been off work four months and the Personnel department sent me a letter

saying they would have to terminate my employment, if my sick-leave extended beyond six months. Desperate to get back to work, I started swimming three times a week. On the first visit, I was too weak to complete one width, but I persevered. Slowly, I built up my lengths and the puffiness began to diminish, despite very stiff tendons, I started to feel more myself. Finally, my specialist agreed to let me back to work, on reduced hours initially. I got back to work with two weeks to spare. My blood tests continued to show no R.A.

As the summer of 1987 approached, I was relieved to have 1986 and my mystery illness behind me (or so I thought). Work was going well and from left field, Mike came into my life, we were very happy. However, as winter set in again, so did my white fingers. On seeing them, my rheumatologist's face said it all! The skin biopsy results for scleroderma came through three days before Christmas.

My doctor was very kind, but a big dollop of hopelessness filled the air, as he told me I had a rare disease, for which there was no real treatment. He knew then, what I didn't understand at that time, that I had the RNA Polymerase anti-nuclear antibody - a diffuse form of scleroderma, associated with aggressive skin thickening and catastrophic renal failure(as it was known). We discussed a drug called D - penicillamine, which sometimes manages to slow disease progression - he would put me on it. However, I was also told not to get my hopes up, because I may not be able to tolerate the side effects and even if I could, it simply might not work. Next, he mentioned a young rheumatologist called Carol Black, who worked in London, collecting scleroderma patients for research purposes. He offered me the choice of staying under him locally, or, travelling to London to see Carol.

I chose London and one of the first questions I asked her, was how long I had to live! If we can slow it down, you might get five good years. If we can't, it will all be over in two, came the reply. When I relayed this conversation to Mike, I told him we had no future, I was going back to N.Z. and he had to forget me. Mike's crazy reply was astonishing - We'll take the two years! I can look after you better if you stay here!

Dr Black was very nice and very thorough. She admitted all new patients for three days of base-line tests. At every out-patient appointment, she weighed us, listened to heart and lungs and did a full skin-score. The D-penicillamine began to work really well for me - it stabilised my condition for the next eleven and a half years.



During this time, Carol Black took a promotion at The Royal Free hospital and engaged Chris Denton as her long-term deputy. She now had fourteen hundred scleroderma patients under her wing. Her research team and the number of drug trials increased, as she gained a growing reputation in Europe, for stabilising challenging cases. She seemed to have an innate sense of what drug therapy would work for each patient. Now awarded the title of Professor, she used her position to acquire an empty ward, solely for her scleroderma patients. To meet the growing need, she had a fifth bed installed in every four-bed room. This was not ideal, but reflected her drive and compassion to improve the lot of scleroderma patients.

In 1990, Mike and I got married and then in 1997 I had a major flare up - my skin itched and tightened remorselessly. By the time I was admitted to the Royal Free, I was very ill. With Prof. Black overseas, the team put me on the IVIG (Intravenous immune globulin) trial, which was to be followed up with mycophenolate. The IVIG was supposed to knock the disease flat, but it didn't really work for me. I got serum fever and in the six week recovery period, the itching and tightening returned as aggressively as ever. I did not expect to see the following Christmas. But Prof. Black arrived back from the USA and declared that I needed methotrexate, not mycophenolate. The doctor running the trial was extremely put out, but Carol Black's judgement saved my life, I'm sure! Twenty one years later, I am still taking the methotrexate. I've had three further flare-ups, all of which were stabilised by increasing the methotrexate dose.

In 2002 Mike and I returned to N.Z. to support my elderly parents. Dame Professor Black retired the same year, but maintained close links with the Royal Free. Professor Chris Denton has taken the reins and the Royal Free Hospital remains the biggest European centre for research and treatment of our condition.

I have digestive issues like most of us and a raft of other problems have surfaced, over the last thirty three years. However, whether I've been in the U.K. or here in N.Z., the doctors have made the right decisions and got me through, despite a large sprinkling of pessimism. I couldn't have got this far without Mike's support and I am so grateful for every day I've been given. Diffuse scleroderma which flares up repeatedly is very rare. Out of every hundred scleroderma patients, about seventy will have the limited form of systemic scleroderma and the other thirty will have diffuse disease. Of the thirty with diffuse disease, only one or two of them will have recurrent flare-ups, such as mine.

The health system in England is set up differently to ours in N.Z. With a population of sixty five million, Britain now has nine specialist scleroderma units (or tertiary referral centres) through the country. Professor Denton completed a set of treatment guidelines for the U.K. in 2016 and under those guidelines, all new patients must be assessed by a tertiary referral centre. While I would like to see a tertiary referral centre in N.Z., I don't think it will happen because of the multiple health board system we have here. Instead, I understand a set of N.Z. guidelines are being drawn up, which will possibly be used to implement a "scleroderma management protocol" within each hospital.

Adriana Nicholls

Members Stories:

Linda Waters - She is Inspiring!

Have you ever refurbished a piece of furniture ?

Linda Waters has always wanted to rejuvenate a vintage bedroom chair (see photo) and once she completed that she was hooked.

Linda attends a workshop every week, achieving practical techniques with real results.

The pieces completed are fun, artistic and practical.



Note the lovely cushions and very mod ottoman. Linda completed both these prior to holidaying to UK / Somerset, to spend precious time with family. Now back, she is planning a much larger project of covering their lounge suite. Very inspiring Linda. Thankyou.

By Chris Carlyon



Members Stories:

Beth Richards – So positive!

I would like to share my Scleroderma journey with you all.

Hello to my Scleroderma friends.
My name is Beth Richards.

I would like to share my Scleroderma journey with you all.

From my mid 40s I experienced symptoms, from cracks in my finger tips that bled. Then my fingers were turning white and tingly when it was cold.
My fingertips became infected which sometimes led to gangrene, which took months to heal.
One finger refused to heal so my surgeon amputated the top knuckle. It doesn't bother me at all now.

I was diagnosed with high BP in 1997 and it is managed with medications.

We owned and managed an orchard growing Apples and Pears in Lower Mouere near Motueka for 14 years. It was very physically demanding, but I was super fit from the orchards work plus my running half marathons for many years. I started to tire easily and limp from my arthritic hip, so I walked from then on.

When I turned 50 in 2002 I felt like the wheels had fallen off.

I had my first hip replacement in early 2006 then my first shoulder replacement late 2006. From then until 2019 I've had at least 25 operations and several dislocations of both hips and one shoulder.

I developed a Haematoma in my right shoulder from an aspiration to check for infection. It finally burst then bled on and off for a week. By the time I was admitted to Nelson Hospital I had a massive infection. After 4 operations in 3 weeks the Surgeons removed my shoulder. I had septic arthritis which took months to heal. I cope very well without it.

I fell heavily and broke my pelvis and hip in 2011 which has resulted in major weakness.

I have muscle weakness which has led to my inability to walk far.

I've just been diagnosed with mild PAH.

I try to be a happy positive person and enjoy life.

Meeting my 4 Nelson friends in March this year has been wonderful. We meet when we can and share our stories over cake and coffee. Rosemary, Lisa, myself and we have enjoyed Terry's brief friendship. Sadly he passed away 2 weeks ago. We hope his wife Maggie will join us when we all meet again.

Last year I purchased a mobility scooter.
It has changed my life.
I have independence!!

I scoot down to Mapua from Ruby Bay hills in 35 to 40 mins.

Its lovely being in the fresh air and meeting with friends for coffee or lunch. My 2 granddaughters bike with me on the cycle tracks and footpaths. Lots of fun in the sun.

My life has changed a lot over the last 20 years.
I'm now 67.

I do miss not being able to spend time in my beautiful garden and walking on the beach collecting shells and interesting stones for my garden art.

My family, especially my children and siblings are so supportive and caring.

My husband Ron is wonderful and so caring.

He will do anything to make my life easier.

I have amazing friends who help me in many ways as well.
I'm a very lucky lady!

It's very easy to look back at what you used to do, but it's far more positive to look forward to what you can do now and be thankful and happy.

Summer is on its way☀

Cheers everyone

Fond regards Beth Richards. ☀



Beth with her daughter Liana and granddaughters Zoe & Pepa before her scootering days



When Choosing My Medical Team, It's All About Attitude

Kim's column from sclerodermanews.com

SCLERODERMA AND THE ORDINARY GIRL

by Kim Tocker



In my last column, I promised to share my experience with a new cardiologist, as well as his ideas about the likely cause of my heart issues.

I had been trying to find out why my heart goes into tachycardia, particularly when I attempt to do anything physical like making the bed or emptying the dishwasher. My general practitioner suggested I seek a second opinion.

The probable answer is a form of postural orthostatic tachycardia syndrome. I will explain more about this as the diagnosis becomes clearer and the specifics unfold. I've been struggling with this issue for a number of years, and the jury is still out as to the particular variety. It is likely associated with pooling of blood in my lower limbs, possibly caused by damage to my autonomic nervous system from my scleroderma.

It is complicated, and I need to see more specialists to get a better picture. However, I have discovered that although I thought it was a clear diagnosis I was desperately seeking, I was really looking for something else when I agreed to seek a second opinion.

I was searching for someone who would take my symptoms seriously, without implying that anxiety was the cause. It wasn't as important to me in terms of what he found, but rather that he was invested enough in me as a patient to search for an answer. At the end of the day, a diagnosis cannot be made if a doctor doesn't believe in me enough to bother investigating.

I have thought back to my gut feeling when I met my cardiologist for the first time. I immediately felt he was meeting me with an open mind and a genuine concern and curiosity about my symptoms. Instead of acting like an expert, he appeared open to a collaborative approach that put me at ease.

This particular doctor is just beginning his practice and is not well known in medical circles. Sometimes, I have stuck

with a specialist based on reputation rather than my own gut feeling during a consultation. I don't think I will make that mistake again.

While it is good to hear about others' experiences with a specialist and to consider training and reputation, I believe a doctor's attitude is essential.

From now on, an invitation to join my medical team ultimately will be decided by my instinct and a doctor's attitude. This scleroderma warrior is learning to trust herself a little better, and to ensure she gets the proper care she needs!

About the author Kim Tocker:

I'm 49 and live in Christchurch, New Zealand. I was diagnosed with Limited Systemic Scleroderma in 2013, and the disease has slowly progressed over the past three years. Prior to my diagnosis, I worked as a Counsellor/Therapist in private practice, however I was forced to close my practice in 2014 because the fatigue associated with the disease had become profound. Well before I studied, trained and worked as a Counsellor many years ago (at least 20) I was employed as a Dental Assistant. It is my belief that whilst working in this capacity I handled a number of chemicals that are now considered dangerous and this exposure may have been the trigger for my disease, together with an already existing genetic component. These days, my full time job is to work hard at my self-care and manage my symptoms as best I can. Part of this management is to reflect on and write about my experiences about living with Scleroderma in ordinary day to day life. This helps me a great deal, and I hope it helps my readers, both those who also suffer with Scleroderma, and to help raise awareness in those who do not. I enjoy adding a little humour to my writing, because honestly, I feel it's important we all have a wee laugh from time to time. However, my writing usually includes a serious reflection of some sort. On a personal note, I am the wife of one, and the Mother of three boys. My husband Max is my main caregiver, and I am very fortunate to have such a loving and giving spouse. My children are aged 21, 19 and 13, and our two oldest boys live in different parts of New Zealand to study and work. Our youngest will be starting High School in 2017. We live with a menagerie of animals, including two dogs and four cats.



Coping With Scleroderma :-From the Scleroderma Foundation.

Any chronic disease is life changing. Symptoms demand your attention. You have to adjust your schedule to accommodate medications, doctors appointments and treatments of various kinds. You need to arrange for rest and relaxation and do things more slowly than you used to. You need to balance work and rest. You will have to confront changes in your body and the way you see yourself as well as the way others are used to seeing you. The people around you need to adjust as well. They live with the changes of your disease, too, even though they don't experience your symptoms. Perhaps the biggest adjustment is learning to work with and through the changes in order to cope with daily life. We hope this information below will help you learn to live well with scleroderma.

THE BEGINNING

Because scleroderma can present itself in so many different ways, diagnosing it can be difficult. That means many tests and many trips to the doctor's office may be necessary before a definitive answer can be found.

For the patient, family and loved ones, the waiting means lots of "what ifs" and anxiety can result from anticipating the worst. Sleeplessness, irritability and the tendency to be distracted are common at this point. The tendency to mis-hear what doctors say because of worry is also common.

People sometimes report that any aches and pains they have may be made worse by the increased anxiety during this phase.

Hints

- Take notes about what your doctor tells you. If you have any questions later after you have absorbed the information, you can refer to those notes and ask questions. If you can, take a friend, a family member and/or a tape recorder along so the information can be reviewed later. This reduces the chance that worry will inhibit hearing the information. It may also help your family member understand the disease.
- Share your worry with people you trust, if this method of reducing anxiety works for you. Spouses and partners can be especially eager to know how you are being affected

- Recognize that this can be a difficult time. Just knowing that fact might help you balance some of the challenges. Being proactive in doing things can channel stress and anxiety into positive action. Examples include going after and finding information; asking questions of medical professionals; partaking in relaxation techniques and/ or

exercise; getting away for a day or a weekend either with someone or alone. All of these can help you reduce stress and can help you cope during this difficult time.

- It has been reported that people who are struggling with a set of problems new to them often drop the fun activities in their lives because they don't have the energy. Remember to retain the activities you enjoy and are capable of doing. Learn to delegate other activities to those who care. They won't mind, especially if it helps you manage things better.

THE DIAGNOSIS

The second part of your journey starts after you have been diagnosed with scleroderma.

You might get a definite diagnosis of scleroderma and then have a physician say that it is terminal, untreatable, or that the treatments are all experimental. These are all situations that people with scleroderma have reported and they have also reported being angry and discouraged. You are not alone in your frustration.

Hints

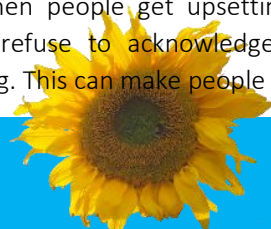
- Keeping notes and lists of questions are important. Start a workbook: keep your lab work reports, medication lists, important phone numbers, reports of appointments, and lists of questions in one loose leaf notebook that you can add to or subtract from as necessary.
- Express your concerns to your physician; if he/she can't help you, ask to be referred to someone who can.
- Remember to take a friend or a tape recorder along. Many people with scleroderma experience a smoother course. For example, you might have tests that all point to the same diagnosis and you also have a physician who knows what the diagnosis means and can either treat you or refer you to someone who can.

People who have smoother experiences often report that it was still a difficult time because they initially knew nothing about the disease. Patients say having a healthcare provider who listens and works with them as partners in their care makes it much easier to adjust.

THE EMOTIONS Denial, Anger and Depression

Once testing has occurred and a diagnosis is made the next step is to determine what you want to do about it.

Sometimes when people get upsetting news they feel disbelief and refuse to acknowledge that anything is seriously wrong. This can make people feel better for a



Coping With Scleroderma – continued...

short time, but the reality of the situation will eventually become undeniable.

When you keep denying that something is wrong, you cannot move forward into helpful activity. One way to absorb and deal with the news of your diagnosis is to give yourself some time to think and accept what has happened. Listen to your favorite music, watch videos that make you feel good, bask in the sun in a garden, or lie in a warm tub and think.

Hints

- Think about your resources—people who care about you, your talents and abilities, available information that can help you understand what is happening to you, crises you've confronted in the past and conquered.
- Think about your options: learn about your illness and how you can live and function with it, meet others with scleroderma who are functioning well, talk to someone who can help you confront your illness and support you while you do it.
- Call the local support group or **Scleroderma New Zealand 04 479 5548**.
- Think about the possible consequences of not tending to yourself—increasing worry, pain, disability, and depression.

Anger and Depression

After you've had time to understand the implications of the diagnosis, you may get angry and depressed at the same time. This is the next phase of moving toward an acknowledgment that changes are occurring. This isn't an easy phase to move through—not for you, and not for those close to you. But it is necessary, and as long as you know you're going through it, go through it with your eyes open.

Anger can be a very energizing emotion. It's during this time that patients typically do the following :

- Find and join support groups
- Seek out a physician who knows how to treat scleroderma
- Search libraries and the Internet for information they feel might be helpful.

Depression can slow people down. Patients describe feeling negative about everything, an increase in physical

symptoms and helpless/hopeless feelings, as well as a decrease in energy.

Fearfulness is also common. This is the phase during which a counselor (preferably someone who has experience helping people deal with chronic disease) could be helpful since he/she can be objective and help you to get angry/depressed feelings out in the open in a safe place—not on the job, directed at your loved ones or yourself. Your physician might also prescribe a medication that will help your energy level and even treat the physical pain.

Bargaining and Acceptance

While trying to cope with anger and depression, some people find themselves bargaining. This stage may take the form of praying, "God, if you'll only take this from me, I promise..." or being willing to take medicine with uncomfortable side effects if only it might "cure" the disease. Some go to herbalists, chiropractors and acupuncturists in hopes of a "cure." These are all ways of bargaining and another way of denying the reality of the disease.

Acceptance

So, how does a person come to accept scleroderma? There isn't any one way that patients reach that stage; some never do and some do so in part. Patients who cope well with their disease have these things in common:

- They have discovered the hope and strengths they have inside
- Have found people to help them along their way (friends, relatives, loved ones, healthcare providers, scleroderma support groups, counselors, or faith groups)
- Have learned to help others by getting involved in scleroderma organizations, educating their friends and the public and helping other patients through difficult times.

The most important underlying factor seems to be that patients who successfully cope with scleroderma have discovered that their lives are worth the fight.

The Scleroderma Foundation says

Please note that the above information is provided for educational purposes only. It is not intended to substitute for informed medical advice.



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.



"More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google."



Two-hour 'dose' of nature significantly boosts health – study

Researchers say simply sitting and enjoying the peace has mental and physical benefits.



Thank you Jo Harris for sharing

A two-hour “dose” of nature a week significantly boosts health and wellbeing, research suggests, even if you simply sit and enjoy the peace.

The physical and mental health benefits of time spent in parks, woods or the beach are well known, but the new research is the first major study into how long is needed to produce the effect. If confirmed by future research, two hours in nature could join five a day of fruit and veg and 150 minutes of exercise a week as official health advice.

The finding is based on interviews with 20,000 people in England about their activity in the previous week. Of those who spent little or no time in nature, a quarter reported poor health and almost half said they were not satisfied with their life, a standard measure of wellbeing. In contrast, just one-seventh of those who spent at least two hours in nature said their health was poor, while a third were not satisfied with their life.

“What really amazed us was this was true for just about every group we could think of,” said Dr Mathew White, at the University of Exeter Medical School, who led the study. The benefits of a two-hour dose were the same for both young and old, wealthy and poor, and urban and rural people, he said.

It also applied to those with long-term illnesses and disabilities, White said. “So getting out in nature seemed to be good for just about everybody. It doesn’t have to be physical exercise – it could be just sitting on a bench.”

The researchers were also surprised that it did not matter whether the two hours in nature were taken in one go or in a series of shorter visits, or whether people went to an urban park, woodlands or the beach.

Prof Helen Stokes-Lampard, the chair of the Royal College of General Practitioners, said: “It’s fascinating to see this link between exposure to nature and better health and wellbeing. This research makes a strong case for people to get out and about in more natural environments.

“More widely, patients often benefit from non-medical interventions such as an exercise class, learning a skill or joining a community group – often referred to as ‘social prescribing’. However, with the pressures currently facing primary care, many GP practices [can’t] spend the necessary time with a patient to link them with the most appropriate activity.”

The research, published in the journal Scientific Reports, used data from a Natural England survey, the world’s largest study collecting data on people’s weekly contact with the natural world. It did not include time people spent in their gardens, as this was not measured. But White said half of people saw their gardens as representing more of a chore than a pleasure in any case. The data showed that two hours was the threshold for positive impacts: spending much more than that in natural environments did not appear to have any additional benefits.

“I am continually surprised by the size of the effect,” White said. The boost to health was the same as previous studies have shown come from taking recommended levels of exercise, or living in well-off neighbourhoods compared with poorer areas.

The study did not attempt to find out why being in nature was so beneficial, but White suggested a sense of tranquillity could be the key: “Most people are under multiple pressures at any given time. So you go away in a natural setting, it is quiet, it is relaxing and it gives you time to start to process things.

“We are also increasingly finding that the richness in biodiversity of a setting seems to be important.

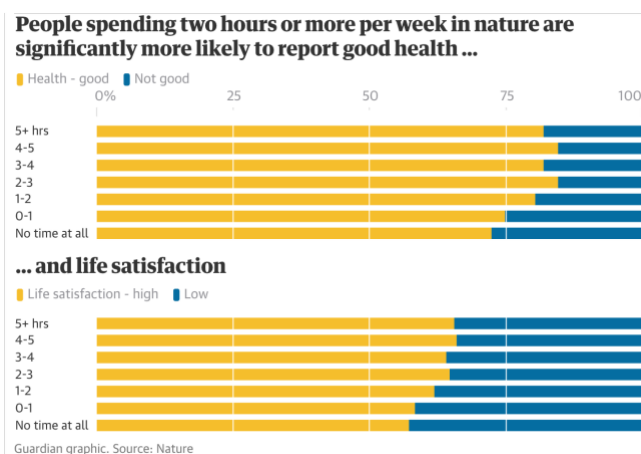


Two-hour 'dose' of nature significantly boosts health – study - continued...

We have tracked 4,500 people's visits from the same survey and what you find is they get more stress reduction if the location was an area of outstanding natural beauty, a site of special scientific interest or that kind of thing."

The researchers took a series of factors into account in reaching their conclusions, including the greenness of a person's neighbourhood, levels of air pollution, and whether they were married, had children or had dogs.

They could not completely take account of whether the health boost was down to taking more exercise. But the researchers wrote: "Research into shinrin-yoku – **Japanese "forest bathing"** – for instance, suggested that various psychophysiological benefits can be gained from merely sitting passively in natural versus urban settings."



Reminder: 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.

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.

How to apply for your permit by post or in person

Download the application form,

<https://ccsdisabilityaction.org.nz/assets/resource-files/CCS-DA-2018-Mobility-Parking-Permit-Form-Electronic-Editable.pdf>

or contact your local branch of CCS Disability Action and we will post a form to you.

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).

Check with your local branch which payment method they are able to process and post the completed form to them, or take it in to the branch.

A permit will be sent to you within ten working days from the date that we receive your application and payment. Permits can be cancelled if misused.



Members News:

Wellington Scleroderma Group

The Wellington Scleroderma group met up for a scrumptious High Tea provided by Dianne and Gordon .

On very wet windy cold **17th of August**, a group of us from the Wellington support group popped down to the **Epuni Mobility centre** to have a little tour through the shop, by their wonderful, empathetic retail managers.

We saw all sorts of helpful goodies, for the use in and around the home.

Like these soft grip utensils , Tap handle turners, Kettle Tipper, Mobility scooters, Walking frames



You name it, you can buy it.

You can buy on line at www.mobilitycentre.co.nz if you missed out on the visit, or if you live else where in New Zealand. The team at the Epumi mobility centre will be very keen to help.



Next we headed back to our meeting rooms in central Lower Hutt for a most welcome Devonshire Tea and chat. We all had a great time. Our Wellington group were very lucky to have Dianne and Gordon provide all the lovely and yummy afternoon High Tea that day. Dianne had made us fresh filled sandwiches and baked delicious scones, served with fresh cream and jam – yum! It was all very yummy and we devoured it all. Thank you Dianne and Gordon for making it such a wonderful meeting, on a very wet, windy and cold wintry afternoon. It was certainly worth getting out and about on the cold wet August day.

Tina



Wellington Group



Members News:

Nelson Update -

Beth Richards and Chris Carlyon met up in Richmond Mall for coffee.

From Beth:



Beth on left and Chris

Hi there. My name is Beth Richards and I live in Ruby Bay Nelson.

A few weeks ago Chris Carlyon and I met up in the Richmond mall with our hubby's for a coffee and a chat.

We hadn't met before but we got on so well.

I found it fascinating to talk to someone with the same problems that I had.

We both learnt a lot about the different procedures and operations we went through after being diagnosed.

It certainly makes it easier to talk to someone else who is dealing with Scleroderma and being able to cope.

I enjoyed Chatting to Chris and we hope to meet up again next time they visit Nelson.

Take care and keep warm everyone

Cheers Beth 🌻

From Chris:

It was a delight to meet Beth and her hubby Ron last month, while visiting our daughter and family in sunny Richmond, Nelson.

I am still thinking about Beth's friendly nature and the beautiful jewellery Ron makes. I felt Beth and Ron create something awesome together and are extremely happy to meet and share knowledge, time and experiences.

We will meet again and enjoy another informal face to face over a cuppa. Such a great way to connect and strengthen relationships and gathering understanding.

Thanks Dianne for putting us in touch.

Christchurch Update -

A group of lovely ladies met on the 27th of July at Merivale Mc Cafe.

It was a great turn out, they worked industriously working out a wish list for the seminar being held in CHCH this coming November.

The seminar is coming together, really well. The seminar is supported by the members of the group and we are having some pleasing results.

We hope that as many people as possible can come along and enjoy the seminar, it will be the first one for CHCH. The Christchurch group is a small group, so if as many people as possible can turn up and support these lovely ladies you will be made very welcome and your presence it will be greatly appreciate.

Southland Update

Jenny and Heather bring us up-to-date with happenings from down in Southland

Our Southland group sadly lost a valued member just recently with the passing of Lorraine Holbrook. Lorraine had been coming along to our group from the very beginning and she was always such a bright and positive person no matter what curve balls were thrown at her. She will be truly missed by all who knew her.

Since the last newsletter the Southland group have met up a couple of times. Firstly, on International Scleroderma Day with lunch at the Croydon Lodge in Gore. We had 20 turn up and were lucky enough to have Lorraine's sister Louise and her 4 children along also. Was lovely to see the children and they were so well behaved, the twin boys who were around 3 months old slept most the time. Unfortunately, because we changed our day from a Sunday to Saturday to accommodate scleroderma day the lovely Heather and Graham missed out. Still having the Sunday in their diary. Luckily, we rang them or they would have had a cozy lunch for 2 on the Sunday. Due to Heather not being there though we missed out on our usual group photo. The rest of us seem to forget. We had a wee discussion about our upcoming seminar in 2020.

Jenny



Members News:

Southland Update Continued...

Our next lunch was in Winton at the Magnolia Tree on Sunday 15th September. The lovely Jenny organised for us to meet in a café in Winton, I think we made the café our own as it was almost like musical chairs most of us moving around catching up with others and listening to the stories we all have, yes lunch did get eaten, but it was secondary to seeing each other and the time just flew by.

We did remember Lorraine Holbrook, there were a group of Southlanders who were able to attend her funeral service the previous Thursday. She will be so missed.

We congratulated Jenny and Tina as being worthy newsletter successor to John and Barbara..... And being 'good friends' with an editor we got a sneak preview to the Christchurch seminar in November.

Heather

Due to us being so far South we have decided to run a seminar in September 2020. This will be open to everyone in the country and will be on Saturday 26th September next year.

We are having it at Southland Hospital, Kew Road, Invercargill. Rachel Nally the rheumatology nurse at the hospital has agreed to work with us and help organize the speakers. So, save the date and we will update you with more info in the next newsletter. Would be great to welcome others from around the country.

If you would like to join in with the Southland Group, please contact either:

Email: Heather: milliganseeds@xtra.co.nz or
Jenny: jennyred@xtra.co.nz



Southland Group

Scleroderma Waikato Update

We have 10 members and we have been meeting at Robert Harris Café, Chartwell, Hamilton once a month for the past 7 Years now ?

Next year will be another seminar for Hamilton which helps the newly diagnosed and family's to learn and understand and most of all to meet other people around the Waikato area.

More information about the seminar coming soon—keep an eye out for it in the next Newsletter.

If anyone gets the Entertainment Books go to my Facebook page and where you can either get online anywhere in NZ or call in to Target Hamilton only to pick a book up. The money raised goes towards Scleroderma Waikato funds to help with the cost of Seminars.

LINDA BELL
SCLERODERMA WAIKATO



Southland Group



Events & Happenings:

Christchurch Scleroderma Seminar 2019

Burwood Hospital
Room 2.3a Second Floor

23rd November 2019

All Welcome

A Great Opportunity not to be missed !



Helen Hills:- Hand Therapy for Scleroderma Patients

Jan Ipenburg:- Medicinal Cannabis and Information from the Australian Scleroderma Conference

Maureen Anderson:- Psychological Impact of Scleroderma

Kirsten Rosser:- Gastro Problems and diet for Scleroderma Patients

Heart and Lung for Scleroderma Patients
(To be confirmed)

Lunch, Morning and Afternoon Teas Provided.

Cost to be advised soon Approx. \$20-\$25 to cover food.

Registrations
Accepted now
Please email Dianne Purdie on
diannepurdie@xtra.co.nz

Details and Program to follow soon via email and Facebook



Upcoming:

Wellington

- Our next Meeting will be on Saturday 16th November 1pm-4pm, Christmas Get Together. Topic to be advised.

Please contact Dianne Purdie if you would like to join in, you would be most welcome. Email:

diannepurdie@xtra.co.nz

Christchurch

Our hard core group of ladies still meet every couple of months in Christchurch at the Merivale McDonalds Community Rooms. A good time is held by all, they have recently had a couple of new people join with them, but they welcome more to come along too.

- Our next Meeting will be on 28th September, 2pm-4pm

Event: Christchurch Scleroderma Seminar 2019

Place: Burwood Hospital

Date: 23rd November 2019

Please contact Dianne Purdie if you would like to join in, you would be most welcome.

Email: diannepurdie@xtra.co.nz

Hamilton

- Regular coffee meeting once a month at Robert Harris Café, Chartwell, Hamilton.

We will be having coffee group in October/November then on 23rd Xmas break up details to be confirmed later.

If you would like to join in with the Hamilton Group, please contact Linda Bell.

Email: Linda.bell@hotmail.co.nz

Southland

- Our next Meeting will be on November 24th at Buster Crabb, Invercargill, 12pm.

Southland Seminar, Saturday 26th September 2020, Kew Hospital, Invercargill

If you would like to join in with the Southland Group, please contact either:

Heather: milliganseeds@xtra.co.nz

Jenny: jennyred@xtra.co.nz



Noticeboard:

Wellington support group meets:

Saturday 16th Feb 2019 1.30pm to 4.00pm
Saturday 18th May 2019 1.30pm to 4.00pm
Saturday 17th Aug 2019 1.30pm to 4.00pm
Saturday 16th Nov 2019 1.30pm to 4.00pm

Venue:

Russell Keown House, Queens Drive, Lower Hutt

Christchurch support group meets:

Saturday 23rd March 2019 2:00pm to 4:00pm
Saturday 25th May 2019 2:00pm to 4:00pm
Saturday 27th July 2019 2:00pm to 4:00pm
Saturday 28th Sept 2019 2:00pm to 4:00pm
Saturday 23rd Nov 2019 2:00pm to 4:00pm

Venue:

McDonalds Merivale, 217 Papanui Road, Merivale, Christchurch in the free community room, as long as you buy a coffee at the Mc cafe.

Respiratory support group meets:

Venue:

327a Whangarata Road, Taukau Auckland 2694

Southland support group meets:

Saturday 29th June 2019 12:00pm Gore
(Scleroderma Day)
Sunday 15th Sept 2019 12:00pm Winton
Sunday 24th Nov 2019 12:00pm Invercargill
(Buster Crabb)

Hamilton support group meets:

Group meets once a month at Robert Harris Café, Chartwell, Hamilton

If you would like to join in with the Hamilton Group, please contact Linda Bell.

Email: Linda.bell@hotmail.co.nz

Contacts:

Find a Scleroderma a Support Group near You:

Auckland Respiratory: Allan Edmondson, Email alsand327a@gmail.com
Hamilton: Linda Bell, Email: linda.bell@hotmail.co.nz
Palmerston North: Chris Carlyon, Email: ningandalley@clear.net.nz
Wellington: Dianne Purdie, Email: diannepurdie@xtra.co.nz
Christchurch: Dianne Purdie, Email: diannepurdie@xtra.co.nz
Nelson: Beth Richards, Email: ronbethrichards3@gmail.com
Southland: Heather Milligan, Email: milliganseeds@xtra.co.nz

Scleroderma New Zealand Inc.

President: Dianne Purdie
diannepurdie@xtra.co.nz

Newsletter: Tina McLean
altinamclean@xtra.co.nz

Jenny Andrews
jennyred@xtra.co.nz

Does your area plan a meeting? For times, venue and directions to all meetings that we know about:

www.scleroderma.org.nz/calendar/

New Support Groups:

If you would like a support group in your area please contact: Dianne Purdie **04 479 5548** or email diannepurdie@xtra.co.nz and she will be happy to help you set one up.

