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Scleroderma

New Zealand support group

Autumn 2020

Greetings to you all.

Welcome to the Autumn edition of our Scleroderma Newsletter. We hope everyone is keeping well and safe in their Bubble.



Well this year has flown by pretty quickly, we are now into April, but for me, it seems like time stood still. The whole time we have been in Level 4 Lockdown because of the Covid-19 virus, I've been resting, as I picked up the flu virus early and haven't felt well enough to do much at home.

I hope for everyone else though, you are all well in your Bubble. I'm sure, most of you out there who are industrious, would have probably done just about everything possible in your home or garden while being told by our lovely Prime Minister – Jacinda Ardern, to stay home.

We have lots of information to share and news from our members in our Scleroderma Community.

We hear first from **Dianne Purdie** with the Presidents report. Dianne gives us good advice and keeps us up to date with what's going on around New Zealand.

We have information on Covid-19, including some helpful advice and information on how to keep mentally healthy during this Lockdown we are in.

Remember to follow the advice of Government

- Stay home.
- If you go out, for essential errands or for outdoor exercise, do not be closer than two metres to anyone, other than members of your household.
- Cough or sneeze into a tissue, your elbow or clothing, not your hands.
- Wash your hands as often as you can, for 20 seconds with soap and water, and dry thoroughly. If you can't do that, use hand sanitiser.
- Don't touch your face.
- For official information go to www.covid19.govt.nz

For COVID-19 health advice and information, contact the Healthline team (for free) on: **0800 358 5453**



Presidents Report:

April 2020



Hello to you all, I hope that you are all keeping well and staying safe.

Firstly a big welcome to our new members over the last few months, it is always nice to see new members being part of our community I hope you all feel welcome.

It has been a difficult time for the country since February, when we all got quite concerned about covid-19, and as we see New Zealand is showing resilience and with holding together and following the rules we just might pull through and knock this virus on the head, as long as the government keep to strict border control and quarantine procedures.

Being part of this scleroderma community it goes without saying that we are very vulnerable and it is best not to get the covid -19 especially if you have lung involvement.

I would like to say, that it is preferable that we all wear masks and gloves when we need to go outside our bubble, regardless of what the World Health Organisation advises. It is clear from what is happening over seas, many are wearing masks despite the WHO advice. Our front line workers wear masks, to cover themselves. We are vulnerable so we need to maximise our precautions. There are likely to be just as many asymptomatic people with covid-19 as there that are symptomatic according to recent statistics.



Meetings for our Scleroderma community for the future will be virtual by zoom, until it is safe to meet again. We had our first meeting this week with 19 members on. We will be having more sessions in the near future to look out for. Everyone is welcome to join in.

We will work out as a group as to how we would like to run these meetings, we may want to split up into our regional groups, and have another group for all our geographically isolated members and possibly a newly diagnosed support group if these new people would like that.

We can of course keep these zoom meetings going for the geographically isolated and newly diagnosed members going as long as they would like too.

I recently signed up with the SPIN covid-19 study that I sent you all a week or so ago. The research is to determine how we cope mentally over the covid-19 pandemic. The initial survey was in depth and very interesting. I am yet to find out if I become a participant in the initial study or if I will be on a wait list. I hope that a few more of us have signed up too, it will be a unique experience.

A reminder that you all should have had your flu jab by now, if not please remember to get it soon with your GP.

Remember to keep your activity levels up, there are gentle exercises you can do in your own home. Even if it is walking around your garden a few times.

I hope you are all finding ways to fill in your days. I found an interesting free course on Edx through Victoria University to do, to keep my mind working, a good way to stay positive, during covid-19.

We have had heaps to do in the garden, along with craft projects on the go too. We have found that this last four weeks have flown by.

I hope you all keep warm and well and Gordon and I will look forward to seeing you at a zoom meeting soon.

All the Best Dianne and Gordon



How to cope with Covid19 Lockdown.

Dianne Purdie, President of New Zealand Scleroderma Inc.

Focus on What you can control over difficult times.

Many of us might be feeling a general lack of control these days—like we're out of the driver's seat and just along for the ride. Usually, the more in control we feel over what's happening in our lives, the more motivated, happier, and less stressed we are. At a time when we're all reaching to take back the steering wheel, it's helpful to shift our focus and actions to what we can control and influence.

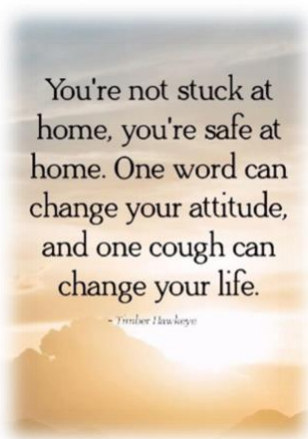
Internal vs. External control

We have a strong sense of internal control when we're in the driver's seat, knowing that our choices and actions impact what happens to us.

We have a strong sense of external control when we feel like we're in the passenger seat and that other people or circumstances determine what happens to us.

3 fast facts

- At any given time, both internal and external control are at play. There are things we can and can't control, and things that fall somewhere in the middle.
- The more control we feel we have over what happens in our lives, the more motivated we are to take action.
- To regain a greater sense of internal control, we can shift our thoughts and focus our actions on what we can control and influence—not what we can't.



List what you can- and can't- control.

Then use that information to help you get back in the driver's seat.

What you can't control or influence. Government decisions, what's left in the supermarket...the list goes on. The more time spent focusing on those things, the more likely you are to be stressed. Once we've accepted what's out of our control, it can actually help you feel more in control.

For example: Schools and restaurants being closed, trips being cancelled.

What you can influence. Sure, you can't fix what's on the news these days (we wish!) or how constant it is, but you can change how you're responding to it. Try hitting the off button or dedicating one time each day for a news check-in. You can also spread positivity with other members in Connect!

For example: The wellbeing of others, sharing only the information you know.

What you can control. Focusing your attention here is powerful. Zone in on what's in front of you in the present moment—instead of worrying about what may or may not happen in the future. Try practicing mindful breathing, listening to music you love, or diving into a book. Another idea? Try something you've always wanted to do but haven't had time for. Learning a new language or cooking from scratch, anyone?

For example: The amount of time you spend on social media, the food you choose to eat.



Expert tips for staying mentally healthy During Difficult Times...

If watching the recent news unfold has left you lying awake at night, you're not alone. "Humans like control and like being in charge," says licensed clinical health psychologist Dr. Robyn Pashby, PhD. "In times like these, stress is primarily driven by lack of control, lack of predictability, and fear of harm or danger to oneself or loved ones."

Sound familiar? While it's impossible to control much of what you see in the news, employing self-care techniques that make you feel grounded and connected can protect your mental health in spite of the current climate. If anxiety is seriously impacting your daily life (i.e., you wake up not wanting to get out of bed), a mental healthcare visit should be on your agenda. Otherwise, these coping strategies can help you mind your mental health:

1. Prioritise sleep hygiene

The average adult needs about seven to nine hours of sleep per night. But stress and anxiety can make it difficult to clock that much let alone get good quality rest, Dr. Pashby explains. The thing is, poor sleep doesn't just leave you with droopy eyelids—it can contribute to mood dips and heightened anxiety. What's more, skipping sleep can mess with your insulin sensitivity in a way that increases your appetite, according to a review article in the journal *Nature and Science of Sleep*.

To outsmart stress and get good quality sleep, try to:

- **Develop a restful and relaxing bedtime ritual** such as shutting your laptop and stowing your phone out of reach, turning off the news, and taking a bath or stretching.
- **Get into bed at the same time every night.** Not sleepy? Only then should you get out of bed and read a book or magazine until you begin to feel tired. Swiping through your phone isn't the same as turning pages since the blue light that emanates from your device may suppress melatonin, the hormone that regulates your sleep/wake cycles, and keep your brain on high alert.
- **Avoid excessive caffeine consumption.** Typically, it takes four to six hours for your body to metabolise half of the caffeine you've consumed. So, if you drink a cup of coffee at 3 p.m., you may still feel remnants of the buzz around 9 p.m.

- **Opt for non-alcoholic beverages.** While alcoholic beverages may initially make you sleepy, having even one drink in the evening may affect your second and most important stage of sleep, leading to sleep disruptions throughout the night, according to the *US Institute on Alcohol Abuse and Alcoholism*.
- **Expose yourself to bright sunlight first thing in the morning.** Natural sunlight supports your natural circadian rhythm, or internal clock that regulates your sleep/wake cycles. Research suggests that exposure to daylight can also improve the duration and quality of sleep.
- **Get out of bed at the same time every day.** Even if you didn't sleep too well the night before, maintaining a consistent wake-up time and resisting naps over 30 minutes helps your body develop and stick to a natural sleep schedule.

2. Maintain your regular routines

When things feel unpredictable and out of your control, your body may produce an abundance of the stress hormones adrenaline and cortisol. Over the course of weeks or months, a chronic surge can heighten your risk of depression, heart disease, and obesity. However, sticking to a typical schedule, i.e., eating lunch at the same time every day rather than grazing all day when you're working from home, can help you feel more in control and rein in hormonal fluctuations, Dr. Pashby says.

3. Amp up your physical activity

Exercise can help reduce stress—one reason why it's smart to follow the Department of Health guidelines and get 150 minutes of moderate-intensity or 75 weekly minutes of vigorous-intensity physical activity every week. Because spending 20 to 30 minutes out in nature may help lower cortisol levels, taking your exercise outside can deliver a double-whammy.



Expert tips for staying mentally healthy continued...

4. Reframe self talk

Stressors can trigger negative thoughts (i.e., “I can’t handle this” or “I feel out of control”) that reinforce pessimistic beliefs and attitudes. To reverse the effects, Dr. Pashby recommends taking four to five deep breaths and then reframing those thoughts to feel less catastrophic (i.e., “I’m feeling very anxious about what is going on around me, but I am taking as many precautions as I can to keep me and my family safe.”).

5. Avoid emotional isolation

Interacting with other people—whether it’s a phone call, video chat, or text message—can ease the symptoms of stress and to help you cope, according to a small 2015 study of 77 healthy adults published in the journal *Clinical Psychological Science*. Can’t fight the urge to hole up by yourself? Think of others: Reaching out to neighbours or elderly friends with an offer to prepare a meal, pick up a prescription, or walk a dog can help you feel more in control—and helpful, Dr. Pashby says.

6. Side-step stress-eating

While digging into a tub of ice cream or another treat that’s high in fat and sugar may temporarily distract you from stress, indulging won’t stomp out the source of it. Before you reach for a handful of chips or a second serving of lunch, ask yourself: Is your stomach really grumbling, or are feelings fueling your appetite? *If you’re dealing with complicated emotions rather than actual hunger, calling a friend, going for a walk, or doing another non-eating activity may help you feel even better than a pint-sized, sugar-laden pick-me-up.*

By now, most of us know the basic rules of social distancing, aimed at slowing the spread of the contagious coronavirus: Leave home as little as possible, and when you do, stay at least 1.5 metres away from anyone who doesn’t live in your household. The question is: With gatherings off-limits—and with shops, cinemas, and cultural attractions temporarily closed—how do you keep boredom at bay? Here are some ideas that support public health and personal happiness.

If cabin fever is getting to you

Make a video date

It’s a pretty safe bet that your friends feel as cooped up as you do. Even if a real-life coffee catch up can’t happen, video conferencing apps such as FaceTime, Skype, and Zoom let you connect virtually and see everyone’s faces. Even better, a group video chat allows you to include people from around the world.

Play some music

Great tunes can spark positive shifts in mindset, motivation, and mood. Use a streaming service such as Spotify or Apple Music to craft a feel-good playlist of your personal hits, or dust off your old vinyl collection.

Try a home workout

Sick of your living room? Turn it into a gym. WW has tons of free home workout tutorials to get you started, including guides on yoga, kettlebells, high-intensity-interval training, and dance. WW members also get on-demand access to personalised Aaptiv audio workouts through the app.

Get some air

Sometimes the best cure for cabin fever is, well, leaving the cabin. Even if you sit on a park bench and spend 20 minutes marveling at nature, studies suggest you could come away feeling calmer and more focused. As long as you’re maintaining a safe physical distance from people who don’t live in your household, it’s all good.



Expert tips for staying mentally healthy continued...

If you feel like nesting

Do a wardrobe clean out

Like many people, you probably own more stuff than you actually use or need. Now might be a good time to sift through those clothes at the back of your wardrobe, the sports gear gathering dust in your garage, and other forgotten possessions. Set aside unwanted items to donate once social-distancing guidelines are lifted. Your home will feel more orderly, and you'll feel good for setting a positive intention.

Clean your fridge

When was the last time you checked the expiration date on that bottle of steak sauce in the back? Or wiped every stray garlic or onion skin from the crisper drawer? Doing a deep clean of the refrigerator and freezer will help you clear out those ancient perishables so you can see what you really have to work with. Also, you won't know how weirdly satisfying this is until you do it.

Start a healthy garden

Consider starting an outdoor (or indoor!) garden. Herbs can be a great place to start and you can order seeds, soil, and tools online to start putting down roots.

Rearrange your living space

While you can't stroll through home-goods stores in search of decorating inspo, you can freshen up your home simply by rearranging. Try swapping out photos in your wall frames, angling your lounge another way, or creating a reading nook by repurposing a cute lamp from another room. You can collect FitPoints for major rearranging, and you'll help your home feel new again.

Up your cooking game

With many restaurants temporarily closed, now may be the perfect moment to stretch your skills in the kitchen. Have you been curious about how to butterfly a full chicken? Or make homemade pizza from two-ingredient dough? Go for it. You don't need a ton of fancy ingredients—or chef credentials—to cook boldly.

If you want to help others

Support someone you know

Tough times can have a way of bringing out our deepest humanity. One way to make a direct, positive impact? Help people you know to the extent you are able. Who among your family, friends, or neighbours might be hurting right now? Perhaps you know of an older person who'd be grateful for some grocery-shopping help, or a single parent down the block whose household could use a nappy donation. Research suggests that generosity sparks happiness, which makes helping out a powerful win-win.

Donate to food relief

With many schools and food pantries across the country closed during the pandemic, many households are facing hunger. If you're in a position to make a charitable donation, consider giving to an organisation such as Foodbank Australia and New Zealand or Meals on Wheels, all of which are working to address hunger during the crisis. (They're also good places to start if you're in need of help.)

Support neighbourhood businesses

Social distancing protocols have been tough on restaurants, coffee shops, and other businesses that traditionally rely on foot traffic. Keep your community thriving by continuing to support those local entrepreneurs. Many restaurants are offering takeaway and home delivery, and lots of shops on temporary closure are continuing to sell digital gift cards that customers can use once restrictions are lifted.

Dispel fear mongering

If bad news travels quickly, misinformation moves at warp speeds. Next time you hear an alarmist rumour or spot a sketchy "news" item, check the source before you pass it around. Did the information come through an official channel, or your local officials? If not, no need to spread the scaremongering. You'll be doing everyone a service.



Expert tips for staying mentally healthy *continued...*

If you're home with kids

Hold a game night

In these smartphone-saturated times, it's easy for an entire evening to slip past with everyone just staring at tiny screens. Take a break and come together over an analogue game instead.

Put kids to work in the kitchen

Even when you're not social distancing, it's great to get kids involved in meal planning. Peer into the pantry and fridge together, have them pick a few favourite ingredients, and then delegate age-appropriate tasks such as measuring, cracking eggs, and washing fruits and veggies. They'll learn about healthy eating habits—and cut down on work for you.

Take a virtual tour

You can't exactly hop on a plane to Paris and cruise the Louvre right now, but thanks to virtual tours, you and your kids can still marvel at the museum's iconic Galerie d'Apollon right from the family laptop. It's one of many free virtual field trips being offered by cultural sites, zoos, aquariums, and other attractions around the world—proving you don't need to leave home to broaden your family's horizons.

Try free teaching tools

Whether your family is in full homeschool mode or you just want your kids to enjoy some extra enrichment, many educational companies are now offering free online subscriptions during the coronavirus outbreak.

Create some TikToks

If you have tweens or teens in your household, chances are you've heard of TikTok, the wildly popular platform for sharing short-form dance, lip sync, and comedy videos. Next time your family needs a laugh, try choreographing some clips together. Yes, you'll probably look ridiculous, but that's kind of the point.



If your mind needs a boost

Read for pleasure

Lots of us have been devouring more reading material lately, everything from lessons for the kids to neverending news reports. Your brain deserves a break! Whether you're pulling old faves from your bookshelves, ordering hardcovers online, or reading ebooks through your local library, opt for selections you find immersive and pleasurable. Try a graphic novel that tickles your visual senses, a funny memoir to help get your mind off current events, or a riveting mystery novel you just can't put down. Even better: Start a virtual book club with friends.

Check out a podcast

This is a great idea if you want to jog your brain without making your eyeballs do the work of reading.

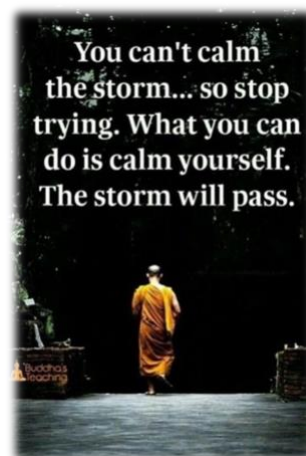
Tackle a new skill

Challenging the mind with "demanding tasks" may actually support long-term brain health, according to a 2013 review article in *Dialogues in Clinical Neuroscience*. If you have downtime during your hours of social distancing, it might be beneficial to try a new skill or hobby. Ideas that don't require special tools or gear include learning a language, drawing, and writing. Search YouTube for tutorials to get started.

Meditate

Regular meditation may help lessen the strain of being stuck at home by supporting mental resilience and reducing anxiety.

Source: Weight Watchers



Members Stories:

Heather's thoughts on Scleroderma.



By Heather Milligan

I'd liked to have titled this article 'Scleroderma surprises the ordinary girl', but Kim Tocker has already claimed it in her superb writing. 'Scleroderma surprises the older woman'

does not quite have quite the right ring I was hoping for. So, I have called it 'Heather's thoughts on Scleroderma'.

I grew up in Canterbury. My favourite photo of me is just before my 4th birthday, in July, outside with bare feet in the winter. I and my two siblings lived a life in the outdoors in all sorts of weather. I grew up eating Dad's and Mum's homegrown veggies. There wasn't an overabundance of meat. We biked or walked everywhere. I never smoked.

In my late teens I found drinking even small amounts of alcohol sent me to sleep so I gave that up (more about that later).

Graham and I married and lived on a low-spray regime farm. I was now growing the veggies, drinking artesian water and breathing clean Southland air. We kept many pets, including dogs, that needed lots of walks. I was an unintentional poster child for a positive lifestyle.

Four children later, doctors investigated why my liver function test results were so high. They had checked them when I started taking statins. They diagnosed me with primary sclerosing cholangitis. The jury is still out on whether it is an auto-immune disease. It came as a surprise as I was feeling fine, but it did explain going to sleep after drinking alcohol!

A few years later other health problems emerged. They arrived at a stressful time; as one of our children was having mental health problems and I developed shingles. Fortunately, shingles was not too hard on me.

I saw a rheumatologist (who did not diagnose me with scleroderma) for a couple of years. Finally, a locum at our medical centre, to whom I am so grateful, did confirm scleroderma. Like many of you, thanks to Dr Google, I had an idea that it may have been the problem. I am so fortunate now to be under the care of our Southland District Health Board's rheumatologist.

Those of you with scleroderma should take heart. Even though I live a healthy lifestyle, scleroderma still came to stay. Scleroderma happens - it is what it is. Sighing and thinking 'what if' won't change anything.

I am so blessed that Maureen and Jenny set up our Southland group. We are not going to cure scleroderma but it's great to meet up with others on the same journey. Because of it, Graham and I have met Diane and Gordon and many other people around New Zealand. We've learned so much from the seminars. Wasn't I fortunate to arrive just when our society was being formed?

Without this support and the Internet, having scleroderma would be a very scary place.

I found the following tips to '[Overcome a Crisis](#)' in a magazine many years ago and I still refer to them.

1. Face facts -Some things refuse to go away and if ignored may even explode in our faces. Shutting your eyes is crazy. Hoping for the best is OK, but of little real use. On the other hand, remember that nothing is the end of the world, however much it may seem that way.

2. Act – do what you can do. Something can be done, however little. Try to feel self-reliant, at least more than you did an hour ago. Don't act rashly, just because you are feeling crushed or upset.

3. Get expert help. To survive, you must be practical. When the dust has settled and the shock absorbed a little, assess your main problems then seek expert advice. Don't be ashamed of making a fuss to get it. Don't try to struggle on alone.

Make your own decisions. Refuse to be hustled, brow-beaten, pressured or otherwise to make decisions you are not sure about.

Thanks to John and Barbara Spavin for their help with the article and Word's thesaurus and grammar check making me sound much cleverer than I really am.

Heather Milligan



Members Stories:

The Gift of New Life – By Amy Ng-Thomson

A bilateral lung transplant in September last year has given a nurse a future she feared she might have lost...



Amy Ng-Thomson encourages people to talk to their loved ones about organ donation.

2018 was a year of reminders and learning, as a patient, as a nurse and as a human being. I was reminded of karma, compassion, humility, resilience and patience.

Never in my life did I anticipate having to one day rely on someone else, or on so many other people's

decisions to keep me alive. Let alone having to receive a bilateral lung transplant!

My transplant journey began in 2006 when only a year after getting married, I was diagnosed with scleroderma an autoimmune disease that may result in changes to the skin and internal organs. I'd never even heard of it before.

I attended many rheumatology clinics and started on a myriad of drugs. My swollen hands, AKA my "boxing gloves", started getting in the way of my work as a nurse in the theatre recovery department. Methotrexate worked for me and my hands finally went down in size, but then I noticed I couldn't take in deep breaths. I was referred to the respiratory service in 2008, started on other drugs and after numerous tests I was diagnosed with lung fibrosis.

I knew this was going to eventually get worse and so my husband and I travelled while we could.

In 2010 my scleroderma flared up and further lung fibrosis was picked up by a CT scan, so chemotherapy (cyclophosphamide) was prescribed for six months to suppress my immune system. I was then referred to the transplant team who concluded I was sick enough for chemotherapy, but not sick enough for a transplant. So I carried on working during and after chemotherapy and we went back to travelling after the cycle had finished.

By 2016 my health had deteriorated and I was getting short of breath doing simple tasks. At the end of that year another CT scan showed that my lung fibrosis had progressed and I was sent back to the transplant team for a full assessment in May 2017.

In June 2017, much to my surprise and shock, I was placed on the active transplant list due to pulmonary hypertension. My husband and I left that clinic appointment stunned!

My nursing background meant I knew a lot about operations and theatres, but not enough about transplant surgery. I personally had never had an operation before! I had so many questions and I wanted to see the surgeon and anaesthetist first. So the following day the transplant coordinator called me and we agreed that I could come off the active list temporarily to have more time to gather the information I needed.

In August 2017 I went back on the active transplant list not knowing how long I would be waiting for a donor. I also started oxygen therapy for several hours a day and I initially felt better. Unfortunately over time, and I'll never forget how bad I got, I ended up on oxygen 24 hours a day and I became very dependent on it. I would be anxious about how much was in my tanks and I would constantly check.

Besides my physical decline - relying on a wheelchair and oxygen, my mental health also declined; to the point where I became quite withdrawn and sad about what could be the end of my time at age 36.

I've cared for many people throughout my nursing career as a recovery and theatre nurse, seeing them at their most vulnerable, weakest, sickest and most desperate times of their lives. I'd like to think I was able to demonstrate to my patients in the short time that I met them, the compassion, care and dignity they required at their time of need. I hope this was the good karma that blessed me when I finally became a patient.



Members Stories:

The Gift of New Life –

By Amy Ng-Thomson continued..

Later in 2018, after over a year on the transplant waiting list, a family selflessly agreed to donation and I received my lungs. I underwent an eight hour bilateral lung transplant surgery and I now have tailor made lungs, cut down to size to fit me as my donor was slightly taller than me – not many people can say that! I bled post operation and had to be returned to theatre. So I now have many other people's donated blood running through my veins to go along with the new lungs I received.

Post-surgery I was on ECMO for eight days, followed by a tracheostomy for 11 days along with multiple other necessary life-preserving tubings. I cannot praise the care I received from the CVICU nurses enough. They were thorough; I was closely monitored from head to toe.



Amy Ng-Thomson shortly after her eight-hour bilateral lung transplant surgery.

I hated being a patient though as I couldn't do anything for myself, I had so many lines in and couldn't shower - yes I felt gross! The worst thing was I couldn't talk due to the tracheostomy, but I appreciated the care, dignity and compassion I was demonstrated by my fellow colleagues in health. I communicated by writing and as a lot of CVICU staff can also tell you – a lot of eye rolling.

I was in CVICU for three weeks where I relearnt to eat, drink, breathe and walk again. I impatiently thought I was ready for the next task so I would keep asking – what's next? Patience was eventually imposed on me and I finally understood that I had to go with the slow flow that is recovery from major surgery.

I completely underestimated the surgery and the recovery period. I had a lesson in humility as I was not comfortable letting others see me at my weakest, most vulnerable and sickest and not being in control.

I have learnt so much about the transplant process as a patient, more than I ever have or could have as a nurse.

My transplant journey is still very fresh, I look well on the outside, however a lot of hard work and tears have gone into getting this far. I've already had two episodes of rejection and infections - transplant patients are so vulnerable because of their immunosuppression. I know I still have many bumps in the road to deal with, but my Tacrolimus tremors and easy breathing remind me I've made it to the "other side." Looking back I realise just how resilient the human body is.

I went to my first post op concert in February 2019; I didn't have to worry about my oxygen supply or getting stared at in a wheelchair – I was leash-free and breathing freely. I can now walk with my dogs, go on dates with my husband, contribute to the housework and work again. I get to spend time with my siblings and my mother again and most importantly I'm alive!

Thank you to the ICU who looked after my donor and their family, to ODNZ for organising the donation, to the transplant team who looked after me before and continue to, and thank you donor family for your selfless gesture in donating your loved one's organs.

Be kind to each other, you never know how someone will be able to help you in the future! Most importantly talk to your loved ones about organ donation, it made yesterday, today and tomorrow possible for me.

Amy Ng-Thomson

Amy Ng-Thomson, RN, BN, works for Middlemore Hospital as a clinical quality specialty nurse in surgery, anaesthesia and perioperative services.

**Source: Kai Tiaki Nursing New Zealand*vol 25 no 4
*May 2019**



Members Stories:

Scleroderma Waikato – Linda Bell

Scleroderma New Zealand has come a long way in the past few years that I have been involved. We are now incorporated since February 2015 which means we can raise more awareness and fundraise. In the Waikato which I run; we are about to have our next Seminar later in the year in Hamilton. With the help from Rheumatology Department and guest speakers and the aim is to help the newly diagnosed to meet other Scleroderma member's from all over the North Island.

My own personal journey, I have diffuse Scleroderma, systemic sclerosis, and became ill in June 1988, starting with Raynaud's. I noticed that my fingertips were very white, felt cold. I began to have flu like symptoms with several visits to the doctors, finally admitted into the Waikato Hospital with inflammation of the heart lining, pericarditis and Acute renal failure. I had a pericardial window procedure on my heart a week later. Over the next couple months had tests, saw specialist then the diagnosis of Scleroderma however my hands had already clawed my onset was rapid and progressive. My prognosis was that I would not see Christmas. But, I spent the next 5-6 years in and out of hospital. Had my 1st encounter with Work and Income, as my husband had been dismissed from his job due to my illness. Not only, did I have my disease to deal with, but financial problems. Over the next few years had many tests, biopsy's lung involvement, Pleurisy and a course of chemotherapy and extreme weight loss. Also lost my sense of smell and taste, which has never come back.

I was put in Hospice Care and spent many weeks at Queen Elizabeth Hospital, Rotorua. It was hard going from a normal life to the disabled not only on myself but my family and my children were 13 and 11 when I became ill, days were taken up Doctors and Hospital appointments and treatments. But I have seen a huge change in the medical profession and treatments. In the Waikato, we have an excellent Rheumatology Department with Dr Kamal Solanki specialising in Scleroderma. Anna Schollum, Specialist Nurse and we have an advice line available for all patients. After spending many years coping, noticing your circle of friends change or stay away. I had good and bad days, keeping warm during winter is most important. I was now able to shower myself and do light housework and feed myself, and was coping better each day. But each year I would ring Arthritis Office asking is any support

groups or other Scleroderma people had made contact it was always NO. But 7 Years ago Catherine Swift, Educator for Hamilton answered the phone said Yes come into the office. I did, she spoke with Dr Solanki at the Rheumatology Department and said that he had 80 women and 9 men in the Waikato area at that time. Good news, I was about to meet others, so a date was decided on in October.

At the same time my son in Melbourne had made contact with Robyn Sims, who was the President of Victoria at the time. I planned a visit to Melbourne met with Robyn who gave me advice on starting a support group of my own. 1st buy a computer, face book group called Scleroderma Waikato, email address. And posted details of the 1st Seminar in New Zealand for Scleroderma patients. I brought back the little black books and gave out at seminar, and made contact with Wellington and Auckland. I am very grateful to Robyn and the committee for helping us out much appreciated.

I have been busy in the Waikato raising funds. I have done movie fundraiser's which help fund our own Scleroderma Books. About 4 years ago did my 1st presentation on Scleroderma and my own personal journey at the Waikato Patchwork and Quilts Guild and was presented with a Large Quilt we did a National Raffle to raise funds. Our membership is free but we have a give a little page and have June as our fundraising month. After the 1st Seminar I formed a Coffee Group and we meet once a month at **Robert Harris Café, Chartwell Hamilton.**

In June we have a Luncheon to celebrate **World Scleroderma Day**. This year will be at **St Andrew's Golf Course** on 27th at 11.30 am. Will contact all later.

And November we end the year with a Christmas Luncheon.

Scleroderma is like a Roller coaster up and down in health but since starting the coffee group and doing the seminar's have met wonderful, caring people, I love them all. So, blessed to have met them all.

Regards,

Linda Bell

PH: 07 8535434

MOB: 027 548 1214



Members Stories:

Our Son's Wedding - Jenny Andrews

Well what a time we are having at the moment as a nation and as a world population. I think it has given us time to reflect on what is truly important to us and how much we should perhaps be slowing down and enjoying the life we have been gifted with.

For myself it is my family that is by far the most important thing in my life, not only my husband and children but my siblings and wider family as well. We were lucky enough to have a very special day happen two days before the country was told we would be locking down at Midnight Wednesday 25th March.

Our son got married. He and his fiancé had been planning it for three years and saving as much as they possibly could during that time. They organized everything and had everything sorted down to the smallest of details. The service and reception were held in a marquee at our home and we had the most amazing day.



The weather wasn't as kind, but the rain stopped after the service and with the indoor/outdoor flow, a lot of guests spent the evening outside talking.



My Family

It was a bit of touch and go as to whether we should be going ahead with it due to everything happening but the bride and groom made the call to continue and the guests then made the decision whether they wished to attend or not. We were missing about 9 people who had had contact in some way with Covid 19. We were extremely lucky and thankful for how well the day went. And everyone had a fantastic time. A day I will never forget.



With my Granddaughter Willow



My husband Jeff



*Our Grandson
Reegan,
In charge of the very
important rings*



Study of 'Pre-Ulcer' Stage May Inform Treatment of Digital Ulcers in Scleroderma

From Scleroderma News...



A pre-clinical stage preceding the development of digital ulcers could provide a window of opportunity for treatment before serious tissue damage occurs in people with scleroderma, according to a new study. The study was summarized in a letter to the editor titled, "Patient experiences of digital ulcer development and evolution in systemic sclerosis," published in the journal *Rheumatology*.

Digital ulcers — small sores in fingers and toes — are seen frequently in patients with scleroderma and frequently do not respond well to treatment. These small sores, which are prone to infection, are generally considered to result from tissue ischemia, which refers to insufficient oxygen supply reaching tissue.

Little is known about the stage preceding overt tissue damage related to digital ulcers. Prior work, from the same international team behind the current research, identified five major themes that characterize the patient experience of digital ulcers in scleroderma: disabling pain and hypersensitivity; broad-ranging emotional impact; impaired physical and social activity; factors worsening occurrence, duration and impact; and easing, managing and adapting.

Now, the researchers set out to explore patients' perceptions and beliefs about digital ulcer development to inform clinical practice and design of clinical trials. They recruited 29 patients with scleroderma (average age 59.9) to participate in four focus groups across the United Kingdom. Average disease duration was 12.8 years.

Participants had a variable history of digital ulcers, having experienced one to five or more sores. Most (20)

had limited cutaneous scleroderma. Also, the majority of patients were receiving treatment with vasodilators (blood vessel wideners), including calcium channel blockers and phosphodiesterase type-5 inhibitors. During the course of the focus groups, three major topics emerged.

The first was underlying cause of digital ulcers. Most participants believed there were both "external" and "internal" reasons behind the development of the ulcer rather than being a random occurrence.

"External" factors included experiencing trauma, cuts or skin splitting, being exposed to water or chemicals, infection, and cold or variation in temperature.

In turn, "internal" causes included "poor" blood circulation, calcinosis (formation of calcium deposits in soft tissue), and residual effects of previous ulcers, which would make specific areas of the fingers more vulnerable to new ulcers.

The second theme was symptoms before the development of digital ulcers. Most participants reported they knew when an ulcer was about to develop.

While the most common symptom was pain below the skin, some participants also reported physical skin signs, such as a white patch.

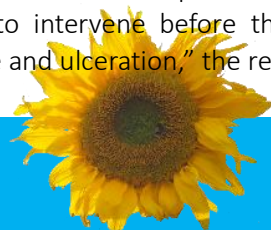
The third theme was patient experiences during digital ulcer development and healing, which were variable between individuals.

Some patients reported feeling the surface of the ulcer moist, while others said it was dry. Pain related to the small sore also varied greatly between participants.

"Our data provide novel patient-perceived insights into the pathogenesis and natural history of SSc-DU [digital ulcers in scleroderma]. The emergence of SSc-DUs is not considered a random event and many patients have explanations for, and sometimes can anticipate development of new ulcers," the investigators wrote.

They added that these findings can help develop strategies to prevent digital ulcers, such as avoiding severe cold, hand hygiene, and avoiding mechanical injury.

"To our knowledge, we are the first to describe a 'pre-ulcer' stage that could provide a 'window of opportunity' to intervene before the onset of overt tissue damage and ulceration," the researchers wrote.



Sjogren's

By Mayo Clinic Staff...

A number of us have Sjogren's along with our Scleroderma. I have copied some information from the Mayo Clinic a good safe source of information. Occasionally I may receive a few questions on how to cope with the symptoms. This information may be of help for you. If you have any concerns, it is best to check with your GP and Medical specialist.

Dianne Purdie

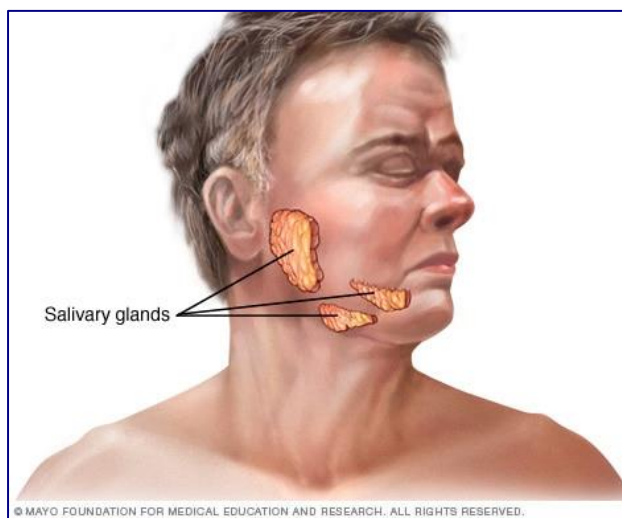
Overview

Sjogren's (SHOW-grins) syndrome is a disorder of your immune system identified by its two most common symptoms — dry eyes and a dry mouth.

The condition often accompanies other immune system disorders, such as rheumatoid arthritis and lupus. In Sjogren's syndrome, the mucous membranes and moisture-secreting glands of your eyes and mouth are usually affected first — resulting in decreased tears and saliva.

Although you can develop Sjogren's syndrome at any age, most people are older than 40 at the time of diagnosis. The condition is much more common in women. Treatment focuses on relieving symptoms.

Symptoms



Salivary glands

The two main symptoms of Sjogren's syndrome are:

- **Dry eyes.** Your eyes might burn, itch or feel gritty — as if there's sand in them.
- **Dry mouth.** Your mouth might feel like it's full of cotton, making it difficult to swallow or speak.

Some people with Sjogren's syndrome also have one or more of the following:

- Joint pain, swelling and stiffness
- Swollen salivary glands — particularly the set located behind your jaw and in front of your ears
- Skin rashes or dry skin
- Vaginal dryness
- Persistent dry cough
- Prolonged fatigue

Causes

Sjogren's syndrome is an autoimmune disorder. Your immune system mistakenly attacks your body's own cells and tissues.

Scientists aren't certain why some people develop Sjogren's syndrome. Certain genes put people at higher risk of the disorder, but it appears that a triggering mechanism — such as infection with a particular virus or strain of bacteria — is also necessary.

In Sjogren's syndrome, your immune system first targets the glands that make tears and saliva. But it can also damage other parts of your body, such as:

- Joints
- Thyroid
- Kidneys
- Liver
- Lungs
- Skin
- Nerves

Risk factors

Sjogren's syndrome typically occurs in people with one or more known risk factors, including:

- **Age.** Sjogren's syndrome is usually diagnosed in people older than 40.
- **Sex.** Women are much more likely to have Sjogren's syndrome.
- **Rheumatic disease.** It's common for people who have Sjogren's syndrome to also have a rheumatic disease — such as rheumatoid arthritis or lupus.

Complications

The most common complications of Sjogren's syndrome involve your eyes and mouth.

- **Dental cavities.** Because saliva helps protect the teeth from the bacteria that cause cavities, you're more prone to developing cavities if your mouth is dry.



Sjogren's continued....

- **Yeast infections.** People with Sjogren's syndrome are much more likely to develop oral thrush, a yeast infection in the mouth.
- **Vision problems.** Dry eyes can lead to light sensitivity, blurred vision and corneal damage.

Less common complications might affect:

- **Lungs, kidneys or liver.** Inflammation can cause pneumonia, bronchitis or other problems in your lungs; lead to problems with kidney function; and cause hepatitis or cirrhosis in your liver.
- **Lymph nodes.** A small percentage of people with Sjogren's syndrome develop cancer of the lymph nodes (lymphoma).
- **Nerves.** You might develop numbness, tingling and burning in your hands and feet (peripheral neuropathy).

Diagnosis

Sjogren's syndrome can be difficult to diagnose because the signs and symptoms vary from person to person and can be similar to those caused by other diseases. Side effects of a number of medications also mimic some signs and symptoms of Sjogren's syndrome.

Tests can help rule out other conditions and help pinpoint a diagnosis of Sjogren's syndrome.

Blood tests

Your doctor might order blood tests to check for:

- Levels of different types of blood cells
- Presence of antibodies common in Sjogren's syndrome
- Evidence of inflammatory conditions
- Indications of problems with your liver and kidneys

Eye tests

Your doctor can measure the dryness of your eyes with a test called a Schirmer tear test. A small piece of filter paper is placed under your lower eyelid to measure your tear production.

A doctor specializing in the treatment of eye disorders (ophthalmologist) might also examine the surface of your eyes with a magnifying device called a slit lamp. He or she may place drops in your eye that make it easier to see damage to your cornea.

Imaging

Certain imaging tests can check the function of your salivary glands.

- **Sialogram.** This special X-ray can detect dye that's injected into the salivary glands in front of your ears. This procedure shows how much saliva flows into your mouth.

- **Salivary scintigraphy.** This nuclear medicine test involves the injection into a vein of a radioactive isotope, which is tracked over an hour to see how quickly it arrives in all your salivary glands.

Biopsy

Your doctor might also do a lip biopsy to detect the presence of clusters of inflammatory cells, which can indicate Sjogren's syndrome. For this test, a sliver of tissue is removed from salivary glands in your lip and examined under a microscope.

More Information

- Chest X-rays
- Eye exam
- Needle biopsy
- Urinalysis

Treatment

Treatment for Sjogren's syndrome depends on the parts of the body affected. Many people manage the dry eye and dry mouth of Sjogren's syndrome by using over-the-counter eyedrops and sipping water more frequently. But some people need prescription medications, or even surgical procedures.

Medications

Depending on your symptoms, your doctor might suggest medications that:

- **Decrease eye inflammation.** Prescription eyedrops such as cyclosporine (Restasis) or lifitegrast (Xiidra) may be recommended by your eye doctor if you have moderate to severe dry eyes.
- **Increase production of saliva.** Drugs such as pilocarpine (Salagen) and cevimeline (Evoxac) can increase the production of saliva, and sometimes tears. Side effects can include sweating, abdominal pain, flushing and increased urination.
- **Address specific complications.** If you develop arthritis symptoms, you might benefit from nonsteroidal anti-inflammatory drugs (NSAIDs) or other arthritis medications. Yeast infections in the mouth should be treated with antifungal medications.
- **Treat systemwide symptoms.** Hydroxychloroquine (Plaquenil), a drug designed to treat malaria, is often helpful in treating Sjogren's syndrome. Drugs that suppress the immune system, such as methotrexate (Trexall), also might be prescribed.

Surgery

A minor procedure to seal the tear ducts that drain tears from your eyes (punctal occlusion) might help relieve your dry eyes. Collagen or silicone plugs are inserted into the ducts to help preserve your tears.



Sjogren's continued....

Lifestyle and home remedies

Many Sjogren's syndrome symptoms respond well to self-care measures.

To relieve dry eyes:

- **Use artificial tears, an eye lubricant or both.** Artificial tears — in eyedrop form — and eye lubricants — in eyedrop, gel or ointment form — help relieve the discomfort of dry eyes. You don't have to apply eye lubricants as often as artificial tears. Because of their thicker consistency, eye lubricants can blur your vision and collect on your eyelashes, so you might want to use them only overnight.

Your doctor might recommend artificial tears without preservatives, which can irritate the eyes of people with dry eye syndrome.

- **Increase humidity.** Increasing the indoor humidity and reducing your exposure to blowing air can help keep your eyes and mouth from getting uncomfortably dry. For example, avoid sitting in front of a fan or air conditioning vent, and wear goggles or protective eyewear when you go outdoors.

To help with dry mouth:

- **Don't smoke.** Smoking can irritate and dry out your mouth.
- **Increase your fluid intake.** Take sips of fluids, particularly water, throughout the day. Avoid drinking coffee or alcohol since they can worsen dry mouth symptoms. Also avoid acidic beverages such as colas and some sports drinks because the acid can harm the enamel of your teeth.
- **Stimulate saliva flow.** Sugarless gum or citrus-flavored hard candies can boost saliva flow. Because Sjogren's syndrome increases your risk of dental cavities, limit sweets, especially between meals.
- **Try artificial saliva.** Saliva replacement products often work better than plain water because they contain a lubricant that helps your mouth stay moist longer. These products come as a spray or lozenge.
- **Use nasal saline spray.** A nasal saline spray can help moisturize and clear nasal passages so that you can breathe freely through your nose. A dry, stuffy nose can increase mouth breathing.

Oral health

Dry mouth increases your risk of dental cavities and tooth loss. To help prevent those types of problems:

- Brush your teeth and floss after every meal
- Schedule regular dental appointments, at least every six months
- Use daily topical fluoride treatments and antimicrobial mouthwashes

Other areas of dryness

If dry skin is a problem, avoid hot water when you bathe and shower. Pat your skin — don't rub — with a towel, and apply moisturizer when your skin is still damp. Use rubber gloves when doing dishes or housecleaning. Vaginal moisturizers and lubricants help women who have vaginal dryness.

Preparing for your appointment

Depending on your symptoms, you might start by seeing your family doctor, dentist or eye doctor. But you might eventually be referred to a doctor who specializes in the treatment of arthritis and other inflammatory conditions (rheumatologist).

What you can do

Make a list that includes:

- Detailed descriptions of your symptoms and when they began
- Information about your current and past medical problems
- Information about your parents' or siblings' medical history
- All medications and dietary supplements you take, including doses
- Questions you want to ask the doctor

For Sjogren's syndrome, basic questions include:

- What is likely causing my symptoms?
- Are there other possible causes?
- What tests do I need?
- What treatment approach do you recommend?
- How soon can I expect my symptoms to improve with treatment?
- Am I at risk of long-term complications from this condition?
- I have other health conditions. How can I best manage them together?
- Do you have brochures or other printed materials that I can have? What websites do you recommend?

What to expect from your doctor?

Your doctor is likely to ask you a number of questions, including:

- Do your symptoms follow a pattern — worsening throughout the day or when you go outdoors?
- Do you have chronic conditions such as high blood pressure or arthritis?
- Have you recently started new medications?
- Do any close relatives have rheumatoid arthritis, lupus or a similar disease?

By Mayo Clinic Staff



Sing Your Lungs Out

By Dianne Purdie....

I was listening to a post cast on Radio NZ a few weeks ago about a group of singers with compromised lungs in Wellington. (Sing your Lungs Out SYLO)

Singing is used to help lung health and the SYLO members have found benefits like: less stress, improved breathing, lower blood pressure, improved mood and quality of life. There is no need to be shy about your singing as singing with a group is very supportive and so beneficial to your health.

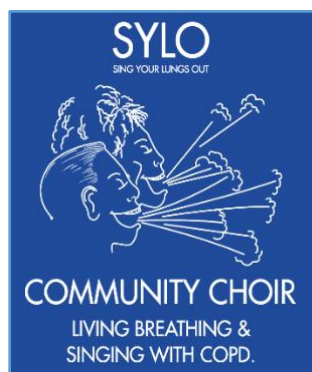
I contacted Gayle at the Wellington group in Kibirnie and the below article is one which she sent on to me to share.

I will be joining them in January next year, they were happy to except me even when I told them I was chucked out of the school choir, for being to high!.

I am hoping to encourage a few more of us from the Wellington group and I hope a few more join the Palmerston North group and the Motueka group. Maybe there may be more around the country I will keep you all posted.

But if there isn't one in your area, join a local community choir, and just have fun.

See Below page



SING YOUR LUNGS OUT

(COPD Choir Trust, registered charity #CC51121)

The Sing Your Lungs Out (SYLO) choir was established in Wellington in October 2014 by Dr Amanda

McNaughton and Dr Sarah Aldington to research the effects of singing on the health and well-being of people with chronic respiratory disease. The choir has continued following completion of the research.

Medical benefits were not proven, but psychosocial benefits were strongly evident. Choir members reported the following positive outcomes from participation in the choir:

- Laughter and fun – fun is their focus, not their health condition.
- Relaxation –the concentration required for singing cleared their heads of other concerns.
- Emotional and community support – members look after, and are interested in, each other.
- Purpose - the choir members prioritise their choir days over other appointments.
- Breathing control – this must be optimised to cope with singing.
- Learning new skills - many did not realise they had singing ability.
- Confidence improves – from performing in public, which helps them cope better with daily activities.
- Safety – members feel safe in the choir environment.

Most importantly, the choir improves the quality of life of members to the extent that they are no longer defined just by their chronic disease.

See research papers at:

<http://bmjopen.bmj.com/content/6/9/e012521> and

<http://bmjopen.bmj.com/content/7/1/e014151>

The choir is a registered charitable trust, with volunteer help.

In 2016 the choir was awarded the Minister of Health's Volunteer of the Year award. See:

<http://www.health.govt.nz/new-zealand-health-system/minister-health-volunteer-awards/previous-volunteer-awards-recipients/2016-volunteer-awards-recipients#year>

Contact: Gayle Williams: pgwilliamsnz@gmail.com
021 217 0889

On Facebook: <https://www.facebook.com/Sing-Your-Lungs-Out-279477085595109>



Members News:

Scleroderma Waikato Group

We have a number of members and we have been meeting at Robert Harris Café, Chartwell, Hamilton once a month for the past 8 Years now...

My Coffee Group in Waikato are all good and looking forward to starting again which I think will be in June.

If anyone gets the Entertainment Books go to my Facebook page and where you can 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

Nelson Scleroderma Group

Beth Richards going out on her mobility scooter with a face mask...



Beth Richards wearing her mask

Good morning to my fellow Scleroderma friends. It's a beautiful Autumn day in sunny Nelson which means It's time to get out in the fresh air.

I go for rides on my mobility scooter with my 2 granddaughters who ride their bikes. We ride on the bike tracks close to Tasman, Ruby bay & Mapua.

We have stunning views and wide tracks so it makes it easier to keep far enough apart.

I wear my mask for safety reasons and reassurance. It's a friendly village feel to our area so everyone is smiling and seemingly coping well during the lockdown.

We take our drinks and a snack by the sea at Ruby Bay. There are many people who are doing the same thing. Some will stop to chat but most just say a friendly hello.

What a wonderful feeling it is to be in the fresh air and to boost your morale.

I hope that many of you are able to do the same. Keep safe and stay well.

Fond regards Beth Richards ❤️🧐



Nelson Group

Thought for the day:

To all nurses and doctors
THANK YOU
for all you are
doing to take care
of people with the
CORONA VIRUS
We admire you greatly



Members News:

Southland Scleroderma Group

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

Thank you, Jenny, for organising our lunch get together in Gore at the end of the February. There were 26 of us. I still don't know if I am pleased that three new members were able to attend or be downhearted, they have Scleroderma. Great organisation skills from the Invercargill and Winton people to carpool to get to Gore.



Southland Group

Some topics of conversation (there was lots of talking):

- Sonia and family being evacuated from their home with the flood in Gore a week earlier. So pleased your home was not flooded Sonia, but the section and sheds needed a big clean up.
- Leeanne feeling better after a medication change, it is hard work trying to find the best medication for the job!
- A huddle in the corner of us comparing lumps on our elbows and hands, you can't do that at non scleroderma lunch out! I think you won Kim with your dramatic elbow!
- One member's partner dealing with disbelief of a diagnosis of cancer crashing into her life.
- What topics to discuss at our Southland Seminar in September.
- Gwenda regaling us with her recollection of looking after her young twin grandchildren overnight, then getting them into their car seats and out again at Day Care, what a mission when your body doesn't work as well as your brain would like.
- So pleased that Rachael brought her 2 littles ones along, they are growing so fast.

- Bronwyn in the past had told her podiatrist about Scleroderma, so when Pat visited the podiatrist and told her about her recent diagnosis, the podiatrist got them together, also well done to the nurse at Southland Hospital who connected Neil and Nigel. Lynette enjoyed catching up with Murray. Murray had been her athletics coach a few years ago! Networking is alive and well in Southland.

Great choice for the venue Jenny, space for us to move around and a lovely lunch and they didn't mind too much that we were still there a wee while after closing time.

I look forward to next time.

Heather Milligan



Rachael and her children



Members News:

Wellington Scleroderma Group

The Wellington Scleroderma group met for a shared Afternoon tea at Adrienne's home in Paraparaumu...

Wellington Group all met up at Adrienne's lovely home in Paraparaumu on the 15th February 2020. It was a beautiful summers day, and we all moved out to Adrienne's back garden where there was a lovely breeze under the shade of some trees.

We welcomed some new members, the Davis Family who brought their lovely children along.

Susan showing us Aircycle:



Adrienne had organised a lovely lady by the name of Susan to come to talk and demonstrate on some helpful apparatus's for our hands and feet.

Susan showed us a product made by a New Zealand company called Aircycle, which is an aid to help with circulation in your hands, feet and improve muscle strength and function.

At the meeting Adrienne, put forward her idea about having alternative meetings between Kapiti and Wellington. Wellington people will need to decide whether they want to have all their quarterly meetings in Wellington or alternate between Kapiti and Wellington, which we were to decide later.

A huge thank you goes to Adrienne for making us all feel welcome in her home and organising such an informative meeting. We all enjoyed ourselves, had lots to eat, caught up with each other and had lots to talk about.

Susan demonstrating how Aircycle can be used for



Excersing the Feet



Excersing the Hands

Thank you to everyone who came, brought lovely food to share and for making it a wonderful get together for the start of the New Year.

Take Care and look after yourself and your family in your Bubble.



Tina McLean



Members News:

Christchurch Scleroderma Group



Back row - Marion, Carolyn, Nikki and Barb
Front row - Chris and Glynis

Unfortunately Carla left the meeting before the photo was taken, hopefully she'll be in the next photo shoot.

Chris and her husband were due to go to Fiji next month with a large family party for a special celebration, but plans have changed due to Covid19.

Marion mentioned: Warren Agencies, at 79 Wrights Road, Christchurch (Tel. 03 338 0171) to have clasps on necklaces and bracelets changed over to magnets. Much easier to put on necklaces and bracelets. They charge a very reasonable price for doing this.

Carolyn and Carl were over at Musket Cove, Fiji for a holiday in early January and had a wonderful time. It was great to catch up with Fijian friends too. Carolyn tried paddle boarding, but it was a disaster, she couldn't stand and was always falling off - she only managed to kneel on the board. Definitely not as easy as it looks!

Always game to try new things though



All our Christchurch family are well and coping inside their 'bubbles'. Roll on when we can all get together again for a few laughs.

Keep well, keep safe everyone.
From the Christchurch ladies.

Upcoming Events: Southland

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

More information about the seminar coming soon – keep an eye out for it in the next Newsletter. (Preparations have halted for now due to Covid 19)

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

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

Waikato

In June we have a Luncheon to celebrate **World Scleroderma Day**. This year will be at **St Andrew's Golf Course** on 27th at 11.30 am. Will contact all later.

This 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.

LINDA BELL
SCLERODERMA WAIKATO

Scleroderma NZ AGM

AGM Notice Saturday 27th June via email 10am-4pm



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.

We would like to extend a very big warm Welcome to: - Lynley, Carol, Aubrey, Nigel, Pat, Murray, Philip and the Davis Family

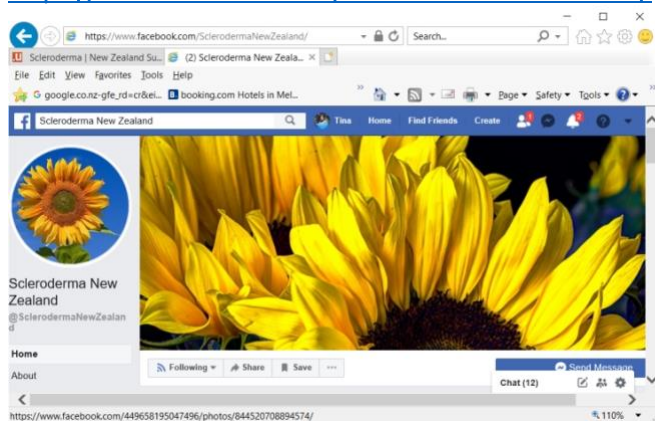
Our **Website** address Link is as shown below: -

<http://scleroderma.org.nz/>



Link to our **Scleroderma NZ Facebook** page and **Auckland Facebook** page as shown below: -

<https://www.facebook.com/SclerodermaNewZealand/>



<https://www.facebook.com/groups/sclero.akl/>



<http://scleroderma.org.nz/>

Virtual Support Group Meetings

Many scleroderma support groups around the world are adapting to local Stay at Home directives by using online meeting tools. To participate in an online meeting, your computer needs a webcam, speakers, and microphone. Laptops generally come with these features built in. Tablets and smart phones can often be used to access online meetings too, by using an app from the same site.

Our First Zoom Virtual Meeting

As we meet as a community group..... some of us in public places, others in homes or meeting rooms, we need to take special care because most of us have a compromised immune system and have underlying complications with our lungs and other organs.

Scleroderma NZ will need to think about not meeting in our groups until the course of covid -19 is clear and hopefully a vaccine in the near future, but that could be at least one year away.

Dianne looked into electronic forums to keep up the community support, and on Wednesday we had our first zoom meeting for members to join in on. Below is a screen shot taken during the meeting. It was fantastic to see everyone on there.



Noticeboard:

Wellington support group meets:

Saturday 16th May 2020 1.30pm to 4.00pm
Saturday 15th Aug 2020 1.30pm to 4.00pm
Saturday 14th Nov 2020 1.30pm to 4.00pm

Venue:

Hardwick Smith Lounge, Belmont Domain, Lower Hutt

Christchurch support group meets:

Saturday 23rd May 2020 2:00pm to 4:00pm
Saturday 25th July 2020 2:00pm to 4:00pm
Saturday 26th Sept 2020 2:00pm to 4:00pm
Saturday 28th Nov 2020 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.

Auckland Respiratory support group meets:

Venue:

327a Whangarata Road, Taukau Auckland 2694

Southland support group meets:

Sunday 17th May 2020 **Buster Crabb** Invercargill
Sunday 16th Aug 2020 Winton
Sunday 8th Nov 2020 **Thomas Green** Gore

Hamilton support group meets:

We will be at Robert Harris Chartwell starting on **Tuesday 4th February 2020.**

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

Due to Covid-19 Virus, we are suspending meetings Face to Face....

Contacts:

Find a Scleroderma a Support Group near You:

Auckland Respiratory: Allan Edmondson, Email: alsand327a@gmail.com

Waikato: Linda Bell, Email: linda.bell@hotmail.co.nz

Palmerston North: Dianne Purdie, Email: diannepurdie@xtra.co.nz

Wellington: Dianne Purdie, Email: diannepurdie@xtra.co.nz

Nelson: Beth Richards, Email: ronbethrichards3@gmail.com

Christchurch: Carolyn Barkhausen , Email: barkman@xnet.co.nz

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/

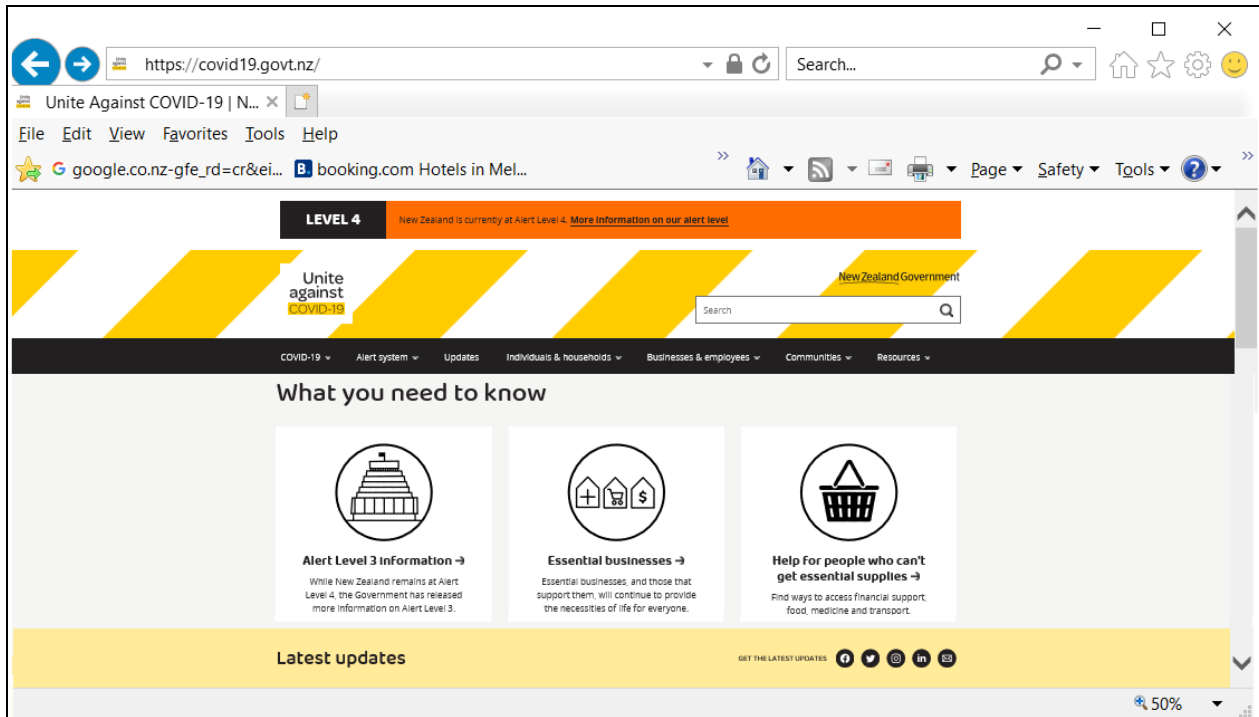
New Support Groups:

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.



Government Website on Covid-19 Information

On your Computer, Laptop, iPad, Tablet or even your Smart mobile phone, open your <Internet Browser> application and type in this address: - <https://covid19.govt.nz/> (screen image as shown below)



New Zealand COVID-19 Alert Levels Summary		
<ul style="list-style-type: none"> The Alert Levels are determined by the Government and specify the public health and social measures to be taken in the fight against COVID-19. Further guidance is available on the Covid19.govt.nz website. The measures may be updated based on new scientific knowledge about COVID-19, information about the effectiveness of control measures in New Zealand and overseas, or the application of Alert Levels at different times (e.g. the application may be different depending on if New Zealand is moving down or up Alert Level). Different parts of the country may be at different Alert Levels. We can move up and down Alert Levels. Essential services including supermarkets, health services, emergency services, utilities and goods transport will continue to operate at any level. Employers in those sectors must continue to meet health and safety obligations. Restrictions are cumulative (at Alert Level 4, all restrictions from Alert Level 2 and 3 apply). <p>Published 16 April 2020</p>		
ELIMINATION STRATEGY – New Zealand is working together to eliminate COVID-19		
Alert Level	Risk Assessment	Range of Measures (can be applied locally or nationally)
Level 4 – Lockdown Likely the disease is not contained	<ul style="list-style-type: none"> Community transmission is occurring. Widespread outbreaks and new clusters. 	<ul style="list-style-type: none"> People instructed to stay at home (in their bubble) other than for essential personal movement. Safer recreational activity is allowed in local areas. Travel is severely limited. All gatherings cancelled and all public venues closed. Businesses closed except for essential services (e.g. supermarkets, pharmacies, clinics, petrol stations) and lifeline utilities. Educational facilities closed. Rationing of supplies and requisitioning of facilities possible. Reprioritisation of healthcare services.
Level 3 – Restrict High risk the disease is not contained	<ul style="list-style-type: none"> Community transmission might be happening. New clusters may emerge but can be controlled through testing and contact tracing. 	<ul style="list-style-type: none"> People instructed to stay home in their bubble other than for essential personal movement – including to go to work, school if they have to or for local recreation. Physical distancing of two metres outside home (including on public transport), or one metre in controlled environments like schools and workplaces. People must stay within their immediate household bubble, but can expand this to reconnect with close family / whānau, or bring in caregivers, or support isolated people. This extended bubble should remain exclusive. Schools (years 1 to 10) and Early Childhood Education centres can safely open, but will have limited capacity. Children should learn at home if possible. People must work from home unless that is not possible. Businesses can open premises, but cannot physically interact with customers. Low risk local recreation activities are allowed. Public venues are closed (e.g. libraries, museums, cinemas, food courts, gyms, pools, playgrounds, markets). Gatherings of up to 10 people are allowed but only for wedding services, funerals and tangihanga. Physical distancing and public health measures must be maintained. Healthcare services use virtual, non-contact consultations where possible. Inter-regional travel is highly limited (e.g. for essential workers, with limited exemptions for others). People at high risk of severe illness (older people and those with existing medical conditions) are encouraged to stay at home where possible, and take additional precautions when leaving home. They may choose to work.
Level 2 – Reduce The disease is contained, but the risk of community transmission remains	<ul style="list-style-type: none"> Household transmission could be occurring. Single or isolated cluster outbreaks. 	<ul style="list-style-type: none"> Physical distancing of one metre outside home (including on public transport). Gatherings of up to 100 people indoors and 500 outdoors allowed while maintaining physical distancing and contact tracing requirements. Sport and recreation activities are allowed if conditions on gatherings are met, physical distancing is followed and travel is local. Public venues can open but must comply with conditions on gatherings, and undertake public health measures. Health services operate as normally as possible. Most businesses open, and business premises can be open for staff and customers with appropriate measures in place. Alternative ways of working encouraged (e.g. remote working, shift-based working, physical distancing, staggering meal breaks, flexible leave). Schools and Early Childhood Education centres open, with distance learning available for those unable to attend school (e.g. self-isolating). People advised to avoid non-essential inter-regional travel. People at high risk of severe illness (older people and those with existing medical conditions) are encouraged to stay at home where possible, and take additional precautions when leaving home. They may choose to work.
Level 1 – Prepare The disease is contained in New Zealand	<ul style="list-style-type: none"> COVID-19 is uncontrolled overseas. Isolated household transmission could be occurring in New Zealand. 	<ul style="list-style-type: none"> Border entry measures to minimise risk of importing COVID-19 cases. Intensive testing for COVID-19. Rapid contact tracing of any positive case. Self-isolation and quarantine required. Schools and workplaces open, and must operate safely. Physical distancing encouraged. No restrictions on gatherings. Stay home if you're sick, report flu-like symptoms. Wash and dry hands, cough into elbow, don't touch your face. No restrictions on domestic transport – avoid public transport or travel if sick.

Announcement: COVID-19 Alert Levels

from the Prime Minister of New Zealand— Jacinda Ardern...

Part of the Statement speech from Monday 21 April 2020 at 4.00pm :

“ With that in mind, here’s a reminder of the principles for life at Alert Level 3.

1. **Stay home:** If you are not at work, school, exercising or getting essentials, then you must be at home, the same as at level 4.
2. **Work and learn from home if you can:** We still want the vast majority of people working from home, and children and young people learning from home. At-risk students and staff should also stay at home, and they will be supported to do so. Early learning centres and schools will physically be open for up to Year 10 for families that need them.
3. **Make your business COVID-19 safe:** COVID-19 has spread in workplaces, so the quid pro quo of being able to open is doing it in a way that doesn’t spread the virus. Important industries like construction, manufacturing and forestry will be able to open, as will retail so long as it is not customer-facing.
4. **Stay regional:** You can exercise at local parks or beaches within your region, but the closer to home the better. Activities must be safe – keep two metres away from anybody not in your bubble. Make minimal trips.
5. **Keep your bubble as small as possible:** If you need to, you can expand your bubble a small amount to bring in close family, isolated people or caregivers.
6. **Wash your hands often with soap:** Then dry them. Stay home if you are sick. Cough into your elbow.
7. **If you’re sick stay at home:** Please seek advice from your GP or Healthline about getting a test. And quickly. There is no stigma to COVID-19. We will only be successful if everyone is willing to play their part in finding it wherever it is.

These rules are important. We all want to continue to progress down the levels, and the best hope of getting back to normal as soon as possible is not getting ahead of where we are right now.

To recap, where we are right now is in Alert Level 4 lockdown for the next week.

From Tuesday the 28th of April, we will move to Alert Level 3 and stay there for two weeks. Those two weeks give us another cycle of transmission to assess how we are doing. From there, we will move if we can and if we’re ready. But only when we’re ready, and only when it’s safe.

This is a five million strong team effort and I couldn’t be prouder of the start we have made, but let’s not waste this chance to eliminate the virus.

So please, stay strong, stay home, be kind. And let’s finish what we started.”

Jacinda

Joke of the day:

