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# Scleroderma

## New Zealand support group

## Summer 2021

Greetings to you all.

Welcome to the Summer edition of our Scleroderma Newsletter.

Happy New Year for 2021. We hope everyone is keeping well and enjoying the warmer weather we are having.



I thank God we have made it through, as we step out of 2020 - the year that was and will hopefully never be again. We still have the Coronavirus, but let's hope that 2021 will be a better year for all of us. We all need now to focus on what we want to change this year.

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 a Memorial for Judith Trewartha.

We have Questions and Answers regarding the Covid-19 Vaccine from the Scleroderma Foundation Medical & Scientific Advisory Board. We have information on Eating Well with Scleroderma and we find out how we can get an Instant Mood Boost.

In the Member's Stories section, I would like to introduce a little about myself. As a person with scleroderma, I thought it would be nice to share my goal for this year with our members and look at some forms of exercises that a person with scleroderma might be interested in. We have Erena Bruce talk to us about making time for yourself and we have a lovely photo of Glenys and Ian Findlay at Christmas time.

Linda Bell talks about her cat, Strawberry in the Pet Corner, then we have Member's News and Upcoming Events from around the country.

We still have the two new sections called; Book Club, and Today's Recipes. I have added another new section called Some Useful Websites.

Members are encouraged to submit something to us to keep the newsletter fresh and interesting.



# Presidents Report:

January 2021



**"Happy New Year to you all."**

I would like to thank the Scleroderma NZ committee and all the group leaders and group members for staying in contact this year. We enjoyed

catching up with each other from around the country via zoom meetings, which was appreciated by those who could make it along. Now we are able to meet at face to face meetings taking good precautions.

A special thanks to our Newsletter Editor team Tina McLean and Jenny Andrews. Jenny and Tina have helped hold us together throughout the year with their very interesting newsletters and news from the regions, their efforts have been terrific, and enjoyed by many.

Also special mention and thanks to our Facebook administrators Cushla Marsters and Catherine Thompson. Both Catherine and Cushla have also kept up good contact through the year for all those people with Scleroderma, on a national and global level, which has meant a lot to people knowing that there is someone there keeping the coals burning.

A few of our members have had very sad difficult times this year, our thoughts go out to them.

Wellington enjoyed a fun Christmas meeting in November, with great company from our members old and new and especially lucky to have Catherine and Paul along to get us singing and having great festive time.

It has been a challenging year for everyone this year, but I think we all deserve to pat ourselves on

the back, we have made it through one of the most difficult times of recent New Zealand history.

It won't be long now and within the next six months or so and we will be granted with a vaccine to help protect people though out the country from COVID -19.

As time has gone by New Zealand appears very lucky compared to many countries, like Europe, USA and Canada, who are currently in lockdown over the holiday season.

We should not be complacent and I know how easy it is to be so, after working so hard for so long, and our luck, to be able to control any out breaks so far.

So remember to wash your hands, still adhere to level 1 guidelines by keeping good social distancing where possible and remember to use your contact tracing app. Remember stay home if you are unwell, and health line on **0800 611 116**.

Enjoy those holidays and fun times, we are so fortunate!

All the Best,

**Dianne and Gordon**





# Memorial for Judith Trewartha

It is with great sadness that we bring the news of Judith Trewartha passing on the 1<sup>st</sup> December 2020



Judith Helen Trewartha



**TREWARTHA,** Judy (nee Murtagh). Peacefully at North Shore Hospital on Tuesday the 1 December 2020, after a long

valiant journey; aged 76 years.

Cherished wife of the late Ian Trewartha. Beloved Mother and Mother-in-law of Marie and Gordon, and Ben. Loving Granma of Erin, Kahlan and Dana.

A private family service will be held mid-December.

A full memorial service will be held for Judy in February for all to come and celebrate her life.

In Lieu of flowers, donations to Kidscan will be greatly appreciated.

Source:

<https://notices.nzherald.co.nz/obituaries/nzherald-nz/obituary.aspx?n=judy-trewartha&pid=197217449&fhid=12561>

## Scleroderma New Zealand Member

Judy had been struggling with health issues for a long period of time, and had a serious stay in hospital for many weeks over the lock down period.

We sent her some lovely flowers during that time from us here on the committee and she did get back to me and thanked us, once she was able.

Judy was a very kind lovely lady who gave us and many others support over the years. We will miss hearing from her.

Our kindest thoughts are with Judith's family.

Dianne Purdie



# Questions and Answers Regarding the COVID-19 Vaccine

*Reviewed January 2021 by the Scleroderma Foundation Medical & Scientific Advisory Board Leadership Committee\**

## Preamble

The COVID-19 pandemic is from the SARS-CoV-2 virus and thus far is responsible for more than 75.2 million cases and 1.67 million deaths worldwide, with 17.3 million cases and 311,000 deaths in the USA (as of Dec 18, 2020). The numbers are rising. COVID-19 is now the leading cause of death in the USA.

Recommendations about receiving COVID-19 vaccinations may be changing as we learn more. These questions and answers are only a guide and should not replace discussion with your health care provider.

The two vaccines to be approved in North America are the Pfizer and the Moderna vaccinations and other vaccines are available in different parts of the world the vaccination will be in a series of two injections provided either three weeks (Pfizer) or 28 days (Moderna) apart.

## Commonly Asked Questions

### Should I get the COVID vaccine?

Yes, however if you have systemic sclerosis (scleroderma) there may be some things you should know before you receive it. The vaccines so far have not been tested in pregnant women, children below age 16, or large numbers of patients with autoimmune diseases. As more data are available, recommendations may include them.

### What is the benefit?

The vaccines against COVID-19 seem highly effective. However, they have not been tested in large numbers of people with autoimmune diseases and/or patients receiving immunosuppressive medications. There may be a dampened response such as in people with systemic sclerosis (scleroderma) who may be taking immunosuppressive medications. The benefits include prevention of COVID-19 infection, or less severe infection, and herd immunity (stopping the spread in your community when enough people are vaccinated). Due to the significant amount of people who have died or been very sick with COVID-19, the hope is to prevent severe infection and its long-term effects.

### What do I do with my medications/drugs when I get the vaccination?

At this time, there is not enough information regarding the effect of immunosuppressive medications on the efficacy of the COVID-19 vaccine, and you should consult your health care provider on this matter.

Some medications may be interrupted briefly during vaccination, however if you have been on prednisone for a long time, it cannot be stopped for the vaccination.

We know that with the flu shot, patients receiving methotrexate may have a better response if they hold their methotrexate for 2 doses after receiving the vaccination. There is no firm recommendation for the COVID-19 vaccination but perhaps interrupting your immune suppression medication for 2 weeks after each injection may lead to a better response. However, this is only speculation. This could include methotrexate, mycophenolate mofetil, azathioprine, tocilizumab, JAK kinase inhibitors, TNF inhibitors, abatacept. If you are receiving rituximab, the timing may be best to receive the vaccination 4 months after the last dose of rituximab and waiting a couple of months to receive your next dose of rituximab. This is only a guideline and you can show this as an example to your health care provider.

### Will this flare my scleroderma?

We do not know, but a flare of scleroderma should not be common as many other vaccinations that boost the immune system do not routinely flare autoimmune diseases in the vast majority of people who receive vaccines.

The vaccine will not be 100% effective, so all recommendations after being vaccinated will still be present such as wearing a mask, frequent hand washing, and social distancing.

### Is there a special risk for me as I have SSc?

The main risk factors for poor outcomes with COVID-19 infection are advanced age, heart disease, chronic obstructive lung disease, diabetes mellitus, high dose prednisone use, and other minor risk factors such as high blood pressure and high body mass index (obesity). It is likely that those with recurrent infections and those who are frail also have a higher risk of doing poorly. We suspect that having interstitial lung disease or pulmonary hypertension or recurrent aspiration from poor motility of the swallowing tube (oesophagus) put those with systemic sclerosis at a higher risk, making vaccination an important consideration for these and most other patients. The risk is likely not increased in those with morphea and linear scleroderma unless they are on strong immune suppression treatment.

### How long will the vaccine be effective for?

We do not know. The vaccine trials contained large numbers of patients, so antibody response and the safety are known for the short term, but the long-term benefit is currently unknown.



# Questions and Answers Regarding the COVID-19 Vaccine continued

*Reviewed January 2021 by the Scleroderma Foundation Medical & Scientific Advisory Board Leadership Committee\**

## Will vaccines stop the pandemic?

This depends on how effective the vaccines are and how many people receive the vaccine (for herd immunity) and how long the benefit / response to the vaccination lasts. Also, so far, the virus is not mutating very much but if it mutates then benefit may be less. This is true for the flu vaccination where the influenza virus mutates every year, and the flu shot reflects the strains that are expected to be in your community.

### *Scleroderma Foundation Disclaimer:*

*The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials or studies referenced in this document. Information is provided to keep the readers informed. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician for proper evaluation and treatment.*

[Revised January 8, 2021]

- [1/8/21 MSAB Statement](#): Questions and Answers Regarding the COVID-19 Vaccine
- [12/15/20 Webinar Recording](#): "Scleroderma and COVID-19," Leroy Griffing, M.D., Mayo Clinic Arizona Scleroderma Program
- [10/21/20 WEBINAR](#) Coping with Both a Pandemic & Scleroderma, Lee Shapiro, M.D.
- [5/1 UPDATED Statement](#) COVID-19 (Coronavirus) Information & Recommendations
- [4/24 Webinar Recording](#): "Balancing Your Immune System: A Special Webinar on Nutrition for Scleroderma Patients," Elizabeth R. Volkmann, M.D., M.S., University of California, Los Angeles
- [4/16 Webinar Recording](#): "Taking Care of Yourself at Home: Maintaining Hand and Face Mobility," Janet Poole, Ph.D., University of New Mexico"
- [3/27 Webinar Recording](#): "Staying Well During COVID-19," Tracy Frech, M.D., M.S., University of Utah
- [3/21 Video Forum Recording](#) "Scleroderma & COVID-19: A Conversation with the Experts"
- [3/21 Statement](#) "Important Information Related to COVID-19 and Juvenile Scleroderma"
- [3/20 Message](#) from Scleroderma Foundation CEO, Robert J. Riggs
- [1/4/20](#) Información Importante Traducida al Español Sobre COVID-19 y Esclerodermia Juvenil
- [30/3/20 Español](#) "COVID-2019 ("Coronavirus") Información y Recomendaciones del Comité de

Asesoría Médica y Científica de la Fundación de la Esclerodermia

### Source:

[https://www.scleroderma.org/site/SPageServer?pagename=patients\\_COVID19\\_MSAB\\_Vaccines&AddInterest=1281#.XuHvOBYays](https://www.scleroderma.org/site/SPageServer?pagename=patients_COVID19_MSAB_Vaccines&AddInterest=1281#.XuHvOBYays)

The helpful information about the covid-19 vaccine and scleroderma in the above link was sent to **Dianne Purdie** from **Prof Brett Thombs** the Director of the **Scleroderma Patient intervention Network** of which we are a partner of.

### [Brett D. Thombs, Ph.D.]

Professor, Faculty of Medicine, McGill University  
Senior Investigator, Lady Davis Institute of Medical Research, Jewish General Hospital  
Canada Research Chair (Tier 1)

Member, College of the Royal Society of Canada  
Fellow, Canadian Academy of Health Sciences

<https://www.thombsresearchteam.ca/>  
Chair, [Canadian Task Force on Preventive Health Care \(CTFPHC\)](#)

Director, [Scleroderma Patient-centered Intervention Network \(SPIN\)](#)

Director, [DEPRESSion Screening Data \(DEPRESSD\) Project](#)

## Remember to follow the advice of our Government

- Download the **NZ COVID Tracer** app
- Turn on **Bluetooth Tracing** (Bluetooth tracing is not intended to replace our existing contact tracing processes or the NZ COVID Tracer QR codes.)
- Scan the **QR codes** where ever you go to keep track of where you've been. (Bluetooth tracing is an added tool — it helps keep track of the people we've been near.)
- 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](https://www.covid19.govt.nz)

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

<https://covid19.govt.nz/alert-system/current-alert-level/>

**What we all need to do this summer**

 <b>Stay home if you're sick →</b> If you're feeling unwell, isolate wherever you are and call Healthline about a free COVID-19 test. By getting a test, you're helping keep your community safe.	 <b>Use the NZ COVID Tracer app →</b> The NZ COVID Tracer app keeps us 1 step ahead of the virus. Scan QR codes wherever you are, and turn on Bluetooth tracing.	 <b>Wash your hands →</b> Washing your hands is 1 of the easiest ways to keep yourself safe. Wash often. Use soap. 20 seconds. Then dry. This kills the virus by bursting its protective bubble.
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# EATING WELL WITH SCLERODERMA:

Continued from last Newsletter on Living with Scleroderma from the Scleroderma Society website ...

## EATING WELL WITH SCLERODERMA

Scleroderma is a chronic disease in which tiredness, digestive problems and nutrient deficiencies are common. A diet for it full of good nutrients is vital to manage symptoms and thereby improve quality of life. There is not one simple 'scleroderma diet' since the symptoms, and their severity varies from person to person. However, establishing a balanced diet with food that fights inflammation whilst at the same time providing energy, protein, vitamins and minerals should be the aim for everyone with the disease.

## MALNUTRITION

Malnutrition is something that people with scleroderma are at increased risk of, even if following a healthy diet. This can be caused nutrients not being absorbed well by the gastrointestinal tract, or because appetite is poor and not enough food is being eaten or because preparation of the food is challenging or because chewing and swallowing can be difficult. Monitoring your weight at home regularly should reduce your risks for falling into malnutrition.



Iron, Zinc, Vitamin B12 and Vitamin D supplements

Health professionals can take blood samples to test for protein and specific vitamin and mineral deficiencies. This includes blood tests to assess iron levels as well as zinc and B12, vitamin D, carotene and more.

If chewing or swallowing is a problem, fruit and vegetables can be blended into a juice and making home-made smoothies with protein powders are also helpful. Soft proteins that make good snacks are cottage cheese and scrambled eggs. There are a number of healthy fats to add to a diet including olive, canola and peanut oils; nuts, seeds and nut butter; avocado; fatty fish; and oil-based salad dressings.

## GENERAL DIET RECOMMENDATIONS

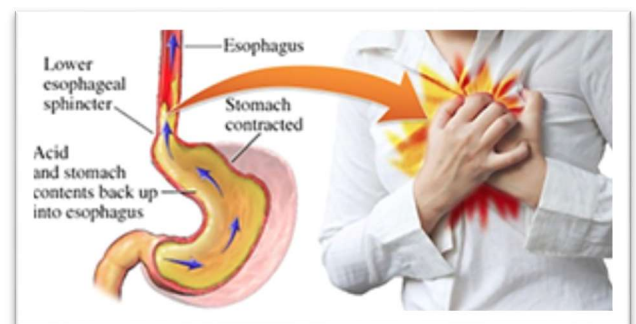
Eat small meals every three to four hours if you can only eat small amounts at a time. Some eat every two hours to

maintain optimal weight. Keep processed foods to a minimum, cutting out preservatives, artificial ingredients or hydrogenated oils. Herbs are good to add to foods, including antioxidant, anti-inflammatory herbs and spices, including basil, rosemary, oregano, cinnamon, ginger, paprika, cayenne, turmeric and curry powder. Try to remove added sugars, though natural sugars in milk, fruit and yoghurt are not a concern.

## FOOD FOR GASTROINTESTINAL SYMPTOMS

For severe gas, bloating, discomfort, diarrhoea and/or constipation, consider removing foods containing wheat (gluten) or dairy (lactose) from your diet, one food item at a time. These foods often are difficult to digest. If removing wheat and/or dairy products does not provide relief, starting diet low in sugars and carbohydrates that are difficult to digest can be helpful

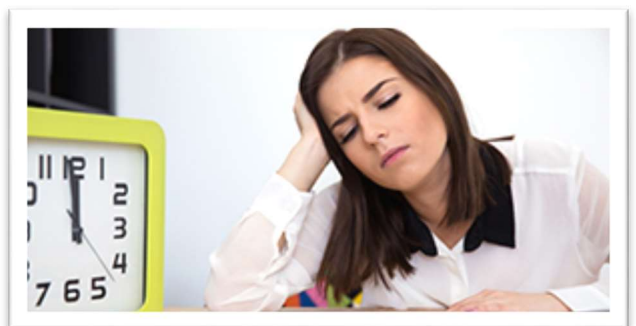
## REFLUX OR HEARTBURN



Acid reflux, heartburn

Eat small meals often and avoid eating two or three hours before bedtime. Avoid citrus fruits, tomato products, fried foods, coffee, garlic, onions, peppermint, gas-producing foods like beans, spicy foods and fizzy drinks as well as alcohol.

## FATIGUE



Maintain stable energy levels with small, frequent meals, so that blood sugar levels remain stable. Moderate daily exercise, like walking or yoga help. Try and get at least seven hours of sleep each night and take an iron supplement if levels are low, taken with vitamin C for better absorption.



# EATING WELL WITH SCLERODERMA Continued ...

## INFLAMMATION



Hand inflammation

Dark coloured fruit and vegetables will increase antioxidant intake, especially dark green, red, purple and blue. Fatty fish, walnuts and foods rich in vitamin E like nuts, seeds and olive are all good too. Vitamin D helps with the absorption of fats.

## CONSTIPATION



Constipation

Exercise helps food move through the digestive tract — eat whole grains, fruit and vegetables and increase fluid intake.

## POOR CIRCULATION



Legs with poor circulation

Exercise is important, and zinc and iron will help wound healing and can be found in beef and pork.

## TIGHT, THICKENED SKIN



Thickened skin on the hands

Eat food rich in vitamin E and consider taking a biotin supplement.

## Source:

<http://www.sclerodermasociety.co.uk/eating-well-with-scleroderma.html>



# Looking for an Instant Mood Boost? -

## Here are 7 Proven Happiness Boosters:

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When you're stressed or sad, it's easy to bury your head under the covers or hit the fridge. And in the time of social distancing and coronavirus quarantine, every minute may feel like a struggle to keep your mood up. If you're looking for instant mood boosters, or the best ways to lift your spirits and feel more positive, here are seven simple, science-backed secrets to try.

So let's try to smile again—here are the best mood boosters.

### Instant Mood Boosters

#### 1. Grab some art supplies

The adult colouring craze is still going strong, and it's more than good fun: A 2017 study in the journal *Art Therapy* found the act of colouring an image lowered anxiety and improved mood. Want to explore a new creative pursuit? Try painting. Studies have shown it can improve quality of life and depression in cancer patients, so it might help you beat the blues, too.

Related: 30 Adult Colouring Books

#### 2. Schedule a weekly video chat

At a time when loneliness is on the rise, it's important to make connecting with your loved ones a must. Schedule a weekly video chat with your best friend, a family member, or even reconnect with an old friend. You can play BINGO, watch a show together, and even take a virtual painting class!

Related: Best Video Chatting Apps

#### 3. Exercise your gratitude muscle

We know that expressing gratitude, especially daily, can make us happier. The problem? The average person runs out of things to say they're grateful for, says Michelle Gielan, positive psychology researcher and author of *Broadcasting Happiness*. Her advice: Focus on unique, specific, small stuff. Instead of saying you're grateful for something general like your health, try, "I'm grateful for my health because it allowed me to go for a 20-minute run today," Gielan says. "If you keep it up, you'll start to notice all these things to be grateful for, including conversations at work or a flower in someone's yard."

Related: Gratitude Is Having a Moment—Here's Why That Matters (And How You Can Incorporate It Into Your Own Daily Routine)

#### 4. Get real about social media

Facebook, Twitter and Instagram can boost your mood or drive it into the dumps, according to 2016 research in *JMIR Mental Health*. Do an honest assessment of how it makes you feel. Supported and connected? By all means, log on and feel the love. On the other hand, if social media tends to bring out negative emotions, step away from the screen.

Related: How Telemedicine Works

#### 5. Get more green in your life

More time in nature can boost your happiness. In fact, a 2013 study in *Global Environmental Change* found that people are "significantly and substantially happier outdoors in all green or natural habitat types than they are in urban environments." Of course, there are plenty of urban green spaces too, and a 2014 study in the *Journal of Environmental Psychology* found that even those can lower stress.

Related: Feeling Overwhelmed During the Coronavirus Crisis? Here's Everything You Need to Know About Online Therapy

#### 6. Smile!

It's probably the last thing you want to hear when you're sad or mad, but a study in *Psychological Science* found that when assigned to stressful tasks, participants who were asked to smile while doing them recovered from the stress faster than non-smiling participants. Other research suggests that if you make yourself smile by recalling happy memories, you can improve your mood.

Related: How to Stay Mentally Tough

#### 7. Ask your doc about vitamin D

If you're depressed and have a vitamin D deficiency, taking a supplement may help turn things around, according to a 2017 review in the *Journal of Affective Disorders*. How do you know if you're low on D? Your doctor can give you a simple blood test to find out. Don't be surprised if you have low levels: Research in the *Archives of Internal Medicine* found that nearly 75 percent of adolescents and adults don't have enough of the sunshine vitamin in their bodies. The recommended daily maintenance dose is 600 IU.

#### Source:

<https://parade.com/584686/hopecristol/best-mood-boosters/>





# Members Stories:

## Tina McLean - my next goal: Exercise for Strength, Mobility and Flexibility...



I was diagnosed with Diffuse Scleroderma in 2004, at the age of 33, and Myositis in 2007. The first 3 years were the hardest as a lot of changes were happening to my body and I was in constant pain. I was gradually losing my ability to do things for myself but because these changes were happening so quickly, I didn't realise how much I'd lost. Each day was a battle just to keep going and try and continue as normal, even

though I was finding simple tasks, such as dressing and undressing becoming slower and more difficult. It took longer to get dressed, tying up my hair became impossible, as I couldn't lift my hands above my shoulder level. I also couldn't bend down and reach below my knees, and eventually, I had to have my husband, Alastair help me get dressed, tie up my hair and put my socks and shoes on. These were just simple day to day tasks, and yet I was struggling. Never mind about doing house work or going out. I was finding I couldn't walk more than a block without having to stop because I was out of breath, exhausted, tired and in pain. I didn't even know which came first, being tired, out of breath or the pain. The only form of exercise I could do by this stage was Yoga, but eventually I had to stop that too as my thigh muscles had become so stiff and tight, that I was in extreme pain when I bent my knees. Besides being in pain all over the body, I was also suffering from Raynaud's constantly, not just during cold weather, but also when I was under stress.

My fingers were fat and puffy and I couldn't close them to make a fist. Both my legs were sore all over, my left thigh felt like someone was stabbing it with a knife, and I couldn't tell which part was sore, whether it was the muscle, the bone or what? The skin surfaces of my face, hands and shins were all tight and shiny. My jaws and neck had become very tight and stiff, so that opening my mouth and turning my head from side to side was getting harder. My ankles were puffy, tender, swollen and bruised looking. Over the next few months I noted changes in different parts of my body. The fingers, one by one started to curl and become crooked. My right toes had also curled (my GP said they were called hammer toes). I had all four signs of **CREST**. Raynaud's in my fingers and toes. Oesophageal dysfunction with food leading to constant reflux and regurgitation of whatever I ate. The crooked fingers and toes was the Sclerodactyly part. The red spots on my face, chest, back, inside palm of my hands was Telangiectasia. I also had patches of pigment loss on my back and arms called vitiligo.

By the end of 2007, I got so weak, and in so much pain, that I ended up being in hospital where I was diagnosed with Myositis. When I was discharged from hospital, my muscles were so weak that I couldn't get in and out of bed on my own, and I needed my husband to help. I couldn't walk from room to room without feeling exhausted and needed a walking frame or stick for support. I ended up having to use a wheelchair for about 10 months. I started a new regime of taking Methotrexate by injection once weekly and slowly began regaining some strength. It took a long time. Over the years my muscles have slowly increased in strength, and I no longer require a wheelchair, or a walking stick for support or stability. I still find climbing stairs quite a challenge, and can only manage a few steps at a time before needing a rest in between, as well as needing handrails for support. I find walking a few blocks and climbing hills quite a struggle, and I discovered recently, after having to go down 3 flights of stairs at my work place, that any exertion is quite a challenge for my thigh, knees and calf muscles, causing pain that lasts for quite a number of days afterwards.

Despite all this, I think I've come a long way from where I was in 2004. After several discussions with my Rheumatologist, and checks with my cardiologist, lung specialist and an obstetrician, I was given 1 year off from taking my methotrexate injections to try for a baby. We stopped the methotrexate injections at the beginning of 2010, and it took us till the end of 2010 to conceive. My pregnancy was not straight forward and I was put into the high risk category. My baby was born by caesarean operation at 29 weeks and then spent the next 8 weeks in NICU at Wellington Hospital. I spent my 40<sup>th</sup> birthday visiting him in hospital and thinking he was the best early birthday present ever. After waiting 7 long years, since being diagnosed with scleroderma and told initially that having children may not be an option for me, it was a miracle when Ian was born. We now have a healthy 9 year old boy, who is very cheeky and keeps me busy and on my toes every day.

I feel now I'm ready for the next goal in my life. I know you should not tell everyone your new year's resolution, as when you do, you put pressure on yourself to carry it through, but if I don't tell others I feel there is no motivation to even get started. This way, I'm making some kind of commitment. After all the Christmas and New Year celebrations, lots of eating, lots of non-activity, I've decided this year I need to focus on doing some form of exercise that will help me increase my muscle strength, improve my mobility and increase my flexibility. If I lose some un-wanted weight along this journey, well that would be an extra bonus. In the past, I've always had some reason as to why I couldn't exercise. From being too busy, not enough time in the day, not having any strength, not being able to do the exercise and scared that I'd be in pain. My motto up to now has always been, "No pain, no gain" when people say to me, "no pain, no gain". People also say, "If you don't use it, you lose it", so this year, I've decided to do something about it, not just think about it.



# Looking at Exercise:

## For Strength, For Mobility, For Balance...

There are lots of places you can find information about exercise, but I had to be careful that I chose exercise that suited my abilities. Not just do I have limited range of movements, but I also have very limited strength and flexibility. I was petrified of falling over when I was out on my own, as I had no strength to pick myself up. For a long time this was something I had accepted as part of my scleroderma journey, with so many other things going wrong with my health and being in pain and short of breath, I was happy just to get through the day. Exercise was the last thing I wanted to think about. Now that things have settled, my medications have kicked in and kept my scleroderma stable and my 9 year old son is more independent, I feel I'm at the next stage of my life and I'm ready to focus on exercise for strength, mobility and balance.

I have to be careful that I don't venture onto an exercise routine that will be great the first day and then put me in pain for the next few days. In the past, any form of exertion/exercise has caused a flare up in my muscles and I've ended up hobbling about in pain for a few days. I need exercise that will help increase my strength, mobility and flexibility, but won't cause pain in the few days after – is there such an exercise?

I decided to go straight to the Arthritis New Zealand website. (If there is group that should know about exercise for people with pain, and limited movements, it's definitely Arthritis NZ).

Arthritis New Zealand have a very useful guide you can download called "ARTHRITIS - Exercise to keep you moving" – below is the link to the Pdf file.

<https://www.arthritis.org.nz/wp-content/uploads/2018/10/ARTHRITIS-NZ-Exercise-Book-Nov-2011-FINAL-WEB.pdf>



The topics covered in this Exercise Book sounded exactly what I needed, and I wanted to share with everyone in case anyone else thought they

might like to exercise but may not be able to do so due to pain, limitations or fear. Below is list of the contents:

- ARTHRITIS: Exercises to keep you moving
- PICKING THE BEST EXERCISE OPTIONS
- MANAGING A FLARE-UP
- WAYS TO MAINTAIN GOOD POSTURE
- TYPES OF EXERCISE
- EXERCISES (e.g. Exercises you can do while sitting at the table, Exercises you can do while sitting, Exercises you can do while standing, Exercises you can do while lying on your back)

The two main topics I was really interested in was: -

- **Picking the Best Exercise Options**
- **Types of Exercise**

Picking the Best Exercise Options talked about "What kind of activities do you enjoy?" such as:-

- Outdoor (e.g. walking, gardening)
- Indoor (e.g. table tennis, weights)
- Group (e.g. dancing, lawn bowls)
- Water (e.g. swimming, fishing)
- Sports (e.g. net ball, jogging)

It also talked about "Which area of your body limits your physical activity?" such as:-

- Neck or shoulders
- Wrists, hands or fingers
- Hips or knees
- Lower or middle back
- Ankles, feet or toes

– This sounded exactly like me.-

**Types of Exercise, talked about the three main types of exercise, which was:**

1. **Aerobic:** to increase your general fitness level
2. **Strengthening:** to make the muscles stronger
3. **Stretching:** to stop you getting stiff.

### **Aerobic:**

This type of exercise can fit around your usual routine for 20-30 minutes, three times a week. Walking to the shops, taking the stairs, or mowing the lawns can count as an aerobic form of exercise.

Other more vigorous examples include walking, swimming, biking, aqua-jogging, aqua-aerobics, cycling, Tai Chi, yoga, dancing, bowls, petanque and golf.



# Looking at Exercise:

For Strength, For Mobility, For Balance continued...

## Strengthening:

Building strength requires you to tighten your muscles and either hold them in a specific position or move them through a range of motion. To build strength further, weight or resistance can be added, and repetition can be increased.

It is important to work with a trained professional, such as a physiotherapist, when tailoring an exercise programme to suit you.

Some strengthening exercises are included in the exercise section of the Arthritis New Zealand guide, starting on page 7.

## Stretching and flexibility:

A stiff joint or tight muscle can cause pain, discomfort and poor function.

Stretching and improving flexibility is important to maintain or improve movement.

Ideally, stretching and flexibility exercises should be done daily. Don't force a stretch. Do the movement until you feel a comfortable stretch, and maintain it for 10-20 seconds

The Arthritis New Zealand website has a lot of information, from *"Starting out with exercise"* to *"Motivation tips and tricks with arthritis"*, which I think we can apply to us as scleroderma causes similar limitations. Below, I wanted to look at these two topics: -

## Starting out with Exercise:

**Start low** – by this we mean the weight or loading that you use. If you are using weights start with something that after 10-12 repetitions is beginning to feel challenging but not impossible.

**Make it slow** –perform your exercises or stretches slowly and with control to ensure your technique is correct.

**Keep it short** – this is the activity duration whether it is taking a walk, a swim or lifting weights. Start with a time that does not leave you overly fatigued – and build up by no more than 10-20% at a time.

**Keep a record.** This is invaluable to track progress, see patterns that you can learn from and provide you with motivation when you see how you have improved over time.

## Motivation tips and tricks:

"Exercise and physical activity are among the most important things you can do to manage your arthritis. Regular exercise can reduce pain, prevent your symptoms from worsening and improve your everyday function. Exercise can also help you feel more positive and get a good night's sleep.



But at times motivation to go out and exercise can be difficult, especially if you're aching all over.

*"Here are some motivational tips and tricks that have helped others living with arthritis:"*

- **List why you should exercise** versus why you **want to**.

Take a piece of paper and make two columns. In one column list all the reasons **you should** exercise and in the other all the reasons **you want** to exercise. Ideally the 'want' column will be more emotionally connected. *Examples may be:*

- I want to exercise to be able to play with my children or grandchildren
- I want to exercise so that I don't end up in a wheelchair when I am older
- I want to exercise because it makes me feel good about myself.

Afterwards keep this list handy and refer to it regularly to remind yourself of your WHY.

- **Be flexible** with your exercise routine. Some days will be better than others. Know what you can do and have a **PLAN B** for the days when you are sore.
- **Set realistic goals** and review them according to how circumstances change for you. It doesn't matter if they're very simple to start with. Gaining a sense of achievement, no matter how small, will keep you motivated to continue. Keep a visible record of these exercise goals and achievements.
- **Reward yourself** when you hit a goal or target.
- **Run a movie** in your mind seeing yourself exercising as you plan to and then conjure up the feeling of satisfaction you will feel and the positive effects on your body when you have done it. You could add a personal mantra like "I'll feel great when I have done this" or "I always feel better when I exercise"





# Looking at Exercise:

For Strength, For Mobility, For Balance continued...



- **Start short.** Make a deal with yourself that you only have to do a short amount (say 5-10 minutes) and then after this time ask yourself if you can do more. Chances are that you will have warmed up sufficiently to go on for longer.

- **Move to music.** Distract yourself by playing some motivating music that inspires you to want to move.

- **Lay out your exercise clothes in clear view** so you get into it in the

morning without having to hunt it out. Once you are dressed to workout you may as well workout!

- **Make a date.** Just as you would for any appointment or meeting, diarise your exercise and only forgo it under extreme circumstances.
- **'Phone a friend'** Speaking to or exchanging texts with someone who supports you is often the little nudge you need when it is tough to get going.
- **Embrace social media.** Join a Facebook page with others that understand your situation. Knowing that others living with arthritis can and have overcome the same issues you have is very powerful in helping you stay connected and motivated."

## WHERE to get more help

From Arthritis NZ Website:

*"Taking charge of your condition relies on you having knowledge and getting ideas about the resources available to you."*

"These classes are not run by Arthritis New Zealand. We suggest you make contact with them to discuss if they are right for you."

Arthritis New Zealand is working with Exercise New Zealand to compile a national directory of exercise classes that may be helpful for people with arthritis so this list of possible choices is by no means definitive.

Source:

<https://www.arthritis.org.nz/where-to-get-more-help-for-exercise/>

## Website Links that help with Exercise:

### Green Prescription

A Green Prescription is written advice from a health professional (usually your doctor or practice nurse) to be ACTIVE and improve your diet. It's a support service that helps you to improve your health and feel better at the same time. Go to [www.health.govt.nz](http://www.health.govt.nz) and search for **Green Prescription** to find the agency in your area.

### Exercise Professionals

A register of exercise professionals – go to [www.reps.org.nz](http://www.reps.org.nz) and look up a registered exercise professional in your area.

### Health Navigator

Go to [www.healthnavigator.org.nz](http://www.healthnavigator.org.nz) this is a comprehensive website with lots of useful information about managing long term conditions.

### Live Stronger

Go to [www.livestronger.org.nz](http://www.livestronger.org.nz) this website talks about exercising safely while you're at home with free videos and resources. If you have a smartphone or tablet, register to use the free Nymbal balance training app. Go to <https://nymbalscience.com/nz-fallsfree-welcome/>

### Balance and Strength Classes

Go to [www.livestronger.org.nz](http://www.livestronger.org.nz) and in the **Menu**, Choose **Find a strength and balance class**

### Find classes in your area.

An excellent Link to check various exercise offered in your area [www.livestronger.org.nz/home/find-class/find-a-class-near-you/](http://www.livestronger.org.nz/home/find-class/find-a-class-near-you/)

### Funding Subsidies to Gym Membership

The Exercise Association wants to get more Kiwis active. As a part of this, they are subsidising a limited number of memberships for Kiwis who are not a currently members of any fitness centre (and have not been one for the last 12 months). Go to <https://exercisenz.org.nz/subsidised-gym-memberships/>

My conclusion is to get started with exercise classes offered in my local area that includes a variety of exercises:

- **Hydro Motion** – gentle water class exercise
- **Aligned Pilates** - class to strengthen the core, back, hips and arms which also includes standing and balance exercises.
- **Ezy Movers** - Build cardiovascular fitness and strength in a fun, low-impact aerobics class
- **Enliven Modified Tai Chi** - Modified Tai Chi is a form of gentle exercise that combines deep breathing with slow gentle and deliberate movements.

Take care everyone,

Tina McLean



# Looking at Scleroderma Exercise

## From Self-Manage Scleroderma website

**Self-Manage Scleroderma** have module lessons which look at:

1. Stretching for muscles/skin for people with scleroderma
2. What happens in the hands and arms in persons with scleroderma?
3. Exercises for the hands
4. Exercises for the shoulders
5. Exercises for the legs
6. Exercise Guidelines for General Fitness
7. Developing an Action Plan
8. Resources

### Source:

<https://www.selfmanagescleroderma.com/lessons/stretching-for-muscles-skin-for-people-with-scleroderma.html>

They have good resources such as a video and Pdf Printout – which is an Exercise log.

### Developing an action plan

<https://www.selfmanagescleroderma.com/lessons/developing-an-action-plan.html>

One way to achieve a goal, such as starting or increasing an exercise program, is to make an Action Plan. This is an agreement you make with yourself to do a new activity regularly.

### An Action Plan has several parts.

#### Identify an activity that you would like to do

If you are not really interested in the activity, it is sure to fail. So pick something you like! You could do it by yourself, with a buddy (a better idea), or even in a class. Take some time to make this selection.

#### It must be reasonable

This should be something you can accomplish in 1 week. It may be a small piece of the overall goal. For instance, if walking 30 minutes is the overall goal, and you are just starting out, perhaps walking 5 minutes is a good goal for the first week. This way, you can applaud yourself when you accomplish the task.

#### It should be behaviour-specific

For example, the idea of just “getting stronger” is not a behaviour, but “lifting weights” is a specific behaviour.

#### It needs to answer the following questions:

**What exercise?** The answer could be walking, swimming, or climbing the steps instead of using the elevator.

**How much?** The answer could be walking 5 minutes or going to a yoga class.

**When?** The answer could be after the kids leave for school or Monday, Wednesday, and Friday.

**How often?** The answer could be 2 days a week, 4 days a week, or every other day (if you say every day, you may be setting yourself up for failure because it is probably too difficult to do; give yourself some slack).

When you rate how confident you feel about completing your Action Plan should rate at least 7 out of 10, where 0 is no confidence and 10 is total confidence you will complete the entire Action Plan.

Now write it down and place it where you will see it as a reminder – for example on the fridge, on the bathroom mirror, or by the front door. Set the Action Plan up as a 7-day plan. At the end of the 7 days, review the plan. If you were successful, give yourself a round of applause. Redo your plan for the upcoming week, and increase your goal slightly.

If you did not reach your goal for the week, give yourself a round of applause for trying, and review your action plan to see why you did not meet your goal. Did you plan to do too much, do it too often, or do it too long, or was the activity not really something that interested you?

Do not give up! Redo your **Action Plan**, think about why you did not reach your goals for the week, and make next week's action plan more realistic.

### GOOD LUCK! GET STARTED TODAY!

#### Source:

<https://www.selfmanagescleroderma.com/index.html>



# Members Stories:

## Erena Bruce – Time for yourself People

### Time for yourself People!

With so much going on and events out of our control occurring this is the best time to 'stop take a breath and smell the roses' as they say. Time is our own if we prepare and commit to something that makes us smile, brings us joy...for me I enrolled in my first art class in Hamilton. Artmakers with Sylvie. (Check Artmakers webpage) Man was I in for a pleasant experience, such a wealth of knowledge, accepting of artists at any level, and so accepting of anything one could bring to the group. Our art medians were not limited but like my 'Bouquet for Pete' shows we used pastel, paints, (water, acrylic) fine line perspective tip pens and pencil sketching. Totally recommend this folks, it was my time to chill and learn.

At a time, we may be experiencing much sadness I truly encourage you all to share and do experiences you keep putting off. Our holidays now our children are 10 and 13, included, week long swim camps, cricket camps, walking Tongariro crossing, relaxing at the Chateau, even cleaning our own carpets was fun. We had great times, cricket was in Hawkes bay the fruit was so delightful, beach was fun and every day there was time for nana naps. We also had two funerals very sudden but the get togethers were lovely.

Therefore, people write your lists, complete your plans and **MAKE TIME FOR YOURSELF!**

Best wishes for 2021

Erena Bruce



Erena's Artwork - 'Bouquet for Pete'

## Glenys Findlay – Seasons Greetings

Glenys and Ian Findlay sent me this lovely photo of them at Christmas Time. So lovely to see them sitting amongst all the gorgeous Christmas Lights.

Thank you for sharing.



Glenys and Ian Findlay





## Some useful Websites:

*Readers you are welcome to submit a link of useful website links that you may want to share with other members here..*

I was visiting these websites and thought our members may want to read:

### Foot Problems:

<https://www.footmechanicspodiatry.co.nz/foot-problems/>

I have had problems with my feet since I got diagnosed with Scleroderma (2004) and Myositis (2007).

Over the years, my toes on my right foot have curled like my right hand, and has become increasingly problematic when wearing shoes. I have an extremely hard time trying to find shoes to wear that are comfortable to wear as well as wide on the broad of my feet so that there is enough room for my toes.

Since all the toes on my right foot have curled, they rub on the inside of the shoes and create callouses and corns. This causes me great pain and I have to visit my podiatrist every 4 – 5 weeks to have them removed.

### Nymbi:

If you have a smartphone or tablet, register to use the free Nymbi balance training app.

<https://nymbiscience.com/nz-fallsfree-welcome/>

The website says “The free, at-home balance training solution that’s easy to use. Nymbi is for older adults wanting to maintain or improve their balance in the comfort and safety of their home. All you need is a smartphone or tablet. “

The trial says it’s limited to 20,000 users, I tried, but you have to have an ACC membership number, so I may have to further investigate with a Physiotherapist how this can be obtained.

### Laughter Yoga is good for you:

At our recent Wellington Scleroderma group meeting, one of our members Temu mentioned that she had been to a Laughter Yoga course. We were all very interested to know about it, so Temu has sent me their link below: -

<https://laughteryoga.org/club-profile/upper-hutt-laughter-yoga/>

## Information Wanted:

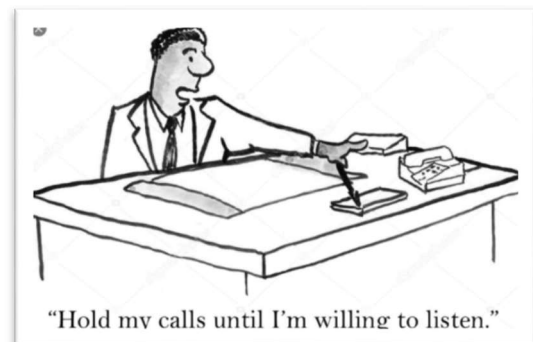
### Compression Gloves (full fingered)

Leonie has been in touch and is on the hunt for **full fingered compression gloves**. Does anyone have any recommendations for her? She would love some feedback on what has worked.



If you have any information for Leonie, please email me on: [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz) for me to pass on to her and we will publish in the next newsletter

## Joke of the day:



## Pet Corner:

*Readers you are welcome to submit a photo of your companion animal and write a little story about your pet and how your pet makes life a little more joyful for a scleroderma patient.*



**Linda Bell and Strawberry reading**

This is Strawberry, who we adopted as I found her in our garage, she was microchipped so we took her to the vet's and her owner's sold their house and went overseas and left the cat behind. But she found us and sometimes catches a ride around the house.



**Linda Bell and Strawberry delivering food to the other cat**

She is helping me take food to our other cat Bella.

She gets up to trouble at times and sleeps at the end of my bed. I think she is happy with her family.

The photo below, shows Strawberry wanting to open the crackers on Christmas Day.



**Strawberry with Christmas crackers**

Best Wishes  
Linda Bell

## Today's Recipes:

*Readers you are welcome to submit your favourite recipes, ideas, suggestions, hints...*

My attempt at making the traditional Pavlova for our Christmas dessert last year. I have found the most easiest and simplest recipe to make Pavlova by using the good old **NZ's Edmonds Cook Book** (19<sup>th</sup> Edition).

### Quick and Easy Pavlova

#### Ingredients:

3 Egg Whites (at room temperature)  
3 tablespoons Cold Water  
1 cup Castor Sugar  
1 teaspoon Vinegar (white vinegar)  
1 teaspoon Vanilla Essence  
3 teaspoon Edmonds Cornflour



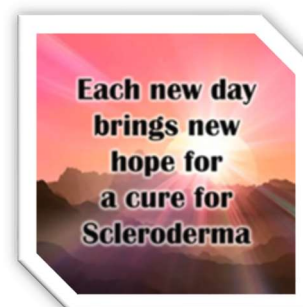
Beat egg whites until stiff, add cold water and beat again.

Add castor sugar very gradually while still beating. Slow beater and add vinegar, vanilla and cornflour.

**My freshly baked Pavlova** Place on greased paper tray and bake at 150degC (300degF) for 45 minutes, then leave to cool in the oven.

Decorate with whatever fruits you like. The picture above is the end result of the Pavlova I made. I had to use tin peaches, as we forgot to get kiwifruits during the mad rush at the supermarket with everyone all doing their Christmas grocery shopping.

Happy baking everyone,  
**Tina McLean**



# Members News:

## Southland Scleroderma Group

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

### Southland Lunch in November.

Thank you to Jenny for organising our lunch in Gore and thank you all for taking the time to be present.

As usual we did a great deal of talking, laughing, discussing serious Scleroderma topics, eating and enjoyed being together.

We did deliberate what format we should have our meetings in the future, a topic to be discussed more in the new year.

Best wishes for 2021, surely it cannot be any more dramatic than 2020!!!!

I asked the young waiter to take a photo of our group, it does look like we are in a Batman movie!!!! He did get us all in, including the top of Gwenda's head at the end right 😊



We hope you all had a very Merry Christmas and enjoyable New Year from Heather, Lorraine and Jenny. We had an enjoyable 'spur-of-the-moment' afternoon tea at a café in Winton and were enchanted with the Christmas decorations and wanted to share.



Jenny, Lorraine and Heather

## Nelson Scleroderma Group

Beth Richards bring us up-to-date with happenings from Nelson...

Our small group of ladies met up last week with one new member Michele Street.

Lisa, Rosemary, Michele and Beth all met up in Richmond for coffee and a snack.

Unfortunately Jenna couldn't make it due to ill health. We discussed lots of our health issues and enjoyed a few laughs.

It certainly helps to get things off your chest and realise that we all have similar issues. The support we give each other is amazing and helps each other to cope with our Scleroderma journey.

Cheers everyone and here's to a very festive season with our family and friends.

Beth Richards.





# Members News:

## Wellington Scleroderma Group

The Wellington group met up for Christmas celebrations in November 2020. It was the first face to face meeting we had since February 2020, where we had met at Adrienne's house in Paraparaumu, prior to the Covid-19 Lockdown.

Below are photos of our group having a lovely shared Christmas lunch.

Catherine and Paul brought along musical instruments so that we could all get to sing some songs. There was a lot of eating, talking and singing. We had a wonderful time catching up with one another



# Members News:

## Christchurch Scleroderma Group

Carolyn talks to us about their catch up in Christchurch...

We had a great meeting on Saturday 30th January, held in the cafe on the ground floor at Burwood Hospital. This will be our venue for meetings this year.

Chris made sunflower head bands for us, they are amazing! A big thank you to you Chris.

It was wonderful that Julie James was able to be at the meeting. Julie is very involved with cycling events all over the country. Julie has a very busy schedule

There was lots of chatting and laughter catching up on everyone's news. There were 5 of us at the meeting, Barb, Chris, Janine, Julie and Carolyn.

With the sunflower blouse that Carolyn was wearing and the sunflower headbands, I think we stood out. We plan to wear the headbands at all meetings.

Best wishes,  
Carolyn



*Carolyn in her sunflower shirt*

## Scleroderma Waikato Group

Linda Bell bring us up-to-date with happenings from Hamilton...

Everyone is fine and coping, hoping that 2021 will be a better year.

Our Coffee Group will meet at 10am Tuesday 9th February at Robert Harris Chartwell Hamilton

We are also going to every other month this year so the next meeting will be 6th April.

Best Wishes

**LINDA BELL**

**SCLERODERMA WAIKATO**

If anyone gets the Entertainment Books, go to my Facebook page where you can get it online anywhere in NZ. The money raised goes towards **Scleroderma Waikato** funds to help with the cost of Seminars.

## Cambridge Trio Get Togethers

Erena Bruce bring us up-to-date with happenings from Cambridge...

So far in Cambridge we have three of us Susil, Chantel, and I. We meet weekly if we can generally at least for a cuppa.

We have also had the pedicure treatment and plan our next outing to have a reflexology, massage treatment as two out of three of us recommend it works.

We have also been trialling successfully an Iron Boost product from Harkers Products, purchased from Health 2000.

So far so good. Our comradery is great. We'll text and try to keep in touch with various physios, doctors' advice, appointments etcetera and share the load.

If anyone else is keen to meet up give me a text, it would be awesome to be in contact.

**Erena Bruce**

0211869680





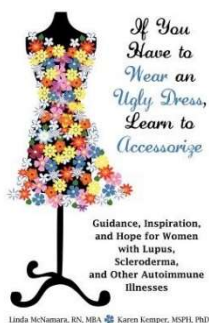
# Book Club:

Welcome to a new section of the newsletter we have added. Readers are welcome to submit their favourite book, video or film...

At a recent zoom meeting, members mentioned books/videos/films they wanted to share with other members. The titles are listed below:

## If You Have to Wear an Ugly Dress, Learn to Accessorize by Linda McNamara & Karen Kemper

Guidance, Inspiration, and Hope for Women with Lupus, Scleroderma, and Other Autoimmune Illnesses



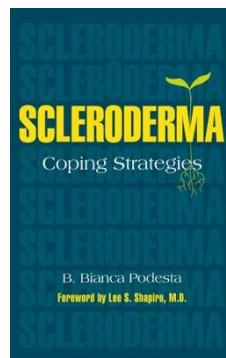
Chronic illness forces you to slow down and re-examine your values, your choices, and the way you define yourself. In *If You Have to Wear an Ugly Dress, Learn to Accessorize*, Linda McNamara and Karen Kemper offer companionship throughout the process, helping you face your challenges with dignity and grace. "Lupus and scleroderma

are our shadows but they do not define us. We may have to wear the ugly dresses of chronic illness but we don't have to be the ugly dresses." -- Linda and Karen. If you are experiencing a long-term illness or disability, this book is for you -- as well as your family and friends. The authors share a collection of deeply personal stories and poetry to describe their journey from illness to health, well-being, and fruitful living. Their creative life management strategies provide a road map to help you:

About the Authors: **Linda McNamara, RN, MBA**: Linda is a registered nurse, healthcare consultant, and certified health coach with over forty years' experience in health and wellness. She has been living with systemic lupus since 1996. **Karen A. Kemper, PhD, MSPH**: Karen is a health educator and university professor in health promotion and public health. She has certifications in health fitness and life coaching and has worked in health and wellness for twenty-five years. She has been living with scleroderma since 1992.



## Scleroderma Coping Strategies by B. Bianca Podesta



Systemic scleroderma ("hard skin") is an autoimmune connective tissue disease. An overproduction of collagen may cause hardness, or fibrosis, not only in the skin but in many of the body's tissues and organ systems.

*Scleroderma Coping Strategies* carefully describes the disease mechanisms of scleroderma, reveals the psychological challenges sufferers face and explores the relationship between contemplative or spiritual reality and the healing process.

## Facebook:

We are so very lucky to have Cushla Marsters and Catherine Thompson as admin for our Facebook page. Cushla has been doing this for years, and now has the help of Catherine...- "Thank you both for doing such an awesome job" from us all here...



Cushla Marsters



Catherine Thompson





# Upcoming Events:

## Southland

Is there anyone in the Otago Area who would like to join our group until we can get one up and running in Dunedin? If so please get in touch with either Heather or Jenny.

Heather: [milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)

Jenny: [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

## Waipa

Looking for fellow Scleroderma folk who live in Cambridge, Te Awamutu or even Morrinsville to come and join Susil and I once or twice a month. Just the two of us. We meet lunch times but are open to meet Saturday afternoons. Depends on what suits really. We chat, share resources, ideas, networks anything really. Open to zoom as well. Let's endeavour to support each other as best we can.

If you would like to join in with the **Waipa** Group, please contact **Erena Bruce**, you would be most welcome.

Email: [glenanderena@xtra.co.nz](mailto:glenanderena@xtra.co.nz)

Mobile: 021 186 9680

## Waikato

We meet once a month at **Robert Harris Café, Chartwell Hamilton**.

**Next coffee group:**

Date: **Tuesday 6<sup>th</sup> February 2021**

Place: Robert Harris

Time: 10.00am

Please email to [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz) to confirm.

Phone: 07 8535434

Mobile: 027 548 1214



## Christchurch

Our hard core group of ladies still meet every couple of months in Christchurch in the cafe on the ground floor at the **Burwood Hospital**. A good time is had by all, they have recently had a couple of new people join with them, but they welcome more to come along too.

Please contact Carolyn **Barkhausen** if you would like to join in with the **Christchurch** Group, you would be most welcome.

Email: [barkman@xnet.co.nz](mailto:barkman@xnet.co.nz)

## Wellington

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

Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)



## Thought for the day:

*"If you want to conquer the anxiety of life, live in the moment, live in the breath"*



# Events & Happenings:

Dear Members,

Please read the below announcement, this is a well worth programme to attend. I was part of the first SPIN CHAT Programme along with others from New Zealand. There are some good skills to learn.

I hope you are all looking after yourselves.

All the Best Dianne



## SPECIAL ANNOUNCEMENT:



Thanks to the success of the **SPIN-CHAT** (COVID-19 Home-isolation Activities Together) **Program** and in response to public demand, we decided to offer weekly webinars of our educational segments!

Starting **February 2nd** and held every Wednesday thereafter, for a total of 11 webinars.

Take a look at our presentation line-up below:

- 02/02: Healthy information management - Laura Dyas
- 10/02: Worry management - Ghassan El-Baalbaki
- 17/02: Relaxation techniques - Ghassan El-Baalbaki
- 24/02: Adapted home exercise - Kelsey Ellis & Delaney Duchek
- 03/03: Home activity engagement - Laura Bustamante
- 10/03: Worry management (Part 2) - Ghassan El-Baalbaki
- 17/03: Relaxation techniques (Part 2) - Ghassan El-Baalbaki
- 24/03: Adapted home exercise (Part 2) - Kelsey Ellis & Delaney Duchek
- 31/03: Home activity engagement (Part 2) - Laura Bustamante
- 07/04: Worry management (Part 3) - Ghassan El-Baalbaki
- 14/04: Adapted home exercise (Part 3) - Kelsey Ellis & Delaney Duchek

Stay tuned for more information! And register to our first session here: <https://fb.me/e/1Pe1KN8xI>

## NOTICE BOARD...



Your Event Date ?

**SPIN-CHAT  
WEBINARS**

Starts on  
**2 February 2021**

**Next Zoom  
Meeting**

**Saturday**

**17th of April 2021**

From 1.30pm – 4pm

## WANTED:

- News, Items
- Experience
- Achievements
- Jokes/ Recipes



# Noticeboard:

## Wellington support group meets:

Saturday 15th May 2021 1.30pm to 4.00pm  
Saturday 21st Aug 2021 1.30pm to 4.00pm  
Saturday 20th Nov 2021 1.30pm to 4.00pm

### Venue:

Hardwick Smith Lounge, Belmont Domain, Lower Hutt

## Christchurch support group meets:

Saturday 27th March 2021 2:00pm to 4:00pm  
Saturday 29th May 2021 2:00pm to 4:00pm  
Saturday 31st July 2021 Lunch at the Garden Restaurant  
Saturday 25th Sept 2021 2:00pm to 4:00pm  
Saturday 27th Nov 2021 2:00pm to 4:00pm

### Venue:

Café, ground floor at Burwood Hospital

## Auckland Respiratory support group meets:

### Venue:

327a Whangarata Road, Taukau Auckland 2694

## Southland support group meets:

Sunday 14th Feb 2021 **Mag Tree** Winton  
Sunday 16th May 2021 TBA Invercargill  
Sunday 22nd Aug 2021 TBA Gore  
Sunday 28th Nov 2021 TBA Invercargill

## Hamilton support group meets:

We will be at **Robert Harris Chartwell** starting on:  
Tuesday 9th February 2021 at 10am.

**Note:** A change for the Hamilton group this year. The group will be meeting **every other month**, so the next meeting will be **6th April 2021**.

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

Email: [Linda.bell@hotmail.co.nz](mailto:Linda.bell@hotmail.co.nz)

## 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](mailto:diannepurdie@xtra.co.nz) and she will be happy to help you set one up.

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

[www.scleroderma.org.nz/calendar/](http://www.scleroderma.org.nz/calendar/)

# Contacts:

## Find a Scleroderma a Support Group near You:

**Auckland Respiratory:** Allan Edmondson, Email: [alsand327a@gmail.com](mailto:alsand327a@gmail.com)

**Waikato:** Linda Bell, Email: [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)

**Hawkes Bay:** Jane Sainsbury, Email: [jsainsbury@xtra.co.nz](mailto:jsainsbury@xtra.co.nz)

**Waipa:** Erena Bruce, Email: [glenanderena@xtra.co.nz](mailto:glenanderena@xtra.co.nz)

**Palmerston North:** Dianne Purdie, Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

**Wellington:** Dianne Purdie, Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

**Nelson:** Beth Richards, Email: [ronbethrichards3@gmail.com](mailto:ronbethrichards3@gmail.com)

**Christchurch:** Carolyn Barkhausen, Email: [barkman@xnet.co.nz](mailto:barkman@xnet.co.nz)

**Southland:** Heather Milligan, Email: [milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)



## Scleroderma New Zealand Inc.

**President:** Dianne Purdie  
[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

**Vice President:** Jenny Andrews  
[jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

**Secretary:** Jane Sainsbury  
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**Treasurer:** Gordon Purdie  
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# Welcome to Scleroderma New Zealand Inc

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

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

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



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



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



## Virtual Support Group Meetings

Due to the uncertainty of things with Covid-19 we are still offering Virtual Zoom Meetings for those who do not wish to attend a meeting in person, or if we are unable to hold them in person. This keeps us involved and in touch with each other.

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.

Due to Covid-19 Virus, we are still offering Zoom meetings....



## NEXT ZOOM MEETING:

**Topic:** Importance of Keeping Warm, and Monitoring for Scleroderma (directed for recently diagnosed, but everyone is welcome.)

**Date:** Saturday 17th of April 2021 - via zoom

**Time:** 1:30pm - 4pm (includes a chat)

