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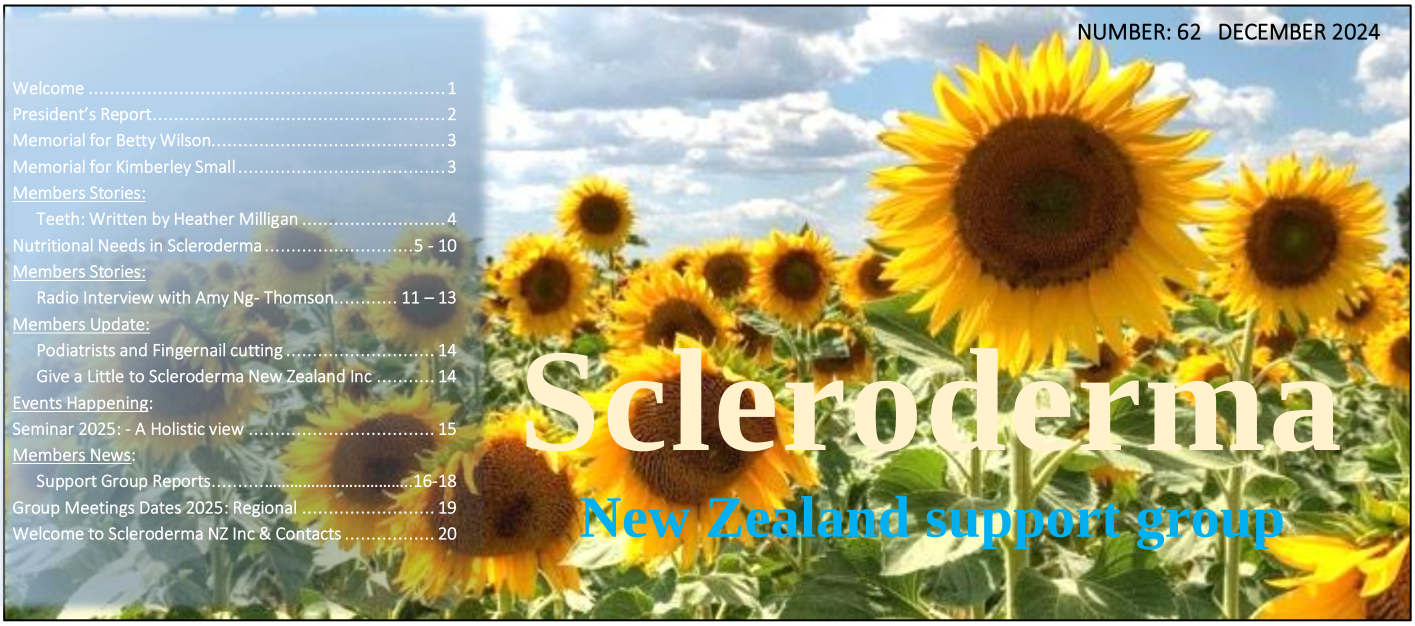

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Scleroderma

New Zealand support group

SUMMER 2024

Greetings to you all…

Welcome to the Summer edition of our Scleroderma Newsletter…

We hope everyone and their families are well. This year has flown by so quickly, with Christmas getting closer and New Year being just around the corner.

We warmly welcome all our new members and we hope you will find some of the articles in this newsletter useful and informative.

First up we hear from our President, Jenny Andrews with her report. Jenny gives us good advice and keeps us up to date with what's happening on in our Scleroderma community.
We have a memorial for two of our members, Betty Wilson and Kimberley Small.

We have an informative article on nutritional needs for people with Scleroderma from the Scleroderma Australia website.

In our members stories, Amy shares with us her radio interview and Heather talks to us about oral health. We have our regular members news and updates from our different support groups around New Zealand.

We've had inquiries from our members about which Podiatrists will do fingernail cutting. Dianne has done some investigation and provided a list.

We have a flyer advertising our next Seminar. Thank you to the Waikato/Waipa group.

We wish everyone a wonderful Christmas, a happy New Year and a safe and relaxing holiday break.

Take care everyone.
Tina and **Jenny**

Presidents Report:

Yay!!!! Summer 2024

Hello all and welcome to our Summer newsletter. There are a number of new members who have joined us, so welcome. I hope you are doing ok with your new diagnosis which can be extremely daunting. Remember you are not alone and there is a whole new family out there for you to lean on.

My condolences to all those who have lost loved ones in the past few months. Our Southland Group are mourning the loss of two wonderful members just in the last couple of weeks. Betty and Kimberley who have both been a big part of our group for many years. You can read more about these two lovely ladies in our memorial page.

I am excited about feeling warmer on a regular basis. The rain we have had down here has been wicked this year. Very damp under foot and we are all desperate for some constant sunshine. Weird because we had such a dry Winter but Spring has been just the opposite. Haven't even made it out to the golf course for the past two months. But today is the day that I go back. Had a wee hit on my lawn just to make sure I remember how to swing a club. Yep I need lots more practise!!!

Thanks to Perry for running another zoom meeting last weekend. I was unable to attend due to being away but I am sure it was a great time for all who did make it on.

The committee are working away on the Constitution at the moment and we have the next seminar being organised which will be held in the North Island. Look to page 15 for the date and we will bring more information on that in our next newsletter.

Tina and I are always on the hunt for people to share something in the newsletter. Anything is welcome as variety is what makes for a good read. There are some sad and in your face things, so we really want to have some fun, happy adventurous stories. It's great to see what can be done even though you are dealing with such a tough condition.

With the festive season approaching it is important to be prepared. Don't leave everything to the last minute in case you are unable to do it at that time. Do what you can when you can and don't overdo things. Remember though that it is about the people who are around us rather than how tidy the house is or how well tended the garden is. No-one will judge you as they will just be pleased to have this time together with you and your loved ones. Enjoy that good food and conversation. You will all have those traditions of food etc that you have at your families Christmas. Ours are the hot ham, and new potatoes, the familiar salads and my Toblerone Mousse in chocolate cups is always a hit. Although I am thinking of making a change this year, So I will see if I am actually able to do it or whether the kids (well they are big kids now) might kick up a stink. I do like to ask each of them what they would prefer. Funny, because Christmas is a different request from their birthdays. Birthdays are normally homemade Cookies and Cream Ice Cream and Death by Chocolate dessert, but they don't make it to the Christmas List for some reason.

I wonder what is your favourite or non-favourite thing to do a Christmas. I spoke to someone the other day who just loved to go out and buy the presents but really did not like wrapping them. Whereas I am the opposite. I get very stressed about what to buy and don't think I am a very good present purchaser, but I do love to wrap them and see them all under the tree. Being empty nesters I am enjoying being able to put the Christmas Tree up in mid-November without the judging from the kids and them telling me that it is not even December yet. Hehe. I do love to see the lights shining and decorations all around the house. I have a fake blossom tree that has found its way to my home entrance (long story) and when Granddaughter Willow, 6 was here for the night at the weekend I asked her if she would like to decorate it. She was very excited and had a blast decorating it. When she had gone back home Jeff asked me "It's not staying like that is it?" Oh absolutely I thought. How times have changed from when I used to wait until the kids had gone to bed to then make the tree the way I wanted it. Being a Grandma is quite different to being a Mum.

Merry Christmas everyone and be sure to have a safe festive period.

Take care and keep smiling
Jenny ☺

Memorial

Southland Scleroderma Group Member

Betty Wilson

Betty with her sunflowers

Betty was a Motherly soul to everyone who knew her. She was always checking in on how you were and was such a kind, loving person. Betty was a very talented lady. As her daughter Sandra said she was an environmentalist way before it was a thing. She didn't waste anything. She loved to preserve, bake, sew, knit, garden. Her tins were always full of fresh baked goods, her freezer would be bursting with yummy food and the shelves weighed down with jars of jams and preserves. Betty sewed and knitted to sell at craft shows and not for herself but for charities. Betty planted sunflowers last year and kindly gathered up all the seeds and sorted them and cared for them with love, then bagged them up and generously gave them out to members of our Southland Group. I planted 108 seeds in my patch of garden and look forward to seeing a sea of smiling sunflowers at the time that would be Betty's Birthday. This just happens to be 3 days after Kimberley's birthday so they will be a very special display. Betty was a Wife, Mum, Nan, Great Nan, Sister, Aunt, Friend to many and the list goes on. She will be sadly missed. I am so thankful to have had her in my life.

Southland/Christchurch Scleroderma Group Member

Kimberley Small

Kimberley on her 50th Birthday

With her diamond Art

– one of a kind, you will be remembered—

It was so sad to read this message on Facebook written by Maureen, Kimberley's mother.

5 November 2024 'It's with a heavy heart that we write this post. Kimberley sadly passed away yesterday afternoon at Ashburton Hospital aged 53. She fought a long tough battle with scleroderma over the last 15 years and can now rest in peace. We know that Kimberley touched many lives, and we're devastated to have to break this news. She was well-loved and will be missed by many.'

Kimberley come into contact with us with Scleroderma in Southland. I became a friend of Kimberley as we journeyed through our struggles with Scleroderma.'

She grew up in Ohai, Southland and enjoyed especially interacting her friends who she kept close over the years. She had varied work, a fellow worker has fond memories working at the moss factory for several years, he said she a great worker and a very determined young woman. Also working at Tiwai Aluminium refurbishing masks for the workers. Playing rugby in her younger years and then following it on Sky Sports was her passion. Woe betide the Highlander Rugby team if they didn't perform up to Kimberley's expectations. She did enjoy the company of the Invercargill scooter club who met regularly. She did attend the Christchurch Scleroderma seminar and our Southland lunches. One memorable occasion was celebrating both Kimberley's and Jenny Andrews 50th birthday.

As her health deteriorated she came more dependent on others and to have aids to make her life easier. She did appreciate devices like her St Johns alarm and was thrilled recently to have one which went with her when she went out. She did have a number of caregivers both in Invercargill and then when she shifted to Ashburton just over a year ago. She did praise and welcomed

Memorial

Southland/Christchurch
Scleroderma Group Member

Kimberley Small

those who listened to what she needed and did not override her in what they thought would be the best.

I had written about her expertise with diamond painting in the March 2023.

Facebook Messenger will be quieter place with her as she did enjoy communicating with family and friends through this medium. She enjoyed card making with the friendly group in Ashburton

When she moved to Ashburton her mum Maureen and dad Russell become more involved in her care, both day to day care and her health care. They did strive to be the best for Kimberley, it would have been a labour of love for them as Kimberley was one independent lady.

I am sure we all agree with her quote for Scleroderma was 'remember we all have different complications" . 5 days before she died she was questioning her specialist on her many medications and was going to give a new medicine a go to help her lungs.

Sadly Kimberley died with lung complications just as she had purchased a house in Ashburton. She was looking forward to this change from a rental to make her own nest.

Our sympathy to Maureen, Russell and family, you did so well enriching Kimberley's life over the years. Thank you.

Heather Milligan

When I come to the end of the road
And the sun has set for me
I want no rites in a gloom filled room
Why cry for a soul set free?

Miss me a little, but not for long
And not with your head bowed low
Remember the love that once we shared
Miss me, but let me go.

For this is a journey we all must take
And each must go alone.
It's all part of the master plan
A step on the road to home.

When you are lonely and sick at heart
Go to the friends we know.
Laugh at all the things we used to do
Miss me, but let me go.

Members Stories:

Teeth: Written by Heather Milligan

I did have very good teeth until Scleroderma arrived 12 years ago. Since then I have had 4 teeth extracted, not because they infected, but there was no gum to hold them in my mouth. My dentist has said that I am looking after my actual teeth so well, but your gums and lips are causing your oral health to decline. He has a superficial knowledge of Scleroderma but does his best. I think it would be a rarity for a dentist to have a good knowledge of oral health and the effects of Scleroderma. I see a Dental Hygienists every 4 months who tells me my mouth is looking good.

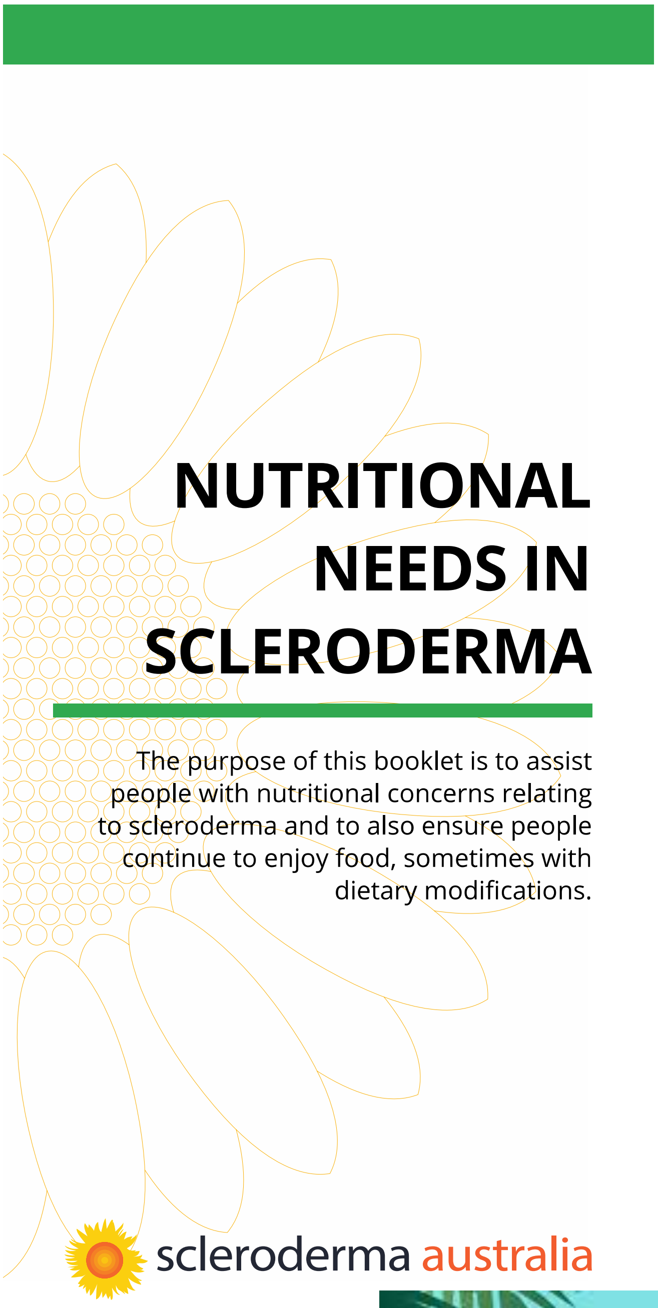
These are my weapons of choice every night. Starting with a long handled flosser, I cannot use dental floss as my hands are not supple enough to manoeuvre the floss around my mouth. Next a little interdental brush. Followed by the Waterpik water flosser. Then an electric toothbrush. I have to use children toothpaste with fluoride, there is no adult toothpaste that does not have mint in, mint and quite a few other foods burn my mouth. Lastly Listerine mouth wash for kids.... again can't use adult mouthwash as they all have mint it.

................AND GRAHAM WONDERS WHY I TAKE SO LONG IN THE BATHROOM AT NIGHT.................

Heather Milligan

Nutritional Needs in Scleroderma

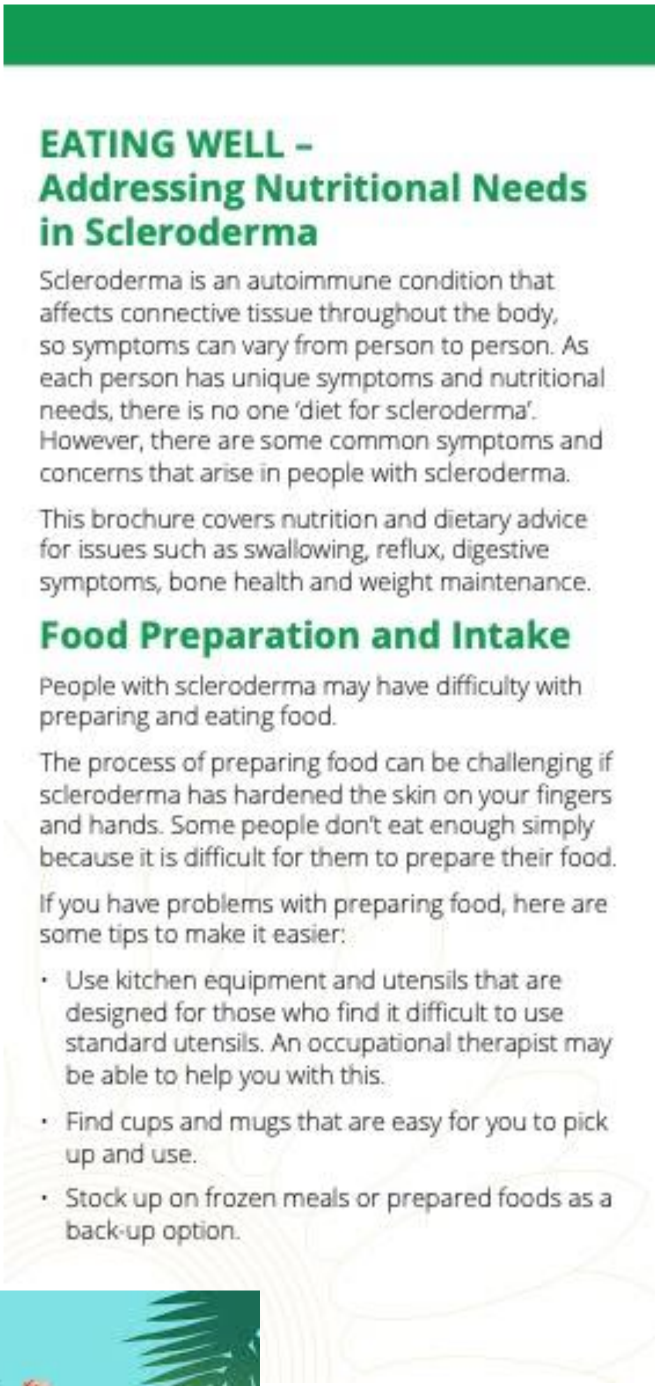
From: Scleroderma Australia Website



NUTRITIONAL NEEDS IN SCLERODERMA

The purpose of this booklet is to assist people with nutritional concerns relating to scleroderma and to also ensure people continue to enjoy food, sometimes with dietary modifications.

scleroderma australia



EATING WELL – Addressing Nutritional Needs in Scleroderma

Scleroderma is an autoimmune condition that affects connective tissue throughout the body, so symptoms can vary from person to person. As each person has unique symptoms and nutritional needs, there is no one 'diet for scleroderma'. However, there are some common symptoms and concerns that arise in people with scleroderma.

This brochure covers nutrition and dietary advice for issues such as swallowing, reflux, digestive symptoms, bone health and weight maintenance.

Food Preparation and Intake

People with scleroderma may have difficulty with preparing and eating food.

The process of preparing food can be challenging if scleroderma has hardened the skin on your fingers and hands. Some people don't eat enough simply because it is difficult for them to prepare their food.

If you have problems with preparing food, here are some tips to make it easier:

- Use kitchen equipment and utensils that are designed for those who find it difficult to use standard utensils. An occupational therapist may be able to help you with this.
- Find cups and mugs that are easy for you to pick up and use.
- Stock up on frozen meals or prepared foods as a back-up option.

- If your joints are stiff or you are having trouble cutting, buy pre-cut or frozen fruit and vegetables.

Protein

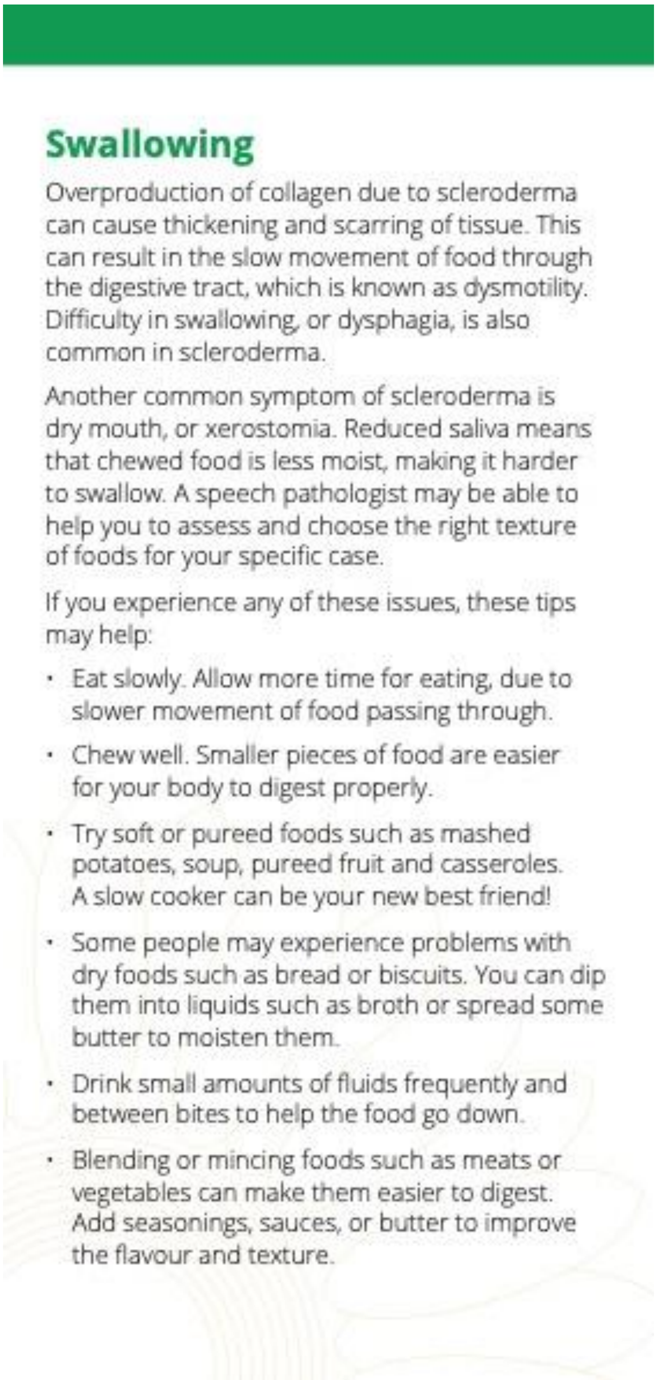
Protein is made up of amino acids, which are the essential 'building blocks' of the body. Many people with scleroderma don't consume sufficient protein, as they find it difficult to prepare, chew and/or digest.

If you have difficulties with eating enough protein, you can try:

- Consuming small amounts of protein at each meal and snack.
- Marinating meats well using a marinade that includes acidic ingredients such as lemon juice or vinegar.
- Using bone or meat-based broths in cooking.
- Using a high-quality protein powder as a supplement to add into your smoothies, cereal and yoghurt.

Sources of Protein

Cottage cheese
Pumpkin seeds
Pork chop
Egg
Chicken breast
Yoghurt
Almond
Lamb loin
Black beans
Ham
Cheese
Salmon



Swallowing

Overproduction of collagen due to scleroderma can cause thickening and scarring of tissue. This can result in the slow movement of food through the digestive tract, which is known as dysmotility. Difficulty in swallowing, or dysphagia, is also common in scleroderma.

Another common symptom of scleroderma is dry mouth, or xerostomia. Reduced saliva means that chewed food is less moist, making it harder to swallow. A speech pathologist may be able to help you to assess and choose the right texture of foods for your specific case.

If you experience any of these issues, these tips may help:

- Eat slowly. Allow more time for eating, due to slower movement of food passing through.
- Chew well. Smaller pieces of food are easier for your body to digest properly.
- Try soft or pureed foods such as mashed potatoes, soup, pureed fruit and casseroles. A slow cooker can be your new best friend!
- Some people may experience problems with dry foods such as bread or biscuits. You can dip them into liquids such as broth or spread some butter to moisten them.
- Drink small amounts of fluids frequently and between bites to help the food go down.
- Blending or mincing foods such as meats or vegetables can make them easier to digest. Add seasonings, sauces, or butter to improve the flavour and texture.

The Oesophagus

A common condition that occurs in patients with scleroderma is GORD. GORD, or Gastro-Oesophageal Reflux Disease, can cause irritation in the œsophagus, the pipe that connects the throat to the stomach. This condition is commonly known as 'acid reflux'.

In GORD, the ring of muscle known as the lower oesophageal sphincter becomes damaged or weakened. This allows stomach acid to rise into the œsophagus, causing irritation. There are liquid supplements available for people with swallowing difficulties.

To reduce acid reflux, consider the following:

- Decrease or eliminate the intake of alcohol, fizzy drinks and caffeine, which are common triggers for acid reflux.
- Possible triggers for acid reflux include citrus fruit, tomatoes, tomato products, spicy foods and onions. If you notice your symptoms flaring after consuming these, reduce or eliminate them.
- Fatty and oily foods are another common trigger for reflux. This is because they can relax the lower oesophageal sphincter. Keep your portions of good fats such as olive oil and avocado on the smaller side, avoid high-fat and processed.
- Remain upright for 1 to 2 hours after eating. Avoid eating just before lying down, napping, or going to bed at night.
- Eat smaller, more frequent meals (4- 6 small meals per day).
- Raise the head of your bed by a small amount (~10cm).
- Keep a food diary to establish the foods that cause symptoms. Show this list to your dietitian or nutritionist, so they can help you to adjust your diet.

Tips for Acid Reflux

The Stomach and Intestines

Absorption of nutrients from the gut is compromised in scleroderma due to a number of reasons. Supplementary nutrients may be of use, particularly when there are known digestive issues.

Including foods that contain good bacteria or probiotics may be beneficial. Some studies have suggested that specific strains of probiotics may help to relieve digestive symptoms for people with scleroderma.

It's important to start slowly when adding probiotic foods and supplements, as some digestive conditions may be exacerbated with probiotic use. If this occurs, seek professional advice from a qualified health practitioner.

Diarrhoea, constipation , bloating and other digestive problems can be unpleasant symptoms of scleroderma.

Diarrhoea can be caused by medication use, malabsorption of foods, dysmotility and imbalances in gut flora. Foods that have soluble fibre may help with diarrhoea. Soluble fibre sources include bananas, apples, oats and prunes.

Avoid highly processed and refined foods, as these may trigger diarrhoea. If severe diarrhoea or constipation persists, seek professional help.

Constipation can be caused by medication use, malabsorption of foods, dysmotility and imbalances in gut flora. Dehydration and insufficient physical activity can also contribute to constipation.

If you experience constipation, these tips may help:

- Aim for a fluid intake of 1.5 to 2 litres per day, depending on your body weight and needs. This can include broths, smoothies, herbal teas and nutritional supplements. If you have Raynaud's, allow your beverages to come to room temperature, particularly in cold weather.
- Gentle exercise is beneficial for digestion and movement of the bowels. Going for a short walk is a good place to start, but even incidental activity such as light housework or collecting the mail counts.
- Include fibre-rich foods in your diet. Aim for 20 to 35 grams/day.

Be sure to add fibre gradually into the diet. You may experience digestive symptoms such as bloating, colicky pain and gas if you increase fibre too quickly. Dietary fibre sources include fruit, vegetables, nuts, seeds, beans, legumes and wholegrains.

Bone Health

To maintain strong, healthy bones, you need a variety of nutrients including calcium, magnesium and vitamin D.

Calcium

Calcium is needed for strong bones and healthy teeth. When you don't have enough calcium, your body takes what it needs from your bones for other essential processes.

If you use steroids such as prednisolone, your calcium levels can become depleted and lead to osteopenia and osteoporosis. This is why it's essential to consume calcium through the diet, and supplement if needed.

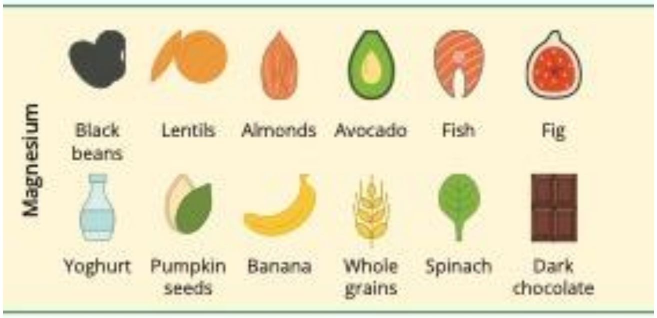
Dairy products are rich in calcium, but many people are intolerant to dairy foods and/or lactose. You can also find calcium in bone-based broths, green leafy vegetables, nuts and tahini (sesame seed paste). Fish with soft bones such as tinned salmon and sardines are another good source of calcium.

Magnesium

Magnesium works alongside calcium to build bone density. Many Australians don't consume enough magnesium to meet their needs. This is particularly concerning for those with scleroderma, as some symptoms such as diarrhoea and kidney issues can lead to further depletion of magnesium.

Dietary sources of magnesium include nuts, seeds, green leafy vegetables and dark chocolate.

Many people with scleroderma could benefit from a magnesium supplement. It's best to seek advice from a qualified nutrition professional, as some forms of magnesium are poorly absorbed and can cause digestive symptoms such as diarrhoea.



Vitamin D

Vitamin D is essential for healthy bones. It promotes the absorption of calcium from food and supplements, as well as helping to build and maintain bone density.

Research has found that low vitamin D levels are associated with poor outcomes in scleroderma. Unfortunately, many patients with scleroderma are deficient in vitamin D.

Unlike other nutrients, our main source of vitamin D is sunlight. If you live in one of the southern states or you spend the majority of your time inside, you have a higher risk of deficiency.

Vitamin D supplementation is often warranted in scleroderma. The right dose will depend on your specific requirements, so seek professional guidance.

Aim For A Healthy Weight

Unintentional weight loss can be a problem in scleroderma due to malabsorption, difficulties with eating and swallowing and digestive issues.

To avoid any unintentional weight loss, give these tips a try:

- Eat smaller meals frequently – aim for 4-6 mini-meals

- Extra calories can be easier to consume in liquid form. Smoothies are a great option for adding calories and protein.
- Add calorie boosters such as nut butters, cheese, Greek yoghurt, avocado, eggs, olive oil, coconut milk and oily fish to your meals and snacks.
- Seek advice from a qualified nutritionist or dietitian. They can give you advice about healthy higher calorie options and nutritional supplements that may be beneficial.

The goal is always to keep you well nourished.

If you have gut symptoms and weight loss that is not well explained, speak with your doctor about the need for investigations.

Conclusion

Navigating nutrition with scleroderma can be challenging. However, making small adjustments over time can add up to big improvements. Going slowly with dietary changes will often be more beneficial than changing everything at once.

If you are concerned about your food intake or need tailored advice, you should make an appointment with a qualified nutritionist or dietitian who has experience with scleroderma.

The information provided in this brochure is general in nature. It is not intended as a substitute for tailored dietary advice from a qualified nutrition professional.

Author Samantha Gemmell - Nutritionist (BHSc)
Barbara Gemmell - Scleroderma Nurse

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September 2021

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Members Stories:

Radio Interview with Amy Ng- Thomson:

Amy: I write a gratitude letter every year to them and just provide them with up-dates. Always thank you, thank you, thank you's.

Interviewer: Amy Ng-Thomson was 35 when she was placed on the waitlist for a new lung after 10 years of battling an autoimmune condition called Scleroderma. She was diagnosed in 2006 shortly after getting married.

Amy: I noticed that my hands went all puffy and accentually I couldn't wear my wedding rings any more. My fingers got swollen, fat. I couldn't make a fist so accentually I had boxing gloves for hands. I also had shoulder and knee joint pain so I went to see my GP and she referred me to a specialist. And at the very first appointment she just said 'you've got scleroderma'.

Interviewer: Amy was put on immunosuppressants which helped with her symptoms. Over the next few years she endured persistent flareups but she was still able to continue working as a nurse, living a relatively normal life then in 2008….

Amy: I noticed I couldn't take in deep breaths, for some reason I'd take in a deep breath and it would stop halfway.

Interviewer: Amy's health and lungs specifically continued to deteriorate and she ended up having chemotherapy but specialists still deemed her at that time too healthy for a transplant so how do you determine if someone is sick enough?

Dr Jamie: It depends on what their underlying condition is but we have a variety of testing, so looking at their exercise tolerance, looking at imaging of their hearts and their lungs.

Dr Jamie O'Loughlin is the clinical lead for the Auckland based heart and lung transplant program. That means she oversees the care of patients like Amy who are waiting, receiving, and recovering from these life-saving operations.

Dr Jamie: So for our lung patients, they will do lung function testing, so that's looking at the volumes and how much lung function they have in a variety of measures we have for that. We also do regular tests of like a distance they walk with a six minute timeframe and our physiotherapist will do that regularly with our patients to see how much functional reserve they have. Our cardiology patients will be having echoes to have a look at their heart function and monitoring both ventricles and how they're working overtime And we do catheter studies of patient's hearts to see the pressures with their heart to look for conditions like pulmonary hypertension. So it can depend on the underlying condition and it's not just physical testing, you are seen by a social worker, by a psychiatrist and by a psychologist, by the physios to test how strong or frail you are and then there's some other criteria like going to education sessions, having support people in your family or friends that are willing to be part of the process as well so there's more than just a physical requirement. There's requirements for vaccination. There's requirements from abstinence of drugs and alcohol. Indeed once you get accepted we have a meeting every Friday morning where we discuss patients who have been worked up and as a multidisciplinary team everyone decides whether they're an appropriate candidate or not, and then you get put on the active list and then we basically have that list active all the time and if people become unwell we will raise them up the list but it's an urgency thing, and some people are more urgent than others but then really it's just when it's your time when we get a match for you. If we have something that matches a couple of people it will be the most unwell person, but sometimes you might be the best match on the list for that particular offer.

Interviewer: And tell me about that so it's not just a matter of this person is top on the list for a lung, a lung becomes available they get it,

Dr Jamie: Yeah, yeah, it's a complicated process, but size is a big thing so obviously the lungs; that's done on your height but also the predicted size of your lungs. So some conditions your lungs actually are bigger and so we try and match the donor to the right size for the lung patients but then they need to match on blood group and blood antibodies as well. For hearts we do it mostly on the predicted mass size of the heart so the size of your heart. We always have a waitlist. We always need more donors and indeed we probably as a program could

Radio Interview with Amy Ng- Thomson:

grow our waitlist for more referrals from different parts of New Zealand for patients that should be considered for heart transplant that maybe haven't been recognised by their local teams. We have about just under 20 people waiting for hearts and lungs at the moment and when you think about it, we've done 26 lungs this year and around 15 hearts a year just under 20 so that comes out with people waiting about a year to get a match but definitely more difficult for people, so our paediatric patients, it's really hard to get small enough donors for our paediatric patients and they can wait a very long time. We've agreed to go on a regular rotation with Australia now and so all of our paediatric transplants have come from Australia in the last little while.

Interviewer: Jamie says organ donation NZ and her team are two parts of the same equation, but it's important that they work as two separate entities.

Dr Jamie: They need to manage the donor and that needs to be a completely separate process from the recipient side of the medicine. We obviously crossover a lot in policy and how we run. We have regular meetings with them and regular contact. On the actual day that we're going to do a transplant the donor coordinators from OD NZ will be looking after the donor and our team actually fly to where ever the donor is to do the surgery. At the same time up in Auckland we're preparing our recipients.

Interviewer: How much notice would a recipient get when an organ becomes available.

Dr Jamie: We try to give them as much notice as possible and sometimes that can be quite quick but obviously we need time to get them up to Auckland and get them ready for their surgery, and it depends where they live. So are our very unwell urgent people are obviously in hospital in Auckland, so they're already there, but they might be able to drive to Auckland hospital to be able fly from the West Coast of the South Island and can take us quite a bit of time to get them up to Auckland and we will be delaying the donor surgery until we can fit all the pieces of puzzle together timewise. So we want to have a tight control on how long the organ is out of one body before it's transplanted.

Interviewer: How long is that period of time?

Dr Jamie: Well it can depend how far away we have to go to get the organ, but how long the organ in a transport period has really well linked to how well that organ will work in the recipient. There's a lot of work in transplantation about how we do that now, especially for hearts we used to have a 4 to 6 hours we knew that we were going to be having trouble. We now have a very impressive Box that we put our hearts in and if we think we're going to be at the four hour time limit or if we have a very complicated patient up here in Auckland, that we know that our surgery is going to be a little bit longer and we want to be able to take our time.

Interviewer: And when you say Box, I mean I'm imagining a chilli bin on ice

Dr Jamie: So the standard for the last 50 years around the world has been a chilli bin from Bunnings with ice, and that If we're in a hurry at a donor Hospital we go to get one from the local petrol station.

Interviewer: Then the heart Box?

Dr Jamie: The box we've got the next vivo, it's made out of Sweden so the heart sits in a special thing and it's plumbed in with cold cardioplegia, which is a solution to protect the Heart and blood, and blood is continuously delivered to the heart at 4°C so the heart is cold so it's protected, but it's also getting oxygen and other nutrients and the outcomes from studies have been phenomenal for this device and we're lucky to have it here.

Interviewer: Let's get back to Amy: six years after her first transplant assessment she was seen again and put on the waitlist for a new lung, despite knowing it was coming the news was still a shock.

Amy: I mean it's not something you want to hear at 35 years old. I was in denial. I thought well I'm still working full-time, I'm not on oxygen and not in a wheelchair, why am I getting put on a list. The day after a transplant coordinator called me who was at my appointment and could obviously see that I wasn't coping with the decision and at the end of that conversation we came to the conclusion that I wasn't mentally ready to have a transplant, so we agreed to take me off the list because you don't know when a donors going to turn up and if one turned up that night, I would've freaked out. I don't know if I would've gone ahead with it, so I took myself

Members Stories: continued...

Radio Interview with Amy Ng- Thomson:

off to essentially wrap my head around the whole concept. I wanted to get my affairs all sorted. I wanted to see the surgeon, the anaesthetist, I wanted to speak to other people. Then in August I put myself back on. So the average wait time is 7-9 months. I waited 13, and by the end of that I was on oxygen permanently, I was in that wheelchair. I was exhausted eating, drinking, getting dressed, walking around the house was a marathon; so I was so ready for that transplant. But I was also talking about my funeral because I'd waited so long, I'd deteriorated so quickly, my quality of life was absolute crap; who wants to live like that at Thirty Six years old right? but when I got the call, hallelujah.

Interviewer: yeah so that was going to be my next question, cause like you say you don't know when that call's going to come. Can you describe the situation that you were in when you got the call?

Amy: So funnily enough that night I had asked my family to come over for dinner, we were about to start and I've got a phone call and he said "it's a Sunday night the office is closed so you know what this call is. We have a potential donor for you" I don't know. I think I felt numb. There was not necessarily excitement or anything because he said potential donor. I'd also heard about other people's experiences where they had false calls so I didn't want to get myself hyped up and then disappointed, and then he called back at seven and said "Yep, good to go" . My husband and I went to the hospital but we didn't get confirmation until 2 o'clock in the morning that the organs were good to go, but between 8pm and 2 o'clock there was this huge sense of peace. We did acknowledge and we did lose a few tears, which I might now; we acknowledge that during our time of hope a donor family was losing their family member and they were gracious enough to say yes to organ donation for us. There is no amount of gratitude that we could express to our donor families.

Interviewer: Amy was in surgery for eight hours which was followed by eight days of being sedated with a ventilator breathing for her.

Amy: I remember all of that but it wasn't until I opened my eyes that I realised I had the surgery. There are some days, because I'm so many medications that you wonder did I actually have it because it's painful. It is such painful surgery. I mean your chest has been opened up and as I said, because I needed small lungs, my donor, she was a bit taller than me so what they actually had to do was tailer make my lungs so they've trimmed them down to size, so when I woke up I felt like they were jammed in there. So every time I coughed I was like, please don't burst out.

Interviewer: I mean no doubt you would've been appreciating it through all of the pain but how long did it take for you to get to the point where you were in a level of pain where you could actually appreciate these lungs?

Amy: I think the appreciation is definitely at the six month make when I made it up one tree Hill because it's a life passage for us kind of lung recipients and man when you make it up there, it was a beautiful March day. I always do it in March now because my birthday is in March. Seeing the blue skies, the views, feeling the breeze. I get the sense that she's with me every time I go up there. Now for me, not only is a right of passage, It's also my yearly gratitude acknowledgement for her, but also for her family and to say thanks for that without you I wouldn't be up here.

Interviewer: Six years later. Amy describes her life as normal. She's still on medication but is back to nursing full-time and enjoying life. She thinks about her donor often.

Amy: My first anniversary we went to Port Douglas. On the way to the airport I was in the backseat by myself, I was looking at the passport, I was looking at my air tickets going, this wouldn't have been possible without you. I'm going on a plane, again. Even if it's a year longer, three years longer, six months longer, it's just that extra time, and time; I don't think a lot of people realise is one of the most valuable things that we could have in this world, more than money. There's not going to be anyone on their deathbed thinking I wish I had more money, it would be, I wish I had more time and I think that donors and donor families need to realise they're giving us precious time with our loved ones.

Here is the link to listen to it:
https://www.rnz.co.nz/podcast/the-detail?share=4d0f8e0b-182e-4113-abe1-c4dd02c48f1c

Members Update:

Podiatrists and Fingernail cutting

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

***Jessica Dobbs Podiatry** is a Hamilton based Podiatry clinic in Flagstaff, Hamilton and also specialize in mobile podiatry across the **Waikato**.*
Our Podiatrist are trained in fingernail cutting and are happy to assist your members
2 Endeavour Avenue, Flagstaff, Hamilton 3210
0274 242 442

Dr Althea Page-Carruth, Central Otago
Dr Carruth does this only as part of general foot care.
To get in touch with her, her contact details are 02041785262
Clinics are in Cromwell and Alexandra

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

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

Auckland
Simon Speight
www.speightspodiatry.co.nz
https://www.facebook.com/Speights-Podiatry
https://www.instagram.com/speightspodiatry
2nd floor, 43 High Street, Auckland Central, Phone (09) 306 4006
Mob 021535511

Home Visits from Takaka to Blenheim
Greig Price
Contact Number
022 419 0205
Email info@mobilepod.nz
" Just to let you know Greig goes to Blenheim and Wakefield monthly, Takaka every two months and Motueka on a Tuesday. The rest of the time he is usually driving around the Nelson area so he can usually find time to see people"

Timaru
Catie Rowe Podiatry
0276882036
17 Dee St
Seaview,
Timaru
Ph 03 683-1448

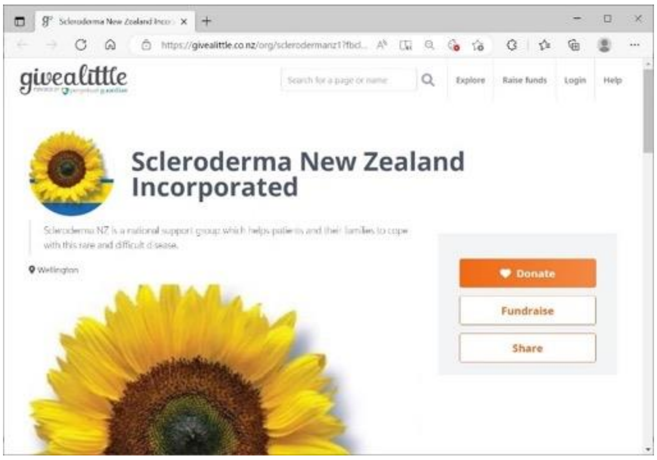
givealittle Give a little: Scleroderma NZ Inc.

From Scleroderma New Zealand Incorporated - Givealittle

Scleroderma New Zealand Incorporated

Scleroderma NZ is a national support group which helps patients and their families to cope with this rare and difficult disease.

An example of what our give a little website page is shown below:
Scleroderma New Zealand Incorporated - Givealittle



Scleroderma New Zealand Incorporated

Scleroderma NZ is a national support group which helps patients and their families to cope with this rare and difficult disease.

Our give a little URL link address is shown below: -
https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPHtXV7UFf9KIAnAzM

If you are donating or you are circulating the givealittle link, please make sure you use the above address link, thank you.

Many General Practitioners have not had experience with this disease and Scleroderma NZ aims to help promote knowledge among our medical professionals and patients, by supplying them with educational booklets and hospital checklists for special requirements.

SEMINAR 2025

‘A holistic view’

One and all are invited to the annual Scleroderma Seminar for 2025. Hosted by the Waikato Scleroderma group and supported by the Rheumatology team in attendance

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

Nau mai, Haere Mai

Members News:

Southland Scleroderma Group

We had a good turnout of 21 at our recent lunch in Gore at the Croydon Lodge. We had a bit of a festive touch with decorations on the tables, party hats and a Christmas cake slice to take home. We welcomed new member Allison along for the first time, Thank you to Glenys and Ian for picking her up and looking out for her; Sandra came the nearly 3 hours from Lake Hawea to join us for the first time also. A very big day for her. I was very pleased to hear she made it home safely, just very tired..

I tried to make the day as festive as possible as we were missing two very special members in Betty Wilson and Kimberley Small both who passed within a couple of weeks of each other. We raised a glass to the ladies and talked about how they will both be so sadly missed. We were so thankful that Betty had made our last catch up and generously gave out the sunflower seeds she had lovingly produced. Kimberley had moved to Ashburton so we only had messenger chats with her in the last year.

We were missing a few other members who would normally be there, with a bug going through the household of Heather and Graham Milligan and Lorraine and Barney away to a 100 years of dairy factory dinner. Also some members who are going through a very tough time at the moment so were supporting their loved ones, our thoughts go out to them and their families.
Thanks to everyone who were able to make it. It was lovely to have a catch up. Merry Christmas to you all.
Jenny

Hawkes Bay Scleroderma Group

We had our November meeting on Saturday and there were three of us present. Gail unfortunately was in hospital so we sent her our best wishes. We also had meetings in September and October and we are pleased that, although we haven't all been able to attend, we have always managed a minimum of two people. Our next meeting

This photo was from September's meeting.
Natalia, Di, Diana, Lorraine and Gail.

Christchurch Scleroderma Group

The Christchurch group met for an afternoon tea at the Burwood Hospital Café. Thank you to Nicky for taking on the leadership role of the group.

Auckland Scleroderma Group

Five (including my husband Roger) of us attended this coffee meetup. The last one for the year.
I think we all had a good time. Liz George told us of the freedom she enjoys now that she has an electric mobility scooter.
Janet pulled out the replacement inner sole of her shoes to display the how soft, flexible and absorbent they were.
And we discussed actually taking a prescription to be filled at the chemist. It had sat on the fridge door for a few weeks. Do we really want to begin with more drugs?
We're a small group; one or two constant people, and then others joining every so often.
But I believe we do give each other good support. And we learn from each other.
We laugh, we tell stories of family, travel, and holidays.
I'm looking forward to seeing people at our next meet up at the end of January.
Helen Parsons
books@parsons.co.nz
021 248 3869

Mary Daniel, Helen Parsons, Liz George, Janet Miller.
Roger Parsons took the photo.

Lifestyle Mobility
Martin Smith
Ph: 0800 555 669
Mob: 0277 877 477
martin@lifestylemobility.co.nz
Sales and service enquiries welcomed
www.lifestylemobility.co.nz

Where Liz got her Scooter from

Bay of Plenty Scleroderma Group

The Bay of Plenty Group met up recently and had a smaller number as there were a few unwell folks who had to pull out on the day. They continue to meet though so if you would like to join them get in touch with Alumie Nguyen: alumie.uow@gmail.com

Waipa and Waikato Scleroderma Group

Kia ora tatou,
A little update from us. Our last four or five get togethers we have combined with Waikato group. This has been very pleasant and quite diverse in what each individual is managing. Having that time together discussing and building rapport over a cuppa and light refreshment is invaluable.

The main purpose for joining as a collaborative, is to plan for 2025 Seminar, entitled 'A holistic view'. After our brainstorm sessions we felt what would be something to offer those who by attending can take away. We figured at some stage in our journey we get to management stage of our symptoms with monitoring peaks and lows. From a holistic view what non-invasive management techniques, strategies can we find that will allow us to have good quality of life. This will be our focus, for seminar.

We have chosen Spring as the time of year, warmer and quite a pretty time of year for the Waikato. Our Rheumatology Team led by Dr Solanki have generously offered to provide a medical wrap around group to attend. Doctor Solanki is in good health and whilst his private practise will not have his attention his time with Rheumatology and public speaking will increase.

Our communication we use Whatsapp, for me I find it so useful and with ability to take photos, and record it's so easy, for our little group of 11 contacts now to keep in touch. We welcomed two new ladies recently, one which keeps in contact with visits and morning tea with Linda bell.
Linda has been such an advocate for finding fellow scleroderma people so fabulous someone close to her address is taking time to keep in touch.

I so admire diversity of our group members, working full time or donating a great deal of their retired time to charitable work, maintaining good physical health with cycling, hiking overnight, pickle ball, grandchildren adventures, one ex Hamilton has gone off grid up North it's very exciting. Yes, there are those of us who have challenges with various injuries, loss of loved ones, even barriers with inability to managing day to day however keeping these in perspective, keeping in touch with someone and maintaining a sense of humour is vital.

Otira, kia koutou ma ngaa manaakitanga kia koutou i tenei wa,
Mere Kirihimete

Waipa, Hamilton, Putaruru, Morrinsville,
Please contact Erena Bruce if you wish to join them. bruceerena@gmail.com

New Plymouth Scleroderma Group

The New Plymouth group met recently for a chat and friendship.
If you would like to attend the New Plymouth Support Group please get in contact with
Kelsi Tidswell: kelsitidswell@gmail.com

Wellington / Kapiti and Wairarapa Scleroderma Group

The lower North island support group gathered for our last lunch for the year on Saturday 23rd November at Boulcott Farm Heritage Golf Club which is always a lovely setting.
We were a smallish group but as they say quality over quantity. With a lot of colds and Covid seeming to do the rounds, some were unable to attend for which we were sorry but grateful for.
Perry & Annette, Tina, Sandra (my Mum), Richard & Sue, Jan and Val were in attendance and we had a very nice time catching up, comparing notes and checking in to see how we are all doing.
It was also a great opportunity to wish Perry and Annette a fond farewell and to thank them for all that they do for us as they are moving down South.
A big thank you to Annette and Tina for adding the Christmas crackers and chocolates to give it a festive feel.
From all of us, we wish everyone a very Merry Christmas and New Year and may we all have a healthy and happy season.

Have a great day.

Cheers
Cushla

Group Meetings Dates 2025: Regional

Wellington / Kapiti and Wairarapa support group meets:

Date and Time	Venue
Sat 15th February @ 12:30pm	Chocolate Fish Café 100 Shelly Bay Road, Miramar
Sat 19th April @ 12:30pm	The Farm Café & Bar 33 Military Road, Boulcott, L/H
Sat 19th July @ 12:30pm	The Fisherman's Table (To be confirmed)
Sat 20th September @ 12:30pm	Chocolate Fish Café 100 Shelly Bay Road, Miramar
Sat 22nd November @ 12:30pm	The Farm Café & Bar 33 Military Road, Boulcott, L/H

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

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

Christchurch support group meets:

We welcome any new members to come along.
Please contact **Nicky Moore** if you would like to join in:
nicky.moore@xtra.co.nz **Phone:** 021 110 6123

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

Southland support group meets:

Venues to be confirmed
February 16th, Winton at 12pm
May 4th, Gore at 12pm
August 17th, Invercargill at 12pm
November 23rd or 30th, in Gore at 12pm TBC

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

Waimate/Oamaru support group:

We have members meeting up in these areas so if you are interested in joining them please get in touch with **Helene Sunitsch** at: hkjsunitsch@gmail.com

Waikato/Waipa support group meets:

No meeting booked in yet but will be held either within the next couple of weeks or in January. The group will be notified with the details.

If you would like to join in with the Waikato/Waipa Group, please contact
Erena Bruce, Mobile: 021 186 9680
Rachel Burgoyne, Mobile: 027 3661881

Palmerston North support group:

See Wellington Support group.

Otago support group:

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

Auckland support group:

Venue: *Dailey Bread, Kings Garden Centre,*
11 Porana road, Takapuna,, Auckland
Time: **Monday 27th January, 10am**

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

New Plymouth support group:

Venue: *Locals Café, 11 Wallath Road, Westown, New Plymouth*

Saturday, 7th December, 2024 at 11am
If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell**:
kelsitidswell@gmail.com

Hawkes Bay support group meets:

Venue: *Frances' Home, Villa 147, Willowbank Retirement Village, Napier*
Saturday 14 December 2024, 10.30am
If you would like to join in with the Hawkes Bay Group, get in touch with Gail.
Gail Neilson: gail_neilson@hotmail.com

Bay of Plenty support group meets regularly:

Come join us for more informative discussions and good company!
Please contact one of us for information.
Jane: janepuckey99@gmail.com
Mary: marybestrd3@gmail.com
Alumie: alumie.uow@gmail.com

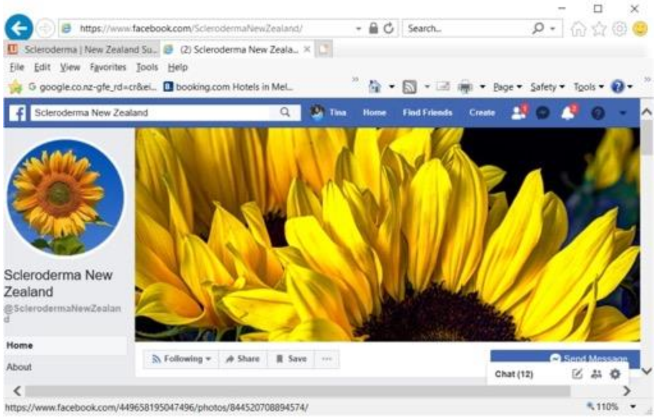
Welcome to Scleroderma New Zealand Inc.

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

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

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

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



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

Scleroderma New Zealand

President:	Jenny Andrews jennyred@xtra.co.nz
Vice President:	Tina McLean tinaoaisamclean@outlook.com
Secretary:	Jane Sainsbury jsainsbury@xtra.co.nz
Treasurer:	Gordon Purdie gordon.purdie@xtra.co.nz
Newsletter:	Tina McLean tinaoaisamclean@outlook.com Jenny Andrews jennyred@xtra.co.nz

Committee Members:

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

Contacts:

Find a Scleroderma a Support Group near You:

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