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Scleroderma

New Zealand support group

Spring 2016

Spring is just round the corner and I can't wait for those long, hot summers days once more. This last month has been very cold, but thanks to a variety of merino apparel I managed to stay pretty warm.

We have a full issue this month with a variety of topics. First we have the President's report. Dianne has been busy with all sorts of things and you can read about this further down.

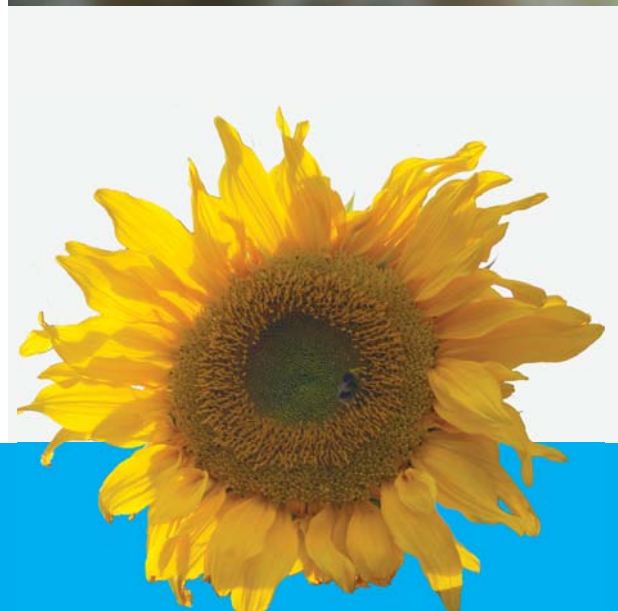
We also have a report on Arthritis Educator, Robyn Tuhoy's presentation to our group, about stress and pain management. We all enjoyed what Robyn had to tell us and hope now to put these ideas into practice.

There are photos from our members around the country. See what they are up to - you can send us yours too. Also there is a good report on managing Raynaud's. You will get some ideas and tips on staying warm and reducing the effects of this condition. A worthy read.

A sad farewell to Val Smith, a founding member of the Wellington group, who sadly passed away recently. She is greatly missed.

A piece of good news for those of you with dry eye. You can read about the latest treatment for this. It's based in the lower South Island

Enjoy your read. Don't forget to send me your pictures, news, ideas, questions, crafts and recipes so we can all enjoy..



President's Report

Bring on Spring, we all need that boost of sunshine, and we have had a good taste of it over the last few days.

I hope that you have all mostly come through the winter spell here in New Zealand quiet well. We have been reasonably fortunate throughout New Zealand as it has mostly been mild, with just with one or two heavy snow storms here and there around the country.

We had a sad start to July with the loss of Valerie Smith as you will read about later in this newsletter, she will be missed by our group here in Wellington. Valerie was one of our founding members. She had lead a very active 86 years and was a great source of encouragement for us all.



I am pleased to say that we now have the New Zealand Edition of **Understanding and Managing Scleroderma** booklet at the printers and we should all get copies in late September.

The format is very similar to the previous booklet. The new booklet has a practical help section for New Zealanders nationwide. We are looking at a bright warm and happy front cover, so we are currently looking forward to sighting the graphics before the final print.

I would like to sincerely thank you all for your support with the fundraising required to get these booklets printed. It has been a huge effort from all of you and your families.

A special mention to Linda Bell and Maureen Kirby for their fundraising ideas and work towards this: Maureen with the sale of the calenders and Linda with the movie-night fundraiser and quilt raffle.

Thank you all so very much. I know that we are all going to benefit from the booklet by distributing it to our GPs, family members and anyone else who you may think will benefit.

I will be sending out quantities to all the rheumatology clinics

around the country and to any of you who would like a copy. I will get you all to notify me of how many you will need, with postal addresses.

John and Barbara will also make the booklet available on the website, so that you can download it. We have been given free envelopes from New Zealand Post to send you all a physical copy. We will also send out a hospital check list with the booklets.

Now that the booklet is organised, there is time for the committee to think of other ways in which we can help our wider scleroderma community. This also means that I am very happy to hear from any of you out there, of any ideas or concerns you may have and I will be very happy to pass them onto our committee to formulate a way through. You can email at diannepurdie@xtra.co.nz



Once again, thank you all for your support.

Keep well and enjoy the up and coming spring.

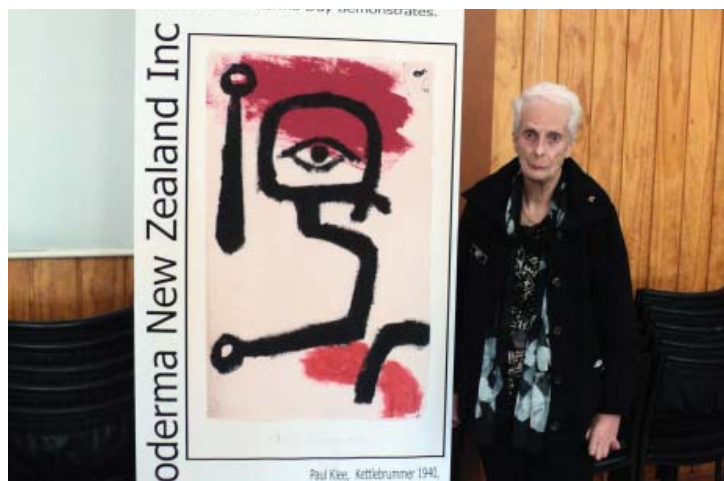
Dianne

Quilt Fundraiser

Linda Bell has raised \$800 for Scleroderma New Zealand by raffling a locally made quilt.

Linda received the quilt after doing a presentation on scleroderma and talking about her personal experiences to about 80 women at the Waikato Patchwork and Quilter Guild .

Part of the proceed from the quilt raffle will go towards this year's Waikato scleroderma seminar too.



Managing Pain and Stress

Arthritis educator, Robyn Tuohy, speaks to Wellington's August meeting

Robyn's focus was on managing the pains and stress that accompany scleroderma. She says self-management is crucial to how scleroderma affects your life.

Causes of Pain

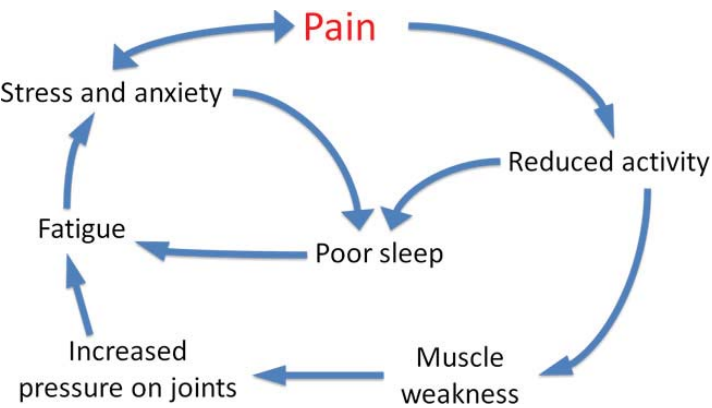
- Inflammation
- Stiffness
- Joint damage
- Tense muscles
- Weakened muscles

Robyn explained that, when your brain concludes that your body is in danger, you need to do something about it so it causes pain in the local nerves. It's a protective system.

Not all pain is equal though. Acute pain is protective. Chronic pain is less useful - it's the brain overreacting to discomfort, injury or illness. The pain can continue and spread even when no harm is happening. She says chronic pain is pain that lasts longer than 3 months.

Many factors can influence how you experience pain.

- Emotions (anxiety, excitement)
- Thoughts (what we think)
- Behaviours (what we do)
- Other people's responses
- Stress



Managing Pain

Your mind and attitude can influence how you experience pain, from place you go and see, your attitude to life, your experiences, things you say and do, amongst others. Robyn gave a detailed analysis of events that can be positive or negative to how you face life and experience pain. Positive steps could be meditation, massage, gentle exercise, prayer



and aromatherapy.

Managing Stress

Robyn finished a comprehensive afternoon explaining how to manage the fatigue and stress that result from chronic pain and illness.

It's perhaps easily summed up in the graphic she provided.



Quilt Fund-raiser

Big Congratulations to Judy Trewartha. Judy was the lucky ticket winner for the Quilt Raffle (Number 43).

Judy says she will donate her prize to her local hospice. President, Dianne says we reached 100 tickets and:



"I would like to thank Linda for her great energy and with her kindness of donating the very lovely quilt to Scleroderma NZ for the raffle, and to all of you out there who have supported us by buying the tickets, you have been all very wonderful."



North and south mingle. Earlier this year, President Dianne and husband, treasurer and general all-round organiser, Gordon were down south and had a cuppa with the southern-most members of Scleroderma New Zealand. Heather Milligan and husband, Graham, are usually the ones to travel, attending the Wellington seminars. There are four Support Group members in Southland.

Farewell to Valerie



Val attacks the candles at a Support Group, celebrating a recent birthday.

One of our original members, Valerie Smith died on 15 July in her 85th year.

Val was a literate woman, the published author of three books, based on her career and experience of nursing in the 50s.

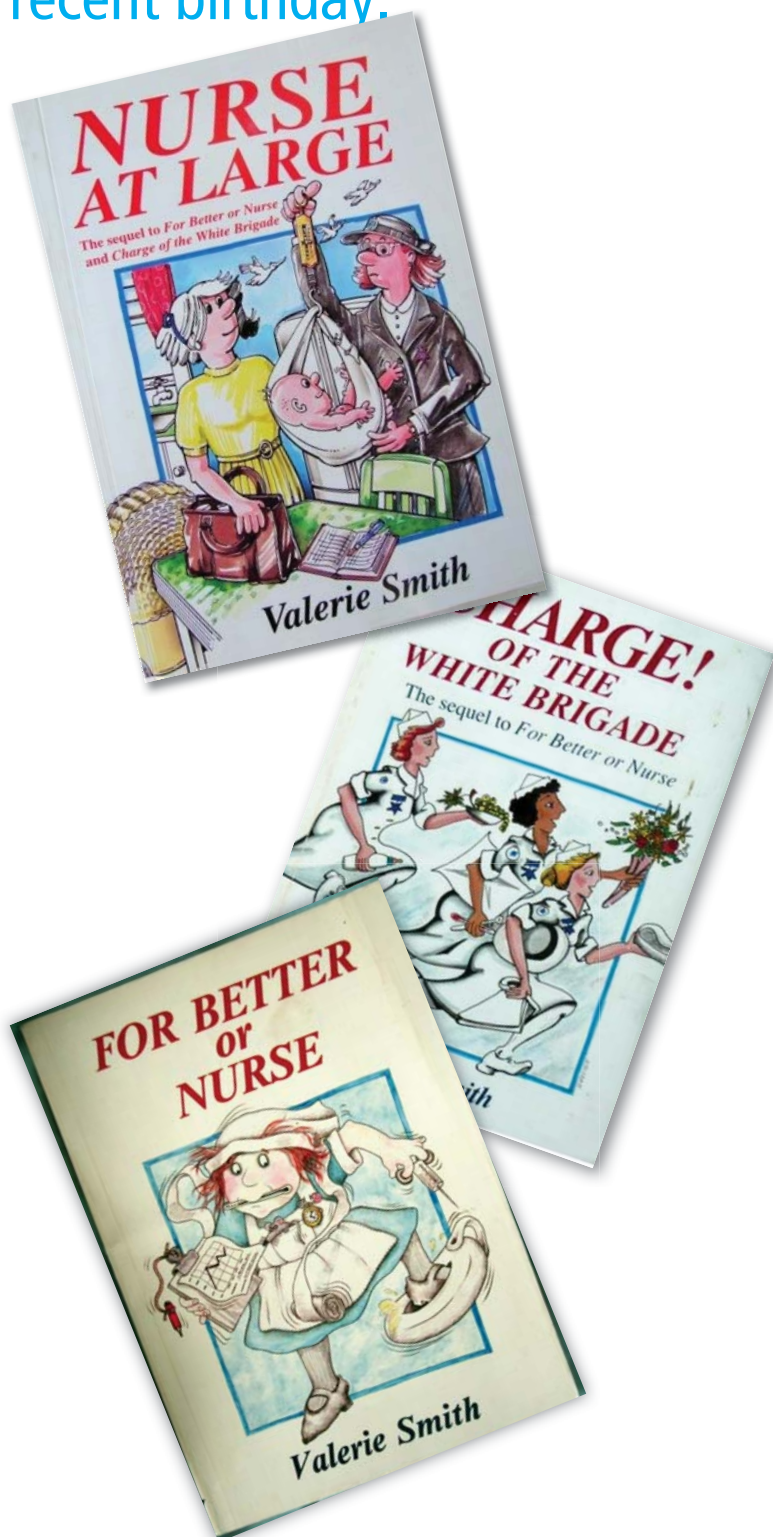
In those days, staff wore starched uniforms, caps, and veils. Today's principal and charge nurses were called Matron and Sister.

Student nurses were very much at the bottom of the hierarchy.

Val's *For Better or Nurse* was published in 1988 with two follow-ups

There was a celebration of Val's life attended by Support Group members a few days after Val's private funeral service.

Amongst other activities in a full life, Val was a tramper, keen conservationist and Samaritan's volunteer. At the August meeting we observed a moment of silence in remembrance of Val.



Waikato Activities

Waikato's recent movie fund-raiser went well, with organiser, Linda Bell reporting 67 people, mostly family and friends and some Scleroderma members attending. They raised \$800 for Scleroderma NZ.

Their monthly coffee group is going at Westfield Shopping Mall, Chartwell at the Robert Harris Café. Birthdays of group members are an excuse for a nice lunch.

The Waikato seminar this year will be on Saturday, 5th of November at the same venue: St Johns Methodist Church Hall Hamilton East. More information plus presenters will be provided in a couple months time.

Please also help support Scleroderma NZ by either calling into Target Furniture, Hamilton which is selling Entertainment Books either in store at Te Rapa Road, Hamilton or online please click on your area: www.entbook.co.nz/935q727

For any more information on the above please contact me on Ph 07 8535434 or email linda.bell@hotmail.co.nz



Winter in Palmerston North

What's a support group to do when it's a Palmerston North winter? Why, get inside out of the cold, crack a good vintage and enjoy each others company. Which is exactly what they did!

US Scleroderma Advocacy Summit

Scleroderma patient advocates from across the US get a face-to-face with Senators and Representatives in mid-September. It's their chance to try to convince lawmakers to support a new law that would:

- Create a commission of leading scientific experts to work together a draft a comprehensive long-range plan for systematic research in this area.
- Establish a working group to implement the research plan and coordinate research activities.
- End the millions of deaths each year attributed to chronic fibroproliferative illness.

So far they have the support of both Democrats and Republicans. It is budget neutral - the bill will not increase federal spending. Advocates are after numbers now to get the bill before Congress ahead of all other advocates, each of whom lobbies for their own field of interest.

They get time in 15 congressional offices on the day



Managing Raynaud's

Manage Raynaud's symptoms by planning and live as normal-a-life as possible.

Take gentle exercise

Exercise within your limits, can boost circulation and may improve Raynaud's. Even gentle exercise can help the blood flow – if you are feeling cold, for example, try swinging your arms as you walk.

Occasionally, exercise can trigger Raynaud's attacks. Look out for signs of this happening and change your fitness plan if needs be.

Many find swimming can help their Raynaud's, but please check the temperature of the water before swimming as a cold pool could trigger an attack.

Try one of these low impact exercises to see if it helps your Raynaud's.

Exercise is a great way to lift your mood and ensure that you stay fit and healthy:

1. Walking

By far the most popular low-impact exercise, walking works the cardiovascular system and burns calories. To get your heart rate up, walk faster than a stroll. Picking up the pace can increase the intensity of your workouts. Add short bursts of speed or walk up an occasional steep hill.

2. Swimming

Swimming works the whole body. It's a great way to tone up and get trim. Swimming a few lengths involves most of the muscle groups, and you'll get a good aerobic workout if you increase the pace. Swimming can also help you lose weight if you swim at a steady and continuous pace throughout your session.

3. Cycling

Cycling is a low-impact activity. But you can still injure yourself if you have the wrong size bike, or if the saddle and handlebars are at the wrong height. Cycling is an aerobic exercise that works your lower body and cardiovascular system. Start slowly and increase the length of your cycling sessions gradually.



4. Yoga

Yoga can improve both your physical fitness and your general wellbeing through a series of postures and breathing exercises. Regular yoga practice helps develop strength, balance, and flexibility. It can also lift your mood.

5. Pilates

Pilates focuses on rebalancing the body and improving posture through slow, controlled movements and exercises. Regular practise can improve muscle strength and your sense of wellbeing. It can be helpful for people who can't or must not jump around too much.

6. Dancing

One of the best things about dancing is that while you're having fun moving to music and meeting new people, you're getting all the benefits of a good workout. From Cero to the foxtrot, there's a dance style to suit all tastes.

Please consult your GP before making any major lifestyle changes.

Keep ~~Calm~~ Warm and Carry On.



Exposure to cold or even a slight change in temperature can trigger a Raynaud's attack. Scleroderma and Raynauds UK has some advice on how to keep warm.

At Night

Warm the bed with a hot water bottle or electric blanket. Wear flannelette night clothes, night cap, bed socks, gloves etc. Keep extra blankets ready during a cold spell. Thermal under blankets add extra warmth.

Air Conditioning

Wear a thick headscarf, especially in air-conditioned buildings and on aircraft when the cold air circulates around your neck.

Clothing

Outside, wear several thin layers of clothing to trap warm air rather than one, heavy garment. Avoid tight clothing - it may restrict your blood flow. Thermal clothing is excellent.

Natural fibres like wool, cotton or silk will keep you warmer than most synthetic ones. Try thin cotton or silk gloves under thicker mittens or gloves. Gloves and socks made with pure silver reflect 95% of the body's energy back to the skin. A scarf can keep the nose, mouth and cheeks warm and there are even face masks, to fit over the nose and protect your face, neck and ear. A polo neck will help to keep your neck warm.

Eating for Warmth

Your body needs warming 'fuel' to brave the cold. Start the day with a bowl of hot porridge or cereal with warm milk. Try to eat lots of small meals to maintain your energy and heat levels and whenever possible have a hot meal at midday. Plenty of hot drinks between meals and before to bed are essential. Keep a good supply of food in the house and eat plenty of fresh fruit and vegetables. Good sources of protein and energy are bread, milk, meat, fish, eggs, potatoes and baked beans. Keep a pair of oven gloves by the fridge. Raynaud's can attack just by going into the freezer or picking up a cold object.

When going out, microwave a couple of jacket potatoes, wrap them in tin foil and put them in your pockets. They'll keep your hands warm and you can eat them later.

Handy Hints.

Avoid touching cold surfaces like milk bottles.

Don't have ice cold drinks straight from the fridge.

Take a flask of hot water or soup with you in a car.

Warm up doing the ironing. A metallised ironing board cover will reflect heat and help to keep you warm.

Warm clothes and shoes with a hair-dryer before going out.

A hot bath before bed aids a good night's sleep.

Leave the bath water in while you dress - it will give off enough heat to keep you warm.

Stop smoking - it's harmful and smoking can reduce your temperature by one degree over a twenty minute period.

Warm your hands on public air hand dryers when shopping.

Keep your clothes and shoes for the next day in the airing cupboard overnight.

When your eyes see red you feel warmer. Fires with a red glow make you feel warmer than convection heaters. Add warmth with red flowers or a red lamp shade or bulb.

Fill a box with packaging polystyrene balls and place your hands in it. This is a good way to warm them.

When watching television place a hot water bottle behind your back or under your feet.

Keep doors closed - leaving a door open to talk to the milkman or neighbour can drastically reduce the temperature.

Breathe in through your nose and out through your mouth when outdoors - this stops cold air being sucked in through your mouth and sent straight to your lungs.

Use shoulder bags for shopping where possible rather than ones with handles as these can restrict blood to the fingers.

Make a delicious warming drink with finely minced, crystallised ginger. Just add lemon juice, ginger and a teaspoon of honey to boiling water. It's tasty and will help boost the circulation.

Plan ahead - make sure you have hand warmers with you.

Carry a pair of gloves or mittens with you at all times - frozen food aisles in supermarkets can be extremely cold, especially when handling food packaging.

Dry Eye Treatment

A Wanaka optometrist, Eyes on Ardmore, has acquired a specialised Intense Pulsed Light (IPL) machine to improve the health of dry eyes.

It's the first of its kind in the lower South Island. The \$47,000 machine treats and helps prevent dry eye disease and meibomian gland dysfunction.

The machine aims to treat dry eyes rather than provide temporary relieve as eye drops do.

Optometrist, Danielle Ross , says clinical trials indicate that patients experience an 86% improvement in the symptoms of chronic dry eyes, such as eye soreness, grittiness and blurring. In a 15-minute treatment, the machine transmits bursts of light into the eye's blood vessels. It improves the oily layer volume, and rejuvenates eye tissue. It also counteracts problematic bacteria on the skin and eyes, which can cause eye discomfort.

She says there are minimal side effects and patients typically enjoy immediate results lasting up to 24 months.

The clinic charges \$94 for an examination Three sessions of the IPL treatment spread over 45 days cost \$589. For more information, visit www.eyesonardmore.co.nz/dry-eye/



Arthritis New Zealand

Arthritis New Zealand, to which we are affiliated, is 50 years old. Here are a few interesting facts about the organisation, and arthritis in New Zealand

ANNUAL RUNNING COSTS



60%

OF MEMBERS
AGED OVER 65



% OF INCOME
FROM FUND-
RAISING:

65

CURRENT MEMBERSHIP



4,500

NEW ZEALANDERS AFFECTED BY ARTHRITIS

65,000



Barbara gets an infusion of Rituximab at Hutt Hospital to keep a little bit of the 'auto' out of immune. It's an annual chance for a half-day's uninterrupted reading.

We welcome photos from members. What have you been up to?

Find a Scleroderma support group near You

Auckland: Allan Edmondson Email-
allanedmondson@xtra.co.nz

Hamilton: Linda Bell Email:-
linda.bell@hotmail.co.nz

Palmerston North: Chris Carlyon-
ningandalley@clear.net.nz

Invercargill: Maureen Kirby-
Maureen.Kirby@southerndhb.govt.nz

Christchurch: Kim Tocker-
akaroakim@gmail.com

Wellington: Dianne Purdie-
diannepurdie@xtra.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 and I will be happy to help you set one up.

Noticeboard



Contacts

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