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Scleroderma

New Zealand support group

Summer 2019

Greetings to you all.

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

Well this year has flown by so quickly, we are almost at Christmas, and New Year is just around the corner. We wish everyone a wonderful Christmas, a Happy New Year for 2020, a safe and healthy holiday season.

We have some stories from our members and a wealth of information from the Christchurch seminar to share.

Thank you to everyone who came to the Wellington Christmas shared afternoon tea in November. We had a great time, made some new friends, and celebrated Adrienne Burleigh's birthday. We also had some yummy and delicious food to eat as well enjoyed catching up with one another.

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

We have a Memorial to **Joan Hardiman** and **Win Weir.**

We have the presentations from the Christchurch Scleroderma Seminar 2019: -

- **Jan Ipenburg,** Clinical Nurse Specialist Rheumatology:- Medicinal Cannabis and Information from the Australian Scleroderma Conference
- **Professer Lutz Beckett,** Respiratory Physician/Sleep Physician -Head of Department
- **Helen Hills:-** Hand Therapy for Scleroderma Patients
- **Maureen Anderson:-** Psychological Impact of Scleroderma
- **Kirsten Rosser:-** Gastro Problems and diet for Scleroderma Patients
- **Allan Edmondson,** Living with Pulmonary Arterial Hypertension (PAH) and Patient Advocacy.

Presidents Report:

December 2019

Seasons Greetings to you all,

I would like to thank all of the committee for all their work this year, and special thanks to John Spavin for his much appreciated continued work on the website and to Tina McLean and Jenny Andrews for their continued special work with the newsletter. Also to Cushla Marsters and Catherine Thompson for their great work on Facebook.

The Southland Scleroderma group had the sad news of Joan Hardiman's death on Friday 15th of November.

And the Wellington group also had the sad news of Win Weirs death on the 4th of September along with the death of her husband Graham a few days earlier. Memorial notices will be seen later in the newsletter.

Wellington also had a nice celebration for Adrienne's 80th Birthday which perked us all up. The best of good health to Adrienne until her next big 0 number birthday :-) I would also like to acknowledge the kind support Adrienne has given us over the years and also a huge thank you for the very kind donation recently in acknowledgment of Adrienne's Birthday and Scleroderma from all her friends and family.

I have been busy lately organising the Christchurch seminar. We were very fortunate that Burwood hospital gave us the use of their seminar room for free, and that we were lucky to get a good number of speakers.

Congratulations go out to the ladies of the Christchurch Scleroderma group. They all worked hard together to make it a success.

We had people come from Auckland, Havelock North, Southland, West Coast and Christchurch.

A terrific turnout. Thank you all for your participation, you all made it a special day!

The groups from all around New Zealand have been keeping up and meeting and supporting one another during the year, which is very much valued. We all have something to share and bring to the table. New members are most welcome to come and ask questions, and you will be made to feel like part of the family.

Raising awareness for Scleroderma in New Zealand will be looked at by the committee.

Also the health and well being of people with scleroderma will be looked at, along with some Scleroderma introduction sessions for newly diagnosed patients in some areas around New Zealand.

We now have 166 members throughout New Zealand, from Northland to Invercargill and the east and west coasts of both islands. We also have members from Australia and the Philippines.

If any of you out there have any ideas that you would like to put to our committee, you will be most welcome, be emailing me at diannepurdie@xtra.co.nz

My Very Best Wishes go out to you all for the season.

Take care on the roads and have a wonderful time with family and friends over the lovely summer months ahead.

The Best of Health…

Dianne Purdie

Memorials

It is with great sadness that we bring the news of Joan Hardiman, one of our members who passed away.

Memorial for Joan Hardiman

Friday 15th of November 2019

Joan was a lovely lady and also a private person. Always smiling, Family was everything to her, having raised 4 daughters and 2 sons with husband Steve. She loved gardening, was involved in her little local church and was in the women's group choir. I am not sure of the correct timeframe but know that Joan had been diagnosed more than 18 years ago. Hard to believe that Steven died 5 months ago of M.N.D. and now Joan's death. An end of an era for her family. R.I.P.

Written by **Bronwyn Ludke**

We also have sad news to hear the passing of Win Weir and her husband who passed away.

Memorial for Win Weir

On September 4, 2019, peacefully at Burlington Village, in her 86th year.

Win was a dear lady, who was very quiet and just got on with life. Win always had a smile regardless of what trials she was going through with scleroderma and she was always willing to help at any time to give advice and support to our members here in Wellington and around the country. Her lovely husband Graham also came and supported Win and us all at times. Graham sadly died just a few days before Win on the 28th of August.
They had only just moved to Christchurch to be near family.

We will miss them both.
Dianne Purdie

CHRISTCHURCH SCLERODERMA SEMINAR 2019

Jan Ipenburg, Clinical Nurse Specialist Rheumatology, Christchurch Public Hospital

First, we heard from Jan Ipenburg. She explained what Scleroderma was…..

SCLERO – HARD

DERMA – SKIN

- Generalised disorder of connective tissue affecting skin and internal organs
- Autoimmune process
- Overproduction of collagen
- Blood vessel damage
- Inflammation
- EVERYONE IS DIFFERENT

Associated with specific autoantibodies

- ANA – 98% positive (non-specific)
- Anticentromere - Limited (41%)
- Scl-70 – Diffuse (29%)

Collagen:

Collagen being a major protein portion of connective tissue, which holds the cells together.

Collagen is found in skin, joints, tendons and parts of internal organs. It's made up of woven fibers and an over production of collagen = thickening.

Scleroderma (SSc)

Scleroderma is prevalent in 5-23/100,000, its cause at this stage in unknown,

6:1 Female: Male and the average age of onset is 42 years.

The Scleroderma Spectrum of disorders

Raynaud's Phenomenon

- (Primary)
- Autoimmune

Systemic Sclerosis

- Limited cutaneous SSc
- Diffuse cutaneous SSc
- Overlap syndromes

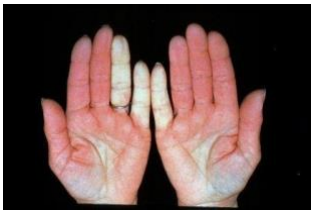
Localised scleroderma

- Morphea plaque
- Linear scleroderma

Raynaud's phenomenon

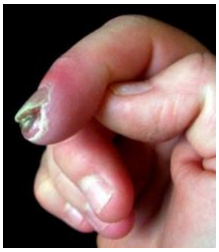
Primary

- Onset in adolescence
- Positive family history
- Benign course



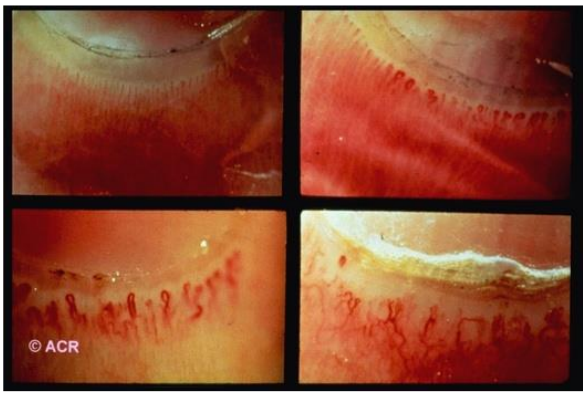
Autoimmune

- Initial symptom of CT disease
- Abnormal nail fold capillaries
- +ve autoimmune serology (ANA, centromere)
- More severe course



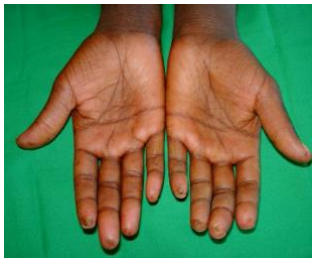
Nailfold capillary changes

When at the specialist and they are looking at your fingernails. This is what they are looking for.



Management of Raynaud's

- Avoid cold, keep core warm, gloves
- Don't smoke, avoid caffeine
- Vasodilators- Ca channel blockers, ACE inhibitors,
- Some antidepressants.

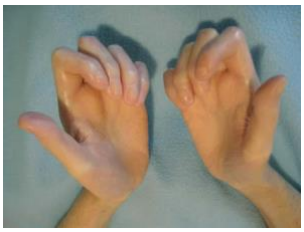


Jan Ipenburg, Clinical Nurse Specialist
Rheumatology, Christchurch Public Hospital

Continued…

Scleroderma (SSc) diagnosis

- -90% Raynauds – usu. first symptom
- sclerodactyly -95%
- ANA +ve -95%
- degree of skin involvement determines classification
  - limited SSc (lSSc)
  - diffuse (dSSc)



Limited SSc

CREST syndrome

- C Calcinosis
- R Raynaud's
- E oEsophageal dysfunction
- S Sclerodactyly
- T Telangiectasia
- Sclerodactyly and telangiectasia are most common features
- Calcinosis – no treatment, may be painful

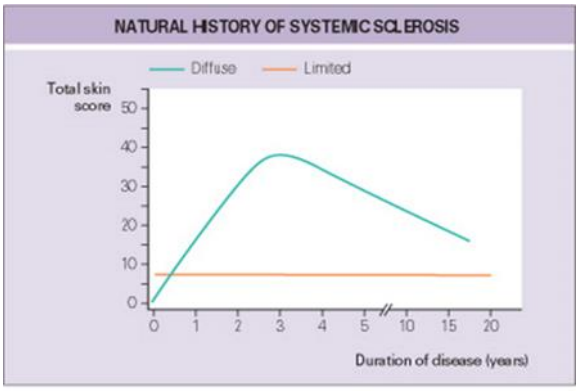
PAH – 5-10%

- 10 years post onset ISSc
- Screening

Diffuse SSc (dSSC)

- More widespread & severe skin involvement
- 64% skin alone
- 31% organ involvement

	Limited Scleroderma 70%	Diffuse Scleroderma 30%
Raynauds	95%	80%
Skin	95%	95%
Gastro-oesophageal reflux	75%	90%
Lung Fibrosis	30%	30%
Heart	Less than 5%	10%
Pulmonary Hypertension	15%	5%
Kidney disease	Less than 5%	20%
Telangiectasia	91%	64%
Calcinosis	42%	17%
Consider psychological as well as physical health		



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SKIN

Thickening
- Contractures
- No proven treatments
- May use MTX
- Hand therapy/physiotherapy

Fingertip ulceration
- Needs prompt treatment
- Avoid/treat infection
- Consider trauma
- IV prostacyclin, sildenafil
- Pain relief
- Dressings that remove eschar and promote healing

Telangiectasia
- Cosmetics

Calcinosis
- Avoid infection
- Rarely surgery

Dry Skin
- Avoid skin contact detergents
- Moisturizing soaps
- Moisturizers with lanolin or sorbelene

Itchy Skin
- Moisturizers
- Cortisone cream

Other
- Decrease in hair
- Decreased perspiration
- Increased pigmentation
- Spotty loss of pigment

CHRISTCHURCH SCLERODERMA SEMINAR 2019

UPDATE ARA CONFERENCE 2019

Several studies looking at new targets, trials are underway

ILD

- not all progress
- Most occur within 2.5 years of first non-Raynaud's symptom
- May lead to PAH
    - Initiate therapy for GORD
    - Quit smoking
    - Consider vaccinations
    - Oxygen if required
    - MMF or cyclophosphamide
    - ?stem cell transplantation
- Need to consider DLCO may drop due to muscle dysfunction, thoracic restriction, aspiration or deconditioning

PAH

- Assess for iron deficiency and treat if appropriate

ARA

Renal crisis

- Presents with hypertension and raised creatinine
    - Rare but more common in diffuse
    - Consider BP machine at home
    - Routine bloods
    - Treat hypertension
    - Empirical use of ace inhibitor not recommended

Stem cell transplantation

- Option for those at risk of organ failure
    - DcSSc – in first 4-5 years with mild-moderate organ involvement
    - LcSSc – with progressive visceral involvement
- Only in non-smokers
- Extensive work-up required
- 3-10% mortality
- Increased cardiac complications

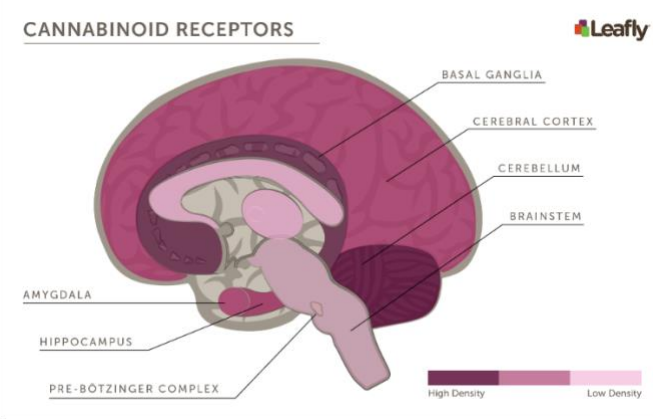
Medicinal Cannabis – Ara Pharmacist

Cannabis refers to the whole plant whereas the medicinal cannabis term is used to describe a wide range of products made from the whole plant.

- The most common of these is cannabis oil.
- It does not include buds or plant for smoking.
- To be medicinal it should be prescribed and dispensed.

The pharmacology:

- Cannabinoid CB1 receptors exist in the brain and have a similar effect to opioid.
- Cannabinoid CB2 receptors are in the periphery and are anti nociception.
- THC works on multiple receptors and is very complex.
- THC = main psychoactive component of cannabis.



Medicinal cannabis

There are still a lot of unanswered questions,

- Medicinal cannabis may be effective in inflammatory and neuropathic pain and may have an effect on cytokines but this is complex.
- Smoking cannabis only gives very low dose.
- CBD receptors may be present in synovial cells.
- There is a paucity of evidence, there are some studies reporting benefit but may not be statistically significant and adverse events are common.

Medicinal Cannabis – Ara Pharmacist continued…

There is currently not enough evidence that these medications should be considered first line in any condition.

- They may be used last line but need to use goal based therapy with an end point.
- Consider: ABCDFI - adverse effects, pill burden, cost, treatment delay, false hope and interactions

Meeting Report "Considering medical cannabis for chronic pain"

Faculty of Pain Medicine (FPM), ANZCA House, Melbourne Saturday 7th Oct 2017

- The overall "headline" result of all included pooled studies was moderate strength evidence that cannabinoids were just better than placebo in achieving a 30% reduction in pain (Odds Ratio – OR – with cannabinoids vs placebo was 1.51, with a 95% confidence interval – CI – of 1.2-1.84).

Faculty of Pain Medicine Australian and New Zealand College of Anaesthetists

Cannabinoids

- Substances (regardless of chemical structure or whether they are natural or synthetic) that bind to biological receptors and produce the classical spectrum of pharmacological effects demonstrated by extracts of C. sativa.
- Principal botanical cannabinoids are
  - delta9-tetrahydrocannabinol (THC)
  - cannabidiol (CBD)
  - cannabinol4 (CBN)

CADTH RAPID RESPONSE REPORT: SUMMARY WITH CRITICAL APPRAISAL

Medical Cannabis for the Treatment of Chronic Pain: A Review of Clinical Effectiveness and Guidelines July 24, 2019

Chronic pain is defined as pain that persists for more than three months.

- Cannabis-based medicines contain cannabinoids derived from the cannabis plant, including delta-9-tetrahydrocannabinol (THC), cannabidiol (CBD), or a combination of THC and CBD6.
- There is, however, uncertainty and controversy regarding the use of cannabis-based medicines for the management of chronic pain.

Based on four overviews (with overlapping systematic reviews), and one systematic review of guidelines,8

- There is some suggestion of benefit with cannabis-based medicines for neuropathic pain. However, benefits need to be weighed against harms.
- Findings are inconsistent for effect of cannabis-based medicines in patients with fibromyalgia, musculoskeletal pain, Crohn's disease, and multiple sclerosis.

CADTH

Six evidence-based guidelines were identified.

- The majority of the guidelines present recommendations for chronic neuropathic pain.
- The guidelines report that cannabis-based medicines may be considered as a treatment option for patients with neuropathic pain, with chronic non-cancer pain, and with chronic non-cancer, non-neuropathic pain, but with some caveats.

CHRISTCHURCH SCLERODERMA SEMINAR 2019

CADTH cont…

- Recommendations are against the use of cannabis-based medicines for pain associated with fibromyalgia and back pain in two guidelines and for pain associated with headache, rheumatoid arthritis and osteoarthritis in one guideline.
- For pain management in multiple sclerosis patients, one guideline mentions that cannabis-based medicines may or may not be offered, depending on the type cannabis-based medicine and patient condition.

Findings need to be interpreted considering the limitations

- studies of variable quality [low to moderate], and studies of short duration
- There are inconsistent results on tolerability and safety of cannabis-based medicines for any chronic pain.
- The available evidence comparing patient outcomes following cannabis-based medicines treatment versus placebo appears insufficient to make well-founded conclusions about the clinical advantage and use of cannabis-based medicines for the management of cancer and non-cancer pain.
- According to the quality criteria of evidence-based medicine, the available evidence for cannabinoids is inadequate for the indications of loss of appetite in patients with cancer or HIV/AIDS, fibromyalgia syndrome, Crohn's disease, musculoskeletal pain, rheumatoid arthritis, chronic pancreatitis, and cancer pain.
- Cannabinoid use in pain management and palliative medicine may cause relevant central nervous system (e.g. dizziness) and psychiatric adverse events (e.g. confusion, psychosis).

Maureen Anderson

CNS Rheumatology – Greymouth

Maureen spoke to us about the phycological impact of Scleroderma. We could all relate to what she was saying and it does make one feel better knowing that most other people feel exactly the same us we do. She shared a story from Sam and Karlin. As told by Sam who was diagnosed with Scleroderma and Kahlid her partner…..

Hi my name is Sam. Maureen asked me if I would like to share my story about scleroderma. I said OK.

So here goes. I am 30 years old and have had scleroderma for longer than I have been diagnosed with it. Sounds weird but that's because it took a while to diagnose. It also took a while for the symptoms to show up.

I remember the first time I heard the term scleroderma. I couldn't pronounce it for ages after I first heard it but eventually got my tongue around it. My friends and family still struggle with it.

I had Raynaud's for years but wasn't really sure what it was called. I can remember as a teenager in winter or when it was cold having white and purple fingers. It was a great party trick to put my hands in ice and once they had changed colour scare everyone with them. I stopped doing that pretty quick as my fingers became quite painful when cold.

I remember wee sores on the tips of fingers that had white lumps or squashy white stuff under the skin. If it was hard I would pick at it to remove the lumps.

It was diagnosed in 2015 when I was 26. It was late autumn and the leaves on the trees were changing colour. So pretty.

I remember sitting with the rheumatologist looking out the window thinking I wish I was a tree. So strong and stable and can bend to suit any situation the wind threw at it.

Dr Brown was a lovely doctor who seemed to genuinely care about her patients. I remember feeling embarrassed as I cried during the appointment. For goodness sake I was a lawyer used to standing up in court and facing the most horrible perpetrators and yet when it came to my health or personal stuff I was reduced to a snivelling wreck. The words swarm around in my head as I tried to make sense of what I had heard. Words like collagen, hardened skin, digital ulcers, no cure, symptom treatment. I couldn't think. Everything was muddled. I thought collagen was great to get rid of wrinkles. I remember pinching my hand and feeling the skin that had changed.

I was so surprised and shocked by the diagnosis. I had no idea what to expect or what it all meant. What was I going to say to Kahlid, my family, and friends? I didn't want sympathy or pity. I wanted to ignore it but finally I knew I couldn't any longer. I had noticed changes over the last 18 months but they were subtle. I had no idea what the changes meant or potentially how serious they were. I brushed them aside. I was too busy. I didn't have time. Deep down part of me was wondering what was happening. I had tried to run a half marathon but it was too much for me. I had collapsed breathless with only 5kms to go. I had been so angry with myself for not finishing the race. I had trained so hard but now that I thought about it I didn't think I was finding it any easier to run. It actually took more effort.

QUESTIONS:

1. *What was Sam feeling regarding her diagnosis?*
   :Disbelief
   :Sadness
   :short changed
   :Uncertainty, unprepared – wasn't sure what the future held, how the disease would affect her, jobs worries, financial worries
   :Embarrassed - tears
   :disappointed- future stolen
   :Confused, muddled, forgetful, fearful, anxiety,
   :Unable to retain information or to think – "She couldn't think. Everything was muddled"
   :Bargaining, too busy – "She brushed them aside. She was too busy. She didn't have time"
   :Realisation, frustration – "Deep down part of her was wondering what was happening. She had trained so hard but now that she thought about it she didn't think she was finding it any easier to run. It actually took more effort."
   :Depressed- "She felt down, hacked off, fed up".

The above feelings can lead to depression

PART TWO

Hi my name is Kahlid. I'm Sam's partner. Sam badgered me into writing this wee bit about what it feels like for the family or partner of the person who has scleroderma. I remember feeling frustrated. Sam had been so moody since seeing the doctor. She hadn't said much about it. I had tried to press her but she had closed me down. She had said something about hard skin and too much collagen. I couldn't remember the term she had called it. I talked to Rose, Sam's mum. She said Sam is struggling with this and wants to deal with it in her own time. That we have to be patient. I wanted help but Sam is very independent. She's still out to prove she can conquer everything on her own terms and without help.

I was worried about our relationship. We hadn't seen a lot of each other recently. Sam was always working, some nights when I phoned her she was still at work at 9pm. She couldn't keep doing that. I thought she's going to crash again like she did during the half marathon.

In my culture our women aren't use to being so independent or strong minded. I knew Sam wouldn't stand being bossed around or mollycoddled. She didn't want to be treated as an invalid. I wanted to help but didn't know how. I felt like I had not protected her, had failed her. I know that sounds dumb but that's the way I felt. I could see Sam hurting and struggling to come to terms with this condition and felt helpless.

I had a good talk with Rose. She told me how to say things, like using 'I feel' or 'I think' sentences. Not you make me feel …phrases. I had to admit that I was struggling. I decided to take Sam out for a nice meal and have a chat.

QUESTIONS:

1. *What was Kahlid feeling?*
   :Frustrated
   :Helpless, excluded
2. *What did Kahlid do to help him understand Sam?*
   :Spoke with her mother
   :Took action, made a plan to talk to Sam

PART THREE

It took time for me to process everything. I got a bit down, a bit depressed. I didn't need antidepressants but did need time and someone to talk it through with. I had so many questions and that's where my nurse was really helpful. She was able to spend the time talking about what was bothering me and what I needed to know. I mean what was life going to be like? What is the best outcome with scleroderma? What was the worse outcome? As a lawyer I like to know all the questions and answers and not have any nasty surprises turn up. It's not the look you are after when defending clients in court. In my personal life it was the same. I had to think things through. What did the future hold? Could I have children? It was something I always thought I would eventually do when I was ready not when my body dictated or my health. Now I had to think about treatment options like methotrexate, cyclophosphamide and other nasty drugs. Some of these drugs made you infertile, some had nasty side effects or harmed the baby. There were also so many tests to have and what did they all mean and how often was I supposed to have them?

As you can see I had a lot to think about and forgot to include Kahlid. It took me about two months maybe longer to get to the stage I could talk about it. Kahlid although frustrated was patient. We did talk. Or rather I did and he listened. It was helpful. Kahlid isn't a Dr Google fan but had done a bit of digging and was rather concerned about what he had read. So we talked about that too. I'm not good about talking about myself or my feelings. I'm use to listening to clients poor out their problems so this process took me quite some time to adjust to. I still struggle with it. It doesn't come naturally to me to talk about what I'm thinking or feeling. I have positive phrases and sayings all over the house so that if I'm feeling down or struggling I can look at these and feel better. They get changed each month. I have a box of them given to me by a thoughtful friend.

My body image was taking a battering. I didn't feel attractive. I felt very conscious about the red spots on my face and even my fingers. I knew my mouth had changed and my skin felt tight. I didn't like looking in the mirror. I had taken to applying makeup especially foundation and a concealer to hide the spots. I eventually talked to Kahlid about it and he said it was just me and how I looked. He didn't see all those details like he did when he first meet me. I thought about it and it's true. The first time you meet someone you notice lots of things but after the first couple of meetings you just accept the person as they are and don't notice the changes to the same extent.

I was worried about my relationship with Kahlid. We had been a couple for two years but I was worried he wouldn't want to stick around a sick woman with an uncertain and unknown future. I really worried about that but I needn't have. About five months after that talk Kahlid proposed to me and we have now been married for 4 years. I was worried about having children also but once the disease settled down and my health was stable we were given the all clear. I had harvested some eggs prior to starting treatment in case I became infertile. We tired for eighteen months had no success. So we used IVF and now have an eight month baby boy.

KAHLID

I too struggled with Sam's independence. I had to not take over. When Sam became pregnant I wanted to wrap her up in cotton wool. It was a real test of our relationship. I had to learn to trust Sam not to over-do it. At the same time I wanted to offer help but not in the way of making Sam like pitied or dependent. I got used to waiting for Sam to ask me to help. We had decided that worked best for us. It doesn't for everyone but did for us. We got there in the end. Talking and keeping the communication lines open. I think it was hard for Sam to let go and let me do more e.g. house hold chores, meals, grocery shopping. Now I think she revels in it, not having to cook and clean so much. Seriously though, it hasn't been easy. We are lucky as we have supportive family and friends and have had to learn to ask for help. It actually makes

them feel valued and helpful which is great. We have a very supportive church we go to which helps also.

I also felt a bit short changed with our future. I thought we would do anything we wanted whenever we wanted. I felt bitter for a while and self-pity but soon got over that when I saw what Sam was going through. She didn't go into details with her health but ended up twice in hospital with cardiac effusions. It really knocked the stuffing out of her. It was a wakeup call for me. I'm just grateful I live in the 21st century with so much modern technology and medicine. I know doctors don't have the cure or all the answers but it's better than what it was.

QUESTIONS:

Sam and Kahlid lives have changed. They realised that life would be different for both of them. Adjustments would need to be made. Being diagnosed with a rare, incurable illness is a life-changing event. This life-changing event is unwanted and isn't voluntary. Living with uncertainty and change takes time to adjust. Continual adjustment now becomes part of life.

How has your diagnosis changed or impacted on your life and that of your partner?

e.g. Do you hesitate to make plans? Do you feel you impose or rely on people too much? Does this make you feel like saying no to outings?

For partners how have you adjusted to the diagnosis of your loved one being diagnosed with a long term condition? What changes have you made?

Has this brought you closer together or has the stress of it been a challenge that has been hard to bear? How did you help each other? What were the things you did or said that made a difference to you as a couple? What were the things you did or said that made a difference to coping with the changes?

How can Sam and Kahlid help each other?

1. By talking about what they are feeling, the good, the bad and the ugly. The positive and negative feelings. Life is unfair. How is this going to impact on their relationship, having children, careers, goals and dreams? What are the cultural implications?
2. Try to find a balance between being helpful and taking over. Watch out for pity, passivity.
3. Talk to each other and listen also. Change isn't easy but keeping the communication lines open is imperative.

Southland Group couldn't miss the opportunity to have a photo with Maureen who started our group and brought us all together.

Southland Group with Maureen Anderson

Graeme Milligan, Jenny Andrews, Kimberley Small, Lynette Graham, Maureen, Glenys Findlay, Heather Milligan and Ian Findlay.

CHRISTCHURCH SCLERODERMA SEMINAR 2019

Professer Lutz Beckett

Respiratory Physician/Sleep Physician
Head of Department

Breathing is easy – you breathe in, you breathe out, and blood goes round and round.

Professor Beckett had a relaxed and jovial approach to sharing information with us. Pacing the room, he learned our names, enquired where we were from and explored what we wished to know about. It was lovely to hear from everyone. He focused on what we wanting to hear about rather than bamboozling us with lots of info.

One of his mantras are, that breathing is easy.
You breathe in, you breathe out, and blood goes around and round.
This led to explaining the role of lung functions. There are some illness where you can't breathe in well. Lung fibrosis of course, which can be part of scleroderma in some patients, or muscle weakness or injury can all prevent you from breathing in. The vital capacity measurement "breathe all the way out until you have no more air in the lung", is used to monitor any effect of lung fibrosis. This test is often done about once a year.
Some patients can breathe in and have problems breathing out. This classical illness is asthma. The same happens in patients with smoking related lung disease (emphysema) or also in patients with bronchiectasis. It is not normally a problem in patients with scleroderma, it is a big problem in New Zealand on the whole, about 10% of people suffer asthma.
Some patients can breathe in, and can breathe out, however the blood can't take up the oxygen. That can happen with blood clots (pulmonary emboli) or in pulmonary hypertension, where the small blood vessels in the lungs are affected and disappear. These patients often take a while to diagnose as they have a normal chest radiograph, normal lung functions and are still short of breath. The test is the specialist test which is performed in the 'body box'. Take a deep breath in, hold, hold, hold, and breathe all the way out. You need to travel to a big centre for this diffusing capacity test.

Everyone has slightly different lung functions test, in the same way as everyone is a different height. To work out if somebody is 'too short' or 'too tall' one can compare the height to the 'normal range'. The normal range can be quite large. A more powerful way to detect changes in the lung functions is to compare to the patient's own data. This will pick up lung problems much faster, hence the frequent (yearly) lung function tests.

Exercise is really important; more people get better with exercise than with any other medications. With 100 people exercising, 80 % will have an improved quality of life. There will be less hospital admissions and better resilience. What I found interesting was that with exercising it wasn't my lungs that are getting fitter. The heart is getting fitter and the oxygen in my muscles are working more efficiently. As you get fitter your muscles need less oxygen.

Patients with scleroderma could become short of breath because of:

1. Lack of fitness

2. Stiff lungs (Interstitial lung disease, scarring of the lungs)

3. PAH, which means the blood vessels in the lungs disappear, less oxygen going through the lungs so the heart has to work harder to put it through the body.

Not everyone will progress to develop lung problems. About 15% of patients develop lung scaring and about 20% of patients develop pulmonary hypertension, often after living with scleroderma for 20 or more years. Most patients with scleroderma life a long and productive life.

Lutz was asked when we take our shortness of breath seriously enough that we should be calling an ambulance. When is your shortness of breath serious enough to be heading to the hospital? It's all about "your normal". An acute change could mean a minor illness such as an infection but for scleroderma patients could cause a major problem. Be aware of your own body and what is changing.

The current treatments for lung disease can improve survival rates by slowing the progression down, these do have a lot of side effects though. Should your lung disease progress fast, have a discussion with your specialist about the trade off in quality of life because of side effects and possible improved survival a decade down the track.

"If old age is catching up, then walk a bit faster"

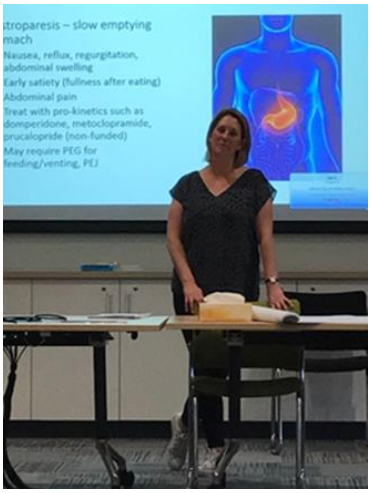
CHRISTCHURCH SCLERODERMA SEMINAR 2019

Fantastic Bunch, thank you for supporting Christchurch

CHRISTCHURCH SCLERODERMA SEMINAR 2019

Gastrointestinal (GI) Problems and diet for Scleroderma Patients

Kirsten Rosser
IBD Clinical Nurse Specialist

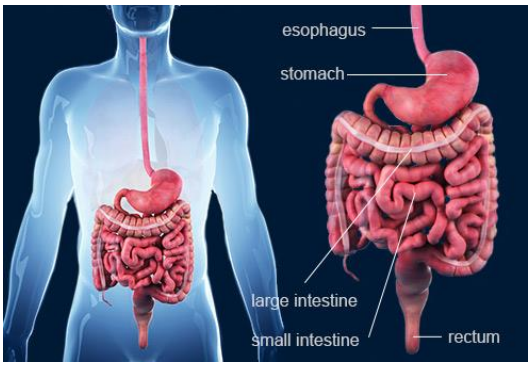


Dr Malcolm Arnold
Gastroenterologist

After lunch we were lucky enough to hear from Kirsten Rosser, IBD Clinical Nurse Specialist and Dr Malcolm Arnold Gastroenterologist. Kirsten kindly invited Dr Arnold along. With his lovely Scottish Accent and humor, he kept us captivated.

The GI tract and Scleroderma

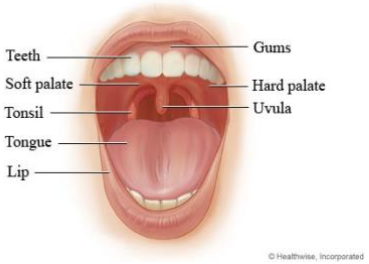
-The GI tract is the most common of the non-skin organs to be affected by scleroderma.
-Approximately 90% of people have GI involvement
-Of these up to half have no symptioms of the GI Problem
-Can lead to malnutrition and greatly impact on quality of life



GI Problems in the mouth

-Microstomia—decrease in mouth aperture
-Microcheilia—decrease in mouth width
-Can affect speech and chewing
-Xerostomia—dry mouth

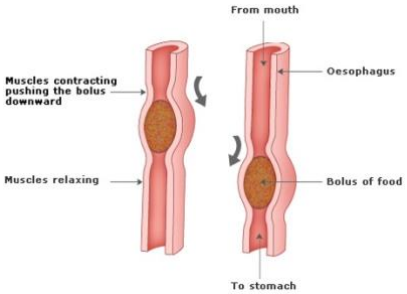
- Can lead to an increase in dental caries and cavities



GI Problems in the oesophagus

-Odynophagia (painful swallowing)

-Dysphagia (difficulty swallowing)



-Dysmotility (muscles not moving as they should)

-Pill-oesophagitis

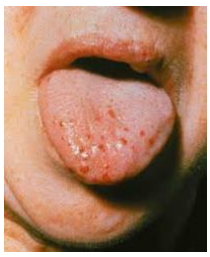
- Gastroesophageal reflux (GORD)
    - Cough, pharyngitis (throat inflammation), Ulceration/oesophagitis
- Treated with:
    - Lifestyle changes
    - Antacids e.g. Gaviscon, Mylanta, Quickeze
    - PPI's e.g. Omeprazole (Losec), lansoprazole, pantoprazole

If your oesophagus is working normally you would be able to stand on your head and drink water and it would go up.

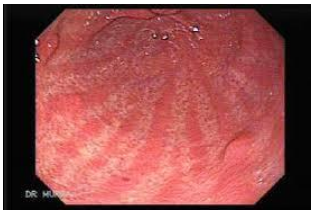
GI Problems in the stomach

Gastroparesis—slow emptying stomach

- Nausea, reflux, regurgitation, abdominal swelling
- Early satiety (fullness after eating)
- Abdominal pain
- Treat with pro-kinetics such as domperidone, metoclopramide, prucalopride (non-funded)
- May require PEG for feeding/venting, PEJ
- Telangiectasia—similar to those seen on the skin, lips and tongue

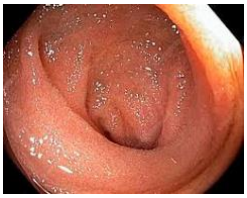


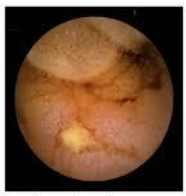
- NSAID-related damage
- GAVE (5% affected)
    - May bleed overtly or subtly



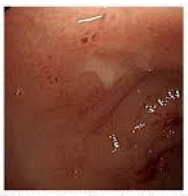
GI Problems in the small Bowel/intestine

- Telangiectasia
- Diverticulae (pockets)
    - May become colonized by bacteria resulting in SIBO (small intestinal bacterial overgrowth) resulting in diarrhea, malabsorption, vitamin deficiency, anemia
- CIPO (chronic intestinal pseudo-obstruction) – pain, vomiting, distension
- NSAID enteropathy
- Strictures, narrowing





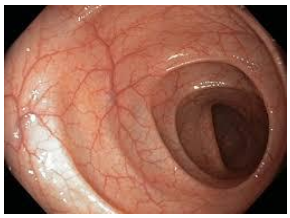
Capsule endoscopy



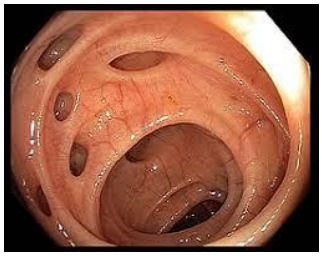
Colonoscopy (terminal ileum)

GI Problems of the colon/large intestine

- Telangiectasia (may bleed)
- Diverticulae (pockets)
    - May become infected or perforate (puncture), diarrhea, constipation, pain



- CIPO (chronic intestinal pseudo-obstruction)—pain, abdominal distension
- Tenesmus (feeling of incomplete evacuation)



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Dietary considerations with scleroderma

- Balanced, nutritious diet
- Hydration, lubrication
- Soft diet, occasional low residue diet may be required
- Vitamin supplements if malabsorbing (regular blood tests)
- Supplements (Ensure, Fortisip etc.)

Maintaining Hand Function in Scleroderma

Helen Hills

Hand Therapist/Physiotherapist CDHB

We had a bit of a discussion about different things people do for their hands.

Coban adhesive tape is great to cover your PIP joints and other sore bits to protect them. Someone in the room talked about using nutrigena foot cream on their hands (but not on open wounds), also Paw paw cream is fantastic for sore hands. If you have ulcers on your fingertips/nailbed you should see your doctor.

Scleroderma

- **Scleroderma**-literally means hard skin
- **Rare**, **chronic**, often **progressive auto immune** disease-affects women 3-4 times more than men. Affects one in a thousand new Zealanders
- **Connective tissue** of the body (holds muscles , joints, organs, blood vessels together) makes **too much collagen**-causing **hardening and tightening** of the affected area
- **Two main types**:
  1. **localised-affects** mainly skin and sometimes tissues under the skin e.g. muscle
  2. **Systemic**-also affects organs
     (a) limited scleroderma-skin involvement mainly limited to the hands lower chance of internal organ involvement
     (b) diffuse scleroderma-skin of whole body affected and internal organs often affected

Hand Involvement in Scleroderma

- First Symptoms-swelling and tightness. Often Raynaud's. Sometimes polyarthritis and general malaise, joint pain and fatigue
- Swelling subsides, skin becomes tight, dry, coarse and itchy
- 3-5 years later the skin may become softer but still loss of oil and sweat glands and hair follicles.
- Increased risk of developing ulcers on the fingers
- Increasing stiffness and loss of movement in the hand and wrist
- Carpal tunnel syndrome is common-tingling, numbness in hands
- Calcinosis-calcium salts(like a small chalky stone) accumulate under the skin

Raynaud's

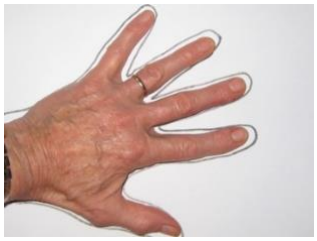
Episodic constriction of the blood vessels causing lack of blood supply to the fingers-fingers go completely white/blue, aggravated by cold and stress.

Tips to manage Raynaud's

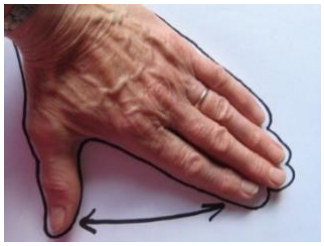
- Don't smoke
- Outside- wear hat gloves, scarf. Inside- wear fingerless gloves.
- Use electric blanket.
- Dress for warmth-use layers, keeping the trunk warm helps arms and legs keep warm.
- Warm hands in warm water (wear gloves to prevent drying effect of water) before going out. Can do this several times a day.
- Eat modest meals. (large meals divert circulation away from the hands and feet).
- Steering wheel cover may help.
- Pre warm car if travelling. Heated car seat
- If possible have car in internal garage.
- Take wheat bag with you on lap and warm hands at the lights.
- Re-chargeable hand warmers, or pocket hand warmers from camping shops -keep in pocket or hand bag-stays warm 3 hour.
- Avoid handling frozen food or shopping at night in winter.
- Use wide cloth handled bags for groceries.
- Avoid sitting for too long.

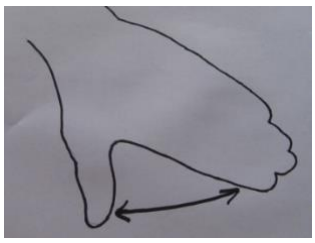
Monitoring Range of Motion in your hands

Draw around your hand to record finger span



Record thumb span



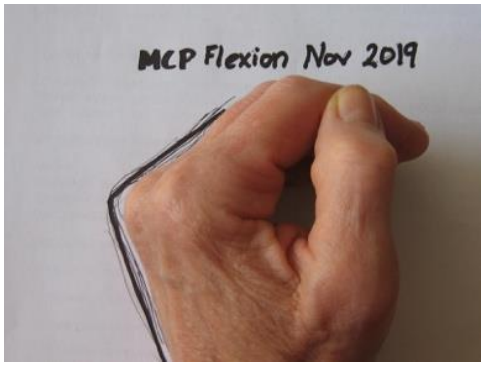


Record finger closure- pulp of fingertip to palm

Place card at palmar crease and draw where fingers can close to

Record MCP (knuckle) flexion

Draw around knuckles



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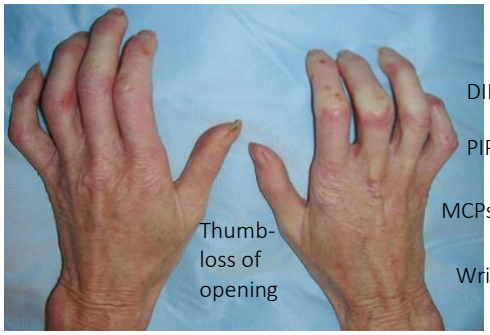
Maintaining Hand Function in Scleroderma

Helen Hills continued…

Hand Therapist/Physiotherapist CDHB

Stretches to maintain Range of motion

- To prevent or slow down the development of contractures
- Do often and maintain position of stretch 5-10 seconds
- Begin early in the disease process



Thumb around container. Stretch web space of thumb

Stretch fingers straight

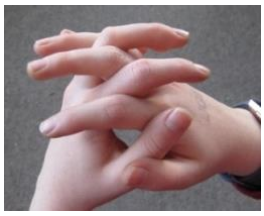
Hand and wrist stretches

Stretch fingers together
Stretch wrists back

Stretch fingers down to palm

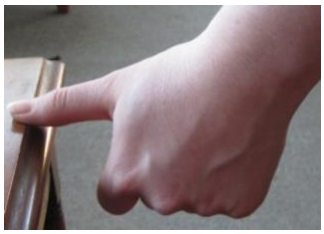
Hand Stretches

Stretch MCPs down into flexion



Interlace fingers

Stretch fingers straight



Stretch fingers down to palm

Splinting at night

-aim to hold fingers and thumb at tolerable end range

Maintaining Hand Function in Scleroderma

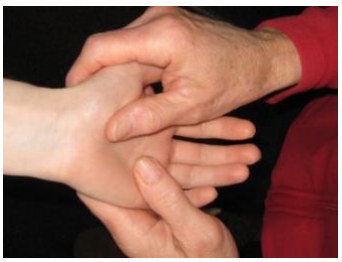
Helen Hills

Hand Therapist/Physiotherapist CDHB..

continued…

Ways to help manage hand pain

Heat- wheatbag



Massage
with moisturizer

Paraffin wax- 3 layers-wrap in plastic bag then woolly bag, don't do if any open wounds

Reproduce wax effect at home-baby oil on hands, gloves-into hot water

Preventing protecting from ulcers

- Gloves,
- moisturize skin regularly
- Recommended by person with scleroderma:
- -lanolin cream at night to keep skin supple
- -viscopaste dressing or sudocreme to dress ulcers
- If infection-seek medical advice
- Coban tape over PIP joints
- Sticking plasters
- Thimbles
- Splints

Assistive Devices for Daily living

Jug Tipper.

Tap Turner

Button Puller

Enlarge handles of utensils with rubber tubing

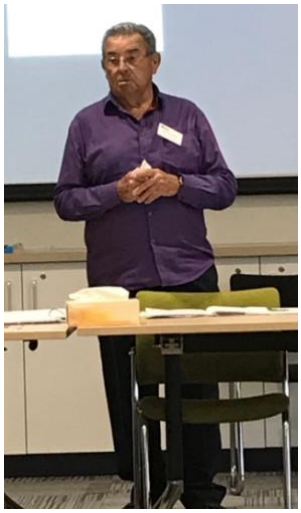
Also:

- Electric Toothbrush
- Electric Can Opener
- Shoe Horn
- Elastic laces

CHRISTCHURCH SCLERODERMA SEMINAR 2019

Living with Pulmonary Arterial Hypertension (PAH) and Patient Advocacy

Allan Edmondson



Lastly, we were lucky enough to hear from Allan Edmondson

- Memory Stick

Back in 2013, I developed an idea to carry our health and other specific data with us on a Memory Stick BUT How should I develop the various Folders? After many trials and discussions with people in similar positions and Health Personel - we arrived at the following as a starter.

- Advance Care Plan
- Ambulance
- Blood Type
- Drivers Licence - Don't forget renewals
- Doctor – GP – Specialist
- Earthquake Plan
- Hospital Discharge Summary Listing
- Fire Evacuation Plan
- ICE Contact – (In Case of Emergency)
- Insurance
- Marriage Certificate
- Medical Certificates
- Medical Equipment
- Medical History***
- Medication / Pharmacy You are dealing with***
- National Health Index (NHI) You Hospital Number
- Passport – Don't forget Renewals
- Personal Details (Address Telephone Numbers etc)
- Tax File Numbers
- Develop the habit of using a DIARY DAILY (A5 Page size is sufficient)
    - Record your Blood Pressure daily along with Oxygen Level – Doctors Appointments, Better Breathing Classes, Next Support Group Meeting Birthdays etc
- In the back of the Diary, paste a few loose pages and record on a page date time of when something DIFFERENT happened to you (your body) and the next time you have an appointment with your GP – take your diary and refer to these page/s and relay the information you have gathered since the last time you have visited the GP.
- SO OFTEN, you have just come out of the Clinic and you say DAM – I forget to mention this or that which I was going to ask the GP for some advice on. That is going to cost you another appointment.
- This loaded Memory Stick has been a "Life Saver" on a number of occasions. Particularly when we were overseas twice.

Some other GENERAL items to take into consideration

- Don't be patronising to your Patients or somebody else's patient/Caregiver. That's of no help whatsoever.
- Please ***DON'T STRESS*** – Stress is a shocker and can cause so much damage to your body. PLEASE – just talk to someone
- Caregivers - Learn to walk in the shoes of your patient. Just consider their situation and forecast (if you can) what is required.
- Seek out a Local Support Group and attend as often as you can. They are so helpful and understanding. Plus a great reliever of stress and loneliness. A concern shared is 50% reduced for you.
- Purchase your own Blood Pressure machine and take it daily – a record in your diary. This will be just a general guide on how your body is reacting to your medication.
- Purchase Pulse/Oxygen meter – Take daily – a record in your Diary

Living with Pulmonary Arterial Hypertension (PAH) and Patient Advocacy

Allan Edmondson

- Generate a telephone/email buddy and when you feel a little down make contact and/or arrange to meet for coffee somewhere. ***You WILL have UP & DOWN days and normal days***. That is only natural.
- ***Don't get angry*** - That will only bring on UNWANTED Stress and chew up your Oxygen/energy levels
- Get help from those within the Support Group (listen to what they have to say). They have been living with this for some time and have found out how to tackle various inconsistencies over time. Some discussions may be of great help to you and then again maybe not. ***You take in what you want to know.***
- Don't just sink into your favourite lounge chair and become inactive and go into a dark place in your mind – that will not help
- Ask your GP about these:
  - Green Prescription
  - Standford Self Management Education program (SME)
  - Exercise classes (Designed for the older folk)
  - Home Exercise routine sheets
  - Better Breathing Classes
  - Maintenance Classes following the normal Better Breathing SIX week course x 90 minutes
  - Home Help – There are so many different groups that are available. – JUST ASK your GP!
  - NEVER have a consultation with a GP, Specialist etc by yourself. If by chance they tell you some news that is not really good news, it is only natural, your listening system will shut down or turn OFF. The Doctor may carry on talking more about the treatment of that bad news BUT – You're not listening and that's when a family member or a friend comes in who will repeat whatever the Doctor had to say, some time later when you have settled down somewhat.
- When you are holding discussions with your GP and He/She replies in jargon you fail to understand – Ask to explain what he/she is talking about in plain English. Doctors and Nurses sometimes forget just who they are addressing.
- If invited to perform a 6-minute walk (6MW) don't try to prove to the attending Nurse just how GOOD and how FAR you can walk in your FIRST 6 minute Walk, **WHY? Because you will be measured against that distance for every 6MW thereafter.
- Take your medication as prescribed by your Doctor/Specialist/Chemist. If you don't there is a chance you could be OVER or UNDER medicated and your Doctor will treat you accordingly on your next visit.
- Develop a very strong working relationship with your Doctor / Chemist. This is a must as you cannot afford/luxury of running out of medication, particularly Special Authority medication. Planning is required and I would suggest you use the "Blister Packs" They are brilliant, easy to use and you know where you are if you have the dates on your Blister Pack meds accordingly. This will enable your med taking planning day by day so much easier. Speak to your Pharmacist as he can organise the dates to be inserted on your blister packs if you let him know what date to commence with etc.
- Tear off the 'tops' of these blister packs and keep the 'latest' sheet in your handbag or purse (SORRY Fellas) as you will always be asked by various medical departments "What Meds are you on?" then you produce this top tag of your blister pack. Mind you - you may have some individual meds which you will have to have with you and be smart enough to remember what they are and for what reason you need them, I write on mine so as to remember! For me – It is all Okay,
- That raises another very important item. DO YOU REALLY KNOW WHAT YOUR MEDS ARE FOR? If you don't know – I would suggest the next time you see your GP ask the question and ensure you get the answer. It is critical to know what you are taking your meds for.

Living with Pulmonary Arterial Hypertension (PAH) and

Patient Advocacy

Allan Edmondson

- Request a copy of your 6MW test results, Respiratory results and enrol within your GP's Clinic for the ***E Share Care Plan*** –allowing you to sight your GP's notes of your Health Condition and latest Medication Listing.
- Generate a 'HABIT' with taking your medication. With the word 'Habit' I really mean, try to generate a time habit. I refer to my medication as my second breakfast or second dinner etc. So, between my porridge and my 1st cup, of tea - I line up and take my breakfast meds and after I've had my cuppa, I take my blood pressure and record it in my Diary. That is PART 1 of a 4 part medication day for me. You could say 'I rattle when I walk'
- **Develop an Advanced Care Plan (APC)** which will give you priority with Ambulance, Hospital and after-hours consultations at the emergency section at your local DHB. Invite your children to be part of producing it.
- **Develop a Fire Safety Evacuation plan.** Discuss this with your family, neighbours each side of your property and also across the road from you.
- **Develop an Earthquake Evacuation Plan.** Your Local Council will have documentation available on this. Particularly, ways, means of communicating and 'Safe Place' to you, your family, friends and neighbours. Watch out for each other and get to know this plan.
- **Additionally, when capable – take this to the next step. By this, I'm meaning – PLAN your END TIME - Yes your Funeral**. This is essential because you may have mentioned it in passing conversations – LIKE - when I go, I want this and that to happen to me. Your partner, children, relatives, and friends WILL BE INCOMPLETE SHOCK OF YOUR PASSING they will not be thinking straight and everybody will come up with different suggestions and processes etc. This unplanned timing of your life/passing etc can develop into a big Family break up. I have known some families, who have split for years and I know that is not what you would want for your family. True or False. Think about it!
- It is your duty to develop a PLAN with your selecting/nominating an Administrator/Executor) (this in itself is a huge question of WHO will administer THIS process for me?) Really think this out - as your partner/closet friends/family etc would not be in any condition to facilitate such a process as these people have just lost you. Whoever you select will follow this and other processes as you would like and have written prior to your demise. He or she should also become the Administrator of your Last Will and Testament commencing immediately following your demise thereby elevating any confusion and or family stress / arguments. Let me add – Family arguments do happen more often than you may think. Consideration is required well beforehand.

- **If you are on Oxygen Therapy and planning an Interstate or overseas flights.** Begin the administration exercise some 10 to 12 weeks prior to your intending departure date. If you have your own Oxygen machine, be sure it is aircraft approved. By that I mean – look on the specification panel, if there is a little aeroplane picture there, it will be approved for in-cabin flight use BUT always ask the question from you Supplier – ***Is my Oxygen machine approved for flying?.*** Contact the Aircraft Company you are planning to use and request from their Medical Department, Documentation which YOU have to have completed by the Specialist and the GP plus your flight details for submission back to them for their approval. This can take some time to be finalised – You have been warned! ALSO, when you are flying at 30,000 feet, your machine will not be as efficient as it is at ground level. PLUS, you will be required to carry additional batteries that will equal 50% more flying time than planned on your itinerary. Some aircraft companies' require 100% additional to planned flying time.

Living with Pulmonary Arterial Hypertension (PAH) and Patient Advocacy

Allan Edmondson

- *ALWAYS carry a copy of your oxygen prescription.* We had a case where our Portable Oxygen Concentrator was wrecked by a Customs X-Ray machine and we were on a boat cruise, 3 days into a 10 day Alaskan Inner Passage Cruise when this happened. Fortunately, the medical department of that cruise ship had an electric Concentrator and as I was about to wheel it out of their Clinic when the Doctor demanded to view the Patients Oxygen Prescription. Fortunately, I carried all our Medical Details on a Memory Stick, the Clinic printed a copy of the Oxygen Prescription and I was permitted to wheel the concentrator to my wife. That was all OK but it killed any excursion trips from the ship PLUS I had to somehow organise another Portable Oxygen Concentrator for when we arrived back at San Francisco, to fly to Los Angeles then to NZ. The ship gave me free ship to shore telephone service where I made contact with a company I noticed at the Pulmonary Hypertension America Conference we had just attended and he agreed to meet us a Los Angeles International Airport on the Sunday of the American Independence long weekend where we could exchange money for a brand new Oxygen Concentrator with several additional charged batteries plus the compulsory demonstration etc within the airport lounge. That Sunday sales trip to the airport cost me additional $200 American. Again, if I did not produce the Doctors Oxygen Prescription I would not have received the machine. I now have 2 portable Oxygen Concentrators as the first one was replaced under warranty on arrival back in NZ. That is $16,000 in capital cost (in 2014) when you can only use one at any one time.

Oxygen Thief:

- If you have an open fire in your home and a person on Oxygen Therapy who feels the cold like most of you do, you may have to consider doing away with the open fireplace and installing an electric Air Conditioner as the open fireplace could be robbing the majority of the oxygen from within the house. That does not help your patient.

Do you feel the COLD from the inside out??

- Most Scleroderma patients do so and they dress for the condition BEFORE you turn cold from the inside out (further explanation required here) Once you feel the cold on the outside of your body, YOUR INNER ORGANS are now working under full load and stress. It will take considerable time to generate heat back into your body to allow your internal organs to settle down to function as they should, BUT it will take quite some time.

Some helpful hints to maintain heat within your body

- Bedtime Gear: Artic Flannel sheets are THE MOST WONDERFUL SHEETS you could use. We use them throughout the year. One of the main reasons for that is >>>> when you first enter the cotton bedsheets, a cold shock hits your body thereby abruptly waking your body. It is totally different when you do the same exercise with Arctic Flannel Sheets – NO SHOCK at all. They are aways lovely and warm – SO easy to glide off to sleep and sleep the whole night through. In winter, you could find them NOT SO EASY to get out of, they are so cuddly. Sometimes available for $30 at the warehouse for a Double set of sheets, one fitted and one flat sheet, plus two pillow slips with Arctic flannel on one side and Cotton on the reverse side. What else could you ask for eh! Easy to wash and very quick drying

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Allan Edmondson

- **Goldair Electric Micro Fleece Throw:** Use the Electric Throw for your lounge chair. They are in size 120cm X 160cm, with 9 heat settings, Detachable Controller and a 6 hour Timer Function. I use mine on my lounge chair and I cannot have it above No 3 level. A couple of years ago, they were retailing for $180 but I purchased mine online from Mitre 10 for $70. They could be even cheaper today. For people who feel the cold, I would suggest you have a look at one of these items. I had better add this: - These Micro Fleece Throws automatically power down and switch off after one hour if you have not programmed it for longer.
- **There are even smaller Electric Throws;** something like 200M\L X 250M/L. This will give you the top half of your chest wonderful heat treatment, or you could wrap it around your arm in readiness to give blood. These can sit on your tummy or your chest while watching TV as you lay back on your recliner chair. Some people prefer these smaller Electric Throws with ease of handling. These Micro Fleece items replace what we use to call BLANKETS. Blankets were good but you needed several to generate warmth. With Micro Fleece 'throws' they are so light but OH So Warm!
- **Hanging up your wet clothes from the washing basket.** Use those metal "A" frames (Airers - I think they are referred to) available from any Hardware store. Lift your basket of wet clothes onto a chair so you are only lifting from your waist height to your underarm height of the metal frame for pegging. To use the normal clothesline is costing far too much energy consumption (Body Oxygen) as you are raising your arm above your shoulders and exhausting huge amounts of body oxygen/energy each time you lift an item. Next time when you are doing this - just count the times you do - do it and listen to your body trying to regain and recover spent energy during the process.
- **Stanford Self Management Education. (SME)** If you are given the opportunity by your GP to enrol in an SME class – grab it with both hands. This is a Stanford University production. It is a course where you are given the tools and instructions of how to use them to develop a Healthier YOU over a 6 weeks (one day (2.5Hrs) @ week) duration. I have personally received copies of letters written by attendees who have gained so much from this particular course.
- **If you have Independent Living Service** or similar business within your area– Give them a call and invite them to come along to your next Support Group Meeting (Say early next year) to give a talk and demo of some of their products. You will be surprised just what they have for the elderly, disabled and those with afflictions during a healing process::::::

Just a couple of other items to consider:

Personal Overnight Bag always at the ready. You never know when an Ambulance may be called to ship you off to the hospital.

Some of the contents to be in the Emergency Bag:

Many times I have called an ambulance and this has taught me to be prepared as I may be held in hospital overnight or two.

- Medication: – Medication Listing with your comments
- Toiletry Bag: - toothbrush, toothpaste, hairbrush, comb, face cloth, small container of your favourite face/body moisturiser, Razer and lead
- Extra Underwear: – PJ's – Nightwear – Nightgown – Slippers – non-slip socks. Gloves. Be selective in the type of nightgown you pack into your bag. Plus, Casual clothing for going home.
- Personal Items: - Mobile Phone & Charger plug, Sanitary Pads, Reading Book, Puzzle Book and pen, Address book. Don't forget your pen!
- For Diabetics: - Your special lollies and specific medication as prescribed.

Living with Pulmonary Arterial Hypertension (PAH) and

Patient Advocacy

Allan Edmondson

- DO NOT TAKE - Jewellery. Cash, Devices
- DO TAKE (if medically required and prescribed): - Portable CPAP machine or any other specialised equipment as prescribed by your GP or DHB. Headphones, earphone jacks and the suchlike's if you want to listen to your radio station or play your mobile if permitted by the Hospital and which does not disturb your fellow patients. Consideration is required. Your fellow patient may not have the same interest in your type music or the output of some 'Facebook' productions etc.
- If you are a person who feels the cold: Also take a zip-up Polo Fleece type jacket and gloves to keep your top half warm during your stay in hospital.

Websites:

You can spend hours skimming through various websites and you can find a ton of information on them. The best way I can describe this to you – ***it is just Window Shopping:*** Have something in your mind prior (A specific item of reference) to open the computer for.

Support Group Meetings/Seminars:

You will take more away for a specific meeting/seminar like this one today. Your brain can only absorb so much BUT if you walk away today with that one thing stuck in your mind then your attendance today has achieved another item that will satisfy your enquiring mind and will help you overcome a particular obstacle. We hope we have been of help.

Please bear in mind – We (that's us) are training the Doctors and Nurses of our Illness, so the more info you can give them, the better. Your words could be the answer to opening a mystery door helping others looking for answers etc and so on.

If you would like a list of relevant websites – just email me on alsand327a@gmail.com and I will email them back to you.

Okay, How about you put some questions to me? I will try to answer them but bear in mind I'm NOT A DOCTOR

I have lived as a patient advocate/Carer since 2008. I will listen to whatever life-preserving skill set you can offer as our learning never stops.

You can also visit my website ***www.nzpah.org.nz*** for some valuable Patients Stories which have been so helpful to many others on their journey, according to the verbal feedback I've received. Why don't YOU produce Your Story, of the road you have travelled to arrive here today and pass it on to Dianne Purdie *diannepurdie@extra.co.nz*.

You never can tell, some of your words about your journey may strike a nerve of a listener/reader thereby generating a way forward for that listener here today. Wouldn't that be brilliant to know you have helped someone today?

Thank you

November 2019

Members Stories:

Heather Milligan – my thoughts on Christchurch Seminar…

Arriving at Burwood Hospital, a huge handicapped parking area adjacent to the entrance, a beautiful new building. A friendly receptionist pointing us in the right direction to the lifts. In the lift with 2 other ladies, recognising one but not from other Scleroderma events, but from Farm Forestry events, lovely to meet up again Lynne and the other lady from Hokitika. Out of the lift, around the corner being greeted by ever smiling Kim and her husband and being sent down a corridor to the seminar, you didn't need to tell us where to go Kim, we zeroed in on the reverberation of conversations.

Being greeted by Carolyn and her partner. Saying hello to fellow Southlanders and meeting new people with Scleroderma who have been diagnosed from just a few weeks ago to 44 year ago as well as catching up with those we had met at the Wellington seminars!

Speakers with so much information: Jan Ipenburg giving us an overview of treatment of Scleroderma and her thoughts on Medical Cannabis. Maureen Anderson's novel presentation had us thinking about our reaction to being diagnosed, our immediate support people's responses and our way in the future. So much to learn from Professor Beckett about our respiratory systems. In reply to the question about 'free divers' how big do their lungs get? I think we were all surprised to find that your lungs cannot expand! and no, you cannot hurt your lungs by pushing yourself. After lunch we had a presentation on our digestive systems, I was a bit worried that I might feel a bit nauseous hearing about that after such a lovely lunch, (sushi and nibbles, a great choice for food), but it was so interesting I need not have worried. Helen Hills who talked and showed us about her work, mainly with hands, as an Occupational Therapist So good to see Allan making the journey from Auckland, in amongst other Patient Advocacy to remind us to keep a diary of our problems, specialist/doctor etc visits, have a record that travels with us about our condition and medication.

So great that many of the speakers stayed to listen to other speakers, especially Helen who stayed the day to become more aware of our condition. Especially lovely to meet the young lady and her husband from Auckland, who to my amazement she has had a lung transplant. I think most of us thought that major surgery was out of the question when you have Scleroderma.

Thank you again to those who organised and helped at the seminar.

By Heather Milligan

With Scleroderma, Exercise Comes at a Cost

Kim's column from sclerodermanews.com

My cardiologist has given me the OK to go back to the gym. I've been waiting for his clearance for a long time. Working out at the gym was how I stayed healthy and in shape before being diagnosed with scleroderma.

Since becoming ill, I have spent what seems like years in my recliner, medicated with prednisone and opiates, and feeling hungry, sluggish, fatigued, and in pain. The weight has piled on. My body has become something that does not represent my inner self.

My medical team is all smiles and encouragement. They want to see me get fit and lose weight. But while listening to their motivational talk designed to get me going, I got a whiff of a "used car salesman." Notions of "let's get this old bomb off the lot" came to mind. I dismissed these as my own defenses.

Returning to the gym was daunting. My bright pink leotard and leg warmers from the 1980s weren't going to cut it. But squeezing myself into a modern pair of Lycra workout tights was an experience. By the time I got them on, I was out of breath and felt like I'd completed my first workout.

Over the past four months, I've made small steps as I've gotten into the swing of things. I can now manage 30 minutes on the recumbent bike, and another 30 minutes using machines to work out various muscle groups.

Everyone is encouraging, which is lovely, but here's the thing: I have found that the cost for chronically ill patients to exercise is high. And I'm not referring to gym membership fees.

Health professionals enthusiastically tell me that working out three times a week is best. They remind me of the benefits and spur me on with positive affirmations. They know I can achieve it. I also know this to be true, but it has cost me in other areas of my life.

When I go to the gym, it costs me an entire day. That leaves me four weekdays to achieve everything else, including light housework, catching up with friends, writing my column, spending time with family, and having time for myself. Those are the basics of life, and are difficult enough to balance without scleroderma.

After working out, I experience extreme fatigue and increased pain. No matter what adjustments I make in the gym, it is always the same. Once I am home, I can manage a shower before falling asleep for at least two hours. Often, I am still fatigued when I wake up and I need extra pain relief.

To reach my healthy weight, keep my ligaments and muscles oxygenated, and increase my circulation, I have to stop my life three days a week. The personal cost is high. And while my body is beginning to get a new shape inside and out (in a good way), so is my life (in not such a good way).

Don't get me wrong. Exercise is important for chronically ill patients. The benefits are proven and worth the effort.

But do enthusiastic health professionals understand the high cost of exercise for chronically ill and immunocompromised patients? I don't usually sign up for something unless I know the real cost before parting with my money.

Would I have started exercising had I known my cost? Definitely. But honest disclosure about the reality would have been best. At least I would have been able to prepare mentally. It's only fair.

About the author Kim Tocker:

I'm 49 and live in Christchurch, New Zealand. I was diagnosed with Limited Systemic Scleroderma in 2013, and the disease has slowly progressed over the past three years. Prior to my diagnosis, I worked as a Counsellor/Therapist in private practice, however I was forced to close my practice in 2014 because the fatigue associated with the disease had become profound.

Well before I studied, trained and worked as a Counsellor many years ago (at least 20) I was employed as a Dental Assistant. It is my belief that whilst working in this capacity I handled a number of chemicals that are now considered dangerous and this exposure may have been the trigger for my disease, together with an already existing genetic component. These days, my full time job is to work hard at my self-care and manage my symptoms as best I can. Part of this management is to reflect on and write about my experiences about living with Scleroderma in ordinary day to day life. This helps me a great deal, and I hope it helps my readers, both those who also suffer with Scleroderma, and to help raise awareness in those who do not. I enjoy adding a little humour to my writing, because honestly, I feel it's important we all have a wee laugh from time to time. However, my writing usually includes a serious reflection of some sort.

On a personal note, I am the wife of one, and the Mother of three boys. My husband Max is my main caregiver, and I am very fortunate to have such a loving and giving spouse. My children are aged 21, 19 and 13, and our two oldest boys live in different parts of New Zealand to study and work. Our youngest will be starting High School in 2017. We live with a menagerie of animals, including two dogs and four cats.

Members News:

Scleroderma Waikato Group

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

On the 23rd November the Hamilton Coffee Group celebrated together Christmas Lunch at my home. Great way to end the year together.

Hamilton Group

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

I would like to wish all members a Merry Christmas and Happy New Year from all Hamilton members.

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

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

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

LINDA BELL
SCLERODERMA WAIKATO

Wellington Scleroderma Group

The Wellington Scleroderma group met for a shared Christmas afternoon tea and to celebrate Adrienne's special birthday..

Wellington Group

Members News:

Happy Birthday Adrienne Burleigh

Adrienne Burleigh

Adrienne's birthday cake

Our Wellington group met up on **16th November** and we all brought lots of lovely and yummy food to share

Wellington Scleroderma Group

Adrienne cutting the Birthday Cake

Welcome to Leonie, who is new to our group

Members News:

Wellington Scleroderma Group

Steve Russell brought a lovely lady named Roslyn, who came along with her husband. Roslyn has a condition which is the opposite to our condition (a lack of collagen). Roslyn has to speak very softly and can't handle loud noise. We learnt a bit about Roslyn's condition, which was very interesting for us all.

Welcome to our group Roslyn

We would also like to welcome Karen, Leonie, Catherine and Caryl who are new members to our group over the past year.

Wellington Group

Thank you to everyone who came, and for making it such a wonderful pre-Christmas celebration.

Take Care and looking forward to seeing you all next year.

By Tina McLean

Members News:

Southland Group

I never thought I would be meeting up with Scleroderma people in 2 different provinces on 2 consecutive days!! At the Christchurch seminar and then lunch in Invercargill the next day.

Jenny at the beginning of the year organised the last meeting of our Southland Get together on the Sunday the 24th November Later in the year we saw the Christchurch group had organised their seminar on the 23rd, no problem, flights worked out so Jenny, Graham and I on Sunday could be in Christchurch in the morning and sitting down to lunch in Invercargill with our Southlanders in the afternoon. We were impressed Jenny had our name badges and Scleroderma leaflets on hand, wow, Jenny great logistics.

We had a new lady turn up, Mary, she has a friend who knew a friend of our member Linda (who I think knows almost everyone in Invercargill). We are troubled that Mary did not receive any Scleroderma NZ information from Southland Hospital's Rheumatology Department. Jenny has emailed them to see if this can be remedied and perhaps, we can put a poster along the corridor to the department, a corridor we all know well.

Graham, Jenny and I shared just a small segment of the information imparted at the seminar, so much information.

Betty was the only one to bring along her lovely Christmas hat….. we will do better next year. Betty is feeling great, a Doctor reviewed her medications and recommended that we do the same, as some she was taking were not needed or not appropriate.

What a lovely end to the weekend, great to meet up with our Southland ones again. We are not going to cure Scleroderma, but our support groups and seminars are where we can share personal experiences and feelings, coping strategies and receive first-hand information are so important.

By Heather Milligan

Members News:

Southland Group celebrating Christmas

Southland Update

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

Due to us being so far South we have decided to run a Scleroderma Seminar in September 2020.

This will be open to everyone in the country and will be held on: -

Saturday 26th September 2020

We are having it at **Southland Hospital**, Kew Road, Invercargill. So, save the date and we will update you with more info in the next newsletter. Would be great to welcome others from around the country.

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

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

Nelson Update -

2 months ago Rosemary, Lisa and I met up in Richmond for morning tea.
Rosemary was about to have treatment so we haven't caught up for a couple of months.

Lisa and I have met up at my place 3 weeks ago and shared date scones and coffee.
Then 2 weeks ago we both met up for morning tea at "Bloom" in Motueka.
We have shared many stories about our lives and health issues which helps us both so much.

We hope to see Rosemary after Christmas New Year once she feels better.

I'm having an operation soon to remove the worst calcinosis from my left thumb and wrist.
Have done pre admission etc.
Hope it helps.
I've had several procedures over the last few months so have been out of touch.

If you would like to join in with the Nelson Group please contact:
Beth Richards: ronbethrichards3@gmail.com

Upcoming Events:

Hamilton

- Our next Meeting will be on **Tuesday 4th Feb 2020** at **Robert Harris**, Chartwell

Hamilton Seminar, will be held in **2020.** The seminar for Hamilton, helps the newly diagnosed and family's to learn and understand and most of all to meet other people around the Waikato area.
More information about the seminar coming soon – keep an eye out for it in the next Newsletter.If you would like to join in with the Hamilton Group, please contact Linda Bell.
Email: Linda.bell@hotmail.co.nz

Wellington

- Our next Meeting will be on **Saturday 15th Feb 2020,** 1pm-4pm, at Russell Keown House, Queens Drive, Lower Hutt

Please contact Dianne Purdie if you would like to join in, you will be most welcome.
Email: diannepurdie@xtra.co.nz

Christchurch

- Our next Meeting will be on **Saturday 25th January 2020**, 2pm-4pm, at McDonalds Merivale, 217 Papanui Road, Merivale

Please contact Carolyn Barkhausen if you would like to join in, you will be most welcome.
Email: barkman@xnet.co.nz

Southland

- Our next Meeting will be on **Sunday 23rd Feb 2020** Rustic Café, in Gore

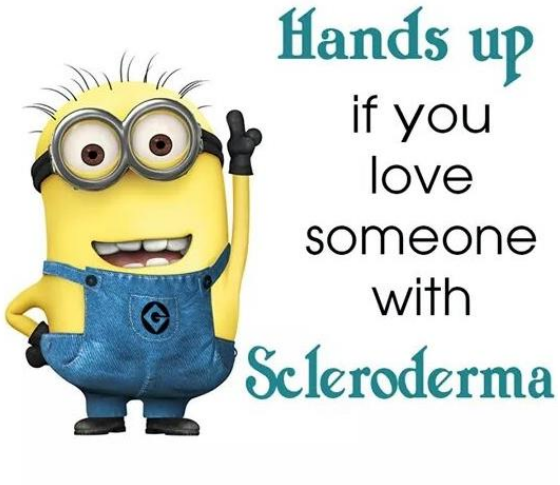
Southland Seminar, **Saturday 26th September 2020**, Kew Hospital, Invercargill

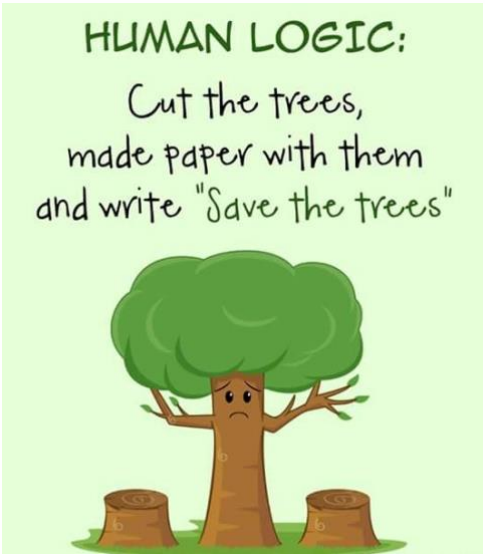
More information about the seminar coming soon – keep an eye out for it in the next Newsletter.

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

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

Thought for the day:





Noticeboard:

Wellington support group meets:

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

Venue:
Russell Keown House, Queens Drive, Lower Hutt

Christchurch support group meets:

Saturday 25th Jan 2020	2:00pm to 4:00pm
Saturday 28th March 2020	2:00pm to 4.00pm
Saturday 23rd May 2020	2:00pm to 4:00pm
Saturday 25th July 2020	2:00pm to 4:00pm
Saturday 26th Sept 2020	2:00pm to 4:00pm
Saturday 28th Nov 2020	2:00pm to 4:00pm

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

Auckland Respiratory support group meets:

Venue:
327a Whangarata Road, Taukau Auckland 2694

Southland support group meets:

Sunday 23rd Feb 2020	**Rustic** in Gore
Sunday 17th May 2020	**Buster Crabb** Invercargill
Sunday16th Aug 2020	Winton
Sunday 8th Nov 2020	**Thomas Green** Gore

Hamilton support group meets:

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

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

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

Email: Linda.bell@hotmail.co.nz

Contacts:

Find a Scleroderma a Support Group near You:

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

Scleroderma New Zealand Inc.

President:	**Dianne Purdie** diannepurdie@xtra.co.nz
Newsletter:	Tina McLean altinamclean@xtra.co.nz
	Jenny Andrews jennyred@xtra.co.nz

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

www.scleroderma.org.nz/calendar/

New Support Groups:

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