NUMBER 33 MAY 2017

Scleroderma
New Zealand support group

Winter 2017

Greetings to you all.

We have a great newsletter this month with all sorts of info from the recent Wellington seminar. Dianne and Gordon organised a good line-up of speakers, who gave their time to talk to us on their specialist topic. Many thanks also go to the scleroderma sufferers who travelled from Dipton in the south and from Auckland in the north and all points in between. Without you it wouldn't have been such a success. We hear first from Dianne with her president's report. She has kept us up to date with what's going on around New Zealand.

Next we have an account from a psychologist and a psychiatrist, who talked to us about living and coping with a chronic disease. We know what it is like living with it day-to-day. Dr Atkin has suggested ways for us to deal with this.

Sandra Forsyth spoke to us next. She gave us her personal experience of living with a chronic disease and her other related conditions. I could relate to some of her comments, especially the one about 12-year-old doctors. It is an interesting read.

Two young, optometrists spoke to us about our eyes. This was especially interesting for those of us with Sjögren's. They talked about the eyes, the importance of keeping them moist and ways to keep them in top condition. They even gave us some samples of products available on the market today.

Dr. Andrew Aitken gave a great talk on PH and PAH with a good discussion on drugs available and Pharmac, who allow some but not other suitable drugs for this condition.

Yvonne has an article on her canoe trip down the Wanganui River. She wasn't going to let her scleroderma get the better of her. Also we have some news from the Southland group on their get-together after the seminar. And a few pics or everyone to bring back your seminar memories.

President's Report

Winter is on its way, but we still have the odd day that is quite mild and pleasant.

Firstly thank you all for your support at the National seminar here in Wellington this past weekend.

We had some long distance travellers amongst us, Dipton in the deep South, Nelson, Palmerston North, Wairarapa, Kapiti Coast, Auckland and our folk from Wellington.

Thank you to all of you for your help on the day, helping it run smoothly and the generous morning and afternoon teas, that Adrienne Burleigh, Tina Mclean and Sandra Forsyth put together for us.

We had some very special raffle prizes on the day donated by our members, Jo Harris and Yvonne Bird, which has helped cover the costs of the seminar. Judy Trewartha had also donated some lovely quilted crafts for sale for fund-raising for Scleroderma NZ.

John Spavin, worked non - stop all day long, doing lots of photography and taking down notes which you will be reading in this very interesting newsletter.

We were also treated with some very colourful art works from our own artist, Catherine Thompson. The selection of her paintings was a series of 8, which depicted her journey with scleroderma, a very moving piece of work.

Our line up of speakers was exceptional and I have had a great number of emails, of appreciation from attendees, which has been delightful.

We all learnt a lot and each of us took something home of value, which will help us in some way.

Gordon and I have started the year with a review of guidelines and recommendations for kidney monitoring. We are working with Dr Rebecca Grainger on this.

Next will be access to pulmonary arterial hypertension treatments here in NZ.

There seems to be some good research in progress in the way of biomarkers for lung disease and pulmonary arterial hypertension, which would be effective in monitoring and treatment for Scleroderma patients in the future.

I wish you all well, keep your core warm at least three layers of merino or its equivalent to help prevent internal Raynaud's and peripheral Raynaud's.

All the Very Best

Dianne

2017 Scleroderma Seminar

Coping with a chronic illness

Dr Charles Hornabrook, Consultant Psychiatrist and Dr Aleisha Atkin, Clinical Psychologist

Consult-Liaison Psychiatry Team, Wellington Hospital

Professionals like Drs Hornabrook and Atkin see themselves as just part of a team that helps people who are suffering chronic diseases. Members of this team extend beyond medical professionals to friends, family and work.

That team is needed, they say, when a patient first receives a diagnosis of a disease like scleroderma, or, say, cancer: "I'm worried or sad about what's happening to me. I don't understand," Dr Hornabrook says. Through that process we adjust as human beings to bad news or setbacks in life. People cope differently and sometimes can be overwhelmed by threat to one's good health.

It's common to go through a period of shock or stress or upset. He says that's the human response. But, Dr Hornabrook says, if symptoms persist for days or weeks, you might ask whether there's an emotional problem that's complicating the physical illness. Isolated or unsupported people may develop clinical anxiety or depression.

to next page...

London University's team-based approach

2017 Scleroderma Seminar

Coping with a chronic illness *continued*

There is a continuum or "seesaw" of emotional distress," he says. "If the predominance is sad and low, that's depression. If it's tense, worry, fear, that's anxiety." Each often overlaps and often responds to the similar medicines e.g. antidepressants work for both anxiety and depression.

Dr Hornabrook, a psychiatrist, says it's unusual for him to see a scleroderma patient as it's rare for the disease to attack the central nervous system, unlike other connective tissue disorders. The symptoms for scleroderma are more like the psychological sense that I'm coping with illness and symptoms: pain and discomfort.

But scleroderma is chronic so the doctor says it's not uncommon for patients to report sadness and depression but he points out that life itself can bring that on - it's not uncommon.

From a psychiatric point of view, he says a condition like scleroderma can bring on anxiety, depression, hostility and somatization (distress at bodily symptoms). On top of that, we all change as we age and we can get physically sicker as a result.

Dr Hornabrook pointed out that some medicines themselves may cause emotional symptoms. He cites steroids, which alter both appetite and mood, and can cause insomnia. Codeine and morphine can affect your thinking and memory. Those are the sorts of things he pays attention to when he sees patients, which, rather than adding medication, might benefit from reduction depending.

Coping with chronic disease

Having canvassed the effects that a chronic disease like scleroderma can inflict on someone, Dr Atkin concentrated on coping. She summarised the emotional changes that can affect someone newly diagnosed and which can continue: "Whenever change occurs we have a response to that and we have an emotional reaction," she says. Common reactions include anger, grieving for your previous life, denial, depression, fear and anxiety.

Dr Atkin described the typical reactions that some follow upon diagnosis. It begins with shock and denial, can move to anger, frustration and even shame and at its deepest, it can cause depression and detachment.

As patients learn to adapt to change and cope, they learn to share their experiences and find meaning to what's happened. They can accept the change and find how to live with it.

Returning to meaningful life, she says patients can feel empowered, secure in their situation and regain their self esteem.

But, returning to meaningful life doesn't mean returning to how life was. The acceptance stage means accepting a life that's lived in a new normal. It's important to realise she says, that this cycle of down and then up is a natural response to all life's changes, not just chronic disease.

Ground yourself

Dr Atkin advises that you ground yourself, throw out an anchor. Work to mitigate the worst effects:

- Sleep - Address changed sleep patterns - whether too much, or lack of. Your GP can help with this
- Diet - Pay attention to what you eat, and how often. Avoid poor nutrition
- Safety - Feel secure in your environment as you process your emotions
- Structure - Follow a daily routine or structure so that you might try to wake at the same time each day or maintain regular family mealtimes
- Exercise - Ensure you get your body moving regularly
- Daylight - Keep regular exposure to daylight to keep your day/night rhythms working.
- Personal - Socialise, keep your circle of friends and maintain personal interests.

Mindfulness

Perhaps the most interesting lesson that Dr Atkin left the seminar with is to look up a topic called mindfulness. She says our minds wander off into the past, grieving for things we've lost, or into the future, anxiously wondering about what's going to happen.

"In order to get through a difficult period it's important as much as possible to be in the now," she says. Mindfulness connects us with the now, rather than all the thoughts going on in our head. "When you're doing something, be in that experience because you'll never get that time back again."

She took the audience through some exercises to 'living in the now', as she calls it. She says it takes perseverance but mindfulness can be learned with practice.

Google 'mindfulness'. There are even smart phone apps.

2017 Scleroderma Seminar

Sandra Forsyth, Vice Chair of WellMe, the Wellington and Horowhenua Support Group network looks after those living with ME/CFS or chronic fatigue syndrome and fibromyalgia and related conditions.

Far from an academic address, Sandra spoke from the heart to the seminar. Here's an edited extract. (the full text is up on the website)

My personal health journey started many decades ago with endometriosis when in my 30s. It was pre-internet and support or information was impossible to find.
In 2010 while living and working in Dubai, I was diagnosed with the potentially fatal blood disorder called myelodysplastic syndrome – a year later back home supposedly to die, I was diagnosed with Sjogren's syndrome. Autoimmune diseases hunt in packs and love company – my accessories, as I like to call them. A girl can never have enough accessories.

Whenever I field inquiries on WellMe's 0800 number, or talk to someone through Arthritis New Zealand's newly diagnosed service I am always struck by the shared commentary of being unwell, of emotional bewilderment and anguish.

For most of us with a chronic illness spend years being unwell and undiagnosed – anywhere from 2 to 5 years - or 7 years if you hit the jackpot. Years of lying on a bed in A&E staring up at a 12-year-old masquerading as a doctor, praying for the dots to be connected.

Throughout this time, we slosh about in the public health system until diagnosis comes as a profound relief. This is our shared story.

With chronic illness comes grief, a natural reaction and no one escapes it. And grieve we do - for our former lives, our former selves, our careers, our financial robustness, our relationships, our abilities and talents, what we thought defined us. It is yet another invisible component of chronic illness.

For us, being ill is like being parachuted into a strange country over night. We awaken in a new country, without a map and not knowing the language. I call this process the Journey through the Land of Rejection. *to next page*

2017 Scleroderma Seminar

Sandra Forsyth, continued

You will travel through the land of rejection and you will find your home, but it won't be where you left it [Anon]

We have an overpowering need for support, to find the others like us.

Sadly, for most of us, our friends, family and our networks are unable to cope, withdrawing their support and presence, leaving us isolated and vulnerable. We may also become withdrawn and isolate ourselves.

Lack of social interaction undermines our wellbeing and distorts our social identity. Studies show that social isolation can be just as life-threating as obesity and smoking. Cancer-related research shows that 25% of cancer patients spousal relationships do not survive and two major outcomes of that disease are depression from post-traumatic stress and financial devastation. I suggest these statistics apply equally to chronic illness.

It is unhealthy to walk this journey alone. Support is vital.

Scleroderma NZ and networks like WellMe provide that place of belonging. We are all whanau and belong to a special club with a truly international membership. Welcome to Club Knackered – no one is excluded.

Speaking and being with people who share our diagnosis is a crucial and important part of our journey.

Our support groups have an informal buddy system following the sudden death of two of our members – one from suicide and one from a medical emergency. The buddy system came into its own last year during the November earthquakes and again in December when two of Levin Support Group members died of medical emergencies.

Mortality issues are a fact of life with chronic illness. It is important to discuss them within the support group and, where necessary, seek advice from independent, qualified health professionals.

Support groups have their own life force with members being at different stages of coping. Those further along can help those who are just starting out. This is the power of support – we can't cure ourselves but we can make informed choices, take control of our emotional wellbeing and be diligent about our overall health. We can learn the language to talk to our medical team as equals.

Even with chronic illness we still have a life and belong to something bigger than ourselves.

We can be there for others and be an active member of Club Knackered. We are still who we were before we became ill - the new improved version. We do have a life.

I leave you with this quote from Maya Angelou:

'*My mission in life is not merely to survive, but to thrive, and to do so with some passion, some compassion, some humour and some style*'.

Sandra Forsyth

6 May 2017

Follow WellMe's activities on its website:

https://wellmecfs.wordpress.com/

Seen at the seminar

2017 Scleroderma Seminar

Opthalmology Registrars, Dr Cameron Loveridge-Easther and Dr Tiffany Ma

Dry Eyes

Dry eyes a one-slide talk? Drs Ma and Loveridge-Easther set the record straight from the start; it's a complex problem and to leave it untreated invites trouble.

It's a problem, Dr Loveridge-Easther says, that can start small but become very serious. He took the first half of the presentation to describe the problem. Dr Ma's section talked about treatment.

Tears cleanse, lubricate, and nourish the eye's surface and provide physical and immune protection against infection.

A small change in this film can cause significant changes to vision and lead to that burning, sandy feeling.

Ultimately, the changes can lead to permanent loss of vision in cases of severe dry eye.

The tear film consists of three distinct layers, produced by different glands around the surface of the eye and in the eyelids

The tears increase if even slight damage is inflicted on the eye's surface. The tears' contents change to protect the wound. Blood vessels dilate, causing reddening of the eye. Everything works together to protect the eye.

It's automatic - touch your eye and the process is poised to start healing any damage. Your emotions can trigger tears too. Blinking, we do it 20 times a minute, smooths this tear film and disperses it evenly across the eye.

It all works well. But how does it go wrong? If you produce the wrong types of tears, they pour out and can damage the eye. The eye reacts to that damage by producing yet more tears, which compounds the problem.

The outer layer of the tear film is oily, to restrict evaporation. If the oily layer isn't there, tears evaporate too quickly and become salty. The same thing happens if you can't produce enough tears. The salt level begins to damage the eye.

"You start damaging the front of the eye. You start asking for more tears and the tears that get there to help out have increased salt, causing a vicious cycle of damage," he says.

Sjögren's

Sjögren's brings a lot of these symptoms together. Sjögren's is an auto-immune disease affecting moisture-producing glands and results in dry eyes and dry mouth. Dr Loveridge-Easther says there is primary and secondary Sjögren's.

to next page

2017 Scleroderma Seminar

Opthalmology Registrars, Dr Cameron Loveridge-Easther and Dr Tiffany Ma

continued

The first is straight-out Sjögren's. Secondary means there's also another connective tissue disease like scleroderma present: 13% of those with Sjögren's have vision-threatening complications.

"You end with this cycle of toxic tears," he says. "It causes damage but all you can send are more toxic tears." As well as damage to the eye's surface, the gland that produces the tears gets damaged too.

Treatment involves diagnosing the problem and working to break that cycle of damage.

Treatments

The treatment you receive for your auto immune disease has a beneficial effect of lessening the effects of secondary Sjögren's, including dry eye, according to Dr Ma. She says, "Our objective of management is to improve your comfort, vision and your quality of life. Treatment depends on the severity of dry eye and also the underlying cause.

1. Tear supplementation

Eye drops

All patients with dry eye require lubricant eye drops.

This is used in conjunction with other treatments that may be required.
A wide variety of eye drops are available, and it may take trial and error until you find what works best for you. Eye drops with preservatives are available in multi-use bottles and are suitable for use up to 4 to 6 times a day. If using eye drops more than this, she recommends preservative-free eye drops. They're costlier but they avoid the potential toxic effects of preservatives when overused. In particular, Dr Ma recommends against using any drops that contain benzalkonium chloride (BAK). Preservatives such as polyquad, sodium perborate and sodium chlorite are gentler on the corneal surface.

Gels and ointments

Lubricants also come in gel and ointment form. The advantage with this medium is longer-lasting action and therefore less-frequent application required.

The trade-off is that gels and ointments will blur vision more than eye drops.

to next page

Table showing an example of grading dry eye severity and the escalation of possible treatments

Level	Symptoms	Signs	Treatments
1	Mild/episodic discomfort	Mild tear debris +/- lid disease	Education and environmental/dietary modifications. Elimination of offending systemic medications Artificial tear substitutes, gels, ointments Eyelid care and hygiene
2	Moderate/episodic discomfort Blur	+/- redness and corneal stain +/- lid disease	*If level 1 treatments are inadequate, add:* Anti-inflammatories Tetracyclines Punctal plugs Moisture chamber spectacles
3	Severe/frequent discomfort Chronic blur	Red Marked staining Tear debris Lid disease	*If level 2 treatments are inadequate, add:* *Serum* *Contact lenses* *Permanent punctal occlusion*
4	Severe/disabling constant discomfort Chronic blur	Red Severe staining Tear debris Ulceration Keratinization	*If level 3 treatments are inadequate, add:* *Systemic anti-inflammatory agents* *Surgery (lid surgery, tarsorrhaphy, mucus membrane, salivary gland, amniotic membrane transplantation.*

2017 Scleroderma Seminar

Opthalmology Registrars, Dr Cameron Loveridge-Easther and Dr Tiffany Ma

continued

2. Tear retention

Occluding a passage of tear drainage can help retain tears around the eye for longer.

Punctal occlusion can be trialled with punctal plugs which can be made of permanent material such as silicone or hydrogel, or with temporary dissolving material such as collagen. More permanent measures such as punctal cautery can also be considered.

Moisture Chamber Spectacles work by increasing humidity of the eye and the thickness of the lipid layer of the tear film.

3. Tear stimulation

Secretogogues, (substances that enhance secretion) are under investigation for their use in dry eye. Pilocarpine is a systemic oral medication, which makes eyes water more. However, it has unfavourable side effects like excessive sweating, blurred vision and headaches. In practice, these are seldom used, Dr Ma says.

4. Biological Tear Substitutes

Serum eye drops are effective in many ocular surface diseases, however they're not suitable in use in dry eye disease associated with Sjögren's.

5. Anti-Inflammatory Therapy

Anti- inflammatory medicines can help by reducing the inflammatory drive in the vicious cycle of dry eye and also improving the quality of tears.

Cyclosporine-A (Restasis) is a medication that helps the eye produce the maximal amount of tears it is capable of.

Corticosteroids (e.g. Fluorometholone) are effective at reducing inflammation however, they should be for short-term and supervised use because of other effects to the eye.

Tetracyclines (e.g. Doxycycline) are a class of antibiotic that stabilizes the lipid layer and improves tear quality.

6. Essential Fatty Acids

Omega-3 fatty acids have multiple health benefits. They improve the lipid layer of tears and reduce inflammation. They generally come in fish-oil tablets. Vegetarians can substitute flax-seed oil.

7. Environmental

Your environment may affect the condition of your eyes. Dr Ma says things like low-humidity air conditioning will dry your eyes. Some of your regular systemic medications may be doing so too. It is important also to make sure that the eyes are fully closed while sleeping.

If there is nocturnal eye opening, taping the eyelids shut may stop moisture loss at night.

8. Surgery

In very severe cases of dry eye especially in those with resulting eye disease, surgical procedures may be indicated. Tarsorrhaphy is a surgical procedure in which the eyelids are partially sewn together to narrow the eyelid opening to prevent exposure and drying out of the eye.

There are other surgical procedures to improve tear retention and to fix ingrown lashes.

Dry eyes - certainly not a one-slide talk!

Seen at the seminar

2017 Scleroderma Seminar

Dr Andrew Aitken Cardiologist Wellington Hospital

Pulmonary Arterial Hypertension (PAH) and Scleroderma

Just what is PAH, what's its relationship with scleroderma, how do doctors diagniose it and manage it? Dr Aitken set out to provide some answers.

Pulmonary arterial hypertension is a type of high blood pressure. It affects the arteries in your lungs and the right side of your heart.

The right side of the heart is designed to pump at the lower pressures found in the lungs. If the lung arteries and capillaries are constricted, the right side of the heart must pump harder to force blood through.

You need good blood flow through the lungs because that's where your blood picks up oxygen. Inadequate oxygen absorption can cause breathlessness, a build-up of fluid in the legs and abdomen and it strains the heart.

There are many types of hypertension. Pulmonary arterial hypertension is less common.

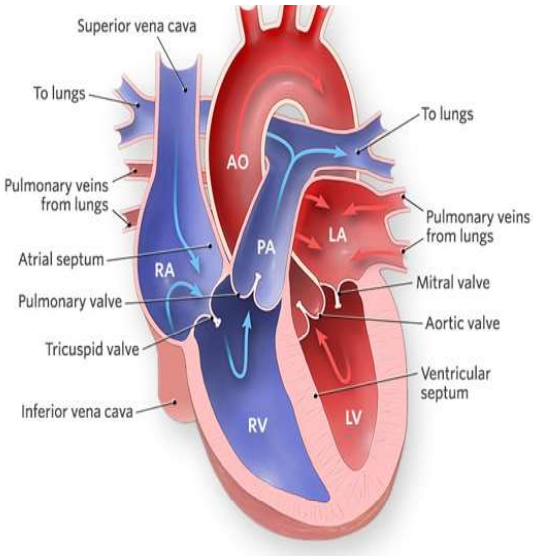
Its causes include:

- Left heart disease
- Lung disease
- Clots in the lung arteries
- Miscellaneous

The good news for those with PAH as a result of scleroderma (and those with clots in lung arteries) is that specific treatments are available.

to next page

PAH: Increased pressures in lung arteries
Effects
Increased strain on right side of heart
Decreased lung function
Less oxygen uptake
Fluid build up
Reduce heart function



2017 Scleroderma Seminar

Dr Andrew Aitken Cardiologist Wellington Hospital

Pulmonary Arterial Hypertension (PAH) and Scleroderma *continued*

Scleroderma PAH

"While pulmonary hypertension, or PH, is reasonably common, PAH, or pulmonary arterial hypertension is relatively uncommon," Dr Aitken says. It's a specific concern amongst a sub-group who have scleroderma.

There are around 50 PAH cases per million of population. That's nearing 250 cases in New Zealand. Dr Aitken says there are about 160 cases receiving treatment so around 90 cases present in New Zealand aren't receiving therapy.

Around a third of patients who are being treated have scleroderma as an underlying cause, so it's relatively common, in an uncommon group.

PAH Symptoms

- Breathlessness
- Dizziness
- Fatigue
- Cyanosis (blueness)

Testing for PAH

Investigating whether a patient has PAH ranges from old-fashioned exercise to modern electronics. There's a 6-minute walk test up and down a room between markers to assess changes in oxygen levels and heart rate, and the level of breathlessness. It's a good test to repeat a few months after treatment begins, to measure progress.

Other investigations include electrocardiogram (ECG), Echocardiogram (ECHO) and lung function tests. Then there's CT scans to find if there's scarring or clots that might contribute to problems.

In the end, there is a test that can definitely confirm the presence of PAH: a cardiac catheter test. Doctors insert a catheter into a leg or arm and feed it right up into the heart chamber. The catheter measures pressure inside the heart's chambers.

"If someone tells you that you have pulmonary arterial hypertension and you haven't had this test then we don't know that you do have it," he says. "This is the diagnostic tool that's required." He says that although it sounds serious to have a catheter wind its way through your leg or arm, into the right side of your heart, you'll be able to walk away after a couple of hours lie-down. "It's not a big deal at all. It's a relatively non-invasive procedure," Dr Aitken says. And it specifically identifies whether you would benefit from the medicines available. Early detection seems vital.

Patients in whom PAH is detected and treatment begun, even before they display symptoms, have longer life expectancies than those whose PAH are treated only after PAH symptoms arise.

A 2011 study found that 64% of those whose systemic scleroderma-related PAH had been detected early and treated with relevant medicines, had a survival rate of 64% after 8-years. That compared with 10% survival for those who received treatment only after their symptoms made it clear that they had PAH.

Dr Aitken says the catheter inserted through the right side of the heart gives that early warning and suggests that early screening would be beneficial to people with scleroderma.

In 2013, an international group of medical researchers and doctors studied 460 scleroderma patients, each of whom had had scleroderma for at least 3 years. Their study encompassed 60 countries. Their "gold standard", Dr Aitken says, was the right-heart catheter study. They were trying to find a standardised way to identify those who should have further study for PAH, without over-investigating and also not missing any.

They were able to identify 70 out of 450 patients at risk of PAH. That's more than 20% who were detected before showing symptoms. Again, Dr Aitken says a screening programme would be beneficial as the incidence of PAH was greater than thought.

15 years ago, Dr Aitken says general physicians would have said there was little point in trying to detect PAH as there was little or no treatment for it anyway. But that's no longer true. Modern treatments change the way people feel and improve their quality of life.

Supportive therapies include physiotherapy and breathing exercises. General, specific exercise and, in some cases, oxygen, all work to mitigate the effects of PAH.

Modern drugs help dilate lung blood vessels, decrease heart strain and improve symptoms. Things are moving on for those with PAH, particularly if it's detected early.

2017 Scleroderma Seminar

Dr Stephen Inns, Gastroenterologist, Hutt Valley DHB

Scleroderma and the Gastrointestinal Tract

"90% of people with scleroderma will get problems with the gut. It's the normal, not the exception."

Dr Inns says the problem can affect any part of the gut, from the mouth to the anus. "We've got a lot to talk about today," he told the seminar.

There's something about your immune system, Dr Inns says, in the way it sees the tissues in the gut, that leads to an immune response. It cause two levels of damage; both into the muscle layer and the nerves.

The damage happens to the muscle layer and the connective tissues. The nerves that determine how wide and open blood vessels are, are damaged too. It happens in the gut in the same way that those with Raynaud's experience it in their fingers.

The cycle of damage is exacerbated when blood flow is restricted to the layers of the gut.

The severity of scleroderma in the gut is unrelated to how it affects the rest of the body. It may be severe elsewhere but mild in the gut and it could be seriously affecting the gut but not the rest of the body. It's one of scleroderma's uncertainties, he says.

The gut has more nerve endings than the brain. Dr Inns described the complexity of the stomach as almost like it being its own individual creature, over which you have no control. It just gets on with the job most of the time.

"But we certainly know about it when it stops doing its job." It's that time when it stops doing its job, that he set out in detail to describe, beginning, when you swallow a meal..

Difficulty Swallowing and reflux

Dysphagia is the medical term for difficulty swallowing. It is associated with scleroderma because the disease damages the nerves and muscles in the oesophagus (American spelling is esophagus).

Swallowing problems may not just be the movement of food. There can be narrowing problems as a consequence of scleroderma.

Food can move from the mouth to the gut because the oesophagus forces it down. "It's why you can swallow in space." The oesophagus delivers food into the stomach through a sphincter.

to next page

2017 Scleroderma Seminar

Dr Stephen Inns, Gastroenterologist, Hutt Valley DHB

Scleroderma and the Gastrointestinal Tract *continued*

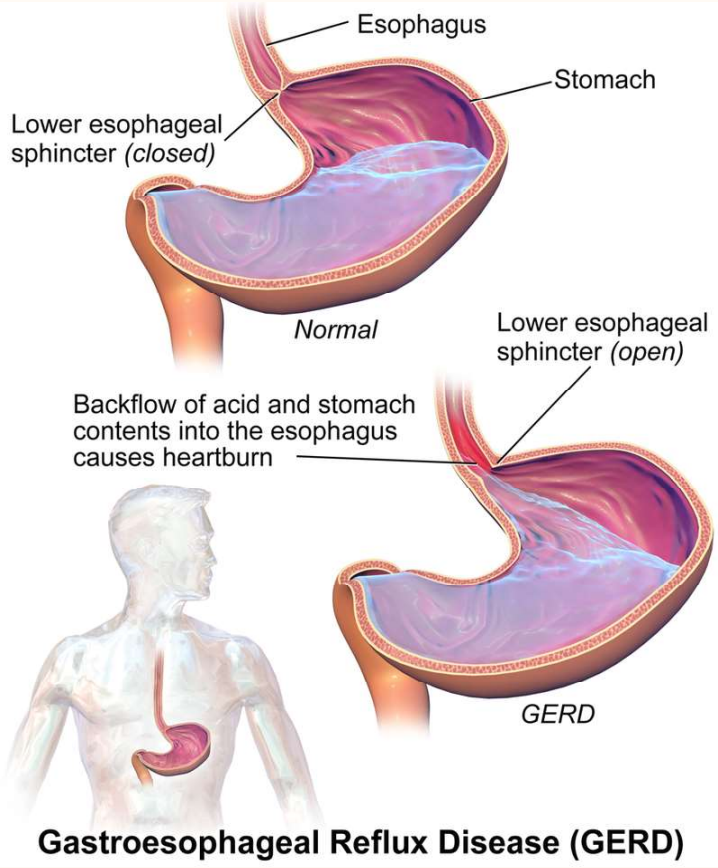


Image credit: BruceBlaus - Own work, CC BY-SA 4.0, https://commons.wikimedia.org/w/index.php?curid=44923646

The sphincter holds the food in your stomach. You need to burp and that's a reflux. Dr Inns says everyone does, it's normal but while normal reflux quickly settles the food and acid back down into the stomach, the presence of scleroderma can affect the severity..

"If your stomach's not emptying out very well, then there's going to be more food and fluid there, every time you reflux." Big meals cause it too and when you gain weight. Fatty meals slow the stomach emptying down.

Because patients with scleroderma get more reflux, the complications are greater. The frequent effects of stomach acid bathing the oesophagus, causes its lining to become more like that of the acid-resistant stomach. That would seem to make sense but Dr Inns says it can lead to oesophageal cancer, and that's a cancer that is increasing.

"We are seeing increasing rates of oesophageal cancer compared with most other cancers, which are pretty static, and that's because we've an obesity epidemic and therefore a reflux epidemic," he says.

There are things you can do and medicines you can take to mitigate the effects of reflux.

Measuring Reflux

Doctors measure the amount of acid that is entering the oesophagus by inserting a catheter down the throat to determine how much acid is present. Patients can push a button when they feel a symptom and correlates with the measurement of acid rising into the oesophagus.

Where once the catheter had to come out the nose for 24 or 48 hours, Dr Inns says in his Boulcott Hospital, it's monitored wirelessly and much more conveniently.

Treatment

Steps you can take yourself, Dr Inns says, include:

- Eat small meals
- Avoid eating before sleeping
- Reduce fat intake
- Don't smoke

As for medicines, Omeprazole, sold under the Losec brand name, seems effective for long-term use. Dr Inns says the discovery of Omeprazole more that thirty years ago made reflux a much more manageable problem.

In a wide-ranging talk, Dr Inns covered the remainder of your digestive system and the effects scleroderma has on it.

Appreciation Awards

It gave me great pleasure at the seminar to present awards of appreciation to some of our key people who keep Scleroderma NZ Inc alive and active. It shows that a lot of people put a huge effort to keep a society running. Thank you all for keeping us together with everything you do. *Dianne*

Barbara and John Spavin : for their high quality work on our newsletters and Website. Their work is widely appreciated throughout the international scleroderma community. We are extremely lucky to have their expertise and their commitment to Scleroderma NZ Inc. They are both well appreciated.

Sandy and Allan Edmondson : for supporting pulmonary hypertension patients throughout New Zealand. Both Allan and Sandy travel the country to support and encourage patients. They also host, in their own home, meetings for PAH/ scleroderma and other respiratory disorders. Both Allan and Sandy are very much appreciated by a large number of people.

Cushla Marsters : for dedication to the Scleroderma NZ Facebook page. Cushla keeps the pulse going, for our facebook community. She always keeps something new up on our screens to help our wider community. Facebook is a lifeline for some patients. Cushla's work is much appreciated on an International level as well as our local scleroderma community.

Adrienne Burleigh: for dedication to patient support. Adrienne works for the newly diagnosed and the seasoned scleroderma patients among us. Adrienne has a wealth of knowledge that she's willing to share. Adrienne also instigated a national survey for scleroderma members on how well they're monitored. The results highlighted concerns. Adrienne also spoils us all with specially handmade gifts and beaut cooking.

Linda Bell : for dedication to fundraising for Scleroderma NZ - movie nights and quilt raffles. Most of the proceeds have gone to print new booklets: Managing and Understanding Scleroderma, the NZ edition. Linda has worked hard over the years and leads the Hamilton support group. She stages seminars in Hamilton for the scleroderma community.

Judy Trewartha: for dedication to fundraising for Scleroderma NZ. Judy has worked hard to make quilts for national raffles sold around Auckland and online for our greater scleroderma community. Judy kept working away when it was a difficult time for her. We are all very appreciative of your kind generosity

Maureen Anderson: for fundraising of the booklets for Managing and Understanding Scleroderma . Maureen put together a calendar for a number of charities in New Zealand, including Scleroderma NZ. Maureen is a rheumatology specialist nurse, and led the Invercargill Scleroderma Group until recently. Maureen still works with us on our committee.

Sandy and Allan Edmondson

Cushla Marsters

Adrienne Burleigh:

Paddling the Whanganui

Support group member, Yvonne, doesn't let scleroderma tie her down. Previously, she has reported from the back of a pushbike in the wilds of Otago. This time, it's from the river rapids.

Eight people, four canoes. One unforgettable journey. We put our canoes into the Whanganui River at Taumarunui, and pulled them out for the final time at Pipiriki, 5 days and 145km later.

The Whanganui is a small river where our trip began, passing through farmland and gradually into native bush. That first day was a mixture of fear, exhilaration and laughter, as we learnt to control our canoes and paddle them through many rapids; some members grounded in the shallows, or slid backwards through rapids.

hours for food and rest; the first and last days were shorter. Day four we tied up at Mangapurua Landing and walked in to the famous Bridge to Nowhere for lunch. Along with canoes, lifejackets, transport etc, the hire company provided waterproof barrels to stow our gear in. These were strapped into the canoes, and on arrival at our destination had to be carried up to the campsite – always high above river level! We soon developed a team approach to accomplish this, along with pitching the tents and cooking meals. Each incoming stream adds to the Whanganui, until the river is deep and wide, and rapids on the last day are challenging.

Did I have misgivings about doing this trip? Of course. Could I stay warm enough? Layers of merino were the answer; warm

As days passed, we left farmland and road access behind, entering stunning gorges sculpted by the river, trees in every shade of green cloaking and clinging to soaring cliffs. Here were long tranquil stretches of water mirroring perfect images, cascading streams cutting deep slots through soft rock, and swirling eddy currents boiling up from the base of cliffs. At times we glided quietly, watching early morning mist rise through trees, kereru swooping on air currents, and listening to occasional birdsong.

Most days we paddled for 5-6 hours, stopping every few

even when wet, light enough for an unscheduled swim, easy to peel off as exercise warms the muscles. Would aching shoulders and upper arms be up to it? "Get fit first", I said, and swam weekly in the local pool. Could I last the distance? No question; this was the opportunity of a lifetime, and I wasn't going to miss any of it.

Our journey down the Whanganui River was a truly unforgettable mix of magnificent scenery, teamwork, and discovering just how much you can do.

Southland Update

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

Eleven of us met in Invercargill for a get together in May. It was great to have 4 partners there too.

Lots of talking went on, it's always good to compare notes and learn from others.

Graham and Heather spoke on the topics covered by the speakers in the Wellington seminar the previous weekend.

We ooohed and aahhhed when Lorraine, showed us photos from a few months ago of her badly ulcerated finger and then photos of just after her pointing finger had been removed.

It was all very straightforward operation with excellent healing - and her hand now looks very impressive, but she can only count to nine on her fingers!

The NZ Scleroderma booklet was well received and will be in lots of handbags and doctors' offices around Southland

Thank you so much to Jenny Andrews for getting us organised.

Thank you Yvonne for the lovely sunflower bag you donated to the raffle at the seminar, just right for taking the booklets/ name labels,camera etc. to our get togethers.

Eh?

A old man was going deaf and finally went in to get his hearing checked, at his family's insistence.

The tiny hearing aid attached to his glasses and it was almost impossible to tell when he was wearing it.

"Well, how do you like your new hearing aid?" Asked his doctor when the man returned for a follow-up examination.

"I like it great. I've heard sounds in the last few weeks that I didn't know existed."

"And how does your family like your hearing aid?"

"Oh, nobody in my family knows I have it yet. I'm having a great time! I've changed my will 3 times in the last 2 months."

Noticeboard

Next Wellintgon Meeting:

12 August

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: Heather Milligan
03 248 5147

Wellington / Christchurch:: 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.

Contacts

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Newsletter: Barbara Spavin

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