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Scleroderma

New Zealand support group

newsletter

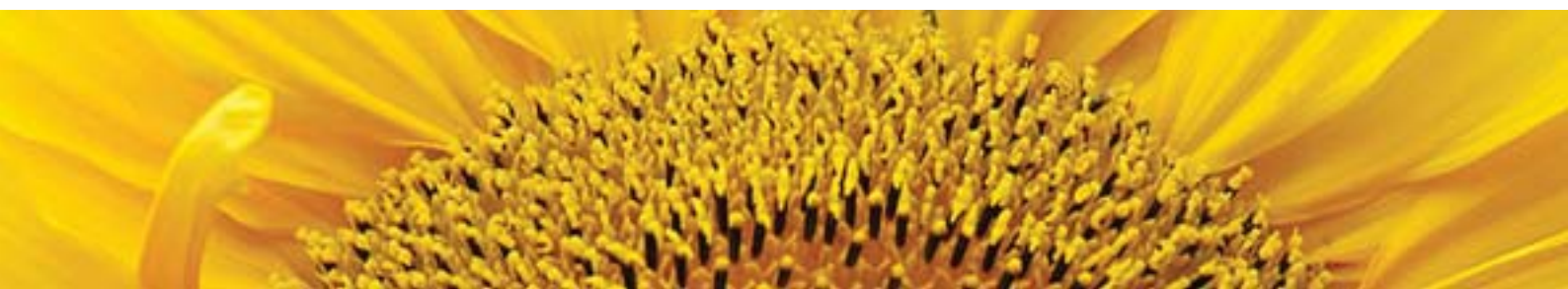
Summer Issue 2013



Greetings everyone. This will be the last newsletter for the year. Hasn't this year just sped by? Good to see the sun again and let's hope that we have a summer like we did last year.

At our meeting this month, we had a talk from Zoe McGavock. Zoe is an arthritis educator in the Lower Hutt area, and she talked to us about the outcome from the National Rheumatology Association conference she went to. Zoe concentrated her talk on the Scleroderma part which you will read about further down. She also talked about home help for Scleroderma sufferers.

Welcome to the two new members we have:
Dawn, who hails from Wellington and Linda who comes from Palmerston North.



Join the fight against arthritis

Fresh from Arthritis New Zealand's national conferences, arthritis educator, Zoe McGavock, brought our November meeting up to date with developments

The annual conference's theme was "Join the fight against arthritis", attracting an audience of about 200 on the third day, when the conference was opened to the public.

The conference covered many aspects of arthritis and heard that chronic back pain carries the highest burden of any disease, beating out depression. Muscular/skeletal pain comes high on the burden list too. Gout is the second-most common arthritic disease after osteoarthritis with rheumatoid bring up the third spot.

Dr Dinesh Khanna

One of the keynotes came from Dr Dinesh Khanna, associate professor of medicine at the University of



Michigan's scleroderma programme. US Scleroderma Foundation voted him its doctor of the year in 2011. He researches scleroderma full-time and at the conference he highlighted the presence of pulmonary hypertension or, high blood pressure in the pulmonary artery on the right side of your heart. He says it's present in about

10 - 15% of people with systemic scleroderma and it affects many others with connective tissue disease. Dr Khanna says rheumatologists should be routinely screening their patients for the problem.

He says it's the leading cause of death in both conditions. Zoe elaborated on the problem, explaining that pulmonary hypertension begins when tiny arteries in your lungs, called pulmonary arteries, and capillaries become incapacitated. This makes it harder for blood to flow through your lungs, and raises pressure within your lungs' arteries. As the pressure builds, your heart's lower right chamber (right ventricle) must work harder to pump blood through your lungs, causing your heart muscle eventually to fail.

Pulmonary hypertension is a serious illness that becomes progressively worse and is sometimes fatal. Although pulmonary hypertension isn't curable, treatments are available that can help lessen symptoms and improve your quality of life.

Dr Khanna told the conference that the most rapid period



of decline in lung function happens within the first 4 years of contracting an auto-immune disease such as scleroderma.

Home help

Zoe also outlined problems many members have with gaining approval for funded home help. She cited the example of a young woman with scleroderma who was denied home help because she "didn't have arthritis". Zoe says criteria should be based on the extent of disability, not the diagnosis.

She says no one should be declined simply because they are in paid employment. Arthritis New Zealand is gathering experiences of funded home help from members and through Zoe, would like to know of cases where it has been declined or reduced.

Household management support ranges from housework, or assistance with things like doing the shopping or lifting heavy items. Personal care includes providing support for a person's care such as assistance with showering and dressing.

Zoe outlined home services available in the Wellington region but each region will differ in its policy and to find out what is available in your region you will need to ask your local health administrators.

Mobility Centre

Barbara discovers a wee gem in Lower Hutt

Tucked away in a quiet corner store in the Lower Hutt suburb of Epuni there is a shop which aims to help those who are no longer able to complete some of the simple tasks about the home.

The store is called Mobility Centre and it sells the sorts of tools and appliances that will help you to do things that you find difficult.

The shop has helpful and friendly staff on hand to suggest and offer the best product to suit individuals' needs. There is a wide range of goods for sale and hire from mobility scooters and bathroom aids to kitchen utensils, bendy cutlery and respiratory accessories.



For those who can't get to the shop, try the website: www.mobilitycentre.co.nz



Alternatively you could ring 0800 243 866 and talk to the staff who can advise you on what product is available for you or someone you know.

Note: this is not an endorsement of the shop or its products; it just a tip for those looking for an aid.



The US national scleroderma organisation, the Scleroderma Foundation, has issued a list of links to products that help those without full strength or mobility to cope with everyday tasks.

The site has published this list for the past 3 years. There are links to products such as Velcro iPad grips, foot pads, hairdryer stands and cosy slippers.

A few of the links go to dead sites or some that have been abandoned and left to advertisers to fill with irrelevant links but most do lead to useful and relevant products and some of the sites export their goods. Freight can be the killer though.



Microweave-heated slippers anyone?

The Scleroderma Foundation's web page for around-the-house aid is [available here](#).

Coping with chronic illness

"Chronic illness" is a blanket term for a disease or condition that endures. There are hundreds of known chronic illnesses, and each affects the body differently. Some chronic illnesses, such as Scleroderma or lupus, are potentially life-threatening. Others, such as rheumatoid arthritis or fibromyalgia, are not but may be physically debilitating. Beyond that chronic illnesses may have emotional and psychological effects. How you live with a chronic illness depends on its nature and there are coping mechanisms that apply to any situation.

Step 1

Embrace the positive and negative emotions surrounding your diagnosis.

When first diagnosed with a chronic illness, you might feel fear about your health and uncertainty about your future. You may feel anger or guilt, wondering if you could have done something to prevent the disease.

You might feel relieved that your symptoms finally have a name and the possibility of treatment.

All of these emotions are a normal part of the process.

Step 2

Educate yourself about your chronic illness and how it affects you.

Knowledge is power and the more you know, the better able you will be to cope with the symptoms, complications and treatments for your disease.

It is also possible for the same disease and treatments to affect people differently. Understanding how you feel when you're sick, and how your body responds to the treatments, will help you take better control of your care.

Step 3

Remember that you are more than your disease.

You might have haemophilia, diabetes, chronic fatigue syndrome or hypothyroidism but that is only a small part of who you are. You are also an artist, someone's best friend, a mum, or a world-class Jenga player.

Having a chronic disease can be overwhelming, especially if you have to take several medications or endure a lot of medical treatments to control your condition.

Focusing on who you are outside of your illness helps you feel like a human being, not a list of symptoms, treatments and test results.

Step 4

Recognize that you will have good days and bad days.

Medications and other treatments can keep your symptoms under control but you will have periods where your symptoms will flare up.



These flare-ups could coincide with changes to your medication or treatment plan, alterations to your schedule, physical changes within your body or exposure to something, such as an allergen, that triggers an attack.

Understand that these flare ups are natural and do not necessarily indicate that your disease is worsening, but that you might need to contact your doctor and make changes to your treatment plan.

Step 5

Join a support group, but take their advice with a grain of salt.

Patient-to-patient support groups provide you with information from other people who actually live with the disease.

Some of this information includes helpful tips for how to live with a chronic illness such as planning your day around your treatment schedule, relieving your symptoms, and methods for coping with the bad days.

But, understand that some of this information, such as fad diets, alternative medicines and supplements, could be questionable and even dangerous.

Additionally, medications and treatments that work for one patient might not work for you.

Step 6

Work with your doctor to manage your care and tell him or her if you experience side effects from your medications, or if your condition worsens or does not improve.

Advise your doctor if you are trying alternative treatments and supplements in addition to your regular course of treatment.

Do not stop taking your medications or make changes to your treatment without first consulting your physician.

Excerpted from scleroderma.org

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Links: www.arthritis.org.nz | www.scleroderma.org.nz | www.sjogrensnewzealand.co.nz

Another year draws to a close



The raffle at our Christmas meeting spread its favours wide, with three winners gaining some loot to take home. Dawn, Liz and Linda won one each.



Sunflowers set the scene for our well attended Christmas meeting. We had air conditioning and unusually for Lower Hutt in November, it was set firmly to cool. Luxury!



Tina ponders the raffle prizes and also has the chance to look over a good selection of booklets and brochures from Arthritis New Zealand that Zoe brought along.



The Southland support group shares a Christmas lunch along with friends and supporters last week. The group credits Maureen Kirby (standing at right rear) with getting them all together. Maureen is a nurse in the Southland Hospital rheumatology clinic. The group says she is due a big thank you. So thanks Maureen!!

CONTACTS

Newsletter: Barbara Spavin barbara@netco.co.nz

Links: www.arthritis.org.nz | www.scleroderma.org.nz | www.sjogrensnewzealand.co.nz

Southland support group Noticeboard



At the beginning of 2013 Maureen Kirby of the Southland Hospital Rheumatology Clinic contacted those with Scleroderma in Southland to set up a 'Support Group'.

It was lovely that some of those she contacted knew of others not under the Southland Hospital and passed the invitation on. We have met informally 3 times, both in Gore and Invercargill.

It has been wonderful over the year to meet others with our condition and discuss about how we are coping with this. Not everyone was able to get to the meetings, but with emails we are all up to date as to what is happening (thanks to Dianne Purdie whose emails us news from time to time and thank you Barbara for your newsletter).

Over a Christmas lunch on the 1st December we (along with a couple husbands and friends) caught up with each other again and talked about the highs and lows over the last few months (great to say it was mainly highs!).

Thanks to Maureen for facilitating our get togethers, Jenny Andrews for being our contact person and the members of the group for their candor and positive support.

To take the lines from Greg Lake's Christmas song:

'I wish you a hopeful Christmas
I wish you a brave New Year

All anguish pain and sadness
Leave your heart and let your road be clear'

Heather Milligan



Graham and Heather Milligan flew from Southland to attend this year's scleroderma conference in May

Merry Christmas
everyone. Have a
happy and peaceful
yuletide season.

Next Meeting

1 February 2014

A Christmas Story (of sorts)

Three men died on Christmas Eve and were met by Saint Peter at the pearly gates.

'In honor of this holy season' Saint Peter said, 'You must each possess something that symbolizes Christmas to get into heaven.'

The Englishman fumbled through his pockets and pulled out a lighter. He flicked it on. 'It's a candle', he said.

'You may pass through the pearly gates' Saint Peter said.

The Scotsman reached into his pocket and pulled out a set of keys. He shook them and said, 'They're bells.'

Saint Peter said 'You may pass through the pearly gates'.

The Irishman started searching desperately through his pockets and finally pulled out a pair of women's panties.

St. Peter looked at the man with a raised eyebrow and asked, 'And just what do those symbolize?'

The paddy replied, 'These are Carol's.'