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# Scleroderma

support group

## *newsletter*

## Happy New Year

Greetings everyone: Happy New Year to you all.

I hope you enjoyed your Christmas break and had a relaxing time over the summer holidays. If any of you did something on your bucket list, feel free to share it with the rest of us. We'll all be very interested I'm sure.

This is a new year and we hope you all have a healthy and prosperous one.

To start us off this year we had a talk from Diane Barker, an occupational therapist. Read about her tips, ideas and ways we can tackle tasks easier.

Diane had much good information and we'll drop this into subsequent issues of the newsletter.

We are always on the lookout for your experiences as you cope with scleroderma and strive to lead as normal a life as you can.

If you care to share your triumphs, challenges and even setbacks (as always, with a nice photo or two) we will surely find a place for them here. Remember the middle word of our group's title: "support". Sharing experiences is a part of that.

It hardly seems possible but already, this is the autumn issue!



# A physical and mental approach to fight illness



Diane spoke with great enthusiasm about the therapeutic benefits of a mind that works with the body to mitigate the effects of physical illness. Physical aids play a part too.

First, Diane us took through some of the physical aids that she makes available through the unit and which the Ministry of Health also makes available in other parts of the country - it's not just Greater Wellington members who benefit from them.

The Ministry's programme is called Enable and at priority 1 it provides for those who, through their illness, would be unable to live alone without the aids. That's the good news; the bad news is that it Diane says can take up to a year actually to receive the aids from the time of requesting them. An alternative is to buy them for yourself. Diane's unit will lend equipment on a short-term basis following a referral from a GP. In Lower Hutt, the Eponi Mobility Centre also has a wide range of these aids for sale and sends them nationwide.

Amongst the physical aids, Diane showed off clever gadgets designed to make physical work easier for sore fingers and hands. There are many varieties of kitchen utensils for



cutting, scraping and peeling vegetables into shape. There are tricky yet simple devices that pry open reluctant and tight jar tops; calipers for reaching to the ground to pick stuff up without having to bend the back and even a forked ballpoint pen that lessens the pressure required to grip it and write freely.



There were eating utensils against which the toughest steak would stand little chance and a host of protective clothing, such as gloves, to protect against abrasion, cold and painful knocks.

Diane's unit both lends and sells equipment to those who would benefit from it. She says members outside Greater Wellington should approach their local DHB to enquire about similar, local programmes that might benefit them.



February's invited speaker, Diane Barker, is an occupational therapist at Hutt Hospital, attached to the rheumatology unit.

Diane spoke with great enthusiasm about the therapeutic benefits of a mind that works with the body to mitigate the effects of physical illness.



February's guest speaker, Diane Barker, demonstrates one of the physical aids that she makes available to patients.



Diane tries out a sock aid herself at the meeting. It's designed to allow putting on socks without the usual bending and straining.

It worked too!

# Mind over matter - the February meeting *contd.*

The mind is a powerful weapon with which to resist some of the affects of illness, according to Diane Barker, occupational therapist, at February's meeting.

Diane says she's a firm believer in the therapeutic affects of mind power. It's not so much mind over matter as attitude, as she explained how the correct mental attitude can lift low spirits and even physical well being.

Part of the mental approach sounds like practical common sense when explained, although it's not always obvious until someone sets it out logically.

## Self management of scleroderma

Diane applies these steps to any chronic illness that involves accompanying degree of pain.

<b>Prioritise</b>	Delegate tasks and eliminate those that are not urgent or superfluous
<b>Plan</b>	Decide when it's best to tackle a task. Morning? Afternoon? After a rest? Before a meal? Plan for when it's your best time of day to cope. Clear the big tasks first then complete the lesser ones
<b>Pace</b>	Don't rush whatever it is that needs doing. Why should it all be done in one go?
<b>Position and posture</b>	Ask yourself whether you have set the task up the easiest way. For example, perhaps get a trolley to carry working things about rather than carrying or stooping to pick them up from the floor.

Diane welcome patients who have been referred by their GP, to examine their hands and develop both physical and mental therapy. Diane is a great believer and extremely enthusiastic about the benefits of patients using the mind for its calming and relaxing benefits and had some examples of patients she had seen improve markedly from following her advice.

The programme she advocates aims to get you through the hurly burly of thoughts that your mind generates, to calm it and get it to concentrate on the things that matter.

She says thoughts can be negative and destructive but they also be positive and it's that side of the mind that

she teaches patients to use. The key to it all is to use the act of breathing, concentrating on it to exclude racing and negative thoughts.

Diane says it's important to take stock of yourself from time to time. Just stop and forget that tea might need cooking or chores might be waiting. Have some time to yourself, think how you're feeling and what's going on in your mind. Become aware of your breathing and concentrate on the rise and fall of your lungs to the exclusion of the day's worries.

She says even a 2-minute spell can be beneficial. Use a trigger, says, waiting at the pedestrian lights to cross and drop into measured breathing and shut out the day's worries. Perhaps at events that usually stress you, such as in a doctor's waiting room, use the breathing technique to calm yourself and realise that what you're fearing is not that bad.

This, of course, is not to be learned from a cursory glance at a newsletter and Diane coaches patients thoroughly on these breathing techniques before she expects them to gain the full benefits.

This type of therapy is available at other DHBs for members of the group who live outside Greater Wellington.

For those interested in learning more, a quick Google of "mindfulness" breathing techniques should give much information.



It's not all controlled by the mind. Diane suggests you place your hand flat on paper and draw its outline. In few months, compare your present hand size with the outline and observe changes in the finger spread. She has hand exercises to help make fingers more supple.



# Tip for those heading overseas in cattle class

It's not just insurance companies warning about the dangers of long-haul plane flights, couped up in a tiny seat with inadequate leg room and little chance to exercise. Many travel sites now caution against the cramped conditions faced by those who can't afford the luxury of



business and first class.

It's called deep vein thrombosis and it does seem to be a danger for those back in the cheap seats.

Pressure stockings seem to be beneficial but they are extremely difficult to get on and off because they are tight, that's why they are said to work.

Here's a tip from February's meeting to make the effort of getting them on and off easier.

Sprinkle some talcum powder over the stockings' inner lining. Put on a pair of rubber gloves (for grip) and the stockings will slide over your feet and onto your legs easily, smoothed by the talcum powder.

Try this in a busy international terminal and see if it attracts attention. It might but it might also prevent a nasty thrombosis!

# Gastrointestinal involvement in scleroderma

**The US Scleroderma Foundation is, by New Zealand standards, a vast organisation with huge resources.**



Its web site carries many informational articles about the disease, its affects and research aimed at mitigating its effects.

One of the articles in particular, describes the results of surveying more than 200 scleroderma patients and listing digestive system involvement in their disease.

It's to be found on the Foundation's website, [www.scleroderma.org](http://www.scleroderma.org).

Its author is Dinesh Khanna, MD, MSc, Assistant Professor of Medicine, Division of Rheumatology, University of California, Los Angeles.

## Contacts for the Lower Hutt Mobility Centre

In person

103 Copeland Street, Epuni Shops, Lower Hutt, Wellington

Mon - Fri: 9.00am to 4.45pm

Sat: 10.00am to 1.30pm

They will visit anywhere throughout the greater Wellington region.

Nationwide Freephone: 0800 243 866)

After Hours 021 243 8662

Fax (04) 577 1189

Email: [sales@mobilitycentre.co.nz](mailto:sales@mobilitycentre.co.nz)

Online catalogue:

[www.mobilitycentre.co.nz](http://www.mobilitycentre.co.nz)

# Change: quality of life! – despite my illness



Alan Hobman is a Queensland Registered Mental Health Nurse and he gave this as part of a talk to the Scleroderma Association of Queensland a couple of years back. But the advice still holds true.

- change happens!!!
- sometimes it's planned and sometimes it isn't
- change can bring gain, excitement, new insights and learning
- change can bring loss and grief
- change can bring stress and anxiety
- change can challenge our sense of safety, predictability and control
- change can challenge the assumptions we make about our world
- change is a transitional time which cannot be avoided

## FIGHTING SPIRIT

- rise to the challenge of your illness - face it
- seek valid information and be involved in choices
- be positive and optimistic, and realistic
- stick to what you know, not what you

imagine

- care for yourself
- manage your stress
- \*maintain as usual a life style as possible
- \*acknowledge and express your emotions
- \*seek joy

## 10 COMMANDMENTS FOR SELF CARE .... Anonymous

- Thou shalt not be perfect, nor even try to be
- Thou shalt not try to be all things to all people
- Thou shalt leave things undone that ought to be done
- Thou shalt not spread thyself too thinly
- Thou shalt learn to say "no!"
- Thou shalt schedule time for thyself, and thy supportive network
- Thou shalt switch off and do nothing regularly
- Thou shalt be boring, untidy, inelegant and unattractive at times
- Thou shalt not even feel guilty
- Especially, thou shalt not be thine own worst enemy but be thine own best friend



## ..and the last word goes to

Now I lay me down to sleep  
I pray this cushy life to keep

I pray for toys that look like mice  
and warm cushions soft and nice

For grocery bags where I can hide  
Just like a tiger crouched inside

I pray for gourmet kitty snacks,

someone nice to scratch my back

For window sills warm and bright  
for shadows to explore by night

I pray I'll always stay real cool  
and keep the secret feline rule

To never tell a human that  
The world is really run by cats.

## CONTACTS

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Links: [www.arthritis.org.nz](http://www.arthritis.org.nz) | [www.scleroderma.org.nz](http://www.scleroderma.org.nz) | [www.sjogrensnewzealand.co.nz](http://www.sjogrensnewzealand.co.nz)