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# Scleroderma

support group

## *newsletter*

## Our support group - an example for Arthritis NZ

The Scleroderma support group's way of meeting and offering fellowship and support is a model towards which Arthritis New Zealand is moving.

Arthritis New Zealand will to close many of its service centres, switching to support groups such as ours, as its new way of helping sufferers.

The most obvious sign of change is Arthritis NZ's decision to close down its Petone centre, our former meeting place. It will build larger centres in Auckland, Wellington

and Christchurch, from which staff will support local groups, host events such as workshops, seminars and educational talks throughout New Zealand, and use telephone and Internet services more.

Arthritis New Zealand still exists to help those with arthritis, it's going about it in a different way.

Arthritis New Zealand says it must live within its means while still providing core services.

For information about help in your area: **0800 663 463**



### Winter.

Hi Everyone. As winter is upon us we all know what to do about keeping warm and protecting ourselves against the cold. Out comes the scarves, gloves and woollens to protect our joints, hands and feet against the wind and chill of winter. Hearty soups and casseroles are the fare of the day and just the thing to warm us after a day's work or a stint out in the garden. A dietician and fellow Scleroderma sufferer, talked to us about food and diet while living with Scleroderma.

# Living a healthy life with a chronic condition Course

Dianne's report on her attendance at an Arthritis New Zealand course held in March and which ran for 6 weeks.

While scleroderma and its hangers-on, raynauds and Sjogrens inflict their misery on some of us, they're just a few of a bewildering variety of chronic illnesses that affect people, with varying severity.

They go by many names: arthritis, cancer, heart disease, diabetes, inflammatory bowel disease, irritable bowel syndrome, multiple sclerosis, stroke, renal failure, congestive heart failure, HIV and chronic pain.

In March this year I attended a course called Living a Healthy Life with a Chronic Condition, facilitated by Arthritis New Zealand and generously funded by the Capital Coast DHB. The chronic conditions of attendees differed but we all shared the need to cope and that's what the course was designed to help us with.

The course ran for six, weekly sessions, each two and a half hours long. The diversity of different conditions within the group helped us each to understand how the other's specific difficulties affected them. It was a cheerful group though - we weren't trying to outdo each other's symptoms.

The course's main goal was to teach self-management skills for chronic conditions. The course taught skills :

- to deal with your illness,
- needed to continue your normal life and
- to deal with emotions.

We also looked at the Vicious Symptom Cycle: symptoms such as pain, stress/anxiety, difficult emotions, tense muscles, fatigue and depression. We learnt skills to help us break the cycle by setting goals.

Each week we completed an action plan for a different goal.

The goal was meant to be simple and achievable but part of what the course taught was that we had to have a plan to see how we were going to achieve this goal. The action plan included:

1. what you are going to do,
2. how much you are going to do,
3. when you are going to do it, and
4. how many days a week you are going to do it.

And yes, I was surprised that I had to fill in a form for my goals, as we think we can just decide what we are going to do and she'll be right and it will all fall into place. And if you're honest we all have good plans that just don't seem

to happen or be completed when we would like them to. Well I was very surprised at just how good this technique was especially if I kept my goals simple and didn't bite off more than I could chew.

Each week we reported back on how much of our goal for the previous week we had achieved. This was very helpful to overcome difficulties with achieving goals and we all learnt from each other. These are all things we know but putting them into practice was very helpful. We all found that completing our goals gave us good sense of wellbeing and brought normality back into our lives. Hey presto! With this attitude you can work around most situations that pop up from time to time, instead of shelving your objectives.

We had numerous brain storming sessions about different topics during the course. As a group it was very interactive and everyone felt very much part included.

We were all given a 411 page book called *Living a Healthy Life with Chronic Conditions* to take home and keep so that we can go back over and refer to it. I found the course very helpful and it brought me great awareness and understanding of the big picture of accepting and managing a chronic condition.

If you would like to find out more information about this course, contact the Arthritis New Zealand National Office in Wellington on 0800 663 463. I highly recommend it.

## Overview of self management and chronic health conditions

Make an action plan

Use your mind to manage symptoms

Feedback and problem solving

Difficult emotions

Fitness/exercise

Better breathing

Pain

Fatigue

Nutrition

Future plans for health care

Communication

Medications

Making treatment decisions

Depression

Working with your health care professional

Working with the health care system

Future plans

# The cactus convention

Behind every successful convention there's someone who's done the hard work behind the scenes. This year it was support group member Dianne Purdie's chance to organise the Annual Cactus and Succulent Society AGM and Convention, held in March in Wellington.

In the past we have attracted around a hundred members to our annual convention, but in recent years, that number has dwindled to little more than half that. Perhaps it's due to the recession or maybe people have found new species of plants to interest and amuse them. So the big unknown about our convention was how many we needed to cater for and how big a venue we needed to cram them all in to - food and venue being the most expensive bit of the whole affair.

In the end we snared 50 members from around the country, for whom the lure of the cactus was just too much to resist.

If you admire cacti and succulents, this weekend is prickly heaven, so to speak and we proceed to have a most enjoyable time, in the end attracting fifty members.

The lure of a weekend engrossed in their growing hobby attracted enthusiasts from Australia, Christchurch, Timaru, Auckland, Hawkes Bay, Fielding, New Plymouth and the Bay of Plenty. A good number of Wellington locals also packed in to Lower Hutt's Angus Inn.

Throughout the weekend, while Super 15 Rugby, netball, movies pubs, horse racing and roller skating kept most of New Zealand amused, we gathered around small, prickly plants and had a ball.

There was a talk from a guest speaker on his trip to South Africa, in which he gave a lot of information on the plants he found, not on a greenhouse trestle, but growing where they've evolved over millions of years in their natural habitat. We also had plant sales, in which any members of the society who has plants to sell can do so and there were good bargains to be had.

The weekend progressed with more sales, knowledgeable talks on the more unusual aspects of cacti and succulents: Crassula in habitat in South Africa, Hybridising Echinopsis, Euphorbia and Opuntia. There's lot's of Latin bandied about but the reality is that it's plants that make an enthusiast's heart skip, not fancy names.

Sprinkled amongst the plant talks and displays were good food, companionship and an auction that showed

a highly competitive spirit amongst the cacti crowd - keen competition is not the sole preserve of rugby players by a long shot.

Sunday disappeared in a rush with visits to local members' gardens. It causes a flurry of activity knowing that you are going to have visitors, so it's always a big re-pot and a dust down of the glass house before they all turn up to inspect. If you have time its good to get the rest of the garden looking respectable as well.



Echinopsis in flower in its native South America

I was still getting rid of the last few cobwebs as the first visitors arrived, and I got a few smiles as I tried to get the last of the webs out of my tangled hair, having spent the previous few minutes contorted in the glass house just before they arrived.

We were the third-to-last of eight garden visits. Life can be tough on a cactus trail that stretched from Upper Hutt / Blue Mountains to Lower Hutt, out to Miramar, then from Northland to us at Crofton Downs and on to the last at Paekakariki, where the convention weekend ended with a BBQ.

It was a great experience. The cactus houses have returned to peace and next year, we do it all over again in another town. Can't wait.



The pretty Opuntia travels under another name: prickly pear and it had a ball in Queensland a hundred years ago until locals cut it back to size. See last page for Dianne posing with her Opuntia plant



## Prickly pal



Dianne in front of what to us would be a cactus but which, to her, is the opuntia, or prickly pear. Nice to look at but don't try stroking the leaves as you might as flax or cabbage tree.

## World scleroderma day - June 29

World Scleroderma Day will be celebrated across Europe, Australia, the USA, Brazil and other countries.

It's the third year that the day has been celebrated, to raise awareness of scleroderma and for people with scleroderma.

## Seeing double

The face of the Arthritis New Zealand's scleroderma information pamphlet was at the June meeting. Cushla Marsters, diagnosed with scleroderma in March 2010, posed for the cover image a few months back. Cushla's aunt worked for Arthritis New Zealand, which

was searching for a cover image for the pamphlet. Next thing you know, the pamphlet is out and teaching people about a rare disease.

It's been distributed to libraries, surgeries and community groups.

## Obituary

It is with much sadness we inform you that Adrienne's husband Colin, lost his battle with cancer and died on 11 April 2011. Colin was a miniature railway enthusiast and an avid collector of all sorts of things.

His enthusiasm for life was reflected in his hobbies, his wife Adrienne and his three children. Our deepest sympathy is with you Adrienne and we wish you all the best.

Barbara, Dianne and Val attended Colin's funeral on behalf of the group

## Group origins recounted

The origins of this scleroderma support group go back 17 years to when Kokila Solanki joined 12 people and established it. Kokila stays in touch with some of the early members. She needed to meet fellow sufferers for support and an exchange of ideas.

Kokila had a lunch with some of our members and was at the June meeting, prior to her departure to live with family in Auckland. Kokila was diagnosed with scleroderma in 1994.



Barbara, Kokila, Dianne and Val wait for their cuppa at a city cafe while they talk of the early days of the group with Kokila.



### 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)