

- ▶ ARTHRITIS NZ... 1
- ▶ PHYSIOTHERAPY 2
- ▶ BARBARA'S ADVENTURE 3
- ▶ THE DEEP SOUTH 4

Scleroderma

support group

newsletter

Arthritis New Zealand - coping and learning

Next meeting: date to be decided

Arthritis New Zealand's Greater Wellington Educater, Robyn McFarlane joined the November meeting to discuss ways of alleviating the stresses and strains that happen daily with scleroderma.



Her organisation is planning several events for next year to this end.

"Living a healthy life" courses will be held in Porirua in March and April next year and in Central Wellington in May and June. Contact Amanda Williams on 04 570 5794 for more information.

Again in Central Wellington on Tuesday 29 march next year there is an arthritis and hand care seminar. arthritis.org.nz will carry details nearer the dates. Although not of use to our members outside Wellington, Arthritis NZ does have other events planned elsewhere later in the year. We will provide details when we have them.



Summer...

Spring has by now well and truly sprung itself and the air has warmed considerably. Taking up the theme of the talk at the November meeting, it's a good time to get out into the garden or to walk along a beach or even the street to the shops regularly. Jo Rae, a Hutt Hospital physiotherapist, told the November meeting that exercise, tailored to your own condition, offers enormous benefits to health and a feeling of well being. Jo set out her enthusiasm for the benefits of exercise and a summary of her presentation occupies the next page.

Exercising your way through the aches and pains

Jo Rae, a physiotherapist with the Wellington Regional Rheumatology Unit, based in Lower Hutt, told the November meeting of the support group how to exercise joints and muscles even when restricted mobility or pain tries to limit what you can achieve.

One size does not fit all!

If there was any single message to take away from Jo's talk it was that exercise, while beneficial to all, needs to be tailored and one size definitely doesn't fit all.

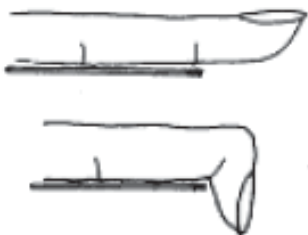
If you think about it, that's also true of anyone else, even those with perfect health but different levels of fitness. And Jo stressed that even within a group such as ours, there will be different levels of ability to carry out exercises without undue stress to joints and muscles. So it's not a competition to see who can carry out a set of exercise. Any therapeutic exercise needs to be tailored to suit the individual.

Having dispensed with the competitive side of it, Jo summarised the benefits of a course of physiotherapy as maximising potential for function and movement by teaching patients self-management plans to use all their lives. Exercise, it seems, is as necessary to maintaining healthy bodily functions as is breathing (although stopping breathing has far more immediate effects!). Jo listed the benefits of exercise as:

- increased muscle strength and general fitness
- Increased flexibility and balance and the ability to maintain them
- an improved sense of well being
- better digestion and sleep
- a sense of control over the disease

Scleroderma and exercise

Scleroderma causes skin tightness, which stretching can't prevent. But beneath the hardened skin, you still have muscles and joints that benefit from stretching exercises. Exercise can help reverse their decreased movement.



Again, Jo stressed that exercise should be carried out within the limits of your disease. If the disease is



Physiotherapist, Jo Rae prepares the slides for presentation at the scleroderma Support group's November meeting in Lower Hutt.

'flaring' it may be best to limit exercise altogether and pick it up again as things ease. Build up slowly rather than jump in with too-active a regime. She says exercise can take many forms. It can be as simple and relaxed as walking, gardening, checking the mail box or just gentle stretching as you go about your day.

Jo says there is no need for expensive gym equipment required to be able to exercise. Steps, a chair, a footpath or a Coke bottle filled with sand can all effectively substitute for professional equipment.

To get you started, Jo brought some exercise pamphlets sourced from the Scleroderma Society in the UK. You can get your own copy from the Society's website, downloadable as PDF files:

www.sclerodermasociety.co.uk/newsite/leaflets.php

Our thanks to Jo for a well-delivered and enthusiastic presentation. The physiotherapy unit at Hutt Hospital will accept patients with GP and specialist referrals.

Barbara in Bangkok

Winter cold get you down this year? Try the soothing warmth of 30+ degrees, high humidity and freedom from Winter's aches and pains for a couple of weeks.

It was a very early 3am rise to get to the airport and the 6am flight to Sydney. I found this quite difficult because of the medication I had to take before we departed. I took it in a 3 litre click clack container and also had two little containers with morning and evening medication in each. I had to take this in hand luggage because I would certainly be up the creek if it went missing with my suitcase. From Sydney we travelled to Melbourne to get the flight to Bangkok. The airline didn't tell us about that one or we would have travelled direct to Melbourne. Go Qantas!!! The flight from Melbourne to Bangkok was about 11.5 hrs - a long time to be cramped and plonked on your butt. However, once there it was worthwhile. The temperature was a very warm 32°, about twice as warm as Wellington, and we scanned the sea of faces until we found our daughters'.

Bangkok has 12 million people and most are very poor. This is reflected in their living quarters, the soon-familiar sight of elderly people out working and the type of work they were doing. Contracting scleroderma here and being poor is something not worth contemplating!

The traffic was horrendous with gridlocks in a stationary taxi for twenty minutes common. But it's a vibrant city: cars, buses, trains, sky train, taxis, tuk-tuks, motorbikes, hand carts and bicycles all added to the cacophony, and then there's the people. They're very friendly and helpful and even when they didn't speak English they smiled and bowed. The food is delicious too and we ate at many varied restaurants eating Chinese, Italian, English and of course Thai food.

We went on a day tour to Ayutthaya, the ancient capital of Thailand until the Burmese invaded in 1767 and destroyed it. In the ruins of the ancient temples are many decapitated statues of Buddha. It was still interesting to see though and our guide told us the history behind each temple. Ayutthaya is an island in a canal that surrounds the city. We were lucky enough to get a long-boat ride around the city. People were fishing and lived in little houses all along the river and we glimpsed a small part of their lives. Next were the elephants, what huge animals they are. Even the babies are large. We got to ride on one and had a very good elephant guide. He took us along the road and down by the canal and back again. We learned that an elephant's skin is about two inches thick and it is



also hairy. The trainer sat just behind the elephant's head and guided it with little nudges from his bare feet behind its ears. Each trainer gets the elephant from a baby and works with the same elephant for the length of its life.

Shopping in Bangkok is so much fun. They have local markets and stores where they sell mostly Thai things and then in the very large shopping complexes they have all sorts of shops like Louis Vuitton, Armani, Hermes, Cartier, Rolex and many others. Stores like Marks & Spencer and Zara sell English-size clothes in bewildering variety. M B K is the cheapest of the malls and most of the locals shop there too. Things are reasonably cheap and you can get anything from a lounge suite to souvenirs. Thailand makes beautiful silk, on sale in many shops.

Overall I think I coped reasonably well. My knees were swollen but didn't get any worse even with all the climbing up and down of the old city steps. Scleroderma did its best to slow me down and remind me it was on holiday with me too. My elbows were sore, maybe heavy shopping bags played their part. My hands were sore too, but I just had to ignore them. I think the heat helped the joints but it also made my feet swell. I was very tired, however, I can be tired in Wellington and I just enjoyed my holiday very much.

Greetings from the Deep South



Since reading the Scleroderma newsletter and hearing about the regular meetings held in Wellington, we decided to start up a support group down South here.

We are a large group of three ladies. 39, 52, and 60-something. We catch up every couple of months to see how we are fairing for tea and bickies and a chat.

It is great being able to talk to others who can understand fully how we feel. I really enjoy reading the newsletter and hearing about the speakers you are lucky enough to get hold of. No one else seems to have come out of the woodwork down here but we will be there for them if they need someone to talk to.

Scleroderma seems to be so unknown here. I must say it was a breath of fresh air reading about Diane Purdie and how positive she is. It took me about 4 months to get my head around this after I was told but I now try and do something new every week.

It can be something as easy as trying a new food, or as challenging as doing the Routeburn Track, which we did in April. This became an event in itself when we were stranded on it for an extra day due to the bad weather. They told us they had never had to close the track due to weather before and we were the lucky first.

I must say I found it rather hard. Day one was mostly uphill and big rocks to step up and down on. Day two which was



Southern supporters - Gwenda Gray, Jenny Andrews , Kath Tilyard

There is a small support group established now in Southland. Members meet regularly to swap experiences and back each other up. Jenny sent in an account of her latest

and big rocks to step up and down on. Day two which was over the summit, and we faced thunder, lightning (which you could nearly touch as we were so high), gale force winds that were trying to blow us over the edge of the huge drops, and driving rain that felt like needles sticking into your face.

I think the adrenaline must have kicked in because that was my favourite day. On day 3 we all had cabin fever as we were not allowed to leave due to there being a bridge out. Then on day 4 we were choppered for one minute down to the bottom, which saved us one hours walking and we then walked the last two hours out, which was

horrible.

I think my body was over it by then. Lovely to say I have done it though and can now tick it off my to do list.

Hopefully you have all survived through the winter months ok. The weather was pretty cold down here but we seemed to miss a lot of what the rest of the country got.



Jenny nears the top of the Routeburn after hours of slogging upwards..



..and gets the express back down.

CONTACTS

Newsletter: Barbara Spavin Email Barbara@netco.co.nz

links: www.arthritis.org.nz | www.scleroderma.org.nz