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# Scleroderma

support group

## *newsletter*

### One year on...

Next meeting 13th November 2010

With spring all but here we will all be feeling better and able to get outside and to do our favourite things once again.

We had a good meeting on Saturday 21st August. It was more of an informal chat than an organised and strictly run meeting but enjoyable for that.

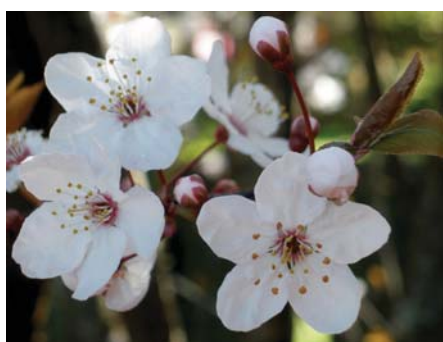
We were going to look at Yvonne's holiday slides of her South Island cycle trip but the projector refused to talk to her computer so we missed out on seeing all that south island beauty, but gained more time to talk to each other.

However, by her experience, Yvonne proved that even with the restrictions of our arthritis we can still get ourselves motivated to get up to all sort of interesting things.

It was the first anniversary of our group. Time flies and it doesn't seem that long ago.

The website is up and running. However, just like the newsletter, it needs content. Suggestions and contributions on issues relevant to the group are always welcome.

The web site address is [www.scleroderma.org.nz](http://www.scleroderma.org.nz).



### Spring...

Spring is well and truly jumping out of its skin and the group begins its second year of coping with this rare disease.

In our first year we have heard from specialists in how to handle the stress of day-to-day coping with scleroderma and from an immunologist who has exciting plans to explore ways of combating it.

At our next meeting we are organising a physiotherapist to find out how to get those reluctant joints moving again.

# 80th spring for Val

If spring is a time for new life it's also a time for reflecting on a long life and Val shared hers with the meeting, celebrating her 80th birthday.

## Yesterday Today and Tomorrow.

Yesterday my best friend woke when I stirred.  
Instantly alert  
leaping from bed, panting by the door  
then out of the gate, prancing on the leash  
Reading each newspaper message, leaving replies  
all the way to the river.  
Then running, leaping, joyous energy  
swimming, shaking dry., fetching,  
running., all-the way home.

Yesterday I too woke at dawn each day, instantly alert,  
Eager to walk with my friend in the crisp early chill  
and watch the sun rise.  
Spring in my quick step, the miles flying unnoticed,  
till home again, invigorated, inspired,  
eager to tackle whatever the day would bring.

Today my best friend wakes when I stir beside  
her then buries her nose and pretends to sleep,  
Ignoring the newspapers to read, messages to leave,  
rubbish bags to sniff.  
Time for those later. When it's warmer. Or nature calls  
for a stiff stagger.

Today I still wake at dawn, through a strange gene  
and habit that makes me rise, and stiffly leave my bed.  
My companion slumbers still, and I leave for my walk  
alone  
all the way to the gate for the newspaper.  
Then back to bed with coffee, for a few minutes  
till guilt drives me out to start the day. Except on  
Fridays when apprehensive, yet inspired and suddenly  
young again, I leap from bed to catch the No.17 bus to  
school.

Tomorrow.  
One day soon she will know the time has come,  
when she can no longer hear my loved voice and see  
my loved face  
She will creep away into her favourite part of our  
garden.



I would rather she say goodbye in my heartbroken arms.  
But she knows best.

Tomorrow.  
One day soon I too will know the time has come.  
No hospital bed, or even hospice, or loved ones to  
watch in agony.  
I will wait outside on a cold, cold night, in my favourite  
part of my bush garden,

**Valerie W.Smith**

# Adventure on the Otago Rail Trail

Yvonne Bird, wanted to ride a bike along the Otago Rail Trail. She says she could forsee a time, if she delayed, when her physical condition would prevent her. There being no time like the present, here's her account of how a little determination and a lot of training got her through. She's done it now and is still looking for other challenges.

The journey began long before we ever got to Otago, one winter evening when I remarked "I'd love to ride the Otago Rail Trail some day."

Husband Colin's head came over the top of the newspaper, just long enough to say, "Well, you'd better do it while you still can." As I dithered, Rowan (our son) promised he'd ride with me, help me to get fit and ,of course, he was coming too. We recruited a couple of friends and 2 couples on the plus side of 50, and our 17-year old lad were determined to go. I had 8 months to get fit enough to ride nigh on 160km.

I dusted off the old bike and under Rowan's direction rode once a week, twice when I could. At first I could only manage a few kilometres but gradually fitness and confidence grew. And Rowan and I had a few adventures along the way, which usually started with "We could take a shortcut...". The preparation was well worthwhile; it meant that I could enjoy the Trail without ever feeling that it was too hard.

You can bike the trail easy or tough, and and we planned to make it as easy as possible. March was good: not too hot and with settled weather. We started at Clyde rather than Middlemarch, to



*On the road on the Otago Rail Trail*

put prevailing wind mostly behind us and cycle over over 4 days. With rented bikes specifically built for the trail, our gear booked to be trucked ahead and B&B accomodation along the way, we kept weight to a minimum and set out.

The Rail Trail follows the old Central Otago branch railway, between Clyde & Middlemarch, a distance of approximately 160km. It passes through awesome scenery: little old historic towns and spectacular viaducts and bridges. There are only gentle gradients, designed for old trains and, these days, not-so-old cyclists. I enjoyed riding through the steep rocky gorges of Poolburn and the upper Taieri River. I loved cycling the magnificent, wide open Maniototo Plains under a vast, dramatic sky; the trail disappearing far into the distance. And it's hard to beat the sheer exhilaration of free-wheeling all 5kms downhill from the summit into Wedderburn, after a day's gradual uphill climb.

The entire Rail Trail journey was such a positive experience, not only for myself but for those who shared it with me. I am glad such adventures are still within my reach.



*The hard work's over as Yvonne celebrates reaching the summit. It's mostly downhill from here with husband Colin and son, Rowan.*

**Yvonne Bird**

# Herbal Infusions

There's nothing easier than making a cup of tea with your plants- just put them in a teapot and pour freshly boiled water over the top.

This is called an infusion and it's definitely the quickest way to take in the goodness of plants (apart from those you can eat raw in salads).

To make an infusion you'll need about 30g fresh or 15g dried leaves or flowers for every 500ml of boiling water.

If you don't have a teapot use a bowl and cover it – a large plate will do- so the essential oils don't evaporate.

Leave to steep for about 10 minutes.

Enjoy

Remember though, don't try this with hemlock!

## Gardener's Honey & Oatmeal Hand Scrub.

Honey moisturises, jojoba oil softens and oatmeal cleanses. Then you can add fresh elderflowers, chamomile or marshmallow to customise this hand scrub to suit your skin type.

### Ingredients

1 tablespoon oatmeal or oat bran  
1 teaspoon honey  
1 teaspoon jojoba oil (optional but good for dry skin)  
Juice of ¼ lemon  
1 tablespoon of an infusion ( in instructions above ) of one of the following.

- Elderflowers, to whiten the skin
- Chamomile for sensitive hands
- Marshmallow for dry hands
- Marigold flowers for chapped hands.

### Method

Mix all the ingredients together, adding a little more lemon juice if the mixture is too dry.  
Use as a hand scrub, then rinse off with warm water.  
Makes enough for one scrub.  
This scrub won't keep well, so make it up as you need it

ARTHRITIS NEW ZEALAND



## We welcome new members

We are a small group but bit by bit we are growing.

This month we welcome new members to the group:

- Linda Bell from Hamilton
- Jocelyn Logie from Dunedin
- Janice Ralton from Upper Hutt
- Jan Blackwell from Whangamata
- Karen Rieper from Wellington

The monthly meeting caters for those members who live within convenient driving distance of Petone.

But our geographical spread shows even more the desirability of newsletter and web site contributions to involve others from outside this area and to help them learn about and cope with scleroderma.

## Simon says

Doctor Simon is known throughout Wellington as one of the best consultants on arthritis. He always has a waiting room full of people who need his advice and specialist treatment.

One day, an elderly lady, slowly struggles into his waiting room. She is completely bent over and leans heavily on her walking stick. A chair is found for her. Eventually, her turn comes to go into Doctor Simon's office.

15 minutes later, to everyone's surprise, she comes briskly out of his room walking almost upright. She is holding her head high and has a smile on her face.

A woman in the waiting room says, "It's unbelievable, a miracle even. You walk in bent in half and now you walk out erect. What a fantastic doctor he is. Tell me, what did Doctor Simon do to you?"

"Miracle, shmiracle", she said, "He just gave me a longer walking stick."

## CONTACTS

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links: [www.arthritis.org.nz](http://www.arthritis.org.nz) | [www.scleroderma.org.nz](http://www.scleroderma.org.nz)