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# Scleroderma

support group

## newsletter

### Stress - coping and overcoming

*A clinical psychologist talks to the group about stress: its affects; how to recognise it and ways to overcome its excesses*

Stress affects many people and it has many causes. Melissa Porritt, a clinical psychologist with Gains Psychology and Consulting Services, in Lower Hutt, says the World Health Organisation claims 30% of the workforce in developed countries suffers from stress.



Melissa Porritt M.Sc.(Hons)

Melissa told the November meeting of the scleroderma group that stress is expected to become the second-leading cause of disability by 2020. Attendees

talked about the frustrations and stress resulting from a restricted lifestyle, and particularly, disrupted sleep.

“People don’t get the problems of Scleroderma because you look so well,” was one comment.

Melissa described stress, saying worry is only a small part of it. She defined stress as: when demands from the environment or internally, exceed a person’s resources.

*(Contd. p2)*



### Summer awaits...

Greetings to all and welcome to our newsletter for November 2009.

It was good to see everyone at the meeting and know that we all survived a very cold and wet winter. With summer on its way let’s hope the improved weather has a good effect on our sore joints and cold hands.

We had a good meeting and there were some good suggestions which we hope to carry out as our group progresses into the New Year.

# Stress - coping and overcoming *cntd.*



- **Body:** The body's reaction to stress includes symptoms such as fatigue, headaches, diarrhoea and an inability to relax.
- **Actions:** Stress modifies your actions so that you can't sleep through the night, lose libido, develop poor eating habits and are tempted to smoke and drink to excess.
- **Mind:** Stress causes you to suspect others' motives, makes you uncertain and forgetful and causes your mind to race away with thoughts.
- **Feeling:** Stress works on your feelings too, causing anxiety, tearfulness, impatience and a loss of joy and motivation.

All around, stress gnaws away on your body and mind. Managing stress is beneficial and important. Remember, Melissa says, some stress is necessary but you need to recognise the symptoms of excess stress before they become normal to you. You can't manage it until you can recognise it.

Management, Melissa says, includes changing the external influences and changing old habits and expectations.

Melissa's suggestions for management, apart from professional help, include:

- Eat healthy foods
- Exercise (even if your conditions limits the extent of it)
- Make time to enjoy yourself
- Visualise a pleasant scene while breathing deeply and rhythmically.

Melissa's advice: If you feel stressed, analyse situations and examine options. Is this really important? If it is, am I responding appropriately? If not, is it not as important as I first thought? Plan your reactions accordingly.

She says there is no easy way to manage stress and no easy way to develop the resilience to overcome it. Work on your self esteem, learn from past experience how to cope in future, be joyful and positive and avoid negative things.

Easier said than done? Melissa says many PHOs have psychological services offering up to 6 free visits for those not coping or managing stress themselves.



An attentive audience at the Scleroderma group's November meeting listens to clinical psychologist, Melissa Porritt describe the symptoms of stress and ways to cope with them.

## NEXT MEETING

Saturday,  
13 February 2010

The meeting dates for next year have been confirmed with Melissa O'Connell at Arthritis NZ:

- Feb 13th
- May 8th
- August 14th
- Nov 13th

Each meeting will be held at the same time 2pm

## CONTACTS

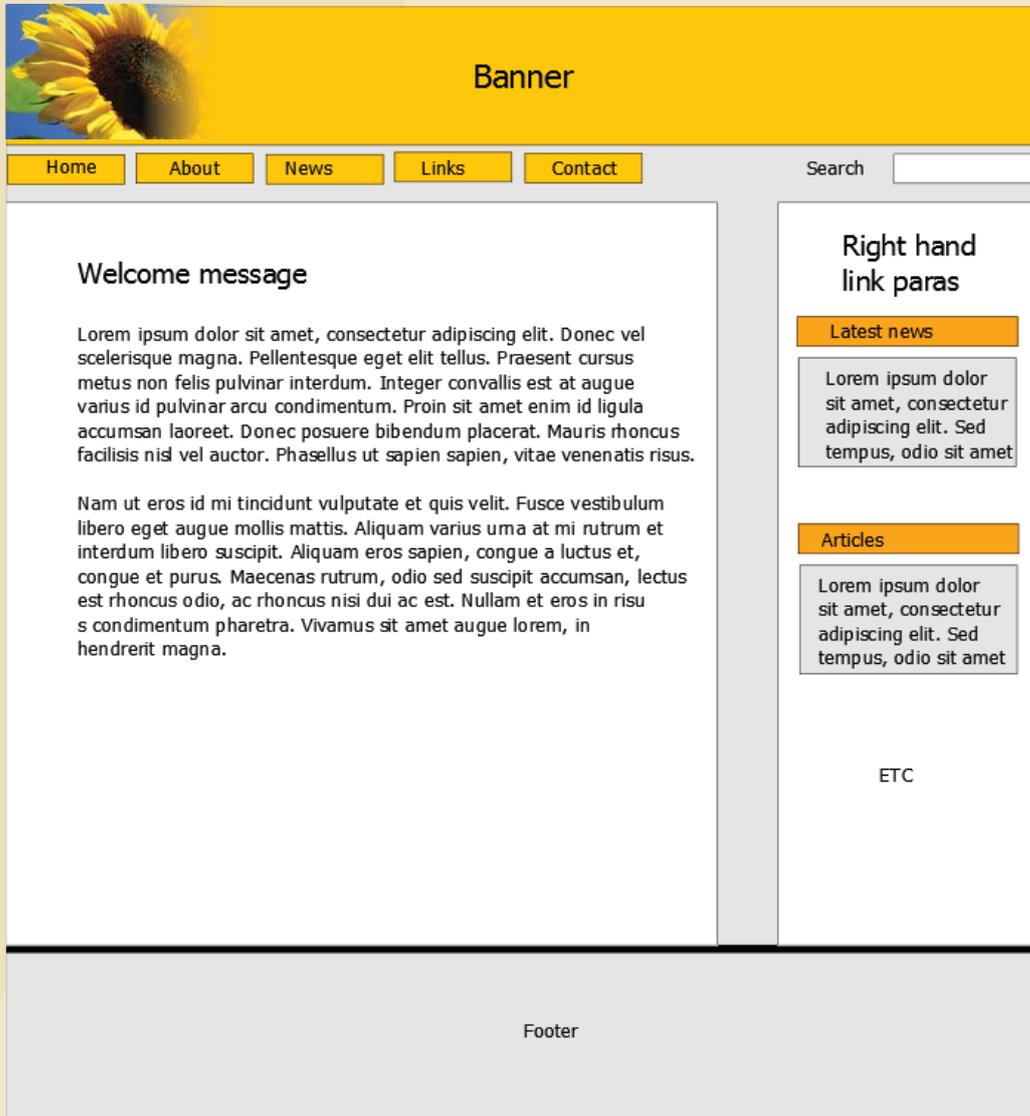
Newsletter Barbara Spavin  
Email [Barbara@netco.co.nz](mailto:Barbara@netco.co.nz)  
Our New Web address:  
Details to come  
Other links:  
[www.arthritis.org.nz](http://www.arthritis.org.nz)  
[www.scleroderma.org](http://www.scleroderma.org)

# Web site planning begins

We have secured the domain name scleroderma.org.nz and plan a web site that members can manage themselves.

It will allow for a site administrator and 'helpers', who can load and format content. It might be a good idea at February's meeting to elect/select an editorial team of 2 or 3 members who would oversee content.

Any member with content to contribute could submit it to this editorial team. A possible layout is as follows:



Wordpress is acutally blogging software but we will adapt it to become a standard, content-managed web site.

The only problem with having a web site is that it needs to be current. Keeping it up-to-date by sharing the work about should mean that no one person struggles to think of things to add.

By its nature, the site will be available throughout New Zealand (and every other country) so it may be that suggestions, contributions and requests for link exchanges come in from people who are not connected with the group. That's where the editorial committee will need to decide whether the contribution is worth linking to or publishing.

We'll put the site up on a test server with password protection prior to its going live so the group can suggest changes and additions.

## Web content

Initially, we'll offer the following content:

**Awareness.** For the public and for those affected by and those who are new to the condition.

**Member information:** For members of the group to keep them up-to-date

**Links:** A good set of links for both members and the public to find out more about scleroderma.

Arthritis NZ will add a link to their website once it's up and running. They can also be approached to spread the link to the wider medical profession.

Most web sites evolve from day one and we should presume that this is a start and that it can grow as the need arises.

## Scleroderma on the web

A simple search, entering only the word scleroderma into Google produces 1,780,000 results (hits).

Restricting results to New Zealand pages produces 2,550 hits.

Microsoft's Bing search engine shows a little less than half of Google's hits for all the world, and just under 600 for New Zealand.

A search on New Zealand's largest group of newspapers on one web site, Fairfax's stable at [www.stuff.co.nz](http://www.stuff.co.nz), results in just a single hit.

Of course it is the story the Dominion ran last year (complete with photo) about Diane and Gordon's battle with ACC

# November meeting notes

The group's second meeting was held on 14th November 2009 at the Arthritis New Zealand rooms in Petone.

We had 13 members and partners attend with one apology from Linda Lum. Tina chaired the meeting and introduced the guest speaker Melissa Porritt who spoke to us about stress. We also talked about getting a website, continuing with the newsletter and more ways of distributing it, where our meetings would be held and having a social event.

## Website

John investigated options and opinions for the Scleroderma website. See more detail on the preceding page. Arthritis NZ will add a link to their website once it's up and running. They can also be approached to spread the link to the wider medical profession.

The name scleroderma.org.nz was suggested and has now been secured.

## General Business

**Pamphlet:** Currently Arthritis New Zealand doesn't have a pamphlet on Scleroderma. We agreed that it would be useful if they produced one and had this information available for the newly diagnosed and the public.

**Meetings** Diane indicated that only 20 people can meet in the Arthritis NZ rooms. Other venues may need to be investigated if our numbers grow. There could also be a cost involved in this.

Hutt Hospital could be given notice of our next meeting to be posted on their notice board.

A gold coin donation was suggested to cover afternoon tea

**Newsletter** Barbara requested that material for the next newsletter should be received within the next two weeks in order to get the newsletter out before Christmas.

A flower image to represent the Scleroderma group was discussed. The sunflower, which is used by the Queensland Scleroderma group, was used in the last newsletter and seemed a popular choice.

Copies of the newsletter could be distributed through Hutt Hospital. Arthritis New Zealand held copies of the first newsletter and distributed these. They will do the same with the next issue.

**Socials** The possibility of holding a social event was raised. It was greeted with enthusiasm and may possibly be held at someone's home. A middle-of-the-year function seemed popular. We will discuss this further at the next meeting.

**Meetings** The next meeting for the Scleroderma Support Group will be held on:

**Saturday February 13th 2010.**

There will be no speaker for this meeting. Speakers will be sought for every second meeting.

The meeting closed at 4.40pm

# Background

The Internet is full of references to scleroderma, some sites offering only quack remedies while others are extremely helpful.

Here's an authoritative one: the American Scleroderma Foundation, founded 10 years ago. Its web site is packed with reference material, case studies and explanations of the disease in everyday language.

A good place to start is its PDF download, describing scleroderma, its health implications, its varying forms and tips for its management.

<http://www.scleroderma.org/pdf/NewlyDiagnosed/2009/U&M.pdf>

## Scleroderma factoids

The Ministry of health's web site doesn't mention scleroderma even once.. It mentions diabetes 281 times; ulcers 11 times, piles once; tuberculosis 312 times.

Hippocrates wrote about a disease with symptoms similar to scleroderma way back around 400 BC. It was first described in 1753 in Naples.

## Ouch!

A little old man shuffled slowly into an ice cream parlor and pulled himself slowly, painfully, up onto a stool. After catching his breath, he ordered a banana split. The waitress asked kindly, 'Crushed nuts?' 'No,' he replied, 'Arthritis.'

# Recipe: Golden Pork

An unusual but successful combination of fruit and vegetables suitable for a family dinner. Satisfying and so delicious.

- 4 l lean butterfly steaks (500g)
- 1 cup unsweetened apple juice
- ½ cup water
- 2 Tbsp soy sauce
- ½ tsp ground ginger
- 2 medium – sized kumara, peeled and sliced
- 2 apples, peeled, cored and sliced
- 1 Tbsp flour
- 1 Tbsp water



Remove all visible fat from the meat and cut each steak in half. Brown the meat in a non-stick frying pan. (It is easier to brown a few pieces at a time than to do them all at once.) Place the browned meat in a large casserole dish. Add the apple juice, water, soy sauce, ginger and kumara. Cover and bake at 160 degrees C for 1 hour, add the apples and cook for a further 30 minutes. Drain the juice from the casserole into a small sauce pan. Mix the flour and water to a paste. Add to the juice and heat gently until thickened. Arrange pork, apple and kumara on a serving plate. Pour the sauce over.

**Serves 4. 1319kj (314 cal) per serving.**

# Recipe: Apple Crunch

Rolled oats and cinnamon always combine well for a tasty, high-fibre topping. Serving apple halves are a quick innovative variation of a traditional crumble.

- 4 medium- sized apples
- 1 cup rolled oats
- 2 Tbsp brown sugar
- 1 tsp ground cinnamon
- ¼ Cup polyunsaturated margarine
- ¼ Cup natural low fat yoghurt



Core the apples, cut in half horizontally and place cut side upwards in an ovenproof dish. Blend the rolled oats, sugar, cinnamon and margarine together. Pile the mixture on the cut side of each apple half. Bake at 180 degrees C for 35- 40 minutes or until golden brown. Serve with a spoonful of yoghurt.

**Serves 4. 1375 kj (327 cal) per serving.**

## Medical Journal

survey on

## Raynauds

Gordon and Dianne Purdie, together with Dr Andrew Harrison, have recently published in the New Zealand Medical Journal the results of their survey of Raynauds phenomenon.

They sampled 350 people from the electoral roll and 234 people responded (67%). 19% of females and 5% of males reported symptoms of Raynauds. These were people whose fingers had two different



colour changes. The prevalence decreased with age. There was a higher prevalence in the warmer

north of the country. People of Maori descent and in those in manual occupations had more severe symptoms. Among those reporting symptoms 11% had consulted a doctor. The researchers concluded that New Zealand has high rates of RP and that few people with RP consult medical practitioners about their symptoms.

## Merry Christmas

We hope you all enjoy a merry Christmas and a have great New Year.

