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Scleroderma

support group

newsletter

Winter Issue 2012

Greetings and welcome to another newsletter.

In this newsletter, as discussed at the meeting, we are hoping for recognition on World Scleroderma Day which is 29th June. We should all do our best that day and enlighten at least one person about this condition. Or maybe even give them a copy of the newsletter to read.

Dianne has given us handy hints on ways to cope with the cold for this coming winter, which you are probably not looking forward to.



And there is another episode from Diane Barker on how to cope with our energy reserves and ways on dealing with this.

A must for all of us to read and apply.





World Scleroderma Day

At the Wellington Scleroderma support group meeting on the 12th of May we decided to acknowledge the 4th World Scleroderma Day on the 29th of June 2012.

We will acknowledge this via a media release, to raise awareness to the New Zealand public

What is World Scleroderma Day all about?

June 29th is World Scleroderma Day, an international event to raise awareness of scleroderma. The day started in Europe in 2009 and is now worldwide. The 29th of June is the anniversary of the death of Paul Klee, a Swiss painter who had scleroderma.

To quote Scleroderma Australia:

"We campaign for a world in which equal rights, treatments and care are offered to people with scleroderma, and in which such diseases are not forgotten, but afforded the consideration and attention of other more widely known diseases."

"Having a disease that nobody has heard of is a lonely business."

So World Scleroderma Day was created to raise awareness of what it means to have this disabling disease.

June 29 is a day to recognise the bravery of those who live with this disease and to demand equal treatment and equal care for people with scleroderma."



Paul Klee died June 29, 1940

The gifted Swiss artist Paul Klee made painting his life's work, but it was strongly influenced by his illness, systemic scleroderma, as the painting chosen for Scleroderma Day demonstrates.



Paul Klee, Kettledrummer 1940, 270 (coloured paste on paper on cardboard), 34.6 x 21.2 cm, Zentrum Paul Klee, Bern, © DACS 2008

Energy conservation

Energy conservation is about carrying out activities in the simplest, least tiring way so that you have energy left for the things you want to do. These techniques are designed to help you cope with fatigue and to simplify the way you carry out tasks.

February's guest speaker, Diane Barker, continues a series on self-help. Diane is a therapist at the Occupational Therapy department at the Hutt Valley DHB.

Kitchen

- Cook larger quantities; freeze individual portions to be used when you are feeling tired.
- Sit to prepare vegetables.
- Use recipes that require minimal effort. Gather all necessary equipment/ingredients before beginning.
- Use a trolley or a tray to transport items.
- Soak dishes to eliminate scrubbing. Air-dry dishes.
- Avoid holding on to items. Use stabilisers such as a wet cloth under a mixing bowl.

Personal Care

- Sit to shower, dress and dry. Use long handled brush in shower to avoid bending.
- Use lukewarm water in shower to avoid over-relaxation.
- Avoid having to dry too much by using a towelling robe.
- Dress your lower body first; place underwear and pants on at same time; pull up together to avoid unnecessary bending.

Laundry

- Sit to fold and sort washing.
- Buy clothes that do not need ironing.
- Use a peg apron or sit pegs on a stool to avoid stooping.
- Use a wheeled trolley to avoid lifting. If using a washing basket sit it on a stool to avoid bending. Lower your washing line to avoid reaching or use a clothes airer.

General

- Use energy saving devices such as electric can openers.
- Use a duvet instead of sheets and blankets.
- Arrange cupboards so everyday items are stored between shoulder and hip level.
- Operation mobility cards can be applied for so that you can use disability carparks close to your destination. Talk to your GP or the NZ Arthritis Foundation.
- Don't try and do so much in hot, humid weather or on cold windy days as you would in cool, pleasant weather

Thanks to: *South Auckland Health – Middlemore Hospital*

The four Ps of energy conservation

Prioritise

Do your most important tasks first so if you run out of energy, you have completed your priority tasks.

Delegate tasks or ask for help. Ask yourself, "Do I have to do the task? Could someone else help?"

Eliminate unnecessary tasks. Ask yourself, "What would happen if the job is not done? Is it really necessary?"

Planning

When is the best time to complete the task?

Plan ahead so that jobs can be distributed over the week.

Plan light tasks to follow heavy activities and spread them out over the day.

Do heavier tasks at the time of day you have most energy.

Pacing

Pace yourself. For example, work for 30-40 minutes then take a short break. Always include rest periods in your work.

As soon as you feel tired or aching – STOP. Do not push

Avoid rushing and take breaks when you are tired. Taking breaks during the day can save energy for more enjoyable tasks.

Posture and Positioning

Use efficient methods to complete tasks. Is there an easier way to complete the task?

Set up your work place with all the required equipment and place within your reach. Organise storage within easy reach and in the right position to grasp and use straight away.

Lift correctly - hold objects close to your body and avoid bending and twisting. Reaching or stretching are energy consuming.

Avoid long periods of standing and sit where possible.

Use both hands to lift objects.

Slide objects along a surface rather than lifting and carrying. Consider using a trolley or laundry trundler to carry objects.

Now you need to assess your daily routine and alter methods and habits if they use unnecessary effort.

Spreading awareness of scleroderma

At our last meeting in Wellington we discussed whether our support group would like to raise awareness of scleroderma by perhaps wearing printed T shirts, hats, scarves and pens, and we finally came up with the idea of wearing a badge with a New Zealand Scleroderma logo, and opening the floor to everyone around NZ for design ideas.

As it happened we were scouting around the internet and came across that Scleroderma Australia have designed a sunflower logo. They presented it to the World Scleroderma Foundation at the World Scleroderma Congress in Italy in 2010. They proposed that the logo be adopted internationally as a logo for scleroderma, their proposal was accepted. The logo is now used in many European countries, South America, Indonesia and the Philippines. We now recommend that New Zealand join in with the use of the logo.

We contacted Robyn Sims, the President of Scleroderma Australia, as they have some lapel badges with the sunflower logo on them. We thought it was a good idea to purchase some. We will let you know the price and how to purchase them when they arrive.

Why the sunflower?



To raise awareness about the condition, Scleroderma Australia has adopted the sunflower as the national icon.

The sunflower is symbolic, as, like the sunflower which turns towards the sun for warmth, people with scleroderma are usually more comfortable in warmer weather.

In other words we are both heliotropic (tendency to seek the sun, particularly in winter for people with scleroderma).



Ideas to increase circulation

- Lower your caffeine intake
- Exercise moderately each day.
- A good night's sleep
- Light Yoga exercises
- Arthritis NZ has some good light exercise CDs that you might like to purchase.

Things to avoid.

- Stress can trigger an attack.
- Don't Smoke
- Avoid drinking ice cold drinks
- When handling cold objects from the fridge and freezer, it is best to have a set of gloves by the fridge freezer so you get yourself into a routine.
- Try to avoid carrying heavy plastic shopping bags by the handles.
- Wear disposable plastic gloves over your woollen gloves when gardening.

If you personally have any other handy hints please share them - we all need to learn what you can help with.

Keeping warm over autumn and winter

ARTHRITIS NEW ZEALAND



It is that time of year again, when the cold affects most of us. So just a reminder that it is very important to keep warm, not just to protect our hands, feet, nose and ears, but our internal organs as well, as the cold can induce internal Raynaud's.

Here are some helpful hints.



Wear enough layers of wool clothing to keep your core warm, I generally need three layers of wool over winter. Keep your eyes out for some good deals for merino wool, you can get up to 20% off in some cases.

Warm your gloves before you put them on. Put your gloves on before you get cold. Don't let your hands get Raynaud's before putting your gloves on as it can take a very long time before the gloves have any effect.

If you do get Raynaud's in the hands bath them as soon as possible in warm water to bring back the circulation.

You can use small wheat bag hand warmers or pocket warmers for extra warmth inside your gloves or just to hold for warmth comfort.

If you are not near any warm water then rub your hands together very quickly and blow into them.

Same for your feet, wear thick woollen socks and warm them before putting them on before going outside. I bet you can blow on your feet too.

Wear a hat to cover your ears and scarf over your mouth

and nose if it is icy cold.

Wear wool leggings under your trousers. You can purchase some nice soft fine merino wool ones from outdoor specialist shops for a reasonable % off at times.

If you are out in the wind for your walk it is very important to wear over trousers and a fairly down jacket or a good quality wind proof jacket over your three layers

Soak your pegs in hot water when hanging out the washing.

Keep your hands out of cold water, wear thick plastic dishwashing up gloves when washing the veges for cooking etc

Have a warm drink after being outside, this can be help you feel nice and warm inside.

Keep your home warm and avoid going out in the cold when it is unnecessary, try going for a walk in the middle of the day for your exercise if possible.

Three sisters

Three sisters, aged 91, 93 and 95, live together. One night the 95 year old draws a bath for herself. As she sticks her foot in, she pauses. She yells to her sisters downstairs, "Was I getting in or out of the bath?"

The 93 year old shouts back

loudly, "I don't know. Let me come up there and see." She begins walking up the stairs, but then pauses. She yells to her sisters "Was I going up the stairs or down?"

The 91 year old is sitting in the living room, sewing another scarf. She listens

to her sisters, shakes her head and mutters to herself, "I sure hope I never get that forgetful. Knock on wood."

She then turns and shouts, "I'll come up there and help both of you as soon as I see who's knocking at the door."



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