

Momentum

NEW ZEALAND



The Otago Multiple Sclerosis Newsletter

Balclutha Dunedin Alexandra Wanaka Oamaru



Sister with two of her brothers 90 Year old Ray and 72 year old Frank.

She was up a ladder, resplendent in her 1950's Nun's habit, cleaning out the Convent guttering when she realised something was badly wrong – she couldn't get down the ladder, her right leg refused to move.

Unbeknown to this 29 year old teaching Sister this was the start of her 59 year association with Multiple Sclerosis although Sister de Lourdes Campbell was not to know this for another seven years.

"I just knew that something was terribly wrong, to this day I really don't know how I got down that ladder - perhaps God just picked me up and put me on the ground I just don't remember."

Sister de Lourdes Campbell was born in 1921, one of nine children, six brothers and two sisters. Her siblings' births stretched over a 20 year period on either side of the Great Depression, from 1920 through to Rita's birth in 1940.

It is little wonder then that she became such an adaptable, resilient person. By the

age of 11 she had had to learn the skills of "life"; gardening, sewing, meal preparation, baking and of course child care. These skills were to provide her with her life long teaching career and the instilled ability and desire to help her fellow man.

When she got "this awful thing" it also provided her with the resilience to adapt and carry on.

For seven years Sister had waited to be received into the Convent, but the war years intervened and it was not until 1947 when she had been teaching for six years that she was accepted into the "Sister of Mercy" as a Teaching Sister. Her teaching career continued in Mosgiel but it was just three years on years in 1950 when she first began "...tripping up the stairs...".

"For seven years after that ladder incident I visited every doctor I could, I went from doctor to doctor.

"Of course because I was in the Convent Mother Superior had to come with me to each appointment – I was really lucky

that she believed in me, that she knew something was really wrong

"All the doctors just told us the same thing - it was my imagination, there was nothing physically wrong with me. I looked healthy, I was healthy except for my leg. At 88 I still am.

"Then in 1958 someone told me about a doctor called "Noffy" Lewis. We went to see him, we didn't have any great hopes he was just another doctor. He examined me and said those words ... "I think you might have Multiple Sclerosis.

"Well what mixed emotions. I didn't know what was Multiple Sclerosis but I wanted to give him a hug just because he recognised something beyond my imagination. He said I would have to spend a night in hospital to have some tests. This included a lumbar puncture that was quite a procedure in those days. This confirmed the diagnosis."

Typical of this feisty woman, after accepting the diagnosis Sister decided that MS would not become a barrier to her teaching career.

"I love children, I loved teaching, I loved learning and there is always a way, you just have to adapt."

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Inside:

- Prevalence of MS in NZ
- Intimacy and Sexuality in MS
- New events calendar
- Vitamin D fact sheet
- Chronic Cerebrospinal Venous Insufficiency



Have you ever heard someone proclaim that there are defining moments in all lives, defining moments that change the very path along which we walk – scoff you may but it happened to me.

Here I am approaching advanced middle age, watching my eccentricities deepen, my waistline girth increasing, my memory fading just a little more, stumbling somewhat listlessly along, around the metaphoric and hey presto I fall - hopelessly, totally, unexpectedly and completely in love.

It all began with the phone call from my son – “Mum, could you look after the dog for three weeks for us – I’ll fix the fence, he won’t be a problem...” Why is it that when a mother opens her mouth to say ‘no’, ‘yes’ comes out.

So here we are several days later, one large, gangly 11 month old, bearded pup and I waving as the van carrying Tussock’s father, my only son, disappears down the road and out of sight.

Tussock looks at me, sinks to his haunches and begins to cry. It’s pathetically sad, gut wrenching, heart-rending. What can a doggy grandmother do but put her arms around him, sink to her haunches and cry right along side him.

This lasts for three days, no eating, the sad, pathetic driveway vigil, my bed (which he was absolutely not going to get on) covered in muddy footprints.

Then on Thursday, suddenly, it was as if the sun was out – everything changed.

5.30 in the morning he leaps on the bed. “Granny, granny wake up, time for a walk, out of bed, lovely day, come on now granny

time to be moving...” 6.30 and the rural delivery man is more than a little amused to see us playing catch the ball along the grass verge.

Lunchtime – “Granny put the paper down, come on Granny we need another walk, lets go swimming Granny, come on, come on.”

Mid afternoon – “Hey I know Granny lets go for a drive – hey Granny I love cars...”

Late afternoon – “It’s beach time Granny – come on let’s go chase sticks...”

Somehow this formed a pattern, Tussock’s pattern, we walked, we chased balls, we learnt to surf, we upset the white baiters, we chatted with all the other dog walkers – and one day I paused amid all this frenetic activity. I realised I was having such fun, I had ‘someone’ to talk to, I laughed, we both did, a lot, I exercised more than I had in years, I was suddenly busy with heaps of things to do.

Somehow over the years I had forgotten how nice it was to share the car, to come home to ‘someone’, to wake up to another being. It was great. I had accepted loneliness and under achievement as the norm of middle age. But hey life was suddenly good again. Tussock and I were in love

But as time has a want to do the inevitable was happening, that fateful day was approaching. Tussock would have to go home. We would be separated. We discussed elopement, perhaps just getting in the car and driving over the distant horizon, hiding in the long grass till they had gone away, he agreed with all these ideas I swear he did... then the day was here, the gate opened, the van drove up the drive.

An excited yelp of recognition, scarcely a backward glance and Tussock was down the drive, over the lawn and into his father’s arms... ah yes puppy love.

But, you of little faith, love can last forever just like in the books - I pick up my puppy in three weeks – he’s Tussock’s half brother and I can’t wait. I have told him all about surfing and chasing sticks and sea gulls and all the exciting things we are going to

do – together - just him and me... we’re both counting the sleeps.

Till next time, keep smiling and watch out on that path through life you never know what might be round that next corner.

Cathy Morrison

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Disclaimer

The information in this newsletter is for the purpose of informing people about multiple sclerosis, events and interesting reading.

The contents of this newsletter neither indicates or reflects the views of the Otago MS Society.

You should not rely on any information produced in this newsletter in place of a visit, consultation or advice of a doctor or other qualified healthcare provider.

Letters to the Editor

I read with interest your article in a recent journal.

I am a paraplegic, have end renal failure, I’m on dialysis (every night) have a 3 acre rural property, work full time as an employment consultant.

Its all to do with attitude!!!

David Barry

Employment Consultant

Workbridge

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President's Report

The new year has come round really fast and we are already at the end of February and the end of the summer (hopefully not).

The committee has been busy since November looking at ways the society could restructure and run its self more efficiently.

Quite a lot has changed over the last five years for the society many of the older practices are ending and new strategies are needed to keep the society healthy and viable.

The committee has acknowledged at the end of 2008 and noted at the 2008/2009 AGM that the door to door appeal is quite a challenge to function as collectors are difficult to find and the number of returning ones has been dropping for years.

However there are other fundraising opportunities for the society and the trick for the society is to shift focus and dependence on the door to door, that has traditionally raised about a third of the income it takes to run the society annually.

Following the disestablishment of lynley,s position the committee set about researching what the job description would be that the society needed to run it self in the future.

To assist with this the committee functioned a strategic planning session with the

members on Sunday the 31st of January to help get feed back from the members over the direction the new position should take for the society.

The committee is very grateful to all the members who turned up and to all of the helpful suggestions that were made on the day.

The committee is looking forward to moving the society forward in a professional and coordinated way and to give the society new energy.

The AGM for the society is coming soon and there are a number of positions available on the committee if any one knows of someone the society would be pleased to hear from him or her.

The committee has plenty of work ahead of itself as it develops fundraising options and develops support mechanisms for the members.

The 2009 year has meant some big changes for the society rooms with the completion of the long awaited day room extension which has made the society rooms more useable and friendly.

I look forward to seeing members at the AGM.

Gavin Mead.

Otago Multiple Sclerosis Society

Wish to advise and invite you to our

Annual General

MEETING

with Guest Speaker

At: 8 Baker Street

Caversham Dunedin

15th March 2010 at 6 pm

All welcome to meet current committee members and staff.

Registration of interest to stand for our committee

Please contact us below for a registration pack.

For catering purposes also, please confirm attendance to;

Reply to: msotago@actrix.co.nz or msadmin@actrix.co.nz

or leave a message on: (03) 455 5894 or (03) 455 5273

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- \$194.00 per night (usually \$240.00 per night)

There are 3 wheelchair accessible apartments available; wet area shower, pull out kitchen drawers.

The above rates are GST inclusive, NZD, per apartment, per night, nett non commissionable, book direct and subject to availability. Bookers/guests would simply need to advise they are a member or from the Otago Multiple Sclerosis Society organisation to qualify (at the time of the booking).

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**Winner – Quest New Zealand
Franchisee of the Year 2009**



Sister de Lourdes Campbell with her “baby” sister Rita (now 70 years old).

And adapt she did. Soon after visiting “Noffy” Lewis Sister began using a wheel chair to get the short distance from the convent to school. One day one of her students suggested he could help by calling by the Convent in the mornings and pushing her to school.

And that was what happened – the wheel chair was modified slightly, a bar fitted across the handles – a bar just big enough for two pairs of little hands to hold and push.

“Every morning for the next 17 years boys turned up at the Convent to push me to school!”

Sister de Lourdes said that early on the disease could be really frustrating. She recalls when her right hand decided it wasn't going to work. She was sewing, something she had done since she was a child, when she couldn't get her sewing lined up. She then tried to have a drink – the glass fell from her hand and shattered. But once again she “adapted”.

“OK I couldn't work the sewing machine pedal with my foot, or my hand, so I simply used my elbow. You can manage; it's amazing what you can do if you just keep trying. Sure you get frustrated but keep trying, there will be a way.”

Strangely after many years of adapting and relying more and more on her left hand, Sister's troublesome right hand has decided she can use it again.

Fifty-eight years ago Sister had no idea what MS was. She said that doctors had trouble explaining to her how the disease

progressed, what her outcome was.

“They really didn't know themselves. And they are still explaining. The difference is that now they know what it is, what causes it. I find that the specialists now are trying really hard to help people; there is more research, more knowledge.

“For a long time I wouldn't read about MS – I would get angry when people and companies made promises, when people wrote things they didn't know about. Now I pick and choose what I read about M.S.

“I have been lucky – I have had my faith and this has helped me enormously. I had only been in the Convent for three years when I got this awful thing. But yes I have my faith.”

Last year Sister got her motorized wheelchair and she says she is “never out of it.”. If the sun is shining in Dunedin Sister de Lourdes will be sitting outside, preferably in the rose garden with the flowers she loves so much. She still loves her books and reads at least two a week.

She has been made a life member of Adult Literacy in New Zealand for the many years she has put into teaching other people - children, adults, and people from all walks of life, to love the written word as much as she does. As an adult literacy tutor she was asked to help prisoners who couldn't read, therefore spent 16 years helping them. As a direct result she was also awarded the QSM medal for her amazing achievements.

Not bad for someone who has had MS for a mere 59 years!

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“Diamonds are forever – and so are the days of the Coombes lives”



Nancye met Lance in the Summer of 1946/47 out at Brighton, when Nancye was visiting there with a friend. Nancye's friend met up with a cobbler of hers who happened to be there on his bike with Lance. Lance took a shine to Nancye and they quickly arranged an outing to the movies.

And the rest they say – “is history”, until the day when they have happily celebrated their *Diamond Wedding Anniversary*

Lance was a local Mosgiel lad, who had a passion for many things, but the thing he felt most passionately about was Nancye, once he'd met her. They courted for about 16 months, eventually becoming engaged in 1948 just prior to going on holiday to Queenstown with Nancye's family.

Nancye was a Green Island lass, with a full and happy life, made happier by meeting Lance.

A beautiful Wedding was celebrated at the Green Island Presbyterian Church, under the guidance of Rev' Oliver.

From the 10th December 1950, married life for Nancye and Lance began. They report to have enjoyed a happy life together, and have great memories and stories to share with their two daughters, Maureen and Eleanor plus their many friends and relatives.

A great story to share is how they began living together as husband and wife; they spent their first 3 months living in a tent on Nancye's folks front lawn, “it was fun really ... lovely memories of that summer ...” Then they rented their 1st cottage in Mosgiel for 4 years, before buying their first own home in Green Island. Maureen was two at the time. Eleanor came along later.

Nancye developed Multiple Sclerosis in the early 1970's, and was eventually diagnosed with MS by 1976. She has remained in reasonable health, with the occasional relapse which has been managed very well by her with the devoted support from Lance. They travel everywhere together companionably, holidaying in favourite places like Kakanui and Queenstown.

They are very proud of their daughters, and are completely devoted to each other; it is a delight to see in this day in age. They are a true inspiration to us all.

From us all at the MS Society, we would like to extend our warmest and most heart felt congratulations to Nancye and Lance Coombes, when they celebrated their Diamond Wedding Anniversary at the end of last Year.

JUST A REMINDER...

We would love to hear from you! Letters to the Editor, news, photos or anything you think maybe of interest are welcomed.

We can't promise that everything will be able to be published, but your input would be appreciated. We wish to create a very really link between us and our readers.

Snail mail can be sent to:
MS Society
PO Box 2293
Dunedin

Or email to:
cmorrison@xtra.co.nz

Looking forward to hearing from you.

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Prevalence of Multiple Sclerosis in New Zealand

In 2006 a survey was initiated with support from the National MS Society of New Zealand as a partnership funded project with the New Zealand Health Research Council.

This was the first nationwide study ever done to accurately determine the prevalence of MS.

A report detailing the findings of the study was released late last year and made interesting reading. Below I have attempted to précis the report into a more concise article.

Results:

The authors identified 2,917 PwMS (People with MS) living in New Zealand on census day (March 7th 2006).

Worldwide prevalence:

The overall prevalence of MS in NZ is 72 per 100,000 people

Scotland range between 145 and 193 per 100,000

England, Wales, and Northern Europe range between 74 and 112 per 100,000

Asian countries appear to have very low rates. Japan reports 8 per 100,000

Latitude and prevalence of geographical New Zealand

- | | |
|---------------------|-----|
| • Northland | 51 |
| • Auckland | 59 |
| • Waikato | 46 |
| • Bay of Plenty | 50 |
| • Gisborne | 47 |
| • Taranaki | 67 |
| • Hawkes Bay | 54 |
| • Manawatu/Wanganui | 54 |
| • Wellington | 86 |
| • Nelson/Tasman | 78 |
| • Marlborough | 87 |
| • Canterbury | 103 |
| • West Coast | 119 |
| • Otago | 119 |
| • Southland | 135 |

This shows the latitudinal gradient of 50 per 100,000 in the north through to 100 per 100,000 in the south.

This lends further support to the theory that sunlight levels and vitamin D may be an important factor in the instances of MS

Gender

75% were woman and 25% men – this is a ratio of 3:1 female to male

Ethnicity

Maori have a substantially lower prevalence of MS than European

Of the 2917 people with MS only 67 were identified as Maori.

The very low rate of MS in Maori confirms that they do not have the same genetic or environmental susceptibility to MS as those of European ancestry.

Socio-economic Factors in NZ

- In March 2006 68.1% of New Zealanders were employed – the rate for PwMS was 37%
- 58.6% of PwMS were unemployed
- 65.8% of PwMS say their employment status has changed due to MS
- The median income for PwMS was \$20,000 compared with \$24,400 the median for the NZ population
- All age groups over 30 of PwMS earned less than their NZ peers
- 52.7% of PwMS have a tertiary qualification compared to the NZ population of 40%

Summary

This resource is one of the largest and most comprehensive ever compiled. It is hoped that ongoing analysis of this resource will help direct appropriate and targeted support and treatments for PwMS.

In addition the study has provided a body of new information in the quest to identify the cause of MS on which further studies both in NZ and internationally will be based.

(The editors and contributors to the original report include:

Bruce Taylor; Anne Richardson; Deborah Mason; Ernest Willoughby; David Abernathy; Glennis Clarke and Clive Sabel.

We congratulate and thank them)

MS Society Vitamin D Fact Sheet

Early last year the scientific open-access journal PloS Genetics published the results of a trial funded by the UK MS Society and MS Society Canada.

The results of this study for the first time show clear associations between genetic and environmental risk factors associated with developing multiple sclerosis.

What does this study tell us?

- In this study researchers investigated how vitamin D affects a gene associated with MS
- This preliminary work suggested that vitamin D deficiency early in childhood or before birth MAY increase this risk of a person developing MS later in life
- Genes instruct the way proteins are made, and proteins are the building blocks of the body. This includes your immune system.
- A lack of vitamin D means a 'weaker' version of these proteins are produced. When 'weaker' versions of these proteins are produced a person may be slightly more likely to develop MS.

What does this mean to someone suffering from MS?

- It is important to keep in mind that MS is a very complicated condition that stems from a mixture of environmental and genetic factors that may or may not be inter-linked. Although this study is interesting and it's the first study that shows that environmental and genetic factors MAY be linked, more work needs to be done to prove the theory and determine further environmental factors that may affect genes associated with MS.

Would it help if an MS sufferer were to take vitamin D supplements?

- It is good health advice that everyone (whether you have MS or not) should get the recommended daily amount of essential vitamins and nutrients. You can get the vitamins and nutrients your body needs from a balanced diet and healthy life style. If you can spend a healthy amount of time outside it is a sensible course of action, not just for MS but for your health in general.

What can one do to prevent vitamin D deficiency?

- A typical person needs 2,000-4,000 international units (50-100mcg) of vitamin D per day which can mainly be obtained through exposure to sunshine; however your body can store up some vitamin D for days when you don't reach this requirement.
- 15 minutes sunshine is enough to give you up to 20,000 (500mcg) international units of vitamin D. A healthy amount of exposure to sunshine during the summer months, along with a balanced diet, will in most cases enable the body to store enough vitamin D to last through the dark winter months.
- However, care must be taken as overexposure to sunshine may lead to other problems (e.g skin cancer). It is best to consult a health professional before dramatically changing your health routine.
- If you are pregnant and would like to supplement your diet with vitamin D you can take a multivitamin that includes vitamin D specifically recommended for pregnancy. Any changes you make to your diet or lifestyle during pregnancy or otherwise should be made after consulting with a healthcare professional.
- Please note that the causes of MS are not clear and there are probably more factors involved than just vitamin D, so it is not known whether taking vitamin D supplements will stop you getting MS.

If you are considering vitamin D supplementation please ask a healthcare professional for advice eg your pharmacist, nurse, GP or neurologist.

(Taken from the MS Society Fact Sheet on Vitamin D)

Thanks to our invaluable sponsors.





Chronic Cerebrospinal Venous Insufficiency - CCSVI.

According to a recent item on Canadian Television, and later copied on to their web site, a group of doctors in Italy is investigating a new treatment for multiple sclerosis. Further according to the CTV's W% investigation team, if proven true this treatment could stop the disease from spreading.

CCSVI is a condition called "Chronic Cerebrospinal Venous Insufficiency" and was discovered by Dr Paolo Zamboni, a vascular surgeon at the University of Ferrara in Italy. It refers to a narrowing or blockage of the primary veins draining blood from the brain to the heart. These include the jugular veins, veins along the spinal column and the azygos vein in the upper chest.

The narrowing restricts the normal outflow of blood from the brain. As a result the blood often 'refluxes', flows backwards into the brain, resulting in toxic iron deposits that some believe may trigger inflammation, injury to brain tissue and cell death.

What is CCSVI's relationship to MS?

Dr. Zamboni has subsequently used Doppler ultrasound to scan the heads and necks of over 500 MS patients and found the blocked, narrowed and sometimes missing veins of CCSVI in almost 100 percent of them. These problems were found in MS patients only, not in healthy people nor in those with other neurological conditions.

Following these revelations doctors in the USA and Poland have also scanned a number of MS patients and found that they too have CCSVI.

What role does iron play in MS?

Scientists have long recognised MS patients have increased amounts of iron in the brain compared to healthy people. Iron is dangerous to the brain because it produces free radicals which kill brain cells. Zamboni noticed iron deposits occurred around veins and he surmised the iron accumulation was caused by a problem with drainage in the veins that flow from the brain.

He believes the narrowing or blockages in the veins of MS patients cause blood to flow backward into the vein and deposit the toxic iron. According to Zamboni's theory, this causes inflammation, and triggers an immune response – the picture of MS. New MRI technology is allowing scientists to more clearly see iron in the brain, speeding study.

What causes CCSVI?

Doctors are not sure but they believe that veins that are susceptible to blocking and twisting develop in the womb as a congenital birth defect or early in childhood. There could be environmental factors as well.

There is also a theory that low levels of vitamin D might play a role. It's been well documented that higher rates of MS are seen in countries with lower exposure to vitamin D through sunlight and diet. Since vitamin D is critical to the normal development of the immune system and also in the development of blood vessels and endothelial tissue – the thin layer of cells that line the interior surface of the blood vessels. The Theory is that low levels of vitamin D in utero or early childhood may impair the body's ability to form healthy vessels and lead to narrowing and blockages seen in CCSVI. But this

is not yet proven. More research is needed.

What has been the MS Society's reaction?

The MS Societies of Canada and the US are reticent to support Zamboni's theories. They maintain that: "... based on results published about these findings to date, there is not enough evidence to say that obstruction of veins causes MS...It is not clear whether relieving venous obstructions would be beneficial".

(Information obtained from CTVglobalmedia.)

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Heating up in the Hot Weather?

Have a look at this idea to assist with cooling down core body temperature and save your energy.

These items are available in New Zealand, and have been used by quite a few of our Otago members so far, and have found them beneficial with reducing the heat stress experienced especially in Summer.



Sleeveless Jacket

1. A cooling sleeveless jacket containing water absorbent crystals throughout. This is not designed for ice and compression treatment, its simply to aid cooling and keep the body's core temperature down.

With Velcro fastenings down front and elasticated, adjustable sides this garment can be worn during most activities. It does not restrict the wearer. The Chinese style neck contains cooling crystals as well. Useful for any one working or recreating in an environment where their increasing body temperature prevents them from maintaining peak performance.

Neck Wrap

2. The large neck (40-60cm, 16-24") wrap (shown) provides hot or cold pressure and immobilisation of the cervical spine region post surgery and trauma.

The small neck (40-50cm, 16-20") wrap is narrower and of less robust construction but still provides cervical support and cooling. It can be worn during summer months as a means of keeping cool. The neck wrap can help tremendously with control of hot flushes, headache and raised temperatures.

The neck tie is a small, 2-channel neck scarf worn by the sports person, gardener, walker, etc to help keep cool in summer.

Flat Chilla's

3. Flat Chillas for laying over or holding onto a part or region of the body.

Slab - The Slab Chilla is a 35x40cm (14x16") rectangle.

Small Slab - 25x33cm (10x13")

Hockey - 12x12cm (5x5")

New Product

4. New products (a wrap called a UNIVERSAL that can be applied anywhere on the body) It will have its own aluminium storage canister that can be stored hygienically in the fridge or freezer.

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Field Officer's Report



March 2010

Welcome to another Year, I do hope you all celebrated the Festive Season in a suitable manner and have been able to begin the New Year and Decade with a happy and promising outlook.

I for one had a fab break, as I married my best friend, and had a ball.

This Year is looking like it will be a busy one again, with the usual groups and gatherings planned, but I am also hoping to add suitable groups for those that are saying they need or want; such as "carers group, young mums group and art sessions or workshops"

I intend to hold a Relationship Seminar this Year, the dates are to follow. I think I may also look at running a monthly workshop on Alternative Therapies and Nutrition.

Each month there will be a guest speaker, these will be announced as the speakers confirm their attendance; March 1st will be WINZ agent, Denise Kelly. March 15th, Carers Society agents, Susan and Annaloes.

For those that may not realise, I am available for;

- * Support. Advocacy. Also I am able to liaise with support agencies and/or health professionals with you or on your behalf.
- * I visit you in your home or where ever suits if you work.
- * I can provide you with information or referrals to appropriate agencies.

If things are getting on top of you or your carer/family supporter;

- * I can provide information and support which may aid in suitable solutions being available.

You do not have to struggle along, there is support for you, all you need to do is ask if I have not been to visit you for a while.

**(03) 455 5273 027 296 5254
msotago@actrix.co.nz**

Our MS Centre is in the midst of restructuring how we operate; therefore I was left with a whole lot of extra things to do since November; please accept our sincerest apologies to anyone inconvenienced during this time. There maybe some delay's with administrative tasks until we employ our new Office Manager. This maybe a welcome change for some folk but not for others, however we will move into this New Decade with promise and increased prosperity. We are hoping to provide an improved service delivery with a welcoming friendly manner.

Change can be difficult for some, as bonds are made or broken. All I can advise is, if there is something you want to share, or get off your chest – either myself or someone from the committee are always available to listen.

Change, is inevitable really, so I try to embrace it, and make the most of the situation. Changes can be enlightening, refreshing, inspiring - and that's a good thing, as we move swiftly into this New Century. With scientific research, new hope being developed and studied, with brilliant Academics out there seeking the cure for MS, change can't come quick enough for some.

Summer has been unusually hot this year so far. Fatigue continues to be an issue for some folk in the heat, so if you are interested in a cooling aid read the small advert for "Chilla" garments which are available in New Zealand.

Some exciting news about Quest Serviced Apartments being a National MS Sponsor, they will have some special offers for MS Members.

There is good news about affordable health care services: please read the article on "Servants Health Care"

Kakete - Julie Jones

Have you visited our new web site yet? www.msotago.org.nz

Intimacy and Sexuality in Multiple Sclerosis



Everyone retains the capacity to give and receive love and pleasure, although at times when a partner has MS it must sometimes seem just too difficult.

However, through understanding and creative problem-solving solutions can be found.

To continue to share and achieve intimacy requires creativity, patience and resource management, but perhaps most importantly communication. Through this and understanding, a person is able to maintain his or her sexual identity and dignity.

Sexual changes in MS

40 – 80 % of women and 50 – 90% of males have sexual concerns.

Sexual dysfunction is common in women with a neurological disease. Most female MS patients will have some sexual dysfunction at some stage which can have a major impact on the quality of her life and interpersonal relationships.

Sexual dysfunction in men is also prevalent. Men require coordination of arousal, penile erection and orgasm including ejaculation. These activities must also combine with emotional and relationship components to achieve satisfaction.

In men the diminished capacity to attain or maintain an erection or have an orgasm and in woman partial or total loss of libido, vaginal dryness/irritation, diminished orgasm and uncomfortable changes in the genitals are the most common complaints.

These changes can be characterised in three categories; primary, secondary and tertiary.

Primary sexual dysfunction stems from changes in the nervous system that directly impair the sexual response or feelings. This can include partial or total loss of sexual desire, unpleasant or decreased sensations in the genitals, dryness in the vaginal area, decreased erectile capacity and decreased frequency or intensity of orgasms.

Secondary refers to MS-related physical changes that indirectly affect the sexual response such as bladder and bowel dysfunction, muscle weakness, problems with attention and concentration, hand tremors and non-genital changes in sensation. MS can affect responses by making sexual activity difficult both physically and emotionally.

Changes in **muscle tone**, lack of **coordination** or **pain** can frustrate sexual expression and extinguish desire. **Bowel and bladder dysfunction** can also cause embarrassment.

Finally **tertiary** dysfunction results from psychosocial and cultural issues which can interfere with sexual feelings and sexual responses – depression, performance anxiety, change in family roles, lowered self esteem, body image concerns, loss of confidence and internalised beliefs and expectations about what defines 'sexual man' and 'sexual woman' in the context of having a disability.

Cognitive changes can be amongst the most potentially damaging to the relationship since they can undermine the person's sense of who she or he is. A partner may not feel that they are the person they once were.

Fatigue is one of the most common complaints and can be misinterpreted as 'disinterest'. Changes in attention and concentration can also be perceived as a lack of interest in achieving intimacy as can changes in mood, memory loss and depression. These can in fact become frightening, frustrating and sometimes infuriating for both partners.

Lack of coordination and **tremor** can make sex and sexual expression feel clumsy. Good communication between partners can minimise embarrassment and maximise closeness and pleasure.

Mobility and the subsequent use of canes, wheelchairs, braces and walkers are often identified with being 'sick' or 'old'. Spontaneity can become a problem when mobility is limited.

Adjusting expectations from performance-orientated sex, where intercourse is seen as the only desirable outcome, can be liberating and allows for pleasuring and sexual satisfaction despite the limitations of impaired mobility. In understanding the problem, solutions can be sought.

You are not alone, nor are your problems unique although at times they may certainly seem that way to you and your partner. Never feel that you cannot discuss the problems with your neurologist or doctor. There are answers, there are treatments and the medical profession is well versed in both.

MS or not you can still achieve sexual satisfaction and the maintenance of a meaningful and satisfying relationship - many non-MS couples in our community also struggle in issues of sexuality and intimacy – enjoy your partner, keep your friendship alive, and never be afraid to ask for help if and when you both feel it is necessary.

(Thanks to Dr Vic du Plessis, Patron of MS Otago and Otago DHB neurologist for his valuable assistance with this article.)

Events Calendar March 2010

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
	1 Lunch Group 11.45am - 2pm WINZ speaker	2 Games Group Julie in Central network meeting	3 Information Expo Balclutha	4 Home visits	5 Home visits	6
7	8 Home visits and administration	9 Games Group 10am to 2pm	10 Mosgiel home visits and group day	11 Home visits and administration	12	13
14	15 AGM 6pm Social lunch 11.45am - 2pm Carer society speakers	16 Games group 10am - 2pm	17	18 ISIS 9.30am Men's Group at Mitchells 11.00am Youth Group 5.30pm	19 Admin half day	20
21	22 Otago Anniversary Day	23 Games Group 10am - 2pm (OT poster presentation)	24 Talk to AWA group 2pm	25 Oamaru home visits and group at 1pm at 8 Nen St	26	27
28	29	30 Games Group 10am - 2pm	31 Central Otago Wanaka - Cromwell			

Events Calendar April 2010

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
				1 Central Otago Alexandra Social Group 7pm Speaker	2 Good Friday School Holidays	3
4 Easter Sunday	5 Easter Monday	6 Games Group 10.45am - 2pm	7 Art Group Notice to be sent out	8 Home visits & administration	9 Home visits & administration	10
11	12 Home visits & administration	13 Games Group 10.45am - 2pm	14 Mosgiel Group 1pm at 95 Bush Rd Home visits	15 ISIS 9.30am Men's Group at Mitchells 11.00am Youth Group 5.30pm	16 Oamaru MDT	17
18	19 Social Group 11.45am - 2pm School resumes	20 Games Group 11.45am - 2pm	21 Art Group Notice to be sent out	22 Oamaru Group 1pm at 8 Nen St then home visits	23 Home visits & administration	24
25	26 Balclutha Group 11.30am at cafe', then home visits	27 Games Group 10.45am - 2pm	28 Home visits & administration	29 Home visits & administration	30	