

# MS+PD



Multiple Sclerosis and Parkinson's Society of Canterbury (Inc)

August 2010



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**Carnation Day Volunteers Needed**

**Annual Donations Due**

**Upcoming Workshops and Seminars**

[www.ms-pd.org.nz](http://www.ms-pd.org.nz)



## Rewarding Experience

One of the most rewarding experiences each year is volunteering as a collector for the Carnation Day Street Appeal. I have been participating in street appeals for over 10 years, both for Carnation Day and other charities through Rotary and I find the support and people's willingness to give amazing.

I have always found that to be a great collector you have to believe in the charity you are out there to support and enjoy yourself. If you wear a smile on your face and engage with the people who walk by, not only are they going to put money in the bucket, but they will ask questions about the Society.

As volunteers we have to remember that it is not just about the money we are raising, it is about the awareness of MS and Parkinson's we are creating.

This is our one chance a year to get our message to the public and I am proud to be one of the 400 (hopefully 400+) people bringing that message to Canterbury.

So, please fill in the volunteer form enclosed with this Newsletter and help us raise not only the money needed to continue to provide the support needed in Canterbury, but awareness of MS, Parkinson's and the Society.

Yours Kindly,



Malcolm Rickerby  
President  
03 338 1770  
[malcolm.jeanie@slingshot.co.nz](mailto:malcolm.jeanie@slingshot.co.nz)



## Carnation Day – 3 September 2010

NOW is your chance to volunteer for the Society! Carnation Day is the Society's biggest fundraiser of the year and we need your help to raise the money needed to continue to provide support, information and education to those with MS and Parkinson's.

### Here is how you can help:

- **Volunteer to Collect** – The volunteer form is enclosed with this Newsletter. Please fill it out and return it to the Society as soon as possible. If you know of friends or family who would like to collect, contact Lindsey for additional forms.
- **Become a Team Leader** – Call Lindsey today if you and a group of friends would like to help collect together. You can be the "Team Leader" and look after the collection at a supermarket or store for the day. This is a great help to the Society and we would love to have Team Leaders throughout Canterbury!



- **Bucket for your Workplace** – Request a bucket to place at reception or in the lunch room at your work. This can be done for several weeks prior to Carnation Day.
- **Hold your own Fundraiser** - Host a dinner or drinks for friends, family or co-workers and ask that each person gives a gold coin donation to go towards Carnation Day. Let Lindsey know and she can give you a Carnation Day bucket or stickers for your event.

If you have any questions please contact Lindsey on 03 366 2857 ext. 9 or email [lindsey@ms-pd.org.nz](mailto:lindsey@ms-pd.org.nz).



# Notice Board

## Carnation Day

Friday 3 September  
Send in your volunteer  
form ASAP!

## Have you paid your Annual Donation?

If you are not sure  
contact Annette on  
03 366 2857 ext. 6

## Workshops

**MS Presentation on Short Term  
Memory Issues**  
Tuesday, 17 August  
5.30pm at Holiday Inn on Avon

**Pain & Pain Management**  
Tuesday, 5 October  
10.30am at the Society  
More information on page 7

## Spouses Group

Presentation by Van der Veer  
Clinec Research Nurse  
Wednesday, 25 August, 2pm

**Morning Tea**  
Thursday, 23 September, 10.30am  
More information on page 7

## Dorothy Newman Scholarship Application

Due 24 September  
More information on page 9

## Suburban Morning Teas

Held throughout Canterbury.  
Contact Shirley on 03 366 2857  
ext. 8 for more information.



*Shirley, Jan, Raewyn, Annette, Donna, Jenny, Lindsey, Sandy, Janet, Jessie*

## Staff Visits

One of the most important services offered by the Society is the free home visiting programme. It may be that you haven't seen a staff member for a while or you have something that you need to discuss. The visits can be made at a time and place to suit you: at work, at your home or at the Society.

As staff members work outside of the office at times, and your call is important to them, please leave a message on their answer phone and they will contact you as soon as possible.

If your call is urgent, please call the Manager or Office manager for assistance.

## To Contact

Please dial (03) 366 2857 and then the appropriate extension number listed below:

<b>Jessie/Jan</b>	<b>1</b>
<b>Jenny</b>	<b>2</b>
<b>Sandy</b>	<b>3</b>
<b>Janet</b>	<b>4</b>
<b>Donna</b>	<b>5</b>
<b>Annette</b>	<b>6</b>
<b>Raewyn</b>	<b>7</b>
<b>Shirley</b>	<b>8</b>
<b>Lindsey</b>	<b>9</b>

## Congratulations Jessie!

We would like to congratulate our Physio, Jessie Snowdon, on the birth of her baby girl. Lucinda Rose arrived on 16 June 2010, weighing a healthy 8lbs 12oz. Both mum and baby are doing great. Jessie, we are so happy for your wee family!



## Thank You Adam Glubb & Avon City Ford Sockburn

Adam Glubb recently took part in the SBS Half Marathon. As a result of collecting sponsorship from many supporters, he will be donating almost \$2,000 to the Society!

We thank Adam and all those businesses who contributed towards his very generous donation. Adam, who is a car salesman at Avon City Ford Sockburn, completed this event in 2008, again giving the proceeds to the Society.

Well done Adam, we are very appreciative of your continuing support of the work we do.



# Overdue Annual Membership

The Multiple Sclerosis and Parkinson's Society of Canterbury provides its members with excellent services through numerous programmes and information resources.

The overall driver within your committee and staff is to enhance our services for the well-being of people with MS and Parkinson's as well as their caregivers. For this to become a reality it relies on members to pay their annual donation/subscription.

## Services available to you include:

- Home visits from a Resource Nurse with provision of information
- Subsidised Podiatry Services
- Gym Facilities & Exercises Groups for your health and well-being
- Total Mobility Vouchers
- Invitations to Workshops and Information Sessions
- Suburban Coffee Groups
- Website Information
- Quarterly Newsletters



We are aware of the financial pressures and constraints one has personally, however for your Society to **continue** to offer excellent services we rely on our members to pay their annual donation/subscription.

If for any reason you are unable to pay your annual donation, please contact Jenny on 03 366 2857 ext. 2 and she will be happy to discuss this with you.

If your annual donation remains unpaid, we will no longer send you newsletters, but we will always willingly respond to any contact from you.

**To pay your donation/subscription, or if you are unsure if you have paid, please contact Annette on 03 366 2857 ext. 6.**

# Multiple Sclerosis for DUMMIES

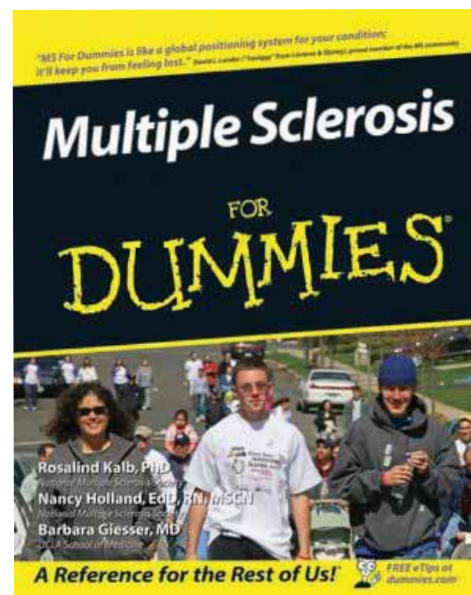
– by Rosalind Kalb, Nancy Holland and Barbara Giesser

The following is a book review from one of our members, Sue Keogh.

When I was first asked to review this book, I took one look at its cover and thought, 'Yeah right, do they think we're all idiots as well now!!' In actual fact, I found it to be the most comprehensive book that I've come across for sensible and well-researched information about MS.

This book dispels a lot of myths and is easy to read and navigate your way through if you want quick information or a more in-depth view. Its authors appear to have rock solid credentials and they give you information on heaps of websites that you might find useful.

There is a bit of irrelevant text that doesn't apply to the health system here in New Zealand but still plenty that does. The only thing you really need to be aware of is that the brand names of drugs are sometimes different to NZ. That doesn't necessarily mean that they are not available here, it just means that you have to use their generic name when talking with your GP or Neurologist.



I would thoroughly recommend this book to anyone whether you are newly diagnosed or an 'old hand like me'!

# Hallucinations

- Janet Wills, Parkinson's Resource Nurse

*The following is an edited version of the Hallucinations Fact Sheet which is available on the Parkinson's New Zealand website or by phoning Janet on 03 366 2857 ext. 4.*

## What are hallucinations?

A hallucination is defined as a perception of something in the environment which is not there. Hallucinations can involve all of the senses; however people with Parkinson's are more likely to experience smell, auditory or visual hallucinations.

Hallucinations often begin in a mild form – you may see spots, dots, lines or small shapes in your peripheral vision. You may also have persistent feelings that someone else is in the room when you are alone. These are called delusions of presence and share many similarities with hallucinations.

Hallucinations can last for seconds, minutes or hours, and are commonly reported as involving animals, bugs, children or people. These visions do not usually respond when engaged or spoken to. Hallucinations can be frightening and difficult to deal with for you and your family.

## Why do people with Parkinson's experience hallucinations?

There are two factors that can contribute to hallucinations in Parkinson's. Firstly, many of the drugs used to treat Parkinson's may contribute to hallucinations. It is important to remember that this doesn't happen with most people, but the possibility grows with higher doses and greater numbers of medications taken. We know that Parkinson's drugs are not the only cause of hallucinations, and some people with Parkinson's may have them even if they are not taking these medicines.

The second factor in hallucinations is the brain itself. Brain perception circuits can be affected by the development of Parkinson's, and areas that interpret visual images may have some inherent instability. This is presumably due to the same neuro-degenerative process that causes the tremor and motor symptoms of Parkinson's.

## What can be done?

If you are beginning to experience hallucinations it does not necessarily mean your Parkinson's has taken a turn for the worse. They are nothing to be ashamed of, but they should be reported to your Doctor or Specialist as soon as possible.

If the hallucinations are associated with Parkinson's, but are not troublesome, the Doctor may suggest that the situation is simply monitored. However, if they are becoming a problem, the medication used to control Parkinson's will often be adjusted. Such measures can often eliminate or reduce the hallucinations, and improvement is usually noticed within a few weeks. Because hallucinations are not just a side-effect of Parkinson's medications, making adjustments to the drugs does not always eliminate them.

## What can I do if someone I care about is experiencing hallucinations?

It can be difficult to care for someone who is experiencing hallucinations, as it is not always easy to know how to react and what to say. It can often take a while for the person with Parkinson's and their families to ascertain that they are hallucinating.

It is important to stay calm. Don't pretend that there is something there when there is not, but try not to let an argument develop. Instead, offer reassurance, particularly if the person is distressed. It is sometimes useful to explain that you can not see or hear what they are experiencing, but that you understand that it is very real to them. Distracting the person can often be effective. The experience will eventually pass and any loss of insight may be restored.

If you are worried about yourself or someone you care about, do not hesitate to speak to your GP or Specialist as it is likely that something can be done to help.

*Sources: The Parkinson's Disease Treatment Book, PDS UK Fact Sheet FS11, American Parkinson's Disease Association Journal, Parkinson's at your Fingertips 2<sup>nd</sup> Ed.*



## Educational Workshops

*We extend a very warm invitation for our members and their spouse/partner/family to attend the following:*

**Presentation:** **Short Term Memory Issues & Keeping the Brain Stimulated for People with Multiple Sclerosis**

**Date:** Tuesday 17 August 2010

**Time:** 5.30pm – Refreshments  
6.00pm – Presentation

**Venue:** Holiday Inn on Avon – 356 Oxford Tce, Rolleston Room

**Speaker:** Joyce Alberts – Clinical Psychologist, Brain Injury Rehabilitation Service, Burwood Hospital

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**Presentation:** **Pain & Pain Management**

**Date:** Tuesday 5 October 2010

**Time:** 10.30am

**Venue:** 314 Worcester St, Linwood, Christchurch

**Speaker:** Diane Wood RN – Part of the Psychosocial team at the Pain Management Centre. This Centre is a coordinated interdisciplinary service working with people with chronic pain to develop understanding of the complex nature of chronic pain. It teaches self management skills to manage pain effectively to improve quality of life and functional abilities.

**For more information or to RSVP to either event, please contact Annette on 03 366 2857 ext. 6 or email [support@ms-pd.org.nz](mailto:support@ms-pd.org.nz).**

## Parkinson's Spouses Support Group

**Event:** Helen Skene, Clinical Research Nurse, will talk about her role and her work at the Van der Veer Clinic. At the Van der Veer Institute, patients have access to specialist diagnosis and management and the latest international treatments.

**Date:** Wednesday 25 August, 2pm

**Venue:** 314 Worcester St, Linwood, Christchurch

**Note:** A cup of tea/coffee will be available, please bring a gold coin donation to cover costs.

**Event:** Morning Tea – Our morning teas are a good way to meet up and chat with other spouses.

**Date:** Thursday 23 September, 10:30am

**Venue:** Hillyers Cafe - 23 Langdons Road, Papanui

**Note:** Coffee and cake available to purchase.

**Please RSVP to confirm your attendance at these events to Annette 03 366 2857 ext. 6 or email [support@ms-pd.org.nz](mailto:support@ms-pd.org.nz).**

## Focus on MS

The MS Society of New Zealand is holding Focus on MS, a seminar on research, rehabilitation and emerging treatments for Multiple Sclerosis. This seminar is for both Health Professionals and those with MS (and their family/carers) and will be held in **Auckland** on Saturday **18 September 2010**.

**The seminar will cover:**

- Emerging Treatments for MS
- The Genetics of MS
- Latest MS Research
- Bias & Influence in Medical Research
- Many other topics...

The cost of the seminar is \$75 per person (or \$60 if you register prior to 31 July). For more information or to register please call the MS National Office on 04 499 4677 or email [info@msnz.org.nz](mailto:info@msnz.org.nz).

## Society Representatives Needed for 2011

The Society is looking for members who are willing to represent the Society in a variety of capacities in 2011. We would like to enlist one or two people with MS and one or two people with Parkinson's to become our 'Ambassadors' for 2011.

We anticipate that this will take approximately two hours each month. The duties may include: speaking at presentation to organisations (such as Lions and Rotary clubs), having your story printed in donor appeals, and appearing with a staff member at media interviews. These duties mean that the Representative must be comfortable speaking in public.

If you are interested in becoming a Society Representative for 2011, please contact Lindsey on 03 366 2857 ext. 9 to further discuss the role.

## Generous Donation



Recently the President of the Mayfield and District Lions Club, Grant Early, contacted the Society to say that they held an annual golf tournament in June and would like to donate the proceeds to the Society. We are delighted to announce that the Society has been given a donation of \$10,000 from this event. Thank you to the Mayfield and District Lions Club, the Mayfield Golf Course and the other Lions Clubs in the district for their generosity.

## How you can help a person with MS or Parkinson's in your Community

By remembering the members of the MS and Parkinson's Society in your Will, you can secure the future programmes the Society provides. The sample bequest below may be useful, but we always recommend that you seek legal advice from your Solicitor when adding a bequest to your Will.

### SAMPLE BEQUEST

I give \$\_\_\_\_\_ or \_\_\_\_\_% of my estate to The Multiple Sclerosis and Parkinson's Society of Canterbury (Inc), to be applied for its general purposes. A receipt taken by my trustees as being given on behalf of that beneficiary will be a complete discharge to my trustees for this legacy.

## 2010 UPBEAT Weekend

UPBEAT is a special interest group for people with early onset Parkinson's – diagnosed under the age of 60. This year the UPBEAT Weekend will be held in Palmerston North 5-7 November at the Rugby Institute of New Zealand.

Partners are welcome as there is always plenty of information for carers and time to share and network with other people. To register your interest, please contact Parkinson's New Zealand on 0800 473 463 or email [deirdre@parkinsons.org.nz](mailto:deirdre@parkinsons.org.nz).



## Fun Walk 2010

We are getting closer to the first annual Fun Walk. For this event the Society is looking to team with other MS Societies around the country to hold a National Fun Walk. It would be great if all throughout New Zealand there are hundreds of people raising thousands of dollars with just one goal: **To Support people with MS and Parkinson's.**

The purpose of this event is to:

- Raise awareness of MS and Parkinson's through event advertising and word of mouth
- To raise money for our Society – We ask that each person/team obtain sponsorship from their friends/family/co-workers for their walk
- To meet other people

We are planning this event for November 2010, but we need to get an idea of how many people are interested.

We need you to take action today. Phone Annette on 03 366 2857 **ext. 6** and tell her that you, your family, friends, neighbours and/or co-workers will mark it in your diary to be a part of this national event.

## Entertainment Books

The Society would like to thank our members, their families and friends for supporting us by buying an Entertainment Book. We have raised \$3,016 so far, and we still have some books left. If you know of anyone who would like to purchase a book, please contact Annette on 03 366 2857 ext. 6.

## Educational Presentation Review

The very informative and lively presentation on Fatigue/Motivation/Moods/Emotions was given by Dr Debbie Mason, Neurologist and Dr Cameron Lacey, Neuropsychiatrist.

As you can imagine, Health Professionals are very busy people and it takes a lot of planning to book them, so it was very heartening to see so many people attending this evening. **THANK YOU!**



**100%**  
of your  
**DONATION**

provides direct support for people with MS & Parkinson's in Canterbury.

So please remember to:

**PAY YOUR ANNUAL DONATION  
&  
VOLUNTEER FOR CARNATION DAY**



## Dorothy L Newman Scholarship – For Study in 2011

This scholarship is available to assist people who have been diagnosed as having Multiple Sclerosis and as a result are unable to continue in their present employment and who need to change their employment and undergo a course of retraining in order to do so. The two successful applicants will each be eligible for up to \$7,500 for their course fees.

If you would like an application form, you can either phone Annette on 03 366 2857 ext. 6 or send her an email at [support@ms-pd.org.nz](mailto:support@ms-pd.org.nz).

**Applications must reach the MS Society of New Zealand office by Friday 24 September 2010.**

## Speech Research Programme

Dr Megan McAuliffe and Professor Tim Anderson are currently undertaking a study examining how listeners comprehend the speech of people with dysarthria. Dysarthria is a speech problem that commonly occurs in both Parkinson's and MS. People with dysarthria experience a variety of speech symptoms including – imprecise or slurred speech sounds, slow rate of speech, and voice and nasality problems. This speech problem often negatively affects quality of life.

The aim of this research is to determine how common speech therapy techniques change the way that listeners or communication partners comprehend the speech of people with dysarthria.

If you have MS or Parkinson's and difficulty with your speech, and are interested in participating, our research funding will pay for your transport to the University of Canterbury for a one-off speech assessment session. This usually takes a total of 2 hours with breaks provided.

If you are interested in participating or would like further information about this research, please contact Sharon Broadmore, Research Assistant, on 03 364 2987 ext. 8264 or email [sharon.broadmore@canterbury.ac.nz](mailto:sharon.broadmore@canterbury.ac.nz).

If you do not have Parkinson's or MS, but are interested in this research, we are also looking for people aged 60+ to participate as listeners in the second half of the study. If you wish to register your interest, please contact Sharon Broadmore.

## Welcome to Lisa Wood

We extend a very warm welcome to Lisa, who is our new Yoga instructor. Lisa currently holds a weekly session on a Tuesday from 1pm – 2pm in the Hall at the Worcester Centre. We ask for a gold coin donation to assist with our costs. We hope you enjoy your time with us Lisa.

If you would like some more information about these sessions, please contact one of the Nurses on 03 366 2857.

## Free Nurse Health Checks

Registered Nurse Karolien McBride will take blood pressure and blood tests, check ear and throat infections as well as conduct general checks. These health checks are available to anybody from any area. While bookings are not essential, they are recommended to reduce the wait time to see the nurse.

**Where:** St Albans Baptist Church  
– 64 McFaddens Road  
**When:** Wednesday Mornings from 9am – 12pm  
**Contact:** Neighbourhood Trust (Tony or Ginny)  
**Phone:** 03 355 6522

## TV Needed

The Society has been the lucky recipient of a Wii Fit. For those who have not see one of these in action, it is a gaming console that combines fun and fitness into one product. It helps with exercise, balance, and even how you move. This will be a great tool for our Physio in the upcoming years.

The only missing piece is a TV to plug the Wii into. We are in need of a TV that could be used in the gym in conjunction with the Wii Fit. If you have a TV which you would like to donate, please contact Annette on 03 366 2857 ext. 6.



## Exercise Benefits Member with MS

Society member Daphne Pickering recently wrote to the Society to tell of how exercise has benefitted her over the last year.

'Exercising 4-5 days a week has made such a difference to me. Strengthening my back muscles and legs has been so rewarding' says Daphne. 'I fall over far less frequently, even though I am using the walking stick less and less. My balance has improved and my strength also.'

Daphne began attending regular exercise classes at the Society, but due to day/time conflict was no longer able to attend. She sought out an alternative and found that Curves (an exercise facility just for women) worked well for her.

'I still have MS, but have improved rather than deteriorated' says Daphne.

The gym at the Society is open two days a week, on Monday and Wednesday afternoons, but we are aware



that our location and times may not suit everyone. Please remember there are numerous options for physical activity in the Community and we can help you access these, set up a programme and offer support as you need.

To make a time to talk with our Physio regarding your exercise regime, please contact Annette on 03 366 2857 ext. 6.



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Bayer Schering Pharma

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Every day take charge of your future with Copaxone<sup>1</sup>

Ask your specialist if Copaxone is right for you. Copaxone is Fully Funded with Special Authority Criteria for Multiple Sclerosis. Your specialist can advise on funding criteria. Normal doctors fees apply. Additional information can be obtained from My Support Team. Freephone: 0800 502 802

COPAXONE<sup>®</sup>  
(glatiramer acetate for injection)

COPAXONE PRE-FILLED SYRINGE (glatiramer acetate 20 mg) INJECTION is a Prescription Medicine for the reduction of the frequency of relapses in patients with Relapsing Remitting Multiple Sclerosis. Do not use if you have an allergy to glatiramer acetate or mannitol. Should be administered by subcutaneous injection only as directed by your specialist. Should not be given to: children under 18 years; patients with a history of severe allergic reactions; patients with asthma; during lactation or pregnancy; patients with impaired immune responses. Side Effects: Soreness at the injection site, flushing, chest pain, rapid heart beats, feeling of weakness, nausea, joint pain and muscle stiffness, dizziness, constipation, anxiety and difficulty breathing. See full Consumer Medicine Information available on the Medsafe website ([www.medsafe.govt.nz](http://www.medsafe.govt.nz)). There are no known interactions with other MS therapies. Always use strictly as directed and consult your specialist if symptoms persist or you have side effects. References: 1. Copaxone Approved Data Sheet June 2007. sanofi-aventis new zealand limited, 56 Cawley Street, Ellerslie, Auckland. PP5970 NZcop08091

A special thanks to the following organisations for their continued support.

## Multiple Sclerosis and Parkinson's Society of Canterbury (Inc)

314 Worcester Street  
(PO Box 32-135)  
Linwood, Christchurch

Phone: (03) 366 2857  
Fax: (03) 379 5939  
Email: [support@ms-pd.org.nz](mailto:support@ms-pd.org.nz)

			Burrows Brothers Charitable Trust
			
		Jones Foundation	
	New Zealand Community Post		
			
			Thank you for your continued support.

### Officers of the Society

Patron: Mr Cyril L.L. Smith M.B.E  
 President: Malcolm Rickerby  
 Treasurer: Graeme Ell CA, PP  
 Committee: Eunice Benger  
 Ann Morrison CA  
 Noel Noonan  
 Lew Airey  
 Bryan Beechey  
 Mike Cameron  
 John George  
 Life Members: Keith McArtney  
 Noeline McIlroy Q.S.O

### Staff

Manager: Jenny Boyer  
 Office Manager: Annette MacFadyen  
 Resource Nurses: Sandy Connolly RGON, ADN  
 Janet Wills EN  
 MS & PD Outreach Nurse: Donna McLelland EN  
 Administration Assistant: Raewyn Turner  
 Project Coordinator: Lindsey Kerr  
 Physiotherapist: Jessie Snowdon  
 Exercise Supervisor: Jan Rait  
 Social Activities Coordinator: Shirley Noonan

*The views and opinions expressed in this newsletter may not necessarily be the views of the Multiple Sclerosis and Parkinson's Society of Canterbury (Inc) or its members.*

