

MS+PD



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

February 2010

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www.ms-pd.org.nz



For Your Donation...

We are truly grateful for the extraordinary support we continue to receive from our members and the community. One hundred percent of the money donated to the Multiple Sclerosis and Parkinson's Society of Canterbury stays with our Society and directly benefits people in our region affected by MS and Parkinson's.

In 2009, your thoughtful gifts helped the Society:

- Provide 4,630 visits to members, family and caregivers through our Home Visiting Programme
- Make 3,929 phone calls to members and 888 phone calls to Health Professionals on behalf of our members
- Hold 771 Exercise Groups, including Tai Chi, Nordic Walking and Yoga
- Organise 34 Morning Teas throughout Canterbury with an average of 17 people attending
- Conduct 10 Educational Workshops for members and Health Professionals
- Produce and distribute four editions of the MS+PD Newsletter to over 800 households

The money alone would not be enough to keep the Society going, volunteers are also an essential part of the information and services we provide. I would like to thank those who generously donated their time this past year for our:

- Gym/Exercise Groups
- Morning Teas
- Newsletter Mailout
- Carnation Day Street Appeal
- Parkinson's Awareness Week Information Day
- Plus many more activities and events

We have limited resources and we are often unable to individually thank each person who helps with these events, but we are truly grateful for the time our members, their friends and family and people in the community give.



Malcolm Rickerby

We have many new events taking place in 2010 and a pool of volunteers is desperately needed. If you or a family member or friend would be happy to be called upon to help at the Society or with fundraising events, please contact Lindsey, our Project Coordinator on 366 2857 ext. 9.

None of the services the Society provides would be possible without your generous contributions. The new fiscal year has begun, so let's make this year even better than last.

If you are able, please make an additional donation on your Subscription Form or go to the Donation page of our website <http://www.ms-pd.org.nz/donate.html> for additional ways you can give to the Society. Make your own gift in support of the Society and help us get off to a great start in 2010.

Malcolm Rickerby
President
03 338 1770
malcolm.jeanie@slingshot.co.nz



AGM

The Annual General Meeting of the Society will be held at:

Venue: The Worcester Centre
314 Worcester Street
Date: **Monday 15 March 2010**
Time: 12.30pm

If you wish to nominate anyone for the Society Board, please contact **Annette on 366 2857 ext. 6** for a nomination form which includes a proxy form to complete if you are unable to present. **FORMS MUST BE RECEIVED IN THE OFFICE BY FRIDAY 12 MARCH 2010.**

Following the formal part of the Meeting, there will be a presentation about the Society hosted by Malcolm Rickerby and Lindsey Kerr. This presentation will be used extensively in the Community to promote the services of the Society and to increase our profile.

Podiatrist

Please note the dates for the Podiatry services are back to the first Tuesday of the month. This service is available in Room 6 at the Worcester Centre, 314 Worcester Street from 9.00am – noon.

The fee for this service is \$15.00 and is significantly subsidised by the Society. If you cannot make your appointment you must ring to cancel. **If you do not cancel at least one day in advance you will be charged for the missed appointment.** There is a long waiting list, so if you are unable to attend we can allocate your appointment to someone else.

To book or cancel an appointment, please contact Annette on 366 2857 ext. 6.

Entertainment Books

Enclosed with this Newsletter is a flyer/order form for the very popular Entertainment Book, which the Society has been selling for a number of years.

The cost to purchase a book is \$65.00 (the same as last year). Every book purchased means the Society retains \$13.00; therefore your support of this fundraising opportunity would be greatly appreciated. Last year, we made \$3,000 and we would like to match or exceed that figure this year.

With some new additions including: QEII, Reading Cinemas, Crumpet Club, Burgers & Beer, Mt Cheeseman and more, this book makes it very appealing for all ages and gender and would make a great gift.

Please Order Early

To save disappointment and to secure your book(s) – **PAYMENT MUST BE MADE BY THURSDAY 25 MARCH 2010.**

The book is due to be launched in **Mid May**. If you would like more information please phone Annette on 366 2857 ext. 6.

Welcome to Lois Young

We extend a very warm welcome and say a huge thank you to Lois Young, who has volunteered to assist Jan with the three Parkinson's Exercise Sessions. Lois, we all appreciate you giving your time and energy to the Society each Monday and hope you will enjoy the time you spend with our members.



Jessie, Jan, Raewyn, Annette, Jenny, Donna, Lindsey, Margaret, Janet (not pictured: Shirley)

Meet The Staff

For your reference, listed below are the staff, their role at the Society, extension numbers and their hours of work.

Jenny Boyer

Manager **Ext. 2**
 Monday – Thursday 8.30am – 4.30pm
 Friday 8.30am – 1.30pm

Annette MacFadyen

Office Manager **Ext. 6**
 Monday – Friday 8.30am – 4.30pm

Margaret Chapman

MS Resource Nurse **Ext. 3**
 Monday 8.30am – 3.30pm
 Tuesday 8.30am – 12.30pm
 Thursday & Friday 8.30am – 3.00pm

Janet Wills

PD Resource Nurse **Ext. 4**
 Monday - Wednesday 8.00am - 2.30pm
 Thursday 8.00am - 12.00pm

Donna McLelland

MS & PD Outreach Nurse **Ext. 5**
 Monday 8.30am – 2.30pm
 Wednesday & Thursday 8.30am – 2.30pm
 Friday 8.30am – 12.00pm

Jessie Snowdon

Physiotherapist **Ext. 1**
 Monday 8.30am – 5.00pm
 Wednesday 1.00pm – 5.00pm
 Friday 8.30am – 5.00pm

Jan Rait

Exercise Supervisor **Ext. 1**
 Monday 9.30am – 4.00pm

Raewyn Turner

Administration Assistant **Ext. 7**
 Monday & Tuesday 9.30am – 3.00pm
 Thursday 9.30am – 3.00pm

Shirley Noonan

Social Activities Coordinator **Ext. 8**
 Tuesday 9.30am – 1.00pm
 Wednesday 9.30am – 1.00pm
 Thursday 9.30am – 2.00pm

Lindsey Kerr

Project Coordinator **Ext. 9**
 Monday - Wednesday 8.30am – 4.30pm

**The Society's phone number
 is: (03) 366 2857**



An Invitation to our Brand New Course

Living Well with Parkinson's Disease

A 6 week education series aimed to improve self management for people living with Parkinson's Disease and those living with somebody with Parkinson's Disease.

Participants:

People diagnosed with Parkinson's (PD) and their spouse/support person

Venue:

The Multiple Sclerosis and Parkinson's Society, 314 Worcester Street, Christchurch

Start date:

- Tuesday 9th March @ 5:30 pm
(for 6 continuous Tuesdays at 5:30 pm)
- Thursday 25 March @ 10 am
(for 6 continuous Thursdays at 10 am)

(Two separate series will run simultaneously – please enquire as to which is the most appropriate for you)

Cost:

\$50 or \$20 for Community Services Card Holders

Costs include:

- Workbook
- Speakers
- Light refreshments
- One spouse/support person free with each person with Parkinson's

Contact:

Please contact Jessie Snowdon (Self Management Coordinator and Physiotherapist) on 366 2857 ext. 1 for further information or to be sent a registration form.

Please note that each night is not independent of the others and there will be themes and ideas that run throughout including 'homework' each week. Ideas and information will be shared within the group. Out of respect for others in the group you are asked to commit for the whole 6 weeks.

This course will be advertised in external publications to involve people with Parkinson's who are not members of the Society. Please be sure to register with Jessie as soon as possible to reserve your space in the course.

A Lasting Legacy

A bequest is a gift made through a Will, and it is your opportunity to make a lasting difference. It offers flexibility – you retain use of your assets and can make changes at any time to reflect your philanthropic and financial goals.

As little as 1% of your estate will make a lasting difference to the Multiple Sclerosis and Parkinson's Society, and will support our many services and allow essential programmes to continue. If you would like to leave a lasting legacy and remember those with Multiple Sclerosis and Parkinson's, please include a bequest in your Will to the Society. We recommend that you seek legal advice from your Solicitor when adding a bequest to your Will.

If you choose to leave a gift in your Will to the Society, our bequest wording may be useful for you.

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.

By remembering the Society in your Will, you can secure the future programmes for people with Multiple Sclerosis and Parkinson's in your Community.

Annual Donation 2010

The Annual Donation for 2010 is now due. You will find this form included in your newsletter and will see from the list below the extensive services you receive for this payment.

The Annual Donation has increased slightly and has been set at \$35.00. The Society regrets having to do this, but is aware that our costs are continually increasing.

It costs the Society approximately \$330 per year per member to provide services, such as: Home Visits, Exercise Sessions, Social Activity Programme, Workshops, Podiatrist, and the Newsletter. Your Annual Donation therefore provides you excellent value for your money.

If you would like to discuss this donation, you can phone Manager Jenny Boyer on 366 2857 ext. 2 or President Malcolm Rickerby on 338 1770.

There is a great benefit of paying without delay. If you pay your Annual Donation by 31 March 2010, you can claim 1/3 rebate as part of your tax return.



Changes to the Total Mobility (Taxi Voucher) Scheme

Environment Canterbury, who co-ordinate the Taxi Voucher Scheme, asked us to give them the amount it costs the Society to provide this service to you, our members. This figure is about \$95 per person per annum – a cost the Society has had to find over the many years that we have been associated with this scheme.

From 2010, members who have been assessed to use the vouchers will be sent, as part of their Annual Donation account, a request for an additional \$15 Administration Fee. The Society is very mindful that this is an extra cost for those using the vouchers, but it is one the Society can no longer carry.

If you would like to discuss this further, please contact Jenny on 366 2857 ext. 2.

Services you can access when you pay your Annual Donation

Here is a list of some of the services the Society offers its members throughout the year. If you would like to take part in any of these services, please contact **Annette on 366 2857 ext. 6** for more information.

Home Visiting Programme

- Home Visit to people who are newly diagnosed with MS or Parkinson's and free follow-up visits
- Support and information for members, their family, friends and caregivers
- Up-to-date evidence based information about MS, Parkinson's and medication
- Counselling and/or referrals to appropriate agencies
- Rest Home & Hospital visits



Exercise Programme

- Individual and group exercises and assessment
- Specific MS and Parkinson's Exercise Classes
- Yoga, Tai Chi and Nordic Walking groups
- Open Gym with the Society's Physiotherapist



Social Activities

- Suburban Morning Teas
- MS Lunch Group
- Parkinson's Spouses Support Group
- School Holiday Programme



Other Services

- Educational Sessions/Workshops
- Immunotherapy education, training and support
- Referrals to health professionals for assessment and assistance with daily living
- Assessment for total mobility/taxi vouchers
- Access to subsidised podiatrist
- Library & Newsletter

A Hilarious Night of Entertainment

The Court Theatre presented a private showing of The Court Jesters to a full house on Sunday 31 January. The Society would like to say thank you to all who purchased tickets (and sold tickets on behalf of the Society). The night was a huge success and the Court Jesters are a group of amazingly talented people with unbelievably razor-sharp wit.

The Society would like to thank the following sponsors of our raffles: The Court Theatre, Hinton's Restaurant & Café, Super Liquor Papanui, Bohemian Café & Bar, Life Pharmacy – The Palms, C4 Coffee, Waitikiri Golf Course and Rangiora Golf Course.

Thank You



We would like to say 'Thank You' to the Papanui Club for continuing to be such a generous Sponsor of the Society. They generously donated \$5,000 to the Society and sponsored our end of year BBQ. We had 70 members, staff and Board Members in attendance and a great time was had by all.

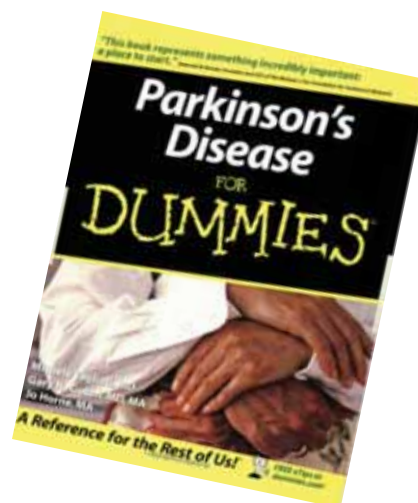
Book Review – 'Parkinson's Disease for DUMMIES'

Article written by Greg West

As a male and not used to asking for help or following instructions, I was still curious about this book. The book is described as 'something incredibly important: a place to start' by the Michael J Fox Foundation. I thought it was worth a look.

There is a 5th Wave cartoon by Rich Tennant at the start of each chapter. It starts with a couple at the Doctor's office with the Doctor saying, 'As explained, Parkinson's Disease is the depletion of dopamine in the brain. But before you fill up that space with a lot of negative thoughts, let's discuss your treatment options.' I thought this was a great start.

A deceptively clever book of 'All you need to know about the disease but were afraid to ask plus what you should also know.' Especially Chapter 19 containing a 'Bill of Rights for the PD care partner' which I copied and placed on my refrigerator. It sets out as a reference manual that can be read out of sequence as each chapter is on a different topic. There are six parts (plus Appendices) with each part having alerts such as Warning, Remember and Tip to help you take note of the important points.



The book was designed for Americans with references that do not apply to NZ, but in this digital age the website references can be a useful for searching on the Internet. It is up-to-date with information on Stem Cell research, 'Alternative Remedies' and the key roles of Diet and Exercise.

This is the best and most comprehensive treatise on Parkinson's that I have read. It is easy to follow with explanation and clarification at each stage. A summary at the start of each chapter enables you to select what you need to read.

This is a great reference manual and recommended reading.



When someone you care about has MS or Parkinson's

Jessie Snowdon, Physiotherapist

Being diagnosed with Multiple Sclerosis or Parkinson's can often be a life changing event, not just for the person being diagnosed but also for the people whose lives touch theirs – their spouse, partner, children, parents, whanau and friends – the list goes on. Recently Health and Disability Research and organisations are taking a more active look at informal 'carers' and are developing strategies and resources to offer support for people who fulfill this vital role.

The Ministry of Social Development defines a 'Carer' as 'anyone who supports a person with ill health, a disability, mental illness, an addiction, or in their old age' (The New Zealand Carers' Strategy and Five-year Action Plan 2008 – copies available from www.msd.govt.nz). Caring can be as involved as physically moving, washing and dressing a person, or as simple as answering the phone when they are too tired or their voice is not up to talking. Simply living with someone, offering encouragement and attending medical appointments can be seen as 'caring'.

It has been found that people who provide care may suffer from stress, poor physical and mental health, reduced social networks and be financially worse off if their previous career path has been altered. They may find themselves with new responsibilities such as child care, cooking, and dealing with household accounts that they may not be prepared for. Often the needs of carers/spouses can be overlooked.

The MS and Parkinson's Society Mission statement is to offer '...support, information and education for people with, **and those providing care for** people with Multiple Sclerosis and Parkinson's'.

As a 'carer' or spouse of a member you are welcome to make contact with our Nurses to talk through any issues that are occurring for you. We also have copies of 'A Guide for Carers' published in 2009 by



the Ministry of Social Development, which is a practical guide full of information about where you can get help such as equipment, financial help, respite care.

Another excellent publication is **Familycare** – a quarterly magazine, which is highly recommended and full of useful information as well as being a good read. It is free and you can subscribe by contacting tanya@carers.net.nz. The website www.carers.net.nz has useful links and information.

We will continue to offer support to people and their carers the best we can and welcome your suggestions and comments.

Parkinson's Spouses Support Group

The Society offers a Parkinson's Spouses Support Group, which includes educational sessions and social gatherings for spouses and partners of people with Parkinson's. Please see the 'Important Dates' section of the newsletter for up-coming events, including how to help someone up following a fall.

Email

It is hard to ignore email as a main source of communication throughout the last decade. It is a timely and inexpensive way to communicate with the people around us and here at the Society we are embracing this technology. On this year's Annual Donation Form we have asked you for your email address.

By providing this you enable us to:

- Make contact with you on short notice regarding workshops, speakers and events throughout the community
- Target a specific group of people (i.e. Early Onset Parkinson's) regarding an event in a cost effective way
- Reduce costs

We respect your right to not be inundated with emails and therefore will use your email address only when we feel there is a real need for you have the information. Please help us to easily and cost-effectively contact you throughout the year and provide your email address on your Annual Donation Form. Thank you from the staff at the Society.

MS+PD City 2 Surf Challenge



Join the MS+PD relay team for the City 2 Surf on Sunday, 21 March and get fit while raising money for the Society.

We are looking for members and their family and friends to be a part of our team. We will organise the event like a relay, so it is your choice to walk, run or use a wheelchair for 3km, 6km, 9km or all 12km (we can even arrange someone to push you).

People with MS Wanted for Physical Activity Research

The School of Physiotherapy in Dunedin and Christchurch are conducting a study called '**Blue Prescription: physiotherapy activity support package for chronic disability.**'

Participating in physical activity is important for health and wellbeing, particularly for people with chronic disabling conditions. Exercise has been shown to be beneficial for people with Multiple Sclerosis, however maintaining a long term programme of physical activity is challenging.

We have developed a programme, 'Blue Prescription', to support and optimise physical activity participation for people with MS. In this pilot study we would like to see how well our programme works and if it is feasible and acceptable to the people participating in it.

We would therefore like to invite you to participate in our study. Should you wish to participate or would like to find out more detail please phone **Hilda Mulligan at the Christchurch School of Physiotherapy at 03 364 0690.**

Entry cost is only \$12 (or \$17 to include food after the race). This entry cost entitles you to training and fundraising tips at the Registration Night on 1st March, a free fitness test with Jessie our Physio and two training walks the two weeks prior to the event.

This event is also a fundraiser for the Society, so we are asking those that sign up to get sponsors for their walk. Our goal is to raise \$5,000 and with your help we will be able to raise awareness and at the same time generate needed funds to support the hundreds of people living with MS & Parkinson's.

For more information on the MS+PD City 2 Surf Challenge, for a registration form or sponsorship form, go to www.ms-pd.org.nz or phone Lindsey on 366 2857 ext. 9.



Important Dates

Mark your calendar for the up-coming MS+PD events.

Morning Tea

Morning Teas are organised regularly and are held in a different suburbs of Christchurch. Please ring Shirley Noonan, Social Activities Coordinator, on 366 2857 ext. 8 or visit the Society website to see when and where the next Morning Tea is being held or go to <http://www.ms-pd.org.nz/social-activities.html>.

MS Lunch

The MS Lunch Group is held in the hall at the Society (Worcester Centre), 314 Worcester Street, on the first Thursday of each month.

Upcoming dates are: 4 March, 1 April, 6 May

Sponsors



Parkinson's Spouses Group

Event: 'Get up off the floor!' – Following on from a similar session last year, Jessie, our Physiotherapist, will take us through a session on how to cope if your spouse has a fall and needs help to get up, how to offer assistance without causing further injury and when extra help is needed.

Date: Wednesday 10th March

Time: 10.30am

Venue: Worcester Centre Hall

Note: Practical session so comfortable clothes. Gold coin donation to cover costs please.

Event: Morning Tea

Date: Tuesday 20th April

Time: 10.30am

Venue: Browsers Café, 110a Riccarton Road (opposite Westfield Mall)

Note: Coffee and cake will be available to purchase

***Please RSVP to Annette 366 2857 ext. 6 or email support@ms-pd.org.nz to confirm your attendance to any of the above events.

Available for mortgage, insurance or financial advice.
Phone Peter Sullivan on 03 372 1917.

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

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Officers of the Society

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

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



Staff

Manager: Jenny Boyer
Office Manager: Annette MacFadyen
Resource Nurses: Margaret Chapman RN, BA
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

