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AGM Presidents report



Members of the 2012 Parkinson's Board, from left: Andrew Sugget, Treasurer Peter Walker (retiring), Jo Hill, President Peter Raymond, Damien Farrell, Vice President Fred Van Ross, Treasurer Adam Conrad, Professor Meg Morris

Parkinson's Victoria held its 2011/12 Annual General Meeting at the Eastern Golf Club, Doncaster, on Friday 26 October.

Formalities included a presentation of the organisation's financial statements by CEO Ann Burgess, the election of new Board Members, an overview of the year by President Peter Raymond, and acknowledgment of various award winners, including this year's Sir Zelman Cowen Award for Outstanding Service. The day was attended by special guests Lady Anna Cowen, Professor Bob Iansek, John Williams, CEO Disegno Marketing, past and current Board members, members and staff of Parkinson's Victoria, supporters and friends.

Following his welcoming address, Peter Raymond highlighted some of the work and achievements of our team throughout the year:

Appointment of Parkinson's Nurses

- ✘ An Australia-wide initiative gaining momentum
- ✘ In Victoria, a Parkinson's nurse has been working in the Western

Health Region since 2007. This year we have been successful in placing one at the Lower Murray (Mildura) Medicare Local. Just recently we reached agreement with Goulburn Valley Health for an appointment and the groundswell has started in Bairnsdale for an appointment in Gippsland.

- ✘ Parkinson's Victoria's contribution, enhanced by the work of local Support Groups includes: Advocacy, lobbying, clinical expertise, direction and financial support.

Parkinson's Victoria Health Services team

- ✘ Our team continues to provide support by phone and foot annually to nearly 7,000 people all over Victoria, not just metro-Melbourne.
- ✘ We also provide support and partnership to Progressive Supranuclear Palsy (PSP) Australia and their leader Anne Mooney.
- ✘ We have added Hindi resources to our multi-lingual information suite, again courtesy of the Lord Mayor's Charitable Foundation.

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News & Highlights

Help for those living with CBS/CBD & MSA



Information Kits for CBS/CBD and MSA are now available on-line.

PSP Australia, in collaboration with Parkinson's Victoria, has recently launched an Information Kit for those living with **Cortical Basal Syndrome (CBS)/Degeneration (CBD) and Multiple System Atrophy (MSA)**, including family and carers. The kits

may also be useful for health professionals who are working with individuals who have been diagnosed.

Cortical Basal Syndrome (CBS)/Degeneration (CBD) is a rare neurological (brain) condition, characterised by a gradual loss of brain cells in the areas of the brain responsible for movement and thinking. CBS/CBD is a progressive condition meaning that symptoms worsen over time.

Multiple System Atrophy (MSA) is also rare neurological condition. It is caused by a gradual loss and shrinkage of brain cells in the parts of the brain that control movement, balance and the automatic functions of the body such as the bladder and blood pressure.

Information Kits can be ordered online. Simply visit www.psp-australia.org.au and click on the link in the side bar to either "CBS/CBD or MSA information", download the brochure and complete the order form (include payment details) and return to PSP Australia: PO Box 2594, Cheltenham 3192.

Alternatively, you can simply download and print the Information Fact Sheets found on the PSP Australia website (follow the same link in the side bar).

If you would like further information about PSP, MSA or CBD/CBS, please contact Dianne Rayner, PSP Support Worker and Client Services Officer, Parkinson's Victoria: (03) 9581 8700 or 1800 644 189.

Parkinson's lecture

Professor Malcom Horne will deliver a lecture titled **"Are we nearly there yet?"** on Thursday, December 6, exploring treatment and research options in relation to Parkinson's.

The venue is the Melbourne Brain Centre auditorium, Genetics Lane, Melbourne University, Parkville campus (opposite the Royal Melbourne Hospital, Melbourne ref: 43 F4).

Reasonably priced parking is available under the building, with easy access to the auditorium. Register at www.florey.edu.au (visit the 'news and events' tab then click 'events and seminars').

This is a free public lecture, proudly supported by Parkinson's Victoria.

Parkinson's "Passport"

Parkinson's Victoria's latest resource to assist those living with Parkinson's, particularly in relation to getting medication **on time, every time**, is a "Parkinson's Passport".

Individuals (or carer) complete the 'passport' by filling in their personal medication regime (name of medication, dosage and timing), along with the

contact details for their neurologist/GP/case worker. This can then be handed to a health worker or hospital staff, who can then use it as a reference to ensure medication is delivered on time, every time.

The passport also includes useful 'tips' for health workers to assist them in optimising the quality of care provided to clients and patients. The booklet may also be a useful tool to carry with you when out and about, should you need emergency or other assistance.

For a free copy of the 'passport' please contact our Health Team.

Parkinson's Victoria Annual Report



Parkinson's Victoria held its **2011/12 Annual General Meeting (AGM)** at the Eastern Golf Club, Doncaster on Friday 26 October. A summary of President Peter Raymond's speech can be found on page 1 of this newsletter.

Annual Reports for the financial year are included with this newsletter. If you have not received a copy, please request one from our office.

Stop press: Class action update

A class action has been commenced in the Federal Court of Australia, arising out of the alleged side effects of changed and abnormal behaviour following the consumption of Permax[®].

Members who meet the below requirements are considered a class member for the purposes of this action, unless they choose to opt out.

If you wish to opt out you must complete an **opt out notice**, which can be obtained from Parkinson's Victoria, or by contacting Arnold Thomas & Becker on (03) 9614 1433 / 1300 333 300 or email:

reception@arnoldthomasbecker.com.au

The class action may apply to you if:

- You were diagnosed with Parkinson's or Restless Legs Syndrome; and
- You obtained at least one prescription of Permax[®] tablets from a doctor in Australia between 1994 and 2010 to treat that illness; and
- Both before and after 28 March 2003 you used the prescription and consumed the tablets; and
- After commencing to consume and while consuming the tablets you suffered changed and abnormal behaviour for you being:
 - ✘ Compulsive gambling
 - ✘ Compulsive spending
 - ✘ Compulsive eating
 - ✘ Hyper sexuality
 - ✘ Punding (meaning a compulsive fascination with and performance of repetitive, mechanical tasks)
 - ✘ Or a combination of one or more behaviours referred to above
- You suffered loss and/ or damage as a result of that changed and abnormal behaviour caused by the tablets.

If you have any concerns about Impulse Control Disorders, contact our Health Team for advice.

New initiative for the global Parkinson's community

A new "wiki" has been started for all those interested in scientific research into Parkinson's.

A "wiki" is a website which allows its users to add and modify its content via a web browser. The new wiki, called **The Science Behind Parkinson's Disease**, is a 'Learning Project' within Wikiversity, a sister project to the highly regarded Wikipedia and everyone throughout the world, particularly those affected by Parkinson's, is invited to participate as a reader or a contributor.

The wiki promotes itself as "*An Active Community, Contemplating and Communicating - the Complexities of Parkinson's Comprehensively and Comprehensibly*".

What's the general idea?

People affected by Parkinson's want to know what the prospects are for better treatments and a cure.

There is an increasing amount of research going on but it is a difficult and time-consuming job to follow this and to understand the significance of the various developments. For the lay person, understanding the science is a big hurdle, but a lot of people around the world want to do this and many are trying to do so in their own individual ways.

This wiki has been set up so people can share the results of their often painstaking investigations and explain to others in accessible language what they have learnt. Through this wiki the 'creators' envisage building a framework to make sense of the concepts, ideas and discoveries about what Parkinson's is, how it affects the nervous system and how it might be confronted, continually updating it as progress is made. Above all this wiki portal can be a vehicle to explain new discoveries and their significance in terms that are clear and understandable.

This wiki is an entirely volunteer-run initiative, is not controlled or sponsored by any organisation and is open to anyone to participate by editing and contributing material.

This Parkinson's Science wiki has been started by a few individuals and now is being opened up globally to interested parties who would like to participate in its development.

http://en.wikiversity.org/wiki/Portal:The_Science_Behind_Parkinson%27s

It is hard to believe that 12 months ago we held our **2010/11 Annual General Meeting**, saying farewell to some long-standing Board Members who had served us so well, over many years: Kate Brown, Mary Jones and Royce Pepin.



It can take some time for new Board members to become familiar with their responsibilities and Board procedures, but Joanna Hill, Professor Meg Morris and Andrew Suggett have each brought to the Board their unique personal and professional qualities.

Joanna joined the Research Sub-Committee, chaired by Fred Van Ross, and with her mother Julie Sewell continued her wonderful Tulip Ball fundraising activities, which together with her business management skills make her a wise and valued contributor.

Professor Morris' academic experience and professional contacts, in Australia and internationally, enabled us to sponsor workshops at the **Seventh World Congress of the World Federation for NeuroRehabilitation**, funded by the generous support of the Colin and Sheila Marshall Trust. Post-Congress, Meg facilitated a "**Meet the Experts**" workshop, also funded by the Colin and Sheila Marshall Trust. Meg also represents our Board on a Parkinson's Australia Sub-Committee.

Once a month, Andrew Suggett catches the train from Warrnambool to Melbourne so that he might contribute his decades of business experience and Rotary International leadership to the deliberations of our Board. And, of course, he brings to the Board first-hand experience of supporting people with Parkinson's who live outside Melbourne with all the challenges that can bring.

In the next issue of **Signpost**, I hope to introduce you to some more new Board members; people who have volunteered their time to ensure that the Board continues to serve Parkinson's Victoria with wisdom, vision and care.

However, before extending on behalf of the Board the most peaceful and healthiest of Christmas wishes to you all, may I thank CEO Ann Burgess and her team, for their untiring efforts to serve the needs of all Victorians living with Parkinson's. Formal and informal feedback from you, our clients, is nothing but warm and positive about their initiative, commitment, knowledge and responsiveness in times of need.

The community events, fundraising activities and incorporation of volunteers into Parkinson's Victoria, are all second to none.

We are indeed blessed to be so well-served by our staff, all of whom make the Board's job so much easier.

May I wish you all a very happy Christmas, and a happy and healthy New Year.

Peter Raymond, President

AGM President's Report

Support Groups

- Support Groups continue to provide invaluable support to local communities at the 'coalface' of need, and in 2011/12 many celebrated their 30th Anniversary.

Research

- We established a more coherent and consistent process to allocate funds to worthy projects and more actively engage with the **National Health and Medical Research Council (NHMRC)**

Following this synopsis, Peter highlighted the importance of fundraising:

The Financial Statement for 2011/12 showed that income from Fundraising, Donations and Merchandise was just on \$450,000. One item alone, Events including activities such as **Walk in the Park**, Film Nights and Golf Days, generated Income of just on \$300,000. Six years ago in 2006, Events contributed just \$9,500 to our income.

In 2006/07, the same 3 items (Fundraising, Donations and Merchandise) generated income of \$150,000; Parkinson's Victoria's expenditure was \$630,000. This year we doubled that spending to just on \$1.2m.

Also in 2006, Membership Subscriptions contributed \$43,000. In 2011/12, they again contributed \$43,000!

Six years ago, our organisation employed the equivalent of 8 full time staff. This year we still employ the same complement.

Peter posed the question whether this meant they were working twice as hard, our supporters were twice as generous, or we were twice as efficient?

One thing for sure is that today we welcome volunteers by the hundreds. Six years ago **all** our volunteers would meet in the Board Room in our old office at the Kingston Centre.

In congratulating the Parkinson's Victoria team, Peter deliberately refrained from individualising staff, but he did request that CEO Ann Burgess and her team stand and receive a sustained round of applause and the sincere thanks of the Board and Members.

Peter then specifically acknowledged the support of Vice President, Fred Van Ross. His knowledge and wisdom gleaned over nearly 9 years of service to the Board is a constant and valuable source of comfort and advice.

Similarly, he extended thanks to Peter Walker who for 7 years, 6 of them as Treasurer, has been a wise and practical custodian of our finances. Never one to be strident or domineering, Peter Walker has always ensured an appropriate balance between financial rectitude and reckless spending. Taking over at a time when our deficit was quarter of a million dollars, his legacy is a balance sheet of \$2m.



From top: Lady Anna Cowen (right) presents Ann Atkin with the **2012 Sir Zelman Cowen award for Outstanding Voluntary Service**, named in honour of her husband, Sir Zelman Cowen; President Peter Raymond (left) presents retiring Board Member and Treasurer, Peter Walker with a **Certificate of Appreciation**; Professor Bob Iansek's service to the Parkinson's community was recognised with an award for **Outstanding Achievement**; Five Year Award recipients included (from left) Margaret and Geoff Nickson (Essendon), Cheryl Barnes (Mildura), Audrey Thornton (Mildura) and Judy Buckley (Camberwell), standing with Vice President Fred Van Ross (centre). [Award recipients Moira Lewis, Mel Dougherty (Warragul), Judy Lawes, Bert Lawes, Brendan Lourey, and Linda Walsh (all members of Essendon) were unable to attend]; Ten Year Award recipients included (from left) Tom and Margaret Redpath and Jill Goss (all from Essendon) with Vice President Fred Van Ross (centre).

A Message from our CEO

At this time, Peter drew our attention to some of the challenges facing our organisation:

- ❖ Competition: We need to establish Parkinson's Victoria as a 'charity of choice' – many will support us because they are connected to the cause and believe in the work we do. We need to not only maintain that position of value and credibility in the eyes of the Parkinson's community, but in the broader community, where competition for the 'charity dollar' is becoming harder and harder.
- ❖ Engaging more people with Parkinson's: Market research by Disegno revealed that only around 16 percent of those surveyed knew about Parkinson's Victoria (compared with an estimated 98 percent who said they 'knew of the condition'). We need to ensure that everyone who needs our help knows about us and has access to our services. This will also ensure we can lobby on behalf of the community, knowing we are genuinely representative.
- ❖ Providing even better and more extensive Health Services for all Victorians with Parkinson's. This one needs no explanation!
- ❖ Building an organisation that is relevant, reliable, and forward thinking for generations to come.

That means aggressive marketing, innovative fundraising, and using social networking and digital communication to spread the word and win ambassadors to our cause.

This is all designed with one purpose in mind: to deliver the best health services possible and move ever closer to our mission of "a world without Parkinson's"

In closing, Peter shared three personal anecdotes, which he felt in their own way demonstrated what Parkinson's Victoria has achieved for health professionals, individuals, families, carers and the people who support them, not to mention the generation of children who will carry on the fight to achieve our Mission. They included reference to our **Get it on Time** campaign which Peter experienced – successfully - first-hand after a recent spell in hospital; how a schoolmate of some 45 years, long-time neighbour and friend turned immediately to Parkinson's Victoria after recently being diagnosed, and the proud moment his grandson chose his '**Walk in the Park**' t-shirt for show and tell.

"Parkinson's Victoria is doing wonderful things for the community, and with your continued support has the capacity to do even more," concluded Peter.

Given the lack of funding from both state and federal governments, it is reasonable for people living with Parkinson's to feel ignored, unsupported and forgotten.

Whilst I share this frustration, I sense a change in the direction of the wind. There are two external indicators that have made me feel more optimistic about things.



In the last few years, we have seen the Federal Government introduce two new initiatives; the **National Disability Insurance Scheme (NDIS)** and **Medicare Locals**.

The **NDIS** is a scheme that aims to provide health insurance to people with a disability.

I urge everyone in the Parkinson's community to visit www.ndis.gov.au and sign up to the **NDIS Your Say** initiative; even if you have nothing to say at present, at least sign up for the updates.

Make sure that the **NDIS** knows that you want a scheme that reflects your needs and works for people on the ground.

Medicare Locals are a new, locally-based primary health care structure.

If they work well, as we hope they will, these new organisations will improve primary health care and make it more relevant for ageing populations and those with a long term disability, like Parkinson's.

In your region, your Medicare Local will support front-line health care providers, especially general practitioners and allied health providers, to improve their services, fill gaps, coordinate care and make it easier for you to negotiate the maze of services.

You can find out more at www.medicarelocal.com.au

In August, Parkinson's Victoria was pleased to announce that the Mildura Medicare Local had appointed a Movement Disorder Nurse. In addition, there is ever growing support to establish Movement Disorder Nurses in Shepparton and Bairnsdale.

I am also optimistic about results from a survey commissioned by Parkinson's Victoria and completed by Disegno, a creative marketing agency. Disegno surveyed 300 Victorians by telephone interview, on line questionnaires and face to face meetings. Ninety-eight percent of those surveyed stated they "knew of Parkinson's", while 79 percent said that they were "accepting of people with Parkinson's". This indicates there is greater awareness of Parkinson's in the community, which will lead to greater acceptance and support – and we all know what that means!

Our office is now facing the last few weeks of 2012, with a number of events, education seminars and support services still to deliver. For our team, it has been another challenging year as we strive to respond to the increasing need and changing landscape.

On behalf of our team, I wish you and your family the very best for a safe and happy festive season and for the New Year. We hope we can continue to provide assistance, advice, reassurance and hope to you in 2013.

Ann Burgess, CEO

Psychological aspects in Parkinson's

Having worked in the area of mental health services for 12 years, DIANNE RAYNER, Client Services Officer in our Health Team, is especially interested in the psycho-social aspects of Parkinson's specifically, and chronic illness in general.

In collaboration with the MS Society, Dianne recently presented a professional development program to allied health professionals on the psycho-social aspects of chronic illness. This article covers some of the information from that workshop from an individual and carer perspective.

Psychological problems are common in Parkinson's and their impact can be significant, exacerbating the challenge of living with a chronic condition. These days, the psychological or 'psycho-social' aspects of Parkinson's are viewed as both a clinical aspect of the condition and a by-product. Unfortunately, understanding, acknowledging and effectively treating the psycho-social impact of Parkinson's has a long way to go.

What exactly does 'psycho-social' mean?

Up to 75 percent of those diagnosed with Parkinson's will experience symptoms of depression at some stage, while approximately 30 to 40 percent will be affected by anxiety problems.

Symptoms of this nature, which are associated with Parkinson's, can often be invisible to family, friends and carers, making it more difficult to understand the experience. Some of the symptoms may include anxiety, stress, fear, grief, sadness, anger, irritability, mood swings, and depression.

Motor symptoms and the fluctuations of non-motor symptoms, such as anxiety and slowed thinking can be quite disabling. While not everyone with Parkinson's experiences major cognitive changes or psychological disorders, it's important to highlight that individuals and/or family members may struggle to adjust to the social, emotional and personal changes brought on by Parkinson's.

Identifying and recognising these issues – or any one of them – is vital, because when left untreated such psychological problems can lead to poorer quality of life, greater cognitive decline, and decreased mobility and independence in those diagnosed with Parkinson's.

Despite these outcomes, there is no doubt that the difficulty of adjusting to a diagnosis of a chronic illness impacts on one's decision and ability to acknowledge and address psychological problems. It is estimated that only 20 percent of those experiencing psychological problems will seek some form of professional help.

A diagnosis can be a long, drawn-out process and

complex. How people respond to a diagnosis will depend on a variety of things, including personal perceptions about the condition, cultural and social expectations and other stressors in a person's life such as reduced 'ability' (physical and/or cognitive) which can be ongoing and cumulative.

Depression

We all have periods of feeling "down" or "low". Therefore, given the impact Parkinson's can have, it is normal for those diagnosed with the condition to experience a degree of emotional distress from time to time. This may not necessarily require any significant intervention other than a supportive environment. However, when periods of feeling "down" or "low" become chronic, ongoing and persistent, with distressing or low moods occurring most of the time and lasting for weeks or more, medical intervention may be required.

A GP is a good place to start for consideration of treatment including counselling and/or medication.

Depression causes significant distress and can impact on a person's social and/or work functioning. People with depression often report a loss of interest and pleasure in daily activities and may feel worthless and guilty. Remember that if you are feeling tired or unwell it can be challenging to be happy all of the time.

Chronic illness can also impact on spousal relationships, family dynamics and others in our personal and social networks, so it's important to explore the degree of impact with your family (or others) and determine whether additional support is necessary.

Cognitive changes

Cognitive changes associated with Parkinson's may develop, including working memory. The ability to hold and operate information for short periods of time can often be impaired in the early stages of Parkinson's. Slowed information processing, rigid thoughts and losing one's train of thought can have an impact on everyday life. This may cause stress and misunderstanding and can be difficult to accept. UK trials are currently investigating the potential of pharmacological therapies (drugs) as an effective treatment for cognitive problems.

Sleep problems

Sleep disturbance can result in sleep disorders. An estimated two-thirds of people with Parkinson's experience sleep disturbances, with around one-third of those experiencing moderate to severe sleep problems.

Specific sleep disorders associated with Parkinson's include insomnia (falling or staying asleep), hypersomnia (excessive sleepiness), parasomnia (abnormal or unnatural movements), and [rapid eye movement \(REM\) sleep disorder](#).

Sleep disturbance can be under-recognised and therefore under-treated by clinicians.

Participate 4 Research

Fatigue is also common in Parkinson's and can be a distressing non-motor symptom. **Cognitive Behavioral Therapy** (CBT), such as changing your attitude towards sleeping, and combining methods such as education, advice and psychotherapy, can all be helpful in managing fatigue.

Carers and support networks

The needs of carers and family members resulting from the impact of Parkinson's can be enormous.

The change in relationships between individual and spouse (or wider support network) that results from living with a chronic condition can be challenging for all involved, so it's not surprising that the associated stress can affect the physical and psychological health of a carer.

Carer responsibilities, including the physical demands of caring, and the subsequent personal, emotional, social and financial impact on carers and family members can all be significant. Carers and family members are encouraged to seek professional advice for any prolonged distress.

The psycho-social aspects of Parkinson's are a growing area of interest for clinicians and researchers.

Some of the information in this article has been sourced from the Parkinson's Disease Society UK website, www.parkinsons.org.uk. The site offers a range of excellent Fact Sheets and resources on this topic.

For further information regarding the psychological impact of Parkinson's on the individual and their support network you can also visit The British Psychological Society www.bps.org.uk (use the 'search' function to find articles relevant to Parkinson's) or contact our Health Team.

Researchers from the **School of Psychology and Speech Pathology** from Curtin University in Perth are currently exploring attitudes to seeking psychological help among people with Parkinson's. You can participate in the online survey by visiting: <http://psych.curtin.edu.au/research/phd/ltroung.cfm>

All research programs supported by Parkinson's Victoria have met our protocols regarding relevant ethics approval.

A holistic approach

The ESSENCE program: The impact of a mindfulness-based lifestyle program for Parkinson's, is a research program being undertaken by Dr Craig Hassed and his team.

'Essence' stands for: Education, Stress management, Spirituality (meaning), Exercise, Nutrition, Connectedness (social support) and Environment.

The course will explore the potential role each of these elements has in helping individuals to manage their Parkinson's symptoms and its impact on their lives, hopefully leading to improved quality of life.

The program involves attending a weekly, 90-minute group session. If you are fluent in English, under the age of 75, able to attend a minimum of 4 out of 6 sessions, able to stand up or walk straight most of the time without assistance you may be eligible for participation.

The Essendon Support Group will be hosting sessions in November and January, and the Camberwell Support Group will be running sessions in November, December and January. For further information, please contact the Recruitment Officer Brooke Vandenberg: (03) 9902 4920 or brooke.vandenberg@monash.edu.

Dancing project

Recent studies have shown that dance, as an alternative to traditional exercise for people living with Parkinson's, can have a beneficial impact on motor skills, balance and overall quality of life. Also, as dance is an enjoyable and engaging activity there is generally a higher rate of adherence and participation for those involved.

To date, there have been no Australian studies undertaken in relation to the possible benefits of dance for people with Parkinson's. To explore this potential therapy from an Australian context, Professor Meg Morris and associates from the University of Melbourne are currently conducting a pilot study exploring the feasibility and benefits of an 8-week modern dance program on balance, mobility and quality of life for people living with Parkinson's.

This project will kick start in November and we look forward to providing you with some initial feedback in 2013.

Lending a hand

Special thanks to Jason Lavery for making sure everyone in his local community (Pakenham) and surrounds knew about this year's **Walk in the Park**. Jason handed out flyers during his garage sales, asked local retailers to display posters, and also spoke with his local media. He also secured a donation of three vouchers from local restaurant, Shanikas at Viale (www.shanikasatviale.com.au) – 'the best restaurant in town' (and with sister eateries in Berwick and Carrum Downs).

For your chance to win a \$30 voucher for the Pakenham restaurant, log onto www.parkinsonsvic.org.au, view the "Message from Jennifer" (scroll down the homepage) and then tell us your thoughts about the video on our Facebook page: <http://www.facebook.com/parkinsonsvic> Entries close: December 17, 2012. Thank you Shanikas Restaurant!

Symptom Management

Frequently Asked Questions

Our Parkinson's Clinical Nurse Consultant, VICTOR MCCONVEY, reflects on some of the questions the Health Team has encountered over the years.

How does Parkinson's affect sleep?

Sleep problems related to Parkinson's are numerous and very frustrating. They can range from difficulties moving in bed (due to lowered levels of medication) to experiencing REM sleep disorder, where you may act out your dreams or move violently in your sleep. To make things worse, both problems can occur on the same night.

- ❖ You can improve bed mobility by using satin sheets to increase 'glide', and a bed stick can assist you to manoeuvre in bed.
- ❖ Speaking with your neurologist about having additional medication at bed time or during the night can also help.
- ❖ For REM sleep disturbance, it's important to make sure you can't hurt yourself or your bed partner as a result of extra (unexpected/violent) movements. Sometimes additional medication to aid sleeping can help.
- ❖ Nocturia or frequency of urination at night can also affect sleep (see next question).

Does Parkinson's cause bladder problems?

Parkinson's can cause bladder difficulties, such as the need to pass urine frequently; having little warning that you need to pass urine; and *nocturia*, which is passing urine frequently once you have gone to bed. All of these will naturally impact on an individual's sleep quality.

These difficulties are caused as a result of poor functioning of the brain's micturition centre, the part which interprets signals from the bladder muscles.

Often bladder problems worsen during a period of "wearing off", so taking your medications on time is one of the best ways to address this problem.

Other helpful strategies are to avoid drinks that may be irritable to the bladder or have a diuretic effect, such as coffee, strong tea and alcohol. Pelvic floor exercises for men and women, and the use of oestrogen cream on the perineal area for post menopausal women, will also be helpful.

Other good 'habits' to develop include going to the toilet before you leave home and knowing where the toilets are located at your destination (or along the journey). Try www.toiletmap.gov.au

Does Parkinson's cause constipation?

The number one continence issue in Parkinson's is constipation and it often occurs long before any motor symptoms appear.

Constipation can be persistent throughout the condition's progression, and can cause further problems such as fatigue and bowel incontinence.

The good news is that constipation can be managed with medical treatment, extra fibre in the diet and/or lifestyle changes.

While this symptom is extremely common in Parkinson's (not to mention very annoying), it is also a symptom you may not think to discuss with your neurologist or GP.

There are a number of causes for constipation in Parkinson's. One is the lack of dopamine in the small and large bowel: Like other muscles of the body that become slow and rigid without sufficient dopamine, so do the bowel muscles slow down, affecting the body's ability to efficiently and effectively process food and waste. Other causes include: weak bowel muscles, insufficient dietary fibre and water (possibly caused by swallowing difficulties), lack of exercise (being sedentary can slow the passage of food through the intestines) and medications (Parkinson's and otherwise) which can cause constipation through slow bowel movements and reduced appetite.

Some of the best ways to address constipation are to ensure you drink at least 2 litres of water per day and exercise regularly, as well as adding fibre to your diet (try increasing your fruit and vegetable intake, adding psyllium husks to your cereal and salads, and drinking prune juice).

Constipation is an issue that should be taken seriously. After falls, constipation is the second most common cause of emergency department attendance for people living with Parkinson's.

For many people living with Parkinson's, constipation will need to be managed by regular *aperients* or *laxatives*. Choosing the best aperient is important (particularly as the gut is slowed down by Parkinson's), but can be confusing.

Some good information to start with is to avoid irritant-type laxatives, such as *coloxyl* so as to reduce abdominal cramping, and be aware that osmotic agents such as *Atilax* or *lactulose* will not work unless sufficient fluid is also taken. The best laxatives to take on a regular basis are lubricating and bulking agents, such as *Movicol*. *Taking them regularly will also ensure you stay regular!*

Parkinson's can be confusing and the symptoms, medication regimes and side effects can be unexpected and unusual. The calls we receive through our Help line reflect this, with enquiries ranging from simple to complex.

Our Health Team take every call seriously and our priority is providing assistance and information that is timely, relevant and reliable. Our emphasis is enabling individuals, carers and families to make informed decisions. Of course, the relative anonymity of our Help line means you can freely discuss problems you may otherwise feel embarrassed about, and you can feel confident that all information is treated with respect and confidentiality.

Aids and Equipment: One size doesn't fit all!

There is a range of equipment that may assist in managing the day-to-day symptoms of Parkinson's. BREANNA WOTHERSPOON, Health Promotion Officer in our Health Team, provides a brief overview of some of the most common aids available.

The following are just a few examples of aids and equipment that may be helpful to those diagnosed with Parkinson's (though there are more than just those listed here).

- ❖ Medication timers and pill boxes can help ensure you get your medication **on time, every time**, even while you are out and about enjoying your day (many will fit discreetly into your handbag or pocket).
- ❖ Personal alarms can offer peace of mind to you or your family, knowing that if you need assistance or have a fall there is a reliable way to call for help – particularly if you live alone.
- ❖ Bed poles or satin bed sheets can make it easier for you to roll over in bed, or get up in the morning.
- ❖ As your mobility needs increase, hand rails or a walking frame can ensure you move safely around your home, and around the general community.

It is important that these aids are considered carefully though, to ensure you are safe when using them, that you are using the best equipment for your specific needs, and that you are spending your money wisely.

Buying for others

While it's true that we are entering the 'traditional gift giving season', we advise against purchasing any aids or equipment for someone without consulting them first.

Ensure that the item is something they feel would be of value and would be willing to use. Family members will gain little peace of mind from purchasing a personal alarm for someone who spends a lot of time in the garden, but who leaves the alarm sitting on the kitchen bench!

Learn to use it

It is important to ensure that you, or the person who will ultimately be using the equipment, understands how to use it.

Read through the operating instructions or ask someone to explain/demonstrate the mode of operation for you.

Medication timers or mobile phones can remind you to take your medications, provided you know how to program them (of course, in the case of technology such as a computer or mobile phone devices, you may like to ask the nearest 10 year old – they often have a better grasp of technology than the average adult!).

A walking frame may be a good mobility aid to assist you in walking around your local shopping centre, but it is of little value if you don't know how to fold and pack it into the car that you take to the shops.

Consult the experts

When it comes to aids and equipment it is not always a case of 'one size fits all' and health physicians and specialist are on hand to help.

For example, mobility aids such as a walking stick or frame need to be the appropriate height and size in order to be used safely; equipment such as handrails or ramps need to be installed correctly by a professional and are required to meet certain building standards.

It is recommended that you consult a physician such as an Occupational Therapist before purchasing equipment or installing equipment at home.

Occupational Therapists (OTs) assist clients to achieve maximum function and independence despite illness, injury or disability. OTs can assess which aids and equipment would be most relevant for you and ensure that you are able to use them safely. They may also be able to offer strategies to assist you in your daily movement and tasks.

Consider funding options

In some circumstances you may be eligible for funding to subsidise the cost of aids and equipment, for example through the **State Wide Equipment Program (SWEP)**.

SWEP is a government-funded scheme for people who require aids and equipment or home modifications on a permanent or long-term basis.

To access this funding, an assessment and prescription is required from an appropriate medical specialist and/or allied health professional (such as an Occupational Therapist).

Do you have a question about aids and equipment that might assist you or a loved one to improve their mobility or enhance their quality of life? Contact our Health Team.

Personal Dopa-meanings



Breanna Wotherspoon (standing, left) from our Health Team with the author, Bev Beattie (in stripes) and members of the East Wimmera Parkinson's Support Group.

My story

Diagnosed with Parkinson's in her 50's, BEV BEATTIE shares her experience undergoing Deep Brain Stimulation surgery and its impact on her life.

I came down with a fever in 1992 when I was 52 years old. I noticed a shaking right hand and whilst walking one day, I noticed in my shadow that my left side was not swinging anything like my right side. Consequently, I was diagnosed as having Parkinson's.

Over the course of the next 8 years I was taking a cocktail of drugs and I was in a pretty bad way.

It was suggested that I have Deep Brain Stimulation (DBS) surgery.

I feel really lucky that I was selected to have DBS, as not all people are suited. I was one of the 'older' patients chosen.

I was referred to a Neurosurgeon to see if he thought I was suitable to undergo the procedure.

Next I had to see a Psychiatrist to see if I was mentally fit (my husband Jack still queries that outcome!).

Then a Neuropsychologist gave me a two-hour test to see if I had any signs of dementia or Alzheimer's.

A social worker met members of my family to see if I had supportive people around me, particularly for the first few months after the surgery.

Then I had to meet the manager of the Parkinson's Program who explained things more fully and arranged admission to the hospital, and finally the Gait Researcher at the Kingston Centre. They do walking and balance tests which are recorded on video to show you "on" and "off" medication.

I was advised that DBS can only provide results that are the same as when you are at your best when taking Parkinson's medication, and there is a chance of side effects including stroke, epilepsy, depression. Less serious side effects were problems with speech

and changes in behaviour such as euphoria and greater risk-taking. (My husband will be keeping a close eye on me at the pokies I guess.)

I got the call to go to the Kingston Centre in preparation for my DBS operation in August 2011.

I arrived on the previous Monday, with the operation planned for the Friday.

Intense scrutiny started immediately on arrival, with exercises being performed and videoed.

A program was mapped out, consisting of walking quickly for 6 minutes and getting to my feet with no help from the chair arms 10 times; marching on the spot and twisting my body so many times; I had to put my fingers to my nose, turn palms up and down, etc.

Thursday afternoon I was transported to Jessie McPherson Hospital in readiness for the operation. I had an MRI scan, and a CAT scan so they could locate the most suitable targets to implant the probe leads.

Would you believe my family rang to advise me to watch the TV that night as there was going to be a story on DBS! My Neurosurgeon even gave an interview! (Five minutes after watching it on TV, the Neurosurgeon walked into my room, I nearly asked him for an autograph!).

He prescribed a sleeping tablet and I bedded down for the night early as I could have nothing to eat or drink from then on.

At 7:30am I was pushed in my bed down to the operating theatre which seemed to be miles away. There, the anaesthetist and his assistant introduced themselves.

At about 8am they explained that they would sedate me for about 10 minutes so they could drill some holes in my head. When I came to, there were about 10 people around me. The Neurosurgeon started to shave my hair off; the clippers were blunt and it felt like they were chewing my hair. That was the most painful part of the whole operation!

Once my hair was gone, they attached the 'halo' and screwed it down so I couldn't move, even if I wanted to. It took so long to screw down and then they had all that plastic to rearrange. I think it was a precautionary measure against germs or people breathing.

Then they started sawing into my skull which had been deadened slightly (although the brain itself doesn't feel any pain). I heard the Neurosurgeon exclaim that I had a hard skull! I couldn't feel the drilling as he was cutting into it, but I could feel pressure.

They were talking to me the whole time during the operation - getting me to move my hands, fingers, checking body parts for tingly sensations and so on. They used computer mapping to guide the surgeon to locate the precise angle for maximum improvement.

Personal Dopa-meanings

At the end of the operation I was sedated again so that they could put the wires under the neck skin and down to the little transmitter (just like a heart pacemaker).

The operation took around 8 hours. When I came to, I immediately knew that the operation had been a success.

In my mind, I felt the fog had lifted and things were already clearer. I looked at my hand and it wasn't shaking, even though I had not had any medication for days, and my transmitter wasn't even turned on at this stage! I was conversing with family with great wit I thought. No aching discomfort in my groin area. I already felt like a new woman. I could dress myself, pull up my socks and pull up my pants.

On Monday I was allowed to go home. Normally on the third day, patients would be 'activated' but the doctor had to go away, so he decided that I would return home in the interim and be 'activated' in a week's time when he returned. On the way home, we stopped at the Keilor Petrol station and when we walked in I could smell coffee! What bliss! I hadn't smelt coffee for over 10 years and I had drunk weaker and weaker tea and coffee until I pretty much gave it up altogether as it made me sick. I could have sat there all day, drinking cup after cup.

I think I had euphoria. I felt like a dog that had been let off the chain after 10 years and I was rushing around marking my territory (but didn't have enough piddle I found out).

I am now 'sniffing' everything, roses, soups... my sense of smell and taste have returned and it's wonderful.

After a week at home I got the call to present myself at the Kingston Centre to be 'activated' the following day.

Tuesday morning arrived, activation occurred and was altered marginally daily until I had weekend release to be back for release on Monday (all going well). And it did go well. I think everyone could see the difference in me now!

The staff instructed my husband and I on how to use the transmitter and to adjust my setting up or down, depending on how I was feeling or if I was lacking energy and general wellbeing. Then I was advised to take it easy for the next three months, even though I would feel really good, and to remember that I had just had a major brain operation.

Six weeks later, I had an appointment at the Kingston Centre where they deactivated me in preparation for a review of my situation.

Almost immediately, my right arm started flapping like a dying fish in a thunderstorm! My limbs started getting deep bone aches and my vision started to become impaired. It was not a pleasant feeling.

They put me through the dexterity tests which resulted in alterations to my stimulator.

I have another appointment in 6 weeks, and things are only getting better.

This operation has been carried out successfully in Melbourne since 1995 on people suffering from epilepsy, depression and Tourette's Syndrome but has been the most successful in relieving the symptoms of Parkinson's.

I appreciate all the little things now and am so glad I didn't let fear hold me back when I was given the chance.

Effects of the successful DBS operation can be summarised as follows:

- ✘ Less tablets to take on a daily basis
- ✘ Return of sense of smell and taste
- ✘ Can think to play Scrabble
- ✘ Dexterity has returned to my fingers
- ✘ Foot cramps have disappeared
- ✘ Ability to whistle has almost returned
- ✘ Redness across cheeks hardly occurs
- ✘ Dialling the phone is easy
- ✘ Dry eyes not as prevalent
- ✘ Constipation less of a problem
- ✘ Bladder works well

and finally -

- ✘ I requested that my physio exercises were to help my golf swing, so watch out Wyche Pennant!!

Editor's note: Bev sent us this story in November 2011. We understand Bev has gone from strength to strength since her DBS and we wish her all the best for continued good health!

In 2013, Parkinson's Victoria will be starting a Support Group in the Cheltenham area for people who have undergone DBS surgery. For more information and to express your interest in being involved, contact Breanna from our Health Team.

Parkinson's Victoria Companions

Parkinson's Victoria recently launched a "Companion Program" giving the community the chance to make a personal and significant contribution to support our work.

Companions make a donation of \$1000 (over 3 years or one-off) and in return receive a limited edition **Companion** badge to demonstrate their commitment to the cause and to highlight their contribution. They also receive a **Certificate of Appreciation**, and their name will be listed in a special 'Honour Roll', on display in the foyer of Parkinson's Victoria.

This is a limited opportunity, with only 100 'Companions' available.

For more information about the Parkinson's Victoria Companion initiative, please contact Judith Mooney, Marketing Manager: Judith@parkinsons-vic.org.au or (03) 9581 8700.



Walk in the Park

WOW! 2012 Walk in the Park makes a real difference!

Thank you to everyone who turned out for this year's **Walk in the Park**, proudly hosted by Parkinson's Victoria and supporting all those living with Parkinson's!

We hope you enjoyed a fantastic day with family and friends... And, we hope to see back at Federation Square for next year's **Walk in the Park** – on Sunday, 25 August, 2013.

The day was incredibly moving, and for many of you it was an emotional experience. It was heartwarming to see such tremendous community spirit from individuals who are living with Parkinson's and their supporters, and from those who were celebrating the life of a loved one.

A HUGE THANK YOU TO ALL THOSE WHO MADE A DONATION AND/OR ACTIVELY FUNDRAISED TO HELP US REACH OUR 2012 FUNDRAISING GOAL!

This year, **Walk in the Park** raised a whopping grand total of \$190,897.

This was achieved through registrations, corporate sponsorship, fundraising, donations, merchandise sales and our charity BBQ, which just goes to show, every penny really does count!

Once again, just under 2,000 people participated in this year's event – 1769 to be exact. While this was down on our anticipated number of 2,200, it was an amazing site to see so many come together to show their support for the cause!



Fundraising superstars

There were so many amazing fundraising heroes this year. **Everyone** who supported our fundraising efforts this year are **Superstars** in our eyes, and we are blown away by your incredible efforts! Thank you!

Extra special fundraising stars are acknowledged online www.parkinsonswalk.com.au

*Congratulations to our lucky Walk in the Park winners**

Team Fundraising Prize: A Round of Golf for four players at Woodlands Golf Club, 4 Village Cinema Gold Passes, a gourmet hamper from Charity Greeting Cards.

Winner: Demkiw Travellers

Individual Fundraising Prizes included: \$200 Cotton On Voucher; \$50 Village Cinema Gift Card and a Eureka Skydeck Family Pass; Two (2) Back to the Future Trilogy Family Passes

Winners: A Robinson; B Giovaneti; T Harvie; L Bellert

Special 'Early Bird' Fundraising Prize: Two tickets to the Footy Show

Winner: D Melder.

And, the first 100 people to fundraise \$200 will be receiving a Gecko Stylus and Pen (RRP \$29.95) courtesy of Gecko Gear. (These will be posted out in the coming weeks).

Thanks to our generous corporate supporters who donated terrific prizes!

**Team Fundraising winner was randomly drawn from a list of all eligible Walk in the Park 2012 participants who fundraised \$1000 or more by 30 September, 2012. Individual fundraising winners were randomly drawn from a list of all eligible Walk in the Park 2012 participants who fundraised \$500 or more by 30 September, 2012. Early Bird fundraising winner was randomly drawn from a list of all eligible Walk in the Park 2012 participants who fundraised \$500 or more by 31 August, 2012.*

Thanks to our amazing corporate sponsors for their financial and in-kind support, and really getting behind this year's event:

- Segue Financial Services • Martin and Pleasance (Kidz Minerals) • Outlook Financial Solutions • Australian Unity Retirement Living • Medtronic • City of Melbourne

And our corporate supporters and preferred suppliers:

- Bunzl Australasia • Federation Square • Cargo Apparel • Golden Days Radio • Ernie Kempay Quartet • Arakataka • Rotary Club of Glenferrie and Members • Timeout Café • Gecko Gear • City West Water • Lincoln Flynn Graphic Design • Cargo Apparel • Mosaic Photography • Perfect Events • La Manna Direct • Palace Cinemas • Woodlands Golf Club • Cotton On • Delica Meats • The Enchanted Maze Garden • Ballarat Wildlife Park • Eureka Skydeck • Aribar • Artisse Organic • The Footy Show • Luna Park



& to Jill, Natalie and students of Avonde Calisthenics College for warming us up before the walk!

And of course, extra special thanks to the one and only Vince Colosimo, who was our MC for the day and did a great job!

Glenferrie Rotary takes a walk

Club member, TERRY ROLLESTON, shares some highlights and challenges other Rotarians to 'join us for a Walk in the Park'.

Rotary is an organisation of business and professional people, united worldwide, who provide humanitarian service, encourage high ethical standards in all vocations and help build goodwill and peace in the world.

The Rotary Club of Glenferrie was founded in 1975 and currently has 46 members. PP Terry Rolleston, who was diagnosed with Parkinson's in 2005, felt the Club could assist in raising money for Parkinson's Victoria and research. He presented this idea to the Board of the Club as a Community Service Project and they agreed to do so.

As a result, in 2010 the Club had the largest team of 58 Walkers participating in the **Parkinson's Walk**, the organisation's major event.

In 2011, the Club generously agreed to host a sausage sizzle during the walk, with all proceeds going to Parkinson's Victoria. Fifteen volunteers manned the BBQ at Federation Square, led by Community Service Director, Janie Pirret, President Don Heath and Secretary Michael Berry. Takings were \$1835.

In addition, amongst the 2000 walkers were 28 Glenferrie Rotary members, who enjoyed the leisurely 4km stroll behind the banner so ably carried by PP Ian Salek.

While registrations amounted to \$601, a number of Rotarians who were unable to walk made a donation, and this figure was close to \$600. As a result of the 3 facets of support, Rotary raised to excess of \$3,000 – A FANTASTIC EFFORT.

In 2012, the Club once again had a strong contingent walking and fundraising. Members again volunteered at the BBQ, raising around \$2000, and an additional \$1000 donation was made by the Club.

The result is that one Rotary Club in Victoria has - to date - raised in excess of \$10,000 to support the work of Parkinson's Victoria.

I would like to suggest to other Rotary Clubs that they give consideration to supporting the Parkinson's Victoria Walk next year to help Rotary become a major supporter, assisting this organisation to raise funds for research and support services, helping everyone who lives with Parkinson's.

Take up the challenge and let's see Victorian Rotarians can give 'Service above Self' in the fight against Parkinson's.

Terry Rolleston

Counting his pennies

Walk in the Park 2012 corporate sponsor, Outlook Financial Solutions is pleased to announce the winner of their Money Box competition, held at our **Walk in the Park** annual event at Federation Square on Sunday 26 August.

Young Zachary King correctly estimated \$172 as the total amount in the money box. His efforts were rewarded with the Piggy Bank in question (and the contents!).

The team at Outlook was pleased to have Zac and Mum Debbie visit them at their Southbank offices to celebrate his win and award the piggy bank prize.

"We wish Zac luck, and hope that he will use the money box to save and plan for the things he wants to do."

Outlook Financial Solutions continues to be a proud partner and supporter of Parkinson's Victoria.



9 year old Zac and mum Deborah with Stuart Langdon, General Manager (Victoria & South Australia) Shadforth Financial Group Limited.

Peer Support

Earlier this year, the Peer Support Network, under the auspice of the Chronic Illness Alliance, hosted the inaugural Peer Support Conference in Melbourne. The event was attended by BREANNA WOTHERSPOON from our Health Team and more than 100 others involved in the delivery of health and support services to the community, representing a variety of organisations supporting those living with a chronic illness.

The opening address was given by Andrea Coote MLA, The Parliamentary Secretary for Families and Community Services in the Baillieu Government, Speakers included staff from the Department of Human Services, The Chronic Illness Alliance and Dr Craig Hassed of Monash University.

The conference showcased the benefits that peer support can provide to those living with chronic illness, and looked at the developing research underpinning the practice.

The conference also explored the Best Practice Framework for providing peer support and the increasing use of emerging technologies in the area, and it provided attendees with an opportunity to network and share their knowledge around the issues of peer support in practice. Breanna, who also coordinates our 48 Support Groups, is working with a number of individuals regarding the establishment of a range of new special interest groups. Breanna and other members of our health team provide support and information through our Help Line, Parkinson's Victoria resources and can provide tailored support information and advice regarding other services, allied health support, and referrals.

Support Groups

Living with or caring for someone with Parkinson's can be challenging, but you don't have to feel alone. Parkinson's Support Groups offer members a chance to meet and talk with others who share similar experiences, situations and problems. They can be a great source of information and support. Monthly meetings are informal and friendly, and new members are always welcome.

Parkinson's Support Groups currently operate in the following areas:

Bairnsdale	Ballarat
Beechworth	Bellarine Peninsula
Benalla	Bendigo
Bentleigh/Bayside	Camberwell
Charlton/East Wimmera	Cobram
Cohuna	Colac
Corryong	Echuca
Eltham	Epping

Essendon	Frankston
Geelong	Grampians
Hamilton	Horsham/Wimmera
Kororoit/Melton	Lakes Entrance
Mansfield	Mildura
Moe	Monash/Glen Waverley
Portland	Ringwood
Rosebud	Sale
Shepparton	South Gippsland/Leongatha
Swan Hill	Wangaratta
Warragul	Warrnambool
Wodonga/Albury	Werribee
Yarrawonga	Young @ Park Melbourne
Young @ Park Geelong	
Painting with Parkinson's (Berwick, Essendon and Mt Martha)	
Tai Chi for Parkinson's	
PSP (Progressive Supranuclear Palsy) Support Group (Cheltenham and Mornington)	

Can't find a Parkinson's Support Group in your area? Why not consider starting one?

If you are interested in leading a Parkinson's Support Group in your area or getting one off the ground, contact Breanna Wotherspoon, Support Group Coordinator, to discuss the idea further.

Special interest groups

A new **Painting with Parkinson's** group has started in Mount Martha.

Meeting twice a month, the group uses creativity and painting to exercise the body and the mind.

This supportive and social atmosphere is an ideal environment to explore your creative side, while meeting new people with a similar interest. All are welcome, and no prior art experience is necessary.

When: The 2nd and 4th Tuesday morning of each month, 10am-12noon

Where: Mt Martha Community House, corner Esplanade & Dominion

Cost: Donation only

For more information contact group leader Pamela Farrington: 0408 135 488

Do you have a song in your heart? Parkinson's Victoria is looking into the viability of running a singing group for people with Parkinson's in the Williamstown area.

The group would be open to anyone with Parkinson's, regardless of singing ability. All that is required is enthusiasm!

Reduced movement and coordination of the muscles used in breathing, voice and pronunciation can lead to changes in speech for people with Parkinson's. The voice may be softer and the speed of speech may increase, making it difficult for others to hear and understand what is being said.

Speech pathologists can offer individual advice and/or therapy to help overcome these issues, but one potential treatment that is being explored around the world is singing for Parkinson's!

From a medical perspective, singing out loud exercises the lungs and abdominal muscles. Singing is also a natural "mood regulator"; it helps to focus and stimulate thought, and it relaxes and invigorates. It is also a good way to interact with others, and have a bit of fun along the way!

If you are interested in participating in a Parkinson's Singing Group, particularly in the Williamstown area, please contact Support Group Coordinator Breanna Wotherspoon.

Celebrating a lifetime of support

Camberwell Parkinson's Support Group member (and newly appointed Group Leader) JUDY BUCKLEY recently wrote to us to acknowledge and thank, on behalf of all group members, their leader of several years Ruth Harrop, who retired recently.

We are very pleased to share Judy's thoughts with you, and to celebrate the success of the group's 31st year!

"The Camberwell Parkinson's Support Group was formed in 1981 and has offered continuous support to its members for 31 years.

This month, November, the group will celebrate its success and the dedication of the many committee members with a Christmas party and entertainment.

Gladys Morris was a foundation member of our group in 1981. As a carer of husband Ross and a doctor, Gladys was ideally suited for the role of Support Group leader and secretary, which she did for the group's first eleven years. She then went on to become treasurer, adviser and librarian for many years after.

Originally, meetings were held in a private home, but as the group became bigger, they outgrew the lounge rooms and moved to St Mark's Church in

Camberwell/Canterbury, where they still assemble monthly.

There have been many wonderful and dedicated people over this time, and to mention a few from the past years; Jean Oswald, Wendy Heisler, Evan Jones, Lyn Ackland, Joann Bakey, Judy Buckley and Ruth Harrop. Plus the many members who have all contributed to the group's success with their involvement.

Ruth Harrop has just retired as leader, and we thank her for her leadership and caring and positive attitude to all the problems that one faces with Parkinson's.

She and her husband Jim joined in 1996 and in 1997 Ruth became our leader. She filled this role until July 1999, when her husband's illness required her full attention and Evan Jones became our leader for the next 2 years. Evan was the carer for his wife Bev. When Jim Harrop passed away in 2001, Ruth returned to the leader's position, as Evan now needed time with his wife, and Ruth remained our leader until the AGM of this year.

The last ten years have all been under Ruth's leadership, and we are all very grateful to the wonderful, welcoming atmosphere created by Ruth and her committee. The purpose of the group is support for people living with Parkinson's. Ruth has endeavoured to table at our meetings various information regarding treatment, facilities, seminars and help available to our members. She has encouraged the exchange of ideas and problems encountered by people with Parkinson's. Ruth has introduced many interesting speakers to our meetings, and we have had trading tables and luncheons where our members are encouraged to mingle and meet each other in a warm and friendly atmosphere.

We are all very grateful to Ruth for the years of dedicated service, and we thank her profusely and wish her happiness and improved health in her retirement.

From all of us here at Parkinson's Victoria, we too wish Ruth all the best and extend our sincere thanks for her years of hard work and dedication, providing support to her local community.

We also commend Evan Jones for his leadership and all members, past and present for creating and maintaining a group that has obviously provided so much support and friendship to so many, for so long.

We wish Judy all the best in her new role.

Living well

Driving is a convenience - and in many ways a privilege - that can often be taken for granted. The neurological nature of Parkinson's can impact on many of the key skills required for safe driving. ALISHA CHAND, Client Services Officer offers some important information to ensure your safety on the roads.

While it is a legal requirement of VicRoads that a diagnosis of Parkinson's is promptly reported, this does not necessarily mean your licence will be affected. However, reporting it and undertaking any relevant assessments will help to ensure your safety and the safety of others on the road.

How can Parkinson's affect driving?

As the symptoms of Parkinson's progress, issues may develop which can impair an individual's alertness and reaction times and this may impact driving performance. These include:

- ✘ Reduced physical reaction time
- ✘ Impaired problem solving
- ✘ Reduced cognitive reaction time
- ✘ Fluctuations in physical symptoms
- ✘ Tremor
- ✘ Fatigue
- ✘ Difficulty performing dual/multiple tasks, for example radio, passengers, traffic
- ✘ Concentration lapses
- ✘ On/Off phenomenon (in relation to Parkinson's medication).

Some Parkinson's medications can also affect an individual's ability to drive, though unfortunately it is not always possible to predict whether specific medications will have an impact. Each individual will respond to medications differently but some of the warning signs may include:

- ✘ Fatigue and drowsiness
- ✘ Dizziness, light headedness and fainting
- ✘ Unclear thoughts
- ✘ Unsteadiness
- ✘ Change in mood, for example aggressiveness
- ✘ Nausea

When prescribed a new Parkinson's medication it is important to check with your doctor or pharmacist whether it has the potential to affect your driving performance. You should also discuss any of the above symptoms (or other 'strange' symptoms) you may experience with your doctor.

Parkinson's may also alter a person's ability to self evaluate so it is advisable to discuss your driving with your doctor, family members or those around you, as they may have a different perception of your driving skills.

What will the assessment involve?

Initially, there will be a Medical Review consisting of some or all of the following:

- ✘ A medical report from your doctor
- ✘ Advice from VicRoads medical advisors
- ✘ Eyesight and specialist reports
- ✘ Your treatment plan and ability to manage the condition
- ✘ Reports from police and other third parties

After analysis of this information, VicRoads will determine whether you will also need to undertake a driving test. This should be conducted by an independent and specially qualified Occupational Therapist (OT). They will develop strategies, provide advice and recommend any appropriate aids or modifications to ensure your safety on the roads.

There are three parts to an OT driver assessment:

1. Firstly, a medical report will need to be given by your doctor or specialist indicating you are medically fit. Other reports, if applicable, will need to be provided as well (such as from an optometrist).
2. Next is an off-road assessment which may take up to two hours. The OT will ask you about your driving history, your understanding of road laws and assess your physical, visual, sensory and thinking abilities.
This information will allow the OT to assess your understanding of safe driving, any necessary vehicle modifications, and license modifications which may need to be considered, and the requirements for your *on-road assessment*.
3. Finally, you will have an on-road assessment in a dual controlled car, with a driving instructor present.

The driving instructor will instruct you on the route of the test and ensure the safety of the vehicle, while the OT will be observing any physical limitations, your judgement and ability to adjust to different traffic situations, your reactions to traffic and whether you are abiding by road laws. If any vehicle modifications are recommended these will be implemented and trialled to ensure you can use them safely.

Once the assessment is complete, the OT will send a report through to VicRoads who will contact you by phone to notify you of the outcome: if you are able to retain your full licence, whether conditions will be placed on your licence, or whether your licence will be cancelled. If you disagree with the decision or recommendations you have the right to appeal and re-sit the test.

What will it cost?

Unfortunately, there are no subsidies or Medicare rebates available for these procedures. Generally, the most cost effective option is through a public rehabilitation centre or a movement disorder clinic with a specialist OT driving rehabilitation program.

An up-to-date list of OT driving assessors in your area can be found on the Occupational Therapy Australia website www.otaus.com.au/find-an-occupational-therapist

One of the most important things to remember is that a diagnosis of Parkinson's does not automatically or necessarily mean your licence will be revoked. Your legal requirements to inform VicRoads and any review or recommendations regarding your ability to drive are aimed at ensuring your own safety and the safety of others.

For more information about Parkinson's and driving, contact our Health Team.

Tulip Tributes

Media megastars

We are so grateful to all those who responded to our call for media spokespeople to share their story. This helped raise awareness of Parkinson's and our major event, **Walk in the Park** – which helps us to reduce the cost of paid advertising.

Thanks for telling us what you think

Earlier this year, we asked for your feedback about **Signpost**.

This will assist with our re-design to ensure the look and content are what you want! Stay tuned for a new-look **Signpost** in 2013!

Special support

We can't thank the team at RAPP/DDB Group creative agency enough for their continued pro bono support and commitment to the cause.

The team was the incredible force behind the powerful 'short film' **A Message from Jennifer** (check it out at www.parkinsonsvic.org.au).

The film has gone on to win 2 industry awards at the prestigious Spikes Awards – the most revered in Asia, <http://www.campaignbrief.com/2012/09/spikes-asia-jwt-melbourne-take.html>.

The Parkinson's Victoria and RAPP partnership was also recently acknowledged with a **Rotary Southbank Community Service Award***.

Most importantly, the film has opened the door for Parkinson's Victoria to connect with potential corporate supporters and we continue to benefit from this unique and emotive campaign.



From left: Jennifer Allison, Parkinson's Victoria President, Peter Raymond, Managing Director Tess Doughty and Account Executive Richie Taaffe, from RAPP/DDB GROUP accept an award at the 2012 Rotary Community Service Awards.

We are also indebted to Jennifer who shared her story with such candour and who opened her home for the filming. She gave so much of her time – and heart – to the project and we are truly grateful.

We also thank RAPP's partners who donated their time and expertise to bring the campaign to life:

Production Company: Fiction

Post Production: Iloura and Sight & Sound

Sound Mix: Risk Sound

Music Supervision: Level Two Music

Music Track: 'Indian Summer' by Jonsi & Alex c/o

Universal Music Publishing Group Pty Ltd, Kobalt

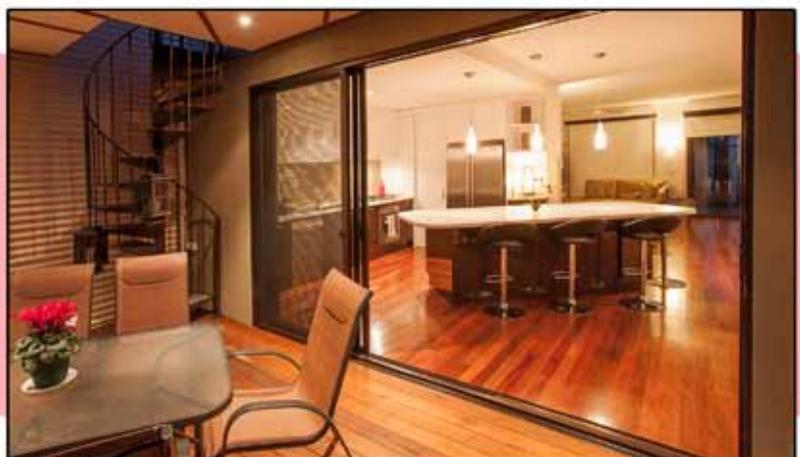
Music Publishing Australia Pty Ltd, EMI Music Australia

***The Rotary award prize included expert support from Disegno to re-develop our website. Disegno have been recently working with us on a market research campaign. This was the result of Parkinson's Victoria winning a similar award in 2011, for our partnership with Outlook Financial Solutions.**

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Air conditioned, and gas log fire.

WWW.INVERLOCHVIEWS.COM or phone Peter Jackson, 0407 100 070

Volunteers

Volunteer Coordinator and Events Assistant JOSEPHINE (JO) BERTHELEMY provides an overview of recent volunteer efforts and upcoming opportunities.

As we take stock of the busy months that have just passed, we express our gratitude to all those who have volunteered recently at one of our many fundraising activities. The variety of tasks undertaken and the support our volunteers have provided to our team is extraordinary.

A BIG THANK YOU!

What an amazing event **Walk in the Park** was on **Sunday 26 August** at Federation Square!

Now in its fourth year, this event just gets bigger and better. We are eternally grateful to our volunteers for helping to make it possible for the Parkinson's and wider community to come together at such a fun, engaging, friendly, well-organised, professional and stress-free event.

On the day, it was reassuring to have a wonderful team involved in all the important aspects of the day: registration, event ambassadors, course marshals, merchandise and information tent staff, kids' corner, morale walkers and tin rattlers.

In many ways, our volunteers are the 'face' of The Walk, and every year, they really make the day. We thank them for their enthusiasm and energy, and for displaying a positive work ethic as representatives of Parkinson's Victoria.

Turning up the heat

Huge thanks to: Mauricio, Jerry, Laura, Shyan, Amy, Haylee, Moira, Olivia, Rachelle Thao and Judith, for cooking, serving, counting, smiling, smelling, schmoozing, setting up, cleaning up and volunteering at our August Bunnings Moorabbin sausage sizzle which raised over \$1,400.

We've got one more BBQ for the year: **Friday 30 November** at Bunnings Mentone (*the brand new super store on Nepean Highway*) and we're looking for helpers across the three hour shifts (8.30-11.30am; 11.30am-2.30pm; 2.30-5.30pm). Contact me if you're interested: jo@parkinsons-vic.org.au or call our office.

HO, HO, HO... 'Tis the Season

Special thanks to teams from **Mercer** (Anita, Michael, Thomas & Phoenix) and **GE Capital** (Matt, Ashley, Anna, Christine & Justin) for making light work of our Christmas card packing on **Tuesday 4 September**. Together, they prepared and boxed 10,000 cards ready for our 2012 campaign!

Volunteers take centre stage

We'll be hosting our annual **Thanks A Bunch** end-of-year function for volunteers and supporters on **Sunday 2 December** at the Mordialloc Sporting Club 1-4pm. All volunteers, including Support Group Leaders and Ambassadors are welcome. Register to attend online: <http://www.trybooking.com/cavr>.

The year ahead

We're in the throes of planning for 2013 and there's lots more in store for next year, but please regularly check our website for updates and volunteering opportunities. You can also contact me directly if you are interested in volunteering (and sign up to receive our volunteering e-newsletter): (03) 9581 8700 or jo@parkinsons-vic.org.au

Personal Dopa-meanings

The Parkinson's thing

I shake in the morning
I shake when it's night
I shake when I'm wrong
And I shake when I'm right
I shake when I'm cold
And I shake when I'm hot
I shake when I'm tired
And I shake when I'm not
I shake when I'm hungry
I shake when I'm full
I shake when it's sunny
I shake when it's dull
I shake when I'm eating
Food drops on my knees
Especially when chasing
Those little green peas
But get on the dance floor
At a wedding or ball
Where everyone's shaking
I can't shake at all.

Sheila Lockett, Mildura Parkinson's Support Group

We want to hear your story!

Thank you to those who have already contributed to Personal Dopa-meanings. We are slowly growing a great bank of personal reflections which we look forward to sharing with you in coming editions of Signpost.

For those who haven't yet, please don't be shy or reticent to share your story with our readers. By doing so, we can help each other by showing that we are not alone in our fight against the effects of Parkinson's. Please forward any thoughts, anecdotes or experiences to me C/- Judith Mooney, Signpost editor:

Judith@parkinsons-vic.org.au (write PETER NASSAU SIGNPOST in the subject line). Alternatively, you can write C/- Parkinson's Victoria PETER NASSAU SIGNPOST, PO Box 2606 Cheltenham VIC 3192.

If you need assistance in writing your contribution I am ready, willing and able to assist. Peter Nassau

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Editorial policy:

While submissions for inclusion in **Signpost** are welcomed, the final decision rests with the editor. All submissions are subject to the publisher's editorial guidelines and may be edited for space or clarity.

Parkinson's Victoria Inc.:

Parkinson's Victoria is a not-for-profit organisation and is the peak state body which provides information, education, advocacy and support to the 20,000 Victorians living with this chronic progressive condition, their family, friends and allied health professionals.

THANK YOU for your generous support of Parkinson's Victoria in recent months. Listed below are those who kindly donated \$500 or more, those in whose name In Memoriam donations were received, Team Parkinson's fundraisers, and corporate/organisation supporters from 1 July - 31 October, 2012.

We extend our sympathies to the families who have lost loved ones, and we thank those who have donated anonymously.

Donations of \$1000+

Joyce Arthur
Robert Danchin
L & M Di Santo
Fay Kitching
Dennis Nassau
Allan Penney
Marjorie Roberts
Takako Subocz
Ian Williams
Bruce Worcestor

Donations \$500+

Merle Blundy
Belinda Bonazza
Craig & Amanda Gemmell
Margaret Livermore
Ann McGeary
Alan & Margaret Stocks

Bequests from the estates of...

Marie Lillian Monckton
Joe White
Miss Mary Eva Kentish
Mr John Williams
Mrs Cecily Joy Dannock

In Memory of...

Anonymous
Harald Ackermann
Noel Ballard
Gordon Bate
Jill Bolto
Lex Bryant
Julia Campbell
Lewis Catania
Wilma Clare Childs
Angelo Cianchi
Douglas Hall Clark
John Collier
Salvatore Curcio
Peter Robert Dalzell
Peter Dawson
Concetta DiGiglio
Roger Douglass
Margaret Rose Ennis
Colin Ford
Antonio Gattellaro
John Arthur Gerdtz
Bill (William) Gray
John Wayne Greene
Ted Greetham
Panoyiota Kafkas
Panagiotis Kioussis
Ann Leigh
James Watt Marshall
John McKenzie
Maxwell Graham Meek
Geoffrey McLean
Zah Michalopoulos
Emilio Montanaro
Geoffrey Oakley
Elio Pace
Anthony Pattenden
Ian Pederick
Keith Pepper
Kevin Phyland
Janet May Pinheiro
Brian Quigley
Remo Raffin
Colin Ritchie
Wallace Ferguson Ritchie

Teresa Mary Ryan
Ted Sadler
Michele Simonetti
Elizabeth Irene Swain
Lois Thompson
Newton Thompson
Margaret Turner
Euripidis Velezis
Georgia Vissaris
Stanley Warner
Kevin Williamson
Frank Winstanley
Albert Roy Young
Graeme Young
John W Young
Salvatore Zizza

In Remembrance of...

Edward Drohan
Lila Jeffries
Angelo Ricci
John Steele

In honour of...

Anonymous

In celebration

Belinda Bonazza
Geoff & Kitty Clarke
Anonymous (Engagement)

Team Parkinson's Fundraisers (third party) - \$1000+

Spring Valley Golf Club

Team Parkinson's Fundraisers (third party) - other

Open Garden, Gail Pagon
ANZ Collection Team (Casual Dress Day)
Ian Tweeddale
Monday Movers (Ringwood)
StarTruck Transport (Casual Day)
CWA-Benworden
CWA-Toongabbie
Tin Rattle Collection, Linda Walsh
Australian Council for Education
CWA-Greensborough
Shaky M, Rowena Hutson
The Read Family

Support Groups

Bendigo
Frankston

Corporate, Community & other donations & support

A & J Gabriele Tiling Co Pty Ltd
Advent Care Whitehorse
Age Concern Pty Ltd
Airport Total Health Care Clinic
All Souls Opportunity Shop
ANZ Collections
Armanasco Management
Australian Council for Educational Research (ACER)
Blue Illusion Australia Pty Ltd
Breville Pty Ltd T/As HWI Electrical
Clayton Italian

Pensioners Group
Country Women Association - Bengworden
Country Womens Association - Toongabbie
Country Womens Association-Greensborough Branch
Ferraro's Gardening Service
Heathmont Flowers
Heathmont Fruit Basket
Heathmont Meat & Poultry
Ipsos Australia Pty Ltd
John Brunning & Sons
Kelly's Motor Club Hotel
Cranbourne
Kiwans Club of Doncaster & Templestowe
Knights of Leonthatha
LBW Chartered Accountants
Lerida Park Pty Ltd
LSC Motor Repairs Pty Ltd
MD Kirby Nominees Pty Ltd
Menzies Creek Caring Women
Militsa Pty Ltd
Monday Movers (Central Ringwood Community Centre)
Nunawading Hungarian Senior
Citizen Club Inc
PBL Promotions
Point Cook Village Social Club
Pahran Seafoods Pty Ltd
R & M Kennedy Drafting
Services Pty Ltd
Rio Tinto Exploration Pty Ltd
Rotary Club of Glenferrie
Rotary Club of Oakleigh
Segue Financial Services
Seymour & District Historical
Society Inc
StarTrack Express - Tullamarine
Sunshine Scenic Tours
The Anglican Parish of Westmeadows/Bulla
The Dartmoor Uniting
Fellowship Group
UHY Haines Norton Melbourne
Pty Ltd
Ulbrich Products Pty Ltd
Wonthaggi Croquet Club

Matched Payroll Giving

National Australia Bank-Payroll
Matching

Payroll Giving

Phaik See Chong
Julian Clarke
Rodney Moore
Anonymous-NAB
Anonymous-Telstra
Anonymous-Thiess P/L

Regular Giving

Vince Spano
Anonymous

Trusts & Foundations

Lord Mayor's Charitable Fund
G & I Meagher Charitable
Trust
Lord Mayor's Charitable Fund

Fundraising

Fundraising results!

The year was another busy one as far as fundraising events went.

Why do we fundraise? Because the state government provides only 14% (around \$215,000) of the funds we need to keep our doors open, our Help line running and our health team on the road.

In addition, the 'self generated funds' that come through donations, bequests and community support of our fundraising events helps us to grow services, develop resources, expand our support programs and undertake various advocacy initiatives.

Upcoming events

Movie event: SKYFALL: 007

Thursday 29 November, Dendy Palace Brighton
6pm for 6.45 screenig.

The 23rd adventure in the longest-running film franchise of all time is coming. See it FIRST with us! Daniel Craig returns as James Bond in one of the year's most anticipated films. Purchase tickets online: <http://www.trybooking.com/BSCF> (\$35 movie, nibbles and a cocktail).

Christmas Cards on sale now

Christmas Cards are once again available through Parkinson's Victoria. Order securely online at www.parkinsonsvic.org.au or contact our office for an order form.

This year's cards include two exclusive designs by Jill Goss and Jean Smith – both living with Parkinson's. Thank you Jill and Jean!

Cards are also available for purchase from the following charity card shops:

Fundraising Highlights for 2012:

- ✘ **Walk in the Park** raised: \$190,897
- ✘ **Movie nights** raised a total of \$12,800 (Skyfall:007 \$ still to come)
- ✘ **Bunnings BBQs** raised a total of \$2,500 (with one more still to come!)
- ✘ Our annual train station **Tin Rattle** raised: \$6,409
- ✘ Theatre nights: \$530 (with **Me and Jezebel** \$ still to come!)
- ✘ **Mid Year Appeal:** \$13,075 (End of Year \$ still to come)
- ✘ **"Steps"** donor update (2 editions): \$24,804

- ✘ Bendigo: St Paul's Christmas Charity Card Shop, 4 Myers Street, Bendigo
- ✘ Ballarat: Combined Charities Card Shop, 1A Eyre Street, Ballarat
- ✘ Geelong: Combined Charities Card Shop, Wesley Church, 100 Yarra Street, Geelong
- ✘ Heidelberg: Banyule Support & Information Centre, 101 Burgundy Street Heidelberg
- ✘ Camberwell: Camcare Charity Christmas Card & Gift Shop, 51 St John's Avenue, Camberwell
- ✘ Mornington: Community Information & Support Centre, 320 Main Street, Mornington

Personalised, corporate cards and special occasion hampers can also be purchased, ideal for your clients (company, social club, organisation or supporters), with a percentage of proceeds donated to Parkinson's Victoria.

Visit www.parkinsonsvic.org.au (scroll down on the homepage) or contact our partner, **Charity Greeting Cards** to make an order over the phone (02) 9779 1533. Let them know you wish to support the work of Parkinson's Victoria.

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