

# SIGNPOST

•Spring 2012 •Volume 11 Issue 3 A Magazine for people living with Parkinson's

PARKINSON'S VICTORIA

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# News & Highlights

## *Funding win for regional support*

Parkinson's Victoria is pleased to confirm that funding has recently been secured for a Movement Disorder Nurse to be based in the Lower Murray Medicare Local region.

This is the result of a lobbying partnership between the Mildura Parkinson's Support Group, the lower Murray Medicare Local and Parkinson's Victoria.

The announcement of the funding success was made at Mildura Support Group's Christmas in July luncheon, and was covered by both local television and newspapers.

The position, which will be based at the Medicare Local offices in Mildura, will care for people living with Parkinson's and other Movement Disorders such as Progressive SupraNuclear Palsy (PSP), Cortical Basal Syndrome and Multiple System Atrophy (MSA), who currently receive no support.

The nurse will work with local health practitioners in a variety of settings and will become an essential link with city-based neurologists and Movement Disorder Clinics.

This position is likely to be filled by the end of August and both Parkinson's Victoria and the Movement Disorder and Parkinson's Nurse Faculty will play a role in their training and will provide ongoing support.

## **Background to the funding decision:**

Recent reforms to federal health care have seen the rise of the **Medicare Local**, many of which were previously Divisions of General Practice.

The Government has set the task of identifying health care priorities within the Medicare Local regions. In the case of the Mildura/Lower Murray region, support for the Parkinson's community was identified as being one of the top ten priorities (as a result of the area's high prevalence), resulting in an allocation of funds to employ a Movement Disorder nurse.

*The funding of a Movement Disorder nurse in the Lower Murray area is the first of its kind in Australia, and hopefully will be the first of many.* Parkinson's Victoria will continue working with Medicare Locals as well as state and federal governments as it works towards its mission to ensure every person with Parkinson's has access to a specialist nurse or clinician.

## *New health team member*

Parkinson's Victoria recently appointed a new member to its Health Team, in the role of Client Services Officer.

Alisha Chand completed a Bachelor's degree in Biochemistry and Pharmacology in 2011, with an interest in Community Health Education. She took a break from work and studies earlier this year to spend 3 months in Goa, India, working at a school in a small fishing village. During her time at the school,

she taught students about health, hygiene, nutrition and basic English (although Alisha is sure the kids taught her more than she taught them!).

Packing away her travel bags for a while, Alisha is excited to begin her career in health education with Parkinson's Victoria.

***Alisha will play a vital role supporting the mission of our Health Team to deliver support and education to the community. She will assist in taking enquiries to our phone line and visiting Support Groups, and in the near future will conduct community and professional education seminars.***

***We look forward to introducing you to Alisha at a Support Group meeting or education seminar soon.***

***Health Team note: We appreciate the understanding of members and the wider community during the recent staff shortage in our team.***

## *Notice of Annual General Meeting*

The 2011/12 Annual General Meeting of Parkinson's Victoria will take place on Friday 26 October, 2012. Official notification will be posted to all members a minimum of 30 days prior.

Further details regarding venue, timing and guest speaker, will be available on our website, [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) or register your interest to attend by contacting our office.

**When:** Friday 26 October, 11.00am - 2.00pm

**Where:** The Eastern Golf Club  
473 Doncaster Road, Doncaster

**Registration:** Contact Parkinson's Victoria.

## *Volunteer Recognition Awards*

Parkinson's Victoria values the outstanding contribution volunteers make in reducing the impact of Parkinson's and we have several ways to ensure these amazing people are appropriately recognised for their services. The following awards are open to nominations from all members of the community (not only members of Parkinson's Victoria) and will be awarded during our AGM in October.

**Certificate of Appreciation:** Recognises the contribution of an individual or an organisation to an event or activity.

**Five and Ten Year Services Awards:** Recognises the continuous service of volunteers in an administrative, project or service capacity.

**Honorary Life Membership:** Recognises outstanding service, normally over a period of at least 15 years.

Further to these awards, in 2006 we introduced the **Sir Zelman Cowen Award**. This award, the highest honour available, is presented annually to an individual, recognising their outstanding service to Parkinson's Victoria and services to people living with Parkinson's.

Sir Zelman Cowen generously gave permission

for the award to be in his name, which is most appropriate, recognising his own outstanding community service to all Australians, and his personal journey with Parkinson's. **Following his passing in December 2011, Lady Anna Cowen graciously gave permission for this legacy to continue in her late husband's name.**

Last year, we were delighted to present the **Sir Zelman Cowen Award** to Val Lester for 25 years of service to the Bendigo Parkinson's Support Group and local community.

**Is there someone you would like to see acknowledged for their service to your local community or the wider Parkinson's community? Why not nominate them for one of the above Parkinson's Victoria special awards. It may be a support group leader, local business supporter or health care professional or anyone who has shown outstanding support. Nominations for these awards and which meet the above criteria, should be forwarded in writing to CEO, Ann Burgess, by 14 September for consideration by the Board of Parkinson's Victoria. For further information about the application process or to request a nomination form, please contact our office.**

### ***New clinician for Sunshine Hospital***

There has been a recent change at the Sunshine Hospital in relation to the resident Parkinson's clinician. Jo Bolton is currently on maternity leave and from July 2012 to May 2013, Joy Tan will be filling the role in a part time capacity (Monday – Wednesday). Joy will be based in the **Community Based Rehabilitation** team at Sunshine Hospital and will also attend the fortnightly **Movement Disorder Clinic** at Western Hospital Footscray Campus

Joy is a physiotherapist with a wide range of skills and clinical experience. She also has a long

standing interest in Parkinson's, which includes collaborating with Professor Meg Morris on research into the value of exercise in improving gait and balance and reducing falls in Parkinson's carried out at Melbourne University.

**Appointments with Joy can be arranged by calling her directly: (03) 8345 1283 or 0466 151 862.**

### ***New Monitoring Device for Parkinson's***

The **Parkinson's KinetiGraph (PKG)** is a movement monitoring and reporting system (worn like a wristwatch) that is designed to assist clinicians in assessing slowness of movement (bradykinesia) and the involuntary movements associated with Parkinson's medications (dyskinesia).

The device is programmed by a clinician or Neurologist to remind a person with Parkinson's when to take their dopamine replacement medication, and is worn for a ten-day period.

At the end of this period, the stored information is downloaded as a report on the individual's level of bradykinesia and dyskinesia.

This information is vitally important in understanding symptoms and assisting the Neurologist to effectively manage an individual's medications.

The PKG is based on technology emanating from research at the Florey Neuroscience Institutes and St Vincent's Hospital, Melbourne.

It is currently being piloted at a limited number of specialist centres in Australia, including three in Melbourne. At present the PKG is used by specialists at these centres to provide a report on a patient's clinical state.

**For any further information please contact [info@globalkineticscorp.com](mailto:info@globalkineticscorp.com)**

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# President's Report



Parkinson's Victoria staff and supporters during the National Parkinson's Conference in Brisbane. From left: Judith Mooney, Karyn Spilberg, Victor McConvey, Peter Raymond, Breanna Wotherspoon, Linda Walsh and Sharon Daborn.

I was privileged in July to attend the **Parkinson's Australia "Better Knowledge, Better Outcomes" National Conference**, at the Brisbane Convention and Exhibition Centre.

Our CEO, Ann Burgess and several of her team also attended, together with some of our members who delivered outstanding presentations.

Held about every three years, the conference provided an opportunity for our staff to learn and assimilate new knowledge, share experiences with their peers (not only from around Australia, but from overseas as well) and, most importantly, communicate directly with people living with Parkinson's.

Parkinson's Australia, of which Parkinson's Victoria is a member, held its Board meeting prior to the Conference and all 'round, it was an ideal opportunity for the States to meet, share ideas and plan ways in which the national body might become a more effective, unified voice.

Indeed, a common theme enunciated by many delegates was the need for Parkinson's Australia to advocate more strongly, even aggressively, on behalf of the Parkinson's community.

As we sat and listened to keynote speeches and participated in workshops, it was apparent that whilst our delivery of services, care and comfort to members and the wider community is outstanding, we can still do better.

It was also apparent that, for some reason, very few people with Parkinson's choose to become a member of their State organisation. Membership fees are modest across Australia (less than a dollar a week), yet the level of membership, in any State, rarely changes. In Victoria, we sit steadily on around 1300 members, despite the incidence of Parkinson's increasing significantly (around 4 percent per annum).

Imagine if we could achieve a membership level of even **30 percent** of Victorians living with Parkinson's! That would give us over 6000 members. Imagine a similar level Australia-wide. That would give us over 24,000 members.

**What a voice that would be to increase awareness and support services! What lobbying power!**

Yes – we can **all** do better and that's the challenge facing your Board in Victoria, and other Parkinson's organisation boards around the country.

**We are up for the challenge. Are you?**

To find out how you can get involved, contact Parkinson's Victoria. Why not attend our forthcoming Annual General Meeting on October 26. Further information can be found on page 2. Members will be sent a personal invitation but to register your interest contact Parkinson's Victoria.

**Peter Raymond**  
**Parkinson's Victoria Board President**  
[pdr@netspace.net.au](mailto:pdr@netspace.net.au)

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*This section aims to inform and empower individuals to play an active part in managing their Parkinson's, or to assist a loved one, by providing information about your rights, assistance schemes and subsidies, as well as aids and support. In each edition of **Signpost**, this section highlights useful or topical information.*

We take our role as Advocates for the Parkinson's community seriously and understand that this extends beyond lobbying government for improved funding and services. We have a responsibility to act on behalf of the Parkinson's and wider community, particularly in relation to 'novel' and unsubstantiated commercial therapies.

### **TGA orders retraction of 'cure' claims**

In July this year, The Herald Sun and Nine MSN ([www.ninemsn.com.au](http://www.ninemsn.com.au)) featured articles in response to recent print advertising which claimed colostrum from cows could alleviate the symptoms of conditions such as Parkinson's and Multiple Sclerosis.

In February 2012, following a submission by Parkinson's Victoria to the Therapeutic Goods Administration (TGA) and a subsequent investigation by the TGA, it was found that there was no evidence that testimonials featured in the advertisements were genuine. Further, the TGA panel found the advertisements to be misleading and in breach of the Therapeutic Goods Act and Advertising Code. The Panel ordered a retraction be printed by the New-Zealand-based company.

<http://www.heraldsun.com.au/news/breaking-news/ms-parkinsons-supplements-concern/story-e6frf7kf-1226434089135>

Parkinson's Victoria closely monitors the latest research and therapies for Parkinson's, and only endorses those which have strong scientific-based evidence supporting their findings and efficacy.

We keep a close eye on any promotions, advertisements or media stories touting a "miracle cure" and we advocate on behalf of the Parkinson's community to the Therapeutic Goods Administration and other relevant authorities.

We urge anyone who has any questions relating to new research, findings or therapies to contact Parkinson's Victoria: 1800 644 189 and speak with a member of our Health Team.

<http://news.ninemsn.com.au/health/8504407/ad-spruiked-supplements-benefits>

*The team at Parkinson's Victoria has been very busy on a number of fronts. While things may look calm, like a duck moving on a smooth pond, beneath the water line we have been paddling madly with a range of activities on the go.*

### **Some major developments**

- Most recently, we have been advocating to the **National Disability Insurance Scheme** (NDIS) and the **Neurological Alliance of Australia** to ensure that the needs of people with Parkinson's are included in these important initiatives.  
You can support the push for a better deal for people living with Parkinson's by letting the Prime Minister know what you want in the National Disability Insurance Scheme. Send a message online: visit **Every Australian Counts** [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)
- The **GP online education program** is once again available online at [www.rrmeo.com](http://www.rrmeo.com) and the **Pharmaceutical Society of Australia** has circulated its **Continuing Professional Education** material on Parkinson's to more than 14,000 community pharmacists.  
Why not mention these critical resources to your GP and pharmacist during your next visit? Copies are available from Parkinson's Victoria.
- The **Personally Controlled e-Health Record legislation** has been approved and has been in effect since 1 July, this year. This initiative enables you to hold your own health records and decide who you will give the details to. While you can register for the scheme now, it will be some months before you can create your own records with your doctor.

### **NATIONAL CONFERENCE**

In July, several members of our team de camped to Brisbane to attend the Parkinson's Australia National Conference.

Karyn Spilberg, from **Young @ Park**, spoke about her experience undergoing Deep Brain Stimulation and Anne Atkin, founder of the Painting with Parkinson's program (Victoria), spoke about the benefits of painting. Victor McConvey and Breanna Wotherspoon, from our health team spoke about the role of Parkinson's Nurses and Support Groups, respectively.

### **BOARD UPDATE**

Many of you will know Brendan Lourey, who served recently on our Board, was forced to resign due to ill health. In his place, we have appointed Damien Farrell who has great expertise in education, training and management. Welcome Damien!

### **TAKE A WALK WITH US**

We are now gearing up for our major annual fundraising event, **Walk in the Park** on Sunday 26 August at Federation Square.

It's a great day out for the whole family – don't forget the four-legged member! Register online at

[www.parkinsonswalk.com.au](http://www.parkinsonswalk.com.au)

I hope to see you there.

**Anne Burgess, CEO, Parkinson's Victoria**  
[aburgess@parkinsons-vic.org.au](mailto:aburgess@parkinsons-vic.org.au)

# Symptom Management

## Wearing off

Medication is probably the single most important therapy used to help manage the symptoms of Parkinson's. Unfortunately, it is not without its own challenges, including side-effects. Our Parkinson's Specialist Nurse Consultant, VICTOR MCCONVEY, explains one of the unique challenges of Parkinson's medication: *wearing off*.

### What is Wearing Off?

Wearing off is a decline in the benefit of a dose of dopamine replacement therapy. In other words, you notice a return of Parkinson's symptoms before your next dose is due. This is also referred to as '**end of dose deterioration**'.

The underlying cause of this is your body processing the medication more quickly than expected.

Recent research indicates that *wearing off* is common within two years of commencing dopamine replacement therapy, although initial symptoms of wearing off are often too subtle to be identified easily.

### Why does it occur?

Most people with Parkinson's, if not all, will rely on a medication form of dopamine to replace the body's natural supply in order to help control symptoms.

Taking Parkinson's medications "on time" is absolutely critical. Medication is like the body's fuel and if it runs out the body can simply, and literally, stop moving. However, the dosage and release of the chemicals into the body, and the speed with which those chemicals are processed, also impact significantly on the effectiveness of the medication.

One of the challenges of Parkinson's medication is that dopamine replacement therapy comes in tablet form. The way the body processes this tablet form of dopamine is not the same as how it processes dopamine produced naturally. As a result, dopamine levels experience peaks and troughs (or pulsatility). It is during a low level phase that individuals experience a recurrence of symptoms or *wearing off*.

Parkinson's is a chronic and progressive condition, meaning its effects will continue and increase over time. As a result, while the need for dopamine replacement increases, your body's ability to effectively metabolise the dopamine replacement therapy (medication/tablets) alters, with *wearing off* symptoms becoming less predictable. Individuals who have lived with Parkinson's for some time, may experience unpredictable *wearing off* symptoms such as freezing or dyskinesia.

### The signs

The signs of *wearing off*, or *end of dose effect*, can

be subtle and difficult for even the person living with Parkinson's to detect. However, over time they become more pronounced.

*Wearing off* typically occurs around two years after commencing dopamine replacement therapy and experiencing motor difficulties is a common early symptom. A range of non-motor symptoms may also be evident or worsen as a result of this phenomenon.

Early non-motor symptoms of *wearing off* include anxiety, fatigue, mood changes, sadness, increased salivation, increased perspiration, and bladder frequency or urgency. Motor symptoms include an increased tremor or stiffness, diminished sensation and reduced fine motor coordination.

### Can wearing off be treated?

*Wearing off* can be screened for and treated effectively, but a large part of the challenge is identifying the symptoms and doing so as soon as possible.

Tools such as **wearing off question cards** have proven to be effective in identifying the condition, particularly as they ask questions about motor and non-motor symptoms. Keeping a diary of symptoms and using this as a communication tool during visits to your neurologist is also useful in identifying the symptoms associated with *wearing off*.

Treatment is often in the form of medications that **enhance** the up-take of dopamine in your brain (for example, a dopamine agonist such as *Sifrol*) or **slow** the metabolism of dopamine (such as *Comtan* or *Azilect*).

The use of continuous therapies in advanced Parkinson's will also minimise *wearing off* and include *Duodopa* (an infusion of levodopa in the gut), *Apomine* (a subcutaneous infusion of a potent dopamine agonist) or deep brain stimulation (a continuous electrical impulse into the deep brain which short circuits specific areas causing symptoms)

*Wearing off*, or *end of dose effect* is a condition whose unpredictable motor and non-motor symptoms have been identified as significantly impacting upon quality of life in those living with Parkinson's.

Initially, symptoms may be very subtle, such as experiencing fatigue or anxiety prior to taking dopamine replacement therapy medication. However, symptoms may escalate to include increased tremor, stiffness and reduced motor coordination. Fortunately, once identified, *wearing off* is a symptom that can be treated effectively.

**For more information about wearing off, its symptoms and treatments contact the Health Team at Parkinson's Victoria.**



## A move in the right direction

*Research finds that Tai Chi offers significant gains in balance and stability among Parkinson's patients.*

Medical News Today – An **Oregon Research Institute** (ORI) exercise study conducted in four Oregon cities has shown significant benefits for patients with mild-to-moderate Parkinson's.

In an original article published in the **New England Journal of Medicine (NEJM)**, ORI scientists Fuzhong Li PhD and colleagues report that a tailored program of twice weekly Tai Chi training resulted in improved postural stability and walking ability, and reduced falls in the participants.

"These results are clinically significant because they suggest that Thai Chi, a low-to-moderate impact exercise, may be used, as an add-on to current physical therapies, to address some of the key clinical problems in Parkinson's, such as postural and gait instability. Since many training features in the program are functionally orientated, the improvements in the balance and gait measures that we demonstrated highlight the potential of Tai Chi-based movements in rehabilitating patients with these types of problems and, consequently, easing cardinal symptoms of Parkinson's and improving mobility, flexibility, balance, and a range of motion," noted Dr Li.

In the 4-year project funded by the **National Institute of Neurological Disorders and Stroke**, the investigators randomly assigned 195 patients to one of the three exercise groups: Tai Chi, resistance training, or stretching. The patients then participated in 60-minute exercise sessions twice weekly for 24 weeks.

The results of the study showed that the Tai Chi group performed consistently better than the stretching group in how far they could lean in any direction without losing balance, as well as demonstrating better levels of directional control of the body and walking ability (i.e. increased stride length).

Tai Chi participants also outperformed those in the resistance training group on the balance and stride length measures.

Finally, Tai Chi training was shown to significantly

lower the incidence of falls compared to stretching, and to be as equally effective as resistance training in reducing falls.

Impaired movement, especially the loss of ability to maintain standing balance, adversely affects function and quality of life in patients with Parkinson's. With progression of the condition, patients lose stability and have trouble walking, difficulty managing activities of daily living, and experience frequent falls.

Exercise is an important part of the management of Parkinson's because physical activity has been shown to retard the deterioration of motor function and to prolong functional independence. However, research on alternative forms of exercise, such as Tai Chi, that could improve balance, gait, and function in patients with Parkinson's is scarce.

The Tai Chi program developed by Dr Li consisted of six Tai Chi movements integrated into an eight-form routine that focused on weight-shifting, controlled-displacement of the center of gravity over the base of support, ankle sway, and front-to-back and sideways stepping. Natural breathing was integrated into the training routine.

"There are a number of practical advantages to using Tai Chi to improve motor dysfunction of Parkinson's – it is a low cost activity that does not require equipment. It can be done anywhere, at any time, and the movements can be easily learned. It can also be incorporated into a rehabilitation setting as part of existing treatment. Similarly, because of its simplicity, certain aspects of this Tai Chi program can also be prescribed to patients as a self-care/home activity," Dr Li added.

**Source: Medical News today:**  
<http://www.medicalnewstoday.com/releases/241386.php>

## Tai Chi Workshop

Are you interested in a Tai Chi workshop being conducted in the Southern Suburbs? Read more on page 15.

# Carers' Corner

## Some considerations for Carers

*DIANNE RAYNER, Client Services Officer and PSP Support Worker, shares some helpful advice for carers.*

Parkinson's is a condition that affects the "family": it takes a whole team of involved and supportive people to help an individual with Parkinson's move forward. However, in some circumstances the main responsibility will fall on one care partner, a spouse, a child, or a friend. For this person, life is changed forever when their loved one is diagnosed with Parkinson's and they must take on many new roles.

This will be a challenging job, involving compromise, encouragement and strength. Their focus will be on providing emotional and physical support, as well as advocating on behalf of their loved one and learning all they can about Parkinson's.

What is the best approach then, to manage and maintain long term care without feeling the effects of "burnout"?

### *Independence*

It is important that carers do not help the person they are caring for 'too much', but encourage, and where possible, facilitate the person with Parkinson's independence.

It is vital, for both physical and mental benefits that the care recipient maintains as much independence as possible, for as long as possible.

### *Communication*

Communicating what you, as a carer, are willing and unwilling to do will prevent unrealistic expectations being created. Setting boundaries doesn't mean you don't care about the person you're caring for, rather, it's a sign of assertiveness and your ability to exercise it.

If you take on things you don't want to do (for whatever reason), you can end up feeling resentful. Try looking for an alternative solution, such as agreeing on the time you will spend together to help out. This allows you time to take care of your own things without feeling guilty. It also lets the other person know exactly when you are available and the parameters of that availability.

### *Roles*

If you live with the person you care for, you may find, as most people in this situation do, that you can agree to alter responsibilities for certain tasks. For example, you could agree to take on physically demanding tasks such as vacuum cleaning and gardening. In return, the other person might take responsibility for finances or other household paperwork. Even though at times this may mean a change of 'traditional' roles and a new way of doing things, a change like this can work quite well.

It is important to remember that changes in responsibility and control can be difficult to handle at times. Just as the original relationship you had can change, so too can the person you care for

become more dependent on you over time, and this can cause new challenges for both caregiver and recipient.

Caregivers may feel that the relationship used to be an equal one, but now they make all the decisions (and subsequently carry all the responsibility). Similarly, the care recipient can also experience a significant shift in feelings and their sense of contribution and control. If this is how you are feeling, it is a good idea to discuss the change of balance in the relationship with the person you care for or receive care from, this will assist you both in adapting to the new situation.

Another good idea is to celebrate any achievements you make, small or large and either separately or together, such as participating in **Walk in the Park**. A sense of connectedness and unity can be felt with each other as you may be stepping out of your individual comfort zones. Celebrating 'joint' achievements is not only rewarding and important, but recognising the difference it has made can bring a lot of joy to yourself and your relationship with each other.

### *Asking & Accepting*

Asking for, and accepting help can be difficult at times for both carer and care recipient for a number of reasons such as embarrassment, fear, lack of control and uncertainty.

It's important to remember that accepting help is not a sign of weakness but a sign of strength. As you slowly relinquish control and begin to 'let go', a sense of relief and empowerment will be experienced. Treating each other with respect and being supportive whilst receiving help can often create a stimulating environment where an opportunity to solve problems can arise.

What networks do you as a carer have that you may be able to turn to for help? Many people want to be of assistance but are unaware of what you need and what *they* can do, or are unsure how to offer assistance.

There are probably many people in your network of family, friends, work colleagues, sporting and community groups that you could consider asking for help. Be open and honest in your request. Letting them know how they can best assist you will not only help you, but will be encouraging to them as well. Involving others in your caring role will also give them a sense of fulfilment, will make a difference for you, and will provide more stimulation and support for the person receiving care.

It may be with simple things, such as household tasks, basic errands, or visiting or calling you at certain times. They may be able to assist by giving you a break or treating you to something you enjoy.

**Carers and partners are welcome to call our free Help line at any time to discuss their specific needs or with a general enquiry. You do not have to be a member to access our information and support services.**

# Upcoming Special Events

## Off to the movies

Thursday 6 September

Charity Movie screening of "Kath & Kimderella"

Opening Night: Kino Cinema, City, 6.00pm start

The foxy ladies of Fountain Lakes will be turning more than heads when they star in their first feature film.

Join Parkinson's Victoria and the girls for a glass of "kar-doe-nay" to see this side-splitting adventure starring Gina Riley, Jane Turner and Glenn Robbins. Come along dressed as your favourite character for a chance to win a great prize.

Why not get a group of "second best friends" together and have a great night out!?

Tickets \$30 per person (includes a glass of wine and movie ticket).

Purchase online and all details:

<http://www.trybooking.com/BRME>

Sunday 16 September

Charity screening of "Madagascar III: Europe's Most Wanted"

Palace Westgarth Cinema, Northcote, 11.30am start



Kick off the school holidays with a laugh and join us for this fun day out for the young, and young at heart!

All your favourite friends from the original movie are back on the big screen for their latest adventure; fighting to get home to their beloved Big Apple.

All tickets one price: \$22 per person (kids receive popcorn and drink combo). Purchase online and all details: <http://www.trybooking.com/BRMM>

Saturday 27 October

MASSIVE Charity screening

"Back to the Future 1, 2 and 3"

The Astor, St Kilda, 4.00pm start

Following last year's phenomenal success, we are once again hosting one of the greatest movie trilogies of all time, 'Back to the Future'.



Take a ride with us as we hit 88 miles per hour and break through the time barrier in support of 80,000+ Australians living with Parkinson's.

Real cinephiles will be excited to know the films will be screened in digitally re-mastered print that will come to life on The Astor's state of the art Barco 4K 32B projector.

This year the original film celebrates its 27th anniversary (can you believe it was that long ago?). The star of all three movies, Michael J Fox, was diagnosed with Parkinson's in 1991 and he disclosed his condition to the public in 1998. He has since become an activist for research towards finding a cure, leading him to create the Michael J Fox Foundation in the US. Many of you will know he was planning to visit Melbourne this month but unfortunately due to unforeseen circumstances, this event was cancelled. This movie marathon will be your best chance to see Michael, up close and personal!

Get into the spirit of the event for the chance to win one of our terrific prizes; come dressed as your favourite character or period from one of the films (1950s, 1980s, 1850s or future). There'll be other competitions on the day, and guess who else is back? Yes, Doc's DeLorean car!

Thursday 29 November

Charity movie screening "Skyfall: 007"

SAVE THE DATE – Kino Cinema, City

The 23rd adventure in the longest-running film franchise of all time is finally here!

Daniel Craig once again stars as James Bond 007, who's loyalty to M is tested as her past comes back to haunt her. As M16 comes under attack, 007 must track down and destroy the threat, no matter how personal the cost.

This will be one of the year's most anticipated films. See it first at this special charity screening. Register to receive more information: [info@parkinsons-vic.org](mailto:info@parkinsons-vic.org).

## Live theatre

Thursday 8 November

Production of "Me & Jezebel"

Unicorn Theatre at Mt Waverley Secondary College, Lechte Rd, Mt Waverley (Melways map 61 F 11), 7.30pm start

Join us for an intimate evening at The Unicorn Theatre in Mt Waverley for this Peridot Theatre Company production.

**Me & Jezebel** is Elizabeth Fuller's true life account of the summer of 1985 when screen legend Bette Davis came to her home in Connecticut to stay for one night, and ended up staying a month.

Tickets: \$23 per person (\$20 concession) includes light supper

Book online and all details:

<http://www.trybooking.com/BPTZ>

# Research Registry

## Australian Parkinson's Disease Registry (APDR)

The **Australian Parkinson's Disease Registry (APDR)** is an initiative to establish and maintain a database of people living with Parkinson's in Australia.

Parkinson's Victoria provided a major grant several years ago which made it possible to start the *Victorian Parkinson's Disease Research Registry*. Over 200 people have enrolled and many of these subjects are being assessed for the second time (following an initial assessment 3 years ago).

### *Background to the Australian Parkinson's Disease Registry (APDR)*

A National Registry was always the long term aim but funding was an obstacle.

Recently the **Cooperative Research Centre (CRC)** for Mental Health provided funds to allow centres in Sydney and Perth to join and so the Victorian Registry became the **APDR**.

Through this growth the Registry continues to provide a powerful platform for Parkinson's research and Parkinson's Victoria encourages all members and the wider community to participate.

The aim is to have enrolled a further 200 subjects from WA and NSW by the middle of 2013.

Because of the substantial injection of funds by the CRC for Mental Health, the APDR is managed by its board, but there is a **Scientific Advisory Committee (SAC)** which is responsible for the management of the Registry, and Parkinson's Victoria sends a representative to this SAC.

### *Why do we need a Registry?*

A registry is a database of information collected over a period of time and the **APDR** is an important research resource which promotes and facilitates efficient and collaborative research into Parkinson's.

There is no test for Parkinson's and diagnosis depends on clinical judgement. Unfortunately, even in the most experienced hands it transpires that the diagnosis was incorrect in a significant proportion of patients. Because of this, effective treatment for Parkinson's symptoms may take much longer to be proved effective or may even be overlooked if treatments have a real but modest effect.

It is also much harder to conduct research on the causes of Parkinson's if we are uncertain about whether or not a study subject's actually has the condition.

One of the best ways for researchers to overcome this problem is to study large populations whose Parkinson's is very well described and whose medical records and progress is well known, hence the **APDR's** "living database".

It is also vitally important to study a matched control group at the same time. However, it takes time to put together a cohort of suitable patients and this is often a factor that slows research down.

The **APDR** aims to speed up this process and research trials by developing a registry of Parkinson's patients whose condition is well described and who are available as a research population.

The Registry is also building a wealth of biochemical and laboratory data (based on blood and genetic materials gained from subjects) to support the clinical picture.

A well developed Registry such as this is a scarce resource around the world and we anticipate a high level of international interest.

### *How can the Registry be used by scientists?*

Any scientist around the world can approach the SAC for approval to use the Registry. They need to have approval from an ethics committee and the SAC would need to be convinced that the research is of high enough standards to justify access to precious biological materials.

In many cases, the request is to approach people in the Registry to ask if they would participate in research to collect new data.

### *How will the Registry benefit people with Parkinson's*

People with Parkinson's who participate in the Registry will benefit by having access to new tests and treatments as they become available. Their treating neurologists will also have access to their results from the detailed examination that is performed on entry to the Registry.

The broader Parkinson's community will benefit because the Registry will aid research directed at improving the quality of life, treatment, diagnosis and prevention of Parkinson's.

### *Who can be involved in the APDR?*

The Registry is open to people with Parkinson's as well as "healthy", community-dwelling people without Parkinson's (so called 'control' participants). The control group is important because it allows for scientific comparisons to be made between the two groups, which will assist in better understanding the causes of Parkinson's.

### *What does Registry participation involve?*

For participants with Parkinson's, a 2-3 hour clinical assessment is performed and repeated every 3 years to update the clinical information. Assessment involves a detailed characterisation of Parkinson's for that individual (examining walking, movement, balance), cognitive tests (looking at thinking and memory), as well as fasting blood tests (if you are unable to fast for the test alternate arrangements can be made).

# Research

For 'control' participants, a brief clinical assessment (around 20 minutes) and fasting blood test is performed, with repeat assessment every 3 years. All confidentiality is protected and all participants are assigned a 'code', so that identity and personal details are only known by the Registry team.

Assessments for all participants are performed at St Vincent's Hospital, Melbourne.

Participants receive a newsletter from the **APDR** on research progress, and information about research studies being conducted, with an invitation to participate. All participation is optional and voluntary, so a participant may decide to participate in some studies and not others. In addition, participants can decide to end participation at any time by letting the Registry team know.

## *Developments from the Registry*

To date, the Registry has made 15 Parkinson's-related studies possible. These include:

- studies into the genetics of pain in relation to Parkinson's,
- the development of a device for measuring Parkinson's,
- Developing a blood test
- studies into the genetics of the condition
- examination of eye movements to study impulsiveness.

## *How can I read more about the APDR, ask further questions and/or indicate my willingness to participate?*

For further information or indicate your willingness to participate in the Research Registry, you can:

- Email: [parkinsons@florey.edu.au](mailto:parkinsons@florey.edu.au)
- Phone: (03) 9288 3190 (Leave your contact details and someone from the APDR will get back to you).
- Write to: Sarah Osborn, APDR Research Coordinator, St Vincent's Hospital Melbourne, PO Box 2900, Fitzroy VIC 3065.

## Putting Bequests to work

*In addition to our regular program of information, support and advocacy, Parkinson's Victoria is committed to facilitating and financing research projects, particularly focusing on improving the quality of life for people with Parkinson's, their families and carers.*

*Board Member FRED VAN ROSS, who is also a member of our Parkinson's Research Sub-Committee, explains why major gifts are so important.*

Parkinson's Victoria has a dedicated Research Fund, supported by bequests and general donations. Through this fund we are able to support and fund valuable research projects, not only into the cause of Parkinson's and finding a cure, but research that will improve quality of life. Throughout the year, we receive many requests from researchers seeking grants to help fund their project. While many of these applications have merit, not all of them meet the stringent criteria set by Parkinson's Victoria.

In addition, many bequests are made with specific wishes and instructions from the bequestor, and the Board and Research Sub-Committee is very diligent in observing these.

To help decide which research projects best meet these instructions, the Research Sub-Committee thoroughly assesses each application, taking into account criteria such as:

- clarity, originality and innovation
- soundness of rationale and methodology
- feasibility of the project and probability of success
- experience of the applicant(s)

Of course, the research project must also meet the highest ethical standards and no project is undertaken without first sighting its ethical approval.

In the recent past, Parkinson's Victoria has committed funds in excess of \$300,000 to the following research and education projects:

- **Parkinson's Research Registry Victoria**, Professor Malcolm Horne, Florey Neuroscience (now the **Australian Parkinson's Disease Research Registry ADRN**, read more on page 6)
- **Essence of Managing Parkinson's**, Southern Academic Primary Care Research Unit, Dr Craig Hassad (read more on page 6)
- **Brain Bank** ongoing research
- National Health & Medical Research Council (Awaiting approval from NH&MRC as to suitable applicant)
- **7th World Congress for NeuroRehabilitation**

We trust that you share our pride in the vital research funded by **your** donations and bequests, and generously supported by our fundraising activities.

***If you would like further information about our Research Fund, how you can make a donation to research, or you would like to know how you can support Parkinson's research through a bequest to Parkinson's Victoria, please contact our CEO, Ann Burgess: (03) 9581 8700 or email: [aburgess@parkinsons-vic.org.au](mailto:aburgess@parkinsons-vic.org.au)***

# Living well

*The decision to disclose a diagnosis of Parkinson's is a very personal one. There are lots of things to consider in deciding who, when and how you disclose your Parkinson's. You may be someone who finds it relatively easy to talk about Parkinson's, or you may be more private. You may simply find it difficult to come up with the right words. BREANNA WOTHERSPOON from our Health Team looks at some of these factors and provides some helpful tips.*

## **Choosing the 'right time'**

In general, it's up to the individual to decide when they tell people they have Parkinson's.

If you have only recently been diagnosed, you may need some time to adjust before telling others. On the other hand, you may find it isolating trying to deal with things on your own and opening up to people can help you share what you're going through and reduce that feeling of 'going it alone'.

Try to stay in control of when, where and how you tell people, but be prepared for the possibility of an unavoidable situation where you need to tell someone unexpectedly.

It is a good idea to start by talking it over with someone you are close to, and then they may be able to support you when talking to others.

Be selective about when you tell people - family celebrations may be a good opportunity to tell a number of people at once, but may not be the ideal place to talk for the first time about Parkinson's.

It is important to give partners, family members and friends space to come to terms with your diagnosis, as they will deal with the experience in their own way. Keep the communication channels open and talk with each other about the impact of this information.

## **Delivering the news**

Talking about Parkinson's does get easier with practice. Be prepared and think in advance of a good way to start the conversation, or the kinds of things you will say.

When talking about your diagnosis, it can be beneficial to explain something about Parkinson's itself. Many people know little of the condition or have preconceived ideas that might not be accurate. You may find it useful to have some fact sheets on hand for your family and friends to read through in their own time (Parkinson's Victoria has a number of easy-to-understand resources that outline the condition and the symptoms that can be experienced). Explain that symptoms can vary for each person with Parkinson's.

Let your friends and family know how you want to share the information with others. There may be certain people you want to tell personally, while you

may be happy for others to pass the news on so that you don't have to tell everyone yourself.

## **Dealing with the reaction of others**

It's hard to predict how people will react to news of your Parkinson's diagnosis, but in the majority of situations the reaction will be supportive.

If you are calm and appear comfortable with your diagnosis, others are likely to reflect that and be positive in their response.

People will often take cues from you. If you occasionally mention Parkinson's in conversation, or can refer to it with ease, this will signal to your friends and family that it is ok for them to talk about it too.

Reinforce to family and friends that while you have been diagnosed with Parkinson's, you are still the same person. Parkinson's is simply a part of your life now, and you are adjusting to living with it.

Let those around you know what you do or don't want them to do. Often people are eager to offer support, but are not sure how – give them examples of ways they may be able to assist or support you.

## **Sharing with strangers**

You may find yourself in situations where your symptoms are apparent to people you don't know well.

As you become more comfortable with your diagnosis, you might like to tell more people you have Parkinson's.

People are more likely to be patient if they understand the reason for things, for example if you are having trouble getting money out of your purse or wallet at the cash register. This has the added benefit of raising awareness of Parkinson's in the general community.

## **Informing your employer/work colleagues**

Generally speaking, there is no legal obligation to disclose a diagnosis of Parkinson's, *unless there is an occupational health and safety risk* (to yourself or others).

You may have concerns that disclosing your health status will be bad for your career, or mean your co-workers and supervisors perceive you as less capable of doing your job. However, disclosure can have a beneficial impact, such as explaining visible problems or symptoms which others have witnessed, rather than people making incorrect assumptions.

Telling colleagues about your Parkinson's can also lessen stress levels that arise from attempting to disguise symptoms. You may also be able to make modifications at work to allow you to continue working (without further compromising your health). This may involve varying your role, working more flexible hours, or modifying your workspace.

# Volunteering

If and when you decide to disclose your Parkinson's, approach the conversation professionally. Provide your boss or co-workers with information about Parkinson's and present them with solutions rather than problems.

## Driving

It is a legal requirement that people with Parkinson's inform VicRoads (or other relevant Roads and Traffic Authority) of their diagnosis.

This does not mean that your licence will be revoked; however you may be required to provide a medical report from your doctor confirming that you are fit to drive. Alternatively, you may be required to undergo a driving assessment which satisfies driving requirements of VicRoads.

**For further information about how and when to share your diagnosis of Parkinson's with others, or ways to support a loved one making this decision, please contact our Health Team.**

## STOP PRESS

Are you the loved one of someone living with Parkinson's?

Carers/partners are invited to participate in a valuable PhD research project which aims to improve our understanding of the care-giving journey, and will potentially inform clinicians on how to develop programs and services that will positively influence the well-being of those in the care-giving role.

Participation will involve a brief one-on-one phone interview (completing an anonymous questionnaire) and/or attending a small discussion group with other carers.

Researcher Deborah Worboys is a Registered Psychologist with a professional and personal interest in Parkinson's.

**Interested? Please contact Deborah: 0404 860 164 or [debworboys@gmail.com](mailto:debworboys@gmail.com). This project has received formal approval from the University Ethics Committee (Ref. no: Q2011 12)**

*Every day, do something that will inch you closer to a better tomorrow: An update from our Volunteer Coordinator, JOSEPHINE (JO) BERTHELEMY.*

As Volunteer Coordinator, I work with a number of Melbourne's tertiary institutions to place students in volunteering roles. I always find these students to be vibrant, extremely enthusiastic and ready to lend a hand!

One of our biggest volunteer needs is for our annual Walk. Every year, volunteers play a major role in the success of **Walk in the Park**, ensuring the day is safe and enjoyable for everyone. With more than 2,000 people taking over Federation Square on Sunday 26 August, executing this event is no mean feat!

## Swinburne University partnership

**Parkinson's Victoria** is proud to be partnering with **Swinburne University** during the month of August and providing volunteer placements at **Walk in the Park** for up to 140 students as part of their upcoming Semester of Service Learning.

This is a 'win-win' scenario for both organisations: Parkinson's Victoria will benefit from the enthusiastic manpower of the students, and the students will have the opportunity to experience volunteering at a fantastic Melbourne event, knowing they are making a difference to those living with Parkinson's.

We are grateful for their valuable contribution and trust they all thoroughly enjoy the day!

## Sausage sizzles

Thanks to all the volunteers who will be helping at our next Bunnings Moorabbin sausage sizzle on **Saturday 11 August**.

We'll let you know how we went in the next edition of **Signpost!**

And, before the end of the year, there's just enough time to squeeze in one more Bunnings Charity Sausage Sizzle, this time at the new **Bunnings Mentone** on **Friday 30 November**.

If you can help for a three hour shift, I'd love to hear from you.

## Tin rattle collection results

On **Thursday 7 June** we hosted our annual tin rattle at Melbourne's city and some suburban train stations.

I am delighted to report that we collected an impressive total of **\$6,409** from commuters in just two hours!

Given that times are tough and people are seemingly giving less, this is an extremely positive fundraising result. Thanks to everyone who got up at the crack of dawn and helped!

*One of our tin rattle volunteers wrote to us afterwards and we thought her feedback was worth sharing: "For me it was a novel experience; 'shaking for Parkinson's' instead of because of it! I enjoyed the chance to do something positive, to give back to Parkinson's Victoria for the help I have been given, and to know the funding will help others less fortunate than me. Thanks again for the giving me the chance to help." Marja.*

**If you would like to donate your time or skills, or if you have other ideas about how you can help, please contact me, Jo Berthelemy, Volunteer Coordinator: (03) 9581 8700 or [jo@parkinsons-vic.org.au](mailto:jo@parkinsons-vic.org.au)**

# Personal Reflections

## Personal Dopa-meanings



*PETER NASSAU (above) recently joined our editorial team as a volunteer to help source and present personal contributions from the community for Signpost.*

I sit and wait with expectation  
As I am not one for resignation  
That you will send me anecdotes  
Or any other form of notes  
That share with us how you are dealing  
With PD and how you're feeling  
A few short sentences will do  
And I'd be happy to help you too  
By sharing all your thoughts and fears  
With all our other PD peers

**I look forward to your story (or that of your partner, carer or family member) relating to your journey living with Parkinson's.**

**You are not expected to break out into poetry – that's just my way of communicating. Your contribution of a maximum of 500 words would be appreciated.**

**If you need help writing your story, I am more than happy to assist via phone discussions and/or receiving draft material via 'snail mail' or email. I will be happy to review your draft in collaboration with you in order to finalise it to our mutual satisfaction.**

**Please contact me C/- Parkinson's Victoria: Peter Nassau (03) 9581 8700 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au) (please mark it "Signpost").**

### *Personal Reflections from GRAEME HARPER*

When I was 53 I was diagnosed as having Parkinson's and I am now 69. I qualified academically with a PhD in education and I lectured at the University of Melbourne on evaluation and assessment of students.

After a couple of years I had to leave the University because of this damn disease that so many of us share and it seemed to me it was better to leave

the lecture podium at a time of my choosing, rather than be asked to do so.

So here I was, over 50, kids almost off our hands and that once colossal mortgage was almost under control. It was time for me to be self-indulgent and this meant taking up water-colour painting.

I therefore looked back to earlier days and my love of the sea, ships and painting.

My first marine illustration was a River class freighter etched into my bedroom wall alongside my bed. I loved it. Dad hated it, for whenever he tried to fill it with patching plaster and paint over it, it always came through.

I also remember as a child being taken to Port Melbourne to see the **Himalaya**. I was enamoured by the size and beauty of the vessel. Somehow, I never painted such ships that were so awesome and beautiful.

About eight years after being diagnosed with Parkinson's I had half a dozen lessons at the CAE and then a few more at the Victorian Artists Society. This was enough to set me up. I set out to paint pictures of boats that sailed the waters of Port Phillip Bay between the years 1920 to 1970.

The paintings seemed to be interesting right from the word go. But would I reach the point of excellence that I desired?

Parkinson's began to bite a little harder and the passion to paint waned. I paint differently now. I am happy to paint things other than boats and it is more difficult than in earlier times. Still, I enjoy painting with my fellow *Parkinsonians*. I am glad to be among my fellow sufferers and enjoy their success. Painting with Parkinson's also gives one a chance to defy this damn disease.

I am a member of the Parkinson's Victoria Essendon Support Group.



Artist Graeme Harper and some of his watercolours

**Editor's note: Keep an eye out for our new blank notecards featuring one of Graeme's stunning watercolours, available for sale soon through Parkinson's Victoria and ideal for any occasion.**

**Thank you Graeme for sharing some of your story, and for allowing us to re-produce your beautiful artwork.**

# Education & Information

## Parkinson's Seminar: Melton

Parkinson's Victoria invites those living in the Melton and surrounding area to an information and support seminar for those recently diagnosed with Parkinson's and their families.

This **Introduction to Parkinson's** seminar will provide general information in terms of symptoms, as well as treatments and strategies to help with movement. Frequently Asked Questions will be answered and there will be a focus on living well with Parkinson's. This seminar is specifically aimed at those who have been diagnosed within the past 5 years.

**When: Thursday, 13 September, 1.00pm-3.00pm**

**Where: DJ Cunningham Centre, Mt Carberry Recreation Reserve, Exford Road, Melton South (Melways ref: 342, K3)**

**Cost: \$5.00 per person (payable on the day)**

**Register: Registrations are essential and seats are limited. Contact Parkinson's Victoria: (03) 9581 8700 or 1800 644 189 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)**

## Tai Chi workshop

A **beginners tai chi** class, suitable for people with Parkinson's, has just begun in the Cheltenham area.

Classes involve a combination of seated and standing Tai Chi movements, depending on the abilities of each individual. There will also be some participants experiencing other health issues such as Osteoarthritis.

Ideally, we suggest the person with Parkinson's bring along a friend, relative, partner or carer to support them, and of course enjoy the benefits too!

Requirements\*:

- Ability to walk independently with or without a walking aid
- Medical clearance to state it is ok for person to undertake the exercise class
- Comfortable clothing
- Comfortable full shoes with low heels which fit securely
- Water bottle
- Medications (to self administer)
- Emergency contact details

\*If you are unsure of your suitability for this class, please contact Anastasia (below) to discuss. Anastasia is a qualified trainer in Tai Chi for Parkinson's and has learnt under Dr Paul Lam, Tai Chi for Health Institute.

**When: Wednesday's (during school terms), 11.30am – 12.30pm**

**Where: Exodus Hall, Our Lady of Assumption, 9 Centre Dandenong Road, Cheltenham**

**Cost: \$8 (pay on the day)**

**Registration: Contact Anastasia on 0422 652 866**

## Help Sheets for "Parkinsonian" conditions

PSP Australia, in collaboration with Parkinson's Victoria, has recently launched a range of information/help sheets on **Cortical Basal Syndrome (CBS) /Degeneration (CBD)** and **Multiple System Atrophy (MSA)**.

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

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

The CBS/CBD and MSA information help sheets are now available to download from [www.psp-australia.org.au](http://www.psp-australia.org.au).

**Parkinson's Victoria provides information and support for these conditions, as well as Progressive Supranuclear Palsy (PSP), and supports PSP Australia. If you would like further information, please contact Dianne Rayner, PSP Support Worker: (03) 9581 8700.**

## Professional education

**MS Australia** (ACT/NSW/VIC) is hosting a **Professional Development Program on Understanding Parkinson's Disease**.

Facilitated by Parkinson's Victoria, this session for **health and allied health professionals**, will explain Parkinson's and explore strategies that assist clients to live well with this chronic condition.

**When: Friday 31 August, 1.30pm - 4.30pm**

**Register: Online through Try Booking**  
<http://www.trybooking.com/BRBS>

**Health Team note: a recording of this program will be available (\$45), contact Parkinson's Victoria.**

## Swallowing seminar

On Thursday, 6 September, Parkinson's Victoria, with the support of Southern Health and Cabrini Health, is hosting a specialist workshop for health professionals titled **'A Tough Act to Swallow': Dysphagia (swallowing problems) in Movement Disorders**.

**When: Thursday, 6 September**

**Register: Online through Try Booking:**  
<http://www.trybooking.com/BQZR>

# A time for change

*"It's just not sexy enough: the ultimate threat to education & understanding" was originally delivered by author JENNY WHITE at the Parkinson's Australia National Conference, 13-14 July, 2012. The article has been re-printed with kind permission from the author.*

Historically Parkinson's was a disease for the elderly. While it is still mainly diagnosed in persons 60+, Parkinson's is rapidly becoming one of the fastest growing neurological disorders in Australia, and the age range of those diagnosed is widening.

My first introduction to the condition was of my elderly grandmother with trembling hands, soft voice and rigidity many years ago.

Little did I know that as a "youngster" in my mid fifties, the subtle changes I was experiencing (like loss of sense of smell, difficulty getting out of a chair, favouring an arm, sleeplessness, slowness in bathroom routines, inability for my left hand to undertake with deftness the same tasks as my right, or finding handwriting more difficult) would culminate in my own diagnosis of Parkinson's.

Since that diagnosis, I have realised that in the majority of cases, diagnosis of Parkinson's is reflective, and not imperative!

I believe that the major hurdle for early Parkinson's diagnosis is the lack of recognition, education and understanding within the community (both medical and general) of the telltale symptoms of this insidious disease.

Generally when someone has a lump, they immediately consult their physician to reduce the risk of cancer. Similarly with chest pains, they will consult their physician for fear of heart disease.

**There is immediate action and an urgency** associated with those medical conditions (and rightfully so), and the need for immediate medical assessment and diagnosis. This is reinforced by media and exposure. But not so it seems, with Parkinson's.

This is a degenerative disease with reported increases of 4 percent per year (or 30+ people a day). This disease is said to now be more common than bowel cancer and leukemia.

**So why are we waiting and not responding to early onset symptoms? Why do we and our families not respond sooner to those early onset signs?**

Because in the main, people don't know what these symptoms mean and (depending on the age of the individual) Parkinson's is the furthest thing from most minds!

**Why is that?** Because there is so little talk about it, and because Parkinson's remains an 'old' person's disease (in the mindset of most).

But tell that to the increasing number of younger men and women who are being diagnosed, and to those who have been through an exhaustive and frustrating process in an attempt to find out what is wrong with them.

Since being diagnosed and in meeting other people living with Parkinson's, I find that generally it's a family

member, workmate or friend who finally points out the changes in an individual and a possible health issue. It is only then that there is recognition there is a problem, and medical assessment is required.

This is typically because we dismiss the vagaries happening within our bodies as possibly just us starting to get that bit older, perhaps an old sports injury kicking in, or perhaps that we are just not serious enough to worry about our health in our busy daily routine.

**However such is the increase of Parkinson's there is the need for change.**

In these challenging and competitive times for the charity dollar, it is going to be even harder to raise the funds required to deliver the vital education that is required for the recognition of those early signs of Parkinson's.

**So what can we who have been diagnosed with early onset Parkinson's do about it?**

We, who now know what those telling, but seemingly unimportant early signs can really mean.

*We need to TALK! TALK! TALK! And, get people to LISTEN! LISTEN! LISTEN!*

We need to tell people of our experiences. We need to be open and candid in sharing that experience and information wherever possible.

It is a shock to be diagnosed with early onset Parkinson's, and we all react differently at being prematurely confronted with what our futures may now well be.

Receiving a diagnosis of a chronic illness is a blow for everyone - the individual, family and friends.

Whilst I say I am lucky (the alternative diagnosis to Parkinson's could have been an imminent terminal illness), the early onset Parkinson's diagnosis was both a surprise and shock to me.

As I mentioned before, everyone is different and symptoms vary, as does the effect and impact of the disease itself. It impacts significantly on the individual, their partner and family, work colleagues and friends. It impacts on the ability to continue with employment, drive a vehicle, play sport, and most worrying is the loss of independence and at times dignity.

Relationships change; partners and family members become carers. Friends change and increasingly, one's limitations in having a "normal life" continue to advance.

And yet, ignorance in the wider community remains, in spite of the rapid increase in prevalence and the significant impact of Parkinson's across health, independence, emotional and financial issues.

This is where I believe that we - who are **living** with Parkinson's - can play a significant role in reducing the knowledge gap and explaining to the greater populace that you don't have to be in a nursing home in the latter stages of life for this to happen to you or someone in your family. We can educate others on what it is like to unexpectedly get an "old person's disease" at such an early stage of our lives.

But what to look out for? What could be a symptom? Am I experiencing any symptoms? Will

# A time for change

my doctor think I'm silly for having a consultation for such a seemingly small issue, like loss of sense of smell or not swinging my left/right arm properly anymore, or having difficulty washing my hair or drying myself after a shower?

Or more significantly for the younger person who hasn't had a grandparent with the illness - then what IS Parkinson's disease?

After my diagnosis, the majority of my friends said to me "Jenny, I don't know anything about Parkinson's - talk to me. What happened to you? How did you know?! What were the signs?"

A contractor at home recently said "I don't mean to be rude, but what is that "condition" you have?" He hadn't heard of Parkinson's, but he was curious and asked many questions.

That leads me to believe that **we** who are living with Parkinson's should empower ourselves to be leaders, advocates and shining lights in raising awareness about this condition and to play a key role in the education and improvement of knowledge for the sake of those who come after us, who may, unfortunately, walk in our shoes with a Parkinson's diagnosis.

Let's think about what has changed over the last few years that, with great success, has heightened public awareness and understanding for other medical conditions. Conditions such as:

- Depression: Think of "Beyond Blue". To talk about and acknowledge having depression is now OK; people are supported and it is recognised as a legitimate medical condition.
- Prostate Cancer: Previously men's prostates were private, but now there is open, public conversation about - and promotion of - the importance of early action for early detection.
- Breast Cancer: The public campaign in recognition of "pink" as the universally accepted symbol of breast cancer and the successful campaign for self examination and specialist support.
- Illicit drugs: High profile TV and radio advertisements promoting the anti-drug message and urging people not to take speed or ice are part and parcel of our everyday life. Who would have thought this issue would ever be so openly addressed?

And the list goes on. Those messages are highly profiled through media awareness and convey the acknowledgement that action is required.

And yet in relation to Parkinson's (and remember the rapidly growing numbers), the black hole of public knowledge, understanding, and awareness of increasing prevalence and its widening generation span is deafening in its silence.

Again, I say we must talk to people, speak about the symptoms we have experienced, tell people what is happening in relation to the rapid increase of Parkinson's, talk about what we now know and how we felt and feel. And, most importantly, we must get behind our State Parkinson's organisations

and local support groups to help increase the recognition that we have a serious problem, but that there **is** help and support.

We can contribute significantly and meaningfully in supporting the efforts of State Parkinson's organisations.

Of course it is not "sexy" to have a chronic illness.

Of course I am not being flippant in my attitude for those of us afflicted by this horrible illness.

Like everyone else with Parkinson's, I am reminded on a daily basis of my diminishing capabilities and the impact this condition has on one's life. (My Mum at 82 has a driver's license; I am 59 and have had to surrender mine!)

I maintain that improved public knowledge, perception and education about Parkinson's are an imperative for change.

The increasing prevalence of Parkinson's in Australia has to be elevated in people's minds to help gain support for funds for research.

Parkinson's has to become "sexy enough" to be talked about and to be publicly discussed; to highlight its substantial presence in our community (similar to those illnesses like prostate cancer, depression, drug use and so on) and to receive the same levels of awareness and support.

If this does not happen, then all we **do** know about the increasing prevalence and early onset, not to mention how it affects our lives (and those caring for us) will remain within the "black hole" of ignorance, overshadowed by conditions which **do** manage to grab the spotlight (and perhaps, while equally worthy, affect fewer people or already garner significant support and attention).

For a disease - with no known cause or cure - it is staggering (and alarming) to accept the current status quo; that the increasing prevalence of Parkinson's, the increasing early onset numbers and the significant impact on our lives doesn't matter. It is staggering to believe that in spite of the 'numbers', comprehension in the wider community, media and government remains so low.

There is an urgent need to change this.

And so, I reiterate, it is those of us who are **living** with Parkinson's who must support our local Parkinson's organisation. We must become financial members, support fundraising activities, volunteer, join local support groups and **participate**.

But, more important is our individual role as people living with Parkinson's.

I firmly believe we have a significant and strategic role to play in changing the public's knowledge, perception and understanding of Parkinson's.

Until that cure can be found, **we** must be messengers, advocates and sharers of information.

Parkinson's **is** "sexy enough" to talk about. It **is** time for change, and individually and collectively we can be the "swing shift" for that change!

Thank you,

Jenny White [jennywwhite@yahoo.com.au](mailto:jennywwhite@yahoo.com.au)

# Participate for Parkinson's

## The Essence of Health

Dr Hassed from Monash University and a research team are seeking participants for a research study titled **Essence Project: The impact of a mindfulness-based lifestyle program for Parkinson's disease**.

The Essence program is a 6-week mindfulness and lifestyle course developed by Dr Hassed.

'Essence' stands for: **E**ducation, **S**tress management, **S**pirituality (meaning), **E**xercise, **N**utrition, **C**onnectedness (social support) and **E**nvironment.

The course will explore the potential role each of these elements has in managing Parkinson's and improving quality of life.

The researchers aim to find out if the program has any impact on Parkinson's-related function, health behaviours, mental health and people's ideas of self-empowerment.

The program will introduce participants to simple strategies that may help them to live well with Parkinson's and they will be encouraged, but not pressured, to apply aspects of the Essence model that are most relevant to their own lives.

The researchers are seeking the help of volunteers who are living with Parkinson's and able to participate in the program, which involves attending a weekly 90-minute group session.

You may be eligible to participate if you are:

- Fluent in English
- Under the age of 75
- Able to attend a minimum of 4 out of the 6 sessions, and,
- Most of the time you are able to walk straight and stand up without assistance.

**If you are interested in participating or would like more information, please contact the Recruitment Officer Brooke Vandenberg: (03) 9902 4920 or email [brooke.vandenberg@monash.edu](mailto:brooke.vandenberg@monash.edu)**

**Health team note: Please be advised that the criteria for this trial has recently been expanded, meaning more people may now be eligible to participate.**

## Depression in older carers

Keeping your partner or parent living at home as they age is a priority for many. And, while providing care for someone who needs extra help and support might bring you much joy and satisfaction, it can also be quite stressful and exhausting, especially if you're getting older yourself.

Research has shown that the burden of caring for a friend or family member at home can sometimes lead to depression, which can also impact on a person's physical health and wellbeing.

People providing care who are experiencing depression may find themselves feeling overwhelmed, guilty, irritable, frustrated, unmotivated or unhappy. While everyone

experiences low mood from time to time, feeling like this intensely and for long periods (such as more than two weeks) may indicate depression.

While studies have indicated that physical exercise can help improve mood and combat depression, it can be difficult to find the time to exercise when you're busy looking after an older person who might have an illness or increased frailty that stops them from joining you in exercise the way they used to.

The **National Ageing Research Institute** is currently investigating the effectiveness of an exercise program in reducing depression and improving the wellbeing of older people and their carers, and volunteers are required to assist.

The idea of the trial is to develop ways older carers and the person they are caring for can exercise together at home.

While the primary measure is whether exercise improves the mood and physical function of the **carer**, it is also hoped that this benefit will improve the physical abilities and mood of the person being cared for – taking some of the stress and effort out of the care relationship.

Titled **IMPACCT (Improving Mood through Physical Activity for Carers and Care Recipients Trial)** the study is looking for volunteers in the Melbourne and Ballarat region. Recruitment will continue until mid 2014.

**To participate in the study, you need to:**

- be a carer (60 years of age or over)
- be caring for someone who is 60 years or over with whom you live
- have agreement from the person you care for to also be involved in the study
- live within 50k radius of Melbourne, Ballarat or Geelong

All assessments and interventions will take place in the home and over the telephone, so no travel is required.

**What's involved?**

The project will involve an initial visit (approximately two hours) from a research therapist to undertake an assessment (questionnaires and tests) with you and the person you care for, including a screen for depressive symptoms. After the assessment you will be allocated to one of 3 groups for a 6 month period (physical activity, social visits or usual care). The assessment will be repeated after 6 months and after 12 months.

**Find out more about this project, please contact Aurora Elmes at NARI: (03) 8387 2315 or email [a.elmes@nari.unimelb.edu.au](mailto:a.elmes@nari.unimelb.edu.au)**

**For information and support on caring, please contact Carers Victoria: 1800 242 636.**

**This study has been approved by the Melbourne Health Human Research Ethics Committee and been funded by the National Health and Medical Research Council.**

# Supporters

## Publication details

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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 to those who have given so generously to support our work. Listed below are those who kindly donated \$250 or more, those in whose name In Memoriam donations were received, and corporate/organisation supporters from 1 May - 30 June, 2012.*

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

## Donations of \$1000+

Damien Farrell  
Justus Lonel  
A Lonel  
Anitonio Palazzo  
Trevor & Pearl White

## Donations \$500+

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## In Memory of...

Imolo Aloisio  
George Armen  
John Kevin Baldwin  
Victor Bell  
Beverly Berry  
John Beryman

John Brodie  
Eleanor Campbell  
Giuseppe Cara  
Peggy Chapman  
Robin Darling  
Norman Day  
Giuseppina Gallenti  
Maxwell Hitchins  
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Robert Jone  
Ivan Kamener  
Mary Eva Kentish  
Carmeline Lonel  
John McKenzie Waugh  
William Thomas Miller  
Godon Murrell  
Michael O'Shea  
John Ring  
Kham Soukseun  
Eddy Swainston  
Anna Weber  
Anonymous

## In honour of...

Anonymous

## In celebration

Merle Pritchard (Birthday)  
Rhonda Day (wedding)

## In Remembrance of...

Giuseppe Spadaro  
Janice Knox  
John Silberberg  
Michael Posterino  
Norman Smith  
William Mitchell

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

### Run Melbourne:

Kieran Ball  
Kate Barsby  
Julian Clarke  
Tanya Gausam  
Jason & Justine Vaisutis  
Angela Matkovic  
Pauline Mcculloch  
Josephine Pope  
Kathryn Read  
Kristen Robinson  
Tom speirs  
David Willis  
Helen Wright

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

Sally Pittard (Postie Party)  
Allan & Vanessa Humphrey (Tea Party)  
Linda Walsh (Tin Rattle)

### Run Melbourne:

Kyle Gray  
Johanna Lourey  
Olivia Rejman  
Lauren Robinson  
Simon White

## Team Parkinson's Run Melbourne has raised (to date): \$29539.75

## Corporate, Community & other donations & support

Balance Physiotherapy  
Cranbourne Masonic Lodge

No. 290  
Elly Kay Aged Care Facility  
Fawpec Pty Ltd  
FHB Holdings Pty Ltd  
Foster Fyans Japanese Auto  
Specialists P/L  
Guinness Peat Group (Australia) Pty Ltd  
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Lonsdale Inc  
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Tabtimer Pty Ltd  
TR Group Pty Ltd  
Wolter Steel Company Pty Ltd  
Yarra Valley Bridge Club Inc

## Matched Payroll Giving

Phaik See Chong  
Anonymous

## Payroll Giving

National Australia Bank

## Regular Giving

Vince Spano  
Anonymous

## Parkinson's Support Groups

South Gippsland  
Warrnambool  
Warragul

## Trusts & Foundations

Peter Craig  
Stuart Cumming  
George Dore  
David Henning Memorial  
Foundation  
Handelsman Charitable Trust  
Wayne Sidwell  
Barry Williams

We gratefully acknowledge the generous support of those who gave to our major appeals and are pleased to provide this update on donations received from May-June 2012.

- **Mid year appeal 2012:**  
\$2,880 (\$300 members:  
\$2,580 non-members)
- **Steps Autumn donor newsletter:** \$14,924 (\$3,375 Members:\$11,549 non-members)
- **2011 Christmas Appeal (recent donations):** \$4,295 (\$320 members: \$3,975 non members)

# Tulip Tributes

## Charity Golf Day success

On Friday, 6 July, Spring Valley Golf Club once again hosted its annual Charity Golf Day. The fantastic event was not only enjoyed by everyone, but it raised an incredible sum of \$14,585 (of which 50 percent will be donated to Parkinson's Victoria)!

Thank you to the Club, Club Members and Margaret Hancock and her Charity Day committee for organising such a successful and fun day!

**A very special Tulip Tribute goes to Mr John Philp (former Spring Valley Golf Club President). John, who was diagnosed with Parkinson's a few years ago, was instrumental in securing the Club's initial support for Parkinson's Victoria (back in 2008) when he nominated us as a beneficiary of the Charity Golf Day funds. To date, the Club has donated almost \$50,000 to support the everyday work of Parkinson's Victoria and vital research.**

## The kindness of strangers

We'd like to send a special thanks to the family, friends and workmates of people living with Parkinson's who have instigated or supported a fundraising initiative.

'Third Party Fundraising', where members of the community host or undertake an activity in order to raise funds for Parkinson's Victoria, makes a significant financial contribution to help fund our information and support services.

In addition, members of Team Parkinson's (which is what we like to call them) act as powerful Ambassadors to increase awareness and reduce the stigma associated with Parkinson's (as a result of ignorance and lack of 'visibility' of this increasingly prevalent condition).

**So, if you know someone who has been moving to make a difference to help people living with Parkinson's, why not let them know how much you appreciate their efforts? It could be a son, daughter,**

**grandchild, workmate, neighbour or a local retailer. They may have hosted a coin collection tin, put up a Parkinson's poster, organised a morning tea at work, nominated Parkinson's Victoria for workplace giving or participated in Run Melbourne. Have no doubt; they have been inspired to get moving because of someone like you!**

## Up, Up and away!

In July, we received an unexpected – but very welcome donation of \$150 from Vanessa Humphries.

Vanessa explained that she and husband Alan recently took the trip of a lifetime to Coober Pedy, which included a flight over Lake Eyre and Birdsville. During the flight, Vanessa announced to fellow travellers that she was putting together a book of photographs she had taken from the holiday. When she said that proceeds were being donated to Parkinson's Victoria, many travellers were keen to purchase a copy of the book, with some even making an extra donation! The photos Vanessa took were incredible, ensuring the finished product made a stunning memento, while at the same time supporting a great cause!

**Thank you Vanessa for using your creative touch to raise funds for us!**



Alan Humphries boards the plane in Birdsville.

# THANK YOU!

**CONGRATULATIONS AND THANK YOU TO OUR 67 COMPETITORS!**



Parkinson's Victoria celebrates the amazing achievements of Team Parkinson's Run Melbourne 2012. Thank you for **moving** to make a difference for people living with Parkinson's! Congratulations on Running Melbourne **and** exceeding our fundraising goal of \$20,000! You are all superstars!

Donate until 29 August: [runmelbourne.everydayhero.com.au/run\\_melbourne\\_team\\_parkinsons](http://runmelbourne.everydayhero.com.au/run_melbourne_team_parkinsons)

Why not join Team Parkinson's for your next fitness challenge?  
Email: [Judith@parkinsons-vic.org.au](mailto:Judith@parkinsons-vic.org.au)

For information, support or to donate:  
[www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au) or 1800 644 189

