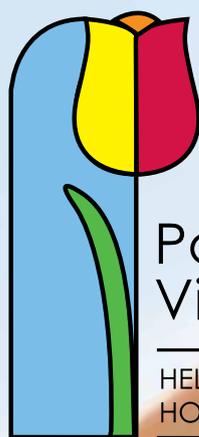


SIGNPOST

• Winter 2013 • Volume 12 Issue 2 A Magazine for people living with Parkinson's

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Parkinson's
Victoria

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News & Highlights

Appointment of CEO

The Board of Parkinson's Victoria Inc. is delighted to confirm the appointment of Emma Collin to the position of Chief Executive Officer.

Emma commenced with us on Tuesday April 23.

Emma, who has a Bachelor of Business, is both a member of the **Fundraising Institute of Australia** and the **Victorian Institute of Public Administration of Australia**. In 2009 she completed the Leadership Victoria Board Program.

Emma brings to us broad executive and management experience in the not-for-profit, local government and commercial sectors having held roles with Carer's Victoria and Melton Council.

Most important of all, she brings enthusiasm, commitment and dedication born from personal family experience with chronic illness including Parkinson's and Motor Neurone Disease.

Emma is excited about the challenges facing Parkinson's Victoria as it seeks to become a more influential advocate for all Victorians living with Parkinson's – individuals, their families, friends and carers.

As CEO, Emma is looking forward to helping her team deliver improved services, education, help and support, all of which will need significant funding and cost-effective technologies.

Emma has the vision, the managerial expertise and the strategic planning skills to lead Parkinson's Victoria into and through such a period of exciting growth, at a time when competition is fierce for government and private enterprise support.

Please join with the Board in welcoming Emma and offering to her your generous support.

Peter Raymond, President

Young Onset Survey

Are you under the age of 60 and living with Parkinson's? Would you like to help us gather data around the issues that matter most to you?

Parkinson's Victoria is conducting a survey investigating current and proposed services and supports for people living with Young Onset Parkinson's.

We are seeking your feedback on what support services you currently access, what you would like to see offered, and any ideas you have for improving the experience of younger people living with Parkinson's.

This valuable feedback will help us to shape the future of Young Onset services.

To complete the survey follow the link to the 'Young Onset Survey' on the homepage of our website www.parkinsonsvic.org.au

Survey responses close Friday 31st May.

Winter and Parkinson's

One of the first symptoms of Parkinson's, which can occur years in advance of a diagnosis, is a loss of the sense of smell.

This may seem like a relatively harmless symptom – sure, you may miss the smell of coffee in the morning, or be disappointed that you can no longer appreciate the scent of freshly cut grass or a floral bouquet – but it certainly isn't life-threatening. However, it is important to consider how we might use our sense of smell to stay alert. For example the odour of gas may alert us to the fact that we have forgotten to turn the stove off, or a whiff of smoke may wake us in the night to discover a fire.

In light of this and with the approach of winter it's timely to remind ourselves to be extra vigilant and to ensure that a Parkinson's symptom, such as loss of sense of smell, doesn't put us or a loved one at risk.

- Make sure that you have smoke alarms installed, *and that the batteries are working!*
- Clean heaters and fans to make sure they are free of dust and dirt
- Have your gas appliances checked and maintained regularly
- Check appliances for fraying cords and other signs of wear and tear
- Check that power points and power boards are not overloaded or prone to overheat

For more tips about managing Parkinson's during the colder months, or for information about symptoms and early signs of Parkinson's, contact our Health Team.

Young Onset Parkinson's Conference - Save the Date!

Parkinson's Victoria is currently planning its second Young Onset Parkinson's Conference, to be held across two days in September (Friday 20-Saturday 21).

As well as providing an overview of Parkinson's (symptoms, support, medication and research), the event will provide those diagnosed with Young Onset Parkinson's with information from experts on a range of issues specific to this demographic.

The two-day event will also be a great opportunity to meet and socialise with others living with Young Onset Parkinson's.

We want to hear from you!

If you have suggestions for topics that you would like covered as part of the Young Onset Parkinson's Conference, please send an email with your suggestions to youngonset@parkinsons-vic.org.au

Further details about this event will be included in the next edition of Signpost, but in the meantime, save the date and you can also register your interest by contacting our office.



care /ke()r/

noun: *The provision of what is necessary for the health, welfare, maintenance, and protection of someone or something; the care of the elderly | the child is safe in the care of her grandparents | health care.*

A few weeks ago, I was invited by the City of Whitehorse to speak on behalf of Parkinson's Victoria to 160 professional carers at their General Meeting.

They were a keen and enthusiastic audience, employed by **Whitehorse's Home and Community Care Department**. Many were familiar with the topic because some of their clients were people with Parkinson's who were reliant on their service and support around the home - vacuuming, mopping, washing and shopping – in order to remain at home and continue their active involvement in community and social life.

Others in the audience were not so aware of Parkinson's, particularly its impact on young people.

Because their work focused on the elderly, frail and house-bound, many carers in the audience were surprised to learn that 20 percent of people with Parkinson's were under 65 years of age: in Victoria that's around 5,000 people.

The care required by younger people with Parkinson's might be provided by local government, but it is more likely to be a joint family effort involving children and partners (even parents) or in many cases, employers who care enough to modify working hours or conditions of employment.

Indeed, there are many ways in which we *all* care.

Board Members of Parkinson's Victoria care enough to give freely of their time and expertise to ensure that Parkinson's Victoria provides comprehensive and relevant services, encourages independence and improves the quality of life for people living with Parkinson's.

Staff and volunteers show they care with dedicated hard-work to deliver services, support, resources, special events and activities, all of which are absolutely essential if we are to continue providing assistance to those living with Parkinson's – now and into the future.

Support Groups all over Victoria care for their members, filling the gaps where professional carers might not be available. (*They don't care if your painting skills need brushing up, your singing warbles out of tune or you dance with three feet!*)

So the next time you hear the word carer, think beyond the person in a blue uniform or the partner caring for a loved one. We are ALL carers, and so much richer for it.

Peter Raymond, President

Tulip Tributes

Moving to make a difference

Once again we have an awesome – and growing – team of supporters participating in Run Melbourne (5km run/walk, 10km run or half-marathon), on Sunday 21 July.

Last year, Team Parkinson's boasted 68 members who together raised an incredible \$29,795! This year, we currently have 29 participants who have so far raised \$1,915.

It's been inspiring to hear from some of them, like Nicole:

"I've signed up for a 5k run, which will be an achievement for me, as I am not really a runner.

My dad was diagnosed with Parkinson's many years ago, when he was just in his 40s, and mum was his full time carer for several years.

Dad's mum had Parkinson's, as does his sister and his brother (I understand this is highly unusual).

Dad passed away 5 years ago from an unrelated cancer, asbestos at 68.

*Mum spent many years figuring out how best to deal with the situation and the one thing that came to the fore is **medication on time**.*

Mum is now helping dad's sister and ensuring her medication is correct and on time. Mum has spoken to someone at Parkinson's Victoria (even though she lives in QLD), and found them to be incredibly helpful with information which she has passed onto all the nurses at my aunt's care facility in Brisbane.

I hope that any money I raise will go towards helping families deal with this disease." Nicole Trapnell

Check out our team page:

www.runmelbourne.everydayhero.com.au/run_melbourne_team_parkinsons

You can also donate or join the team!

- Choose Team Parkinson's when prompted during the online event registration.
- You can also join our Team Parkinson's fundraising team by first registering to fundraise (again as part of the online registration, tick 'fundraise as an individual) and then entering the team password: teampv.
- Or simply register to fundraise and choose PARKINSON'S VICTORIA as your charity of choice!

Did you hear the news?

A big Tulip Tribute to Linda Walsh and her local SupaNews outlet at Highpoint Shopping Centre for their efforts in collecting small change donations from shoppers. Linda arranged with the newsagency to host a Parkinson's Victoria collection tin on the counter in recent months and a total of 3 tins have since been returned, with a total of \$155 raised.

Thank you to Nicole Lamb and Linda, and of course to all the generous supporters!

In loving memory

Recently, we gratefully received a generous donation of \$1,000 from James Steele and Family in remembrance of their father John Steele.

Thank you to the Steele family for thinking of others at this time.

The lighter side

We love it when people get creative with fundraising ideas!

Rob Tassie's father has Parkinson's, as did his grandmother, and while he'd always wanted to try his hand at stand-up comedy, the idea of turning the occasion into a fundraiser for Parkinson's Victoria was the perfect incentive to put his dream into action!

More than 50 friends and friends-of-friends attended the event to laugh and support and afterwards, Parkinson's Victoria received a donation of \$500 (proceeds were shared with the **Post and Ante Natal Depression Association**).

"I learned a lot about me, what goes into doing such a show and also realised how wonderfully generous friends and family really are, with both their time and money! The good news is that I'm likely to do it again! When you do it for something like this it is a pretty good motivation to be the centre of attention. That's what I tell myself anyway." Rob Tassie

We like your style Rob! Thanks for your amazing support!

Little legs, big heart



In March, eight year old Charlotte Gray (above with her poppa John) competed in the **Weet-Bix Kids TRYathlon** to raise money for Parkinson's Victoria. She started with a goal of \$500, but raised a whopping \$1,824!

The race, which took place in St Kilda, included a 100m swim, a 3km cycle and a 500m run.

Charlotte said she was eager to help raise money for Parkinson's. "My poppa has Parkinson's and I'm trying to help him," she said. He shakes a lot."

To prepare for the race, Charlotte said she did lots of training in the lead-up to the event, including riding her bike up and down her street – a lot!

She also prepared for teaching her classmates and teachers about Parkinson's and for her media interviews! Charlotte's efforts were featured in the Frankston Weekly, Mornington Peninsula Weekly, and the Herald Sun!

Congratulations Charlotte – your poppa must be so proud! We are too!

Run of a lifetime

On 2 June, 33 year old Joanne Tremonti will compete in the gruelling **Comrades Marathon** in South Africa – a 90km race across the desert to raise funds for Parkinson's Victoria.

To date, she has raised \$4,480 and is likely to break the \$5,000 mark, thanks to the support of friends, family and workmates – in some cases, even strangers who read of her efforts in a recent online article (www.australianwomenonline.com).

Inspired by dad Gerry who has Parkinson's (Joanne initially took up running because he was a keen runner), she has completed a number of marathons but this one will top the list for being closest to her heart.

Joanne's parents will head to South Africa to provide moral support during the race and to welcome her across the finish line!

You can read more about Joanne's journey and donate at: www.everydayhero.com.au/joanne_tremonti_2

Joanne – our thoughts are with you in the final weeks before race day and we will be sending you our very best wishes for a great run and a big finish on 2 June! Thank you for pulling out all the stops to raise awareness and funds to help people like your dad!

Cooking up a storm



The Warragul Support Group held a charity BBQ at their local Pakenham Bunnings store in March (above) and raised an incredible \$1,500 to support our work.

We'd like to send a big Tulip Tribute to Support Group members, and especially Mel Dougherty who came all the way from Cobram for the day to help out. Thanks of course to Pakenham Bunnings for it support! And on behalf of the Support Group – thanks to Bunnings and Mel!

From the desk of the CEO



What a wonderful, warm welcome I have had from the Parkinson's community since joining the team last month.

It's been a pleasure meeting with so many of you already and hearing firsthand about your journeys and hopes for the future.

I was delighted to travel to Mildura recently for the **Behind the Mask III Art and Craft Exhibition** and Mildura Community Seminar. During this 3-day trip, I had the opportunity to meet members of our Mildura Parkinson's Support Group and others who came from all across the state to attend these events, including people from the **Geelong Young Onset** and **Painting with Parkinson's** groups.

Cheryl Barnes, Mildura Parkinson's Support Group Leader and Vanessa Humphrey, Beyond the Mask Coordinator, with the support of group members, local businesses and health service providers, delivered two exceptional events.

The community seminar included an interactive session with neurologist Dr Richard Peppard, who answered many questions regarding the cause and current medical treatments for Parkinson's.

This was followed by a presentation by Victor McConvey, our Specialist Nurse Consultant, on issues many people have questions about but are often 'too afraid (or self-conscious) to ask'.

There was also an inspiring presentation by Alan Humphrey on his 30 year journey with Parkinson's and the impact of recent deep brain stimulation (DBS) surgery on his quality of life.

This month, I was welcomed by members of the Essendon Parkinson's Support Group for a very special presentation to accept a bequest from William (Bill) Regan's Estate.

Bill's interest in Parkinson's Victoria grew from his initial support for the **Parkinson's Victoria Charity Challenge Vietnam bike ride** in 2009 and his ongoing relationship with Brendan Lourey from the group. We look forward to sharing you more about Bill and the presentation in the next edition of **Signpost**.

As I write this, I am also planning a visit to Shepparton, where the local Shepparton Support Group, Goulburn Valley Health and Parkinson's Victoria will launch a demonstration project for the region with a newly funded Parkinson's nurse specialist.

The alliance hopes the project will not only provide critical support to the Shepparton area, but will develop important research evidence to support our ongoing lobby for more specialist nurses throughout the state.

At Parkinson's Victoria, we know there is a real need to increase government and community support for people living with the condition. Services and

continued page 21

Symptom management



More than the shakes

Often the community and medical staff characterise Parkinson's as a physical condition and there tends to be an emphasis or focus on motor symptoms. While this means we tend to worry about falling or being slow, there are many silent symptoms of Parkinson's, sometimes referred to as non-motor symptoms. VICTOR MCCONVEY from our Health Team explains.

While the impact of non-motor or cognitive symptoms of Parkinson's is significant for individuals, there continues to be a lack of understanding or recognition of these aspects of the condition by both health professionals and the individuals themselves.

Typically, these symptoms are more common than we realise. Unfortunately, the belief that they are uncommon or that their impact is not significant, only adds to the problem; people are self-conscious discussing these symptoms, even with family and health professionals, symptoms are not correctly diagnosed, and/or doctors do not know how to manage them.

Depression

Depression is thought to impact around 70 per cent of people with Parkinson's, making it an incredibly common symptom.

Depression in Parkinson's may be the result of a number of factors. It may be a **reactive** depression; in other words, you become sad in response to being diagnosed or after experiencing certain symptoms.

This is a typical response to a significant life-changing event. However, there is also a chemical imbalance linked to depression. Low levels of dopamine cause depressed mood, as well as causing the more obvious physical symptoms of Parkinson's.

The signs of depression include: disturbed sleep, irritability, withdrawal from communication and social engagement, and loss of interest in hobbies or enjoyable aspects of life.

It can be very difficult to live with someone who is depressed as they are often irritable and 'grumpy', so often family or carers identify depression before the person living with Parkinson's does.

To make the situation more confusing, moods may fluctuate, with episodes of low mood and irritability contrasting with periods of 'normal' mood.

These fluctuations usually correlate with medications, with low mood often occurring not long before the next dose of *dopamine* is due.

Because of this, you will need to observe when low moods occur throughout the day and ensure medications are taken on time.

Although an adjustment to medication (dosage or timing) may be the answer, for most people, medication fluctuations may only be part of the cause and it is necessary to explore **reactive** causes as well.

A simple **depression screen**, which can be administered by a GP, will identify if depression is a concern and develop a treatment strategy if necessary. This may include counselling and a carefully selected anti depressant.

Anxiety

Similar to depression, this non-motor aspect of Parkinson's commonly fluctuates throughout the day, and again is linked to fluctuating medication levels, in other words anxiety is at its worst when medication is at its lowest level.

Anxiety is also a symptom which will particularly impact upon carers - it can be socially disabling and lead to staying at home and the need for 'reassurance' from others.

Again, counselling, and ensuring medications are taken on time, every time will help manage this symptom.

Sleep

Sleep problems are common for people diagnosed with Parkinson's and are a symptom which can be very disturbing for partners.

During REM sleep phase, the body achieves sleep atonia (sometimes known as sleep paralysis), where very little movement occurs. This is also the phase when we dream. However, people living with Parkinson's can experience a condition called REM sleep disorder, where their bodies remain active to the point that they may physically act out their dreams. An example might be that if they are dreaming of being in a fight or waving at someone, their arms will flail about in their sleep. This may result in injury to themselves or some bruising or worse for their sleep partner.

An interesting phenomenon in Parkinson's is that the movements expressed during REM sleep disorder may actually be free of Parkinson's symptoms, so the movements may be better than when you're awake.

Hallucinations

Research by Melbourne Neurologist, Associate Professor David Williams suggests that more than 60 per cent of people living with Parkinson's will

Symptom management

experience hallucinations at some stage during the course of their illness. Hallucinations are distressing, both for the individual experiencing them and also the carer or family member. The first response is often to believe that dementia or some kind of mental illness is present. This isn't the case.

When hallucinations occur, don't panic. Make sure you tell your doctor, who will check that there is no other explanation for them, such as infection. Following this, your neurologist may adjust your Parkinson's medications, or commence medication that will help stop or reduce the hallucinations.

Cognitive change

There are some cognitive changes that occur in relation to Parkinson's, but like many Parkinson's symptoms, changes in 'thinking' may fluctuate and be unpredictable.

This may be caused by fluctuations from medication "highs and lows"; it is common for people with Parkinson's to describe feeling "foggy" or experiencing "clog-nition" when medication is wearing off.

Cognitive change can be a frustrating and distressing symptom for individuals and carers/family, and understanding the symptom is the best way of managing it.

Lewis and Naismith's research (Sydney 2008) indicated that when patients started to report *Freezing of Gait* (FOG) some higher cognitive changes were also apparent, especially the reduced ability to simultaneously carry out multiple tasks. The research also noted these changes were more apparent once a person had been living with Parkinson's for around 8-10 years. Often this memory alteration will mean families and carers need to modify communication methods, reduce distractions (e.g. not walking and talking at the same time) and ensure they don't ask someone with Parkinson's to multi task.

The silent or non-motor symptoms of Parkinson's are challenging for everyone, but the best way to manage such symptoms and reduce their impact is to acknowledge them, understand the cause and extent of the problem, and then explore treatment options to reduce the impact.

Parkinson's Victoria has a number of resources available to assist those experiencing non-motor symptoms or who would like to know more. Fact sheets include: **Depression and Parkinson's** and the **DASH** booklet (Depression, Anxiety, Hallucinations, Sleep). Both are available on the Parkinson's Victoria website and the Health team is also able to provide tailored information.

No 'Bias'* in Shepparton

It was early in January when Geoff Alexander, Shepparton Support Group Leader, invited Parkinson's Victoria to keep Friday, 15 March free.

"You are invited to Shepparton for the annual Shepparton Park Lawn Bowls Charity Day. Last year the event raised over \$4000 to support our group and Parkinson's Victoria, and once again we have been chosen as the beneficiary of proceeds from this great day!

And so it was, on the Ides of March, that Judith Mooney, Development Manager, and I drove to represent Parkinson's Victoria at the Shepparton Park Bowls Club. Not as bowlers, but as guests!

We were made very welcome by Ray Phillips, the Club President, John Davy, Chairman of the Charity Day Committee and Robin Squire, Chairman of the Shepparton Parkinson's SG.

John explained that the Charity Day always focused on local Goulburn Valley initiatives, including projects such as the provision of a Movement Disorder Nurse.



(L-R) Rob Squires, Peter Raymond, Geoff Alexander.

Media had been arranged and we were able to get some of our key messages across, about the importance of local support and specialist services, as well as promoting the community partnership between us, Goulburn Valley Health and the Support Group.

Bowlers had come from all over the district to compete for the trophies on hand. There were the usual raffles and art and craft stalls, not to mention a sumptuous lunch and, of course, for the tired and weary bowlers, plenty to drink!

It was my first visit to Shepparton representing the Board and one which certainly lived up to Geoff's description as "a great day."

Peter Raymond, President, Parkinson's Victoria

Congratulations and thank you to the Shepparton Park Lawn Bowls Club and members for organising what was a fantastic and successful event, raising \$7,564. These funds will assist Parkinson's Victoria in funding specialist, local support services to regional communities, in particular, in this instance, the Shepparton district.

Thank you also to the Shepparton Parkinson's support group for their continued efforts supporting the needs of the local community and the work of Parkinson's Victoria.

* Lawn balls are designed to travel a curved path because of a weight bias, which was originally produced by inserting weights in one side of the ball. This is no longer permitted by the rules and bias is now produced entirely by the shape of the bowl. However, reference to 'bias' is often said in jest to competitors, implying underhanded play!

Education & Learning

Seminar: Deep Brain Stimulation (DBS) Surgery

Parkinson's Victoria is hosting an education seminar in May for people with Parkinson's **who are considering** Deep Brain Stimulation (DBS) surgery.

DBS is not for everyone and there is a stringent selection and preparation process to ensure, as much as possible, a successful outcome.

Speakers will explain what the surgical procedure involves and, importantly, will also discuss the selection and preparation process and possible outcomes for patients. Handouts and afternoon tea will be provided.

When: Thursday, 30 May, 1-4.00pm

Where: Bridge Hotel Mordialloc (Starlight Function Room), 1 Nepean Highway, Mordialloc

RSVP: Places are limited and RSVP is essential. Contact our Health Team on (03) 9581 8700 or email info@parkinsons-vic.org.au

Parkinson's Victoria is establishing a DBS support group. More details on page 17.

For a great video presentation on DBS visit: www.ted.com/talks and search for "Andres Lozano: Parkinson's, depression and the switch that might turn them off": Deep brain stimulation is becoming very precise. This technique allows surgeons to place electrodes in almost any area of the brain, and turn them up or down -- like a radio dial or thermostat -- to correct dysfunction. A dramatic look at emerging techniques, in which a woman with Parkinson's instantly stops shaking and brain areas eroded by Alzheimer's are brought back to life. Lozano is Chair of Neurosurgery at the University of Toronto, Canada.

TedTalks is a great website where you can find presentations on just about any topic – a bit like YouTube – though the emphasis is on thought provoking and innovative ideas and the engaging speakers, who are typically leaders in their field, have been filmed in front of a live audience. You can register to receive 'daily Ted Talks' or simply search a topic. Presentations are usually less than 20 minutes.

Support for those living with PSP

In March, Parkinson's Victoria and PSP Australia hosted a one-day education seminar for 70 Victorian and NSW health care professionals who work with those living with PSP, MSA and CBS*.

The event was opened with a very personal presentation from PSP Australia convenor, Anne Mooney, and Mark Silver, Social Worker - providing an essential insight into the important role of carers.

This was followed by keynote speakers: Dr Luke Smith, Dr Jim Howe and Associate Professor David Williams, who provided insights into the cognitive and underlying causes of the conditions, as well as the appropriate approach to management through the duration of these illnesses.

In the afternoon, the audience heard discipline-specific presentations from various Physiotherapy, Occupational Therapy, Nursing and Speech Pathology professionals.

The final presentation of the day, from the Movement Disorder team at the Kingston Centre, explored the team approach to managing these complex conditions.

The over-riding message to attendees was the need to use a range of skilled health professionals to deliver the most comprehensive care.

An important part of this event was the launch of information kits on **Multiple System Atrophy** and **Cortical Basal Syndrome**. These kits will provide an accessible resource for people living with MSA and CBS, their carers and health care professionals. They have been contributed to by leading movement disorder professionals in Victoria.

From PSP Australia: "We would like to sincerely thank the Parkinson's Victoria Health Team, particularly Victor McConvey and PSP support worker, Dianne Rayner, for organising an engaging, professional and information-packed day of presentations and open discussions on PSP, MSA and CBS.

Associate Professor David Williams was an exceptional keynote speaker and excellent presentations were given by other guest speakers. I am sure the attendees had a very informative day and as a result will be better informed about the conditions and thus, better able to provide support to individuals and families." Anne Mooney

There are approximately 1300 Australians living with Progressive Supranuclear Palsy (PSP). There is no known cure or treatment. If you are a health professional, or you or a loved one has been diagnosed with PSP, MSA or CBS, Parkinson's Victoria and PSP Australia can help with information and support.

***PSP: Progressive Supranuclear Palsy; MSA: Multiple System Atrophy; CBS: Cortical Basal Syndrome.**

Community expos

There are numerous community expos taking place around Melbourne which are a terrific way for Parkinson's Victoria to further engage with the general public and those working in, or studying to work in, the health, disability and aged care sectors.

During these events, our team provides information about Parkinson's and support services, and sometimes support group leaders and members, ambassadors or volunteers provide valuable assistance.

Often these events are available to not for profit organisations like Parkinson's Victoria at no cost or a significantly reduced cost.

Recently our team attended the annual **CAREX** expo, billed as Australia's Premier Health, Aged Care & Disability Services Expo for CEOs, Managers, Health/other professionals, staff and members of the general community (held at Caulfield racecourse), and the **Cultural Diversity in Aged Care Expo** (held at the Melbourne Town Hall).

If you know of an expo taking place in your local area that you think Parkinson's Victoria should be involved in, please contact Judith at the office.

Parkinson's medication added to the PBS



Neupro, often referred to as the 'Parkinson's patch' has been available in Australia as a private prescription since 2006. It has recently been listed on the Pharmaceutical Benefits Scheme (PBS), reducing its prescription cost and thus making it more widely available to those living with Parkinson's who may benefit from its use.

Neupro patches contain the active ingredient rotigotine, which is a type of medicine called a dopamine agonist.

Rotigotine works by mimicking the activity of the brain chemical *dopamine*, which is depleted in the brains of those diagnosed with Parkinson's.

Neupro is similar to another dopamine agonist, *Pramipexole* (brand names include Sifrol and Mirapex). However Neupro is delivered as a patch that is applied to the skin, and which slowly releases the drug over 24 hours.

The patch would appeal to those who have difficulty swallowing pills or who need to take a large number of pills. The patch also means consistent release of the drug into the system, which can reduce the incidence of 'wearing off' and the return of visible Parkinson's symptoms.

As a dopamine agonist, rotigotine carries all the same precautions and side effects as other medications that fall into this class. Some people may develop impulse control disorders and skin irritation can occur where the patch is applied.

For more information please contact the Parkinson's Victoria Health Team or refer to the Consumer Medicine Information sheet available on our website: www.parkinsonsvic.org.au

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Dr Rodney Marsh – Neuropsychiatry Consultant,
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What all carers need to know



DIANNE RAYNER from our Health Team provides some tips to help those in a care-giving role continue to provide effective care without compromising their own health.

Caring for someone with Parkinson's can be a long and sometimes difficult journey, and many people will react differently to the challenge. This will depend on a variety of factors, such as your relationship with the person prior to them developing Parkinson's, and also your own lifestyle before diagnosis. If you are caring for someone, you need to consider your own health and needs, and the level of support you have from other people. This will assist you and the person you are caring for to have a better understanding of the situation, each other's needs and an open and honest view of your relationship.

Communication

Effective communication between yourself and the person you care for can never be over-emphasised.

When you are caring for someone, good communication is absolutely vital. Communication is more than just speaking. It includes gestures, body language such as eye contact, a certain look or shrug, and of course writing/typing. All of these are ways of conveying thoughts, feelings, opinions and needs to others. Using a wider spectrum of communication techniques, rather than relying on speech alone, especially from someone who has difficulty speaking as a result of Parkinson's, will help both people to make the most of the communication skills they have, reduce frustration and feelings of dependence and helplessness.

Some simple tips for improved communication (speech)

- One simple strategy for effective communication is sitting down beside the individual or preferably facing them so you can see each others' faces. Suggest that before they begin to talk they raise their head and swallow the saliva to clear their mouth. Be careful to **suggest** and not **command**.
- Remind them to take a breath before each phrase, which will assist them in enunciating their words.
- Try not to finish sentences for them.
- If you do not understand what they are saying, ask them to repeat what they said.
- Ask the person to speak more slowly if necessary and echo their phrases to help them in slowing down, this will also show how much of the message is actually being understood.
- If you have understood part of the message repeat that part out loud so they do not need to repeat everything.
- A gentle reminder that you will give them time to respond will reduce any feelings of anxiousness they may have.
- Ask them to use shorter phrases or single words if it is difficult to make complete sentences.
- Speak at a normal volume - don't shout unless they have a known hearing loss.

Adopting some of these simple strategies will create a better environment for communication and earn greater respect for each other.

Planning for the future

Planning for the future is an important consideration for carers and people living with Parkinson's. Many people put-off dealing with this issue, especially if legal and financial matters are involved; it's either too hard, too unpleasant or they simply don't know how to broach the subject. It's natural for most people to not want to consider or even think about legal matters, but "now" really is the time to start ensuring your affairs are in order. Planning ahead is **always** a good idea, and more so when you receive a diagnosis of Parkinson's.

A good place to start is speaking with a financial planner and an important question to ask is whether your savings and superannuation will be sufficient to support you both.

Another good idea is to review your finances and reduce any unnecessary expenditure. Setting up a budget and checking your health insurance on a regular basis, and as your needs change, will

help safeguard you against the unpredictability of Parkinson's and life's journey.

Over time, the spouse or partner you are caring for is gradually going to be less able to manage on their own, meaning you are likely to take on more in the role of carer, with increasing responsibility for legal and financial matters. For peace of mind and a sense of security, the main areas that should be addressed early are a **Will, Power of Attorney** and **Enduring Power of Attorney**.

A Will is a legal document which sets out the wishes of a person for the distribution of their property and assets upon death. If you do not have a Will, your assets are divided and distributed according to legislation set by government. **Power of Attorney** and **Enduring Power of Attorney** are legal documents which give another person the authority to make financial and legal decisions on your behalf. They can only be drawn up while you are able to sign your name and make decisions. An Enduring Power of Attorney remains valid if you become unable to make decision but a Power of Attorney lapses at that point.

The person with Parkinson's and the spouse or partner should both appoint an Enduring Power of Attorney. If anything happens to either of you, you would both have someone entrusted to manage your affairs.

If you are not familiar with legal matters, consider talking to a lawyer or financial adviser. Legal Aid or a local community legal centre may be able to assist you at a reduced cost. You can contact your local Commonwealth Centrelink on: 1800 052 222 to find relevant services in your area.

Suppose something happens to you or the person you care for? Do you have an emergency plan? An easy way to draw up a plan is to get an Emergency Care Kit from Carers Vic (1800 242 636).

This kit contains a Carer Emergency Card, Medi-list and Emergency Care Plans that are easy to complete. A contact number is provided should you require assistance in completing the forms.

General tips for looking after yourself

A good carer will understand some of the special difficulties associated with Parkinson's and as such, they'll also have a sense for when to help and when to allow the person they are caring for to do things for themselves, without feeling the urge to hurry them up or take over. An example of this is trying not to speak for someone when they are having difficulty speaking (see above).

Coping with Parkinson's and the variability of symptoms - hour-to-hour and day-to-day - can make it difficult to plan ahead. Physical slowness

can be a problem and many carers have to resist the urge to help. The best practice is to encourage people with Parkinson's to do as much as they can for themselves, even if it takes longer. With Parkinson's, doing one thing at a time is best.

You can also reduce stress levels and create a more secure environment, as well as feel empowered by:

- knowing where to turn for information and assistance (such as equipment and aids to manage walking or eating difficulties)
- having some 'survival' strategies; and adopting a day-by-day approach.

As a carer, it's vital to recognise and acknowledge the fact that frustration, depression and sleep disorders are a reality and there are steps you can take to help manage them. It is important for carers to have access to information, encouragement and support, as well as a 'listening' ear.

In addition, the following tips all contribute to the care-giver's total wellbeing:

- Set up support networks earlier rather than later (which will provide opportunity to express frustrations)
- Develop good communication with health professionals
- Enjoy quality time away from the caring role
- Access respite care and emotional support
- Get a good night's sleep. Too many nights of broken sleep is one of the most significant problems carers of people with Parkinson's have to contend with.
- Maintain a sense of humour
- And, treat yourself with some pampering or something you enjoy, such as a walk on the beach, trip to the art gallery or watching the footy.

Joining a carer's support group is one way to fulfill some of these needs. A support group consists of people who voluntarily come together to give and receive support and assistance by sharing their experiences of living with a common problem, such as Parkinson's.

Carer support groups are not a substitute for medical advice, and groups will vary in the type of activities they undertake. Support groups may share mutual experiences, learn together, host guest speakers, provide information on community support services, and educate others about the needs of people with Parkinson's and their families.

For further information about the topics covered in this article please contact the Health Team at Parkinson's Victoria.

Caring & Young Onset



The psychological and social implications of Parkinson's, as well as management of symptoms, are very different for those diagnosed with Young Onset Parkinson's and those caring for them. ALISHA CHAND from our Health Team explains.

Young Onset Parkinson's is defined as a diagnosis under the age of 65 and of course, individuals are typically at a different life stage to those diagnosed in later years.

Care-giving is more than a full-time job, particularly for those in the under 65 age bracket; carers in this demographic may also be working, thinking about finances, raising a family, maintaining relationships and planning ahead. Undertaking all this while caring for someone living with Parkinson's can be challenging and exhausting.

This is also an age where individuals are often caring for and supporting elderly parents and/or their own children, so adding this to the mix of living with or caring for someone with Parkinson's can mean additional challenges.

Maintaining relationships

It can be easy to let the physical and emotional challenge of Parkinson's "monopolise" your time. When caring for a spouse or partner, it is important that your own needs are not overlooked or downplayed.

Communicating with your partner or spouse about the challenges of Parkinson's, and discussing your needs within the relationship can help to ease some of the tension that might arise if you feel your own needs are being neglected.

Learning more about the condition and accessing available resources can help dispel uncertainty about the future and assist you in understanding the needs of your spouse/partner and the changes they may be experiencing.

It is also important that you maintain your own wellbeing, ensuring you are looking after yourself (physically, emotionally and mentally) so you can give your best to those depending on you.

Caring for children while caring for a spouse

All children need support, love and guidance and it is important to make sure that the time dedicated to caring for a spouse with Parkinson's does not come at the expense of your children.

Taking time out to talk honestly with your children about what is happening and how they are feeling can make a big difference.

Teenagers growing up in this kind of environment may find they are torn between a sense of obligation to family and home on the one hand and wanting to participate in peer-activities, such as sport and weekend activities, on the other.

It is important for children to have a healthy balance between responsibilities at home and their own lives. Encourage teens to make use of opportunities to engage with their peers and activities outside the home and let them know they have your support so they can enjoy these without feeling guilty.

Work, finances and planning ahead

Parkinson's can impact on a person's ability to work (length of working hours and type of work), leaving the spouse or partner with the bulk of – or all – financial responsibilities.

Carers have the right to request flexible working arrangements from their employer and it is required by law to seriously consider such a request. Employers must provide "good reason" if refusing it.

It can also be advantageous to consult with a financial planner who will be able to advise on matters relating to superannuation, the amount of hours you should be working to receive financial assistance and when might be the best time (financially) to retire or resign. A financial planner can also assist in developing a financial plan for the future, taking into consideration when your partner or spouse is no longer able to work and how to prepare for the cost of medications, equipment and other things that are likely to be required over time.

Sharing the workload and asking for help

Staying on top of medical appointments and relevant information, as well as day-to-day errands and household chores can become stressful. A simple tip is to make a list of all the household chores and responsibilities over the course of a week and delegate or share tasks with other members of the family.

Often those around you will be more than willing to assist but do not know how to help. Delegating tasks will not only ease your workload but, importantly, it will help other members of the family to feel as though they are contributing. Asking friends to pick up the kids or a relative to pick up some bread and milk on their way over means you will have fewer things to think about and they will be able to contribute in a tangible way.

For more information about living with or caring for someone living with Young Onset Parkinson's, including information about financial planning, your rights at work and relevant government assistance, contact our Health Team.

Personal Dopa-meanings

My story - Jovo Cirkovic

A Parkinson's diagnosis is enough to promote fear and uncertainty in most people. For me, it was just another of life's unexpected twists.

I migrated from Bosnia in the former country of Yugoslavia in 1971. To say life offered many unusual directional changes would be an understatement.

Losing my mother at age 12, I had to grow up quickly and I became the interpreter for my father who spoke no English.

The early years in Melbourne were tough for migrants and I had to learn to adapt to my environment ... just to survive.

I trained in martial arts for 18 years - attaining a 4th degree black-belt. The mental training would come in handy throughout my sales career over the next 26 years. Prior to being diagnosed, I ran my own property investment real estate business.

I have been a wordsmith for many years, penning love poems and telling stories through verse.

After *Parky* came into my life at the age of 47, I decided to write a book of poems about my experience. Titled 'Shaken but Not Stirred', the book is an informative and emotional read for other *Parky* sufferers and their carers.

The first poem in the book is titled '**A big river in**

Egypt'. It addresses the issue of men and their ability to put off seeing medical practitioners when something is wrong. Other poems deal with such matters as telling my sons about *Parky*, how *Parky* affects my wife, depression and anxiety, and my positive attitude and physical fitness regime and how it is benefiting me in my day-to-day life.

Since diagnosis I have retired from work and have written a further two books, one on teenage suicide and one on gambling addiction. In the past year, I have written 190 poems. I have also, along with my wife Eileen, set up the *Happy Hands Foundation* which helps orphans in Chiang Mai, Thailand.

When asked about *Parky*, I am quick to explain, "in life it is 10 percent what happens to you, and 90 percent what you **make** of what happens". My belief, that you can change the changeable, accept the unchangeable and remove yourself from the unacceptable, is a philosophy we can all take on-board.

Copies of Jovo's book, 'Shaken but Not Stirred' can be downloaded at www.murfic.com.au and donations of \$15 to the Happy Hands Foundation are welcome. To find out more about Jovo and Eileen's orphan program visit www.happyhandsfoundation.com.

The following poem sets out my *Parky* experience, by Jovo Cirkovic.

On 10 August 2011 whilst travelling
along life's path with ease
A neurologist diagnosed me with
having Parkinson's Disease
Unexpected and unwanted.... but
to someone else's tune we dance
Had to take it in my stride and plan
how my life could enhance
I have always loved poetry and
rhyme....many tales that I have
penned
Like the Irish 'Shanachie'
storyteller....I'd write poems for my
friends
Be they stories about love,
birthdays, celebrating life, death or
change
I pen my verse with feelings be they
sad, happy or something strange
Whilst on a trip to Thailand for nine
weeks of rest and recuperation
Eileen and I volunteered at an
orphanage with some trepidation
But when we saw young toddlers
walk with their arms stretched up
high

Wanting to be picked up and
cuddled....brought a tear to both
our eyes
Eileen and I were lucky in Australia
our four boys were raised
Every opportunity open to them....
their efforts always praised
Due to my Parkinson's illness I have
had to retire from my work
Sit around and do nothing was not
on....I would simply go berserk
I wondered how I could combine
my poetry and the orphans' plight
Then a thought popped into my
head....you could say I saw the
light
In the words of Michael J Fox.... a
fellow Parkinsonian just like me
'I gave up my job to do my life's
work'....it set my spirit free
Eileen suggested we help the
orphans by replacing their
playground
The fear of creating
dependency....kind of turned our
thoughts around

What if we could create a
sustainable way to help the
orphans grow
Through training and education,
seeds for strong self esteem we'd
sow
Here we are six months later and
with much anticipation
We're pleased to announce
the launch of our Happy Hands
Foundation
Not ready yet for donations....
instead 500 friends we'd like to find
We encourage you to join us....
pass our message on in kind
I have written my first book of
poems about living with my disease
It's called '*Shaken but not stirred*'
.... others plight I hope it will ease
Everyone knows somebody whose
life Parkinson's has affected
In Australia 30 people a week with
the disease are being detected.

Research & Participation

Stem cell research

Have you travelled abroad for stem cell treatment – as a patient or a carer? Have you considered travelling abroad, but perhaps decided against it? If so, researchers at Monash University would like to capture your story via an interview.

Stem cells and the great promise they hold for new treatments have captured the public's attention. However, there are currently very few conditions where stem cell treatments are routinely offered in Australia. While some Australians are seeking treatments abroad, we know little about their views. This project seeks to capture the experiences of those who have travelled or thought about travelling overseas to undergo stem cell treatments.

Late last year, Monash University researchers conducted a sociological study; 'Patients who travel overseas for stem cell treatments: stakeholders' views'. The research team is now interested in talking to people who have contemplated travelling, as part of a new phase of the project titled 'High hopes, high risk? A sociological study of stem cell tourism', which commenced in September 2012.

The project aims to understand the socio-cultural context of stem cell tourism, particularly the factors shaping Australians' views and expectations of stem cell treatments offered abroad.

Interviews will involve answering a series of questions over the phone and will usually take 30 to 40 minutes. Insights from the study will help in producing information for patients and their families who are contemplating stem cell treatments. The identity of all participants in this project will be protected. This project has been approved by the Monash University Human Research Ethics Committee.

If you would like to share your story or find out more about the project please visit: <http://artsonline.monash.edu.au/stem-celltourism-research-project> or contact research fellow Claire Tanner: claire.tanner@monash.edu.au

Dancing and Parkinson's

It is thought that dancing can improve mobility and reduce the number of falls in people living with Parkinson's.

Researchers at La Trobe University are undertaking a study to find out more and are seeking healthy men and women under the age of 75 who have been diagnosed with Parkinson's.

Participants will be invited to take part in Argentine Tango dance classes led by a professional dance instructor. There will be 2 classes per week for 4 consecutive weeks, with classes being held on Thursdays and Saturdays, 11.00-12.00pm.

For more information, contact Professor Meg Morris, La Trobe University: (03) 9479 1578 or 0433 405 662.

The role of protein in the brain

Researchers at Flinders University have discovered a protein in the brain may play a role in the development of Parkinson's.

"Parkinson's is often not detected until a late stage when the patient is already suffering many adverse consequences of the disorder, including tremors, muscle stiffness and impaired mobility," said Dr Wei-Ping Gai from the University's Human Physiology Department.

"It's the second most common neurodegenerative disorder in older populations and it's extremely prevalent in countries like Australia, which is why it must be a research priority."

The protein, known as **VAMP2**, is critical in communicating messages between brain cells. However, Dr Gai said it had also been found to induce cell death, possibly by aggregating inside brain cells.

The exact mechanisms by which the protein causes cell death are now being investigated by Dr Gai as part of a \$15,000 research project, funded through the FMC Foundation.

"VAMP2 is involved in neurotransmission, but we recently discovered that it could also be involved in Parkinson's," Dr Gai said.

"We just don't know how it causes it or to what extent it's involved.

"In Parkinson's, brain cells die and we think that dying process comes as a result of the protein aggregating inside these brain cells for some reason, leading to toxicity and, eventually, cell death."

Using mass spectrometry, an analytical technique that determines the chemical structure of molecules, Dr Gai hopes to find out why the protein aggregates in brain cells, thereby paving the way for early diagnosis and targeted treatments.

"At the moment there's no cure for Parkinson's because we only know brain cells die; we don't know exactly how they die or why the proteins aggregate," Dr Gai said.

"So if we can find out what causes these proteins to group together we might be able to find a cure or use the protein as a biomarker so the disease can be detected much earlier than it currently is."

Source: www.thesenior.com.au (20/03/2013)

Our future doctors need you!

The **Patient Teaching Associate** (PTA) program is managed by the Eastern Health Clinical School, part of the Monash University Medical School located at Eastern Health. Medical students having their clinical training at Eastern Health participate in this new program to learn more about patient-centred care and peoples' experience of living with a chronic condition.

Research & Participation

The program provides students with the opportunity to work with 'real life' patients who have volunteered to meet a small group of students and their tutor in a GP clinic setting.

This is an opportunity for those living with Parkinson's to contribute to the learning of our future doctors: improving their understanding of the various aspects of Parkinson's, the wide range of symptoms (both physical and non-motor), its impact on the individual, how to recognise symptoms and – importantly – helping them improve their 'bedside manner', the way in which they engage with patients and provide clinical support and information.

The students share the role of the doctor in a consultation in which the patient is asked about their medical story and undergoes a physical examination related to their condition. Students, patient and tutor all contribute to a discussion to clarify the key points and also to provide the students with feedback on how the session went.

No special skills are required of patient volunteers, just a willingness to give some time a couple of times a year, and to share your personal story. The sessions are for teaching purposes only, your information is treated with confidentiality and no treatment or medical advice is offered. Parking or taxi vouchers and afternoon tea are offered in return, plus of course, the opportunity to work with the doctors of tomorrow.

If you are interested in more information, please visit: <http://www.med.monash.edu.au/ehcs/msp/index.html> and click on **Patient Teaching Associates**, or call the PTA Coordinator: (03) 9091 8821 or email pta.ehcs@monash.edu

Research trial online hub

Clinical Trials Connect Pty Ltd (CTC) is a free online patient recruitment service designed to help people interested in volunteering for Australia-wide medical research to find clinical trials that are relevant to them. It is important to note however, that the website does not list all current clinical trials taking place in Australia, only those which have been registered with the website by the researchers.

The website also provides researchers with access to willing, able and eligible participants for their specific clinical trials.

In addition to searching for current trials, you can register your details to participate in trials which are seeking patients with a particular medical condition. Specify your current disease/disorder and complete the registration form and when a trial becomes available that matches your profile, CTC contacts you directly. All information is treated confidentially.

For more information or to search for a research trial, visit the Clinical Trials Connect website: www.ctc.asn.au

Keen to support Australian research into Parkinson's?

Why not donate to Parkinson's Victoria's research fund? This might be as a regular donation or a bequest.

In addition to its regular program of information, support and advocacy, Parkinson's Victoria is committed to facilitating and financing research projects and focuses its efforts on improving the quality of life for People with Parkinson's, their families and carers.

Parkinson's Victoria is very diligent in observing the instructions, which often accompany generous bequests. Through a sub-committee of the Board it ensures that any specific instructions, conveyed by the Bequest's Executor, are adhered to.

To help decide what projects best meet these instructions, the Research Sub-Committee thoroughly assesses each research funding 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 project must meet the highest ethical standards.

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, Prof. Malcolm Horne, Florey Neuroscience
- Essence of Managing Parkinson's, Southern Academic Primary Care Research Unit, Dr. Craig Hassad
- 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. Please contact Emma Collin, CEO to discuss your support and any specific areas of interest you may have.

Symptom Management

Continence and Parkinson's

Amongst healthcare professionals, continence is acknowledged as one of the most confronting and difficult symptoms for people living with Parkinson's and their carers to manage.

Both normal bladder and bowel function are interrupted as a result of Parkinson's. However, as VICTOR MCCONVEY from our Health Team explains, with good management and some helpful tips, these difficulties can be overcome and the impact of these symptoms can be effectively reduced.

An early and persistent difficulty in Parkinson's is constipation. Constipation is one of the most frequent issues prompting people to call our Help Line and it is the second most common cause of a trip to emergency for someone with Parkinson's.

The body's inability to produce dopamine is the main cause of Parkinson's and its symptoms. When dopamine-producing cells in the gut are affected, the result is a sluggish system which can result in constipation.

Prevention is better than a cure when it comes to constipation: drinking plenty of fluids, staying active and increasing the amount of fibre in your diet are all good places to start. However, adding a medication or laxative may be necessary to assist with maintaining normal bowel elimination. A laxative that will lubricate and provide bulk to the stool is preferred over irritants that increase gut movement and which may cause feelings of bloating or abdominal cramping.

Constipation will also significantly worsen bladder difficulties. Bladder difficulties, such as urgency and nocturia, are also problems most likely to impact upon carers. Nocturia is the frequent need to get up during the night to urinate. While bladder problems are common in Parkinson's, they are often over-

looked or considered to be part of 'normal' ageing.

Normally, the bladder is "off" and relaxed while filling with urine. When the bladder is full, the brain is alerted and when appropriate, the brain signals the bladder to turn "on" or contract to release urine.

Dopamine producing cells serve to hold the bladder switch "off" during storage and prevent it from contracting. In individuals with Parkinson's, the loss of these cells can create "on and off" problems with the bladder, resulting in the sensation of needing to urinate with little warning (*urgency*) and sometimes, this sensation happens frequently (*frequency*).

This symptom often fluctuates with the medication cycle. Urgency is best addressed by ensuring medication is taken **on time, every time**. You can also work on strengthening the pelvic floor muscles and reducing fluids that may be irritating to the bladder, such as caffeinated drinks and juices that may cause the urine to become acidic.

The urgent need to urinate, combined with lowered blood pressure and reduced mobility (all of which are common in Parkinson's) cause fluid retention. The body then needs to excrete this fluid as urine during the night, which naturally will disrupt sleep patterns.

You can reduce fluid retention in the lower limbs by lying down in the afternoon with your feet elevated, allowing the body to metabolise the fluid. This means your need to urinate happens during the day or prior to going to bed, rather than during the night. You can also try wearing compression stockings.

Parkinson's Victoria has collaborated with the National Continence Foundation to develop Fact Sheets on bladder issues and constipation. Check out our website or contact our Health Team for more information.

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Activities to get involved in

Yoga workshops

We are excited to announce the launch of Yoga Workshops for people living with Parkinson's!

Research has shown that yoga can enhance range of movement, strength, balance and mental focus, all of which may be compromised by Parkinson's.

Sessions will be run by an experienced yoga instructor with a special interest in Parkinson's, and will involve a range of stretches and exercises at varying levels and a relaxing meditation.

Come along and engage your body and mind, and meet other like-minded people. Carers are welcome to join in as well and no previous yoga experience is necessary.

The sessions will commence on Wednesday, 5 June and then will run every Wednesday morning until further notice.

When: 10:00am- 11:30am

Where: Camberwell Uniting Church, 314 Camberwell Rd

Cost: \$4 per person or \$7 per couple

If you are interested in attending a yoga class, please contact our Health Team.

DBS Support Group

A new Parkinson's Victoria support group for people with Parkinson's **who have undergone** Deep Brain Stimulation (DBS) is set to begin in June.

The group will meet on the last Thursday of each month in the City of Kingston (venue to be confirmed).

If you have had DBS surgery and are interested in attending meetings, contact Support Group Coordinator, Breanna Wotherspoon: breanna@parkinsons-vic.org.au or phone (03) 9581 8700.

New support groups

Parkinson's Victoria has recently established two new Support/Social Groups:

Pakenham Parkinson's Support Group

Earlier this year, Victor McConvey and Breanna Wotherspoon from our Health Team hosted a community seminar; **'An Introduction to Parkinson's'** in Pakenham, and there was sufficient interest in the establishment of a local support group.

The new Pakenham Parkinson's Support Group meets on the 4th Thursday of each month at 1.30 - 3.30pm the Pakenham Senior Citizens Centre. Meetings are open to people with Parkinson's of all ages, as well as carers, friends and family.

Singing for Parkinson's

The Parkinson's Singing Group in Williamstown is now up and running – loud and clear!

They meet monthly (every third Thursday) at the Williamstown Mechanics Institute, Corner Melbourne Road and Electra Street (2.30-4.00pm).

This exciting new group adds to our growing number of Special Interest Groups, which now include: **Tai Chi** (Cheltenham) and **Painting with Parkinson's** (Berwick, Essendon, Melton, Mt Martha and Warrnambool).

Special Interest Groups not only provide an opportunity to connect with others who are living with Parkinson's, but are a fun way to exercise, express your creativity or raise your voice!

Interested in joining the Pakenham Support Group or Williamstown singing group? Like to learn about support in your local area? Contact our Health Team.

Parkinson's singing group finds its voice

MELISSA KING, Parkinson's Victoria OFFICE MANAGER and the friendly voice you'll usually hear on the end of our phone attended the first get-together of our new singing group.

The Parkinson's Singing Group held its first ever meeting on 21 March and I had the pleasure to attend.

Even though the weather was wild with wind and rain, it was amazing to see so many people brave the elements to attend, and not just from the Williamstown area but from all over Melbourne.

The session was led by Doug Heywood OAM, famous for conducting Melbourne's annual **Carols by Candlelight** orchestra and who, by the way, is a fabulous singer!

Doug started the session by leading the group in numerous vocal exercises that assist with breathing and projecting the voice. Assisting Doug were speech pathology students Aretha and Kristen, who are completing Masters of Speech Pathology at Melbourne University.

The girls took the group through another range of exercises that also help with voice control and breathing. The emphasis was on being "loud", and people whose voice is normally quite soft could be heard producing a veritable bellow. I was pleasantly surprised and impressed with the harmonisation that was already forming within the group!



(L-R) (left) Kristen Wegener, Aretha De Kretser, Heather Jobling and Douglas Heywood OAM.

The thing that I will take out of this first meeting of the singing group is that singing can be both physically and emotionally invigorating, especially when experienced with others who share the same motivation and enthusiasm. The group is a great chance for people to socialise and chat with others living with Parkinson's, and to enjoy a fun afternoon of singing.

Congratulations to Heather Jobling and her Steering Committee for their energy and commitment to helping establish the singing group. A special mention also to Hobsons Bay City Council for their support, especially to Lorraine Callow and Mayor Councillor Angela Altair.

Access, Advocacy and Assistance

An update on the NDIS

Over two days in April, BREANNA WOTHERSPOON from our Health Team attended a workshop titled, "Imagining and planning for the future under an NDIS". In the following article, Breanna shares her learnings and what the impact might be for the Parkinson's community.

On the 21 March this year, the National Disability Insurance Scheme Bill passed through Parliament.

The NDIS Bill establishes the scheme and the NDIS Launch Transition Agency is to deliver the scheme across the five Australian launch sites. Since the passing of this Bill, the National Disability Insurance Scheme has been renamed **DisabilityCare Australia**.

DisabilityCare Australia is a social insurance scheme designed to ensure people with a disability have the support they need to be part of the social and economic life of the community in which they live.

Under a social insurance scheme, the costs of disability support would be planned for and put aside on a yearly basis by the government. This is a similar model to schemes such as Medicare which cover medical costs, and the Transport Accident Commission (TAC), which covers the cost of treatments and benefits to people injured in transport accidents. The idea is that people have access to support which is based on their individually-assessed need.

The workshop was made possible through funding provided by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), and was one of many workshops being run for people with disability, their families and carers, and support workers.

The first day of the workshop provided the group with information about DisabilityCare Australia as it currently stands. The details of the scheme are still being worked out, leaving many questions still unanswered, however consultation with the community and disability services consultation is underway

The second day of the workshop focused on feedback from group members, which gave attendees the chance to provide the government with suggestions or concerns about the scheme.

DisabilityCare Australia – the details

Who will it affect?

- Australians under the age of 65 and living with a disability for which they need assistance or support.
- As far as Parkinson's goes, DisabilityCare will only be relevant for those diagnosed with Parkinson's before the age of 65.

Who will be eligible?

You will be eligible for the scheme if:

- You are under the age of 65 when your request for DisabilityCare is made
- You are an Australian resident
- You have a disability attributable to intellectual, cognitive, neurological, sensory and/or physical impairments, which is likely to be permanent
- The impairment results in substantially reduced functional capacity with regard to communication, social interaction, learning, mobility, self-care or self-management, and those needs are likely to continue for a lifetime

What happens if I don't need to access DisabilityCare until after I turn 65?

- If you are under the age of 65 when you are diagnosed, you may be able to enter the scheme for the purposes of 'early intervention' supports.
- People who enter DisabilityCare before the age of 65 will be able to choose whether to stay in the scheme once they turn 65 or move into the aged care system.
- People who require support after the age of 65 will have to go through the aged care system (as is currently the case).

When and where will it start?

The scheme will have a number of 'launch sites' around Australia which will act as trial sites. These will provide feedback for the full (national) rollout of the scheme, planned for 2018.

Launch sites will begin on 1 July, 2013. Some sites will have a particular focus, for example, South Australia will initially only launch the scheme for children, while in Tasmania the focus will be teenagers.

The Victorian launch site will be the Barwon region.

What kind of support will it provide?

"Reasonable and necessary disability support" including (but not limited to):

- Aids, equipment, home and vehicle modifications
- Personal care, community access, respite, specialist accommodation
- Domestic assistance, transport assistance, therapies
- Guide and assistance dogs, case management and coordination
- Specialist employment services, crisis/emergency support

How will the resources/funds provided to individuals be managed?

Either:

- Directly through the service being accessed
- Through an independent broker (to assemble a package of supports)
- Directly to the individual (family to manage themselves)

How will it be funded?

Funding will be provided jointly by the Federal and State Governments. So far, the Australian Government has committed \$1 billion* to support the first stage (beginning July 2013).

What sort of support can Parkinson's Victoria offer?

As Parkinson's Victoria is not a registered service provider we are unable to manage funds on behalf of individuals, however if you or a family member or health care professional has questions in relation to the application process, we encourage you to contact our Health Team.

How can I find out more?

For more information visit the website: www.ndis.gov.au

*At the time of going to press, the Federal Government has proposed an increase of 0.5% in the Medicare Levy to help fund its contribution.

Access, Advocacy and Assistance

Keeping Movement Disorder Nurses on the agenda

We are pleased to provide you with an update on Parkinson's Victoria's advocacy on the issue specialist nurses and support workers.

For the best part of a decade, Parkinson's Victoria has participated in the Australian debate on the value of Movement Disorder Nurses placed within community health services, especially in regional and remote areas.

This model of care in the UK has saved the community millions of dollars in terms of more accurate diagnosis, improved use of medication, timely referral to allied health services, reduced medical appointments and support for carers.

In Australia, discussion has been very locally-focussed, with West Australia and Tasmania enjoying bi-partisan support for community Movement Disorder Nurses who are accessible to anyone living with a movement disorder. In Victoria, we are just starting to see some "movement"!

Mildura

Twelve months ago the Mildura Parkinson's Support Group worked with the Lower Murray Medicare Local* to identify the need for a Movement Disorder Nurse.

This was assessed as a Medicare Local health care priority and a qualified, full-time movement disorder nurse was subsequently appointed.

Since her appointment, Catherine Healy, a nurse with 20 years' experience in hospitals, critical care and community, has been active in establishing a practice which is supported by technology, including tele-health and Skype. A valuable tool to assist her in her work has been an iPad, where patient presentations have been filmed and e-mailed to tertiary providers to identify symptoms and treatment plans.

Catherine has also formed a working relationship with Parkinson's neurologist, Dr Richard Peppard, who visits the area quarterly.

Goulburn Valley

Late last year, Parkinson's Victoria, the Shepparton Parkinson's Support Group and major stakeholder, Goulburn Valley Health joined forces to sign off on funding the two-year appointment of a Movement Disorder Nurse.

The Shepparton Parkinson's Support Group, under its very active leader Geoff Alexander, has lobbied aggressively to achieve this positive result and the support of key players. Local MP, Sharman Stone, has been keen to receive regular progress reports.

At the time of going to print, an official announcement in Shepparton with key stakeholders was planned for 14 May.

East Gippsland

In August last year, the Bairnsdale Parkinson's Support Group, under the leadership of Beverley Campbell (support group leader), hosted a public meeting to promote the case for the placement of a Parkinson's specialist nurse consultant in the region.

The meeting was attended by a representative from the region's Medicare Local, Peter Raymond, President, Parkinson's Victoria and Victor McConvey, with the latter delivering an overview of the issue and the benefits that such a health care worker would bring to the local community.

Unfortunately, this Medicare Local is still in the process of establishing itself and will conduct a community health needs review, prior to making any decision or commitment on the issue of specialist Parkinson's or movement disorder support.

To coincide with World Parkinson's Day (11 April) and to highlight developing services in the area, Breanna Wotherspoon and Alisha Chand from the Parkinson's Victoria Health Team co-presented a community seminar in Lakes Entrance. Professor Iansek, who has established Movement Disorder Services at Gippsland Lakes Health, was the keynote presenter at this event.

Albury-Wodonga

To date, this Medicare Local has not commenced a health needs

review. However, staff attended a health care/GP education session delivered by the Parkinson's Victoria Health Team in March.

Greater Dandenong

An initial meeting has taken place, but this Medicare Local is not considering becoming a service provider. They did however welcome the opportunity to discuss the issue of specialised and local support with Parkinson's Victoria and are interested in continuing this conversation.

Peninsula Medicare Local

The Frankston Support Group first made contact with the regional Medicare Local at a community health expo. Since then, an estimated incidence of Parkinson's within the region and subsequent "burden of disease" has been provided to the Medicare Local. Parkinson's Victoria was also in attendance.

Bayside Medicare Local

This region is covered by the Kingston Centre's Movement Disorder Outreach Program. Parkinson's Victoria also sits within its boundaries.

A meeting in March this year was valuable in establishing a relationship and providing a platform for ongoing discussion.

What are Medicare Locals?

Medicare Locals, funded by the Commonwealth Government, were established in 2011 as part of the Government's National Health Reform.

Their focus is ensuring patients have access to the right health service, at the right place and time.

They are designed to work with GPs, nurses, allied health professionals, indigenous health organisations and Local Hospital Networks to identify and respond to gaps in local health services and help patients and health professionals navigate our often complex system more easily.

Source: Department of Health and Ageing, 2011.

First steps in walk to a cure

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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.

Many don't realize that the very first Australian Walk for Parkinson's was held in 2003, on Sunday, 23 of February. KARYN SPILBERG, founder and current coordinator of our Young @ Park, Melbourne group, was there and today she reflects on how far we've come.

I had been diagnosed just four months before, and was keen to meet other "Parkies", when I heard of a Walk being held in Caulfield Park by Margaret Bagnato to honour her father, Annunziato Bagnato and the thousands of people suffering from the disease.

Margaret's motivation in organising the walk was to raise awareness and also to raise funds towards research.

The seeds were sown in my mind for many things after participating in the inaugural **Walk for Parkinson's**.

The next year, I sought out Margaret and another person living with Parkinson's, Amanda Tehan, to repeat the Walk but on a larger scale.

I decided to dedicate the next walk to my father, Leon Gott, who had passed away with Parkinson's in 2003.

They say that "two heads are better than one", and in our case, three heads was even better!



Original Walk organisers (L-R) Margaret, Karyn and Amanda.

We all brought different skills and contacts together, and worked fabulously as a team.

There was a lot to be done. As for the first walk, we had to get Council Permits, but this was to be an even bigger event. We had to organize advertising flyers, sponsors, show bags, water bottles, a band and entertainment for the children.

By joining forces, we were able to focus on sponsorship, raffle prizes, Advertising Real Estate Boards in front yards of local houses, pre-event fundraising and leaflet drops in the local area.

Then, in 2005 on April 10, the second Walk became a reality.

Over 300 people turned up on a 'picture perfect day' and, with raffles and donations, we made over \$9,000 in donations for Parkinson's Victoria.

Two years later, in 2007, I travelled to New York City to participate in another Parkinson's walk - **The Unity Walk**.

Besides meeting lots of my 'online friends', one of the highlights was scoring Michael

J Fox's autograph - though I was almost crushed in the surging queue!



Karyn Spilberg, far left, at the 2007 Unity Walk in New York.

Now, Victoria proudly hosts its own annual **'Walk in the Park'** in August, with almost 2000 people participating in 2012, and numbers growing every year.

Federation Square is a magnificent place for the start and finish, with a walk around The Yarra River in between.

I encourage everyone to participate at their own level; it is NOT a race!

In 2011, I was proud to have the largest team, with almost 100 people and 9 dogs registered. Though I had a smaller team in 2012, I will continually aspire to network with friends, family and work colleges to raise awareness and funds for Parkinson's.



'Karyn's Crowd', Walk in the Park 2011.

In 2011, Karyn underwent Deep Brain Stimulation (DBS) surgery. Her goal was to recover sufficiently to complete the 4km Walk - which she did, thanks to her 'crowd' of supporters!

Walks for Parkinson's take place around the country, with Parkinson's Victoria's Walk in the Park taking place this year on Sunday 25 August. www.parkinsonswalk.com.au.

Parkinson's Victoria is proud to have had the continued support of Karyn Spilberg, since she was diagnosed over a decade ago. Her hard work, enthusiasm, creativity, and preparedness to 'get moving to make a difference' is inspiring and she makes an incredible personal contribution to our work while providing friendship and support to many others, both here in Melbourne and Australia, and around the world.

We also gratefully acknowledge the foresight of Karyn, Margaret and Amanda who saw the need to bring the community together in the fight against Parkinson's.

We hope to see all of you at this year's Walk on Sunday, 25 August. www.parkinsonswalk.com.au

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supports need to be appropriate, relevant and timely. More resources are also needed to support both scientific and qualitative research to improve treatments, quality of life and the pursuit of a cure.

We know we will need to raise community awareness and support, lobby government and build stronger community relations to deliver these ends.

I am excited by the challenges and opportunities ahead and hope to meet with as many of you as possible in the coming months so that you too can share your thoughts and ideas for strengthening our work and planning our future.

Emma Collin, CEO