

# SIGNPOST

•Spring 2013 •Volume 12 Issue 3 A Magazine for people living with Parkinson's

## Inside this ISSUE

<i>Save the date: notice of AGM.....</i>	<i>1</i>
<i>News &amp; Highlights .....</i>	<i>2</i>
<i>President's Report .....</i>	<i>3</i>
<i>New Books .....</i>	<i>4</i>
<i>Access, Advocacy &amp; Assistance .....</i>	<i>5</i>
<i>CEO's Message .....</i>	<i>5</i>
<i>Medication News .....</i>	<i>6</i>
<i>Personal Dopa-meanings ..</i>	<i>7</i>
<i>Research Update .....</i>	<i>8</i>
<i>Special Events .....</i>	<i>9</i>
<i>Advocacy &amp; the Federal Election .....</i>	<i>10</i>
<i>Symptom Management ...</i>	<i>11</i>
<i>Tulip Tribute .....</i>	<i>12</i>
<i>Young Onset Conference .</i>	<i>13</i>
<i>Taking Control of Communication .....</i>	<i>14</i>
<i>Online Survey .....</i>	<i>15</i>
<i>Medication News .....</i>	<i>16</i>
<i>Support Groups .....</i>	<i>18</i>
<i>Health &amp; Wellbeing.....</i>	<i>19</i>
<i>MDS Congress Update... </i>	<i>20</i>

## Calling all members, but everyone welcome!

### Annual General Meeting

SAVE THE DATE! The Annual General Meeting (AGM) of Parkinson's Victoria will take place on Friday, 22 November, 2013. Official notification will be posted to members a minimum of 30 days prior to the meeting.

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

**We look forward to welcoming you to this special event.**

### Volunteer Recognition Awards

Each year, Parkinson's Victoria recognises the significant contribution volunteers make in supporting people living with Parkinson's and their families.

Our annual awards program recognises the services of both individuals and groups for their contribution to activities, years of service and outstanding contribution to the Parkinson's community.

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.

**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.

**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.

In 2006, Sir Zelman Cowen (1919 – 2011) generously gave permission for this 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.

Since Sir Zelman's passing, Lady Anna Cowen has graciously given 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 Anne Atkin for her outstanding voluntary services to the Painting with Parkinson's Support Groups and for her work in raising awareness of Parkinson's in the community.

**There are so many people volunteering their time to support the Parkinson's community. If you would like to see someone or a group 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, a health care professional or anyone who has shown outstanding support. Nominations for these awards, in line with the above criteria, should be forwarded in writing to CEO, Emma Collin, by 4 October 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.

### Constitutional Review

From time to time, the Board of Parkinson's Victoria review the rules of the Association to ensure they meet the needs of the Parkinson's community and statutory requirements.

In response to new legislation introduced in December last year, the Associations Reform Act 2012, the Board is currently undertaking such a review.

The new statutory requirements seek to support greater consistency in the structure, responsiveness and reporting of and by associations across Victoria.

The Parkinson's Victoria Board has used the model rules provided under the Act to redraft its rules, while making small changes to reflect our structure and purpose.

Later this year we will share the draft with members and then seek support for the new rules at the Annual General Meeting.

# News & Highlights

## *Parkinson's advocate back in the headlines*

Since being diagnosed with Parkinson's in 1991, Michael J Fox has become one of the most vocal and active advocates for Parkinson's research. While his acting has taken a back seat to his advocacy work, Fox continues to appear in various TV programs, most notably, *The Good Wife* as a not so nice lawyer.

In a welcome return to form, it has been announced that Fox will be starring in a new (as yet unnamed) comedy-series, inspired in part by the actor's real life. The show follows Fox as a husband and father of three from New York City dealing with family, career and challenges, including Parkinson's. To view a preview clip visit: <http://www.youtube.com/watch?v=7SFTwTZOzwU>

## **No word yet if the program will be screened in Australia.**

## *A different perspective*

As a young adult in art school, Phil Hansen developed an unruly tremor in his hand that kept him from creating the pointillist drawings he loved. Hansen was devastated, floating without a sense of purpose. Until a neurologist made a simple suggestion: embrace this limitation ... and transcend it.

Taking a cue from his own artistic journey, Phil Hansen challenges us to spark our creativity by thinking inside the box.

**To hear Phil's inspiring and thought provoking story, and to see some of his incredible creations, which really do need to be seen to be believed, visit:**

[www.ted.com/talks/phil\\_hansen\\_embrace\\_the\\_shake](http://www.ted.com/talks/phil_hansen_embrace_the_shake)

## *Preparing for a good end of life*

Thinking about death is frightening, but planning ahead is practical and leaves more room for peace of mind in our final days.

In a solemn, thoughtful **"TED talk"**, Judy MacDonald Johnston shares 5 practices for planning for a good end of life.

By day, Judy MacDonald Johnston develops children's reading programs. By night, she helps others maintain their quality of life as they near death.

**To hear and see this presentation, visit [www.ted.com](http://www.ted.com) and then enter "Prepare for a good end of life" in the search box.**

## *A story of life, love and learning...*

"My name is Lina Ricci and I am "living with Parkinson's".

Since the passing of my husband, I felt compelled to tell my story.

**"Lina's Story"** describes my journey in life as an only child of New Australian parents, growing up in the sixties, and being challenged by a strict Italian upbringing. Most of all, my book is a story of love defying all of life's challenges that were handed to us.

I have dedicated my book to my late husband, Mario Ricci. His dignity and integrity when confronted with several life-threatening encounters are to be admired. My story is a story of inspiration and determination.

**Copies of *Lina's Story* can be purchased from Parkinson's Victoria for \$20 (includes postage). 100% of proceeds will help fund our support services, and on Lina's request, will help fund vital research into finding a cure. Thank you Lina, for sharing your story and your generous support!**

## *Young @ Park website gets a freshen up!*

[www.yap.org.au](http://www.yap.org.au), the online resource for those living with Young Onset Parkinson's and established by the Young @ Park group, has recently undergone some changes.

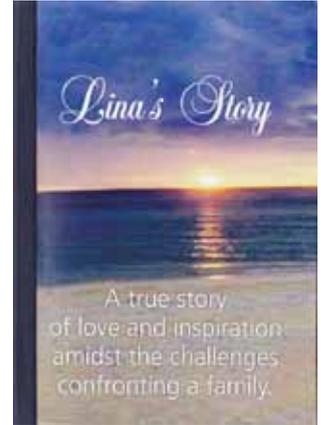
It has a fresh new look, and there are some changes to the way the content is organised making it more user-friendly.

The updated website has information about Parkinson's symptoms and treatments, a message board where you can connect with others, and details about upcoming Young @ Park news and events.

**To check out the Young @ Park website, visit <http://yap.org.au>**

## *Accessing support in Shepparton*

As many of you will have read in the last edition of Signpost, a unique collaboration between Parkinson's Victoria, the Shepparton Parkinson's Support Group and Goulburn Valley Health is supporting a demonstration project where a



# President's Report

Movement Disorder Nurse, Sheree Ambrosini, has been employed.

The project, which is jointly funded by the three parties for two years, will provide the local community with direct access to a Movement Disorder Nurse and importantly, will result in the gathering of important data and information about how effective this local support service is. The results will provide powerful evidence to support our case to government as we continue to seek funding support for the placement of clinicians throughout the state, and specifically to convince government to fund the Shepparton position permanently.

Since taking on the role, Sheree has attended the Movement Disorder Congress in Sydney and spent time developing the "model of care" for the project. In addition, she is supporting the Movement Disorder Clinic, and people both in hospital and in their own homes.

People living within the Goulburn Valley healthcare boundary are able to self-refer to Sheree and can contact her via the Service Access Unit at Goulburn Valley Base Hospital, which will also be able to advise whether you fall within the GV health boundary.

**Service Access Unit: (03) 583203100**

## Special thanks from Parkinson's Victoria!

We received a phenomenal response to our mid-year appeal about Chris, who was diagnosed with Parkinson's in 2002, and are thrilled to say a total of just over \$78,000 was donated! This is the highest ever donor response and we really do say "Thank You"! The appeal, which went out to some 7740 households and businesses, also talked about our critical support services, like our free Help Line.

**Thank you to everyone who generously supported this request for donations, and to everyone who gives throughout the year.**



*I doubt in recent times if there has been a more devalued word than **Communication**, especially at the moment when we are so beguiled by "spin" - and I don't mean leg-spin.*

Where once there were "witch-doctors", we now employ "spin doctors". Too often we confuse communication with persuasion or indoctrination.

Your Board understands only too well its obligation to facilitate genuine communication, based on factual information, exchanges of considered opinion and the contribution of all our stakeholders, some of whom are not always loud or brave enough to be heard. We also understand the need to embrace modern technologies and communicate using both traditional and social media.

And how do we manage that responsibility?

One obvious way is through the pages of the publication you are reading right at this moment. **Signpost** is an outstanding vehicle through which our professional staff inform the Parkinson's community – those diagnosed, carers, families, health professionals, and care workers - about all aspects of symptoms, care and treatment. We can read the latest research, confident that it is authentic.

**Signpost** not only educates and informs, but through its pages people living with Parkinson's are able to share their stories and experiences, in both pictures and words. I love to read about what's happening in Support Groups - small and large, city and country. I am excited to hear about the innovative fundraising activities so important to our work. I am saddened to read of personal struggles.

In addition to the traditional forms of communication, we are going to see and hear more of what sounds like the language of the underworld: **Facebook, Twitter, Blog** and **YouTube**. Just when some of us have mastered email communication, we will soon have to become used to **eNews**. And where will all our digital information be stored? In the "**cloud**".

Communication, however, is much more than the written word or digital video.

The most effective and endearing communication is often the friendly exchange at a Bunnings BBQ or charity movie screening.

**National Parkinson's Awareness Week** (in September) and **World Parkinson's Day** (in April) are popular forums through which we communicate with the broader community: schools, service organisations and churches. Similarly, our Ambassador program is a wonderfully successful means of presenting and communicating the Parkinson's message.

And of course, **A Walk in the Park** is fast becoming a highlight of the community calendar; an event attracting the interest and involvement of literally thousands of people across Victoria and Australia, where similar events take place.

Effective communication enables us all to come together as we do for **A Walk in the Park**.

And, as we come together, we learn that we are not alone; that we share responsibility for the well-being of others, in particular people with Parkinson's, their carers, families and friends.

And, with that responsibility comes **opportunity** and **privilege**. Please make the most of your opportunity: Share. Cooperate. Communicate.

**Peter Raymond, President**

# New Books

## Still Laughing

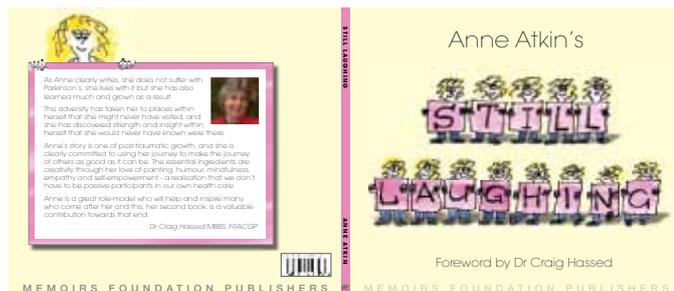
Anne Atkin recently published a second book of cartoons, **"Still Laughing"**, which highlights some of her journey with Parkinson's.

An art teacher and artist, Anne was diagnosed in 2005. Since then, she has gone on to establish the **Painting with Parkinson's Group**. Anne has said that humour has helped her through the tough times in her life.

The book was launched at a function in July, attended by Holt MP Anthony Byrne, City of Casey Mayor Amanda Stapledon and Councillor Geoff Ablett, as well as the president of the Parkinson's Victoria Peter Raymond.

Anne's first book, **"Living and Laughing with Parkinson's"**, was a major hit and both books are a wonderful tool to start a conversation with family and friends, as well as to explain in ways we can all relate to, what living with Parkinson's can be like.

**Copies of both books are available from Parkinson's Victoria (\$30 per book or \$55 for both, plus postage)**



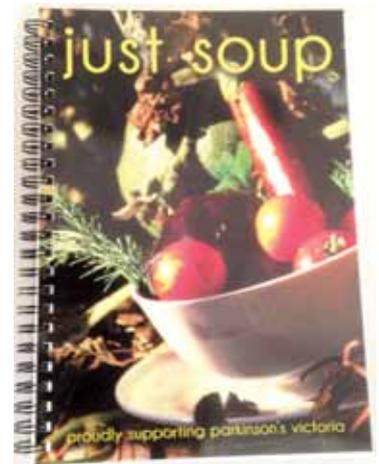
## Liquid Gold

The Shepparton Parkinson's Support Group recently published, **"Just Soup"** a collection of soup recipes. Several years ago, the group began the tradition of serving home-made soup during the winter meetings.

Now, 82 of their tried-and-tested favourite recipes have been combined in this enticing cookbook: **'Just Soup'**.

All money raised from sales will help fund the services provided by Parkinson's Victoria, and in particular will help fund regional support services, specifically the recently appointed Movement Disorder Nurse. The book is also proudly supported by Goulburn Valley Health.

**For a copy of the book, contact Parkinson's Victoria for an order form or order over the phone. Copies are \$17 per book (including postage and handling) or \$15 per book (pick up only from Parkinson's Victoria or the Shepparton Support Group)**



### Advertisement

# Agilitas

## WALK WITH CONFIDENCE

Available now at [www.agilitas.com.au](http://www.agilitas.com.au)



**"Agilitas promises to improve the quality of life of countless patients with Parkinson's Disease."**

**Dr Rodney Marsh – Neuropsychiatry Consultant,  
Neurosciences Queensland**

Agilitas is a world-first product that uses visual cueing to overcome the debilitating Parkinson's disease symptom, "freezing of gait".

### FAST FACTS: AGILITAS...

- ... is compact, lightweight and easy to use.
- ... is so discreet that other people are often not aware that it is in use.
- ... has a conveniently rechargeable battery.
- ... automatically switches off the cueing light as soon as the freeze of gait episode has passed.
- ... may help the wearer negotiate corners, doorways and even stairs with confidence.
- ... is available only from [sales@agilitas.com.au](mailto:sales@agilitas.com.au) or Freecall in Australia: 1800 91 31 41

### Mind the gap

The **Enhanced Primary Care Plan** is a Medicare supported scheme providing access to some Medicare-supported allied health services.

Under the *Chronic Disease Management Plan*, eligible individuals are able to access up to five visits per year with an allied health professional, such as a physiotherapist, and up to 10 subsidised visits to an approved counsellor or psychologist under a *Mental Health Treatment Plan*.

Allied health professionals must have a Medicare Provider number to be able to participate in the scheme.

**If you are planning to access a therapist under this scheme you will need to do a little homework beforehand: the rebate from Medicare is a set amount and the therapist may charge above this, leaving you with a "gap" between the rebate and cost. Sometimes this gap may be significant, so planning ahead can help avoid any nasty surprises!**

### Taking control

Following an article on carers in the last edition of Signpost (p10-11), we received a letter from Dr Margi Gould providing additional information on the topic.

Dr Gould drew our attention to the Office of the Public Advocate and their free kit on guardianship and medical enduring powers of attorney entitled Take Control. In addition, the Office provides education sessions for the general public and for health care workers, and has an excellent website [www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au)

While people can talk to a lawyer or financial advisor or community legal centre they can also discuss this matter with their GP.

In some areas people can be referred to the district nurse for assistance with advanced care plans.

"I have to admit I'm interested in this area as I have Parkinson's and I'm employed by the Hume Region Palliative Care Consortium to educate GPs about advance care planning, (I'm also an academic GP)," said Dr Gould.

**Thank you Margi for this helpful information for our readers.**

## CEO's Message



Our major annual fundraising and community event, **A Walk in the Park**, is just around the corner on Sunday 25 August. If you haven't signed up yet, there is still time to join in the fun and the post walk activities taking place at Federation Square by registering at: [www.parkinsonswalk.com.au](http://www.parkinsonswalk.com.au)

If you are unable to join us in Melbourne, I encourage you to get behind this important event by sponsoring someone who is Walking or by making a donation. Please contact Parkinson's Victoria to find out how: (03) 9581 8700 or [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

Parkinson's Victoria relies on the generosity of people like you and the wider community. Your support, by way of donations, funds key programs and services including information, education, raising awareness and advocacy. Fundraising events such as **A Walk in the Park** also generate significant income to help fund our support services.

**Communication** is the theme for this edition of **Signpost** and will also be the focus for Parkinson's Awareness Week, taking place from 1-7 September.

One of the major events taking place during this week will be a seminar for Speech Pathologists, **"More than Words"** which will provide health professionals with an insight into some of the communication challenges that people with Parkinson's face, as well as strategies to assist.

**Communication** will also be a focus for Parkinson's Victoria over the coming six months, as we develop and re-invigorate our website. Disseminating current, relevant and supportive information is a critical component of our work, often provided directly through our free information phone line. The need to provide quality information to complement this service, on a 24/7 basis is a priority.

There is also a great opportunity to support and enhance our engagement with the broader community and build support for our work in a variety of ways through new technology. The new website will be a critical tool to support the future development of our work.

Key alliances will be a focus as we pursue opportunities to collaborate with our friends in the neurological sector. **MS Australia, MND Victoria** and **Brainlink** all share key advocacy areas with Parkinson's and Parkinson's Victoria, which will be explored before the next state election. Many of us are advocating strongly on the lack of specialist neurological nursing advice and support in the health system.

When meeting with State and Federal Members of Parliament, such as Colleen Hartland from the Greens, Gavin Jennings the Shadow Minister for Health and Josh Frydenberg, the Federal Member for Kooyong, we have been advocating for recurrent funding for neurological nurses and for the need to increase funding to build both stronger education services and support group networks for people living with Parkinson's.

There is also an update in this issue on the national campaign, supported by Parkinson's Victoria through Parkinson's Australia in the lead up to the federal election. It is a good time to bend the ear of your local member, share your story and raise your issues as well as those of the broader Parkinson's community. You can read more about this campaign on page 10.

I hope to welcome you personally to this year's **A Walk in the Park**, on the 25 August.

**Emma Collin, CEO**

# Medication news

## Dopamine Agonists

The symptoms of Parkinson's are caused by a decline in the number of *dopamine producing cells* in the brain. Dopamine is a neurotransmitter, or chemical messenger, which assists in movement.

One treatment option for Parkinson's is levodopa (medication brand names include *Sinemet™*, *Madopa™*, *Kinson™*, *Duodopa™*, *Stalevo™*). Levodopa is converted into dopamine in the brain.

Another possible approach is to use medications referred to as dopamine agonists (*Sifrol™*, *Cabaser™*, *Permax™*, *Neupro™*) which stimulate the dopamine receptors directly, optimising dopamine uptake in the brain.

These medications may be delivered as a tablet, absorption patch applied to the skin or intravenously (under the skin).

Dopamine agonists can be used at all stages of Parkinson's. You may take them on their own, or alongside levodopa to help the levodopa work more effectively.

In **some** cases, people with Parkinson's who are on these medications experience problems with impulsive or compulsive behaviours as a side-effect. Examples include compulsive gambling, shopping or eating; hyper-sexuality; and punding (meaning a compulsive fascination with and performance of repetitive, mechanical tasks).

These behaviours can have a substantial impact on people's lives, so if you have concerns that you may be experiencing such side-effects, speak with your GP or Parkinson's specialist straight away so that they can help.

Dopamine agonists have many positive effects on Parkinson's symptom management and many people do not experience the side-effects outlined above, so people should not be discouraged from considering them as a treatment option.

For those who do experience impulsive or compulsive behaviours as a result of taking dopamine agonists, reducing or stopping the medication also stops these effects. In other words, they are not a permanent side-effect. However, you should not stop taking your Parkinson's medication without first consulting your doctor.

**If you have any concerns about the medications you are taking, contact your GP or Parkinson's specialist.**

### *Peer Support for Impulse Control Disorder*

Parkinson's Victoria, with the support of the Salvation Army Financial Counselling Program, is looking to establish a support group for people who have experienced *Impulse Control Disorders* (such as compulsive gambling) as a result of being on a dopamine agonist.

**If you have experienced Impulse Control Disorder and would like to meet with others who have had a similar experience, please contact Breanna at Parkinson's Victoria. Enquiries will be treated confidentially.**

### *Update on dopamine agonist class action*

Two class actions are currently being pursued in the Federal Court of Australia on behalf of all Australians

diagnosed with Parkinson's, Restless Legs Syndrome, or Pituitary Tumours, who allege to have developed compulsive behaviour as a result of the consumption of the dopamine agonist medication Permax®, Cabaser® and/or Dostinex®

Individuals may fall within the class if they were taking Permax®, Cabaser® and/or Dostinex® in certain periods between 1994 and 2010, and, after consuming the tablets, suffered changed and abnormal behaviours such as compulsive gambling, spending or eating; hyper sexuality; punding; or a combination of these.

*Breanna Wotherspoon from our Health Team recently attended a community meeting in relation to this class action and provides an update on the progress:*

"Class actions" are representative proceedings brought by one person on behalf of a group of people.

The main benefit of class actions is that they enable a dispute involving potentially large numbers of people to be resolved by way of a single case, i.e. one case is run and the findings apply to all claims. If a class action **fails** only the individual who brings the case – the applicant – is liable for costs, while the rest of the class are not. If the primary case is **successful**, there will be a finding as to liability which determines the liability in all cases – however the amount of money awarded will differ for each case (individual claimant).

The two class actions currently under way (outlined above) allege that the three pharmacological companies (which distributed the medications involved) knew or ought to have known that the medications had an effect that would cause these compulsive behaviours, but that they failed to warn consumers of the risk.

The cases seek to obtain damages (monetary) to compensate for financial losses suffered by individuals as a result of medication-induced compulsive behaviours. In the claim, there is also provision for non-economic loss, such as damages for pain and suffering.

It is important to note that, even if the case is successful, members of the class are still required to prove loss and damage suffered as a result of the compulsive behaviour.

Lawyers acting on behalf of this class action are currently in negotiations with the relevant pharmaceutical companies. If the companies and the class can reach an agreement on a 'global figure' for damages (and the court is satisfied that this figure is fair and reasonable), then a settlement will be reached. If settlement is reached, all could be resolved within 12 months. If a settlement is not reached, the case will go to trial, and the process could take up to 3 years.

At this stage, the class is open for both cases (i.e. individuals can still join). However at some point the judge will close the class.

**If you would like more information about these class actions, or if you wish to register a potential claim, contact Arnold, Thomas & Becker: 1300 333 300.**

# Personal Dopa-meanings

## My left eyebrow

I have an early morning ceremony  
It's a very vital procedure for me  
That's when I have to fix my face.  
I need Powders, lipstick and lots of space

It takes me forever, it's a formidable task,  
For a detailed procedure, you just don't ask  
It involves spackfiller and lots of varnish  
With constant polishing so it won't tarnish

But there is one task that's essential for me  
I have to draw on half an eyebrow you see  
In the process of age, half my eyebrow has gone  
Just disappeared! It's ridiculous! and it looks all wrong

I have a tremor caused by Parkinson's Disease  
My hands shake and wave around a bit in the breeze  
So to draw on half an eyebrow is a funny sight  
It looks like both hands are going in for a fight

A magnifying mirror is being shaken left and right  
The other shaking hand holds an eyebrow pencil tight  
It is hilarious, a bit of fun,  
How ridiculous to lose half an eyebrow  
I wonder where it's gone?

**Gay Miller, July 2012**

### *Parkinson's disease & Me*

I have a shaky friend with me  
It's Parkinson's disease you see  
It causes me to shake about  
And while it's a nuisance there's no doubt  
That it's also been a blessing for me

I have been humbled by people's care  
Disbelief and shocked stare  
then outpourings of sympathy  
I really felt that God above  
Was surrounding me with people's love

Family and friends supported me  
I felt a fraud, 'cos I could see  
Others were far worse off than me  
I really am quite fortunate  
I haven't suffered much to date

My hands and arms tremor,  
my lips they do too,  
So does my tongue and jaw.  
There are a myriad of symptoms  
That I didn't have before

Suffice to say I'm happy and well  
Tomorrow, no one can ever tell  
There's been such joy along the way,  
I met an old friend from years ago  
Surprise, surprise, he had Parky's too.  
Our get-togethers are really great,  
A friendship that Parky's did create.  
I feel blessed by others' care  
Care I might not have known  
But for Parkinson's being there

So I carry Parky along with me,  
Wherever I happen to go  
But he is not me and I am not him.  
I accept him in my life and know,  
it is understood,  
it is an ill wind  
that blows no body any good.

**Gay Miller, July 2012**

### Gay Miller

I am not telling you how old I am, but six years ago, just before I turned 60, I noticed a little tremor in my thumb and a specialist diagnosed a benign essential tremor. However, after a couple of years I went back to my GP and said I thought the diagnosis was incorrect and that I had Parkinson's, and I did.

Parkinson's, combined with ageing has given me some very funny and wonderful experiences and a desire to fill each moment of the day and enjoy life.

I left school at 15 years old, and worked for many years as a secretary. But I always wanted to go to University, so at 50 years of age I commenced part time study and completed a double degree in Arts and Law by the time I was 60. Then I did my Articles and have since worked two days a week at Fitzroy Legal Service as a volunteer solicitor.

I am enjoying life; I am a singer (which I believe helps me with my voice/volume problems), and I entered my first eisteddfod at 65 years old.

I go to a personal trainer once a week to keep fit, and in recent years I have started to write poetry, fiction and a song. I particularly love poetry, and recommend it to anyone to try.

I am attempting to publish my poems, to write a book on some funny experiences in my life, and am planning a CD of my singing, including a song with my 94 year old Dad.

# Research update

## Community walking & Parkinson's

With **A Walk in the Park** just around the corner, it was timely to read a recent article in **The Parkinson's Disease Journal** (Vol. 20) by Lamont, et al, which explored the value of community walking for people living with Parkinson's.

This physiotherapy-driven research has been able to identify motivations and barriers to community walking.

The research has found internal personal strategies as motivators to walking and external factors, especially environmental factors, as barriers to walking.

**Motivators** for walking include concentrating on walking speed and size of step, planning your route ahead and factoring in some discrete cueing (usually a thought process such as counting 1-2, 1-2). This was contributed to by ensuring the individual took their medication on time, every time, and generally enjoyed the experience of 'walking'.

Meanwhile, the **barriers** to community walking identified were largely external, including crowded environments, walking surfaces, weather and occasions when medications didn't work as expected.

This important research has helped identify that with some planning and a little additional concentration while walking, you are able to reduce the impact of Parkinson's on walking.

**Victor McConvey, Health Team.**

## Strategies to combat depression

*In Western Australia a Curtin University trial is showing promising results in improving the health of people with Parkinson's by treating anxiety and depression.*

Up to 75 per cent of people living with Parkinson's are affected by anxiety and depression, which have been linked to a faster progression of motor symptoms, poorer quality of life, and greater cognitive decline.

However, PhD student Lakkhina Troeung said that a cognitive behavioural treatment [CBT] program, specifically designed for people with Parkinson's, was proving effective, and more people were now needed to take part in the research.

"Our clinical trial has been running over the past 12 months and the initial results are very positive. However, we still need more volunteers to take part in order to get a clear picture of the CBT program's effectiveness," she said.

The treatment consists of eight counselling sessions, one a week, covering specific Parkinson's disease issues. The Western Australian program will be run by two clinical psychologist trainees under the direct supervision of a registered clinical psychologist.

Study supervisor Dr Sarah Egan said participants would learn new skills and strategies to cope with anxiety and depression, and be asked to complete a set of questionnaires four times throughout the study.

Parkinson's is a progressively degenerative neurological disorder which affects the control of body movements. It occurs when nerve cells in a part of the brain die or are damaged. These cells are normally responsible for the smooth co-ordinated function of the body's muscles and movement.

At present there is no known cause for the condition, which occurs predominantly in people from about the age of 50 to 75. Diagnosis is difficult and based on a progressive history of deterioration.

**People interested in volunteering for the trial should phone Lakkhina Troeung: (08) 9266-3436 or email: [lakkhina.troeung@postgrad.curtin.edu.au](mailto:lakkhina.troeung@postgrad.curtin.edu.au)**

**Source (online): [www.thesenioren.com.au/Health/Health-News/Promising-results-for-Parkinson-s-patients](http://www.thesenioren.com.au/Health/Health-News/Promising-results-for-Parkinson-s-patients)**

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## Community comes together

*In 2005, an Art exhibition titled **Beyond the Mask** was hosted to showcase the creative spirit of people living with Parkinson's. The name was inspired by the facial masking that some people with Parkinson's experience, and to expose the idea that behind the mask there lies a world of possibility and creativity. The original convenors, the Eastern suburbs support group, **Parkies with a Purpose** (since disbanded), followed this exhibition with **Beyond the Mask II** in 2010. Earlier this year, **Beyond the Mask III** took place in Mildura, coordinated by two members of the original **Parkies with a Purpose** group, Vanessa Humphrey and Ursula Smee.*

**Beyond the Mask III**, an art and craft exhibition was officially opened on Friday, 3 May at Hill Corner Gardens, Merbein, by Mildura Mayor Glenn Milne, with Master of Ceremony's Richard Morfaw. Both had a great appreciation for the works on display, and a keen sense of humour. More than 90 invited guests enjoyed the creativity of the exhibiting artists, all of which were people living with Parkinson's, family members or friends from the Mildura area.

The exhibition was then open to the public until 7 May, and gave participants a chance to showcase their creativity as well as their spirit of determination and inspiration. The exhibits ranged from magnificent Bedfordshire lace to oil paintings, ceramics to fruit cakes, stuffed toys to photography.

Newly appointed CEO of Parkinson's Victoria, Emma Collin, and President, Peter Raymond were in attendance, and the next day they joined a Parkinson's Community Seminar, hosted by Parkinson's Victoria.



Cheryl Barnes, Mildura Support Group Leader with Victor McConvey and Breanna Wotherspoon from the Parkinson's Victoria Health Team, Alan Humphrey, Emma Collin, Parkinson's Victoria CEO and Peter Raymond, President, Parkinson's Victoria.

This seminar was attended by more than 70 people, and again there was humour with Dr Richard Peppard, before he discussed more serious topics. Morning tea was followed by a presentation from Victor McConvey, from the Parkinson's Victoria Health Team, who spoke about the day-to-day issues of good bowel health and medication. President of Parkinson's Victoria, Peter Raymond introduced Emma Collin, new CEO and the newly appointed Parkinson's nurse, Katherine Healy, from the Medicare Local. The last to present were Alan and Vanessa Humphrey, who shared their experience of Alan undergoing Deep Brain Stimulation (DBS) surgery, the difference it has made in both their lives, and the good and bad they have gone through. Their talk was followed by a DVD Alan has created: "A 30 year Journey through Parkinson's", showing his story. (The DVD is now available through Parkinson's Victoria (\$25)).

Russell James from Artic Designs had donated a lucky door prize of a caricature, which was won by Belinda Dixon. Russell has been a supporter of the Mildura Parkinson's Support group for years, and said he was thrilled to be part of **Beyond the Mask III**.

Vanessa Humphrey and Ursula Smee, who organised the exhibition, working closely with the amazing Cheryl Barnes, were happy to see so many of the exhibits sold, with the event raising close to \$1,500 for Parkinson's Victoria to go towards research into Parkinson's.

Overall it was an amazing week; from setting up the exhibition, the excitement of the Opening night, and the informative Community Seminar the following day. Two years in the planning and on all accounts it was a great success.

# Advocacy & the Federal Election

## Heading to the voting booth



*“Change will not come if we wait for some other person or some other time. We are the ones we’ve been waiting for. We are the change that we seek.” US President, Barack Obama. Parkinson’s Victoria CEO Emma Collin provides some timely information on how you can play a role in advocating for change this election year.*

In the lead up to the 2013 Federal Election, the Parkinson’s Alliance, of which we are a member through Parkinson’s Australia, has developed a campaign to demand a better deal on behalf of the 80,000 people living with Parkinson’s in Australia and their carers.

The Alliance has written to all sitting members and met with many of them to highlight key issues and demands of the organisation.

The real strength of any campaign comes from individuals who are willing to tell their own stories and bring to the attention of their local members how government action could improve life outcomes for people with Parkinson’s and those who care for them.

With this in mind, in the lead-up to the Federal election, Parkinson’s Victoria is seeking your support in raising the demands of the Parkinson’s community, as well as your own individual concerns, with your local sitting members and other candidates.

This may seem a challenging task because of lack of time or energy, or simply because it is something you’ve never done before.

To assist you, the Parkinson’s Alliance has prepared a campaign fact sheet (included as an insert with this edition of **Signpost**). In addition, Parkinson’s Victoria has prepared some helpful information to support you, including links to the contact details of your local members and some tips on advocating.

The election will be held sometime before the end of the year, so time is of the essence and the earlier

you write or request a meeting with your local members, the better.

### Advocacy tips and hints:

- Approach your Federal Member of Parliament for both the Upper and Lower Houses and any candidates who will be standing against them.
  - Here is a link to the Australian Parliament website, where House of Representatives and Senate members and their contact details can be found: [www.aph.gov.au](http://www.aph.gov.au)
- Write to your member outlining your own story and ask them to address your needs.
- Your personal story is a strong advocacy tool, so writing a short case study regarding your own experience with Parkinson’s will illustrate how greater investment by government will lead to real improvements for both yourself and for others.

A case study should include information about you, your circumstances, two or three key issues for you or your family and how the situation could be improved. It should ideally be no more than 400 words in length.
- Write and request a meeting to discuss the Parkinson’s Alliance campaign and your story. If you request an interview, you are likely to be given a short time slot to meet and put forward your case.
- Most interviews are short (15 minutes), so prepare well, know what you want to say (focus on your key issues) and importantly ask your politician to do something for you. Make it specific: this could be a request for the member to speak to the relevant minister/ shadow minister. As the meeting concludes, clarify what was agreed on, the timeframe and how progress will be communicated.
- It is important to stay in contact, so write and thank them for their time and restate any commitments made.
- Share your advocacy with family and friends. Let them know about the campaign and your approach to your local member. Ask them to join you or write letters of support.

**We would like to share your advocacy stories with the Parkinson’s community so please let us know about what action you’ve taken and your progress. You can email me directly on:**  
[emma@parkinsons-vic.org.au](mailto:emma@parkinsons-vic.org.au)

# Symptom Management

## More than an 'Optional Extra'

*Communication is a vital part of everyday life. It is through conversation, written language and nonverbal communication that we are able to connect with others. Caterina Marigliani, Speech Pathologist from Kingston Centre Movement Disorders Clinic (Monash Health) identifies some helpful tips and strategies to improve communication and quality of life.*

Our social lives, work, relationships and quality of life depend significantly on our ability to communicate. Parkinson's can present a complex range of challenging and perplexing communication changes, affecting up to 90 percent of those diagnosed.

As part of my clinical work in an outpatient clinic for movement disorders, I often find myself trying to emphasise 3 key points.

Firstly, the idea that communication is incredibly important in everyday life and should perhaps not to be seen as "just an optional extra". Secondly, that early intervention is recommended. Unfortunately, it is common for clients to delay seeking help for communication difficulties until they become severe and markedly interfere with quality of life. Thirdly, that a commitment to actively participate in the communication rehabilitation process is essential in order to achieve improvement, as is a preparedness to change one's approach to communication.

Understanding how Parkinson's affects communication is important. Communication is both a motor (physically) and cognitively (mentally) demanding task. Although the changes in voice, articulation, fluency and facial expression are prominent and well-recognised, changes in the "thinking-language" aspects of conversation are also common, important and need to be addressed in order to improve communication.

*Seek Speech Pathology assessment and therapy if you notice any of the following (even if they only seem mild):*

- Fast or slow speech rate
- Slurred or imprecise speech
- Frequent need to repeat yourself
- Difficulty managing phone conversation
- Voice changes, such as soft, harsh, breathy speech
- Stuttering-like speech
- Difficulty getting your speech started
- Reduced motivation for conversation. Tendency to let someone else speak for you.
- Word finding or word selection difficulties
- Difficulty formulating sentences in conversation

- Getting "stuck" mid-sentence or losing "train of thought"
- Difficulty maintaining the topic of conversation
- Difficulty concentrating on conversation/feeling "overloaded" with information
- Taking longer to process and understand other people's speech or written information

*In addition to accessing information and therapy intervention, consider the following:*

- As with everything else, you need to "use it or lose it". Try not to avoid conversation. Make a point of being the one to answer the phone, order the coffee or ask the questions, rather than leaving it to others.
- Studies indicate that you sound louder to yourself than you do to others.
- Use conscious attention when speaking. Parkinson's-related speech difficulties will surface when you try to speak "automatically".
- Slow down, break up your message and concentrate on one sentence at a time.
- Take a breath before each sentence to fuel your voice.
- Concentrate on your vocal effort whilst speaking.
- In group conversation, "signal" with a gesture or verbally that you have something to say. You may otherwise miss your turn.
- If you lose your train of thought, say it in your head before you say it out loud.
- Communication strategy practice should be frequent and ongoing. Try to make it part of your daily routine.

**If you have questions about this article or would like to find a speech pathologist who can help, please contact the Health Team at Parkinson's Victoria.**

## Carer resources - correction

In the winter (May) edition of **Signpost** ("What all carers need to know", p 11) we referred to an **Emergency Care Kit** from Carers Vic. We have been advised that the resource (produced by the Department of Health and Ageing) is no longer available in hard copy, however, carers may download and print it themselves from [www.carersvictoria.org.au](http://www.carersvictoria.org.au) website (go to **Publications – Factsheets**).

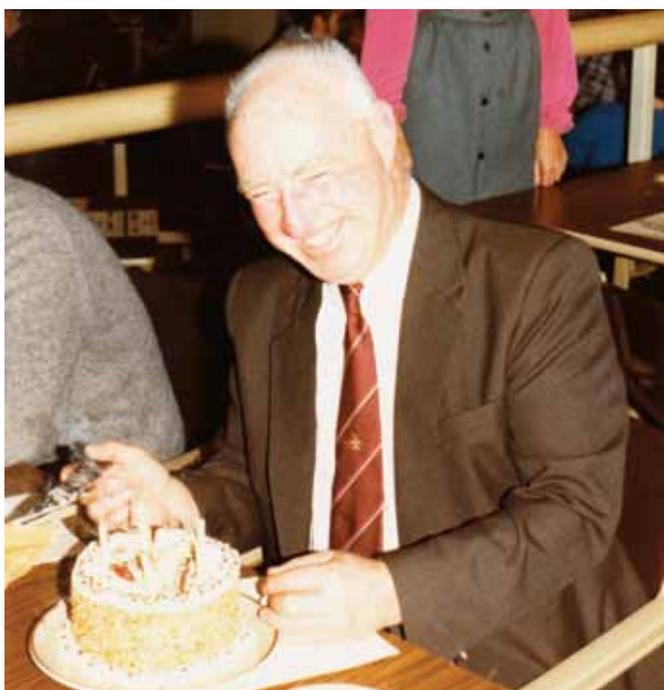
**Thank you to Carers Vic.**

# Tulip Tribute

*Parkinson's Victoria was recently honoured with a significant bequest from a generous benefactor, Bill Regan (below).*

*During a special presentation with the Essendon Support Group, President Peter Raymond and CEO Emma Collin, joined with Fred Van Ross, Essendon Support Group Leader and Parkinson's Victoria Vice President, to accept this wonderful donation. We were also honoured to have in attendance members of Bill's family.*

*Peter Raymond is pleased to share some of the story behind Bill's decision to remember Parkinson's Victoria in his will with a bequest donation.*



In 2008, when Essendon Support Group member Brendan Lourey was wrestling with whether or not to join the Parkinson's Victoria charity challenge - a cycling tour of Vietnam in 2009 - little did he know the consequences of his decision-making.

Max Bradfield, his life-long best friend, on hearing about the charity bike ride, had decided to sign up. Now all he had to do was convince his best mate Brendan to come along for the ride.

Brendan, a person with Young Onset Parkinson's, just wasn't sure. It wasn't the \$550 to register or even the \$6000 that had to be raised: his bike-riding skill left a lot to be desired!

The night before the deadline to register, Max prevailed and Brendan put pen to paper. It was now Max's turn to panic: how on earth was he to raise \$6,000?

Max sat down and made a list. Into the early hours of the morning he composed a list of possible donors and wrote a personal letter to all fifteen of them.

One of them was his wife Trish's Uncle Bill, who sent Max \$75.00. Max was on his way.

Little did he know that Uncle Bill was so impressed by the cycling venture for Parkinson's - the determination, the courage, the spirit and the cause - that he amended his will to acknowledge Parkinson's Victoria with a bequest. This amounted to a significant financial donation of just on \$120,000.

Mr William Joseph Regan - **Uncle Bill** - was born 25 April, 1923 and died 25 February, 2011, aged 87.

He worked as a fireman for the Metropolitan Fire Brigade all his working life and served as a transport driver in the army in Darwin during World War II.

For most of his life, he lived simply in the family home in Byfield Street Reservoir. He was committed to his family and to St. Gabriel's church in Reservoir, where he did charity work for 'The Children of Mary' organisation.

Uncle Bill was devoted to all his nieces and nephews, and loved visiting his sister Nancy and the family in South Warrnambool, his brother Laurie and the family in Queensland, and later in Moondarra, Gippsland.

He was always generous in his support of the family when in need, especially financially. Bill began buying shares as a young man and became an astute investor; something he continued to do all his working life.

William was a quiet gentle man totally committed to his Christian values and his extended family.

And, so it was that on 8 May, during the Essendon Support Group's monthly meeting, Max and Trish proudly presented *Uncle Bill's* generous bequest to Parkinson's Victoria.

It was fitting that Brendan introduced Max and Trish to the guests, and that fellow cyclists from the 2009 adventure, Fred and Christine Van Ross were also present to see that **from little things big things grow**.



*(From L-R) Peter Raymond, Parkinson's Victoria President and Vice President Essendon Support Group Leader, Fred Van Ross, Trish and Max Bradfield, and Emma Collin, Parkinson's Victoria CEO.*



# Young Onset Parkinson's Conference

**Friday 20 & Saturday 21 September 2013**

**O**ne in five people with Parkinson's are under the age of 65 when they are diagnosed. That works out to approximately 5,000 Victorians living with Young Onset Parkinson's.

On Friday 20 and Saturday 21 September, Parkinson's Victoria will run its second Young Onset Parkinson's Conference at the Jasper Hotel, Melbourne.

This conference will focus on the issues that impact upon a young person living with a chronic illness. It will provide people diagnosed with Young Onset Parkinson's and their families with an opportunity to:

- Meet other young people with Parkinson's from around Victoria;
- Find out about the latest in Parkinson's treatments, research and developments;
- Learn about living well and taking control of their wellbeing.

The Friday night program will include a buffet dinner, research update, entertainment, and the chance to socialise with others living with Young Onset Parkinson's.

The Saturday program will include an update on Parkinson's and a number of workshops presented by highly regarded experts.

## FRIDAY

6.00pm—9.00pm  
Welcome presentation and dinner:  
**\$40 per person**

## SATURDAY

8.45am—4.00pm  
Arrival tea, conference morning tea, workshop sessions and lunch:  
**\$60 per person**

## FRIDAY & SATURDAY

Save and register for both days:  
**\$90 per person**

*Prices inclusive of GST*



Register by completing the online registration and payment process at:

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

**Please ensure you print your ticket which serves as your tax invoice.**



## VENUE

Jasper Hotel  
489 Elizabeth Street  
Melbourne

## EVENT ORGANISERS

Parkinson's Victoria

**T** (03) 9581 8700

**F** (03) 9583 9952

**E** [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au)

**W** [www.parkinsonsvic.org.au](http://www.parkinsonsvic.org.au)

# Taking Control of Communication

*DIANNE RAYNER from our Health Team discusses how being able to effectively communicate with health professionals can make all the difference to your Parkinson's journey.*

A diagnosis of a neurological illness such as Parkinson's is the beginning of a long journey into the unknown; a journey that may begin with shock, then pass through periods of denial and frustration, and finally lead to acceptance and hope.

With any journey, but especially one where you're not sure where you're going, a map is needed.

You need to 'pack and prepare' for the journey and it's important to have some sense of what to expect along the way. Educating yourself about Parkinson's – symptoms, treatment management, side effects of medication and so on - will form just such a map. But it's important to remember that, as with maps of ancient times that often made no mention of hidden rocks or land or had incorrect coordinates, the map of your Parkinson's journey may still hold unknown areas and uncertainties, in spite of planning.

An individual's Parkinson's journey can be influenced by their personality, environment, culture and those around them. Someone who has had a negative healthcare experience previously may not be able or willing to work **with** their doctor to manage their Parkinson's; people who do not read or speak English well may feel a greater sense of fear because they do not understand the information they are receiving; others from different cultural backgrounds may not be comfortable asking for help from others, even family.

Understanding this variation in the way people might handle information, face life's challenges or respond to unexpected news is important for reducing the chances of a negative "journey".

At Parkinson's Victoria, we have heard many stories from people who said the delivery of their diagnosis had a significant impact on the way they handled the news. Negative experiences include the information being delivered in a way that the individual feels they cannot 'grasp' or adjust to, nor can they make sense of what it really means. As a result, the discussion of the diagnosis often has to be repeated, with some people so shocked and confused by what they hear that they are too stunned to ask questions. In the extremes of distress, people may hear what they want to hear or get the wrong message altogether. Sometimes, in trying to calm patient's fears, some professionals may be responsible for half-truths.

While the doctor or specialist has significant influence on managing how information is delivered to the patient, individuals should also understand their particular situation and be prepared. This may mean asking someone to accompany you to your appointment if you feel you may not be able to understand what is being said (for example, if English is not your first language) or simply to act on your

behalf and ask questions if you think you may not be able to 'think straight' or are likely to get too emotional.

## **Two-way communication**

Communication is about giving and receiving information, and nowhere is this more critical than in your relationship with your health care professional or multidisciplinary team. This team may include a Nurse, Psychotherapist, Occupational Therapist, Dietician, Speech Therapist, Physiotherapist and Social Worker. Expressing your health needs and concerns and getting answers to your questions are key elements for effective communication in a health care setting.

## **Plan ahead**

Before each appointment it's important to take time to prepare. Being prepared will help you provide your health care professional with detailed information about your symptoms or concerns, and may help lessen feelings of anxiety about your appointment.

Thinking beforehand about what **you** would like to discuss, writing down questions, and then referring to this list during your appointment and asking the specific questions **you** want answers to or concerns **you** want to raise, will make the best use of everyone's time during your appointment and will result in effective meetings with improved outcomes for you or your loved one.

It's also useful to keep a weekly or monthly diary of medications you are taking and any side effects or problems you are experiencing, including changes in behaviour or emotions.

The World Health Organisation Charter for People with Parkinson's Disease (1997) states:

People with Parkinson's Disease have the right to:

- Be referred to a doctor with a special interest in Parkinson's disease
- Receive an accurate diagnosis
- Have access to support services
- Receive continuous care; and
- Take part in managing the illness

It is the right of every Australian to receive continuous care and take part in managing their Parkinson's throughout the condition's progression. The **Australian Charter of Healthcare Rights** also outlines standards which mean patients, consumers, families, carers and healthcare providers to share an understanding of the rights of people receiving health care. See [www.safetyandquality.gov.au](http://www.safetyandquality.gov.au).

Having discussions with your healthcare professional about the best treatment options is recommended. This will facilitate the development of the best possible treatment plan for you in relation to managing your Parkinson's as well as ensuring you receive the best possible (continuous) care.

**If you would like further information or would like to discuss any concerns please contact our Health Team.**

# Tulip Tributes

## Charity Bake-off

A big tulip tribute goes out to the team at NAB team (Bourke Street, Melbourne) for their recent fundraising efforts!

Staff held a charity bake-off in June and raised a total of \$200. First prize went to Sam Glasson for his profiteroles in the shape of swans, and second place went to Helda Chan for her carrot cake.

**We love it when people get creative with their fundraising ideas. Thank you to the team and the bakers for their generous (and edible) efforts to support our work!**

## Another great hit

On May 24, Spring Valley Golf Club once again hosted a fantastic charity golf day with just over \$16,000 raised. All proceeds are once again shared between Parkinson's Victoria and the Kingston Charitable Trust.

The day was a great success on all counts, with attendees enjoying a terrific round of golf on the stunning green and then lunch, with the chance to win some terrific prizes, generously donated local businesses and organisations.

**Parkinson's Victoria gratefully acknowledges the generous support of Spring Valley Golf Club, the charity day committee, Club members, the players who supported the day, and all those who donated prizes!**

**Since the inaugural Charity golf day in 2009, the Club has donated a total of \$40,580 to help fund our support services! Thank you!**

## He's a mover and shaker!



Pictured from L-R are: Ben from the Chicken Shop, President Peter Raymond, Richard and Alan, and Nick and Col who provided musical entertainment during a "Piping Hot Chicken Shop fundraiser".

Talk about moving to make a difference! On 3 November, Alan Barber of Ocean Grove will be taking on the New York Marathon to help raise awareness and funds to support the work of Parkinson's Victoria.

Inspired by his friend Richard, who is living with Young Onset Parkinson's, Alan has set himself a goal of \$10,000 and has already raised close to \$8,000.

Alan has also been busy planning and hosting a number of fundraising activities, including a photography competition and, on the afternoon/evening of Sunday August 25 (that's after **A Walk in the Park** Melbourne), Alan is hosting **"Shake your Boogie"**, a Family Fun Day in aid of Parkinson's Victoria at the Football Club Rooms.

**To stay up to date with Alan's training and fundraising events happening in the Geelong/Ocean Grove area, including "Shake your Boogie", visit his facebook page: <https://www.facebook.com/NewYorkMarathonForParkinsons?ref=hl>**

**Thank you Alan for making such an incredible contribution to the fight against Parkinson's!**

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## Continuous therapies & motor fluctuations

*In this article, VICTOR MCCONVEY from our Health Team, takes a look at motor fluctuations and how they are increasingly being managed by what is referred to as “continuous therapies”.*

Motor fluctuations, or unpredictable movements related to highs and lows of dopamine replacement therapies, are considered to be some of the most difficult symptoms people living with Parkinson's encounter and are identified as significantly impairing quality of life.

Dopamine is a chemical messenger in the brain that acts like fuel for the body. It is responsible for helping your body to move smoothly and with control – from walking to picking up a cup.

One of the challenges of Parkinson's medication is that dopamine replacement therapy comes in the form of a tablet, and the way the body processes the *tablet* form of dopamine is not the same as how it processes dopamine produced *naturally* (the latter typically results in a constant and sufficient supply of the chemical to the brain). Dopamine provided through medication can create high or low levels of the chemical, resulting in motor fluctuations.

It is during a low level phase that individuals experience a recurrence of symptoms or *wearing off* (see below).

In the early stages of Parkinson's, when the body is still producing sufficient amounts of dopamine, the highs and lows associated with the chemical do not have a significant effect on the individual's movements. This period is sometimes referred to by neurologists as the *Honeymoon period* and usually lasts 7-10 years.

However, as Parkinson's progresses and this period draws to a close, the impact of fluctuating dopamine levels (the highs and lows) is more significant; medication is required more frequently in order to manage symptoms and individuals become more aware of the dopamine level in their body. If dopamine levels get too high there may be some involuntary movement called **dyskinesia**, but more common is dopamine levels going too low and individuals experiencing “wearing off”

Wearing off symptoms include physically slowing down, increased tremor, difficulty walking, bladder urgency, low mood, anxiousness and increased perspiration.

To help reduce these highs and lows, medication should be taken on time, every time, and may need to be taken more frequently. Other medications that stimulate the brain's dopamine receptors to work more effectively might need to be added (these

are known as “dopamine agonists”, and include the brand name *Sifrol*). Alternatively, medications may need to be added that slow the breakdown of dopamine (referred to as “COMT or “MAO-B inhibitors” and brand names include *Comtan* and *Azilect*).

If the motor fluctuations are troublesome or unpredictable, affecting quality of life for the individual, a **continuous treatment** may be considered.

The underlying principal of a continuous therapy is that the highs and lows outlined above are eliminated because the medication is administered intravenously or topically to the skin, or, in the case of Deep Brain Stimulation (DBS) surgery, an electrical pulse fires continuously.

*There are four types of continuous treatments:*

### *Tablets & Patches*

Parkinson's medications in this category are long-acting (over 24-hours) dopamine agonist medications, *Sifrol ER* and the *Neupro patch*. Medication is delivered in the form of extended release tablets, and patches which release the medication over a period of time.

They provide a mild “agonist effect” – in other words, they improve the body's uptake of dopamine.

Because the effect is mild, this form of continuous therapy may be replaced over time or used in conjunction with other continuous therapies.

### *Duo-dopa*

This medication provides a continuous infusion of a levodopa (dopamine) gel subcutaneously or directly into the part of the small intestine known as the *jejunum*. This part of the gut most readily absorbs dopamine.

The infusion is administered by a small pump worn by the individual (only worn during the day) and via a tube which is inserted through the stomach wall and a smaller tube that threads through to the small intestine.

This continuous infusion smooths out the highs and lows, reducing off periods and peak dose dyskinesias.

Medication side effects such as Nausea and peak are the same as oral dopamine replacement therapies and consideration needs to be given to tube and wound care as this treatment involves the surgical placement of a gastrostomy tube. In deciding whether this therapy is right for you, you should consider the invasive nature of delivery and the need to wear an external pump to administer the medication.

## Apomine

Apomine (*Apomorphine HCl*) is a potent dopamine agonist medication which can be administered as an injection or as an infusion under the skin (during the day only).

If used as an injection, the individual would take a small dose every time they noticed the sensation of wearing off. Many people feel that the infusion method is more convenient, especially if it is necessary to administer the drug several times throughout the day.

Apomine, a *dopamine agonist*, can be particularly useful if the individual experiences dyskinesia while on levodopa tablets as it enables the reduction in levodopa based medication.

Considerations include needle insertion every day, and the need to carry a small infusion pump to administer the medication.

Apomine can also cause some skin nodule formation, and the injection site needs to be monitored closely to identify nodule formation or other problems with injection sites.

As Apomine is a dopamine Agonist it has the same side effects of oral medications such as nausea and Impulse control disorder.

## Deep Brain Stimulation (DBS) surgery

Deep Brain Stimulation is a surgical procedure where electrodes are placed into the part of the basal ganglia affected by Parkinson's, referred to as the 'deep brain'.

The area selected will depend on the particular symptoms the individual is experiencing. The electrodes then discharge high frequency electrical impulses into this region of the brain and have the effect of "short circuiting" the misfiring impulses which are causing symptoms (sent by the part of the basal ganglia affected by Parkinson's).

The continuous stimulation of DBS removes the highs and lows and related motor fluctuations.

DBS is an increasingly common treatment for Parkinson's and recent 'EARLY-STIM' German Parkinson Study Group (GPS) research has identified DBS as a treatment to consider when motor fluctuations become noticeable.

Considerations include the fact that the procedure requires the patient to be awake for parts of the surgery (an anaesthetist will ensure any discomfort is prevented and the brain itself has no pain receptors).

If you have had a good response to medical treatments you will generally have a good response to DBS. However DBS is not a cure and it is not suitable for all people with Parkinson's. Usually,

only patients who have benefited from levodopa therapy and have symptoms that aren't adequately controlled by medication can be considered for the surgery. There are extensive criteria in place to select eligible candidates.

Adverse effects from surgery, while rare, include speech difficulties, lowered or changed mood, stroke, seizure and faults with the stimulator.

The treatments available to help with motor fluctuations are improving and advancing all of the time. Providing a continuous level of dopamine or electrical stimulation helps reduce the highs and lows associated with tablet-form medication.

Continuous therapies are increasingly acknowledged as the best treatment available when motor fluctuations become troublesome and start to impact upon your quality of life.

Deciding on the most appropriate treatment is a conversation you need to have with your treating Neurologist or doctor. However, not all Neurologists are involved with all treatments so you may need to seek a second opinion. The most important consideration is YOU and receiving a treatment you are comfortable with and which addresses the symptoms you are most concerned about.

**For more information about treatment options, speak with your treating neurologist or the Health Team at Parkinson's Victoria.**

## Hey Mr Postman!



Big thanks to Peter B, Merv, Peter K, Philip, Peter J and David from Zurich Financial Services, who volunteered a day at our office to help with mailing 3,541 'A Walk in the Park' promotional packs. These have now been distributed to businesses, day care centres, libraries, gyms, sports centres, pharmacies, leisure centres, Laundromats and local councils!

It took just over a day to complete – what an amazing effort! Thanks guys!

**If you can help with distributing posters in your local community, please contact Judith at Parkinson's Victoria.**

# Support Groups

*Parkinson's Victoria works with a network of 56 Support Groups around the State. While some are 'traditional' groups, with a formal meeting style and loads of information and fun, others are based around a social or other activity. Of course, both types offer comfort, friendship and support to members. BREANNA WOTHERSPOON from our Health Team explains how a Support Group can be a chance to try something new or connect you with others who 'truly understand'.*

## *How can a peer support group help?*

Peer support groups provide support and encouragement to assist someone diagnosed with Parkinson's, or their carer, to make sense of their experiences, to feel less-isolated and anxious, and to come to terms with the changes in their life.

There are a range of peer support groups for the Parkinson's community located throughout Victoria. Support Groups are open to the general public (typically residents from the surrounding area), and might involve guest speakers or social meetings. Some groups are centred on a specific activity; there is a singing group, **ParkinSong Victoria** and **Tai Chi** and **Yoga** for those who are keen to get a weekly dose of exercise or simply keen to try something different or meditative. For the creative types (or those who would like to

discover their inner creativity) we have 6 painting groups!

Some groups are geared towards a particular profile, such as the **Young Onset** groups in Melbourne and Geelong, the newly formed **DBS** group for those who have undergone Deep Brain Stimulation surgery (meetings take place on the last Wednesday of each month in Highett), and the **PSP** support groups for atypical Parkinson's conditions.

We are also starting up new groups all the time, in response to community requests. A new Parkinson's Support Group has just begun in Kingston and offers people living in the local areas who have been diagnosed or who are caring for someone with Parkinson's the chance to meet and talk with others who share similar experiences, situations and challenges. Meetings take place on the second Tuesday of each month in Mordialloc.

**To learn more about attending the *ParkinSong Victoria*, *Parkinson's DBS*, or other Parkinson's Support Groups, contact the Health Team.**

**Editor's note: The newly formed singing group, based in Williamstown, has found itself a name... *ParkinSong Victoria*. Congratulations to competition winner Peta Hannan for her clever suggestion! Thank you to Cicciolina restaurant for donating a \$100 voucher for the prize winner.**

## In remembrance

*Parkinson's Victoria was saddened to hear of the recent passing of Ruth Squire, a member of the Shepparton Support Group. We are pleased to honour and remember Ruth with a touching obituary from Ruth's husband, Robin, and Shepparton Support Group Leader, Geoff Alexander.*

"Ruth was born in Mount Isa on the 5 October, 1939 to parents Jack and Vida Jasper, who were Home Missionaries at that time.

The family moved "back home" to Echuca when Ruth was about 5 years old.

Ruth trained as a nurse at Echuca Hospital and married in 1960. In the 1960s, Ruth gave birth to two sons and two daughters. The next 35 years were actively spent in the dairy industry, though Ruth re-entered the nursing field in 1970's, when things were very tough in the dairy industry. Food was always kept on the table.

Ruth's other interests were many, including music and she played both organ and piano, officiating at many wedding and funerals, as well as church services throughout Australia, and musical shows. Ruth also taught music to many young and older students.

Knitting was another talent she mastered, and each of Ruth and Robin's twelve grandchildren (six boys

and six girls) were given a Christening shawl lovingly knitted by Granny, as well as many 'knitted' toys. (The neat stitching created by correct tension on the wool was always noted).

Other 'jobs' included Guide Commissioner and Parish Council Secretary. Ruth was also an accomplished cook, with **Ginger Fluff** a speciality for birthday parties, and veggie soups a family favourite. Relaxing times were spent doing crosswords, with cryptic clues, Scrabble and trivia. Although Ruth did not participate in sport ("no time"), she followed the children and grandchildren's sport with strong support.

Ruth was diagnosed with Parkinson's ten years ago, and medication helped early on. Unfortunately, during the last three years, Ruth was restricted to a wheel chair or bed. She remained strong through all of this though, and passed away peacefully on 4 June, 2013."

**Robin Squire**

"Ruth was a wonderful member of our Support Group. When able, she was always willing to do whatever needed to be done. Ruth was never heard to complain or be angry with her Parkinson's. She was always a joy to be with and always a gracious lady. We will always remember her for the example that she showed."

**Geoff Alexander, Shepparton Support Group Leader.**

## Finding your voice

*Difficulties with verbal communication can be frustrating for people with Parkinson's and for those trying to communicate with them. ALISHA CHAND from our Health Team offers some helpful suggestions for carers, family and friends when talking with someone diagnosed with Parkinson's.*

### Setting the scene

"Wearing-off"\* of medications, anxiety, depression and fatigue may impact on a person's ability to communicate effectively with those around them. Keep this in mind when choosing a time to have a conversation.

If you want to have a conversation with them about something important, it's best to plan this for when they will be calm and at ease, their medications are working well, and they are well-rested.

Ensuring the environment in which the conversation is taking place is quiet and free from distractions is also important. It can be difficult to hear or speak over the television or radio, which can also be a distraction. However, it is not always possible to control your environment, especially when you are not in your own home, so try and plan to have important discussions during times when you are in a more controlled environment.

### Talking the talk

When engaging in conversation, ensure you are speaking slowly and clearly and that you are giving adequate time for the person to respond.

It can be easy to assume a person with Parkinson's does not understand what you are saying because of a delayed response time, but this may simply mean it is taking them longer to process what you have said and what they want to say in reply.

When talking, try asking specific questions which will elicit short-phrased responses. For example, instead of asking "What would you like to eat?" try providing options, such as "Would you like chicken or fish?" And, try to limit questions to one at a time, allowing for an answer/reply to each one, before moving onto the next.

If you do not understand what has been said, be honest and say so. Explain that you did not hear or understand and ask them to repeat themselves.

Ask for clarification as the conversation goes on and repeat important information back to them, to make sure you are both on the same page and there are no misunderstandings.

Another important thing to consider is body language, facial expressions and gestures – all forms

of communication. It's easy to forget how much we say without actually saying anything.

Assuming a relaxed posture and being mindful of your facial gestures will play an important role in putting the person with Parkinson's at ease and hopefully less self-conscious when talking. Ensure you are making lots of eye contact and talk at eye-level so they feel confident you are paying attention to, and **value** what they are saying. The more relaxed they are, the easier it will be for them to engage in conversation with you.

### Things to avoid

It can be difficult when you are in a hurry, but avoid rushing the conversation as this is likely to only add stress to the situation for the person with Parkinson's, making it harder for them to engage with you.

When talking, avoid using patronising tones or "talking down" to them. Treating them as 'an equal' will help them to feel you value their input.

Over-correcting mistakes is another potential hazard; doing this might discourage people with Parkinson's from participating in group discussions, especially in social situations.

Feeling as though they are unable to contribute in group discussions (or that their contribution is unwelcome) can be isolating and can contribute to depression and anxiety.

Another thing to remember when participating in a group conversation is to avoid finishing their sentences or speaking for them. Instead, try and encourage them to join in the conversation by asking direct questions and waiting for a response. Importantly, this can set a great example (and helpful strategy) to others.

**\*Wearing off: for a brief explanation of wearing off refer to page 16**



# MDS Congress Update

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## Editorial policy:

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

## Parkinson's Victoria Inc.:

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

*The Movement Disorder Society's 17th International Congress of Parkinson's Disease and Movement Disorders was held in Sydney in June. Considered to be one of the most important global meetings for those involved with Movement Disorders, the MDS International Congress provides a forum for learning and discussion on a variety of related topics, including available treatments, and information and debates on latest research.*

*VICTOR MCCONVEY from our Health Team, attended the MDS Congress and was also a presenter. Here, he shares some of the highlights from the two-day event.*

## Stem cell therapies

Use of stem cell therapies remains a contentious issue in Parkinson's. The Congress acknowledged that there are currently no therapeutic stem cell transplants which have the potential to slow or stop Parkinson's. However, this remains an important area of research. Animal models have demonstrated that while improvements can occur, Parkinson's remains progressive.

What has been particularly interesting is that over time, the donor stem cells transplanted into the Parkinson's patient display the same changes as Parkinson's-affected cells, and lewy bodies\* develop within the host cells. This provides valuable insights into how Parkinson's affects brain tissue.

*(Stem cells are "poorly differentiated cells", meaning they have the potential to become any type of cell in the body, including dopamine producing cells.)*

## Further follow up to human growth factor (GDNF)

In the early 2000's, it was thought that the use of the human growth factor **GDNF** (given as a direct infusion or injection) had the potential to slow or stop Parkinson's. This was an invasive therapy, which involved placing a canula in an area of the brain called the **ventricle** in order to deliver GDNF.

While the initial trial (largely involving patients in the UK) was ceased due to a number of adverse events, many of the participants were disappointed as they believed GDNF had produced

positive effects. Although recent follow up of these patients indicated there was no sustained improvement, the benefits reported by trial participants has resulted in continued investigation into the potential benefits of human growth or trophic factors.

Current research is looking at the possibility of administering GDNF with another human trophic factor called *nurr-1*, using injection of a viral vector. Early research into this therapy using rat models is promising.

## IPX06

This new 'micro pellet' form of dopamine replacement therapy offers increased duration of the release of dopamine. The results of the first phase of human trials have been positive, with patients reporting increased 'on' time, which has enabled a reduction in the frequency of administration. In addition, the *sustained release* reduced the incidence of troublesome dyskinesia.

The results are even more encouraging given that medications which slow the body's metabolism of dopamine (such as COMT inhibitors) or medications which increase the uptake of dopamine (such as Dopamine Agonists) were not used during the trial.

## Exenatide

This medication is used in the management of diabetes where insulin is not required. Patients with this diagnosis and Parkinson's and who received this treatment frequently made the observation that their Parkinson's symptoms improved.

Results from a clinical trial, where people with Parkinson's took this medication and underwent pre and post motor function assessments, seemed to indicate a slight improvement in motor function *during* the trial period and which continued *following* the trial (even after use of the drug had ceased).

While this appears to be a very positive result, researchers emphasised that the trial was very small and as such, a placebo effect (causing a false positive) cannot be ruled out. These preliminary findings are an indication that further work is required.