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21 years of "lending a shoulder"

During our 2009/10 AGM, we were pleased to present Cynthia Hicks, Secretary of our Wimmera Parkinson's Support Group, with the 2010 Sir Zelman Cowen Award in recognition of her outstanding contribution and voluntary years of service to the Parkinson's community.



Wimmera Parkinson's Support Group Secretary Cynthia Hicks receives her award from Royce Pepin.

Support services for people living with Parkinson's in regional Victoria are scarce so the local Support Group, which services the entire Horsham region, performs a vital role at the coal face of the community.

The Support Group, which meets monthly in Horsham, began with just 8 members, but today boasts up to 25, with three of the original members still actively involved, including Cynthia. Members come from as far as Nhill, Warracknabeal, Dimboola and Kaniva.

While officially Cynthia's role is Secretary of the Group, she also coordinates – or assists in coordinating – the group's newsletter, guest speakers and excursions, proving to be a terrific and unofficial Second in Charge to Group Leader, Gordon Fisher.

Cynthia was nominated for the award by Gordon, on behalf of group members. In the letter of nomination, Cynthia's dedication to the Group was highlighted, along with the fact that she goes out of her way to stay up to date on news and important information so that she can pass it on to members.

Cynthia's pragmatic but caring approach to providing support and friendship is summed up in her words of advice to members; "hang in there". No doubt, such advice has been influenced by her own experience of providing support and companionship to a loved one, as she helped them through the tough times simply by providing friendship, company, and good old fashioned, "back to basics" support.

Cynthia's involvement with the Group came about following the diagnosis of her brother-in-law, husband Bill's brother Alex, around 1989.

It wasn't long before Cynthia's care and concern for her brother-in-law extended to other's living with – or caring for someone with Parkinson's, and in 1989 she found herself in the role of Secretary for the newly established Wimmera/Horsham Support Group.

Her first-hand experience with all aspects of the condition, as a carer, and also with issues such as poor medication management in hospitals, has enabled Cynthia to provide reassurance and 'a shoulder' to hundreds of people over the years – helping to ease the burden of those living with Parkinson's and to face the various day-to-day challenges that it brings. Cynthia is always quick to highlight the positive, inspiring attributes and actions of others.

In addition to providing care and support to the local community, Cynthia has been a strong advocate for the Parkinson's cause and for increasing awareness especially amongst health care providers, ensuring that information is readily available.

In receiving the award, Cynthia commented "I've just got so much admiration for our members and sometimes my heart just aches – I'm so proud of them and the fact that they just get on with things".

Congratulations Cynthia and thank you for your dedicated, enthusiastic and continued service to the Parkinson's community.

Editor's note: The Wimmera Mail Times and Nhill Express both ran stories about Cynthia's award.

Previous Sir Zelman Cowen Award winners:

- 2009 Geoff Alexander, Shepparton Support Group
- 2008 Harold Waldron, Geelong Support Group
- 2007 Rhonda Kennedy, Bendigo Support Group
- 2006 Merl Bridges, Ringwood Support Group (inaugural)

The Sir Zelman Cowen Award is the highest honour awarded by Parkinson's Victoria to an individual for outstanding services to the Parkinson's community. It is named in honour of former Governor General Sir Zelman Cowen.

News & Highlights

Annual General Meeting Update

The 29th Annual General Meeting of Parkinson's Victoria Inc. was held at the Hemisphere Conference Centre Moorabbin on Monday 29 November 2010. Over 120 were in attendance. Brendan Lourey and Fred Van Ross were re-elected to the Board. The Board comprises the following members:

- Royce Pepin AM, MBE, GCSJ, Ph.C, President
- Kate Brown, Vice President
- Peter Walker, Finance Committee Chairman
- Mary Jones
- Brendan Lourey
- Peter Raymond
- Fred Van Ross

AGM Highlights

- President Royce Pepin and all present congratulated Kate Brown who was recently elected as President of Parkinson's Australia.
- Cynthia Hicks was announced as the recipient of the **2010 Sir Zelman Cowen Award** for her outstanding service to people living with Parkinson's over many years in the Wimmera/Horsham region. Cynthia is a worthy recipient and it was wonderful that the award could be presented to her in the presence of her family and friends.
- Following the formal AGM, our guest speaker was Dr Craig Hassed who spoke on **the Essence of Managing Parkinson's**, which incorporates education, stress management, spirituality, exercise, nutrition, connectedness and environment. This presentation was very well received and we look forward to further presentations from Dr Hassed in the future.

Copies of the 2009-2010 Annual Report are enclosed with this edition of **Signpost**.

View our annual report online: www.parkinsonsvic.org.au (go to the "publications" section).

New leadership

Announcement from the Board of Parkinson's Victoria:

As announced in the last edition of **Signpost**, Chief Executive Officer, Glenn Mahoney will be retiring from his role with Parkinson's Victoria as of 31 March, 2011.

Following a comprehensive and thorough selection and interview process, which outlined her professional experience including health services, at its December 2010 meeting, the Board of Parkinson's Victoria confirmed the appointment of Mrs Ann Burgess to assume the position of Chief Executive Officer, as of 1 April, 2011.

Ann will join the staff on 1 March to work with Glenn

during that time to ensure a smooth transition, allowing Glenn to provide a thorough briefing on the organisation's current standing, key issues and relationships, and five-year strategy.

We look forward to providing further details in the May edition of Signpost.

Enquiries to the CEO should be directed to Glenn Mahoney until 31 March, 2011.

Celebrating 30 years

2011 marks the 30th anniversary of Parkinson's Victoria. Stay tuned for more details about how we'll be marking the occasion and an update on how we'll be moving forward!

New exercise group

Dr Paul Lam's Tai Chi for Health - developed with a team of Tai Chi experts and medical specialists - is a safe and effective program which has many diverse health and lifestyle benefits including:

- Improving mental and physical wellbeing
- Improving balance and mobility thereby helping to prevent falls
- Improving coordination
- Promoting relaxation and alleviating stress
- Fun and social

Parkinson's Victoria, together with Uniting Aged Care, Oakleigh Rehabilitation Programs, will be running Tai Chi classes suitable for people with Parkinson's, commencing early March 2011.

The session will be followed by morning tea and a group discussion with information sharing.

When: Weekly on Thursdays 10:30am – 12:30pm

Where: Oakleigh Rehabilitation, 68-72, Atherton Road, Oakleigh

Cost: \$5.00 per session

Register your interest by contacting Anastasia or Glenda: (03) 9568 0466.

Medication side-effects class action

The potential for negative side effects occurring as a result of a certain class of Parkinson's medications has gained significant public attention in recent years.

Many of those who developed Impulse Control Disorders (ICD), a desire to engage in pleasure-seeking behaviours and which typically manifest as excessive gambling, shopping, eating or hobbyism, as well as hypersexuality, have been unaware of the association between their ICD and Parkinson's medications.

In 2008, an Australian class action was initiated by lawyers on behalf of a group of people who had been placed on dopamine agonist medication and who developed an I.C.D. as a side effect. Now, lawyers are encouraging others to come forward. Specifically, anyone who was prescribed Cabaser

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or Permax in the late 1990's-2005, and who developed an ICD, and who believes they were not adequately informed of the potential side effects by their administering doctor are encouraged to join the class action.

To find out more or to register your interest in the information and support session, please contact Catherine on 9551 1122 or catherine@parkinsons-vic.org.au

Extending support

PSP Australia is widening its mission to include providing support for those living with Multiple System Atrophy (MSA) and Cortical Basal Syndrome (CBS).

People diagnosed with these conditions and their partners and/or carers are invited to join monthly PSP Support Group meetings, attend other activities and special events that may be of interest, and receive correspondence and updates from the organisation.

Although all three conditions are unique, they do share a number of common features. This, together with the fact that there is currently no support network for those living with MSA and CBS, means there is a lot to be gained from sharing information



Could you help us deliver a Message from Parkinson's?
Literally. Click on the link at www.parkinsonsvic.org.au to find out more

about general support options.

PSP Australia will continue to develop resources that provide information and support across all three conditions. Currently, the organisation offers bimonthly meetings in Melbourne and publishes a regular newsletter.

Joining together will strengthen the voice of people living with PSP, MSA and CBS, to the benefit of all.

For more information and to get in touch with the PSP Australia Support Group, contact the Health Team at Parkinson's Victoria.

"We all know at least one older person who makes an exceptional contribution to our community.

Each year, through the **Victorian Senior of the Year Awards**, [the Government] recognises the many men and women, aged 60 and over, whose passion, drive and commitment support and inspire us. These remarkable seniors aren't afraid to learn new things, take on new challenges or engage with the people around them. They are people with energy, vision and commitment who play a vital role in making Victoria a great place to live and they are exceptional role models for remaining active, healthy and engaged in the community. Their achievements and contributions inspire Victorians of all ages." (Source: **Victorian Senior of the Year Awards Information brochure www.dpdc.vic.gov.au**)

Do you know someone who has made a significant contribution to the Parkinson's community?

Keep them in mind when nominations open for the 2011 Sir Zelman Cowen Award (details provided in a later edition of **Signpost**).

You may also like to consider nominating them for one of the following government awards:

- Australian Senior of the Year (60 years and over)
- Australia's Local Hero
- Young Australian of the Year (16-30 years of age)

For more information or to nominate someone visit: www.australianoftheyear.org.au. Nominations for 2012 awards should be open from July – August 2011 (winners are announced in January 2012).

The following awards for 2011 are open to nominations from May. Winners will be announced in October as part of celebrations to commemorate **International Day of Older Persons**.

- Premier's Award for Victorian Senior of the Year 2012 (60 years and over)
- Council on the Ageing (COTA) Victorian Senior Achiever Awards
- "Go for your Life" Award

Research update

Genetic Testing in Parkinson's

In the Summer 2010 edition of *Signpost*, we featured a brief, personal account from a woman living with Parkinson's who had participated in the '23 and Me' genetic screen. Here, CATHERINE WATSON from our Health Team explains in detail the science – and hope – behind genetic testing.

What is genetic testing?

In simple terms, **genetic testing** is a highly technical procedure used to identify genetic mutations and disorders through the screening of a person's DNA*.

Genetic testing is already helpful in a number of situations, such as detecting single gene disorders which may run in families, and identifying genes which may increase a person's risk of developing a health condition. Genetic testing in the future may assist in understanding health conditions and their treatments, such as why some people respond better to certain medications, while others do not.

In general terms, genetic testing has the potential to dramatically improve lives as it can identify people who may be at high risk of passing on serious health conditions, or who may themselves be at high risk of developing a preventable condition. However, as the costs associated with genetic testing decrease and commercial accessibility to testing increases, there has been intense debate about the pros and cons of undergoing such tests for the individual, as well as a plethora of legal and ethical considerations for the wider community.

How is genetic testing relevant to people with Parkinson's?

Although Parkinson's is not widely considered a hereditary condition (only a very small percentage of the population have a familial version of the disease), a number of genes have been identified as playing a role in the development of Parkinson's.

While as many as 16 genes have already been associated with Parkinson's, it is predicted that many more are involved but are simply yet to be identified. Some of these genes play a significant role in increasing the risk of developing Parkinson's, while others have a less understood association to the condition.

Currently there are only a couple of Parkinson's-associated genes that can be easily tested for and in most cases, there are still significant limitations with genetic testing in determining susceptibility to Parkinson's. Certain gene mutations may be solely responsible for the onset of Parkinson's, however it is probably due partly to a genetic predisposition to the condition, and partly to other environmental factors. It may even be that the onset of Parkinson's is due to a combination of a Parkinson's-specific gene mutation plus other undiscovered genetic mutations.

There is still so much to learn in understanding the causes of Parkinson's, so at this stage, merely identifying a gene associated with Parkinson's will not change a person's particular situation.

What are the merits of genetic testing?

Why would you consider undergoing a genetic test for Parkinson's?

Family history of Parkinson's

In most cases, Parkinson's is *idiopathic* (its cause is unknown); as such people with Parkinson's are not "carriers" of a gene that can be passed onto a family member.

However, in some cases where more than one primary family member or other relative has been diagnosed there is greater likelihood that a genetic mutation may be responsible.

To provide timely, accurate diagnosis

Genetic testing is already able to provide an accurate diagnosis of Parkinson's for a small number of people.

If genetic testing continues to be able to provide an accurate (and earlier) diagnosis of Parkinson's, people with the condition will be able to make more informed decisions about their future and the stress and frustration that many experience as a result of delayed or mis-diagnosis will be reduced. Overall, genetic testing may have the potential to improve long term health outcomes, especially if medications which delay or alter the progression of the disease become available.

To advance research

It is likely that an earlier and accurate diagnosis of Parkinson's would greatly enhance our understanding of the cause of Parkinson's.

Currently, diagnosis relies on the presence of various motor (physical) symptoms. Unfortunately, symptoms don't tend to appear until the condition has progressed significantly, meaning the individual has actually been living with the condition for a number of years. This delay makes it very difficult for researchers to identify the cause of onset, which is still largely unknown.

It is hoped that by screening certain people who may have Parkinson's, or family members with the condition, we will be able to better understand the various genes involved and their roles. It may be that additional genetic mutations will be discovered, which will further our understanding of the influence of genes in Parkinson's.

If genes do play a significant role in the onset of Parkinson's, then this information is vital in providing clues to researchers and will ultimately assist in finding more effective treatments, and eventually a cure.

Genetic testing for Parkinson's may lead to improved treatments and symptom management for specific individuals, as treating specialists will better understand the needs of their particular

patient, enabling a tailored, personal medication plan. For example, a particular medication may have certain side effects for someone with a particular genetic makeup but not someone else. Personalised medicine will greatly assist in improving symptom management while lessening side effects.

Why would you decide NOT to have a genetic test?

A gene test is not a conclusive predictor of Parkinson's

For the majority of people the presence of a Parkinson's-associated gene cannot accurately predict the future onset of Parkinson's.

Many people found to have these genes will never develop Parkinson's. More importantly, as there are currently no means of preventing or delaying the onset of Parkinson's, a person should ask themselves what are the likely benefits of knowing they have the condition (earlier than current diagnosis allows)?

Even for those people who do develop the condition, Parkinson's is such a unique experience for each individual that it is not a crystal ball for anyone's future. Knowing you may or will develop the condition does not mean you (or anyone) can say exactly how the condition will affect you, which means decision making and planning for the future can still be difficult.

The impact on family members

It is important to consider the implications on the wider family network if a person was to learn they carry a gene that increases their likelihood of - or susceptibility to - developing Parkinson's.

Would you feel obliged to tell other family members of their increased risk? Is it your responsibility to do so? What if they do not wish to know? Would you be causing them concern about developing a condition which they currently have no chance of preventing?

Further, if you knew there was a significant chance that you had or will "pass on" a Parkinson's-associated gene to a family member, who might then develop Parkinson's, are you likely to feel guilty, angry and/or responsible for that, and how will this affect you and potentially your relationship with that person or family members?

A final thought...

As science continues to move forward, genetic testing will become even more accessible to the general population.

This will have considerable impact for the community as it is likely to significantly affect not only an individual's decision making in relation to their health, treatment options, even reproduction decisions and beyond, but also that of their family.

As important as this is, there is no doubt that genetic research is promising for its potential benefits and it may well hold the key to improving the lives of millions of people. But it is imperative to think through

the positive and negative implications of obtaining such health information. Anyone considering undergoing genetic testing should learn as much as possible beforehand about the different tests which are available, what information such tests will provide, and what you might do with such information.

Talk to your treating specialist about any opportunities to participate in carefully controlled research projects.

Regulatory guidelines will continue to be developed in Australia in relation to genetic testing, but caution is paramount in deciding whether genetic testing is right for you (and your family).

Where can you go to learn more about genetic testing?

The topic of genetic testing cannot be thoroughly explored in this article, however if you would like to learn more we recommend the following websites:

- **National Human Genome Research Institute (USA):** This website explains how genetic tests may be helpful to people who are living with Parkinson's or who feel they are susceptible to developing Parkinson's. www.genome.gov/10001217
- **Gene Tests:** Is an independent site funded through the National Institute of Health (USA). It provides an educational resource section which explains genetic tests in more detail. www.genetests.org
- **23andMe:** USA-based '23andme' is a commercial venture providing "DNA analysis" for individuals (for a fee). The emphasis is on health issues (such as whether someone carries a particular gene that causes cystic fibrosis) and ancestry (so people can trace their family history). The 'DNA' kit and analysis is available at a subsidised rate to people with a diagnosis of Parkinson's, including those living in Australia.

23andme is seeking 10,000 participants to build a comprehensive database of DNA profiles, which it is hoped will advance medical research on a global scale. Participating will not only assist the individual to learn more about their genetic makeup, but will help advance research into understanding the role of genes in Parkinson's. www.23andme.com/pd

Health Team note: It's important to note that if you are seeking results from **23andme** in relation to Parkinson's, this will test for one specific gene mutation only, one that is most common and typically relates to Parkinson's in the older adult.

No additional genetic testing is available with this test.

***Deoxyribonucleic acid, or DNA, is a nucleic acid that contains the genetic instructions used in the development and functioning of all known living organisms (with the exception of RNA viruses). The main role of DNA molecules is the long-term storage of information.**

Health & Symptom Management

A balancing act

Falls are amongst the most incapacitating and common features of Parkinson's. While there are obvious physical results, such as a broken bone, a fall may also cause several non-physical effects, such as loss of confidence and a heightened sense of vulnerability. SHELLEY POLLAK, our health team physiotherapist, takes a look at some of the latest techniques for addressing falls and balance in relation to Parkinson's. (Based on the article [Recent advances in the assessment and treatment of falls in Parkinson's Disease](#), by A. Snijders, J. Nonnekes, B. Bloem, which appeared in the journal [Medicine Reports](#), October 2010).

A 2008 study, which followed 136 people newly diagnosed with Parkinson's over a 20 year period found that the prevalence of falls was 87 percent. It also found that from those falls, 35 percent resulted in bone fractures.

These statistics are certainly eye catching, but it is also important to think about the practical significance of these falls.

On a personal level, falls can lead to hospitalisation, temporary or permanent immobility, and reduced confidence and quality of life. On a more communal level, every year, in Victoria alone, there are approximately 250 fall-related deaths, and 24,000 hospital and emergency department admissions related to falls for people over 65 years of age.

In 2003-04, the estimated total cost of fall-related acute care in Australian hospitals for people aged 65 and older was \$566 million. This represents a substantial proportion of the burden of disease and health expenditure for the older population.

For the management of falls in Parkinson's it is important to appreciate the complex and multifactorial causes.

Both the *balance deficits* and *gait disorders* inherent to Parkinson's can obviously lead to falls. Environmental factors such as slippery floors, loose rugs or mats, poor lighting, or inadequate footwear may also contribute. There is an increasing awareness that **freezing of gait** – a sudden inability to take an appropriately sized step forward and a common symptom in Parkinson's – is one of the leading causes of falls, presumably because people are caught by surprise by the sudden freeze of movement. Much research has also explored the importance of cognitive function as a key contributing factor.

Other risk factors - not specific to Parkinson's but still relevant - include a history of falls, poor vision, low bone mineral density (osteoporosis), dizziness and low levels of physical activity.

Preventing falls can be difficult because of these complex issues, but the reward is certainly worth

the effort. Following are some areas that play an important role in the treatment of balance, and therefore may assist in combating the incidence of falls in people with Parkinson's.

Optimising medication

While most balance problems are resistant to medication, **optimising dopaminergic medication** (which works to restore dopamine levels and address gait impairments) can certainly help to reduce the risk of falling.

Optimising medication for **cognition** (thought processes) is also important and may assist in reducing the risk of falls by helping people to think clearer, make safer choices and be less impulsive.

Deep Brain Stimulation

Deep Brain Stimulation (DBS) surgery has been shown to be very effective for people whose symptoms still respond well to levodopa*.

Gait, tremor, and other motor symptoms have all shown good response to surgical intervention, however, falls have unfortunately tended to increase in some people. Different sites are being studied to see whether problems with balance can be improved by stimulating different areas of the brain, but so far results have not been impressive.

Physiotherapy

Physiotherapy has provided people with Parkinson's many treatment options to combat poor balance and prevent falls.

Examples of evidence-based strategies include **cueing techniques**, **cognitive movement strategies** and **exercise**.

Cueing can include visual, auditory and proprioceptive** cues, and can either be external or self prompted. For example, the use of visual cues, such as a line on the floor or auditory cues, such as following the sound of a metronome or listening to marching music, are useful strategies to assist someone to get moving again. Breaking a long sequence of movements into small sections - using cognitive movement strategies - can also assist.

Each person will respond differently to different cues, and the best approach is to be creative in finding which cue works best for you.

Another area that has received much attention lately is the effect of cycling on freezing of gait, though no concrete evidence to explain or support this has been published as yet.

With respect to exercise, many different types of exercise have been shown to effectively improve balance. This can range from high intensity weight training to treadmill training and Tai Chi. The most important point to remember about the effectiveness of exercise though is that it is only effective while you are doing it and improvements

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soon wane, once exercise has ceased.

While there is no quick fix to the problem of falls, the benefits of improving balance are far reaching. Not only will improved balance improve quality of life for the person with Parkinson's, but this will also extend to families and carers.

For further information and advice on balance and falls, please contact our Health Team. We are able to provide advice over the phone and if necessary, can refer you to a relevant health care professional.

***Levodopa is a prescription drug used to treat the symptoms of Parkinson's. It works by increasing the amount of dopamine in the body, converting to this neurotransmitter chemical once it enters the body. Trade names for levodopa include Madopar, Sinemet and Kinson.**

**** Proprioceptor: a sensory receptor, found chiefly in muscles, tendons, joints, and the inner ear, that detects the motion or position of the body or a limb by responding to stimuli arising within the body.**

Young Onset Parkinson's

Inaugural National Conference

Over a weekend in November last year, Parkinson's Victoria, with the support of Parkinson's Australia, hosted the inaugural Young Onset Parkinson's Conference. Conference coordinator CATHERINE WATSON, our Community Development Officer, shares a brief update on how the conference went and what it means to those living with Young Onset Parkinson's.

The **2010 National Young Onset Parkinson's Conference** was the culmination of several years of hard work and research into the unique needs of those diagnosed with Parkinson's under the age of 65.

All states were represented at this inaugural event, with more than 100 people in attendance. They had the opportunity to hear from a number of high calibre international and national speakers, and participate in a range of break-out sessions which were informative and, in many cases, interactive.

The Friday night program featured a Welcome Reception and the opportunity for attendees to meet others in a relaxed setting. The highlight of the evening was a presentation from Tom Isaacs, live from London via videoconference. Tom was diagnosed with Parkinson's at 27 and his subsequent fundraising and awareness raising work for the cause is an inspiration. He also founded **The Cure Parkinson's Trust** (UK). Tom's presentation was educational and highly entertaining, as his self-deprecating style managed to draw on the 'lighter side of Parkinson's' – or at least his personal experience of it – to a humorous advantage.

On Saturday, attendees heard about the '**Essence of Health** and living well with Parkinson's' from Melbourne-based keynote speaker Dr Craig Hassed.

Also featured in the plenary sessions was a research update by Dr Julie Anderson (USA), who presented an update on research which she and her team are currently involved in. We are extremely grateful to both Dr Hassed and Dr Andersen for generously giving their time and such valuable insights. We

also acknowledge the support of the **Mental Health Research Institute** in arranging Dr Andersen's visit.

Our Parkinson's Specialist Nurse Consultant, Victor McConvey delivered information on treatment options.

In the afternoon, there were a range of breakout sessions to choose from, including topics on: **Deep Brain Stimulation (DBS) Surgery, Planning for the Future, Relationships and Intimacy, and Looking after Yourself as a Carer.** This was followed by "Come and Try" sessions, where attendees had the chance to try a new activity including **exercises and stretching, tai chi, art and creativity** and **meditation.**

The afternoon and conference concluded with an interesting **Q and A panel.** The formal activities were followed by an extended mingling session by participants keen to hear more from new friends, trade contact details, and generally make the most of this unique opportunity to meet and share with others.

While attendees gave glowing feedback on the "formal education" part of the Conference, there is no doubt that the opportunity to meet others living with Young Onset Parkinson's and partners was a real highlight. Face-to-face networking like this provides reassurance, support and comfort in a way that no education seminar can.

Parkinson's Victoria would like to acknowledge and thank Medtronic for their generous sponsorship of the event, and all our guest speakers.

If you would like to be added to the Young Onset Parkinson's mailing list to learn of future events, please contact catherine@parkinsons-vic.org.au

Young Onset Ambassador Nerissa Mapes, founder of **Perspectives on Parkinson's (POP)**, recently uploaded '**How Parkinson's Disease affects fashion and dating**' to the POP Youtube site. Check it out at: <http://www.youtube.com/user/POPorganisation>

Medication news

Getting it on time

Medication and Parkinson's can be confusing. Many people living with Parkinson's learn the importance of taking medications on time the hard way; by experiencing worsening and even debilitating symptoms, as a result of taking medications late or forgetting to take them all together.

VICTOR MCCONVEY, our Parkinson's Specialist Nurse Consultant, explains the importance of Parkinson's medication and "getting drugs on time", and provides some handy advice for maintaining optimal medication management.

The main treatment for Parkinson's is medication which works by either replacing or mimicking the actions of dopamine (a chemical messenger produced in the brain). Often people with Parkinson's will be on a range of medications that need to be taken at specific times of the day and at regular intervals. If medications are not given on time, every time, Parkinson's symptoms can become uncontrolled and patients can become very ill. Even taking one dose half an hour late can cause a person to experience movement difficulties and distress.

The way the most common medications work to treat the symptoms of Parkinson's is by:

- 1) **Replacing the dopamine:** Drugs such as **Madopar**, **Sinamet** and **Kinson** are known as **Dopamine Replacement therapy** and aim to control symptoms by normalising dopamine levels in the brain.
- 2) **Stimulating the Dopamine Receptors:** These are referred to as **Dopamine Agonists**, and include medications such as **Sifrol**, **Cabaser**, **Permax** and **Apomine**. They enhance the body's use of dopamine by stimulating the dopamine receptor cells in the brain.
- 3) **Changing the metabolism:** Medications such as **Comtan** block production of COMT (an enzyme that breaks dopamine down), and **Selgene** blocks MAO-B production (another enzyme which destroys dopamine). The use of both of these drugs will prolong the life (effectiveness) of dopamine in the brain.

NB: The drug Stalevo is a combination of Dopamine Replacement therapy with a COMT-inhibitor added.

When a medication regime is first commenced, it may take some time to work out the most effective dose and timing. As the condition

progresses, ongoing medication adjustments are also necessary, made by the treating specialist. Ascertaining the most effective level of medications and then making sure that person's "correct" dosage is administered properly is vital for achieving optimal symptom control. As everyone is different, everyone will need different levels and combinations of medications.

To assist your neurologist in determining if and when an increase in medication is necessary, it's a good idea to get into the habit of taking your medication at regular times. For example if you are taking one medication daily, take it at the same time every day. (NB: typically it isn't so important to take medication through the night (during sleeping hours) as your movement needs are greatly reduced).

If you forget to take a dose or feel you need a little more medication than usual - perhaps you are experiencing worsening symptoms referred to as 'wearing off' - it may be that the level of dopamine in your brain has dropped. At this time, you may experience symptoms including an increased tremor (shaking), stiffness, slowness of movement, freezing, urinary urgency, anxiety, sadness and in some people, pain and discomfort.

If you are experiencing wearing off symptoms and you have taken your medication on time, advise your GP or Neurologist – a medication adjustment may be required.

To assist in developing good medication habits, many people use a **medication timing device** to prompt them to take their medication on time (according to their own prescribed timetable). There are a range of different products available, including medication-timer watches and pill-box timers, and it is important to choose the best device that works for you.

It is not necessary to go to the expense of buying a specialty product; small kitchen timers or even mobile phone alarms can be just as effective.

It is important to remember that some medications taken for non-Parkinson's conditions can have a negative effect on Parkinson's symptoms or interact with Parkinson's medications, and this may have potentially serious consequences.

One of the most common medication interactions is when Maxolon or Stematil (used for the relief of **nausea and vomiting**) are prescribed. These medications may reduce the uptake of dopamine and can significantly worsen Parkinson's symptoms, particularly rigidity.

Another medication interaction to be aware of is that between dopamine and amino acids.

Amino acids, which are contained in dietary protein and essential for cell growth, are carried from the gastro intestinal tract and across the blood/brain barrier by the same cells that carry dopamine, so having protein-rich food at the same time as, or close to your Parkinson's medication, can affect the uptake of that medication.

Health Team note: A comprehensive list of medications to be used with caution is available from Parkinson's Victoria.

As a general rule of thumb, if you are commencing any new medication you should be aware of potential side effects, especially in relation to Parkinson's. Read the product information and discuss the medication and any symptoms/side effects and concerns with your doctor. If you notice a change in your Parkinson's symptoms after commencing a new medication or treatment (whether prescribed, over the counter or a naturopathic/dietary product) it is essential that you discuss your experience with your doctor as soon as possible.

One of the most common difficulties that people living with Parkinson's experience is not getting medication on time when they go into hospital or a care facility, including respite. This is a common problem and unfortunately is often the result of hospital and facility staff being unaware of the importance of Parkinson's medications, the way they work, and the often complex timing requirements of Parkinson's medications specific for each individual. It can also be the case that staff do not have the time to administer Parkinson's outside of usual medication rounds.

Some tips to ensure you receive your medication on time while in a hospital or care facility:

- Ask about self administration: Many hospitals allow patients to manage their own medications under certain circumstances. This relates to the specific protocols of each hospital, so unfortunately is not an option at all facilities.
- Check your in-patient drug chart: When the doctor writes on your medication chart, make sure he marks in when you need to have your Parkinson's medications, and ask him to make sure the nursing staff are aware of this.
- Ask Parkinson's Victoria for a **Hospital Kit**: This kit has information on how to plan for hospital, how to raise any concerns about your hospital

experience with staff, and how to escalate a complaint - if necessary. It also includes information materials you can forward to nursing staff that explain what Parkinson's is, how it might affect you as a patient, the role of medication, and the precautions staff should take to ensure your optimal care while in their facility.

- Keep your pill timer close by during your hospital stay and use it to remind you (and the nurses) that your medications are due.

While there is no cure for Parkinson's, treatments are available and effective for many symptoms, with the main aim of treatment being optimal symptom control and quality of life.

Being aware of how Parkinson's affects you specifically, and how you respond to various treatments, including medication, are good skills to develop, and you can enhance that by getting into good medication habits. Developing a partnership with your neurologist, GP and any other health care workers you encounter, ensuring they are aware of how Parkinson's affects you over time will not only assist them in developing the best treatment plans to respond to your needs, but will help you feel empowered and in control of decisions relating to the management of your condition.



Here's looking at you

Do you have a special pet in your life? Send us a photo with your pet's name to info@parkinsons-vic.org.au, and we will add them to our 'Parkinson's Pets' photo album on our Facebook page: www.facebook.com/parkinsonsvic



And remember, All pooches are welcome at Parkinson's Unity Walk, Sunday 28 August, 2011, at Melbourne's Federation Square!



Tulip Tributes

We've had some wonderful support in recent months and here we share just a small selection of some special contributions.

Super sizzlers

A terrific bunch of volunteers helped make our January Charity Sausage Sizzle at Bunnings (Moorabbin) a brilliant success.

Special thanks to Lynda B, Peter W, Peter R, Anne and Gordon A, Jodie T, Angela P, Amanda W, David G, Ted B, Murray F, Jenny P, and Denise and Lesley from the Parkinson's Victoria Team.

The day raised a total profit of \$1023, which equals: over 400 sausages (and bread), 10 kilos of onions, and more than 130 cold drinks (in 30 degree heat!)

Our volunteers worked hard all day, and made sure the generously donated Bunning BBQ was sparkling clean at the end. They greeted Bunnings customers with a smile and did a wonderful job raising awareness and representing Parkinson's Victoria to the community. Thank you!



Cooking up a storm: (from left) Amanda, Anne, Gordon and Lesley.

We also send our heartfelt thanks to the following companies who generously donated goods:

- BUNNINGS MOORABBIN
- HEINZ
- COLES SUPERMARKET, SOUTHLAND (Cheltenham)
- CRISP 'N' FRESH (Parkdale Plaza)
- WESTERN FRESH MEATS (Parkdale Plaza)
- BAKERS DELIGHT AT THE GLEN (Glen Waverley)
- SOUTH CITY MEATS (Hampton)
- COLES SUPERMARKET (Brighton)
- MORRIS MEAT SUPPLIES (Mentone)
- COLES SUPERMARKET (Mentone)

The kindness of strangers

In the lead up to **Parkinson's Unity Walk** last year we were lucky to secure the support of Channel 10's weatherman Mike Larkin. Mike did a fun live cross from Federation Square to promote the event and a friendly family who were sightseeing in the Square were happy to join in the spirit of things, donning a T-shirt and doing some on-camera stretches.

Special thanks to Noelene Maciejewski, Brad and Ruby Adkins and Kylie and Callan Holmes for their good humour and enthusiastic support!



From left: Peter Raymond (Parkinson's Victoria), Brad Adkins, Judith Mooney (Parkinson's Victoria), Mike Larkin (centre), Noelene Maciejewski, Kylie Holmes, 'the Production Guys', and at front are Ruby Adkins (left) and Callan Holmes.

Dynamic duo

Early last year, we received a wonderful call from Nicola Randall and Paula Donnelly who were keen to put their thoughts into action for two causes close to their hearts – Parkinson's and cancer.

Together – and with the help of wonderful friends, corporate supporters and the wider community - they hosted a **"Charity Band Night"** with the support of Pugg Mahone's Irish Pub (Carlton).

The event drew a crowd of around 100 people who enjoyed the combined talents of 4 different bands (who donated their performances), nibbles and the chance to win one of the fantastic 'experiential' raffle prizes on offer!

Judith Mooney, Fundraising & Marketing Coordinator from our team, attended the event and had the opportunity to formally acknowledge the girls' efforts and share a little about the Parkinson's cause and the work of Parkinson's Victoria.

Congratulations and thank you to Paula and Nicola on such a terrific effort, which raised just over \$4500 to support the work of Parkinson's Victoria (\$4500 was also donated to the Peter Mac Foundation).



Girl power (from left): Tulip Ball organisers Julie Sewell and Jo Hill with Nicola Randal (one-half of the organisers of The Charity Band Night).

Editor's note: We were fortunate to have Nicola join us for our recent AGM. She told us about her passion for making a difference for those living with Parkinson's, and her plans to create an even bigger and better event in 2011!

Putting the "art" in "Heart"

Throughout the year we receive many wonderful and unexpected donations and offers of support from the community, and it is always lovely to receive an accompanying letter explaining how a particular donation came about. Often it has been as simple as "our regular swimming group took up a collection" or "our exercise group had a cake stall".

On behalf of the Warragul Parkinson's Support Group and all those who benefit from our work in the community, special thanks to David Parry and John and Helen Stait who organised an Art and Craft Show in November last year, with the help of their church, The Salvation Army, Warragul.

During the show, people had the chance to view and purchase some artwork by John and David, who both have Parkinson's, enjoy Devonshire tea and purchase flowers.

Parkinson's Victoria has since received a cheque for \$1374, being proceeds from this event – outstanding!

Music to our ears

Congratulations and thank you to Ernie Kemplay on the success of his inaugural **Jazz & Blues Concert** held at the Church of Christ, Southern Community church in November last year.

This enjoyable afternoon of music and song is the second charitable venture of Ernie, and once again combined his love of music with his desire to make a positive contribution to the lives of others living with Parkinson's. (A talented pianist, Ernie has previously recorded a musical CD and donated proceeds of sales to Parkinson's Victoria).

Judith from our team acted as MC for the event, and this was a great opportunity to raise awareness about the need for funding and how Parkinson's

Victoria puts donations to work.

A cheque for \$800 was recently received, representing proceeds from ticket sales. We are also grateful for the contribution of all the performers who generously donated their time and talents, and the contribution of the members of the Church of Christ Southern Community, not only for their support of the Parkinson's cause, but their support of Ernie.

Bloomin' Terrific

Special thanks to Roz Harding, who opened up the beautiful gardens of her home in Mount Waverley to more than 250 members of the public in November last year and raised \$1329. Roz is a member of **Australia's Open Garden Scheme**, a not for profit organisation whose aim is to promote the knowledge and pleasure of gardens and gardening across Australia. While most of the nominal entry fee helps support the Open Garden Scheme, 35 percent is donated to the home owner's charity of choice. (Roz's Open Garden secured a \$500 donation from the Scheme as part of this program.)

In addition, all visitors received information about Parkinson's to help spread awareness.

Thank you Roz for opening up your home in support of the Parkinson's community, and putting in many hours of hard work beforehand to make sure it looked perfect on the day!

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An update from Canberra

KATE BROWN, a long serving Board member of Parkinson's Victoria, was recently appointed President of Parkinson's Australia. Here she provides an insight into the role of the National body.

Parkinson's Australia brings together representatives from all state and territory Parkinson's organisations to lobby the Federal Government and support cooperation between the states.

There are six state Parkinson's organisations and one in the ACT. As yet, there is no organisation in the Northern Territory, however there are two support groups that are assisted by Parkinson's WA.

At the November 2010 Council meeting I was appointed President of the organisation. This is a big challenge for me, however I have the support of an experienced team as you will see below, and we are focused on supporting all states and territories to achieve an Australia where ease of access to care ensures all people with Parkinson's have the best possible quality of life.

Let me introduce the current members of the Council:

- President, Kate Brown, Board member, Parkinson's Victoria
 - Vice-President: Helen Connor-Kendray, President, Parkinson's Tasmania
 - Treasurer: John Bird, President, Parkinson's Queensland
 - John Silk, Parkinson's New South Wales
 - John McDonald, President, Parkinson's Western Australia
 - Jan Creswell, President, Parkinson's ACT
 - John Power, President Parkinson's South Australia
- Parkinson's Australia exists to influence government

to be more responsive to the needs of people living with Parkinson's and their service providers, and to increase the capacity of its members of effectively deliver services.

Parkinson's Australia is still a young organisation; the first meeting of the national body was held in Sydney in November 1988. At that time the organisation was a loose affiliation which met once or twice a year.

Since the beginning, apart from lobbying, what is done in the name of Parkinson's Australia is delivered through the co-operative approach of the States. For instance, one of the earliest initiatives was the production of a set of videos covering all aspects of Parkinson's. These were produced in Adelaide and made available to newly diagnosed people and to general practitioners across the country.

The first **Parkinson's Australia National Conference** was held in Hobart in 1995. These conferences - held for people with Parkinson's, their carers and for health professionals - continue to be held every two to three years. The next conference will be held in Queensland in 2012.

In 2005 it was decided to employ a CEO/advocate in order to improve the organisation's ability to lobby the Federal Government. Prior to the creation of a paid position, all work was performed through voluntary labour. The decision to create a paid position lead to the introduction of a levy on states, based on population. The focus of the CEO's role is lobbying and submission preparation. The CEO is also responsible for building alliances with other peak bodies in order to enhance our ability to influence government policy to improve the lives of people with Parkinson's.

As a consequence of having a staff member in Canberra, Parkinson's Australia has been able to:

Advertisement

We offer specialist massage & acupuncture for Parkinson's disease

As part of our commitment to offer people living with Parkinson's disease (PD) the highest level of care at Neurology Network Melbourne we have developed a program that takes advantage of the proven health benefits of massage and acupuncture: non-drug treatments for PD. Massage has been shown to reduce muscle pain and stiffness. Specifically in PD, massage appears to mildly reduce symptoms for at least one week following treatment.¹ Acupuncture is established as a non-drug treatment for many of the muscle and orthopedic injuries that are common in PD (e.g. frozen shoulder, joint and muscle pain). It appears to improve the 'quality of life' in people living with PD.²

Our Parkinson specialist massage therapist and acupuncture doctors welcome all enquiries, as no GP referral is needed

Medicare and Health Fund rebates apply to most treatments

Massage Jennifer Drummond
Acupuncture Dr Michael Ben-Meir MBBS FACEM
Dr Allen Yuen MBBS FACEM
Neurologists A/Prof David Williams PhD FRACP
Dr Kelly Bertram MBBS FRACP
Dr Saman Punchichewa MBBS FRACP

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Call (03) 9500 8366
www.neurologynetwork.com.au

References: 1 Movement Disorders (2006), 2 Journal of Complimentary and Alternative Medicine (2006)

- Commission Access Economics (a company specialising in gathering data through research) to produce the first study of the economic cost of Parkinson's. The findings in this report have been used worldwide and have been invaluable to the national and state body's advocacy initiatives.
- Receive funding from the Federal Government to provide online training in Parkinson's for General Practitioners, and for a trial into the benefits of employing Neurological Nurse Educators. Both of these initiatives are currently underway.
- More recently, Parkinson's Australia has worked with other peak not-for-profit organisations to form the Neurological Alliance Australia, a vehicle for combining advocacy efforts on behalf of all people with chronic neurological conditions.

A major achievement has been the formation of the Parliamentary Friends of Parkinson's, this group is coordinated by Senator Carol Brown, Labor senator for Tasmania, and the member for Gilmore, Mrs Joanna Gash.

The primary objective of the group is support the work of Parkinson's Australia in improving funding for services and to broaden research and awareness on behalf of people living with Parkinson's. The Parliamentary Friends of Parkinson's boasts a broad membership across both houses of Parliament.

Parkinson's Australia is indeed fortunate to have Senator Brown convene this group. They have hosted several events for us at Parliament House. You may have heard of the morning tea at which the Hon Mark Butler received the report on Young Onset Parkinson's, and Nerissa Mapes from Victoria was a speaker. And, late last year, Senator Brown hosted a presentation by Dr Simon Lewis on the benefits of the Parkinson's neurological nurse specialist pilot project in the NSW Shoalhaven district. Following that, Senator Brown's adjournment speech highlighted the benefits of and need for Parkinson's specialist nurses.

We are among a select group of not for profits with a Friends Group; some of the others are Epilepsy, Red Cross, Dementia, Vision and Schizophrenia.

Parkinson's Australia is YOUR organisation; it exists to represent you and your needs to the Federal politicians and bureaucrats. Further updates on the priorities and initiatives of Parkinson's Australia - and the results of such initiatives - will be provided in future editions of **Signpost**.

I look forward to representing you and all members of the Parkinson's community at a national level and helping to make a difference for those living with Parkinson's, today - and tomorrow.

You can contact Kate Brown at:
info@parkinsons-vic.org.au

Man's best friend, in more ways than one

The power of pet therapy has long been known - at least anecdotally. More recently however, science has attempted to understand and prove the phenomenon, particularly in the area of aged care, mental health and disability. Now researchers are investigating whether or not there are specific benefits to owning a pet for those living with Parkinson's.

In what is believed to be a world first, doctors in the UK were astonished to find the Parkinson's symptoms of a 28 year old woman significantly reduce after being given a pet dog.

The woman, who had begun taking large doses of four different drugs a day to control symptoms just three years after being diagnosed, had a morphine pump for 14 hours a day and her health was deteriorating fast. But after being given a highland terrier by a friend, doctors reported improvements in symptoms and a drop in the drugs she needed. What's more, she no longer needed her daily morphine.

Doctors at **Imperial College London**, who report her case in the **Journal of Neurology**, said: "Remarkably sustained benefits occurred, with improvement in her walking and symptoms including appetite, sleep and bowel function, as well as socialisation."

Doctors were not able to zero in on the exact reason as to why or how the dog had such a dramatic effect, but they say that having to walk, feed and look after the pet encouraged the woman to exercise regularly. (Source: topnews.co.uk)

And closer to home...The School of Population, Auckland, is currently conducting a study which aims to understand the personal meaning and significance of pets (cats and dogs) for people with Parkinson's.

Some promising points about pets

- Studies have shown that owning a pet can lower the risk of death from heart attack by 3 percent.
- Children who are in regular contact with two or more dogs (or cats) before they turn one were 66-77 percent less likely to develop allergies.
- Stroking dogs can have an effect similar to antidepressants: Patting a dog releases serotonin (just as antidepressants do), the chemical that makes us 'happy'.

Source: Reprinted from the Parkinson's Tasmania Journal, Nov. 10, Issue 21.

FEBRUARY

- 1-2nd Support Group Visit by Health Team to PORTLAND, COLAC & WARRNAMBOOL
- 8th Support Group Visit - BENDIGO
- 17th Education for GPs, PLUS community seminar in SPRINGVALE
- Mid-February (to mid-May): St Kilda Road's iconic Flower Bed will feature the Parkinson's Victoria logo

MARCH

- 2-4th Support Group Visit - SWAN HILL & MILDURA
- 31st "Brain Surgery for Parkinson's" community seminar
- Launch of our **Movement Strategies** and **Exercise DVD's**

APRIL

- Entertainment Books 2011/12 now available
- 6-7th CAREX EXPO
- 11th World Parkinson's Day

MAY

- **Signpost** out now
- ANNUAL MID YEAR APPEAL for donations
- 4th Nursing and Allied Health Seminar in BENDIGO
- Nurses Seminar TBC
- Tai Chi training for health professionals
- 11-13th Support Group Visit - LAKES ENTRANCE, BAIRNSDALE & ORBOST
- Spring Valley Charity Golf Day

JULY

- 17th Run Melbourne: Get your Team Parkinson's gear on and **get moving to make a difference for people with Parkinson's!**

AUGUST

- **Signpost** out now
- Physiotherapy Seminar
- Charity Sausage Sizzle (Bunnings MOORABBIN)
- 27th Support Group Leader Day
- 28th Parkinson's Unity Walk MELBOURNE

SEPTEMBER

- Nursing & Allied Health Seminar in WANGARATTA

OCTOBER

- CHRISTMAS CARDS now available
- 5-7th Support Group Visit - STAWELL, CHARLTON, HORSHAM

NOVEMBER

- **Signpost** out now
- Recently Diagnosed Seminar
- ANNUAL END OF YEAR APPEAL for donations

Register your email to be the first to receive immediate updates about all our events. Send to info@parkinsons-vic.org.au

Late last year, more than 200 guests came together for the 2010 Tulip Ball: an evening of glamour, luxury, fine dining and "wishes come true" (as in "I wish those \$300 earrings on the silent auction table are mine by the end of the night").

Even Cinderella would have been begging her fairy godmother to wave her magic wand for a ticket to this event. One Prince Charming in attendance was our very own PETER RAYMOND, Ambassador and Board Member. Here, he shares his experience as a guest.

They came from everywhere. From all parts of Melbourne and across the State. Dazzling. Glamorous. Elegant. Mostly in black.

They spilled out of the lifts into the rooftop dining room of the exclusive RACV Club where they bought lucky tulips in exchange for a prize.

This was the third occasion on which mother-and-daughter hosts Julie Sewell and Joanna Hill had created a grand night of entertainment and fundraising. Inspired by John, Julie's husband and Jo's father, their mission is to raise awareness and funds to assist people living with Parkinson's.

Warmly welcomed by Royce Pepin, on behalf of Parkinson's Victoria, the revellers enjoyed a delicious three-course meal and danced to the music of renowned Melbourne band "21/20".

Media personality Terry Laidler compered the evening and ensured fundraising activities were not forgotten as guests ate, drank and danced the night away. An amazing array of prizes and gifts attracted generous bids at auction and we're pleased to say this story has a fairytale ending...

The final amount raised from the evening was an incredible \$36000! This means that since starting their amazing quest, Jo and Julie have raised nearly \$100,000 to support the work of Parkinson's Victoria, making them our highest individual fundraisers. 100 percent of proceeds raised through Tulip Ball events are donated to Parkinson's Victoria.



A glamorous affair (clockwise from back left): Parkinson's Victoria President Royce Pepin, John and Julie Sewell, Mrs Joyce Pepin and Joanna Hill.

We commend Julie and Jo on their commitment to make a difference by hosting such memorable events, of which we – and the Parkinson's community – benefit from so significantly.

Thank you Julie and Jo! We look forward to the next sequel to this wonderful fairytale!

Access, Advocacy & Assistance

Finding a cashflow

Parkinson's can be challenging enough – emotionally and physically – without the added stress and strain of financial hardship. Unfortunately, when suddenly faced with myriad symptoms and medication regimes, the seemingly all-consuming diagnosis itself, or even “not feeling all that different”, the idea of assessing one's financial situation is too-often way down the list of priorities, if not completely overlooked. Advice and help is available and we encourage you to consider speaking with a finance professional, just as you would seek out professional advice regarding symptom management.

Having a family member with a health condition, illness or disability can put considerable emotional and sometimes physical strain on those around them. Depending on your financial situation, it can also put a significant strain on your household budget.

Faced with mounting medical bills, a significant outlay to modify the family home, or even a hungry mortgage, people inevitably look to where they can find some cash to ease the strain. While financial opportunities may exist, you need to be wary of unintended consequences.

Loss of income is a common occurrence when someone close to you is unable to cope without assistance from another family member or a carer. In many cases it's a double whammy – the person who has lost mobility or other function/s and can no longer work and their partner also has to stop working, or shift to part-time work to look after them. Inevitably people ask themselves, “Why didn't I take out insurance when I had the chance to?” Or perhaps, “I thought I was adequately covered for this.” Or even, “I had some life insurance but I didn't think twice about income protection.”

Where do you look for some relief if your insurance cover isn't adequate? Can you sell an asset, like a rental property for example? If you have such an asset it would be tempting, but it may not be the best idea. For starters, the rental income provides you with a regular cashflow. And selling the property will not only take a while, at least 2-3 months, but will

attract capital gains tax. On balance you might walk away with a smaller amount than you need, not to mention the opportunity to cash in on the property in years to come as part of your retirement plan.

In these situations people sometimes look at superannuation, assuming they've accumulated enough at that point. It is possible to access a super benefit on hardship grounds, but like the property sale mentioned above, there can be other, unintended consequences if you go down this path.

For example, it could have an impact on Centrelink eligibility. And there will be a tax impact, based on the age of the person accessing their super. Delving into super savings could also have longer term retirement funding consequences, especially if one family member is likely to significantly outlive their partner with the medical condition.

Addressing your cashflow is not as simple as it sounds. If you'd like to explore your options, or other aspects of your family's financial future, you may find a discussion with a financial adviser worthwhile. A financial adviser is someone who will understand how to help you or your family, given your unique circumstances.

This information was provided by Outlook Financial Solutions who specialise in finding solutions to help people achieve their goals - regardless of their current financial circumstances, or stage they're at in life. This covers anything from advice on one small issue, through to a complete investment strategy, or a full financial plan.

For more information, call 1300 657 872 or visit www.outlookfs.com.au.

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Understanding DBS Surgery

Deep Brain Stimulation or **DBS** surgery is a medical procedure that may be beneficial in reducing some of the symptoms associated with Parkinson's. It's important to note however, that not everyone is a suitable for surgery and there are stringent measures in place to screen possible candidates, with the aim being to ensure the procedure is as successful as possible.

If you are considering DBS surgery or would like to know more, this is your opportunity to attend a free community information session.

Find out what's involved in the selection process

and surgical procedure, how effective the operation can be and what side effects can occur; Hear from Associate Professor David Williams - a specialist Parkinson's neurologist - who currently works with neurosurgeons in the operating room!

- What: Free community seminar “**Brain Surgery for Parkinson's: Who is it for and what to expect**”.
- When: Thursday, 31 March, 2011, at 10am
- Where: Karralyka Centre, Mines Road, Ringwood East
- To book your seat: Contact Parkinson's Victoria **(03) 9551 1122**.

Access, Advocacy & Assistance

Making the most of support

In each edition of *Signpost*, we provide information and updates on a range of topics and issues, including your rights, how to access peer, financial and professional support, and various assistance schemes, products and services.

If you'd like further details about any of the information covered in this section, or have a question in general about what support services might be available, our health team is just a call or email away:

(03) 9551 1122 or info@parkinsons-vic.org.au
(Enquiries can be anonymous).

Government support for workers

It's a misconception to think a diagnosis of Parkinson's means early retirement from the workforce. Depending on the type of employment, many people living with Parkinson's continue to work for the length of their intended careers.

The following information is taken from an information sheet entitled, '**Disability Employment Services**', written by the Australian Government's Centrelink office, and refers to a Government-funded service that may assist you to find or maintain employment.

What kind of assistance does a Disability Employment Service provide?

If you have a disability, injury or health condition, you may be eligible for assistance from *Disability Employment Services* to find a job or maintain your current employment.

If you are currently looking for work, you will meet in person with your Employment Consultant on a regular basis, as well as receive support over the phone. They will be able to help you prepare a cover letter and resume, do some career planning based on your interests and skills/abilities and help you job search.

They will also assist you to apply for suitable jobs, cold-call potential employers, and practice interview techniques.

If you are already employed, and have been working at least 8 hours a week for 13 weeks, you may be eligible for assistance as a 'Job in Jeopardy' client.

'Jobs in Jeopardy' services are not designed to assist with finding new employment but are intended to assist customers to maintain their current employment.

Jobs in Jeopardy participants will receive face to face support, as well as assistance such as:

- Advice about job redesign: things like going from physical work to an office position, part-time, working from home, different hours, taking more frequent breaks, flexible days and leave options.

- Workplace assessments
- Workplace modifications: the implementation of technology such as speech to text programs, ergonomic chair and desk, building accessibility, the use of prompts, reminders and labels, the installation of air-conditioning.

If you decide to leave the workplace in which modifications have been installed, you have the right to take the equipment with you to a new job.

How do I get a referral to a Disability Employment Service?

If you are not currently employed, you will need to contact Centrelink Employment Services (13 28 50) or visit your local Centrelink office to make an appointment to have a 'Job Capacity Assessment (JCA)'.

If you are a 'Job in Jeopardy' client, you may be able to contact a Disability Employment Service directly without needing to visit a Centrelink office or have a JCA.

You can find your local Disability Employment Service by searching the 'Find a provider' section of the 'Australian JobSearch' website:

www.jobsearch.gov.au

What is a Job Capacity Assessment (JCA)?

A Job Capacity Assessment (JCA) is a comprehensive assessment of an individual's ability to work. The assessment involves identification of any barriers to employment and any assistance that may be required to overcome those barriers. For people with medical conditions or disabilities, the assessment also identifies their current and future work capacity. Information provided by individuals will be used by a Job Capacity Assessor to complete this assessment, to assist in determining the appropriate type and level of support that the individual requires.

When you go to your assessment, you will meet with an assessor and they will talk to you about your employment skills/background and barriers to employment.

The assessment is not a medical examination, however, if you have information from your doctor or health service, the assessor will look at this.

The appointment will normally take between 45-90 minutes.

Afterwards, the assessor will write a report to inform Centrelink how much work you can do, and what assistance you will require to find and maintain employment. The people at Centrelink will then make a referral to a Disability Employment Service in your local area. You may not be able to attend your preferred service initially if they do not have a vacancy, however, you will have the option to request a transfer when a spot does become available.

A copy of your JCA report will also be provided to

Access, Advocacy & Assistance

the Disability Employment Service that you have been referred to.

What incentives do employers have to employ a person with a disability or health condition?

Through the Disability Employment Service, your employer will have access to the 'Wage Subsidy Scheme', which will allow them to claim up to \$1,500 (one-off) to put towards your wages.

For your employer to claim the wage subsidy, you must have been employed for at least eight hours per week for at least 13 weeks and have a reasonable expectation of continuing for more than 13 weeks (or six weeks in a seasonal industry).

The Disability Employment Service can retain up to a maximum of \$400 of the wage subsidy to put towards the purchase of incidental items necessary to support you to take up the job placement, such as steel capped boots or a compulsory work shirt.

The employment must be under open employment conditions. That is, under a legal industrial agreement that complies with minimum standards established under Commonwealth, state or territory law. It must also guarantee the worker a weekly award-based wage, for example: no commission-based or subcontracting type positions.

Funding of up to \$5,000 is available through the Workplace Modifications Scheme (WMS) for essential workplace modifications or special or adaptive equipment for eligible employees with a disability.

This could include the installation of a ramp, air-conditioner, ergonomic chair or speech-to-text computer software. Your Disability Employment Service can assist your employer to apply for funding and will help to coordinate the purchase and installation of any assistive technology or building modifications you may require.

What if I do not wish to disclose that I have Parkinson's to my current or future employer?

It is your personal choice whether or not you disclose a health condition or disability to a future or current employer, unless it could potentially be a health and safety issue.

For example, if you were applying for a job in an office, and your health condition would have no effect on your ability to perform the inherent requirements of the job, then it is not necessary to disclose. However, if you were applying for a position as a forklift driver and you tend to get fatigued in the afternoons, then it may be necessary to disclose for the safety of yourself and others in the workplace.

You may also need to disclose if you require assistive technology or modifications to the workplace, or if you wish for your Employment Consultant to apply for jobs on your behalf or have contact with your future or current employer.

What happens once I get a new job?

Your Employment Consultant will provide you with

ongoing support in person and over the phone until you reach your 26 week employment milestone, and then as long as you need after that.

You will be required to attend regular appointments with your Employment Consultant to discuss how the job is going, and to resolve any problems you may be having. Your Employment Consultant may also be in regular contact with your employer to negotiate your work conditions and any technology/modifications required if your work capacity is expected to change over time as your condition progresses.

If you decide in the future that your job is no longer suitable, or you would like to find alternative employment, your Employment Consultant will help you to job search and update your resume and cover letter.

"Click" for concessions

The Department of Human Services (DHS) has an excellent website outlining the various concessions and entitlements available to people with Parkinson's and which you or a loved one may be eligible for: <http://www.dhs.vic.gov.au/concessions/entitlements>

Such entitlements are designed to reduce the financial (and emotional) impact of Parkinson's on individuals and families and are an indication that the Government is starting to listen.

We encourage you to visit the website and/or contact a member of our health team to discuss the available concessions and your eligibility. Not only will you possibly benefit directly, but you are confirming the need for such support services, and hopefully that means the Government will really begin to sit up and take notice.

We want to make as much noise as possible about the insufficient support and services currently available. Through your actions, you can add your voice to the campaign.

Power of the pen

During last year's World Parkinson's Congress in Glasgow, Scotland, a **Global Parkinson's Pledge** was launched on 28 September, with the aim of securing one million signatures. The Pledge will then be presented at the next World Congress in 2013, in Montreal, Canada.

The Pledge aims to build a global Parkinson's movement, to make Parkinson's a health, social and economic priority around the world, and to advance the cure.

You can add your signature to the pledge online today and join the growing international community (5014 signatures to date) showing their support.

By signing the pledge, you will be joining a global Parkinson's movement for change.

www.parkinsonspledge.org

Making a difference

Volunteer opportunities

"The heart of a volunteer is not measured in size, but by the depth of the commitment to make a difference in the lives of others." DeAnn Hollis

Our ever growing team of volunteers is integral to our work, and their contribution to the Parkinson's community is invaluable. JOSEPHINE BERTHELEMY, Volunteer Coordinator, highlights the volunteering opportunities coming up in 2011.

Happy New Year to you! In my role as **Volunteer Coordinator** at Parkinson's Victoria I spend a lot of time recruiting volunteers for our various fundraising events and other activities.

Our fundraising efforts in 2010 were fun and successful for everyone involved; from our flagship event **Parkinson's Unity Walk**, to smaller community activities including tin rattles at Melbourne CBD railway stations, and charity sausage sizzles at Bunnings.

In December, we hosted a **Thanks a Bunch** party as a token of appreciation to all the wonderful volunteers who helped us throughout the year. Volunteers, Support Group Leaders, special fundraisers, Ambassadors and a number of other supporters joined the staff and Board of Parkinson's Victoria for an enjoyable afternoon at **Sandy by the Bay**, Sandringham, and a surprise visit from Santa brought the house down!

This year, we have set even **higher** goals for raising

funds and awareness in support of those living with Parkinson's in our community, which means lots more fantastic and fun ways to make a difference and get involved by volunteering.

The coming year will see us replicating the successful events of 2010 – and introducing some new ones – and we are always on the lookout for volunteers who are keen to donate their time and energy to help out! Our fundraising activities not only help raise money to fund our support, advocacy and service initiatives and help improve the quality of life and care of people with Parkinson's, but they also help to increase the community's awareness and knowledge of Parkinson's. And of course, our volunteering and fundraising activities are loads of fun and a great opportunity for social interaction, so spread the word to your family, friends and workmates.

Our largest fundraising event is Parkinson's Unity Walk, which will be held on Sunday 28 August, 2011, again at Melbourne's Federation Square. Judging by last year's attendance of nearly 2000 people, this year's walk will be bigger than ever and we will need loads of helpers to assist with tasks, from the registration desk to course marshalling.

If you would like to volunteer for Parkinson's Unity Walk or are interested in volunteering in general, please contact me for more information: (03) 9551 1122, or via e-mail: jo@parkinsons-vic.org.au.

May 2011 bring you and your family health, happiness and good fortune.

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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 twenty thousand Victorians living with this chronic progressive condition, their family, friends and allied health professionals.

Thank you to all those members and special supporters who gave generously towards our annual end of year appeal. We also appreciate those members who made a donation with their membership renewal.

A total of 102 members and 107 non-members made a donation and a total of \$23740 was raised.

In addition, we are grateful to everyone who purchased our 2010 Christmas cards; a total of 15,575 cards were sold, which raised a whopping \$15,054! (Donations made with card purchasers: \$2,900).

Thanks to the following card shops for their support and their wonderful volunteers: **Camcare** (Camberwell Combined Charities Card Shop), **St Paul's Bendigo Charities Christmas Card Shop**, **Banyule Support and Information centre**, **Mornington Community Information and Support Centre** and **Ballarat Combined Charities Shop**.

And the following corporate supporters who made large orders:

City of Casey, **Florey Neuroscience Institutes** and **Rodpak**; between them 1700 cards were purchased, which resulted in a donation of \$689 to Parkinson's Victoria.

A big Tulip Tribute to Anne Atkin and Jean Smith for their beautiful artwork which graced the cover of two cards.

Donations of \$5000 and over

Anna Lepore

Donations of \$2000 and over

Mary Kentish

Donations of \$1000 and over

Paul & Elizabeth Atkinson
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Ross Price
Bryan Ross
Salvatore Sanni
Arthur Schweiger
Ted Smethurst
John RF Smith
Norman Smith
Stewart Terry
Mr/Ms Van der Paal

Bequests

The Late Stella Margaret Hansen
The Late Sheila Marshall

In Celebration of...

Trevor Lau-Gooley (Birthday)

Third Party Fundraising

Girls Night In: hosted by Anne Brozyna
Jazz & Blues Concert: Ernie Kemplay
Charity Band Night: Nicola Randall & Paula Donnelly
Open Garden: Roz Harding
Ruth and "the Tennis Girls"
Tulip Ball: Julie Sewell & Jo Hill

Corporate, Community & other donations/support
Australia's Open Garden Scheme

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Rotary Club of Warrnambool East
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Reflections



The author with husband Chris - and four-legged friends Bailey, Radar, and Allen - during one of the couples regular walks around Lydale Lake. (Radar and Allen were both adopted from Animal Aid).

Change for the better

Sure, Parkinson's means having to change a few things, but JO BOLAND, who was diagnosed at 54, shares her thoughts on how - in many ways - it's been a change for the better. Her personal reflections highlight how important it has been to look after herself, both mentally and physically, and not just rely on medication.

I am 54 years old and I was diagnosed with Parkinson's in 2006.

After years of feeling unwell, I finally had a diagnosis. Oddly enough, my initial emotion was relief; even though I knew the news would not be good, when I was diagnosed with Parkinson's I thought "at least there is medication." If I had to have a neurological disease, this was the 'better' one to have.

I was started immediately on medication and initially felt better than I had for years, almost a euphoric feeling of relief from symptoms.

It took me sometime though to really get my head around the fact that I had a degenerative illness and would not regain my health so I researched alternative treatments.

I did find some forms of massage and meditation helped, and I take Spirulina an excellent and affordable supplement and fish oil capsules*.

However, I was soon disillusioned by claims to be able to cure Parkinson's with every thing from healthy chocolates to fruit juice diets costing hundreds of dollars.

So, instead began to look for stories about people who were living and coping with Parkinson's. I knew that everyone's journey would be different, but I craved reassurance that, **Yes! You can still have a life.**

I definitely will not say that I am grateful to have Parkinson's, but it has been the catalyst to make some huge lifestyle changes that I would not have had the courage to make otherwise.

My family is debt free, thanks to the sale of our property, and I am enjoying retirement from a very demanding (although much loved) job as the CEO of an animal welfare charity.

I am coping with Parkinson's and I love this quote: I have Parkinson's but it does not have me.

People ask me how I cope and I say that I don't have a choice, so I just get on with living. I don't allow self pity, nor do I look to the future I just take it day-by-day. In fact, I've found that a real problem for me is not so much how I handle my illness, but how other people react to it!

The reaction of some of my family and friends has been the most difficult thing for me to deal with. Many were sceptical about the diagnoses of Parkinson's, saying that the symptoms were more likely to be caused by menopause and a bad back. When I tried to talk about Parkinson's, I would sense the scepticism or get the dismissive comment "Oh, I get that (insert symptom) all the time". Frustratingly for me, I could not find the words to adequately describe the weird feelings, pain and discomfort that is Parkinson's.

I can be feeling lousy...but still look perfectly well, so it's hard for some people to understand that I am not seeking attention or sympathy. I don't need to talk about Parkinson's now, but it was hurtful initially, in the early days after diagnosis when I needed support and understanding. Thankfully I have a wonderfully supportive husband.

I walk my dogs rain hail or shine, even on the days when I move like I belong to the ministry of funny walks. I cannot stress enough the importance of exercise in my management of pain and other symptoms associated with Parkinson's. I am about to start Yoga and my husband purchased a TENS machine** to help with pain management and i've found it works really well. I also find foot massage and a form of shiatsu massage bring temporary relief from stiffness and pain. Meditation helps me cope when my medication is wearing off.

To keep my brain active I play Mah-Jong, a Machiavellian Chinese game with tiles that really helps with memory and focus. It has also helped me meet people and make new friends. I have joined the local garden club and I continue my association with the Animal Aid as a volunteer Board Member.

I applied for Total Permanent Disability Insurance [a payment provided through Superannuation funds] in July [2010], which was approved and we received a lump sum payout.

My Parkinson's is progressing and I take a number of medications now to control symptoms, but I just adapt my life to accommodate and when necessary devise new ways to manage tasks.

Life does continue after diagnosis. Yes, quality of life is affected, but yes, you can cope if you have the right attitude and a sense of humour.

Authors note: If people with Parkinson's are experiencing difficulty managing pets or would like advice on how to obtain a suitable companion animal Animal Aid may be able to assist.

www.animalaid.com.au

*Health team note: Both Spirulina and Fish Oil capsules are dietary supplements which some people believe may have neuro-protective qualities. Some small studies may suggest that they are beneficial in Parkinson's. Like most dietary supplements, they should be used as a complimentary therapy – and may be helpful for general wellbeing.

TENS machine works by delivering little, painless electric pulses via electrodes attached to areas of your body. These electrical pulses encourage your body to produce endorphins and can block pain signals travelling between the area of discomfort and your brain. **TENS are used as pain relief and pain control. They are not a cure for the underlying cause of the pain. You should only use a TENS machine if recommended to do so by your GP or other healthcare professional.