

# SIGNPOST

Winter 2014 • Volume 13 Issue 2 A Magazine for people living with Parkinson's

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# News & Highlights

## PRESIDENT'S MESSAGE



Welcome to the second edition of Signpost for 2014.

When I think about 'time' – the theme of this issue – I think about change; I think about how very different the world we live in now

is from the world of our grandparents, and how different the world will be for our grandchildren. And I think about my own role in this world, and what I will do with my time here. How will I make a difference?

Like many of the wonderful people in the Parkinson's community, the desire to create a better world for future generations is a key driver for me. As a board member, it is a privilege and a great responsibility to have the opportunity to take an active role in shaping the future of Parkinson's Victoria and to support positive change for people with Parkinson's and their families.

But I always remember that Parkinson's Victoria is an organization that belongs to its members – we are here to represent you, to reflect your needs and expectations. This is why the board initiated a market research project, to better understand our successes, and to clarify where we must improve. The results of the market research are being studied by the board and staff, and from that we will create goals and objectives to ensure we're on track and in-line with the community's needs.

The results to date have been very encouraging. The survey participants were asked to describe the function of Parkinson's Victoria in their own words. The key words nominated were support, information, awareness and education. This was an exciting result for us, because it corresponds so well with our organisational vision of Parkinson's Victoria as a leader of the global knowledge network – championing the value of innovation and education in changing the future for people with Parkinson's and their loved ones.

You, our members and supporters, are at the heart of everything we do. With your continued support, we will make the most of the time we have in 2014 to improve the lives of people with Parkinson's in Victoria and all over Australia.

Damien Farrell  
President  
Parkinson's Victoria Board

## CEO'S MESSAGE



Welcome to the Winter 2014 issue of Signpost. This issue revolves around the theme of time, something we all think about – whether it's trying to find time for self-care, make time for our friends and family, thinking about the future, or remembering the past, time can't be ignored!

For the team at Parkinson's Victoria, 'time' is also about making the most of our time here as supporters, advocates and leaders of the Parkinson's community. It is our goal to represent and move the community forward, which can only be done with hard work and a strong grasp of the issues that face the Parkinson's community. This is why, earlier this year, we undertook some market research – to better understand our role, your experiences with us and to find a shared vision to strive for in the coming years.

We were pleased with the outcomes of the research; it has reinforced the importance of Parkinson's Victoria as an educator and connector within the community, but also showed us where we need to improve: notably, in building awareness of the services and supports available to our members, and growing our capabilities online.

A few key notes from the research:

- The most accessed support was community events, followed by support groups
- 81% of respondents rated our services as good to excellent
- 84% of respondents rated the information we provide as good to excellent
- 30% of respondents are employed full-time, 26% part time/casual, and 36% are retired
- Education services were used by more than 60% of respondents
- Webinars and online education were nominated as favourable methods for information delivery and engagement

Over the coming months, we will be working further to analyse the results of our research and, in turn, use that information to build better services, supports and resources. 2014 will be a year of growth, change and action for Parkinson's Victoria – we have a fabulous community behind us; I thank you for your ongoing support, and look forward to going on this exciting journey with you.

Emma Collin  
Chief Executive Officer  
Parkinson's Victoria

## WORLD PARKINSON'S DAY 2014

World Parkinson's Day is marked on April 11 each year, the date of Dr James Parkinson's birthday.

World Parkinson's Day seeks to raise awareness of Parkinson's and improve the lives of the more than 7 million people living with the condition globally.

Our focus for this year was the Parkinson's Victoria motto 'Help for Today, Hope for Tomorrow'. Parkinson's Victoria partnered with the Florey Institute of Neuroscience and Mental Health to put together a symposium of neurologists, clinicians and researchers, looking at the latest developments in Parkinson's research.

Held on the eve of World Parkinson's Day, this was followed by a public lecture at the Melbourne Brain Centre in Parkville. The event was attended by 250 people with Parkinson's, their family and friends, health professionals and researchers.

Professors Meg Morris and Mal Horne delivered a highly informative session discussing current treatments for Parkinson's, as well as up-and-coming research.

### Dance for Parkinson's

We are excited to inform you of two different groups that are now offering dance classes for people with Parkinson's!

#### *Dance for Parkinson's*

Modeled after the Dance for PD® program in the United States, this is a creative movement class for people with Parkinson's and their carers or friends. No dance experience is required and the class is suitable for all stages of Parkinson's (much of the class is chair-based).

Classes run on Friday mornings in Camberwell.

For more information and to register call 0449 058 360 or email [quixoticdancetech@gmail.com](mailto:quixoticdancetech@gmail.com)

#### *Tango for Parkinson's*

Tango teacher Rina Sawaya has created the content of these classes specifically for people with Parkinson's. Music with a strong beat – such as tango music – can act as a cue to trigger movement in Parkinson's, and there is currently research exploring Tango for Parkinson's further. No dance experience is required, but you do need to bring a letter from your doctor stating you are able to participate in Tango.

Classes run on Thursdays in Lower Templestowe.

For more information and to register email [rina@tangotherapyaustralia.com.au](mailto:rina@tangotherapyaustralia.com.au)

### PD Warrior Comes to Victoria

Two specialist neuro-physiotherapists from the Advanced Rehabilitation Centre in Sydney visited Melbourne in February to deliver a two-day instructor course for the PD Warrior™ program.

PD Warrior™ is a unique therapy approach using various exercises to help build confidence, improve mobility and fight the symptoms of Parkinson's disease. The exercises performed in PD Warrior™ have been specifically designed for people with Parkinson's and are targeted at creating more efficient neural pathways in the brain.

The instructor course in February was attended by health professionals (predominantly physiotherapists) from across Victoria. There were also many members of the Parkinson's community who volunteered their time to assist in the training of instructors.

Although there are currently no PD Warrior™ programs operating in Victoria, there are various physiotherapists across the state trained to implement the program. If you are interested in PD Warrior™, please discuss it with your physiotherapist or phone Parkinson's Victoria. Hopefully we will see this innovative program up and running in Victoria soon.

# Tulip Tribute: Paddle for Parkinson's

On April 6 2014, Sam Faulkner and Tyler McPhee set off on an incredible journey: kayaking 800 kilometres along the Murray River, from Echuca to Mildura, to raise money and awareness for Parkinson's Disease.



Before they left, Tyler took the time to speak to us about this trip of a lifetime.

## **First things first: where did the idea come from? Are you regular paddlers?**

We haven't kayaked, really, at all; we just decided one day that we were going to do it! We had paddled from Lock 11 in Mildura to Lock 10 in Wentworth, which is about 50 kilometres; we did that once last year, and we were talking about doing it again at some stage, and then it sort of just escalated really quickly. We didn't want to just paddle 100 kilometres – that was too far – then the next minute we were doing 800 kilometres.

## **That's quite a big jump!**

We don't really know how we came up with it – we were just sitting around talking about it, and went 'Oh yeah... we can do it', so now we're going to do it.

## **Did the idea to make it a 'Paddle for Parkinson's' come first, or later?**

That came later; after we decided we were going to do the paddle, we thought that since we're doing it to such a big scale, we may as well try and make it for a good cause. Paddle starts with P, so we ended up choosing Parkinson's! It's close to

home for Sam; his mum's mum has Parkinson's and his dad's dad has it too. I have a few family friends who have it, as well.

## **Have you learned about Parkinson's since you started fundraising?**

We have a little bit – we know a lot more about it now than when we started, that's for sure. We've read quite a few things about how many people it affects, the general statistics; we've spoken to a local support group leader, he gave us some more local information, and had a chat with us about it.

Everyone we go and see about sponsorship or raising money is somehow connected to Parkinson's; we didn't realise it was such a big thing, and then everyone everywhere seems to know someone who is affected by it.

## **You've been fundraising as you've been going...**

We've been doing pretty well on that side of things – everyone in Mildura seems to be helping out heaps. The local support has just been incredible; everyone seems to be helping out as much as they can, any way they can. We haven't had a problem fundraising.

It actually only took us a month or so to raise our first \$3000 – people donating, or saying they would donate. And we've got shirts made up for the event with sponsors.

The community response has been fantastic; it's been a bit of everything. A lot of family support, family friends and surroundings; even in general, the local businesses donating goods.



# Tulip Tribute: Paddle for Parkinson's

## Any friends/family keeping you company during your trip?

Not yet – we're just going, the two of us. By the time we get home, I won't want to see him for three weeks! No-one's planned on following us; [our parents] wanted to be a support crew, but we don't know what the river's like that end... Here it's great, you can stop nearly every kilometre and find someone really easily. But down there, we think it's a lot more stranded, it would be more difficult if we had a support crew and they had all of our stuff – if we got stuck by the tide, or it started raining and all of a sudden we had nothing... we didn't want to bug anybody like that.

## How long have you and Sam known each other?

We met in Year 9, so six or seven years.

## So you know you can put up with each other then...

Yeah – we've probably become better friends since we left school. After school a lot of people went their separate ways, but Sam and I stayed in Mildura and have become better friends since school finished.

We've already started planning the next trip... We've decided we need something to talk about on the river, so we'll start planning the next one.

## How long is this trip meant to take?

It's meant to take about 17 days, if we keep to schedule; but that means we come home Easter Tuesday, and we're trying to make it so we come home on Good Friday. We're aiming for about 50 kilometres per day, but I think that around Echuca the river runs a lot quicker than it does around here, so we'll be able to do that fairly comfortably... and to get home 5 days early, we need to do about 80 kilometres a day.

## You've done a paddle of 50 kilometres once or twice... but that's nothing compared to what's coming up! How have you trained for the trip?

Good question... I'll fill you in next week, because we haven't trained yet! We're still casual



paddlers. We have done four or five training sessions of, like, 10 kilometres.

## You're going to be camping the whole time... what's on the menu?

We bought 10 kilos of pasta.... and 10 kilos of rice. And that's sort of, it really.

## Is there a plan for something goes wrong?

We have a GPS device that's connected to the Facebook page; it's setup to call our parents, and there's an emergency beacon on it that will go to the SES or someone... we've got time to figure it out. We have a satellite phone as well.

## Are you looking forward to heading off?

I can't wait to get on the river, and get away. It's been pretty stressful here at home – every five minutes someone's ringing you, or vice versa. We just haven't had a break. Sam and I used to both go to bed reasonably early-ish, and I haven't made it to bed before midnight for the last three weeks, just trying to organise stuff and having meetings. We just can't wait to get on the river.

**As we go to print, Sam and Tyler have raised over \$16,000! If you would like to contribute, donations can be made directly to their fundraising account with the Bendigo Bank:**

BSB: 633-000  
Acc No.:151 253 549

*Please leave your name as a reference.*

*Any donation over \$2 is tax deductible and you can be provided with a tax invoice upon request.*

## MAKING THE MOST OF TIME WITH YOUR DOCTOR



Time with your doctor – particularly a specialist – is often limited, so it's important to make the most of your appointments. Here are some tips to help you get the most out of the time you have with the doctor.

### Prepare in advance:

- If you think you'll need more time, ask for a longer appointment. Some doctors allow you to book a double or extended appointment in advance
- Think about the questions you want to ask before your visit and write a list so you don't have to keep them all in your head. List your most important questions first, in case time runs out
- Keep a *brief* diary of your movements and medications in the couple of days before your appointment and take it along with you - your doctor may pick up on patterns or symptoms and adjust your treatments accordingly
- Consider taking a family member or friend with you as a second set of ears

### During the appointment:

- Don't be afraid to ask questions, especially if you don't understand something, or if you want more information about something your doctor has said
- Write down any important information or instructions that you are given, or ask the doctor to write them down for you

- Tell your doctor about any new or unusual symptoms that you have noticed – even if you think they are unrelated to Parkinson's
- Tell your doctor or health professional if you need time to think or to discuss something with family members

### Time between appointments:

Typically there are a number of months between doctor appointments. If issues arise during this in between time, don't feel that you are 'stuck' until you have the chance to see your doctor again.

Do you actually need the doctor, or can someone else help?

- Parkinson's is a complex condition and it is beneficial to have a few health professionals who can address the range of Parkinson's symptoms. For example: a pharmacist can help you to understand your medicines and how to use them safely and correctly; occupational therapists, speech pathologists, physiotherapists and counsellors can help you manage various symptoms
- The health team at Parkinson's Victoria may be able to answer your questions or concerns, or refer you to someone else who can

If the matter can't wait:

- See if you can move your appointment forward. Most doctors can put you on a cancellation list, meaning that you can get in earlier if another patient cancels their appointment
- Try phoning the doctor's office – some questions can be answered quickly over the phone and may not need a face-to-face appointment. While the doctor may not be available straight away, they can often return your call at a later stage
- Consider using other quick-response services that can 'tide you over' until you can see your doctor, such as Health Direct Australia on 1800 022 222 (after hours GP helpline) or Nurse-on-Call (1300 60 60 24). While these services are not Parkinson's-specific, they can offer medical or nursing advice of a general nature

# Welcome to PSP Pages

Welcome to PSP Pages, a new section of Signpost dedicated to the needs of people impacted by Atypical Parkinson's.

The conditions we know as Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico Basal Syndrome (CBS) have been supported by PSP Australia and Parkinson's Victoria for many years.

Parkinson's Victoria is moving forward, and to reflect the diverse community we represent and their many shared issues, the PSP Australia newsletter will now be incorporated into **Signpost**.

A message from Anne Mooney, Convener of PSP Australia

*Hello dear members and friends,*

*As you have read, PSP Australia will now sit firmly under the 'umbrella' of Parkinson's Victoria. Over the past five years, we have grown in membership – in no small part, due to the fact that we now care for MSA and CBS, as well as PSP.*

*The complexity and nature of these conditions requires and deserves nothing less than professional input, contribution and advice. I would like to assure everyone that the vital aspect of carer support which we as a group have provided in the past, remains unchanged.*

*Moving forward, by benefitting from the professionalism of Parkinson's Victoria, PSP Australia will continue to nurture our carers and their loved ones through their journey.*

*Two support groups currently operate, and we are looking to establish further groups in Victoria and interstate in the near future.*

*This union with Parkinson's Victoria ensures PSP Australia will continue to increase its awareness, advocacy and the community's knowledge and understanding of these conditions.*

*Please join me as we look forward to an exciting future.*

Anne Mooney

## Facts about CBS

- **Cortico Basal Syndrome (CBS)** is caused by a disease called 'Cortico Basal Degeneration' (CBD)
- CBS/CBD is very hard to diagnose
- Around 150 Australians have CBS/CBD, but there may be many who have the condition and have been incorrectly diagnosed

- Symptoms usually begin around the age of 60
- CBS/CBD is not contagious, and does not run in families
- People with CBS develop problems with stiff muscles, memory loss, swallowing, movement and balance
- There is no cure, however research is underway to provide hope for the future

## Facts about MSA

- **Multiple System Atrophy (MSA)** is a rare neurological (brain) condition
- MSA is very hard to diagnose
- MSA is rare; approximately 2,500 Australians have been diagnosed
- Symptoms usually begin between the ages of 50 and 60
- MSA is not contagious, and does not run in families
- People with MSA develop problems with low blood pressure, bladder control, constipation, weakness of arms/legs, sleep, swallowing, poor balance and coordination
- There is no known cure, however research is underway to provide hope for the future

## Facts about PSP

- **PSP** stands for '**Progressive Supranuclear Palsy**'.
- It is sometimes known as 'Steel Richardson Syndrome'
- PSP is very hard to diagnose
- As many as 1300 Australians may be living with PSP
- PSP most commonly affects people aged between 60 and 70
- PSP does not run in families
- People with PSP develop problems with communication, swallowing, movement and balance
- There is no cure, however research activities are ongoing in Australia and around the world

# PSP: Planning Ahead

## PLANNING AHEAD FOR PSP

In keeping with this month's Signpost theme of *Time*, this issue's article for PSP Australia will centre on the idea of looking forward in time and planning ahead. For people living with PSP and related disorders a common question is 'What can I do now to prepare for future changes?' We hope that this article will provide readers with practical advice on how to plan and prepare for the future.

### Accessing In-Home Support

Throughout Victoria, the HACC (Home and Community Care) program is available to support people whose capacity for independent living is at risk. The main types of services include:

- Domestic assistance
- Personal care
- Property maintenance
- Nursing (community nursing)
- Allied health services (physiotherapy, occupational therapy, speech pathology, dietetics, social work, podiatry, etc)
- Food services (e.g. Meals on Wheels)
- Planned activity groups
- Respite services

If you are unsure about the services available in your area and how to access them, your local council is a good first port of call. In Victoria, local councils are a major provider of HACC services. They assess your needs and can refer you to other HACC services.

Community health centres provide a range of nursing and allied health services. The majority of their services are funded via the HACC program. They can also be a good source of information.

Aged Care Assessment Services (ACAS) provide comprehensive assessments for older people in order to help them access services that are appropriate to their care needs. If necessary, ACAS will arrange referrals to HACC providers following assessment. Depending on your level of function, you may be assessed as eligible to receive a



funding package, which entitles you to a specified amount of in-home support.

### Accessing Health Services

There are numerous community and hospital-based health services available across Melbourne to assist people with PSP and related disorders. To access specialist multidisciplinary treatment, it is advisable to gain a referral to a Movement Disorder Centre. These centres normally provide access to a range of medical and allied health professionals with specific experience in PSP, MSA and CBD. For contact details of the Movement Disorder Centres located across Melbourne, please contact Parkinson's Victoria on 1800 644 189.

# PSP: Planning Ahead

As mentioned previously, community health centres provide various HACC funded services; while staff there may not have specialist knowledge in atypical movement disorders, they can often provide tailored support. Most community health services have various mobile health teams who are able to provide in-home care, treatment and advice on how to remain safely in your own home.

## Equipment and Home Modifications

A useful way to remain safe and functional in your own home can be to set up adaptive equipment and home modifications. These changes can enable the person with PSP and their carer/s to compensate for impairments and changes in function.

In Victoria, there is funding support available to assist with the purchase of equipment and the completion of home modifications through the State-Wide Equipment Program (SWEP). SWEP provides a subsidy toward the cost of aids, equipment or modifications. To obtain SWEP funding you must have an Occupational Therapy or Physio assessment to determine the equipment or modification best suited to your needs. They will also complete the relevant documentation.

### Equipment

People living with PSP and related disorders often benefit from equipment such as walking frames, pressure care equipment, shower chairs, over-toilet aids, continence supplies and transfer aids. The Independent Living Centre is a valuable resource for information related to equipment. You can visit their website at <http://ilcaustralia.org.au> or speak to a health professional on 1300 885 886.

In most instances, equipment provided by SWEP remains the property of SWEP. It is considered a permanent loan and can remain in your possession for as long as needed. The benefit of this is that SWEP will cover most repair and maintenance costs.

Keep in mind that in some instances it may be quicker and more convenient to purchase the equipment yourself (instead of waiting for SWEP funding). However, this can easily become a costly expense if multiple items of equipment are required.



### Home Modifications

Whether you are applying for SWEP funding or not, it is advisable to be assessed by an OT to determine your home modification needs. OTs have specialist training and experience in recommending home modifications to meet your specific set of needs.

However, if you do not wish to receive SWEP funding you can go ahead and have modifications completed at your own expense. This will most likely be quicker than waiting for SWEP approval but it is likely to be more costly. If you have chosen to complete the modifications without consulting an OT, you may also find that the changes are not suited to your needs.

If the OT is not familiar with atypical movement disorders such as PSP, MSA and CBD, advise them to contact Parkinson's Victoria for further information. When considering the need for home modifications, **keep in mind that these disorders are progressive and the patient's level of function will continue to decline over time, often quite rapidly.** People living with PSP and their carers should carefully consider if it is worth spending thousands of dollars on home modifications which may only be suited to your needs for a short period of time.

*For more information, contact SWEP on 1300 74 7937.*

*If you have any questions related to this article, please phone the Parkinson's Victoria health team on 1800 644 189.*

# Get it on time

Getting your medication on time is something everyone living with Parkinson's is focused on. We know that the fluctuations in dopamine levels directly affect how well you move, as well as the less visible non-motor symptoms of anxiety, depression and even worsening bladder control. These ups and downs are connected to the dopamine replacement therapy coming in tablet form, creating peaks and troughs in dopamine levels.

When you start taking medication for Parkinson's, getting into the habit of taking it on time every time is a good thing! When you first start taking medications you probably don't notice the peaks and troughs, and may not even notice if you forget your medication for the whole day. However the longer you live with Parkinson's, the more important it becomes!

To help get your medications on time many people will invest in a medication timer; this could be a watch, a pillbox timer or setting alarms on your mobile phone. We are also seeing a rise in smartphone applications (for iPhones, etc) that can have medication alerts (see page 14 for a review of one such app). If you're going to use a device, it may be valuable to put some thought into what you select. For example, purchasing a medication timer watch may be a good idea, however unless you are in the habit of carrying your meds with you, it may not be the ideal solution (HINT: when you buy your watch or smartphone, buy a pillbox as well, so you associate the two items as being connected).

Maintaining good medication habits can become more difficult when you go into hospital or somewhere where you hand the control of your medications over to someone else. Not getting medications on time when in hospital is the number one difficulty experienced by people living with Parkinson's worldwide, so you are not alone in this.

To help reduce this problem, you can take a few precautions!

- Ask if you are able to self-medicate when you are in hospital
- Tell the staff when you take your medications, clearly emphasising that if you don't get your medications within 10 minutes of the time they are due, your symptoms will get worse (and you will need to ask them for more help)
- Keep using your medication timer so you can ask for your medications when they are due
- Never be worried to speak up and raise concerns with the nurse in charge

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The next state election is looming large on our calendars! As the political campaigns ramp up, and the pointy end of the election cycle approaches, we are reminded of the importance of running a strong, community led advocacy campaign to drive change.

Though the election is a fantastic opportunity to bring the needs of the Parkinson's community to the fore, systemic reform – greater awareness of, and support for, the needs of people with Parkinson's Disease, their carers and their families – cannot and will not come from election-cycle campaigning; it must come from a continuous and cohesive advocacy agenda that is vigourously and tenaciously pursued every day of the year.

Parkinson's Victoria is here to ensure voices from the Parkinson's community are heard in the offices of politicians, policy makers and influencers all year-round; this ongoing advocacy means that when opportunities present themselves, we have the voices, stories and evidence to make ourselves heard, seen and understood.

To make the most impact, however, we need your voice. How can you be an advocate for Parkinson's? Here are a few simple ideas:

### Talk to other people with Parkinson's

If you're not a member of a support group, find out if there's one near you... or maybe you could even start one! Talk to the team at Parkinson's Victoria to find out about support groups around Victoria.

Groups can be really effective in getting the word about Parkinson's out into the community through events, fundraisers and lobbying local politicians about Parkinson's issues.

### Talk to your local MP

Talking to your local MP is easier than you may think – and whether you choose to tell them your own story or meet with them to lobby for a specific service or issue, each mention of Parkinson's that reaches our politicians' ears is an opportunity to put Parkinson's on the political radar. Go to <http://www.parliament.vic.gov.au> to find lists of members of parliament and relevant ministers to contact, as well as advice on how to address them.

### Talk to the public

If there is an issue that you are passionate about, a person with Parkinson's you think deserves a pat on the back, or a fundraiser that needs promoting, try contacting local media. Local papers and radio stations are a great place to start - just remember that they're looking for stories that will interest and engage the community, so make sure you have a 'hook'.

# Advance Care Planning

## ADVANCE CARE PLANNING: HAVING THE CONVERSATION

Have you ever thought about what would happen if you got sick and couldn't tell your doctors what you wanted? Living with Parkinson's, we can become very familiar with doctors, interact frequently with health services, and by default become 'experts' in managing Parkinson's and related movement disorders. We trust our neurologist will make the correct decisions in managing our health, and often we do not consider what we may do in the future, or if we were involved in a medical emergency.



When thinking over these issues, many people who are living with movement disorders consider quality of life to be more important than length of life; however, in the event of an emergency, medical staff are compelled to provide active life-saving measures unless they have been made aware of your wishes otherwise.

This difficulty is not isolated to Parkinson's and for the last four years the state government, in collaboration with key health workers and patient representative bodies including Parkinson's Victoria and PSP Australia, have developed a tool for health care professionals, **Advance care planning: have the conversation**. This toolkit provides a user-friendly resource to assist health care professionals in speaking with patients about the need to think about future medical treatments and to document your wishes. Here are some of the common questions raised by health care consumers as we developed this tool.

### What is advance care planning?

Advance care planning is the process of planning for your future health and personal care where your beliefs, values and preferences are made known to assist in making decisions about your medical treatments. An advance care plan documents your wishes in the event you are not able to communicate these wishes for yourself.

An advance care plan may come under several names: medical directive, statement of choice, or living will. Putting your wishes in writing strengthens them; the gold standard is to seek legal support and formalise your plan in a document supported by assigning medical, legal, financial and lifestyle powers of attorney. Guidance on the powers of attorney is available from both State Trustees and The Office of the Public Advocate. In Australia each state has different ways to document powers of attorney and, if you are moving or your address is interstate, you will need to check which laws apply to you.

### Why is it important?

Thinking ahead in Parkinson's and other movement disorders is particularly important as they are slow, progressive and can leave you in a situation where, with little notice, a crisis arises. This could be a fall or a serious infection, and all of a sudden a medical decision needs to be made quickly. Removing the decision-making burden from our families, thinking ahead, having the conversation, and then writing it down is a great way of reducing the pressure in a stressful situation.

### When should you consider getting an advance care plan?

Ideally, everyone should think about an advance care plan and have the conversation with their

# Advance Care Planning

families. Often this conversation is a natural progression into a discussion about organ donation, or if you have considered donating your brain to the Parkinson's and movement disorder Brain Bank.

Even if you don't initially write everything down, it's worth making a few notes that will provide a guide for your family in the event they are called upon to represent your wishes.

## Side note:

Donating your brain to the Brain Bank can be an important contribution to Parkinson's research. You are able to be an organ donor and a brain donor, however organ donation will take precedence and in this circumstance brain donation will not be able to occur. For more information about donating to the Brain Bank, or if you want to discuss this further, please contact the Parkinson's Victoria Health Team via the contact details below.

A reason for developing an advance care plan early is so we can overcome any concerns in regard to 'capacity'. Capacity means your ability to make reasoned decisions, free of influence and unimpacted by any changes in cognitive ability. Generally, the older we are when we make decisions that may impact serious issues like health care or finances, the more likely it is that someone may question your capacity. As many people with Parkinson's may have slower communication that may be misinterpreted as reduced capacity, considering an advance care plan earlier can help in avoiding conflict and stress in the future.

## What happens if my family have to use it?

The advance care plan, which reflects your wishes, will help medical and hospital staff by providing insight into your wishes in regard to treatment, so they can provide the best information to your family. This doesn't mean that the hospital won't provide the treatment you need; for example, if you have stated you don't want treatment in a situation where a medical assessment identifies that the current problem is reversible and easily treated, this will be discussed with your family, who will be able to make the best decision possible for you.



In the event an advance care plan needs to be used, if it has been shared with the healthcare staff, they will be able to start putting your plans into action. Your plan provides a framework for communication, as well as treatments, helping to keep your family informed.

## What happens if my condition changes or I change my mind?

When you develop an advance care plan, it's not set in stone! As your condition changes, or when you do more thinking about what treatment you would want, you are able to modify your wishes at any time. If you have developed a plan, it's a good idea to periodically reflect on the wishes you have written down, as our thoughts and attitudes may change as life progresses.

Advance care planning is about having a conversation with your family, your GP and your neurologist. This is an ongoing conversation, and it's normal for the plan to change over time.

We often worry about upsetting people when we raise these issues – it reminds us progression is occurring and the future will be different, and it can be a hard conversation to have. The benefit of having the conversation is that it really does provide some peace of mind and gives your family members the confidence to represent your wishes in the event that you are unable to.

*Further information about advance care planning is available from the Health Information Team at Parkinson's Victoria on (03) 9581 8700 or email [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au).*

# App Review

## MEDISAFE MEDICATION AND PILL REMINDER

Getting medications on time is one of the most important parts of medical care for people living with Parkinson's. However, remembering to take prescribed medication at the correct time is easier for some than for others. Luckily, there is now an abundance of apps available to assist people in maintaining compliance with their medications. The *MediSafe Medication and Pill Reminder* app is one such example. It is not a Parkinson's-specific app, but is applicable to people living with Parkinson's.

MediSafe is a free app available on both Android and Apple operating systems.

### Content

*MediSafe* offers a single location for users to record their complete list of medications, and the schedule for taking those medications. The app sounds an alarm or alert tone each time medication is due. Alarms will continue to sound every five minutes until acknowledged that the correct dose has been taken.

Additional functions of the app include the ability to:

- notify a nominated person in the event of a missed medication,
- receive a notification when scripts are due for refill, and
- export information to Microsoft Excel.

### Useability

Upon opening the app, users are prompted to enter their medications. The colour and shape of each medication can be selected to provide a visual cue as to what medications are due to be taken.

Alarms will alert the user to take their medication. Selecting 'take' when the notification appears, acknowledges the medication has been taken.

After medications have been entered, the only reason to open the app again would be to modify your medication schedule or review past medication compliance. To edit medication names, dosage or timing, simply open the app, click on the image of the medication, and select the small pencil symbol.

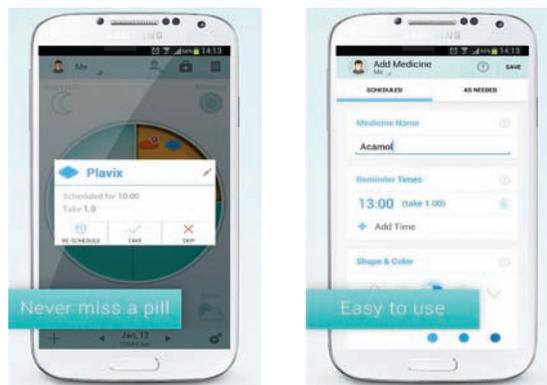
All in all, *Medisafe* was simple to use and visually appealing. The reminders were reliable and on time.

### Limitations

The *Medisafe* app performs its function as well as can be expected. However, there are some limitations associated in the use of apps as medication reminders in general. For instance, the user must have their smartphone or tablet with them at all times. If the device's volume has been turned down, it may be difficult to hear the notifications (although a vibrating alert is possible). If the device has lost its battery charge, medication reminders will not be possible.

### Other medication reminder apps

There is an abundance of apps, available on both Android and Apple app stores, offering a medication reminder function. Parkinson's Victoria does not favour any app over another. The *Medisafe* app was selected in this instance as it had high user ratings and favourable reviews. If you're interested in trialling medication reminder apps, just search "medication reminders" in your app store. When selecting an app, people with Parkinson's should ensure the app is able to handle multiple different medications, dosages and timings. It is also important that medications, dosages and timings can be easily changed, as the medication schedule for people living with Parkinson's can be subject to regular changes.



# A WALK IN THE PARK 2014

## SUNDAY 31 AUGUST, 2014 FEDERATION SQUARE, MELBOURNE

Since A Walk in the Park was first held in Victoria in 2009, more than \$300,000 has been raised to assist Parkinson's Victoria in its work supporting people living with Parkinson's and to fund vital research.

Be part of Victoria's biggest charity event in support and celebration of all those whose lives have been touched by Parkinson's... all you need to do is take A Walk in the Park!

A leisurely, non-competitive 4km (return route) walk, or 2km shortcut, along Melbourne's picturesque Yarra River, A Walk in the Park is the major fundraising and awareness-raising event for Parkinson's Victoria. With free entertainment, activities for the kids and a traditional Sausage Sizzle, A Walk in the Park is the perfect day out to meet new people and catch up with friends and family.

When you participate in A Walk in the Park, you'll join hundreds of others who are living with, or are touched by, Parkinson's. Joining in makes a powerful and public statement of support. But even better, you can make a significant personal contribution to the everyday work of Parkinson's Victoria and the search for a cure by making a donation or actively fundraising.

With 2,500 people expected to participate in A Walk in the Park this year, and a record \$145,000 raised last year, we believe our goal of \$150,000 is definitely achievable. Just think: if every participant was able to fundraise \$100 –that's just \$10 from 10 friends - we'll get there in no time!

### **There are lots of ways you can get involved and show your support.**

Whether you walk, roll or stroll on the day, fundraise on your own or make a donation, everyone can help make a difference.

- Register to take A Walk in the Park at [www.parkinsonswalk.com.au](http://www.parkinsonswalk.com.au)



- Invite friends, workmates, family, neighbours, local retailers – everyone you know – to join you
- Actively fundraise
- Make a donation
- Sponsor a walker
- Get your workplace, school, community group involved
- Display posters in your local neighbourhood. Contact Parkinson's Victoria to get your copies!

If you raise just \$25 you'll receive a limited edition A Walk in the Park 2014 t-shirt, and we'll post your t-shirt and event kit out to you before the event (if funds have been raised by 15 August)!

*50% of all funds raised will go to support the everyday work of Parkinson's Victoria; the other 50% supports important research to find a cure and to improve quality of life for people living with Parkinson's.*

**Go to [www.parkinsonswalk.com.au](http://www.parkinsonswalk.com.au) for more information and to register for A Walk in the Park 2014.**

# Taking time: for carers

One of the biggest shifts a person faces as they transition into caring is the time restrictions it can place on their life – especially if they're balancing work and care. Many carers feel they have little or no time to themselves. And that's where time management strategies can relieve stress and make way for vital 'me' time. Here are our top 4 time management strategies.



## 1. To-do-list

Taking a few minutes in the morning to write a to-do-list can end up saving you valuable time later in the day. Start with writing the top priorities for the day, and leave the less important things till last. Shopping lists can also be an effective time saving tool – they can mean the difference between one supermarket trip a week and time-consuming daily shops. The most important thing to remember with a to-do-list is to accept that you may not have time to accomplish everything you wanted to... but be proud of what you do achieve. Try highlighting two or three important things to get done, and anything else on the list you achieve will be a bonus.

## 2. Allocate your time

Setting an allocated time and deadline for a task can save you a lot of personal stress. For example; rather than spending the whole day cleaning, you could choose to allocate an hour on Monday to clean the bathroom, an hour Tuesday to do the

washing and ironing, and so on. This can make larger tasks seem more manageable.

This approach can also be used by children who are old enough to do chores. If they're able, try setting a timer and challenge them to get dressed and ready as quickly as they can in the morning. Every day they've got a record to beat! It might not work for all kids, but if it does, you can expand the challenge to things like tidying their room or helping with the dishes. This encourages them help around the house and adds time to your day.

## 3. Delegate

Write a list of regular tasks you do throughout the week (cooking dinner, getting the kids dressed, etc) – try to make it as detailed as possible. Now read the list back and try to think about who you can delegate some jobs to... and be creative! Can the person you care for help with cooking or cleaning? Maybe a neighbour is a keen gardener, and they can help you with the pruning? The kids might be able to make school lunches the night before. People might surprise you with their willingness to help; don't be afraid to delegate... you are worth it.

## 4. Reward yourself

Giving yourself time just for you is essential to your health and wellbeing. Often carers find it hard to take extended 'breaks' – if you can, try taking several five-minute breaks throughout the day to enjoy 'me' time. Alternatively, it might be easier to take 15-20 minutes at the start or end of the day when everyone's asleep. It takes getting used to, but it's important to acknowledge how hard you work and take time out to reward yourself.

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[www.carersvictoria.org.au](http://www.carersvictoria.org.au)

# Personal Dopa Meanings

## PARKY: A DECADE SINCE DIAGNOSIS by Peter Nassau

I was diagnosed 10 years ago,  
But Parky's progress has been slow;  
I'm gradually increasing my medication  
And view the future with trepidation.  
My sense of smell has deserted me,  
But I'm glad I can hear and see.  
I fear that I'll soon be in a situation  
To submit to deep brain stimulation.  
But can I resort to positive thoughts  
The way good athletes compete in sports;  
To only think that I shall win,  
This requires a very positive spin.  
It's hard to see the glass half full  
When I sense the strength of Parky's pull,  
As I shuffle more and spill my drink,  
And sometimes find I cannot think.  
It's hard to get up after sleep,  
I can't walk easily I have to creep,  
But after an hour or so I'm pretty right  
Having successfully endured another night.  
My medication is becoming unable  
To hide my symptoms under the table;  
Some cause side effects that must be addressed,  
So I really wonder what is best.  
So when I'm up and about, no-one would know,  
Unless my symptoms decide to show.  
Every 31/2 hours I take my pills each day,  
But sometimes I feel like my feet are of clay;  
I start to shuffle and movement requires thought,  
My gait is hampered as though my feet are caught.  
I don't like to be seen like this when I'm out,  
It's all to do with pride, no doubt.  
It's not easy to maintain a positive mind

As the joys of life become harder to find.  
To be a burden to my family makes me sad,  
So I convince myself that I'm not that bad.  
I want to be there to support my wife,  
To have a better outlook on life;  
I don't wish to become a problem for her,  
As we continue life's ballet as a pas de deux.  
My wish is for a miracle cure,  
So that I no longer need to endure  
A one way direction of this disease,  
Allowing my symptoms to gradually ease.  
Michael J Fox is a champion for the cause,  
And for that he deserves a round of applause;  
But the outcomes of the research that he leads  
Will unlikely be available to meet my needs.  
The progress of testing of proposed new ideas  
Generally tends to take many years,  
So it's unlikely that I'll be lucky enough  
To benefit from any new medical stuff.  
However I'm lucky that I live in an age  
Where medical developments have reached the stage  
Where dopamine comes in tablet form  
Which reduces the effects of Parky's storm.

*Personal dopa-meanings are being sought!*

*Please provide a short report;*

*400 words will be enough,*

*This should not be so very tough.*

*I am happy to provide some help*

*If necessary, just give a yelp.*

*And you'll be able to happily boast*

*That you've contributed to the Signpost!*

## SEXY TIME

It's a topic that we often feel self-conscious or reluctant about raising with health professionals. However, the physical symptoms of Parkinson's combined with changes to sexual desire may have an impact on your sex life.

### Dopamine, the body and sex

In people with Parkinson's, the production and use of dopamine – a neurotransmitter that plays an important role in motor function, motivation, cognition and sexual arousal – is reduced. When there are lower levels of dopamine you may feel less inclined to have sex, or notice that the frequency of sexual activity is reduced. For women, lower dopamine levels will result in reduced vaginal secretions (normally produced when aroused), which may mean sexual intercourse is uncomfortable or painful. For men, achieving or maintaining an erection can be challenging. Both men and women report that achieving an orgasm can be more difficult, sometimes prolonging the duration of sexual activity, which may become fatiguing.

### Management and changing habits

As with many Parkinson's symptoms, the key to management is good medication habits: getting medication on time every time and understanding that your medication needs change and sometimes adjustments are needed.

Be creative with the time of day that you engage in sexual activity – like many activities, sex may be easier when Parkinson's medication levels are higher. This may also overcome some of the other challenges that Parkinson's has posed to your sex life – such as sleeping in separate beds as a result of REM sleep disturbance.

To assist some of the more physical challenges Parkinson's may create, use of lubricants, gels and oils\* can be of benefit during foreplay and intercourse, and are useful to help overcome reduced vaginal secretions. Use of topical oestrogen creams can help reduce vaginal dryness and improve the elasticity of perineal tissues.

Men may find maintaining an erection difficult; medications such as Viagra and Cialis are effective and able to be used alongside Parkinson's medications. Note that these medications may cause a worsening of blood pressure fluctuations and should be avoided if this is already an issue for you. Use of non-pharmacological aids such as cock rings can also help to maintain an erection – this

device is in part a splint and also slows the blood flow from an erect penis enabling erections to last longer.

Muscle stiffness and other motor symptoms of Parkinson's can also impact upon sex. Often changing position or type of sexual activity can help. Remember that sexual activity is not limited to intercourse: massage, caressing, use of sexual aids and prolonged foreplay leading to orgasm are all possibilities.

### Emotions

Depression is a very common symptom in Parkinson's and experiencing depression will impact on your desire to engage in sexual activity. Depression can be managed well in Parkinson's through appropriate counselling and/or medication management. For some people the addition of an antidepressant is needed, however caution is required – some antidepressants can worsen the physical symptoms of Parkinson's and can create difficulties with erectile dysfunction – so be aware that some treatments for one problem may lead to the creation of others.

For the partners of people living with Parkinson's, be aware that you can also be affected by depression, and you should seek treatment and support if necessary.

### Too much of a good thing?

An occasional, but not uncommon, side effect of some Parkinson's treatments (Dopamine Agonist Medications) can be an increased level of sexual desire and arousal known as hypersexuality. In deciding whether this is a problem that needs to be addressed, consider the following:

- Has your sexual desire increased significantly, or just returned to what used to be normal for you now that you are receiving better treatment?
- If you are engaging in more sexual activity – is this actually a problem for you or your partner?

If you think hypersexuality may be a problem for you, talk to your doctor and review your current treatment – there are alternatives available.

*\*Oils should not be used if you are using condoms or dental dams for birth control or safe sex purposes.*



Research is increasingly reinforcing the importance of exercise for the bodies and minds of people living with Parkinson's. Physical exercise is vital in maintaining balance, mobility and day-to-day activities - it can also help enhance cognitive function. The following are some exercises adapted from an exercise DVD, called *Keep Moving*, which you can try out at home. Seated stretches offer many benefits for people with mobility issues, including increased core strength, improved flexibility and circulation, and an opportunity for meditation and stress release.

### Diagonal reaching in a sitting position

Find a comfortable chair to sit in where your feet can easily reach the ground.

Start sitting up straight then with your right arm reach down and across your body towards the front left leg of the chair.



Then move your arm up and across your body so that you end up with your arm straight in the air, keep your elbows straight throughout the entire movement and feel your body opening up as your stretch up and outwards.



Try to do 3 lots of 10 repetitions of this exercise, then repeat with the other arm.

If you feel comfortable with this exercise and would like to challenge yourself further, you can hold a small weight (such as a full water bottle) in your hand as you do it.

The *Keep Moving* DVD has a range of interactive exercises targeting posture, flexibility, and strength – all of which may be compromised in Parkinson's.

Contact Parkinson's Victoria on 1800 644 189 or via [info@parkinsons-vic.org.au](mailto:info@parkinsons-vic.org.au) for more information or to purchase a copy of *Keep Moving*.

# Time Management

**G**ood time management is a valuable skill that can help you to manage all aspects of day-to-day life with Parkinson's; here are some ideas for how you can take your schedule into your own hands and get the most out of your time. Some of these tips are easy to implement straight away, some will take practice. The good news is that anyone can master time management, all you need to do is start... and there's no time like the present!



## Plan your time

Being organised and having a schedule can help you remember and find time for everything that you need to do on any given day.

You probably have an idea of when your high energy/good times are, so try to plan your activities based on what works best for you and your energy levels. You may find that it takes an hour for your body to get going in the mornings, so perhaps a 9.00am appointment with the physiotherapist wouldn't work for you. On the other hand if you find your brain is a bit foggy in the afternoon, then maybe visiting the bank or running errands would be best done in the morning.

Try to plan your schedule based on what you are able to do now, not what you used to do five years ago! Understanding the changes in our bodies and minds is key to ensuring we make the most out of the time we have each day.

Having a routine can also help if you experience anxiety or memory problems, or if you often forget to take your medication.

Remember: While it can be valuable to have a schedule, it is also really important to be flexible. There will be days when you just won't be able to accomplish all the things you planned to, and that is okay!

## Prioritise your time

Imagine that your body is a car and each day you are given exactly five litres of petrol – no more. Will you use those five litres to go to the bank, Centrelink, the doctor, and the supermarket? To get to work? To spend time with friends or family? You could do any of these things, but you can't do all of them in one day, so it's important to make sure you are doing the things that are a priority for you. Distinguish between what you want to do, what you should do and what you need to do.

Perhaps you "should" do the ironing right now, but the energy it would take you to do that ironing means you won't have enough energy to play with the grandchildren when they visit later; if playing with the grandchildren is something you, and they, enjoy... does the ironing really need to be done now? (Hint: The ironing will still be there tomorrow!)

# Time Management

## Make health a priority

Too often we don't make our health a priority until we have received a diagnosis of ill-health. Make it a priority to take care of your mind and body.

Schedule exercise in your diary just like you would an appointment with your doctor – this can help ensure you don't forget or run out of time to exercise.

Include rest breaks as part of your routine – this may mean allowing time for a nap, or scheduling in something relaxing such as a bath or some quiet time listening to music. Don't try to do too much in any given day or week - for example, if you have guests coming over for dinner on Saturday night, plan to have a quiet Sunday.

Keep in mind that fatigue and stress can exacerbate your Parkinson's symptoms, so if you are pushing yourself too hard to get things done, you may find that Parkinson's is more of a challenge on that day.

## Effective use of time

*Make the most of those around you*

If you are finding it hard to get to everything you need to do, consider whether others can help. The term “delegating” is not restricted to the workplace!

- Home and Community Care services can be accessed through your local council and can provide assistance with housekeeping, property maintenance, meals, personal care and more
- Family and friends are often eager to help out, but don't know the best way. Asking them for help can ensure that you make the most of your time and can allow them feel they are making a valuable contribution. If you know that once you make dinner, it'll push you beyond your endurance to also set the table and clean up, then assign those chores to others in the family

*Use time and labour-saving devices where possible*

You may have done things for yourself in the past that aren't the most effective use of your time now. Consider installing a dishwasher so you don't have to hand wash anymore or using an electric mixer in the kitchen instead of mixing ingredients by hand.

*There's no time like the present*

Are there tasks or activities that you have been meaning to get to 'one day' but haven't done yet? Well, there's no time like the present! Whether it is cutting back your work hours and starting a new hobby, travelling with your partner or just getting a whole lot of photos printed and putting them in an album, if it is something you want to do and you have the time and energy to do it now... why not?

**“Never put off until tomorrow what you can do today” – Thomas Jefferson**



# Peer Support

Each edition of Signpost features a dedicated section tailored specifically to Parkinson's Peer Support Groups.

## Idea X-Change

Some of the best ideas for running a support groups come from the support groups themselves!

Be inspired by updates from support groups across the state:

- In March, the **Ballarat Parkinson's Support Group** had an open meeting on the topic 'Challenges and Coping Strategies'. Recognising that one of the greatest sources of information on living with Parkinson's is each other, group members were asked to either write down in advance – or be prepared to talk about at the meeting – what they have found useful in managing Parkinson's.
- The **Essendon Parkinson's Support Group** enjoyed lovely weather when they held their March meeting at a local park, sharing a picnic and barbecue with over 40 group members.
- The **Grampians Parkinson's Support Group** normally meets in Stawell, but they moved their April meeting to nearby Ararat so that people with Parkinson's there could meet and experience the benefits of the support group, and to encourage them to attend in the future.
- The **Moe Movers and Shakers** have recently had a speaker from RACV attend their meeting to discuss the 'Years Ahead Program' which looks at safe driving for seniors

## FUN-raising

Friday 11 April was World Parkinson's Day. To mark the day a number of our Support Groups held special events in their local area. Some sought to raise funds, some sought to raise awareness, while others just sought to enjoy some good Parkinson's company!

- **Warragul Parkinson's Support Group** held a 'High Tea'
- **Pakenham Parkinson's Support Group** organised a Bunnings barbecue

- **Essendon Painting with Parkinson's** launched their Art Exhibition (the exhibition, titled '4 Seasons in 3 Scapes', is running until May 26 – see the Events section on the back cover for full details)
- **Benalla Parkinson's Support Group** set up an information stall in their local shopping centre

And in the state's north-west there was lots of FUN-raising happening along the Murray River...

To support the fundraising efforts of Sam Faulkner and Tyler McPhee in their Paddle for Parkinson's, the **Mildura Parkinson's Support Group** organised a Fashion Parade and the **Swan Hill Parkinson's Support Group** organised a two course dinner at the **Swan Hill Club**. (See page 4 for more details of Tyler and Sam's adventures!)

## In the spotlight

*This edition... highlighting Werribee Parkinson's Support Group*

The **Werribee Parkinson's Support Group** is situated in the City of Wyndham. In the midst of a growth corridor, the population of Wyndham has almost doubled in the last 10 years from around 85,000 to 160,000. Meeting at the Kelly Park Community Centre each month, the Werribee Support Group has been offering information, support and some good old-fashioned fun to the expanding population. The group leaders eagerly organise activities and outings for the group – but are



*Artists from the Essendon Painting with Parkinson's group at the opening of their exhibition, '4 Seasons in 3 Scapes'.*

also involved in fundraising activities as well. The daughter of one of the co-leaders has just organised a trivia night, in conjunction with the Queen's Guide Association, to raise funds for Parkinson's Victoria!

If you are interested in attending the Werribee Parkinson's Support Group, or any of our other Parkinson's Support Groups around the state, please contact the Parkinson's Victoria Health Team.

## Advice for running a successful Support Group

There may be times when, in the context of the meeting, an individual brings up a problem that they are having. The following are ideas on how to approach the situation.

- **Work out if the problem needs to be solved**

Does the individual want a solution or do they just want to talk about what they are going through with people who understand? Sometimes a sympathetic audience or hearing that others are experiencing the same issue is enough.

- **Remember that it is not your responsibility as leader of the group to solve every problem a group member has**

You are there to facilitate the group and, while you may facilitate a discussion on the issue, you do not have to find a solution. Encourage others to take part in the problem-solving process – this takes the pressure off any one person and strengthens the connection between group members.

- **Clarify exactly what the problem is**

Make sure everyone understands what the problem is and ask questions if you need to clarify anything or get more information.

- **Try not to inadvertently blame the person with the problem**

Sometimes phrases like “you should...” or “why didn't you...” can make the individual feel



attacked or uncomfortable. Consider alternative phrases such as “maybe you could...” or “do you think it would help if you...”.

- **Discuss a number of potential solutions**

There are often multiple ways to solve one problem, so discuss a range of options. Ask the individual with the problem what they think might work. Ask other members if they have experienced a similar problem and what has worked for them in that situation.

- **Offer help**

It may be that the members of the group can be part of the solution. For example, if the problem involves getting to meetings another member may be able to assist with transport.

- **Take time to work through the options**

Discuss the pros and cons of each potential solution as a group, or encourage the individual to take the time to do so on their own.

- **Don't be afraid to refer**

Not all problems can or should be dealt with by the group alone. Consider referring the individual to Parkinson's Victoria, their GP, allied health practitioners or other relevant professionals.

- **Follow up**

Encourage the individual to talk to the group about how the problem was resolved. This can be really encouraging for group members who see that they can tackle problems together and can help others if they face a similar problem in the future.

# Events

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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.

## Seeking Expressions of Interest: Yoga for Parkinson's

Parkinson's Victoria is seeking to launch a new Yoga for Parkinson's program in the eastern suburbs of Melbourne. This will likely run as an 8 week program specifically targeting people recently diagnosed with Parkinson's (less than 5 years). If you are interested in registering your interest or finding out more please contact Toby Osborn on 1800 644 189 or (03) 9581 8700.

## On now

### Art Exhibition:

#### Essendon Painting with Parkinson's

Runs until 26 May, open  
11am – 4pm, Tuesday to Sunday

The Incinerator Gallery, 180 Holmes  
Road, Moonee Ponds

Titled '*4 Seasons in 3 Scapes*', this exhibition will feature over 30 original paintings by artists from the Essendon Painting with Parkinson's Group. The exhibition, opened on World Parkinson's Day, is on display in the Keilor East and Strathmore Community Bank® Boadle Hall.

Entry to The Incinerator Gallery is free.

## Coming up

### AUGUST

#### A Walk in the Park

Sunday 31 August 2014

Federation Square, Melbourne

A leisurely, non-competitive 4km (return route) walk, or 2km shortcut, along Melbourne's picturesque Yarra River, A Walk in the Park is the major fundraising and awareness-raising event for Parkinson's Victoria. Since A Walk in the Park was first held in Victoria in 2009, more than \$300,000 has been raised to assist Parkinson's Victoria in its everyday work supporting people living

with Parkinson's and to fund vital research.

There are lots of ways you can get involved and show your support; whether you walk, roll or stroll on the day, fundraise on your own or make a donation, everyone can help make a difference.

Go to [www.parkinsonswalk.com.au](http://www.parkinsonswalk.com.au) for more information, and to register for A Walk in the Park 2014.

### SEPTEMBER

#### Living Well Seminar

Thursday 11 and Friday 12  
September

Further details will be available soon

This seminar is designed to meet the needs of people who have been living with Parkinson's for more than 5 years and want to increase awareness of treatment options and effective symptom management. There will be two components to this seminar, with a portion for health care professionals who treat people with Parkinson's, and another portion for people with Parkinson's and their carers. Topics will cover latest treatments, cognitive and non-motor aspects of Parkinson's, support for daily living and the importance of planning for the future.

#### Recently Diagnosed Seminar

Saturday 25 October (not 15  
November as previously published)

Further details will be available soon.

This annual event in Melbourne is tailored specifically to people who have been diagnosed with Parkinson's in the last 5 years, as well as their family and friends. It is an excellent opportunity to learn more about living with Parkinson's from experts, have your questions answered, and meet others facing the same day-to-day challenges.