Stand *by* Me


Bendigo Bank

Front cover: Matthew Prowse in his workshop.
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FROM THE PRESIDENT

The Parkinson's movement has initiated a series of triennial conventions, around the world – the World Parkinson Congress. The third in the series took place in October 2013, in Montreal, Canada and it was attended by 3,334 delegates from 64 countries. The unique feature of this event was the participation of all the key people: over 40% of the delegates registering as neuroscientists, researchers, nurses, rehab specialists; 25% registering as people with Parkinson's; and 15% registering as care partners/givers, and family members. Although we don't have exact figures, it seems that around forty Australians took part: among them were our CEO, Miriam Dixon (who made a poster presentation), and me.

The size and scope of the Congress was quite daunting. There were plenary sessions, parallel sessions, workshops, panel discussions, a trade exhibition, performances and more; so delegates had to prioritise and dash from one activity to another, and it was only possible to get to a fraction of all the offerings. On the program, each session had an icon of a laboratory flask – a full flask denoted a very technical presentation, and a near empty one was accessible to lay people.

Before the main event began, two days of policy discussions were held for an invited audience. A highlight was a presentation by a Deloitte Access Economics representative on the 2011 update of the 2007 report which assessed the impact of PD in Australia. Evidently, the problem of enumerating people with Parkinson's is a universal one and our work is a benchmark.

The range of topics covered overall in the Congress was: interdisciplinary care; science and advocacy; genetics; drugs; exercise; sexuality; non-dopaminergic mechanisms; non-motor features; hallucinations; sleep and fatigue; complementary medicines; quality of life; speech; and much more.

In the space available, it is not feasible to provide much more than a taste of the proceedings, so themes that came through strongly included:

- More evidence is emerging about the benefits of vigorous, challenging, ongoing exercise to improve quality of life
- Gene therapy holds enormous promise, but hasn't yet reached the point where it can validly be offered in practice
- Interdisciplinary management is important to get the best possible outcomes for people with Parkinson's
- Although many potential new drugs are being developed, levodopa remains the 'gold standard' for most patients.

If you are interested, the website, www.worldpdcongress.org, offers webcasts of many of the presentations, including video of each speaker, and corresponding PowerPoint slides.

A global PD video competition was won by Kiwi, Andy McDowell, whose touching animation, 'Smaller' is available on the WPC website and on YouTube. Also on the performance front, The Alan Parkinson Project was a musical by Canadian playwright Doug Curtis, who has Parkinson's – it left many in the audience in tears, but was ultimately uplifting.

The World Parkinson's Coalition has already started planning the 4th World Parkinson Congress which will take place on September 20-23, 2016 in Portland, Oregon. I would commend that event to everyone for whom PD is important. The content will definitely be stimulating and Portland is an attractive, accessible city.

Make a note in your diary.

Chris Davis

PRESIDENT

FROM THE CEO

I hope you have all had a wonderful festive season. 2014 is going to be a busy year for Parkinson's NSW, so please check the calendar on page 22 for some key events.

Parkinson's Passport

It is with absolute pleasure and delight that we are finally able to announce the Parkinson's Passport. This passport has been a joint initiative of Parkinson's NSW and the National Prescribing Service (NPS) and is designed to assist people, with a diagnoses of Parkinson's, with a hospital stay. The idea for the passport came about many years ago when I set up a working party to look at how to improve the experience of hospitalisation for people living with Parkinson's. Larraine McAnally, the then Parkinson's specialist nurse at Westmead Hospital, Professor Lynn Chenoweth, Professor of Aged and extended care nursing, UTS, Sue Mercer, Nurse Co-ordinator Parkinson's Clinic, and Dr. Sarah Mott were in the original working group.

A copy of this passport has been included in this edition of *Stand by Me*. My thanks go to The Lundbeck Institute for funding the printing costs.

If you know of anyone who would like to receive a copy please ask them to call the InfoLine.

I would be most interested to hear how the Parkinson's Passport has made a difference to your experience as a patient with a diagnosis of Parkinson's. Please write to me at PO Box 71 North Ryde BC, NSW 1670 or send an email to PNSW@parkinsonsnsw.org.au. Please put Parkinson's Passport in the subject line.

Parliament of New South Wales Spring Ball

Parkinson's NSW was privileged to be one of five charity partners at the 2013 Spring Ball. The Hon Shelley Hancock MP, Speaker of the Legislative Assembly, nominated us. The evening recognised many people within communities across the state rely on the compassion and assistance of volunteers and non-government organisations. It brought together leaders in the political, corporate and media fields. It was a spectacular evening and I was privileged to able to attend and speak with many members of parliament.

Sponsors were NRMA, Telstra, Newsgate, Capital Investment Group and Australian Hotels Association NSW.

Staff Changes

In December, we said farewell to Jayne Walker-Smith, who has relocated with her family to Bathurst. Both Jayne and her husband are originally country folk and Sydney finally got to them. We wish Jayne and her family well in their new life in Bathurst.

Rachael Chippendale has joined our team as our Office Manager. Rachael works Monday – Friday and is a highly proficient administrator.

Remembering Faye Moran

Faye Moran sadly past away in September last year. She was president when I came for my first interview at Parkinson's NSW and was passionate about establishing services for people living with Parkinson's. It was Faye's vision to establish a specialised counselling service. She was always warm, friendly and encouraging to all those who met her on her many trips to support groups across NSW and was awarded an OAM for her services to Parkinson's. She always signed off her correspondence 'Yours in Parkinson's friendship'. She will be sadly missed.

Miriam Dixon

CEO

MATTHEW'S PARKINSON'S BEATING HOBBY

(Far left) Linda, Matt's wife says, "this jewellery chest is, I think, one of the best he has made. They are popular with the people who buy his work and one does not last very long once it goes on the craft table. He has just finished one like this for his niece who has just been married".

(Left) Matt in his workshop with a tallowood burl.

Matthew Prowse was diagnosed with Parkinson's disease in August 2007 whilst working as a bowling greenkeeper at Cowra in western NSW.

Matt with his acoustic bass guitar. It was the first one he made. He bought a book and CD *Bass guitar for beginners* and taught himself to play basic notes after he made it.

He had been greenkeeping since he was 18 years of age working at bowling clubs at Mudgee, Drummoyne, Hornsby, Camden and Campbelltown. Although Matt continued to work at Cowra for another 12 months post diagnosis, he found the hard physical nature of the job was exacerbating his symptoms so his neurologist recommended he retire at the relatively young age of 47.

Matt and his wife Linda moved to Ebor in 2009 in the New England District of NSW where they bought a small cottage. After getting to know their neighbour who was a woodworker, Matthew, with no previous experience other than some projects at high school, took this up as a hobby.

He started out with a wheelbarrow load of cedar generously given to him by our neighbour and made drink coasters cut from a branch and a couple of small pots with lids, a model stage coach and farm wagon. He found that he had a talent for making these things so of course; he needed more wood.

Matt purchased a large trailer load of various dressed timbers from a deceased estate, which included a lot of cedar and some magnificent red gum burl. In addition, a number of their other neighbours gave Matt some timber for him to work with including some lovely Ebor Wattle and Banksia.

Matthew's father gave him his wood lathe not long after he started woodworking and he continued on to make other items including jewellery boxes of various sizes, candle sticks, turned fruit bowls, drinks trays, clocks and surprisingly, a bass acoustic guitar and four other six string guitars plus a 'lutar'; a guitar with a lute shaped base. He also made a medieval wind instrument called a Serpent after seeing a picture of one on the internet.

Matt and Linda joined the local Lions Club 12 months after arriving in Ebor and the president of the club, who is also the owner of Fusspots Café in Ebor, offered Matt a place in the shop for him to set up a permanent craft table from which he could sell the things he makes in order to fund his hobby. This has proved to be a good move for all concerned as Fusspots receives a lot of passing tourist trade. Matt's work has now travelled far and wide including overseas.

Matt spends most of every day in his shed making beautiful pieces and the activity is good for his brain, hand/eye co-ordination and his general wellbeing. His Parkinson's disease is currently stable and managed well on medication. Recently he started making wooden tulips after viewing a tutorial on YouTube and has donated a set of three in a turned vase to Parkinson's NSW to display on their reception desk.

It is evident woodworking has helped Matt deal with the effects of his Parkinson's disease in a positive way and given him a reasonably good quality of life.

"The quality and creativity in his work is astounding, particularly as he self/internet taught," Linda said.

Photos by Gary Fry, Danieli Studios, Armidale. First published in the Armidale Independent, October 2013

NEW BOARD MEMBERS

Parkinson's NSW Board

Chris Davis	President
John Hassett	Vice President
Phillip Maundrell	Treasurer
Graham Dawkins	Secretary
Samuel Chu	
Sandra Elms	
Colin Hall	
Vera Heil	
Malcolm Irving	
John Silk OAM	
Rebecca Silk	
Andrew Whitton	
Kay Double	

Sandra Elms

Sandra Elms is a retired high school science teacher, working in both the UK and Sydney, specialising in HSC Biology. Prior to teaching she was a Medical Research Technician at University College London.

At the beginning of this year Sandra was elected as a committee member for the Newcastle Support group. Her goals are; to raise public awareness of PD, to support the group members and to raise funds for Parkinson's NSW.

Her most recent success is to make contact with the Arts Health Institute to help form a choir in Newcastle for PD sufferers and their carers. This choir, now known as the Shake Rattle and Roll choir began to sing at the beginning of November.

Malcolm Irving

Malcolm Irving has over twenty years of senior practice and programme management experience working for corporate organisations, consulting services companies and international agencies. Malcolm is adept at successfully driving business and technology strategy programmes in Energy and Utilities, Publishing, and Finance industries. His skills include: practice management from business strategy and planning, governance, partnership building, finance and commercial management; programme management, from the complex with multi-vendors, multi-locations and multiple executive stakeholders to consulting type projects; and project management of mergers and acquisitions.

Malcolm has a PhD in Control Theory from Warwick University and a 1st class BSc in Mathematics from Edinburgh University.

Assoc. Prof. Kay Double

Assoc. Prof. Kay Double is a neurochemist and Associate Professor of Biomedical Sciences, School of Medical Sciences, The University of Sydney. Kay has focused her research in the area of Parkinson's disease for the past 15 years and is particularly interested in the causes of Parkinson's disease, as well as in diagnosis of this disorder and in the potential of stem cells for novel treatments. Kay is a long time member of the Parkinson's Advisory Committee and has been a council member since 2006.

She believes she can contribute best by assisting members of the board to understand Parkinson's disease research and by helping to make members, the general public and medical professionals more aware of Parkinson's disease, and to understand the progress and challenges of research in this area.

PARKINSON’S PASSPORT

To help you get the care you need

It’s not uncommon for someone with Parkinson’s to go into hospital ‘for a few days’, and end up staying for three weeks because their medicines were ‘mucked around.’ You may have heard this from friends with Parkinson’s, or had first hand experience. Either way, you probably know that getting your Parkinson’s medicines on time in hospital, or in an aged care facility, can be a challenge.

The Parkinson’s Passport will help you avoid medicine problems in several ways. It is a compact booklet containing:

- a plastic card stating that you need your Parkinson’s medicine on time, to show if you go to a hospital emergency department
- a checklist about symptom management, to give to nursing staff
- facts and tips about managing Parkinson’s medicines, to give to health professionals
- a Medicines List, so all your health professionals can see exactly which medicines you take and when you need them.
- Plastic card for emergencies

The plastic card contains only the essential information so a busy triage nurse in emergency can quickly see that you have Parkinson’s, you need your medicines on time and that there a two common anti-nausea medicines that you should not have. These two medicines, metoclopramide (e.g. Maxolon) and prochlorperazine (e.g. Stemetil) make Parkinson’s symptoms worse, and are a common cause of problems in people with Parkinson’s.

The flipside of the card may be useful when you are out and about in the community, as it simply states ‘I have Parkinson’s’ and explains a few of the symptoms that may cause you problems in public. Keeping the card in your wallet or purse will make it easy to find in an emergency.

Symptom management checklist

The symptom management checklist emphasises that you need your medicines on time, and also gives tips on managing common symptoms of Parkinson’s such as swallowing difficulties and freezing. As everyone’s experience of Parkinson’s is not the same, you can tick the symptoms that apply to you. The checklist is contained within the Passport booklet, and extra copies can be printed from our website as separate sheets. The extra copies can be kept in the pocket at the back of the passport so you can give them to your nurses.

Medicine facts and tips

The ‘Parkinson’s medicines’ section gives practical tips such as how to avoid interactions with meals and manage nausea. It also suggests that the person with Parkinson’s self-medicate in hospital, if possible, as this can help make sure medicines are taken on time. The medicines information can be printed as separate sheets from our website and kept in the back of the passport to hand out. The web version also gives extra information about the different types of Parkinson’s medicines.

Medicines List

The Medicines List gives space to record the names of all your medicines, dose, times and special instructions. It is a great way to keep track of your medicines all the time — not just when you go into hospital. Review your List with your doctors and nurses regularly to make sure it is up to date, and always show it before starting any new medicine. This can help your health professionals review which medicines are needed and which aren’t, and to check for potential problems such as interactions.

If you go into hospital or an aged care facility, make sure you show your Medicines List to all your doctors, nurses, pharmacist etc. The Medicines List is a separate sheet so it is easy to take in and out of the booklet pocket, and you can carry it separately in your wallet or purse if you wish. You can also print off fresh copies from our website when you need to update it.

Where to get the Parkinson’s Passport

Copies of the passport booklet and sheets are available from your State Parkinson’s Association by calling 1800 644 189. Copies of the booklet information, plus the separate sheets, can be printed from the Parkinson’s Association websites or from the NPS Medicinewise website: nps.org.au/parkinsons-passport.

SELF CARE OF CARERS:

dealing with grief and loss associated with Parkinson's disease

by Shushann Movsessian
Parkinson's Specialist Counsellor

Parkinson's disease will bring up loss on multiple levels: health, career, ability, confidence and your intimacy with your partner. We will probably feel the loss of each of these and it is a natural process to grieve for them. The loss of good health is like dying on a small level and may be something to be grieved for before true acceptance can be experienced. Elizabeth Kubler Ross who teaches and writes about the grieving process identifies five stages in the grieving process: denial, anger, bargaining, depression and acceptance. As a carer of someone with Parkinson's, unless you find ways of moving through this process towards acceptance, you can find yourself stuck in feeling angry, resentful or depressed around your life process. During this article we will look at Clare's story of dealing with the grief around her husband's diagnosis of Parkinson's as well as specific tools in dealing with carer self care.

Clare's story

Clare was in her 50s and had been caring for her sick mother on and off for most of her adult life. When her mother had passed away she decided to take herself on an extended holiday in Europe where she met David and they immediately felt an ease and connection. She loved his strength and confidence and the best part was that David only lived in the next suburb to Clare back home. Things were looking on the up and over a short period of time dating, they decided to get married. Clare was feeling the happiest she'd felt in a long time.

A year later their life was changed around completely when David was diagnosed with Parkinson's Disease. He had in fact noticed symptoms at least two years beforehand. His coordination wasn't the best and he was noticing stiffness in his body that he hadn't experienced before. He also noticed his right hand would occasionally shake slightly. When he went to see the neurologist with Clare they couldn't believe it. Both were in shock. There was no history of Parkinson's in David's family, he was still just in his 60s, had recently retired and was feeling quite well otherwise. The impact was devastating. Over the following 12 months David's condition deteriorated very quickly and once again Clare found herself in the role of primary carer, whilst holding down a busy business in retail.

As she came to grips with David's physical abilities and his increasing loss of memory, she started to feel disheartened and depressed. She hadn't bargained for the amount of care David was needing on a daily basis and there was very little support from his children who were living interstate.

She was grieving not only for the loss of the David she'd met only a year ago, but also for the life she was imagining they would share as they grew old together. She felt she couldn't really show David her grief because he was dealing with his own personal challenges with his health. She felt guilty for feeling the level of grief she was experiencing and didn't feel she could share it with anyone for fear of seeming selfish.

When she made the decision to see a counsellor it was a relief to have a neutral place where she could bring out her conflicting feelings and be open about her experience of grief and loss without feeling judged. At times she felt sad, but other times she felt a surge of anger and resentment. Until she spoke with her counsellor she hadn't realized that these feelings were all also part of her grieving process.

Clare's grief is a normal reaction to a major loss that a chronic condition like Parkinson's can bring on. The experience of being a carer will be different for everyone and how they manage the day to day demands of caring for another person will depend on: time, financial circumstances, their own health and wellbeing and their access of support networks. For many people caring is a meaningful, fulfilling and positive experience particularly in the early stages of a partner's chronic condition.

As time passes many carers can start to feel their own carer fatigue and their sense of ongoing loss from their lives not turning out as they had hoped for. This experience for some people can be a time of deep sadness and distress. For carers responding to the regular losses associated with a degenerative illness that effects their partners or family member not just physiologically but cognitively, grieving may be an ongoing process as each level of the illness presents itself. When Parkinson's progresses to a point where symptoms are severe it is not uncommon for a caregiver to experience what is known as 'anticipatory grief'. Family members may begin grieving the loss of the person's 'former self' long before the person dies.

Anticipatory grief may include extreme concern for the person their caring for and frequent thoughts about the person passing away and their own feelings in dealing with this loss. Chronic anticipatory grief can lead to carer stress and sadness as well as depression. Family members may feel guilt around wishing it was over. These are completely normal feelings and it is crucial for a carer to have support from someone who is more neutral and where they won't feel judged around their feelings. Care for the Carer could take on a variety of forms: e.g. through a support group, a supportive extended family, caring friends, or speaking to a professional Parkinson's special counsellor.

Keeping up Care for the Carer

For many carers, the time and energy expended to look after their partner or family member leaves little or no time to address their own physical, mental or emotional needs. Many can even feel numbed out around their own sense of loss. There are no quick or easy solutions to address the grief and conflicted emotions connected to a partner with a chronic condition. Here are some simple tools to help the imbalance of giving and receiving carers may experience and the feeling of being overwhelming at times:

1. As mentioned it may be helpful to speak to a neutral person who knows and understands Parkinson's as a chronic illness. Part of the process of dealing with grief is the acceptance of our own limitations. Understanding that we are doing the best we can do.

2. Taking care of yourself physically and emotionally. Caring and nurturing yourself allows you to continue being an effective carer to others, as well as improving your own quality of life.

3. Working out a balance around caring for yourself and others. Recognizing the sort of care you may need on a practical level. Not feeling you have to do it all yourself, all the time.

4. Be patient with yourself, be kind with yourself, in the same way that you would be with the person your caring for.

5. Take the time to talk to someone about the process of grieving – particularly around how to best deal with any 'anticipatory grief' you may be experiencing around your loved one.

6. Find a place where it is safe to talk openly about your experience as a carer.

7. Continue learning about Parkinson's and tools for treatment. Keep yourself up to date on the medical support around this.

8. Be sure you include your needs in any discussions around medical treatment plans.

9. Make sure you are eating well, getting enough exercise and addressing way to relax and reduce your stress levels.

10. Give yourself permission to have breaks and live your own life

MONTREAL 2013

June & Karl Ritah attended the World Parkinson Congress where they were inspired by the stories and lives of people living with Parkinson's

June is support group leader of Mid Western group, based in Mudgee. She is married to Karl who runs merino sheep on their property near Mudgee.

The four day World Parkinson's Congress iMontreal was well worth attending with over 3000 delegates, 25% being people with Parkinson's, 15% their partners and the remainder researchers, doctors and health care professionals.

The outstanding feature of this conference was the emphasis placed on the Person with Parkinson's. They were the centre of each day, were given opportunities to speak, to ask questions and their opinions were treated with respect. Every day one of these patients would tell of their experience with PD, their diagnosis, their treatment but most importantly how they were dealing with it. Their stories were awe inspiring, with one man writing and producing a very moving musical, which was presented by a cast of professional actors & musicians each day during the lunch break. Another man, diagnosed at age 45, decided to do what he could while he could and he and his son competed in the Great Race across Canada to raise awareness of PD and they won!

Another highlight was the round table talks, where two professionals sat with 12 people with PD and their partners to discuss issues such as mood changes, anxiety, apathy and depression. At other tables subjects such as speech pathology, physical therapy, clinical trials, deep brain stimulation and living alone with PD were covered.

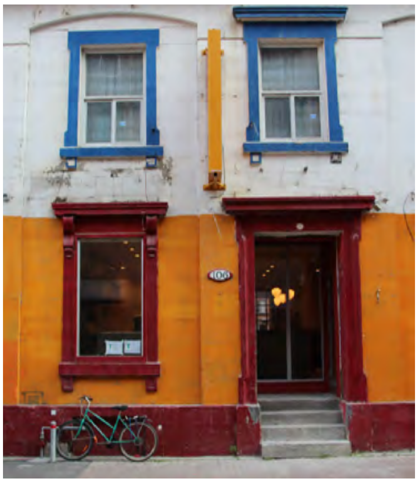
At the end of this conference we came away confident many researchers were working to find a cure and we had added to their knowledge by being there.

The next WPC will be held in Portland, Oregon in September 2016.

Advice and tips gleaned from the Montreal Congress

We are all in this together.
The patient is the centre of the problem but through the patient we will find the cure.
Be involved in your care. Take part in clinical trials.
Look forward – have ambition.
Be needed. Be strong.
Be an inspiration to others.
Be curious, be cautious and be informed.
Motivation is an antidote to depression.
Laughter is the best medicine.
Take care of yourself through diet and exercise. Be active.
Be part of building the PD community.
Be active in your support group.
Be involved in a fund raising event.
Be in control, take charge & lead the dance.
Our challenges don't define us. Our actions do!

Photography: Chris Davis



Assoc. Professor Simon Lewis

WEATHER FORECAST
Predicting the FOG

Dennis O'Connor wearing the headband

Photo: Terri Shine

Falls represent a distressing symptom especially in the advanced stages of Parkinson's disease (PD). Often these falls are the result of a puzzling symptom known as Freezing of Gait (FOG) where patients are suddenly left standing in their tracks unable to move their feet. This symptom affects over half of all patients and responds poorly to current treatments.

The cause of FOG is not well understood but studies conducted at the Brain & Mind Research Institute, University of Sydney have given some very recent insights into the phenomenon. Initial work funded by the Michael J Fox Foundation combined a Virtual Reality walking paradigm with a novel form of brain scanning. The results from this approach supported the hypothesis that FOG is due to a lack of reserve in the brain that was first proposed by Assoc. Professor Simon Lewis in 2009. Specifically, the brain scanning revealed that during freezing, the brain changes its pattern of activation, arresting movement of the feet. In this knowledge, Simon's team were keen to know whether it was possible to detect these changes in the brain before a FOG episode occurs. They also knew that solving this problem would require specialist help!

Professor Hung Nguyen is the Dean of Engineering and Information Technology at the University of Technology, Sydney who has been involved in the research field of biomedical engineering and artificial intelligence for more than 20 years. Hung has been a pioneer in the use of electroencephalography (EEG) classification systems, which can record the electrical activity of the brain in real time.

Given the synergy between their research activities, Simon and Hung have formed an active collaboration targeting FOG in PD. Working together their research teams have published a technique using just four scalp electrodes worn with a headband to identify a robust signal change on EEG that can be detected five seconds before an episode FOG.

These preliminary studies were all performed in a group of patients with the analysis done after the data was collected. However, the significance of this landmark work has been recognised by new funding from National Health & Medical Research Council, the government's main health funding agency. In early 2014, Simon's team will begin work to enhance the FOG detection algorithm in order to identify the specific EEG pattern associated with FOG in 'real' time.

If successful, this approach would enable patients to wear a simple headband to warn them about FOG a few seconds before they freeze and possibly fall over. In addition, it might be possible to connect this early warning system to some form of intervention. Whilst not effective if used continuously, cueing techniques like a light beam displayed on the floor might be better, if delivered "on demand". This approach could be triggered by the headband recording meaning patients would only need to respond to the cue when it was actually needed. Furthermore, whilst Deep Brain Stimulation (DBS) has not been very effective in treating FOG, a system that could automatically change the system's settings on demand for just a few seconds when required might prove to be a more effective strategy.

Simon's team are now actively seeking people with PD who experience difficulties with their walking to help with this ground-breaking research.

For more information please contact:

PD Research Clinic BMRI
T: 9351 0702
E: pd.clinic@sydney.edu.au
94 Mallett Street
Camperdown
Sydney
NSW, 2050

ANXIETY?
Don’t go it alone...

Deborah England
Parkinonson’s Specialist Counsellor

One of the concerns people often bring to counselling is anxiety. You can manage anxiety, but first let’s have a look at what anxiety is and how it might present.

Anxiety can be defined as being stressed, worried, afraid or uncertain about the future. It can range from worry about the progression of disease, financial matters, employment, and attractiveness to others, to matters such as “who will look after me”.

Social anxiety is another form anxiety takes and this condition is common among women. It may present as a fear they may act in a way that is embarrassing or even humiliating. “What will people think if I spill something” or “what if I shake too much?”

There is also the anxiety many carers face. The worry about leaving the person at home on their own, fear about falls and so it goes on. And the often very pervasive fear about not being adequate carers.

Symptoms of anxiety are very often camouflaged by PD symptoms. These symptoms can include your heart racing, breathlessness, sweating, trembling, chest pain, nausea, feelings of choking or dizziness.

Some people may have an underlying anxiety issue that is made worse when they are diagnosed with PD. Anxiety produces muscle spasm which inhibits movement when coupled with PD. Some medications can also cause ‘panic like’ symptoms.

Anxiety can certainly impact people’s lives. It often leads to social withdrawal as the person worries what other people may think about them. As such, the person begins to avoid social situations. This can also play out as an emotional withdrawal from the world.

When someone is anxious they are more inclined to interpret circumstances in a way that supports their particular anxiety, thereby making themselves even more anxious. An example of this could be:

Someone doesn’t say ‘Hello’, with this then being interpreted, as ‘They don’t want to admit they know me’. This sort of negative self-talk then further exacerbates the anxiety. It also feeds back into the social anxiety they are experiencing and produces further strain on relationships with others.

The self-talk that we all do can have an anxiety producing spin or an anxiety reducing spin e.g.

- 'I'm a clumsy fool' could be 'I spilt my tea'.
- 'Good things never happen to me' could be 'Some good things do happen to me'.
- 'I can't get over the fact that life is so unfair' can be 'I can accept things don't always go as I wish them to'

What can be done?

- Chat with your doctor to see if there is any anxiety producing effects in the medication you are taking.
- Think about chatting to someone you trust e.g. one of our Parkinson's counsellors.
- Attend a group for people with anxiety.
- Your doctor may suggest some anxiety relieving medication – talk to him about your concerns.

Be your own best friend

- learn to recognise the symptoms of anxiety
- learn to relax
- re-organise
- communicate
- resist PD being the central issue in your life
- confront anxiety provoking situations gradually
- challenge unhelpful thoughts
- seek help

2–4

May

Young Working Age

WEEKEND

Point Wolstoncroft Sport and Recreation

30

May

Parkinson's NSW

ANXIETY WORKSHOP

To register your interest and to receive more information, phone the InfoLine
1800 644 189.

5

June

New to Parkinson's MORNING TEA

4

September

New to Parkinson's MORNING TEA

If you have recently joined Parkinson's NSW, or would like to visit the office and meet the staff and volunteers please register for our New to Parkinson's morning information session. You will learn a little bit about Parkinson's, the services Parkinson's NSW offer and meet staff and volunteers over morning tea. Please call the InfoLine: 1800 644 189

PARKINSON'S NSW GOLF CLASSIC

On the 14 November 2013. Parkinson's NSW celebrated the 7th Annual Parkinson's NSW Golf Classic.

In just seven years with the support of many corporates and individual golfers, we have taken this event from humble beginnings to become one of the most successful charity golf days in the country.

This is due, in no small part, to the excellent team behind The Classic who strive to present a day full of great entertainment, fun, prizes and, of course, great golf, on one of the most beautiful and well maintained golf courses in Sydney.

We would also like to congratulate this years overall team winners, Geoff Moles, Will Mortlock, Peter Best and George Sutton and Claudio's Seafood who won the President's Cup.

We anticipate the event will provide a further $40,000 to the Parkinson's NSW Counselling Service that has phones staffed by trained and experienced counsellors, who provide vital support and counsel to people with Parkinson's, and their carers. Funds raised by the golf day have enabled us to employ additional counsellors to meet the growing demand.

Top to bottom

(L to R) George Costi, Job Abood, Piers Lloyd, Don Ashley

George Costi collecting President's Cup on behalf of Claudio's Seafood Steve Cost (L) & John Silk (R)

Paul Whitman, CEO of Cromwell Property Group Presenting Sponsor, being awarded appreciation plaque by John Silk.

Carlton & United Breweries

Inside Golf
AUSTRALIA'S GOLF NEWS LEADER

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AUSTRALIAN PARKINSON'S REGISTRY

Australian Parkinson's Disease Registry (APDR)

Dr Michael Hayes is currently recruiting participants for this registry at Concord Hospital.

People diagnosed with Parkinson's Disease and those without PD (controls, e.g. partners or relatives) are invited to become involved. The Registry requires one visit every three years.

All consenting PD participants will be asked to have blood tests and to complete a variety of physical and cognitive assessments. All information will be stored on a national database and the information is confidential.

Registry participants will be sent information on PD research studies and be invited to take part, if interested.

If you wish to be a participant or to find out more information about the APDR please call Rosie Portley, Neurosciences Study Coordinator on:
T: (02) 9767 5184 or
E: rosemarie.portley @ sswahs.nsw.gov.au

The aim of this proposal is to establish an Australian registry of people with PD who are willing to a) have their phenotype recorded b) have blood and genetic material stored for future unspecified research into PD and 3) be approached to participate in future clinical studies of PD. This registry will build on several different registries that are already established in NSW, WA and Victoria (including the Victorian Parkinson's Disease Research registry). The intention is to draw these together so that the descriptions and basis of collection and storage is uniform across the registry.

PD typically affects people for approximately 15 years and in 3 stages.

Stage 1 is characterised by good symptomatic response to medication.

Stage 2 is characterised by continued response to medication but there is a shortened therapeutic benefit of medications which is increasingly unreliable and often marred by dyskinesia.

Stage 3 is characterised by the emergence of features non-responsive to medications, including frequent falls, psychosis and dementia.

We wish to register a cohort of 1000 PD patients, spanning the 15 years and representing all three stages. Each year, newly diagnosed patients will be added to the registry as patients at end stage leave it. These patients will be well described clinically using internationally recognised rating scales, will be tested for the known genes and will have their DNA and biochemistry banked, and they will have a video and MRI record maintained. The registry is to be maintained indefinitely. This cohort and material will be curated and available as a research population for bona fide research.

The 9th Asia Pacific Parkinson Association Meeting

Sponsored by the Movement Disorder Society

DVD AVAILABLE

Parkinson's NSW have DVDs available from the conference held in Australia in June 2013

Watch and hear some of the keynote speakers
Professor Lynn Rochester.
Bastiaan Bloem
Jennifer G. Goldman, MD, MS

Please call 1800 644 189 to order your copy. $25 each.

IN THE NEWS

Showing carers they are valued

By **Brittany Searle**

DAVID and Ruth Matthews have always taken care of each other.

So when Mrs Matthews of Como West was diagnosed with Parkinson's disease, Mr Matthews dedicated his time to taking care of her as best as he could.

"Time to myself is pretty rare but overall we do pretty well," he said.

Celebrating carers: David and Ruth Matthews will be sharing their knowledge of the services available to people who suffer from Parkinson's disease and their carers during Carers Week.
Picture: Lisa McMahon

"I try to make this as good for her as possible. I guess if I was not fit enough to take care of her she'd have to be in full-time care which is horrible."

Mr Matthews is an active member of the Parkinson's Support Group which gives a place to connect to people who suffer from the disease and their carers.

He said many of the new carers he met did not know where they could find the help they needed.

"One of the biggest problems I see is that when people become carers they don't know where to turn," he said. "There are many services no one tells you about."

Carers Week, which was established to educate carers about the variety of services available to them, is on until Saturday, October 19.

Sutherland Shire Carer Support Service Inc's senior project worker Katie Matthais said it would help bring attention to the needs of carers, that were often overlooked.

"Carers Week celebrates the tireless work that carers do and the great importance to those they care for and the wider community," she said.

The shire group is a not-for-profit organisation that supports local carers with services including outreach programs and support groups that will be hosting events during Carers Week.

Details: 9542 6292.

CHARITABLE CHILDREN: Ben Venue Public School vice-captain Georgia Vaughan, 12, and prefect Zoe Davidson, 11, with some of the cards they made and sold to raise money for Parkinson's disease.

Crafty card-makers raise cash for a good cause

BEN Venue Public School students have become entrepreneurs, but only so they can do a good deed for charity.

They took on the Club Kidpreneur challenge, which encourages primary students to start their own small business at school to raise money for a chosen cause.

For school vice-captain Georgia Vaughan and her fellow prefects that cause was Parkinson's Australia and the business they started manufactured candles, cards and cupcakes and sold them in the playground last week."We've been making them all term and now we're selling them," Georgia said.

"The money we make is going to Parkinson's Australia.

"It's a good cause and we did it because some of us have family with Parkinson's."

They also invited guests from Parkinson's NSW to join them during the day and the whole school learned more about the disease.

- GRANT ROBERTSON

Thank you to THE ARMIDALE EXPRESS, who ran the story Crafty card-makers on Wednesday, September 25, 2013.

Thank you to the ST GEORGE AND SUTHERLAND SHIRE LEADER, who ran Showing carers they are valued on Tuesday, October 15, 2013

PANCAKES FOR PARKINSON'S

Parkinson's NSW would like to thank Sharon Doherty and her dedicated team, as well as all the local businesses in Narromine that supported the event and made it such a HUGE success! Also a special thanks to Green's our wonderful sponsors of the Pancakes for Parkinson's initiative.

Sharon Doherty from Narromine hosted what has to go down as our most successful Pancakes for Parkinson's to date. A strong desire to raise awareness and funds for Parkinson's was the motivation for Sharon and of course a very determined mindset. Sharon and her team engaged with local business and so far has managed to raise over $9,000.

On October 12, spring provided her best weather and Sharon and her team fed, entertained and educated approximately 300 people at Dundas Oval in Narromine.

They went all out, running wonderful events including a kids pancake decorating competition and a pancake eating competition. Parkinson's Awareness Relays' had the added attraction of prizes for the winners. A wonderful part was gloved participants (simulating living was Parkinson's) struggled to button shirts and sort jellybeans giving them, young and old a small glimpse into the world people with Parkinson's live in daily.

In addition to all the pancake activities people clambered into sumo suits and kids played the enormously popular ring toss game. Patricia Wilson's Tai Chi demonstration with class members from both Narromine and Dubbo was a soothing 25 minutes in an otherwise full-on morning. Petra Mellor sang some tunes and, Stewart McDougall of McDisc provided background music; a boxing demonstration courtesy of Kelli Rowles and the ever-entertaining Tim Wiggins generously donated his time to commentate throughout the morning.

Sacha Whitehead, Parkinson Portraits and Natasha Riche-Walker, Dirt Thirsty displayed their wonderful art, adding a snippet of culture. Both are collaborating in an exhibition opening on the 1 November at Dundullimal Homestead Dubbo, with a raffle to raise money for Parkinson's disease research.

The event was such a success that Sharon and her team sold all the pancakes before midday.

WHAT'S ON

To RSVP or for more information about events please call the InfoLine 1800 644 189

2–4
May
Young Working Age
WEEKEND
Point Wolstoncroft Sport and Recreation

SAVE THE DATE

Join us for
The Big Ride 4 Parkinson's
from Sydney to Parkes
29 - 30 March 2014
Don't let Parkinson's fly under the radar

To register your interest go to
thebigride2014.gofundraise.com.au
or call 02 8875 8900

3
April
Life Members'
MORNING TEA

11
April
WORLD PARKINSON'S DAY

30
May
Parkinson's NSW
ANXIETY WORKSHOP

5
June
New to Parkinson's
MORNING TEA

31
August
UNITY WALK & RUN

4
September
New to Parkinson's
MORNING TEA

3
September
Parkinson's
AWARENESS WEEK

22
October
Allied Health Awareness Seminar
(For Health Professionals only)

13
November
GOLF DAY

18
November
AGM

WHO WE ARE

Parkinson's NSW Inc is a not for profit, community-based organization established in 1979 to provide information, counselling and support to people living with Parkinson's disease.

We work in partnership with a network of support groups throughout the state.

We encourage research into Parkinson's disease and co-operate with those undertaking it.

We advocate on behalf of the Parkinson's community and strive to increase community awareness of the disease.

We look towards taking a leadership role in representing the Parkinson's community in New South Wales and Australia-wide.

OUR VISION

A community free of Parkinson's disease.

OUR MISSION

To enhance the quality of life to all people living with Parkinson's disease.

PARKINSON'S NSW INC.

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