

STANDBYME

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These specialised art classes designed to provide a "can do" activity for people whose abilities have been compromised by Parkinson's.

A typical art class begins with a "cuppa" and a chat.

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EXERCISE TIPS FOR PARKINSON'S

Exercise is a vital part of the daily routine. But it doesn't have to be repetitive or boring! It can be as fun and as imaginative as you allow it to be.

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FROM THE CEO

Welcome to all our readers. I trust you are in the swing of 2018 and had a wonderful Easter.

I would like to begin by congratulating Mr David Veness on his appointment as President of the Parkinson's NSW Board. David has previously held the position of our Rural Representative for the past three years. I look forward to working closely with him. He brings a wealth of knowledge to the position and is passionate about the cause.

We have just completed an overall review of our services and I would like to thank all of those who so kindly gave us their feedback. This will enable us to continue to further improve our services, ensuring that they are relevant to you, your family and your carers.

We know that access to information is important to our Parkinson's community and this year we will continue to grow the education seminars for our consumers, allied health professionals and G.P's.

I look forward to meeting you all throughout the course of the year.

Jo-Anne Reeves
CEO



WORLD PARKINSON'S DAY

World Parkinson's Day was on Wednesday April 11th 2018. It was an amazing opportunity to raise awareness and have fun for not only our support groups, but for the community in general.

The Parkinson's support groups across NSW were out in force celebrating the day with picnics, cake stalls, information booths, parties and even a gala cocktail party. In Sydney, guests were honoured to spend the morning with our Patron, His Excellency General The Honourable David Hurley AC DSC (Ret'd) and Mrs. Hurley at Government House. We will be featuring this event in our next edition of Stand By Me.

Across the world, 50 nations came together to celebrate the day, with the global message **#UniteforParkinsons**.

If you had a World Parkinson's Day event and haven't yet let us know, please drop us a line at events@parkinsonsnsw.org.au

UNITE

this World Parkinson's Day

11 April 2018

www.parkinsonsnsw.org.au/support-us/unite



EDUCATION SEMINARS

At Parkinson's NSW we are committed to keeping you up to date with the latest advances in treatments and programs to support people living with Parkinson's. And to do this, Parkinson's NSW regularly hold Education Seminars throughout NSW.

Our guest speakers may include Neurologists, Exercise Physiologists, Parkinson's Nurses, Speech Therapists, Counsellors, Occupational Therapists and more. The aim is to bring you a broad variety of speakers to ensure that you receive excellent and up to date advice and have an opportunity to ask questions.

A donation of \$10 towards the cost of the seminar would be appreciated to help cover the catering costs.

Following is a list of upcoming Education Seminars being held during May and June.

Where	When	Venue
Tamworth	Tuesday May 1 9.30am – 2pm	Wests Tamworth Phillip Street
Campbelltown	Monday May 28 9.30am – 2pm	Wests Campbelltown
St George / Sutherland Shire	Wednesday June 27 9.30am – 2pm	Tradies Gynea

For full details about our education seminars, please visit our website parkinsonsnsw.org.au and connect with us on [facebook.com/ParkinsonsNSW](https://www.facebook.com/ParkinsonsNSW)

Please contact the InfoLine on 1800 644 189 to register your attendance at any of the seminars

(L-R) Education Event Executive Christine, Dubbo Support Group leader Lorna White, Professor Simon Lewis (photo courtesy Daily Liberal)



Neurologist Dr. Paul Clouston



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ART FOR PARKINSON'S

Wendy Davis began her the Art for Parkinson's classes three years ago in the Sutherland Shire. Together with Kerry Blake, an Art Therapist, Wendy encourages anyone with Parkinson's to join in and have a wonderful time expressing themselves through their artwork.

Designed to provide a "can do" activity for people whose abilities have been compromised by Parkinson's, a typical class begins with a "cuppa" and a chat. You then begin with time to calm the nervous system through guided breathing exercises to focus the mind, followed by seated stretching to kick-start the body into action.

Wendy says "We find that once our participants have picked up their paintbrush, or whatever instrument they are using, they really focus on creating the art and so their concentration means that often their Parkinson's symptoms are lessened".

Research shows that in addition to medications, there are some activities that ease motor symptoms and improve the quality of life of those diagnosed with Parkinson's.

Recent studies by Dr Julie H. Carter, Professor of Neurology at Oregon Health & Science University (OHSU) and Associate Director at the OHSU Parkinson Centre of Oregon, have shown an individual can have some control over the symptoms of Parkinson's by teaching the brain to change and adapt to new circumstances, an ability called neuroplasticity.

Scientific evidence now suggests that certain activities - exercise, social connectedness and creativity - may not only be therapeutic for Parkinson's symptoms, but may actually change the brain and allow it to form new pathways of communication among brain cells.

Wendy loves to see that there is an overwhelming use of bright colours and she says that art brings such joy and happiness to all who participate. There are no hard and fast rules; it is not an art lesson as such, merely a chance to be expressive, abstract and creative.

The classes are kindly funded by the Revesby Workers Club.

If you would like to join in the details are:

Where: Sefton Community Centre, Batt Street

When: Every second Monday
10.00am - 12 noon

Cost: \$5 each class.
All supplies and morning tea included.

Contact: Wendy Davis 0415 361 991



EXERCISE TIPS FOR PARKINSON'S

We all know that for anyone with Parkinson's, exercise is a vital part of the daily routine. But it doesn't have to be repetitive or boring! It can be as fun and as imaginative as you allow it to be.

The key is consistency, force and complexity. Firstly, let's have a look at how your symptoms can be improved with specific exercises;

If you have difficulty in these areas	Focus on these exercises
Strength	Weight training, body weight training, swimming, household lifting
Flexibility	Stretching, yoga, body balance, tai chi classes
Gross Motor Skills	Jumping, balancing, obstacle runs
Fine Motor Skills	Drawing, puzzles, writing, juggling
Stress / Anxiety	Meditation, yoga, hypnotherapy

Every day you should be aiming to;

LEARN SOMETHING NEW

That can be reading different newspapers, listening to radio shows, listening to audio books, or even joining a book club. What about doing the various memory training puzzles?

CHALLENGE YOURSELF

Volunteer, perhaps with a Parkinson's Support Group or Rotary or even in a knitting or sewing group. Make sure you go out each day, even if you feel a little unsteady on your feet. By using a cane or walker, you will have greater confidence.

PRACTICE WRITING BY MAKING BIG SWEEPING MOVEMENTS

A pen grip may help with control and make it easier to grip your pen lightly and decrease the force when squeezing your pen.

EXERCISE YOUR VOICE, LA LA LA LA!

Practice speaking slowly, loudly and clearly. Read aloud daily and don't forget to sing!

EXERCISE YOUR BODY

Tailor the specific exercises that you need to suit you and your needs to maintain your health. See our chart to the left.



PARKINSON'S SYMPTOMS IMPROVE WITH SINGING

They say laughter is the best medicine. But singing is just as good, according to a group of people with Parkinson's who took part in an Australian first trial, reported in February on ABC News.

More than 70 patients from Queensland participated in the ground-breaking Griffith University study that looked at how song could help battle the disease.

Queensland Conservatorium Research Centre's Professor Don Stewart said it did not matter if they could hold a note or not, they just had to commit to "trying" to sing for an hour once a week for six months.

Professor Don Stewart found all participants experienced a better quality of life during the trial.

In each session participants not only sang, but did vocal warm ups, breathing exercises and got to take part in social activities afterwards.

The study was based on a UK program called "Sing to Beat Parkinson's" that had not previously been clinically tested. "We set out using the "Sing to Beat Parkinson's" project to see if we could enhance the quality of life of people with Parkinson's as well as their carers," he said.

UK Professor Grenville Hancox, who set up the first "Sing to Beat Parkinson's" group 10 years ago in England, has been involved in the Australian study. He said the results were ground-breaking because they confirmed all the "anecdotal evidence" he collected, but had never been able to put under the scientific microscope.

Researchers from the US, Europe and Asia attended an international symposium in Brisbane where the results of the study were released. We will tell you more about this exciting project once those results are publicly available.

FUNDRAISING FOR MY DAD

Kate Marshall's dad, Peter was diagnosed with Parkinson's about 12 years ago. At the time he was supremely fit, an avid cyclist, runner and swimmer. Even now, Kate says he still maintains his six-pack and is still riding his bike regularly. He had also just retired from his company that he owned with his wife. Together, they were looking forward to an incredible retirement after many years of working hard.

So naturally it came as a huge shock for Peter to be diagnosed with Parkinson's. It is only recently that Kate has realised how the diagnosis has made her feel.

Kate said "It is quite confronting, to see my dad struggle is hard. It breaks my heart seeing a man who I know is so capable and so driven and active – and then to see him stuck in a chair and not move because he is exhausted. I don't like to see him in pain with his muscles and his tremors. Dad is only 63. He is rapidly losing his independence, but despite Parkinson's he still looks really good".

Kate decided that she would fundraise for Parkinson's NSW as a way of helping her dad. She felt that she wanted to support the research efforts so that anyone who has Parkinson's can better educate themselves on what is available to achieve a better quality of life.

At the time, Kate was training for the Gold Coast Marathon, a 42.2km race. She decided to turn this into a fundraiser for Parkinson's NSW, successfully raising \$4000. She completed the marathon in an amazing 3 hours and 41 minutes.

Kate said "I enjoyed every minute of it. Every time my mind wandered and I thought that I was having some doubts about being able to run it, or if my legs were starting to hurt, I just reminded myself I'm running for Parkinson's. I'm running for people who can't run marathons. I'm running for these people so that hopefully one day in the future, they might be able to run a marathon again".

So what is Kate up to next? That will be supporting her dad through his surgery in Switzerland. Peter and his wife Janice are planning on leaving in March for Peter to have Transcranial Radiation Therapy. We will let you know how that goes.

Many thanks once again to Kate for her magnificent fundraising efforts.

REMEMBERING LOUISE

The Snowy Monaro Parkinson's Group has sent in a wonderful tribute about Louise and we would like to share it with you.

Louise Young of Jindabyne passed away 28 Dec 2017.

Louise played a large part in the formation of the Snowy Monaro Parkinson's Support Group back in 2009. She put a lot of time and effort into getting the group on to a sound footing. After a year or so she felt she couldn't continue with it. Her illness played a large part in her decision, driving was becoming difficult (it is quite a drive from Jindabyne to Cooma and much more so during winter) and her voice was deteriorating amongst other things. The group missed Louise and we were very sad to hear of her passing.

Louise was diagnosed with Parkinson's around 2009 by a doctor at Concord Hospital involved with the Parkinson's clinic there. It wasn't until around 2015 that it was realised that Louise was suffering with Multiple

Systems Atrophy as well as Parkinson's. The prognosis for MSA is not good and Louise was dealt a devastating blow with this diagnosis.

"Louise was not one to sit around waiting, if possible she would be out there directing proceedings," mentioned her friends at the Snowy Monaro Parkinson's Support Group. Vale Louise.



Kate Marshall giving dad a low-five



Kate with her mum & dad

HELP US GIVE PEOPLE ANSWERS

When you're told you or someone you love has Parkinson's first there's shock, then the questions. Julie takes enquiries from people with Parkinson's and their families as one of the wonderful nurses on our InfoLine 1800 644 189. She says it's a privilege to help them.

"We fill a gap – this is really the only way people can get accurate information and answers, and we're just a phone call away, between 9am to 5pm, every weekday," says Julie. "We get lots of people saying the information they received was so valuable. It's satisfying to know you've helped someone."

Please consider a donation today towards our Parkinson's InfoLine and other essential services which only exist thanks to the generous people like you

Your gift of any size would be of great help

parkinson's IN THIS TOGETHER
NSW

Julie listens to concerns, offers advice, sends information packs and steers people towards local support such as exercise programs and speech therapy.

"People can be upset, frightened. We don't make light of it – yes, Parkinson's is a terrible diagnosis to be hit with, but it's not the end of the world, things can be done, positive things. If someone is devastated and distressed, normally by the end of the conversation with us, they're not as frightened. They feel more on top of things."



YES, I would like to help improve the lives of people with Parkinson's and their families...

Please accept my donation of the following amount:

\$15 \$30 \$50 Other \$_____

I would like to make a monthly donation of \$_____ (\$15 minimum)
Please debit my credit card monthly, until further notice.

I would like to pay by:

Cheque/Money order (payable to Parkinson's NSW)

Credit Card (details below)

Card number _____

Name on card _____

Signature _____

Exp date _____

Please send me at no obligation, information on how I can leave a bequest to Parkinson's NSW

I have already included Parkinson's NSW in my will

THANK YOU FOR YOUR SUPPORT
Donations of \$2 and over are tax deductible