

InTouch Newsletter

March 2022

Step Up for Parkinson's – Registrations are now open

We recently launched our new fundraising campaign Step Up for Parkinson's. Step Up will allow you to fundraise and show your support for Parkinson's NSW. The concept is simple – get active and raise funds for people living with Parkinson's your way.

You can get active and Step Up for Parkinson's by,

- Actively set yourself a walking goal per day, i.e 1K a day throughout May,
- Actively set a physio goal,
- Actively give up coffee during the month of May

The sky is the limit, you can choose how you get active and Step up for Parkinson's. You can take part as an individual or come together as a support group community and get active as a team.

Best of all it's free to take part and you will be raising funds for Parkinson's NSW.

You can Step Up as an individual or why not get your Support Group together and Step Up as a team. There is also an exclusive incentive for Parkinson's NSW Support Groups. The Support Group that has the highest amount raised on their Support Group team fundraising page at the end of May, will receive a \$500 Gift Card of your choice.

To make it easy for you I have gone ahead and already created your Support Group team page. All you need to do is join.

To get started and join your Support Group team page flow these steps:

1. Visit www.stepupforparkinsons.org.au/support-groups
2. Search for your Support Group and click on the tile,
3. You will be taken to the team page and click on the green 'Join team' button,
4. Follow the steps to create your individual fundraising page,
5. Once you have finished creating your individual fundraising page it will be automatically linked to your Support Group team page.

[We have also created a downloadable how-to guide.](#)

Tips on growing your Support Group

The following tips have been submitted by Lesley Errington of Kiama Support Group. This is the first of a series of tips from leaders of various Groups across the state.

Venue: Comfortable and neutral, with food and drink provided.

Informal format: Welcoming. We start with 30 minutes to buy your own coffee in the club coffee shop. During this time established members invite new folk to join them and small groups form for informal chatting.

Formal meeting: Move to a large quiet room for a proactive meeting. People enjoy the information (always about Parkinson's issues), the exercise segment, and the sing-a-long – a often with old rock songs on YouTube. We always use a microphone so everyone can hear and have relevant information on PowerPoint so people can copy it down. We keep our meetings lively and fun. Invite folk to stay for lunch in the Bistro.

Advertising: We have a brochure to hand out, put in pharmacies, the local library, and doctors' and physiotherapists' rooms. We haven't had much success with the local paper, but this is the best outreach when something is published.

Special Meeting: A morning with a Sydney neurologist once a year is a big attraction, advertised as above and it attracts new folk to join our group.

Newsletter: Emailed, hand delivered, and posted once a term.

Facebook: Our Facebook page has attracted some new members.

Most important: Be friendly, learn names and follow up new folk or those who have missed a few meetings with an email or phone call.

Introducing the new Parkinson's Passport

One of the biggest contributing factors for people not having their medications on time in Emergency or upon admission to hospital is that people present without their medications or an up-to-date list of them.

The Parkinson's Passport addresses this issue. It is a single page A4 document that folds down to a convenient pocket size – yet holds all the information you may need to communicate to medical staff.

If you present at hospital with your Parkinson's Passport and your Webster-pak[®] (including the list of medications that comes tucked into the back of the box), it will ensure that you receive your correct medications on time, every time.

The Parkinson's Passport can be downloaded from the Parkinson's NSW website <https://www.parkinsonsnsw.org.au/parkinsons-passport/>

Just write in the required information for your:

- Medical practitioner contacts
- Emergency contact
- Enduring Guardian contact and location of form OR location of Advance Care Directive form

This information, plus the guidance already printed on the Passport for medical staff and the information in your Webster-pak® will be all you need.

We suggest you keep your completed Parkinson's Passport under a magnet on your fridge door, so you won't forget it on the way out.

Changes to Support Group Leadership Teams

Many Support Groups have recently had changes to their Leadership Teams.

It is important to keep us updated on who is in your Leadership Team and what role each Team member plays in the Group so that we can support them and ensure that they are receiving the relevant communications.

We have templates available for Support Groups planning a committee election or Annual General Meeting.

To update us on your current Leadership Team or for access to the templates, please reach out to Cassie Morgan, Support Group Coordinator.

Cassie Morgan

Support Group Coordinator

T: 02 8051 1900

E: supportgroups@parkinsonsnsw.org.au

Have you done your Annual Plan yet?

Developing and submitting an Annual Support Group Plan is a requirement for all Parkinson's NSW Support Groups.

Plans are not just 'red tape'; they are a way of keeping your Group on track and meeting regulatory and legislative reporting requirements – as well as insurance needs.

As Support Groups are part of Parkinson's NSW (and not independent), we are required to report on all of your Group's finances plus any fundraising activities to our sector's governing body – the Australian Charities and Not-for-Profits Commission (ACNC) as well as to the Australian Tax Office (ATO).

Additionally, Support Groups are covered by Parkinson's NSW Public Liability Insurance. Parkinson's NSW annual insurance renewal is currently underway.

We must report on all social or recreational activities undertaken by Parkinson's NSW Support Groups. This includes monthly meetings, outings, stalls, social events, art classes, dance classes, etc.

If your Support Group doesn't do any additional activities outside of regular meetings, you are still required to submit an Annual Plan reflecting this.

As changes are made to your Plan throughout the year, you are required to update the Plan and submit the updated version.

To complete your Support Group's Annual Plan, click here for the *Simple Guide to Annual Planning*. Consult with your Support Group Leadership Team and participants and submit the plan to Cassie Morgan, Support Group Coordinator.

We can provide advice and support to help you develop your plan. Contact Cassie to make a time to complete the Plan together over the telephone or Zoom.

Cassie Morgan

Support Group Coordinator

T: 02 8051 1900

E: supportgroups@parkinsonsnsw.org.au

M: PO Box 71, North Ryde BC, NSW 1670

What exercise can I do if I have difficulty standing or walking?

You can still reap the benefit of exercise, even with advanced Parkinson's. If walking or balancing is difficult, use a bar, heavy table, or chair to hold onto when exercising or stretching. If standing or getting up is hard, exercise and stretch in a chair or bed.

There are loads of different seated exercise classes such as general exercise, dance, yoga, and balance. You could also use a recumbent bike (a bike with a low seat and back support) which can help you exert yourself safely.

If none of the suggestions above can help you to do some exercise, here are some more to consider.

You can do facial exercises that can help fight facial masking and speech and/or swallowing difficulties:

- Chew your food longer and more vigorously.
- Exaggerate your face and lip movements when you speak.

Parkinson's NSW Limited **ABN** 93 023 603 545 **ACN** 622 455 985

PO Box 71 North Ryde BC NSW 1670

P 1800 644 189 **E** pnswn@parkinsonsnsw.org.au **W** www.parkinsonsnsw.org.au

- Make faces in the mirror.
- Sing or read out loud. Or join a choir or online singing group.

You can also do mental exercises give your brain a workout and can improve memory as there is also cognitive decline with Parkinson's, For example:

- Name as many animals, vegetables (or colours, or cars) as you can in one minute.
- Play brain games and do puzzles.
- Solve math problems in your head, or try Sudoku or a crossword

Another way to get some exercise is to add an activity in small bits throughout your day:

- Stretch or do leg exercises while watching TV.
- Swing your arms in a multitude of directions each mealtime.

Talk to your neurologist and your primary care provider before starting a new exercise regimen. They can assist you on how intense your exercises can be and recommend exercises appropriate for your individual abilities.

References:

- <https://my.clevelandclinic.org/health/articles/9200-exercise-for-people-with-parkinsons-disease#:~:text=You%20should%20begin%20an%20exercise,outcomes%20and%20overall%20well%2Dbeing.>
- <https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/fighting-parkinson-disease-with-exercise-and-diet>
- <https://www.stlukeshhealth.org/resources/managing-early-onset-parkinson-s-disease-with-exercise>