

## Parkinson's NSW Support Group Manual

The *Parkinson's NSW Support Group Manual* is a guide to establishing and operating a nurturing Support Group which both meets the needs of participants and complies with current laws and regulations governing Parkinson's NSW.

### Vision – Our aspiration

Quality of life now, as we work towards a community free of Parkinson's.

### Mission – Our focus

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

### Purpose – What we do

To connect people living with Parkinson's with life-enhancing support and services.

### Services

Parkinson's NSW services include an InfoLine staffed by experienced Registered Parkinson's Nurses, community-based Parkinson's Specialist Nurses, counselling, exercise physiology, personal training for individuals and groups, education, social work, and advocacy for people living with Parkinson's, including those who are applying for funding under the National Disability Insurance Scheme (NDIS).

We are also a Registered Service Provider of the National Disability Insurance Scheme delivering the following services:

- Support coordination – implementing all the supports funded by a person's NDIS Plan and teaching them how to manage their supports
- Coordination of supports – helping people to develop greater independence and the ability to self-direct their supports over the longer term
- Speech pathology
- Physiotherapy
- Personal training
- Group skills training

### We are committed to

- Keeping the needs and aspirations of people living with Parkinson's at the centre of all that we plan and do
- Being inclusive, treating all with dignity and respect
- Delivering excellent evidence-based service every time
- Listening and learning
- Innovating and striving for continual improvement
- Responding to requests in a timely manner
- Sharing information and communicating regularly
- Measuring and reporting outcomes with accountability

**Everything we do must be financially, logistically, legally and ethically sustainable over the long term. We must deliver results while making the most of existing resources.**

**This applies to Parkinson's NSW staff, volunteers, service delivery partners and Support Groups.**

### **The legal status of Parkinson's NSW and its Support Groups**

Parkinson's NSW is a public company limited by guarantee.

It operates as a registered charity to promote and advance the prevention, management, cure and control of Parkinson's disease.

Like all companies, Parkinson's NSW has a Constitution – a legal document that spells out the organisation's fundamental principles and how its structure and operations are governed.

The full Parkinson's NSW Constitution is available in the Appendix section of this manual. It states that the main purpose and activities of the organisation are:

- a) Support and promote research into the prevention, diagnosis, causes, manifestations, treatment, management and cure of Parkinson's Disease;
- b) Support, provide and promote the development of quality care and treatments for people affected by Parkinson's Disease;
- c) Support, provide and develop tools and support services that help people with Parkinson's Disease, their families and carers;
- d) Facilitate sharing of information and other resources relating to Parkinson's Disease;
- e) Promote a deeper understanding and awareness of Parkinson's Disease within the medical and broader community as well as within Government.

Support Groups align with all these purposes of Parkinson's NSW by:

- Providing non-judgemental peer support for people living with Parkinson's in their communities
- Educating the public and raising awareness of the challenges of living with Parkinson's
- Advocating for Parkinson's funding and facilities
- Fundraising for Parkinson's research and service delivery

The actions, outcomes and reporting requirements of Parkinson's NSW and its Support Groups are governed by:

- The Australian Charities and Not-for-profits Commission (ACNC)
- The Australian Tax Office (ATO)
- Fair Trading NSW
- The Corporations Act 2001
- The Privacy Act 1988

**Since 93 percent of Parkinson's funding is derived from fundraising, loss of its ability to fundraise through a violation of laws or regulations would result in termination of the services currently provided to the Parkinson's NSW community.**

**That is why there is such a strong emphasis on processes and governance in this Support Group Manual.**

## **1. Establishing and operating a Support Group**

Support Groups come in all shapes and sizes, operate in different styles and tend to establish their own cultures over time. Therefore, it is not realistic to take a 'one size fits all' approach. Following are the basic requirements.

Support Group Leaders and Leadership Team members are invited to join the *Parkinson's NSW Support Group Leaders Private Facebook Group*.

This Group is a place where SG leaders can connect, share ideas and tips and generally support each other in running your SG. To join please click this link or search Facebook for *Parkinson's NSW Support Group Leaders*

<https://www.facebook.com/groups/2461421880551955/>

Following are the basic roles suggested for all Parkinson's Support Groups:

- Support Group Leader
- Secretary
- Treasurer

Deputy Support Group Leaders may be appointed along with other Officers, and committees may be established according to the size and needs of the Group.

## Support Group Leader

Responsibilities	Skills and Characteristics
<ul style="list-style-type: none"> <li>• Preside over meetings.</li> <li>• Lead and set a positive example for other Leadership Team members and participants of the Group.</li> <li>• Establish and maintain two-way communications with the Support Group Coordinator and other key employees of Parkinson's NSW.</li> <li>• Share all Parkinson's NSW updates and instructional emails and publications to participants of the Group.</li> <li>• Ensure all contact details for Group participants are up to date and shared with Parkinson's NSW.</li> <li>• Oversee risk management and governance within the <i>Support Group Guidelines</i> provided by Parkinson's NSW.</li> <li>• Ensure an annual plan and budget are provided to Parkinson's NSW as per Section 4 of the <i>Support Group Guidelines</i>.</li> </ul>	<ul style="list-style-type: none"> <li>• May come from any background or walk of life. No formal education or qualifications are required.</li> <li>• Basic Information Technology skills are essential. Must be able to send and receive emails, open attachments, create and attach documents to emails, and use the Internet.</li> <li>• Insight into the progressive and degenerative nature of Parkinson's is essential – to ensure empathy for the challenges faced by Support Group participants, and insight in the Leader's own changing circumstances.</li> <li>• Needs to have a vision and be able to lead the development of a plan for the Support Group.</li> <li>• Comfortable speaking in public and representing the Group in different settings.</li> <li>• Be able to lead, motivate and delegate work in order to bring out the best in each individual Support Group participant – and the Group as a whole.</li> <li>• Be a good listener but also able to manage conflict if it arises.</li> </ul>

## Secretary

Responsibilities	Skills and Characteristics
<ul style="list-style-type: none"> <li>• Maintain a register of participants attending each meeting.</li> <li>• Establish, maintain and monitor a Support Group email address that may not be used for personal or any other purposes other than Group business.</li> <li>• Store, control and ensure the safety of Support Group documents and records.</li> <li>• Perform all secretarial functions and duties e.g. receiving, distributing and responding to official correspondence with Parkinson's NSW and other Groups.</li> <li>• Keep the Parkinson's NSW Support Group Coordinator up to date through regular reports on the progress and activities of the Support Group.</li> </ul>	<ul style="list-style-type: none"> <li>• May come from any background or walk of life. No formal education or qualifications are required.</li> <li>• Basic Information Technology skills essential. Must be able to send and receive emails, open attachments, create and attach documents to emails, and use the Internet.</li> <li>• Good verbal and written communication skills.</li> <li>• Good attention to detail and well-organised.</li> <li>• Knowledge of basic meeting protocols including ability to make accurate notes of meeting discussions and decisions.</li> <li>• Must keep lines of communications open with Parkinson's NSW</li> </ul>

## Treasurer

Responsibilities	Skills and Characteristics
<ul style="list-style-type: none"> <li>• Maintain accurate and up-to-date financial records of the Support Group</li> <li>• Promptly bank all monies received into the Group's bank account.</li> <li>• Issue receipts in line with the <i>Support Group Guidelines</i>.</li> <li>• Prepare financial statements for Parkinson's NSW auditors at end of each financial year.</li> <li>• Submit financial plans and reports as required by Section 5 of the <i>Support Group Guidelines</i></li> </ul>	<ul style="list-style-type: none"> <li>• A range of basic financial skills such as petty cash management and receipting</li> <li>• Basic Information Technology skills required – ideally the use of simple accounting software such as Microsoft Excel.</li> <li>• Manage and use basic accounting practices to track petty cash outlays on Group operational costs such as refreshments, copying, postage, etc.</li> <li>• Honest</li> <li>• Fine attention to detail</li> <li>• Able to maintain Support Group accounts in a form that is acceptable to Parkinson's NSW auditors.</li> </ul>

Smaller Groups may include additional responsibilities with these basic roles. For example, the Leader or the Secretary can also liaise with the local media and other key contacts such as the local council and community service groups.

However, it would be ideal to create one additional role as soon as your Group can manage it: Welfare Officer.

### Welfare Officer

Responsibilities	Skills and Characteristics
<ul style="list-style-type: none"> <li>• Welcome new Support Group participants and introduce them to others</li> <li>• Follow up with new members after their first meeting to hear their feedback and encourage them to continue attending.</li> <li>• Help to arrange transport for participants who can no longer travel independently.</li> <li>• Greet all Support Group participants as they arrive at meetings or functions.</li> <li>• Assist with enquiries from Support Group participants.</li> <li>• Facilitate connections between SG participants and those who are unable to attend the group for various reasons</li> <li>• Provide moral support for people living with Parkinson's, carers and family members.</li> </ul>	<ul style="list-style-type: none"> <li>• Compassionate.</li> <li>• Warm and outgoing.</li> <li>• Able to create and maintain social connections.</li> <li>• Good listener.</li> <li>• Good communication skills.</li> <li>• Good understanding of the Group's activities and operations and ability to find information for participants</li> <li>• Have personal experience of Parkinson's</li> </ul>

## 2. Support Group Charter

### Statement of Mutual Rights and Responsibilities

Parkinson's NSW regards Support Groups as partners which share its purpose of connecting people living with Parkinson's with life-enhancing services.

This partnership is important to us and we want to work together with mutual trust and respect. The following summary of our mutual rights and responsibilities demonstrates our commitment to this partnership.

#### Support Groups commit to:

- Provide an inclusive, welcoming forum for people living with Parkinson's to learn, connect with their community and support one another.
- Help promote and further the vision, mission and purpose of Parkinson's NSW

- Increase the effectiveness of communications between Parkinson's NSW and Support Group members by regularly and openly sharing publications, letters, emails, links to digital and social content, and other forms of information.
- Appoint or elect a Support Group Leadership Team with the approval of Parkinson's NSW. The Support Group Leader will act as the Group's spokesperson and key point of contact with Parkinson's NSW.
- Conduct meetings in accordance with proper governance processes. These processes are defined by the *Support Group Guidelines* and *Support Group Manual*.
- Keep proper written records of Support Group business and the decisions of the Support Group Leadership Team. This will include providing copies of all meeting minutes to Parkinson's NSW in a timely manner
- Prepare an Annual Support Group Plan for the period of 1 July to 30 June each year. This will include Support Group meeting dates and locations for meetings, meeting topics and a budget for the year ahead.
- Remain financially viable – meaning Support Groups should not run at a loss.
- Open a bank account in the Support Group's name with the Commonwealth Bank. Funds over a certain amount must not be retained (with limit to be advised by Parkinson's NSW). Funds in excess of the limit will be transferred to Parkinson's NSW before 31 July each year.
- Invite external speakers at Group meetings in accordance with the *Support Group Operations Manual*.
- Not undertake fundraising except as approved in advance and in writing by Parkinson's NSW.
  - Seek approval each time. One authorisation does not cover all future events.
  - Only fundraise in compliance with the *Parkinson's NSW Fundraising Guidelines* and all applicable laws, regulations and authorities.
  - Comply with Australian Taxation Office requirements regarding the issuing of tax-deductible receipts.
- Also obtain written approval from Parkinson's NSW before:
  - Entering into any agreements – including deeds, contracts or other similar arrangements
  - Using the Parkinson's NSW name, logo or brand.
  - Creating and distributing any Group publications, media releases or any other communications materials – whether in print or digital form.



- Establishing or maintaining a Support Group web site or creating or utilising social media accounts or pages.
- Providing or receiving any form of sponsorship unless that event has been listed in an Annual Support Group Plan which has already been approved.
- Keep information obtained from Support Group Participants confidential and secure. This information is not to be shared outside the Group, except with Parkinson's NSW.

**Parkinson's NSW commits to:**

- Treat all Support Group members with dignity and respect, considering them partners who share the Parkinson's NSW vision, mission and purpose.
- Grow both the number and quality of Support Groups – particularly in under-served areas of NSW.
- Strengthen all Support Group operations by providing clear written information and requirements, including the *Support Group Guidelines* and the *Support Group Operations Manual*.
- Provide templates and advice to support the development of Annual Support Group Plans.
- Provide evidence-based advice and expertise via the Support Group Coordinator and the Fundraising, Events, Education, Corporate Services, InfoLine and Marketing & Digital teams.
- Have a variety of Parkinson's NSW staff members attend as many Support Group meetings as possible over the course of each year in order to listen and learn from members.
- Welcome feedback from Support Groups and act on it as appropriate. We encourage regular two-way communications.
- Respond to requests in a timely manner – particularly when approval is sought for fundraising, events, sponsorships, local advocacy, media outreach, etc.
- Share information and communicate regularly via publications, letters, emails, and the Parkinson's NSW web site and social media channels.
- Innovate and strive for continuous improvements that will further develop Support Group operations and enhance outcomes for members.
- Not to share private or confidential Support Group information or sell or provide the Support Group membership contact list to any outside party.



### 3. Quick tips on Support Group meetings

- If you are the Support Group Leader, take some time to prepare for the meeting. Think over what was discussed last time, what needs to be followed up and what issues or ideas were raised that merit further discussion.
- Greet everyone who comes to the meeting. If they are new, make sure you introduce them around.
- Start the meeting on time.
- Encourage participants to listen to one another. It encourages honesty and openness and provides a sense of security as people share their personal stories and challenges with the Group.
- Start the meeting with a Thought for the Day, followed by reports from the Leadership Team. Ask for comments or feedback.
- If you have a guest speaker present, be sure to acknowledge and thank them for coming in your opening remarks. Then introduce them in more detail later, just before inviting them to speak.
- After your guest has spoken, encourage questions from the Group.
- Many participants want to help with meetings, so encourage people to undertake tasks like setting out and removing the chairs, setting up for morning tea, cleaning up afterwards, etc. Sharing the tasks helps to encourage socialising as well.

How you run your regular meetings will depend on the size and culture of your Group. For more hints and tips on how others run their Support Groups, visit the Parkinson's NSW Support Group Leaders Private Facebook Group.

To join please click this link or search *Facebook for Parkinson's NSW Support Group Leaders*

<https://www.facebook.com/groups/2461421880551955/>

### 4. Autonomy of Support Groups

Your Support Group is part of Parkinson's NSW. Therefore, all the laws and regulations which apply to Parkinson's NSW apply to your Support Group.

That is why the enclosed *Constitution, Support Group Guidelines* and the content of our 2019 Support Group Leader Conference\* all emphasised governance, risk management and appropriate process.

These guidelines and requirements are not new. They have been in place for some years.

On the advice of its lawyers and auditors, Parkinson's NSW is placing greater emphasis on these governance and risk management by publishing the new *Support Group Guidelines* in the Appendix section of this *Operations Manual*.

Support Groups still have the autonomy to operate in their own communities. We are simply seeking Support Group cooperation to obey the laws and regulations – and so enable Parkinson's NSW to retain its status as a Registered Charity.

Without this status we would be unable to raise the funds required to continue delivering services to the NSW Parkinson's community.

\* *If your Support Group Leader or Conference attendee did not report back to your Group on risk management or other content of the Conference, please contact the Parkinson's NSW Support Group Coordinator.*

### **Expectations of Parkinson's NSW Support Groups:**

- Share the content of this Support Group Operations Manual with the participants of your Group so everyone understands the requirements.
- Communicate with Parkinson's NSW regularly, openly and accurately.
  - It's better to find answers to your questions before they become assumptions or misunderstandings.
  - It's easier to solve a problem or take advantage of an opportunity with information in advance, rather than during or after the fact.
- Use Parkinson's NSW resources
  - Call our Registered Parkinson's Nurses and other health professionals on the InfoLine: 1800 644 189
  - Any time you have a question or need help with any Group matter, call or email the Parkinson's NSW Support Group Coordinator. She will then assist you directly or connect you with another staff member who can help.

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- Distribute all publications and advisory emails to all Support Group participants

- Don't filter them or use Parkinson's NSW content in your newsletter without permission – that is violating Parkinson's NSW copyright.
  - Your feedback on the content of these emails and publications is always welcome.
  - Talk to the Parkinson's NSW Support Group Coordinator for tips on finding funding or assistance to photocopy publications for those participants who do not use email.
- Maintain accurate records of your Support Group participants' contact details and their attendance at meetings.
    - Keep Parkinson's NSW up to date with the latest contact details. This enables us to contact all participants directly with urgent news and information as required.
    - Under the Parkinson's NSW Privacy Procedure (enclosed in the Appendix section), we do not share the details of Members or Support Group participants with any outside organisation or individual for marketing purposes.
  - Maintain and regularly report accurate financial records for your Group
    - Requirements are detailed in the enclosed *Support Group Guidelines*
    - You may be contacted by Parkinson's NSW auditors with requests for information or questions during the organisation's end-of-financial year audit.
  - Send Parkinson's NSW a general annual plan for your activities

We understand it is difficult and, in some cases, impractical for Support Groups to plan in detail for the year ahead. However, it would be helpful for us to identify and share good ideas and avoid duplication of activities if you could:

- Use the enclosed format to show the planned number of meetings and their rough timing (Monthly? Bi-monthly?)
- Summarise the planned number and type of speakers you would like to invite (One for every meeting? Emphasising health and medical? Focused on Parkinson's, or a wider range of health advice?)
- Indicate where and when you plan to take advantage of national or local events e.g. World Parkinson's Day, a Melbourne Cup luncheon fundraiser, a local festival, Unity Walk in the Park, etc.
- Estimate your anticipated budget for the year by meeting/activity

**Within the law and fundraising regulations (supported by the enclosed *Support Group Guidelines* and this *Manual*) you have autonomy to:**

- Elect and appoint your leadership team (elections to be reported to Parkinson's NSW)
- Run meetings and activities and represent Parkinson's NSW within your local community (and keep the lines of communications with Parkinson's NSW open).
- Maintain a petty cash float to fund local operational requirements – See *Support Group Guidelines*. (For any major local opportunities that require additional funding or support, consult Parkinson's NSW.)
- Invite speakers who provide evidence-based information and advice (if in doubt, check with Parkinson's NSW)
- Choose a patron if you require one (with guidance from Parkinson's NSW)
- Participate in activities which further the cause and objectives of Parkinson's NSW
- Reach out to other Support Groups for fellowship and sharing of expertise (but not for the purpose of forming cliques or excluding Parkinson's NSW or other Groups or individuals)