
Parkinson's NSW Limited Support Group Guidelines

1 Preliminary matters

1.1 Background

Parkinson's NSW is a not-for-profit organisation registered with the Australian Charities and Not-for-profits Commission (**ACNC**) as a health promotion charity. Parkinson's NSW is established and conducted to promote and advance the prevention, management, cure and control of Parkinson's Disease.

Parkinson's NSW delivers value to the community (including its Members and Support Group Participants) through a variety of mechanisms, including its Support Groups and the related Support Group meetings.

1.2 Terms used in these Support Group Guidelines

In these Support Group Guidelines, the following defined terms are used:

Board means the Parkinson's NSW board of directors or such other group or individual to which it may have delegated its powers from time to time.

Support Group means a committee of Parkinson's NSW established, governed and operated in accordance with these Support Group Guidelines and the Support Group Operations Manual.

Support Group Deputy Leader means the person elected or appointed to perform the role of deputy chair for the Support Group.

Support Group Leader means the person elected or appointed to perform the role of chair for the Support Group.

Support Group Leadership Team means the group of individuals responsible for governing and operating the Support Group.

Support Group Operations Manual means the Parkinson's NSW Support Group Operations and Procedures Manual as amended from time to time.

Support Group Participant means a person belonging to a particular Support Group (whether or not that person is also a Member).

Member means a fully paid up member of Parkinson's NSW.

Parkinson's NSW means Parkinson's NSW Limited (ABN 93 023 603 545).

1.3 Purpose of these Support Group Guidelines

The purpose of these Support Group Guidelines is to:

- provide high level guidance to all Support Group Participants about how Support Groups are to be established, governed and operated; and

- describe how Support Groups are to relate and report to the Board.

1.4 Policy is binding

These Support Group Guidelines bind all Members. All Members that are part of a Support Group must know and comply with the contents of these Support Group Guidelines.

A breach of these Support Group Guidelines could result in the suspension or cessation of membership of Parkinson's NSW and/or your removal as a Support Group Participant.

1.5 Other relevant documents

The following documents are relevant to these Support Group Guidelines and should be read and acknowledged by the Support Group Leadership Team:

- the Support Group Operations Manual;
- the sample Annual Support Group Plan;
- the Parkinson's NSW Conflicts of Interest Policy;
- the Parkinson's NSW constitution;
- the Support Group Charter.

1.6 Keeping Up-to-Date

The most up-to-date version of these Support Group Guidelines is maintained on the Parkinson's NSW web site at <https://www.parkinsonsnsw.org.au/> and can otherwise be obtained upon request to marketing@parkinsonsnsw.org.au

It is the most recent version of these Support Group Guidelines that applies.

2 Support Groups

2.1 What is a Support Group?

A Support Group is a group of people who are affected by Parkinson's Disease, usually, but not necessarily, defined by a geographic area or interest, which is established, governed and operated in accordance with these Support Group Guidelines.

Each Support Group is governed by a Support Group Leadership Team drawn from Support Group Participants, and is led by a nominated Support Group Leader.

While Support Groups are, to some degree, autonomous, they are not separate entities. They are committees of, and therefore part of, Parkinson's NSW.

2.2 The purpose of Support Groups

The purpose of Support Groups is to:

- help promote and further the Parkinson's NSW purpose;

- increase the effectiveness of communications between Parkinson's NSW, its Members and Support Group Participants; and
- provide a forum for Support Group Participants to learn and support one another.

2.3 Establishing a Support Group

A Support Group can only be established by a resolution of the Board. The Board may independently decide to establish a Support Group or may do so upon request of an individual (whether or not that individual is a Member). If asked to establish a Support Group, the Board may accept or decline to do so and is not required to give reasons for its decision.

When deciding whether to establish a Support Group, the Board will consider a number of factors, including:

- the purpose for which the Support Group is to be established;
- the geographical area within which the Support Group is to operate;
- the number of potential participants living and/or working in the geographical area;
- the location of other existing Support Groups; and
- the qualifications and experience of the people who are to form the initial Support Group Leadership Team.

The Board may also disband a Support Group at any time without the need to give reasons.

2.4 Joining a Support Group

The Support Group Leadership Team must ensure all those wishing to become a Support Group Participant complete an application form and read and acknowledge the Support Group Charter. A copy of all completed paperwork must be mailed or emailed to Parkinson's NSW in the form and in accordance with the timeframe required by Parkinson's NSW.

Applicants for a Support Group should not be charged a joining fee.

3 Support Group Leadership Team

3.1 Composition of a Support Group Leadership Team

Support Groups must be run by a Support Group Leadership Team comprised of:

- a Support Group Leader;
- up to two Support Group Deputy Leaders; and
- such other positions as the Board determines.

All those comprising a Support Group Leadership Team must be current Support Group Participants of the corresponding Support Group and:

- be current Members; or
- if they are not current Members, apply for and be accepted as a Member within two months of their appointment or election to the Support Group Leadership Team.

Any individual on a Support Group Leadership Team who fails to be accepted as a Member within two months of their appointment to the Support Group Leadership Team, or who otherwise ceases to be a Member during their term of office, will automatically cease to be on the Support Group Leadership Team.

3.2 Appointment or election of the Support Group Leadership Team

The Support Group Leadership Team is:

- for the initial Support Group Leadership Team, to be approved by the Board; and
- for each subsequent Support Group Leadership Team, to be:
 - elected by the corresponding Support Group Participants (based on the Support Group Leadership Team composition determined by the Board); and
 - presented to the Board for endorsement and the Board may refuse to endorse a person for a position on the Support Group Leadership Team at its discretion.

The initial appointment of the Support Group Leadership Team will be for a period of 12 months or until an election of the Support Group Leadership Team is held in July.

For subsequent Support Group Leadership Teams, will be placed annually in July each year the current Support Group Leadership Team must convene a meeting of the Support Group – being sure to provide notice to all corresponding Support Group Participants. At that meeting all Support Group Participants present must, in addition to any other business or activity, determine by a vote of the Support Group Participants who will be the Support Group Leader, the Support Group Deputy Leader(s) and any other members of the Support Group Leadership Team (based on the composition determined by the Board).

In the case of a vacancy in a Support Group Leader or Support Group Deputy Leader position, including where a vacancy arises due to the Support Group failing to elect a Support Group Leader and/or Support Group Deputy Leader for whatever reason, or if the Board refuses to endorse one or more of these people, the Board may fill such vacancy for the period until the next annual appointment of the Support Group Leadership Team.

3.3 Support Group Leader

Once appointed or elected, the Support Group Leader is responsible for the overall good governance of the Support Group and:

- is to act as the Support Group's representative and spokesperson; and

- is the person through whom the Support Group reports to the Board.

3.4 Support Group Leadership Team responsibilities

Each Support Group Leadership Team, led by the Support Group Leader, is responsible for the governance and operation of that particular Support Group, including ensuring that:

- regular Support Group Meetings are held and appropriately conducted;
- contact details of all Support Group Participants are obtained and updated;
- all Support Group Participants are encouraged and assisted to comply with the Support Group Guidelines;
- all Support Group Participants agree to the Support Group Charter and a copy of such agreement is appropriately recorded;
- all Support Group records are properly kept and stored;
- communication channels between the Support Group and the Board is open and professional;
- the Support Group is financially sustainable; and
- all Parkinson's NSW policies and procedures are properly followed.

3.5 Support Group Leadership Team meetings

Unless there is only one member of a Support Group Leadership Team, the Support Group Leadership Team must:

- meet as often as is required to properly satisfy its responsibilities under section 3.4;
- conduct their meetings in accordance with proper governance processes, these Support Group Guidelines, the Support Group Operations Manual and in such way as may be determined by the Board from time to time;
- keep proper written records of the business and decisions of the Support Group Leadership Team; and
- provide copies of all meeting minutes to the Board in a timely manner.

3.6 Annual Support Group Plan

Each Support Group Leadership Team must meet once each year (generally no later than two months after the Parkinson's NSW AGM) for the purpose of preparing an Annual Support Group Plan, which is to run for the period 1 July to 30 June.

The Annual Support Group Plan must conform to the Annual Support Group Plan Template as provided by the Board from time to time and will commonly require the Support Group Leadership Team to:

- set meeting dates and locations for Support Group meetings;

- determine meeting topics for the year ahead; and
- prepare the budget for the year ahead.

The Annual Support Group Plan must be submitted to the Board on or before the date determined by the Board. It may be shared by the Board amongst other Support Groups to encourage collaboration and cooperation between Support Groups.

4 Reporting and contributions

All Support Groups must report to Parkinson's NSW at such times and in such way and format as determined by the Board from time to time, including, for example, through the use of a reporting template.

Support Groups also have a number of other reporting requirements which are detailed throughout these Support Group Guidelines and the associated Support Group Operations Manual. They include, in summary:

- **Annual Support Group Plan** – to be provided by Support Groups to the Board by no later than three months after the Parkinson's NSW AGM each year; **Content** – content for the Parkinson's NSW website detailing latest branch news; and
- **Finance** – regular updates to the Board on finances (as required).

5 Finance and Banking

5.1 General

Parkinson's NSW is a registered charity, as such all profits are to be spent or reserved to further its charitable purpose.

Every Support Group is expected to be financially viable – meaning Support Groups should not run at a loss.

Parkinson's NSW's finances are managed at a national level and all invoices, payments and budgets are to be managed via the Board.

5.2 Expenses and operating costs

Support Groups may have expenses and operating costs throughout the year – e.g. expenses for conducting Support Group Meetings, by paying for venues, catering, etc.

Support Groups must liaise with the Board and have appropriate plans and approvals in place for expenses. The Support Group budget should be supplied each year as part of the Annual Support Group Plan.

All expenses should be reported in accordance with the Parkinson's NSW expense form which is contained within the Support Group Annual Plan.

Notwithstanding the above, Support Groups must seek and receive written approval from the Board before incurring any costs, which may be provided as part of the Board's approval of the Annual Support Group Plan.

5.3 Requesting funds

Support Groups are expected to be self-reliant financially. If, in exceptional circumstances, a Support Group requires funding, it must make a request to the Board in such way and format as the Board determines from time to time and must provide the Board with any information it requires to assess the Support Group's request for funds. The Board may accept or decline such a request for funds and is not required to provide reasons for its decision.

5.4 Bank accounts

As part of the transparent and accountable management of Support Group funds, Support Groups are required to open a bank account with the Commonwealth Bank.

The account name is to be *NAME OF LOCATION OR SPECIALITY* Support Group of Parkinson's NSW'. For example, "Dubbo Support Group of Parkinson's NSW".

Support Groups are not permitted to hold more than one bank account.

The Board will have the ultimate say regarding who the signatories of bank accounts will be, which will include at least one Parkinson's NSW employee (as appointed by the Board).

5.5 Excess revenues

Support Groups are not permitted to retain funds beyond a certain amount, which will be advised by the Board from time to time.

As at [30 June] each year, where a Support Group has funds above the limit specified by the Board it must transfer those funds to Parkinson's NSW by no later than [31 July] of that year and the funds will become part of the general funds of Parkinson's NSW.

6 Entering into agreements

Support Groups must not enter into any agreements (including deeds, contracts or other similar arrangements) without the prior written permission of the Board. This permission should be sought in such way as determined by the Board from time to time.

The Board may, from time to time, delegate certain responsibility to a Support Group Leader, which may include the ability to enter into binding agreements on behalf of Parkinson's NSW but only in accordance with Parkinson's NSW's constitution.

7 Confidentiality and use of data

The Support Group Leader and Support Group Deputy Leader(s) must ensure that all confidential and personal information, including information obtained from Support Group Participants, is:

- kept confidential and secure;
- is not discussed or otherwise shared outside a Support Group Meeting unless required or permitted by the Board;

- handled and used in a way consistent with the Parkinson's NSW's Privacy Policy, which is available at [insert];
- only used for the purpose for which it was given. For example, for emailing Support Group Participants about events.

Under no circumstance should a Support Group, a Support Group Leader or a Support Group Deputy Leader collect or store credit card details.

8 Communication and branding

8.1 Name logo and brand

Support Groups must not use the Parkinson's NSW name, logo or brand without the prior written approval of the Board.

All such use must be conducted in conformance with the Parkinson's NSW Branding and Style Guidelines.

8.2 Publications

Support Groups must not create or distribute their own publications, newsletters, media releases or other communications materials (whether in print or online) without the prior written approval of the Board.

8.3 Website

Support Groups will not be permitted to establish or maintain their own website without the prior written approval of the Board.

The Board may arrange for pages within the Parkinson's NSW website to be dedicated to a Support Group upon request of that Support Group.

The Board may accept or decline such a request, or if granted revoke such permission at a later stage and is not required to provide reasons for its decision. If space on the Parkinson's NSW website is made available to a Support Group, then it is the responsibility of that Support Group to provide the content for it and ensure content is up-to-date and accurate.

The Board may also require a Support Group to remove content from or cancel its page on the Parkinson's NSW website at any time without the need to give reasons.

Where a Support Group has an existing website, it may request permission from the Board to retain such website for a transitional period. Where a consent is granted, the Board will work with that Support Group to determine an appropriate transition plan to the Parkinson's NSW website and the Support Group must comply with all directions from the Board, including in relation to use of the Parkinson's NSW logo and any language to be included on the Support Group website.

8.4 Email

Parkinson's NSW will assist each Support Group to set up a generic email address using a Gmail account (e.g. NewcastleSupport@gmail.com) and guidelines on how to use the

email account. The Support Group Leader must only use this account for emails relating to the activities and operations of Parkinson's NSW and must not use a personal email address for such purposes.

This email address must not be used for personal matters or for purposes other than those of Parkinson's NSW.

8.5 Social media

Support Groups must not create or otherwise utilise their own social media accounts or pages without the prior written approval of the Board.

Parkinson's NSW may arrange for groups or other similar pages within the relevant Parkinson's NSW social media account or page to be dedicated to a Support Group, upon request of that Support Group.

The Board may accept or decline such a request, or if granted revoke such permission at a later stage and is not required to provide reasons for its decision. If a group or other similar page within the relevant Parkinson's NSW social media account is made available to a Support Group, then it is the responsibility of that Support Group to provide the content for it and ensure content is up-to-date and accurate. The Board may also request the Support Group may choose which Support Group Participants will be moderators or administrators of the relevant page.

The Board may also require a Support Group to remove content from or cease using any social media account or page at any time without the need to give reasons.

Where a Support Group has an existing social media account or page, it may request permission from the Board to retain such account or page for a transitional period. Where consent is granted, the Board will work with that Support Group to determine an appropriate transition plan to the Parkinson's NSW social media accounts and the Support Group must comply with all directions from the Board, including in relation to use of the Parkinson's NSW logo and any language to be included on the Support Group social media account or page.

8.6 Speakers and Events

Coordination of invitations to State or Federal Members of Parliament, Senators and the Governor General will be coordinated by the Board. Support Groups may request that the Board issue an invitation to one of these people. If a Support Group is directly approached by one of these people in relation to an event, the Support Group Leadership Team must promptly notify the Board who may make decisions regarding the conduct and communication in relation to such an event.

Where a Support Group wishes to invite an external speaker to speak at a meeting of the Support Group it must do so in accordance with the Support Group Operations Manual.

9 Sponsorship and fundraising

9.1 Fundraising

Support Groups must not raise funds other than as prior directed or approved in writing by the Board.

If a Support Group intends to undertake any charitable fundraising it requires written authorisation from the Board to do so. Any fundraising must be conducted in strict compliance with the Board's authorisation and the Parkinson's NSW Fundraising Guidelines. If the Support Group has been given authorisation to conduct a particular fundraising event in the past it does not automatically mean the Support Group is authorised for all future events and activities and must seek approval each time.

Undertaking charitable fundraising requires compliance with strict laws, regulations and authority conditions. Broadly speaking it is unlawful for an individual, group or organisation to undertake charitable fundraising activities without a government authority to do so. Parkinson's NSW has been issued with a charitable fundraising authority by the NSW Department of Fair Trading and is responsible for all fundraising activities conducted for, on its behalf or under its name. This means Parkinson's NSW needs to know about and give permission for all fundraising activities undertaken by Support Groups. It also means that Parkinson's NSW is ultimately responsible for ensuring that the strict legal and regulatory fundraising requirements are complied with. This is a serious matter as Parkinson's NSW's authority to fundraise can be revoked for non-compliance, which, should this occur, would see the end of all of Parkinson's NSW's fundraising and significantly jeopardise its ability to continue to operate.

In addition to the charitable fundraising requirements, there are also strict Australian Taxation Office requirements regarding when gifts and contributions are tax deductible and when and how tax-deductible receipts can be given. If Parkinson's NSW, or anyone acting on its behalf, fails to comply with the tax-deductible gift rules and regulations, Parkinson's NSW could have its tax deductibility status revoked which, just as with losing its charitable fundraising authority, would have significant negative consequences.

9.2 Sponsorship

Support Groups are not permitted to provide or receive sponsorship of any type (including for any event or activity) without the Board's prior written approval.

10 Events

Support Groups must not hold any event without the prior written approval of the Board unless that event is listed in the Annual Support Group Plan and approved by the Board.

All events must:

- be related to the purposes and activities of Parkinson's NSW;
- be conducted in accordance with all relevant Parkinson's NSW policies and procedures (including those relating to media and Work Health and Safety); and
- otherwise be conducted as directed by the Board.

11 Disciplining, suspension and expulsion of Support Group Participants

The Board (or its delegate) may resolve to warn, suspend, expel or otherwise discipline a Support Group Participant if that Support Group Participant:

- has refused or neglected to comply with the provisions of these Support Group Guidelines or the Support Group Charter; or
- has acted in a way that, in the opinion of the Board, is, or could be, prejudicial to the interests or reputation of Parkinson's NSW,

(Disciplinary Resolution).

The Board must give the Support Group Participant in question at least 10 business days' notice of the date that the Board will consider the Disciplinary Resolution. This notice must be in writing and inform the Support Group Participant:

- that the Board is to consider warning, suspending, expelling or otherwise disciplining the Support Group Participant;
- of the reasons why the Board is considering taking the determined action;
- of the right for the Support Group Participant to give the Board, either orally or in writing, any explanation or defence relevant to the proposed disciplinary action;
- of the date, place and time of the meeting at which the resolution is to be considered; and
- of the right for the Support Group Participant to attend the meeting at which the resolution is to be considered but not to be present during any Board deliberations or the putting of or voting on the resolution unless the Board otherwise resolves.

The Board must notify the relevant Support Group Participant in writing about the Board's decision within 10 business days after the date a Disciplinary Resolution is passed.

The Board's decision is final and takes effect on the date the Disciplinary Resolution is passed.

12 Parkinson's NSW contacts

Any queries about these Support Group Guidelines can be directed to:

Felicity Jones
Support Group Coordinator
T: 02 8051 1900
E: felicity.jones@parkinsonsnsw.org.au