



Together we can

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## Peer Support Group Leader Manual



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# Welcome

## From the CEO

Peer support groups bring together people who share common and lived experiences, conditions, concerns, goals and interests. They offer opportunity for peer support, friendship, social connection and learning from others.

Fight Parkinson's Peer Support Groups provide local communities throughout Victoria with a safe and friendly environment to meet and support others living with Parkinson's.

This manual has been developed as a leadership tool and to provide guidelines for you to deliver and facilitate Peer Support Groups. It offers a range of information and resources as well as tips and ideas for ensuring groups run successfully and smoothly. It provides information on appropriate governance, group management, leadership and resources needed to effectively run peer support services within your local community.

As well as being a practical guide for leaders, it provides important information about the responsibilities that come with running a Fight Parkinson's Peer Support Group, and the assistance we can provide.

I hope this Peer Support Group Leader Manual makes your valuable work easier. We thank you for taking on the responsibility of becoming a Peer Support Group Leader; without you we would be unable to offer these valuable programs to our community.

Remember, we are here for you, to support and help you and your group in any way we can. Please take the time to familiarise yourself with this manual. Questions and feedback can be directed to the Community Development Coordinator at Fight Parkinson's.

I also encourage you and your group participants to utilise all of our support and services, including our education programs and 1800 931 031 health information phone line.

Thank you and I wish you every success as a Peer Support Group Leader.



**Emma Collin**  
Chief Executive Officer



*Fight Parkinson's CEO  
Emma Collin*

# Chapter 1

## Fight Parkinson's Peer Support Groups

### IN THIS CHAPTER:

- What is peer support?
- Different types of Peer Support Groups
- How Fight Parkinson's can support your group

### WHAT IS PEER SUPPORT?

A Peer Support Group provides participants with a safe, comfortable and respectful place to share, socially interact, learn and support each other. It provides opportunities for every participant to benefit from:

- lived experience
- collective wisdom
- access to accumulated knowledge, from multiple perspectives
- new insights, widening understanding of their health
- an unmatched source of support, inspiration and empowerment
- self-respect, knowing that their experience and insight is valued.

Peer support follows the belief that individuals who have lived experiences, like Parkinson's, can better relate to other individuals trying to deal with similar issues, than those who have not had those experiences. People with lived experience are uniquely able to help others like themselves. Sharing lived experiences provides multiple perspectives of the experience, thereby broadening understanding.

The knowledge drawn from the lifelong learning journeys of many people becomes an invaluable source of insight and an unmatched source of support and inspiration for people dealing with Parkinson's.

A Fight Parkinson's Peer Support Group is a gathering of people whose lives are impacted by Parkinson's, who meet regularly in a relaxed, welcoming environment. It is a place where people with Parkinson's and their carers can:

- be themselves, and not worry about exhibiting symptoms as everyone is on a similar journey
- connect and empathise with others, and empower one another by discussing experiences and feelings

- find motivation; the group setting can help cultivate self-esteem, inspiration, personal growth and hope for the future
- share information and solutions to common situations, particularly in the local community
- hear from health-care professionals about new developments in Parkinson's medication, treatment and research
- be reminded that they are not alone. This is a place where participants feel understood and accepted. Participants have reported feeling better after attending meetings, with increased confidence in dealing with Parkinson's.
- be part of a fun social network which often includes social activities in the local community

Peer support is not a substitute for formal counselling or therapy. Group participants should check any information or advice with their doctor or neurologist and multi-disciplinary team of professionals.

Fight Parkinson's Peer Support Groups are open to people at all stages of the illness. As a leader, and for participants too, it can be confronting to attend a group where there are people with different or more advanced Parkinson's symptoms than yours. Remember that Parkinson's is progressive and that everyone's symptoms and experience of Parkinson's are different, so one person's journey is not an indication of what your experience will be like.

If any participants ask you medical questions, please refer them to Fight Parkinson's on 1800 931 031 where they can be appropriately referred. Likewise, if you are concerned about any participant's emotional wellbeing, please refer them to Fight Parkinson's.

Every individual experience of Parkinson's is unique. Fight Parkinson's Peer Support Groups play an important role in offering people with Parkinson's, their families and carers the opportunity to learn more about living with the condition and to enjoy the company of others who share similar experiences and challenges.

Fight Parkinson's Peer Support Groups are open to people living with Parkinson's and their carers/family members.

## DIFFERENT TYPES OF PEER SUPPORT GROUPS

Fight Parkinson's supports over 70 Peer Support Groups across the state.

Each group is different and as diverse as the individuals who participate. There are different types of Peer Support Groups and groups will evolve over time depending on the needs of participants.

While most groups are formed to provide information and social interaction, there are some groups who meet for a shared activity, like painting or singing (Chapters 11 and 12).

Fight Parkinson's facilitates specialist Peer Support Groups which people are welcome to attend, including a Young and Early Onset Parkinson's Peer Support Group and a Peer Support Group to support those living with Atypical Parkinson's. Two other groups support those who are looking into Parkinson's treatments including a Deep Brain Stimulation Peer Support Group and Infused Therapy Peer Support Group.

Contact the Health Team at Fight Parkinson's on 1800 931 031 for more information regarding these support groups.

Some groups choose to have an elected committee or coordination structure; others have less formal governance. Regardless of structure, Fight Parkinson's encourages Peer Support Groups to engage participants in decision-making.

Some groups choose one person to be the Facilitator/Group Leader at every meeting, while other groups like to have people take turns to be the Facilitator/Group Leader. This means different people get to be the Group Leader at each meeting. There is no right or wrong way, it depends on the group. The form of leadership should be a group decision.

## HOW FIGHT PARKINSON'S CAN SUPPORT YOUR GROUP

Fight Parkinson's raises awareness and funds for services and research that improve the quality of life for people living with Parkinson's in Victoria.

Every day, we provide information, education and peer support services to members of the Parkinson's community.

Our support extends to those living with Parkinson's, their families and carers, peer support groups and healthcare professionals.

We are here to help and support you and the members of your Peer Support Group and can assist you in ways including but not limited to the following:

- support from members of our Health Team to assist you in your role as a group leader
- Visits from the Fight Parkinson's Team
- regular updates and information, both in person and online
- referrals of local people to your group
- Peer Support Leader training
- Collaborative networks and connections to other Peer Support Leaders to share knowledge and experience
- insurance coverage for Peer Support Group activities and fundraising
- assistance to start a group Facebook Page and promoting your group
- promotion of your group through PV's membership magazine *InMotion*, website and Facebook pages.

Encouraging group participants to become Fight Parkinson's members is a good way to ensure they will benefit from the wider services, support and events that Fight Parkinson's provides. Peer Support Group members are not automatically members of Fight Parkinson's. Please refer those interested in joining to Fight Parkinson's on 1800 931 031. See the Appendix for the membership form.

If you would like to understand more about Parkinson's, fact sheets with more information about Parkinson's signs and symptoms, and the best ways to manage them, are available on the Fight Parkinson's website: [www.fightparkinsons.org.au/information-for-you/publications/](http://www.fightparkinsons.org.au/information-for-you/publications/) or you can call us on 1800 931 031.

# Chapter 2

## Starting a New Peer Support Group

### IN THIS CHAPTER:

- Deciding on a group committee
- The venue
- When should we meet?
- How often should we meet?
- Launching your group
- Guest speakers and topics

A person with Parkinson's, a carer, a health professional — anyone who sees the need and is willing and able to act on it can start a **Parkinson's Peer Support Group**.

Fight Parkinson's considers the Peer Support Group Leader the key contact for your group, unless another member is nominated.

Each Fight Parkinson's Peer Support Group varies depending on interests and activities and may change over time. The essence of every support group is its participants. You should recognise and draw on the skills, abilities and resources offered by group participants.

Group meetings may be run formally or informally. Participants can help determine the style that best suits the group, although this may change over time as the group evolves.

Most groups will have a leader or committee to coordinate and lead the group to benefit all participants. The leader may be a person living with Parkinson's, a carer or volunteer. Some groups are run by health professionals as part of their professional role.

There is no standard measurement of success for a Peer Support Group, but groups that are welcoming, accepting of people's differences and respectful of others' privacy and confidentiality are more likely to attract and retain participants.

Participants are not required to be signed up to a My Aged Care Plan or the NDIS in order to attend Fight Parkinson's Peer Support Groups.

Fight Parkinson's encourages a minimum of two people to be contacts for each Peer Support Group.

### DECIDING ON A GROUP COMMITTEE

There are many roles that participants can take on, to feel more involved in running the group and lighten the load of leaders. Some include:

**Secretary/newsletter editor/minute taker:**

To record information and decisions taken in meetings and use this as a basis to write, compile and distribute the monthly report, email or group newsletter.

**Refreshment organiser:** Tea and coffee can be provided by participants or purchased with donations collected from the group. People should make their own drinks where possible; sharing food is discouraged.

**Host or greeter:** Someone who welcomes and greets participants as they arrive.

**Buddy:** Someone who may contact new participants prior to a meeting and 'buddy up' with them at their first meeting, introducing them to others.

**Guest speaker organiser:** Someone who plans, books, greets and thanks guest speakers for appearing at support group meetings.

**Social activity planner:** To liaise with all participants and organise suitable outings for the group.

**Fundraising planner:** To liaise with Fight Parkinson's and the group about any fundraising activities they would like to participate in.

**Treasurer:** See Chapter 6.

### THE VENUE

Deciding where to meet is a priority. The venue will play a significant role in creating a comfortable environment. Important considerations:

- avoid venues with poker machines. Problem gambling may be an issue for some people on certain Parkinson's medications as well as for many others in our community.
- accessibility for people with all levels of mobility, including wheelchair access
- good lighting, heating and cooling
- meetings must not be held at participants' homes as this can pose safety and access issues and will not be covered by the Fight Parkinson's insurance policy

- meeting at a venue such as a community hall, you may be required to provide a 'Certificate of Currency' for public liability insurance. Fight Parkinson's retains such insurance cover for the groups they support. A copy of the Certificate is available on request.
- number of people attending
- a central location, accessible by public transport with plenty of accessible parking
- a welcoming, quiet, clean and comfortable environment that allows for privacy
- evening or after-hours access if required, with safe access to parking before and after the meeting, and good drop-off points near the entrance
- cost of room hire
- a safe environment without physical hazards, eg, steps.
- accessible toilets
- a kitchen where refreshments can be prepared and served. This can help people relax and encourage the sharing of experiences and support. Are table and chairs provided and set up?
- is the venue staffed?
- is audio-visual equipment available?
- is there internet access for presentations and online meetings?

Your local council or community spaces such as neighbourhood houses or libraries can be a good place to start and may assist you with information or point you in the right direction. Many places should be available free of charge, though some groups offer a donation at the end of the year to help cover maintenance costs.

## WHEN SHOULD WE MEET?

A couple of points to consider:

- Time of day – what is the most appropriate for members?
- Day of the week – a weekday or the weekend?

As Group Leader you need to consider yourself too – are you working? If so, you may look at evening or weekend meetings. If you are not working, keep in mind that others may be.

An important factor for many people with Parkinson's and on medication is the time of day – when are they most likely to be "on" and have the most energy?

Many people with Parkinson's may prefer a daytime meeting to avoid driving at night. There are also more transport options during daytime hours, particularly on weekdays. However, a weekday meeting will leave out most people who are employed or whose carers work.

It is nearly impossible to find a day and a time that suits everybody, however there are ways to compromise and make sure everyone can be included.

Some groups have alternate daytime and evening meetings. Occasional weekends are another possibility, with Sunday afternoons being popular, offering the opportunity for a family day or lunch gathering. Eating together can make the meeting feel like a special event and create a more social atmosphere.

## HOW OFTEN SHOULD WE MEET?

Monthly meetings tend to be the most popular, as they are far enough apart to not be too taxing, yet close enough to allow people to get to know one another.

Most Peer Support Group meetings tend to run for one to two hours.

Once your group is up and running, ask members if they'd like to arrange additional meetings or extra activities, like lunches. Or this might happen naturally, with members who live near each other making their own plans to meet up outside formal group times.

## LAUNCHING YOUR GROUP

You can launch your Peer Support Group at an informal social get-together with the founding participants, at a community seminar or at a larger launch event. Fight Parkinson's can support new groups with their launch by:

- providing a Fight Parkinson's Health Team guest speaker (pending availability)
- promoting the event via the Fight Parkinson's website, Facebook page, local networks and social media
- providing promotional templates.

What brings people to the first meeting? It may be through personal contact with yourself or group participants, or via Fight Parkinson's. There are also those who respond to flyers and ads they see locally, so local advertising is always a good option (see Chapter 7 on Marketing).

Check with your local council to see if they can include you in their listings of local community groups. Many councils will have these on their websites. It is also useful to have council staff know of your existence for local referrals.

## GUEST SPEAKERS AND TOPICS

Finding guest speakers who can talk to your group about a range of subjects is a great idea.

A member of the Fight Parkinson's Health Team will be available to visit your group. Consider inviting other Parkinson's or health-related speakers such as a local health professional or complementary therapist.

More ideas for guest speakers include:

- local historian
- artist or craftsperson
- hobbyist
- emergency services, eg police, ambulance, CFA
- health service providers, eg pharmacist
- community agency, eg Centrelink, Probus, Rotary clubs.

Speakers should only talk about therapies that are evidence-based, or scientifically proven, and should not speak beyond their expertise. Check with Fight Parkinson's if you have any concerns.

Speakers should also not promote a service or product, as this may be seen as the support group providing an endorsement and allowing advertising to its members.

Encourage participants to give a presentation on their hobbies or interests or to think about people in their circle of family or friends who could speak on a topic of interest. Participants often have a particular interest in hearing from someone with a personal connection to the group.

# Chapter 3

## Running your Peer Support Group

Running a Peer Support Group takes time, planning and organising. A leader's work is varied and encompasses many roles. Not only does it involve developing the agenda, so that meetings run efficiently and productively, but it also means supporting all participants so that everyone feels welcome and included. It may also mean working with mailing or telephone lists – again, remember Fight Parkinson's is always here to help.

Leaders are encouraged not to go it alone. Knowing when to delegate tasks to others is an important aspect of leadership. Fight Parkinson's encourages all groups to have a leadership committee so that responsibilities and tasks can be shared.

### TRANSITIONING LEADERSHIP

If you are considering retirement or handing over the leadership role, it is important to begin conversations with other potential leaders early – six months to a year before you intend to step down.

It is always preferable to have at least two contacts for the group. This could be two people sharing the leadership, or a committee. The positives:

- it shares the load
- it allows others to understand the leader role and contribute
- it keeps the group running when the leader isn't there or is on holiday
- it makes for a smooth leadership transition, when required

Contact Fight Parkinson's as early as possible to inform us of your intention to resign.

### LOOKING AFTER YOURSELF

Being a Peer Support Group leader should be enjoyable, challenging, rewarding and satisfying.

Leaders are not trained counsellors and should be mindful that they are not to provide medical advice to people they are supporting. The nature of the relationship is one of sharing stories and experiences – letting participants know that they are not alone and that their problems share many commonalities.

Peer Support Group Leaders, as well as participants, should always be mindful of their own welfare and not put themselves into situations where they feel uncomfortable or unsafe.

### TAKING MINUTES

Minutes are meant to record basic information such as who has attended and key points discussed. Minutes should be saved and used as a reference or as material for future meetings. Minutes are a record of what happened during the meeting, they are not a record of who said what.

Focus on subjects discussed and record action items - who is responsible for looking after those items? Send the final copy of the minutes to attendees right away. Many groups use the minutes from their meetings as the foundation to write their reports, group emails and newsletters.

Before the meeting, prepare the agenda in consultation with the group leader. A useful tip: create a template for recording your meeting minutes and make sure you leave some blank space to record comments. A template for taking minutes can be found in the Appendix. Minutes should include the following information:

- date and time of the meeting
- list of attendees and apologies (absentees)
- the meeting leader's name
- welcome to new participants
- topics raised and discussed
- assigned action items – who is looking after each task
- decisions made during the meeting
- news from Fight Parkinson's
- finance report
- date, time and location of next meeting.

### GROUP NEWSLETTER

Many Fight Parkinson's Peer Support Groups find that producing a regular newsletter is a great way to keep in contact with local communities and with members, particularly those who are unable to regularly attend meetings.

A regular newsletter can strengthen the support network between group members and serve as a reminder about upcoming meetings and events.

Your newsletter can be simple and brief; it is not necessary to include photos or colour. Newsletters can be a good resource to give to new participants and when visiting other support groups. The job of designing and producing the newsletter could be given to a member who has some basic skills in using a computer or who is willing to learn.

Fight Parkinson's Peer Support Group newsletters generally include:

- information about the previous meeting and any decisions made
- upcoming activities or events
- Fight Parkinson's latest news or coming events
- a Parkinson's Fact Sheet
- a joke or funny story.

Additional content that you may wish to include in the newsletter can be found at several reliable Parkinson's sources:

- Fight Parkinson's: [www.fightparkinsons.org.au](http://www.fightparkinsons.org.au)
- Fight Parkinson's *InMotion* magazine
- Fight Parkinson's Facebook page
- Parkinson's Disease Society UK: [www.parkinson.org.uk](http://www.parkinson.org.uk)
- World Parkinson's Disease Association: [www.wpda.org](http://www.wpda.org)
- European Parkinson's Disease Association: [www.epda.eu.com](http://www.epda.eu.com)

There is no prescribed way to report on your group meetings; this is something you decide in consultation with your committee and participants.

You can share your minutes or newsletters or provide a brief report to Fight Parkinson's following your meeting. We love to hear from you after each meeting. A reporting template can be found in the Appendix.

## TIPS TO KEEP YOUR PEER SUPPORT GROUP GOING

**Keep track of your group's progress.** From time to time, ask participants for their feedback. Are they enjoying the meetings? What would make them better? Are there any topics that they would like to discuss or be informed about? Use this information to plan future meetings.

**Share responsibility.** Letting others take on leadership roles and other tasks helps them feel more committed to and invested in the group.

**Make sure everyone has a chance to talk.** Some people are naturally more talkative than others. Asking questions to encourage quiet participants to speak up is important. Conversely, keep more vocal participants on-topic and gently remind them to let others have a turn at times.

### Assist quietly spoken participants/presenters

**to be heard.** Provide a hand-held microphone that can be passed around to assist those who have reduced voice volume. Repeat questions/ responses from softly spoken attendees so that everyone can follow and maximise the benefit of discussion.

### Emphasise the importance of confidentiality.

What's said in the group stays in the group. Make sure this is well understood by everyone.

**Keep recruiting.** If you have an open group, continue to get the word out. Groups can stagnate when membership remains the same all the time, and if participants who leave are never replaced, your group will not last.

**Remember that this is a support group.** The dynamics of a group may change over time - for example, it could become more social in function. No matter the changes, your group's primary purpose is to provide support and understanding to its participants.

# Chapter 4

## Managing Group Dynamics

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All members of your support group are individuals and will come from different backgrounds, have different needs, experience different emotions and have different ways of dealing with their Parkinson's.

Although rare, challenges or tensions can arise within a group.

It is beneficial for Fight Parkinson's to be aware of any issues that arise in case a concerned participant calls the office, so we know what has occurred - for example, if someone becomes very distressed or angry at a meeting.

Dealing with emotional situations and group members can sometimes be hard. To do this you can draw on skills such as active listening, acknowledging in an empathic way what you are hearing, being patient with members while they voice their feelings and concerns, and providing support. These are not always easy things to do; the most important thing is to be present and listen. You can always follow up with a participant after a meeting to check on how they are feeling. And as a Leader, you can always call Fight Parkinson's after the meeting to debrief.

Below are some suggestions for dealing with issues that may come up within your group.

### PEOPLE WHO DO NOT ACTIVELY PARTICIPATE

If you're concerned someone isn't actively participating in the group, consider speaking with them before the meeting begins or during a break to find out if they simply prefer to sit back or if they wish to participate more. Some people may be shy or prefer not to talk too much, and it's important to respect this.

For example, try encouraging them to share an interest or hobby with the group.

Some participants who are shy may prefer to take a specific role in the group, like minute-taker or coffee-maker. So ask them what they would like to do. You may need to consider the cultural or linguistic backgrounds of the participants and how to involve them in the group.

### PARTICIPANTS WHO TALK TOO MUCH

When a person dominates a discussion, other members may be less likely to contribute. Try not to focus on getting a particular member to talk less – acknowledge their contribution and try to use it to engage others more. For example: 'Thank you for sharing that with us, John. Has anyone else had a similar experience?'

If you have a group member who consistently talks too much, try giving them a particular role within the group – such as greeting new attendees or compiling the group newsletter.

### PARTICIPANTS WHO ARE UPSET OR DISTRESSED

Living with Parkinson's can be challenging and group members may get upset when talking about it. Your Peer Support Group may be the place where people feel most comfortable talking about the range of emotions they are experiencing. Getting upset or distressed can be a natural response to a given situation, so it's important not to suppress people's emotions.

Acknowledge the emotion itself, without singling out the person. Acknowledge they are upset to give them some time to compose themselves. For example: 'I'm very sorry that has upset you. It's OK, many of us get upset from time to time. Would you like a few moments to compose yourself?'

Encourage them to contact Fight Parkinson's to talk about how they are feeling. The Health Team can support them and provide information about how and where to access further support and assistance.

### PARTICIPANTS WHO ARE ANGRY OR FRUSTRATED

Everyone gets angry or frustrated at times, especially when living with a chronic condition.

Having the opportunity to express emotion and share issues and concerns is an important function of a peer support group. However, it's important to ensure that people's anger or frustration is not directed at group members and that participants do not feel burdened with other people's problems.

If possible, try to keep the discussion focused.

If the complaints are not relevant to the topic of discussion, suggest coming back to it another time. For example, you might try saying: 'I'm sorry to hear about your experience with hospital staff, Jane. Perhaps at a future meeting we could invite Fight Parkinson's to speak about preparing for hospital stays.'

## PARTICIPANTS WHO STOP COMING

If a participant does not attend a meeting for a few months, make contact to let them know that the group is thinking of them and they are welcome back if and when they want to return. Ask why they decided to stop coming to the group; is there a reason we can address or a concern that may be shared with other participants?

If there are problems that you are comfortable in addressing, let them know of the action you will take and that they are welcome back when they are ready. Remember the Community Development Coordinator is available to help you and your members.

## HOW TO RESPOND TO DIFFICULT QUESTIONS

You may be asked a lot of questions about Parkinson's, such as managing symptoms, available treatments and even miracle cures. Parkinson's is a complex condition, and no two people experience the same symptoms.

In your role as Peer Support Group Leader, you are not expected to be an expert on Parkinson's nor to be abreast of the latest research or treatment options. Advise participants to call the Health Team at Fight Parkinson's (1800 931 031) with any questions.

## HOW TO RESPOND TO CONTENTIOUS HEALTH ADVICE

An invaluable aspect of support groups is information-sharing between participants to help them better understand and manage life with Parkinson's. In most cases this advice will be helpful, but it is important that all participants consider it objectively.

People should be advised to follow up with their own doctors or discuss with the Fight Parkinson's Health Team on 1800 931 031. Under no circumstances give out medical advice.

Everyone will have different treatments specific to their individual symptoms and while it is normal to discuss and compare, members of a Peer Support Group should not give each other treatment advice.

If issues arise because group members are suggesting radical treatments, trying to give medical advice to others, or disagreeing over how best to manage their Parkinson's, call Fight Parkinson's. The Health Team can discuss potential treatments or complementary therapies directly with the member, or with the group as a whole.

Exercise caution with speakers who approach your group wanting to present their "revolutionary" treatment. Should this occur please contact Fight Parkinson's. If you are unsure about a particular speaker, discuss the matter with Fight Parkinson's.

## GRIEF AND LOSS

Due to the very nature of Parkinson's, and life itself, there will be occasions when the group, or a certain member, has undergone a loss and is experiencing grief. It is at these difficult times that the great value of a support group is seen.

If a member has suffered a loss and stopped attending the group, make contact and let them know you are thinking of them and that they are welcome back.

There will be times when a current or past group participant passes away, either suddenly or after a period of illness.

There is no one correct way to respond to the loss of a group participant, but the following are some ideas on special ways to pay respects:

- send a condolence card from the group to the family/next of kin
- acknowledge the participant in subsequent newsletters
- acknowledge the participant during a meeting eg. hold a moments silence, give the group a chance to share their memories of the person. Be respectful to how different cultural backgrounds acknowledge loss.
- speak to the partner or next of kin to find out how they would like the group to provide support to them

If there are concerns about the wellbeing of a group participant experiencing a significant loss, gently encourage them to seek further support. Contact the Health Team at Fight Parkinson's for advice on 1800 931 031.

# Chapter 5

## Privacy and Confidentiality

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Running a Peer Support Group involves collecting personal information about your group members. This information needs to be kept confidential and not shared without consent. There are legal obligations regarding the handling of personal information and ensuring it is held in a secure environment.

Fight Parkinson's is committed to respecting the privacy of its support group leaders and members. This section gives some guidance on what information you need to obtain and how to keep it confidential.

### YOUR PRIVACY

As a Peer Support Group Leader you will typically be the contact person for group members and the wider community wanting to get in touch with your group. But this does not mean you are on call 24/7 or are obliged to share personal information.

Details of group leaders and contact people are not listed publicly. When promoting your Peer Support Group, to maintain your own personal privacy, the contact details you use should be those of Fight Parkinson's (1800 931 031, [info@fightparkinsons.org.au](mailto:info@fightparkinsons.org.au)), and not your own.

### GROUP MEMBERS' PRIVACY

Only collect necessary information for your Peer Support Group. This includes names, phone numbers, email addresses, postal addresses and emergency contact details of participants.

It's important to take the time to ensure this information is current. When you collect information, tell members how it will be used and that you will store it securely. You can only share this information if you have consent or if you need to pass it to the emergency services.

### PHOTOGRAPHS AND VISITS BY THE MEDIA

If a photo is being published in a public forum, such as the local newspaper, make sure that everyone who is in it has given consent for their picture to be used. A copy of a Photograph and Video release form is included in the Appendix.

### CONFIDENTIALITY IN MEETINGS

It is important to establish a trusting and open group environment where people feel comfortable sharing their experiences. Discussions within a group should be considered confidential. Reminding group members of this can be a good way of starting a meeting.

There may be members who attend a Peer Support Group but have not disclosed their diagnosis to family, friends or employers, so maintaining confidentiality is paramount.

Frequent reminders about confidentiality should be a regular part of meetings. At the beginning of any new group, and as each new person joins, the importance of confidentiality should be raised and reinforced.

# Chapter 6

## The Business Side of Peer Support Groups

### IN THIS CHAPTER:

- Relationship with Fight Parkinson's
- Financial Matters
- Applying for grants
- Insurance
- Fundraising

This chapter provides guidance and information on managing Peer Support Group finances and assets, applying for grants, and fundraising.

Fight Parkinson's Peer Support Groups are supported by Fight Parkinson's and this includes coverage under the Fight Parkinson's insurance policy.

### RELATIONSHIP WITH FIGHT PARKINSON'S

Fight Parkinson's Peer Support Groups are community groups lead by local members of the community to support members of the community who live with Parkinson's. As such, they:

- need to demonstrate they are not subject to direction or control by any individual or organisation, including any department or other agency owned or controlled by any government or political party
- will not express an independent view on any issue related to Fight Parkinson's
- accept responsibility for managing their own activities and resources, including finances
- are able to promote that they are a Fight Parkinson's Peer Support Group and can use approved logos as per marketing guidelines (see Chapter 7)
- have no authority to enter any contract or arrangement, or to make any representation, on behalf of Fight Parkinson's.

### FINANCIAL MATTERS

There are many ways you can access funding within your local community to support your Peer Support Group. For example - donations of materials and resources, sponsorship of morning teas, grants and providing a free venue for your meetings.

Several Peer Support Groups have been successful in receiving grants from their local councils, service organisations (Rotary or Lions clubs) or businesses (Bendigo Bank).

### Managing income and expenses

Peer Support Groups may receive money from several sources: public donations, government funding or grants and contributions from group members. You need to account for and document income and expenses for the group and be accountable for monies received and spent.

Basic expenses incurred in the everyday running of a Peer Support Group are:

- meeting-room hire
- printing, postage and stationery for meeting reminders, newsletters, correspondence, etc
- marketing costs associated with printed flyers or paid advertising.

Depending on the nature of the Peer Support Group and the funds it is able to secure, there may be other expenses as well, such as a First Aid kit or library resources (books, DVDs). A template to assist you track your expenses is in the Appendix.

### Setting up a bank account

Peer Support Group funds should be held in a dedicated bank account in the name of the group. Peer Support Groups cannot hold funds in a personal bank account.

A minimum of two signatories must be registered with the bank. Both signatories are required to withdraw funds. As with rotating or sharing the Peer Support Group Leader role, you need to plan ahead if you intend to change signatories.

Peer Support Groups should hold less than \$5,000 in a bank account for the day-to-day expenses of their group. This is considered immaterial for tax and audit purposes.

Fight Parkinson's asks all Peer Support Groups to provide a financial statement of income and expenses annually.

## Handling payments

All payments made through the bank account should have supporting documentation, such as invoices or receipts. Those responsible for signing cheques or handling direct bank deposit should sign or initial the supporting documentation as proof the payment has been made.

Always minimise the risk of handling cash within your Peer Support Group. Good cash-handling procedures aim to make cash less visible and less accessible during handling and storage.

Below are some measures you can implement to minimise cash-handling risks.

**Use of cash** - Try to keep cash levels low. Cash payments should be avoided. Encourage cashless donations through online fundraising or EFT deposits. Make payments through cheque or direct bank deposit, or EFT. If you are receiving large amounts, such as sponsorship, ensure this is via cheque or direct bank deposit.

**Cash tin** - Consider keeping a petty-cash tin, including petty-cash slips, for small amounts of money. Keep the tin locked and open only when in use - for example, when someone is giving a donation or repaying petty cash for morning tea expenses. Keep the cash tin in a safe location when in use, away from unlocked doors.

**Counting cash** - Where possible, have two people count and reconcile cash when manually counting and receiving payment. Avoid counting alone. Move large notes or amounts from the cash tin during quiet times of your event to reduce the amount of cash being held. Count cash in a secure and private room, as far as possible from public areas. Do not leave cash unattended.

**Transporting cash** - Use a local bank to deposit any takings on the same day. When practical, avoid depositing cash alone. Where possible, do not take cash home. Vary any regular route you take when transporting cash. Where possible, travel by car, not foot or public transport.

## Managing group assets

Some Peer Support Groups may purchase physical assets, such as equipment, furniture, laptop or microphone.

Asset management involves monitoring, managing and providing a record of what assets have been purchased. This is also important for insurance purposes.

Information to record for purposes of asset management:

- the date you acquired the asset
- if the asset is new or second-hand
- cost of the asset.

If your Peer Support Group does own or purchase assets, you should keep an Asset Register (see Appendix) and keep this in your records. Also keep receipts for the purchase of assets and warranty papers, and note when an asset has been disposed of or sold. The Asset Register helps the group keep a record of the assets under the ownership of the group.

## Keeping financial records

Peer Support Groups should maintain accurate financial records. Groups can record all money received and spent, making sure to keep a copy of receipts and supporting documentation. As a guide, you should record:

- date of income/expense
- item received/purchased
- cash/cheque/deposit number
- amount
- balance

Keeping financial records up-to-date will save time when it comes to acquitting expenses for grants or other funding.

Given these requirements, it is a good idea to appoint a treasurer.

## APPOINTING A TREASURER

The treasurer is generally charged with ensuring that financial transactions are properly recorded and reported. The Leader or secretary can take on this responsibility.

The treasurer is required to be accountable for the bank account and provide information when required at Peer Support Group or committee meetings. The treasurer or nominated person does not need to have qualifications in finance, but it is beneficial if they have book-keeping or accounting experience.

The treasurer's responsibilities include:

- banking of funds or receipts
- payment of Group expenses
- record-keeping for all Group money
- regular reporting to the Group on income, expenditure and balance of funds
- providing an annual financial statement to Fight Parkinson's
- record-keeping to support grant acquittals.

At the end of each financial year, the treasurer prepares a statement detailing Group income and expenditure for that year, including the year-end balance. Fight Parkinson's asks all Peer Support Groups to provide a financial statement of income and expenses annually.

## APPLYING FOR GRANTS

Peer Support Groups can apply for grants from a variety of funding bodies, such as the Department of Health and Human Services (DHHS), local councils and health agencies.

A good first port of call is your local council. Ask to speak to your local councillor about options available to you regarding community grants. These can help cover ongoing costs such as meeting-room hire, catering, excursions, printing and stationery supplies, or for one-off costs such as a First Aid kit, communications equipment or filing cabinet.

Local council community grants are usually available at specific times of the year and have strict guidelines that need to be met to qualify.

Prior to applying for any grants, please contact Fight Parkinson's so we can assist you with your application. Fight Parkinson's will require a copy of the grant and keep it on file. Most grant providers will require a professional body to act as an auspice for the submission to ensure accountability of funds. We can support this.

If groups receive funding, they will be required to keep receipts of all expenditure for accountability and acquittal of funds. Most government departments and local councils will require Peer Support Groups to provide an acquittal report of how the funds have been spent. The funding body will outline their specific requirements when the grant is approved.

If your group is successful in its grant application, funds will be transferred to your group bank account and will be required to be spent within a specified period of time. The funder will outline exactly what is required when they allocate the funds to you.

As Peer Support Group leader, you will be accountable for the funds and the grant requirements. Fight Parkinson's can help you with this process.

## EXAMPLES OF GRANTS

<https://providers.dhhs.vic.gov.au/disability-self-help-grants-program>

<https://www2.health.vic.gov.au/primary-and-community-health/primary-care/health-conditions-support-grants>

### Victorian State Government Grants

Grants are available for a two-year period to peer support groups focusing on a specific disability or health condition that provide mutual support and education to participants and increase community awareness.

#### Two grants which your group can apply for:

The **Disability Self Help Grants program** provides grants to assist Victorian disability self-help groups to meet some of the costs associated with providing social, emotional and practical support to their participants including general expenses, running costs and/or minor works and equipment.

The **Health Condition Support Grants program** provides grants that assist Victorian peer support groups to meet some of the costs associated with providing social, emotional and practical support to participants living with a specific health condition.

Support groups with a Victorian statewide, regional or local focus may apply.

## INSURANCE

As a Fight Parkinson's Peer Support Group, the Group Leader and participants are covered by the Fight Parkinson's public liability insurance. This is because Peer Support Groups operate with the support of Fight Parkinson's and within the guidelines contained in this manual. If this were not the case, groups would have no coverage and be required to buy and maintain their own insurance.

The public liability insurance policy is renewed annually at no cost to Peer Support Groups.

When you run an event, group activity or excursion, or book a venue, you may be asked to provide a copy of your public liability insurance. Fight Parkinson's can provide a certificate of currency confirming insurance cover.

Public liability is essential insurance for Peer Support Groups. It is designed to protect you as a Peer Support Group Leader, your group participants and Fight Parkinson's against the risk of being held liable for causing death or injury to a third party or loss or damage to any property.

As a Peer Support Group Leader you have a responsibility to provide a safe environment for group participants and visitors or guests relating to group activities and third-party property.

A public liability insurance claim could result from:

- an environment where a Peer Support Group participant is injured at a group meeting
- damage occurring to a third-party's property, such as the location of a fundraising event
- a faulty product.

If any incident occurs at your Peer Support Group, contact Fight Parkinson's immediately and complete a Fight Parkinson's Incident Report form (see Appendix).

An attendance record be kept for each meeting so that accurate records exist if they are needed for insurance purposes.

## FUNDRAISING

Fundraising is a fun and engaging way to bring participants together.

However, there is a serious side to fundraising and this section covers important information about your fundraising responsibilities as a Parkinson's Peer Support Group, things to consider before undertaking a fundraising activity, as well as tips and ideas to make your activity successful.

Whether you are fundraising for your Peer Support Group or Fight Parkinson's, you need to know:

- the relevant guidelines and legal obligations
- if you can use Fight Parkinson's fundraising permit as a registered fundraiser
- the parameters of Fight Parkinson's fundraising permit and public liability insurance
- what donations are tax deductible and how a receipt is issued
- the process and paperwork required to fundraise for Fight Parkinson's

### Fundraising for your Peer Support Group

Funds raised to directly support your local Peer Support Group may be used by your group to cover the costs associated with running monthly meetings or for specific one-off activities, such as an excursion or end-of-year function.

It is important to understand that receiving donations to cover the cost of meetings or excursions is not considered fundraising.

When fundraising for your Peer Support Group, it needs to be clear to those donating that the funds are going to support your local Peer Support Group and tax deductible receipts cannot be issued.

### Tax deductible donations and receipts

If someone has donated money to claim a deduction (in other words for a donation to be eligible for a tax deductible receipt), the donation must be made to a charity which is a registered deductible gift recipient (DGR). Fight Parkinson's is a registered DGR. Tax deductible receipts can be issued for donations when:

- the payment is a gift
- the gift is of money or property that is covered by one of the gift types and valued over \$2
- gift conditions are satisfied
- the receipt is issued in the name of the donor.

Not all payments to DGRs are gifts. For example, the following are not gifts:

- purchase of raffle tickets
- purchase of chocolates, pens, or other merchandise
- the cost of attending fundraising dinners or other events (such as A Walk in the Park)
- purchase of auction items at charity events
- membership fees.

### Fundraising for Fight Parkinson's

Some Peer Support Groups may choose to raise funds to support Fight Parkinson's or make a once-off donation.

Please contact Fight Parkinson's before conducting any fundraising activity. We will ask for the details of the event and will require you to complete a Community Fundraising Registration form. Once this is submitted, and we have discussed your event with you, we can issue you an Authority to Fundraise. We can also offer assistance and guidance, confirm all relevant fundraising guidelines are met and support your activities.

After your fundraising event is over, what next? Transfer funds to Fight Parkinson's within 30 days. Ring and let us know how you went! Send us some photos – we love to share stories.

### Fundraising ideas

Here are some ways you can fundraise:

- hold a morning tea with your Peer Support Group or at your workplace
- hold a raffle at your local shopping centre (additional location approvals may be required)
- hold a movie or trivia night
- hold a fancy-dress day at your next group meeting (gold coin to participate)
- conduct a sausage sizzle at your local Bunnings store or shopping centre
- get involved in the Fight Parkinson's annual fundraising campaign, 27 for Parkinson's, or our event, A Walk in the Park.

These fundraising events can increase awareness of Parkinson's within your local community and bring people together to support the Parkinson's community. We love to have Peer Support Groups involved.

Contact our Fundraising Team on [fundraising@fightparkinsons.org.au](mailto:fundraising@fightparkinsons.org.au) or 8809 0400.

### Fundraising permits and licences

To ensure your fundraising activity is run in accordance with Victorian legislation, you may need to obtain required permits, authorities or licences. These include:

#### Public liability insurance

Once you have received your Authority to Fundraise letter from Fight Parkinson's, your fundraising activity will be covered under our public liability insurance. A copy of our insurance cover can be provided to you on request.

#### Local council permits

You may need to obtain a permit from your local council if you are holding an event in a public area. Shopping centres may also require permits for events on their premises.

#### Victorian Commission for Gambling and Liquor Regulation

If you are holding a raffle and the retail price of prizes is over \$5,000, you will require a permit from the Victorian Commission for Gambling and Liquor Regulation prior to the event. You will need to apply for a Minor Gaming Permit – Raffle/Lucky Envelope/Fundraising Event and the cost is \$25.80 (as at July 2019). See: <https://www.vcglr.vic.gov.au/news/minors-and-minor-gaming-activities>

### Online fundraising

Fight Parkinson's has an online fundraising platform. This is a great way to reach a wider audience and best of all, people are able to donate, leave a message of support and receive their own tax deductible receipt so you don't have to worry about collecting money and issuing receipts.

Please utilise the Fight Parkinson's platform for all online donations. All funds raised are allocated directly to Fight Parkinson's and can be easily identified as belonging to your Peer Support Group.

If you are interested in fundraising online, contact us at [fundraising@fightparkinsons.org.au](mailto:fundraising@fightparkinsons.org.au) or call 03 8809 0400.

### Planning your fundraiser

Running a great fundraising event takes time, organisation and enthusiasm. To help share the load, think about setting up an event committee to allocate tasks.

Following is a list of considerations when planning an event:

- How will you resource your event? How can other group members assist with the event planning?
- Do you have sufficient funds to cover initial outlay costs?
- Do you have any contacts who can assist with sourcing prizes, venue, catering, printing, selling tickets?
- How will you promote your activity?
- Are you requesting use of the Fight Parkinson's name, logo, signage, etc?
- Would you like a representative from Fight Parkinson's to attend your event/activity?
- How will you accept donations/funds from your activity - cash, cheque, credit card or online donations?
- Do you want to provide receipts to donors/ sponsors/guests and are these eligible for tax deductions?
- What records do you need to keep in relation to your activity and for how long?
- If prizes are to be awarded, how will you notify winners? What is the "draw" process? What are your legal obligations and requirements?
- How might you acknowledge support and say thanks?

# Chapter 7

## Marketing

This section provides information on promoting your group within your community. Promotion helps people find you and also raises the profile of Parkinson's in your community. Basic marketing and promotion can make a world of difference.

### GUIDELINES FOR USING THE FIGHT PARKINSON'S LOGO



Fight Parkinson's Peer Support Groups are required to use the Fight Parkinson's logo for all promotional materials, flyers and newsletters.

The Fight Parkinson's logo is a trademark of Fight Parkinson's and we take its use and misuse seriously in order to protect the organisation's reputation.

- Do not copy the logo from the Fight Parkinson's website or other documents. This will help to ensure quality and clarity.
- If you're resizing the logo, please ensure the original proportions are maintained - that is, the logo is not stretched or distorted.
- Please ensure the logo is a minimum 15mm wide, is surrounded by clear space and appears in the right-hand corner of your materials.
- If you are printing in colour, the purple in the logo needs to be reproduced exactly. Tell the graphic designer and printer the Pantone reference number – PMS 248C.

### GETTING THE WORD OUT

There are many ways to get the word out about your group. Our most successful groups use some combination of all of them.

First, you need a clear view of why you want to promote your group and its activities. Listed below are some reasons that might apply. Which of these is most important to your group?

- increase understanding of Parkinson's in your community
- attract new group participants
- promote Fight Parkinson's events and services
- build relationships with local businesses and community organisations (which may result in financial or in-kind support)

- improve your success in applying for grants
- help to attract fundraising dollars to your group or Fight Parkinson's.

### STRATEGIES TO PROMOTE YOUR GROUP:

- printing and distributing promotional material about your group and its activities within the local community
- online via social media, local websites, council or community health websites and other electronic forums such as event-listing websites
- displaying signage where relevant people will see it
- placing advertisements in your local newspaper, council newsletters or on local radio
- speaking at local community events and groups
- speaking with media outlets (local radio, newspapers, magazines)
- undertaking and promoting activities or events, such as fundraising activities or awareness-raising events or participant drives.

### WORD OF MOUTH

Word of mouth is still one of the most powerful marketing tools because it's a reliable, credible endorsement – and it's free! Use your meetings, regular communications and newsletters to publicise events and encourage everyone to spread the word to their friends and friends of friends.

### PROMOTIONAL MATERIALS

By taking the time to craft good promotional materials with an attractive design, it's amazing what a single page can do for your group.

Fight Parkinson's can provide a general brochure about the peer support program and an A4 template you can populate with your group's specific information.

If using a Fight Parkinson's template, please use Arial typeface when adding information.

## DEVELOPING YOUR OWN MATERIALS

Your group may want to develop its own flyer or poster to promote meetings and events. Here are some considerations.

Make sure to include information about where your audience can find you, whether it is through your website, social media or your group's meeting venue. Do not use your private address in any marketing material (see Chapter 5, Privacy and Confidentiality).

Use simple, clear and concise language and limit the number of words on your flyer. Use consistent language when talking about your Peer Support Group. For example, use 'Peer Support Group (PSG)' in the first instance, after which you can abbreviate to PSG.

Use customer testimonials to earn trust. Take the time to ask your happiest participants for a few words.

If your promotional materials are funded by a grant, be sure to include any required acknowledgements.

Please also make sure you include the Fight Parkinson's logo, Health Information number - 1800 931 031 - and website [www.fightparkinsons.org.au](http://www.fightparkinsons.org.au) in any marketing materials you design.

An eye-catching design will help to draw attention to your promotional flyer. Here are some design considerations:

- Use colour to your advantage. Bold colour choices and contrasts help draw the eye, even at a distance.
- Two-sided printing. If you have more information than you can comfortably fit on one side of a flyer, two-sided printing lets you get more from a single sheet of paper. This is especially useful for an informational flyer.
- Keep it simple. It can be tempting to overcomplicate your design. Blank space can help make important information stand out.
- Headlines should be clear, big and bold. By setting your headline in a typeface that's different from the copy on your flyer, you immediately create an eye-catching contrast and a focal point.
- Font size matters. Make sure that you don't go below 10 points for copy – you want everyone to be able to comfortably read the material.

For your promotional material to be effective, the printing needs to be clear. Home printers and photocopies often don't produce the best results. Printing can usually be done for a relatively low cost, but you will need to consider your budget.

## Distribution

Promotional material can be distributed in two ways: digitally via email or printed and handed out.

When distributing printed material, it's important to get permission to leave or display your promotions. Also be respectful of other businesses nearby.

Potential locations for distribution that might work for your group:

**Community health care** - medical centres and local GPs, local hospitals, specialist practices (neurologists, physiotherapists, speech pathologists, social workers, occupational therapists), pharmacies, aged care facilities.

**Community groups** - Rotary and Lions Clubs, bowls clubs, cafés, Neighbourhood houses, local libraries, community noticeboards.

## MARKETING ONLINE Websites

**Fight Parkinson's** has a website

([fightparkinsons.org.au](http://fightparkinsons.org.au)) rich with information to support people living with Parkinson's. There are pages dedicated to promoting peer support. Your group can use these links in your promotions to help communicate the benefits of peer support and provide confidence in prospective participants of your group's affiliation with PV.

General information regarding Fight Parkinson's peer support, including the latest list of groups and locations: [www.fightparkinsons.org.au/support-for-you/peer-support](http://www.fightparkinsons.org.au/support-for-you/peer-support)

**Local online news sites as well as community and council websites** often have 'What's On' listings that publicise upcoming events. These listings are usually affordable, and sometimes free, to list event details.

Create a list of local sites that offer these sections and include them in your event promotions, if you can.

### Email

Creating an email database is a great way to keep the community informed of your group and its activities by sending out regular emails to let them know what's happening.

Email promotion follows similar principles to printed promotion. Focus on who could benefit from the information you want to share and how to reach them. Remember not to spam!

Using your existing group participants and relevant contacts in your community, create an email list of stakeholders to whom you can promote your events and activities.

Some examples of contacts you might like to include in your email list:

- local GPs
- local Parkinson's specialists - neurologists, movement disorder nurses, physiotherapists, speech pathologists, social workers, occupational therapists
- local aged care facilities
- local Rotary and Lions Clubs
- local Neighbourhood houses
- community noticeboards
- anyone local who has an interest in supporting the Parkinson's community.

To protect the privacy and personal details of individuals who are on your email list, it is a legal requirement that you do not distribute or share this list.

## SIGNAGE

Signage is a helpful marketing tool and can serve many purposes. It can be permanent or temporary. The types of signage that might be beneficial for your group include:

- A-frame signs
- pull-up banners
- branded flags
- wall posters

When you are thinking about signage for your group, consider how heavy it is and whether it will be easy to move around and display. Also think about where you will use and store the sign - a pull-up banner, for instance, may not be suitable for use outside.

The promotional benefits of signage:

- builds awareness of your group's existence to passing traffic
- reassures people that they're in the correct place
- provides comfort and familiarity via frequent exposure
- delivers a tangible and identifiable element to your group
- shows current and prospective group participants that your group is credible.

Signage can be costly but does have a longer lifespan than other printed promotional material.

When creating your signage, only include information that will not date to ensure best value for your group's investment.

## ADVERTISING

Advertising can also help you reach those in your community who are unaware of your group and its activities.

Not all advertising has a financial cost; some community publications promote your activities without charge if the information is relevant to their readers.

Options for placing advertisements:

- local newspapers - though many of these are now online
- local community newsletters - such as Neighbourhood houses, community centres and community clubs
- community or local radio
- relevant community websites

Most local newspapers have a 'Community Calendar' or 'What's On' section listing upcoming events. This is a great way to get free (or cost-effective) advertising for your group, potentially reaching many readers. For some papers, you may have to submit the piece several times before it gets a run.

Think about any small or alternative media opportunities available in your area. Newsletters, such as those put out by residents' groups, Members of Parliament, schools and environmental groups, can be a good means of gaining free or affordable promotion. Most have a section on upcoming events for community groups.

Community radio stations are usually happy to 'plug' community events and activities and may even run free announcements in the week or so prior to events. Approach a local station and offer to be interviewed on-air. Programs in various community languages would also be keen to hear from group participants willing to speak in their own language about their experience of living with Parkinson's.

## IN THE MEDIA

### Reactive media opportunities

As a Peer Support Group Leader, you may talk to local media but are required to engage Fight Parkinson's if you're approached for a national or state media opportunity.

If contacted by a journalist from outside your local area, please inform Fight Parkinson's as soon as possible so we can ensure a representative of Fight Parkinson's is available to speak to any media with you, as required.

Make sure you let your group participants know the media might be coming along and ensure your nominated spokesperson/people are available and prepared for an interview.

You are also required by Australian Privacy Laws to ensure that any people who may be in any photographs taken by the media approve the use of their image for broadcast or publication.

Please send your local media articles to Fight Parkinson's - we love to see and share media stories.

### Proactive media opportunities

When you have a group event you would like to promote widely, it's a great idea to let your local media know about it.

All you need to do is contact local media outlets well in advance of the event and pitch your story about Parkinson's, your event and/or your support group. For example, you may introduce yourself and say:

'April 11 is World Parkinson's Day. Parkinson's is the second most common neurological condition in Australia (after dementia) and as the local Parkinson's Peer Support Group, we would like to raise awareness of Parkinson's, what it's like to live with the condition, and the local support available.'

Alternatively, you could write and send a Media Release, which provides all the information about the Peer Support Group, its activities, Parkinson's and Fight Parkinson's. Simply use the Media Release template (see Appendix) and include your contact information as the Peer Support Group Leader.

A journalist may contact you or request further information so make sure you respond as soon as possible. Media outlets are usually working to tight deadlines. It's a good idea to ask what their deadline is so that you can meet it.

### Be prepared

Before you speak to the media, familiarise yourself with some key facts and figures taken from the Fight Parkinson's website and/or brochures. You can quote these in your interview for added impact.

It's also useful to get in touch with Fight Parkinson's to check on any relevant new information to provide to the journalist, or events to promote (such as education sessions or a nearby Recently Diagnosed seminar).

Some key messages for promotion:

- Parkinson's is a chronic neurological condition with a range of complex symptoms unique to each individual. The most common symptoms include stiffened muscles, slowing movement and changing posture. Many people also experience resting tremor.
- Other symptoms can include pain, depression, anxiety, speech changes and loss of facial expression. Medication and support from healthcare professionals can help manage these symptoms, however there is no way to slow progression or cure Parkinson's.
- Neurological disorders are now the leading cause of disabilities in the world and Parkinson's is among the fastest growing. Today, 219,000 Australians have Parkinson's and 57,000 are living in Victoria.
- Fight Parkinson's is a not-for-profit, member-based organisation raising awareness and funds for services and research that improve the quality of life for people living with Parkinson's.
- Our multidisciplinary health team provides specialist advice and support to people living with Parkinson's, their families, carers and healthcare professionals. This team also coordinates an extensive network of Peer Support Groups across Victoria.

## MAKING COMMUNITY CONTACTS

Contacting and networking with other relevant small groups in your community offers a range of benefits – from improved awareness of Parkinson's and your Peer Support Group, to facilitating access to resources and facilities.

Groups such as Lions Club, Probus, Rotary, Neighbourhood Houses and Community Centres can be great sources for new participants, support for activities, promotional opportunities, shared resources and even combined events.

## PROMOTION OF FIGHT PARKINSON'S EVENTS AND ACTIVITIES

Fight Parkinson's delivers a wide range of education, events and fundraising activities for people living with Parkinson's, their families, carers and healthcare professionals. All events and programs are designed to educate and empower those impacted by Parkinson's.

We rely on your assistance as a Peer Support Group Leader to promote these activities within your group and encourage members to be part of these events and activities as a means of further improving their knowledge and as a way to meet others from outside your local area.

You can keep up to date on all Fight Parkinson's events via our website's event page:

[www.fightparkinsons.org.au/support-for-you/events](http://www.fightparkinsons.org.au/support-for-you/events)

Please add relevant dates to your group's newsletter and provide members a couple of weeks' notice so they can schedule it into their diaries.

If you have any questions or are looking for ideas regarding promoting your group and its activities, please contact the Fight Parkinson's Marketing department. Phone: (03) 8809 0400, email: [marketing@fightparkinsons.org.au](mailto:marketing@fightparkinsons.org.au)

# Chapter 8

## Accident, Illness and Emergency

Accidents and emergencies happen from time to time. This section will help you plan ahead to avoid or minimise the impact of an emergency situation.

There are two main types of emergency that may arise in relation to your support group:

- 1. An illness, accident or emergency which occurs during a Peer Support Group meeting, for example a fall.**
- 2. A local emergency that may affect the running of Peer Support Group meetings, for example a natural disaster.**

To assist in managing and recovering from an emergency, first and foremost, make sure you have contact details for all group members. This should include an emergency contact for participants – in case a group member becomes unwell and you need to contact a family member or friend on their behalf.

This information should always be on-hand as part of your record-keeping. Also see the contact details sheet in the Appendix.

A record of attendance is required for all Peer Support Group meetings. This is needed in the event of an emergency evacuation, where you will need to account for your attendees.

Retaining a record of who has attended a particular meeting at a particular location can be important in the event we need to contact trace for exposure to an infectious disease or environmental hazard.

This record should be retained for 28 days in a secure location. Please see Appendix for the attendance sheet that can be used for this purpose.

### ADVERSE EVENTS AT A PEER SUPPORT GROUP MEETING

#### Illness

As a general recommendation, if you know someone is unwell, please ask them not to attend a meeting, especially if the condition is potentially infectious, such as a cold, flu or gastroenteritis.

If a person's health deteriorates over the course of a meeting, make them as comfortable as possible and call their emergency contact to come and collect/assist them.

#### Accident or emergency

**In the event of an accident or medical emergency during a meeting or group outing, call 000 in the first instance.**

If you dial 000 you will need to:

- provide information on the nature of the emergency and any known medical information
- seek assistance from others - this may include other people at your meeting venue
- provide first aid if it is safe and you are confident and qualified to do so, or you may need to follow the directions of the emergency services operator
- station a group member at the entrance of the building so they are able to direct emergency personnel. Alert others to the emergency and its location.
- follow instructions of the emergency personnel when they arrive.

If you are meeting in a health-care facility, alert a member of staff as they will have their own emergency procedures.

The most important thing is to not panic – help is never far away.

You may be required to complete an incident report at the meeting venue.

In the case of a serious incident where emergency services are called, Fight Parkinson's must be notified and an incident report completed and returned to Fight Parkinson's.

For any incidents, please notify Fight Parkinson's. A copy of the Incident Report form can be found in the Appendix.

#### Local emergencies

If a natural disaster – such as bushfire or serious flood – affects the region in which your Peer Support Group meetings are held, you may need to cancel the meeting.

On days of extreme heat, or when the fire danger rating is Extreme or Code Red (catastrophic), your meeting should be cancelled.

In the event of other significant emergencies, including severe weather conditions, you should consider cancelling your meeting. If you are unsure, contact the Fight Parkinson's Health Team on 1800 931 031.

If an emergency like severe weather occurs during a group meeting, you need to follow the direction of the Emergency Warden (if available) or the local authorities in the first instance. When you are able, contact Fight Parkinson's and advise of the situation and response.

### [Epidemics and pandemics](#)

In the case of an outbreak of illness in the local community or wider area, Peer Support Groups should consider the health of their members – especially those who are frail or quite advanced in their illness. Depending on the severity of the outbreak you may need to cancel your meeting. Fight Parkinson's will be able to provide guidance to assist with managing this occurrence.

If there is an outbreak of considerable concern, Fight Parkinson's will contact you with recommendations on how your group should respond.

# Chapter 9

## Connecting and Holding Meetings Online

### IN THIS CHAPTER:

- Hosting an online meeting
- What equipment do I need to host an online meeting?
- Group Facebook pages
- Privacy and security
- Help and training

### CONNECTING WITH GROUP MEMBERS ONLINE

Peer Support Groups may choose to hold meetings via online meeting platforms, like Zoom, particularly when they are unable to meet face-to-face given a health pandemic or emergency.

Online meetings still offer participants the opportunity to connect. Even when face-to-face meetings can occur, some groups may choose to run meetings via Zoom or hold carers' meetings online.

Going online also offers inclusivity. If a participant is in an aged-care facility or hospital or otherwise too unwell to physically attend a meeting, they have the option of dialling into a meeting via social media and still participating.

### HOLDING AN ONLINE MEETING

A big bonus of hosting meetings and events online is that it offers your group participants options. Not only can they attend a Peer Support Group meeting in person, but if they are unable to, for whatever reason, they can remotely access the meeting via an online platform. Zoom seems to be the most common live-stream internet platform used by our community.

Like in a face-to-face Peer Support Group, the point of meeting online is for everyone to listen, feel heard and understood whilst sharing their personal journeys. Everyone can have the opportunity to participate in discussions safely and equally.

A host of an online peer support meeting must assign a co-host. There is no limit on the number of co-hosts you can have in a meeting or webinar. It allows the host to share hosting duties with another user, allowing the co-host to manage the administrative side of the meetings, especially useful in the case of internet troubles.

It also means if you as the leader are unable to attend an online meeting, the meeting can still go ahead without you.

### What equipment do I need to host a meeting online?

Regardless of which online meeting platform you choose for a meeting, you will require a good internet connection and a computer or laptop which has speakers, a microphone and a video camera. Group participants who join an online meeting will also require a computer, laptop or phone with a speaker, with or without a camera, that allows them to dial into the meeting. Others will be able to dial in from landline phones if they do not have access to this.

Many groups choose to use Zoom as their online social platform. Zoom offers a 40-minute free licence which anyone can sign up to over the internet, otherwise you will need to subscribe should you wish to hold longer meetings. Only the host needs to register, not the group participants.

When applying for licenses and also looking at computer equipment, it is important to look at your group's finances and see whether these IT costs are something that can be covered by existing funds or perhaps via a grant.

### Camera and microphones

Ask participants to check that their device's microphone and video (webcam) are working before joining an online meeting. It is always good for users to practise with a family member the first time they are using a new online platform.

Most video-conferencing platforms will take you and your participants through an automated check of these features, so ask participants to join the live-stream five to 10 minutes early to run through this check and fix any technical difficulties. Be mindful that you, or a co-host, will need to be online 10 minutes prior to the start of your meeting to help with any technical difficulties.

During the online meeting, keep your microphone on mute when you are not speaking. Remember to unmute it when you would like to speak or ask a question. This is out of respect for all the participants. If you would like to ask a question using your microphone, use the "raise hand" function or physically raise your hand at the camera so that the host can see you. This lets the group facilitator know that you would like to ask a question, and helps avoid people talking over one

another. You can also choose the “chat” feature button and type a question privately to the host or openly to the group.

## PRIVACY AND SECURITY

Most security breaches on the internet result from software that is not up to date. Be vigilant about updating software, including apps, anti-virus and even the humble browser.

If there is likely to be background noise or if privacy cannot be guaranteed where you’re located, use headphones so members of your household can’t hear what other participants are saying. You also might not want other members of your household overhearing what you say.

If you are going to use your webcam, please be mindful of what others can view in the background. Remove or cover any personal items that might be in your background and you would prefer others not see (such as family photos).

Avoid joining the online meeting from your bedroom, if possible, and participate from a study, living room or other “neutral” space. Another option is to have a picture or a Zoom scene as your background.

Be mindful of your privacy settings. Regularly check the privacy settings on your computer, and make sure people can’t track your location. Do not share passwords, and always think before you post.

## GROUP FACEBOOK PAGES

A group Facebook page is a great way for your participants to stay connected between meetings. Facebook can be an easy way to keep group members informed of activities, as well as share stories and stay engaged with each other.

If you are interested in setting up a Facebook page for your Peer Support Group, contact the Fight Parkinson’s Community Development Coordinator on 1800 931 031. To find out how to join Facebook, see the Appendix.

## Coordination

### Facebook administrator

Fight Parkinson’s will set up your Peer Support Group page and act as the site administrator, while a member of the support group will take on the role of moderator.

As administrator, Fight Parkinson’s can provide you with general information, but the moderator plays a key role in generating content for your page.

### Moderating your group Facebook page

As Peer Support Group Leader, your role is to be the moderator of the page. You can choose to share the role with another member of the group. However, it is recommended that you have a minimum of two moderators. This will safeguard succession planning and ensure ongoing activity on the page.

Group members with an interest in technology and online communication would be perfect for the role. However, Fight Parkinson’s can also provide information on how to run the page. You may also choose to allocate this role to a supporter of the group, such as a family member or carer.

Ideally, your page should be monitored regularly if your group actively contributes. Weekly monitoring, at a minimum, is recommended.

Your page moderator is the person who:

- accepts or rejects requests to join the group
- shares information via the Facebook page
- monitors the conversations and comments
- liaises with Fight Parkinson’s regarding page content or any issues arising.

The moderator will also need to have their own personal Facebook page to be able to moderate your group page.



MUTE YOUR MICROPHONE IF YOU CAN



USE HEADPHONES IF YOU CAN



TURN THE CAMERA OFF IF YOU HAVE WEAK INTERNET OR DON'T WANT TO BE SEEN



QUESTIONS ARE WELCOMED AND WE WILL STOP FROM TIME TO TIME AND AT THE END



YOU CAN USE THE CHAT FUNCTION TO ASK A QUESTION OR MAKE A COMMENT



YOU CAN REDUCE THE SIZE OF THE VIDEO BOX AND USE YOUR MOUSE TO MOVE IT AROUND YOUR SCREEN IF YOU WANT TO SEE MORE OF THE SLIDES

# FACEBOOK PAGE CONTENT

## Group privacy

Fight Parkinson's Peer Support Group pages are private. Once a user requests to join your Facebook page and is accepted, all their contributions will be private within the group. This means any contributions or comments cannot be seen by people outside of the group page.

So it is important that all participants adhere to the rules of the group. These rules are displayed on the group's Facebook page and outline the right of each person to privacy.

There is to be no sharing of content outside of the group. While all measures are taken to ensure privacy, please be mindful that nothing shared online is ever truly private.

## How do I post on the Facebook page and what should I post?

When scheduling and posting content, including photos, it is important you have the appropriate permissions beforehand. In gaining consent from individuals featured in an image, you need to be conscious that once an image is online it is there forever.

Content that could be posted on your Facebook site could include:

- Parkinson's information
- research findings from reliable sources like Fight Parkinson's
- educational events
- inspirational stories from your community
- ways to get involved
- the chance to ask questions
- articles from *InMotion*
- Fight Parkinson's website information
- posts from the Fight Parkinson's Facebook page

## Guidelines for Facebook pages

Each Facebook group page must adhere to the following rules, which are placed at the top of each group site.

This private group is for the benefit of the Fight Parkinson's 'Name' Peer Support Group only. It is a safe place to share stories, ask questions, share thoughts and seek and provide peer support with other group participants.

Fight Parkinson's is a not-for-profit organisation and this page is moderated by volunteer Peer Support Group Leaders. You must already be part of the group to view and contribute to this page.

### RULES OF PARTICIPATION

#### 1. Be kind and courteous

We're all in this together to create a supportive environment. Treat everyone with respect. Healthy debates are natural, but avoid being judgemental. Kindness is required.

#### 2. No hate speech or bullying

Everyone has and deserves the right to feel safe. Bullying of any kind is not allowed, and degrading comments about race, religion, culture, sexual orientation, gender or identity will not be tolerated.

#### 3. No promotions or spam

Please give more to this group than you take. Self-promotion, spam and irrelevant links are not allowed.

#### 4. Respect everyone's privacy

Being part of this group requires mutual trust. Authentic, expressive discussions make groups great, but may also be sensitive and private. What's shared in the group must stay in the group. No sharing of other participants' posts or comments.

#### 5. Content integrity

Peer Support Group Leaders, moderators and participants are not speaking on behalf of Fight Parkinson's. Group contributions are offered from a personal perspective and are done with the group's best interests in mind.

Peer Support Group Leaders and moderators will monitor comments and posts and, where appropriate, escalate issues to Fight Parkinson's for resolution.

Fight Parkinson's will share relevant content with the group from time to time.

Fight Parkinson's reserves the right to close this Facebook page if required.

## Qualifying questions to join the group

Only known Peer Support Group participants are allowed access to your group Facebook page. This means that each participant allowed to join the private Facebook page must:

- be known to the Peer Support Group Leader or page moderator as having attended a Peer Support Group meeting in the past
- be living with Parkinson's
- be a carer or family member of a Peer Support Group participant

Before accepting any requests to join the Facebook page, the group's Facebook moderators will need to qualify new members by asking them the following questions:

**1. Are you already on the register as a participant of this Peer Support Group?**

- Yes
- No. Please contact Fight Parkinson's on 1800 931 031 or [info@fightparkinsons.org.au](mailto:info@fightparkinsons.org.au)

**2. Why is this group relevant to you?**

- I have been diagnosed with Parkinson's
- I have a family member who is living with Parkinson's
- I am a carer of someone diagnosed with Parkinson's
- I have a loved one diagnosed with Parkinson's
- I support someone with Parkinson's

**3. What was the year of diagnosis of the person living with Parkinson's?**

## HELP AND TRAINING

Online platforms are constantly changing and evolving. It is a new world to many of us, and a new skill to acquire. Fight Parkinson's offers training courses on new computer technologies that Peer Support Groups may find useful. Keep a lookout for any training programs advertised.

If you have any questions about holding Peer Support Group meetings online, attending Fight Parkinson's online workshops or your online safety, call Fight Parkinson's on 1800 931 031.

# Chapter 10

## Recognition Programs for Peer Support Groups

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### FIGHT PARKINSON'S ANNUAL RECOGNITION AWARDS

Each year Fight Parkinson's recognises the significant contribution members of the community make in supporting people living with Parkinson's and their families. Our annual awards program recognises the service of both individuals and groups for their outstanding commitment to the Parkinson's community.

If you would like to see someone or a group acknowledged for their service or work in your local community or the wider Parkinson's community, why not nominate them for one of the Fight Parkinson's Recognition Awards?

Nominations open in June/July and close at the end of September. Award recipients are announced at the Fight Parkinson's Annual General Meeting by year's end.

For more information go to [www.fightparkinsons.org.au/about-us/recognition-awards/](http://www.fightparkinsons.org.au/about-us/recognition-awards/)

#### Sir Zelman Cowen Award

Fight Parkinson's's highest honour, the Sir Zelman Cowen Award is presented to an individual in recognition of their invaluable voluntary contribution to the Parkinson's community. In 2006, former Governor General Sir Zelman Cowen generously gave permission for an award to be presented in his name, allowing Fight Parkinson's the honour of recognising his outstanding community service and support for people living with Parkinson's.

#### Harold Waldron Carers' Award

Harold Waldron dedicated 40 years of his adult life to the care of his wife and supporting others living with Parkinson's. In 2019, Fight Parkinson's announced the creation of this award to recognise the invaluable contribution of carers, whose lives are also so greatly impacted by a Parkinson's diagnosis.

This award honours a family member or friend who has been touched by Parkinson's and has made a significant difference to the Parkinson's community through their voluntary leadership or support of a leader, through their consistency, length of service and dedication to the community.

#### Honorary Life Membership

This award recognises outstanding service for a period of at least 15 years.

#### Five-, 10- and 15-Year Service Awards

Acknowledges the continuous service of volunteers in an administrative, project or service capacity, particularly those coordinating a Peer Support Group.

#### Community Recognition Award

Recognises the significant contribution of an individual or organisation to events or activities.

### LOCAL COMMUNITY AWARDS

The following are only some of the community awards available. Contact the Community Development Coordinator if you would like us to help with your application. Fight Parkinson's is also proud to celebrate any awards or acknowledgements your group or group participants receive in their local communities. Let us know of any special recognition.

#### The Premier's Volunteer Champions Awards

These were created to recognise the incredible impact volunteers have across Victoria in building our communities, services and connections.

In addition to awards in the categories of Leadership, Impact, Service and Teamwork, the Premier's Volunteer of the Year, Dame Elisabeth Murdoch Award will be selected from all award recipients to honour their significant contribution and outstanding commitment.

For more information, go to: [www.volunteer.vic.gov.au/victorian-premiers-volunteer-champions-awards](http://www.volunteer.vic.gov.au/victorian-premiers-volunteer-champions-awards)

## Local Council Citizen, Volunteer and Community Group Awards

These awards recognise community organisations, clubs or groups who have gone 'above and beyond' to improve the lives of members of the local community.

Nominees must be not-for-profit community organisations who have made a tangible difference to diversity, acceptance, tolerance, community spirit and social connectedness. Check your local council website or office for their awards and nominate those in your support group you think are eligible.

### Awards Australia Community Hero Award

This acknowledges individuals making a significant contribution at a local level in regional and rural Victoria. There are many selfless people who, through their actions, have positively impacted the lives of others and their community.

The Community Hero Award acknowledges everyday people doing extraordinary things. Community heroes may be involved in (but not restricted to) art, health, business, sport, volunteering, the environment, aged care, or education. They may have displayed courage in overcoming personal adversity or demonstrated leadership in trying times.

For further information about nominating someone for the Community Hero Award, phone: (03) 9720 1638 or email: [vic@awardsaustralia.com](mailto:vic@awardsaustralia.com).

## AUSTRALIAN AWARDS

**The Order of Australia** is an order of chivalry to recognise Australian citizens and other persons for achievement or meritorious service.

Anyone can nominate a member of the community for an award in the Order of Australia.

Visit the website of the Governor-General of Australia, [gg.gov.au](http://gg.gov.au), for more information.

# Chapter 11

## ParkinSong

### IN THIS CHAPTER:

- Leadership and assistant roles in a ParkinSong group
- At the venue
- Cost and resources
- Joining a ParkinSong group
- Session structure and format
- ParkinSong program training

ParkinSong is a singing-based peer support group program, specifically designed to encourage and enhance communication for people with Parkinson's. In addition to the enjoyment of singing, vocal exercise and communication activities, ParkinSong offers all the benefits of standard Peer Support Groups: social contact, mutual peer support, information and education.

ParkinSong has been collaboratively designed using speech-pathology and music-therapy disciplines, in line with current knowledge, evidence and communication-therapy principles.

Intensive vocal exercise and warm-up, communication activities and singing are all tailored to specifically target aspects of communication affected by Parkinson's. These impacts are detailed in the ParkinSong Program Training Package.

ParkinSong reminds participants of the importance of communication, and serves to monitor communication ability and encourage access to professional help, such as speech therapy, in order to improve it.

ParkinSong aims to:

- support optimal vocal function and general communication
- encourage participation in communication
- improve communication confidence
- encourage social contact
- improve mood and wellbeing of participants, including carers
- provide support and education regarding communication for carers or significant others

### HOW TO GET STARTED

ParkinSong groups are locally based and initiated by people from, or associated with, the Parkinson's community. ParkinSong groups may be run as stand-alone gatherings or in conjunction with a Parkinson's Peer Support Group.

Ideally a ParkinSong group should be run by a team of two or more people. Participants with Parkinson's and carers are encouraged to be involved in running the group, as is appropriate and physically safe.

Leadership and assistant roles in a ParkinSong group may include the following:

#### Coordinators (Group Leaders)

ParkinSong group coordinators are usually people with Parkinson's and/or carers, who come with valuable first-hand insights into the experience and needs of people with the condition. Sharing the group coordination role reduces the demand and workload for coordinators, providing an opportunity for collaboration, inspiration and mutual support. Group Leaders do not require any musical training or background.

#### Musical team (Program Leaders)

ParkinSong can be musically led by appropriately skilled community volunteers, trained musicians, musically skilled health professionals and carers. The musical team comprises:

**Musical director/choral leader** - leads the musical warm-up and singing

**Accompanist(s)** - plays keyboard, guitar or other suitable instrument

Music teams vary between groups. Some have a band with a variety of musicians such as cellists, saxophonists and/or violinists. Others have only one musician who leads all aspects of the program (vocal exercises, musical warm-up, communication activities, singing and accompaniment).

A musical team, even of two members, lightens the load, fosters collaborative creativity and can be convenient when leaders are on leave or unexpectedly absent.

## Vocal exercise/communication assistant (Program Leader)

Intensive vocal exercise and communication activities are essential elements of ParkinSong. This assistant requires an understanding of communication, how it is impacted by Parkinson's, and skill in leading and motivating the group to work through the exercises and tasks.

## Welcome team (Assistants)

A team of two or three group participants (people with Parkinson's and/or carers) can be responsible for welcoming fellow group members. They can also make sure new participants feel welcome.

The person at the Registration Desk welcomes participants, records attendance and takes contact details (for any necessary communication between ParkinSong sessions).

## Room set up and pack up (Assistants)

Enlist two or three assistants to set up and pack up equipment and seating (as well as other items). This can be a rotating role to share the load but remember to ensure the physical lifting is within the person's ability to perform safely.

For this reason, it is not recommended that participants with Parkinson's pack up chairs and heavy equipment.

## Tea break (Assistants)

Two or three assistants to serve refreshments is recommended. Carers often take this role, to free up people living with Parkinson's to chat and connect.

## AT THE VENUE

A small hall with sufficient room between semi-circular rows is ideal.

Select an easily accessible venue, close to public transport, with adequate on-site parking. A well-equipped kitchen is also useful. See Chapter 2 for more on finding a suitable venue.

The number of participants can vary significantly according to the group. Groups can start with a few participants and grow over time. You will need enough space to allow for:

- participants to face a screen/wall
- a small table for audio-visual equipment
- room for the musical team, instruments and music stands
- good access to electricity points (multiple power-points and power-boards can come in handy)

Ideally, vocal exercise, warm-ups, communication activities and song lyrics are projected onto a screen (or clear wall space) rather than on paper. This is important for encouraging upright posture, which is vital for optimal breath support, speech, voice and singing.

## Seating

To optimise communication and acoustics, a semi-circular seating formation is recommended. Choir experts explain that the curved seating formation helps participants listen, stay in tune and blend voices.

Generous space between rows is advised in order to facilitate movement. Restricted space can worsen motor symptoms of Parkinson's. Firm, standard-height chairs with arms are recommended, particularly for those who may have difficulty getting up from a chair.

Depending on the participants, choral leaders will sometimes divide the group into various sections or voice parts (soprano, alto, tenor and bass), seating them accordingly.

## Registration and welcome

A small table, set up near the entrance of the venue, is handy as a Registration and Welcome Desk, where you can record attendance, take contact details and collect fees or donations.

## COST AND RESOURCES

Consider the potential expenses of running a ParkinSong group: tea break refreshments, basic kitchen items (cups, spoons, platter, paper serviettes), stationery, hall hire and sheet music.

If you intend to project slides for exercises and lyrics on a screen, you will need access to a laptop and projector (if not already part of the venue). If your group does not have access to this equipment and uses printed lyrics, music stands can allow hands-free singing and encourage good posture.

Music stands are only suitable for small groups of about 12 participants. With larger groups and multiple rows of seating, music stands can create a cluttered environment, impacting movement.

## JOINING A PARKINSON'S GROUP

Prospective ParkinSong participants can contact the Fight Parkinson's Health Team for information on local groups. Fight Parkinson's will provide the group coordinator with contact details of those interested in joining.

## SESSION STRUCTURE AND FORMAT

Allow two hours for ParkinSong sessions. The usual format is as follows:

- vocal exercise, communication activities, warm-up - 30 minutes
- singing - 45-60 minutes
- tea break, chat and connect - 30 minutes

The frequency of ParkinSong sessions varies between groups, depending on participant preferences and availability of leaders and resources. Some groups run weekly within school terms, others run fortnightly within school terms while other groups meet once a month.

The tea break is a pivotal part of the program, creating an opportunity for participants to chat and connect in a relaxed, friendly, social environment. The welcome team and other leaders have an important role in facilitating conversation and engagement, introducing new participants to others in the group. This is particularly important for those participants who may have significant communication difficulties and diminished confidence.

### PARKINSON PROGRAM LEADER TRAINING

If you are considering including ParkinSong as an activity for your Peer Support Group, leaders of the group are required to complete group leader training with Fight Parkinson's. This is designed to equip and support program leaders to facilitate the activities according to the standard ParkinSong program.

To discuss this training, contact Fight Parkinson's on 1800 931 031.

# Chapter 12

## Painting with Parkinson's

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Painting with Parkinson's is based on art therapy and occupational therapy principles.

There is no requirement for anyone to be proficient in art to be part of the program. Rather than being taught or directed, the methodology supports participants to become absorbed in their creative work.

Painting with Parkinson's is not about trying to make everyone an artist. Everyone has some level of creativity. Finding and fostering this creativity will in most cases lead to more self-confidence.

Creativity can be expressed in many ways. There is no right or wrong way to show your creativity and participants can find their output expanding into other forms, such as pottery, singing and poetry.

The activity provides distraction from symptoms and activates other parts of the brain which may suppress some Parkinson's symptoms during the activity.

### SETTING UP A PAINTING WITH PARKINSON'S GROUP

Painting with Parkinson's groups are locally based and initiated by people from, or associated with, the Parkinson's community. The groups may be run as stand-alone gatherings or in conjunction with a Fight Parkinson's Peer Support Group.

Ideally, a Painting with Parkinson's group should be run by a team of two or more people.

### Who will lead and run the group?

A leader with a background in art therapy is ideal, but not essential. Teaching experience (not necessarily art teaching) is also useful. Painting with Parkinson's Group Leaders should be flexible and inventive. In general, they enjoy creative play and working with people.

Volunteer roles include room set up and pack up, and serving tea and coffee.

### How many participants can attend?

Usually between 10 and 15. Any more participants would require more support roles to be filled by volunteers. Groups have started with just two participants.

### Cost and resources

The provision of art materials means that running a Painting with Parkinson's group can incur more costs than a regular support group. Consider the potential expenses of running a Painting with Parkinson's group: art materials (see below), occupational therapy items for warm-up/ coordination exercises, fresh flowers to paint or draw, basic kitchen items (cups, spoons, plates, paper serviettes), room hire, stationery/marketing costs for potential exhibitions.

### Art materials

These include paper, canvases, graphite pencils, sharpeners, erasers, good quality paint brushes, watercolour paint, acrylic paint and sturdy water pots.

Some more specialised items could be useful, such as Faber Castel Magnus watercolour pencils, which are a larger size and easier to hold than a normal pencil. These are also softer so more pressure can be applied without breaking the tip.

For participants who have trouble wielding a paintbrush, offer droppers, sponges or cloths to spread paint.

### Other materials

Soft foam balls, sometimes called stress balls, are good for warm-up and coordination activities. Some Painting with Parkinson's groups enjoy fresh flowers to draw and paint at each session. A musical playlist - specific to the group - has also been found to be beneficial.

## THE VENUE

Select an easily accessible venue, close to public transport, with adequate on-site parking and a well-equipped kitchen. You will also require a secure storage space, such as a locked cupboard, so that you don't have to cart materials in for each session. A Neighbourhood House is a good option for community connection.

## Registration and welcome

A small table, set up near the entrance of the venue, is handy as a Registration and Welcome Desk, where you can record attendance, take contact details and collect fees or donations.

## SESSION STRUCTURE AND FORMAT

Most Painting with Parkinson's sessions last two hours. Groups may choose to meet weekly to monthly. The usual format is as follows:

- meet, greet and eat - 20 minutes
- warm-up/coordination exercises - 20 minutes
- pre-drawing - 20 minutes
- go for it! - 45-60 minutes

### Meet, greet and eat

The first 20 minutes (approximately) is a time of greeting each other, catching up with people, showing off paintings and artwork done at home, lots of food and endless cups of tea and coffee. This is when any 'baggage' from the start of the day is left at the front door. Eventually, it disappears.

### Exercises

Exercise sheets are available from Fight Parkinson's. These activities are done while seated and always start with a gentle stretch. No one is forced to do these. Music playing in the background is a great idea.

Using a foam rubber ball to squeeze, passing it between your hands and rotating your wrists is a great way of loosening up before you start to paint.

### Pre-drawing

These activities start the release of 'feel-good' chemicals in the brain. As these are released, the central nervous system starts to relax. Tremors slow down and may even stop while in this mode. Many activities can be undertaken to cross from one brain hemisphere to another, that is, left to right brain, promoting brain plasticity.

## Painting and Creating

We want everyone to be relaxed, have lots of fun and laugh. Now the tables are spread with paper, paints and anything that can be used for putting paint on paper. Let the creativity begin!

For further information, please contact Fight Parkinson's on 1800 931 031.

A comprehensive manual is available for those interested in developing a Painting with Parkinson's group.

# Chapter 13

## Closing a Peer Support Group

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Peer Support Groups may close or stop meeting for a variety of reasons, including low attendance or being unable to find a new leader or coordinator.

If your group decides to close, or is headed that way, please contact the team at Fight Parkinson's so we can support you to revitalise or close the group, support current members and redirect new enquiries from your local area.

### CHECKLIST WHEN CLOSING A PEER SUPPORT GROUP

- Communicate with all participants, even if they have not attended a meeting for a while, to inform them the group is no longer meeting and provide a contact for Fight Parkinson's who can provide support or referrals to other groups in the local area.
- Inform the venue it is no longer required and pay any rent which may be due.
- Document what assets your group may have. This may include funds in a bank account, equipment or property.
- Pay all existing debts or invoices with your bank account funds. Once all payments have been made, close the group bank account.
- If you have received monies from a grant, ensure all grant funds are utilised in accordance with the conditions of the grant and the funding submission, and the grant paperwork is completed and acquitted. If funds are not spent, they may need to be returned to the funding body before closing the bank account. Contact the funding body to discuss what the options are.
- If you have received monies from a donation, ensure all donated funds are utilised in accordance with the donation. If the funds are not spent, you may need to return them to the donor before closing the bank account. Contact the donor to discuss what the options are.
- Notify any community organisations that promote your group and provide contact details for Fight Parkinson's for any future enquiries.
- Notify any local groups with whom you have agreements in place - for example, donations of food, coffee or speakers for meetings.
- Return any borrowed equipment or materials, such as computers or library materials.

### FINALISING THE CLOSURE OF THE GROUP

Any remaining funds in the bank account or group assets will be transferred to Fight Parkinson's for a period of 12 months and will remain owned by the Peer Support Group during this period. The group assets will not be maintained during this time.

Transfer any paperwork relating to the Peer Support Group to Fight Parkinson's, including bank accounts, warranties and all information relating to participants' information.

If the group does not resume within a 12-month period, the funds and assets will be donated to Fight Parkinson's and be utilised in the support of the statewide Peer Support Group program.

# Appendix

## Documents

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# Peer Support Group Report Form



This form should be completed by the group leader or a member of the group, and returned to Fight Parkinson's.

Note: If you already prepare a monthly newsletter for the group, it can be sent in place of this form.

Please return from by mail: Fight Parkinson's  
PO Box 116, Camberwell VIC 3124  
Or Email: [info@fightparkinsons.org.au](mailto:info@fightparkinsons.org.au)

Group Name: \_\_\_\_\_

Meeting Date: \_\_\_\_\_

Meeting Topic/Activity: \_\_\_\_\_

Guest Speakers (Name & Title): \_\_\_\_\_

No. in attendance: \_\_\_\_\_ No. of new members: \_\_\_\_\_

Topics discussed: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Questions/issues raised: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Future meeting activities, guest speakers, or planned events: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Form completed by: \_\_\_\_\_  
(PTO)



If there are any changes to your meeting time, location or positions of responsibility, please contact the Peer Support Co-ordinator at Fight Parkinson's as soon as possible.

If you require any resources, fill out the details below (please specify quantities):

- Hospital Kit
- Fight Parkinson's Membership Form
- Name tags for group members

Names:

Y  N

Do you have any additional comments, requests or feedback for the team at Fight Parkinson's?

# Peer Support Group attendance form



Peer support group name:

Date:

COVIDSafe Marshall/Leader's must retain a copy of this sheet for 28 days in a secure safe place in the unforeseen case that participants need to be contacted relating to a case of COVID-19.

## Contact details including emergency contacts



Peer support group name:

Name	Email	Landline & Mobile	Postal Address	Emergency Contact & Number

# Asset register



Together we can

Peer support group name:

A photograph of each item should be attached.

# Expense Tracker

Peer support group name:



# Photograph & Video Release Form



I hereby grant permission to Fight Parkinson's (ABN 59 604 001 176) the rights of my image, likeness, and sound of my voice as recorded on audio or video tape. I understand that my image may be edited, copied, exhibited, published, or distributed.

I also understand that this material may be used in diverse educational settings within an unrestricted geographic area.

Photographic, audio or video recordings may be used for the following purposes:

- Educational videos
- Websites and social media
- Training conferences/presentations
- Printed promotional materials
- Social Media

By signing this release, I understand this permission signifies that photographic or video recordings of me may be electronically displayed via the internet or in a public educational setting. There is no time limit on the validity of this release nor is there any geographic limitation on where these materials may be distributed.

By signing this form, I acknowledge that I have completely read and fully understand the above release and agree to be bound thereby. I hereby release any and all claims against any person or organisation utilising this material for educational purposes, without payment or compensation.

Full Name:

Phone:

Email:

Signature:

Date:

# Peer Support Group Media Release Template



[Date]  
[Headline]

E.G. - Local support crucial to living well with neurological condition

**[Lead – Start with your location and it is important your lead is punchy]**

**[Insert town name] Parkinson's Peer Support Group .....**

**[Body]** – Expand on the story. Use Quotes to make it interesting but remember to attribute it to a particular person]

**[End]** – This is the least important information but provides background information or summarises]

**END NOTE:** The **[insert name]** Parkinson's Peer Support Group is currently meeting **[enter meeting details]** and new members are welcome. Call Fight Parkinson's on 1800 931 031 for further information on this and other support services available.

**ENDS –**

**[Contact details – Provide the details of who can provide more information]**

For further information about this group/event call **[Enter your contact details]**

## About Parkinson's

Parkinson's is a progressive neurological condition that affects people from all walks of life. There are an estimated 57,000 Victorians living with Parkinson's and 219,000 nationally. Neurological disorders are now the leading cause of disabilities in the world and Parkinson's is the fastest growing neurological syndrome.

It is not easy to diagnose Parkinson's. There are no laboratory tests (such as a blood test or brain scan), so it is important that the diagnosis is made by a specialist, such as a neurologist.

Parkinson's is categorised by clinicians as a "movement disorder." However it doesn't just affect movement. Non-motor symptoms such as pain, depression and problems with memory and sleep can also occur and have an impact on the day-to-day life of the person with Parkinson's.

Symptoms develop slowly and gradually progress over time. Each person is affected differently, and the rate of progression varies between individuals.

Parkinson's doesn't directly cause people to die and it is possible to live with Parkinson's for a long time, although symptoms do get worse over time.

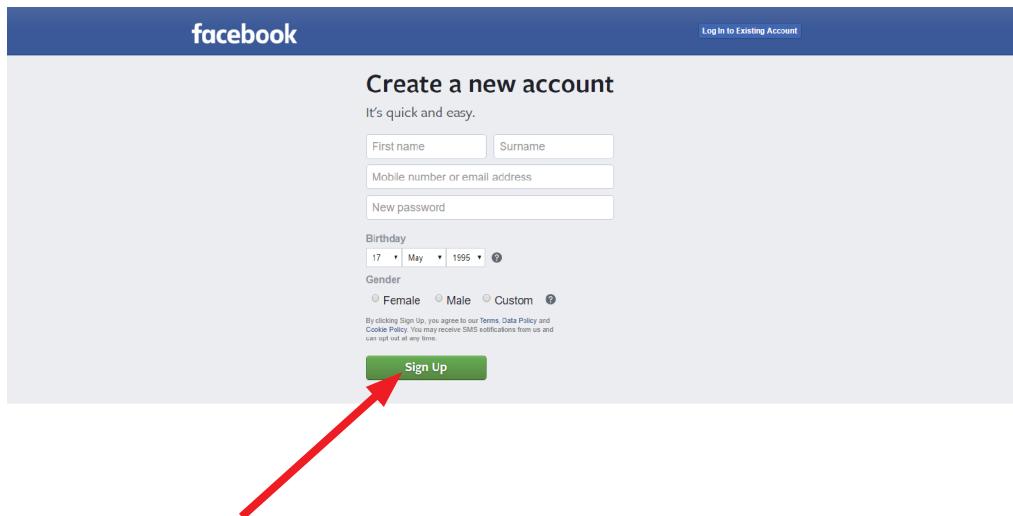
# How to join Facebook instructions

## HOW DO I CREATE A FACEBOOK ACCOUNT?

Follow these instructions or go to this link:

<https://www.facebook.com/help/188157731232424?helpref=topq>

### 1. Go to [www.facebook.com/r.php](https://www.facebook.com/r.php).



### 2. Enter your name, email or mobile phone number, password, date of birth and gender.

### 3. Click Sign Up.

### 4. To finish creating your account, you need to confirm your email or mobile phone number.

- To confirm your mobile number, enter the code you get via text message (SMS) in the Confirm box that shows up when you log in. Learn what to do if you didn't get the SMS.
- To confirm your email, click or tap the link in the email you got when you created the account. Learn what to do if you can't find the email.
- Confirming your email or mobile number helps us know that we're sending your account info to the right place.

Note: Please confirm your email or mobile number as soon as possible. **You may not be able to use your account until you confirm your email or mobile number.**

## HOW DO I JOIN A FACEBOOK GROUP AS MYSELF?

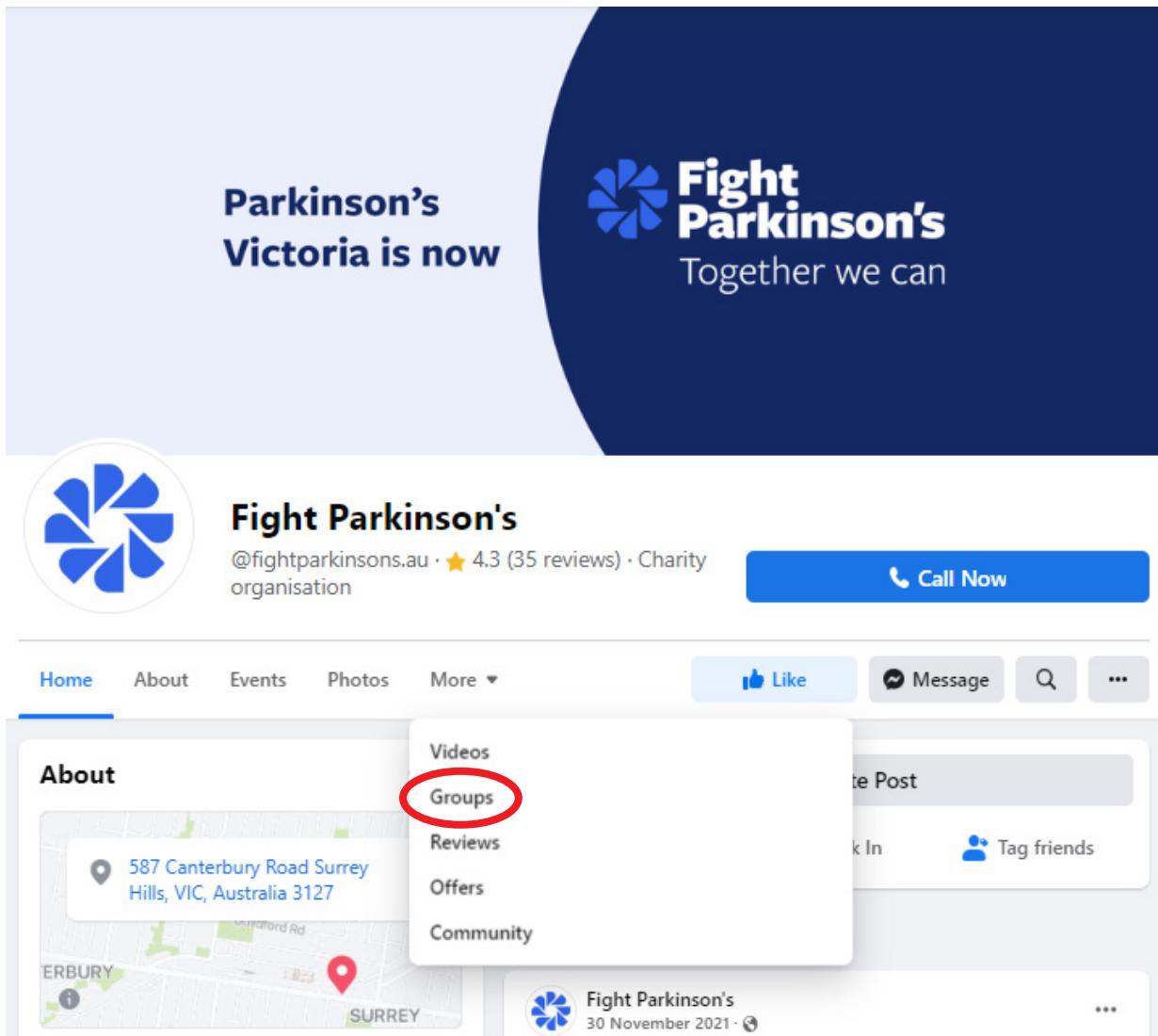
Follow these instructions or go to this link:

[https://www.facebook.com/help/103763583048280?helpref=about\\_content](https://www.facebook.com/help/103763583048280?helpref=about_content)

Groups are a place to communicate about shared interests with certain people. You can create a group for anything — your family reunion, your after-work sports team or your book club.

To join a group as your profile or your Page:

1. From your News Feed click Groups in the menu.



The screenshot shows a Facebook group page for 'Fight Parkinson's'. The cover photo features a blue circle with the text 'Fight Parkinson's' and 'Together we can'. To the left, there is a smaller image of a blue flower-like logo with the text 'Parkinson's Victoria is now'. The group's name, 'Fight Parkinson's', is displayed in large blue text, along with its handle '@fightparkinsons.au' and a 4.3 rating from 35 reviews. A 'Call Now' button is visible. The top navigation bar includes links for Home, About, Events, Photos, More, Like, Message, and Search. A dropdown menu is open over the 'More' link, showing options: Videos, Groups (which is circled in red), Reviews, Offers, and Community. Below the menu, there is a map showing the location '587 Canterbury Road Surrey Hills, VIC, Australia 3127' and a post from 'Fight Parkinson's' dated 30 November 2021.

2. In the search bar at the top, enter some keywords for the group you're looking for.
3. Select the group then click + Join Group below the cover photo.



## Fight Parkinson's

@fightparkinsons.au • ★ 4.3 (35 reviews) • Charity organisation

[Call Now](#)

Home

About

Events

Photos

More ▾

[Like](#)

[Message](#)

[Q](#)

...

### Linked groups



27forParkinson's

313 members • 4 posts a week

Joined



Boronia Parkinson's Peer Support Group

6 members

[Join Group](#)



Geelong Peer Support Group

2 members

[Join Group](#)



Ringwood Parkinson's Support Group

8 members

[Join Group](#)



Friends@Park Barwon Region Peer Support Group

9 members

[Join Group](#)



Langwarrin ParkinSong

6 members

[Join Group](#)

#### 4. Select whether you'd like to join as your profile or your Page and click Join Group.

Depending on the group's settings, you may have to wait for a group admin to approve your request.

Secret groups won't appear in search results, and a current member will need to invite you.

When you join a group other people may be able to see that you're a member depending on the group's privacy option.

## HOW DO I INVITE NEW MEMBERS TO A FACEBOOK GROUP?

Follow these instructions or go to this link:

[https://www.facebook.com/help/162550990475119?helpref=faq\\_content](https://www.facebook.com/help/162550990475119?helpref=faq_content)

To invite new members to a group:

1. From your News Feed, click Groups in the left menu and select the group you'd like to invite new members to. If you don't see Groups, click See More.
2. Click + Invite below the cover photo.



### Young@Park

Private group · 10 members



Joined + Invite

### 3. Enter the names of the people you want to invite and then click Invite.

For all types of groups—public or private—group members can invite anyone they're friends with.

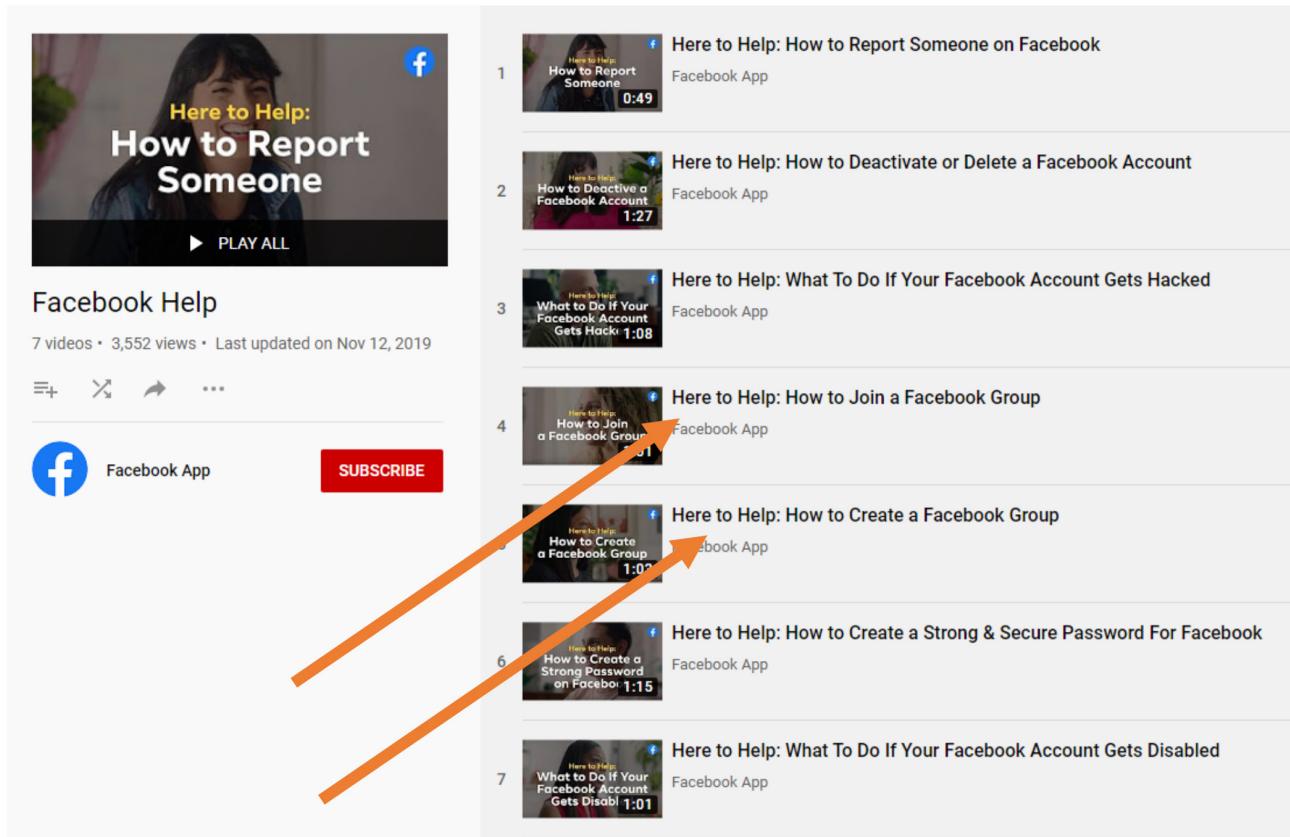
Keep in mind that once someone is invited to join a group, they'll be able to preview the group before deciding if they'd like to join the group. If someone is previewing the group, they won't be included in the total member count.

Note: If you invite people to a group, a group admin may need to approve the request before they can join.

## HELPFUL FACEBOOK VIDEOS:

### Facebook HELP channel

[https://www.youtube.com/playlist?list=PLWcA1X\\_0fRr9B-nAESsR8UBq5FKxIYIPG](https://www.youtube.com/playlist?list=PLWcA1X_0fRr9B-nAESsR8UBq5FKxIYIPG)



Facebook Help

7 videos • 3,552 views • Last updated on Nov 12, 2019

Facebook App [SUBSCRIBE](#)

Rank	Video Title	Platform	Duration
1	Here to Help: How to Report Someone on Facebook	Facebook App	0:49
2	Here to Help: How to Deactivate or Delete a Facebook Account	Facebook App	1:27
3	Here to Help: What To Do If Your Facebook Account Gets Hacked	Facebook App	1:08
4	Here to Help: How to Join a Facebook Group	Facebook App	1:11
5	Here to Help: How to Create a Facebook Group	Facebook App	1:07
6	Here to Help: How to Create a Strong & Secure Password For Facebook	Facebook App	1:15
7	Here to Help: What To Do If Your Facebook Account Gets Disabled	Facebook App	1:01

### How to Install Facebook App on Your Mobile Phone (here's an example of different phones)

<https://www.youtube.com/watch?v=kYLxQeaTkaE>

### How to use Facebook

<https://www.youtube.com/watch?v=fGcHOcj1SQA>

### Facebook: Getting Started

<https://www.youtube.com/watch?v=ocO31AcSLng>

### Facebook Basics Tutorial for Beginners & Seniors

<https://www.youtube.com/watch?v=wkVf8BIE8rl>

# Internal Incident/Hazard/Near Miss Report

Your name:	Date of this report:
------------	----------------------



Address:		
Type: Incident <input type="checkbox"/> Hazard <input type="checkbox"/> Near Miss <input type="checkbox"/>	Date:	Time:
Location:		
Description:		

## People Involved or at Risk, including witnesses and staff members or carers.

First and Last names please. Were they a participant (P) or Witness (W)?

Family Name	First Name	P/W	Injured? (Tick)	Medical attention required? (Tick)	Register of injuries completed? (Tick)
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Immediate action needed: Yes  No

If immediate action has already been taken please describe the action taken:

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What can or has been done to prevent a recurrence?

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CEO Signature:

Date:

## Guidelines:

Fight Parkinson's Incident/hazard/near miss identification procedures are set up to ensure that the occupational health and safety of staff, service users and visitors are protected at all times. The purpose of the identification of hazards is to identify and assess the risk associated with hazards in the workplace and where possible recommend actions to be taken to minimise the risk. It is the responsibility of all staff to use this form to report any incident, hazard or near miss to the CEO. Once completed this form should be passed to the CEO for processing.

# Membership Renewal Form

If you have difficulty writing, we can complete your application over the phone.  
Please call us on 03 8809 0400.



Title: \_\_\_\_\_

First Name: \_\_\_\_\_

Street Address: \_\_\_\_\_

Last Name: \_\_\_\_\_

Suburb: \_\_\_\_\_

Phone: \_\_\_\_\_

State: \_\_\_\_\_

Email: \_\_\_\_\_

Postcode: \_\_\_\_\_

## Step 1:

I would like:  \$35 Annual Membership  \$350 Life Membership

Yes, I would also like to make a donation of \$ \_\_\_\_\_ to support the Parkinson's community.  
(All donations over \$2 are tax deductible).

**TOTAL AMOUNT:** \_\_\_\_\_

## Step 2:

I agree to membership terms and conditions (outlined below).  
 I consent to occasionally be contacted for research purposes.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

### TERMS & CONDITIONS

- I confirm that I am at least 18 years of age
- I agree to abide by the Fight Parkinson's (the operating name of Parkinson's Victoria) as set out in the Parkinson's Victoria Constitution
- I agree to engage in a respectful manner with Fight Parkinson's, its representatives and other members
- I am in a position to be able to pay the published membership fees or am able to demonstrate financial hardship so as to establish complimentary membership
- I agree to not have engaged and not to engage in activities that may harm the reputation of Fight Parkinson's
- I agree not to misrepresent my role or relationship with Fight Parkinson's by virtue of my membership to Fight Parkinson's
- I agree that membership and participation is offered at the sole discretion of Fight Parkinson's, who has the right to offer, accept, reject or revoke any application or existing membership as guided by the Constitution
- I agree that Fight Parkinson's membership is non-transferable and membership fees are non-refundable
- I accept that the benefits and fees associated with the membership program may be amended or changed from time to time by Fight Parkinson's as best serves the purposes of the organisation
- I accept that the Fight Parkinson's board may, by resolution, expel a member if, in their absolute discretion, it is not in the interests of the company for that person to be a member.

## Step 3:

Enclosed is my:  Money Order  Cheque  Or please debit my Visa/Mastercard

Card Number: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Expiry Date: \_\_\_\_\_ / \_\_\_\_\_ CVC: \_\_\_\_\_

Name On Card: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Step 4:

Please return in the prepaid envelope provided or mail to: PO Box 116 CAMBERWELL VIC 3124

# Peer Support Group Meeting Notes

Peer Support Group Name:

Date:

Time:

Location:

## Who's Taking Notes?

## Attendees:

	<b>Agenda Item</b> What is being discussed? What needs to be done?	<b>Who</b> Who is responsible?	<b>When</b> When does it have to be completed by?
1			
2			
3			
4			
5			
6			
<b>Future Agenda Items:</b> List suggested agenda items to be tabled for the next meeting.			
<b>Next Meeting:</b> List date, time, and location of the next meeting.			

# Notes

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# Notes

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Together we can

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ABN: 59 604 001 176

Level 1/793 Burke Rd  
Camberwell VIC 3124

T: (03) 8809 0400  
E: [info@fightparkinsons.org.au](mailto:info@fightparkinsons.org.au)  
[fightparkinsons.org.au](http://fightparkinsons.org.au)