# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and Maintain Group-based Peer Support

INTRODUCTION TO THE TOOLKIT

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www.afterstroke.ca

# Introduction To Peer Support

## What Is Peer Support?

Peers are people who have similar identities, experiences, or interests. For people living with the impact of stroke, other stroke survivors or caregivers can be peers. In a peer support group, people who have had similar experiences in life (e.g., had a stroke) meet to provide hope, and support to each other.

Since they know what it is like to have a stroke, peers can understand the fears and needs of others living with the impacts of a stroke and share useful support.

## What Is The Value Of Peer Support After A Stroke?

Peer support can be valuable to stroke survivors and caregivers. For a person living with stroke or its impact, peer support can help your emotional, physical, and mental health.

**Some benefits that peer support might offer to individuals impacted by a stroke are:**

- Connect with people who have similar experiences and challenges.
- Improve functional, social and emotional outcomes.
- Manage loneliness and social isolation.
- Improve motivation and confidence.
- Support making your own decisions.
- Learn from other's experiences.
- Reduce depression and anxiety.
- Expand social networks.
- Renew hope and strength.
- Increase socialization.
- Improve resiliency.

**Tip:** Peer support is just one part of your care. It is not a replacement for professional emotional or psychological care.

# Introduction To This Toolkit

## Who Can Use This Toolkit?

Anyone interested in starting a peer support group can use this toolkit. You do not need any previous experience designing peer support groups. The toolkit was designed for people affected by a stroke. Most of the information can be used by other groups with a different focus as well.

## How Do I Use This Toolkit?

You can use this toolkit as a step-by-step guide to help you build your peer support group. You can also use it as a toolbox where you pick and choose the information and tools that you need for your group.

**Tip**: The steps described below are to guide you. What steps you follow will depend on your abilities and available resources. You can make changes to suit your group's needs.

# Where To Start

The toolkit is divided into sections based on where you are in your journey of building a peer support group. Use the questions below to help you find the right section to start with.

## Are you thinking of starting a peer support group?

Go to → **Section 1: Before starting a peer support group.**
It discusses things to do before you start a peer support group. This includes checking the need for a new group and finding the right partners.

## Are you ready to start a peer support group?

Go to → **Section 2: Build your peer support group.**
It has information about designing your peer support group, finding group members, and the resources you need to run the group.

## Wondering what to do in peer support meetings?

Go to → **Section 3: Prepare to run your peer support meetings.**
It talks about what to do in peer support group meetings, and how to prepare to run the meetings.

## Do you have a peer support group and are thinking of ways to improve and grow?

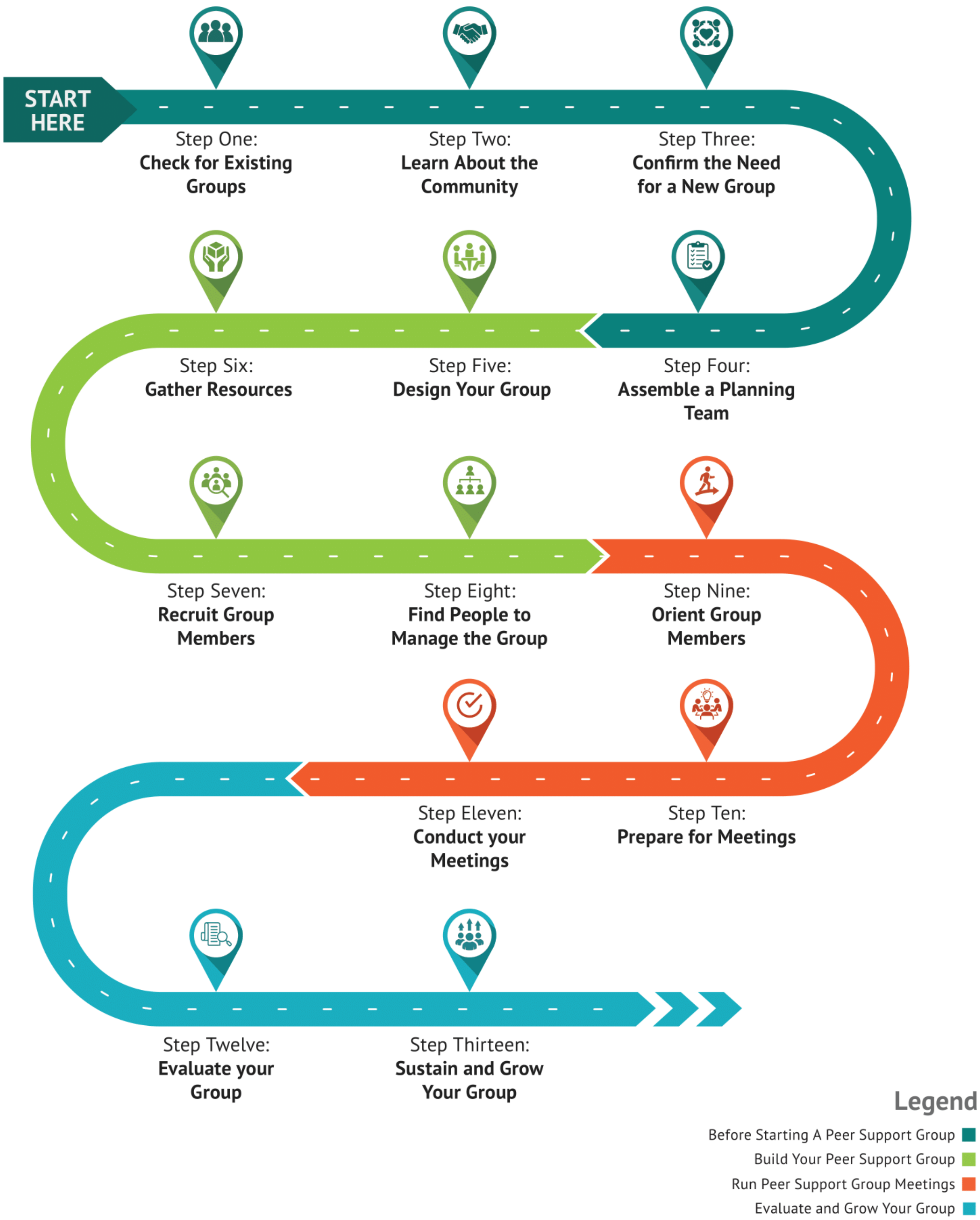
Go to → **Section 4: Evaluate and Grow your peer support group.**
It talks about how to make sure your group is running well, and what you can do to grow your group.

## Looking for some suggestions on how to manage peer support group discussions?

Go to → **Section 5: Facilitator's guide.**
It provides information that may be valuable to people who manage the peer support group discussions. This section is shares tips to help quiet members speak up, solve disagreements, improve engagement, and more.

# Quick Overview

This roadmap describes the steps along the journey of setting up a peer support group. Your group's journey may look a little different.



## How We Built This Toolkit

We built this toolkit using a codesign process. This means that a group of people with different backgrounds, skills, and life experiences shared ideas and made decisions about what this toolkit should include.

**Our codesign group included people who:**

- Have experienced the impact of stroke.
- Have experienced the benefits of peer support.
- Have been involved in the delivery of peer support.
- Are researchers in stroke recovery and community programming.

By using a codesign approach we hope that the toolkit reflects the needs of people living with the effects of stroke, and scientific evidence in the field of after stroke peer support and program implementation.

## March Of Dimes Canada Is Available To Help

March of Dimes Canada welcome the opportunity to help you build your peer support group. March of Dimes Canada is a leading national charity committed to championing equality and empowering ability for people living with disability across Canada.

**Peer support groups that are affiliated with March of Dimes Canada are part of a Canada-wide peer support network and have access to:**

- Support with designing, running, and growing their peer support group.
- March of Dimes Canada templates and forms.
- Support with fundraising and managing finances.
- Liability insurance coverage.
- Assistance with identification of resources and partners.
- Learning and development opportunities for facilitators and volunteers.
- Opportunities to connect and collaborate with other peer support groups.
- March of Dimes Canada’s stroke-related resources and programs.

For more information, please contact us at peersupport@marchofdimes.ca.

# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and Maintain Group-based Peer Support

SECTION 1

Before Starting A Peer Support Group

# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and Maintain Group-based Peer Support

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# Section One | Before Starting A Peer Support Group

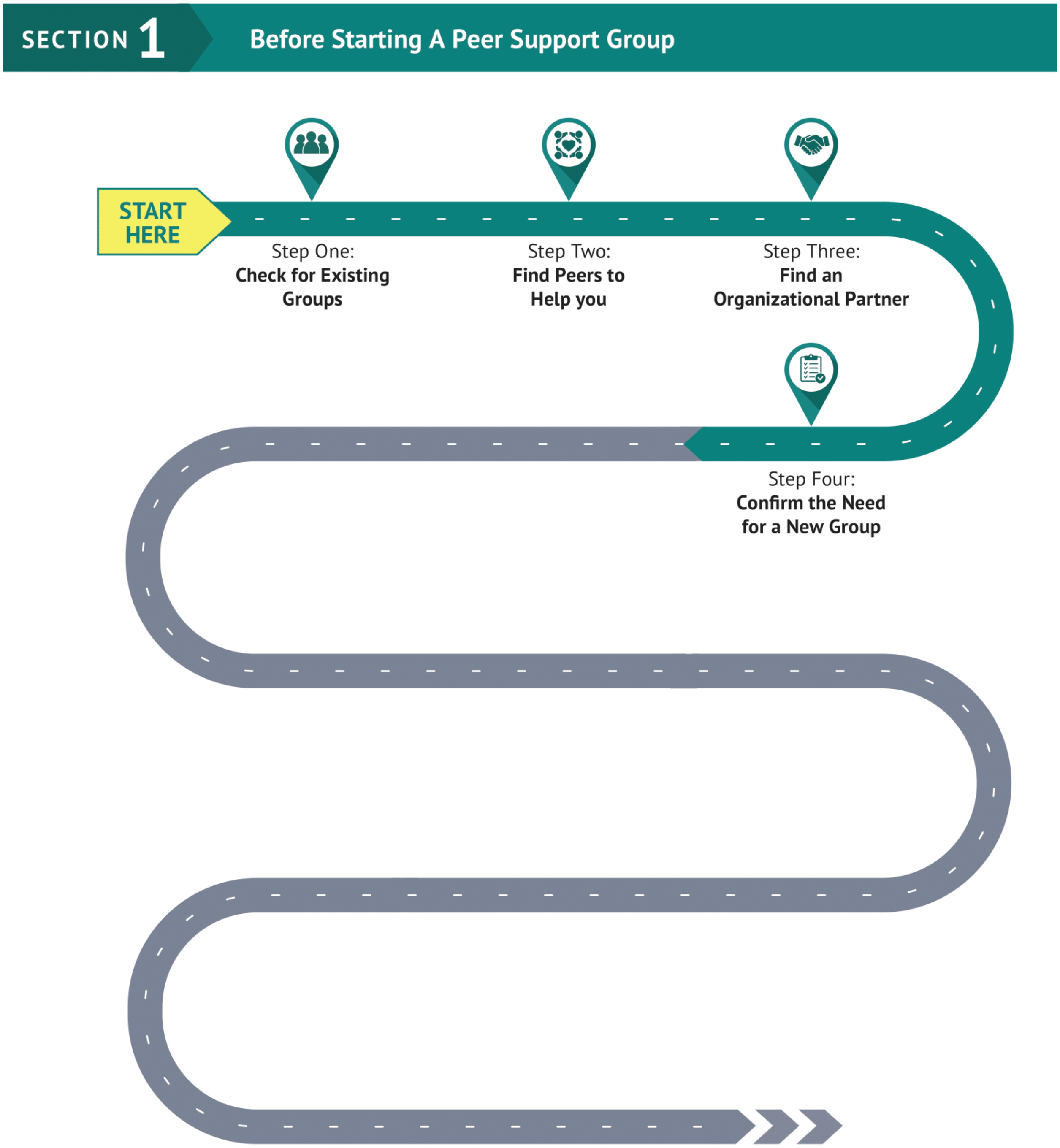
## Table of Contents



## Template List

## Quick Overview

Before we can set up a peer support group, we need make sure that the community needs a group. We also need to find people who can help us.



# 01 Step One | Check For Existing Groups

## How To Search For Existing Groups

It is possible that there is already a peer support group in your community that you could be a part of. Do a quick check in your community before you begin to set up a new group. You might find something local or a virtual group you can attend from any place.

**You can try to:**

- Talk to your healthcare or social service team.
- Check for information in local program guides.
- Ask your doctor, stroke team, stroke navigator, or social worker.
- Connect with local stroke prevention/recovery groups. This could include March of Dimes Canada, Heart & Stroke, etc.
- Search the internet for 'peer support stroke group' and your 'city/town/province'.

If you find a group that suits your needs, reach out and ask about becoming a member. **If no group suits your needs, go to the next step.**

# 02 Step Two | Learn About The Community

## How To Find Peers In Your Community

Try to find peers (other people living with stroke) to join you in starting a peer support group. Setting up a new group may be difficult for one person do to by themselves. Having a team may make the work more manageable and fun!

**You can try to:**

- Connect with your local healthcare team.
    - Ask your social worker or healthcare team (family physician, physical therapist, occupational therapist, speech therapist, hospital stroke team) to connect you with other people who have had a stroke.
- Connect with stroke networks and groups.
    - Regional stroke networks or local organizations that work with stroke populations (e.g., March of Dimes Canada, Heart & Stroke) may be able to help you connect with peers in your area.
- Use social media.
    - Connect with people on social media (Facebook, Instagram, etc.).
- Post flyers.
    - You can post flyers in the local library, doctors' office, grocery store, community centre, or a religious/spiritual centre.

## Template | Flyer

On the next page, we have provided a flyer you can write on and share. You can use this template as is, or as inspiration to create your own.

**Tip**: If you are sharing an email address, you might want to make one just for this work, so strangers don't have your personal information.

# PEER SUPPORT GROUP

## FOR PEOPLE LIVING WITH STROKE

We would like to start a peer support group so people living from stroke can meet and talk to each other.

If you or someone you know would like to join us, please contact:

_______________________________________________

# 03 Step Three | Find An Organizational Partner

This is an important step for people who have no previous experience in starting or running a peer support group. An organizational partner can help support you through all the steps involved in setting up a new group.

## Who Would Make A Good Partner?

**A good organizational partner is one that:**

- Is interested in improving community health.
- Works to support people living with disabilities.
- Works in stroke prevention or recovery (e.g., March of Dimes Canada).
- Has started community groups in the past.

## How Can An Organizational Partner Help?

**Depending on the type of organization, partners can:**

- Help you complete the steps listed in this toolkit.
- Help you find new group members and other resources you need to manage your group and conduct the peer support meetings.
- Develop and conduct community surveys.
- Spread the word about your group in the community.
- Provide consultation and/or support with group management and administration (training, use of templates and forms, taxes, financial statements, liability insurance, charitable status, fundraising, networking, and partnership development, etc.).

**Tip**: March of Dimes Canada can support you in starting your peer support group. For more information, please contact us at peersupport@marchofdimes.ca.

# 04 Step Four | Confirm The Need For A New Group

Setting up a new peer support group will take time and effort. You may want to make sure that this is something that people in your community need. The best way to get this information is by asking people living with stroke.

Your organizational partner can help you build and conduct the survey.

**Tip**: It's OK, if you are unable to conduct a community survey at the start! If you already have a few members, then you know that this group is needed. However, you should consider a survey when planning how to grow the group.

## Distributing Your Survey

Your survey can be printed and shared, completed over the phone, or posted online. Try to get as many people to answer your survey as possible.

You can connect with places frequently visited by people living with stroke to hand out surveys (hospital stroke units, outpatient stroke rehabilitation clinics, stroke recovery/prevention organizations, and doctors' offices).

If you use online survey options (Google Forms, Survey Monkey, etc.) you can share the link to the survey in stroke groups via social media.

## Template | Survey

On the next page, we have provided an example of a survey. You can use this template as is, or as inspiration to create your own.

# Understanding The Need For Peer Support For People Living With Stroke

**Have you experienced a stroke? If yes, please consider filling out this survey.** We want to understand if people living with stroke feel the need for a peer support group in this community.

Please answer the following questions to the best of your abilities. If you don't want to answer a question, leave it blank.

**As someone who has experienced a stroke, would you like to meet and talk to other people who have had a stroke?**

- ☐ Yes, it would be extremely useful.
- ☐ Yes, it would be somewhat useful.
- ☐ It would not be especially useful.
- ☐ It would not be useful at all.
- ☐ Do not know.

**A peer support group allows people with similar experiences (such as stroke) to learn from each other, support each other, and feel a part of a community. Do you think such a group is needed in ________________________________?**

- ☐ Yes, it is urgently needed.
- ☐ Yes, it is needed but is not urgent.
- ☐ No, it is not needed at all.
- ☐ Do not know.

**What kind of support would you like to receive from a peer support group?**

- ☐ Information on managing health, living life with stroke, local resources.
- ☐ Emotional support, talking to someone who understands.
- ☐ Social support, friendships, doing things together.
- ☐ Motivation and hope.
- ☐ Other ________________________________________________

**If a peer support group was started in ________________________________, would you attend?**

- ☐ Yes, I would attend.
- ☐ I may attend.
- ☐ No, I do not think I will attend the sessions.
- ☐ Do not know/do not wish to answer.

**What type of peer support would you prefer to attend?**

- ☐ A group that meets in-person.
- ☐ A group that meets virtually (phone, web conference, etc.).
- ☐ Do not know/wish to answer.

**What resources would help you better attend meetings?**

- ☐ Eldercare
- ☐ Childcare
- ☐ Respite
- ☐ Travel funds
- ☐ Virtual support
- ☐ Other ________________________________________________

**Is there anything else you want to share?** ______________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

**Thank you for filling out this survey.**

If you need any information or have questions, please contact:

____________________________________________________________________

# After Stroke Peer Support Toolkit

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SECTION 2 Build Your Peer Support Group

# After Stroke Peer Support Toolkit

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# Section Two | Build Your Peer Support Group

## Table of Contents

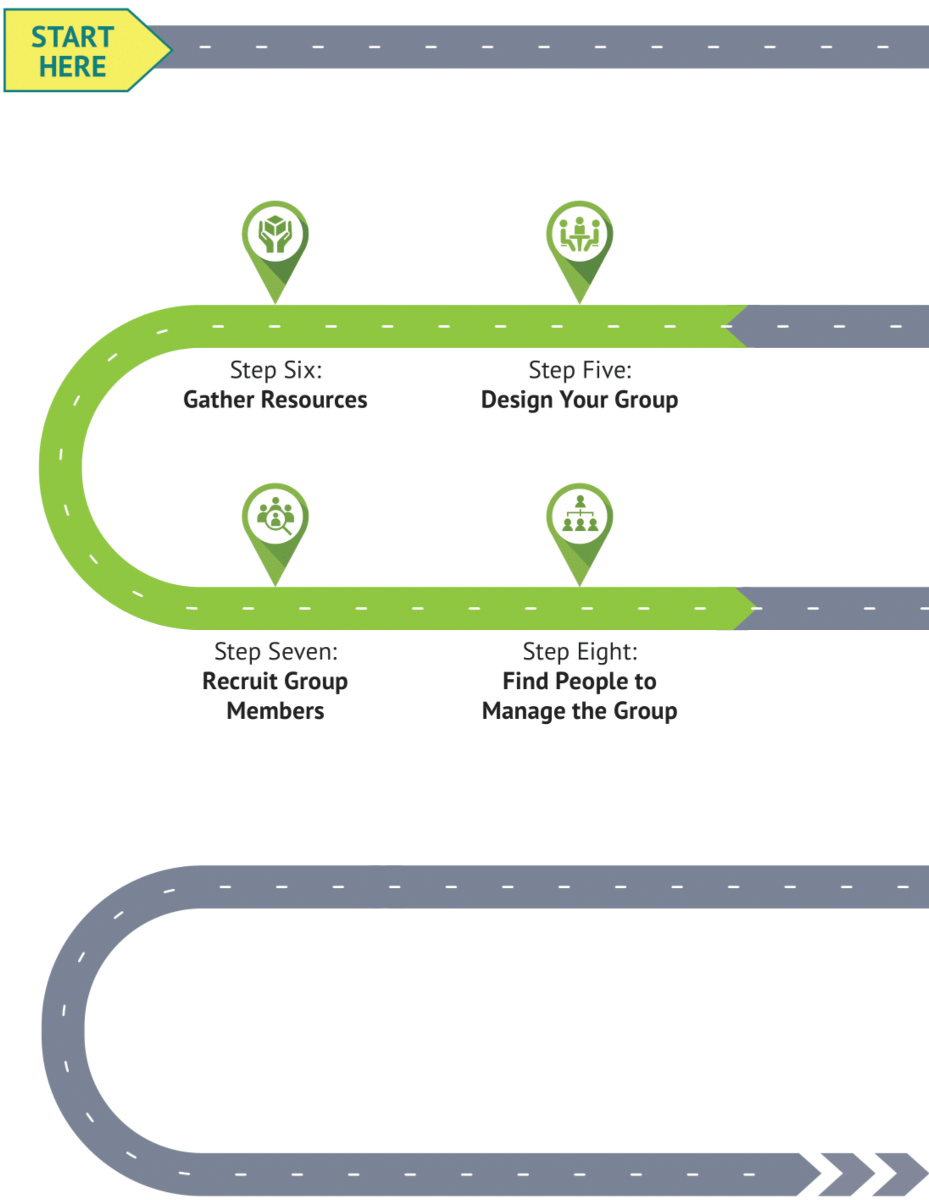


## Template List

# Quick Overview

In this part of the journey, you are ready to build your peer support group. Here you will decide what your group looks like and find the people and resources you need to run the group.

**SECTION 2** **Build Your Peer Support Group**



# 05 Step Five | Design Your Group

So far, you have found a team, and maybe an organizational partner. You are ready to start planning what your peer support group will look like.

**Use the following questions to help you design your group.**

**Tip**: You may not have all the answers right away. That is OK! You will figure out a final design as you go along. Your group design may change as your group's needs change.

## Who Can Join This Group?

This question will help you describe your typical group member. Think about common experiences, conditions, or beliefs the members will share so that they can become peers.

You can have a broad eligibility (e.g. anyone who has had a stroke can be a member) or specific (e.g. a group for young mothers who have experienced a stroke). Age, gender, length of time after stroke, employment status, goals, language – any factor can be used to define your group. Having this shared experience will help members to trust and support each other.

## What Type Of Support Will Members Receive?

**Think about what the members will do during meetings:**

- Will the group share information on how to live with a stroke?
- Will the group meet to motivate each other, share fears and other feelings?
- Will the group meet to socialize, do activities, and reduce a sense of loneliness?
- Will the group include all the above?

## Will Your Group Meet In-Person, Online, Or Both?

When discussing this question think about what a person living with stroke would prefer. There are advantages and disadvantages to both.

Meeting in person (face-to-face) may be better for creating friendships, have more natural interactions, help with socialization. But it also means finding the right space to meet, and ensuring members can manage the travel (cost, time, assistance, accessible transit, etc.).

Meeting virtually can allow people to join the group from anywhere. Members may need devices to connect to the meeting, and help/training to use the technology (chat functions, muting, raising hands, etc.).

## Where Will The Group Meet?

If you would like to meet in-person, you need to find a space to accommodate your group. The space should be central, private, and have enough space to fit your group.

To welcome members who may have difficulty walking, climbing stairs, opening doors, or following signs, the space should also be accessible (all or any portion of the space can be used by individuals with disabilities).

At the start, groups with only a few members may meet at recreation centres, libraries, or local cafes, and then grow into larger spaces as the group expands.

## How Many Members Will The Group Have?

Usually, groups start with a few members and grow into larger groups as the word spreads. As the group becomes bigger you can rethink how and where to meet.

**Smaller groups** (2-11 people) → Members can know each other better.
**Larger groups** (12+ people) → Members can bring in a variety of experiences and viewpoints, but need larger spaces, has higher costs, and needs more volunteers.

## When Will Your Group Meet?

Holding meetings at the same day of the week, time and in the same place can reduce confusion. Most groups meet once or twice a month.

**How often you meet will depend on:**

- How often you have access to the resources needed to run the meetings (space, volunteers, etc.).
- How long each meeting will run (several short meetings or fewer long meetings).
- Costs (supply costs may be higher if you meet often).
- Member preferences and abilities (availability of transportation or assistance, employment, other responsibilities).

## How Long Will Each Meeting Last?

Meetings can last anywhere between one and two hours. Long meetings (more than 2 hours) can become tiring, and members can lose focus and interest. Short meetings (less than an hour) may mean there is not enough time for all members to have a turn, or to have a fulsome discussion on certain topics.

The length of the meeting may also be influenced by member availabilities, travel times, meeting location and timing. Try out different lengths, times and dates, and ask the group members what works best for them.

## Will There Be A Cost To Participating?

Find a balance between covering costs and what members can afford. Free/low-cost groups allow people with financial challenges to join. But it may become difficult to manage group costs over time. Some groups have a small fee, ask member to contribute what they can, split expenses, or have members donate food and drink. Other groups may raise money through gifts, donations, fundraising, or local grants.

## Who Will Provide Support And Guide Discussions?

In its truest form, in a peer support group, members of the group provide support to each other. Groups can work in a few different ways.

**Choose what works best for your group.**

1) Having a facilitator manage discussions.
Some groups choose an individual to guide discussions, encourage participation, and manage disagreements. Groups can have one or more facilitators (also called moderators, or guides). It may be helpful if the facilitator has experienced the impact of a stroke.

2) Group discussions are managed between members.
Some groups can choose not to have a facilitator and manage discussions by themselves. In such cases, groups would need to establish rules around taking turns, managing disagreements, and keeping discussions on track.

3) Having a trained professional as a facilitator.
Some peer support groups have trained professionals (therapist, social worker, etc.) performing this role. In this case, the group is not peer-led and may have some costs.

**Tip**: All facilitators should undergo training to prepare for the role. Refer to the Facilitator's Guide to read more about the role of a facilitator and how to manage some common peer support group challenges.

## Template | Peer Support Group Design

On the next page, we have provided a table with the questions listed above. Your choices may depend on what resources you have or can make available. You can use this template as is, or as inspiration to create your own.

# Peer Support Group Design

**Group Name:** ____________________________________________

**Date:** ________________________________________________

**Individuals Involved:** _______________________________________

| Topic | Your Team's Decision |
| --- | --- |
| Who can join this group? | |
| What type of support will members receive? | |
| Will your group meet in-person, online, or both ways? | |
| Where will the group meet? | |
| How many members will the group have? | |
| When will your group meet? | |
| Who will provide support and guide discussions? | |
| Will there be a cost to participating? | |

## Things To Keep In Mind

Some groups may be casual and informal when they start out. As the group grows, it is important to have policies and procedures to explain how the group is run. These should be built with the group members and partners.

**You will need to think about:**

- A group constitution or charter.
  - A document that outlines how the group will run, core values, roles, responsibilities, etc.
- Emergency planning.
  - Information on what to do in case of a fire or health emergency.
- Information storage and safety plans.
  - Plans to keep information private. This is important so that member information does not fall into the wrong hands.
- Liability insurance.
  - Groups should protect themselves and reduce risk to members.
- Financial accounts and reporting plans.
  - You might need a registered bank account to manage expenses and funds. Templates for maintaining financial records can help.

**Tip**: You may not have these in place at the start. That is okay! You can work on these as your group grows.

# 06 Step Six | Gather Resources

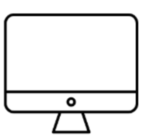
## What Resources Do You Need?

You should make a list of all the things you will need to run your peer support group. You will also need to plan how and where to find these resources. The resources you need may be different depending on if you are meeting in-person or virtually.

## In-Person Meetings Resource List

- Accessible and private meeting space.
- Materials (chairs, tables, pens, paper, name labels).
- Agenda, attendance sheet, incident reports.
- Member and emergency contacts list.
- Facilitators to guide the discussion.
- Volunteers to assist members, room set-up, attendance, etc.
- Refreshments (check for dietary restrictions and eating difficulties).
- Wi-fi password.
- Parking spots.

## Virtual Meetings Resource List



- Web-conferencing platform account.
- Secure internet connection.
- Phone/computer/laptop/tablet.
- Agenda, attendance sheet, incident report.
- Member list, emergency contact list.
- Facilitators to guide the discussion.
- Volunteers to monitor chat, take attendance, assist members with technology, etc.

## Find Resources In The Community

Raising funds for the group is an area where many groups face challenges.

**There are a few ways to raise funds to support group activities:**

- Fees.
    - Some groups opt to include a small, reasonable fee at registration or per meeting. Remember that some people may experience loss of employment or other financial challenges after a stroke.
- Donations.
    - Members can be encouraged to donate whatever they can each meeting. Approaching local businesses, or individuals to donate (cash or in kind) can also help.
- Fundraising drives.
    - Community fundraisers and auctions can help raise money.
- Apply for funding/grants.
    - Look for funding opportunities through local governments, not-for-profit/philanthropic agencies, stroke prevention and recovery organizations.

# 07 Step Seven | Recruit Group Members

It is important to spread the word about your peer support group in the community so that more people with stroke know about it.

## How To Spread The Word About Your Group

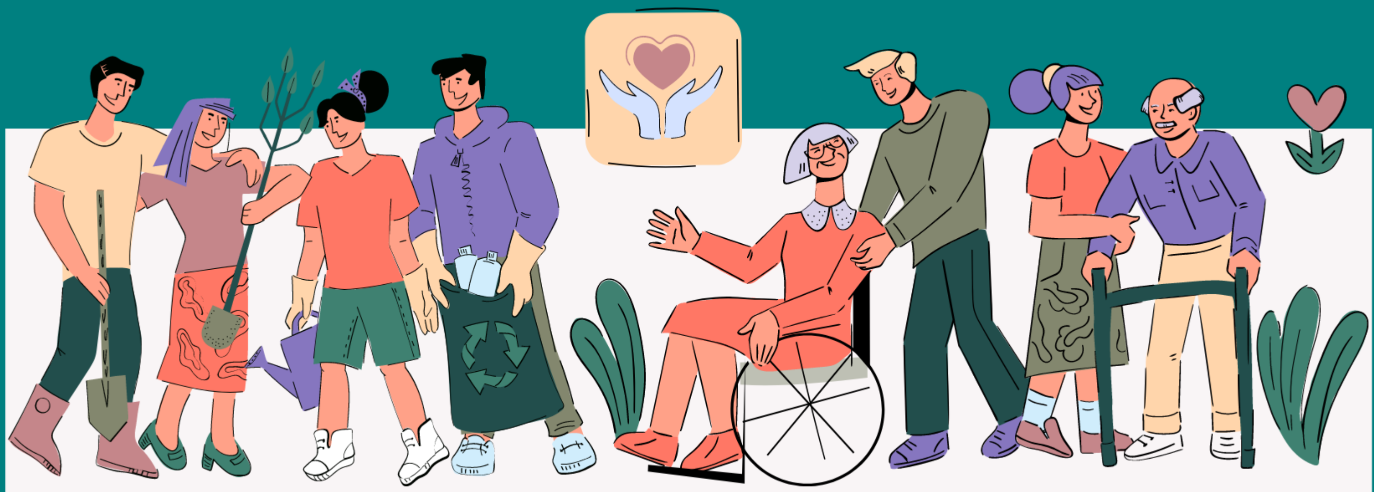
**Here are some ways to promote your group:**

- Local and social media.
  - Advertise in local newspapers, magazines, and recreation guides.
  - Share real life stories and the group on the radio or local news.
- Post about your group on stroke-group pages of social media platforms like Facebook, Instagram, etc.
  - Use bright images and catchy phrases to grab attention.
- Awareness drives.
  - Participate in a walkathon, community event, parade, or other community event. Hand out flyers and talk to the public.
- Word-of-mouth.
  - Ask your members, partner organization, and local partners to share information with other potential members.
- Targeted promotion.
  - Post flyers in hospital waiting rooms, doctors' offices, local stroke recovery associations, etc.
- Request staff share flyers with patients/families.
  - Offer to visit people at the time of discharge from the stroke unit to share information about the group.
- Direct referral.
  - Get direct referrals from local healthcare offices.
  - Talk to local healthcare professionals or your organizational partner about how to establish a referral pathway.

## Template | Recruitment Flyer Example

On the next page, we have a flyer about stroke peer support groups. You can use this template as is, or as inspiration to create your own.

# DO YOU WANT TO CONNECT WITH OTHER PEOPLE WHO ARE LIVING WITH STROKE?



Join our peer support group to meet other stroke survivors and talk about live after stroke.

If you or someone you know would like to join us or have any questions, please contact:

______________________________

# 08 Step Eight | Find People To Manage The Group

## Tasks Involved In Running A Peer Support Group

There is a lot of work involved in running a peer support group. In addition to the work required to have peer support meetings, there are many administrative tasks. In many cases, the work is shared by members of the peer support group. Sometimes, non-members may offer to help with administrative duties.

**Here are examples of common tasks:**

- Orient members and keep track of their participation.
- Plan and prepare for the group meetings.
- Track group activities (topics of discussions, distributing surveys, etc.).
- Assist members during meetings.
- Manage peer support group discussions.
- Manage resources.
- Promote and market the group.
- Evaluate the group's impact.
- Manage and report finances.

**Note**: Some groups (or partners) may require police clearance or other checks for non-members.

## Sharing The Load

Groups can decide to split these tasks between a few people.

**Some common core roles include:**

- A facilitator (to guide discussions).
- A group representative (to orient members).
- A secretary (tracking group activities).
- A treasurer (to manage and report on finances).
- Meeting volunteers (to help with member assistance, room set up, etc.).

## Who Can Hold These Roles?

Anyone who has the skills, the time, and an interest can take on these roles. Members are often eager to help, as it makes them feel empowered. Your organizational partner can help with some tasks (financial reporting, activity planning and tracking, evaluations, promotion and marketing, etc.).

For some roles, it can be helpful if the person has a similar lived experience as the group. Roles involving technical assistance, managing funds, setting up meeting or maintaining records do not require having a lived experience. These roles may be filled by individuals outside of the group (students, retired professionals, spouses of members, family, friends, etc.).

## Having A Facilitator To Guide Discussions

The facilitator role requires someone who can engage members, manage difficult conversations, and keep discussions on track.

**There are four ways groups may proceed:**

- No facilitator.
    - Some groups may decide to manage their discussions between themselves. In such cases, the group should have rules for respectful discussions and managing disagreements.
    - See the Facilitator Guide for suggestions on having effective discussions and managing challenges.
- Members as facilitators.
    - One or more group members may volunteer to guide discussions. Training would be required to prepare them for the role.
- Non-members as facilitators.
    - In some cases, people with lived experience who have attended and led other peer support groups may become facilitators. They can use their previous experience with peer support, and their lived experience to guide the group discussions.
- Trained professional as a facilitator.
    - In some groups the facilitator role is done by a trained professional (counsellor, social worker, or a mental health professional). There may be a cost involved.
    - This means the group discussion may not be peer-led.

**Tip**: Refer to The Facilitator Guide to read more about the role of a facilitator and how to deal with issues as they come up.

## Finding Volunteers

Volunteers can help with managing some of the day-to-day tasks involved in running the group.

If you are looking for volunteers with a shared lived experience of stroke reach out to your group members or reach out to the places where you promote your group (local healthcare clinics or hospitals).

You can also connect with other peer support groups to find if any experienced members are willing to help.

**If you are looking for volunteers without lived experiences, connect with:**

- Local volunteer organizations.
- Your organizational or local partners.
- Spouses, families, or friends of members.
- Students at local colleges, universities.

**Tip**: Some roles may require training. Your organizational partner or local peer support or volunteer agencies may have training programs you can use.

## Template | Tasks Involved In Running A Peer Support Group

On the next two pages, we have a table with common tasks and a place to track who will handle what. You can use this template as is, or as inspiration to create your own.

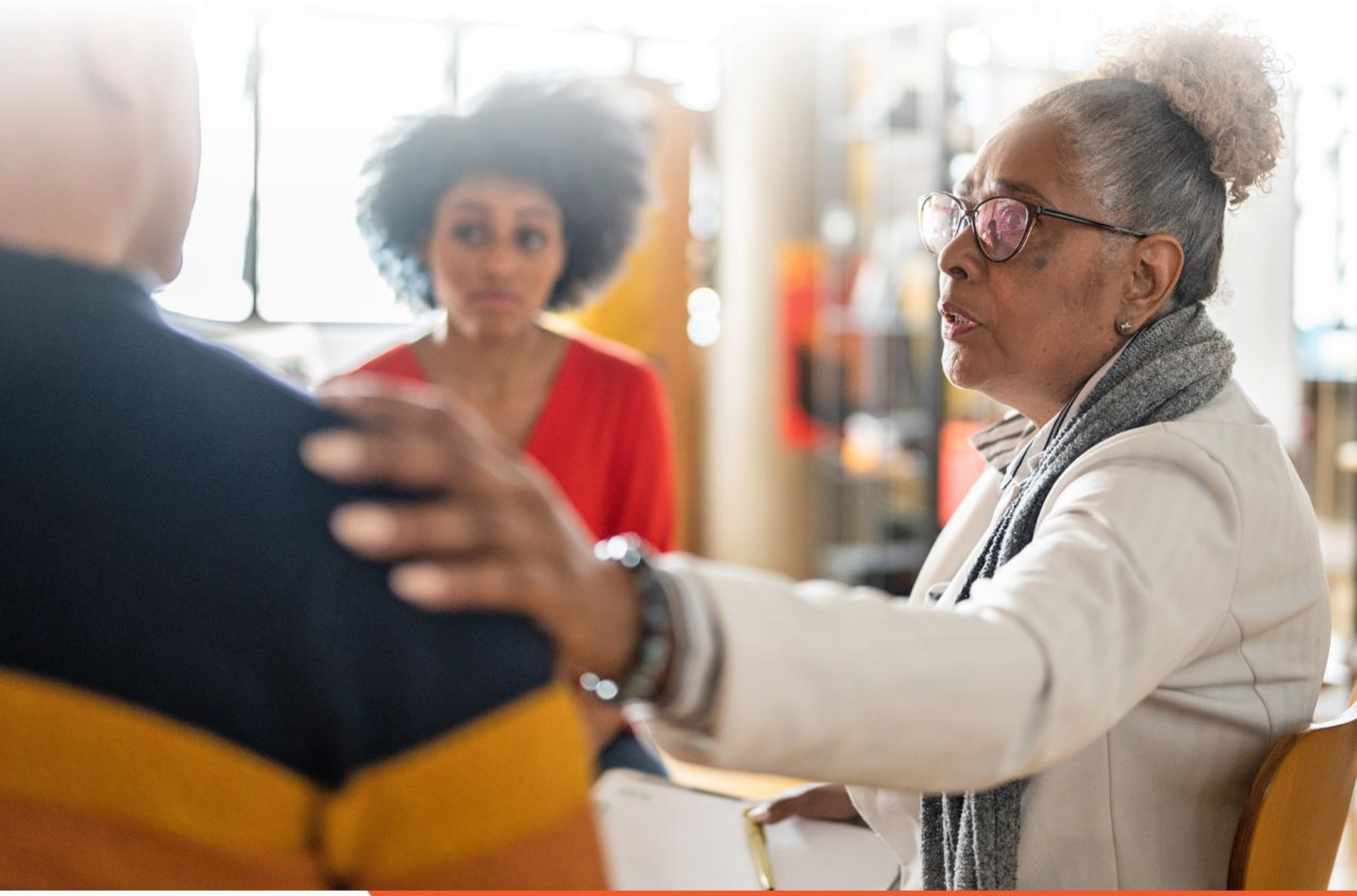
## Tasks Involved In Running A Peer Support Group

| Task | Assigned to |
|---|---|
| **Welcoming and orienting members.**<br>Welcome new members.<br>Share information about the group and meetings.<br>Answer their questions. | |
| **Meeting preparations.**<br>Ensure everything is ready for meeting (space, material, emergency contacts, etc.).<br>Remind members of date, time, and other information.<br>Assist with room set up and clean up. | |
| **Support members.**<br>Help members arrive to the meeting place.<br>Provide technical assistance during virtual meeting.<br>Help with name tags, finding the washroom, etc. | |
| **Program tracking.**<br>Take attendance.<br>Note and share important resources or links.<br>Hand-out and collect surveys. | |
| **Guide and facilitate discussions during meetings.**<br>Guide discussions.<br>Engage members. | |
| **Track members.** | |

| Task | Assigned to |
|---|---|
| Maintain a list of members and attendance.<br>Maintain a list of emergency contacts.<br>Secure and confidential storage of records. | |
| **Managing relationships with partners.**<br>Develop new and maintain relationships with partners.<br>Discuss the needs of the group.<br>Share updates. | |
| **Manage resources.**<br>Find other sources of support in the community.<br>Plan ways to find or raise funds for the program | |
| **Track group finances.**<br>Tracking fees, donations, expenses, etc.<br>Maintain budget.<br>Tax reporting. | |
| **Expand and promote the program.**<br>Connect with more people living with stroke in the community.<br>Plan special events, celebrations, fundraisers, etc. | |

# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and Maintain Group-based Peer Support



SECTION 3 Run Peer Support Group Meetings

# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and
Maintain Group-based Peer Support

## Acknowledgements

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## Citation

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www.afterstroke.ca

# Section Three | Run Peer Support Group Meetings

## Table of Contents

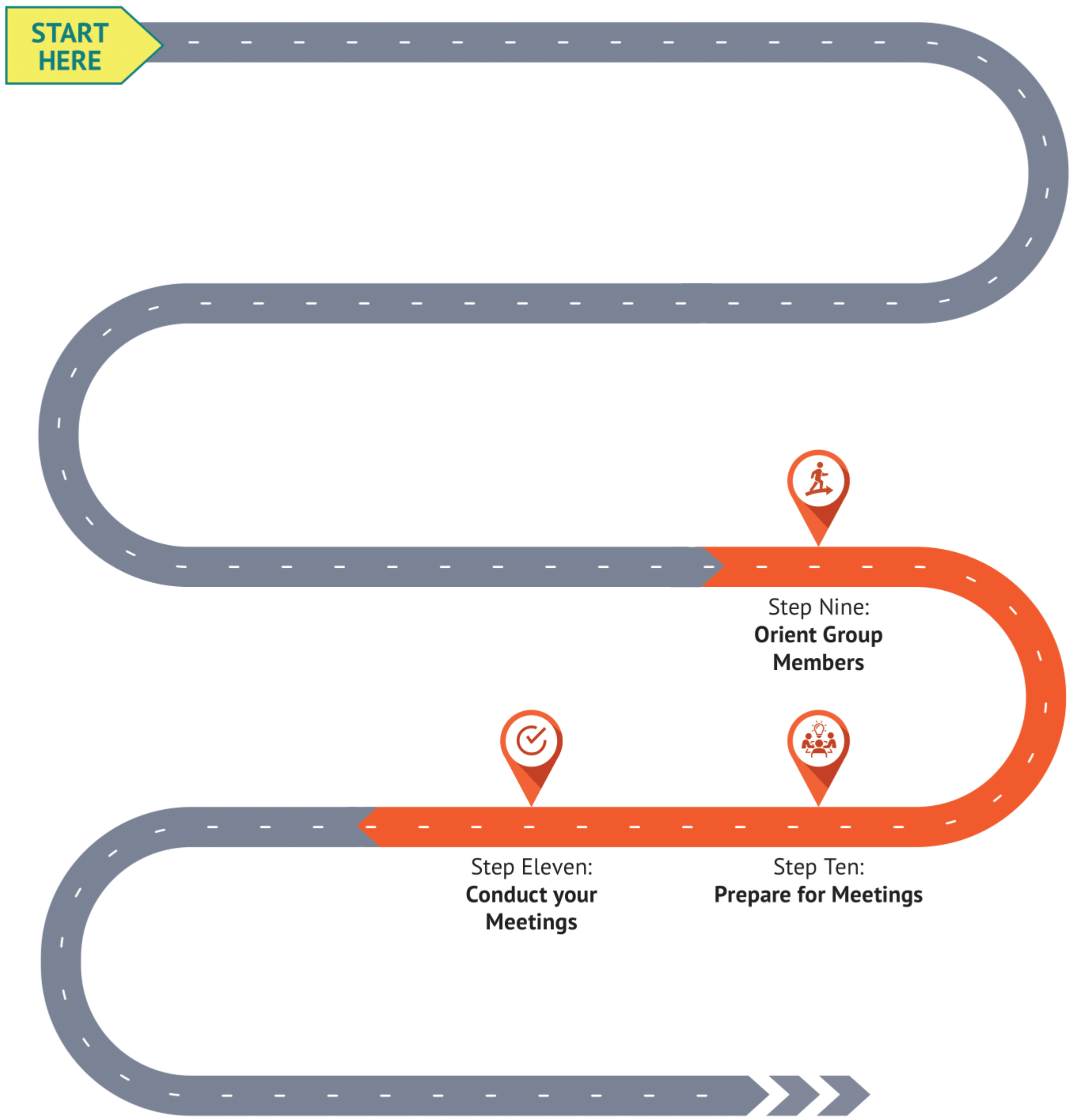


## Template List

## Quick Overview

With your peer support group design complete, you are ready to start holding peer support meetings. This section will help you welcome new members, plan, and run your peer support meetings.

**SECTION 3** **Run Peer Support Group Meetings**



# 09 Step Nine | Orient Group Members

Now that you have chosen and trained your team members, you are ready to move into implementation and delivery of the peer support group. Thanks to your promotion, interested people will begin to reach out to you.

Someone on your team (usually the group representative) can welcome new members, find out more about them, and answer any questions they may have.

Invite interested individuals to understand the program well before deciding to participate. You can provide an informed consent form to help with this. After an individual decides to participate, you can invite them to share some information about themselves.

**Right to Privacy**: Any information that includes a person's name, contact information, or any personal information needs to be recorded and stored securely. With your planning group decide how member information will be stored and how it will be used.

## Template | Member Information Form

It's important to gather information about your new members, including emergency contacts and accommodations. You can use this template as is, or as inspiration to create your own.

# Member Information Form

Thank you in your interest in joining our Peer Support Group!
Please tell us a little bit about yourself.

| | |
|---|---|
| **Basic Information**<br>Name:<br>Pronouns: | |
| **Contact Information**<br>Phone number:<br>Email address: | |
| **Emergency Contact Information**<br>Name:<br>Phone number: | |
| What are you looking for in a peer support group? | |
| What are somethings you would like us to know about you? | |
| Do you need any assistance or accommodations? | |
| Date of Completion | |

Your personal and contact information will only be used for communications related to the peer support group meetings. We will not share this information with anyone. You have the right to modify this information at any time or request that this information be deleted.

## Template | Informed Consent Form

Some groups require participants to sign an informed consent form when signing up. The goal is to make sure the group is protected from liability and that members understand the group's values, and goals. You can use this template as is, or as inspiration to create your own.

# Informed Consent Form

**Thank you in your interest in joining our Peer Support Group!**

This document includes information about some of the procedures and policies for the Peer Support Group. People who are interested in becoming a member of this group are requested to read this document before confirming their participation.

**If you have any questions, please contact:**

______________________________________________________________

**Brief Description** ______________________________________________

______________________________________________________________

______________________________________________________________

**Participation Requirements** ______________________________________

______________________________________________________________

______________________________________________________________

**Description of Activities** _________________________________________

______________________________________________________________

______________________________________________________________

**Group Goals** _________________________________________________

______________________________________________________________

______________________________________________________________

**Personal Information**

Participants must provide their name and contact information so that we can reach you with information and updates about the group meetings. You are also requested to share the name and contact information of an emergency contact. We will not share your personal information with anyone.

During meetings, you may use an alias to protect your information. Sharing details of your stroke, and other aspects of your life is not required for participation. All participants are required to maintain confidentiality about other members' identities and experiences.

**Confidentiality and Privacy**

Confidentiality is critical to peer support. Information that members share during meetings should never be discussed outside of the meeting. Please speak to a member of the planning team if you need any accommodation.

**Signed Consent**

- ☐ I have read and understood the information included in this document.
- ☐ I have asked questions and have received satisfactory answers.
- ☐ I agree to respect the rules set forth.
- ☐ I understand that I can leave at any time, which will void my consent.

**I, ________________________________, agree to be a participant in this group.**

| **Participant** | **Peer Support Group Volunteer** |
| --- | --- |
| Name: __________________________ | Name: __________________________ |
| Signature: ______________________ | Signature: ______________________ |
| Date: ___________________________ | Date: ___________________________ |

A signed copy of this document will be provided to you.
A second copy will be kept for group records.

# Template | Orientation Booklet

An orientation document can help new members learn about the group and feel welcome. This should include details about your group, meetings, and expectations. You can use this template as is, or as inspiration to create your own.

# Peer Support Group Orientation Booklet

Welcome to our Peer Support Group! This orientation booklet has information that will help you understand more about how the group runs. Please review this before your first session.

If you have any questions, please contact:

______________________________________________________________

**Brief Description:** ______________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

**Participation Requirements:** _______________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

**Meeting Details:** ________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

**Cost:** _____________________________________________________

______________________________________________________________

# Core Values

Peer support groups are guided by values that help others feel welcome and safe.

**Hope and Recovery.** You will help promote hope and express realistic confidence in others to be successful in their journey of recovery. You will encourage individuals to find strength, take responsibility to make positive changes.

**Self-Determination.** You may offer suggestions but must always respect other's decisions, goals, and decisions about what is best for them.

**Authenticity and Trust.** You will act ethically and with integrity. You will maintain the anonymity, and confidentiality of the members of this group. You will be your true self and will accept other members as they are.

**Health and Wellness.** You understand that recovery is not a linear process and looks different for everyone. You must respect and care for your own health and well-being.

**Dignity, Respect and Social Inclusion.** You will be intentional with your language and words. You will be welcoming to everyone, regardless of age, identity, ethnicity, ability, or cultural and religious background. You will strive not to assign labels, stereotypes, or being influenced by biases.

# Do's And Don'ts

To have a respectful and effective peer group discussion, please remember:

| Do's | Don'ts |
|---|---|
| • Be supportive.<br>• Encourage others by telling your story.<br>• Ask respectful questions.<br>• Listen patiently and without judging.<br>• Wait your turn to speak.<br>• Treat others with empathy.<br>• Share what worked for you.<br>• Turn off or silence your devices during meetings. | • Use disrespectful or abusive language.<br>• Make inappropriate references or jokes.<br>• Pressure others to follow your advice.<br>• Start or engage in arguments.<br>• Judge the preferences, or experiences of others.<br>• Share stories with people outside of the group. |

# Virtual Meeting Details

The web-conferences platform we use is secure. We use passwords and waiting rooms so that only known members of this group will be admitted into the meeting. During the meeting the members may share private and personal stories, and it is important that these conversations remain private.

Please do not share meeting information without speaking to your group representative or facilitator first.

**You will need:**

- A computer, a tablet, or a phone.
- A stable and secure internet connection (public areas may not be secure).
- A private and safe space for the duration of the meeting.
- Preferably, a camera, microphone, and speaker/headphones.

**To Join the Virtual Meeting:** ______________________________________________

______________________________________________________________________

If you need help or have never attended
a virtual meeting, contact:

______________________________________________________________________

# 10 Step Ten | Prepare For Meetings

Leading up to your first meeting, you will have many things to remember.

**One week before, facilitators, group representatives and volunteers should:**

- Review the session plan.
- Make sure all resources are available.
- Review the member list and identify individuals who may need accommodation or additional support.
- Make reminder calls to the members about the meetings details.

It's always a good idea to plan out your meetings beforehand. Creating and sharing an agenda for the meetings will help members understand how the group will spend its time. They can also mentally prepare for sensitive topics, recall useful resources, and think of important questions.

## Template | Readiness Checklists

Leading up to your first meeting, you will have many things to remember and prepare. A readiness checklist can help you to make sure nothing is forgotten. You can use this template as is, or as inspiration to create your own.

# In-Person Meeting Readiness Checklist

- ☐ Is the meeting space booked?
- ☐ Are the meeting materials ready (chairs, tables, computer, projector, microphone, wi-fi password, etc.)?
- ☐ Are facilitators, and volunteers available and ready for the meeting?
- ☐ Has an agenda been created and shared?
- ☐ Are reminder phone calls and emails done?
- ☐ Do any members need accommodations?
- ☐ Is the paperwork ready (attendance sheet, incident report sheet, etc.)?
- ☐ Is the emergency contact list readily available?
- ☐ Are materials for members ready (name labels, pens, paper, etc.)?
- ☐ Who will pick up the refreshments?

# Virtual Meeting Readiness Checklist

- ☐ Are facilitators, and volunteers available and ready for the meeting?
- ☐ Do you have the license to use the web conferencing platform?
- ☐ Do the facilitators and the volunteers know how to use it the platform? Can you teach it to members who may have challenges?
- ☐ Has an agenda been created and shared?
- ☐ Has meeting information and agenda been shared with members?
- ☐ Have reminder calls been done?
- ☐ Do you have the member list and emergency contact list?
- ☐ Are the meeting materials ready?
- ☐ Are there any accommodations to be taken care of?
- ☐ Is the paperwork ready (attendance sheet, incident report sheet, etc.)?

## Template | Incident Report

Sometimes, no matter how well you plan, something unexpected happens and people get hurt. It is important to track these moments to make you're your members stay safe. You can use this template as is, or as inspiration to create your own.

# Incident Report

## Incident Details

| | |
|---|---|
| **Date and Time** | |
| **Location** | |
| **Participant(s) Involved** | |
| **Witnesses Present** | |
| **Description** | |
| **Actions Taken** | |
| **Follow Up Plan** | |

## Report Details

| | |
|---|---|
| **Report Completed By** | |
| **Date and Time** | |

## Storing Documents And Participant Information Safely

Any document (paper or email) that has the name, contact information, or any personal details of members and volunteers need to be stored safely. This includes consent forms, member information forms, surveys, emails, etc.

**Some suggestions for safe storage of information:**

- Create a system to manage member information.
  - Using an excel sheet or a table on a word document to add member name, contact, emergency contact, etc.
  - Save the document on a secure computer/laptop (password protected and stored safely).
- Store paper documents.
  - Consent forms, surveys, member information forms, etc. should be kept in a safe place such that no unauthorized person can access it. Ensure it is safe from damage from rain, fire, and animals.
- Limit access.
  - Only members of the group who are assigned to certain roles should be allowed to complete forms or access stored documents.
- Create an email address for the group.
  - Only individuals in key roles should have access to the account and password.
- Do not share member information.
  - Member information should not be shared with anyone (even local partners) for any reason. If members would like to connect with each other, encourage them to do so during the group meeting.

**Tip**: Your organizational partner may help create a system to manage your emails and records.

# 11 Step Eleven | Conduct Your Meetings

Your members are oriented, and you have confirmed that all the resources you need for the meeting are available. You are now ready to start the peer support group meetings.

Here are some suggestions for different things you can do during meetings. Do not try to do everything in one meeting. Give your members plenty of time to participate and discuss issues that are important to them.

## Welcoming And Opening Remarks

**Welcome** (5 minutes)
- Hand out name tags.
- Thank everyone for attending.
- Remind members where bathrooms are, how to step away if they need, and that they are welcome to participate as much as they want.

**Acknowledgements** (3 minutes)
- Acknowledge funders, donors, and sponsors.
- Consider including a sincere land acknowledgement.

## Introductions And Ground Setting

**Facilitator Introduction** (3 minutes)
- Let members know what your role is.
- Knowing the facilitator is important for members to feel safe. Consider sharing your journey with stroke, your experience with peer support.
- This may only be required in the first few meetings, or when a new member joins.

**Member Introductions** (1-2 minute per attendee)

- Introductions allow members to build familiarity, trust, and empathy.
- Ask members to introduce and talk about themselves. Introductions need not include details about stroke.
- Add fun questions, like their favourite movie or hobby.
- New members can feel nervous at first. Give them the time and space to engage as they want. Check-in with them after the meeting.

**Icebreakers** (10-15 minutes)

- Icebreakers are helpful early on, to help people know each other and feel comfortable to talk. Examples include:
  - 'Would you rather' questions: Give two options and have members share their opinions.
  - Ask people to share a funny or unique story.
  - Ask people to bring an item and share a story.

**Review Values and Rules of Participation** (10-15 minutes)

- Discuss the values and rules from the orientation booklet.
- Do this for the first few meetings to promote respectful interactions and whenever you think a reminder would be helpful.
- Continue to update your group's values and rules. Members are likely to follow rules and values that they have been involved in creating.

## Session Focus

**Check-Ins** (30-60 minutes)

- The first few sessions of the peer support group can be used to get to know the members better. In these cases, check-ins may be the main activity of the meetings.
- Invite members to share their goals, needs and topics to discuss.
- This will help the facilitator understand common themes, which in turn become topics for future sessions.

**Topical Discussion** (60 minutes)

- Facilitators can start by sharing some basic information about the topic.
- Members can then be invited to talk about their experiences related to the topic. This is a great space for members to share similar experiences, ideas, and solutions to support each other.

### Health and Related Topics

- Return to life after a stroke.
- activities of daily living.
- managing pain.
- Speech and comprehension.
- Mental, emotional, and cognitive functions.
- Diet, exercise, and wellness.
- preventing and managing other diseases.
- Use and care of adaptive devices.

### Personal Life

- Stress management.
- Family and other relationships.
- Social and leisure activities
- Intimacy.
- Employment and volunteering.
- Travelling after stroke.
- Spirituality and religion.
- Taxes, benefits, financial planning and insurance.
- Goal setting.
- Mindfulness and self-care.
- Stroke and caregiver advocacy.

**Guest Speaker** (60 minutes)

- Guest speakers can educate the group about living with stroke.
- Connect with your partners to find guest speakers.
- Save time for a question-and-answer period.
- Ideal speakers include:
    - Healthcare professionals.
    - Representatives from local or national stroke prevention and recovery associations (Heart and Stroke, March of Dimes Canada, etc.).
    - Representatives from community and government services.
    - Health and wellness specialists (meditation, exercise, etc.).
    - Financial planners and tax consultants.

# Debrief And Housekeeping

**Summary and Take-Aways** (10 minutes)

- Summarize the points discussed, helpful tips or ideas, and activities between meetings (2 minutes of mindfulness daily).
- Remind members of the topic for the next session's discussion so they can arrive prepared.
- Confirm the date, time, and place for next meeting.

**Closing Remarks** (5 minutes)

- Thank members and volunteers for their participation and support.
- End the meeting on a positive note. Congratulate members on taking the time and effort to support each other.

**Informal Socializing** (any time)

- Invite members to stay back after the session to talk to others. This will allow members to know each other better and create relationships beyond meetings.
- Refreshments can encourage participants to stay back and provide a relaxed atmosphere for people to interact.
- Check with members for allergies, eating or swallowing difficulties.

## Keeping Members Well

**Grounding Exercises** (5 minutes, as needed)
- Grounding exercises can help bring focus back to the present. They are helpful if members are distracted.
- Depending on the activity, they can be energizing or calming.
- Examples include:
    - Mindful minute: In silence, become present.
    - Breathing: Take three slow, deep breaths.
    - 5-4-3-2-1: List five things you see, four things you feel, three things you hear, two things you smell and one thing you taste.

**Breaks** (once per hour, or as needed)
- It's important to build in breaks during the session. Look for signs or boredom or tiredness to find out when to break.

**Volunteer Debrief** (15 minutes)
- Facilitators and volunteers should meet regularly for post-session debriefs and reflections. Discuss how the session went, challenges, successes, and any changes to be made.

**Tip**: Mix things up! Try a potluck, take a trip, watch a movie, or play a game. This will boost group energy and morale.

**Celebrate special days like:**
- April 5 - National Caregiver Day.
- June - Stroke Awareness Month (Canada).
- October 29 - World Stroke Day.
- December 3 - International Day for Persons with Disabilities.

# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and Maintain Group-based Peer Support

SECTION 4

Evaluate and Grow Your Group

# After Stroke Peer Support Toolkit

## A Guide to Develop, Deliver and Maintain Group-based Peer Support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www.afterstroke.ca

# Section Four | Evaluate and Grow Your Group

## Table of Contents

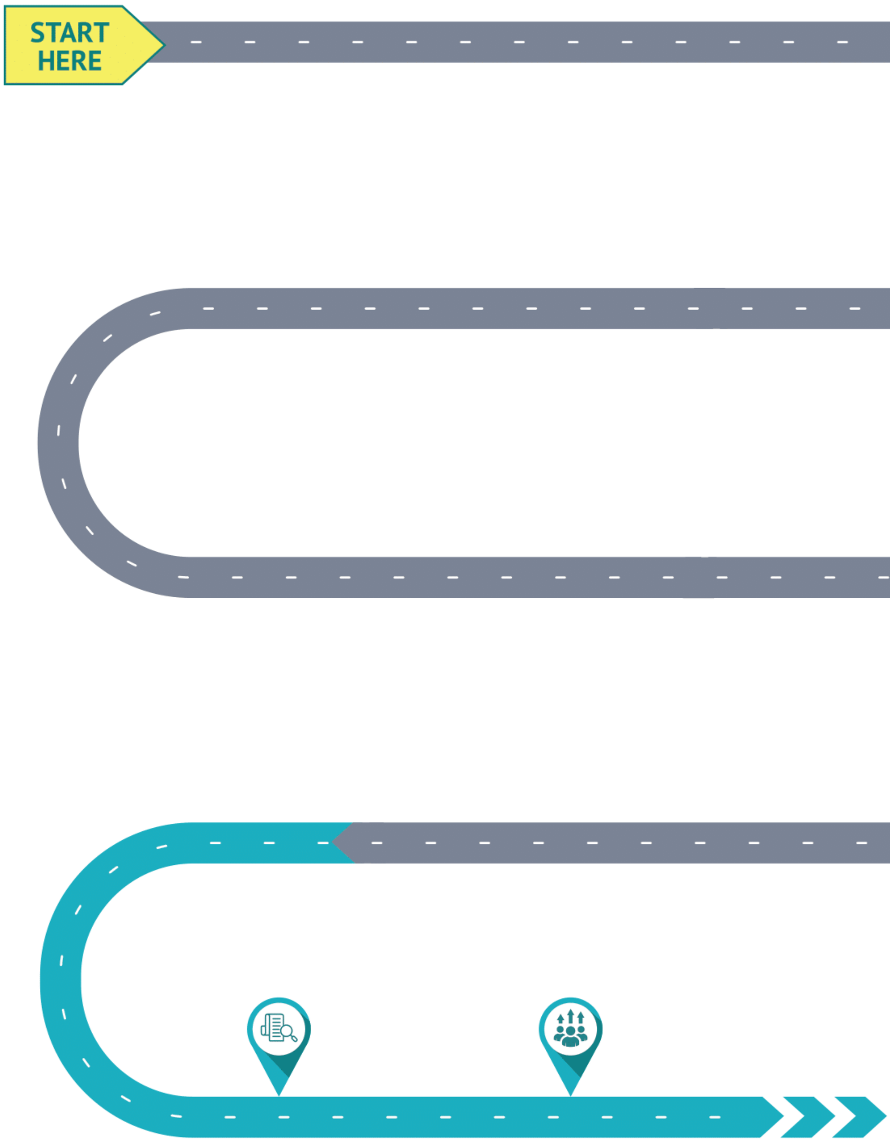


## Template List

# Quick Overview

Check in to see if your program is helping the members and think of ways to grow your program so more people can benefit form it.

**SECTION 4** Evaluate and Grow Your Group




Step Twelve:
**Evaluate your Group**

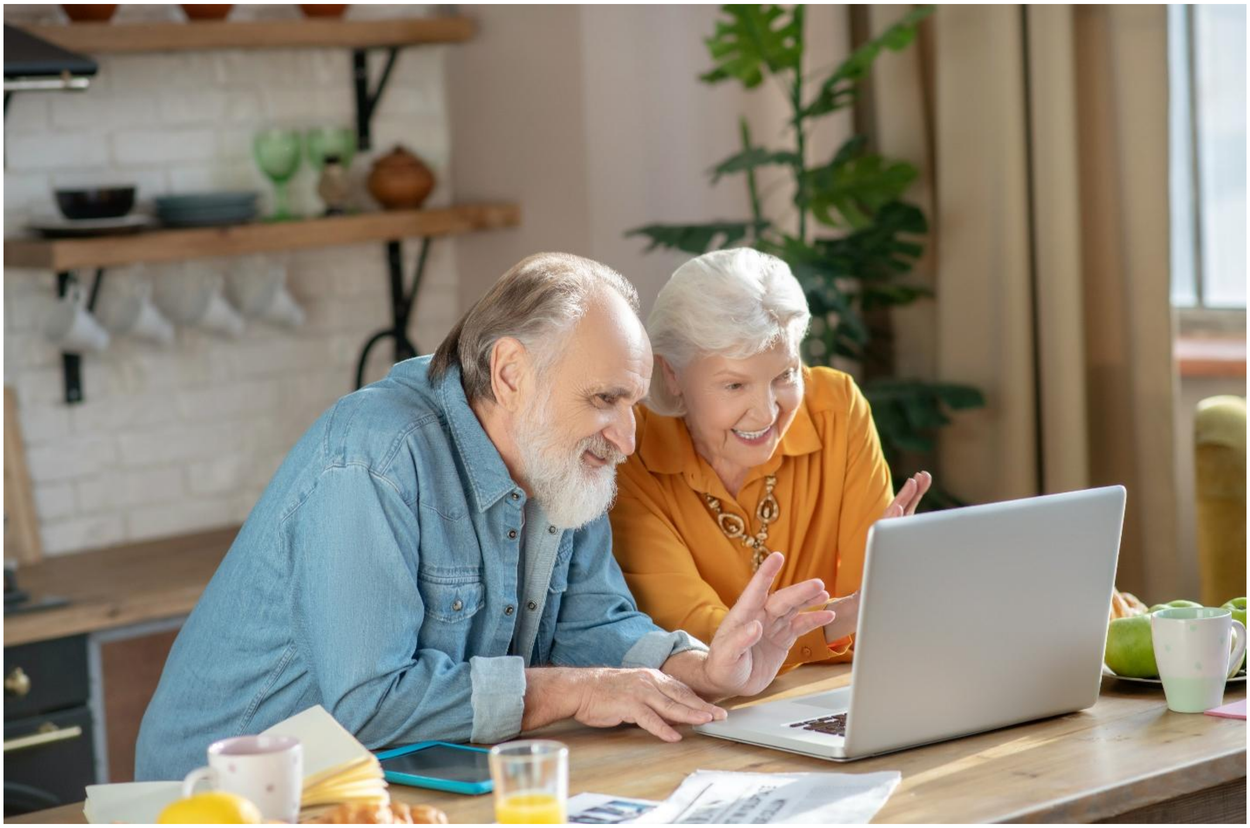
Step Thirteen:
**Sustain and Grow Your Group**

# 12 Step Twelve | Evaluate Your Group

Setting up a peer support group is only half of the goal. The other half is making sure that it is truly helping the group members and the community. Evaluating your group will help you understand what you are doing right and where you can improve.

**There are two kinds of evaluations that groups should do:**

- Process evaluation is to understand if the group is running as planned.
- Impact evaluation is to understand if group members are benefitting from participation in the group.



## Process Evaluation

A simple process evaluation involves checking if the group has achieved its original goals and if its on track with ongoing goals. A process evaluation is a good way to document important decisions, and changes that have happened over time.

For new groups, engage in process evaluations soon after starting and in six months time to help identify and resolve challenges. Later, an annual process evaluation will be enough.

> **Tip**: While listed at the end of this toolkit, evaluation is not a separate phase. You collect information on a regular basis and use it to understand if any changes are needed.

## Template | Process Evaluation Worksheets

Below are few templates below that you can use or modify as necessary to record and monitor program related activities. You can use this template as is, or as inspiration to create your own.

# Process Evaluation Worksheet

**Group Name:** ________________________________________

**Evaluation Date:** ________________________________________

**People Involved:** ________________________________________

| **Process Evaluation Questions** | **Considerations or Indicators** | **Data Collection and Evaluation Methods** | **Timelines** |
|---|---|---|---|
| How closely did implementation follow the original plan? | | | |
| What changes were made to the implementation plan? Why? | | | |
| Were necessary resources available? | | | |
| What challenges were encountered during implementation/ delivery? How were they resolved? | | | |
| How have the targeted clientele responded the peer support services? | | | |

| **Process Evaluation Questions** | **Considerations or Indicators** | **Data Collection and Evaluation Methods** | **Timelines** |
|---|---|---|---|
| Are the program users satisfied? | | | |
| What internal factors influenced implementation/delivery of peer support? | | | |
| What external factors influenced implementation/ delivery of peer support? | | | |
| What was the staff's (including volunteers) perception of the program? | | | |
| Other | | | |

| | Item | Details |
|---|---|---|
| **Resource** | Meeting space | |
| | Meeting refreshments | |
| | Other materials | |
| | Number of volunteers | |
| | Reason and number of volunteer withdrawals | |
| **Meeting Tracking** | Number of sessions | |
| | Number of guest speakers | |
| | Number of special events | |
| | Type of special events | |
| | Donations received | |
| | In-kind received | |
| | Grants received | |
| | Funds raised (sources) | |

| | | |
|---|---|---|
| **Partner Tracking** | Organizational partner | |
| | Contribution of organizational partner | |
| | Local partners | |
| | Contribution of local partners | |
| **Program Promotion** | Current methods of promotion | |
| | Methods that are working well | |
| | Methods not working well | |
| **Membership Tracking** | Total number of members | |
| | Average attendance | |
| | Reason and number of member withdrawals | |
| | Number of people on waitlist | |

## Impact Evaluation

An impact evaluation is used to understand the effects of participating in a peer support group on its members. The results can be important when applying for funds, grants or receiving donations.

The best way to find out member experiences with the group is to ask them. Ask them to fill out a survey or feedback form about what is working well and what can be improved. Impact evaluations should be conducted regularly (every 6 or 12 months) to maintain the quality of support members receive.

**Tip**: Anonymous surveys (where names are not required) will help you get honest answers.

## Template | Member Feedback Survey

The survey below can be used to collect feedback from members of your peer support group. You can use this template as is, or as inspiration to create your own.

# Member Feedback Survey

We would like to know how the peer support group has helped you, and ways to improve in the future. Please take a few minutes to give us some feedback. This survey is anonymous so be honest!

**How long have you been a part of this peer support group?** ________________

______________________________________________________________________

**On average, how many sessions do you attend in a month?** ________________

______________________________________________________________________

**What do you like about this peer support group?** __________________________

______________________________________________________________________

**What do you not like about this peer support group?** ______________________

______________________________________________________________________

**What can we improve?** _________________________________________________

______________________________________________________________________

**Do you have any feedback for the facilitators, and other volunteers who help run this group?** ______________________________________________________

______________________________________________________________________

**What other topics should we cover during our meetings?** __________________

______________________________________________________________________

**Overall, are you satisfied with this peer support group?**

- ☐ Satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Dissatisfied

# Member Outcomes Survey

We would like to know if participating in the peer support group has been helpful for you. Please take a few minutes to give us some feedback. Think about your participation in the peer support group. For each of the following statements, choose the option that best reflects how you feel presently. Where possible, feel free to share examples, details, and other notes that will help us understand more about your experience participating in the group.

| **As a result of participating in the peer support group...** | **Strongly disagree** | **Disagree** | **Neither agree nor disagree** | **Agree** | **Strongly agree** | **Details** |
|---|---|---|---|---|---|---|
| I have made new connections. | | | | | | |
| I feel like I have a community. | | | | | | |
| I feel seen and heard. | | | | | | |
| I feel like I have support. | | | | | | |
| I feel less alone. | | | | | | |
| I have hope for the future. | | | | | | |
| I am less depressed. | | | | | | |
| I can engage in activities that interest me. | | | | | | |

| As a result of participating in the peer support group… | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree | Details |
|---|---|---|---|---|---|---|
| I am motivated to do things. | | | | | | |
| I am less anxious about what is to come. | | | | | | |
| I can manage my worries. | | | | | | |
| I am more confident. | | | | | | |
| I feel empowered to take care of myself. | | | | | | |
| I feel like I have something to offer to others. | | | | | | |
| I have access to information and resources that I otherwise would not. | | | | | | |
| My overall wellbeing has improved. | | | | | | |

**Do you have any general comments?** ________________________________________

________________________________________________________________________

**Date Completed**: ________________________________________________________

## Redesigning Your Group Based On Feedback

Use the help of volunteers or an organizational partner to help you summarize the results of your process and impact evaluations.

As you go through the results, identify what seems to be working well (lots of positive comments), what is not working well (suggestions for improvement and changes), and what else you can do.

| For things that work well... | For this that are not working well... | For things that you need to do... |
|---|---|---|
| ⬇ | ⬇ | ⬇ |
| Keep doing them and monitor. | What changes can you make? | How can you start doing this? |

Thus, slowly the group adapts to the needs and preferences of its members, providing the support they need and value.

# 13 Step Thirteen | Sustain And Grow Your Group

Over time, the group will run like a well-oiled machine. It is a valuable part of the community, and members rely on it to improve their lives. The group has strong relationships with local and organizational partners, and has figured out how to find new members, or raise funds.

At this time the focus will shift to making sure that the peer support group continues to run smoothly. This way new stroke survivors can access its services. This is known as program sustainability.

**For a group to be sustainable, it must:**

- Continue to provide health benefits to members.
- Change to meet the needs of the clients and partners.
- Be able to find and use resources it needs to run smoothly.

## Template | Sustainability Checklist

Groups that sustain over time have a few common features. We have presented them as questions (see template below) so you can check how your group is doing. You can use this template as is, or as inspiration to create your own.

# Sustainability Checklist

**As you answer these questions, think of how the group is doing now.**

| | Yes | Sometimes | No |
|---|---|---|---|
| Is there is match between what the community needs and what the group offers? | | | |
| Does the group have the support and active involvement of local partners? | | | |
| Does the group have a positive impact on participants and the community? | | | |
| Is the group regularly evaluated? | | | |
| Is the group changed based on results of the evaluation? | | | |
| Is the group being promoted/advertised in the community? | | | |
| Are sufficient funds available to manage group costs? | | | |
| Does the group have access to the resources it needs? | | | |

If you have answered **sometimes or no** to any of these questions, they might be areas where you may have challenges going forward.

## Addressing Challenges

Once you have found potential challenges, you can create a plan on how to address them. You can also include areas that are working well in your sustainability planning. This will ensure that they continue to work well.

**The approach would be:**

Identify potential challenges.

↓

think of why current approach is not working.

↓

List the actions required to fix it.

↓

Decide who will be responsible.

↓

Set a timeline.

**Tip**: Have regular discussions about what issues the group is facing and how it can be resolved.

## Template | Sustainability Planning Worksheet

Building on the questions above, fill out this form to help you understand if you are likely to have any challenges soon or in the future. If you find problems, you can discuss solutions with your partners. You can use this template as is, or as inspiration to create your own.

# Sustainability Planning Worksheet

| | Potential challenges | Issue with current approach | Potential solutions | Actions to fix it |
|---|---|---|---|---|
| Match between community need and group benefits | | | | |
| Active involvement and support of local partners | | | | |
| Positive group impact | | | | |
| Regular evaluation | | | | |
| Changes to group in response to evaluations | | | | |
| Group promotion | | | | |
| Availability of resources | | | | |

## In-Depth Evaluation

If you are looking to do an in-depth sustainability evaluation you can use tools like The Program Sustainability Assessment Tool (https://www.sustaintool.org/psat).

## If Challenges Cannot Be Resolved

Sometimes, it may not be possible to fix some problems. For example, group attendance is poor, and no new members are joining. Or there are no trained, experienced, and dedicated team members to run the group.

If you have tried different solutions and nothing is working, it may be necessary to terminate the program and inform your members about other groups they can join.

## Grow Your Group

Once the group has been running for a while, the team can discuss opportunities and ways to grow the group.

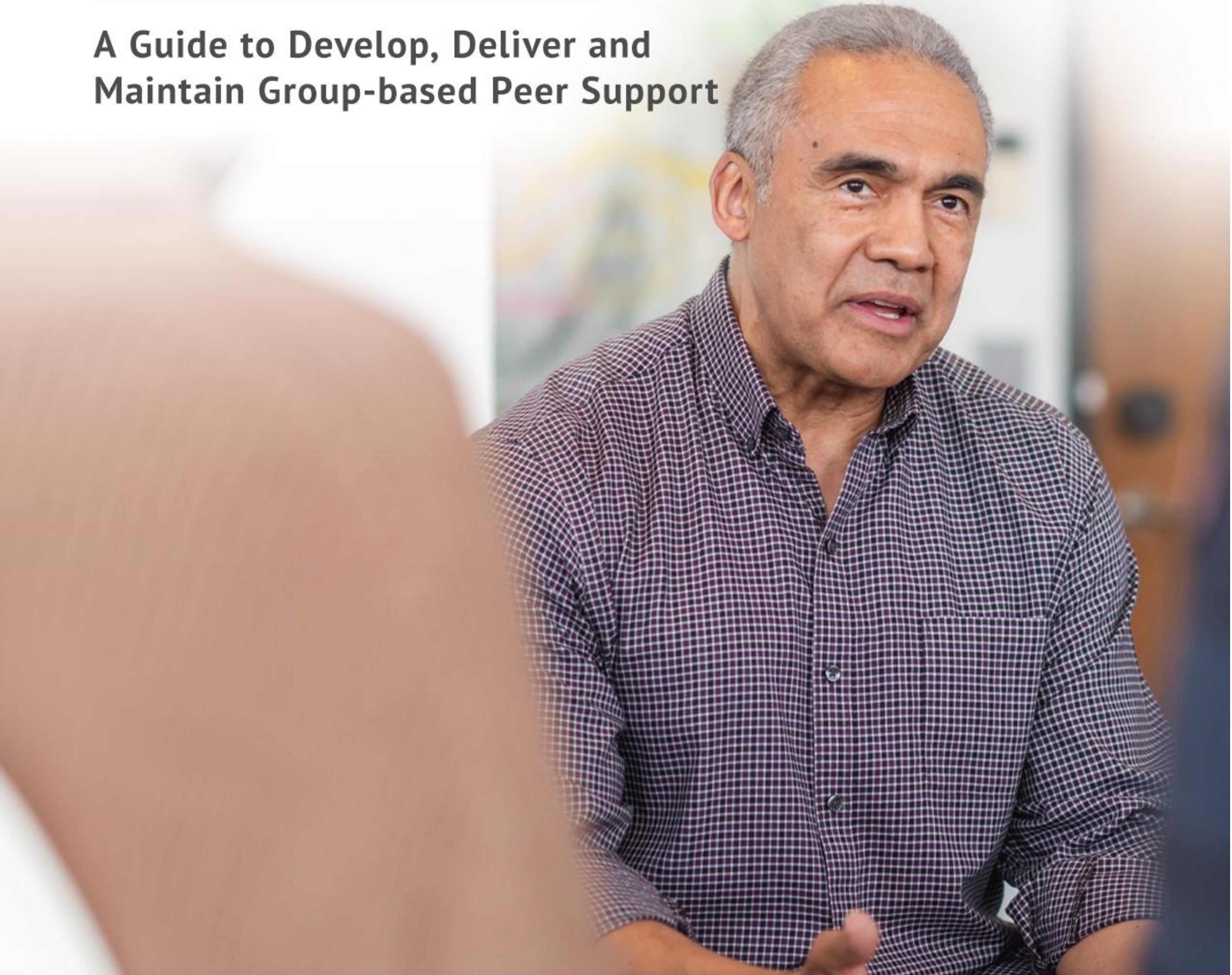
**Here are some ways the group can grow:**

- Conduct an evaluation to find areas where the group can do better.
- Redesign the group to make it more formal and structured. Establish a governance structure, design policies and procedures, register your group as a not-for-profit group, etc.
- Join a network of peer support groups so you can learn from each other.
- Expand the services of your group by inviting more members, specific groups (caregivers, younger people living with stroke, etc.) or offering virtual and in-person groups.
- Expand your partnerships.

**Tip**: This is the exciting part! The group is doing great work and now can have even more positive impact on the community.

# After Stroke Peer Support Toolkit

A Guide to Develop, Deliver and Maintain Group-based Peer Support



SECTION 5 **Facilitator's Guide**

# After Stroke Peer Support Toolkit

## A Guide to Develop, Deliver and Maintain Group-based Peer Support

## Acknowledgements

We gratefully acknowledge the contribution of the members of the co-design group for their lived experience expertise. Their involvement was critical in ensuring that this toolkit reflects the perspectives of people impacted by stroke. We thank Ellen Cotton and Jenna Bang, both Speech Language Pathologists, who have contributed to the section on assisting group members with communication disorders. We also thank our colleagues at March of Dimes Canada for their feedback and insights in creating a valuable and user-friendly resource.

## Funding

The After Stroke Peer Support Toolkit was developed with funding support from an anonymous donor. We recognize the continued support of March of Dimes Canada.

## Disclaimer

This toolkit is not designed to offer medical or health advice. This information is for reference and educational purposes only. The people and groups that developed, contributed to, funded, or were otherwise involved in the toolkit's creation are not responsible or liable for any damages, loss, or injuries that arise from or are related to the use of information in this toolkit. While reasonable efforts were made to ensure the accuracy and completeness of the information within the toolkit, we make no warranties, expressed or implied, regarding errors or omissions.

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# Section Five | Facilitator Guide

## Table of Contents

# Using The Facilitator's Guide

This section includes information on how to guide peer support group discussions and manage common challenges.

**It includes:**

- Information on preparing for the role of a peer group facilitator.
- Tips to improve participation, deal with arguments and sensitive issues.
- Helping members with communication challenges.
- Resources on living with stroke, and peer support.

# What Is The Role Of A Facilitator?

The facilitator is someone who can engage members, manage difficult conversations, and keep discussions on track.

**A facilitator is responsible for:**

- Creating a safe and welcoming space where members feel comfortable to share.
- Inspiring discussion by asking clarifying and follow-up questions.
- Keeping discussions on track
- Encouraging members to help and support each other.
- Modeling good group behaviour.
- Managing difficult members and conversations.

**Tip**: A facilitator is a guide, not a leader. Everyone in the group is equal. One or more persons can take on this role, or a group can rotate the role among the members.

# What Skills Should A Facilitator Have?

**To effectively guide a discussion, a facilitator should be:**

- A guide who supports group members.
    - Warm, empathetic, unbiased, and a good listener.
    - Should not impose their opinions on members.
    - May share own story where relevant to support discussions.
- Must be confident and assertive to keep discussions on track.
    - Accountable and dependable.
- Understand the value and importance of their role.
    - Dependable and consistent in their involvement (constant turnover can lead to low trust and poor group dynamics).

# How Can I Prepare to Be A Facilitator?

Training is important to prepare any facilitator for their role. Check if your partner organizations have their own or preferred peer support training course. They may also know other peer support facilitator training programs. Volunteers can also seek out accredited training or certification courses provided by external reputable organizations.

**You should have some basic understanding in three areas:**

- Understanding What Happens After a Stroke.
- Peer Support.
- Reflective Learning.

# Understanding What Happens After A Stroke

The following resources can help you get a basic understanding of what happens when someone experiences a stroke.

| Resource Name | Description | Link |
|---|---|---|
| **Effects of Stroke** (American Stroke Association) | An 11-page resource about the effects of stroke. | https://www.stroke.org/en/about-stroke/effects-of-stroke |
| **Effects of Stroke** (Stroke Association UK) | A 10-page resource on emotional changes, memory, neuroplasticity, relationships and more after stroke. | https://www.stroke.org.uk/effects-of-stroke |
| **Getting on With the Rest of your Life After Stroke** (Canadian Stroke Network) | A 36-page resource that covers goal setting, exercise, blood pressure, stress and more. Also includes activities to help with brain health. | https://www.strokebestpractices.ca/-/media/1-stroke-best-practices/mood-cognition-and-fatigue/getting-on-with-the-rest-of-your-life-after-stroke.ashx |

# What Is Peer Support?

A facilitator should know and understand the value of peer support, how it works, and what peer support looks like. These resources can help you understand more about peer support.

| Resource Name | Description | Link |
|---|---|---|
| **6 Ways Peer Support Can Improve your Health** (Heart and Stroke Canada) | A list of six reasons that peer support is a useful tool. | https://www.heartandstroke.ca/articles/6-ways-peer-support-can-improve-your-health |
| **Value of Peer Support** (NESTA UK) | A case study about Steve, a peer support group leader since 2016. | https://www.nesta.org.uk/case-study/stroke-association-peer-support/ |
| **Code of Conduct** (Peer Support Canada) | A one-page list of 'I will' statements that facilitators should agree to. | https://peersupportcanada.ca/wp-content/uploads/2019/06/Peer_Support_Code_of_Conduct-ENG.pdf |
| **Values, Principles and Ethics of Peer Support** (Canadian Mental Health Association) | An overview of the core beliefs that peer support is based on. | https://cmhawwselfhelp.ca/wp-content/uploads/2022/05/Values-principles-and-ethics-of-peer-support-v180926.pdf |

# What Is Reflective Learning?

Some meetings might not go as well as you planned, and others might go well. Once the session is done, think about what you did or would like to do differently.

**Some simple questions can help with reflective practice:**

- How did today's session go?
- What could have been better?
- What should we do next time?

| Resource Name | Description | Link |
|---|---|---|
| **Reflective Practice** (Campus Mental Health) | Reflective journal questions and reading about reflective practice. | https://campusmentalhealth.ca/toolkits/campus-peer-support/supervision-support/reflective-practice/ |

# How Do I Keep Discussions On Topic?

When the discussion steers away from the topic at hand, the easiest way to redirect is to point out that conversation is getting off-topic. Use gentle but firm language when communicating this. If there is time after the meeting for casual conversation, members can discuss it then. Creating a public 'parking lot' where off-topic ideas are listed can be helpful, so members can remember their important but off-topic items for the end of the meeting or future sessions.

A useful phrase is: "This is not within the topic for our meeting today. Let's write it down and come back to it in another session or discuss after the meeting."

# What Should I Do If I'm Worried About A Member's Wellness?

**Your approach will depend on the type of crisis you experience:**

- If there are red flags or concerning behaviour.
    - Speak to the member privately and recommend that they get in touch with their local healthcare professional. Share any appropriate resources you may have.
- If there is a medical emergency.
    - Call the local emergency service followed by the member's emergency contact. Complete an incident report.

# How Do I Manage Conflicts And Arguments?

Sometimes members may start arguing with no signs of coming to an agreement. Try to calm the situation and remind the group that members do not need to agree with each other and that everyone can have their own opinion or idea. If there is tension, try a grounding or breathing exercise to change the energy of the meeting. If helpful, review the core values and rules of peer support and remind participants to have a respectful discussion.

# How Do I Manage Disruptive Members?

If you have members who frequently speak over other members, interrupt, or side-track the discussion, the facilitator can step in. To avoid putting the member in an uncomfortable position, talk to them one-on-one.

Remind them to wait for their turn or raise their hand. Let them know that others need some time to talk too. You can also use tricks like – "the person with the blue stick speaks", provide notepads to jot down thoughts and ideas while waiting for their turn, or saving time to highlight one member each session to give them time to share their thoughts.

# How Do I Manage Discussions About Sensitive Topics?

When guiding a peer support group, even the best facilitators encounter challenges. Here are some suggestions on how to prepare for and/or respond. Some group members will find certain topics emotional or sensitive. If you think that a topic may make some members upset, gently inform members ahead of time. Members may then choose not to attend or come mentally prepared. Reach out to these members separately to see if they need any assistance. You could also discuss with your groups on what topics they would like to avoid.

If a sensitive topic is brought up unexpectedly, the facilitator can call for a break. During this time, privately ask affected members if they would like to step out. The facilitator can also ask the group to move the topic to a future meeting. Remind members to feel free to step away at anytime if the discussions are making them uncomfortable.

**Tip**: Do not avoid topics that may be uncomfortable. As hard as they may be, some conversations are especially important. For many members, this group may be the only place they can talk about their fears and concerns openly. Approach these topics with empathy and sensitivity.

# How Can I Support Members With Communication Disorders (Like Aphasia)?

After a stroke, people may experience challenges with communication (like aphasia), and may have difficulty speaking, reading, writing, or understanding what other people say. This does not mean that they are less intelligent!

**Help them feel respected**.

- Make eye contact and use an adult tone of voice.
- Speak to them directly, naturally, and kindly. Don't shout.
- If you need to speak on their behalf, ask them if it's okay first.
- Acknowledge their frustration and be patient.
- Say supportive phrases, like "I know you know".

**Help them understand you.**

- Bring markers and paper or a portable whiteboard.
- Speak clearly and slowly. Pause frequently and use short sentences.
- Write large key words and draw or point to things.
- Use your hands and face to show what you mean.
- Focus on one topic at a time.
- Let them see your lips.

**Help them communicate.**

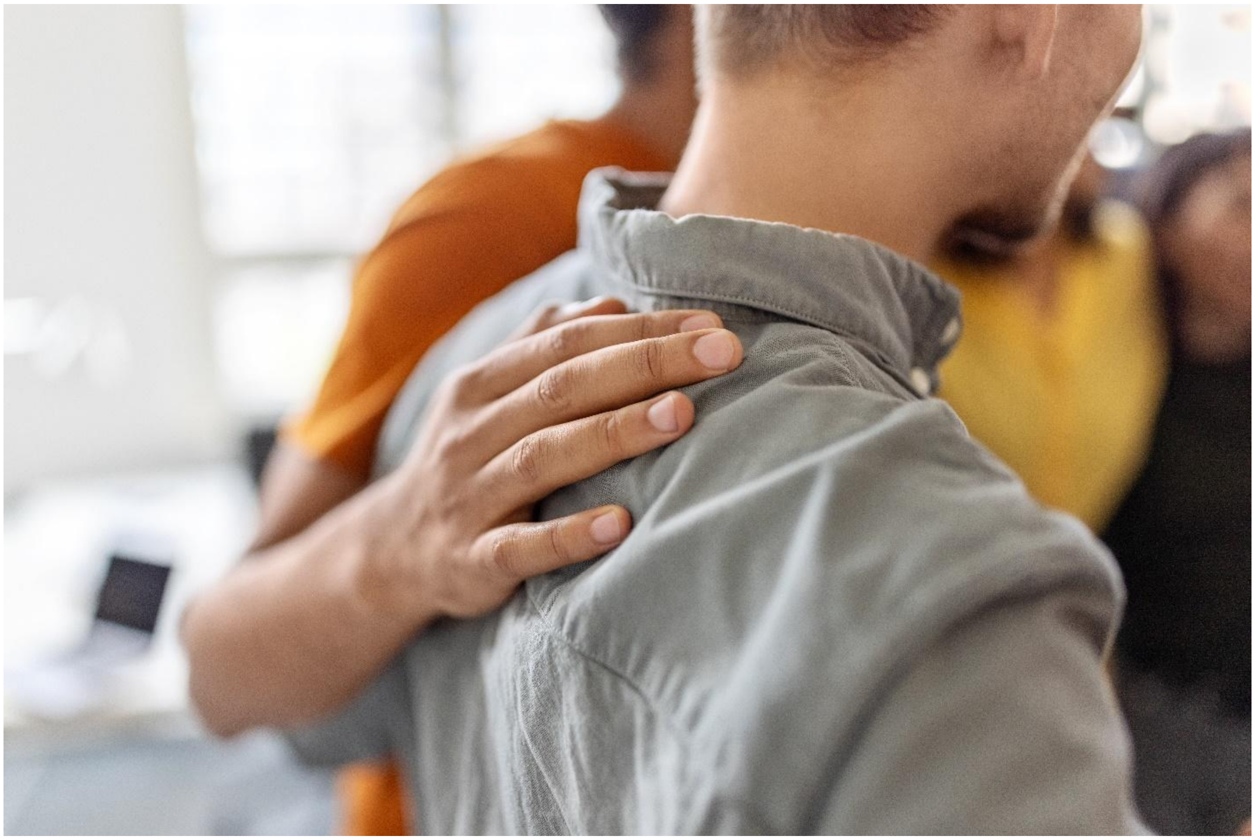
- Ask yes and no questions, one at a time.
- Give them time to answer.
- Don't complete their sentences (unless asked).
- Give them choices to point to (yes, no, I don't' know, etc.).
- See if their face or actions are saying something.
- If they say the wrong word, imagine what they may be trying to say.

**Double-check.**

- Check what you think they have told you. Say it again or sum it up.
- Ask if they have more to tell you, before moving on.
- Sometimes, ask "Should we take a break? Can we try again later?"

**Tip**: Learning how to support people with aphasia in conversation is like learning a new language; it takes practice! We strongly encourage facilitators to take extra training.

March of Dimes Canada has also created a toolkit called: 'Making Peer Support Groups Accessible for Individuals with Communication Difficulties'. This resource is intended to provide information, tools and strategies for peer support group staff, volunteers and members to support members who may have communication difficulties.



| Resource Name | Description | Link |
|---|---|---|
| **Does Your Family Member Have Aphasia?”** (Aphasia Institute) | The above suggestions are adapted from this resource. | https://tbrhsc.net/wp-content/uploads/2020/10/Does-your-Family-Member-Have-APHASIA.pdf |
| **Supported Conversation for Adults with Aphasia** (Aphasia Institute) | A series of communication techniques to encourage conversation when working with someone with aphasia. | https://www.aphasia.ca/communication-tools-communicative-access-sca/ |
| **Aphasia - What a Difference Some Help Makes** (Dyscover) | A 5-minute video demo of supportive communication strategies. | https://www.youtube.com/watch?v=KWVoqM9jmEM |
| **Accessible Information Guidelines** (Stroke Association UK) | A 32-page resource on how to make information accessible for people with aphasia. | https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf |
| **Making Space for Everyone** (Social Planning and Research Council of BC) | A toolkit on how to be more accessible to people with mobility, visibility, hearing and cognitive concerns. | https://www.sparc.bc.ca/wp-content/uploads/2017/01/makingspaceforeveryonebookletweb.pdf |

# How Can I Improve Member Engagement?

**As a facilitator you can improve member engagement by:**

- Ask questions to let your members know you are actively listening.
  - Use open ended questions like "Can you tell us more about…"
  - Use techniques like 'person holding the ball speaks' to bring attention to the speaker.
  - Ask members to face the speaker.
- Minimize distractions.
  - Make sure people can see each other without needing to move.
  - Provide comfortable seating in a safe and private space.
- Allocate plenty of time for discussions, questions, and answers.
- Add movement.
  - Include safe and fun physical activities, like seated ball throwing, feet tapping, drum circles, etc.
  - Music and body movements cause the release of endorphins.
- Discuss different topics.
  - Do not limit meetings to only stroke related topics. Include time for general topics about life, recent movies or books, hobbies, travels/adventures, etc.

# How Can I Get Participants To Trust Me?

**As a facilitator you can gain the trust of members by:**

- Asking appropriate questions – let members know you are listening and interested.
- Remaining calm and neutral but empathetic and understanding.
- Sharing your own experiences (selectively and with intention).
- Being patient, objective and fair.
- Staying committed and consistent – remain involved and committed to support the members. Sometime developing trust just needs time.

# How Can I Improve Involvement And Attendance?

**You can improve involvement and attendance by:**

- Making it easier for them to attend.
    - Ask members what you can do to encourage attendance.
    - Regularly check if the meeting time and place works
    - Have a virtual meeting option if the weather is bad, if transportation is challenging, etc.
    - Offer reminder phone calls.
    - Make wellness check phone calls if members miss a few sessions.
- Involving members in decisions about the peer support.
    - Encourage members to provide feedback about the group.
    - Discuss ways to improve how the group runs.
    - Involve members in discussing future topics, guest lectures, events, etc.
- Mixing things up.
    - Occasionally, have meetings where you do not discuss stroke or challenges.
    - Watch a movie or a play, play games, visit a gallery or museum.
    - Have a potluck, bingo night, go for a hike, etc.

| Resource Name | Description | Link |
|---|---|---|
| **Make Buildings and Spaces Accessible** (AODA) | A webpage with details on how to make spaces more inviting and accessible. | https://www.aoda.ca/make-buildings-and-spaces-accessible/ |

# How Can I Support Members To Advocate For Themselves?

Advocacy involves using your voice, words, actions, and choices to raise awareness or share information about causes that matter to you. When people with lived experience share their thoughts and experiences, it has the potential for greater impact and farther reach. Anyone who is willing to speak about their own needs, or the needs of someone else, and is passionate about making a difference can become stroke advocate.

Advocacy includes all acts- big or small- that help to raise and spread awareness of stroke, life after stroke, prevention, recovery, etc. This can be- connecting the local health authorities or local officials to request improved community support for people living with the impact of stroke becoming a part of the local stroke association, sitting on committees that discuss services/resources for people living with stroke, participating in fundraisers, making social media posts, etc.

| Resource Name | Description | Link |
| --- | --- | --- |
| **Self-Advocacy Toolkit** (March of Dimes) | A toolkit that allows individuals living with disabilities and their families to develop skills to advocate for themselves and others. It provides information and resources on advocacy, navigating systems, and developing personal and interpersonal skills to become an effective advocate. | https://www.marchofdimes.ca/en-ca/aboutus/govtrelations/dan/Pages/Self-Advocacy-Toolkit.aspx |

# How Can I Prepare For Virtual Peer Support Meetings

If you decide to host virtual meetings you will need to prepare for different challenges and opportunities.

- Technical issues.
    - Be prepared for technical issues (poor connectivity, bandwidth issues, device issues, etc.).
    - If needed teach members how to use chat, reactions, raise hands, enter, and exit breakout rooms.
    - Have a volunteer watch the chat and help members.
- Use the virtual features.
    - Offer members an option to remain anonymous by turning off their video or using a pseudonym.
    - Ask members to raise hands when they want to speak.
    - Encourage the use of chat. That way other members can share thoughts without interrupting the person speaking.
- Security and safety.
    - Request that participants attend the meeting through a secure and private internet connection.
    - Use waiting room or passcode features. The meeting link should be private and not shared with anyone else.
    - Reserve a session to talk about online safety.
    - Do not give participants permission to share screen freely.
- Increased structure.
    - Virtual groups may need more structure to ensure that members get a turn to speak, discussions stay on-topic and stay engaged.
    - Include breaks to give facilitators a chance to debrief and discuss.
- Emergency planning.
    - Have a plan to manage crises and/or emergencies.
    - Keep a record of member contact information, and emergency contacts so you can send help if necessary.
    - Prepare an action plan for supporting members who are experiencing distress or need help.

# How Can I Help Members Connect With Each Other Online?

- Review values and group rules.
    - Remind members about confidentiality and respect.
- Spend more time getting to know each other.
    - Prepare introduction questions that aren't stroke related.
    - Try fun questions like favourite cookie, place to travel, and recently watched movies.
- Include team building and bonding activities.
    - Use polling or reactions to get a sense of likes and dislikes.
    - Do a show-and-tell of a unique object in their home.
    - Encourage members to turn on their videos (if comfortable).
- Retain some informality.
    - Invite people to bring their lunch, dinner, or drinks to the session.
    - Include breaks during and after the session for conversations.
    - Share fun information, or interesting stories during breaks.

| Resource Name | Description | Link |
|---|---|---|
| **Step-by-Step Guide to a Zoom Meeting** (Seniors Guide) | A two-page, step by step guide to help you attend a Zoom meeting. | https://cdn.seniorsguide.com/wp-content/uploads/2020/09/02123145/SeniorsGuide-stepbystepguidetoZoom-english0620.pdf |
| **Remote and Online Peer Support** (National Survivor User Network) | A 19-page resource about virtual peer support, written during Covid-19. | https://www.nsun.org.uk/wp-content/uploads/2021/05/Remote_and_Online_Peer_Support_Resource.pdf |

# Other Helpful Resources

These are additional resources for you to refer to or share with your group.

| Resource Name | Description | Link |
|---|---|---|
| **After Stroke Program** (March of Dimes Canada) | Skill redevelopment, peer support, movement and communication support. | https://www.afterstroke.ca/ |
| **Your Stroke Journey** (Heart and Stroke Canada) | A 120-page resource that covers all parts of your stroke journey from understanding what happened, the first weeks, and moving forward into your new normal. | https://www.heartandstroke.ca/-/media/pdf-files/canada/your-stroke-journey/en-your-stroke-journey-v20.ashx |
| **Guide for Stroke Recovery** (Toronto Stroke Networks) | What to expect, managing changes, improving your overall health, and reducing your risk of another stroke. | https://www.strokerecovery.guide/ |
| **Stroke Recovery** (National Health Service UK) | Understanding difficulties after stroke, including swallowing, driving, paralysis, mental health and more. | https://www.nhs.uk/conditions/stroke/recovery/ |
| **Life After Stroke** (American Stroke Association) | A 36-page resource about how to adapt to life after a stroke, including diagnosis, early treatment, and rehabilitation. | https://www.stroke.org/-/media/Stroke-Files/life-after-stroke/Life-After-Stroke-Guide_7819.pdf |

| Resource Name | Description | Link |
|---|---|---|
| **Peer Supporter Competencies** (Peer Support Canada) | A two-page list of competencies for peer support facilitators. | https://peersupportcanada.ca/wp-content/uploads/2019/06/Peer_Supporter_Competencies-ENG.pdf |
| **Guidelines for Practice and Training of Peer Support** (Mental Health Commission of Canada) | A 54-page toolkit that covers the guidelines for peer support and suggestions for training. | https://www.mentalhealthcommission.ca/wp-content/uploads/2021/09/Guidelines-for-the-Practice-and-Training-of-Peer-Support.pdf |
| **Planning Accessible Events** (Accessibility Services Canada) | A booklet with low-cost and no-cost things you can do to make your event more inclusive to people who live with disabilities. | https://accessibilitycanada.ca/wp-content/uploads/2016/06/Planning-Accessible-Events-May-2016.pdf |
| **Making Space for Everyone** (Social Planning and Research Council of BC) | A booklet on how to be more accessible to individuals with specific mobility, visibility, hearing, and cognitive concerns. | https://www.sparc.bc.ca/wp-content/uploads/2017/01/makingspaceforeveryonebookletweb.pdf |