After Stroke Peer Support Toolkit

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

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SECTION 2 Build Your Peer Support Group

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Conflict of Interest Declaration

The contributing members have no conflict of interest to declare.

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Section Two | Build Your Peer Support Group

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Quick Overview

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

Peer Support Group

Design & Implementation Roadmap

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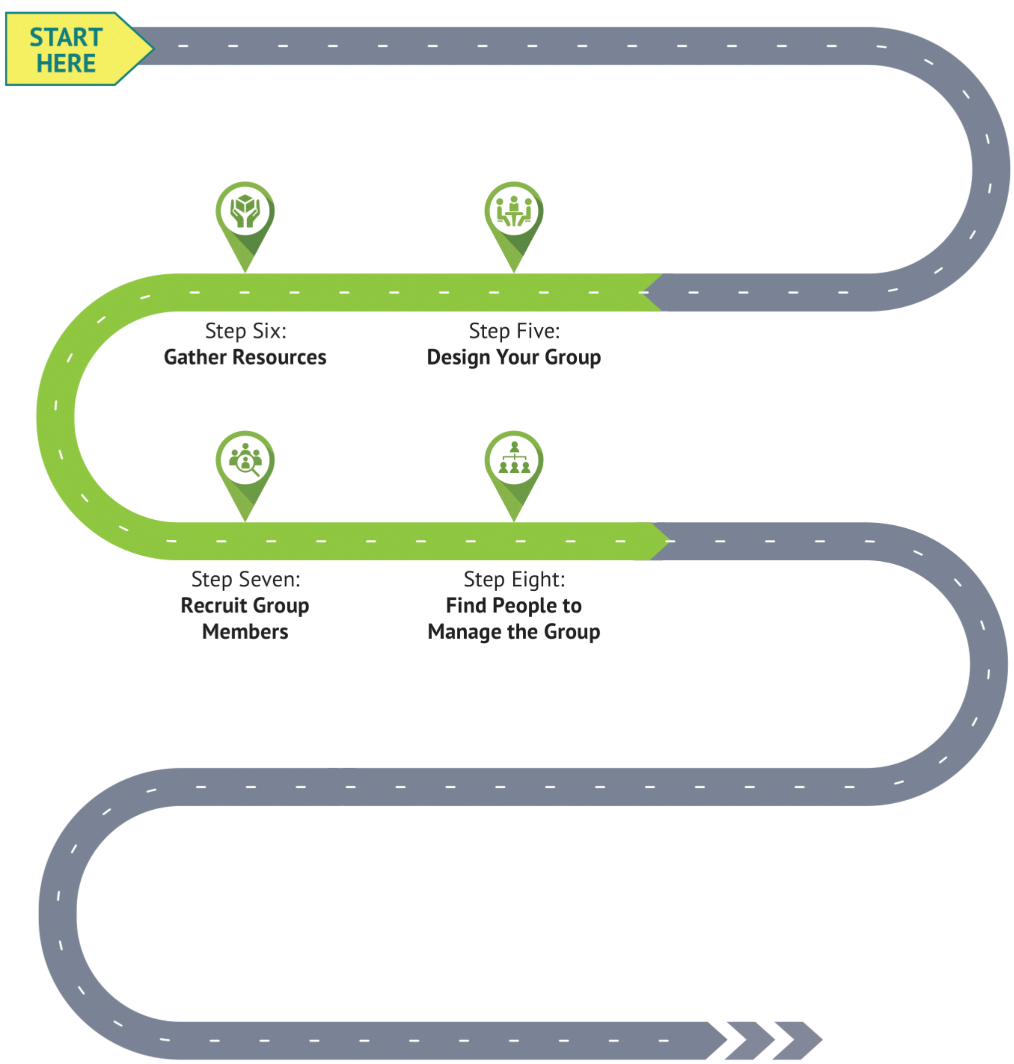
SECTION 2 Build Your Peer Support Group



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Step Five | Design Your Group

So far, you have found a team, and maybe even 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 be able to figure out a final design as you go along. Your group design may also 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 be considered peers.

You can have a broad eligibility, for example, anyone who has had a stroke can be a member. It can also be specific, for example, 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 allow members to trust and support each other.

What Type of Support Will Members Receive?

Think about what the members will talk about and do during the meetings. Will the group mainly share information on how to live with a stroke? Will the group mainly meet to motivate each other, share fears and feelings? Or will the group meet to socialize, do activities, and reduce a sense of loneliness. Or 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, ensuring members can travel, or find the assistance they need to attend the meetings.

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.). the group members will also need access to a device with a camera, microphone and speaker, and license for a web-conferencing platform which may come at a cost.

Where Will the Group Meet?

If your group would like to meet in person, you would 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 → Members can know each other better.
Larger groups → Members can bring in a variety of experiences and viewpoints. But need larger spaces, higher costs, and 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 1-2 times 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 versus 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).

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:

1) Having a facilitator to manage discussions.

Sometimes groups can choose to identify an individual (member or no-member) 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 themselves have experienced the impact of a stroke (i.e., shared lived experience). This would allow them to understand member experiences and guide discussions with empathy and knowledge.

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 some rules – taking turns, managing disagreements, and keeping discussions on track.

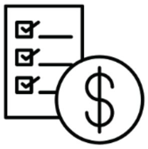
3) Having a trained professional as a facilitator.

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.

Choose what works best for your group.

Tip: All facilitators should undergo training to prepare for the role. Refer to Section 5 to read more about the role of a facilitator and how to manage some common peer support group challenges.

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 program 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.

Template | Peer Support Group Design

On the next page, we have provided a table with additional. Your choice may depend on what resources you have or can make available.

Peer Support Group Design

Group Name: ____

Date: ____

Individuals Involved in Discussions: ______________________________

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?	

Some Things to Keep in Mind!

Some groups may be casual or informal when they start out. As the group grows, it is important to have policies and procedures in place which explain how the group is run and managed. Ideally, these policies and procedures should be built together with the group members and organizational partners.

You will need to think about:

- A group constitution or charter.
    - A document that outlines how the group will run, core values, roles, and responsibilities etc. Having a constitution or charter will ensure the group meets legal and safety requirements.
- Emergency planning.
    - What to do in case of a fire or health emergency.
- Information storage and safety plans.
    - This is important so that member information (names and contact information) does not fall into the wrong hands. (Briefly discussed this in Section 3.)
- Liability insurance.
    - Groups will need to protect itself and reduce risk to members and volunteers.
- Financial accounts and reporting plans
    - Need for a registered bank account to manage expenses and funds. Templates for maintaining financial records, and reporting to national revenue agency etc.

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

Your organizational partner may have templates your can use.

06 Step Six | Gather Resources

Make a list of all the things you will need to run the peer support group. You will also need to plan how and where to find these resources.

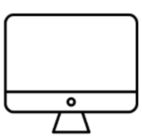
What Resources Do You Need?

The resources you need may be different depending on if you are meeting in-person or virtually.

In-Person Meetings Resource List

- Accessible 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, track attendance, etc.
- Refreshments (check for dietary restrictions).
- 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

Your organizational partner can provide you access to some of their resources. You can also find community partners (individuals, organizations, and businesses) to support your group. In some cases, you may need to purchase resources you need.

Organizational Partner: The group that guides you through the steps to develop, deliver and maintain your group.

Community Partners: Local organizations or people that support your group by offering resources (meeting space, refreshments, materials, technology, etc.).

Potential community partners are:

- Organizations involved in stroke prevention/ recovery/life after stroke.
- Libraries, community, recreation, and religious centres.
- Local community leaders from diverse groups.
- Local businesses.
- Municipal offices.
- Transport service agencies

Raise Funds to Support Costs

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. Note: 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, auctions, etc. 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?

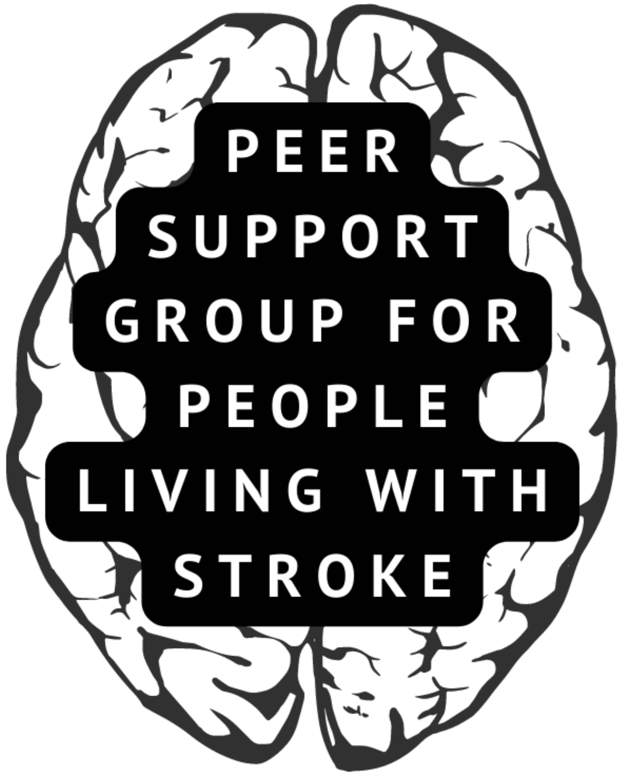
Here are some ways to promote it.

- Local and social media.
    - Advertise in your 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, Twitter, Instagram, etc. Use bright images and catchy phrases to grab attention.
- Awareness drives.
    - Participate in a walkathon, community event, parade, or other community. 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 to 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.
    - Some groups work through direct referrals from local healthcare offices. This requires a plan for confidentiality, safe sharing and storage of personal and health information, and considerations for liability.
    - Talk to local healthcare professionals or your organizational partner about how to establish a referral pathway.

Template | Recruitment Flyer

On the next page, we have a flyer about stroke peer support groups. You can make your own or use this one which you can write on and share.

Do you want to connect with other people who are living with a stroke?



In our group, stroke survivors from all walks of life meet every month to talk about life after a stroke.

If you or someone you know would like to be a part of this group, please contact:

____

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08 Step Eight | Find People to Manage the 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.

What are the Tasks Involved in Running a Peer Support Group?

There are many tasks involved in running a peer support group. Some of these are related to the meetings while other are related to managing day-to-day administration.

Here are some examples of tasks involved in running a peer support group.

- Orienting members and keeping track of their participation.
- Planning and preparing for the group meetings.
- Tracking group activities (attendance, topics of discussions, distributing surveys etc.)
- Assisting members during meetings
- Managing peer support group discussions.
- Managing resources.
- Promotion and marketing.
- Evaluating the group's impact
- Managing and reporting finances etc.

Sharing the Load

Groups can decide to split these tasks between a few roles. Some core roles include a facilitator (to guide discussions), a group representative (to orient members), secretary (tracking group activities), treasurer (to manage and report on finances), and 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. For some roles (e.g., group representative), it can be helpful if the person has a similar lived experience as the group. New members may find it easier to talk to someone who knows what they are going through and can share their own journey after stroke.

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.).

Other 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.).

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

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:

1) 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 Section 5 for some suggestions on having effective discussions and managing challenges).
2) Members as facilitators.
    - One or more group members may volunteer to guide discussions. Training would be required to prepare them for the role
3) 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.
4) 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. It also means that the group discussion may not be purely "peer-led".

Tip: Refer to Section 5 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). 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 make your own or write on this one.

Tasks Involved in Running a Peer Support Group

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

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