After Stroke Peer Support Toolkit

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

SECTION 2

Build Your Peer Support Group

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.

Project Team

Gayatri Aravind, Program Lead, Innovations in Peer Support, March of Dimes Canada. Adjunct Lecturer, Department of Physical Therapy, University of Toronto

Christina Sperling, Director, After Stroke, March of Dimes Canada

Michelle Nelson, Principal Investigator, Science of Care Institute, Lunenfeld-Tanenbaum Research Institute, Sinai Health. Associate Professor (status), Institute of Health Policy, Management and Evaluation, Division of Clinical Public Health (cross-appointment), Dalla Lana School of Public Health, University of Toronto

Co-Design Group

Margaret Hansen, Member
Robert Mahony, Member
Tim McCleary, Member
John McGowan, Member
Christy Nich, Member
Paul Roberts, Member
Susan Robertson, Member
Amanda Nash, Project Lead, Lived Experience Engagement Support, Heart & Stroke

Sarah Munce, *Scientist*, KITE-Toronto Rehabilitation Institute, University Health Network. Assistant Professor (status only), Department of Occupational Science and Occupational Therapy, Rehabilitation Science Institute, Institute of Health Policy, Management and Evaluation, University of Toronto

Copyright

Citation

Aravind G., Hansen M., Mahony R., McCleary T., McGowan J., Nich C, Roberts P, Robertson S., Nash A., Sperling C., Munce S., Nelson MLA. After stroke peer support toolkit: A Guide to Support develop, deliver, and maintain the design and delivery of group-based peer support. March of Dimes Canada, Toronto Canada, 2023.

Contact

March of Dimes Canada
202-885 Don Mills Road
Toronto, ON, M3C 1V9
peersupport@marchofdimes.ca
www.marchofdimes.ca
www.afterstroke.ca

Section Two | Build Your Peer Support Group

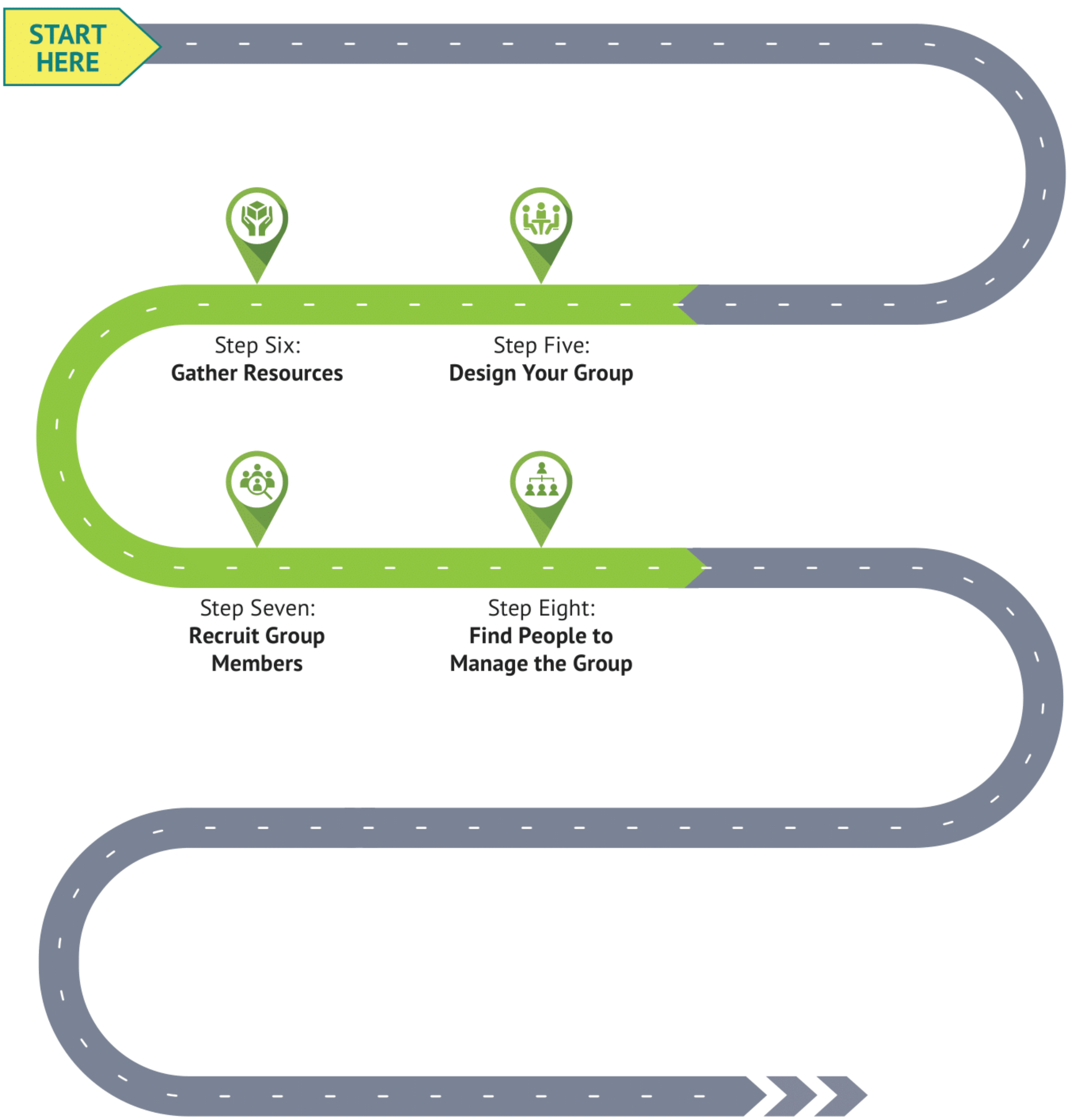
Table of Contents

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, and 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 you will 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

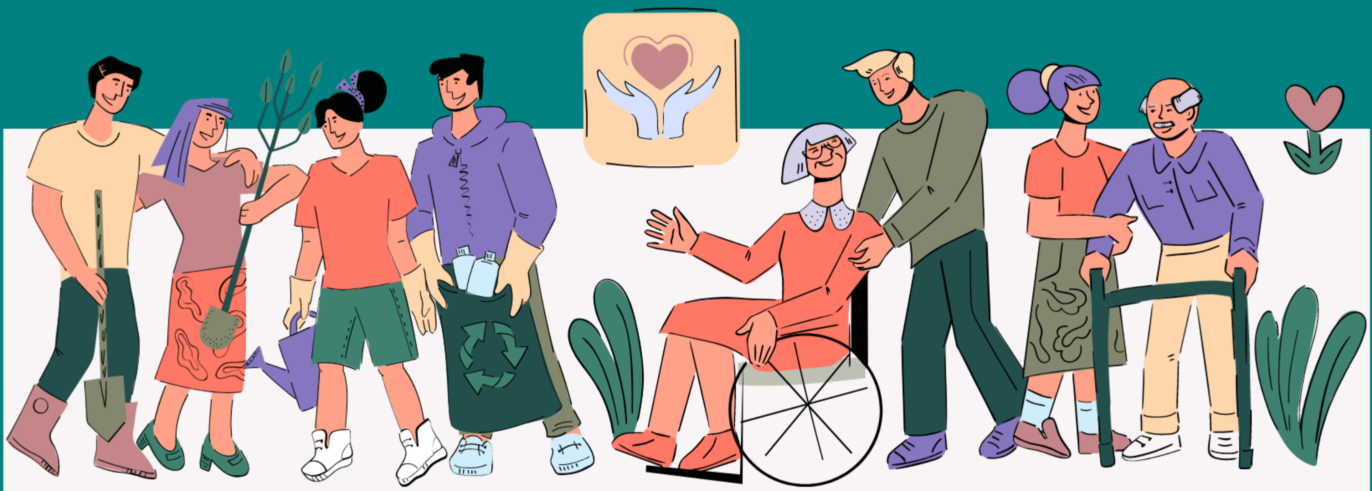
Here are some ways to promote your group:

- 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 (to track 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. 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 setup and clean up.	
Support members. Help members arrive to the meeting place. Provide technical assistance during virtual meetings. 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.	

Task	Assigned to
Maintain a list of members and attendance. Maintain a list of emergency contacts. Secure and confidential storage of records.	
Managing relationships with 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 a budget. Tax reporting.	
Expand and promote the program. Connect with more people living with stroke in the community. Plan special events, celebrations, fundraisers, etc.	