



HOW TO START  
A  
**CAREGIVER  
CONNECTION GROUP**

*An in-person social network for caregivers*

*BY caregivers*

CHANGING  
**CARE**

CONNECTING THE DOTS  
FOR CAREGIVERS

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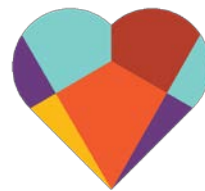
## **Disclaimer:**

This handbook was created for individual caregivers who are interested in starting a social group for caregivers in their living environment (residence) OR organizations who are looking to support the caregivers that access their programs or services. It is strongly recommended that caregivers connect with their building administrators in advance to ensure all company policies and procedures are followed, and to create a plan regarding who to contact should any physical, mental or emotional issues come up during a group session.

Group hosts need to know who to contact in their group facilitation role. Organizations also need to clearly train, educate and support group hosts/facilitators in organizational expectations to mitigate any risk to group participants, hosts and the organization.

If there is a medical emergency during a meeting, call **911**.

For non-emergencies, caregivers can call the 24/7 Ontario Caregiver Helpline at **1-833-416-2273 (CARE)**



## CAREGIVER CONNECTION GROUP

### AN IN-PERSON SOCIAL NETWORK FOR CAREGIVERS BY CAREGIVERS

A caregiver is a family, friend and/or neighbour who provides support, assistance and/or care, for family members and friends in need in any capacity or for any length of time. The Caregiver Connection Group is an informal social gathering for caregivers hosted by volunteer caregivers. The Caregiver Connection Group was created to help all caregivers connect to resources in their community and develop connections with other caregivers.

### ORIGINAL PROJECT DESCRIPTION AND FUNDING AGENCY

Connecting the Dots for Caregivers was a partnership between six healthcare organizations in Huron and Perth Counties, and one of The Change Foundation's four *Changing CARE* projects across Ontario. Together, with caregivers, they collaboratively looked at ways to improve the caregiver experience by co-designing solutions, programs and resources that would ensure caregivers felt valued, respected, engaged and supported in their important role.



The six partnering organizations included: Huron Perth Healthcare Alliance, the North Perth Family Health Team, STAR Family Health Team, ONE CARE Home and Community Support Services, the South West Local Health Integration Network and Alzheimer Society of Perth County.

### Caregiver Host Tip:

*This group is a safe place to share your concerns. We can share resources that may help you. Sometimes just talking it out helps.*

## PRE-PLANNING

Pre-planning is very important for the success of any group. For the Caregiver Connection Group, pre-planning will involve determining who the host (and possible co-host) will be each week or month, location and dates, as well as advertising to ensure caregivers are aware of the group.

Supplies also need to be purchased and organized in advance. If the group decides to bring a speaker in, they need to be confirmed and supported in their volunteer role (ensuring they are aware of location, dates, times, topic, resources they need, etc.).

## VOLUNTEER ROLES

There are ideally two volunteer roles in the Caregiver Connection Group: the host and co-host.

- ☐ Each meeting should be attended by both hosts
- ☐ Hosts will work together to divide up hosting duties throughout the year. (A schedule can be created in advance for the year or duration of the group.)
- ☐ Hosts are responsible for organizing and running meetings (see typical group format)
- ☐ Responsible for setting up room; refreshments, coffee/tea and resources as available
- ☐ Responsible for arriving 15 minutes before meeting to ensure meeting space is ready
- ☐ Responsible for clean up at the end of the session

### HOST

- ☐ Plan guest speakers collaboratively with the co-host and organizational contact person (See Appendix A)
- ☐ Communicate with the organizational contact person when unexpected occurrences happen
- ☐ Be the primary liaison with the venue/organization

### CO-HOST (Supportive Role)

- ☐ Help direct attendees to meeting
- ☐ Answer questions
- ☐ Provide support and resources
- ☐ Collect evaluation forms and provide to group coordinator

## FORMAT OF A TYPICAL MEETING

1. 15 min – Welcome, Housekeeping and Introductions
  - ☐ Review guidelines for participation and participant rights
  - ☐ Review confidentiality and why it is important
  - ☐ Emergency exits and washrooms
  - ☐ Sign in sheet
  - ☐ General overview of meeting
  - ☐ Introduce Guest Speaker or Topic (if applicable)
  - ☐ Offer refreshments
2. 30 min – Programming Or General Discussion
  - ☐ Presentations and/or activities that cover a wide range of topics from local organizations
3. 45 min – Caregiver Café
  - ☐ Connect with others over a coffee and snack
  - ☐ Review available resources as appropriate (Connecting the Dots resources and Community Resources)

## PROGRAM DATES (AND LOCATIONS IF APPLICABLE)

Determine dates and times that will best meet your potential caregiver schedules. Ask caregivers, when possible, what dates and times work best for them. Encourage caregivers to invite other caregivers as well. Post dates and times (and any changes) well in advance of starting the group. Word of mouth and personal invites often lead to greater levels of participation. (See Sample Poster, Appendix B)

## PROGRAM CAPACITY

It is important to determine in advance what the space or room will be for the group and if it will be comfortable for caregivers. Participants sometimes feel apprehensive when first attending a new group, so anything organizations and hosts can do to make the space feel welcoming and easy to access will enhance their experience. Having a host at the first door when coming into a building can be very helpful.

### Caregiver Host Tip:

*Bring your ears to listen and your experiences to share.*

## WEEKLY CHECKLIST FOR MEETING TASKS

As the host, reviewing this checklist in advance will help you to stay organized and ensure items have been addressed for a successful meeting.

- ☐ Arrive 15 minutes before program starts
  - Set up tables for participants
  - Set up resource table
- ☐ Make coffee/tea
- ☐ Communicate with the location contact if there are resources being supplied (e.g., books)
- ☐ Assign someone as greeter (if possible)
- ☐ Ensure all attendees sign in (Appendix C), and keep sign in sheet in the binder for your records
- ☐ Ensure jars and suggestion/feedback box is out
- ☐ Keep meeting on schedule and start on time (welcome any later arrivals)
- ☐ Arrange chairs/tables and the room if necessary
- ☐ Supply snacks and refreshments
- ☐ Record suggestions and sign-in sheets in binder
- ☐ Ensure clean up (coffee maker, tea kettle, dishes/napkins) – leave room in the same state you found it
- ☐ Ensure all participants have left the meeting area before you leave
- ☐ Have fun!

## SUPPLIES

Creating a tote box labelled with the following components works well to carry supplies. The box can include:

- ☐ Coffee and tea
- ☐ Paper cups for coffee/tea
- ☐ Napkins
- ☐ Small paper plates
- ☐ Sugar and sweetener
- ☐ Jar, marbles or chips (see below)
- ☐ Binder with handbook and resources, pens
- ☐ Connecting the Dots resources (Who to Call cards (if applicable), Time to talk pamphlets, Caregiver ID samples, Healthcare Journey Binder, Caregiver Guide, Online Learning Modules, etc.)

### Caregiver Connection Group



Additional items may need to be brought each week if you are leaving your tote box at the location. Determine in advance what you need to purchase weekly (for example, milk or cream).

## CONTINGENCY PLANNING

### WHAT IF NO ONE SHOWS UP?

With new groups, it can take time for the group to gain interest, momentum and participants. Personal invites are valuable in addition to any advertising and posters.

- ☐ Stay for the full scheduled event, as caregivers may drop in at any time during the session
- ☐ Do not take it personally – new groups need time to build
- ☐ Review advertising, venue, time or other barriers that may inhibit participation

### MEETING CANCELLATION

Have a plan in place for potential meeting cancellations due to inclement weather, host illness or hosts not being available. Ensure if a meeting is being cancelled, that participants know as far in advance as possible.

### WHAT IF CAREGIVERS BRING THE PERSON THEY ARE CARING FOR?

This may indeed happen. The Caregiver Connection Group was not designed in a way that supports the person they are caring for, but if they choose to bring that person that is okay. Discuss in advance how any issues, concerns or disruptions, may be addressed. (The co-host volunteer may be an option to meet with the care receiver.)

### WHAT TO DO WHEN YOU ARE CONCERNED ABOUT A PARTICIPANT'S WELFARE

If you are concerned for the welfare of a participant because of words they have said, or the state in which they present, connect with your direct manager, supervisor or volunteer coordinator in a timely manner to proactively discuss next steps together. If a participant is in immediate need of assistance, call 911. If there is urgent emotional support in your area, have the number available and ready to use at the group. For example, in Huron and Perth Counties, call the Huron Perth Helpline and Crisis Response (24 hour) **1-888-829-7484**.

## ORGANIZATIONAL CONSIDERATIONS

In addition, you will need to consider the following items during pre-planning to ensure the success of your group. Please review policies and procedures within your organization/building that will be relevant when offering the Caregiver Connection Group (if applicable). Relevant policies or procedures may include:

- ☐ Volunteer Training
- ☐ Confidentiality
- ☐ Volunteer Screening; Vulnerable Sector Checks
- ☐ Rights and Responsibilities of Volunteers
- ☐ Conflict of Interest
- ☐ Emergency Procedures
- ☐ Infection Control
- ☐ Interacting with People with Various Abilities
- ☐ Volunteer Grievance and Complaint Procedures
- ☐ Any other policies and procedures relevant to volunteers and group planning



## EVALUATION PLANNING

When initiating a new group in any setting, it is valuable and important to obtain feedback from hosts and participants to ensure the group is meeting the needs of all stakeholders. Meet to determine in advance how success will be measured.

Evaluation and feedback can be measured in the following ways:

- ☐ Weekly evaluation by participants through rating scale (See Sample in Appendix D)
- ☐ Attendance trends – focus on consistency, not just volume
- ☐ Ongoing feedback from volunteers, and participants

You are now ready to start your group! Remember, everything does not have to be perfect, and you do not have to have all the answers. Setting the stage for a welcoming group is more important than any checklist! Caregivers will be happy to be with other caregivers who understand their life situation, recognizing that all stories are unique.

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## FACILITATING A GROUP

Once you have spent some time reviewing and pre-planning a Caregiver Connection Group, it is now time to welcome your participants! (See Appendix E for a Quick Checklist of the following information).

### WELCOME

Get excited to lead your group! Facilitating can seem overwhelming but the atmosphere created is very important. Welcome everyone to the group and let them know this is their group. Remind them that this is a social group and the focus is for connection (unlike a therapeutic or support group). Remind them to also sign in at the registration area (Sample Appendix C)

### Caregiver Host Tip:

*Have a statement that you can share at the beginning of the group that includes mentioning this is... 'a safe and confidential place for caregivers'.*

## INTRODUCTIONS AND CHECK IN

Introduce yourself, and your role as host. Sharing part of your story and why you chose to be a host will be important. A potential script may be:

*“Hello and Welcome everyone. My name is \_\_\_\_\_, and I’ve been (or was) a caregiver for XX years (add specifics like the struggles you faced such as social isolation etc.). I decided to volunteer as a co-host of this group to help make sure caregivers have somewhere to go and meet with each other to share their stories. This is a space where you can talk about your journey with others who are going through it or have been through it. If you’re not ready to share, that’s fine too, listen to the others in the room and recharge your batteries for a while.”*

Note: Some hosts will want to begin with an activity OR some hosts may start the social activity time with an activity. (See Appendix F for group activities that have been used successfully in the past.) Be sure to add any activities that you have seen in the past to the appendix section for future reference.

## HOUSEKEEPING ITEMS

Review with participants what they can expect of the group including: the length of group, location of washrooms, if cell phones need to be silenced, and the overall agenda for the meeting. Remind them that they should do whatever they need to be comfortable today (i.e. standing versus sitting). If they need to leave for any reason, just let the host know.

## PARTICIPANT RIGHTS

Review the participant rights with the attendees or other group rules from your organization. Reviewing this list helps participants to feel safe in the group. Allow for questions if they come up.

The participant can expect:

- ☐ That all participant information be kept confidential.
- ☐ To be treated in a courteous, respectful manner.
- ☐ To be free of mental, physical, financial abuse by anyone.
- ☐ To have their dignity and privacy respected.
- ☐ To respect independence.
- ☐ To be respected for ethnic, spiritual, linguistic, familial, and cultural aspects.
- ☐ To have recognition for individuality.
- ☐ To have the right to give or refuse consent to services.
- ☐ To have the right to share any concerns they have regarding the group process.

## CONFIDENTIALITY

Reviewing confidentiality and boundaries in the context of the Caregiver Connection Group does not have to be a long presentation. The goal is to ensure participants are aware of how to treat each other within the group setting. Generally speaking, inform participants that whatever is shared in the group, stays in the group. Review your organization's policy on confidentiality and boundaries. Ensure confidentiality is discussed at the beginning of each session, even if participants are returning and have heard about the importance of confidentiality before.

### Caregiver Host Tip:

*Confidentiality is important and it must be made known to those in attendance. Also, it should be made clear at the onset that hosts are volunteers and that referrals will be made to organizations who can give 'professional' help. This group is a place to talk to someone else who has caregiving experience. It is a good stress reliever to attend.*

## INTRODUCING AND THANKING YOUR GUEST SPEAKER (IF APPLICABLE)

Ask the speaker in advance for the information they would like shared about their role and their organization. Often a presenter will provide a written biography that you simply can read. If not, just share their name, organization and topic and ask them to introduce themselves with any more details they wish to share.

Thanking a speaker for sharing their time and expertise is an important part of the role. Either the host or co-host can do the thank you. A potential thank you may be:

*I would like to thank (Name), for joining us today to talk about (topic). I really appreciated your story/example about:*

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## INTRODUCING RESOURCES

Following your guest speaker presentation is a natural time to review the various resources and how they can be used (if you have invited a guest speaker).

If you do not have a guest speaker, you can present a resource, distribute the resource, allow participants time to review the resource and ask for comments or feedback on the resource to start a general discussion.

You may want to include how you have used the various resource(s) and your success story.

- ☐ Time to Talk pamphlet
- ☐ Who to Call Card
- ☐ Healthcare Journey Binder
- ☐ Caregiver ID
- ☐ Caregiver Guide
- ☐ [www.caregivershuronperth.ca](http://www.caregivershuronperth.ca)

Be sure to demonstrate how to use the website if you have access to a computer/tablet and website. Some caregivers are not comfortable with using the internet and will benefit from a demonstration.

Also, videos were created by caregivers and healthcare providers discussing various topics that impact caregivers. Use these videos to educate and initiate conversations in your connection group. The caregiver videos can be found at: [https://caregivershuronperth.ca/8/Education\\_Resources/](https://caregivershuronperth.ca/8/Education_Resources/)

### Caregiver Education Video Series

#### Video 1 - Who is a Caregiver and Resources & Tools



## TIME TO MINGLE (SOCIAL TIME)

Invite participants to enjoy the snacks and refreshments that are available for everyone! Mingle with participants building connections and asking open ended questions. (i.e. What has been a highlight of your week? What have you found most helpful as a resource during your caregiving journey? etc.)

## WRAP UP AND EVALUATION

Participants need to know how valuable their ideas and experience is. Remind participants of the importance of evaluation and how to use the jar with marbles and chips. Remind participants about the importance of signing in (only first name).

- ☐ Jars with chips/marbles can be put out where participants can provide feedback on each session (A question to be asked may be: How did you feel about today's meeting?) using simple symbols, like those shown here.
- ☐ A feedback box with blank paper can be placed out where participants can write suggestions for future programming or any other feedback
- ☐ A sign-in sheet can be located at the entrance, including:
  - A spot for participants' first name and last initial (It is recommended not to collect last names for privacy reasons.)
  - A check-box to see if they have attended before
  - A yes/no question to see if they would be willing to participate in a survey
    - This survey can include questions on impact of the group
    - If they circle yes - have them leave their e-mail address. (A Survey Monkey link could be created and used for a three month survey: [www.surveymonkey.com](http://www.surveymonkey.com))



## CLOSING

Thank everyone for attending again and remind them of the next session date and topic (if known) and where to look for updates (website or a number to call). Remember to stay until the last participant has left for safety, security and to answer any final questions.

## APPENDIX A – BOOKING GUEST SPEAKERS

<b>Caregiver Connection Group Speaker Booking Checklist</b>	
<p>The Caregiver Connection Group is an in-person social network hosted by volunteer caregivers for caregivers. It is an informal group providing peer and resource connections for caregivers.</p> <p>Caregivers provide support, assistance and/or care, for family members and friends in need.</p> <p>Connection Group meetings may include a 30 minute presentation from a local speaker that is of interest to caregivers.</p> <p><b>**Remember to give the speaker your name and contact information, so that they can call you if something changes and they are unable to attend.</b></p>	
<b>Host Responsible for Booking:</b>	
<b>Date of Presentation:</b>	
<b>Time of Presentation:</b>	
<b>Location of Presentation:</b>	
<b>Speaker Name:</b>	
<b>Speaker Phone Number or Email:</b>	
<b>Presentation Topic:</b>	
<b>Suggestions to Include in Presentation:</b>	
<b>Equipment:</b> <i>(i.e. projector, laptop, handouts; encourage to bring their own if possible)</i>	



# ADD DATES

**Times- 10:00 – 11:30**

**Drop in for a snack, refreshment and time  
connecting with other caregivers and your  
community**

**All are welcome!!**



## APPENDIX C- SAMPLE PARTICIPANT SIGN IN SHEET

# Caregiver Connection Group

## Sign In



Name (first name, last initial)	Have you attended before?	Please leave your e-mail if you are willing to provide feedback about the Caregiver Connection Group
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	
	Yes / No	

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

Location: \_\_\_\_\_



## APPENDIX D- SAMPLE PARTICIPANT SURVEY

<b>Caregiver Connection Group Participant Survey</b>
<p>Caregivers provide support, assistance and/or care, for family members and friends in need. The Caregiver Connection Group is an in-person social network hosted by caregivers for caregivers. It is an informal group providing peer and resource connections for caregivers in Huron and Perth Counties.</p> <p>To evaluate the success of the group we are asking participants to answer the following questions. You do not need to provide your name.</p>
1. How did you hear about the Caregiver Connection Group?
2. At what moment did you feel most engaged with what was happening?
3. At what moment were you most distanced from what was happening?
4. Did you find the guest speaker informative and/or helpful? (if applicable)
5. What did you find most valuable about the Caregiver Connection Group?
6. Were you offered information about education tools and resources that are available in your community to help support you in your role as a family caregiver? (Please circle one)  Never / Sometimes / Usually / Always
7. If you did receive information about education tools and resources available in your community, how helpful was the information? (Please circle one)  Not at All / Somewhat / Generally / Completely
8. Any other comments:

## General Guidelines for Facilitating a **CAREGIVER CONNECTION GROUP**



1. Welcome
2. Introductions and Check In
3. Housekeeping Items
4. Participants Rights
5. Confidentiality and Boundaries
6. Introducing Your Guest Speaker
7. Thanking Your Speaker
9. Introducing Resources
10. Time to Mingle (Social Time)
11. Wrap Up and Evaluation
12. Closing

Notes:

## APPENDIX F - SAMPLE GROUP EXERCISES

Caregivers often experience stress and anxiety related to their role, and the impacts it has on their life. Here are a few activities that you can try in those moments that you need a break. These activities have been chosen because you can do them anywhere. Take a moment next time you are sitting at a bedside, driving to your next appointment, or any other time that you can squeeze in some mindfulness.

### Five Senses Exercise

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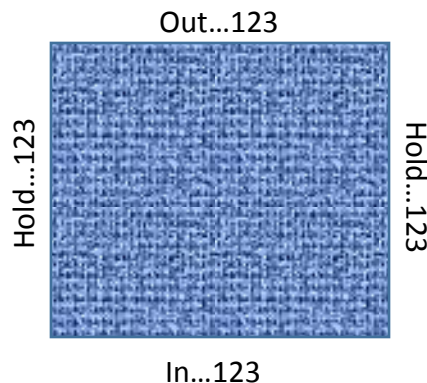
This exercise is called “five senses” and provides guidelines on practicing mindfulness quickly in nearly any situation. All that is needed is to notice something you are experiencing with each of the five senses. **Follow the order to practice the five senses exercise:**



## Breathing Exercises

### 1. Box Breathing

The square breath is meant to balance and cleanse your entire nervous system by inhaling and exhaling in equal proportions. As you get better and your lung capacity expands, you can increase the number of seconds from 4 to 5 to 6 and so forth



### 2. 1,2,3,4,5 Method

Breathe “in for 1... out for 1...”; Breathe “in for 2... out for 2...”; “in for 3... out for 3...”; “in for 4... out for 4...”; “in for 5... out for 5...”

### 3. Abdominal Breathing

With one hand on the chest and the other on the belly, take a deep breath in through the nose, ensuring the diaphragm (not the chest) inflates with enough air to create a stretch in the lungs. The goal: six to 10 deep, slow breaths per minute.

### 4. Alternate Nostril Breathing

Hold your right thumb over your right nostril and inhale deeply through the left nostril. At the peak of inhalation, close off the left nostril with the ring finger and then exhale through the right nostril. Continue the pattern, inhaling through the right nostril, closing it off with the right thumb and exhaling through the left nostril.

### 5. Value Breathing

Pick one word for the whole day that you experience as neutral and is not triggering for you, such as “peace”, “joy”, “content”, etc. You can say the word out loud or silently to yourself. Deep breath in... say “peace”; deep breath out... say “peace”