



# Caregiver Tele-Connect (CTC)

**Information for Healthcare Professionals**



# Caregiver Tele-Connect (CTC)



- CTC is a program supporting caregivers of people with life-limiting illnesses who are likely to die within the next year
- Using teleconferencing, Caregivers Nova Scotia facilitators lead groups providing support, information, and educational resources. Groups meet twice per week for 4 weeks.



# Caregivers Nova Scotia Staff



**Brenda Sangster**  
Admin Support



**Angus Campbell**  
Executive Director



**Carlye Stein**  
Intake & Operations

**All of our staff are or have been caregivers, with experience and training in palliative caregiving**



# Caregivers Nova Scotia Staff



**Lynn Butler**  
Facilitator



**Jennifer Briand**  
Facilitator



**Cindie Smith**  
Facilitator



**Maggie Roach-Ganaway**  
Facilitator

# + CTC Initiative



- Provide short-term peer support and skill-building using a teleconferencing format
- CTC is modelled after Caregiver Tele-Group Support (CTGS) program piloted in 2014/2015

# + CTGS Pilot Program



- Looking for pragmatic solution to assist caregivers unable to attend in-person support groups (both rural and urban)
- Literature review by Dal researchers, NSHA Central Zone, Continuing Care, and Caregivers Nova Scotia
- Project funded jointly by Dalhousie School of Occupational Therapy and Caregivers Nova Scotia

# + CTGS Pilot Program



- Two separate groups met (one weekly and one bi-weekly) via teleconference for about 2 hours over 6 sessions
- Caregiving situations were different: palliative, dementia, frail & elderly, autism, and other conditions
- Discussions included information sharing, resources, emotional support for one another, healthcare system navigation, etc.



# CTGS Participants' Comments



- “When you’re speaking with other caregivers there’s almost a level of understanding that comes naturally and you don’t have to explain to them, the way you would to friends or family, sort of the different logistics of your day, or the effect it’s having.”
- “I learned that there are things you can get help from that I hadn’t known about before, and I have a list of all these things now, and if and when I need these things I can utilize them.”





# CTGS Participants' Comments



- “There was a lot of time for people to share and you never felt like you were being rushed or, you know, shut out or ignored or anything.”
- “Although we know our first names, the telephone provided a certain confidence through anonymity. Sometimes things are easier to say on the telephone than they are in a group setting. I feel like I made four new friends, though I could pass them on the street and not even know who they are.”

# + CTGS Summary



- A teleconferencing support program can be effective in reducing caregiver stress and isolation, and can also increase caregiver knowledge and confidence
- Report by Dr. Grace Warner and Shelagh Abriel available at:

[http://caregiversns.org/images/uploads/CTGS\\_Summary\\_Report\\_20150331.pdf](http://caregiversns.org/images/uploads/CTGS_Summary_Report_20150331.pdf)

# + Caregiver Tele-Connect (CTC): A Unique Program



- Caregivers Nova Scotia has created a program especially for palliative caregivers looking after someone with a life-limiting illness:
  - Using existing research on peer support groups, results of CTGS, and the unmet needs of family & friend caregivers at end-of-life (Burge, et al) as evidence base
  - Applying Caregivers Nova Scotia expertise with supporting caregivers over the phone
- Reminder – CTC Purpose:  
Provide short-term peer support and skill-building via weekly teleconferencing
- CTC aims to provide comfort & confidence for the caregiver

# + Why CTC?



- Most Canadians would prefer to die at home but only 18% of Nova Scotians do (percentage is higher for cancer patients)
- While most people die in hospital, the majority of care is taking place at home, with transfer to hospital in the last 7-8 days for medical emergencies
- Lack of community supports are often stated as the cause of transfer to hospital or a long-term care facility
- “Family emotional and spiritual support were consistently viewed as lacking in all locations and identified as targeted areas for impacting quality care at end of life.”  
-- Burge et al 2014

# + CTC Process



1. Referral/Self-referral to Caregivers Nova Scotia
2. Screening & intake by intake coordinator
3. Selection of group, mail-out of materials, introduction to facilitator
4. Participation in 4-week program
5. Facilitator's follow-up
6. Post-program evaluation interview



# 1 – Referral to Caregivers Nova Scotia



- Continuing Care (CC), Palliative Care (PC), PATH clinic (Palliative And Therapeutic Harmonization), etc. identify a caregiver who is giving care to a loved one with a life-limiting illness who is likely to die within the next year
- Caregiver may feel unprepared for what lies ahead or may report caregiver distress
- Caregiver is referred to Caregivers Nova Scotia for intake
- Caregivers Nova Scotia referral form may be used but not required. Available at:  
[www.CaregiversNS.org/how-we-help/referral-agendas/](http://www.CaregiversNS.org/how-we-help/referral-agendas/)
- Caregiver may also self-refer

## + 2 – Screening & Intake



- Completed by intake coordinator
- Program is fully explained to caregiver
- Caregiver is willing to try to attend all 8 sessions
- Caregiver is willing to complete evaluation survey at end of CTC
- Caregiver is appropriate candidate – does not require one-on-one support or individual counselling (per results of Caregiver Stress Quiz from VON)

# + Caregiver Stress Quiz



- 9 questions:  
score of 0 (never) to 3 (almost always)
- 0-19: Caregiver may be managing well or experiencing some distress – APPROPRIATE
- 20+: Caregiver may be experiencing burnout and facilitator will interview caregiver further





# Preparedness for Caregiving Scale



- Modified from Hartford Institute for Geriatric Nursing
- Added question from Burge et al study
- Added 3 questions from Caregivers Nova Scotia expertise
- This information will help caregivers prepare for the program and let the **facilitator** become familiar with each individual situation

## + 3 – Group Selection & Materials Mail-out



- Caregiver indicates day & time preferences at intake
- Group is formed when 5 caregivers with same date & time preferences are identified
- Caregiver will be mailed a Welcome Kit that includes:
  - Info package (name & picture of facilitator, schedule, calling instructions, etc.)
  - *Preparing for Death and Dying* booklet (DHW 2015)
  - *Living Lessons – A Guide for Caregivers* (GSK, distributed by CHPCA)
  - *Special Patient Program* (EHS) brochure
  - *What you have to do after someone has passed away* (Access Nova Scotia) booklet

\*\* many resources are available online \*\*

# + Potential Days and Times



- Mondays and Thursdays
- 7 – 9 pm or 2 – 4 pm (we expect most will choose evenings)
- One group to begin every 2-3 weeks with 5 participants per group

## + 4 – Participation in 4-week program



- Facilitator reminds each caregiver the day before the teleconference via email or phone
- Discussion topics will be available if needed
- Facilitator researches any info as requested by the group or individuals
- Facilitator keeps notes log in a **confidential** database



## 5 – Facilitator's follow-up



- After the 4-week program, the facilitator will follow up to see how each caregiver is doing, if they require any additional information or support, etc.
- We want participants to know that they can call Caregivers Nova Scotia at any time (during regular office hours)

# + 6 – Program Evaluation



- Intake coordinator will contact caregiver for post-program evaluation interview
- Interview questions mirror Preparedness for Caregiving Survey completed at intake, plus three additional open-ended:
  - Value of CTC
  - Suggested improvements?
  - Recommend to a friend?

# + CNS Management & Reporting



- CNS team is managed by  
Angus Campbell  
Executive Director  
1.877.488.7390  
Director@CaregiversNS.org

Please feel free to contact Angus with any comments.

- Caregivers Nova Scotia will provide ongoing statistical information.

# + Questions?

- Please refer to **Frequently Asked Questions (FAQ)** on our website at:

[www.CaregiversNS.org/how-we-help/ctc/faq](http://www.CaregiversNS.org/how-we-help/ctc/faq)

