

**Meeting Outcomes**  
from the

# Share Care Council

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**May 14, 2016**

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## **ACKNOWLEDGEMENTS**

Thank you to participants for their on-going commitment, willingness to share their experiences and guidance to the people served by Mississauga Halton CCAC.

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Advancement, Mississauga Halton CCAC

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CCAC

Janet Parks, Director, Patient Care, Mississauga Halton CCAC

Rhonda Lawson, Governance Committee Chair, Mississauga Halton CCAC Board of Directors

Marian Pitters, Facilitator, Pitters Associates

Karen Metcalfe, Senior Consultant, Pitters Associates

## EXECUTIVE SUMMARY

On Saturday May 14, 2016 the Mississauga Halton CCAC hosted the eighth Share Care Council (SCC) meeting. The purpose of the SCC is to engage and partner with patients and families from across the region to provide feedback and recommendations to inform the development of new programs and services. This purpose supports the first strategic direction of the CCAC's strategic plan for 2015 – 2020: Meaningful Experiences & Outcomes.<sup>1</sup>

To open the session, Janet Parks, Director of Patient Care, shared how her own history has influenced her work with the Mississauga Halton CCAC. Beginning her career as a social worker, Janet's first case was supporting a mom of three small children who had been diagnosed with cancer and wanted to go home to die. This experience shaped what she wanted to do professionally. Later, Janet became a caregiver for her mother who was diagnosed with cancer. Janet is proud to be part of the much needed work of the Mississauga Halton CCAC and has great respect for caregivers like those on the SCC, who contribute so much to their loved ones. She left the group with a quote from the 14<sup>th</sup> Dalai Lama:

*"If you shift your focus from yourself to others, extend your concern to others, and cultivate the thought of caring for the well-being of others, then this will have the immediate effect of opening up your life and helping you to reach out."*

The next opening speaker was Rhonda Lawson, the Governance Committee Chair of the Mississauga Halton CCAC Board of Directors. Rhonda thanked the SCC for their valuable input and time. She confirmed that the SCC's feedback is taken very seriously: *"We listen, we hear through our Patient Care Quality Committee and your ideas are very much appreciated."* Rhonda emphasized that despite this being a year of change and uncertainty, the goal remains to ensure that quality patient care does not change. She stressed how the SCC is key to ensuring quality when shaping how community care moves forward.

Following the departure of the opening speakers, an update on progress since the January SCC meeting was provided by Nancy Gale, AVP of Strategic Communications and Partnership Advancement. She indicated that all suggestions made regarding the **Patient Information Package** were included in the final version. The package is being priced for production and will be launched in September. Nancy also provided an update on the design of the **regional palliative and end of life care**. The team appreciated the thoughtful direction provided by the SCC at the January meeting. They have requested additional input that will be discussed in today's agenda, as well as the system transition to service providers being dedicated to neighbourhoods. The Shared Care Council members asked a number of questions of clarification, the responses to which are appended.

This report summarizes the meeting highlights and discussion themes, the details of which are appended. The feedback summary indicates that participants thought the outcomes for the session were achieved and also that they appreciated the open dialogue and hearing the voices of all members.

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<sup>1</sup> See

<http://healthcareathome.ca/mh/en/care/patient/Documents/MH%20CCAC%20Strategic%20Plan%20Booklet%20Final.pdf> p. 4

## **SERVICE PROVIDERS DEDICATED TO NEIGHBOURHOODS**

Nancy Gale provided an overview of the realignment of service providers into neighbourhoods across the Mississauga Halton CCAC. One rationale for this system change is that it would reduce the number of different service providers that an individual would see – a concern that the SCC had identified previously. It was acknowledged that some individuals' service providers would change in the realigned model.

The question addressed by the SCC was: ***“As an individual, what do you need your new provider to know about you and your care preferences?”*** A number of themes emerged across the needs.

- Acknowledge that this is a significant and anxiety producing change for the patient and family. Move forward with compassion and respect.
- ***“Do your homework”***, be prepared and know the individual's care history and expectations before the first discussion.
- Provide properly trained workers who consistently provide the right care
- Follow through on the 'Patients First' commitment - plan for transitions and check in on progress.
- Ensure there are connections with hospitals and physicians so no one 'falls through the cracks.'
- Consider the costs on the health care system.

Each of these themes is explained and a sample of the SCC's comments illustrating each theme is provided.

### **Acknowledge that this is a significant and anxiety producing change for the patient and family. Move forward with compassion and respect.**

- The realignment of service providers will generate significant anxiety on individuals' lives and well-being, especially those that are most complex. Emotional comments included:

*“It's like having a divorce and having to be intimate with a new person”*

*“I open the door to a person I don't know. My husband is naked. That bothers me, of course it does. Every move they make affects the family. You need to move with military precision. One missed stepped will affect the patient and family.”*

*“When you make these changes, this creates a lot of stress on peoples' journey to well-being – it gets undermined, derailed. I take a step backwards. MS can be triggered by stress and this will have large health ramifications.”*

### ***“Do your homework”*, be prepared and know the individual's care history and expectations before the first discussion.**

- The new service provider must be familiar with your health history and ask for clarifications only.
- Create tools and checklists for care coordinators and service providers to use to ensure information is shared with the right people at the right time, e.g., a short summary of less

than 100 words about me as a patient should be given to any new person coming to care for me.

*"I would hate to have someone come in and know nothing about me or my loved one."*

*"Make sure the service provider reads My Story." (new patient information package SCC reviewed and recommended)*

*"How can someone be given the responsibility for someone's care, sent into their home and not know what is expected? It makes you feel worse. Makes you feel like a burden when they should be doing their job."*

*"If the person doesn't know what is expected it would be better if they didn't come. It would have been easier for me to do it if someone comes that doesn't know what they are supposed to do. This is too much stress for a caregiver and ends up leading to extra work, laundry, cleaning up, redoing things."*

*"I want the new provider to know what my expectations are. I don't want to have to complain. Reinforce the use of a checklist that s created."*

*"When the person comes to the door they should say, 'I have all your information, I've reviewed it, this looks like the plan, does this sound right to you? Is there anything more I need to know?' This gets the relationship off to a good start."*

### **Provide properly trained workers who consistently provide the right care.**

- People are in vulnerable positions and thankful that they are receiving care. When someone doesn't do the job or is unable to do it, families are hesitant to complain. Patients often keep these experiences from their families because they don't want them to worry.

*"I want to open the door to a person who knows what they are doing, knows what is expected and is trained to do the whole job."*

*"There is no quality of care when someone that doesn't know what they are doing comes to your door. It made me feel that people didn't care about my son, that he wasn't important enough."*

*"I don't like complaining. One worker doesn't make the bed and I feel I should just be thankful that I get something. The care should be consistent."*

*"If I know the person can look after me, is trained for my unique needs and can do it, I don't care who comes through my door."*

### **Follow through on the 'Patients First' commitment - plan for transitions and check in on progress.**

- Plan carefully for those people already in the system

*"If service is working well, don't mess with it."*

*“Every time I have a major stressful event my disease progresses beyond where it should. Family members are going to have to take stress leaves. Don’t forget the impact of this change on the family.”*

- Invest in the transition for complex cases. Care coordinators should overlap for complex cases where a more personal touch is needed or mentoring is required.

Invest in the transition of service providers; nurses and personal support should overlap so treatment is transferred smoothly. People recognized that this will result in additional costs but thought it would be well worth it. The care coordinator should be authorized to do this so there is no delay.

*“If the Ministry is going to make these changes and says it is “patients first”, then they need to pay attention to these transitions.”*

- Before the change is implemented, have the care coordinator call and give information directly to patients, e.g., ‘Instead of agency A you have agency B and these services will be provided.’
- Have the care coordinator meet with patients every three months to check in on how things are going, ‘You have a new provider; how are things going?’
- Some care is far more personal than others. Some individuals thought a patient should have an opportunity to interview the new PSW, however others thought that would not be practical.

### **Ensure there are connections with hospitals and physicians so no one ‘falls through the cracks.’**

- Although there is nothing in writing that says physicians needs to work with CCACs, do all you can to improve these links as they are essential, e.g., create a billing code that is built into the system as a chargeable item; advocate to physicians.

*“The system worked for me because my doctor linked directly with my community care providers. The biggest fear for people is that there isn’t a link and they fall through the cracks.”*

- Anticipate future needs, e.g., if a kidney is removed, anticipate dialysis in the future. This can only be effective if information is being shared between the different care teams. A care coordinator would do outreach to physicians and hospital teams to figure out what is needed. Care coordinator in the hospital should be the responsible for the communications link to my care coordinator in the neighbourhood.

### **Consider the costs on the health care system.**

- The set-backs in the health of complex patients and their families by this system transition will be costly for the ministry.

*“Last time this happened it took me six months to recover. I will lose ground. Impact on people with chronic illness is significant to their well-being. If my situation deteriorates, it will have a huge impact on the health care system.”*

*“This system may work better for new patients but you need to deal with the impact of people already in the system or it will be costly.”*

## END OF LIFE CARE

Nancy Gale, AVP of Strategic Communications and Partnership Advancement, brought forward a request to seek further input of SCC to inform the design of a regional palliative program. Mississauga Halton CCAC is beginning to work with regional partners to build a new palliative program, including an enhanced end-of-life service to support patients and caregivers in the community. At the January 2016 SCC meeting, people provided their input from the perspective of the patient. This meeting focused on the perspective of the caregiver in an effort to anticipate the care that is needed. Members were reminded of the sensitivities of this topic for some participants and were invited to take a moment if and when the discussion became overwhelming. SCC members indicated a willingness to provide thoughtful input on this important topic.

Before the discussion began, a few questions of clarification were asked.

### ***Are they separating paediatrics and adults?***

Yes, for now, this is for the adult population. We will share your recommendation that the design and build of a regional palliative program needs to be for children and adults and be regardless of age.

### ***Do we have a definition of what is palliative?***

There is a British gold standard question for palliative care. It is: "A patient is considered palliative if they meet the criteria of 'the surprise question to a patient's physician.' "Would you be surprised if your patient died within the next 12 months? Enhanced End of Life care provides the services required for patients in their last 30 days of life, although this is not a perfect science.

### ***Are we looking at in hospital or home?***

This program could include either.

The question that guided the discussion was: ***"As family members, what do you need to help you go through an end-of-life journey with your loved ones?"*** The discussion that followed was respectful, candid, and at times extremely personal. A number of themes emerged across the needs.

- Specially trained individuals/teams that value my loved one's life and will help it end peacefully
- Critical information regarding planning, services available and what to expect
- Explanations of options and assistance to help make decisions
- Access to necessary, comprehensive services and supports for the family from the beginning of end of life journey, not just during palliative care

Each of these themes is explained and a sample of the SCC's comments illustrating each theme is provided.

**Specially trained individuals/teams that value my loved one's life and will help it end peacefully.**

- Access to a multi-disciplinary team that makes you feel well taken care of and guides you through the experience. Include social workers, medical professionals, practical supports, psychological supports.

*"Help us know what to anticipate, what could be happening in the next few weeks. The changes we may see; especially, knowing when death is very close."*

*"My father was dying and a palliative care nurse stayed with him at night. She knew he was going to die and woke us up. She made the experience so right for us. She was a tranquilizer in the room. We looked to her when he passed away because we didn't know what death looked like. She said, 'yes, he has passed.' I can't stress enough how important she was. This was in York region 20 years ago and it was accessed through the CCAC."*

*"People who are receiving palliative care deserve to have the very best care no matter where they die."*

*"During palliative is when I needed PSWs to be my support; I needed them to be the lead and needed their expertise. These are the last days of a person's life; it needs to be peaceful."*

*"PSWs were so wonderful. They took my young son to another room and left me to do what I needed to. It helped to have caring people around who knew what to do, people who were thinking about the importance of this moment."*

**Critical information regarding planning, services available and what to expect.**

- Choices available for receiving palliative care in my neighbourhood.

*"We were only given the option of palliative care for children in downtown Toronto and found out later that Dorothy Ley Hospice could have provided palliative care to our seventeen year-old son. This would have been much better for our family."*

- Practical information on:
  - Services available to the family and how to access them
  - When to call whom in order to pronounce death? When to call 911?
  - Can the family get help at home with cleaning, etc?
  - What can happen when someone dies, what to expect and what to do/say, especially when you are at home

*"Pamphlets, information that I can absorb after conversations, spiritual support available, knowledgeable specialists that allow me to be a family member and not the caregiver. Something that would lead to peacefulness."*

*“When my father passed away, the doctor gave me information on when to call him in, but I didn’t know what to expect, e.g., changes in breathing, what to do with pain, what do changes mean.”*

*“Know that you should forgive the person that is dying for leaving you. And forgive yourself for being angry.”*

*“I said to my husband, ‘it’s ok, you can go now. We’ll be ok’. I gave my husband permission to go and he understood.”*

- A timeline - the truth about when the death will occur.

*“When my mother was admitted to the hospital, she had lung cancer. I thought she had bronchitis. I cornered the doctor and said what is the prognosis and he was hedging and I told him I wanted to know the truth. So he said if you are lucky three months. But he didn’t want to tell me. Was she going to die, when?”*

### **Explanations of options and assistance in making decisions.**

- When confronted with stark options, there needs to be trained people who can assist in making decisions about life and death. The CCAC can provide information on resources, e.g., death doulas, other external resources outside the medical profession. This is important.
- Explanation of palliative care and what it means to me and my family.

### **Access to necessary, comprehensive services and supports for the family from beginning of end of life journey, not just during palliative care.**

- Psycho-social support/services for the family members to help with concerns and trauma. *“Survivors need support.”*
- *“It will be helpful to get information from CCAC on bereavement services available to families – kids and adults.”*

*“Support was there when we needed it. They left us alone and let us mourn on our terms. They asked us what we wanted as a family. They gave us options. They respected our wishes.”*

*“There are no psycho-social services for me or my family. So when you start talking about your diagnosis from a medical perspective, I’m not palliative so I can’t get certain services yet I feel like I’m planning for my death. When do the services from CCAC come into play for the patient that doesn’t fit into the model and has to deal with it all on their own? I would have liked my family to have someone come in to talk about family death etiquette; for example, don’t argue with the patient about religious beliefs. There are lots of opportunities to make this a journey rather than a ‘countdown to the casket.’”*

*“Pastors and priests can give much comfort during these times for families.”*

*“As a cancer patient, you begin to think about death the second you are diagnosed. The paradigm shift is thinking about it as an end of life journey, constantly facing death. The journey concept is what seems to be missing with a comprehensive level of support.”*



## **NEXT STEPS**

Participants discussed what steps need to be taken after the day.

### **1. Finalize the meeting outcomes report:**

- Draft report completed by Pitters Associates
- Distribute report for review by participants to make sure it captures what was intended
- Finalize the report and share with Board, Share Care Council members that could not attend, and other stakeholders

### **2. Prepare for next meeting in September (date to be determined):**

- Where: Homewood Suites, Oakville
- Agenda: To be determined

## **APPENDIX A: PRIORITY UPDATE Q&A**

Following Nancy Gale's priority update on progress since the January 2016 SCC meeting, Share Care Council members asked a number of questions of clarification.

### ***Was there any progress on the Minister's paper that we may have commented on?***

- Yes, we produced *The Faces of Care* which highlights all our teams. It was to educate Ministry of Health and Long-Term Care (MOHLTC) and policy people in the ministry to let them know what we do. Nothing has come out of the Ministry yet. We think that during the week of May 30<sup>th</sup> there will be new legislation coming out; however, we are not sure what that will look like yet.
- We meet every two weeks with the LHIN Executive team because we are focused on having no disruption in service and a smooth transition.
- There are three areas of change: CCAC, Public Health and Primary Care (you may have read that the Ontario Medical Association and Ministry are in labour negotiations).

### ***Many of the SCC members are receiving services. If some of the members experience change in service, what should they do?***

- Our complaints and escalation process is as follows: Please speak to your care coordinator. If you are dissatisfied, speak to your care coordinator's manager. If you are still dissatisfied, speak to the Director of Patient Care for your care coordinator and his/her manager. If you are still dissatisfied, you can speak with Kathryn Hales, who works with the ombudsperson and his contact information is public and on the website: (905) 855-9090 ext.7883. You do not need to go through Kathryn first. You can contact our ombudsperson, directly if you have a complaint.
- Our Ombudsperson is Mark Ratner and he is independent and reports directly to the CEO.

### ***How many people who are having issues with care know this mechanism is available?***

- We introduce approximately 7,000 new people to CCAC services every year through our community outreach we call, Your Health, Your Way public information events. We include the ombudsperson information on our website. Having said this, last year, 96% of people would recommend the Mississauga Halton CCAC to friends and family. For more information, visit: <https://healthcareathome.ca/mh/en/Contact-Us/Feedback>
- This information is also in the new *Patient and Caregiver Information Package* in print form; you provided valuable feedback on that package during our last SCC meeting.

### ***One of the things that excited me about SCC was the strategic directions report. It was about the future and the concept of wellness. With this merger going on, has that report been put on the back burner?***

- It is not on the back burner, just the opposite. It informed the Care Coordination Program of Workchanges. It is founded on the principle that our care coordinators are the coordinators for the health system. You provided feedback to us on this as well at a previous meeting. It is garnering much attention by the MOHLTC and may be model the ministry wants to introduce across Ontario.

***When you say ‘a neighbourhood,’ where are the Care Coordinators being placed and how?***

- We don't know that. Right now, our care coordinators will remain working where there are now. Either in one of our offices or from home.

To answer the question, how are we determining which service providers will be in which neighbourhoods; we worked collaboratively with service providers. Part of the discussion was “who is in that community now? If an agency has 80% of nursing then they would likely stay there and be the nursing provider for all patients in that neighbourhood.

***There are only certain PSWs that can look after my father and there are not enough workers in one agency to look after him or they aren't trained so we try other agencies. How is this going to be dealt with?***

- These service providers have an obligation to provide the care. Your father won't be impacted because he receives care from another CCAC so we are not making changes in that area.

***I didn't know that the grass roots were going to be effected. Last week I received a call that all my service providers would change and I'm really not happy with that. Why is this being done at the patient level?***

- Looking at research and feedback, we know that if you have four or five agencies rotating through, there are issues in consistency, service and accountability. We need to narrow how many contracted service providers are going into people's homes.
- Care coordinators went through a comprehensive training program and had a validation process confirm that care coordinators are being consistent so that everyone receives the same experience. We've been working with service providers to have two agencies in each neighbourhood so all patients would receive care from only these two providers.
- I did tell David Fry, our VP, Patient Care that some of you already had new care coordinators and that you would have opinions and feedback to share.
- Starting July 4<sup>th</sup> we will begin moving to this two service provider model and will continue through to December 2016.

***Why when it is working would you take it away? I have had care for 14 years this way. I've spoken to my care coordinator and she gave me a number of someone to discuss this with and that person has never called me back.***

- I will take your feedback to the Patient Care team responsible for your care.

## APPENDIX B: AGENDA

### SHARE CARE COUNCIL



**DATE:** Saturday, May 14, 2016  
**TIME:** 9:30am – 2:00pm  
**LOCATION:** Homewood Suites,  
 2095 Winston Park Drive  
 Oakville ON L6H 6P5

**OUTCOMES:**

- Update progress on priority topics
- Request feedback on identified priorities
- Discuss next steps

Item	Agenda Item Description	Time	Lead
	Breakfast	9:30 am – 10:00 am	
1.0	Opening remarks	10:00 am – 10:20 am	Janet Parks, Director, Patient Care & Rhonda Lawson, Governance Committee Chair, Board of Directors
2.0	Overview of agenda and confirmation of returning membership	10:20 am – 10:30 am	Marian Pitters, Facilitator
3.0	Update on progress since January 2016 meeting	10:30 am – 10:45 am	Nancy Gale, AVP Communications
4.0	Service Providers dedicated to neighbourhoods <ul style="list-style-type: none"> <li>• <i>What would you need your new provider to know about you and your care preferences?</i></li> <li>• <i>What do you need to know before your provider changes?</i></li> </ul>	10:45 am – 12:00 pm	All

	Lunch	12:00 pm – 12:30 pm	
5.0	End of Life Care <ul style="list-style-type: none"> <li>• <i>What would family members need to help them go through an end-of-life journey with their loved one?</i></li> </ul>	12:30 pm – 1:45 pm	All
6.0	Next steps <ul style="list-style-type: none"> <li>• Thinking ahead to next meeting</li> <li>• Meeting evaluation</li> </ul>	1:45 pm – 2:00 pm	Marian Pitters
7.0	Adjourn meeting	2:00 pm	All

## **APPENDIX C: PATIENT AND CAREGIVER BILL OF RIGHTS**

**As Mississauga Halton CCAC patients and/or caregivers, we have the right to:**

**1. Be in charge of decisions about our agreed upon care plan – no decision about us, without us.\***

- 1.1 Discuss our needs, goals, and options for treatment and service within timelines
  - A detailed care plan starting with my needs and showing my care goals and timelines; frequency of assessment as required.
- 1.2 Identify who is providing what care, when
  - Agency name, contact person, phone number, service provider's name/role.
  - Access to consistent care
  - Access to consistent service across CCAC boundaries.
  - Access transition support that ensures consistent and continuing service across care settings within the health system.
- 1.3 A patient can refuse recommended service or elements of the care plan without reprisal on future care, unless otherwise provided in law.

**2. Clarify how we will all work together (me and my care team) to carry out the care plan**

- 2.1 Communicate for understanding
  - Use multiple languages images/visuals, clear medical terminology, etc., as required for understanding
- 2.2 Respect each other, our physical privacy, homes and lifestyles
  - Speak without "talking down".
  - During showering or treatment close the window blinds, close the door, cover me up.
  - Return things to their proper place.
  - Discuss pet management with the care team on an individual basis, so that all parties are comfortable.
- 2.3 Report abuse, harassment, bad care
  - Provide direct contact information to a CCAC Care Coordinator for reporting.

**3. Get assistance beyond the care plan, when we need it.**

- 3.1 Provide one page that summarizes key care team contact numbers.
- 3.2 Provide one phone number to a CCAC Care Coordinator for appropriate on-call medical help and support or a service provider (other than 911 or the health hotline). Include the Mississauga Halton Health Line information.
- 3.3 Provide an updated, one page summary of the care plan and medications for emergency purposes.

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\* The origin of this phrase is the Latin "Nihil de nobis, sine nobis". It has been used for decades by a number of groups involved in health and disability issues internationally.

# APPENDIX D: TERMS OF REFERENCE



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## SHARE CARE COUNCIL

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### **TERMS OF REFERENCE** **(Revised March 1, 2014)**

#### **BACKGROUND**

The Share Care Council (SCC) includes individuals (including patients and family caregivers) representing the patient populations in the Mississauga Halton CCAC (MH CCAC) region, as well as MH CCAC staff representatives. A strategic pledge central to this forum (2011-2014) is that clients and families have a direct voice in our programs and services, as part of our vision to provide “outstanding care - every person, every day.”

#### **PURPOSE**

The purpose of the SCC is to engage and partner with patients and families from across the region to provide feedback and to identify areas of priority from the perspective of community based health care.

#### **SCOPE**

The scope of the SCC is to share ideas based on patient/family member experience to:

- Develop a collective vision of patient centred care and improving the patient experience.
- Generate areas of focus and priorities.
- Advise on strategies for actively partnering with patients in designing, planning and improving health care services (such as experience-based co-design).
- Review evaluation methods to help define success of system improvements.

#### **ACCOUNTABILITIES OF MEMBERS**

- Collaborate on agenda items and priority areas of work for SCC
- Regularly attend and be an active participant in council meetings and important related meetings, prepare for meetings and, review and comment on minutes and reports.
- Members may be invited to participate on other MH CCAC sub-committees and offer advice on other MH CCAC initiatives.
- Submit expected travel expenses within one month of SCC meetings.
- Sign a non-disclosure and conflict of interest agreement.

## **MEMBERSHIP**

- Patient and Family member representatives from client populations (approximately 16 - 18).
- Selected MH CCAC staff members.
- Meetings will be Chaired by the Director, Strategic Communications and Stakeholder Management

## **TERM**

- The term is a two-year membership with the possibility of a one term renewal.
- Members may withdraw from membership at any time and by any means (i.e. written or verbal).
- In the management of term renewals, consideration will be made to maintain a balance of new and experienced members.
- Terms of Reference/ Membership to be reviewed annually

## **MEETINGS**

- Four meetings annually (two conducted in-person and two conducted via videoconference)
- The agenda, previous minutes and related materials will be provided by MH CCAC administrative support at least one week prior to the meeting date.
- Members may be asked to review and comment on relevant documents circulated electronically between meetings or through ad hoc meetings.
- Recommendations will be made by consensus of the members. If the meeting is attended by 50% of the membership, decisions hold.

## APPENDIX E: SUMMARY OF SESSION FEEDBACK

Eleven participants completed the evaluations. Numbers in brackets, e.g., (4), indicate the number of times a similar response was noted. Responses to the same question may represent different points of view.

### 1. The extent to which participants thought the outcomes of the session achieved:

	1 Poor	2	3	4	5 Excellent	Average
Update progress on priority topics	0	0	0	2	9	4.8
Request feedback on identified priorities	0	0	0	2	9	4.8
Discuss next steps	0	1	1	2	7	4.4

### 2. What participants found most useful about the session:

- Open frank discussion; dialogue (4), e.g.,
  - Therapeutic when taking about death
- Hearing all the voices (3), e.g.,
  - Excellent comments from everyone rather than just a few
  - More people opened up today
- Hoping they still continue
- The facilitation – keeping us on track, summarizing, moving on
- The ability to discuss personal stories without deteriorating into a forum for personal complaints

### 3. Words of advice for this year's Share Care Council sessions:

- Keep listening; keep doing what you do – it works (3)
- Follow today's time management – each topic was well discussed and feedback from everyone
- I think we need more feedback on the neighbourhood plan/implementation
- All good
- Use the May 14/16 meeting as a mini role model for future sessions – accomplished goals, built on each other's suggestions, finished on time

### 4. What participants wanted to say but didn't:

- Nothing; never have that problem (4)
- Thank you – glad I was invited
- Question CCAC responsibilities and purpose in hospital vs. home
- Helpful to get information from CCAC on bereavement services available to families – kids and adults
- From end of service providers in neighbourhoods – good use of term “feedback” rather than “complaints”
- Maybe in home caregiver (PSW/nurse) should be encouraged to ask during visit “Do you have any feedback on my service today – is there anything you would like differently?”

- I felt the comfort zone for the level of expression of “caring” and “sharing” reached a new high

**5. Other comments:**

- Thank you; always informative (3)
- Not sure we came to any conclusion or recommendation regarding end of life care