

Meeting Outcomes
from the

Share Care Council

June 21, 2014

CONFIDENTIAL AND NOT FOR DISTRIBUTION

TABLE OF CONTENTS

Acknowledgements.....	3
Executive Summary	3
Thoughts about Attending Share Care Council	5
Guidelines for Discussion.....	5
Update on Progress	6
Community Care Priorities	7
Priority - Navigating the System	8
Next Steps	12
Appendix A: Agenda	13
Appendix B: Terms of Reference	15
Appendix C: Summary of Session Feedback	17

ACKNOWLEDGEMENTS

Thank you to participants for their willingness to share their experiences and provide valuable insights to inspire change.

Share Care Council members:

Caroline Brereton, CEO, Mississauga Halton CCAC

Dieter Pagani, Board Chair, Mississauga Halton CCAC

Nancy Gale, Director, Strategic Communications and Stakeholder Management , Mississauga Halton CCAC

Kathryn Hales, Executive Assistant, Mississauga Halton CCAC

Marian Pitters, Facilitator, Pitters Associates

Karen Metcalfe, Senior Consultant, Pitters Associates

EXECUTIVE SUMMARY

On Saturday June 21, 2014 the Mississauga Halton CCAC invited fifteen patients and/or care givers to attend the second Share Care Council (SCC) meeting. The purpose of the SCC is to engage and partner with patients and families from across the region to receive feedback and to identify areas of priority from the perspective of patients and families. This purpose supports the second area of focus of the Mississauga Halton's strategic plan: Client & Family Focus.¹

To open the session, the newly elected Board Chair, Dieter Pagani, and the CEO, Caroline Brereton, welcomed everyone and thanked the members for making a significant contribution by volunteering their time to this very important council. Caroline Brereton emphasized that the Mississauga Halton CCAC can only plan for providing good care by hearing the voices of patients and family members. Dieter Pagani added that the Board is looking forward to receiving the participants' input to hear what individuals have to say about future initiatives.

Following these opening remarks, new SCC members introduced themselves and expressed their thoughts about attending the Share Care Council. Then they reviewed and confirmed the guidelines for working together in Share Care Council meetings.

Nancy Gale, the Mississauga Halton CCAC's Director, Strategic Communications and Stakeholder Management, provided an update on progress since the March 1st Share Care Council meeting and addressed questions of clarification. SCC members were encouraged by the developments, both within the region and also with the interest expressed by other CCACs across Ontario.

¹ See <http://healthcareathome.ca/mh/en/Documents/MHStratPlan1114.pdf> p. 4

After reviewing the list of priorities established at the March meeting, SCC members explored a priority that they thought was essential to all community care: Quality of care and navigating the system. Within that priority, discussion participants advised the Mississauga Halton CCAC to develop a Bill of Rights for patients and caregivers, and then proceeded to draft the components for a Bill of Rights.

The Director, Strategic Communications and Stakeholder Management wrapped up the session by providing two next steps in sharing the report.:

- The Board would review the SCC's deliberations when they resume their meetings in the September; and,
- The patient care teams would be interested in the SCC's feedback to ensure that patient and family centered perspectives are continually being included

At the next SCC meeting in September, Nancy indicated she would provide an update on these two next steps and also requested that the group tackle core business re-design and seamless intake as the Mississauga Halton CCAC is implementing a new system within the Trillium Health Partners, Credit Valley hospital location.

This report summarizes the discussion highlights of the meeting, the details of which are appended. The feedback summary indicates that participants thought the outcomes for the session were achieved and advised that the SCC continue to do what it is doing. The part of the meeting that council members found most useful was the Mississauga Halton CCAC's desire for their input into change, e.g.: *"Thanks for giving us a voice in the future!"*

THOUGHTS ABOUT ATTENDING SHARE CARE COUNCIL

As the participants from the March meeting returned and new participants to the SCC arrived, people provided their names and a thought they had about attending this June meeting.

- Thrilled that we are doing something about issues that should have been addressed 20 years ago.
- I don't know why I'm here. I'm not convinced but I am honoured to be here.
- Excited because we are addressing problems. And my husband said that I had a sparkle in my eye that I hadn't had in a long time after the last meeting.
- I think this is a great thing that I'm proud to be part of.
- I don't know the direction as this is my first time here, but was convinced by Nancy and decided I wanted to make change.
- It's interesting to be here because we've had very positive interactions with CCAC.
- My purpose was that if my experience can help others that is something I would like to do.
- I'm excited and a little nervous.
- These discussions are very helpful and I enjoyed that last meeting.

GUIDELINES FOR DISCUSSION

Participants reviewed the guidelines for discussion within the Share Care Council that were established during the first meeting. A copy will be included on tables at the beginning of each meeting with a verbal reminder of the guidelines:

- a) Build an atmosphere of acceptance so everyone feels that they can speak up with no fear of service removal
- b) Let other people speak, listen
- c) Build on what others have to say
- d) Be polite, e.g., let people finish their thought, don't interrupt
- e) Allow everyone to complete their thoughts
- f) Address one another by name
- g) Be encouraging, e.g., develop a culture where people feel they can express themselves and not be judged
- h) Make sure everyone is clear before moving to the next topic, e.g., paraphrase to everyone's satisfaction and ensure ideas are captured accurately

UPDATE ON PROGRESS

Nancy Gale, Director, Strategic Communications and Stakeholder Management provided an update on progress:

- Our commitment was to give you an update about the conversation and insights on transitions from hospital to home
- On March 15th we started an early partnership with Trillium Health Partners and the CEO asked why we are doing this. So I shared what you had given us. I then shared all the information, the notes you approved to everyone in the room, gave written copies to everyone
- I briefed our leadership team and our Board of Directors. I also shared with our leaders for Seamless Transitions: Hospital to Home and our core business re-design groups and they are completely changing our processes – those are the process changes and the insight you shared will have great value to them
- Now what are we going to do with it – we've embedded it in into our Seamless Transitions work with Trillium Health Partners. . We are going to have a single transition point where we are starting from scratch. The design starts on July 21; five weeks later they go into prototyping and then five weeks later implementing
- You are impacting this design in a very deliberate way and I will report back with what they come up with. We are hoping that you can see yourself in the new design
- You are influencing other CCACs. We shared some information with other CCACs at a conference and we were approached by two other CCACs for information on how we did this and how to create a SCC.

COMMUNITY CARE PRIORITIES

Members reviewed the following topics from March 1st and discussed additional priorities in small groups.

What is my caregiver's job (PSW, supervisor) and family member's job? (3rd choice)

- Moving people with different abilities and in different situations
- Training people
- When does the caregiver get a break?
- Family members shouldn't be in the room when care is there
- No consistency in the type of worker you get
- Caregiver and patient situations

Quality control experience (relief)

- Checks and balances with PSW agency
- Delivery and efficiency

Choice of agency service provider.

- Who makes the decision and communicates it?
- What say do we have? You like just a number
- What can we say when speaking up?

After much discussion, they decided to focus on ***Navigating the System***. Participants discussed the consequences of doing nothing, what the ideal experience would look like for patients and caregivers, and their advice to the Mississauga Halton CCAC (see next page).

PRIORITY - NAVIGATING THE SYSTEM

Consequences of doing nothing about this topic:

- As demand is increasing, there could be more unsatisfactory situations and poor outcomes
- People who don't have advocates will suffer, *"when I came home to homecare, I was paired up with two women who gave me the ins and outs. They told me that we work together; it should never be them versus us"*.
- Duplication and waste of funding. When you are not clear on process, your time and dollars are wasted – not best use of everyone's time
- Impact on caregivers as well as patients – burnout, frustration, health issues
- General frustration
- In the worst case scenario, patients could die.

Dream in 3 years – what will be different for patients and caregivers:

- A patient will have and know their plan within a given time period
- Care would start with the patients and wrap a defined service plan around them; it wouldn't be fitting the patient into services
- Every patient would say what their dreams are and would have a map put in place on the first meeting that would be followed; including what ifs, what next, actions related, e.g.: if someone doesn't show up this is what you do; if you receive misinformation, who you turn to (ombudsperson, patient advocate – someone to give you the proper information)
- Clear definition of the CCAC system, its reach and how to navigate it will help with all other areas - should not have to go through the system for a year and half before you figure that out. Include knowledge about how to escalate or navigate so you don't get bullied. What this looks like for someone just starting, e.g., *I didn't even know I could do that, I could call about that*. Knowing about navigation changes how your care team speaks to you. If you know the system, you are empowered to make it work for you.
- Transparent information so everyone has access to same level of knowledge
- Consistent, high quality seamless service for everyone
- Roadmaps available that are specific to your diagnosis and situation
- Clear responsibilities for everyone in the system, knowing who is accountable for what
- Proactive suggestions from experts telling people what they need to know
- Caregivers and patients do not feel alone
- Clear understanding of what pathways would be involved along the way with a redefinition of 'home'. Home is where ever you're living, e.g., assisted living, nursing home, your own home, loved-one's home.
- CCACs should be connected, e.g., if caregiver lives in a different area than client, it won't take a long time to get service in place:

"If it was more seamless, my sister who lives in Pickering could share care with me for my mother."

Tips participants would give the Mississauga Halton CCAC about working towards the dream

- Help clarify misinformation, provide clear information, a Mississauga Halton CCAC catalogue of services
- Use this opportunity to better coordinate care
- Scheme of evaluations with success and failures, quality control manual
- Map to follow on first meeting – built around patients. Not a pamphlet, customized. Here is what to expect
- Visual tool with contact names and numbers if someone doesn't show
- Proactively educating
 - Mississauga Halton CCAC care coordinator needs to know options. Don't wait. Tell me what I will need. Give me the options up front so I understand the options that will fill my needs
- Develop a Bill of Rights that is elementary and clear

In discussing a Patient Bill of Rights, members discussed **Patient Bullying:**

- Establish a bullying hotline for caregivers to call e.g., "if you are being bullied, call this number"
- Bullying can be seen during care conferences, e.g., patients and loved ones feel they don't have a voice and are not given choices or compassion. It is happening all around the circle of care with physicians, services providers, staff, care coordinators – all participate. You get tired of fighting and feeling attacked, "*this is not your choice, do it!*"

"My mom would have been in a nursing home if the region or the hospital had their way. They said "this is the only way; this is where she is going to go". Because they couldn't coordinate care, they didn't want to worry about making arrangements. It was easier for them and what was best for her didn't matter."

"That's what I was told 12 years ago [that I needed to go into a home] and the doctor told me they would get me a psychologist to help me deal with the adjustment. It should never come to that. It should be managed much differently"

"I've experienced this with the care partners. When the PSW was sick or the weather was terrible, she wouldn't be able to come. So at 6:30 am they would say 'we can't provide you with care today'. They would say 'so is that ok? We'll just cancel the care?' They should not be making me feel like I'm inconveniencing them. I work, I need the help. They found me a different agency and it is wonderful. But I had to request it; they didn't have back up available; they want to hear a cancellation from me and I tell them that they shouldn't make me cancel, are they cancelling? They have so many new people that call so I try to train people when they call. I refuse to say that we have cancelled so they can put in the system that the customer cancelled. They use the same line so I think they are trained to try and get us to cancel. The service provider seems to promote this kind of customer service. Why are we sending people to agencies that don't provide certain services that are needed? If you can't pack a wound then why send someone who doesn't do it? Some refuse to do it and it seems like a little thing to them but they are big things to us."

"Two weeks ago they told my father, this is the way it's going to happen and this is the way it's going to be done and they weren't going to let him have showers. My father had a panic attack. There is something really wrong when they can do this – who do we go

to? One service provider does so much more than the other service provider – we don't want them there. Why can't they all just give the same care or give us the right agency. Meshing the patient needs with the agency that can provide for them is critical and is not done well."

Draft Patient and Caregiver Bill of Rights

As patients and/or caregivers we have the right to:

- A. Know our treatment and service options
 - Who is providing care
 - A detailed care map starting with my needs and showing my care goals and timelines
- B. Report abuse, harassment, bad care
 - Provide direct contact information for reporting
- C. Assistance
 - One phone number for appropriate on call medical help or a service provider, other than 911 or the health hotline
- D. Choice/access to care
 - Agency, PSW, consistent service providers vs. getting a different person ever day;
"To have anyone present and fully involved in our care"
- E. Be in charge of directing our own care and care decisions
 - *"I need or want this and not that"*
- F. Have a care plan
 - Designed around me, with my goals and a time frame
- G. Understand and have my care fully explained to my satisfaction
 - Be communicated with in a way I can understand (multiple languages, images/visuals, clear medical terminology, including Bill of Rights, etc.)
- H. Regular assessments (quarterly)
- I. Service across CCAC boundaries
- J. Be spoken to with respect and not be spoken down to
 - We have the responsibility to speak to others with respect as well
- K. Respect for our physical privacy
 - During showering or treatment close the window blinds, close the door, cover me up
- L. Respect for our homes and lifestyles
 - Return things to their proper place, be pleasant with pets
- M. Refuse service and/or care.

Additional Discussion Points:

- What is needed is good, practical common sense

“My mom threw up and it was all black, I talked to the pharmacist and they thought it was a blockage. At the time, you don’t know what to do, but the choices were to ignore it or call 911, which didn’t seem appropriate. We need Telehealth but more seniors’ focused where they have access to their records and can talk specifics”

- There are organizations for seniors but perhaps another volunteer organization where the unrepresented can be heard. Volunteer assist program – a resource centre. Something that encourages sharing of information without an agency – sharing beyond this room. A gap for medical between your family doctor and 911 – who do you call, how do you fit?

DO NOT DISTRIBUTE

NEXT STEPS

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

1. Finalize the meeting outcomes report (specifically the Bill of Rights):

- Draft report completed by Pitters Associates
- Distribute report for review by participants to make sure it captures what was intended
- Participants to provide feedback on the Bill of Rights and rank each statement in terms of importance. If we don't hear back within 10 days, we assume people are ok with the report
- Finalize report and share with Mississauga Halton leadership team, the Board of Directors, Share Care Council members that could not attend and other stakeholders

2. Prepare for next meeting on September 20, 2014 (tentative):

- Where: Homewood Suites, Oakville
- Agenda: Check in on progress of partnership opportunity with Trillium Health Partners
- Bill of Rights will be on the agenda

APPENDIX A: AGENDA



SHARE CARE COUNCIL

- DATE:** Saturday, June 21, 2014
TIME: 9:30am – 2:00pm
LOCATION: Homewood Suites,
 2095 Winston Park Drive
 Oakville ON L6H 6P5
- OUTCOMES:**
- Revisit the purpose and guidelines of the Share Care Council
 - Update progress on priority topics
 - Provide input on identified priority topics
 - Determine next steps

Item	Agenda Item Description	Time	Lead
	Breakfast	9:30 am – 10:00 am	
1.0	Opening remarks	10:00 am – 10:10 am	Dieter Pagani, Board Chair Caroline Brereton, CEO
2.0	Overview of agenda <ul style="list-style-type: none"> • Introductions, including a thought you have about attending this Share Care Council meeting • Revisiting guidelines for how we will work together 	10:10 am – 11:10 am	Marian Pitters, Facilitator

3.0	Update on progress since March meeting	11:10 am – 11:20 am	Nancy Gale, Director Communications
4.0	Community Care priorities <ul style="list-style-type: none"> • Discussion: identify and clarify topics that are most important to your health care experience. 	11:20 am – 11:45am	All
	Lunch	11:45 am – 12:15 pm	
5.0	Community Care Topic <ul style="list-style-type: none"> • Discussion: what would the ideal experience look like/feel like? 	12:30 pm – 1:50 pm	All
6.0	Next steps <ul style="list-style-type: none"> • Thinking ahead to September • Meeting evaluation 	1:50 pm – 2:00 pm	Marian Pitters Nancy Gale
7.0	Adjourn meeting	2:00 pm	All

APPENDIX B: TERMS OF REFERENCE



SHARE CARE COUNCIL

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 region, as well as Mississauga Halton 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 Mississauga Halton CCAC sub-committees and offer advice on other Mississauga Halton 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 Mississauga Halton 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 Mississauga Halton 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 C: SUMMARY OF SESSION FEEDBACK

All eight of the participants remaining at the end of the day 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
Revisit the purpose and guidelines of the Share Care Council	0	0	0	1	7	4.9 / 5
Update progress on priority topics	0	0	0	1	7	4.9 / 5
Provide input on priority topics	0	0	0	1	7	4.9 / 5
Determine next steps	0	0	0	2	6	4.7 / 5

2. What participants found most useful about the session:

- Interesting comments and input
- Everything – it's very inspiring for me
- The fact that we can make change
- Genuine desire to seek input. Executive participation
- Great sharing
- All information is good and appreciated
- Good to hear what is happening with CCAC
- The yellow page – helped direct the discussion in useful ways

3. Words of advice for future Share Care Council sessions:

- Keep doing what you're doing; keep it up (6), e.g.,
 - A well run meeting – continue with format; continue this good work

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

- Nothing (3)
- Comment on emergency department visits – can some be avoided
- Still some topics wish to address
- I thought we would talk about "Q: What is my caregiver's job" and felt it wasn't covered in as much detail as needed

5. Other comments:

- Amazing how similar comments were from each of the two tables. Thank you for inviting me
- Thank you for inviting me to be part of this very important endeavor
- Happy to participate
- Thank you for inviting me
- This was amazing! Thanks for giving us a voice in the future!