

Meeting Outcomes
from the

Share Care Council

September 20, 2014

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ACKNOWLEDGEMENTS

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

Share Care Council members

Nancy Gale, Director of Communications, Mississauga Halton CCAC

Kathryn Hales, Executive Assistant, Mississauga Halton CCAC

Marian Pitters, Facilitator, Pitters Associates

Karen Metcalfe, Senior Consultant, Pitters Associates

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EXECUTIVE SUMMARY

On Saturday September 20, 2014 The Board of the Mississauga Halton CCAC invited fifteen patients and/or care givers to attend the third 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 to identify areas of priority from the perspective of community based health care. This purpose supports the second area of focus of the Mississauga Halton's strategic plan: Client & Family Focus.¹

To open the session, Jutta Schafler Argao, Vice President, People, Quality & Planning welcomed everyone and shared her own personal story of optimism and resilience. These two traits run through her work in healthcare and she knew from the first meeting that it was something she had in common with the SCC. She thanked everyone for their commitment, *"the advice you are giving is already having an impact. For example, your Patient Bill of Rights: we talk to staff to see how we can deliver that. It's a great gift that you've given us."*

Following these opening remarks, Nancy Gale, the Mississauga Halton CCAC's Director of Strategic Communications and Stakeholder Management, provided an update on progress since the June SCC meeting and addressed questions of clarification. SCC members were excited to hear that two SCC members are now providing a feedback and recommendations to the Trillium Process Design Team. They were encouraged to hear that their input is making a difference in how patients transition from hospital to home.

Kathryn Hales, Executive Assistant to the CEO office and co-lead of the SCC, provided an update to the group regarding the Bill of Rights. The group then reviewed and finalized the Bill of Rights for patients and caregivers. Members examined the progress to date on addressing the priorities established at the March meeting. They finished their discussion on the topic of "navigating the system" and decided to work next on "my caregiver's job." This topic was identified as a high priority at the first SCC meeting (see page 7).

After members of the SCC were thanked for their continued commitment and participation, participants responded with a few thoughts on their experience to date:

"I really feel like we are contributing to something that is going to come about."

"I learn from everyone else's experience. There are a lot of people worse off."

"I don't like to complain but I'm learning that I need to stand up for my mother."

"We have a responsibility to stand up for those that can't stand up for themselves"

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 follow the format they are using. The part of the meeting that they found most useful was the participation of all attendees and the inclusion of all perspectives.

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

UPDATE ON PROGRESS

An update on progress on progress since June meeting was provided, both within the MHCCAC and broader health care system. Nancy Gale, Director Communications provided an update on the Trillium Design Team.

- Shared the results of the previous meeting regarding seamless transitions to the Trillium Design Team who are looking at recreating the transition from hospital to home, however, the SCC's stories seem most compelling when told by each individual. This led to Nancy extending an invitation to SCC members to tell their stories in person
- The design team heard the stories and used them when trying to solve the problem
- In addition, the design team had a brainstorming sessions with over 80 people representing a variety of hospital and Mississauga Halton CCAC roles
- After the brainstorming and story sharing, they came up with a proposed design for seamless transitions
- Next steps: Identified SCC members are invited back to review the proposed design and see if they got it right. The Team wanted the opportunity for these SCC members to say 'yes this will be better' or 'no you didn't get it quite right'.
- Implementation begins Monday, September 29th until December 12th and then they will measure and evaluate. Nancy emphasized that the information SCC members give, goes directly to informing major changes. The Design Team is also talking about 'why are we doing grand rounds at 6am, etc.'

Response from SCC members regarding Nancy's update:

"Nancy captured these meetings well. They opened their minds by the end of the meeting to see our perspective and see the way we were suggesting. They were listening and accepting."

"They were very receptive, I was impressed"

Kathryn Hales, Executive Assistant and co-lead of SCC, added an update on the presentation of the SCC's draft Bill of Rights to the MH CCAC Management Team.

- Nancy and Kathryn are going to attend a series of Patient Care roadshows with David Fry, Vice President, Patient Care. They will present the Bill of Rights to Patient Care staff at the organization and ask them what they need to make this happen
- David asked them to take it to an operations and management forum with MH CCAC service providers and invite them to accept this as a common Bill of Rights. Nancy and Kathryn will let the SCC know how this goes

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 care plan

- 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 service providers vs. a different person every day.
 - 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 Refuse service and/or care, without reprisal.

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.
 - Recognize pets are family.
- 2.3 Report abuse, harassment, bad care
 - Provide direct contact information 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 for appropriate on-call medical help or a service provider (other than 911 or the health hotline).
- 3.3 Provide an updated, one page summary of the care plan and medications for emergency purposes.

COMMUNITY CARE PRIORITIES: UPDATE

At the first SCC meeting, members rated the topics that were most important to improving their health care experience on a scale of 1 to 8: 8=very important, 4=somewhat important, 1=not important. The highlighted topics were discussed at previous meetings. 'What is my caregiver's job' was the focus for the September 20th meeting.

Topic	Avg	Each Participants' Rating						
		1	2	3	4	5	6	7
(5) What is my caregiver's job (PSW, supervisor) and family member's job? <ul style="list-style-type: none"> 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 	6.7	8	4	8	4	8	7	8
(4) Quality control experience (relief), e.g., <ul style="list-style-type: none"> Checks and balances with PSW agency Delivery and efficiency 	6.6	6	5	4	8	8	7	8
(2) Choice of agency service provider: <ul style="list-style-type: none"> Who makes the decision and communicates it? What say do we have? You feel like just a number What can we say when speaking up? 	6.3	8	3	8	2	8	7	8
Navigating the system, e.g., on a day to day basis who do you call to bring up issues (big or small) <ul style="list-style-type: none"> <i>Patient and Caregiver Bill of Rights</i> 	5.8	4	8	4	1	8	8	8
Caregiver Relief	5.7	8	6	6	2	5	6	7
Your care with your family doctor	5.6	6	5	6	3	6	6	7
Your experience moving from hospital to home	4.6	6	4	4	3	7	8	--
Getting health and wellness educational resources	4.3	7	2	8	2	4	7	--
(1) Taking control of your own health, e.g., health planning for long-term-care and end of life)	4.1	6	7	4	1	4	7	--
Sharing your health record with your circle of care (doctors, nurses, pharmacists, care coordinators and others)	3.8	8	3	4	1	4	7	--

PRIORITY: WHAT IS MY CAREGIVER'S JOB (PSW, SUPERVISOR)

Experiences of SCC members with caregivers:

- Duties vary by person, it really depends on who you get, e.g., when a PSW begins, we don't know what they are supposed to do. What is the job description? Are they supposed to empty the garbage, make a meal, brush teeth, etc.? Different people do different things.
- Consistency and quality of service varies by agency (there is a big difference)
 - Is the CCAC getting what they pay for?
 - The family experience should be included in the CCAC's assessment of service
- It takes a while to get the right care worker that works for you
- Service Provider supervisors contribute to the issues
 - There is no question that PSWs jobs are difficult and often *'their management sucks'*
 - Independent assessors should be getting feedback from employees about supervisors
 - The booking of daily appointments for PSWs are too close together, e.g., not enough time to make it from one end of town to the other; they are not given enough time

SCC members' dream for the caregiver's job in three years' time:

- ***"It's the little things that make the difference"***²
 - *"There is a smile on the face of the person who received service and the family and there is a smile on the face of the PSW when they leave. This is ideal. I don't care if they are 5 minutes late or don't change the garbage, but I want my mom to have a smile on her face, she's taken care of and she looks forward to seeing the person again. The person providing the service leaves smiling and looks forward to coming back. People feel it was a positive experience."*
 - We want to be thankful as much as possible
 - We are all working for the same thing
 - Supervisors provide an excellent example to the staff
 - Complete 360° feedback on service, including patient, employees, managers etc.
 - Have a pamphlet indicating what PSWs do, a list of tasks
 - They take time to engage, communicate and interact with the patient.
 - Have CPR and First Aid training, including what to do when someone is choking
 - PSW takes personal ownership and initiative to be helpful, e.g., they don't need to be told every time what to do. They will think the job through
 - PSW's receive positive feedback – people looking at what they do right, not just what they do wrong
 - Call patient and caregiver by name
 - Bookings are managed so that there is enough travel time for PSWs, safety is a consideration

² Use this as the main message and heading

DISCUSSION

Members were asked to reflect on a time when they **felt most lost in the health care system**. The following scenarios illustrated those times.

- After my world collapsed due to a doctor's poor communication style – telling, not listening

I had gone in with an MS attack, a neurologist came in late at night, stood where I couldn't see his face, read from a chart and said that I wasn't going back to work and I would just have to get used to that fact. I felt useless, good for nothing.

- Not knowing how to get a care situation resolved – no one did basic care

After a recent experience that was difficult to resolve, I didn't know where to go. I did not know how to get a care situation resolved. No one seemed to do basic nursing care in the hospital, e.g., shower. All the services we were receiving at home with CCAC we couldn't get in the hospital. I thought "what am I going to do"?!

- No one that asked: 'what do you need?'

There have been so many times when there have been life threatening moments. You are so lost, there are so many things going wrong, yet there was no one that could say: "what do you need?" The one thing that angered me the most was when a doctor got in my face and yelled: "Perhaps I'm not the doctor for you!" and turned and walked away. I came home and was devastated. In the end, I had to develop my own solution.

- You are in a bad situation where staff think "here's an old lady" and don't focus on care

My mom is 95 on paper but she could be 100 plus, because we have other evidence to suggest it. She was very bad, after two incidents when she was with me. The doctor in the ER at 2am said: "Do you want her resuscitated"? Another time when she threw up, I called the ambulance. They asked again: "Do you want her resuscitated"? The nursing team is supporting the doctor. They are checking her blood pressure and showing its low. I don't want to say don't resuscitate, so that it impairs her care. The doctor assured me that she would get the best care. I told them if they can't do anything I will take her home. Today she has a heart and lungs that are working perfectly and her blood work is perfect. I got good care after that but just seeing how you get treated when you take an old person: you feel like you are going through the wringer. Emergency staff feel stressed out already; they were focused on her dying, not giving her care. I kept my mouth shut so that she would keep getting good care. This is a problem as more older people are getting in the system. Comments were demeaning to the caregiver, family. They should have said: "we are going to do all we can to provide the best care, but if..."

- Unprepared for discharged; doctor not educated on the process

A very good friend, her husband had a stroke in 2000 and 2002 and has been in and out of hospital. He's been in the hospital for the past six weeks. He moved into

palliative care and a week ago the doctor said “Don’s looking a lot better today, he can go home” and he wrote a discharge note. His wife didn’t know what to do. She called me and said she couldn’t look after him. I called my daughter and she said they can’t just kick them out and send them home. I did a bit of digging and I advised my friend the best I could, including that she should take her son with her. She was left hanging and desperate, didn’t know what to do and her husband can’t speak. Once she came armed with information, the doctor back tracked and said he realized she needed transition support.

- Language barriers create misunderstandings and/or misdiagnoses

Often healthcare professionals say people don’t follow directions, they are non-compliant, uncooperative. They don’t realize that these behaviours may be due to language barriers. My mother wasn’t eating and I was told she was non-compliant and was dying, refusing to eat, but it was because she didn’t like the food they were giving her. I went downstairs and made her one of her sandwiches and she ate. There needs to be translation to avoid misunderstanding. Family members are put in difficult decision making positions.

- No consideration for communication/engagement with the person

There is no place on the assessment for communication/engagement with the patient. It is only check lists with tasks, e.g., brush teeth, bath, meals, etc. What about showing an interest in the person by interacting, talking, engaging them in conversation?

- Frustration with lack of long-term care beds
- Patient who can’t speak for themselves

What SCC members said they would need to navigate the healthcare system successfully:

- Have healthcare professionals in your family
- Ability and encouragement to speak up
- Doctors educated, informed about transitions in the location of care
- Protocols for discharge to transition that involves patient and family – needs to be a designated coaching role
- General public and families need to know more about CCACs, e.g., what do they do, who does what when, how to get service (e.g., you don’t need a doctor’s referral)
- Language is key – need translation to avoid misunderstanding
- Ask questions and provide options
- Provide an option to request a second opinion
- Patient engagement – converse about the person’s life experience, interact with them. Need to match people so that mental food is part of the experience. There is more to care than giving people food and a bath; balance task orientation with people orientation
- Everyone needs an individual to advocate for their health services
- There are so many people who want to volunteer and help others – use this

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, including finalized Bill of Rights
- Distribute report for review by participants to make sure it captures what was intended
- Finalize reports and share with Board, Share Care Council members that could not attend and other stakeholders
- Nancy and Kathryn get feedback from service providers on the Bill of Rights during October-November Roadshow and share results at the January meeting

2. Prepare for next meeting on January 24, 2015 (tentative):

- Where: Homewood Suites, Oakville
- Agenda:
 - Revisit caregivers' job
 - Discuss family's/patients' job
 - Move onto quality control

APPENDIX A: AGENDA

SHARE CARE COUNCIL



DATE: Saturday, September 20, 2014
TIME: 9:30am – 2:00pm
LOCATION: Homewood Suites,
 2095 Winston Park Drive, Oakville ON L6H 6P5
OUTCOMES:

- Update on progress
- Discuss Patient Bill of Rights next steps
- Provide input on identified priority topics
- Determine next steps

Agenda Item Description	Time	Lead
Breakfast	9:30 – 10:00 am	
Opening remarks	10:00 – 10:20 am	Jutta Schafler Argao, Vice President
Overview of agenda	10:20 – 10:30 am	Marian Pitters, Facilitator
Update on progress since June meeting <ul style="list-style-type: none"> • Within our MHCCAC • Outside our CCAC 	10:30 – 10:40 am	Nancy Gale, Director Communications
Patient and Caregiver Bill of Rights <ul style="list-style-type: none"> • Discussion: your feedback • Draft #3 	10:40 – 11:10 pm	All Marian Pitters, Facilitator
Community Care Priorities <ul style="list-style-type: none"> • To be confirmed • Discussion of next priority/ies 	11:10 am– 12:00 pm	All
Lunch	12:00 pm – 12:30 pm	
Community Care Priorities <ul style="list-style-type: none"> • Continue discussion priority/ies 	12:30– 1:45 pm	All
Next steps <ul style="list-style-type: none"> • Thinking ahead to next meeting • Meeting evaluation 	1:45 - 2:00 pm	Marian Pitters Nancy Gale
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 (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 C: SUMMARY OF SESSION FEEDBACK

Six of the seven participants completed the evaluations (one participant had to leave early). 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	0	0	0	0	6	5.0
Discuss Patient Bill of Rights next steps	0	0	0	1	5	4.8
Provide input on identified priority topics	0	0	0	1	5	4.8
Determine next steps	0	0	0	1	5	4.8

2. What participants found most useful about the session:

- Very accommodating on all ideas (2)
- Completion of Bill of Rights (2)
- Feedback on progress
- All of it
- Everyone joins in

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

- Keep up the format. It is very rewarding to participate (3)
- Try to be realistic

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

- Nothing (2)
- Let us also look at the positive side of services

5. Other comments:

- Good session, lots of ideas and information
- Glad to be a participant
- Good job, thanks
- Thank you!