

COMMITTEE MEMBERSHIP

Chair:

Brenda Morgan

Members:

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Lori Barrett
Elke Bohdanowicz
Cheryl Burt-DiNino
Stacey Brown
Tara Caslick
Pam Gladysz
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Donna Laurie
Claudio Martin
Lorie Melnyk
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Patient and Family Experience in CCTC

VOLUME 3, ISSUE 1 AUGUST 2018

CCTC PAFE Committee

In September 2017, the CCTC Patient and Family Experience Committee was rejuvenated with the addition of some fresh new faces and ideas. Over the past year, our work was greatly enhanced by the addition of Family Advisors (Donna Laurie, Laurie Melnyk and Cathy Nowacki) and Volunteers (Treena Fidler and Sandra Fox). We also added representation from additional disciplines including: Elke Bohdanowicz (bringing both a Pharmacist and patient perspective), Kristen Abercrombie (Physiotherapist) and Diane Pozeg (funds manager and teddy bear builder). Of course, we can't forget important behind-the-scene contributions from Bob the Builder (AKA Dom). Broadening our committee perspective brought life to both old and new initiatives. The PAFE committee will resume meeting on October 16 from 1300-1500 (third Tuesday of each month). We welcome ALL ideas and interested members of our team.

Our Guiding Principles

The PAFE committee embraces the core concepts of the Institute for Patient and Family-Centred Care (IPFCC). These concepts are easy to recall as they represent the same hopes and expectations we all have for ourselves and our own families. Every day, we witness interactions and acts by members of our CCTC team that demonstrate these principles:

1. Dignity and Respect.

Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

2. Information Sharing.

Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

3. Participation

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

4. Collaboration

Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of care.

Adapted from: Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: IPFCC

"Patients and families don't care how much you know until they know how much you care"
unknown

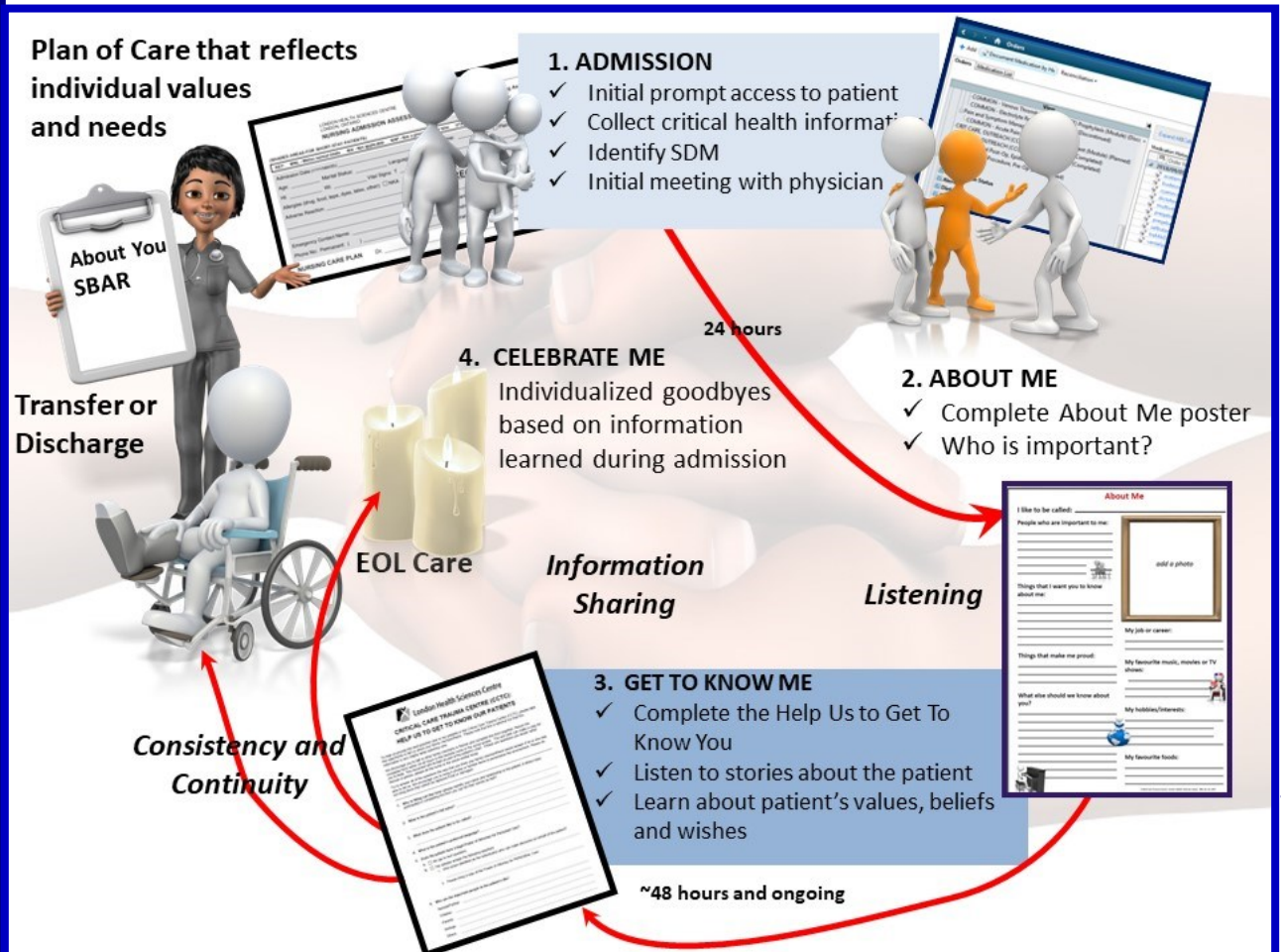
Our PAFE Philosophy

Our PAFE Philosophy builds upon the work that was started by our previous patient and family CQI committees. Our journey began in 2006 when we formed our End-of-Life Care Committee. During this initial phase, our focus was on communication strategies and effective family meetings.

Our EOL Care Committee recognized that quality End-of-Life care is dependent upon the early development of positive relationships. These must be nurtured from the time of our first encounters by demonstrating respect, compassion and consistency. The need to humanize the critical care environment became our emerging theme, therefore, we became the Humanistic Care Committee. The change in name to the Patient and Family Experience (PAFE) Committee aligned our work to the London Health Science Centre's Family Centered Care initiative.

Getting to know our patients is an essential component of Family Centered Care. Our About Me poster and Help Us to Get to Know Our Patients tool provide important baseline information. This knowledge helps us to initiate conversations, understand preferences and engage patients and families during goals-of-care conversations.

The introduction of the comfort cart has been an extension of this work. The comfort cart is a collection of tools, supplies and ideas to support patients and families during the final hours of life. It provides a peaceful backdrop and display of compassion as we help create positive memories at end-of-life. By using information collected from the **About Me** poster and **Get to Know Me** tool, and by listening to stories about our patient's life, we acquire a rich supply of material that can be used to help **Celebrate** our patients. Thus, we have identified 4 phases to our CCTC Patient and Family Centred Care model including: 1) Admission 2) About Me 3) Get to Know Me and 4) Celebrate Me.



1. Admission

Admission is our first contact with our patients and their families and our opportunity to initiate positive interactions. It is also the time when patient care needs may be the most demanding, and the patient's primary care providers have the least amount of time.

The primary *Patient and Family Centred Care* goals during the initial admission period include the following:

- Facilitate family member access as soon as possible
- Collect critical health information including past medical history, allergies, medication history and reason for admission
- Identify the patient's SDM(s) and obtain contact numbers
- Provide a medical update that outlines the reason for admission and initial plan of care
- Conduct an urgent goals of care conversation if required for immediate decision-making
- Defer non-urgent goals of care discussions until the most appropriate physician is available (usually a Senior or Consultant). At the time of admission, a physician can deem a patient "full resuscitation" if a goals of care conversation is not appropriate at the time (e.g. a young MVC, in the immediate postoperative period or a post partum hemorrhage).

Family Access to the Patient

The need for family members to "lay eyes" upon a newly admitted patient is very high. Most families do not expect a long initial visit; they just need to confirm that the patient is alive and receiving care. If it isn't possible to get the family into the room, a quick "window visit" can go a long way to managing their stress. There is likely no worse conversation to have with a family than to advise them that a patient has died before they ever had a chance to visit.

It is easy for care givers to lose track of the family's "wait" time when resuscitating a critically ill patient. For the family, the time can be agonizingly long. We know that we have opportunities for improvement based on some events and feedback. We have "lost" families who sat for prolonged periods of time in the wrong waiting room. We have had other family members arrive without team members being aware. We would like to introduce the following strategies to expedite the first visit (Table 1).

Strategies to Reduce the Time to Initial Family Visit at Admission (Table 1)

- CN to identify a family "point person" when a new admission is expected, whenever possible.
- The point person can be anyone who is available (e.g. Unit Clerk, CN, Social Worker, CNS, Coordinator, RRT or PSW etc.) .
- The point person can be notified by the Unit Clerk / Volunteer if on duty or by leaving a sign at the front desk with an extension to call in.
- The role of the point person is to facilitate early access and support the family during the first visit IF THE PATIENT'S NURSE IS TOO BUSY.
- If the patient is being resuscitated at the time of admission, a nurse or Social Worker can assess the family's need to be present. If family presence is desired, the family must be accompanied by someone who can provide support, orientation and guidance during the visit.
- ONCE THE PATIENT'S ASSIGNED NURSE IS ABLE TO ASSUME THIS ROLE, THE POINT PERSON IS NO LONGER NEEDED. Communicate with the assigned nurse to determine his/her need for assistance.

2. About Me

Two years ago, we introduced our “About Me” poster as a strategy to personalize the critical care environment. Completion of the poster gives families an opportunity to introduce their family member to our team. It can give them a meaningful way to contribute to patient care at a time when they feel most helpless. It also shows them that we want to know about the person in the bed.

Information on the About Me poster causes team members to pause and reflect . It can provide a starting point to engage a patient or family in conversation or explore patient values and beliefs. What we didn’t anticipate when we introduced the poster was the impact it could have on a recovering patient.

Powerful words from a former patient:

One of our former patients shared her experience of awakening from a coma. She recalled seeing the poster on the wall with her own personal story.. and knew that she must be okay.

Please remember to ask families to complete the About Me poster within the first 24 hours after admission. Most of our rooms have paper clips mounted on the wall. Hang the poster where team members can see it as they approach the bed. Please avoid hanging the poster by the sink...it is hard to see and we have already lost a few that have fallen into the garbage!

About Me

I like to be called: _____

People who are important to me:

Things that I want you to know about me:

Things that make me proud:

What else should we know about you?

My job or career: _____

My favourite music, movies or TV shows:

My hobbies/interests:

My favourite foods:

3. Tell Me More About You

Our “Help Us to Get To Know Our Patients” questionnaire augments our initial assessment by examining Values, Beliefs and Goals.

Administration: The tool should be completed by the patient if they are capable (with the assistance of family members if appropriate). If the patient cannot complete the tool independently, it should be given to the patient’s SDM(s). Document to whom and when the tool was distributed for future follow-up by RN or Social Worker. The tool should be given out a couple of days before a decision-making meeting whenever possible, and should be reviewed by the physician before the meeting.

Instructions: Instruct the SDM to take the tool away from the bedside and return it within the next day or two. They should be asked to engage other SDMs or significant family members. The primary purpose of tool completion is to stimulate thoughtful reflection. The process of completion may be as important as the actual content.

When to give it out: Unless there is an urgent need for decision-making, our goal is to distribute the questionnaire at approximately 48 hours (or later as indicated). When given out before the family has an understanding of the medical issue, they may be unable or unwilling to complete the tool.

Story Telling: Story telling is an important way to learn about a patients Values, Beliefs and Goals. The act of telling a story about the patient can help families to process what has occurred, demonstrate respect for the individual and/or help come to terms with a new reality.

Story telling can also lead to reflections about goals of care. At end-of-life, it can be a powerful tool to help celebrate the person.

London Health Sciences Centre
CRITICAL CARE TRAUMA CENTRE (CCTC):
HELP US TO GET TO KNOW OUR PATIENTS

To help us provide the best possible care to our patients in the Critical Care Trauma Centre (CCTC), please take this opportunity to tell us about your family member/friend. Please note that this is optional but that this information is very helpful when planning care.

We encourage you to talk to other family members or friends and complete this form together. Return the completed form within 24-48 hours to the bedside nurse or the social worker. The unit clerk can make a copy for you to keep. This document will be kept as part of the patient's chart. If there are questions you would rather discuss in person, please let the nurse or the social worker know.

Try to answer all of the questions the way that you think your family member/friend would answer if he or she was able to tell us. We encourage you to bring in photos or familiar items to personalize the environment. Please do not bring items that cannot be replaced if lost or damaged.

- Who is filling out this form (please identify your name and relationship to the patient, if others have participated in completing the form you can list their names as well)? _____
- What is the patient's full name? _____
- What does the patient like to be called? _____
- What is the patient's preferred language? _____
- Does the patient have a legal Power of Attorney for Personal Care?
 - No (go to next question)
 - Yes (please answer the following question)
 - Who is/are identified as the individual(s) who can make decisions on behalf of the patient? _____
 - Please bring a copy of the Power of Attorney for PERSONAL Care _____
- Who are the important people in the patient's life?

Spouse/Partner: _____

Children: _____

Parents: _____

Siblings: _____

Others: _____

4. Transfer or Discharge

At transfer or discharge, we need to communicate important information so that patients and families do not have to start over.

Provide your patient care report and complete the SBAR. Communicate important information about Values, Beliefs and Goals as appropriate so that information does not get lost. **Please remember to send the poster with the patient at discharge!**

About Me
"Jack"

I like to be called: _____

People who are important to me:
 Wife Sarah (30 years)
 Son Rob (Julie)
 Daughter Annie
 Dog Duke (lab)

Things that I want you to know about me:
 I like to have things explained so that I understand the reason for why things are being done or suggested.

Things that make me proud:
 My children

What else should we know about you?
 I like to garden
 Grew roses
 I'm a very good golfer

My job or career:
 Electrical Engineer

My favourite music, movies or TV shows:
 CBC News
 Hockey
 Big Bang Theory

My hobbies/interests:
 Woodworking

My favourite foods:
 Roast Beef

4. Celebrating Me

3 Wishes Project and CELEBRATING ME

A group in Hamilton lead by Dr. Deborah Cook initiated and studied a [3 Wishes Project](#) to create positive end-of-life experiences. The “3” wishes focus are:

1. **The Patient:** To dignify their death and celebrate their life
2. **The Family:** To humanize the dying process and create positive memories
3. **The Clinicians:** To foster Patient and Family-Centred End-of-Life Care and inspire a deeper sense of our vocation.

The ICU team at Vancouver General presented their version of the Three Wishes Project at Dynamics 2017. Nicole Burr connected with their team to explore their implementation strategies and ideas. Our PAFE committee reviewed the excellent work being done in these other centres, and recognized that our Comfort Cart project was similar in many ways.

In keeping with our CCTC model for Patient and Family Centred Care which places the emphasis on the ongoing assessment of the patient as a person, we have changed our End-of-Life Care project including the use of the Comfort Care to **CELEBRATING ME**. The focus of our Celebrating Me is consistent with the 3 Wishes Project.

WORD CLOUDS

One of the strategies used in Hamilton and Vancouver to celebrating a patient’s life is to create a word cloud. This can be done by entering a set of words that identify people, things, places, activities and characteristics that are unique to the patient. These can then be entered into an online program and printed to create a personalized story.

Instructions for creating a word cloud (using Wordle) are available on our website (What’s New, Under P for PAFE).

If you know that a patient may pass away in the next day or so, you can begin to create a list for a word cloud. Include important people, characteristics, hobbies and career information. Add any unique information that was collected from the About Me, Help Me to Get to Know You or during story telling. Wordles can be created in advance and printed in color (in administrative office). Please ask if you need help.



Candles and Respect

Several months ago, we introduced our candle initiative. We have 3 flameless candles on the Celebrating Me Cart (AKA Comfort Cart). We ask that one candle be placed at the Charge Nurse desk. This candle helps to alert team members and visitors that a loss is imminent.

The second candle should be placed at the entrance to the specific Bay. For lack of a better location, we have been placing them on the paper shredder (ideas welcome for improvement). During the daytime, the lighting in the unit can make visibility of the candles difficult. Reduce the lighting if appropriate and possible.

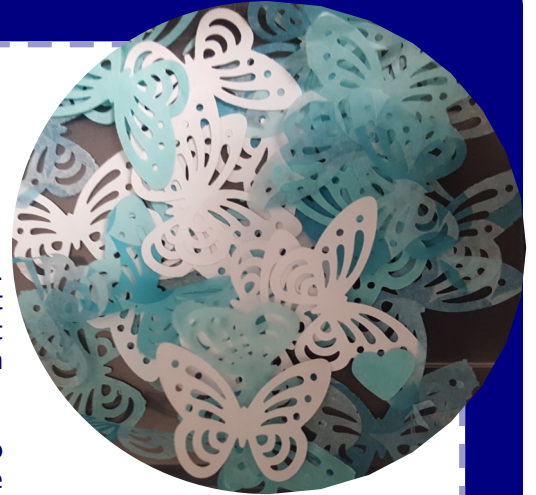
The third candle is placed in the patient's room or on the Celebrating Me Cart. We will be getting a fourth candle to place at the east end of the RRT desk.

Noise is always a challenge in CCTC. Feedback from former family members has made us aware that when loud or jovial conversations are heard by grieving families it can be quite distressing.

Close the door to the patient's room whenever possible to reduce noise and provide privacy. Remind colleagues that a patient is passing away by pointing out the candle. If end-of-life is occurring during rounds, alert the team.

We all need to remind each other as it is easy to forget when we are busy. Please do not take offense if a colleague asks you to reduce your volume!

We considered the addition of a candle to the waiting room, as is the practice in some hospices. For now, we will keep the candles within the actual unit. Families have a different expectation when a patient enters hospice and the frequency of death in CCTC could feel overwhelming if they do not have a place of respite.





Why the Butterflies?

The life cycle of a butterfly is characterized by remarkable change as it evolves from egg to caterpillar to pupa to adult. Each stage is dramatically different than the previous, and the radical nature of these changes can be likened to the human experience as we grieve and adjust to a loss. The emergence of a butterfly from the chrysalis stage can represent the metamorphosis as one's life on earth comes to an end. The beauty and peacefulness of a butterfly is often used to symbolize the relief of suffering, spiritual awakening or new beginning. Many hospices, bereaved parents, neonatal loss and palliative care groups have adopted the butterfly as a symbol of transition, hope and endurance. The butterfly link to the cycle of life and death is also embedded in many cultures and faiths. The following link provides some touching stories of the link between butterflies and healing.

Stories of butterflies: www.gardenswithwings.com/butterfly-stories.html

The PAFE group has incorporated the symbolism of the butterfly into our Celebrating You project. Butterflies have been added to our bereavement card and on a new photograph frame. Share your ideas with your PAFE



Photograph Holders

Available on Celebrating Me cart for presenting family with photographs taken at end-of-life.



New Bereavement Card

New and simplified bereavement cards are now available. They continue to be added to the death packs.



Ideas?

Don't keep them to yourself!

Email: brenda.morgan@lhsc.on.ca

Coming in Next Issue

Protecting Healthcare Information

In mid October we will be rolling out a Family Information Code to ensure that healthcare information is given to individuals who are authorized to receive it. Stay tuned.

Celebrating Me Cart:

Next issue will provide an orientation on how to use features of the Celebrating Me cart.

Inservices on PAFE Activities/Family Code

TBA in October 2017

