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# Patient and Family Experience in CCTC

## From a Family Member's Eyes

Take a moment to recall the last time you admitted an unstable patient in CCTC. It is definitely one of our busiest times. This situation requires extensive collaboration among all members of our multidisciplinary team to provide coordinated and efficient care. I am proud to say that we do this well.

Now, put yourself in the shoes of a family member whose loved one *is* a newly admitted, unstable patient:

*You receive a call to say that your spouse has been rushed to hospital. Upon arrival in the ER, you are told that your husband requires urgent surgery and you are directed to the surgical waiting room after hours. There is no hospital staff in the waiting room, but you are assured an update as soon as possible. You are desperate for any information about his condition and feel isolated, lost and scared. You start to cry.*

*Six hours pass and no one has come to speak with you. Why have you been left here with no follow up? You start to wander alone down a long, dark hallway in search of someone who can provide direction. Finally, you discover a unit clerk at the front desk of the CCTC and she tells you that your husband is here. You breathe a sigh of relief as the clerk leaves to inform the nurse of your arrival.*

*Moments later, you are greeted by a doctor and nurse who are telling you that they have been diligently working to save your husband's life. Their efforts are failing and they encourage you to come to his bedside straight away. Your mind in a fog, you follow them.*

This is a real life experience as told by a patient's wife. Unfortunately, it is not an isolated occurrence. For a variety of reasons, communication can break down

when families are required to move between departments. The Patient and Family Experience Committee is exploring ways to improve this process.

### What can we do together?

The PAFE Committee has set an improvement goal for initial family member contact as **within 30 minutes**. Not only do we hope to improve the patient and family experience by setting a target goal, but hope that this trigger will prompt staff to seek out the family if they have not arrived within the expected timeline.

When you know that an admission is coming, we ask you to appoint an individual to be responsible for finding the family and facilitating the initial visit.

The individual who is most able to assume this role will vary from situation to situation but could include: 1) Charge Nurse, 2) CCOT member, 3) Unit Clerk, 4) a nurse with a less critical assignment, or 5) Social Worker.

Remember, the goal for the initial visit is to let family members lay eyes on their loved ones. The room does not need to be tidy and the visit can be as brief as needed. Detailed information about the patient's condition or plan of care can be delayed. Just let the family know that the team is in the process of completing assessments and an update will be given as soon as you have the details.

Please let Melanie Quinlan or a member of the PAFE committee know if you have any ideas or questions. Thank you as we work together to improve the Patient and Family Experience!

Mel Quinlan

*Patients  
and  
families  
remember  
60 % of  
what you  
tell them,  
but 100%  
of how  
you made  
them  
feel."*

# Update on PAFE QI Projects

## Enhance Bereavement Follow-Up Program (Lead: Pam Gladysz)

Sympathy cards are now included in the death packs, with instructions for use. Please share the card with coworkers who may wish to sign it and return it to the designated box at the front desk. **PLEASE BE SURE THAT THE PATIENT'S NAME IS IDENTIFIED ON THE CARD (place sticky with patient's name onto card).**

## Develop EOL Supply Cart (Lead: Stacey Brown)

Currently, ideas for our cart are being generated that will include supplies to help both adult and child members of a patient's family to create memories and say goodbye. Stacey is currently in the process of prioritizing our "wish list" and identifying the associated costs. Once this is done, we will develop a funding proposal and implementation plans.

## Promote Visiting Guideline Consistency (CCTC/TOU) (Lead: Alison Rowlands)

Strategies to promote consistency in the application of visiting guidelines in CCTC and TOU are currently being examined. Please review "Did You Know" in this issue.

## Develop Child Resource Kit (Lead: Patrycja Birbaum)

The PAFE committee is reviewing books and other supplies to develop a resource library to support the needs of children of critically ill patients.

## Shorten Time to Family Access at Patient Admission (Lead: Melanie Quinlan)

We are looking at ways to shorten the time before family members have their initial visit at the time of admission. We ask that someone be "assigned" to locate the family and facilitate the initial visit (within 30 minutes of arrival). Please read the article on Page 1.

## Establish Assessment Process for Values/Family Needs (Lead: Brenda/Patrycja)

We are now in our third draft of a Values Assessment Tool (VAT). The tool has been administered to the family members of three different patients. The data provided through this tool has been extremely valuable and will undoubtedly help to inform decision-making for many patients in the future. The tool has been tweaked following each test.

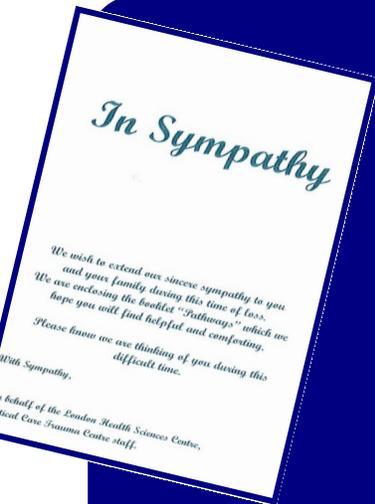
A sample of the tool will be profiled in our next newsletter and is currently available in the S Shared Drive under Patient and Family Experience.

## ABOUT THIS NEWSLETTER

This is the third Issue of our Patient and Family Experience (PAFE) Committee Newsletter. This Newsletter will be published every one to two months depending upon our activities. The purpose of this Newsletter is to keep all members of the team up-to-date on our improvement strategies. We ask that you please take a few minutes to read these newsletters and stay informed of new initiatives. Hopefully, the newsletter will also stimulate additional ideas and suggestions. We welcome any interested members to our Q Third Wednesday of the Month meetings (1300—1500 hrs) in the Large Conference Room. Please forward comments and suggestions to Alison or Brenda.

The work of the committee, along with a number of articles of interest are also available in the shared drive:

S://CCTC/shared/Patient and Family Experience



# The ABC and D of Dignity Conserving Care

In January of 2008, we hosted a two-day cross campus educational workshop to develop competencies among our team around End of Life Care. Those who attended may recall our engaging guest speaker, Dr. Harvey Chochinov from Winnipeg, Manitoba. Dr. Chochinov, a psychiatrist and palliative care physician, developed a model called the ABC and D of Dignity Conserving Care that can be used by healthcare providers to humanize the patient and family experience. We are pleased to see that Dr. Chochinov's work has been recognized through his appointment to the Order of Canada.



## ABC and D of Dignity Conserving Care Model Refresher

**ATTITUDE:** How would I feel in this situation? Have I confirmed that my assumptions are accurate? How might my attitudes be affecting the patient and family?

**BEHAVIOR:** Treat all contact with patients and families as you would any important clinical interaction. Always include respect and kindness. Lack of cure never justifies lack of patient/family interaction.

**COMPASSION:** Consider the personal stories that accompany each patient and family experience.

**DIGNITY:** Tell me how this experience is impacting you and your family. What should I know about (the patient) or your family? What can we do to help you to deal with this difficult time?

## Did you know?

An important way to promote positive Patient and Family Experiences is to ensure that all healthcare providers provide consistent and accurate information. Consequently, it is essential that we all know the visiting policies in CCTC. These are provided to our families through the Family Information Brochure and Family Website.

CCTC does not have "Visiting Hours", and there are no specific times during the day when visiting cannot occur. We also do not have any defined number of visitors per visit. With the exception of a brief interruption during SARS, this has been our policy since the 1990's.

Although we have discouraged routine visiting during the hours of 0630-0730 and 1830-1930 to facilitate nursing report, there is variability in this practice and we have now changed the language for this practice. There is evidence that engaging family members during report and rounds may improve communication, reduce errors, improve family member understanding of the patient's illness and reduce the need for formal family meetings. This time frame may also be the only time when a family member can get to hospital for a visit.

Patient care still needs to be performed, and there will always be appropriate times when visiting restrictions become necessary for privacy, sterility or unit needs. **WHO** is visiting can also be important if there will be an exposure to confidential information such as during rounds. Using our sliding doors (where available) is an important strategy to help when privacy and visiting goals compete.

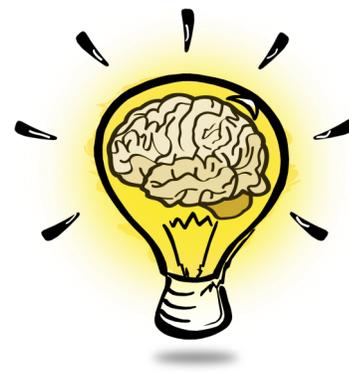
### What IS the Expectation for Visiting Practices in CCTC?

Visiting needs and expectations must be assessed and individualized for each patient. Plans must be communicated to the Kardex to ensure consistency and avoid "good nurse"/"bad nurse" situations. Develop a collaborative plan that meets the needs of the patient, family, unit activities and patient care goals. The plan should engage family members in patient care targets. For example, educate the family and seek their support and suggestions on how best to achieve goals for sleep or rest. Or, have family members stay with a confused patient to avoid the use of chemical or physical restraints. Base decisions on individualized needs versus exceptional situations, and seek help if challenges are identified.

### NEW LANGUAGE IN FAMILY BROCHURE:

Nursing shift change occurs between 0630-0730 every morning and evening. This is an important period where nurses are focused on the exchange of critical information and perform their initial patient assessments. Please speak to your family member's nurse in advance regarding visiting during this period.

## NEXT MEETING



All interested

Ideas?

**CCTC staff are welcome!**

Monthly Meetings (Next: November 19th):  
3rd Wed of each month, 1300-1500 hrs

[Email: alison.rowlands@lhsc.on.ca](mailto:alison.rowlands@lhsc.on.ca)

[Email: brenda.morgan@lhsc.on.ca](mailto:brenda.morgan@lhsc.on.ca)

## Patient Diaries

The date of our October meeting was changed to provide an opportunity to hear from a guest speaker. Gwynne MacDonald, Clinical Nurse Specialist from the Royal Alexandra Hospital in Edmonton, Alberta, provided an introduction to the topic of ICU diaries. Gwynne is halfway through the data collection phase of a study to evaluate the impact of an ICU Diary on PTSD outcomes among patient and family member survivors of a critical care admission.

### Edmonton Study Design

In this pre-post intervention study, the incidence of PTSD among patient and family member ICU survivors who were exposed/not exposed to an ICU Diary will be examined. The results of a previous study of the prevalence of PTSD (measured in the same ICU) will provide preintervention data.

Following consent, an ICU Diary is initiated. At two weeks following discharge, patient survivors are interviewed and data regarding memory recall is assessed using the ICU Memory Tool. Four to six weeks post discharge, an experienced ICU nurse meets with the patient and family member to review the ICU Diary, answer questions, "fill in gaps" and provide a unit tour. At two months, the ICU Memory Tool is repeated, and both patients and family members are assessed for the presence of PTSD using the Post Traumatic Symptom Scale tool (PTSS-14). Scores will be compared to the baseline incidence of PTSD to determine the impact of an ICU Diary. Patients or family members with a PTSD score of > 45 will be referred to one of the psychologists on the study team.

### Post Traumatic Stress Disorder

PTSD is an important problem for both patients and family members following a critical care admission. A key risk for

the development of PTSD in patient survivor's is the absence of memories or presence of delusional memories. An ICU diary may help to fill some of the memory gaps or correct/explain delusional memories.

### What is a Patient ICU Diary?

ICU diaries have been in use in the UK and Sweden for a number of years, and two of our nurses have worked in hospitals in the UK where diaries are used. St. Joseph's Hospital in London also had some experience with Patient Diaries.

An ICU Diary is a personalized record of a patient's critical care journey. The diary begins with an entry by a healthcare provider that explains the reason for the patient's admission. Healthcare providers and family members are encouraged to make entries that highlight significant changes and events. Entries are made in lay terms. Anyone can write in the Diary, and family members are encouraged to share their experience as well.

### Next Steps

At our next meeting, we will begin our discussions to develop strategies and guidelines for a trial (one patient at a time) of a Patient ICU Diary. If you are interested, please join the discussion at our November 19th meeting. Information on Patient Diaries can be found in the Shared S Drive under Patient and Family Experience.

