

Roger's House
Family Advisory Committee Minutes
November 3, 2008

Present: Ruth Hartanto, Georgina Neville, Jennifer Walker, Sharon Liff,
Nancy Graham, Nora Ulyot
Regrets: Mathoni Sanson

1. Review of the Minutes: The September 15th, 2008 minutes were distributed , reviewed and approved.
2. Follow Up Items:
 - **Public Messages:** Nora and Nancy will provide fact sheets on Roger's Legacy and Paediatric Palliative Care (Nancy) and Family Centered Care, Bereavement Program and Multidisciplinary Care Team (Nora).

Action: Nora & Nancy
 - **Prayer Markings:** Nora has met with Khadija Haffajee, a member of CHEO's Multicultural Advisory Committee and artist, Ahmad Humayun who has offered to make prayer markings that incorporate the provincial flowers of Canada. He will be sending an example for approval and Nora will ask Osama for his feedback.

Action: Nora
3. Admissions Coordination:
 - Nancy reported that she has looked at occupancy statistics. Each family will be guaranteed 3 weeks per family per year of respite time. A letter has been sent to families explaining this
 - Stays in the house is determined by 6 levels of prioritization:
 - end of life care
 - emergency respite
 - pain and symptom management
 - transition to home from CHEO
 - secured respite (3 weeks)
 - as available respite
 - In discussion with the executive director it was decided that there would be no restrictions at this time on length of stay or number of other visits. This may change as our occupancy changes
 - Some of the challenges include having to call families to cancel if there is a need for beds for end of life, although this does not happen often. If family is called to let them know their time may be cancelled often the family will cancel the stay.
 - We are looking to have 80% occupancy and Nancy is trying to arrange booked stays to achieve this.

- Current restrictions for booked stays are only one patient with a tracheotomy at a time and only one very active child who requires constant supervision at a time.
- Long term goal is to ensure holidays are even distributed among families
- It was suggested that Nancy could contact Canuck Place and Rotary Home to find out their practice.

Action: Nancy

4. Key Messages

- Ruth brought the Key Messages to the Board. It was suggested that the wording be changed to make it more positive. Ruth will make changes and send it to the membership for approval.

Action: Ruth

- Suggestions for dissemination to staff include presentation at a staff meeting and at an education day. Nora will approach Lynn Grandmaison Dumont to have this included in the next education day.

Action: Nora

- Family Faculty presentation material is ready. Ruth will give the list of available parents to Lloyd. Right now these are all FAC members. Ruth will look into a Toastmaster workshop for presenters.

Action: Ruth

5. Executive Director Report

- Ruth reported on Lloyd's report to the Board.
 - We are 1% over budget
 - Wireless has been installed in the House
 - RH hosted 2 corporate volunteer days where gardening, house repairs, painting etc. was done
 - The tub room floor was replaced with a non-slip floor. This was done pro bono
 - RH has a partnership and mentoring program with Maison Mathieu Froment- Savoie. We will be mentoring their nurses here at RH.

6. Family Survey

The FAC members prioritized which comments they would like to address from the family survey.

- The first priority was to have a communication log. Nora will develop a sheet for child life and volunteers to note activities on. It was felt that nursing would not have time to add to the sheet. It was also recommended that each room have a bulletin board to put messages on.

Action: Nora

- The second priority was the care of family's medical equipment. Suggestions to help with this included
 - Including a list of suggested items to bring in the family handbook.
 - Recommendation to parents to label clothing and equipment
 - Suggesting families bring their medical equipment in a storage container so all equipment remains in one place
 - Include in the care plan the recommended usage of equipment (ie number of times feeding bags can reused etc.)

 - There was a discussion about where families can go if they feel they have concerns that have not been addressed to their satisfaction by the management team. Nancy will talk to Lloyd to see what other hospices do.
- Action:** Nancy
- It was noted that not all families know about the quiet/conference room. This could be added to the Family handbook. The family handbook should be available in each room.
 - There should be a family corner in the newsletter and on the website to facilitate communication. Nancy will speak to Lloyd about this.

Action: Nancy

Next meeting January 12, 2009