Family and Friends Council

Minutes of Annual General Meeting

November 19, 2015
The Games Room
7:00 PM

Attendees: *Linda Hunter, Ben Robert, Josh Landry, Jessie Stephenson, Carolyn Young Steinberg, Akos Hoffer, Mary Boutette, Charles Lemieux, Megan Graham, J. Williams, Rachel Stoparczyk, Bernadette Lee-Wo, Ausliey Cook, Lisa Meldrum, Penny Thompson, Jim LaPlante, Colleen LaPlante, Deborah Evans, Marni Crossley, George Leir, Maureen McReynolds, Georges Couillard, Bob Gemmell, Betty Warnock, Ray Bailey, Doreen Rocque, Diana Hennessy, Brenda Tobin, Fran Cordukes, Mark Bowman, Joan Olinik, Heather Moxley*

1. Welcome from Ray Bailey, Chair of the Family and Friends Council

2. Approval of the AGM Agenda for November 19, 2015. Motion by Doreen Rocque, second Marni Crossley, Approved.
   Approval of the Minutes of the FFC AGM November 20, 2014. Motion by Doreen Rocque, second by Fran Cordukes, Approved.

3. Linda Hunter introduced the topic, **Stages of Palliative Care: Residents' Rights and Family Involvement,** and speakers for the evening.

    a. The Palliative care Committee members are a very cross functional group, and, beyond the many and varied professionals, includes a family member.
    b. In particular the committee looked at what Palliative Care means to the various Perley team members. They initially looked at the challenges and then developed a 2016 plan of goals. Many goals were proposed and the committee then voted on the goals that would be prioritized for 2016.
        i. Increase support for front lie staff re: resident deaths
        ii. Improve understanding and consistency of information for Advanced Care Planning
        iii. Define proper use of terminology related to palliative care approach
        iv. Increase education in palliative approach to care for front line
    c. In the spring a palliative care training program was implemented for volunteers
    d. The Perley Rideau is looking to follow gold standards in palliative care

e. Dr. Ben Robert,
    i. 90% of people want to die at home, 65% actually die in hospital
    ii. Physician role – making sure people live the best possible life they want. The World Health Organization (WHO), approach to improve the quality of life for people and their families that intends neither to hasten nor postpone death. Can be applied early in the patient care in conjunction with other treatment plans.
    iii. Boston study on metastatic lung cancer. Two groups, one that brought in palliative care physicians at the diagnosis or the second group only engaging a palliative care physician when the oncologist felt it was needed. The first group had the best and longest quality of life.
    iv. Many residents at the Perley have a condition now being labelled frailty. Many residents have improved frailty after six months.
    v. Advanced Care Planning – the levels of care. A basic philosophical approach to treatment in the even that a family member cannot be contacted. It provides direction to the staff. Palliative care approach is Level 1 – focus on symptom control, Level 2 – try to cure disease without "swamping the canoe", Level 3 – cure disease with trip to hospital and Level 4 – All actions possible are taken (ICU with all interventions that might be possible).
        1. Level 1 – actively treat pain, cough and other symptoms. Antibiotics would not routinely be started for instance in the case of pneumonia, but for a painful bladder infection antibiotics might be the right treatment for pain. May go to hospital for symptom control that cannot be done within the residence, such as casting for a broken bone.
f. Josh Landry, PhD, a registered ethicist from The Champlain Centre for Health Care Ethics (CCHCE).
    i. In Health care ethicist have a number of roles
        1. Clinical – ethics consultation. Can be requested by anyone, at any time. Conflict between values is often the primary reason.
        2. Organizational – policy development and revision. To support decisions being made in an ethical manner. Governance – ethical dimensions at the Board level.
        3. Education and capacity building.
        4. Research – not a direct involvement at the Perley.
    ii. Josh provided a variety of examples of when he has been consulted.
g. Jessie Stephenson, Spiritual Care Worker
    i. Spirituality is very different to each person. Often people associate it with specific sacraments and Jessie and Father Paul are very happy to coordinate those.
    ii. Liminal – relating to a transitional stage of a process, occupying a position on both sides of a threshold. This is a space or time period when associated with Palliative Care that Jessie in particular and Chaplains in general are very aware of and comfortable working with residents and their families.
h. Carolyn Young Steinberg, Resident Care Liaison.
    i. Advocacy on behalf of residents and family members, education and emotional support
    ii. Psychosocial Assessment – many different topics are captured in discussion with the resident and family
        1. POA details, Substitute Decision Maker, Support System, Occupation/Education, Veteran Experience, Substance Use, Advanced

Care Planning, Funeral Arrangements, Spiritual Belief, Social/Cultural Needs/Preferences, Personality,

iii. Advanced Care Planning – supporting the resident and family members with information and tools.
iv. Enabling Better Decision Making.

i. Nursing – represented by Linda Hunter
    i. Providing comprehensive, coordinated, compassionate and holistic care to residents and their families
    ii. Challenge is that palliative is often associated with end of life. Comfort care – means different things to different people.

j. Medical Challenges – Predicting life projectory, based on disease, intermittent condition trajectory. Finally, end of life. Predicting how therapeutic options will work. Predicting the resilience of some people.

k. Ethical Challenges – involve consent, capacity and substitute decision making. Each of us has the right to consent or refuse consent to an intervention or treatment. Legal capacity would be part of the discussion, but it is right to assume the person has the capacity unless proven otherwise. There is a hierarchy of people who can make decisions. There may be multiple substitute decision makers who would need to agree on the decision. They need to make the decision that the resident would have made, or in their best interests.

a. Spiritual Challenges – First challenge is the barrier of the historical understanding of what the role of the chaplain. Jessie and Father Paul work to be non-judgemental.

b. Resident Care Liaison – Challenges to the role include the difficulty in maintaining professional boundaries, potential for personal bias, managing the large population of residents and families at the Perley and ensuring their own self-care and emotional needs in a palliative environment.

c. Question – Bernie Becker – wonderful information, but he suggested it would be good to provide the information into the units about how help can be found or coordinated.

d. Question – Fran Cordukes – really appreciated the information, but wondering how this information will be shared within the staff. Linda Hunter – building capacity is tricky, level of improvement needed. The Palliative Care Committee understands the need for change and needs to start on the front line. Front line training for staff examples – LEAP program – front line providers get detailed training in Palliative Care. 6 have been trained, 12 will be trained in the next 6 months. Josh Landry – hard to build capacity in an organization this size. There have been a number and variety of sessions on ethics training. As the Perley moves forward this will be part of the baseline training for new staff. Dr Robert – spoke to a historical Palliative research program that was coordinated with the Perley, but the general finding was that the Perley was well positioned.

e. Question – Ray Bailey – how to help families have these challenging discussions. Carolyn – referenced the psychosocial assessment, which has recently been significantly enhanced. This has provided a good structure for discussion with newer families. Linda Hunter- it is challenging and it is necessary to go back and have the conversation again. Good example is the “Speak Up” video. All types of staff need to keep working to have those conversations more actively. Dr Robert – the care conferences are a really good time to have those discussions.

f. Question – Mark Bowman – spoke very highly of the nursing and other staff and the support they provided during his mother’s end of life. The staff were phenomenal. Music has provided, nursing staff were regularly present. Dr Robert – new term being used “a good death”. Doreen Rocque – the music therapists were really appreciated and their presence with her husband were appreciated.

g. Linda Hunter – the support of the Family and Friends Council is appreciated and one way to help share information with families and friends. She recognized the example that Doreen Rocque is taking a Palliative Care course.

4. The FFC Annual report was provided to attendees, and will also be placed on the Website after the meeting. Motion to adopt the FFC Annual Report, moved by Mark Bowman, Second Brenda Tobin. Approved.

5. The FFC 2015-2017 Strategic Plan and 2016 Priorities were provided to attendees, and will also be placed on the Website after the meeting. Adoption of the FFC 2015-2017 Strategic Plan and 2016 Priorities, moved by Heather Moxley, Second by Joan Olinik. Approved.

6. Slate of Council executives. Joan Olinik has agreed to stand in for Jim LaPlante who has stepped down. Three council members have agreed to stand for another term (Doreen Rocque, Brent Mersey, Fran Cordukes). Motion to accept slate – Brenda Tobin, Second Brent Mersey. Approved.

7. The Financial report for September, with the notation that October remains unchanged were provided. Approval of the September and October Financial reports – Moved by Brenda Tobin, Second by Doreen Rocque. Approved.

8. General comment from the Chair
    a. Six members of the council no longer have direct family members as residents and we are continuing to look for additional support to the membership to ensure we can provide the direct support.

9. Moved to adjourn by Doreen Rocque at 8:40 p.m.