

Notes Palliative Care Orillia session

May 30, 2016

Questions from Attendees

- Question on whether the number for hospital deaths has changed. Explained that data is 4-6 years old (data challenges).
- Request for information: current number of deaths in hospice and hospital and those that are palliative
- How will these goals be measured and in what time frame? Need to build on the current work, this is one of CCO's main focuses, but can't really answer that question

Summary of Discussion

Question 1: What do you think are the strengths of the current palliative care system in this community?

- Aftercare for survivors
- Quick response from hospice
- Easy access to education, some good communication
- Good network of professionals and volunteers if the patient gets linked to them
- Passionate volunteers
- Community rounds
- Easily accessible services
- Broad service provision
- Strong faith based community
- Organizations are open to training and education to enhance cultural competency

Question 2: What are the opportunities to improve palliative care in this community?

- Crisis relief built into the system
- Psychosocial supports for the care givers
- Discharge for those into a more rural community and making sure that they have the supports they need
- Creating a team for more holistic care
- Normalizing these conversations
- More education and communication on services available, specifically normalizing conversations about death and dying
- More paid and volunteered individuals for implementation of changes
- Additional locations for people to die
- Advocating for funding for ALC palliative beds and residential hospice beds
- Residential hospice, more facilities
- Caregiver support

Question 3: What three words or phrases would you use to describe your ideal vision for palliative care in this community?

- Quality accessible and equitable
- Responsive, practical, walking in a care givers shoes

- Supported, responsive, accessible services
- Collaborative, needs-based
- Building more facilities, reform the current system, responsive to the needs in community, integration of all pieces (education, communication, etc.), hands-on care

Additional Advice for Creating Structure

- How is the aboriginal community included within this?
- Define the metrics for success, and define what are failures
- PSW and Nurses that are going into the homes, their voices need to be heard (they need to be invited to discussions around the patient's care and around system reform)
- Don't want to spend a lot of time discussing what palliative care is and what it means, need to spend the time on how to get the care to the patients
- Bring families and patients into the conversation to figure out what the metrics are
- Balance qualitative vs. quantitative
- Need to listen to the caregiver
- At time of diagnosis, need to make sure that the patient is fully informed
- One place in health care where you need redundancy, need to put redundancy into the system so the message isn't missed

How we can stay in touch?

- Use the NSM website
- Summary of each engagement sessions

Submitted Worksheets

Repeated Themes:

- Question 1
 - Strong MD presence/provision of palliative care MD services in the home
 - Palliative Care Nurse consultants and our hospice staff
 - Hospice volunteers are passionate and committed
 - Communication and coordination between service providers
- Question 2
 - More education along the journey – in the language that people understand
 - Normalizing conversations about death
 - Improved awareness of what is available
 - Improved Advanced Care Planning
 - Better support to caregivers

Question 1:

- Passion of those in the field
 - Desire to meet needs but demand is greater than the resources
- People willing to work together to support the patient's needs
- Strong MD presence/provision of palliative care MD services in the home
- Access to community services

- Support groups
 - HL
 - CCAC
 - Hospice
- Volunteers @ hospice
- Education to Presbyterian services with good care provided to patient/caregiver as a result – well received
- Willingness to collaborate/educate RE: FNMI/community needs
- Home care providers are doing a great job (passionate/knowledgeable)
- Broad service provision in the community
 - Faith leaders
 - Volunteers
 - Mental health
 - Health care professionals
 - Support groups
- Cultural competence
 - Willingness to collaborate and educate
- Palliative Care Nurse consultants and our hospice staff
- Partnerships – education, community, FHT, Hospital – good communication within region, not just locally/community rounds with multi-disciplinary team
- Caring compassionate service providers in hospital community and LTC
- Easily accessible services and information at any point of entry (work together/cross over)
- Advance care planning champions group enthusiasm
- Never excluded/inclusive process–unit, work with whole family
- Accessible bereavement services
- 24-hour access with nurse consultants for health care providers
- Good network of professional and volunteers, if people can get linked to it
- Hospice volunteers are passionate and committed
- Families are appreciative of support provided – eg. Learning from hospice volunteer
- Bereavement program to support people after
- Engagement of the faith community
- Access to Hospice Simcoe in Barrie
- Good skills in LTC and retirement homes
- Frontline providers are knowledgeable and caring because of the easy accessibility to education, supportive resources for providers (education/consultants)
- Physicians provide home visit/keep patients through trajectory
- Strong network/community connections behind the scenes
- Partnerships eager and invested
- Quick delivery system
- Family health team is smaller, more cohesive
- Emphasis on volunteers (in programs)
- Quick response from hospice and CFHT with nurses
- Community education is strong – which is critical

- CCAC – coordinating health care professional is strong
- Service provider care was good ie: nurses visiting in the home
- Doctor Home visits were great – every 3 days visited in home
- Orillia itself, as a small community, has good communication
- Communication and coordination between service providers
- Services that help you navigate the palliative system

Question 2:

- Training of staff in retirement and LTC
- Demand > resources
- Capacity
- Caregivers/Care providers aren't always allowed the opportunity to provide input or time to discuss needs with MD or others
- Crisis relief should be built into the system (not necessarily placing the patient elsewhere but increase how define crisis, psychosocial and ADL's/etc. to support the caregiver)
 - Caregiver assignment – advocacy for the caregiver – wrap care around the caregiver to support them in keeping the loved one in the home during times of crisis
- Relationship building with FNMI community continue to increase cultural competence amongst professional
- d/c to rural and remote communities
 - better planning
 - discrepancy for home care in these communities
- Lack of referrals – lack of knowledge of hospice services available, improve education with community
- More education along the journey – in the language that people understand
- Normalizing conversations about death
- In the system from the time of diagnosis so people hear info when they're ready to hear it
- Create a team of Care Professional that support the holistic needs of the person and family (including anticipatory grief and grief of the dying person) throughout the trajectory of the illness
- Hospital supportive of palliative care
- More embracing of ACP and death/living (rather than death denying culture). Keep talking about ACP death, continue the conversation cross culturally and socioeconomically
- Not enough staff to do palliative care
 - PSWs, nurse consultants, councilors, hospice volunteers, etc.
- Equitable access to services/regionally – system not supporting patient choice of where to dies if can't afford services, or if they're not available in their geographical area
- Improved awareness of what is available
- Improved Advanced Care Planning
- Implementation of Physician Assisted dying
- Residential hospice
- Language of palliative care/end of life care
- Better support to caregivers

- Too many limitations on supports
- Caregivers have to collapse before support comes
- More physician care in the home
- Additional facilities/locations for people to die – that are accessible
- LHIN advocate for funding for ALC palliative beds and Hospice beds
- More respite supports and services
- Early identification for palliative care
- Common language, identifiers (HRM – two way transmission)
- Chronic disease – disease agnostic approach
- Linking/partnering with chronic disease management programs with HPC programs
- More man/woman power ie: staff and volunteers
- More education and communication on services available
 - Educate doctors
 - Educate funeral homes
 - Educating that it extends to the family
- Need a facility (residential hospice)
- More connections with faith-based community
- More ambassadors for advanced care planning
- Normalizing death and dying
- More education for survivors
- More community connections
- More education to youth on death

Question 3:

- Compassionate Communities
 - Care is inclusive of everyone
 - Healthcare, community supports, faith/spiritual, psychosocial
 - Normalizing death and dying process encourages planning
 - Responsive to individual needs and dignity
 - Responsive, practical, dignity, kindness, passion
 - Walk in someone’s shoes (put yourself in people shoes who is caring)
- Quality, accessible, equitable palliative care
 - Provided by informed/current compassionate individuals to an informed life embracing community that has completed their Advanced Planning.
 - Including the five elements of Advanced care Planning: legal, medical, spiritual, social, and financial
 - In an understandable and standardized way that is held accountable
- Me and my family will be supported through responsive, respectful and linked services
 - Supportive, Responsive
 - Comprehensive
 - Caregivers linked
 - Person centered
 - Respectful – culturally sensitive

- Collaborative
 - Leverage resources
 - Equitable
 - Individualized (meeting Patient/family needs)
- Information/education
 - Building
 - Integration of all the pieces