Notes from Midland/Penetanguishene Palliative Care Session

June 22, 2016

Summary of Discussion:

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

- Excellent volunteers, doing it because they want to and not because they have to
- Support of all 4 municipal mayors and council, they come out to functions and support the seniors
- Two palliative care case managers and physicians and CCAC
- Awareness around palliative care in the area, involving all of the people in the area
- Education that is coming to help other sectors to give them the support they need to support palliative patients
- Multidisciplinary team
- Palliative care rounds at the hospital includes individuals in the community that are involved in the palliative care sector
- Cultural and language supports
- CCAC has strengthened their palliative care supports
- Commitment of volunteers, willing to participate and receive education around palliative care
- Education of the staff about palliative care
- The network provides education on palliative care
- Access to a physician focusing on palliative care

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

- Creation of a residential hospice in Midland/Penetanguishene
- Improve palliative care in LTC and residential care, make the environment more like a home
- Improve system level planning, the system is currently very siloed
- Greater communication, sharing medical records, pilot for a coordinated care plan going on in Midland area
- Educate that hospice is not only a place for individuals to die, public education
- More support for caregivers at home, especially in the last days of life
- Needs to be better communication between active oncology and palliative care
- Developing and spreading some of the strengths in the system to the more rural areas
- Have someone to call for clients that don't have any family members/caregivers
- Organizational buy-in for staff to attend education
- Standardized referral process, accessing resources, how do we know about the resources, how to fill in the gaps for patients
- Teaching physicians to do referrals to community support services
- Funding, in smaller communities everyone is competing for the same dollars, create a better way to spread the money

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

- Whole life care into death, whole including pets, family, caregivers, etc.
- To serve and to love
- Holistically and safe, patient centered
- Educational choice with dignity, you are making an educated choice
- A beautiful death with a coordinated journey …
- Coordinated, passionate and caring

Additional Advice for Creating Structure

- Listen
- Assess what is in place and what should be in place what will be available
- People connecting the dots for palliative care patients
- Remember what the focus should be, the patients and family
- Try to keep things simple
- maybe have an info bulletin
- maybe send a reminder to have a look at the updated info on the website

<u>Submitted Worksheets</u>

Repeated Themes:

- Question 1
    - Good community palliative physicians
    - Palliative care NP
    - Our region has dedicated staff both in hospital and community that has a strong commitment to education in palliative care
    - Our experienced community nurses
    - Great volunteer base willing to participate – strong network

- Question 2
    - Need to expand grief education to clients, families and health care providers
    - Central medical record sharing
    - Need to create standardized system for information access to limit number of assessments required
    - Creation of a residential hospice
    - Greater communication about community resources
    - Caregiver support should increase, and increased homecare

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

- Two amazing palliative care case managers
- Good dissemination of education
- Education opportunities from network accessible for all disciplines plus consultation across all sectors
- Midland/Penetang per capita has excellent community partnerships who are passionate about palliative care
- Good spiritual care presence for p.c. in hospital
- Close knit unit in Midland/Penetang and support each other
- Good community palliative physicians
- Good partnerships between agencies, i.e. Alzheimer's, ALS, Kidney Care, Cancer Centre
- Palliative care NP
- Referrals from physicians to i.e. Hospice
- Volunteers in our community
- Resource consultants – Training education
- Organizational structure from LHIN
- Small community – everyone knows each other and can ask someone what they might know
- Waypoint has palliative care internally
- Hospital currently is a partner for palliative care
- We have a hospice who has a bereavement volunteer visiting program
- 4 Mayors that support programs
- A lot of information for Advanced Care planning
- Palliative care network that provides education and links within the region
- Palliative care nurse provides specific education to staff
- Hospice Huronia deals with the network at a governance level
- Hospice Huronia provides volunteers to help both patients and families; specially trained volunteers for grief and bereavement support
- Physician support is excellent
- Palliative care nurses through CCAC that provide home visits
- GBGH is the only CCC program in the region with 3 dedicated palliative care beds
- Weekly palliative rounds with community partners and the hospital providing early identification and early referrals for priority to dedicated palliative beds when someone becomes end-of-life in the community. Aware of needs when patients come to us
- Our region has dedicated staff both in hospital and community that has a strong commitment to education in palliative care
- Nurse practitioners – palliative care focus
- We have people who are passionate about palliative care
- A rich history of palliative care. Heightened awareness of palliative care encompassing our rich history of palliative care
- Education through Palliative Care Network to LTC by resources nurses
- CCAC, Georgian Bay Cancer, Hospice Huronia – very supportive of each other
- Hospice Huronia has been around for over 20 years and interested in residential hospice

- Dedicated physicians in the area
- Community reach transportation does not have to relate to medical appointment
- Our experienced community nurses
- Palliative care rounds – multidisciplinary team combination of community and hospital staff
- EDITH, symptom relief kit, used consistently. Promotes communication
- LHIN has been supportive of palliative
- Access to visiting physician, nurse practitioner, support family and family doctors
- System for orphaned patients
- Hospice Huronia – Volunteers!
- Experienced visiting nurses
- 2 dedicated case managers – CCAC
- Palliative care resource nurse sees patients in hospital and LTC
- Community social support and awareness
- CCAC – strength in palliative assessment/care/supports
- Hospice Huronia – strength of small community
- Aboriginal support – Georgian Bay Woman's Association
- BANAC – traditional healers, ceremonies
- Access to private care to supplement government supports
- RVH cancer care aboriginal patient navigator
- Doctor visits to homes of palliative patients
- Commitment of our volunteers
- Education of staff about palliative care – nursing families
- Great volunteer base willing to participate – strong network
- Good training and education for volunteers
- Great effort by LTC facilities staff
- Ambulatory care
- Community caring

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

- Need increase p.c. education in area of mental health
- Need more grief & bereavement education
- Need to expand grief education to clients, families and health care providers
- Need more information and awareness where resources are from the CCC's
- Increased palliative care beds (hospice)
- Need increased early connection to p.c.
- Need better standardized referral process and awareness of it for all provider agencies (one stop shopping)
- Time allotment for education – increased workload, not covered, not paid for -> need support from workplaces
- There needs to be 'organizational' buy in and needs to be allocated funds
- Central medical record sharing
- Assign to palliative coordinator earlier
- More ACP education sessions

- Remove silos esp. within CCAC
- Eliminate duplication
- Public profile and how to access palliative care
- Number of beds for palliative care
- Teaching physicians to do the referrals for palliative care – references for family support
- Ontario palliative care network – lack of standardization for policy and procedures
- Need to create standardized system for information access to limit number of assessments required
- Funding – everyone competing for fundraising dollars
- Creation of a residential hospice
- Improved palliative care in retirement homes and long term care
- No access to residential hospice palliative care close to home
- Earlier identification of patients who require palliative care
- Earlier education about the trajectory of palliative care
- Improved funding for hospitals to provide palliative care
- Residential hospice
- More support for the caregiver at home, Respite/PSW. OHIP funded services are focusing more on personal care. Beyond what hospice volunteers can provide, system limited resources
- People do not have opportunity to die where they want
- Less of a focus on spiritual and emotional support due to limited resources
- Discussion of palliative care happening too late in disease trajectory
- Needs to be better integration between active Oncology to palliative care team
- Education around communication strategies discussing palliative approach to care
- Transportation. Access, cost
- System level – access, planning & development. All regions have access to the same services
- Greater communication about community resources
- Sharing medical records – electronic coordinated care plans
- Public health approach
- Palliative care service provider agency, Hospice as the 'Hub' of P.C.
- Residential Hospice – more support for bereavement
- Professional palliative education increased for doctors and volunteers
- Caregiver support should increase, and increased homecare
- Recognizing cultural diversity
- Include chronic illness, not just cancer
- Dedicated system navigator for this region (Health Link) to link programs
- Equitable access that is connected regionally
- Use of technology to improve palliative care (virtual hospice)
- Education and communication with the public and families
- Empower families to be proactive vs. reactive
- Support for individuals without family and dying alone
- Earlier health screening , rural and first nations
- Develop and spread strengths to remote areas and rural. All receive equal access to care
- Increased support to staff, clients & families, LTC and nursing homes

- Public education – what is palliative care
- Improve caregiver support
- Open residential hospice. Not just a place to die
- Provide respite care
- More PSW's in palliative care

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

- Standardized, sustainable, seamless
- Early, equitable access to standardized, sustainable, seamless high quality palliative care which is person and family centered
- Educated choice, dignity, collaborative care – work together for the best care for the client/patient. Remove the 'Turf wars'
- A beautiful death with a coordinated journey while living for today
- Access, choice, community, individual, journey, awareness, custom-built, seamless, supporting the journey
- Collaborative care provided by knowledgeable care providers including families
- Equal access and inclusive
- The right to equal, timely, appropriate, comprehensive, compassionate, seamless palliative care for patients and families/caregivers
- Whole life care into death
- Coordinated, compassionate, caring
- Holistic and culturally safe, patient centered
- To serve – To love
- Honesty and comfort
- Advance planning