# Community Study

Panel Discussion

# Participants

- **Rebecca Bowie**, Coordinator Hospice Palliative Care Services, Community Home Support Lanark County
- **Alice Howarth**, NP, HOspice Palliative Care Program, SELHIN
- **Suzanne Jensen**, RN, CHPCN ©, Palliative Pain and Symptom Management Consultant
- **Sarah Kearney-Nolet**, Care Coordinator, SELHIN
- **Janet Douglas**, Palliative Care Nurse, PSFDH
- **Leigh Wahay**, MD, Community physician, NLCHC and PSFDH

# Objectives

- To present a typical case in our community to highlight common issues and challenges with in home palliation
- To highlight our local resources.
- To understand the concept of initiating palliative care early may allow for smoother transitions for the patient and their families.

# Case Study

- Mrs Brown is a 67 year old married woman who was diagnosed with multiple myeloma in 2011
- She received a stem transplant which failed and then started chemotherapy
- Being managed by the Hematology Team at a tertiary hospital
- Past Medical History – Healthy and on no medications
- Social History – married to her husband, 4 adult children (none lived locally) and was an artist
- Good social support with family and friends

- During the next two years during her treatments she had
  - **3** admissions to the tertiary hospital for complications
  - **17** local ER visits to manage symptoms related to treatment and disease progress
  - **12** transfusions at the local hospital
  - Multiple visits to the family doctor for supportive care

# April 5 to 11, 2013

- Admitted to tertiary hospital for weakness, shortness of breath, uncontrolled headaches and anemia
- Received transfusions of PRBC and platelets which helped her shortness of breath
- She wasn't eating much, had lost a lot of weight and was not able to get in and out of bed on her own.
- The hematology team had a discussion with the patient and her family and she elected for no more treatments, including blood transfusions and wanted to go home to die.
- Meet with the palliative care team who started the PO morphine with bowel regime (restorlax and senokot) and on discharge sent her home with both PO and SC morphine.

# April 5 to 11, 2013

- The family met with the social worker and home care coordinator to make arrangements for daily nursing care.
- The palliative care doctor called her family MD to inform them of the situation and the family MD agreed to do her palliative care at her home.
- She was discharged on a Friday and the family MD was going on holiday for the next 10 days.
- I was asked to cover this patient and was informed that "***everything had been arranged including medications and I likely wouldn't be called as the patient was doing fairly well***"

# April 11 to 14, 2013

- No problems, no calls,
- Palliative Care Nursing was in the home daily

# Tuesday, April 15, 2013

- call to the clinic from the Home Care Nurse
- The patient isn't doing so well and is really SOB.
- Can Dr. Wahay come and assess today

# **Home Visit** – Tuesday April 15, 2013

- Home nursing is new for this family – they did not have Home Care before. Husband is concerned about the different people in and out of their home. Nursing is daily and seems to be going well – they have all the equipment they need
- PPS 20-30%. Patient is alert and engaging in conversation. She is able to swallow medications and denies any constipation or nausea.
- She is having some headaches but finds the morphine 5 mg q3 hours PO is helping with her headaches.
- She is getting more SOB and wonders when the home O2 which was ordered from the hospital is coming.
- I note she is on IV hydration (has a PICC) and getting about 1 L a day.
- Patient is happy to be at home and her children have arrived for the week.

# **Home Visit** – Tuesday April 15, 2013

- Discussion with the family regarding goals of care
  - DNR had been discussed and agreed upon but no DNR-C form completed
  - Wanted to know how long we could keep the IV hydration going
  - Was asked "how long does she have"
  - When are we getting 24 hour nursing
  - Wants to keep her at home as this is where she wanted to die
  - "how are we going to keep her comfortable"

- Nurse is present during my visit and states
  - There is no SRK in the home
  - We have no palliative orders to give sc medications

# My "To do list"

- Order Palliative Home Oxygen since it got missed on discharge
- Wrote Palliative Care Orders and medications and faxed to pharmacies and Home Care
- Did not order a SRK kit because we were now close to needing subcutaneous orders
- Filled out the DNR – C form and explained not to call 911
- Gave my contact numbers to the family

# April 16 and 17, 2013

- No issues
- Called the husband on Thursday and stated things were going well

# April 18, 2013 – Good Friday

- get a call from the nurse - "She is not swallowing well anymore, is less responsive and more SOB".
- Discuss with the nurse to switch to sc morphine for his dyspnea / pain management.
- Call back a few hours later and much improved.
- Wife also expressed she wanted 24 hour nursing.
- Discussed only able to provide night time nursing **IF** available.
- Able to get in PSW overnight on a long weekend!!!

# April 19, 2013 - Saturday

- Phone call from nurse - "running out of morphine injectable and using it every hour".
- Decide that a CADD pump would be useful as the local pharmacies had very little morphine injectable to supply to get us through the weekend.
- Phoned the pharmacy and verbal order for CADD done and delivered 4 hours later. Nurses able to get it running well.

# April 19, 2013 – Saturday
## Home Visit

- patient was at EOL – PPS < 10%.
- Shallow breathing, not agitated, comfortable, no pain, no vomiting and surrounded by her family. Discussed with her husband that the IV hydration should be discontinued and he agreed.
- Their home was full of friends and family. Husband and the son had asked "how much longer". I stated she had hours left but not sure how long. Stated it could be a few days but no one is able to predict.
- Patient died the following day, comfortable and peaceful.

# 6 months later ….

- Husband books an appointment to see me.
- States he was very upset with me.  I was surprised because I felt she had a "good home death" despite the hurdles we had to overcome to get many things in place in a short period of time.
- I also felt the nurses had been wonderful and provided excellent care to this patient and her family.
- I asked what was he upset about.

# 6 months later ….

- He stated that I should have told him that she was going to die that night because if he had known, he wouldn't have left her side even if he had to go to the bathroom.
- We had a long discussion about predicting death and about the guilt he felt around not being at her side at all times.
- He was having a difficult time grieving her death and I referred him to a counselor for his grief.

# Questions

- What went well?
- What didn't go so well
- What things could have been done from the tertiary center to make the transition smoother?
- What should have the family MD done differently before they left for holiday?
- What local/community services could have been implemented earlier to help the patient? The husband/family
- If the Palliative Pain and Symptom Management Nurse and or Palliative NP had seen this patient earlier in the course of his disease, do you think her symptoms may have been better managed?
- If palliative care had been initiated earlier in her disease trajectory, would this scenario have been different?