

ESC EOLCN – Case Studies Illustrating Palliative Care Provision and Requirements across the Care Continuum

Note – These case studies are not the story of any specific patient. These case studies are based on the collective experience of numerous healthcare providers with experience spanning many years.

1) “Angie’s” Case Study

Notes in italics highlight how palliative care experts and services may have changed the outcome for the patient and family

Disease Journey early 2005 - June 2006

Demographics:

Angie is a 35 year old moderately obese woman who lives with her common law spouse, Fred. She has three children, a 12 year old son; 8 year old and 4 year old daughters. Fred is the father of the two youngest children. Angie is the primary financial provider employed as a waitress and has no extra health benefits. Angie’s medical history includes asthma, and diagnosis of Stage II Carcinoma of the Cervix (2005). Treatment included chemotherapy and primary radiation.

Angie smokes a pack of cigarettes a day. She has tried to quit in the past and now feels – “Why not smoke?”

Diagnosis:

Angie visited her family physician three times in 2004, specifically for complaints of lower back pain and Angie reports that she was told to lose weight. Proactive health screening regarding Pap Smears were not done.

- presented in Chatham Kent Health Alliance (CKHA) Emergency department (ER) early 2005 with pelvic pain radiating down left leg (leg very edematous), admitted to Medical bed.
- Doppler and blood work completed followed by CT scan and MRI.
- Diagnosed with Deep Vein Thrombosis (DVT), extensive abdominal tumor (cervical primary) invading muscles, vascular system and there is widespread metastatic disease throughout her skeleton.
- Treated for DVT, pain medication given.
- Referred to London Regional Cancer Program (LRCP) for Oncology consultation and treatment options, palliative chemotherapy & radiation were offered.
- Angie opted for “trial study” palliative chemo however her intention as she stated was to “Beat It” (prognosis not understood at this time).
- Fred took time off work to drive Angie to London and provide support in the home.
- Financial problems caused stress and relationship challenges.
- Angie is angry at the medical system due to her perception that her diagnosis was missed because she was not believed and dismissed because of her obesity.

Stable Stage: PPS-100% - 70 %

- Pain control was an issue as Angie was hesitant to take pain medication even after she received education regarding how the medication works and the benefits of taking it as ordered. Her rationale was to maintain her independence and activity with her children. She stated that the pain medication made her head “fuzzy”. *Primary care providers (expert palliative care team consisting of Palliative care physician(s), advanced practice palliative care nurse(s), social worker and pastoral care worker) who are knowledgeable in pain & symptom management can often manage the pain while leaving the patient with minimal side effects.*
- Goal of chemo was not clearly explained or not understood by Angie and Fred. *A system navigator/advocate could have reviewed the information given by the Oncologist and the treatment goals so that Angie could have made an informed choice and begun End of Life (EOL) care planning.*
- Community Care Access Centre (CCAC) Case Manager (CM) involved and scheduled service provider support: nursing for pain management; social work to assist with financial concerns, psychosocial support for Angie and to initiate discussion about disease process and support available for Fred and the children. (Appointments were scheduled and then cancelled by client). *An expert team would have already developed a relationship with Angie and she may have been more receptive to their support.*
- Seen at London Regional Cancer Centre (LRCP) every 2 weeks for chemotherapy for a total of 5 treatments over 10 weeks and discharged back to her family physician who did not make house calls and did not have hospital privileges. *Liaison between the LRCP team and an expert team in the community would have provided a smooth transition of Angie’s care.*
- Unable to void, she was seen in the emergency department (ER) for catheterization due to extensive disease involvement of the genital/urinary system and Angie panicked and insisted on “going to the hospital”. Angie was admitted to a surgical bed where her pain medications were not managed well and she was labeled as a “drug seeker”. Discharged home saying “I will never go to hospital again!” *The nurse in the home, although very experienced, did not have physician or team support. A specialized palliative care unit with dedicated expert palliative nurses and palliative care physician in the hospital could have managed not only her physical pain but also helped her work through many of the other issues that she was dealing with- fear, anger, grief, anxiety, loss of hope.*
- Second ER visit for exacerbation of pain due to tumor progression, no bed available, returned home with prescription to increase pain medication, no intervention for her present constipation or follow-up note to her physician done.
- When her script from the emergency department ran out her physician would not renew it since he hadn’t prescribed it and she once again had to go to the ER, third visit because she was in a pain crisis. *This is a common situation that could be averted by having a palliative care expert team in the community*
- Angie’s physician did not have anyone on call for him. *An expert team would be available 24/7 and care would be managed with a team approach to avoid ER visits.*
- Admitted to LRCP due to a pain crisis when attending for pelvic radiation.
- Seen again in ER for exacerbation of pain in pelvis, lower back and down left leg. *An expert team would keep ahead of the disease process and avoid ER visits.*

Transitional Stage PPS-60 % - 30% (summer 2005-winter 2005)

Fred returned to work due to financial strain, sister and mother visited daily to assist with children.

- Angie has increased pain and because her physician will not make home visits she spends much of her time suffering and making the difficult journey to his office. On most office visits she can only discuss one symptom and needs to make another appointment for a different symptom. *Patients at EOL often have a many symptoms that need to be dealt with at the same time. Suffering can be minimized with a palliative care physician, expert team or palliative care pain outpatient clinic.*
- Referred to pain specialist at LRCP and was admitted.
- Chemo not effective and stopped.
- Angie refused palliative radiation for bone pain management.
- Angie experienced decreased activity.
- Angie does not want to be admitted to hospital now or at the end of her life.
- Palliative Performance Scale (PPS) score (50%) the visiting nurse introduced the End of Life Care Plan. Angie wants all interventions so she can live as long as possible for her children. She is closed to discussing death or dying. *Angie requires support from a specialized PC team to help her deal with her fears and continue to grow through this illness journey so her children and Fred can experience healthy grief after she dies. A hospice resource centre (geranium House or Myles Miracle Mission) could supply this kind of support.*
- Does not have a Will and has not appointed a Power of Attorney for Financial or Personal Care. Social Worker was consulted again and Angie would not make decisions due to their very strained financial situation, suffering physical and emotional distress, and the determination to “Beat it”.
- Angie sits in recliner 24 hours a day and does not wish an electric bed in her home although she is experiencing increased weakness. *Patient choices are often driven by lack of information.*
- Angie is agreeable to Occupational Therapy to assess equipment needs for safety and transfers. Grab bars, bath seat, and commode chair are brought into the home.
- Agreeable to daily nursing visits for symptom and health teaching in each domain (refer to the Domains of Issues Associated with Illness and Bereavement source: A Model to Guide hospice Palliative care; Based on National Principles and Norms of Practice) as needed. Many nursing visits last 1 1/2 – 2 hours. *Most nursing visits are not funded for more than one hour. This results in the nurse working on her own time or the agency picking up the extra cost through private donations.*
- She declines assistance with activities of daily living (ADL's) from Personal Support Worker. *Patients often strive for independence far past their families' ability to cope. This results with a hospital admission or admission to a residential hospice depending on the complexity of the symptoms.*
- She continues to smoke even though drowsy at times and requires two inhalers/puffers to control asthma symptoms. Danger of fire present as she drops her cigarettes. *Actually requires someone present 24/7 to monitor her activities and assist. Residential hospice would provide this at no cost to the family.*
- Complains of **extreme shortness of breath** due to asthma, anxiety and increased abdominal distension due to ascities, a paracentesis is preformed to drain the fluid and relieve the pressure on her diaphragm. *A palliative care unit in hospital is needed for this type of intervention (short stay), initially.*
- Continues to have difficulty **voiding**, indwelling catheter is inserted.

- **Decreased self esteem/intimacy**, relationship with spouse is affected
- **Tumor invasion of ureters** causes an increase of pain and decrease urine output, this is stabilized by a hospital admission (7 days) to insert a Stent into the left Ureter. *All the above symptoms are difficult to manage in the home setting or residential hospice. Hospital palliative care beds (for a short stay to stabilize things) are required for this type of intervention.*
- Angie presents again at the ER, is admitted (10 days) and this time a hospital internist continues to follow her when she is discharged home. *An expert team would already be in place to handle this in the community.*
- Angie begins to talk about “life losses”.
- Edmonton System Assessment Scale (ESAS) scores indicate that Angie is experiencing anxiety, shortness of breath, depression, pain, drowsiness, poor bowel function, fatigue and hopelessness as ESAS scores for these symptoms are all above 5/10. *Multiple symptoms in crisis is not unusual for a patient with Angie’s prognosis.*
- Fred continues support at home along with Angie’s mother and sister. *Volunteer help has been refused by Angie.*
- Angie has no formal church affiliation and requests “someone to talk to”. *A pastoral care volunteer from Geranium house makes a home visit.*

End of Life Stage: PPS-20 % - 0% (Winter 2005 – June 2006)

Fred remained at work. Angie was nearing death. Compassionate Benefits Plan was discussed however Fred found the paper work too difficult and did not follow through. They are borrowing money from family and visiting the local food bank to make ends meet. Mother and sister remain involved when Fred is not at home however Fred does not get along with Angie’s mother and sister.

- EOL care plan has been completed by Angie and the CM. She has made a Will and designated Fred as her Substitute Decision Maker (SDM).
- Angie would like to remain home as long as possible but she still refuses assistance with activities of daily living (ADL’s) from Personal Support Workers or volunteer support for family respite. All family members are exhausted and the children are having difficulty at school. *Residential hospice could supply a family friendly place for Angie to get the 24/7 care she requires and a place to get support for the children and Fred.*
- Angie goes to the ED for uncontrolled pain and other symptoms and is admitted to a medical bed (6 days) in hospital and the local internist collaborated with LRCP Pain Specialist, Fentanyl drip and Methadone is initiated in the hospital (this Physician’s Methadone Prescribing License only allows Methadone to be initiated in the hospital). *An expert team could initiate this in a residential hospice or in the patient’s home.*
- Social Worker at hospital became involved for EOL support and planning for patient and family. Family was in crisis.
- Angie would like to be discharged home to spend time with her children.
- Fred is unable to provide the support she needs 24/7 even with CCAC shift nursing. Angie remains in hospital until she dies even though she wants to be at home and with her children. *A residential hospice could provide a family friendly place for Angie and her family to be cared for in.*
- Angie’s mother and sister have been told to stop visiting at the hospital by Fred, Angie is distraught and she is actively dying, but cannot be managed at home.
- Fred is concerned about Angie dying at home with the children present and then living in the house afterwards. *A residential hospice could provide this level of care*

- Children continued to have problems at school and at home. *Received support from VON Kid's circle program.*
- CCAC collaborates with hospital staff to arrange weekend visits at home.
- Equipment such as hospital bed, commode, oxygen, etc. has been arranged.
- IV Medication prepared in hospital as Angie requires a continuous drip.
- Home care nurse meets Angie at home to assist with medication management, to provide education/teaching to Fred regarding care needs.
- Myles Miracle Mission covers the cost of Angie's transportation home via Trans-Care.
- Arrangements made by CCAC Case Manager, community support agencies and hospital staff to enable Angie to go home for weekend visits. This includes but is not limited to the following: pharmacy at the hospital, pharmacy in the community, transportation by ambulance transport (cost from hospital to home covered by MMM, from home back to hospital by CCAC), communication with hospital staff nurses, communication with community nurse at home, CCAC Case Manager, oxygen set up, hospital bed, commode, supplies (catheter, IV, incontinence products, wound management). *This planning required hours of the CMs time and all who were a part of the planning.*

Angie was able to return home for three weekend visits. Angie died in the hospital in a semi private room on a Medical Unit. Fred stayed seven nights and slept in a recliner chair in the semi private room. The children visited daily. Angie's mother and sister were allowed to visit. Angie's first husband requested a visit with Angie and his son and when he was refused had to be barred from the hospital after causing a disturbance. Fred was present at the time of Angie's death. Angie's room mate was very upset. Angie's children and mother and sister were distraught that they had not had an opportunity to "say goodbye".

Case Study completed by C/K EOLC committee under the leadership of Cindy Stokes and Ann Brignell

Services Required During Disease Journey Specific to "Angie Case Study"
(This is Not an "All Inclusive" List of Support Services)

PPS	CCAC											Hospital							Support Services - All Community Support Agencies Available to EOLC Patients											Hospice		Physicians				
	Equipment	Case Manager	Nursing	Nursing Complex Care (Shift)	Personal Support Worker	PSW Complex Care (Shift)	Social Work	Nutrition Counselling	Nurse Practitioner	Speech Language Pathologist	PT & OT	Placement Co-ordination Services	CCAC CM	ER	Acute Care - All services available	Specialized Palliative Care Unit	PCCC	LRCP	LRCP / CKHA Chemo	System navigation - CCAC & MMM	Financial aide i.e. Transportation- MMM, Salvation Army	Canadian Cancer Society - Transportation	Volunteers in Home	Respite - Geranium House	VON Children Supports	Child Support - WAYS	Pastoral Care i.e. Sal. Army, GH	Adult/child Grief & Bereavement Supports / CHMA	DAY - Counselling & supports	MMM / GH	RESIDENTIAL - 24 hour care for patient who could be managed at home but unable/unwilling to remain home to die.	Family Physician	Palliative Care Physician	Oncologist	PC Pain & Symptom Specialist	
Stable	O	A	R		R	O	R	O	N		O		A	A	A	N	O	A	O		O	O	O	O	O	O	O	O	O	O	N		A	N	A	N
Transition	A	A	A	O	R	R	A	O	N		A		A	A	A	N	O	A	A		O	O	O	R	O	O	A	O		O	N		N	N	A	N
End of Life	A	A	A	O	R	R	A	O	N		A		A	A	A	N	O	A	O		A	A	O	R	A	O	A	A		A	N		N	N	O	N

Legend
 CHMA - Canadian Mental Health Association
 CKHA - Chatham Kent Health Alliance
 CM - CCAC Case Manager
 EOL - End of Life
 ER - Emergency Department
 ESAS - Edmonton System Assessment Scale
 GH - Geranium House
 LRCP - London Regional Cancer Program
 MH - Mental Health
 MMM - Myles Miracle Mission
 O - Services Available Not Accessed
 OT - Occupational Therapy
 PCCC - Palliative Care Continuing Care
 PPS - Palliative Performance Scale
 Palliative Unit - Complex End of Life Care
 PT - Physiotherapy
 SPU - Special Palliative Unit for Symptom Crisis Intervention & Complex EOL Care
 VON - Victorian Order of Nurses
 WAYS - Western Area Youth Services
 X - Services Accessed

Please Complete PPS Area With One of the Following:

A Accepted
 N Not Available
 R Refused

2) “Dennis” Case Study

Dennis, a 66 year old, retired factory worker was entered into a WSIB “watch” study 12 months ago for suspected mesothelioma. Dennis’ WSIB claim is initiated. Dennis’ wife has osteoporosis and mild angina. One son lives in a city three hours away.

Last week, Dennis awoke at 2 am with shortness of breath. His wife brought him to the local community hospital, 40 km from their home, where he described feeling like he was “suffocating”.

Dennis was admitted to hospital and treated with oxygen, anti-anxiety medication and mild pain relief. Dennis underwent chest x-ray, CT chest and thorax: both indicating plaques across both lung fields – predominantly left. Biopsy of pleural fluid confirmed a diagnosis of mesothelioma. Dennis was transferred four days later to the specialized centre and underwent left lower lobectomy. He had a normal recovery post-op and was discharged 4 days later with home oxygen and analgesia. He agreed to begin a course of chemotherapy in 2-3 weeks. On discharge, the CCAC Case Manager met with Dennis and his wife in his hospital room.

Dennis’ WSIB claim is approved.

CCAC Case Manager (CM) discussed various service available through CCAC program available to Dennis on discharge from hospital. Services offered were:

- nursing to monitor the health status of Dennis and assist with symptom management,
- Physio Therapy to assist with post op exercises, ROM upper as well as lower extremities,
- Occupational Therapy to assist with promoting independence and safety at home, as well as energy conservation techniques and relaxation techniques.
- Dietitian -Dennis stated his appetite was starting to return, so further discussion of dietician services was deferred until home visit by CCAC Oncology CM once Dennis was home.

Nursing visits were initiated when Dennis was discharge home, beginning daily until his symptoms became controlled. Once symptoms controlled, and Dennis and his family were feeling more at ease at being at home, nursing visits were gradually reduced to weekly. When chemo treatment began, nursing visits were again increased to daily post chemo treatment for 1 wk and then reduced to weekly as symptoms were being managed. Initially Dennis did very well post chemo treatment, but gradually he started to experience:

- confusion,
- increased pain,
- weakness,
- loss of appetite causing loss of weight,
- increased shortness of breath and with that, increase in anxiety.

An occupational therapist visited to identify equipment needs and any safety concerns and also addressed energy conservation techniques.

Nursing visits were increased to daily ongoing to address symptoms. The nurse followed up with the Palliative Physician involved with Dennis.

Symptoms increased with extreme shortness of breath (SOB) and pain with increasing anxiety and fear.

Nursing contacted physician and it was determined that further evaluation was required related to possible need for thoracentesis. It was felt that Dennis probably did not require admission to hospital so he was sent to the Emergency room for evaluation and possible thoracentesis.

Dennis went to the ER, and the following interventions were provided:

- thoracentesis completed,
- CT of head completed,
- Medications were adjusted for symptom management.

Dennis returned home post thoracentesis. SOB subsided, pain was better controlled, appetite remained poor. Nursing visits continued once daily and then were increase to twice daily for symptom management.

CCAC Case Manager made a home visit to Dennis and his family to discuss increasing care needs. including the need for a hospital bed Dennis and family were agreeable to hospital bed.(CCAC would normally cover rental for 1 month, for hospital bed, but WSIB will cover cost for as long as Dennis needs as he has an approved WSIB claim.) Need for a hospital bed ended up to be 5 months.

The Case Manager also discussed providing assistance with personal care and respite as Dennis was now unable to be left alone and needed assistance with all care and transferring.

The Case Manager further discussed that as his condition deteriorates, 24 hr care would be authorized to assist family. (after conversations with WSIB Case Manager received approval that WSIB will cover costs of 24 hr care, since this extensive coverage is not within the CCAC budget/mandate)

Dennis/family state that they want Dennis to die at home. End of Life Care plan initiated, DNR completed.

As Dennis' physical condition continued to deteriorate, nursing visits and Personal Support Worker (PSW) assistance was increased. Dennis began to receive PSW shift care at night as he was experiencing increased restlessness during night, keeping his family awake. (WSIB was covering cost of care). Nurse continued to follow-up with Palliative Physician re symptoms of restlessness/anxiety and pain

Scenario 1 HOSPICE

Family decides they are unable to cope any longer, and are finding it difficult to have PSW workers and nurses visiting every day and staying in their home. Dennis' wife is

also very distressed watching Dennis experiencing the various symptoms he is having and she is experiencing an increasing number of angina attacks. Dennis's son visits on weekends, but cannot leave his job to provide more assistance. Social Work referral was initiated to assist Dennis and his family with end of life issues, providing interventions for depression, relaxation and pain management. Dennis and his family manage for awhile longer, but eventually Dennis requested to be admitted to hospital. Dennis is in bed all the time, needs assist with all his care needs and all transfers and repositioning.

CCAC CM discusses with Dennis and his family admission to Residential Hospice rather than hospital. Dennis and his family are agreeable and Dennis is admitted to Hospice where he dies 14 days later.

Scenario 2 -HOME DEATH

Dennis' condition continues to deteriorate. He and his family are agreeable to 24 hr care and shift nurses are available for the night shift to give SQ injections and manage pain/symptoms without waking the family (WSIB covers the costs). Dennis is also starting to cough up increased amounts of bloody sputum. Family make telephone call to nurse who makes nursing visit and does teaching re symptoms of lung cancer. Nurse /Dr are able to keep symptoms controlled; family have built trust with nurse re symptom management and follow through with care suggestions. Dr is making home visits as needed.

Dennis dies at home.

Nurse makes follow-up bereavement visit with spouse.

Scenario 3 HOSPICE RESPITE then HOME DEATH

Dennis and his family want Dennis to die at home but need increasing levels of assistance with his care. Service Providers were only able to provide Personal Support Worker (PSW) assistance during the day from 0700 – 2300. Service Providers do not have enough staff to provide night shift care (prefer Nursing staff due to SQ injections needing to be administered, but family would accept PSW and then have family member get up to give injection when Dennis needs it. However no PSW staff are available either.).

Family tries to manage Dennis' care for as long as possible; son takes vacation days to help mother with care of his dad.

Dennis is sent to hospice due to lack of service providers in the community and then returns to own home when service can be reinitiated.

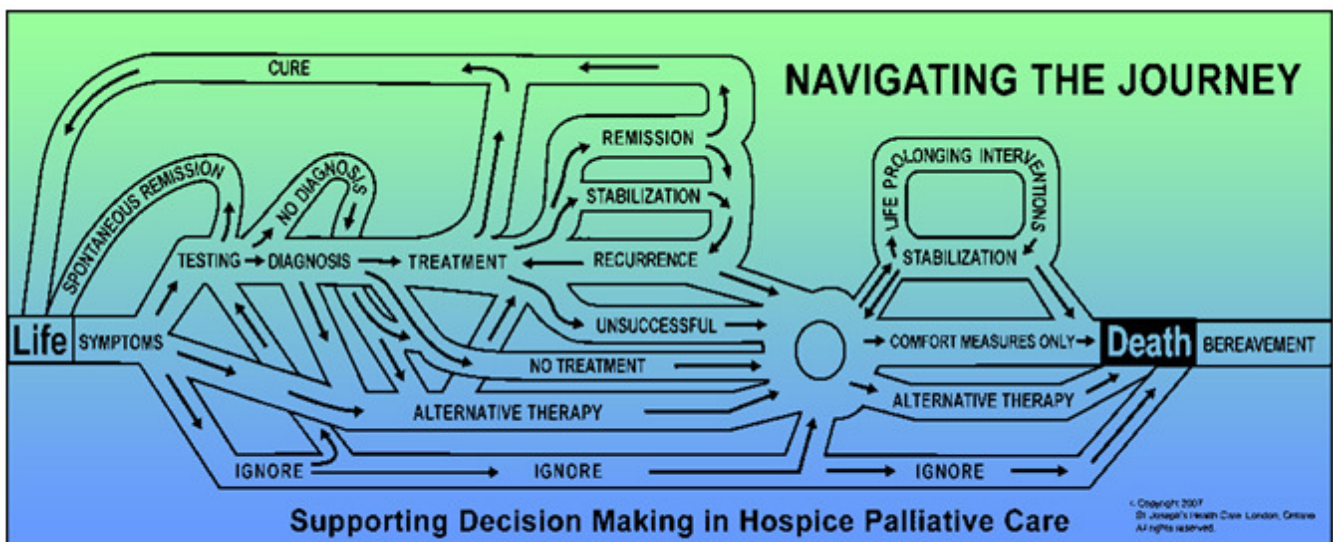
Dennis dies at home.




Scenario 4 HOSPITAL DEATH

Dennis starts to experience increased confusion, trying to get out of bed without assist and becoming angry when caregivers attempt to provide his care. Dennis is coughing up copious amount of blood Dennis needs assist with all transfers, repositioning in bed as well as personal care. Family are expressing to nurse their fear of what is happening with Dennis. A Social Worker is also making home visits to counsel Dennis and his family about death and dying and to provider anticipatory grief counselling. Late one

night, family call nurse to say they have called an ambulance to have Dennis transferred to hospital because he has just had a seizure.
 Dennis is admitted to hospital with uncontrolled seizure activity and increased confusion for symptom management. The goal is to stabilize and control symptoms, however Dennis continues to experience very frequent seizures, with increasing agitation/confusion.
 Dennis remains in hosp until he dies.

Case study completed by S/L EOLC committee under the leadership of Georgie Houston, Karen Dally, and Sue Roger.



-  Living Life
-  Acute Care; Long-Term Care; Chronic Care
-  Palliative Care; Hospice; CCAC