



Palliative Care: More Than Just Cancer



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Janet's situation

Janet, 68, is admitted to hospital with heart failure and advanced arterial and venous ulcers on both legs with gangrenous changes in her feet and considerable peripheral edema. The ulcers create aching pain with some shooting lancinating features. Bilateral amputation has been considered but surgical risks are very high due to her cardiac condition. She has advanced heart disease with periods of ventricular arrhythmia leading to life-threatening status and heart failure. She has been successfully resuscitated three times in the past and remains a "full code". Three weeks prior to admission, she was walking in her home with a cane. She would like to try to walk in hospital.

For a case follow up, go to page 102.

In this article:

1. What are the unique needs of the non-oncology patient?
2. What are the supportive care issues of the patient and family?
3. What are the care planning issues?
4. What is the approach to caring for the non-oncology patient?

The field of palliative care, now 30 years old in Canada, had its roots in the care of patients with endstage cancer. In recent years, attention is turning to patients without cancer but who have great need for palliative care. What are some of the unique challenges presented in the care of the non-oncology patients (Table 1)? In what ways does their care

*"You matter because you are you...
You matter to the last moment of your life"*

Dame Cicely Saunders

Palliative Care

Harold's situation

Harold, 78, has suffered with chronic obstructive pulmonary disease for about 15 years. He has just been transferred out of the intensive care unit, where he had been ventilated because of respiratory failure. This is the third time he has required ventilation in the past two years. Each time it has been of help to him, but he realizes his overall condition has deteriorated, and his breathing is getting worse.

For a case follow up, go to page 104.

Table 1

Unique challenges presented in the care of non-oncology patients

Patients who do not have cancer but who require and can benefit from palliative care comprise a large and diverse group, including:

- Patients in the later stages of heart disease (heart failure or intractable angina)
- Patients with endstage diabetes or lung disease
- Patients with chronic obstructive pulmonary disease
- Patients who have peripheral vascular disease with ulcers and gangrene
- Patients suffering from liver disease and hepatic failure
- Patients with neurologic diseases (such as amyotrophic lateral sclerosis, multiple sclerosis, and Parkinson's disease)
- Patients with advanced cognitive impairment from diseases like Alzheimer's and related dementias, and massive stroke

This group may also include:

- Frail, elderly patients who are admitted to hospital with an acute life-threatening condition, like pneumonia, which proves non-responsive to treatment
- Patients, of any age who suffer multi-systems failure from a number of conditions

differ from that of the patient with advanced cancer?

The components of palliative care include physical assessment with attention to symptom control, information sharing and decision-making about treatments and procedures to be employed in care or not used (e.g., cardiopulmonary resuscitation and hydration). Care also includes emotional and spiritual support for the patient and family and planning with them as to the place of care and resources required for care at home or at another setting. The aims are to provide ongoing support for the patient and family, develop a mutually shared plan of care, provide (through ongoing attentive care) for a peaceful illness course and a peaceful death when that time comes. Also, the aim is to make plans for family support in bereavement and to foster a sense of personal and professional satisfaction for the health team.

The physician and other health team members will be called upon to bring certain qualities, knowledge and skills to the bedside, which can be described as “four Cs and three As”:

- Competence, compassion, communication, companionship; and
- Attentiveness, accompaniment and advocacy.¹

What are the unique needs of non-oncology patients?

Non-oncology patients are at risk for undertreatment of symptoms. This may occur for two reasons: lack of recognition of symptoms and a hesitancy on the part of physicians to order opi-



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Table 2

Symptoms in gravely ill hospitalized patients

Moderate to severe pain	40%
Dyspnea	50%
Severe confusion	25-34%
Serious fatigue	80%
Anxiety and depression	35%
Alone and isolated in last three days of life	6-21%

Adapted from: Freeborne N, Lynne J, Desbiens NA: Insights about dying, from the support project. JAGS 2000; 48:5199-5205; and Desbiens JA, Wu AW: Pain and suffering in seriously ill hospitalized patients. J Am Ger Soc 2000; 48:5183-86.

oid analgesics in this group of patients.

There is evidence that non-oncology patients suffer great distress in the last few weeks of life. The SUPPORT Study teaches us about unrecognized and untreated symptoms in this group.^{2,3} This study assessed 10,000 patients who were in a state of advanced illness at five teaching hospitals over five years. Patients had diagnoses of nine illnesses, including multi-systems failure, sepsis, stroke, endstage heart failure, endstage lung failure, and liver failure. The results of symptom assessment are alarming (Table 2). Clearly there is a large unmet need here. The good news is that, having this knowledge, we can be directed to careful assessment leading to many paths to alleviate the suffering. Much can be done to help patients.

Many of the symptom control approaches are similar to those used to care for the palliative

Table 3

Equal analgesic doses of commonly ordered opioids

Hydromorphone	1 mg
Morphine	5 mg
Oxycodone	5 mg
Codeine	60 mg

Subcutaneous dose: Half of the oral dose (hydromorphone, morphine, codeine)

Transdermal fentanyl: 25 mcg patch equals 45-135 mg of morphine oral per day (mean of 90 mg per day)

oncology patient. However, non-oncology patients generally differ in six ways that will influence orders and approaches for symptom control:

1. Their general physical status may be quite fragile;
2. They will often have combined multi-systems organ failure, affecting medications chosen and doses ordered;
3. They will often be opioid naive (no prior treatment with opioid analgesics);
4. They may often be of older age;
5. They may be taking multiple medications for several diagnoses;
6. Their “organs of life” (heart, lungs, liver) are failing. There is particular symbolism in the life-threatening nature of these illnesses and the periods of sudden crisis that may be inherent to them.

Opioid analgesics are medications of choice for the relief of pain and of dyspnea—two of the very frequent and distressing symptoms in this



Palliative Care

Caring for Janet

Janet reports an aching pain of a Level 4 on a zero to five pain scale. She has some occasional shooting pain features. Pain is relieved for about two hours by 60 mg of oral codeine with acetaminophen 650 mg, which makes her constipated. She also reports feeling increasingly sad and downcast. She looks depressed. She cannot sleep at night, being afraid that her heart will stop and she will die. She is also fearful about the CPR procedures and feels caught between fear of dying and fear of life support machines. She has tried to talk with her family about this, but it upsets them so she doesn't pursue the conversation.

Beginning palliative care approaches include:

- Analgesic orders: Discontinue the codeine with acetaminophen and start hydromorphone 1 mg to 2 mg orally every four hours regularly and 1 mg every one to two hours as needed, for extra pain. Plan to reassess the next day and increase hydromorphone as needed. Prescribe acetaminophen 500 mg every four hours for inflammatory type pain. Consider nortriptyline or gabapentin in a low dose if the shooting pain persists.
- Begin a low dose of antidepressant with plans to monitor and increase as indicated.
- Prescribe a bowel care program of softener and laxative regularly with suppository and enema as needed.
- Order prochlorperazine 5 mg orally every eight hours for the first three to four days of opioid

therapy, to prevent nausea. This can be continued if required.

- Prescribe a light sleeping medication.
- Provide patient and family assessment and supportive care, by the team social worker, to help Janet think through the direction of her treatment, goals of care, and wishes for continued CPR.
- Involve the pastoral care team with Janet and her family.
- Consult with a skin care specialist about her leg ulcers.
- Request nursing assessment for a skin-protective mattress.
- Involve physiotherapy and occupational therapy teams to help Janet meet her goal to get out of bed.

With this approach, Janet is more physically comfortable and, with support, she and her family are able to talk together. She finds the visits of the chaplain helpful and is less frightened. She has some goals of care (to be physically more comfortable, to walk a bit when able and to try to go home with home care services). Over time, her fear of dying is reduced due in part to better pain relief and also to good on-going supportive care. She feels less isolated, frightened and depressed. Through continued supportive care from the whole team and help in talking with her family, she evolves in her thinking about her illness. She requests a NO CPR order.

group of patients.

Hydromorphone is often the opioid of choice for this group of patients. It has no known active metabolites, is well-tolerated by the elderly and by those with any degree of renal impairment. Once symptoms have been relieved with a short-acting opioid, like hydromorphone, a sustained release formulation of hydromorphone or transdermal fentanyl may be an option in selected patients. Sustained release formulations should not be used to bring symptoms under control or

to titrate analgesics for pain or dyspnea. Short-acting formulations, oral or subcutaneous, are more rapidly effective and easier to adjust in dosing. Beginning doses can often be small, but frequent reassessment will guide the increases that may be required for relief. In most cases, a regular dose will be indicated, with a breakthrough dose of one half of the regular dose ordered every one to two hours as needed for breakthrough symptoms (Table 3).

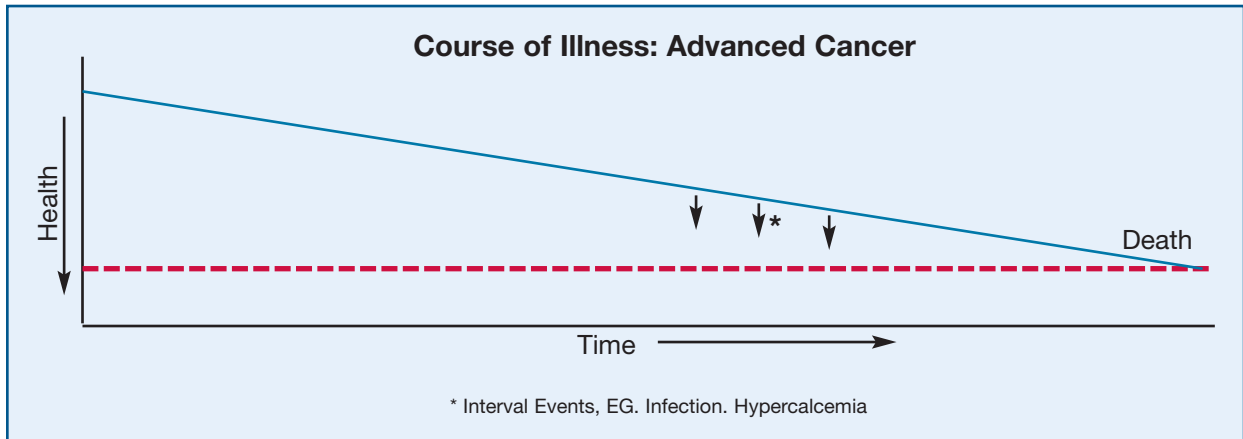


Figure 1.

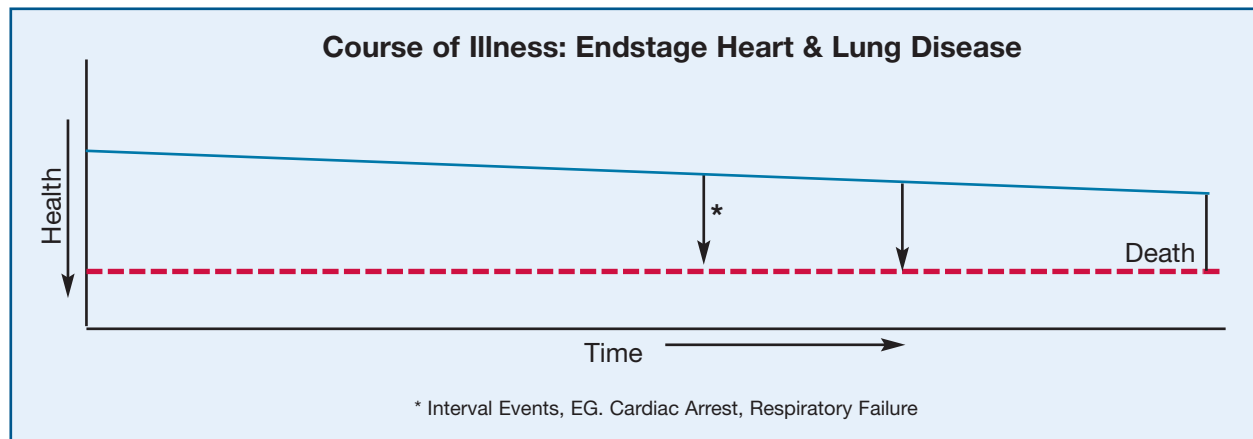


Figure 2.

How do I provide supportive care of patient and family?

There are unique features of care here also. The trajectory of a non-oncology illness may be one of slow gradual decline over time. However, acute episodes of crisis illness may bring the patient to the brink of death and, often, they may recover back to baseline with aggressive life-prolonging treatments. These episodes of near-death crisis create an emotional roller-coaster for patient and for family who will need to prepare for the possibility of their loved one's death each time.

Figures 1 and 2 illustrate, in general, how the trajectory of illness may differ between oncology and non-oncology patients. Understanding the experience of patient and family gives an appreciation of their viewpoints, feelings and care needs:

- How does the physician and team work towards a balance of truthfulness and hope when talking with the patient and family and setting treatment goals?
- When does the team introduce a palliative care approach to care? This can be particularly difficult with patients who have advanced cardiac, lung or renal disease where aggressive life-prolonging measures may be of considerable help to the patient for some time.

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Caring for Harold

Harold is very frail and quite dyspneic. He isn't eating very much. The subject of a feeding tube for temporary nutrition had been raised by the nutrition team. His mouth is dry and his lips are cracked. He is somewhat anxious from time to time, being fearful when he can't get his breath. He cannot get out of bed any more because he is too weak and his breathing is quite limiting. He has asked for no further resuscitation procedures and also, no further antibiotics or similar life-prolonging measures. He has a low-grade fever.

Harold's wife, 77, is in good health although she is frail. She and their two daughters understand the situation. They are most concerned that Harold be peaceful, as he has been through so much.

Harold requires detailed symptom care:

- For dyspnea, start a low dose of hydromorphone 0.5 mg subcutaneously every 8 hours in a butterfly needle with 0.5 mg every one to two hours if needed for dyspnea or distress. Plan to reassess and increase the frequency of dosing and the dose as required, to ease breathing.
- Haloperidol 0.5 mg orally or subcutaneously every eight to 12 hours to help prevent confusion, which may arise from opioid therapy. This will also provide nausea prophylaxis and may help with the anxiety.
- For fearfulness and anxiety, lorazepam 0.5 mg sublingual every four to six hours if needed.
- General care orders for bowel care, regular oral hygiene care, and an enhanced mattress for comfort.
- Nutrition orders for palliative feeding, which is soft foods of preference orally with a goal of quality of life.
- Full social work and spiritual care support for Harold and his family.
- Volunteer visits for support, and music therapy tapes for relaxation and peace.

With these approaches, Harold's sense of dyspnea settles considerably. In the days that follow, he becomes more ill requiring gradual increases in his hydromorphone. As death draws near, the doctor leaves further orders for care (Table 3) and visits regularly to be sure that Harold is comfortable and to provide support to Harold and his family. The chaplain and social worker visit regularly.

Adapted from: Latimer EJ: As Death Draws Near: Care of the Patient and Family in the Final Hours of Life. *The Canadian Journal of Diagnosis* 2001; 18(2):43-50.

The question becomes; when are these no longer of help to the patient and when is their burden greater than their benefit? Fortunately, palliative approaches to care can often be interwoven with life-prolonging measures, with a gradual transition from one to another, allowing patient, family and team some time to shift gears (Table 4).

When does an illness become palliative? Four factors will combine here: evidence of progressive irreversible disease; lack of response to treatments; treatment options exhausted and

patient's wishes for no further life-prolonging treatments. The patient has a major role to play in deciding when this point in the illness occurs. Information and guidance from the physician is of great value in helping patients and families make this transition.⁶

Ongoing treatment and palliative care often involves a blend of acute care management with palliative care approaches to support and symptom control. In the patient with endstage heart failure, the cardiologist may be working closely with the family physician and palliative care team to provide therapies to alleviate peripheral

Palliative Care

Table 4

Suggested medication orders for when death draws near

Every patient's situation is unique. Drugs selected and doses ordered may vary.

Pain relief and physical comfort	Appropriate dose and route of opioid analgesic. Usually parenteral at the end of life. If the patient has been taking oral opioids, the subcutaneous dose is half the oral dose.
Breathlessness, agitation, distress, restlessness	EITHER lorazepam sublingual 1-2 mg or 0.5-1mg subcutaneous OR midazolam 0.5-1 mg subcutaneously every one to two hours if needed for restlessness or agitation. It may be used more frequently, and the dose may be increased if required. Also, haloperidol, 1-2 mg orally or subcutaneously every six to eight hours as needed, or on a regular schedule.
Upper airways secretions/congestion	Hyoscine 0.4-0.6 mg subcutaneously every three to four hours as needed, or on a regular schedule.
Mouth care	Moistening and cleansing of the mouth and lips every one to two hours.

Note: Subcutaneous doses of all medications listed can be given in a butterfly needle set-up to avoid repeated injections.

Adapted from: Latimer EJ: As Death Draws Near: Care of the Patient and Family in the Final Hours of Life. The Canadian Journal of Diagnosis 2001; 18(2):43-50; and Latimer E: Mouth Care: Treating the Often Overlooked Symptoms. The Canadian Journal of Diagnosis 2002; 19(3):43-52.

edema and breathlessness, and to manage the heart failure component of care.

Recognizing that patients are often in the older age group, it follows that their primary caregivers may also be elderly, frail and ill. Families experience the stress of frequent crisis admissions and the necessity of repeatedly preparing themselves for the emotional loss and death of their loved one.

While the palliative needs of non-oncology



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Take-home message



The following questions will help guide the physician and team in beginning planning palliative care of their non-oncology patients:

- What is the diagnosis or diagnoses?
- What is the pathophysiology of this illness and its expected course?
- What is the likely prognosis?
- How will the illness progress? Is there the potential for crisis events? How might these events be managed? What is the role for aggressive life-prolonging management of these events?
- How does the pathophysiology of the illness relate to the symptoms experienced?
- What does the patient and family understand about the situation?
- Who are the team members caring for the patient: family physician, consultants, interdisciplinary team, family members and friends?
- What is the setting where the patient receives care? What is the capability to respond to the patients needs, particularly at times of crisis?

patients are diverse, much can be done to help them. The keys to effective care lie in identifying the point when the palliative phase of an illness is entered, identifying symptoms and supportive care needs of patient and family, and treating them with the help of a broad and inclusive interdisciplinary team. CME

References

1. Palliative Care for Non-Cancer Patients. Addington-Hall JM, Higginson IJ. (Eds). Oxford University Press. Oxford and New York, 2001.
2. Freeborne N, Lynne J, Desbiens NA: Insights about dying, from the SUPPORT project. JAGS 2000; 48:5199-5205.
3. Desbiens JA, Wu AW: Pain and suffering in seriously ill hospitalized patients. J Am Ger Soc 2000; 48:5183-86.
4. Finucane TE: How Gravely ill becomes dying: A key to end-of-life care. JAMA 1999; 282:17.
5. Latimer EJ: The whole person physician: A source of hope for patients and their families. The Canadian Journal of Diagnosis 2000; 17(12):51-6.
6. Latimer EJ: As death draws near: Care of the patient and family in the final hours of life. The Canadian Journal of Diagnosis 2001; 18(2):43-50.
7. Heyland DK, Lavery JV, et al: The final days: An analysis of the dying experience in Ontario. Ann Royal Coll Phys and Surg Ont 2000; 33:6:356-61.
8. Latimer E: Mouth care: Treating the often overlooked symptoms. The Canadian Journal of Diagnosis 2001; 19(3):43-52.

Suggested Readings

1. Levenson JW, McCarthy EP, Lynn J, et al: The last six months of life for patients with congestive heart failure. J AM Ger Soc 2000; 48:5101-09.
2. Somogyi-Zalud E, Zhong Z, Lynn J, et al: Dying with acute respiratory failure or multiple organ system failure with sepsis. JAGS 2000; 48:5140-45.