

## Palliative Care for the Elderly – Challenges of Quality Care in Long-Term Care Settings

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We are all entitled to quality care when we are ill, especially when faced with terminal illness. According to a report by Senator Sharon Carstairs, only 15 per cent of terminally ill persons in Canada have access to palliative care. It is important for us to be familiar with what is happening in palliative care, so that all can have access to quality end-of-life care. The following is a summary of one of the workshops of the 17th Annual Provincial Conference on Palliative and End-of-Life Care, *Hospice Palliative Care: The Quest for Quality*, which I attended in April 2007. The conference was sponsored by the Ontario Palliative Care Association and Humber College.

The program dealt with many of the issues faced by those who care for seriously ill and dying patients. It offered participants opportunities to not only hear from experts in the field but also to network with a wide variety of health-care professionals who deal with similar situations every day. Quality palliative care is important to patients and their families because it helps patients to live as actively as possible until death. The goals of palliative care are to help patients accept that they are dying, take care of unfinished business, reconcile with family and friends, and say their goodbyes.

One of the talks was by Dr. Paul Ferner, a palliative care physician who works in long-term care facilities. In long-term care, the majority of patients die of diseases other than cancer. In his talk Dr. Ferner said that he believes long-term care facilities are ideal settings for the practice of palliative care and the treatment and management of symptoms until the time of death. The reality is that every one of us will die; 10 per cent will die suddenly, and 90 per cent will die after a period of illness. Long-term care is designed for people who require the availability of 24-hour nursing care and supervision within a secure setting.

According to Dr. Ferner, the death rates in long term care and from cancer are about equal, however most of the research and writing on palliative care are done from the cancer perspective. **This may mean that many persons dying in long-term care are overlooked when they reach the stage of needing**

**palliative care.** As a palliative care physician in long-term care, Dr. Ferner is very aware of this fact and sees the need for a change in perspective, to a disease-based symptom management system. This allows for easier care planning and allows physicians to anticipate problems and communicate them to family and staff. Assessing the symptoms properly and regularly is of highest importance, yet may not happen on a regular basis in most LTC facilities.

### Assessing symptoms

Dr. Ferner recommends the Edmonton Symptom Assessment System (ESAS) developed by the Caritas Health Group Regional Palliative Care Program, in Edmonton, Alberta. The Ministry of Health hopes that it will be used for assessing symptoms across Canada and become the accredited standard. ESAS is a valid and reliable assessment and communication tool used to assess nine common symptoms in all patients, terminally ill or not.

The nine common symptoms are: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, and shortness of breath. At the time of assessment each symptom is rated from 0 to 10 on a scale, 0 meaning that the symptom is absent, and 10 that it is of the worst possible severity. Ideally, patients fill out their own ESAS, but a family member or health professional involved in the patient's care can complete it by asking the patient the questions.

This scale is effective because it is the patient's opinion that counts and also guides symptom management. The ESAS should be completed daily, or more often if there is an increased need for clinical assessment in order to provide a concise clinical profile over time. This makes sure patients' individual needs are being met, thus enhancing their quality of life at this stage.

### Implications for long term care patients

The World Health Organization defines palliative care as that which "improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, and spiritual and psychosocial support from diagnosis to the end of life and bereavement." Dr. Ferner feels that the principles of palliative care should apply to **all patients dying** in long-term care. Consequently, the steps that are part of palliative care, i.e., assessment, information sharing,

decision making, care planning, care implementation, and confirmation should be implemented. Support staff should be trained in the basic concepts and practices of palliative care.

Most people have never provided care during the last days or hours of life and have never watched someone die. Health care professionals, therefore, must be able to anticipate events, and, through communication, accompany the family in this experience. It may be helpful for all of us to be able to talk about death more openly, before we are faced with the experience.

### Understanding how death occurs

Caregivers and close family members should understand the dying process and what happens in the weeks and days leading to death, so that they are not confused and angry when their loved one dies. Excluding sudden death, there are basically two ways in which life ends. One way is that the patient gradually loses the desire to drink. This often occurs with cancer patients, end-stage dementia and end-of-life neurological conditions. The kidneys shut down with decreased fluid intake; the patient becomes drowsier and eventually enters a coma.

The other is when a person is in end-stage lung disease such as chronic obstructive pulmonary disease (COPD) or end-of-life congestive heart failure (CHF). When the lungs are not working properly, oxygen levels drop, leading to shortness of breath and eventually coma.

If the family understands that these two processes are part of a natural death, they will know that their loved one is being cared for, and that their loved one is not suffering from hunger and thirst and feels no pain.

### Communicate what is happening

Being able to communicate what is happening to others is as important as knowing what is happening. Communicating with the family helps them to get ready for changes and to be aware of the progress of the disease. Dr. Ferner encourages physicians and caregivers to use the “D” word: “Your loved one is going to die.” Family members need to know what is happening so that they are not unprepared for changes. It is better to be explicit about symptoms and what to watch for, such as signs of pain and changes in breathing patterns. It gives the members of the family a sense of control if they are enlisted in helping to monitor symptoms.

One of the common reactions from families may be anger, a natural outcome that arises from unresolved fear, unresolved hurt, and frustration. Having a loved

one die can bring out the best and the worst in people. A simple way to diffuse anger is an open-ended question or comment. “You seem worried, what is your biggest fear?” “This is a difficult experience; it must be hard for you to accept that we are not in control?” Another reaction to anger is compassion. Compassion means “to suffer with.” Family members need the affirmation from staff and caregivers that what is happening is sad and difficult to bear. They need to know that their emotions are acceptable and should be expressed.

Communication is so important, especially since what is said and done will be remembered by the family forever. They will always remember if caregivers have failed the patient in any way, or if the quality of care was exceptional. We must work for the latter experience.

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### References

- Dr. Paul Ferner MD, CCFP, FCFP, Physician, Palliative Care Unit, Parkwood Hospital and Consulting Physician for the Community Palliative Consultation Team, London; Associate Professor, Department of Family Medicine, University of Western Ontario, London, ON
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