MODULE: PALLIATIVE CARE – STANDARDS AND MODELS

Detailed Case Scenario

Elizabeth Jones is a 44-year-old elementary school teacher. Six years ago she had a lumpectomy for breast cancer followed by adjuvant radiotherapy and chemotherapy. She was well for almost 4 years, when she developed a skin recurrence in her scar. This was treated with further surgery. About two months later, while at work, she had a grand mal seizure. A CT of her brain revealed at least 6 metastases to her brain. She had whole brain irradiation and was placed on dexamethasone, a powerful cortisone drug and anti-seizure medication. Further investigation revealed metastases in her liver, lung and peritoneum. She began chemotherapy but had no response to 3 different regimens. No further treatment is planned.

Symptoms included some abdominal pain from a grossly enlarged liver, nausea, constipation, abdominal distension and increasing weakness. She also has had a number of panic attacks resulting in weekly trips to the emergency department.

Elizabeth is a single parent of two children. Jennifer is 14 and Alexandra is 19. Elizabeth has been divorced for 7 years from Mel who still involved with his children and their support. He has remarried and has 2 stepchildren. Elizabeth was engaged to be married to Frank but she called off the wedding when she developed brain metastases. Frank still visits her frequently. Alexandra is at university in a town about 150 km away. Jennifer is at home in high school but having problems with her school performance. Elizabeth has two sisters and one brother living near her. Her father died of cancer 2 years ago. Her mother, Madge, also lives nearby but has had little contact with her daughter since the divorce. Madge is a devout Catholic and does not believe in divorce. Elizabeth has not allowed any of her friends to visit her over the last four months.

Elizabeth is referred to you for palliative care assessment and follow-up. You see her at home. Your first impressions of her are that of a very ill woman in quite a bit of distress and that she is quite cushinoid. She asks you if you have come to kill her.

Current Medications: Tylenol #3-2 tabs q4h prn, Stemetil 10 mg q6h prn, colace 2 tabs bid and senokot 2 tabs hs prn

Teaching Tips:

- 1. Distribute the case scenario. Allow the participants a couple of minutes to read the information or have one of the participants read the scenario.
- 2. Before diving into the case, spend some time discussing general issues around end-of-life care. Below are several possible discussion points.
 - A. Societal attitudes toward death and dying:

TIP: Ask participants to reflect on society's attitudes.

It is popularly said that North America is "death-denying". Another view is that it is "death-avoidant". We have tried through science to control nature. Death is included as a part of nature. We control/manage/defeat disease. We think we can do the same with death. Most people believe that you can fight death through treatment or you control death by choosing when to take your life (assisted suicide / euthanasia). The average person knows more about euthanasia then palliative care (e.g. on internet, in bookstores, "how to kill yourself").

TIP: Ask participants to reflect on their own feelings regarding death and dying and on what they feel is important with respect to death with dignity.

What is death with dignity? Is it to be pain free and peaceful? Or is it the view of the euthanasia promoters? People are seldom afraid of death. They are more commonly afraid of the dying process, death extension, and prolonged suffering.

- B. Current blocks in the care of the dying:
 - Old paradigm of palliative care practice: that palliative care only begins after all other efforts have failed. Modern view of palliative care pictures active treatment and palliative care occurring together through the course of the disease.
 - Values, beliefs, lack of knowledge / adjustment to new reality of dying, living in the presence of dying, no one practices dying
 - Lack of education among professionals.
 - Current structure of the health care system.

- Current level of home-care services available to palliative patients in your area.
- C. Talking about death, dying, and palliative care with patients and families:

TIP: See Communications Module.

Getting started – "I would like to speak with you about how to support you in your daily living, how to keep you at work, how to conserve energy and diminish pain."

Once in – "What is it that is most important to you now? If we had to change one thing, outside of curing you of your illness, what would it be? How can we make the situation a little bit better?"

- 3. Have the participants brainstorm around the information given in the case. List the relevant issues on a flipchart.
- 4. Facilitate discussion of relevant issues. As it becomes apparent that there are gaps in the participants' knowledge, list the issues that require further investigation. Do not provide answers to all their questions.
- 5. At the end of the session, assign each of the participants one or two of the learning issues for them to review on their own and report back to the group at the next session.

TIP: This case is intended as a general introduction to palliative care. Many of the issues raised here will be more thoroughly developed in other modules. Do not feel you have to cover everything in this one case.