

Dr. Susan MacDonald – Introduction Notes
Palliative Care Media Statement
May 5, 2010

Good morning.

The topic for today, palliative care, will affect each and every one of you in this room. Therefore, all of you have a vested interest in how palliative care is provided in this province. When your time comes, and that of those you love, you need to know that adequate services will be available to ease your suffering.

Thank you for attending this public information session today. We are going to be discussing the challenges that physicians face in delivering palliative care to patients in Newfoundland and Labrador.

I would like to remind everyone that the reason we are continuing to present these issues to the public is that we want people to understand exactly what is at stake if we fail to address the problems in our medical care system.

Our panelists today are Dr. Pat O'Shea, who will be discussing the challenges of providing palliative care while operating a demanding urban family practice, followed by Dr. Eileen St.Croix, who will be speaking to you about the difficulties of providing and accessing palliative care in rural Newfoundland and Labrador.

I'm Dr. Susan MacDonald. I'm a palliative care consultant and Divisional Chief at Eastern Health and an Associate Professor of Medicine and Family Medicine at Memorial University. I confess I'm a CFA. I came to Newfoundland first as a medical student and spent several weeks in both Baie Verte and at the old Janeway. I convinced my husband, also a doctor, to move here 13 years ago. This is now home.

I practice solely palliative care. I see patients in my clinics, on wards of the hospital, in long-term care facilities and in their homes. My job is help ease the suffering my patients experience and assist them in living the best way possible, under the circumstances by providing advice and support the many who provide primary palliative care. I spend a great deal of time, teaching my junior colleagues and students that the dying have value and that it's a gift to managing their symptoms and ease their suffering.

Today you'll have the opportunity to hear from those who care for the dying on a day-to-day basis. Understand the challenges and the rewards in providing this service. Hear where the strengths and weaknesses reside.

I'd like to start by reviewing just what palliative care is. There is a lot of confusion out there, sometimes even among health care professionals. The World Health Organization has the following definition;

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

I'd like to make two points clear. I am not speaking only about cancer patients. Most people only think of palliative care and the association with oncology. It is also very important to repeatedly acknowledge that palliative care is interdisciplinary. Nurses, social workers, dieticians, occupational and physiotherapists, spiritual counselors, and volunteers, among others, work hand in hand with medical personnel. We physicians cannot do this without our many colleagues and the services and support they provide.

Palliative care happens all over the province. It is not just a ward at the Miller Centre. Patients might live their final days, weeks and months at home, or in hospital wards, in long term care facilities and others. We strive to meet patients where they are, both physically, emotionally and somewhere along the path to acceptance. There are challenges to caring for our patients in all settings. Our two panelists will discuss just what some of those challenges are in the community. I can speak to the challenges of patients within the hospital settings.

Patients in hospital are often acutely ill. Decisions about care can change from day to day, leaving the patient and family confused and frightened about the future. Many people are frightened to hear that they've been referred to palliative care. To acknowledge that they need us is to acknowledge their future. Sometimes the referral is very late in the illness and the patient is too unwell to participate in making decisions about their treatments and end of life care plans. Families are often distraught and find it difficult to hear what we have to say. They need to process the information. And that takes time. But in a system of chronic shortages time is usually the least available commodity.

They may wish go home but have no access to medical care once they leave the hospital if they don't have a family doctor. The community health palliative care program, which has been a significant help since instituted, only covers equipment medication and services for a short period of time. Not every patient can even leave the hospital. Many folks I see have limited family in the province and not everyone can leave work to care for a sick relative. It's absolutely

heartbreaking to tell a patient that they will have minimal care if they leave the hospital even though that is their dying wish.

Weekly we are faced with patients who have no family doctor and therefore, no one to care for them. Many family doctors do not have after hours availability or have limited knowledge and experience in caring for this population. Not all graduates of Canadian medical schools and many foreign graduates have had no education in palliative care. There must be education and support on a daily basis for them.

The day-to-day care of patients in community falls to family doctors. As you can imagine the types of discussions that we engage in are not quick. It takes time to review the symptoms a fatigued, frightened person is having. It takes time to deal with the emotions the patient and families are experiencing. Family doctors are often very pressured by a waiting room of sick people all with several complaints they want to talk about. To halt everything for a 45 minute talk about end of life can be almost impossible. Leaving a busy clinic to run out for an emergency home visit, knowing that you'll be at least a hour or more behind when you return is very difficult, especially when you add in the fact that a fee for service Family doctor will lose money if they do. As well, no physician can be available for their patients 24 hours a day 7 days a week, Particularly for this population and yet illness and death aren't 9-5 occurrences. Who cares for the patient after hours?

Here in St. John's, we've discussed the possibility of developing an after hours cooperative group of interested Family doctors, willing to take on orphaned palliative patients and provide evening and weekend coverage for them. However, due to fee code inadequacies and lack of an on-call stipend, we cannot get this started.

Several years ago, Eastern health recognized the importance of palliative care and supported the development of a committee, which reviewed how palliative care services were provided. We were tasked with the development of a regional plan. That regional initiative has been finalized, accepted and the leadership team has been interviewed and will soon be entirely in position. The overall strategy is to develop local teams within the Eastern region. Each team will provide care for patients in their own communities. Each local team will have the support of more experienced clinicians in the tertiary team. Education and organization will come from the tertiary and leadership teams. We hope to develop policy and procedures to assist our community colleagues in coping with the complex situations they may be unfamiliar with that arise in palliative care.

I'd now like to pass the microphone to my colleagues now so that they can discuss with you the day-to-day challenges they face.

Dr. Pat O'Shea is a well-known family doctor here in St. John's. Dr. Eileen St. Croix is a family doctor who gives chemotherapy and provides palliative care in Gander and surrounding area.