

Palliative Care in an ALS Clinic? Absolutely!

Barbara Segal MS, RN
Palliative Care Service
Fletcher Allen Health Care
Burlington, VT

Objectives

- To describe the concept of palliative care and how it differs from that of hospice.
- To understand the evolving role of the palliative care practitioner in the ALS multidisciplinary clinic and how to apply that knowledge to his/her respective settings.
- To appreciate the significance of introducing palliative care early in the diagnosis of ALS.

What is Palliative Care?

- Focuses on pain/symptom management for all patients with life threatening disease regardless of prognosis. No requirements for life expectancy.
- Elements of this care include the psychosocial, spiritual and social domains of life limiting illness
- Focus is on the family unit
- No requirements to forego life prolonging measures
- Advanced care planning and setting appropriate goals of care based on values also are an important aspect of palliative care.

Misconceptions about Palliative Care

- Palliative care is not Hospice care.
- Palliative Care is not just end of life care
- Palliative Care is not just comfort care
- Palliative Care is not just withdrawal of care (giving up)
- Palliative care is not just morphine drips

Why Include Palliative Care in the ALS Clinic Setting?

- Often, focus is on maintaining or improving physical function with less attention to emotional/spiritual issues.
- Lack of expertise re pain/symptom control at EOL
- Lack of familiarity of how to discuss difficult issues i.e. advanced directives and promote venting of fears/concerns.
- Continuity allows time for adjusting to and coping with a life limiting illness. It is a process.
- Liaison to community services, PCP's and resource to patients/families via phone/email/home visit.

Continuum of Care - Optimal

Curative/Restorative
Therapy

Palliative Therapy

Presentation/
Diagnosis

Illness

Death

Acute

Chronic

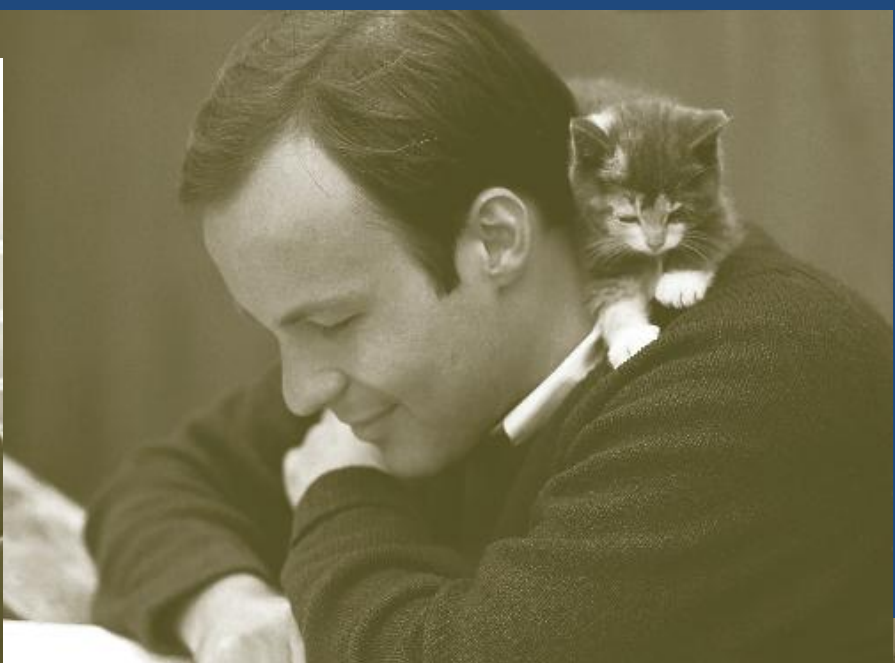
*Life
Threatening*

Figure 2. Adapted from Frank D. Ferris, 2000.



Children
140960
Approved
14-2006
0099604

“I used to look at some of the patients that were in our clinic getting a new diagnosis of ALS and think to myself- you poor bastards. Now **I’m** one of them. And I’m afraid...”



In a note from the Brothers after Brother Philip's death:

“ Brother Philip once said that what he appreciated was your willingness to go into the darkness with him- that you were not afraid of that. And we could see how you would allow the silence between you to develop into a relationship that did not need words. It brought him joy.”

Impact on the Multidisciplinary Team

- Evolving process
- Gradual comfort around:
 - w/d life supporting measures
 - adequate symptom control near EOL
 - own attitudes about death and choices they may or may not make for themselves.

Summary

- Palliative Care should be introduced soon after diagnosis.
- Palliative Care can be viewed as “taking away hope.”
- Sensitive issues about advanced care planning should be addressed gently, focusing on values.
- Coming to terms with these issues is a process, and cannot be rushed.
- The inclusion of PC in the multidisciplinary clinic can enhance communication between team members and ultimately with PALS.

Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out.

Vaclav Havel