CHALLENGES IN TREATMENT AND CARE AT LIFE'S END:
Providing Comfort, Care and Planning in Serious Illness

This is a summary of a lecture by **Robert L. Fine,** M.D., F.A.C.P., Director, Office of Clinical Ethics and Palliative Care, Baylor Health Care System. He is an outstanding physician who not only is direct and kind, but improves planning for life's end, assists in analyzing the right time to let go of medical technology, and addresses the possibility of a sweeping change in attitude by accepting death as a spiritual experience.

No one comes to a physician or a hospital to die. We've never been better at prevention and cure, yet death remains inevitable. Dr. Fine reported several deficits in treatment near life's end. There is a high degree of unnecessary suffering. Suffering should be worth the benefit received. You know when you go in to have a cavity filled that there will be some discomfort but you assume that this will be outweighed by the benefit. Patients who are terminally often suffer with no benefit. There is significant treatment variation near the end of life without significant variability in severity of illness or outcome. In other words, treatment varies even when patients have the same diagnosis. There is often no specific treatment that all physicians use because it works. All of this results in unsustainable costs to the patients, their families, and society.

A 2006 study of medical treatment revealed that patients in TX spent $9-16,000 more but were not sicker than patients in other states. These patients were subjected to burdensome treatments but did not have better outcomes. (This study is available online http://www.rwjf.org/pr/product.jsp?id=28772 – Dartmouth Atlas Project is funded by the Robert Woods Johnson Foundation)

A study of the utilization of health care resources in the last 6 months of life showed

- Days in hospital varied from 6-22
- Days in the ICU varied from 1-8
- Patients who were enrolled in hospice varied from 10-59%

Albert Schweitzer said, "We must all die. But that I can save him from days of torture, that is what I feel is my great and ever new privilege. Pain is a more terrible lord of mankind than death itself."

A large study on seriously ill patients done at 5 different hospitals in 1995 revealed that

- Up to 50% reported serious pain the last 3 days of life
- Up to 60% of patients reported severe pain at days 8-12 of the hospitalization
- The emotional suffering of the patients, their families, and the professionals who worked with them was substantial
- 31% of families lost most of their life savings.

There are now between 20-45 million uninsured Americans. When people have no access to health insurance, they are more likely to die because they wait until they are very sick before they come in to the ER. It is estimated that there are 45,000 premature deaths every year due to lack of health care.

In 2001-2005 expenditures in the last 6 months of life varied from $14,000 - $47,000. In 2004, 29% of Medicare funds were spent in the last year of life for the 5% of Medicare patients who died. 22% of all health expenditures are spent in the last year of life ($484 Billion in 2007) for the less than 1% of us who die each year.

IF we could decrease the cost of end of life health care, we could fund ALL the proposed health care reforms.

What do people who are dying want at their life's end? Nobody wants to suffer on the way to death. Few want to die in a hospital. Patients and their families want remission, recovery or cure. But if this is not possible, what do they want? Quit reading right now and answer the question: If you are dying, what kind of care do you want, where do you want to die, what do you want your death to look like?

Here is how 340 terminally ill patients answered that question, selecting the most important from a list of 44 items.

1. Freedom from pain
2. Peace with God
3. Presence of family

Dying at home was #9.

Palliative Care is a medical specialty focused on relief of pain and other debilitating symptoms of serious illness. Multidisciplinary treatment aims to relieve suffering and improve quality of life for patients with advanced life-limiting disease and their families. Their suffering is not only physical but may be psychological, emotional, financial, spiritual or social. Patients receiving Palliative Care can continue to have aggressive treatment. The unit of care for the Palliative Care team is the patient plus the family.

At some point in many illnesses, even Palliative Care options run out, and the patient may be referred to hospice. Did you know that only 15% of chemotherapy is given to cure? The other 85% of chemo is given for Palliative reasons. Cancer is becoming a chronic illness.

A 2010 study of the benefits of Palliative Care revealed that it was superior to usual care in these areas:

- Pain control
- Care at the time of death
- Information/communication
- Preservation of dignity
- Care and setting concordant with patient preferences
- Emotional/spiritual support

A financial analysis of hospital-based Palliative Care across the country revealed:
Cost savings of $279-374 *per day* for PC patients
Cost savings of $1700-$4900 on each admission of PC patient

Significant reductions in pharmacy, labs, and ICU costs with an average cost saving of $1.3 million - $2.5 million per year
These savings were passed on the families.

Hope is always possible but sometimes our hopes must change. Sooner or later the human condition teaches us that death is not a medical problem to be solved, it is a spiritual problem to be faced. Robert Frost said, “Hope does not lie in a way out, but in a way through.”