Dying Faithfully
Fmb notes
St. Andrew's Church
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it's ironic that I'm standing here talking to you about this subject. I just got back from New York last night where my sister's companion of 20 years died after being on hospice at home for what I think may be the New York City record of 2 1/2 years.

I always thought of the process of his illness as gruesome; I learned yesterday, in a way that I had not known before, it was also, in a sense**, awesome.**

He did have a gruesome diagnosis, PSP , Progressive supranuclear palsy, took him in five long years, from being a charming, very talented, magnetic, somewhat narcissistic, complicated, not-as -well-know-as-he-would-like, visual artist, to being a shadow of himself, who could only communicate by blinking his left eye (no, I am NOT kidding).

My sister, who is not married to him, but describes him as the love of her life, had a very difficult time negotiating all of the family, friends, and material issues around helping him to let go of this life. She stuck with him through very thick and thin.

What I saw, that I had not seen before in my many visits, came to me in his room as he was busy dying (yes, it seems like dying is tough work). I was awed by the community that come together to care for Alan and Lee: Most people post pictures of family and friends and happy times in the past. Alan had arranged the room differently: he had artworks, things made by the hands of his friends, surrounding him. Some of these were very famous artists, some just friends who he loved and who loved him.

And that community was also tangible in the people around him on his last day of this life: his health aid of 2 ½ years, Annette; the hospice volunteer that came 2 1/2 years ago and kept coming even after his own life moved on, because he loved Alan and Lee; his best friend from college, who **so** much wanted to come and see Alan at the end; his sister, who had been estranged from Alan, and who my sister had almost forced to get back involved in the life of her brother; his friend who runs the most powerful art gallery in New York who will probably help to make Allen famous now that he's gone. Allen really wanted to be a famous artist and I think he will get his wish now.

I saw in that room full of art and that parade of visitors, a community. The illness was gruesome. The GRACE brought by the community that formed around him and my sister…was **awesome.**

Two questions: why do our grow old? And why do we die?

Almost all multicellular organisms have a life expectancy Colin on a cellular basis they will only live so long and their bodies will not support life after that. Almost all the cells in our body have a life

expectancy except for our germ cells. Why that is best discussed over a beer, and not coffee; there is lots of controversy from an evolutionary standpoint as to why this is.

The point is that almost none of us here will grow old and die of old age. Almost everyone has something happen, either an accident or illness, that is our terminal event.

Is an illness curable or not curable?

All illnesses have and expected time course, and if serious enough, an estimated lethality. The common cold kills almost no one. It's done in 5 to 10 days. The flu is usually over in 5 to 10 days but does kill a small percentage of people who get it. There are different types of cancer lethality: both metastatic pancreatic cancer and chronic myelogenous leukemia are incurable disorders. The average life expectancy for metastatic pancreatic cancer is approximately six months but now, with new treatments that are widely available, CML which used to kill everyone by five years, now has a normal life expectancy.

HIV is in the other very good example of an illness that is in curable, used to be universally lethal, and now, with proper treatment is more of a chronic disease.

In any case, when we have a serious illness, we need to find out if it's curable or in curable, what the treatments are and what the time course can be expected to be

Illness: Curable vs Incurable
Curable – treatment can eliminate the dz. Goal of Tx is to cure
Incurable – treatment not realistically able to eliminate illness, Goal is to improve symptoms and prolong life, but NOT eliminate it.

Illness and Death

-being mortal (story) Rev Linda
patient story of enduring treatments and coming to accept recurrence, spread, life limiting diagnosis

The Conversation Project and Goals of Care

-medical considerations Dr Fred

your discussion/outline around Measures that can be taken. Inform of what happens as default if no AD's. Medical maximalist/minamalist…

2. Advice on how to approach illness:
-GOALS: Get an understanding of realistic goals.

It is critical that you and your physicians have an agreement about what the goals are in treating your illness, and what steps you agree on to accomplish those goals. Difficulty, conflict can occur in the relationship between the doctor, patient, and family when there is disagreement about these issues.

CURABLE VS NON-CURABLE:
–discover if the illness is considered curable or non-curable. There will be different approaches and goals the depend on this.

-For a curable illness, most people will except more intensive, toxic therapies if the goal of treating their illness is a possible cure

-For illness that cannot be cured with standard means, goals generally include promoting a good quality of life for as long as possible and if possible, prolonging life.

Advanced Directives – If you do nothing else, talk to your family members about you should make decisions for you if you are not able, and whether or not you would want to be aggressively resuscitated in the case of a terminal illness. Filling out the paperwork is the next step.

-Living will/Medical power of Attorney-designating someone to make medical decisions for you if you were not able to make decisions for yourself. You may also direct that person, in writing, about your desires surrounding your death, if you are not able to make your own decisions.

-DNR, do not resuscitate expresses, in a legal document, the desire not to be kept alive artificially, if your lungs stop breathing or you have cardiac arrest. There are different documents for each state.

It is CRITICAL that you talk with your family and medical team about how intensive you want to be treated. Legally, The DEFAULT of the medical community is that you want to be maximally treated and supported, UNLESS you have expressed your wishes through this process.

The Conversation Project and Goals of Care

-value based considerations Rev Linda
patient centered

how to reflect on value based medical decision making—-honoring individual choice and change as medical situation evolves

Based on many factors, age, general health, they are number of children in the children's ages, overall conditioning, support, philosophical or spiritual beliefs, individuals or emphasize different aspects of these goals. Some will emphasize good quality of life and may even forgo therapy if it is offered, and some may choose more intensive therapy in order to maximize longevity.

Prognosis

-how determined, time frames, data based   Dr Fred

per your outline on prognosis

Prognosis: How can we tell the end is near?

Prognosis can be assessed based on what the illness is, and the stage of the disease process, as well as the other medical problems (co-morbidities) that the person has.

For an individual, doctors often use tools estimate prognosis and ability to give treatment; one such tool is Performance Status. This is a simple but very important principle having to do with how much of one's daily activities one can perform.

-Performance Status 1 = no symptoms of the disease, fully active, Able to work

-Performance status 2 = some symptoms of the illness but still able to do most of daily activities. Likely unable to work

-Performance status 3 = in bed or in a chair more than 50% of the time not able to do many aspects of self-care

-Performance status 4= In bed nearly 100% of the time.

In oncology, a performance status of 3 generally means that patients may have, on average, more harm than benefit from treatment. This is true in many but not all cases.

Prognosis is generally given in a range, measured in years, months, weeks or days and is more accurate when survival time is estimated to be shorter.

Last weeks or days:

Signs that the end may be approaching, In weeks or months,

-Functional decline, in bed or in a chair more than 50% of time.

-Lack of interest in food and decreased oral intake, resulting in weight loss and cachexia

- Difficulty transferring from bed to a chair.

Signs that the end may be approaching within days or hours:

-Confusion or delirium

-Accumulation of oral secretions

- Increased anxiety

-Change in respiratory pattern.

-Cooling of skin, starting in the extremities

Prognosis

-prognosis as guideline of service eligibility   Rev Linda

physician prognosis as guideline for hospice or other programs

Palliative Care and Hospice Care

-Medical parameters — Dr Fred

What the medical system can do to help:
Definition of terms:

Palliative care: a service involving doctors, nurses, social workers, spiritual care that is interdisciplinary with the goal of preventing suffering and supporting the best possible quality of life for patient and family is facing serious illness.

Hospice care. Hospice is palliative care at the end of life, usually the last six months. Goal is to maximize comfort and dignity at the end of life. In general, all treatments administered art to further that goal and are not directed at prolonging life but instead enhancing and maintaining comfort.

Services often provided with Hospice Care:

- -Home health aide
- – medical Equipment such as hospital bed or bedside commode, oxygen
- – medications to enhance comfort including morphine and anti-anxiety medications
- – hospice nurses, available to coach family and caregivers
- -Social Work and spiritual care for patient and family counseling

–Pain Control: a primary concern expressed about illness. There many different types of pain: physical, emotional, spiritual/ existential, familial. Morphine address is only the first. Palliative care and hospice care can help with the other forms of pain.

-Respiratory Distress: usually manage successfully with morphine or similar medicines, oxygen and anti-anxiety medications. The hospice team is very skilled at this.

-Place of death. Home vs hospital favored by most. This is possible, if there is a caregiver available, usually around the clock. If not, then transfer to Hospice House facility is always an option

Palliative Care and Hospice Care

-Spiritual considerations — Rev Linda

Final Thoughts

-Letting Go — Dr Fred

AT THE END OF LIFE, KEEP IN MIND THE GOALS EXPRESSED BY THE DYING PERSON:

1. Feeding/Nutrition: when people have a terminal illness, and the goal is to keep them comfortable and maintain their dignity, forcing them to eat, getting intravenous feedings or even intravenous fluids does not enhance their comfort. This has been validated in multiple studies. In general, people can have their thirst slaked by sips of water, ice chips and wetting of the mouth.

2. Agonal Breathing: The loud respirations and raspy sounds that dying people sometimes make are not thought to be uncomfortable for them. They can be very distressing for family members. There are medications that can be given to minimize this for the comfort of those around the dying individual.

3. DNR does not mean "do not treat". It is an expression of your wishes for your end of life but Is distinct from decisions around whether to continue treatment.

A plea for preparation: my in laws died in the past 18 months. Edward and Ruth left a black book. It included information on their desired funeral service, down to what the reading should be, who the funeral director was and his phone number, where the burial plot was, how to dispose of their huge collections—including the 6000 AIDS posters and the stamp collection: who to call and to some extent, who to give what to. It made things so much easier than it could've been.

Closing Poem "Otherwise" Rev Linda

Fred Briccetti MD