Helping Those In Hospice and Their Loved Ones Through the Dying Process
- Receiving the diagnosis and transitioning to the patient role;
- The medicalization of death;
- The decision to move to hospice care;
- Loss, death, and dying: a developmental process.
“Life-threatening illness calls us to a place—metaphorically a desert or mountain peak—where, as we sit, the hard wind of reality strips away all the trappings of life, like so much clothing, makeup, and accessories. We are left naked, only ‘me’ with my in-breath and out-breath in this moment, here and now. Illness reveals that at every moment of every day we are—and have always been—merely a heartbeat away from death.” from foreword to *Being with Dying*. 
Taking on the Role of Patient

- Foreign territory;
- Therapy is about:
  - Assuaging **terror**;
  - Alleviating grief regarding losses, which emerge far ahead of the death;
  - Restoring some sense of control as loss seen as transition toward the unknown.
Tell me about any previous experiences you’ve had as a patient;
Tell me what your experience has been since your diagnosis;
What information have you received about how your specialist(s) will work with you?
What have you been told about the different kinds of support you can get?
When you’ve had very bad news in the past, how did you cope?
Are you the kind of person who feels optimistic about how things will turn out, or do you generally feel pessimistic?
How do family members get through tough times?
Return of Illness is Traumatic

- Catapults one back into the world of uncertainty;
- We are well equipped to help patients & families move through struggles:
  - complicated dynamics of personalities; previous experiences; beliefs; wishes; knowledge; fantasies; protecting others; emotional upheaval...
…guilt; resentment; finances; anger at healthy spouse; conflicting beliefs regarding after death… and more.

Isolation: “suspended in a state of limbo between the world of the sick & the well, belonging to neither yet part of both.”
“Leper”
“Betrayed by my body”
“By my doctor”
Many experience shame or embarrassment.
The *Person* is more than his dx or prognosis

--Psychological distress or sx may be "*a sign of the soul’s struggle to be alive*" (Thomas Moore);

--Spiritual questioning must be supported as it is often part of the acceptance of the new reality;

--Reclaiming *the sacred* or the ineffable in the encounter; allowing *the sacred* to emerge.
As the clinician gives up her agenda to “understand” the dying person, or the caregiver, and allows herself “to know (the person) through the ongoing intersubjective field they are sharing at that moment, an act of recognition (not understanding) takes place in which words & thoughts come to symbolize experience instead of substitute for it.” (Bromberg, 2006, p. 11).
“Adults in states of distress or suffering from illness or aging have a comparable need (to the infant) for affectionate and sensitive response.” (Fosha, Siegel, & Solomon [Eds.] 2009, p. 71).

Communication becomes more nonverbal and emotionally attuned; Brazelton (1979) spoke about attention w/the whole body, embodied listening.
Attentive Empathy

- Embodied listening allows the dying person to be where he needs to be in the moment;

- The caregiver or psychotherapist learns to attend faithfully to the moment by moment communication.
A spouse or other family may know the dying person very well but now a very new set of demands requires more complex & dynamic & flexible responding, much like countertransference responses in psychotherapy.
Siegel’s work on interpersonal neurobiology demonstrates the importance of attunement—the alignment of states of mind—in the therapy relationship;

An attuned other knows when to back off & give space;

A capacity to read signals indicating need for engagement & disengagement (2012, p. 95).
Schwaber (1995) described this non-conscious process of attending to “barely perceptible cues that signal a change in state” in both patient and therapist.
Applying what we know about important, intimate relationships in the dying process;
Most people die in hospitals in the U.S. where medical interventions trump the relational aspects of dying;
Hospice works from a relational perspective.
More Assessment Questions

- What is most important to the patient and family members now and as they look ahead?
- What do they most fear about dying, death, and bereavement?
- How is the family managing together? What is working well? What is difficult?
- Do they have unresolved past losses?
- Are there taboos or cultural issues at play?
Not Knowing

- Beginner’s mind; allows for clarity and openness—“the wisdom mind of enlightenment that is at once groundless, intimate, transparent, inconceivable, and pervasive” (Halifax, p. 2).

- In working with, being with dying, we explore our own stories around death—legacies we inherit from family & culture.
The intimacy of being with being;
Very close attention to the moment;
Nonverbal communication and emotional attunement;
Attending to one’s breath and the dying person’s breath can lead one to deep listening, mindfulness. (Good meditation, p. 15, Strong back—soft front).
“Being with” the dying person is a powerful experience;

It includes the sacred, the holy, what is precious (as body fades, what is left is the sacred);

Attunement to the present moment.
No Good or Bad Dying

- Follow the dying person’s lead;
- Each person will die in his or her own way;
- Learning how to just be present;
- “If there is even one wish for a certain kind of result, then we aren’t being with what’s actually happening.” (Halifax, p. 29)
Thorny issues arise w/Dying

- Wishes of dying person vs spouse;
- Religious vs psychological processing or expertise; (personal examples)
- Tight rope walking for the mental health professional.
The view of development as accomplishment of life tasks (e.g., Erickson), dying can be viewed as a key life task;

Baltes et al. (1980) in their *lifespan* approach to development view dying as one more period of life when the person must integrate the various aspects of the experience in a meaningful way.
- People feel vulnerable and helpless to stop what is happening;
- Struggle to maintain a sense of normalcy & connection with the world;
- Help person and caregiver(s) maintain “sense of self”—one of the more difficult ways a sense of loss is experienced.
- Discuss regrets, wishes, what is being missed.
Siegel (2012) discusses temporal integration as a developmental task; In the dying person it can manifest as longings for certainty, permanence, & immortality vs accepting the reality of uncertainty, transience & mortality.
Medicalization of Dying

- Includes the confusion between keeping someone alive and treating a disease process;
- The medical profession is very good at treating and curing disease so that when a person is dying, it begins to fail that person in many cases;
- But there is no clear boundary between treating and moving towards dying.
Medicalization

- Treating the disease and helping the dying can be contradictory mind-sets;
- Medicine works to eradicate the disease from the living body;
- In order to do that, the person must remain alive.
- When does treatment end and dying begin.
Medicalization of death is partly the result of fearing it so we work hard to keep it at bay, to conquer it.
As Death Approaches

- Increasing shift from *doing* to *being*;
- Difficult transition for some w/many ways of responding from increased fear & irritability to a sense of relief & calm.
- All can be interspersed w/continued denial (my example of scheduling a work appt).
New roles for caregiver(s)

- Administering bodily care (intimate);
- Becoming a nurse (ex. Administering narcotics and other medications);
- Family members may live a long distance from where the dying person is.
- Illness lasts a long time.
- Saying goodbye to family members & friends;
- Exhaustion, both physical and emotional.
Increasing dependence

- As the person is bed bound, relying on others for most needs (teeth brushing, basic hygiene);

- “Patients are coming to terms w/living in bed & thinking about the length & quality of their lives in this state” (p. 171, Transitions).
Increasing Dependence

- Often increasing withdrawal;
- Patients will withdraw from loved ones—fading away;
- Patient may be thinking about non-existence, heaven, life after death.
- Help family members tune in to how they can connect with or just be with the patient.
The notion of “a good death” or even “death with dignity” can put undue pressure on the dying person and family.
Family members often block out thoughts of life without the dying loved one and simultaneously envision this life w/o him or her;

Emotional & physical toll on family is greatest at this time.
Each situation is unique;

The challenge is to evaluate needs quickly but not storm in and take over—a gentle touch is required;

Information should be reviewed repeatedly as it is hard to keep in mind when exhausted.
- Disease process may be less and less predictable so continuous adjustment is required;

- Can the patient remain in the home as death approaches? (My story)
- Crises large and small…(example—when the patient falls);

- Our perceptiveness is crucial at these times, picking up on what is not being said.
Being with dying “allows for a level of deep and essential sharing that most of us do not normally get to experience” (Singh, 2000, p. 270).

Suffering makes us tender—think of days after 9/11.
“Death is ultimately personal; to respond to the fears and human condition of the dying always involves responding to ourselves.”

- [https://www.youtube.com/watch?v=oJAq6VpmgBoSlide 27](https://www.youtube.com/watch?v=oJAq6VpmgBoSlide 27)
- Pass On, by Michael Lee


