Making Sense of How We Die

**DIMINISHING ENERGY**: Regardless of which illness is an underlying factor, the dying process can be viewed as a process of gradually diminishing energies combined with the body’s natural tendency to conserve and prioritize those energies.

**THREE STAGES:**
- SLOWING DOWN: The person is still independent, but tired and experiencing some difficulties requiring assistance.
- WINDING DOWN: The person is becoming bedfast or chairfast, sleeping a great deal, eating very little. This is the most physically demanding time for the caregiver.
- SHUTTING DOWN: The person is in the final days and has limited ability to communicate and respond.

**TIME FACTORS:**
- DIAGNOSIS: Some diseases progress more rapidly than others. For example, cancer growth is exponential.
- AGE/ENERGY: There is great individual variability.

**POINTS TO PONDER:**
- The right to make your own decisions includes the right to make bad ones.
- When faced with a difficult decision ask yourself what you will gain and what you will lose.
- Who is this bothering? Caregiver anxiety.
Changes in Strength and Mobility

Sequential Losses:
- Independence: Very difficult to ask for help
- Endurance: Decreased tolerance for activity
- Strength: Difficulty getting up from chair, bed, and toilet
- Ambulation: Unsteady and exhausting
- Increased need for rest: Napping when not engaged
- Independent toileting: Very personal
- Eating and Drinking
- Inability to move and turn in bed

What to Do?:

Sslowing Down & Winding Down:
- Equipment: Walker, wheelchair, cane, bath chair, Bed-side commode, hospital bed, oxygen
- The right to make decisions……
- Fear of fractures: Falls rarely result in fractures
- Physical Therapy and Occupational Therapy: can be effective in optimizing strength, conserving energy and using proper body mechanics

Shutting Down:
- Simplify clothing: Open back, modify night clothes or T-shirts
- Drawsheet: Helps to move the person without pulling on them
- Changing sheets: turning from side to side, using drawsheet
- Ability to swallow: Modify medications
- Picking in the air: purposeless movement often seen
- Open eyes: Sleeping with eyes open is common, use eye drops
HAZARDS OF IMMOBILITY:

- Respiratory infection: Preventive measures include deep breathing, mucolytic therapy, hydration, and positioning.
- Urinary tract infections: Preventive measures include hydration and acidifying urine. Catheterized persons are more susceptible.
- Antibiotic treatment: Curative or comfort measure?
- Pressure sores: Caused by unrelieved pressure in areas of bony contributing factors. Preventive measures include frequent change of position, keeping skin dry, massage and skin toughening ointments.
- Additional information on pressure sores:
  a. Pressure sores are not always preventable and are not an indicator of caregiver neglect.
  b. Night time care: do not set alarm, simply move when awakening. Use pillow or towel wedge.
  c. Who is the bedsore bothering?

Changes in Nutrition

WINDING DOWN:

DIMINISHING ENERGY:

- Small amounts of food feel like a thanksgiving dinner.
- Breathing is more important than digesting food.
- Tendency towards easier digestible foods.

CAREGIVER ANXIETY:

- Food is not always love: cultural norm.
- Concern about starvation: Metabolic shift. Caloric equation.

DIABETIC MANAGEMENT:

- Adjustment of short and long acting insulin.
- Safer to have blood sugars too high than too low.
FEEDING TUBES:
- Not usually helpful in end-stage terminal illness
- Does not alter the body’s ability to digest food

SHUTTING DOWN:
- Beyond need for food
- Mouth care provides comfort: artificial saliva
- Observe for thrush, an opportunistic disease causing discomfort
- Remove dentures for comfort and improved mouth care

Changes in Hydration

WINDING DOWN
- Decreased fluid intake: what types of fluids?
- Coffee and alcohol dehydrate
- Difficulty swallowing or managing liquids. Straws may become difficult to use. Sippy cups or syringes may work. Thickening agents may be useful. Ice chips, especially SONIC ice
- Is it OK to drink alcohol with all the medications?

SHUTTING DOWN
- Too weak to process normal amounts of fluids
- Swelling of hands and feet: who is it bothering? Diuretics?
- Artificial hydration? Usually not helpful. Dehydration is a friend
- Mouth care with sponge swabs; place head on side. Person may bite down on sponge….just wait…
- Observe for thrush. Brownish mucus may be seen
- Changes in vital signs
Changes in Circulation

WINDING DOWN
- Heart gets weaker: heart rate goes up
- Peripheral edema: who is it bothering?

SHUTTING DOWN
- Rapid heart rate caused by dehydration and nutrition related anemia
- Should heart medications be continued?
- Oxygen? Helps take the workload off the heart. More Oxygen to the brain offsetting effects of anemia
- Peripheral edema and ascites will be re-absorbed
- Peripheral circulation decreased causing coolness and discoloration of the extremities. Coolness will creep from toes upwards.

Changes in Breathing

WINDING DOWN
- Increased respiratory effort due to weakness and mild dehydration
- Thickened mucus limits air movement and may cause cough
- Semi-upright positioning with elbows lifted makes breathing easier
- Use of mucus thinners and bronchodilators will open airways. Pineapple juice, coffee, decreased use of milk products

OXYGEN
- Reduces respiratory and cardiac effort
- Reduces anxiety
- May improve mentation: more oxygen to the brain
- Oxygen tube still works if the patient is mouth breathing
- Avoid using Vaseline for dry lips: may cause burns
SHUTTING DOWN:

- Cheyne-Stoke breathing pattern with a series of breaths followed by a long pauses (apnea). May be seen on and off for several weeks. Also seen in persons with epilepsy, strokes, or other brain injuries.
- Can be very un-nerving to observe. This breathing patterns is NOT seen at the very end

Changes in Elimination
An Issue of Personal Dignity

WINDING DOWN:

- Person still able to transfer and use equipment
- Bed-side commode, urinal: male and female
- Urine becomes darker and decreased in volume. Intake does not produce an equivalent output
- Constipation is often an issue due to medication and limited fluid intake
- Bedpans are difficult for patients with limited strength

SHUTTING DOWN:

- Incontinence is common. Padding can be used; also be conscious of keeping skin in good condition.
- Cather may be inserted in case of urinary retention of perineal skin excoriation. Thrush can occur in groin and abdominal skin folds
- Urine becomes scant as is VERY dark. This does not mean there is blood in the urine, it is simply a function of extreme concentration
- Stool is produced even in the absence of food intake
Changes in Levels of consciousness

WINDING DOWN:
- Diminishing energy: needs more frequent “refueling”. Caregiver concerned that this is caused by medication. How can you tell?
- Increased sleeping and “disengaging” (being just under the surface) conserves energy
- Occasional confusion from fatigue – unable to think straight
- May see, talk to, or talk about persons already dead.
- Expends more energy for visitors – then has to “catch up”. This can cause caregiver to feel “left out”. It is OK to limit number and duration of visits. Who is it bothering? Is it worth it?

TERMINAL AGITATION: Restlessness, agitation, confusion, and hallucinations. May escalate to physical violence.
- This is seen more frequently in persons with a history of alcohol or drug abuse
- Some medications may be able to control this without sedation.
- When agitation cannot otherwise be controlled, palliative sedation is the kindest solution.

SHUTTING DOWN:
- Extreme fatigue caused changes in mentation. This does not indicate a comatose state.
- Decreased ability to concentrate and respond to stimuli
- Confusion: may, for example, call people by wrong name. In addition to extreme fatigue, changes in mentation is caused by anemia and increased toxicity
- The dying grace. Mind, body, and spirit working together to bring peace.
The Final Days

CIRCULATION:
- Dehydration causes rapid heart rate, low blood pressure and weak pulse. Mouth gets dry.
- Stored fluids will be reabsorbed
- Coolness and discoloration of the extremities. Creeping coolness
- Dehydration is helpful in keeping lungs clear. Mouth comfort is important

BREATHING:
- Death rattle: pooled saliva at back of throat. Rarely affects breathing but may be bothersome to family. Drying medications available
- Regular breathing pattern gradually slowing. No more Cheyne-Stoke breathing
- Oxygen demand is decreased. Oxygen saturation finger tests not reliable
- Agonal breathing at the end may include head movement. No distress. Usually a change in facial color will occur immediately before death

ELIMINATION:
- Minimal urinary output. Blood pressure is too low for kidneys to filter
- Release of bladder and bowel may occur at the time of death.

TEMPERATURE ELEVATION:
- Generally seen in the last 2-4 days. Not related to infection. Possibly related to toxicity and loss of the body’s ability to regulate
- Who is it bothering: if the patient seems restless and uncomfortable, medication or cooling baths may be given.
- High temperature at time of death causes more rapid onset of rigor mortis
THE FIVE SENSES: Passive versus active

- Sight: Opening eyes, keeping them open and focusing requires energy which a person rarely has in the last days of life
- Hearing is passive; listening is active: auditory comprehension is limited by lack of energy to focus attention
- Taste is likely still intact, but the person is not usually taking anything but water by mouth at this time.
- Smell: Helps the person recognize those around them. Smells of cooking food can produce nausea
- Touch: intact but diminished by decreased circulation. Hands and feet may not have much sensation.

COMMUNICATION:

- Speech is unlikely at this time
- Facial expression may indicate pain, pleasure, worry, or peacefulness etc.
- Restlessness generally indicates discomfort of some type, could be pain, a full bladder, a need to have position changes, too much noise
- May be able to squeeze hand on request. Remember this may take just about all the energy the patient has got
- Final burst of energy: This does not always happen, but can occur in the last 1-3 days. Very gratifying to family.

SAYING GOODBYE:
There are many ways to say Goodbye: I love you; we will miss you; you have been a great Dad; say “Hi” to Grandma

GIVING PERMISSION TO DIE:

- How important is it? Do I really have to do that?
- Readiness to let go: different for everyone
- Non-verbal permission: spiritual communication
CHOOSING THE MOMENT:

- Incredible amount of control rests with the dying person. They may wait for a special person to be there or they may wait until they are alone
- Spiritual contracts and spiritual communication


