

# LIFE QUALITY INSTITUTE

advancing palliative care through education™

## **Symptoms of Dying: Physical, Emotional-Mental, Social, and Spiritual** Cheryl Eckl, Consulting Community Educator

### **Introduction**

Due to lifestyle (urban vs. rural) and technology, the majority of people in the United States have not experienced an intimate death. Granted, we witness death daily on the Internet or television. But this distant and sanitized observation of death robs us of a personal knowledge of death. What does it look like? Feel like? Smell like? Sound like?

When we find ourselves at the bedside of a dying loved one, we don't know what to expect. This "not knowing" can generate tremendous fear that disables us from being present to the moment. Knowing what to expect can free us to participate fully in the process.

- What do I want to know?
  
- What do I want to share?

### **Two Observable Phases of Dying**

- Pre-active: on average lasts approximately two weeks
- Active: on average lasts approximately three days

### **Common Physical Symptoms of Pre-active Dying**

- Need for increased levels of pain medication
- Increased restlessness, confusion, agitation
- Increased periods of sleep, lethargy
- Decreased intake of food and liquids
- Weight loss
- Inability to heal from wounds or infections
- Increased swelling (edema) of extremities or body
- Beginning to show periods of pausing in breathing (apnea)
- Other?

### **Common Physical Symptoms of Active Dying**

- Final surge of energy
- Severe agitation, restlessness, picking at bed linen

- Abnormal breathing patterns (Cheyne-Stokes)
- Build-up of fluid in lungs—rattling
- Inability to swallow any fluids; speech fading
- Incontinence and decrease in urine output
- Drop in blood pressure
- Extremities cold or numb; bluish (mottling)
- Sleeping a lot leading to semi-coma and coma
- Open mouth; jaw drop
- Other?

### **Common Emotional-Mental Symptoms of Pre-active Dying**

- Possibly experiencing denial, anger, bargaining, depression
- Withdrawal from active social participation
- May be delusional, confused, fearful, or paranoid
- Seem to be working hard on deeply inner process
- “Nearing Death Awareness” (*Final Gifts* by Maggie Callanan and Patricia Kelley)
  - Reports seeing persons who are already dead
  - Talks of going on a trip; speaks in metaphors
  - Admits they are dying; predicts own death
  - Seeks resolution of “unfinished business”
- See also: *Trips, Visions, and Crowded Rooms* by David Kessler
- Other?

### **Common Emotional-Mental Symptoms of Active Dying**

- Dying person may appear more at peace
  - Even eager for the journey they have spoken of
  - Accepting in the knowledge that death is imminent
- As speech becomes more limited, messages become more difficult to understand
  - Observable as deeply meaningful to the dying
- The psychological often tips over into the spiritual
  - Even for those without a religious or spiritual tradition or attitude
- Other?

### **Common Social Symptoms of Pre-active Dying**

- Symptoms present in family, loved ones
- Family members may still be experiencing:
  - Denial, anger, bargaining, depression
  - More difficult to get to acceptance
- The old “we” is passing away
  - How can we create a new “we”?
  - “Does he still love me?”
- Strong emotions can erupt
  - Unresolved issues, fears, regrets
  - Misunderstanding of what palliative care/hospice actually provide
- Other?

### **Common Social Symptoms of Active Dying**

- Symptoms can transition into healthy behaviors at this point
- How palliative care/hospice can help at this point
  - Family needs support for difficult conversations
    - Breaking the conspiracy of silence
    - How to talk to the dying person about death
    - How to be present with the dying process
  - Challenges for caregivers
    - What does the dying person need for a peaceful death?
    - Who will be present?
    - Letting go of “doing”—just “be”
    - Other?

### **Common Spiritual Symptoms of Pre-active Dying**

- Beginning the process of separating from this world
  - Acceptance of mortality
  - Realization that death is approaching
- Contemplate life and its meaning
  - Revisiting old memories
- Powerful sense of connection with a higher power
  - Feeling of unconditional love
- Embarking on the Five Tasks of Dying
- Other?

### **The Five Tasks of Dying**

- Task #1: Ask for Forgiveness
- Task #2: Offer Forgiveness
- Task #3: Offer Heartfelt Thanks
- Task #4: Offer Sentiments of Love
- Task #5: Say Good-bye

(Taken from: *The Four Things That Matter Most* by Ira Byock and Angela Morrow, RN.  
“Finding Closure and Peace at the End of Life” About.com Guide)

### **Common Spiritual Symptoms of Active Dying**

- May be difficult to detect
- The mystery that is hidden from loved ones
- Merging of the physical, psychological, spiritual
- Patient may be very quiet, sleeping, coma
- Sense of peace or serenity
- Reaching up to the ceiling, waving
- Smiling, lips moving
- Other?

(Source: Hospice Patients Alliance, <http://www.hospicepatients.org> and as noted.)

**Questions for Reflection:**

- What have I learned ?
  
- What might this prompt me to do—or to do differently?
  
- What will I do with this understanding?
  
- More importantly—how will I now “be present” with the dying?

**Resources**

*A Beautiful Death: Facing the Future with Peace*, Cheryl Eckl, Flying Crane Press, Littleton, Colorado, 2010.

*Dying Well: Peace and Possibilities at the End of Life*, Ira Byock, M.D., Riverhead Books, New York, 1997.

*Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*, Maggie Callanan and Patricia Kelley, Bantam Books, New York, 2008.

*The Four Things That Matter Most: A Book About Living*, Ira Byock, M.D., Free Press, New York, 2004.

*Visions, Trips, and Crowded Rooms: Who and What You See Before You Die*, David Kessler, Hay House, Inc., Carlsbad, California, 2010.

*What Dying People Want: Practical Wisdom for the End of Life*, David Kuhl, M.D., Public Affairs, New York, 2002.