

## “A Team Approach To End of Life Care”

## Supporting Individuals & Staff Through the Process of Death and Dying

### Objectives...

- ◆ Identify stages of grief that may be encountered.
- ◆ Identify potential caregiver concerns
- ◆ Identify potential concerns with other housemates, family, and friends
- ◆ Discuss concrete strategies for coping with stress of caregiver demand
- ◆ Discuss how to develop a proactive plan for dealing needs of individual as well as others in the home.
- ◆ Discuss physiological changes that occur as death approaches and what to expect during this time.

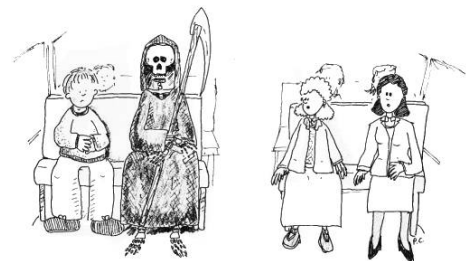
### Dr. Elisabeth Kubler–Ross, M.D.

- ◆ A psychiatrist and author who has done extensive research on the process of death and dying and is known as a leading expert on this topic.
- ◆ Groundbreaking book called, On Death and Dying.

### Concepts Related to Death and Dying

- Some people have time to prepare psychologically and therefore are able to accept or be resigned to death.
- Some people actually look forward to relief from pain and emotional burden.
- Some people are fearful or angry and demonstrate moods that swing from denial to depression.

### Challenges for Caregivers



Whilst on the bus, Bob had a "near death" experience.

## Challenges as Caregivers...

Our perception of the challenges will be affected by...

- Personal experience with death & dying
- Previous work experience
- Life Experience and maturity
- Perceptions & reactions of others
- Additional stressors in our lives
- Additional supports available to us
- Religious beliefs & experiences.
- Personal beliefs and values
- Cultural beliefs and values

## Does this sound familiar?

## Five Stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

## Denial

- Denial can be not only experienced by the dying individual but everyone involved in that individual's life!
- Caregiver denial is common.
- Denial can also arise when death is not anticipated and is sudden, without a chance for caregivers to say good-bye.

## Anger

- Occurs when the person is no longer able to deny loss or death.
- Individuals may experience an increase in behavioral concerns & outbursts
- They may blame themselves, their loved ones, or health care professionals for their illness.
- Staff members may experience anger and lash out at each other
- For some, anger may be manifested as a general increase in physical complaints, irritability, and restlessness.

## Spirituality

- Spirituality encompasses the person's entire being, and varies from person to person
- Can mean formal religion, meditation, relaxation, or simply peaceful activity
- Quiet time just for 'being' can be very healing...nurture time for reflection and rest.

## Bargaining

- Occurs when individuals accept death but want more time to live.
- The individual's will to live is strong, and they may fight hard to achieve goals set.

## Depression

- Occurs when individuals realize that death may come soon and they will have to say good-bye to their loved-ones and leave their goals incomplete.
- Individuals may experience great sadness, and, at times, overwhelming despair.

## Depression and caregivers...

- ◆ Depression and sadness is also normal and expected among caregivers.
- ◆ Allow the individual time to express his or her feelings of depression or hopelessness.

## Acceptance

- The final stage.
- Individuals understand and accept the fact that they are going to die.
- Individuals may complete unfinished business and try to help those around them deal with the impending loss.
- A "sense of peace" is common.

## Something to watch for....

- Sleep disturbances, nighttime anxiety, nightmares
- Appetite changes
- Mood changes, irritability, withdrawal
- Restlessness, agitation
- Wandering, pacing
- Changes in usual routine
- Increased physical complaints
- Return to previous coping behaviors, or recurrence of old behavioral concerns

## "Am I Going to Die?"

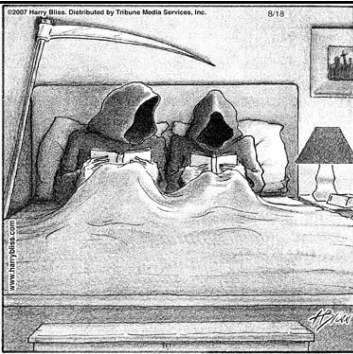
- Responding with honesty and integrity
- Concrete answers on a 'need to know' basis
- Provide additional information or detail when needed
- Expect emotional responses & assist the individual to cope.

## Our Own 'Five Stages' ...

- Caregivers will also experience the five stages at their own pace & in their own time.
- Difficulty & frustration may arise when caregivers and other involved in the individual's life are not 'on the same page' or are in different stages of coping.

## Acknowledging the process...

- Recognize & anticipate challenges
- Be proactive & develop a concrete plan.
- Utilize team supports
- Recognize danger signs & seek assistance
- Revisit, review, & re-evaluate the plan



"Did you lock the front door?"

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## How will the process affect the other individuals in the home?

- ◆ Other individuals in the home may be very sensitive to the climate in the home, and may have a feeling that something is not right.
- ◆ Be sensitive to how, where, and around whom the situation is being discussed.
- ◆ Try to anticipate that there will be emotional needs that need to be addressed during this process for the other individuals that live or work with the dying individual.

## How can we support the other individuals?

- ◆ Allow other individuals time to grieve and cope with loss
- ◆ Do NOT assume that they don't understand the situation!
- ◆ Be honest and up front with individuals that have questions and allow them to express their concerns.
- ◆ Provide support services as needed.
- ◆ Be very careful of using words such as "they went to sleep" to describe the process of death & dying.

## Caregiver concerns...

- ◆ Allow caregivers time in the appropriate setting to vent and discuss anger. Use anger in a constructive manner to find solutions.
- ◆ Take time to take care of yourself physically and emotionally!
- ◆ Take a break!

### A Shift in Mindset...

- Assisting our individuals through these stages is the greatest gift that we could give or receive.
- Involving the team as a 'family' will decrease anxiety & increase the overall quality and level of support for all involved.
- Shift focus back to what is important to the individual..how would he or she like to live out the remainder of his or her life? ASK!

No one is born prepared to deal with these type of situations...we learn through life experience and it does become easier with time as we learn new coping strategies.

The stages for all involved with the care of the dying individual, including the individual him or herself, may not occur in order, may overlap at times, and may not all be accomplished prior to death.

### Despite the challenges...

Our ultimate goal is to assist the individual progress at his or her own pace and hopefully reach the stage of acceptance and peace.

### Utilizing a Team Approach to End-of-Life Care...

Identify strengths of team members, family, friends, housemates, clinicians, and those involved in the life of the dying individual  
Each team member can offer something valuable, contributing to a successful outcome!

### Thinking Outside the Box...

- ◆ How, as a member of the team, do you view your role?
- ◆ Is your role to take charge of the situation or to facilitate?
- ◆ Ask the individual what he or she wants
- ◆ Ask other individuals what role they would like to play & how they would like to lend support

## Who's Life is It?

We are guests in the homes of our individuals...the goal is to enable our individuals to experience life and the process of death & dying in their own homes, on their own terms... not ours.

## Planning ahead...

This is where teamwork becomes vitally important. You must decide...

- Who will come in to work when the end is near. What will each person's role be?
- Who needs to be notified when death is imminent?
- How will we accomplish pain control?
- What additional needs might we experience?
- Clinical support; PT, OT, Nursing, Speech, Behaviorist, Dietary?

## Team Involvement...

- ◆ Encourage the other individuals & family to participate in the comfort and care of the individual if the wish is mutual.
- ◆ Can be sitting next to the person and holding hand, bringing the person a blanket or drink, etc.
- ◆ How can the team support this involvement; think outside the box!

## Continued...

- ◆ Does the individual have a DNR?
- ◆ Will the individual be transferred to the hospital or remain at home?
- ◆ What type of physical and emotional comforts might staff and the individual need?
- ◆ What types of outside supports might we need?

## Organ Donation

- ◆ Must be at least 18 years of age to register, although anyone can be a donor
- ◆ There are no costs to the agency, the family, or the individual
- ◆ Most religions support donation
- ◆ Open casket is possible and donating organs does not usually alter arrangements.
- ◆ Our individuals can donate providing criteria for donation is met in most cases

## Funeral Planning

- Involvement of other individuals
- Involvement of family
- Poems, thoughts, reflections of staff & individuals (collect these prior to the funeral & ask a team member to read these during the service)
- Prepare individuals ahead of time for what they might experience

### Additional touches...

- Donation in the loved one's name
- Funeral flowers individuals and friends
- Favorite items to place in casket both belonging to individual & from friends
- Picture of friends to place in casket
- Other individuals a pall-bearers
- Photo board & guest book- present to family or friends

### Additional Supports

- How do other individuals know that a friend has passed on?
- Do we tell them, even if we don't think that they may understand?
- How do we accommodate religious beliefs and practices? Anointing of the sick, last rites, etc.

- Seating of other individuals & friends
- Gathering after the funeral at the residence or site..sites volunteer items.
- Condolences & announcements within the agency & to family.

### Enabling Our Individuals...

- ◆ Our role is to support our individuals through this process; create a plan for how to 'live' not how to die!
- ◆ Our feelings of helplessness, as well as our individual's, can be greatly reduced when power is taken back by the individual.
- ◆ Allow the individual to express what is important to him or her. How would he or she like to live his or her final days? What does he or she want the rest of his or her life to be like?

### “Wear your Sunday – Best”

Life is meant to be experienced & personal treasures are meant to be enjoyed...

- Celebrate life's joys & little things
- Extra birthdays
- Holidays early, etc
- Be creative!
- Don't save experiences for a 'rainy day' ...enjoy them now!

### Comfort measures...

- Soft lighting, nightlights
- Soft or warm bedding; special sheets, blankets
- Natural lighting and shades in room
- Special mattress
- Comfortable recliner, chair, rocker
- Aromatherapy, oils, lotions
- Special foods, drink, snacks

## Physical Changes as Death Becomes Imminent

- Many of our staff members have never experienced the process of death and dying in their own lives and do not know what to expect.
- A lack of knowledge and preparation may lead to increased fear and anxiety, and a feeling of loss of control.
- Staff members must be prepared ahead of time for what they will see, hear and experience as death becomes imminent.

## Changes as Death Approaches

- Individual is less responsive.
- Body functions slow down.
- Loss of voluntary and involuntary muscle control.
- Individual may involuntarily void and defecate.
- The jaw tends to drop.
- Breathing becomes irregular and shallow, and possibly congested (death rattle).
- Circulation slows and extremities become cold.

- Pulse becomes rapid and progressively weaker.
- Skin pales
- The eyes stare and do not respond to light.
- Hearing is the last sense to go. Do not assume that because death is approaching, the individual can no longer hear.

## Signs of Death

After death, changes continue to take place in the body. These changes are called **moribund** (dying) changes.

- Pupils become permanently dilated.
- There is no pulse or respiration.
- Heat is gradually lost from the body.
- The individual may urinate and/or defecate due to loss of muscle tone.
- Blood pools in lowest areas of body, & purplish discoloration may develop
- Rigor mortis, or rigidity, develops within 2-4 hours after death.

## Giving Permission.....

Sometimes our individuals wait for us to tell them that it is ok to 'let go'. It is ok to let them know this.....

## What can we do to assist the individual?

- ◆ Provide physical comfort and support
- ◆ Soft music, gently massage, hand holding, or just sitting with the individual. Soft lighting can be helpful.
- ◆ Let him or her know that you are there and that he/she is not alone.
- ◆ Provide reassurance

## Continued...

- ◆ Take frequent breaks, if needed.
- ◆ The process of tending to the dying takes a huge physical toll. Remember to drink fluids, take breaks to eat, and rest.
- ◆ Share feelings with other staff, team members, nurse, RM, etc.
- ◆ Don't forget to involve other individuals, family, and staff in the process.

## Long Range Planning...

- ◆ Counseling and support needs will not end with the death of the individual!
- ◆ Plan for supports that might be needed in the days, weeks and months after death.
- ◆ What involvement in the process after death will other individuals and family have? Funeral, etc. Who will attend and how will we help to prepare them for this?
- ◆ It is just as important for the individuals to have closure as it is for you!

## Remembrance...

How will we remember the individual who has passed on?

- Cemetery visits
- Memorial walls
- Gardens, trees
- Scrapbooks (make several & share with family & friends)
- Pictures
- Birthdays, anniversaries
- Family Contact- continue correspondence. Don't forget those first holidays, etc!

## Hospice

- Hospice care has evolved around the philosophy that death is a natural process that should neither be hastened nor delayed.
- Discharge from hospice is allowed & does happen as condition improves.
- Provided to terminally ill people with a life expectancy of six months or less.
- One major goal of hospice is " pain control."

## Questions...?

## Contact Information

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