

PRINCIPLES OF CAREGIVING: AGING AND PHYSICAL DISABILITIES

CHAPTER 9 – GRIEF AND END-OF-LIFE ISSUES

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OBJECTIVES

1. Describe the grieving process.
2. Describe the dying process.
3. Identify and explain emotional issues and coping strategies.
4. Explain the impact of culture and religion on end-of-life issues.
5. Describe advance directives and the significance of the “orange form.”

KEY TERMS

Advance directives	Grief
Do not resuscitate	Hospice
Durable power of attorney	Living will
Dying process	Orange form



A Family-Centered Death at Home

Donna Olsen, at age 15 was diagnosed with Osteogenic Sarcoma, a cancer that was present in a bone in her leg. From the age of 15 to 17, Donna went through several types of chemotherapy, above the knee amputation, radiation, and three lung surgeries. When the cancer spread to Donna's heart lining, Donna knew she was going to die.

Donna wanted to exert as much control over the course of her death as she had over her challenge of cancer. Donna made a choice to die at home. With the help and support of her family she was able to do just that. Donna had her hospital bed and oxygen tank set up in the family room. She wanted to be where the action was. Donna's mom, Diane stated: "Donna was not afraid of dying. In fact, one time while she was playing cards (for money) with her grandma, Donna said: 'you know Grandma, I'm not afraid of dying' then she collected her 3 dimes." Donna had a multitude of family and friends come through to visit – friends from school, from her church, from the hospital, but her world did start to get smaller as the cancer started to ravage her body. For two months before Donna died, the house continued to be filled with laughter, talking, TV, and music. Donna even went into a coma for one week. Diane asked the visiting nurse, "Should Donna be given some kind of nutrition?" The nurse responded: "Feed the body, feed the cancer." Donna came out of her coma two weeks before she died. Diane stated: "Donna was starting to stir for a couple of hours and then she 'woke up' and said she was thirsty and wanted a Coke. I remember Donna telling me she remembers hearing people talk while she was 'sleeping.'" Donna died at home just as she wished. Prior to Donna's death, arrangements were made with the doctor and mortuary, so 911 would not be called. Donna's mother states her biggest accomplishment in life is "We did cancer, we did it well, and we had fun, not to say there wasn't any pain."

When I look back at the time I had with Donna and think of the emotions I experienced, I realized I had acceptance in the beginning. How could I not have acceptance, I had Donna looking at me for strength and our strength always bounced off each other. Did I ever have anger? I remember the time I felt anger distinctly. After Donna died I decided to go back to school and be a social worker. I remember my first class: "New Horizons for Women." I went to class and my teacher shared with us how she was diagnosed with cancer and had her leg amputated. I looked at the teacher and there she stood the same size as Donna, the same hair color, and the same leg that was amputated. When we talked after the class she had the same cancer Donna had. I went to my car and I just sat there and I was angry, I mean really angry. I allowed every cell in my body to be angry. Why was I angry? I then realized I will never experience Donna as an adult, as a wife, as a mother. After allowing myself to experience the deep anger, I was then able to process the anger and let it go. I will remember my husband telling me: "It is okay to be angry but to stay angry becomes a choice. Our feelings are real, but what we do with our feelings is our choice." I continue to thank God for the treasure he gave me to have Donna as my daughter. I had her for 17 years. What a blessing! BUT.... I still do miss her!

By Diane Patton, Mother of Donna Olsen



A. GRIEF AND THE SEPARATION PROCESS

Grief is an emotional reaction to a major loss. The words sorrow, heartache and depression are often used to describe feelings of grief. Whether you lose a loved one, animal, place, or object, or a valued way of life such as your job, marriage, or good health, some level of grief will naturally follow. We are most familiar with grieving as a response to the loss of life, usually tied to losing a close friend or family member.

Years ago, multiple generations lived together and cared for each other all the way through illness and death. Then it became the norm for people who were seriously ill to go to the hospital, and they eventually would die there. Families are returning to the practice of caring for their loved ones through an illness or aging, and many are choosing to spend their last days at home or in the surroundings they choose rather than in a hospital. Laws have been written to allow families to make their own choices about who will care for them, and how and where they will experience the natural process of death.

Scientists have studied people with grief and loss and that has led to theories about grieving that are widely accepted as true. There are stages of grief that many people go through. Although people do experience grief in many of the same ways, remember that everyone will react differently. There is no set time from one stage to the next, people will grieve at their own pace. It is not uncommon for someone to still be grieving 1 or 2 years after a tragic loss.

Stages of Grief

Individuals do not necessarily go through all these stages in order, and they may repeat stages. The grief process is unique to the individual.

- **Shock:** People don't really understand what has happened. They may not remember even being told of the event. This is a protection of the mind to take care of itself, to avoid the hurt. There may be no tears and little or no display of emotion.
- **Denial:** Denial is a temporary reaction after unhappy news. The person refuses to accept what has happened. Some people deny the death of a loved one so much that they won't let anyone refer to them as 'gone.' They may still talk to the person. Some may insist on setting their place at the table, etc.
- **Anger:** Anger is a common feeling after a loss. Some people don't really know who they are mad at, they are just mad that this bad thing happened to them. Some may be mad at the people they feel are responsible for the loss, the person who died and left them alone, the doctor/hospital, or even God or another deity. Anger is hard for families because there is the feeling of blame.
- **Bargaining:** The "let's make a deal" phase. The person attempts to correct the loss by making deals with other people, sometimes with God or another deity. Statements like, "Dear Lord, I promise to start going to church," or "Please let the test on my cancer be

wrong. I promise if the test is wrong I will change my life and join the Peace Corps" are the bargaining part of grief and it is normal.

- **Depression:** This is the most dangerous stage of grief. Everyone goes through depression before they can heal from a major loss. They may not be interested in much of life, eating, sleeping or being with people. Some just want to give up and may not get out of bed. If thoughts or discussion of suicide are present, professional assistance may be needed.
- **Guilt:** Guilt is marked by statements of "If only I had done or been..." It usually comes from things one cannot change. Individuals tend to blame themselves in an effort to make sense of the loss. "This is my fault, I caused this by..."
- **Acceptance:** Living in the present is possible. It's a decision to be at peace with the way things are. To know that no amount of denial, bargaining, anger or depression is going to bring the person back or reverse the situation. Acceptance and hope mean that the person understands that life will never be the same, but that life goes on and the pain lessens over time.

B. THE DYING PROCESS

Death comes in its own time and in its own way, and death is unique to each individual. You may notice these changes in a person nearing the end of life.

One to three months prior to death

- **Withdrawal:** This is the beginning of withdrawing from the outside world and focusing inward. The person's world becomes smaller, possibly involving only closest friends and immediate family. You will see the person possibly taking more naps, staying in bed all day; sleeping more becomes the norm. Verbal communication decreases, as touch and not speaking take on more meaning.
- **Food:** We eat to live. When a body is preparing to die, it is perfectly natural that eating should stop. This is one of the hardest concepts for a family to accept. **It's okay to not eat.**

The person dying will notice a decrease in eating. Liquids are preferred to solids. Meats are the first to go followed by vegetables and other hard-to-digest foods. Cravings will come and go.

One to two weeks prior to death

- **Disorientation:** The person is sleeping most of the time now and cannot seem to keep his or her eyes open but can be awakened from the sleep. Confusion can take place when you talk to the person. The person may start talking about previous events and people who have already died. The focus is transition from this world to the next.
- **Physical changes**
 - Blood pressure often lowers.
 - Pulse beat becomes erratic, either increasing or decreasing.
 - Skin color changes.
 - Breathing changes. It has an erratic rhythm, either increasing or decreasing.

One to two days, to hours prior to death

- **Physical changes**
 - A burst of energy may be present.
 - Breathing patterns become slower and irregular, sometimes stopping for 10 to 45 seconds.
 - Congestion may be audible.
 - Eyes may be open or semi-open and have a glassy haze.
 - Hands and feet become purplish and parts of the body become blotchy.
 - The person may be non-responsive.

C. EMOTIONAL ISSUES

Client and family

Individuals are unique in their display of emotions. The fact that some people do not display what others think is normal does not mean that they are not grieving.

Some differences in grieving:

- Some people are quite vocal; some are quiet.
- Some are accepting; some are in denial or shock.
- Some people weep; some are very stoic (emotionless).
- Some people are angry; some may appear happy.

Direct care workers

It is natural that the DCW and the person being cared for have a connection. When that person dies, the DCW may grieve as though the person were a family member. Some coping strategies are described Section D below.



Exercise

This exercise will help you understand the dynamics of a family dealing with a loss, whether it is through death of a loved one, disability, or any other major change.

- Envision a child's mobile. Imagine on the mobile are five family figures: mom, dad, sister, brother, and grandmother. The family is in balance until a family member's diagnosis takes place.
- Let's say the brother has just been in an accident and has sustained a spinal cord injury. Remove the brother from the imaginary mobile and what happens? The mobile becomes out of balance. For the family mobile to get in balance again, everyone needs to re-negotiate their position in the family
- Other family members may have their own difficulties. Their position in the mobile changes. For example, the sister is going through her own crisis from just being a teenager. Dad might not be able to deal with the added changes and starts drinking. Grandma is in her own world. Sometimes, the whole family mobile is trying to be balanced by one person. In this case. Mom.

D. COPING STRATEGIES

Part of *healthy grieving* is allowing yourself to grieve. Not doing so can cause emotional and/or physical problems later. Take care of yourself by:

- **Talking:** Use your social support system, or talk to a clergyperson or a counselor.
- **Writing:** Take up journaling, even writing letters to the deceased person about things you wished you would have said.
- **Reminiscing:** Remember the good times. Plant a garden in the person's honor, or support causes the person was involved in.
- **Getting enough sleep, exercising, and eating healthy:** Keep your body healthy. Do not turn to alcohol or drugs to numb the pain. This usually makes the situation worse.
- **Planning ahead:** Realize that anniversaries, holidays and special days will be difficult at first. Plan to spend time with a valued social support.
- **Don't be reluctant to ask for help:** Help is out there, just ask. (See Section I, Resources, later in this chapter.)

Client and family

DCWs must be aware of the needs of the people they are assisting. If you think a client is not grieving in a healthy way, talk to your supervisor. He or she may be able to arrange agency or community resources.

Direct care workers

People grieve differently. Allow yourself to grieve in your own way. You may need to talk to a valued social support. You may need to have some relaxation time. Try to be good to yourself and seek out the help that you need. Your supervisor may be very helpful in arranging agency or community resources to assist you.

E. CULTURAL AND RELIGIOUS ISSUES

Cultural and family differences will influence the death and dying process. DCWs should be aware of the various beliefs and practices of the people for whom they are providing care. Cultural differences vary, and it may be difficult to become culturally competent in all areas. Ask your supervisor for direction on how to handle an individual's needs.

Some religions or cultures:

- Discourage or forbid embalming and autopsy.
- Will not allow non-family to touch the body.
- Do not want the body to be touched shortly after death.
- Cover the mirrors in the home after a family member dies.
- Remove water from the room after family member dies.

F. ADVANCE DIRECTIVES

Advance directives are documents that specify the type of treatment individuals want or do not want under serious medical conditions in which they may be unable to communicate their wishes. Generally two forms are involved with advance directives:

- **Living will:** Outlines the medical care an individual wants or does not want if he or she becomes unable to communicate their wishes or make decisions.
- **Durable medical power of attorney:** Lists another person to act as an agent or a surrogate in making medical decisions, if the individual becomes unable to do so.

Advance directives can be done by an individual and do not require an attorney. The advance directive must be completed while the person is still competent. In Arizona, the forms do not have to be notarized. If the individual moves to another state that requires notarization, the Arizona forms would not be valid.

More information on advance directives can be found in Chapter 2, Ethical and Legal Issues in the *Principles of Caregiving: Fundamentals* course manual.

Pre-hospital medical care directive

The *pre-hospital medical care directive*, also known as a *do not resuscitate (DNR) order* or the *orange form*, is a special type of advance directive. This form states that if the heart stops beating or breathing stops, the individual does not want to receive cardiopulmonary resuscitation (CPR) under any circumstances. This special form, which is printed on bright orange paper, notifies the paramedics and emergency medical response team that this choice has been made.

The orange form should be displayed on the refrigerator or behind the living room door where the paramedics can see it, should the individual have cardiac and/or respiratory arrest.



If the client has an orange form, the DCW should contact the supervisor for guidance on the agency's policies and procedures relating to CPR for the client.

The orange form only covers cardiac and respiratory arrest. If the client has another type of medical emergency, the DCW should provide first aid measures, including calling 911 as indicated.

More information on advance directives for individuals residing in Arizona can be obtained from:

- Health Care Decisions, www.hcdecisions.org/
- Arizona Attorney General's website, www.azag.gov/life_care/index.html

G. HOSPICE

Hospice is a program of care and support for someone who is terminally ill. A physician has to certify that the person has less than six months to live. The person's diagnosis can be cancer, kidney failure, emphysema, Alzheimer's disease or any other condition that may be terminal. A specially trained team cares for the whole person. This includes his or her physical, emotional, social, and spiritual needs. Hospice also provides support to family members of the terminally ill person. Services are generally given in the home, but they may also be given at an in-patient facility. Hospice focuses on comfort measures, not on curing an illness. A DCW may provide housekeeping and other supportive services.



H. GRIEF ACTIVITY

The purpose of this exercise is to experience letting go of friends, family, and activities you dearly love. This exercise relates to some of the grieving indicators that your clients may experience.

Supplies

- 15 pieces of paper approximately (1" x 2") for each person.
- Pens.
- Garbage can.

Activity

Think of 5 family members, 5 friends or acquaintances, and 5 activities you like to do (example: reading, watching TV, tennis, bowling, sewing, running, etc.). Write the name of a family member, friend, or activity on each piece of paper. Then arrange the pieces of paper so you can see each one. Take some quiet time (approximately 2 to 5 minutes) and think of *each* person and *each* activity you chose.

- **Scenario 1:** Imagine you were just in a car accident and you have sustained a spinal cord injury. What activities, that now as a wheelchair user, are you prevented from doing? Tear up those activities and discard them. Are there any people you directly do these activities with? Tear up their names and discard them.
- **Scenario 2:** Imagine you have a persistent cough, so you go to the doctor. You find out you have cancer and you will need to undergo chemo therapy. It is suggested that you may need to take a one year leave of absence from work. Did you write down the names of any people you see at work? Tear up those names and discard them.
- **Scenario #3:** Imagine you have just found out you have been diagnosed with inoperable blindness. How will this affect the activities you have chosen? Tear up and discard those activities you will not be able to do because you are blind.
- **Scenario #4:** Now take two people you have chosen and just put them aside. How would you feel if they were not involved in your life anymore?

How did you feel when you had to actually tear up and discard any activities or people?
How did you feel when you removed and put two loved ones aside?

I. RESOURCES

- Area Agency on Aging Senior Help Line, (602) 264-2255
- Community Information and Referral, (602) 263-8856
- If the deceased person was open to hospice services, contact the social worker for that hospice agency.
- Advance directive information for individuals residing in Arizona can be obtained from:
 - Health Care Decisions, www.hcdecisions.org/
 - Arizona Attorney General's website, www.azag.gov/life_care/index.html