

# **PRINCIPLES OF CAREGIVING**

## **FUNDAMENTALS**

### **SECTION FIVE - GRIEF AND END-OF-LIFE ISSUES**

#### Content:

- A. Grief and the Separation Process
- B. The Dying Process
- C. Emotional Issues
  - 1. Consumer and Family
  - 2. Direct Care Worker
- D. Coping Strategies
- E. Cultural and Religious Issues
- F. Resources
- G. Grief Activity

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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.”

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## Key Terms:

Advance directives

Do not resuscitate

Durable power of attorney

Dying Process

Grief

Hospice

Living will

Orange Form

## A. The Grief and Separation Process

In the 1800's and early 1900's death was very much a part of life. Families witnessed the death of a loved one and the preparation of the burial. Then, in the middle 1900's when a family member became ill the family member went into the hospital. If the person died it was very common to "protect" the children and shelter them from the grieving process. Today, we are returning to allowing all family members to share the grieving process. Today, we have hospice and people have the right to choose to die at home or in the surroundings they choose.

### 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.

1. **Shock:** There is disbelief that the loss has occurred.
2. **Denial:** Denial is a temporary buffer after unexpected news. The person refuses to accept the loss has occurred. Denial is encouraged by silence.
3. **Anger:** Anger may be directed toward the loss, the person lost, or even a deity. Families have a hard time with anger because the anger is displaced in all directions.
4. **Bargaining:** "Let's make a deal". The person attempts to reconcile the loss by making deals with other people, sometimes also with a deity.
5. **Depression:** Anger is turned inward.
6. **Guilt:** Guilt is marked by statements of "If only I had done / been. . . ." It usually comes from things one cannot change.
7. **Acceptance:** Living in the present is possible. Acceptance and hope mean that the person understands that life will never be the same but it will go on with meaning and hope.

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## B. THE DYING PROCESS

Death comes in its own time and in its own way.  
Death is unique to each individual.

### 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. With withdrawal you will see the person possibly taking more naps, staying in bed all day, and more time sleeping becomes the norm. Verbal communication decreases and touch and wordlessness 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 not to 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, and 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**

- 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 becomes non-responsive.

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## **C. EMOTIONAL ISSUES**

### **Consumer 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.

### **The Direct Care Worker**

It is only natural that the DCW and the person being cared for build a rapport. When that person dies, the DCW may grieve as though the person was a family member. If this is the case the DCW may want to use the coping strategies in the next section.



**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 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 and for the mobile of the family to get in balance again, everyone needs to negotiate their position to get the family in balance.

This is the best scenario. Often what happens is 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.

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## D. COPING STRATEGIES

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

**Talking** — Use your social support system, or talk to clergy person 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 “Resources.”)

**Consumers and Family:** DCWs need to be aware of the needs of the people they are assisting. If you think a consumer is not grieving in a healthy way, talk to your supervisor. He/she may be able to arrange agency or community resources.

**Direct Care Worker:** As previously mentioned people grieve differently so 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 need to be aware of the various beliefs and practices of the people for whom they are providing care. But as you can see below, the cultural differences are so varied that it is difficult to become culturally competent in all areas. Ask your supervisor to give you direction on how to handle the individual 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.

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## F. RESOURCES

- Area Agency on Aging— Senior Help Line (602) 264-2255
- Community Information and Referral (602) 263-8856
- Valley Interfaith Project (602) 248-0607
- If the deceased person was open to Hospice services, contact the social worker for that Hospice agency
- Advance Directives information for individuals residing in Arizona can be obtained from:  
Health Care Decisions at: <http://www.hcdecisions.org/>  
Arizona Attorney General's Website: [http://www.azag.gov/life\\_care/index.html](http://www.azag.gov/life_care/index.html)

## G. GRIEF ACTIVITY



The purpose of exercise is to have the class experience letting go of friends, family, and activities they dearly love. This exercise relates to some of the grieving indicators the people being served by DCWs experience.

Supplies: 15 pieces of paper approximately (1" x 2") for each student, pens, garbage can.

Activity: Have each student think of 5 family members, 5 friends or acquaintances, and 5 activities they like to do (example: reading, watching TV, tennis, bowling, sewing, running, etc.). Have the students write the name of a family member, friend, or activity on each piece of paper. Then have the students arrange the pieces of paper so they can see each one. Ask the students to take some quiet time and think of **each** person and **each** activity they have chosen. Wait approximately 2-5 minutes. You can even turn the lights low and play some soothing music.

Now the true exercise begins. Talk to the students about the following scenarios.

**Scenario #1:** "Imagine you were just in a car accident and you have sustained a spinal cord injury." Ask your students: "What activities have you chosen to do that now as a wheelchair user will prevent you from participating in the activity? Tear up those activities and discard them. Are there any people you directly do these activities with? Tear their names up and discard them."

**Scenario #2:** "Imagine you have a persistent cough, so you go to the doctor and you find out you have cancer and you will need to undergo chemo therapy. It is suggested that you will probably need to take a year leave of absence from work. Did you write down the names of any people you see at work? Tear up the 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 the activities you will not be able to do because you are blind."

**Scenario #4:** "Now I want you to take two people you have chosen and just put them aside. How would you feel if they were not involved in your life anymore?"

Have class participate on how they felt when they needed to actually tear up and discard any activities or people? How did they feel when they needed to remove and put two loved ones aside?