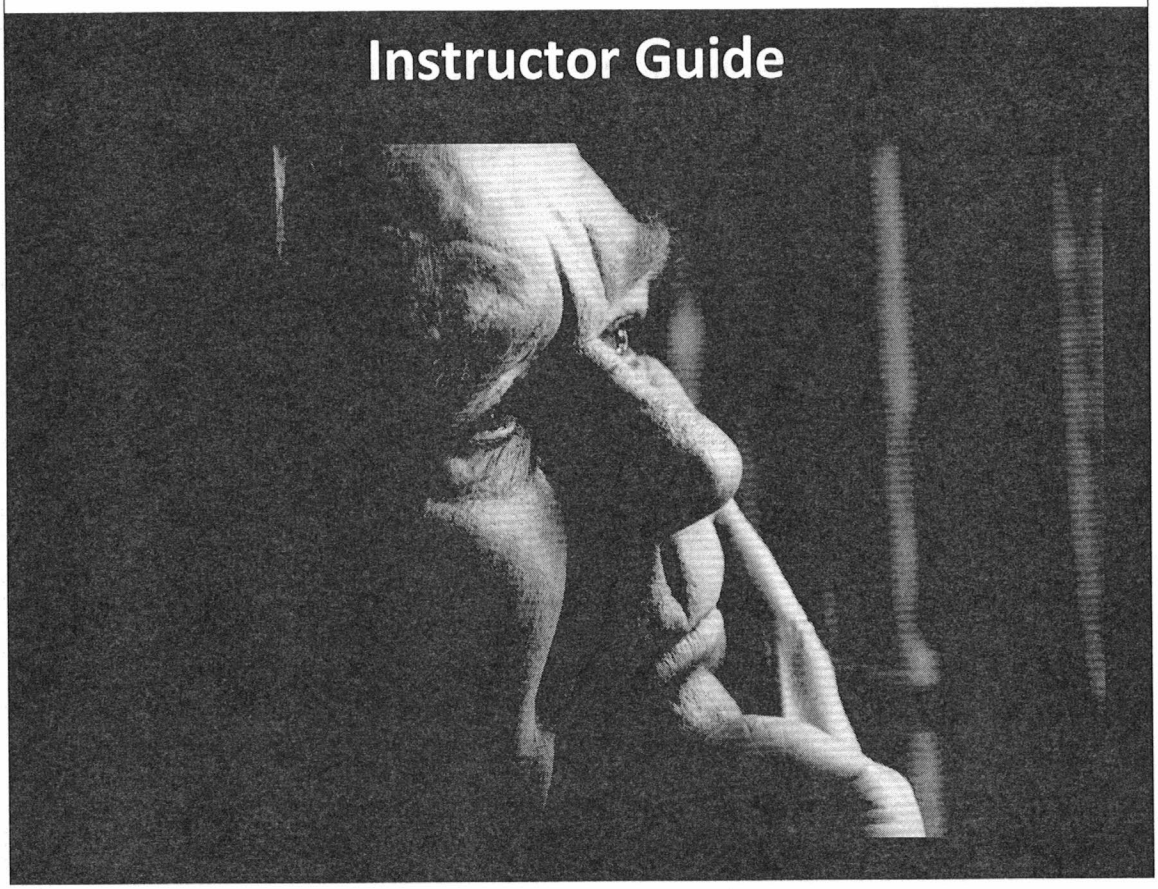
End of Life

Instructor Guide



UPDATED JUNE 22, 2011

Care and Compliance Group, Inc • 800.321.1727 • www.careandcompliance.com

INSTRUCTOR GUIDE:
END OF LIFE

Overview	This module addresses the end of life experience and how it is different for each resident. Care staff play an important role in making the resident feel safe and comfortable. A resident on hospice is still our resident-we do not relinquish all care to the hospice agency. We will discuss what to expect in the dying process, and how to work with the hospice agency.
Video(s)	"End of Life" (60 minutes)
Special Supplies	None
Learning Objectives	1. Introduction to the different ways residents experience end of life; 2. What is grief and loss; 3. Looking through the resident's eyes; 4. Meeting the psychosocial needs of our residents.

QUIZ: END OF LIFE

Name: Date:

1. If a resident is considered "terminally ill." Generally speaking it means they have ___ months of less to live.

   a. 3
   b. 6
   c. 12
   d. 24

2. When a resident is near end of life and bedbound, in many cases they are still able to hear even if they cannot communicate.

   a. True
   b. False

3. When a resident is near end of life, typically their appetite will:

   a. Increase
   b. Decrease
   c. Remain the same as before they were ill
   d. None of the above

4. In the last few days of life a terminally ill resident will typically become:

   a. Less responsive
   b. More responsive

5. Cheyne-Stokes breathing is defined as:

   a. Continuous shallow breathing typically seen in the last day or so of life
   b. Several rapid breaths followed by periods of no breaths typically seen in the last day or so of life
   c. Normal breathing typically seen in the last day or so of life

6. In the last day or two of life, the resident's breathing may sound wet and gurgling. This breathing:

   a. Causes the resident discomfort and the hospice nurse should be called.
   b. Typically does not cause discomfort. However, there are medications than can help this condition.
   c. Does not cause any discomfort. Do not ever call the nurse about this.
   d. None of the above

7. If a hospice resident goes two days without a bowel movement, you should:

   a. Do nothing
   b. Call the hospice nurse
   c. Call 911
   d. Call the resident's family before doing anything else

8. When a resident is near end of life, good skin care is imperative. List three interventions for good skin care:

   _____

   _____

   _____

9. List at least three interventions that may make the physical environment more pleasant for the resident:

   _____

   _____

   _____

10. Which of the following may be signs the resident is in pain?

    a. Agitation
    b. Sitting or lying in a different position than normal
    c. Breathing quickly
    d. All of the above

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   Good incontinence care
   Keeping the resident clean and dry
   Repositioning the bedbound resident at least every one to two hours
   Utilize good bed making skills

9. List at least three interventions that may make the physical environment more pleasant for the resident:

   Encourage visitors, Place plants where the resident can see them,
   Place pleasant smelling potpourri in the room, Place a bird feeder outside the window,
   Have a favorite pillow or comforter available, Have favorite music or TV shows available

10. Which of the following may be signs the resident is in pain?

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    b. Sitting or lying in a different position than normal
    c. Breathing quickly
    d. All of the above

Certificate of Completion

THIS IS TO RECOGNIZE

_____

FOR DEDICATION TO QUALITY RESIDENT CARE
THROUGH EDUCATION AND PROFESSIONAL DEVELOPMENT.

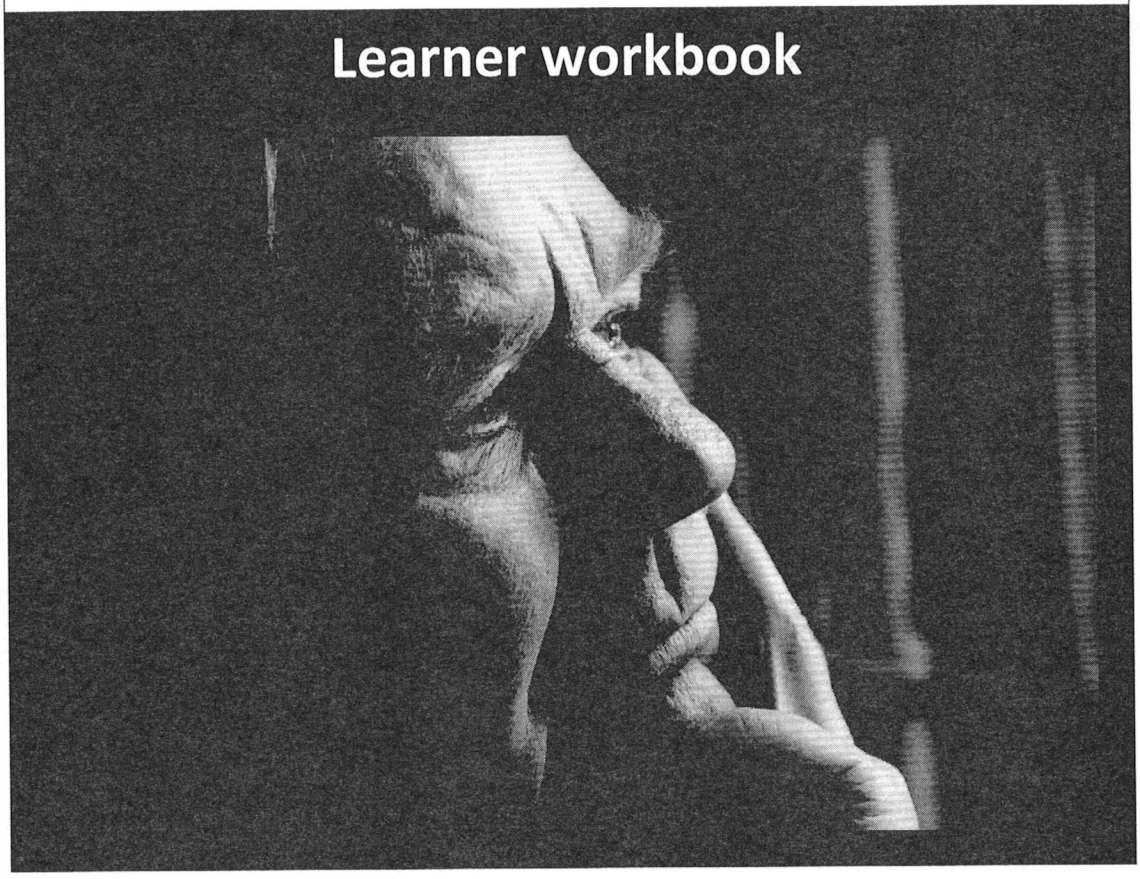
END OF LIFE

_____ _____

Instructor Signature Date

End of Life

Learner workbook



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INTRODUCTION

One of the most important goals in a Community is to understand and meet both the needs and the preferences of each resident. Some residents may verbalize their needs very well; others will not. Their lack of communication may be due to actual physical language problems, it may be due to a resident being polite and not wanting to "bother" the staff, it may be due to a resident really not knowing what he or she needs, and numerous other barriers that get in the way of clear communication.

Outstanding direct care staff are often very intuitive and sensitive to "reading" the needs of residents, often without the resident saying anything at all. A resident's body language, facial expression, tone of voice, and other non-verbal behaviors often provided clues to what a resident may need. Direct care staff is often very "tuned in" to residents and immediately know when something is not quite right with a resident.

Throughout our lifetime we are challenged with different struggles at different stages in life. For example, young persons are dealing with decisions that will set the course of their future; the elderly are presented with challenges and decisions that precede the end of their life. It is difficult to discern opportunities when one is overwhelmed by what he or she has lost.

WHAT IS GRIEF AND LOSS?

Grief is an emotion people may experience strongly and/or overwhelmingly, due to various circumstances, such as a loss of a loved one or possibly from a terminal diagnosis he or she has received. When a person experiences grief they may feel disconnected, numb, and unable to function throughout the day. According to medical studies grief is a natural response to loss, and can be both a universal and personal experience. Understanding why the person is suffering is the first step in healing. There are several stages of grief and loss.

Dr. Elizabeth Kubler-Ross introduced the model of five stages of grief in her 1969 book, *On Death and Dying*, and many of these stages have applied to any significant loss experience not just death and dying. Understanding these stages of grief and loss can help you understand what you residents and their families are going through.

Although it is not a loss to move into a Long Term Care Community, for some it may feel like a loss because of all the things they give up in the process. The stages of grief and loss include:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

Denial

An example of denial may include: "Mom probably doesn't need this, we could probably care for her, but this is really hard on the family."

The resident may say things like, "I can take care of myself. I do not need all this help."

Anger

Anger may come from unmet expectations. Residents may become angry at family for encouraging or urging him/her to move into the Community instead of allowing them to live on his/her own.

Bargaining

Residents may try to bargain in order to get results he or she would like. For example, "If I am good the staff will let me go home." Or possibly, "If I am bad the staff will make me go home."

Depression Depression may result from feelings of guilt. The resident may feel like he or she has lost so much or given up everything. The family may feel terrible for not having the strength or resources to make life better the way it was before. The family may know that the situation is best for the resident, but still have feelings of guilt.

Acceptance As direct care staff we have a large role in assisting the resident to transition to the acceptance stage as soon as possible once he or she moves into the Community. Some people move into this stage more rapidly than others.

Some examples of this stage may include:

The resident may say, "I have made new friends. This Community is like a vacation on a cruise ship."

Families may say, "It is such a joy to visit with Dad again. He's beginning to be like we remember long ago."

LOOKING THROUGH THE RESIDENT'S EYES

Residents will often comment that what is most important in a Community is the staff. Staff who are caring, compassionate, patient, and understanding of residents can be invaluable to the psychosocial health and joy a resident experiences each day. Compassionate direct care staff can bring happiness and a sense of self-esteem even to the most disabled resident. The deepening of natural human compassion often comes from the old saying, "see the world through their eyes." Let us take a look at some of the common life challenges that your residents may be facing so you can begin to see the world through their eyes.

Residents in your Community may be struggling with any one or many of the following issues:

LOSS OF A LOVED ONE

Many residents may have recently lost a spouse, significant other, friend, or family member. To compound the loss, the individual lost may also have played a role in taking care of the resident. A loss of a loved one can also trigger the reality of one's own mortality.

DECLINE IN FUNCTIONAL ABILITIES (Mental and Physical)

Residents who have a decline of functional abilities may feel sadness, anger, or frustration as one becomes aware of the loss of physical strength, greater forgetfulness, inability to perform everyday tasks, etc. These feelings can also become triggered when worry over the failing health observed in a spouse or loved one.

SOCIAL ISOLATION

Prior to entering a Community residents may have lost their mobility, such as the ability to drive, that way necessary to maintain social contacts. Or, their friends may have passed away and/or no longer be physically able to visit. Depression can also play a role in social isolation since person often withdraw and isolate as a result of the disease.

HELPLESSNESS

Residents entering a Community need help with an average of 1.6 activities of daily living (ADLs). Residents may feel inadequate, frustrated, or simply give up trying when they become aware of their perceived helplessness. Not only do they need to depend on others, which results in a loss of independence, they may also be struggling with esteem issues in the role change from being valued to help another (maybe caring for an ailing husband) to requiring care themselves. It is important to encourage residents to continue to do as much as they can for themselves.

CHANGE IN FAMILY ROLE (Caregiver, mom, dad, husband, wife) AND/OR SEPARATION OF SPOUSES

Competence, physical presence, and/or loss may change the family role. For example, the strong family "matriarch" or "patriarch" whose health declines and can no longer maintain that family role. Or, the couple who becomes physically separated due to different care needs, such as when one spouse needs dementia care and the other spouse is very mentally competent.

CHANGE IN SOCIAL ROLE

Entering a Community often changes a person's social role. For example, a resident who was a lead volunteer at church, played an important role in his/her local Chamber of Commerce, was instrumental in getting donations for a new library to be built in his/her local community, or many other significant social roles before moving into the Care Community. Residents may have had to move to be closer to family; thus, are no longer connected to those who know and valued their past social role.

INTERPERSONAL CONFLICTS

Interpersonal conflicts can result from dysfunctional family members fighting over money or control, conflict from feelings of perceived "desertion" when family does not visit as anticipated, and/or interpersonal conflicts that result within a Community. Some residents have the skills to resolve interpersonal conflicts; others do not.

CHANGES IN SOCIAL STATUS

Many residents have held powerful positions in corporations, owned their own businesses, etc. Many have recently lived in very large, prestigious homes. Moving into a Care Community shifts those dynamics into one of more equality among residents. This can be a difficult adjustment for many residents.

Another type of change in social status is the loss of recognition of cultural importance. For example, many Communities promote independence and decision-making (e.g., resident council, advance directives, etc.). But, consider those residents whose cultures value decision making by a group or elders or the cultural differences in end-of-life beliefs.

RECONCILIATION OF PERSONAL ACCOMPLISHMENTS AND DISAPPOINTMENTS

As a person ages, it is natural for him or her to reflect on one's accomplishments and disappointments. For some residents this reflection can bring peace and joy. For others, it can bring despair, depression, feelings of failure, and a sense that they are unable to reconcile their disappointments before their death. Depending upon their religious beliefs, this may be a significant source of emotional/spiritual pain and suffering.

PHYSICAL PAIN AND MEDICAL PROBLEMS

Medical problems can result from a very wide range of issues including: pain of arthritis, fear of memory loss, a newly diagnosed medical problem, recently falling, becoming more frequently incontinent, etc. Depending upon the issue, residents' feelings may range from agitation due to chronic discomfort to fear of disability or death.

FINANCIAL WORRIES

Residents can become very concerned and anxious as they see their investments declining in value and worry about paying for the cost of care. Residents can obsess about what will happen to them if they can no longer afford to remain in your Community.

LOSS OF CONTROL AND INDEPENDENCE

Residents may be used to being about to reach for medications at will for pain relief, constipation, etc. Now they have to wait for doctors' orders and the med tech/med aid to arrive. They have been used to going to the local market whenever they craved a favorite cookie, peaches, or other special treat. Loss of the ability to drive is a very big loss of independence for many residents.

AND, WHAT ABOUT ALL THE "LITTLE THINGS"...

...like residents giving up of life-long passions such as boating, tennis, farming, etc.; being unable to build birdhouses in the garage; having lived in the same home for 40 years; leaving behind favorite rose bushes planted when the resident's parents died; leaving cherished wedding/anniversary presents behind because they are too big; gays having to pretend they are straight to fit in; leaving dogs, horses or other animals that may have brought joy for years; or leaving a community inhabited by a similar culture (Asian, black, Hispanic), etc. The list could go on.

On top of all the life challenges we have discussed are any effects from medications and losses of psychological capacity that may reduce the person's capacity to "cope." Having the knowledge of the numerous sources of resident loss, anger, frustration, sadness, and other emotions can help bring insight and a deeper understanding when providing care to residents.

Everything we have discussed in this course are examples of the psychosocial issues our residents may face when dealing with grief and loss.

MEETING THE PSYCHOSOCIAL NEEDS OF OUR RESIDENTS

As you already know, our Community can be a wonderful solution for those needing assistance. In addition to physical needs such as assistance with medications, activities of daily living (ADLs), meals, and ambulation, our Community offer rich psychosocial opportunities for residents. Let's look at what Communities have to offer and ways to meet the psychosocial needs of residents.

Take the time to connect with residents to develop genuine feelings of compassion, understanding, and concern for the resident's well-being. Residents seek direct care staff who listen and express an attitude that reflects care and respect.

While every staff person is very busy and has many residents to care for, taking the few minutes necessary to read the newspaper headlines to a blind resident, not rushing a resident walking to breakfast, showing patience while the resident methodically takes his/her medications one pill at a time, listening to resident's stories, etc. are all ways to show respect. Respect is also shown in your nonverbal behaviors, such as the expression on your face and your body language.

Offer encouragement to promote the resident's sense of independence and mastery. Independence and mastery is important for both the resident's mental and physical health.

This can be achieved by encouraging the resident to:

- Perform ADLs to the best of the resident's ability
- Make choices for himself/herself
- Participate on the resident counsel and in activities
- Choose when and what to do each day

In addition to the everyday encouragement provided by staff, formal programs to help residents with independence and mastery include:

- Training aimed at reducing the fear and likelihood of falling through programs that improve strength and balance
- Training about diabetes and food choices
- Training about high blood pressure, healthy foot care, and many other topics to promote good health and greater independence

Provide the residents with a sense of safety and security. Some suggestions include:

- A secure building that monitors who has access to residents and their belongings
- Access to appropriate medical guidance from health professionals (nurses, dietitians, physical therapists, physicians, podiatrists, wellness professionals, etc.)
- Access to necessary services by coordination of transportation to events ranging from shopping to doctor's appointments
- Staff who knocks on the door before entering and respects the resident's privacy
- Supervision from direct care staff who are available to monitor and assist the resident 24/7

Offer a variety of structured and unstructured activities for enjoyment by residents.

Activity programs can be designed to meet nearly every level of the residents' needs, including basic exercise and motor skill activities, social activities to build love and belonging, activities that promote self-esteem from successful achievement, and maybe even self-actualization needs through connections with pets and nature. The overall goal of a successful activity program is to promote maintenance or enrichment of each resident's quality of life.

Foster independence. Physical independence requires physical strength and ability. Maintain or build physical strength and balance through exercise programs to promote strength and endurance, range of motion exercises, balance training. Activities can be tossing a light ball, exercises while sitting, walking, exercise bicycle classes, and more.

Independence is also fostered through choices, so allow residents to make as many choices as possible. For example, meal choices, what to wear, what to draw in are activities, etc.

Offer outreach opportunities to create a sense of belonging to the broader outside community.

- Involve the resident's family and staff whenever possible.
- Encourage outside volunteer work or recruit volunteer projects that can be done in the Community.
- Offer transportation and organized trips to museums, shopping mall, zoo, movies, etc.
- Promote intergenerational activities that involve children and young adults.

Promote resident self esteem through participation in activities with a purpose. Build in activities that have a bigger purpose and contribute to the broader world, such as knitting caps for disadvantaged children, building flower arrangements for holiday tables at a food shelter, and sew dog beds or bake dog cookies for the local animal shelter.

Encourage socialization and companionship. Encourage interpersonal communication, social interaction, and the ability to succeed and feel esteem with positive results. Most any activity that involves more than one person encourages socialization and companionship, such as singing, crafts, discussions, and many more.

Recognize and honor the diversity among residents' history and preferences. Help all residents appreciate and learn from each other's differences. Each resident and staff member brings with them a rich background of life experiences and beliefs. Encouraging the sharing of these experiences among residents, staff, and others can promote an environment to values each other's lives.

Inspire continued learning and mental stimulation to reinforce old skills and build new skills. Teach new skills and build upon/reinforce prior skills to promote a sense of self-respect and accomplishment.

Help older persons "reframe" their competence. Reframing competence means:

- Selecting activities which the resident can do well to promote feelings of competence, and

- Judging performance in comparison to others their age to provide positive reinforcement and self-esteem.

Provide pleasurable experiences often including laughter, play, animals and connection with nature. Offer a variety of stimulating activities such as pet therapy, music, dancing, speakers on relevant topics, etc.

Offer opportunities for expression through creative outlets. Self expression in arts and crafts activities can be both fun and provide choices for creativity. Provide the materials, give some guidance, and allow the resident to create their own masterpiece.

Encourage informal socialization. One of the great resources within a Community is the opportunity for residents to interact with others and build friendships. While structured activity programs facilitate socialization, many more informal relationships develop. For example, the importance to residents of dining at a certain table with friends, playing cards with others, or simply sitting with others in the garden.

The very nature of our Communities encourages and provides many opportunities for socialization. While respecting individual preferences, staff should encourage residents to

socialize with others whenever possible. This will also help the resident when suffering from grief and loss to recover from his/her loss by talking with people that he/she enjoys being around.

Meeting your resident's psychosocial needs is a major component in the health and happiness of your residents. How a resident feels about himself/herself and how the resident relates to others greatly influences the resident's daily life experience in our Community, especially when the resident is dealing with grief and loss. While we have many dimensions that contribute to our overall health, understanding resident's needs and actions you can take to meet your resident's needs is important when the resident is going through the grief and loss process. The most important resource you can provide to the resident is human connection.