

A Client Care Module:

END OF LIFE CARE

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Developing Top-Notch CNAs, One Inservice at a Time



A Client Care Module:

END OF LIFE CARE

We hope you enjoy this inservice, prepared by registered nurses especially for nursing assistants like you!

Instructions for the Learner

If you are studying the inservice on your own, please do the following:

- Read through **all** the material. You may find it useful to have a highlighting marker nearby as you read. Highlight any information that is new to you or that you feel is especially important.
- If you have questions about anything you read, please ask _____.
- Take the quiz. Think about each statement and pick the best answer.
- Check with your supervisor for the right answers. You need **8 correct** to pass!
- Print your name, write in the date, and then sign your name.
- Keep the inservice information for yourself and turn in the quiz page to _____ no later than _____.
Show your Inservice Club Membership Card to _____ so that it can be initialed.
- Email In the Know at feedback@knowingmore.com with your comments and/or suggestions for improving this inservice.

THANK YOU!

After finishing this inservice, you will be able to:

Define palliative care and discuss the benefits of providing this type of care with the dying client.



List three documents that may be a part of the client's advance directives.



Describe the dying process and recognize at least five common symptoms of approaching death.



Describe at least three tasks that are part of the process of performing postmortem care.



Describe the five stages of grief.



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A Client Care Module:

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DEATH AND DYING IN AMERICA

As the population ages, medical advances are keeping Americans alive longer than ever.

- In 1950, the average American was only expected to live to be about 68. Today, the average life expectancy is 82 years old!

Those extra years provide more time for Americans to live life to the fullest, watch their families grow and expand and witness new technology and innovations in science, art, and religion. And, it provides time to think about one's own mortality.



Chances are your clients who are aging and ill have thought about their own death and have certain ideas of how they would like their death to be.

- Most people agree that controlling pain is a top priority. **No one wants to die in pain.** Others have views on how much medical intervention they would like. Some feel strongly about wanting to die at home surrounded by family.

Some clients fear death and may refuse to discuss their plans or wishes. This is a normal reaction to what is unknown or not fully understood.

Today, most deaths in the aging population occur in nursing homes or at home with home health care workers present.

As a nursing assistant, you can help your client transition through the dying process and ease them to a peaceful death by understanding their wishes and by seeing the beauty and privilege in providing end of life care.

In this inservice, you will learn about the dying process, how to recognize symptoms that signal death is near, how to provide comfort for the dying client and how to care for the body once death has occurred.

As you explore this topic you will be faced with the challenge of understanding your own feelings about death. Through this exploration and understanding of yourself, you will come to fully understand your clients and be able to truly assist them through this natural period of life.

WHAT IS PALLIATIVE CARE?

Palliative care (pronounced pal-ee-uh-tiv) is an approach to care that strives to improve the quality of life of the client and the family members who are facing a life-threatening illness.

Practicing palliative care involves relieving pain and making the client as comfortable as possible while caring for the whole person . . . physically, emotionally and spiritually.

In addition, palliative care means you:

- Appreciate the miracle of life while understanding that dying is a normal part of living.
- Include the entire family or support system in the process—keeping the client as active and engaged as possible, for as long as possible.
- Support family members as they confront their own fears and anxieties about the impending loss.
- Work as a *team* with the nurse, social worker, and any other team members to meet the client's physical, emotional *and* spiritual needs.



Palliative care is different from Hospice Care. Hospice always provides palliative care, but other healthcare professionals can practice this way too.

Palliative care is not limited to just those clients with terminal illnesses that are no longer seeking treatment. Clients who are actively seeking treatment will also benefit from palliative care.

Palliative care is **COMFORT CARE!**



WHAT MOVES YOU?

No one really enjoys experiencing another human's death. But, it is possible for compassionate caregivers to see beauty in the transition. Death of a loved one can transform people. And, it can transform you too.

Think about a time you have been present with a client or a loved one as they move toward death. How did the experience change you?

Did you become more sensitive? More loving? Were you filled with fear and worry?

jot down your thoughts here, then discuss your experience with your co-workers. Listen to their stories. Learn how experiencing death changed them, too.

WHAT'S NEW?

Grab your favorite highlighter! As you read through this in-service, **highlight five things** you learn that you didn't know before. Share this new information with your supervisor and co-workers!



UNDERSTANDING ADVANCE DIRECTIVES

Everyone has the right to say how they want to be treated in the face of a terminal illness or if the ability to communicate is lost.

Advance directives are legal documents that allow clients to express their wishes regarding their care as they face the end of life. Rules vary by state as to how Advance Directives are handled.

Advance directives may include a Living Will, a Medical Power of Attorney and/or a Do Not Resuscitate (DNR) order.

LIVING WILLS

- The Living Will tells you how the client feels about life-saving medical interventions like ventilators, dialysis or tube feedings. Clients have the opportunity to say if they do, or do not, want these life saving measures.

MEDICAL POWER OF ATTORNEY

- Every client has the right to designate a Medical Power of Attorney. This is a trusted person, usually a family member or friend, who understands the client's wishes and can speak on behalf of the client. The Medical Power of Attorney is able to make important decisions regarding the medical care of the client.



DO NOT RESUSCITATE (DNR)

- The Do Not Resuscitate order tells the healthcare team that the client does not want CPR performed in the event that breathing stops or the heart stops working.

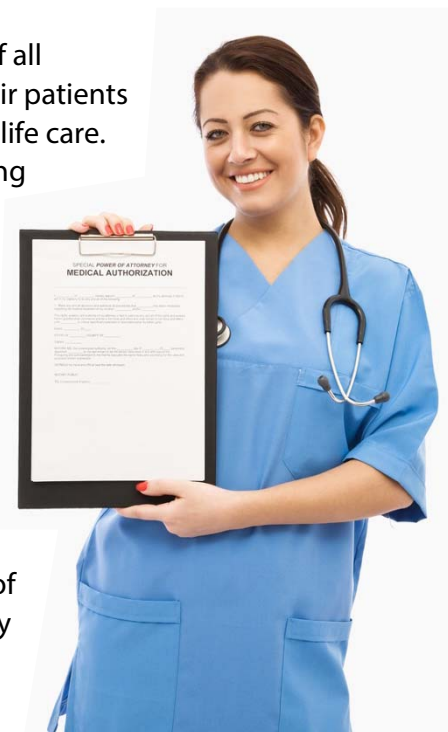
FACTS ABOUT ADVANCE DIRECTIVES

- Advance directives are often misunderstood. Many believe they are documents that mean the client does not want ANY treatment. This is false. Advance directives mean the client gets to determine HOW they want to be treated.
- Its best to discuss advance directives BEFORE the client becomes ill. However many healthcare professionals fail to bring it up because they don't want to make the client feel uncomfortable.

Studies show clients are happy to discuss their wishes and appreciate the opportunity to discuss them before they become too ill.

- A Medical Power of Attorney is NOT a financial power of attorney. Just because someone has the power to speak on behalf of the client regarding medical decisions does not give them the right to have any control over the client's money or possessions.
- Only about half of all doctors know their patients wishes for end of life care. Nurses and Nursing Assistants are the patient's advocate for this issue.

Talk to your clients and their family members about the client's wishes. You may be one of the few who really knows what they want.



UNDERSTANDING THE DYING PROCESS

The process of dying is as unique and varied as the individual human being. No two bodies will respond the same. However, there are some events that all people will experience as they progress through the dying process.

As death approaches, *metabolism* slows down until all the bodily functions simply stop.

DEFINITION

Metabolism—Chemical reactions in the cells that convert fuel from food into the energy needed to do everything from dancing to dreaming.

- As metabolism slows, less oxygen is carried to the brain causing a chain reaction of events in the body.
- Vision begins to blur, the sense of taste and smell become less acute, and there is a decreased perception of pain. Hearing is usually the last sense to disappear.
- Skin becomes mottled (blotchy), cold and clammy.
- There is a gradual decrease in urinary output. Loss of muscle control leads to incontinence.
- Initially there is an increased heart rate, followed by a slow, irregular heart rate and a decrease in blood pressure.
- There may be abdominal bloating, gas, and incontinence. A bowel movement may occur just before or at the exact time of death.
- Breathing is first increased, then slows and becomes irregular. The inability to cough or clear the throat cause gurgling or “noisy” breathing. This sound is also known as the “Death Rattle.”
- Death occurs when all the vital organs stop functioning.



CONNECT it now!

Apply what you know

List 10 signs or symptoms of approaching death (see page 5).

Now choose 2 of the symptoms above and discuss how you would handle them using a Palliative Care approach.

SIGNS AND SYMPTOMS OF APPROACHING DEATH

There are certain signs and symptoms you may observe as death nears.

Understanding and recognizing these signs and symptoms will help you anticipate what is coming next, how to best care for your client, and how to explain the situation to family members.

As you read through these symptoms, keep in mind that not all clients will have each symptom. And, the presence of these symptoms in a client who is *not* terminally ill does not mean that client is going to die.

Some signs and symptoms include:

- **DROWSINESS:** As the metabolism slows, energy decreases and the whole body begins to slow down. You may see decreased responsiveness and increased sleep. Eventually, the client may become unresponsive.

It's important to continue to speak directly to the client and encourage loved ones to continue to visit even if the client becomes unresponsive. Most clients will continue to hear you even though they are unable to respond.

- **CONFUSION:** Changes in metabolism may also lead to confusion. The client may be confused about the date and time, and about people and places.

This can be extremely distressing to family members. If the client is calm and confused, it's okay to give a gentle reminder about where they are and who they are with. However, if the client becomes agitated, it's best not to push the issue. Explain to family members that some confusion is to be expected and should not be taken personally.



- **WITHDRAWAL:** As blood flow decreases, the brain and the body receive less oxygen, causing the client to appear to withdraw. You may also see a decrease in communication as the client begins to mentally prepare to die.

Continue to speak directly to the client. The client may still be able to hear and understand you, just not able to respond.

Experts say giving permission to "let go" helps the client die more peacefully. You can explain to family members that giving their loved one permission to let go is the most compassionate, final gift of love they can give.

- **LOSS OF APPETITE:** As the body shuts down, the need for food and drink decreases. The body no longer burns energy, so it no longer needs to replenish its energy reserve.

Allow the client to eat or drink upon request. Do not push the issue. Keep mouth and lips moist with ice chips, water, or juice. Provide frequent mouth care as the mouth becomes dry and sticky from dehydration.

- **IRREGULAR BREATHING:** Breathing may become decreased, shallow and noisy. You may hear rattling or gurgling as fluids build up.

Place the client in a side lying position, suction out the mouth as needed (if trained to do so). Run a cool mist humidifier, if available.

- **LOSS OF BLADDER OR BOWEL CONTROL:** The muscles of the pelvis begin to relax and make it impossible to control the bowels and bladder.

It's important to keep the client clean and dry. Also, be sure to control odors. This will help keep both the client and visitors comfortable.

PERFORMING POSTMORTEM CARE

Postmortem care is the care you perform on the client just after death occurs.

If family members are present give them time and space to say good bye. Be sensitive to cultural differences, allowing the performance of any rituals or religious practices.

It's common for the body to release the bladder and/or bowels at the moment of death. Offer to clean this up so the family can enjoy the final good bye without the odor and mess.

Place waterproof pads under the head and buttocks as further drainage may occur. Cover the body with a light blanket, leaving the chest, arms and head exposed for family members' visit.

Between 3 and 4 hours after death, rigor mortis will begin to set in. Rigor mortis is a Latin term that translates literally to "stiffness" (rigor) of "death" (mortis).

It's best to perform postmortem care *before* rigor mortis sets in. If family members are lingering too long, you may need to give them a gentle reminder that certain things need to be done to prepare the body for its final rest.

If no family is present, (or after the family members leave) **complete the following procedures:**

- Straighten the body so it is lying supine with arms and legs straight.
- Gently close the eyes. If the eyes will not close, moisten a 2X2 gauze or cotton ball with water and place over the eyes.
- Bathe the body *gently* with water only. Bruising can still occur, which may be distressing to family members.
- Do not remove any tubing, such as a Foley catheter or IV.

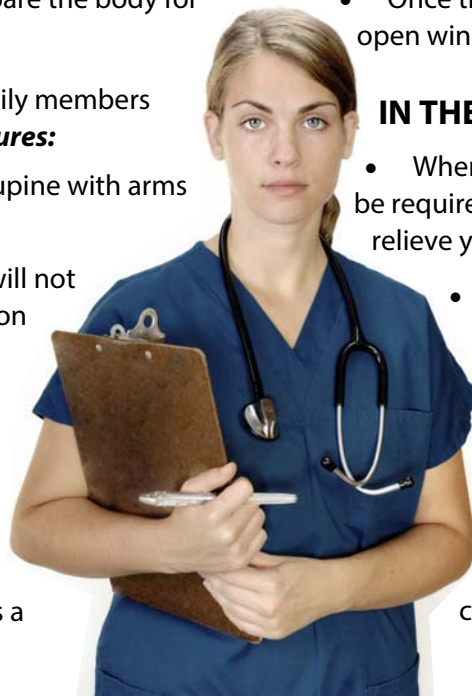
- You can turn off the IV pump if it is still running.
- Follow your workplace policy regarding dentures. Some will want you to place dentures in the mouth. Others will want you to place dentures in a cup and keep them with the body.
- Close the mouth. If the mouth will not close, place a rolled up washcloth or towel under the chin to keep it closed.
- Change or remove any soiled dressings.
- Place a clean gown on the body. Then brush hair as needed.
- At this point, you can allow family members to sit privately with the body for as long as they wish.

When the family leaves, follow your workplace policy to prepare the body for the morgue. To do this, you will likely:

- Fill out ID tags to place on the body, the toe and the body bag.
- Place the body in the body bag, or cover with a shroud.
- Once the body is removed, strip the bed and open windows, if possible, to air out the room.

IN THE HOME:

- When a client dies in the home, you will be required to stay until a nurse arrives to relieve you.
- Ask family members what you can do to help. This may involve making phone calls, answering the phone, comforting family members, or making coffee.
- Do what you can to keep the atmosphere calm. Keep lighting low, turn off the television and speak in a calm, low voice.



CARING ACROSS CULTURES

It would be impossible to list all the different attitudes, beliefs and practices of every culture you may encounter while caring for dying patients.

Instead, it's best to have a general understanding of how to give *all* families the right to practice as they wish—without judgment.

You can do this by:

1. PRACTICING PATIENCE AND EMPATHY

Some families, especially those with low income, or those who have not had much experience in the healthcare system, may have trouble trusting doctors and nurses.

When there is mistrust, your client or their family members may seem angry or suspicious. They may refuse to follow doctors' orders. You will have to be patient and understanding of their fears.

Give brief explanations when possible, but always give them the sense that they are ultimately in charge of their own care and that you are there to respect their (reasonable) wishes.

2. ACCEPTING ALL RELIGIONS

Religious beliefs about death and dying vary widely. Just because someone has different religious beliefs than your own, does not mean their beliefs are wrong.

It's important to accept all beliefs and give the client and family the freedom to worship, pray and practice their beliefs. It's okay to be curious and ask questions about different practices. It is NOT okay to impose your own beliefs on anyone.

3. UNDERSTANDING LANGUAGE AND COMMUNICATION DIFFERENCES

Words and body language can be interpreted differently from culture to culture.

When speaking to clients and family members whose first language is different from your own, be sure to speak clearly and concisely. Avoid using slang terms or medical terminology.

Pay attention to your accent. Some regional accents can make the language very difficult to understand.

4. AVOIDING STEREOTYPING

One reason this lesson will not include a list of practices you may see performed by certain groups is because practices vary even within groups.

You must learn to see and accept the individual for who they are—not what they look like. For example, you may be caring for a client from India who is Muslim. And, later you may care for a client from India who is Christian. Their practices and customs may be very different.

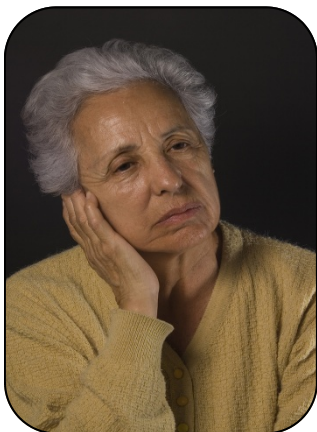
It would be unfair to both to make any assumptions without knowing all the facts.



***“Life lives, life dies.
Life laughs, life cries.
Life gives up and life tries.
But life looks different through
everyone's eyes.”***

~Author Unknown

THE STAGES OF GRIEF



Elisabeth Kübler-Ross developed a model called "The Stages of Grief" to help understand the wide range of emotions humans experience during and after a loss.

Both the client and their loved ones will progress through the stages of grief. The client will experience grief during the dying process. The loved ones will experience the stages after the client is gone.

Bargaining usually arises from guilt. Clients and their loved ones feel there must be something (anything!) they can do to change the reality of the situation.

- **DEPRESSION:** When bargaining fails, depression takes over. Depression and withdrawal are normal in the grieving process. Depression occurs when the sadness becomes so overwhelming, the person finally surrenders to the grief.
- **ACCEPTANCE:** Acceptance occurs when the dying client comes to terms with the reality of the situation. *Not every dying person will get to this stage. Or, it may occur in their final moments of living.*

The five stages are:

- **DENIAL:** Just after a diagnosis, a client may express, *"This can't be happening."* Or, *"Why me?"* Family members may also experience denial. Their first reaction may be to deny the person is really gone.

- **ANGER:** When denial wears off and reality sets in . . . anger emerges. Clients become angry about their diagnosis. Family members may express anger at the loved one who died.

Anger is an important stage of grief. It helps give the grieving person a focus. The only way to move through the stage of anger is to feel it. So, don't deny your clients this emotion. If your client is angry try to simply listen. Never tell someone the feeling is wrong.

- **BARGAINING:** This is the internal struggle—usually between the grieving person and God. *"Please God . . . I will do anything you ask . . . just let me live."*

After a loss, family members may bargain, *"If I just devote my life to others, maybe I'll wake up one day and this whole thing will be a dream."*

GET OUT!

Thinking outside the box!

Working with dying clients often requires coming up with creative solutions to difficult issues.

- **THE PROBLEM:** You are caring for a client with a terminal diagnosis. You have witnessed her progress through the stages of denial, anger and bargaining. Now she is depressed.
- **WHAT YOU KNOW:** She is lonely. She lost her husband years ago, and her children live far away. She has a few good friends at her church, but is having trouble getting there these days.
- **GET CREATIVE:** Think of **3 creative solutions** you could suggest to help your client through this difficult stage.
- **TALK ABOUT IT:** Share your ideas with your co-workers and supervisor and find out how they would solve the problem.

TAKING CARE OF YOURSELF

When you care for a dying client and their family, the focus of care and support is on them. And, it should be! You give them your time, your empathy, your energy and the benefit of your professional knowledge and experience.

Although it is your job, you are likely to get (at least a little) emotionally attached. And, that's okay.

But, caring for a dying client, and losing a client you have become attached to, can be stressful and emotionally draining. So, even though the focus should be on the client and family, you have to remember to take care of yourself, too!

Some things you can do are:

EAT WELL: You get busy; you may feel sad and you hit the fast food restaurant for an easy, no-brainer dinner. That's okay every now and then. But, take the time to fix meals at home most days.

Food you prepare yourself at home is lower in sodium, fat and calories. Use the time it takes to cook the meal to reflect on your day and "let it all go."

Share home cooked meals with your friends and family. It will help you feel more connected to the living after you've been surrounded by death and dying all day.

EXERCISE: It takes a lot of strength and energy to care for a dying client. Exercise can help you build your strength and recharge your energy.

Exercise also helps boost your mood. Getting your heart rate up triggers the release of endorphins in your brain. These are the "feel good" chemicals that give you a sense of peace and well-being!

RELAX: Stress takes a toll on your body and mind. It's important to take time to relax. Whether you like to take a walk in the park, read a book, or "veg out" in front of the TV . . . take a little time every day to relax!

FEEL: Give yourself permission to feel sad when you lose a client. Denying your feelings will do you no good. It will come out eventually in another way.

It is healthy and normal for you to feel some degree of sadness after a client dies. But, if you feel like you are dwelling on it or can't shake it off, talk to someone. Your employer may have services available to help you deal with the loss.

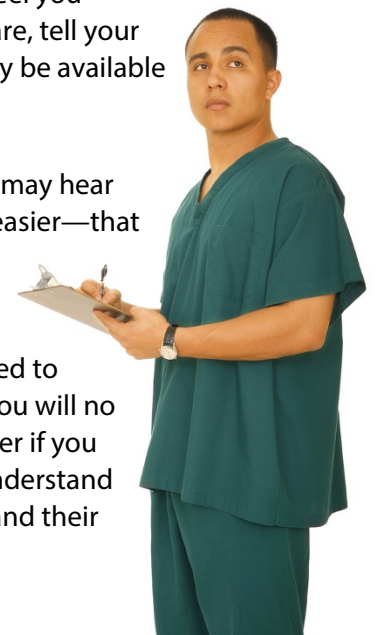
RE-ENERGIZE: When you begin to feel like you are running out of steam, find a way to re-energize! Take a day or two off if possible, take a short vacation, plan a night out with friends, see a movie, or take a bubble bath.

Remember you can't give away what you don't have. So, if your energy is low, you can't give the kind of care your client needs and deserves.

ASK FOR HELP: There may come a time when it just becomes too much to deal with. If this happens, ask for help! Tell your supervisor how you are feeling.

Some Nursing Assistants who become emotionally attached to a client insist on being the one who performs the postmortem care. Others may feel it is impossible to do this. If you feel you cannot do the postmortem care, tell your supervisor. Someone else may be available to help you.

DON'T GET USED TO IT: You may hear that dealing with death gets easier—that you'll "get used to it." But, that is just not true. You may become more *comfortable* with it, but if you ever "get used to it," consider changing jobs. You will no longer be an effective caregiver if you become unable to feel and understand the emotions of dying client and their family members.



FINAL THOUGHTS ON END OF LIFE CARE

Above all else, the goal of end of life care is to keep the client as comfortable as possible. Report to the nurse any changes in the level of pain so that pain medications can be adjusted.

Always keep the client clean and dry. Offer small sips of fluids or ice chips upon request. Perform frequent mouth care for the unconscious client.

Keep the atmosphere of the room calm and peaceful. Control noises and odors. Turn the ringer on the phone down so it does not startle anyone. Keep lights low. Keep the area clutter free.

Make sure comfortable seating is available for visitors.

Play the client’s favorite music, if possible. Ask family members to surround the client with favorite photos or other memorabilia.

Continue to speak directly to the client. Remember, hearing is the last sense to go. So, chances are you will be heard!

Avoid speaking about the client’s condition or the approaching death in the company of the client.

Its okay to just sit with the dying client. You don’t even have to speak.

Read out loud to your clients! Stories, poetry, and the Bible (if requested) are all comforting ways to pass the time.

Remember to tend to family members as well as the dying client. Be sure to ask spouses, adult children and other loved ones how they are doing. Offer to help in any way you can.



THINK about it!

Many advances in End of Life Care have taken place over the past 50 years. Laws have been made regarding Advance Directives. Hospice is now more widely accepted than ever, and the practice of Palliative Care is becoming increasingly common.

Yet, despite all these advances, the medical community, in general, is still mostly unprepared to care for the dying client.

This may be related to the fact that most people go into the medical field because they want to heal people, not help them die.

What are your personal feelings about the “Do Not Resuscitate” or DNR order?

Would you be able to make that decision for yourself or a loved one, if necessary?

How do you feel about clients who refuse medical treatment that you know would *prolong* their lives?



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EMPLOYEE NAME
(Please print):

DATE: _____

- ***I understand the information presented in this inservice.***
- ***I have completed this inservice and answered at least eight of the test questions correctly.***

EMPLOYEE SIGNATURE:

SUPERVISOR SIGNATURE:

Inservice Credit:

<input type="checkbox"/> Self Study	1 hour
<input type="checkbox"/> Group Study	1 hour

File completed test in employee's personnel file.

Are you "In the Know" about end of life care? Circle the best choice or fill in your answer. Then check your answers with your supervisor!

- True or False**
Palliative Care should improve the client's quality of life.
- True or False**
Advance Directives are not legal documents and do not always have to be honored by health care professionals.
- True or False**
A DNR order means you must do everything possible to preserve the client's life.
- True or False**
Hearing is usually the first sense to be lost in the dying process.
- As the end of life approaches, the body:**
 - A. Increases its urine output.
 - B. Becomes very warm to the touch.
 - C. Loses muscle control.
 - D. Feels more and more pain.
- True or False**
Dying people need more calories than usual to help them transition through the dying process.
- Someone experiencing the "Denial" stage of grief may be feeling:**
 - A. Sad and withdrawn
 - B. Irritated and angry
 - C. Guilt
 - D. Disbelief
- True or False**
Death occurs when all the vital organs stop functioning.
- True or False**
Rigor mortis sets in between 5 and 6 hours after death.
- True or False**
You should complete your postmortem care tasks according to your workplace policy even if the family objects.