

A Health Care Module

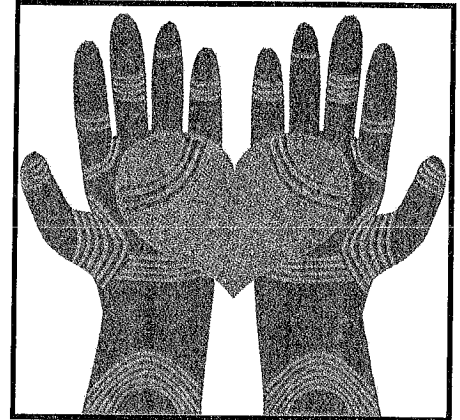
**Understanding
Hospice**



IN THE KNOW

Instructions for the Learner

We hope you enjoy this Inservice, prepared especially for nursing assistants like you. You work very hard, and we appreciate the effort you make to complete these educational materials. It shows your desire to continue learning and growing in your profession!



After finishing this inservice, you will be able to:

- Discuss the basic principles of hospice care.
- Compare hospice and hospital care.
- Describe the roles of at least five hospice team members.
- Describe palliative care and how it relates to hospice.
- Demonstrate your knowledge of the terminally ill in your daily work with hospice clients.

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

- Read through all the attached materials. 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 fill in the best answer.
- Check with your supervisor for the right answers. You pass the quiz with at least eight correct answers! 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.

IN THE KNOW



The Inservice Club for Nursing Assistants

Hospice care:

- Focuses on comfort and dignity.
- Keeps families together during the difficult time of losing a loved one.
- Gives people control over their end-of-life care.
- Tends to save money. (It usually costs less for people to receive hospice care than for them to be in a hospital.)

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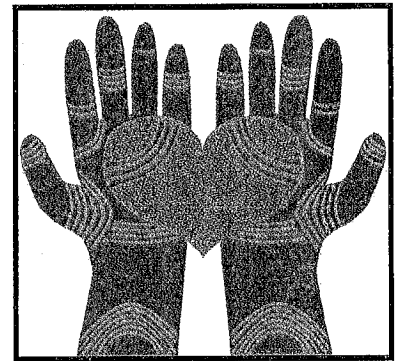
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Hospice: It's Not A Place...It's A Way of Caring!

It's true. Hospice is *not* a location. It's a special way of caring for terminally ill clients and their families. In the old days, a hospice was a guesthouse available to tired or sick travelers who needed to rest during a long journey. Today, the idea of hospice is to offer compassionate care to people who are nearing the end of their life journey.

Throughout a person's life, the focus of most medical care is on **disease**. For example, Mr. Smith goes to the hospital because he has a high fever and trouble breathing. The medical team tries to figure out which *disease* is causing Mr. Smith's problems. Once they figure it out, the team works to make the *disease* go away. That's the goal. Get rid of the disease and send the patient on his way.

Hospice care is different. The focus of hospice is the **client and family**—*not* the disease. Hospice care is provided by a team of people who have chosen hospice as their specialty and who have been specifically trained to work with



"Hospice" comes from a Latin word that means "guesthouse".

dying clients. But, that doesn't mean that hospice is all about grief and sadness! The main goal of hospice is to help clients live *meaningful* lives—with comfort and dignity—for the time that's left them.

The hospice team includes nursing assistants (usually called *home health aides* or *hospice aides*). In fact, aides are very important to the team, especially since they spend so much time with clients and their families. So, whether you already work in hospice or you're just interested in knowing more about it, keep reading to review the basics about hospice care in America.

The History of Hospice Care

"Hospice" belongs to the same family of words as *hospitality*, *host*, *hostess*, *hotel* and *hospital*. And what do all these words have in common? They focus on being kind and caring to strangers. This has been the idea behind hospices for centuries.

In Medieval times, hospices were usually run by monks. These religious men took in sick, tired or hungry people who had nowhere else to go. People who were dying were treated as honored guests who were on a journey to meet God. If hospice workers were unkind to any guest, they were whipped and made to eat bread and water for a week!

Locations for Hospice Care

There are over 3000 hospice programs in the United States. Hospice services are available to people wherever they choose to spend their final days. This includes:

Private Homes

- A hospice client may be living at home or in the home of a friend or family member.

Freestanding Hospice Facilities

- Many large hospices have their own facilities where clients come for care. These facilities tend to be located in cities.
- Remember that not all hospice clients want to die at home. For them, receiving hospice care in a facility might be a better option.

For most of history, families took care of their own loved ones at home—from the time they were born until they died. But, in modern times, doctors and hospitals have taken more and more responsibility. Instead of being born at home, most babies are born in a hospital. And, instead of dying at home, most people end their lives in a hospital.

Modern hospices began in England in the 1940's. The first hospice in the U.S. opened in 1974. Today, hospices combine the comforting power of modern medicine with the "old fashioned" support of caring hospice workers and loving families.

Hospitals

- Some hospitals provide hospice care. They may devote a special floor or wing to hospice clients—and have a specially trained hospice team.

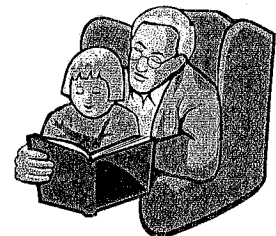
Nursing & Assisted Living Homes

- Hospice care is also provided at some skilled nursing and assisted living facilities. (The facility is considered the client's home.)
- If the nursing home provides hospice care on a regular basis, it may have its own hospice team. If not, an outside team of hospice workers may visit the client in the nursing home.



In olden days, most hospices were run by priests and monks.

Remember... hospice is a way of caring, not a place! Over eighty percent of hospice care is provided in private homes and nursing homes.



Hospice care helps keep families together.

Who Receives Hospice Care?

Before a client receives hospice care, nurses and physicians review the client's disease history, current symptoms and life expectancy. Then, they meet with the client and the family to discuss hospice philosophy and services, pain management and equipment needs.

People who receive hospice care:

- Are usually in the last six months of their lives.
- Can be any age...from child to senior citizen.
- Can be of any religion...or of no religion.
- Have terminal illnesses such as cancer, AIDS, lung diseases, heart disease, nerve disorders and Alzheimer's Disease.
- Often have a friend or family member who helps care for them.
- Can be wealthy, poor or in between!

While hospice is available to anyone who needs it, studies have shown that the most common hospice client is a 65 year old white male, dying from cancer, whose wife is involved in his care.

- Remember...it is possible for doctors to be wrong about how long a person has to live. There have been cases of people "graduating" from the hospice program by getting better! There are also cases of people who live longer than six months while receiving hospice care. Their care doesn't stop just because they've survived longer than expected!
- People have the right to change their minds. If they begin hospice care and don't like it or want to try some new "cure" for their disease, they can be discharged from hospice. Most insurance plans allow people to start hospice again at a later time.



65% of hospice clients are over age 65.

The majority of hospice clients are dying from some form of cancer. Heart disease is the second most common diagnosis.

Who Pays For Hospice Care?

Private Insurance Companies

- Many private insurance companies and HMO's pay for hospice care.

Medicaid

- Most states offer Medicaid coverage for hospice care.

Medicare

- Medicare pays for hospice care for

people who have a life expectancy of six months or less.

Community Funds & Charitable Foundations

- Most hospice organizations work hard to find funds to pay for the care of clients who have no health insurance. They don't want to turn anyone away!



Hospice is an affordable option!

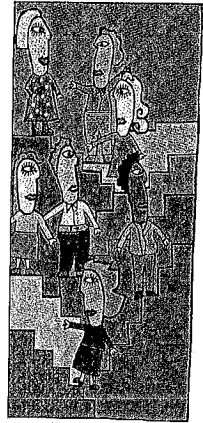
What Makes Hospice Care Different?

Hospital Care

1. When people are admitted to the hospital, care is provided around the clock. And, if patients feel better, they are discharged from the hospital.
2. Hospital care is usually focused on treating a disease.
3. Nurses in the hospital are usually too busy to deal with a patient's emotional pain.
4. Hospital care usually provides services to *patients* only.
5. Hospital care can be very expensive...costing about \$500.00 per day.
6. Families may be restricted from being with their loved one by hospital visiting hours.
7. In the hospital, the goal may be to keep the patient alive—even by using machines.
8. Hospital care ends when the patient dies.

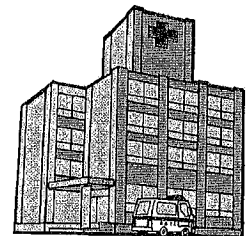
Hospice Care

1. When people are admitted to hospice, the staff comes and goes as needed. (*However, they are available 24 hours a day, 7 days a week.*) If a client feels better, the staff visits less often—but the client is not discharged.
2. Hospice care is focused on caring for dying individuals and their families.
3. Hospice nurses have special training that helps them deal with a client's emotional pain.
4. Hospice care provides services to clients *and* their families.
5. Hospice care is usually less expensive...costing about \$100.00 per day.
6. Most hospice clients remain at home with their friends and family.
7. A hospice client has already decided not to be kept alive by machines.
8. Hospice care continues for up to one year after the client dies.



Hospice supports the client and family.

Many home care clients are required to be homebound. Hospice clients are not! They may leave their homes as much as they like.



If a hospice client lives in a facility, grief counseling is available for the staff.

Most people agree that hospice care promotes the best possible quality of life for dying clients and their families.

Who Makes Up the Hospice Team?

Physicians. A hospice physician and a client's family doctor may both be involved in the client's care. They order studies, make diagnoses, prescribe medications, sign insurance papers, certify death and guide the rest of the hospice team.

Nurses. Hospice nurses assess a client's condition, give treatments according to doctor's orders, keep the doctor informed about the client's condition and spend time teaching the client, family and other team members. They work hard to control each client's symptoms or pain. Hospice nurses are often "on call" 24 hours a day.

Aides. Hospice aides help the client with bathing, dressing, basic bedside care and activities of daily living. Aides assist hospice clients to remain as independent as possible for as long as possible. They help transfer clients from bed to chair and keep the client's care area neat and clean. Aides report any changes in the client to the nurse. In some states, hospice aides can be certified to give some medications.

Therapists. Physical therapists help keep hospice clients moving safely through their home or facility. They also teach clients exercises to keep them strong and show families how to perform safe transfers. Occupational therapists work with clients who are having trouble performing daily tasks like brushing their teeth, getting dressed and eating. The goal is to allow the client to be as independent as possible. Speech therapists help clients communicate and also work with clients who are having swallowing problems.

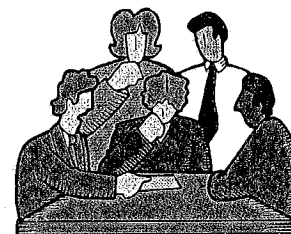
Social Workers. Hospice social workers assess a hospice family's basic needs and help them get whatever resources they need. This may include assisting with financial and legal issues. They also provide counseling to help families deal with the anxieties and struggles of losing a loved one.

Chaplains. Hospice chaplains offer spiritual comfort to the client and family. They don't "push" any specific religion. Instead, their work is guided by the *spiritual* preferences of each hospice client. (Hospice clients are not *required* to see a chaplain, but the service is available to them and to their families.)

Volunteers. Hospice volunteers are an important part of the team. (In fact, Medicare requires hospices to have volunteers.) They are *trained* individuals who provide important assistance to the hospice family such as sitting with the client, running errands, preparing a meal or providing transportation. Many volunteers continue to visit the family after the loved one has passed away.

Bereavement Counselors. These counselors teach grieving families how to begin to heal from the loss of their loved one. They offer group support sessions and individual visits for up to one year after the client dies.

Everyone on the team provides emotional and spiritual support to the client and family. And, everyone works together to promote the comfort and dignity of each hospice client.



Hospice is a team effort. Pharmacists and dietitians may also be involved.

Every hospice team has regular meetings to discuss client care. It's important to attend these meetings—and to speak up when you have something to share!



Team meetings are for communicating.

Why Doesn't Everyone Choose Hospice?

Every year, over 1.6 million Americans qualify for hospice care. Yet, only 500,000 people receive it. Why? There are a number of reasons, including:

- The decision to switch to hospice can be a difficult one to make—for the sick person, his family and his doctor. For some, it feels like “giving up”, so they refuse hospice.
- Some physicians don't like to bring up the idea of hospice. (Did you know that in most medical schools, the idea of hospice is *never* talked about? Remember, doctors are taught to fight *disease*. So, to them, hospice means they've lost the battle.)
- Studies have shown that many doctors *overestimate* how much time their patients have left to live. For example, the doctor guesses that Mrs. Jones has one year left to live, so she doesn't qualify for hospice. (Her insurance requires that her life expectancy be six months or less.) But, Mrs. Jones dies in just two months—without hospice care.
- Fear of dying...either from the client or from family members...can make it hard to switch to hospice care.
- Many clients choose hospice when they are so sick that they die within a few days. This doesn't give the hospice team much time to provide the necessary support and counseling to the client or the family.
- Not enough people know what hospice is all about. That's why it's important to educate people about the benefits of hospice care. Ask your supervisor how you can help spread the word about hospice in your community.

REMEMBER...

Hospice isn't for everyone. People have the right to decide against hospice care. The important thing is that they *understand* the services that hospice offers so that they can make the *best* decision for themselves and/or their loved ones.



Many Americans don't like to talk about issues relating to death.

A few people have chosen assisted suicide over hospice care. Which choice would you make for yourself or a loved one?

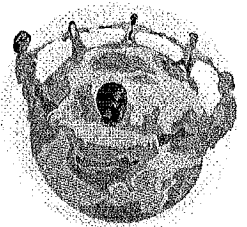
What's the Future of Hospice Care?

A future goal for hospice is to encourage more private insurance companies to pay for hospice care—whether it's delivered in a facility or in a client's home.

Currently, most hospice clients are white senior citizens. So, another

future goal across the U.S. is to increase the amount of hospice care provided to:

- Minority clients.
- Young adults and children.
- People living in rural areas.



Everyone needs to know that hospice care is an available choice.

What Is Palliative Care?

Palliative care focuses on making a person comfortable by reducing or taking away the *symptoms* of an illness. For example, Mrs. Potter has cancer. Her most bothersome symptoms are bone pain, shortness of breath and constipation. The palliative care that Mrs. Potter receives includes pain medications, oxygen therapy and treatment for her constipation. None of this medical care will make her cancer go away. Instead, it will help keep her comfortable as her disease

progresses. People who choose hospice have made the decision to focus their medical care on *comfort* rather than *cure*.

Together, the hospice team develops a plan of care for each hospice client. It includes doctor's orders and a plan for what each team member needs to do to help the client and family. A hospice plan of care is very flexible. Depending on a client's symptoms, it may change from day to day.



Palliative care equals symptom relief.

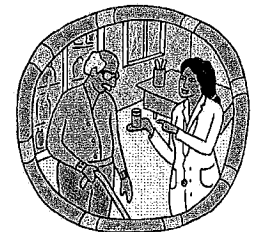
What Is Pain Control?

If you ask people what they fear most about dying, many will say that they are afraid of being in pain. Controlling pain is a big issue for hospice clients—and their families.

Hospice workers are experts at controlling pain—both with medications and with other non-drug methods. And, every member of the hospice team is involved in managing a client's pain:

- Doctors prescribe the best pain medication for each hospice client.
- Nurses observe the client to see if the pain medication is working. They keep in touch with the doctor and the pharmacist. They teach family members how to help reduce their loved one's pain.
- Aides help manage pain by keeping the client clean, dry and warm. They also help the client get into comfortable positions and report any complaints of pain to the nurse.
- Therapists help reduce pain by providing the client with necessary equipment such as a cane, a wheelchair, a bedside commode or a trapeze for over the bed. They can also give massages or teach gentle stretching exercises to reduce the pain.
- Social workers, chaplains and bereavement counselors help reduce the *emotional* and *spiritual* pain that comes with dying—and with losing a loved one.

Every hospice worker is trained on how to help clients and their families manage pain. This includes emotional pain.



Controlling symptoms helps dying clients enjoy more quality time.

Hospice Care Tips

- Skin care is very important for hospice clients since they often spend a lot of time in bed or sitting in a chair. This puts them at risk for pressure sores. Help your clients change position frequently and check their skin for reddened areas every day.
- You may find that some clients ask to sit in a chair, then ask to go back to bed, then ask to sit in the chair again...and so on! Please remember that the client may have a symptom of dying called "terminal restlessness". Tell the nurse about the problem. There are medications that help relieve this symptom.
- Remember that moving around can make pain worse. Try to plan activities (such as bathing) for thirty to sixty minutes after your client has taken pain medication.
- After spending a lot of time lying in bed, your clients may become dizzy when they try to sit up or stand. Guard against falls! You may need a family member to help you transfer the client.
- If your client is losing strength and needs additional equipment—such as a walker or a bedside commode—be sure to tell the other members of the hospice team.
- Your hospice clients may prefer five or six small meals during the day rather than three big ones.
- Keep in mind that it takes less energy to drink than to chew...so try offering "liquid food" like soup, a milkshake or a supplement like Ensure. (Check with the nurse for the best food choices for each client.)
- As people near death, the digestive system slows down. This causes clients to lose their appetite. Family members may be concerned when their loved ones don't want to eat. Remind them that forcing food at this point can cause discomfort, choking, vomiting or diarrhea—and that it's *natural* for the client to be eating less.
- A loss of appetite doesn't necessarily mean that the end is near. The client may simply be constipated! Be sure to document when your client has a bowel movement. And, report any change in appetite to the nurse.
- Some of your hospice clients may be fed through an IV or a tube that goes directly into the stomach. Be sure you understand what you can and cannot do when it comes to IV's and feeding tubes. When in doubt, ask your supervisor.



Many pain medications cause constipation. This can be a life-threatening problem. Don't ignore it!

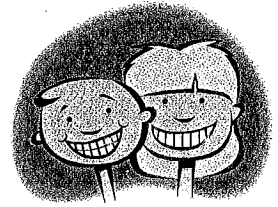
Hospice clients may be weak and unsteady on their feet. Be careful during transfers to prevent falls. Report any falls that do occur.



If a client's symptoms become severe, the client may need 24 hour care for a while. This might be in a hospital or in the client's home.

More Hospice Care Tips

- If a client complains of being hungry, but is having trouble swallowing, notify your supervisor immediately. This problem can be treated. A speech therapist or a dietician may visit the client to determine the best approach to solving the problem. You may be asked to help the family prepare soft or pureed foods for the client.
- Many people with a terminal illness experience breathing difficulties, especially shortness of breath. One way to give immediate relief from shortness of breath is to help the person sit up. If the client has a hospital-type bed, raise the head of the bed. Otherwise, place some pillows behind the client's back. This is just a temporary solution! Report any new shortness of breath to your supervisor right away.
- Some of your hospice clients may be receiving oxygen. Remember to follow oxygen safety rules. Remind the family not to smoke or light candles in the same room as the oxygen.
- As death approaches, it's common for people to breathe differently. For example, there may be longer and longer pauses between breaths. This can be scary for the family. Help them cope by reminding them that it's normal and that it's *not* painful.
- Provide frequent mouth care to keep the mouth freshened and moist. (It can be very painful if the tissues in the mouth become dry.)
- Don't wear strong perfumes when working with hospice clients. Strong smells—even pleasant ones—can be nauseating to the client.
- Maintain a positive attitude during your work with hospice clients and their families. (But keep it *natural*. Don't put on a "phony" cheerfulness.)
- If your clients or their family members want to talk about dying, let them know you are there for them. Don't worry about saying exactly the right thing. The most important thing you can do is listen while they express their feelings.
- Working with hospice clients puts you in a very intimate family situation. You may hear things about the family's finances, personal relationships and spiritual beliefs. Be sure to keep all personal information about your clients or their family members confidential.
- Be sure to respect the religious beliefs of your clients—even if you disagree with them. Don't share your personal views unless you are asked to do so.



Smile as you go about your work. This lets your clients know you are glad to be with them.

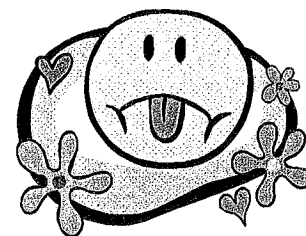
If you are present when a client dies, follow the standard procedure for your workplace and comply with the family's wishes.



Hospice families are going through a stressful time. Don't be surprised if they seem moody or angry.

A Few More Hospice Care Tips

- As the circulation slows down, there is less blood flow to the feet. Check your clients to make sure their feet aren't cold! (A pair or two of socks might help.)
- Some clients may enjoy listening to some soft, restful music. Some like to have the TV on. Others prefer silence. Be sensitive to your client's preferences.
- Some clients may want their curtains opened so they can see outside. Others may want to keep it dark in the room. There is no right or wrong way. Let your clients stay in control over their environment.
- Remember that hearing is the last sense to go when someone is dying. Remind family members that their loved one can probably hear what they are saying.
- If you notice that a client's family members are overwhelmed and exhausted, tell your supervisor. It may be possible to provide the family with "respite care" (during which the client is placed in a facility for a few days to give the family time to rest).



The smell of flowers might make your client feel sick. Explain the problem to visitors who bring flowers.

Being a hospice aide is rewarding work that allows you to make a difference in the lives of your clients and their families.

Take Care of Yourself, Too!

Working with hospice families can be very stressful. Don't be so busy taking care of others that you forget to take care of yourself!

- Remember that your goal is to help your clients—but you are not a "magician". You can't "fix" everything, so go easy on yourself.
- Keep your sense of humor! Find something to laugh about every day.
- Learn to relax when you leave work. For example, read a good book or try a new hobby.
- Get plenty of regular exercise.
- Remember that it's normal to feel sad, angry or upset when a client dies. Sometimes, you might even feel guilty that you didn't do enough for the client. Be kind to yourself and let those feelings out. Maybe you could "buddy up" with a coworker—agreeing to support each other during hard times.
- Try to get enough sleep every night. (Go to bed a little earlier once in a while.)
- If you are feeling overwhelmed, discuss the issues with your hospice team members and/or your supervisor.



Exercise helps reduce job-related stress.