

# MODULE 7: CARING FOR PEOPLE AT HOME OR IN A HOSPICE

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## LEARNING OBJECTIVES:

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1. Understand the unique challenges of caring for a dying person at home or in a hospice
2. Understand the role of food in the life of a dying person and family, and how food affects the quality of hospice palliative care
3. Understand the causes of appetite loss as well as strategies to help people increase their food intake of food
4. Learn about body mechanics and practice lifts and transfers (if allowed/required by your organization)
5. Learn and practice other practical care skills, such as bed-making, positioning and toileting
6. Learn basic safety precautions

## COMPETENCIES:

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At the end of module seven, volunteers will be able to:

- Describe the role of a volunteer caring for someone at home or in a hospice and how it differs from the role of hospice palliative care volunteers in other settings
- Describe the role of food in people's lives
- Demonstrate the ability to implement strategies to help the dying person increase their food intake
- Demonstrate other practical skills that may be required when caring for someone at home or in a hospice
- Explain basic safety precautions in the home or hospice.

## 1. WHAT'S DIFFERENT ABOUT VOLUNTEERING IN SOMEONE'S HOME OR A HOSPICE?

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The volunteer's role in hospice palliative care varies depending on the setting. In a hospital or long-term care home, there are more professional staff – nurses, aids and others – to provide care. At home or in a hospice, more of the care falls to family members and volunteers.

Volunteers who are caring for someone at home or in a hospice may be asked to help with feeding or lifting/positioning people. They may also be more directly involved in personal care tasks such as feeding the person, changing the bed, helping the person use a bedpan, or helping them get to the washroom. Many of these tasks – particularly the ones that involve physically moving the person – create more risk for the dying person and for the volunteer so it's important to learn the correct techniques.

## 2. THE IMPORTANCE OF FOOD AND THE IMPACT OF LOSS OF APPETITE

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What we eat and how we prepare our food are influenced by culture, tradition and choices. Food and eating are not only essential to survival; they are also central to many ceremonies and social events and are one way we express feelings of love, nurturing and community. Food is, in fact, the “staff of life”.

Most people who are dying develop aversions to certain foods and lose their appetite. Changes in appetite may be a side effect of medications, the disease process and even the dying process. Some changes are due to medically prescribed and monitored diets. In some cases, people simply decide not to eat.

Since food is so central to our concepts of health and well-being, it can be very disturbing to both the dying person and the family when normal appetites and eating patterns change. Sometimes families will feel the need to push food on the person to help build or maintain strength. Others will despair as they realize that loss of appetite signals “the end is near”. Volunteers who have a solid understanding of the pivotal role of food in the “human condition”, will be better equipped to support the dying person and family in coping with the challenges of eating.

Keeping a team notebook is an effective way to record the person's fluid and food intake each day, as well as any concerns you may have about their nutrition.

## FOOD AND NUTRITION CARE

The health care professionals on the care team will develop a nutrition plan for the dying person that takes into account the foods the person likes as well as their culture. They will also provide tips on how to increase the energy and protein in the person's diet.

Volunteers can help by:

- being sensitive to cultural and religious dietary requirements and how they may influence the feelings and actions of family members
- normalizing the eating experience and encouraging the person and family to follow the recommendations of the healthcare professionals
- encouraging the person to try small amounts of food and drink, or to eat small amounts more frequently
- cleaning the person's teeth and mouth before they eat to stimulate the taste buds
- supporting the person and family, and communicating their food-related needs to the care team
- helping the person participate in family ceremonies and rituals that they feel are important to their well-being
- using comfort measures they have learned, especially if the client has mouth sores, nausea and vomiting
- helping family members understand the person's decreased need for nutrition at the end of life.

## WHEN FAMILIES MAKE DECISIONS ABOUT NUTRITION

During your volunteer assignments you may encounter family members who are distressed that the dying person is not eating and who think about or ask to have fluids and nutrition administered artificially through a feeding tube or an intravenous drip.

Although providing fluids and nutrition may keep the person from becoming dehydrated and confused or make them more comfortable, it is usually not beneficial in the end stages of life and will not change the eventual outcome. In fact, having a feeding tube or IV line will decrease the person's mobility and cause the skin to breakdown as well as other painful symptoms, such as vomiting, lung congestion, shortness of breath and swelling of limbs.

However, it is not the role of the volunteer to advise the person and/or family in making this type of decision. Volunteers can and should help by:

- supporting the person's and/or family's decision (no matter what it is)
- encouraging the person and/or family members to discuss their feelings of hope and loss.

### 3. BODY MECHANICS, LIFTS AND TRANSFERS

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In some jurisdictions, volunteers helping to care for people in their home or a hospice may be asked to help with repositioning people, getting them to the washroom or changing their beds. To fulfill that role, volunteers must know how to move people safely. If your organization requires volunteers to be able to help with lifts and transfers, your training program will include detailed instructions on body mechanics and the physics of how to safely reposition or assist a person.

But helping to shift and move people involves much more than physics. It also involves knowing enough about the person that you can help them without hurting them. Each person has unique needs. The health care professionals on the hospice palliative care team will tell you what you need to know about each person. The nurse's assessment of the person's pain will include a plan for managing pain during repositioning. For example, you may be asked to be sure that you only reposition a person after he or she has received pain medication and the medication has "kicked in" or you may be told that the person's right arm must be placed in specific position to reduce swelling. You will be shown how to take special care turning someone whose cancer has metastasized to the bone because pathological bone fractures can happen easily.

#### BEFORE YOU LIFT ... ASSESS THE RISKS

The goal is to reposition or help the dying person without hurting them or yourself.

Before starting any lift or transfer, ask yourself the following questions:

- By assisting the client, am I at risk of hurting the client or myself?
- Have I been trained to safely complete this task?
- Is there someone else in the home who can assist with the task?

Remember:

- If you do not feel you can safely perform the task, ask for assistance or wait until someone arrives who can help.
- Check your posture – your back should be straight with its normal curves and your chin should be tucked in.

- Lift with the strong leg muscles – do not use your back.
- Shift don't lift – travel the shortest distance.
- Wear safe footwear, keep your feet shoulder width apart and the person's weight close to your body.
- Position equipment and engage the brakes.
- Lift first, then turn – do not twist your body.

#### ASK YOUR SUPERVISOR

Before using what you have learned about lifts and transfers with a dying person, check with your supervisor. Make sure the supervisor wants you to do this type of task, and that you know what to do for the person you're helping.

#### WHAT TO DO IF THE PERSON FALLS

1. Remain calm
2. Do not attempt to stop a person from falling
3. Protect his/her head

Once the person is on the floor there is no hurry. Assess the situation. Has the person's condition changed? If not, take time to make the person comfortable and reassure them. Laugh, if you can. The person is safe on the floor (there is no danger of falls) so you can wait until help arrives.

Do not try to help the person up from the floor. This requires trained staff.

Tell family members what happened and reassure them the person is comfortable. The person may also want to reassure them directly.

Notify your supervisor and complete the required Incident Report.

#### IF YOU FIND THE PERSON ON THE FLOOR

Say the person's name and ask if he or she is okay or if they have hurt themselves.

Do not try to help the person up from the floor. This requires trained staff.

Reassure the person and call for assistance. Call 911 only if it is a medical emergency.

Tell family members what happened and reassure them. The person may also want to reassure them directly.

Notify your supervisor and complete the required Incident Report.