E-Learning Module J:

End-of-Life Care and Death Management

This Module requires the learner to have read Chapter 9 of the Fundamentals Program Guide and the other required readings associated with the topic.

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Please reference as follows:

GETTING STARTED

This e-Learning Module has been designed to consolidate key concepts from the required readings and provide an opportunity to begin applying these concepts through self-directed reflection and scenario-based work, in preparation for the case-based discussions, in-person, with other learners.
GETTING STARTED

In this module you will review the content highlights associated with Chapter 9 of your Program Guide.

It would be best if you have read Chapter 9 in advance and have the Program Guide, as well as the Domains of Issues Laminate with you as you complete this module.

You will be prompted to write down your thoughts or ideas during this module. You can do so in the ‘notes’ section at the end of Chapter 9 in your Program Guide. These notes are just for you; you are not required to share them.

Consider bringing forward any questions from the e-Learning Modules to your next Peer-to-Peer Exchange or your next Case-Based Learning Session.
TOPICS COVERED

✓ Understanding the Fundamentals
✓ End-of-Life and Death Management
✓ Developmental Landmarks and End-of-Life Task Work
✓ Needs of Person in End-of-Life
✓ Observing the Person’s Experience
✓ Interacting with the Family Caregivers
✓ Planning Issues
✓ Feeding and Hydration Issues
✓ Supportive Care Strategies
✓ Death Management
UNDERSTANDING THE FUNDAMENTALS

Familiarize yourself with the issues listed in the End-of-Life Care and Death Management domain on the Domains of Issues laminate. These are the issues we will explore in this module.
END-OF-LIFE CARE AND DEATH MANAGEMENT

Although hospice palliative care services should begin whenever symptoms of progressive life limiting illness affect the person’s quality of life, the support provided in the last 6-12 months of life is especially important in preparing the person and family to achieve a “peaceful awareness of death”.
END-OF-LIFE CARE AND DEATH MANAGEMENT

Acknowledging that dying is actually happening is difficult for all involved. Determining when the end-of-life phase of the illness trajectory begins is often a challenge, but using tools like the PPS, considering frequency of hospital admissions, and raising awareness of the increase in the person’s peaks and valleys on the illness trajectory can support this process.

The Surprise Question:
A question frequently used by health care providers is, “Would you be surprised if this person died within the next year?” If the practitioner would not be surprised, the person would then be classified as requiring palliative/end-of-life care.
END-OF-LIFE CARE AND DEATH MANAGEMENT

According to PPS, a score of 30% indicates that the person has entered the end-of-life stage of the illness.

At this point, the person has extensive disease, is virtually bed bound, unable to engage in activities, and requires total care for all activities of daily living. The person may be fully conscious or may be drowsy with or without confusion. Intake of food and fluids will continue to decrease as the person approaches death.
The EOL phase of the illness can involve making many complex and challenging decisions, including:

- The withholding of life prolonging interventions e.g. CPR, artificial nutrition, antibiotics, ventilation
- The timing for withdrawal of life prolonging treatments e.g. feeding tubes, cardiac devices, life prolonging medications such as insulin
END-OF-LIFE CARE AND DEATH MANAGEMENT

For these types of decisions, ethical principles need to be taken into consideration to guide decision-making. These include:

- **Autonomy**: the right of a capable person to determine what may be done to his or her body
- **Beneficence**: the duty of health care providers to do good
- **Non-maleficence**: the duty of health care providers to do no harm
- **Justice**: the fair treatment of individuals as well as equitable distribution of health care resources and dollars

Remember the impact of family culture, individual coping strategies, individual emotions, individual understanding, and generational issues on decision-making. Effective communication is of utmost importance to avoid conflict between health care providers, persons and families.
The dying person is often challenged by a number of psychological and spiritual issues as well as the physical issues. Dying can be hard work. Just as there is labour involved in being born, there is labour involved in dying.

As a mother labours she reaches certain stages or milestones throughout the labouring process such as the water breaks, the cervix dilates; each succession is a milestone or “landmark” towards achieving the goal of birthing a baby. There are numerous tasks involved in reaching the milestones or landmarks in the hard work of dying.
Julia is a 53-year-old woman diagnosed with metastatic cancer of the bowel. Her PPS is 30%. She is married and has 2 children in their 20’s, both attending university. Julia was a senior executive with the bank and resigned her position 6 months ago when she was told that her disease was progressing despite chemotherapy treatments. The staff had held a special party for Julia, remembering all of her accomplishments in her 15 years at the bank.

Julia is now spending time with her family, enjoying special times such as viewing family photos on the computer and picking out some that she would want for her funeral and celebration of life. She acknowledges her deep grief around not being able to attend the graduation of her daughters, but she is cherishing the times they spend together talking about her hope and dreams for their future.
DEVELOPMENTAL LANDMARKS AND END-OF-LIFE TASK WORK

Open your Program Guide to chapter 9, chart 9.2: “Byock’s Tasks and Landmarks for End-of-Life”, and document your answers to the following questions in the ‘notes’ section at the end of chapter 9.

1. What tasks indicate that Julie is working toward a “sense of completion of worldly affairs as well as sense of completion in relationships with community”?

2. What tasks indicate that Julia is working toward a “sense of completion in relationship with family and friends”?

3. What tasks indicate that Julia is working toward the “acceptance of the finality of life”?
DEVELOPMENTAL LANDMARKS AND END-OF-LIFE TASK WORK

Not everyone who is dying will complete all of the tasks successfully. Those who do them well are our teachers and mentors. Just as every person and family is unique, the interest and ability to address tasks is unique to every individual. Some will address tasks in great detail and others won’t address them at all.
NEEDS OF PERSON IN END-OF-LIFE

Research indicates that dying persons have common needs:

1. The management of pain and other distressing symptoms
2. Avoidance of inappropriate prolonging of dying (e.g. providing treatments that are futile)
3. A sense of spiritual peace
4. Relief of burden
5. Enhanced relationships with loved ones
OBSERVING THE PERSON’S EXPERIENCE

People who know what to expect have a very different experience of dying and death than those who have not been informed in advance. Providing information in a compassionate and sensitive way will assist the family members to support the dying person as well as each other. It will also reduce the potential for conflict over such things as the management of symptoms.

- Write down at least 6 of the observable signs at end-of-life. Check your answers against those listed in chart 9.3, Changes and Clinical Signs of Impending Death, in chapter 9 of your Program Guide.
Throughout the dying trajectory the demands on the family increase and can lead to exhaustion. Remember from Module E that the person and the family are a unit of care. As health care providers it’s important to be vigilant and observe for signs of family caregiver stress or fatigue.

Signs to watch for are:

- Changes in sleep and eating (e.g. a family member might make the comment, “I hardly slept a wink”)
- Irritability and anger
- Increased forgetfulness
- Increased use of tobacco and alcohol or drugs
- Inability to concentrate; disorganized, seems frantic around normal activities
INTERACTING WITH THE FAMILY CAREGIVERS

Often families have many questions about the dying process. When questions are asked it’s important to consider: what he or she is really asking and what they are looking for from you as a member of the health care team.
INTERACTING WITH THE FAMILY CAREGIVERS

Consider a family member who asks, “Can dad still hear us; does he know we are here?” Write down:

- What he/she might be really asking?
- What he/she is looking for from you as a member of the health care team?
- How you might respond?
INTERACTING WITH THE FAMILY CAREGIVERS

What might the family member really asking?

- I don’t understand what dad is experiencing, would you tell me what’s happening?
- Is there still time to say I love you and goodbye?
- Does it make a difference that I am here?
INTERACTING WITH THE FAMILY CAREGIVERS

What is the family member looking for from me as a member of the health care team?

- Reassurance that it is never too late to express thoughts/feelings
- Permission to do what he/she needs to do in terms of staying or leaving
INTERACTING WITH THE FAMILY CAREGIVERS

How might you respond to the question?

▪ It is thought that hearing remains until death so assume that he can hear everything you say
▪ Continue to speak with him and share thoughts or information that you think he would like to know
INTERACTING WITH THE FAMILY CAREGIVERS

When interacting with the family caregivers, be attentive to the following:
✓ Individual family member’s experiences are unique
✓ Cultural and family norms
✓ The person and family’s goals of care
✓ The person and family’s values and beliefs
As the PPS declines, it is important to review the goals and care plan.

If the person has chosen to die at home, ensure that all the necessary documentation is in place. Strategies can include:

✓ Reiterating the plan and reassuring of support to prevent unnecessary 911 calls or transfers to the emergency department, (e.g. DNRC form, EDITH, etc.)
✓ Leaving a 24/7 telephone contact that is accessible 24/7
✓ Encouraging family to call the number before calling for an ambulance
✓ Confirming decisions around funeral planning, burial and organ donation
FEEDING AND HYDRATION ISSUES

Often families feel helpless when they can no longer nurture the person by providing food. They might say, “Mom’s not eating anything, I’m afraid she’s starving to death”.

It is important for the health care team to explain that:

✓ This is a normal process of dying
✓ The body begins to shut down and is unable to utilize foods or fluids
✓ It’s a natural process to not desire food or fluids at the end-of-life
✓ Forcing food or fluids can lead to choking
✓ Increased fluids can lead to painful swelling in the abdomen and also lead to a build up of fluids in the lungs
✓ Studies have shown that tube feeding is not advantageous at the end-of-life and have potential complications (increased pain, gastric reflux and aspiration pneumonia)
SUPPORTIVE CARE STRATEGIES

Supporting the person and family to achieve peaceful awareness of death requires the efforts, knowledge and skills of the health care team.

- Refer back to Julia (slide 13). Julia is now in her last hours of life. Using your Program Guide as a resource, make a list of the 8 domains and list at least 2 supportive strategies you could employ in each domain to support Julia and her family.
DEATH MANAGEMENT

At the moment of death, life force and consciousness leaves the body. The eyes are fixed in one direction and may be opened or closed. The jaw may be slack. There may be loss of bladder and/or bowel control. There will be no movement, no response and no pain.

It is a sacred time; a moment of privilege for the health care provider to witness. The goal is to support the family, care for the person’s body with dignity, and ensure cultural/religious rituals are followed.
DEATH MANAGEMENT

Being present and providing compassionate care to the family is important. Consider some of the following aspects of care:

✓ Give attention to the environment by providing for practical needs such as extra chairs, refreshments
✓ Manage incontinence of bladder or bowel as necessary
✓ Elevate the head slightly so that gastric fluids don’t escape
✓ Allow the family to participate in care of the deceased before transfer to the funeral home
✓ Allow the family as much time as necessary to stay with the deceased
DEATH MANAGEMENT

Team members have an opportunity to model some of the challenging aspects of care of the dying.

If family members are unable to initiate a conversation with the person to tell him/her how much he/she is loved or to ask for forgiveness, then a team member can quietly go to the bedside and tell the person about the conversation with family members and how they spoke of how much the person is loved or the need for forgiveness.

If family members hesitate to come near the dying person, the team member could give family permission to do so by touching the person, stroking the hair, massaging the hands.
BRINGING IT TOGETHER

Through end-of-life care and death management the health care provider can:

✓ Support the person and his or her family to complete the tasks of the dying and a life review; this can help the person find meaning and purpose

✓ Educate the person and his or her family about the process of dying to relieving stress and fear

✓ Prepare the family for the changes that accompany dying. This makes the family less likely to expect actions to be taken (e.g. starting intravenous therapy when the person isn’t eating or drinking)

✓ Use the Domains of Issues Laminate to help organize the approach to care and consider issues and aspects in all domains
WHAT HAPPENS NEXT

To prepare for the next e-Learning Module, you will need to read the associated Program Guide chapter in advance. In order to complete the next e-Learning Module you will need both the Program Guide and Domains of Issues Laminate with you.