E-Learning Module C:

Disease Management

This Module requires the learner to have read Chapter 3 of the Fundamentals Program Guide and the other required readings associated with the topic.

Revised: July 2020
Contents of this e-Learning Module may be reproduced in whole or in part provided the intended use is for non-commercial purposes and full acknowledgement is given to the Southwestern Ontario Hospice Palliative Care Education Program and St. Joseph’s Health Care London.

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 3 to help prepare you for applying the concepts in case-based discussion.

It would be best if you have read Chapter 3 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 3 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
✓ Navigating Life’s Journey
✓ Palliative Illnesses
✓ Dying Trajectories and Palliative Illnesses
✓ Dying Trajectories
✓ Palliative Performance Scale
✓ Edmonton Symptom Assessment System
✓ PPS and ESAS-r
UNDERSTANDING THE FUNDAMENTALS

Familiarize yourself with the issues listed in the Disease Management domain on the Domains of Issues Laminate. These are the issues we will explore in this module.

An understanding of the process of the disease and the commonly experienced symptoms will promote early identification of the issues that the person and his or her family may experience.
NAVIGATING LIFE’S JOURNEY

Turn to “Navigating Life’s Journey: A Roadmap to Support Decision-Making” in Chapter 3 of your Program Guide.

There are many decision points in the illness experience. Understanding the disease process and treatment, as well as defining clear goals, can assist in tailoring care for the person and helping to ensure the person’s wishes are honoured. Uncertainty contributes to anxiety and stress for the person, his or her family and the health care providers.
The “Roadmap to Support Decision-Making” is a tool that reflects and identifies the significant points in the person and family’s journey.

Think about a trip you might take. How will you prepare, what and who will accompany you, and how many choices do you have in terms of roads that you can take to your destination?
NAVIGATING LIFE’S JOURNEY

In addition to visualizing the many points of entry and routes of an illness journey, the roadmap also highlights the many opportunities that the care provider has to support informed decision-making.

For example, what decisions need to be made at diagnosis? What treatments are available? If treatment is no longer effective, what options are available? Often people are on one journey and don’t realize that they have the option to choose another route.
What are some potential roadblocks or causes for traffic jams in the illness trajectory? For example, waiting for treatment to be scheduled. Write down your responses in your notes.
Navigating Life’s Journey

Identifying your role in the person’s journey, and how to best support informed Decision-Making is critical to facilitating a positive change.

- Identify the ways in which you in your role might provide support to the person and his or her family in Decision-Making along their journey.
The person and family’s informed choice is paramount. As health care providers we can support “navigating the journey” by:

✓ Being aware of resources and advocating for or providing resources for the person and his or her family about burdens and benefits and alternatives when specific treatments are offered

✓ Supporting the person’s choice even if it may not be our choice

✓ Fostering hope as it shifts throughout the journey.
PALLIATIVE ILLNESSES

To provide individualized care, it is helpful to have a basic knowledge of the palliative illnesses listed in the charts in Chapter 3. This knowledge will help you to:

✓ Understand the possible progression or “trajectory” of the disease
✓ Understand some of the common symptoms related to particular diseases
✓ Anticipate and understand the issues that the person/family may experience.
DYING TRAJECTORIES AND PALLIATIVE ILLNESSES

- Using the information in the Common Life-Limiting Illnesses Chart in Chapter 3 and the diagrams of Dying Trajectories that follow in your Program Guide, draw possible trajectory diagrams for each of the following diseases in your notes.

1. Multiple Sclerosis
2. Congestive Heart Failure
3. Alzheimer’s Disease
4. Massive Heart Attack
DYING TRAJECTORIES

Your diagrams should look like these:

1. Multiple Sclerosis

2. Congestive Heart Failure

3. Alzheimer’s Disease

4. Massive Heart Attack
DYING TRAJECTORIES

- How can knowledge of a dying trajectory related to specific illnesses help with care planning? Write down your ideas in your notes.
DYING TRAJECTORIES

Knowledge of the dying trajectory can alert the health care provider to:

✓ Initiate health care services in a timely manner enabling the development of a therapeutic relationship between the person, his or her family and health care team

✓ Promote conversations and the process of Advance Care Planning

✓ Be proactive in the development of a Plan of Treatment for palliative and end-of-life care
PALLIATIVE PERFORMANCE SCALE

There are tools to aid us with determining what treatment options should be offered depending on where the person is in the illness trajectory. One example of this is the Palliative Performance Scale.
The Palliative Performance Scale (PPS) is a reliable and valid tool measuring the person’s functional status. The PPS is divided into 11 categories starting at 100% (stable) to 0% (death) based on 5 observable functions.

These categories may be divided into 3 stages:

1. Stable: 100% – 70 %
2. Transitional – 60% - 40%
3. End-of-Life – 30% - 0%
PALLIATIVE PERFORMANCE SCALE

The five observable categories are:

1. Ambulation
2. Ability to do activities
3. Self-care
4. Intake
5. Consciousness

Note that the leftward columns are “stronger” when trying to determine the “best fit”. Only use 10% increments/decrements, e.g. the score cannot be 45%.
PALLIATIVE PERFORMANCE SCALE

It is important for the health care provider to be aware of the definitions of terms when assessing the person for PPS. For example, there is a difference between significant disease and extensive disease. These distinctions have important implications for decision-making and care planning. You will find definitions for the PPS in the Tools Section of your Program Guide.
PALLIATIVE PERFORMANCE SCALE

Consider the following scenarios. Use the PPS chart in your Program Guide and record your answers in the ‘notes’ section.

Hannah is a 68-year-old woman with a diagnosis of cancer of the breast with metastases to the bone, liver and lung. She always enjoyed walking several kilometers per day but now can only take short walks before getting out of breath. She is unable to do her housework and needs some help with getting in and out of the shower.

According to the terms of definitions for PPS, what is Hannah’s PPS and what stage is she in?
Bill was recently admitted to a long-term care home. He is 62-year-old with a confirmed diagnosis of ALS. Bill has limited use of his arms but still manages to feed himself. He requires a 2-person transfer in and out of bed. He spends most of the day in his wheelchair and attends some activities within the home.

According to the terms of definitions for PPS, what is Bill’s PPS and what stage is he in?
PALLIATIVE PERFORMANCE SCALE

Hannah’s PPS is 50%; she is in the transitional stage. She has extensive disease (metastases to bone, liver and lung); her ambulation is reduced, but she is not spending all of her day sitting/lying down.

Bill’s PPS is 50%; he is in the transitional stage. He is chair and bed bound but does spend a large part of the day in his chair and attends programs. Though he requires a great deal of assistance he is still able to feed himself so he is not requiring “total care”.

PALLIATIVE PERFORMANCE SCALE

All team members are responsible for observing the person carefully and identifying and reporting any changes in ambulation, activity and evidence of disease, self-care, intake and consciousness.
Use of the PPS enables the care team to:

✓ Observe particular physical functions
✓ Advocate for changes in the care plan, e.g. if person is in the end-of-life stage, it is not essential to get the person out of bed to eat
✓ Address changes with person and his or her family to determine goals of care and make appropriate changes to the care plan
✓ Communicate change in PPS to all team members as it may be a decision point for addressing a change in plan of care or setting of care
EDMONTON SYMPTOM ASSESSMENT SYSTEM

Hospice Palliative Care strives to address the physical, psychological, social, spiritual, and practical issues. The “gold standard” for the assessment of symptoms is the person’s own assessment of the intensity of the symptoms.
One of the tools designed to assist in the assessment (including screening) of symptoms experienced by the palliative care population is the revised Edmonton Symptom Assessment System (ESAS-r).

The ESAS-r tool is ideally completed by the person; if the person is cognitively impaired or for other reasons cannot independently complete the ESAS-r, then it should be completed by his or her family. When completed by the family member or health care provider alone, the subjective symptoms of the scale are not completed (i.e. tiredness, depression, anxiety and well-being are left blank).
The ESAS-r can help identify the important issues to assess and act on now. Recall The Boulder Analogy from Module B; the higher the numbers on the ESAS-r, the bigger the boulder.

Once the severity of the symptom is identified, a more in-depth assessment of the symptom is conducted to determine possible interventions.

Documentation of the ESAS-r scores allow for assessment of effectiveness of interventions and the identification of patterns and trends.
Every caregiver has a role in understanding the PPS and the ESAS-r.

What are some examples of how these tools can be used as a means of communication amongst health care providers? Write your ideas down in your notes.
The PPS and ESAS-r can be used as a means of communication:
✓ When the person is being transferred from one setting of care to another
✓ When reporting change in condition to the physician
✓ When reporting amongst team members at change of shift
✓ When the results are a trigger for services and supports (e.g. symptom response kit)
PPS AND ESAS-r

Information sharing amongst the health care team members can be strengthened by:
✓  Knowing each of the team members and how to contact them
✓  Communicating regularly with each other (ongoing and when changes happen)
✓  Using tools such as PPS and ESAS-r to support communication
✓  Respecting the person and family’s goals in any plan of care
✓  Respecting your team members
BRINGING IT TOGETHER

All diseases have an expected path and it is important for the health care provider to understand what symptoms to be looking for and to observe and report identified symptoms so that appropriate interventions can be initiated.

Understand also that, like a fingerprint, each person’s experience of the disease is unique and individualized.
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.

In addition, you will need a drinking straw and a clothespin or paperclip on hand when completing Module D.