This Module requires the learner to have read Chapter 8 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 8.

It would be best if you have read Chapter 8 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 8 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
- Family in Hospice Palliative Care
- Family Roles and Relationships
- Emotional Impacts on Family
- Family Caregiver Government Assistance Programs
- Observing the Individual’s Experience
- Interacting with the Person and His or Her Family
- Supportive Care Strategies
- Supporting Children
UNDERSTANDING THE FUNDAMENTALS

Refer to the Domains of Issues Laminate to identify issues in the Practical Domain. These are the issues we will explore in this module.
FAMILY IN HOSPICE PALLIATIVE CARE

As noted in Module G, the definition of family expands beyond the typical definition of biological family or family by marriage or contract.
FAMILY ROLES AND RELATIONSHIPS

Facing a life-limiting illness is a human experience for all involved. The journey affects the person, the family members and all who are involved in the person’s life and death. The focus in hospice palliative care is on the person and on individual family members.
A life-limiting illness alters roles in the family. For example, the ill person may no longer be able to manage activities of daily living or engage in the work place.

- In your experience, how have you seen the diagnosis of a life-limiting illness impact role changes in a family?
FAMILY ROLES AND RELATIONSHIPS

Role adjustments may include:
✓ Ability to work
✓ Ability to socialize
✓ Ability to parent
✓ Ability to see one’s self as contributing
✓ Ability to see one’s self as independent
✓ Ability to contribute to the household
EMOTIONAL IMPACTS ON FAMILY

Think about a loss you have experienced in your life and write down some of the emotions that you experienced during that time.

- What were those emotions?
EMOTIONAL IMPACTS ON FAMILY

The numerous losses experienced by the person and his or her family along the illness journey has an emotional impact on each person.

Individuals and families may experience a roller coaster of emotions and the person or family may open up about their experience in varying ways and at different times.
Provincial and federal programs can be of practical and financial help to family caregivers involved in the provision of end-of-life care:

- Provincial Labour Code allows for leave up to 8 weeks with job protection
- Federal program called Compassionate Care Benefits (under the EI Program) allows for up to a maximum of 26 weeks of benefits for family members. Information on the program can be found at [https://www.canada.ca/en/employment-social-development/programs/ei/ei-list/reports/compassionate-difficult-times.html](https://www.canada.ca/en/employment-social-development/programs/ei/ei-list/reports/compassionate-difficult-times.html)
How do you think the expected illness trajectory and the PPS might be helpful when it comes to supporting decision-making related to the process of applying for these programs?
FAMILY CAREGIVER GOVERNMENT ASSISTANCE PROGRAMS

Both programs require the completion of application forms.

Knowing the person’s expected trajectory and PPS will assist in information sharing and care planning. It is essential for the person and family to be informed about these programs in a timely manner to ensure completion of the necessary paperwork. Don’t wait until stress and emotions are already escalating.
OBSERVING THE INDIVIDUAL’S EXPERIENCE

As the person’s illness progresses, the family is required to redefine itself and come to terms with the “new normal”. The person and his or her family will have to re-evaluate goals and find meaningful ways of living with the current circumstances, rather than just “getting through another day”.
INTERACTING WITH THE PERSON AND HIS OR HER FAMILY

Individuals and families rely on the health care team to recognize and anticipate practical issues that might affect their lives.

Effective communication using the CLASS protocol (Module B) will support building a therapeutic relationship and impact a positive change in the illness experience.
INTERACTING WITH THE PERSON AND HIS OR HER FAMILY

- Review the elements of the CLASS protocol in your program guide and then review the topic of interacting with the person and his or her family in your Program Guide. Document points that made an impact on you.
INTERACTING WITH THE PERSON AND HIS OR HER FAMILY

Important considerations when interacting with the person and his or her family include:

✓ Each person and family is unique
✓ Reserve judgment
✓ Encourage family communication and understanding of individual needs
✓ Resist promotion of your personal values and standards
✓ Be sensitive to the financial strain of the illness on the family
✓ Be observant of the different feelings unique to each person
✓ Set and maintain boundaries
✓ Report suspected abuse of the person
SUPPORTIVE CARE STRATEGIES

As the illness progresses, hope often shifts from a hope for cure to hope for management of physical symptoms. A spark of hope for a miracle often remains until death.

- What other significant hopes have you heard voiced when cure is no longer an option?
SUPPORTIVE CARE STRATEGIES

Inviting friends and neighbours to form a support team can lessen the burden of care for the person and his or her family. The Share the Care™ program is one example of how supports can be organized.

Information on Share the Care can be found at
http://www.caregiverexchange.ca/6/Share_the_Care/

How might you find out about supportive care programs or opportunities in your area?
SUPPORTING CHILDREN

Children may experience significant discomfort when visiting the ill person whether it’s in the hospital, long-term care home, hospice, or home. There are numerous ways that children can be made to feel comfortable and valued as part of the unit of care.
SUPPORTING CHILDREN

In our roles and scopes of practice, we can support children by:

✓ Listening to their worries and fears; you may ask a question such as, “What’s the hardest thing about this for you?”

✓ Answering their questions truthfully and share information in "bite size" chunks

✓ Inviting them to help with small tasks such as gentle massage of hands or feet (encouraging touch)

✓ Providing age appropriate resources

✓ Ensuring that they are aware that what is happening is not their fault.
BRINGING IT TOGETHER

Every member of the hospice palliative care team plays an important role in assisting the person and his or her family throughout the illness journey.

Your practical care skills and knowledge, as well as compassion and warmth will ultimately influence how families experience and remember living with dying.
WHAT HAPPENS NEXT

To prepare for the next e-Learning Module, you will need to read the associated Program Guide chapter in advance (please note that the next module is module “J”). In order to complete the next e-Learning Module you will need both the Program Guide and Domains of Issues Laminate with you.