This module requires the learner to have read chapter 5 of the CAPCE Program Guide and the other required readings associated with the topic. See the CAPCE Program Guide required and recommended reading list for more information.

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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 *Decision Making*.

You may be asked to write down your thoughts or ideas during this module. You can do so in the Notes section at the end of Chapter 5 in your Program Guide. Have your Program Guide with you as you complete this module.

These notes are just for you; you won’t be required to submit them. However, you may be prompted to use your notes for discussion in your Peer-to-Peer Exchange and Coaching Sessions. Please be respectful of confidentiality.
TOPICS COVERED

✓ Decision-Making: Critical Concepts
✓ Decision-Making
✓ Shared Decision-Making
✓ Legal and Ethical Dilemmas
✓ Advance Care Planning and Health Care Consent (in Ontario)
✓ CPR & Resuscitation
✓ Sedation for Intractable Symptoms
DECISION-MAKING: CRITICAL CONCEPTS

Key concepts associated with Decision Making include:

✓ Every person has right to make informed and shared decisions, determine goals of treatment, and choose disease-related options.

✓ Legal and ethical dilemmas are common in hospice palliative care and must be identified and handled appropriately.

✓ Wishes expressed in an advance care planning process or goals of care conversation may influence decisions for care such as CPR, palliative sedation for intractable symptoms, etc.
DECISION-MAKING

Within the Therapeutic Encounter, Decision-Making includes consideration of:

✓ State of disease or stage of illness for the person
✓ Capacity of the person as it relates to consenting to a treatment or a treatment plan
✓ Goals, values and expressed wishes
✓ Issue prioritization
✓ Therapeutic options including benefits, risks, side effects and burdens of those options
✓ Treatment choices and informed consent
✓ Understanding who is the highest ranked substitute decision maker and their role in decision making
✓ Requests for withholding/withdrawing treatment, therapy with no potential benefit or medical assistance in dying
DECISION-MAKING

Consider the process of buying a house. Would it be adequate for a real estate agent to sit across the table from you and just tell you about the house? Would you rush to the bank for a mortgage based on how the agent described the house? Of course not! You want to see the house, walk through it, open closet doors, measure rooms, and scrutinize the home inside and out, to be assured it will meet your needs.

Decisions in palliative care are really not that different. The person and family need information about treatment options, prognosis, and the disease trajectory in order to make informed decisions that will meet their needs.
SHARED DECISION-MAKING

Shared decision-making is a concept in health care delivery that asks health care providers to engage in therapeutic conversations with the person and family in order to make decisions about a treatment plan based on beneficence and autonomy.

- Think about a person and family you have cared for. Recall an important decision they had to make in the illness journey. What was the decision to be made? Briefly describe the factors that were considered and the decision that was made in your Notes.
Continue to consider that person and family and the pending decision. Using your Notes, answer the following questions and share your answers with your partner(s) at your next peer-to-peer discussion.

1. What information did the person and family need to make an informed decision? How was this information shared with them? If they did not receive the information they needed, why not?
2. In your opinion, did shared decision-making take place? Support your answer.
3. Did the decision meet the person’s need for beneficence and autonomy? Provide your rationale.
LEGAL AND ETHICAL DILEMMAS

The concept of “legal” means pertaining to the law, while “ethical” is about upholding moral standard.

As such legal dilemmas are easier to recognize and define (i.e. is the decision permissible under the law?).

Ethical dilemmas and decisions are much more difficult to recognize, are more open to interpretation, and more emotionally charged.
LEGAL AND ETHICAL DILEMMAS

As a Nurse you will need to be skilled at recognizing and managing legal and ethical issues, using effective communication and conflict resolution strategies.

- For each of the four scenarios that follow, use the information in Chapter 5 of your Program Guide and other resources as needed to:
  - Identify the legal and/or ethical issues (be specific in terms of ethical principle and law)
  - Identify your first or next step as Nurse involved in or observing the situation

Use your Notes to organize your answers and be prepared to share in your next Peer-to-Peer Exchange or Coaching Session.
Max, an 80-year-old man, comes into the emergency department by ambulance with advanced disease, accompanied by his daughter who is on staff at the hospital. He is alert and competent. The nurse who assesses Max speaks mainly with his daughter; the physician who treats Max takes information from his daughter; and consults her about treatment options and decisions.

What are the legal and/or ethical issues? What will your first step be?
CASE STUDY #2

Rita, a 78-year-old woman, is in hospital with esophageal cancer. She develops swallowing difficulties. A referral is sent to consult with an ENT. After assessing her, the physician tells Rita, “your airway is going to obstruct and the only chance you have for survival is a tracheostomy. If you don’t have it done, you will die.” He leaves Rita to make her decision.

- What are the legal and/or ethical issues? What will your first step be?
LEGAL AND ETHICAL DILEMMAS

CASE STUDY #3

Jonathan is 35-years-old and is dying from malignant melanoma, which has metastasized to his brain. He is not married, his parents are his highest ranked substitute decision makers. Jonathon is now no longer mentally competent to make his own decisions but in a conversation with his physician when his PPS was still at 70% and competent, he stated when the time came to die, he wanted comfort measures only. Currently there is a DNR order in his health record. Jon’ mom tells the nurse this morning that she and Jon’s dad want everything done for Jon, including CPR and life support. They want him transferred from the residential hospice to a local hospital for treatment.

- What are the legal and/or ethical issues? What will your first step be?
CASE STUDY #4

Peter is 56 and has AIDS. He has been taking an oral antiretroviral agent, but it makes him very sick. His quality of life is severely diminished and he is depressed. Peter wants to die and has decided to stop all treatment. He is admitted to a hospice and the palliative care physician tells him there are a number of different antiretroviral agents available to try; a different drug may not have as many side effects. Peter was unaware there were treatments options, and makes the decision to try a different drug.

What are the legal and/or ethical issues? What will your first step be?
“Advance Care Planning” is not a recognized legal term in Ontario, but is widely used in common language. The nurse should be aware that each province in Canada has its own laws and expectations around communicating and expressing future health and personal care wishes. We have specific professional and legal responsibilities related to health care consent.

Consider the following questions and write your answers in your Notes.

▪ What is advance care planning in Ontario? Be specific.
▪ What is advance care planning NOT in Ontario? Be specific

Consider sources of information such as Speak Up Ontario and the Advance Care Planning Ontario Workbook - [www.speakupontario.ca](http://www.speakupontario.ca)
ADVANCE CARE PLANNING AND HEALTH CARE CONSENT

In Ontario, Advance Care Planning is:

✓ A process of reflection and communication about values, beliefs and goals of care

✓ A process of planning for a time when a person is unable to make care and treatment decisions (sharing wishes)

✓ A process that involves discussions with family, friends and may include health care professionals

✓ A process in which a person may understand who their default substitute decision maker (SDM) is, or name SDM(s) in a Power of Attorney for Personal Care

✓ A process that results in the sharing of a person’s wishes.

Ontario Speak Up Campaign – www.speakupontario.ca
Advance care planning is not:

- One conversation only
- About treatment decisions with a physician or other health care provider(s)
- Consent to a treatment(s)
- Strictly a refusal of medical treatment(s)
- A document/form/checklist to be completed.
- A secret from the person’s family or SDM(s)

Ontario Speak Up Campaign – [www.speakupontario.ca](http://www.speakupontario.ca)
ADVANCE CARE PLANNING AND HEALTH CARE CONSENT

As a Nurse, what is your role in encouraging the person and family to engage in advance care planning? Have you supported this process to date?

- Consider a person and family you have cared for with whom you have engage in conversation about expressing wishes and values (advance care planning)
  - Do you feel that the conversation was effective?
  - Did you provide the person and family with new information?
  - Given what you know now, what would have improved or made the conversation more effective?
ADVANCE CARE PLANNING AND HEALTH CARE CONSENT

Health Care Provider role in ACP:

✓ Promote the process of reflecting on values, beliefs and goals
✓ Discuss why/when someone might complete a Power of Attorney for Personal Care (POAPC)
✓ Provide information on hierarchy of future SDM(s) to determine if the automatic highest ranked SDM will meet the person’s needs.
✓ Provide health and treatment information
ADVANCE CARE PLANNING AND HEALTH CARE CONSENT

Summary:

▪ Wishes shared (orally or in writing) guide the person’s future SDM(s) to make health care decisions if the person becomes incapable
▪ Wishes are interpreted by the SDM(s) when the person is deemed incapable
▪ Health care providers are required to get informed consent from the person (if capable) or their highest ranked SDM(s) prior to initiating care or treatment of any kind, in any situation

Ontario Speak Up Campaign – www.speakupontario.ca
ADVANCE CARE PLANNING AND HEALTH CARE CONSENT

When you engage in therapeutic conversations with the person and family about their wishes and values, you provide the motivation and opportunity for reflection.

Using the ethical principle of truth telling and your professional and legal obligations to provide health and treatment information gives the person and family the ability to make autonomous and informed decisions about future events.

You also have the opportunity to provide tools, resources, and education to support engagement in the expression of wishes and decision-making process.
CPR & RESUSCITATION

The decision about whether or not to include CPR in a treatment plan should be made, if possible, in advance rather than in a moment of crisis.

Allow natural death (AND) is not a ‘treatment’. AND is a term or language used in connection with “do not resuscitate” in conversation only. It reminds us that death is a natural and inevitable outcome of life.
Review the CPR algorithm in the Tools section of your Program Guide and answer the following questions:

1. What is the issue of importance in step A?
2. What are the four elements of consent?
3. Step 4 states: Determine physician assessment. Is CPR being offered as a treatment option by the physician? Is CPR a legal right of every person? Why or Why not?
4. What steps should the nurse take when it is determined that CPR will not be included in the plan of treatment?
5. Who makes health and personal care decisions for the person if they have not named a SDM in a POAPC document?
6. Who does the DNR confirmation form belong to? Who should it be shared with?
PALLIATIVE SEDATION THERAPY

Palliative sedation therapy is a treatment option when symptoms are found to be intractable.

It is the intentional continuous induction of a reduced level of consciousness in order to relieve one or more intractable symptoms in an individual who is at the end of life (i.e. last days and hours).

The intent is to relieve suffering and not to hasten death. Sedation for intractable symptoms is not medically assisted death.
PALLIATIVE SEDATION THERAPY

The presence of an intractable symptom is the core requirement for initiating sedation. An intractable symptom is defined as: a symptom for which all treatment options have failed or no methods for alleviation are available within the given time frame a person can tolerate.

Initiation and implementation of sedation for intractable symptoms is ideally undertaken by the health care team with involvement by those with expertise in palliative care.
PALLIATIVE SEDATION THERAPY

The Latimer Ethical Decision Model in your Pallium Palliative Pocketbook is a valid, reliable, researched tool. The Richmond Agitation Sedation Scale (RASS) is recommended to assess level of sedation. As a Nurse in palliative care, you must ensure you understand these tools, follow the processes, and document all decisions.

Sedation for intractable symptoms is vulnerable to the principle of double effect, which is a rule of conduct frequently used to determine when a person may lawfully and ethically perform an action from which two effects will follow, one bad, and the other good.
Do you believe palliative sedation therapy is an ethically-sound treatment option in cases where intractable symptoms exist? Why or why not?
BRINGING IT TOGETHER

To care for a dying person and his or her family is a privilege afforded few in our society. Shared decision-making is an important part of the care that the Nurse will provide.

Engaging in the process of advance care planning, assessing decisional capacity, informed consent, sedation for intractable symptoms, and resuscitation can be complex and confusing. Follow up with your peers and your coaches for confirmation or clarification on any of these concepts as you continue through the CAPCE program.
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 to have the Program Guide and the Pallium Palliative Pocketbook with you.