Advance Care Planning

Host and Moderator: Amanda Tevelde

Presenters: Laura Bates, RN

Lynda Meeks, RN

Date: April 25th, 2024

Land Acknowledgement

We would like to acknowledge that the land which we are gathered on today is the traditional territory of the Anishinaabek Nation; specifically, the Chippewa Tri – Council comprised of the Chippewas of Beausoleil, Rama and Georgina Island First Nations and more recently the Mississaugas of the Credit River First Nation. Ontario is covered by 46 treaties and other agreements and is home to many Indigenous Nations from across Turtle Island, including the Inuit and the Métis. These treaties and other agreements, including the One Dish with One Spoon Wampum Belt Covenant, are agreements to peaceably share and care for the land and its resources. Other Indigenous Nations, Europeans, and newcomers were invited into this covenant in the spirit of respect, peace, and friendship.

Most of us have come here as settlers, immigrants, or newcomers in this generation or generations past. **We are <u>all</u> Treaty people.** <u>Every day</u> we are mindful of broken covenants, and we strive to make this right. We commit to collaborating based on the foundational assumption that Indigenous Peoples have the power, strength, and competency to develop culturally specific strategies for their communities. We are dedicated to honouring Indigenous self-determination, history, and culture, and are committed to moving forward in the spirit of reconciliation and respect with all First Nation, Métis and Inuit people.

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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Thank You

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Health Canada Santé Canada

Introductions

Host and Moderator

Amanda Tevelde
Communications, Fundraising and Community Relations Specialist
Hospice Orillia

Presenters

Laura Bates, BScN, RN, CHPCN (C)
Palliative Pain and Symptom Management Consultant (PPSMC)
Mentorship and Education Portfolio
North Simcoe Muskoka Hospice Palliative Care Network

Lynda Meeks, RN, BSCN, CON(C)
Palliative Pain and Symptom Management Consultant (PPSMC)
Mentorship and Education Portfolio
North Simcoe Muskoka Hospice Palliative Care Network

Thank you for joining us today!

Please remember to complete the satisfaction survey following todays session.

Please note that this presentation will focus on Advance Care Planning specifically in Ontario. Each Canadian province and territory has specific individual laws and regulations regarding advance care planning and substitute decision making. Please consult the province or territory in which you practice and/or live for applicable laws and regulations.

Learning Objectives

By the end of the session, participants will be able to:

(in the context of the Province of Ontario)

- Understand and describe the process of Advance Care Planning in Ontario.
- Understand what is required for informed consent.
- Discuss and apply the components of person centered decision-making.
- Understand and begin to apply a variety of conversation tools to assist with Advance Care Planning conversations.


Just imagine...

Common Desires

- To live forever
- To be fully able and then to die suddenly in my sleep
- To die at home
- To die pain-free
- To die with my dignity intact

Some Assumptions About End of Life Care

My friends and family can and will take care of me.

My friends and family will all agree and make caring decisions throughout my illness trajectory.

Care will be available when and where I need it and to the fullest extent.

The Truth

Causes of Death 2021 (Statistics Canada 2023)
1) Malignant neoplasms
2) Diseases of the heart
3) Unintentional Accidents
4) COVID 19
5) Cerebrovascular diseases
6) Chronic lower respiratory diseases
7) Diabetes
8) Alzheimer’s disease
9) Chronic liver disease and cirrhosis
10) Influenza and pneumonia

Why Is Advance Care Planning Important?

Your future wishes regarding your health and personal care will be known and followed

Your family and friends will have less stress and anxiety when making decisions about your care

You and your family and friends will be more satisfied with the care you receive

You will have a better quality of life and death

Informed Consent for Treatment and Care

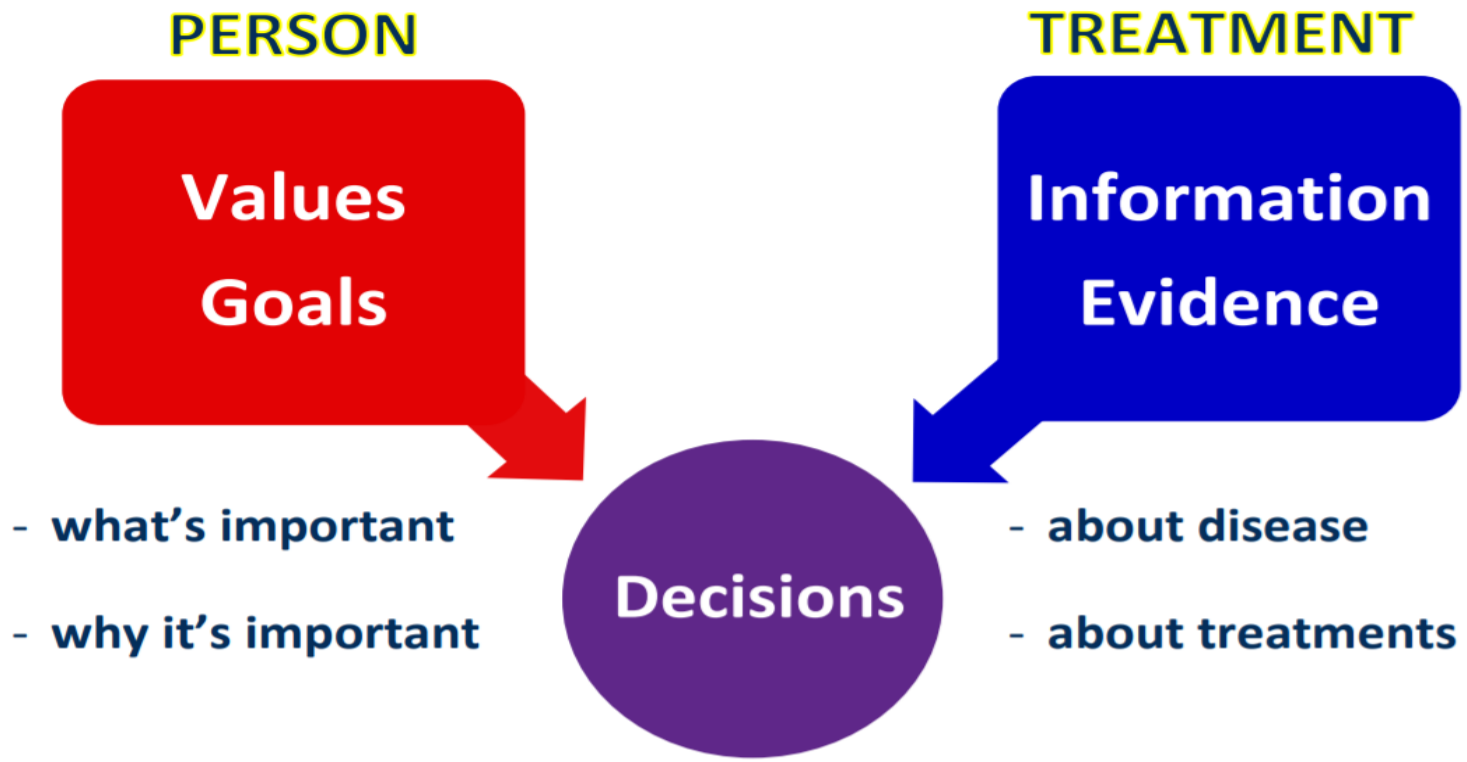
What Makes Consent Informed?

- Must be related to the proposed treatment
- Given voluntarily, not obtained through misrepresentation or fraud
- The individual giving consent must have the capacity to do so
- The information provided must include:
  - The proposed treatment and it's expected benefits and risks
  - The alternative treatment(s) and expected benefits and risks as applicable
  - The expected benefits and risks of refusing the proposed treatment

Types of Decisions in Health Care

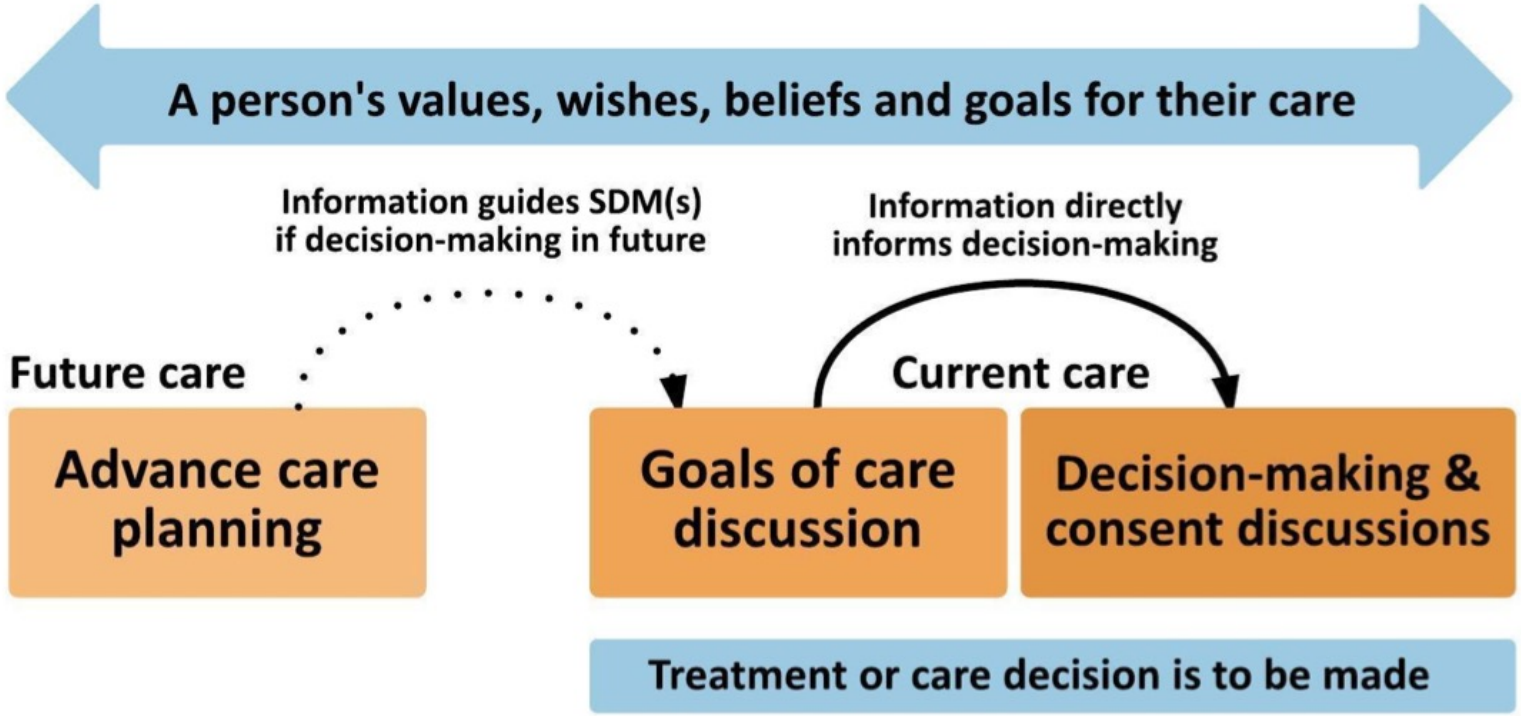
- Long-term care placement
- Consent or refusal of tests, procedures, surgery
- The initiation or withdrawal of life-prolonging measures
- Who will provide medical care
- Admission/discharge from medical facilities
- Goals of Care discussions

HOW a person makes healthcare decisions



Two parts of the equation
BOTH are needed to be effective

Person Centered Decision Making



Making health care decisions for someone else

What is Advance Care Planning in Ontario?

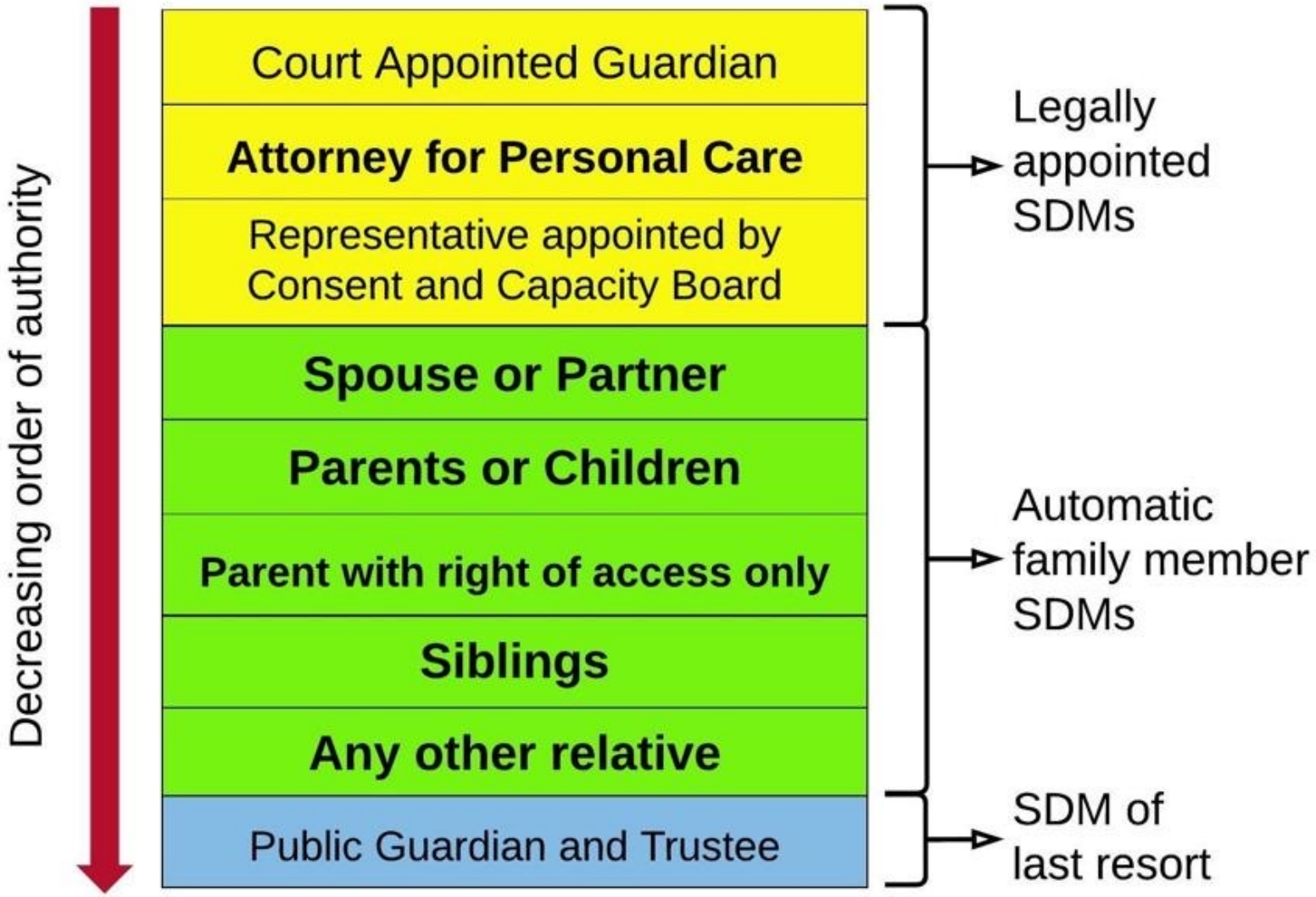
- Step 1: **Identify** and confirm your Substitute Decision Maker(s)
- Step 2: **Learn** about your current health conditions and possible future treatments associated with them
- Step 3: **Think** about what is important to you – your values, beliefs and wishes
- Step 4: **Talk** about your values, beliefs and wishes with your Substitute Decision Maker(s), family, friends, and health care providers – record them if you can!
- Step 5: **Include** your Substitute Decision Maker(s) in these ongoing conversations so they learn what is important to you, remain updated as circumstances change and are prepared to make decisions for you in the future if needed

Step 1: Identify

Who will be your substitute decision maker (SDM) based on the hierarchy?

- Does that person have the ability to make difficult healthcare decisions in a time of crisis?
- Would they make those decisions based on your values, wishes, and beliefs?

Substitute Decision Maker Hierarchy



Ontario's *Health Care Consent Act*, 1996

Requirements of the SDM:

- Willing and able to make healthcare decisions on your behalf
- Willing to honour your wishes, even if it's not what they would choose for themselves
- Mentally capable to speak for you even under stressful times
- At least 16 years old
- Available to make decisions when they are required

Step 2: Learn

What Should You Know?

- Current medical diagnoses
- Projected illness trajectories based on current health status
- Potential outcomes of current medical issues
- Probabilities of expected complications
- Whether current diagnoses and possible/expected outcomes are reversible or not

What Should You Know?

- Likelihood of adverse events or complications based on current medical status
- What possible medical procedures may be required for current and potential future medical issues and exactly what they entail
  - Artificial hydration or nutrition, dialysis, medications, surgery, chemotherapy and radiation, etc.

What Should You Know?

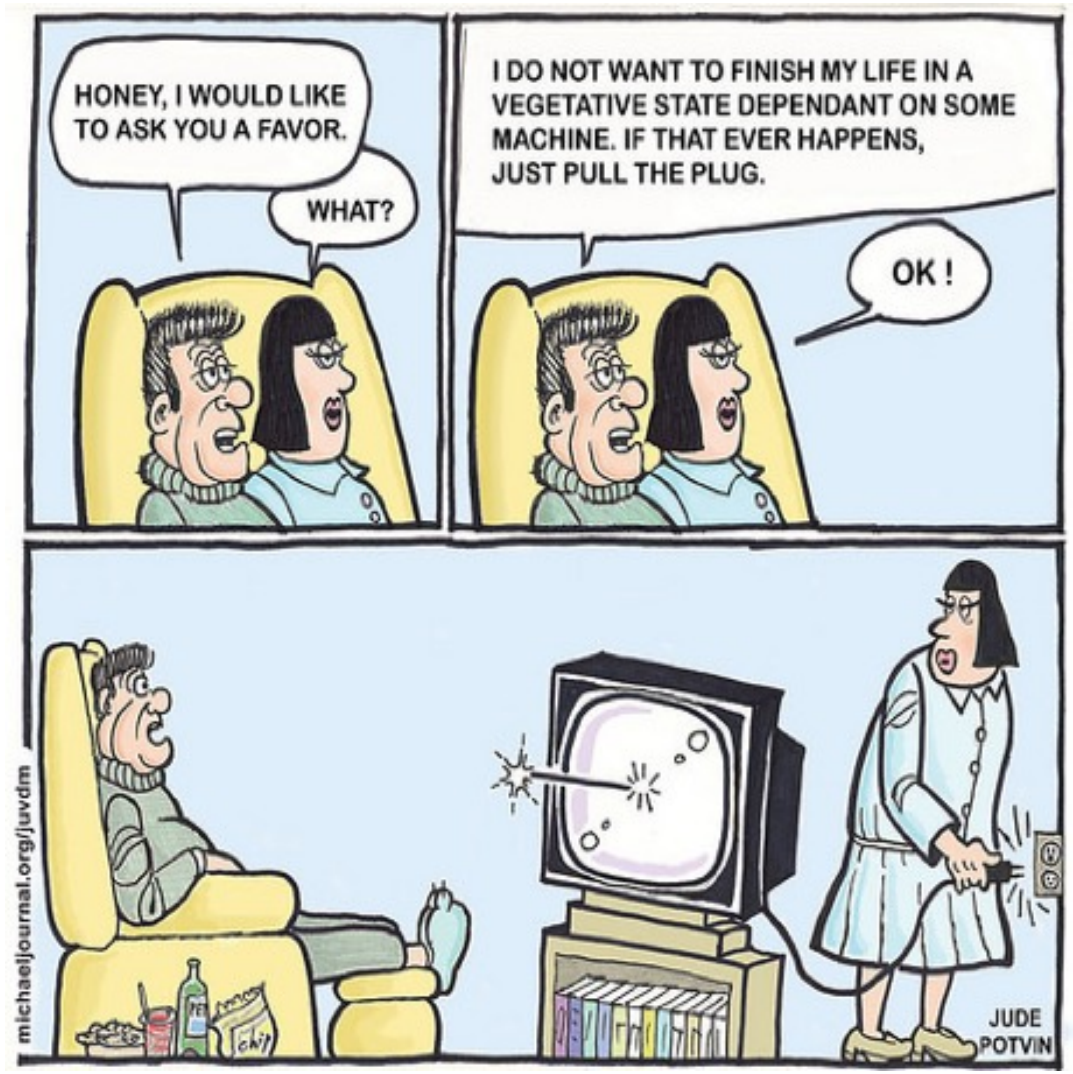
- What do the following terms mean and how might they apply to my expected and potential illness trajectories?
  - Allow Natural Death
  - Cardiopulmonary Resuscitation (CPR)
  - End-of-life care
  - Frailty
  - Hospice Palliative Care
  - Life support/Life sustaining measures (including medication, ventilator, feeding tube)

Step 3: Think

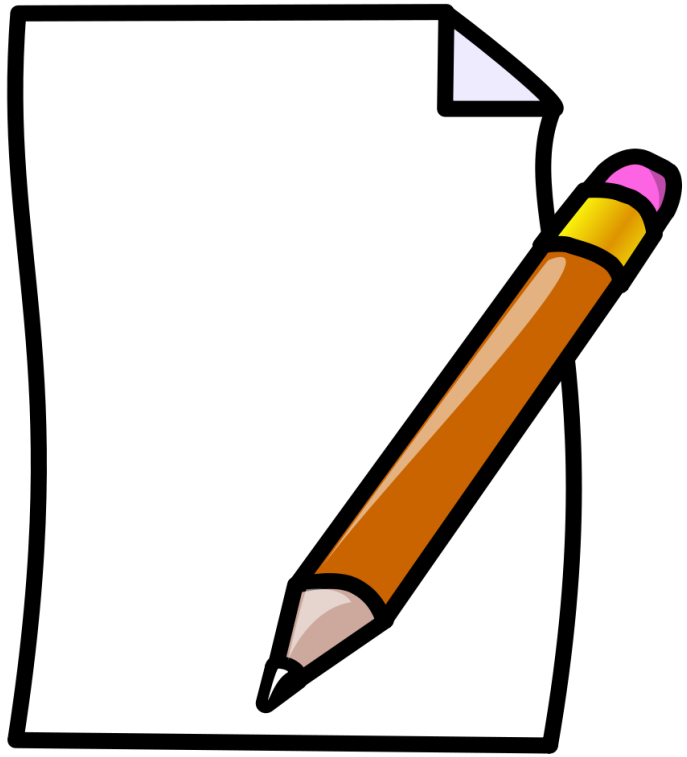
What Are Your Values, Beliefs, and Wishes?

- What do you worry about most when it comes to your future health and when you are dying?
- What is your favorite routine or habit?
- What makes your life meaningful?
- What life circumstances would you find the most unbearable?
- What is your favorite ceremony or special event?
- What gives you strength?
- What is important for others to know if I am ill?

Step 4: Talk


HONEY, I WOULD LIKE TO ASK YOU A FAVOR.
WHAT?
I DO NOT WANT TO FINISH MY LIFE IN A VEGETATIVE STATE DEPENDANT ON SOME MACHINE. IF THAT EVER HAPPENS, JUST PULL THE PLUG.
OK !
michaeljournal.org/juvdm
JUDE POTVIN

Step 5: Include



Review Your Wishes Regularly

Remember Advance Care Planning is a Process of…

- Reflecting and communicating values, beliefs and goals of care
- Planning for a time when you cannot make treatment decisions
- Discussing with family, friends, and health care professionals
- Determine/appoint a SDM
- Sharing your wishes

Advance Care Planning is not…

- One Conversation only about treatment options with a physician or other HCP
- Consent to treatment
- Strictly a refusal of medical treatments
- A document/form/checklist to be completed

How Can Healthcare Providers Encourage Advance Care Planning?

- Utilize websites, handouts, booklets, videos, etc. to provide information to patients and their families/caregivers as early in the illness trajectory as possible regarding Advance Care Planning
- Utilize evidence-based conversation guides and tools that are backed by research to guide your discussions with patients
- Complete your own Advance Care Planning and self-reflect on whether you have biases or beliefs which may impact how you discuss this topic with your patients and their families/caregivers
- Practice, practice, practice!

Conversation Frameworks

"I wish… I worry… I wonder…"

- "I wish" aligns you with the patient's hopes
- "I worry" allows for truth-telling while being sensitive
- "I wonder" is a way to make a recommendation and discuss things further

Conversation Frameworks

- SPIKES protocol for breaking bad news
  - Setting
  - Perception of condition/seriousness
  - Invitation from the patient to give information
  - Knowledge: giving medical facts
  - Explore emotions and sympathize
  - Strategy and summary

(Baile et al. 2000)

Tools for Advance Care Planning Conversations

- Canadian Virtual Hospice website: Click on “Tools for Practice” for professionals, then “Communication” for a variety of videos and electronic/printed materials
  - www.virtualhospice.ca
- Ariadne Labs: “Serious Illness Conversation Guide” (for clinicians) and “What Matters to Me: a workbook for people with serious illness” (for patients)
  - Both available for free download online: www.ariadnelabs.org/serious-illness-care/

Tools for Advance Care Planning Conversations

- Advance Care Planning Canada website: a variety of videos and electronic/printed materials
  - www.advancecareplanning.ca/health-care-professionals/
- Ontario Palliative Care Network website: “Palliative Care Toolkit” for a variety of tools for conversations
  - www.ontariopalliativecarenetwork.ca/resources/palliative-care-toolkit

Case Studies

Let's Discuss

Project ECHO
Palliative Care - Canada
BY Pallium Canada

NSMHPCN
North Simcoe Muskoka Hospice Palliative Care Network

Presenters: Kathlene Bartlett, RN, BScN, CHPNC(C)

Laura Bates, BScN, RN, CHPCN (C)

Date: January 25th, 2024

Let's Meet Jasmine

Jasmine is a 55 year old woman who married later in life and has no children. She is estranged from her siblings and her parents are both deceased. Her wife has just moved out of the home because the couple is separating.

Jasmine is close with a group of coworkers that she has worked with for over 20 years. In the past, she has told them she would never want to be kept alive if she was very disabled and unable to care for herself.

Jasmine has poorly controlled hypertension and type 2 diabetes that is poorly controlled with both oral medications and insulin.

Jasmine sustains a significant brain bleed and undergoes surgery and is now in the intensive care unit. Her doctors explain to her wife and co-workers who are at the bedside that if Jasmine does survive to leave the hospital, it is highly unlikely that she will be able to care for herself ever again.

What if advance care planning had been discussed early on?

What if advance care planning has never been discussed?

If Jasmine And Her Doctor Had Discussed Advance Care Planning…

Jasmine's doctor introduced Advance Care Planning in his early discussions with her about her diabetes and blood pressure control. They discussed her goals for medical care and who she wished to be her substitute decision maker if she was unable to make medical decisions. They also discussed her desire to maintain her independence and wish to not rely on others for care. At her doctor's recommendation, she documents these values and that she wants a co-worker to be her substitute decision maker. The co-worker agrees and is aware of Jasmine's wishes.

Based on these previous conversations and Jasmine's poor prognosis, the decision is made to provide a palliative approach to care for Jasmine and she dies peacefully with her closest friends at her bedside a week later.

If Jasmine And Her Doctor Had Not Discussed Advance Care Planning…

At the hospital, the medical team contacts Jasmine's wife as she is the automatic substitute decision maker based on the hierarchy. Her wife is unaware of the conversations that occurred about Jasmine's wishes and values and has no idea what Jasmine would want in this situation. She clings to the fact that the medical team has indicated there is still a small chance of survival and asks them to do everything possible to sustain her life. A feeding tube is placed and once Jasmine's condition is stable enough, she is transferred to a long term care home as she is fully dependent on others for her care.

Let's Meet Doug and Karen

Doug and Karen are both in their 50's, married and have two teenage daughters. Olivia is 17 years old and Hannah is 14 years old. Doug and Karen are in a car accident and are both in hospital unable to make their own (and each others) health care decisions. They have both named each other in their Power of Attorney for Personal Care documents. There is no back up named.

Doug and Karen both have parents who have come from out of town to the hospital with the teen daughters to find out more about how Doug and Karen are doing. The medical team is unsure of who to ask to make decisions about Karen and Doug's care.

- Who is the automatic substitute decision maker for Karen and Doug?
- What happens if there are multiple automatic substitute decision makers?
- Consider if the automatic substitute decision maker is only their 17 year old daughter?
- Consider if their automatic substitute decision maker is only their respective parents?

Let’s Meet Mrs. Cho

Mrs. Cho has seen her primary care Nurse Practitioner on three different occasions over the past year for COPD exacerbations which have required oral corticosteroids and antibiotics along with a change in her inhalers to treat. Last week, Mrs. Cho required a 3 day stay in hospital due to an exacerbation as it occurred while Mrs. Cho was visiting her son and he called 9-1-1 due to her dyspnea.

On each previous visit, the Nurse Practitioner has attempted to discuss Advance Care Planning with Mrs. Cho, but she became defensive and refused to discuss anything related to her health becoming worse.

Mrs. Cho is expected for a follow up visit after her hospitalization today and the receptionist stated that her son informed her he was accompanying her since she needs to use a wheelchair now due to weakness and dyspnea with walking.

If you were her nurse practitioner, how would you approach this visit with Mrs. Cho and her son?

What tools could be used to support a conversation about Advance Care Planning?

Resources For Other Provinces And Territories

- Prince Edward Island: www.healthpei.ca/advancecareplanning
- Newfoundland and Labrador: www.advancecareplanning.ca/wp-content/uploads/202/06/ahcd_booklet1.pdf
- Nova Scotia: https://novascotia.ca/just/pda
- New Brunswick: https://horizonnb.ca/patients-visitors/advance-care-planning/
- Quebec: https://educaloi.qc.ca/en/capsules/protenction-mandates-naming-someone-to-act-for-you/
- Manitoba: www.gov.mb.ca/health/livingwill.html

Resources for Other Provinces and Territories

- Saskatchewan: www.saskhealthauthority.ca/your-health/conditions-diseases-services/advance-care-planning
- Alberta: www.albertahealthservices.ca/info/page12585.aspx
- British Columbia: https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning
- Yukon: https://Yukon.ca/en/health-and-wellness/care-services/plan-your-future-health-care-decisions
- Northwest Territories: www.hss.gov.nt.ca/en/services/personal-directives
- Nunavut: www.gov.nu.ca/health/

Questions?

We hope you enjoyed todays session. Please remember to complete the satisfaction survey.

References and Resources

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