Advance Care Planning: Whose Conversation is it Anyway?

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May 24, 2016
The information and views in this webinar are those of the presenter(s) and do not necessarily reflect the official opinion of the Canadian Nurses Association.
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Objectives of the webinar

- What is advance care planning (ACP)?
- Why is it important?
- What is the nurse’s role to engage Canadians in ACP?
- How is it done?
- What are some of the available resources on ACP?
Advance care planning

• A process of reflection on values and wishes
• The communication of wishes (verbal, written or otherwise) when you are capable
• A way to let others know your future health and personal care wishes
• The consideration of who will speak for you when you are no longer capable of directing your care — your substitute decision-maker
What do we know about living and dying?

- Canadians are living longer
- Only 10% of Canadians die suddenly
- The other 90% need care and support as they approach death
- Many cannot make decisions for themselves
Most Canadians die of a chronic illness

- Heart: 35%
- Cancer: 28%
- Lung: 10%
- Other: 27%
Of 3,746 people who died in hospital

Did not require decision-making 58%

Required decision-making 42%

Lacked capacity 70%

Had capacity 30%

Source: Advance Directives and Outcomes of Surrogate Decision Making Before Death
Why take part in advance care planning?

Individuals who engaged in ACP and/or appointed a substitute decision-maker:

• Are much more likely to have their end-of-life wishes known and followed
• Have family members who had significantly less stress and depression
• Are more satisfied, as were their families and substitute decision-makers
What we know

Individuals who engaged in ACP and/or appointed a substitute decision-maker:

• Have fewer life-sustaining procedures and lower rates of intensive care unit (ICU) admissions
• Have a better quality of life and death
• Have less costly care in last weeks of life
What we know

The ACCEPT study:
- 75% of patients had thought about their wishes
- 85% had talked to someone about them
- 70% had designated a substitute decision-maker
- Only 25% were asked on admission to hospital whether they had previously discussed their wishes
- Only 30% of documented goals of care were congruent with expressed wishes
What we know

• **86%** of Canadians have not heard of advance care planning.

• **60%** of Canadians think it’s important to talk about wishes for end-of-life care.

• But only **45%** have had a conversation with anyone.

Source: Harris Decima Poll, 2014
Why do Canadians not engage in advance care planning?

- Don’t want to upset family: 48%
- Afraid of death: 45%
- ‘Creeped out’ by the conversation: 38%
- Feeling healthy and don’t have to: 43%
The role of nurses in advance care planning

Nurses provide care

• To Canadians who are healthy along with those who are diagnosed with chronic and life-limiting illnesses
• Across the life span
• Across all settings
Nurses play a key role by

• Initiating conversations
• Honouring values and health-care wishes
• Advocating for and supporting people

Source: The Palliative Approach to Care and the Role of the Nurse (joint position statement)
The nurse’s role

• To encourage people engage in ACP – a process of reflection and communication
• To help people express their wishes for future care – including that received at the end-of-life
• To ensure significant others and substitute decision-makers know their loved one’s wishes
What do Canadians say?

- **88%** of Canadians are comfortable talking with nurses about end-of-life care
- **90%** of Canadians trust nurses
What do nurses say?

- Six in 10 nurses believe that people should start ACP when they are healthy.
- 44% of nurses say they would definitely start this conversation, given training and resources.
- Two thirds (68%) of nurses have discussed ACP with their patients.

What we know

• 18% of nurses working in primary care are experienced and comfortable discussing ACP with their patients and another 51% are somewhat comfortable.

What we know

Nurses need:

• Information
• Materials for patients
• Guidelines on when and how
Who needs to do advance care planning?

Everyone

• You never know when you may face an unexpected event or illness and will be unable to make your preferences known.

• You may hope that you will be able to communicate until the very end, but this is not possible for most deaths.
The conversation

• Central to advance care planning is the conversation — to discuss wishes with family, friends, substitute decision-makers and health-care providers.

• Conversations should begin early — while we are healthy — and certainly at the time of diagnosis of a chronic illness.
“I didn’t expect him to die so soon. My husband resisted talking about dying and after 40 years of marriage I feel he let me down by not opening up and I guess I let him down for not knowing how to talk about some of the things that I needed to discuss. It would have been nice closure if things had been different in the end. I can never get that time back.”

CANHELP study participant
Advance care planning in 5 steps

Think
Learn
Decide
Talk
Record
Advance care planning in 5 steps

Step 1: Think

Think about your values, wishes and beliefs. Consider how much you understand about your care and specific medical procedures.
Advance care planning in 5 steps

Step 2: Learn

Learn about different medical procedures and what they can and can’t do.
Advance care planning in 5 steps

Step 3: Decide

Decide who will be your substitute decision-maker. It should be someone who is willing and able to speak for you if you can’t speak for yourself.
Advance care planning in 5 steps

Step 4: Talk

Talk about your wishes with your substitute decision maker, loved ones and your health-care provider(s).
Advance care planning in 5 steps

Step 5: Record

Record your wishes. It’s a good idea to write down or make a recording of your wishes.
Resources

• Partnership between the CHPCA and CARENET
• Overseen by a national task group — interprofessional and representing many jurisdictions
• Funding has come from the Canadian Partnership Against Cancer, CIHR, Prostate Cancer Canada, Health Canada, GlaxoSmithKline
• Launched the Speak Up campaign to engage people and raise awareness about the need to discuss end-of-life care
Speak Up campaign

• Initiative to promote and facilitate ACP in Canada
• Tools are available on a website for the public, professionals and community organizations/agencies

www.advancecareplanning.ca
Raising awareness

• Social media
• Media engagement
• Seasonal campaigns
• Infographics
• Videos
• Blogs, PSAs, templates
• Champions
Resources for patients, families & nurses

- Workbooks (print and online)
- Videos
- Wallet cards
- Provincial and territorial resources
- Cancer-specific tools
- “Just Ask” conversation card
- Primary care toolkit
Workbook for patients & families

- Think and write about your values and beliefs.
- Learn about end-of-life care and medical procedures.
- Write about your preferences for care.
- Share with your substitute decision-maker, family and health-care team.
In Case of Medical Emergency

I have a Substitute Decision Maker who can speak for me if I am unable to communicate my wishes regarding medical care:

Substitute Decision Maker: ________________________________
Tel: ____________________________________________
Alternative Tel: ___________________________________
Relationship to me: ________________________________
Signature: ___________________________ Date: ____________

www.advancecareplanning.ca
Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate. Learn more >
Cancer-specific resources

Cancer and Advance Care Planning

You’ve been diagnosed with cancer. Now what?

Cancer and Advance Care Planning

Tips for Oncology Professionals
“Just Ask” conversation card

ASK YOUR PATIENT:
What do you understand about your illness or what’s happening to you?

- Then offer to provide your view of prognosis, etc. Check who they may want present for this conversation.

Do you have a living will, advance directive, or advance care plan? Do you know what I mean by those terms?
- If yes, discuss details.

If no, then ask, “If we need to make decisions about your care and you were unable to speak for yourself, whom would you want me to speak to about your care?”
- Leads to natural exploration of role of Substitute Decision Maker (SDM) and need for someone.
Primary care toolkit

- Posters
- Infographics
- Handouts for patients
- Info sheet for providers
- Workbook
- Videos
Let’s talk

• Have you thought about your values and wishes?
• Have you talked with others about your wishes?
• Have you decided on your substitute decision-maker?
Thank you!

It’s about conversations.

It’s about wishes.

It’s how we care for each other.

www.advancecareplanning.ca


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Upcoming webinar

Stay tuned for the next set of webinars to be announced in August
Thank you!