Speak Up Ontario
Train-the-Trainer Workshop

Louise Hanvey RN, BN, MHA
What will we talk about?

- Advance Care Planning 101
  - Why it is important
  - What it is and is not
- The Speak Up Ontario Campaign
  - How it works
  - Available tools
- Facilitating ACP in your Community
Speak Up Ontario

• Partnership:
  • Advance Care Planning in Canada: Canadian Hospice Palliative Care Association
  • Hospice Palliative Care Ontario
  • Provincial End-of-Life Care Network

• Champions
National Project

Advance Care Planning in Canada: National Framework and Implementation

• Is a project of the Canadian Hospice Palliative Care Association

• Overseen by a national Task Group – interprofessional and representing many jurisdictions
Long Term Project Goals

• To raise the awareness of the general public about the importance of advance care planning and to give them the tools they need to do it.

• To prepare professionals/health care providers with the tools they need to facilitate advance care planning with their clients.
Advance Care Planning: Definition

Advance Care Planning is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know what kind of health and personal care you would want in the future if you become incapable of consenting to or refusing treatment or other care.
Advance Care Planning

• A process of reflection and communication
• Communicating wishes – letting others know your future personal and health care wishes
• The consideration of who will speak for you when you are no longer capable of directing your care
Why is ACP Important?

- Our population is aging
- While Canadians are living longer – eventually, we all die
- More Canadians are dying each year
- Most Canadians die of chronic illnesses – and they live with these illnesses for many years before death
Number of people who die each year

- 2010: 259,000
- 2020: 330,000
- 2041: 432,000
Most Canadians die of a chronic illness

- Heart: 35%
- Cancer: 28%
- Lung: 10%
- Other: 27%
Why is ACP Important?

According to a 2012 Ipsos Reid Poll:

• 86% of Ontario adults (18+) have not heard of advance care planning

• less than half (48%) have had a discussion with a family member or friend about their wishes for healthcare treatments if they were ill and unable to communicate

Ipsos Reid Poll, 2012
Why is ACP Important?

• Only 10% of Ontario adults had ever spoken to a healthcare provider about their wishes for care
• Only 48% have chosen a Substitute Decision Maker – someone to speak on their behalf if they could not communicate

Ipsos Reid Poll, 2012
The ACCEPT study is an ongoing Canadian, multi-centre prospective study of current practice related to advance care planning in hospitalized patients at high-risk for dying, and their families.

- Three-quarters of patients had thought about life-sustaining treatments that they may or may not want; 85% had talked to someone about this and 70% had formally designated a substitute decision maker.
The ACCEPT Study

But:

• Only 30% had talked about their wishes with their family doctor

• When admitted to hospital only 25% were asked whether they had had prior discussions about their wishes

Daren K. Heyland, Doris Barwich, Deb Pichora, Peter Dodek, Francois Lamontagne, John J. You, Carolyn Tayler, Pat Porterfield, Tasnim Sinuff, Jessica Simon, for the ACCEPT (Advance Care Planning Evaluation in Elderly Patients) Study Team and the Canadian Researchers at the End of Life Network (CARENET). Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning. JAMA INTERN MED Published Online April 1, 2013
Why is ACP Important?

Individuals who engage in advance care planning 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
- 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
Why is ACP Important?


Central to advance care planning is the conversation – to discuss wishes with family, friends, substitute decision maker(s) and health care providers.
Advance Care Planning: The Concepts of Consent & Capacity

- It is critical to understand the concepts of capacity and consent as they relate to advance care planning.

- Watch the DVDs!

Health Care Consent in Relation to Advance Care Planning
Advance Care Planning: How does someone do it?

• They think about what’s right for them – their values, beliefs
• They learn about end-of-life care options and treatments
• They determine who will make decisions on their behalf
• They begin the conversations – and re-visit it
• They review their plan regularly
• They write it down if that helps them
Advance Care Planning: How does someone do it?

Advance care plan: Can be expressed orally, in writing, or by any alternative means such as through a picture board or computer.
Speak Up

Start the conversation about end-of-life care
Speak Up Ontario

- Initiative to promote and facilitate advance care planning in Ontario

- Resources are available on a web portal with for the public, professionals and community organizations/agencies

- Community of Practice for support and sharing
Website

- Patients and families
- Professionals
- Community organizations/agencies/programs
- Researchers

www.advancecareplanning.ca
Imagine - one day, without warning, you find yourself in a hospital, unable to communicate. Who would speak for you and make health care decisions for you?

Learn more about Advanced Care Planning.

It's Valentine's Day
Share your wishes with others...it's the perfect gift
Download our new Heart to Heart infographic

Advanced Care Planning Webinar
National Advance Care Planning Day: What Works and What Doesn't Work
February 19, 2014 from 1:00pm-2:30pm EST
The objectives of this Webinar are to provide participants with the opportunity to explore what works and doesn't work for providing a successful National Advance Care Planning Day, April 16, 2014.

Register today!
Speak Up Ontario Toolkit

All found at www.advancecareplanning.ca

- ACP Workbook – Ontario Edition
- Slide presentations – for the public and professionals regarding consent and capacity and advance care planning
- Primary care toolkit
- Videos – Speak Up and Conversations
Advance Care Planning Workbook
Ontario Edition

It’s about conversations.
It’s about decisions.
It’s how we care for each other.

www.advancecareplanning.ca
THINK
about what’s right for you.
What’s most important to you about your end-of-life care?

LEARN
about the different medical procedures that can be offered at the end of life. Some may improve your quality of life, others may only prolong life.

CHOOSE
your Substitute Decision Maker. Choose a loved one who is willing and able to speak for you if you can’t speak for yourself.

TALK
about your wishes with your Substitute Decision Maker, loved ones and doctors

RECORD
your end-of-life wishes – write them down, record them or make a video.
Speak Up Ontario Toolkit

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• ACP Workbook – Ontario Edition
• Slide presentations – for the public and professionals – regarding consent and capacity and advance care planning
• Primary care toolkit
• Videos – Speak Up and Conversations
Advance Care Planning in relation to Health Care Consent

Public Information Session

Health Care Consent in relation to Advance Care Planning

Information session for Healthcare Providers
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• Primary care toolkit
• Videos – Speak Up and Conversations
Primary Care Toolkit

- Posters/infographics
- Handouts for patients
- Info sheet for providers
- Info about Power of Attorney for Personal Care
- Template to express wishes

Why should you talk to your patients about advance care planning?

Thinking about my wishes for future health care
Speak Up Ontario Toolkit

All found at www.advancecareplanning.ca

• ACP Workbook – Ontario Edition
• Slide presentations – for the public and professionals
• Primary care toolkit
• Ontario Government resources
• Videos – Speak Up and Conversations
Ontario Resources

A Guide to Advance Care Planning and Wallet Card

Ontario Resources

Form for Power of Attorney for Personal Care in Powers of Attorney Kit

Speak Up Ontario Toolkit

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• Primary care toolkit
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Tools for organizations / associations

• Downloadable or order printed versions
• Templates customizable for logos, event info
• Materials for patients/families, health professionals
• Point of contact materials – posters, Infographics, video loops
• Media resources – news releases, ad templates, newsletter articles
• Access to current research and polls
• Event materials – posters, Infographics, stickers, buttons
• Community of practice for sharing info / best practices/ ideas
Tools for organizations / associations

Speak Up
Start the conversation about end-of-life care

It's about conversations. It's about decisions. It's how we care for each other.

Most of us hope to die peacefully, able to communicate with loved ones until the very end. It doesn't always happen that way. Making your wishes known now helps others who care about you make the right decisions if you can't speak for yourself.

Speak up. Start the conversation about end-of-life care today. Find out more at: www.advancecareplanning.ca

Advance Care Planning
Talk to Your Doctor or Nurse Practitioner

THINK about what's right for you. What's most important to you about your end-of-life care?

LEARN about the advance medical directives that can be offered at the end of life.

Some may increase your quality of life, whereas others may prolong life.

CHOOSE your Substitute Decision Maker. Choose a friend or family member who is willing and able to speak for you if you can't speak for yourself.

TALK with your health care professionals about your Substitute Decision Maker, living wills, and directives.

RECORD your end-of-life wishes. Write them down, record them or talk to a lawyer.

www.advancecareplanning.ca
Toolkits for Professionals

- Videos, Infographics, posters for waiting rooms, offices, etc.
- Tools to support practice
  - Access to current research and polls
  - Workbooks, Quick Guides for patients / families
- FAQs and Decision Aids
“Just Ask” conversation card

- Questions to ask your patients
  - E.g., Have you talked to your SDM (or anyone else) about your wishes or preferences for health care decisions that may come up? May I ask what you discussed?

Questions to ask yourself
- E.g., Did I ask my patient about preferences for end-of-life care?
Other Resources

• Content for newsletters, blogs, editorials
• English/ French spokespeople from ACP Project – health professionals, legal, researchers, etc.
• Participation in webinars, presentations
• Support through social networking
• Profile on website (news/blog/ACP Across Canada)
What can you do?

• Lead by example…do your own ACP
• Inform everyone in your – have staff wear a sticker that says “Ask Me About Advance Care Planning!”
• Exhibit at your main entrance
• Community events / health fairs
• Presentations to community organizations
• Celebrate April 16th – national Advance Care Planning Day
What can you do?

• Sponsor a community event or “town hall” meeting
• Provide a link on your organizational Web site to www.advancecareplanning.ca
• Partner with others in your community – health care organizations, retail businesses, community organizations
• Exhibit tables at your local malls, pharmacies, grocery stores, libraries
• Press releases
• Op Ed, letter to the editor or a feature story

Speak Up
Start the conversation about end-of-life care
What can you do?

- Print advertisements in local newspaper and PSAs
- Provide guest-speaker to radio or TV programs
- Distribute flyers about advance care planning and Speak Up in local physician offices
- Distribute information to patients at health care facilities with their mid-day meal
- Mention ACP day in your organization’s/facility’s telephone on-hold recording
Join the Community of Practice

- Virtual Community of Practice
- Website with opportunity to share resources, communicate, mentor, support
- Teleconferences
- Contact alecoche@hpco.ca
It’s about conversations.
It’s about decisions.
It’s how we care for each other.

www.advancecareplanning.ca