Speak Up: Start the Conversation about End-of-Life Care

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Advance Care Planning in Canada

- Partnership between the CHPCA and CARENET
- Overseen by a national Task Group – interprofessional and representing many jurisdictions
- Funding has come from The GlaxoSmithKline Foundation, the Canadian Partnership Against Cancer, CIHR, Prostate Cancer Canada
- Goals: To raise awareness among the public and professionals and provide them with tools
Focuses on advance care planning

- A **process** of reflection on **values** and **wishes**
- The **communication** of wishes (verbal, written or otherwise) – now 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 (**substitute decision maker**)
Advance care planning...

- Is best viewed as a process, not an event.
- Encourages dialogue, conversations between a person, his/her family, especially his/her substitute decision maker, and the health care team, lawyer.
- Results in sharing of wishes.
- Is not a document/form/check list.
- Is not consent to treatment(s); strictly a refusal of medical treatments.
Palliative and End of Life Trajectories

Cancer Trajectory
- More rapid decline in last months and weeks
- Usually months to years before death
- Last few months to weeks

End-stage Heart or Lung Failure
- Gradual decline over years or months with intermittent crises or serious episodes; more frequent crises & hospitalizations in the last year
- Usually years before death
- Last year

Dementia and Frailty
- Gradual decline over years to months
- Usually years before death
- Months before death

Level of Functioning
- 100% Normal activity
- 50% Mostly sitting or lying down
- 30% Bed bound

Time
- Diagnosis
- Death
Ethical Issues

People weigh issues differently!

- Life itself may be the most important
- Perhaps Autonomy: right to control your body
- Health care providers may need to “do good” (Beneficence) or “avoid harm” (Non-maleficence)
  - But what are the limits?
- Role of Justice?: fairness, treating people equally
- (Resource allocation: the “unspoken issue?”)

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

A capable adult is able to

• Refuse medical treatment
• Request that a treatment be withdrawn
• Provide guidance
  – A “prior expressed capable wish” which must be considered if incapable.
So who is a capable adult?
General Standard

- Capacity is not “all or nothing”
- Capacity depends on the issue/treatment
- Capacity depends on time
  - If people are more capable at some times than others, we need to try to determine wishes at their MOST capable time

Health Care Consent Act Ontario 1996, c. 2, A, s.4(1)
Capacity

• Until the contrary is demonstrated, every adult is presumed to be capable of giving, refusing or revoking consent to health care
• The way a person communicates is not used alone to decide a person is not capable of understanding
• Declaring incapacity limits a fundamental right: control of decisions regarding one’s own body
Capacity

• “The issue ... is not whether the person's actions or choices appear reasonable or will put them at increased risk....

– But whether the individual is able to understand critical information and appreciate the reasonably foreseeable consequences of his or her decisions or lack of them”

Capacity: How do we assess?

Ontario: Health Care Consent Act was designed to **enhance autonomy** by ensuring that those assessed as incapable with regards to Health Care Consent

- Have mechanisms to appeal
- Have the right to be formally represented

- If found incapable, previously wishes expressed while capable are still respected

Health Care (Consent) and Care Facility (Admission) Act 1996, amended 2010 (Government of Ontario 2005)
ACP is about wishes…

- Wishes do not need to be expressed in writing. Wishes may be expressed in any form at any time when the patient is mentally capable.
- Later wishes, however communicated, expressed while capable prevail over earlier wishes.
Consent vs. Wishes

- Under Ontario law, advance care planning is part of the law of informed consent.
- Patient wishes are only relevant where a patient is incapable.
- Patient wishes are interpreted by the SDM – not the health care practitioner.
- Therefore health care professionals must get informed consent (from the person if capable or the SDM(s) if not capable). Consent is related to specific care or treatments(s) offered in relation to a current health condition.
Legal Issues

- Precedents based on individual autonomy
- Capable adults have right to refuse or stop treatment.
- There are special considerations at "edges" of capacity: the young, adults with limitations e.g. dementia
- Substitute Decision Makers held to different standards
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
• 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
Why is focusing on ACP Important?

The ACCEPT Study

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.

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?


Why is focusing on ACP Important?

• The main objective of advance care planning should be to prepare patients and their substitute decision makers to work with their clinicians to make the best possible in-the-moment medical decisions.

Care Consistent with Patient’s Values and Goals

Advance Care Planning
- Conversations about values and wishes
- Appointment of a Substitute Decision Maker

Advance care planning documents
- Care Plans

Decisions about Goals of Care or consent for treatment
- Clarification of previous ACP conversations; values; preferences
- Information re Diagnosis; Prognosis; Risks/benefits of treatment
- Options for care & treatment

Organizational and System Aspects (context specific)

Home or Community Settings

Institutionalized Settings
Advance Care Planning

- Central to advance care planning is the conversation – to discuss wishes with family, friends, substitute decision maker(s) and health care providers.
Speak Up

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

• Initiative to promote and facilitate advance care planning in Ontario
• Tools specific to the Ontario context are available on a web portal with for the public, professionals and community organizations/agencies
• Partnership:
  • Advance Care Planning in Canada: Canadian Hospice Palliative Care Association
  • Hospice Palliative Care Ontario
  • Provincial End-of-Life Care Network
Target Audiences

- Community organizations
- Health care providers
- General public
- Umbrella message focused on the conversation
Website

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

www.advancecareplanning.ca
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
ACP Workbook – The Process

- They think about what’s right for them – their values, beliefs, goals
- They learn about healthcare options and medical procedures
- They determine who will be their substitute decision maker(s)
- They begin the conversations – and write down or record their wishes, if they wish.
- They review their wishes/plan regularly and continue the conversations
Substitute Decision Maker

- Who do you feel would be most capable of honouring your wishes and making decisions on your behalf? (i.e., spouse, trusted family member, good friend)
- You can appoint through a Power of Attorney for Personal Care
- If no one is appointed: Hierarchy of SDM(s) is set out by law
“Just Ask” conversation card

- Questions to ask your patients
  - What do you understand about your illness or what’s happening to you?
  - Do you have an advance care plan? Do you know what I mean by these terms?
  - 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
  - Did I ask my patient about preferences for end-of-life care?
  - Do I know who to contact if the patient cannot communicate their wishes?
Primary Care Toolkit

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

Talk to your doctor or nurse practitioner about Advance Care Planning

What would happen if you were sick or injured and could not tell doctors what kind of care you wanted?

Who would speak for you and make decisions for you?

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

Thinking about my wishes for future health care

Speak Up
Raising Awareness

- Social media
- Media engagement
- Seasonal campaigns
- Infographics
- Videos
- Blogs, PSAs, templates
- PSAs
50% of Canadians have *never talked* to family and friends about what they’d want if they were ill and couldn’t speak for themselves.

- When it comes to talking about the end of life, most of us freak out and run for the hills. Nothing’s more uncomfortable than a *conversation about dying*.
- But *100%* of us will die. So what’s the use of *avoiding* the topic?
- It’s time to take your head out of the sand and talk about your end-of-life wishes.
Decisional Conflict

“The uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret or challenge to personal life values”

O’Connor, 1997
Help reduce the conflict...

- At a time of stress and loss, understanding a loved one's wishes and values is critical to guiding decision making. Knowledge of these issues will help reduce the uncertainty.
Questions? Comments?

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

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An “ethical grid” to assist in decision making

<table>
<thead>
<tr>
<th>Medical Considerations</th>
<th>Patient (and Family) Factors and Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facts of the medical history</td>
<td>Patient/family understanding of illness</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Patient capacity to make decisions</td>
</tr>
<tr>
<td>Treatment options, risks vs. benefits</td>
<td>Patient goals</td>
</tr>
<tr>
<td>Are treatments being considered consistent with goals of care?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality of Life Issues</th>
<th>Contextual Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does quality of life mean for the patient (and family)?</td>
<td>Whose interests are affected?</td>
</tr>
<tr>
<td>What gives meaning and brings dignity to their life?</td>
<td>What are societal norms and expectations?</td>
</tr>
<tr>
<td></td>
<td>What are the thoughts of the caregivers?</td>
</tr>
</tbody>
</table>
Mrs. Unreachable

- 87 year old lady – living in RH
- Suffering from severe dementia
- Suffering from difficulty swallowing (progressive over years)
- Experiencing repetitive pneumonias requiring hospital admissions
- At the last admission, a referral to palliative care consultation service to assist the family and the primary care team with goals of care
- Three children – one in Ottawa, one in Ottawa but not involved, one out of town
- No power of attorney in place
Patient’s point of view

Family’s point of view

Common point of view

Common ground

Family’s point of view

Patient’s point of view

Dialogue

Not that simple!!!
The problem???

One family member's point of view

Other family members' point of view

Who decides?
Mrs. Dance

- 86 year old woman with one son
- Severe COPD
- Lived in LTC facility for 2 years
- Frequent visits to the emergency room for recurrent pulmonary infections

Problem:
- Mrs Dance wants to be admitted to the Palliative Care Unit as she is tired to live.
- She wants to be in an environment where she could wait to death to come...
The problem???

My point of view

The other's point of view
My point of view

The other's point of view

Common point of view

Common ground

Dialogue
Decision Making

Clarify the problem

Factors influencing the decision

Patient, Family, Team

Legal factors

Cultural Context

Patient/family Experience

Patient as person

Team

Disease

Latimer, 2005
Mr Right

- 83 year old man
- Just diagnosed with mild dementia
- Still competent
- Discussed ACP with family

Mr Right named his daughter as POA as he knew very well that his wife would not be able to fulfill his wishes.