Canadian Home Care Association
canadienne de soins et services à domicile

Advancing Excellence in Home Care

KNOWLEDGE NETWORK
Building Capacity... Improving Performance

VIRTUAL LEARNING SERIES

The INSPIRED COPD™ Outreach Program

An INSPIRED palliative approach to care for patients and families living with respiratory disease.

About the Canadian Home Care Association's Virtual Learning Series

The aim of the virtual learning series is to improve the capabilities of individuals and organizations across the home and community care sector.

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ADVANCING OPERATIONAL EXCELLENCE IN HOME-BASED PALLIATIVE CARE

Jeanne Bank
Project Specialist
Canadian Home Care Association

Advancing Operational Excellence in Home-Based Palliative Care

Update on CHCA Project

Showcasing: **The INSPIRED COPD outreach program**

An INSPIRED palliative approach to care

Jeanne Bank, Project Specialist, CHCA

July 9, 2019

Project Overview

Purpose:

To explore opportunities for operational process improvement in home-based palliative care, specifically in:

1. assessment and care planning
2. inclusion of advanced care plans and service delivery
3. effective communication strategies and tactics
4. management of equipment, supplies and medications

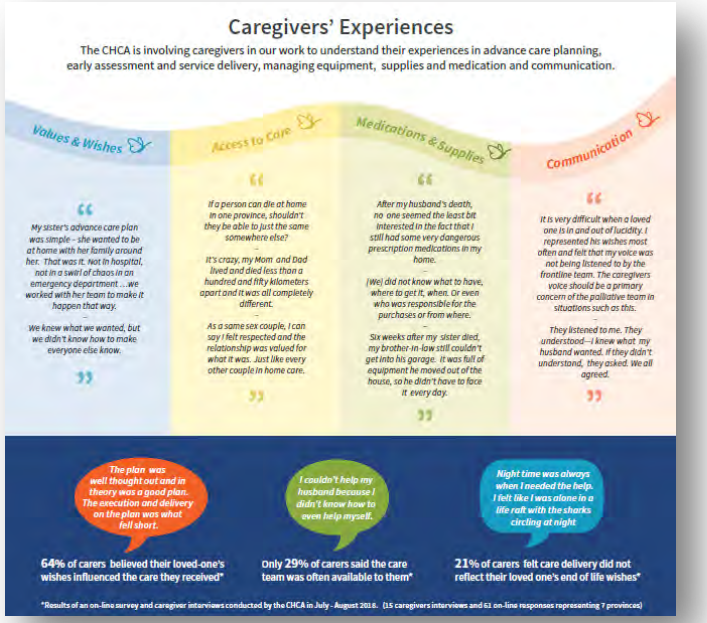
Project Activities

- Multi-phased engagement process
  - One-on-one interviews with caregivers and patients
  - Discussions with key informants
  - Interviews with cultural group representatives
  - Four invitational expert consultations (BC, AB, PEI, ON)
  - Online survey of caregivers, patients, providers
  - Validation of priority areas for improvement (e-Delphi)

- Understanding palliative care experiences
  - Assessment and care planning
  - Inclusion of advanced care wishes into service delivery
  - Effective communication within a palliative care team
  - Access, manage and dispose of equipment, supplies and medications

Project Outcomes – Caregivers Experiences

- “We knew what we wanted, but we didn’t know how to make everyone else know.”
- “Night time was always when I needed the help. I felt like I was alone in a life raft with the sharks circling at night.”
- “After my husband’s death, no one seemed the least bit interested in the fact that I still had some very dangerous prescription medications in my home.”
- 15 caregivers shared their personal experiences - 61 on-line responses



Advance Care Planning
Key gaps and opportunities

- Early and ongoing conversations about end of life wishes and values
  - Lack of skills, comfort and time for end-of-life conversations
- Understand and consistently communicate end of life wishes
  - Inconsistent access to and use of tools, documentation
- Documentation (care plan and legal requirements) reflect wishes and values
  - Knowing if patients wishes are followed

Assessment and Care Delivery
Key gaps and opportunities

- Palliative approach to care in identifying and responding to patient needs
  - Assessment tools and service eligibility
- Involve patients, caregivers and providers in developing and updating care plans
  - Lack of shared decision-making *“nothing about me, without me”*
- Understand and use assessment tools early in the process
  - Lack of recognition and inclusion of family / caregiver needs

Communications
Key gaps and opportunities

- Know and communicate with all team members
  - Lack of understanding of who to communicate with and how
- Consistently communicate changes in the patient's condition and needs
  - Inconsistent and incomplete information sharing
- Communicate with patients, family and caregivers in a manner that is appropriate, timely and practical
  - Information overload – materials not designed for patient and caregiver

Management of Equipment, Supplies & Medications

Key gaps and opportunities

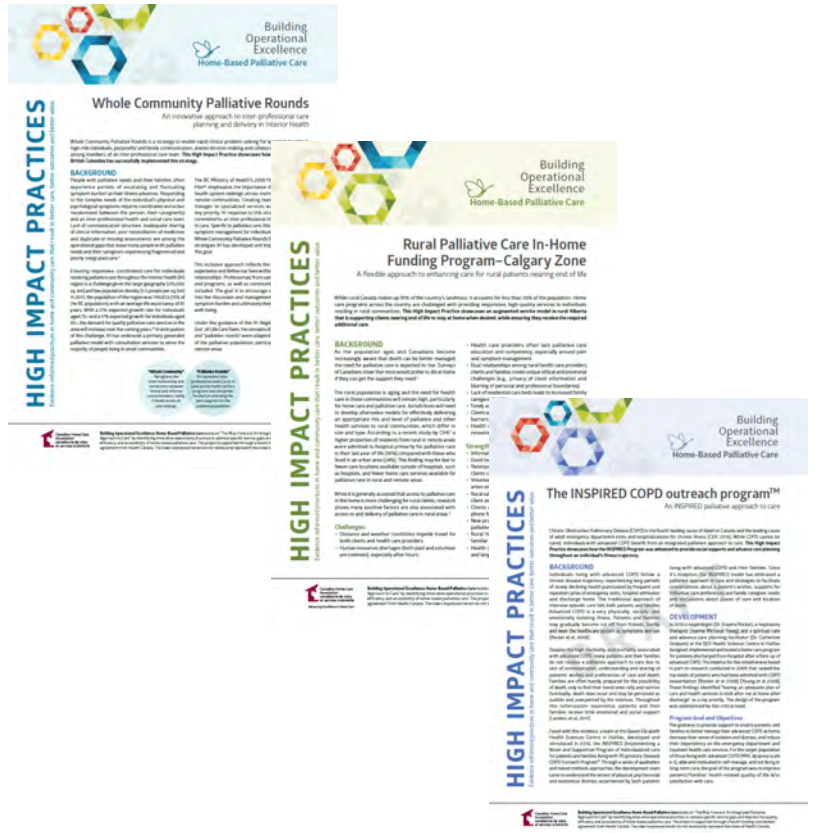
- Know and communicate with all team members
  - Lack of understanding of who to communicate with and how
- Consistently communicate changes in the patient's condition and needs
  - Inconsistent and incomplete information sharing
- Communicate with patients, family and caregivers in a manner that is appropriate, timely and practical
  - Information overload – materials not designed for patient and caregiver

Project Status & Next steps

- Palliative Care Experience Maps developed to share the stories and show opportunities for innovation
- 5 projects have been identified to showcase as High Impact Practices (HIPs) and will be published this summer. These 5 were identified at 2018 Home Care Summit 2018 and selected by panel of home care leaders
- SPRINT Implementation Collaborative
  - 7-month Implementation Collaborative to support teams in testing, adapting and implementing one of the profiled innovations, ***Whole Community Palliative Rounds***
- Development of Implementation Framework and User Guide to help organizations put HIPs into practice

Project Outcomes – High Impact Practices

- **Whole Community Palliative Rounds**: An innovative approach to inter-professional care planning and delivery in Interior Health
- **Rural Palliative Care In-Home Funding Program–Calgary Zone:** A flexible approach to enhancing care for rural patients nearing end of life
- **The INSPIRED COPD Outreach Program™:** Role of the Advance Care Planning Facilitator
- **Virtual Palliative Care:** Right Patient, Right Time, Right Place, Right Care
- **IPACE:** Integrating a Palliative Approach to Care by Having Conversations Early



For more information:

Dedicated webpage on CHCA website

www.homecarekn.ca/operational-innovations

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Darcy Gillis
CASC Certified Spiritual Care Practitioner and Advance Care Planning Facilitator
Nova Scotia Health Authority

Andrew Comstock
Registered Social Worker and Advance Care Planning Facilitator
Nova Scotia Health Authority

Advance Care Planning with the INSPIRED COPD Outreach Program

Darcy Gillis, SCP and Andrew Comstock, MSW
Advance Care Planning Facilitators
Halifax, NS

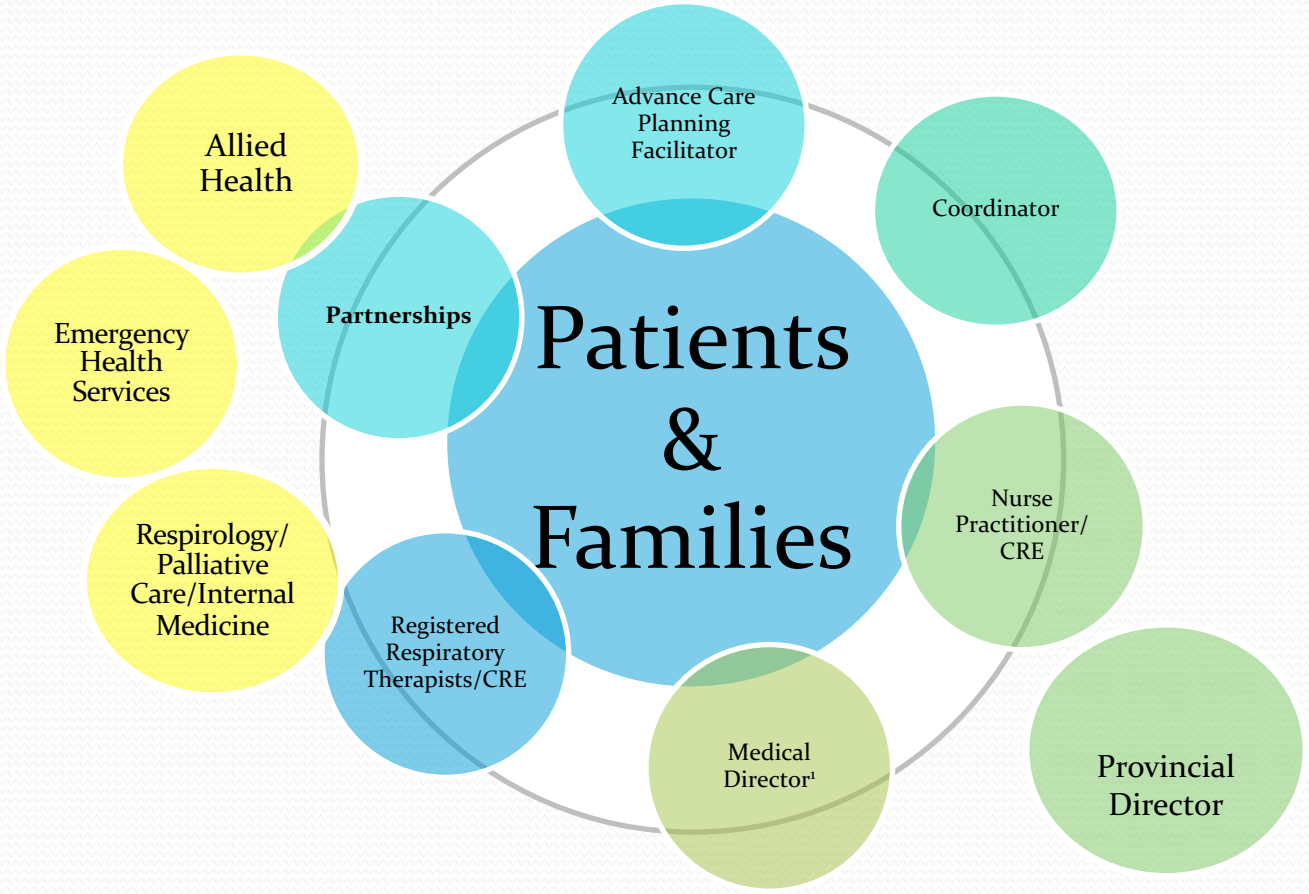
INSPIRED COPD Outreach Program™

Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease

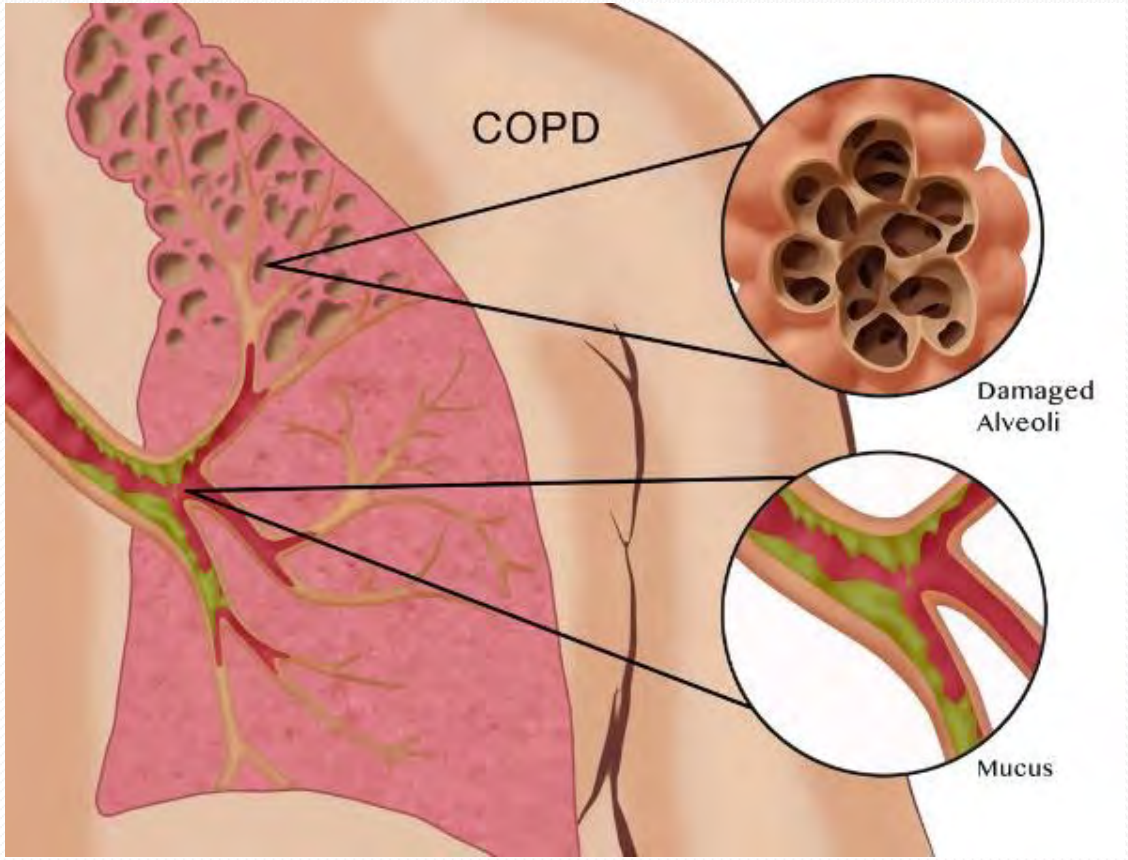
- ✓ Hospital-to-home care, early discharge, transition support
- ✓ Self-management support: home-based education based on need (patient and family focused)
- ✓ Written action plans (per CTS*) for COPD exacerbations
- ✓ In-home psychosocial/spiritual needs assessment and support, and advance care planning

*Canadian Thoracic Society

INSPIRED Team



Chronic Obstructive Pulmonary Disease



The burden of COPD

- Fatigue
- Breathlessness
- Anxiety & depression
- Panic & fear
- Muscle wasting & weakness
- Weight loss
- Financial & relationship burden
- Isolation &loneliness
- Grief from loss of independence
- Guilt, shame, stigma

COPD in Canada

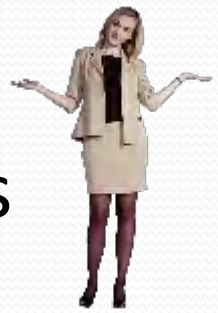
1st

Cause of hospital admissions among chronic illness

4th

Leading cause of death

1 in 4
>35yrs



In Ontario,

12%

of population,

24%

hospital admissions

$750,000,000

annually in healthcare costs

Gershon et al. (2010); CIHI (2008); Mittman et al. (2008)

Why INSPIRED?

- Supports QOL of patients with advanced COPD by:
  - minimizing time in hospital
  - keeping patients at home where requested and where possible
  - improve knowledge and self management of COPD
  - Providing opportunity to prepare for death through ACP
- Demonstrates positive economic impact

Outcomes

Indicator	Results	Period
ER visits	↓ 58%	12 mo.
Hospital admissions	↓ 62%	12 mo.
Bed Days	↓ 60%	12 mo.
% of Home Deaths	38% compared with Nova Scotia average of 8.3%	Over 4 years
PersonalDirectives completed	74% completion rate	Over 1 year

Economic Implications (Nova Scotia)

In **5 years** and reaching **170 Nova Scotians annually** (of the ~33,000 living with COPD):

Preventing	Saving
2,000 ED visits	$2.3 million
1,300 hospitalizations	$19 million
11,900 bed days	
Net Benefit:	**$20 million**

RA | RiskAnalytica $1 invested yields $21 in savings

ACP Facilitator Role

- Provide psycho/social/spiritual support to patients and family members
  - Spiritual Care, Social Work etc.
- ACP facilitation
- Connect patients and family members to additional resources that might be applicable
- Conduct workshops on ACP for other programs (Rehab, Community Health Teams)
- Participate in evaluation of program

Advance Care Planning

- A process whereby a person, often in consultation with his/her family and attending health care providers, thinks about and makes decisions about her/his future personal care

ACP Process

- Reflection
- Discussion with loved ones
- Consultation with healthcare providers
- Decisions
- Communication verbally or written

Personal Directive

- A legal document in which a capable person describes how personal care decisions are to be made in the event that she/he is no longer capable of making these decisions on his/her own
- Completion rates:
  - INSPIRED - typically in the 70-80% range
  - General public-roughly 13%

First Visit

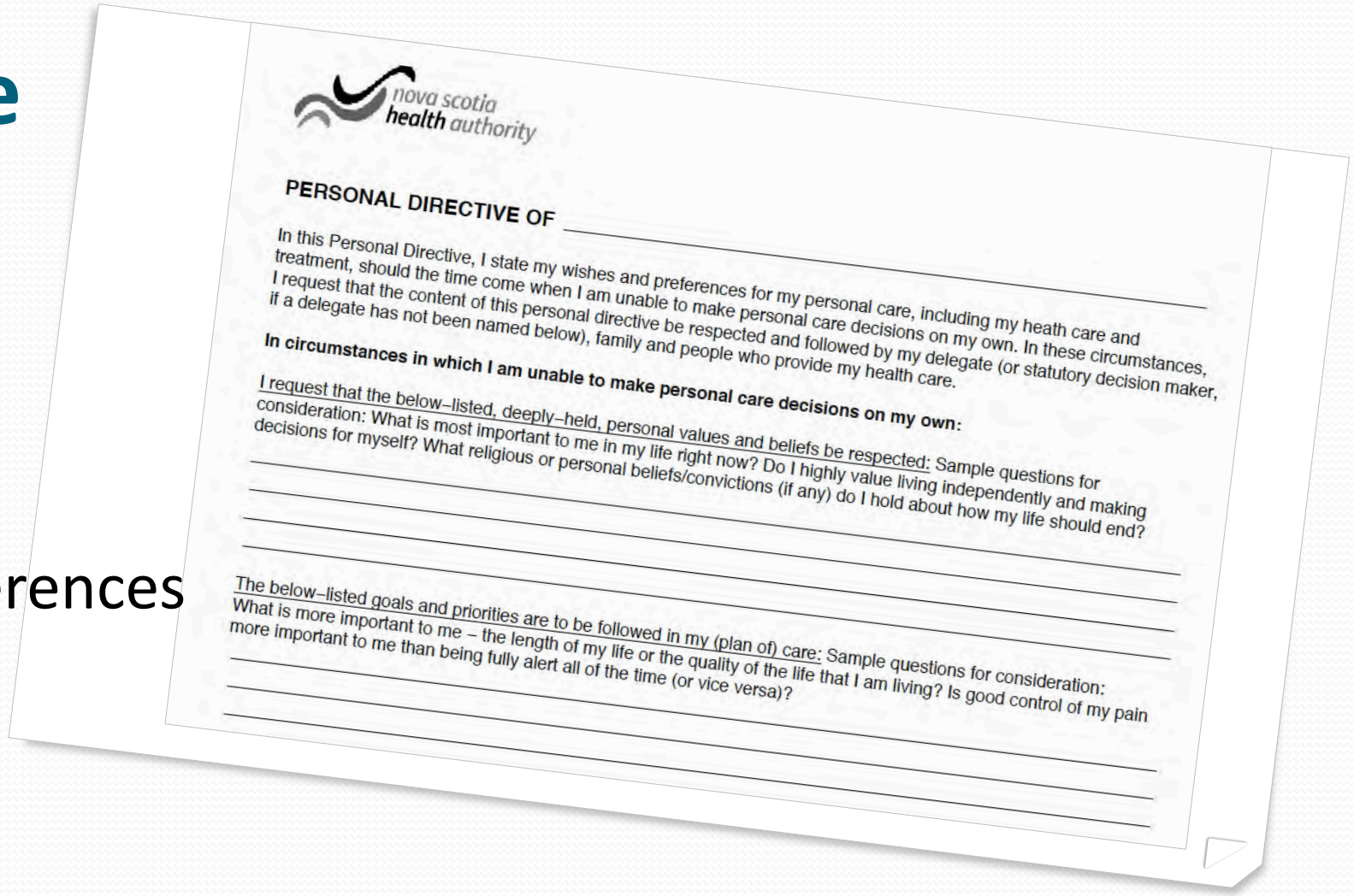
- Focus on assessment/care
  - Build therapeutic relationship
  - Agenda is to listen and support
- Introduce advance care planning
  - Use individual story to make applicable
  - Assess readiness
- Verbal and written information given
  - New booklet
- Encourage discussion with loved ones and health practitioners

Second Visit

- Encourage delegate/family presence
- Patient-driven with delegate/family input
- Respect for time needed
- Interview style
  - Patient reflects and we mirror back

NSHA Directive

- 6 open questions
- QOL
- Goals
- Treatments
- Personal Care preferences
- Delegates



nova scotia health authority

PERSONAL DIRECTIVE OF _____

In this Personal Directive, I state my wishes and preferences for my personal care, including my heath care and treatment, should the time come when I am unable to make personal care decisions on my own. In these circumstances, I request that the content of this personal directive be respected and followed by my delegate (or statutory decision maker, if a delegate has not been named below), family and people who provide my health care.

In circumstances in which I am unable to make personal care decisions on my own:

I request that the below–listed, deeply–held, personal values and beliefs be respected: Sample questions for consideration: What is most important to me in my life right now? Do I highly value living independently and making decisions for myself? What religious or personal beliefs/convictions (if any) do I hold about how my life should end?

The below–listed goals and priorities are to be followed in my (plan of) care: Sample questions for consideration: What is more important to me – the length of my life or the quality of the life that I am living? Is good control of my pain more important to me than being fully alert all of the time (or vice versa)?

Follow-up

- Distribute PDs
  - Electronic record, healthcare practitioner, delegate/s and loved ones
- Offer further coping support or resources as needed
- Offer facilitation of updating PD anytime going forward

Benefits

- Wishes known and more likely followed
- Legal document
- Less ethical/emotional distress for family and healthcare team
- Encourages greater communication between loved ones
  - Allows preparation for death
- Better allocation of resources
- Die with greater dignity

Case Scenario

- 70 y/o female with very severe COPD and is on O2 (last six years). Severe allergies.

- **Social Hx**: Husband died 30 years ago. Two daughters… close with one of them. Grand daughter is a dart champion. Brother in Ottawa who is dying of prostate cancer. Best friend lives in the valley. Her father was an engineer.

- Homecare comes in five days a week. Has assistance with her with iADLs.

- Low autonomy… relatively safe, but lacks reason for living.
- Social isolation.
- Asked about MAiD.
- Advance Care Planning.
- Grief support… relationship building.
- Follow up and support

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Q & A Session

Webinar participants – please post questions for our speakers in the 'Questions and Comments' chat pod to the left of the presentation.

Please tell us who your question should be directed to.

Darcy Gillis

Andrew Comstock

Thank you for joining us.

Please take a moment to complete the 5-minute survey immediately following the webinar.

Your feedback is important to help us improve viewer experience and develop future webinars.