THE WAY FORWARD | ALLER DE L'AVANT

Moving Towards an Integrated Palliative Approach to Care in Canada

Quality End of Life Care Coalition of Canada
January 24, 2013
Sharon Baxter, Executive Director, CHPCA
Leanne Kitchen Clarke, Project Manager

AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE

Agenda for today

- Welcome and introductions
- About The Way Forward
- The National Framework
- Outreach, tools and resources
- Member engagement opportunities
- Wrap up and next steps

Goals for our meeting

By the end of the meeting:

- Understand The Way Forward and what progress has been made to date
- Provide feedback on the working draft of the National Framework
- Get engaged in the initiative and identify opportunities for action

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The Way Forward

Background and context

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About The Way Forward

- Background
- The current environment
- The palliative approach
- *The Way Forward*
- Shaping the National Framework to support an integrated palliative approach to care

From the Blueprint for Action

- QELCCC's Blueprint for Action 2010-2020 identified the following priority:
  - Ensure all Canadians have access to high-quality hospice palliative and end of life care.
    - Establish a multi-sectoral task force or working group that crosses health and social services (e.g., health, education, finance, human resources, First Nations, veterans, and non-governmental organizations, such as unions and insurance associations), whose role is to consult with communities and make recommendations to advance hospice palliative end-of-life care.

Funding

- *The Way Forward* is a three-year initiative being led by the Quality End-of-Life Care Coalition of Canada and managed by the Canadian Hospice Palliative Care Association.
- Funded through a 2011 federal budget commitment from the Government of Canada.
- Announced by Ministers Leona Aglukkaq and Alice Wong in June 2012.

Government of Canada / Gouvernement du Canada

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Quality End-of-Life Care Coalition of Canada
La Coalition pour des soins de fin de vie de qualité du Canada

The initiative

QELCCC Blueprint for Action 2010-2020

Ensure all Canadians have access to high quality hospice palliative end-of-life care

Discussion documents:

- Scope out current landscape, issues and opportunities related to HPC.
- seed the dialogue amongst stakeholders
- determine what needs to be considered to achieve the objectives of the Integration Initiative.

National Framework for Action

Review and revise

Stakeholder Input and Support

Feedback and guidance

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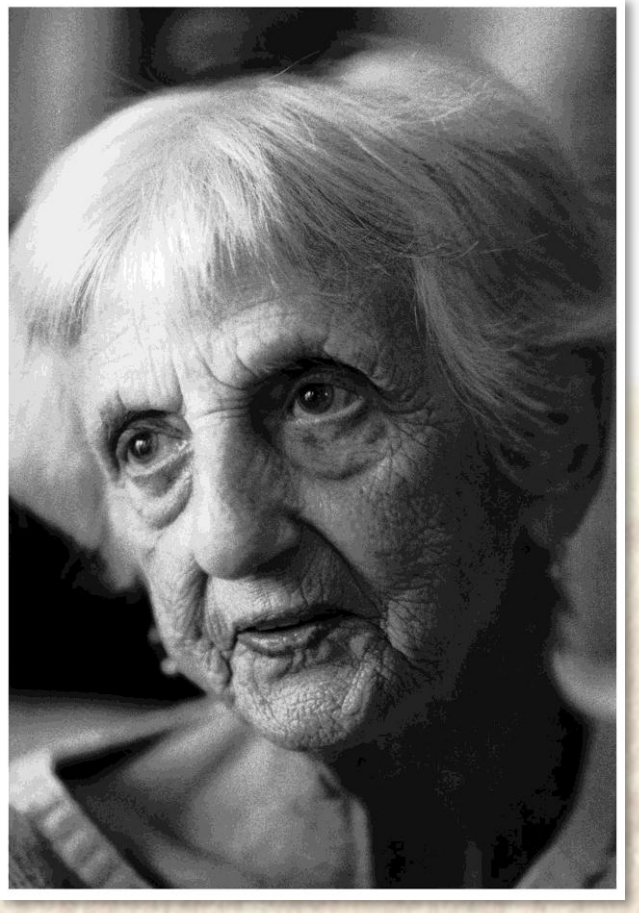
Advisory committee

- **Sharon Baxter**, Executive Director, Canadian Hospice Palliative Care Association
- **Srini Chary**,**MD**, Medical Director; Palliative Care Services, University of Calgary, Pallium Foundation
- **Bobbi Greenberg**, former Director, Communications, ALS Society of Canada
- **Nadine Henningsen**, BSc., Executive Director, Canadian Home Care Association; President, Canadian Caregiver Coalition
- **Melody Isinger**, Ph.D., Ethicist, Canadian Medical Association
- **Julie Lachance**, Senior Policy Analyst, Continuing Care Unit, Chronic and Continuing Care Division, Health Care Programmes and Policy Directorate, Strategic Policy Branch, Health Canada
- **Irene Nicoll**, Person-Centered Care, Canadian Partnership Against Cancer
- **Doreen Oneschuk**, MD, past-President, The Canadian Society of Palliative Care Physicians, Associate Professor, Division Palliative Medicine, Department of Oncology, University of Alberta
- **Denise Page,** Senior Health Policy Analyst, National Public Issues Office, Canadian Cancer Society

Current environment: The changing face of dying

- 30% of the population >65
- 65% of Canadians who died last year were not designated as "dying"
- 2/3 will die with 2 or more chronic diseases after months or years in state of "vulnerable frailty"
- Only 20% of us will die with a recognizable terminal ("palliative") phase



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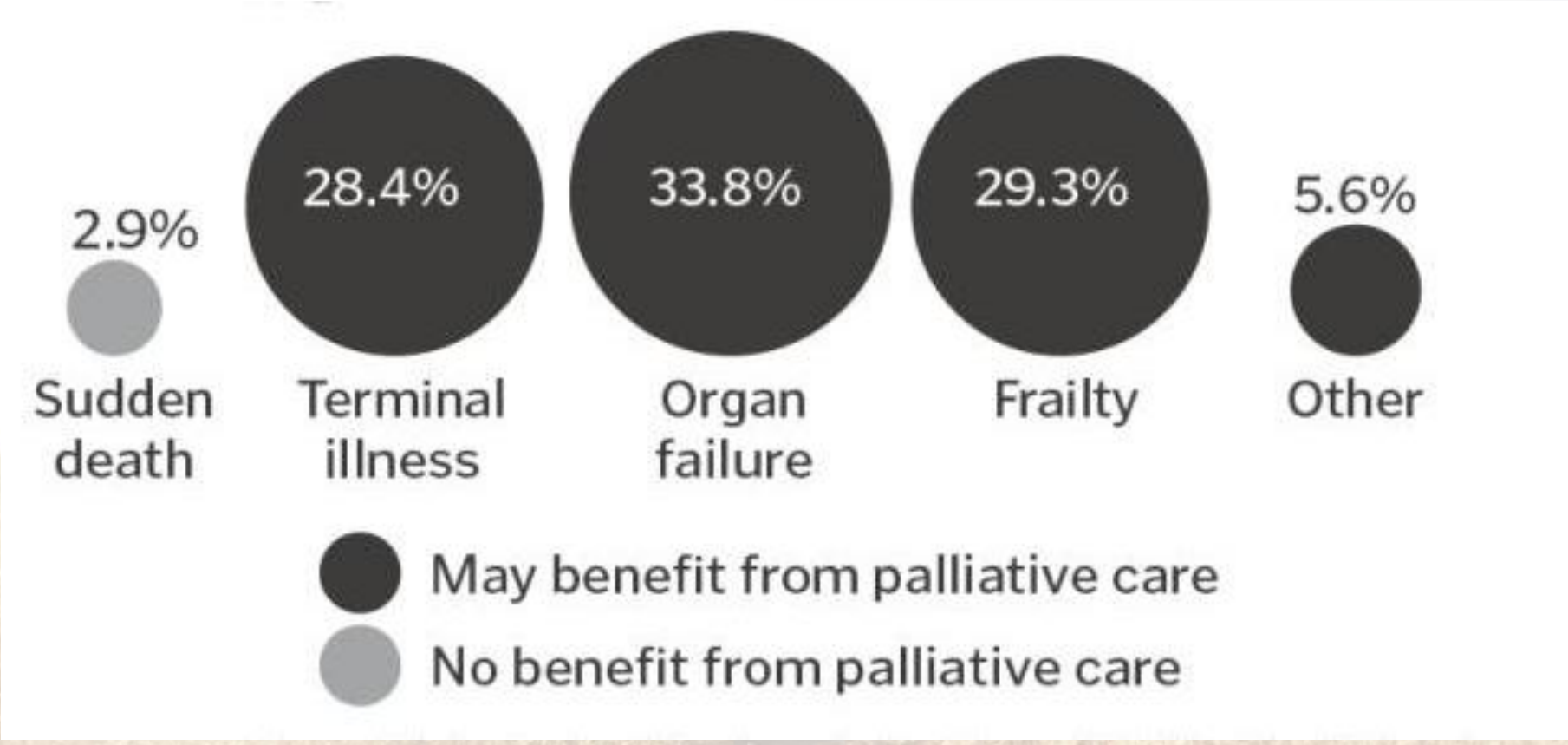
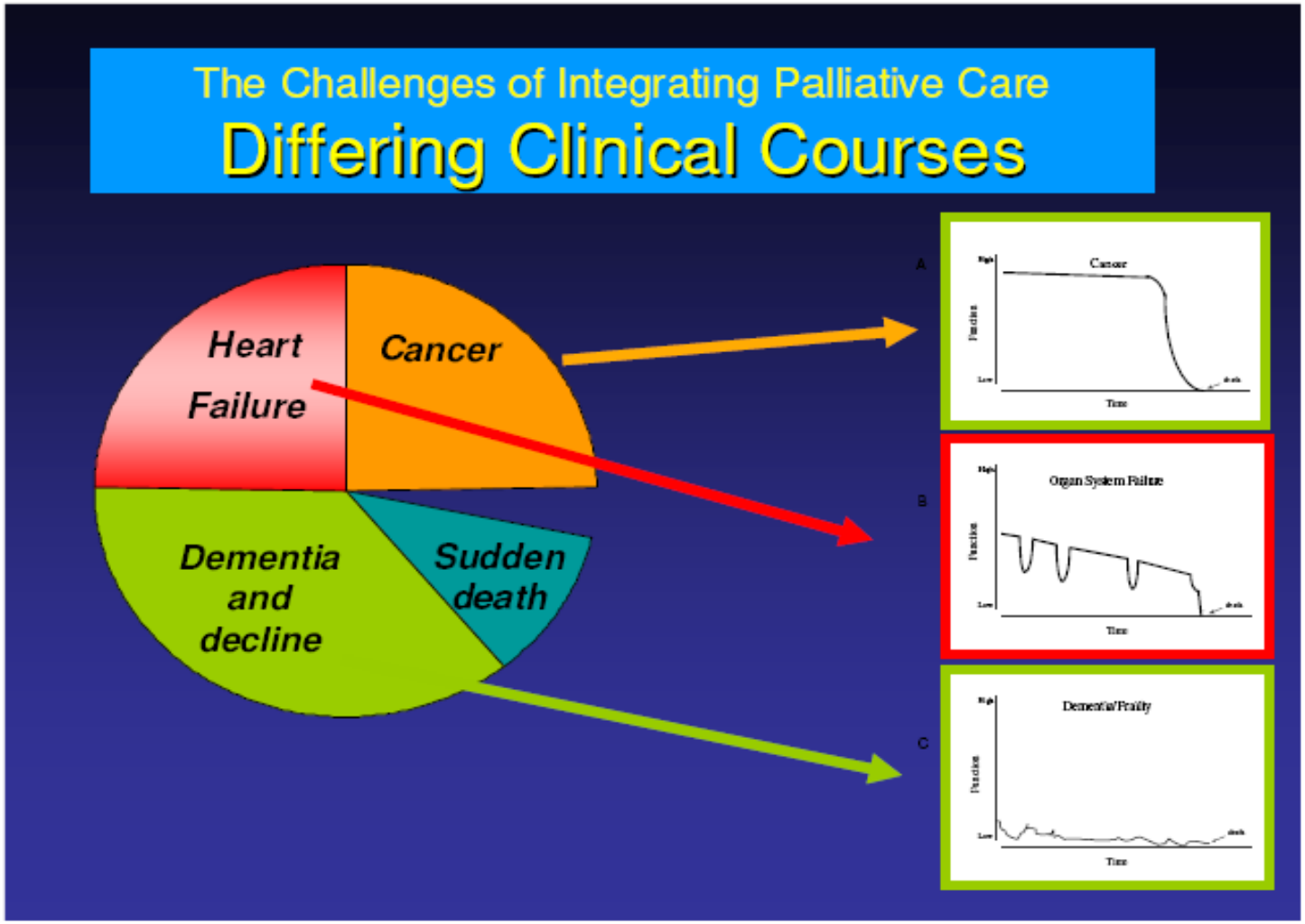
Current environment: causes of death



Palliative Care in Canada. Based on data from the Canadian Institutes of Health Information (2007). Health Care use at the End of Life in Western Canada. Available at: http://secure.cihi.ca/cihiweb/products/end_of_life_report_aug07_e.pdf

Current environment



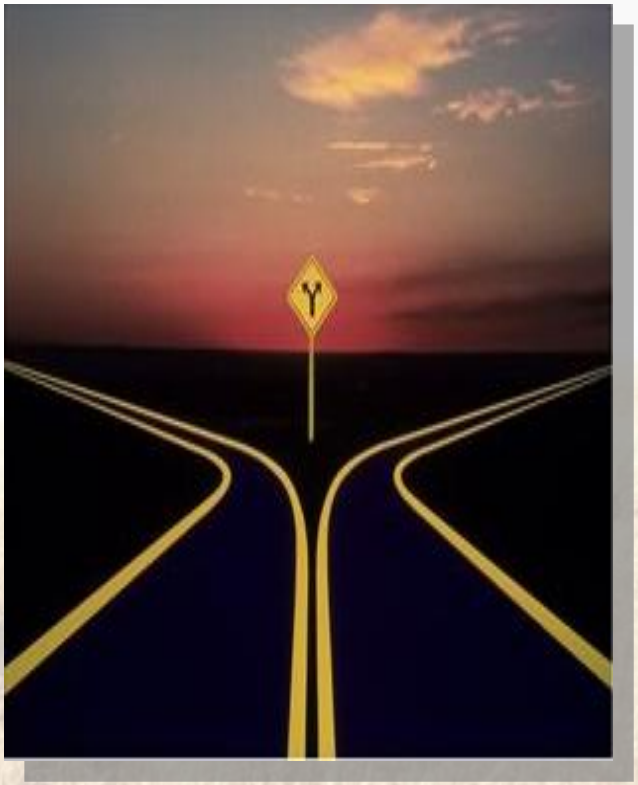
Current environment: ambiguous dying

There will not be a distinct terminal phase.
The week we die will start out like any other,
and some unpredictable calamity will occur.
Amongst those of us with advanced heart failure (for example),
we will have had a 50-50 chance to live for six months
on the day before we died.

Joanne Lynn:
Sick to Death and Not Going to Take it Anymore (2004)

Current environment

- **Hospice palliative care is**:
  - equated with a service / program
  - associated with last months/weeks of life
  - equated with specialized care
- Yet, most people will die:
  - without specialized services or specialized nursing care
  - without a defined time before an expected death
  - never identified as on the 'palliative care road'.



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Where Canadians die

Despite the fact that most Canadians would prefer to die at home,
surrounded by their loved ones,
in 2000, 75% were dying in hospitals or long-term care homes.

Quality End-of-Life Care Coalition of Canada,
Blueprint for Action 2010-2020

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What is an Integrated Palliative Approach to Care?

A few definitions

- An integrated palliative approach to care is about allowing people to live well until dying.
- It's about having earlier, frequent and honest conversations about living with a chronic or life-limiting/threatening illness.
- It's about a person and their families discussing their goals of care, and revisiting them at points in time.
- It takes the principles from hospice palliative care programs and services, and applies them across settings of care:
  - Multi-disciplinary care
  - Pain and symptom management
  - Psychosocial support

Describing a palliative approach

- **A palliative approach** — An approach to care focused on improving the quality of life of persons with life-limiting conditions, and their families. It is provided in all health care settings. It involves physical, psychological, social and spiritual care. The palliative approach is not delayed until the end stages of an illness but is applied earlier to provide active comfort-focused care and a positive approach to reducing suffering. It also promotes understanding of loss and bereavement.
- Specialized palliative units and hospices are essential for end of life care but not appropriate for all persons facing life-limiting chronic conditions. By offering a palliative approach in multiple settings, we can better care for people and their families through the many transitions of chronic conditions like dementia, lung, kidney and heart diseases, and cancer.

www. iPanel.ca, 2012

Integrating a palliative care approach ...

- Concurrent palliative and disease modifying care.
- Advance Care Planning and person and family-centered decision making.
- "Sick enough to die" rather than "certain to die".

Melanie Merriman PH.D. MBA
NHPCO Conference Fall 2003

Palliative care approach

- A palliative approach to care would make certain aspects of palliative care available to people and families at appropriate times throughout the illness trajectory, not just at the end of life.

The Palliative Approach: Improving Care for Canadians with Life-Limiting Illnesses, The Way Forward, Bacon, 2012

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Following diagnosis of chronic, life-threatening illness

- After diagnosis and in the early stages of the illness, the palliative care approach focuses primarily on:
  - Open and sensitive communication about the person's prognosis and illness trajectory, including any changes they may have to make in their lives, such as limiting certain activities;
  - Advance care planning, including discussing the range of treatments available and setting goals of care;
  - Psychosocial and spiritual support to help individuals and families struggling with any issues related to the illness;
  - Any pain or symptom management that may be required.

Later stage illness

- At later stages of the illness, a palliative approach to care focuses more on:
  - Reviewing the person's goals of care and adjusting care strategies to reflect any changes in those goals;
  - Ongoing psychosocial support for individuals and families;
  - Pain and symptom management;
  - If and when to engage specialized palliative care providers, (such as for people and families with challenging physical, psychosocial, or spiritual symptoms, conflicts over goals of care or decision making, family distress).

You can have a palliative approach to care, with a curative intent.

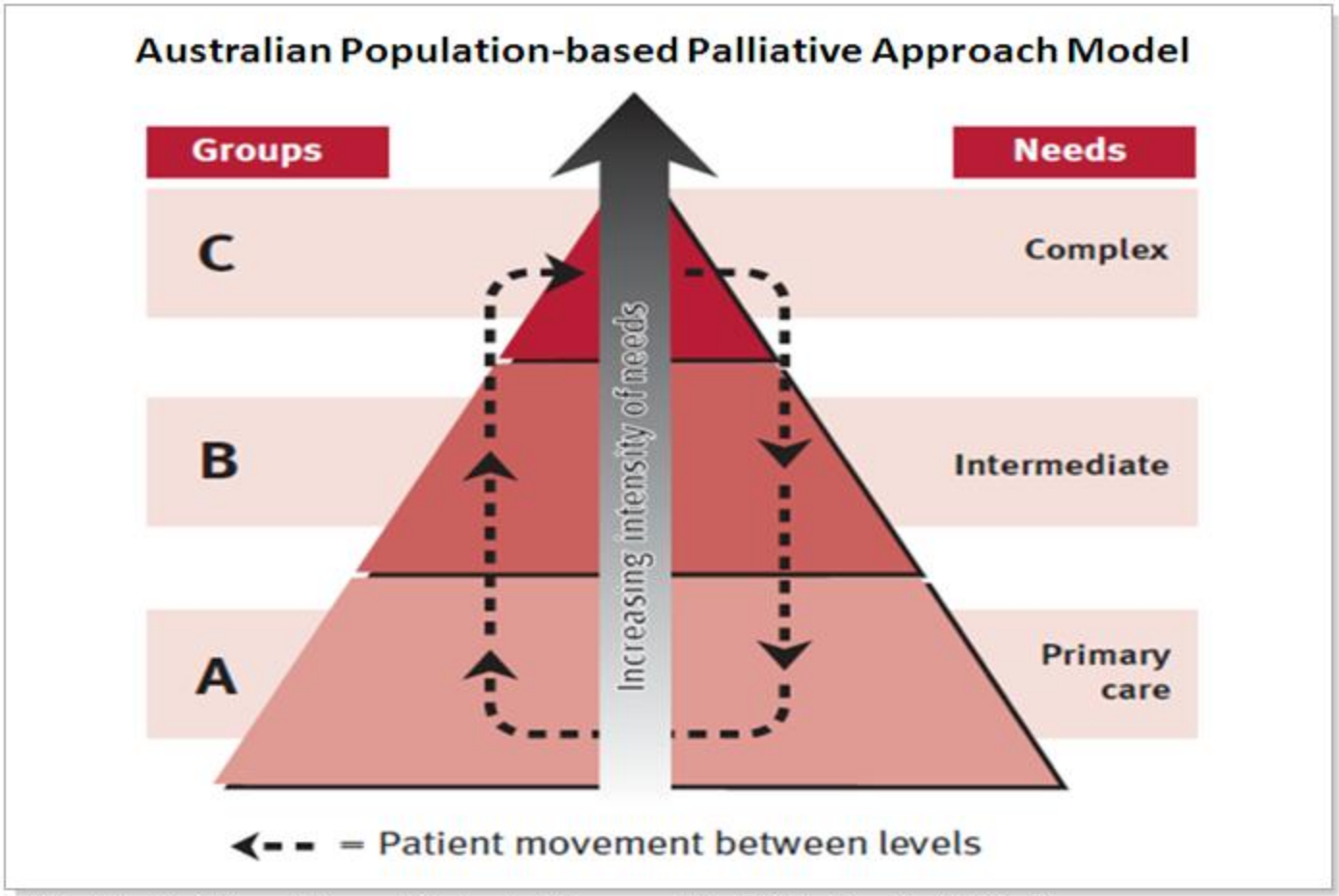

Exhibit 1. Original Australian model for population-based palliative approach [see Palliative Care Australia 2005, p13]

Who will benefit from a palliative approach to care?

CASE STUDIES

Case study: Chronic Heart Failure—Home Care

- John is 67 with advanced heart disease.
- Has had several heart attacks in the last 2 years. Each time he was "sick enough to die". His prognosis might be days or years … impossible to know.
- He lives at home with his 2nd wife, who is very supportive. Both have children from previous marriages.

Case study: Chronic Heart Failure—Home Care

- John recovered from each event, but with reduced heart function each time.
- Is now quite weak, unsteady, and suffers shortness of breath, fatigue and frequent chest pains.
- Sees himself as a "survivor" but knows that could change.
- How could a palliative approach benefit John and his family?

Case study: Dementia

- Vera, 75yrs, was a proficient bookkeeper.
- She has 4 children and several grandchildren. She has always been close with family and involved in community activities.
- She began having trouble with words, memory, and angry outbursts. She was diagnosed with dementia.
- Bob, her husband and caregiver for the last 3 years, wants to care for her at home for as long as possible.
- She still loves short walks and listening to music.

Case study: Dementia

- 6 months ago, Vera started losing weight, was bloated and constipated. She also developed abdominal pain.
- Bob took her to her family doctor who diagnosed her with metastasized ovarian cancer.
- Bob was told there was little to be done because she has dementia.

What thoughts are running through your mind? How might a Palliative Approach help Vera and Bob? What can be done to help them?

… a palliative approach

- takes the principles of palliative care and applies them to the care of people with life-limiting chronic conditions
- does not link the provision of care too closely with prognosis
- broadly focuses on early conversations with patients/families about their needs/wishes and repeats them at times of transitions

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What differentiates or has a greater degree of emphasis in a palliative approach versus palliative care?

- Living with uncertainty having a life limiting illness
- Self care
- Advance care planning early and ongoing
- Journeying through transitions
- Networking with communities to increase support for patient and loved ones

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How can we integrate a palliative approach for those with life-limiting illness?

The Way Forward

- The integrated palliative approach to care that could apply in these case studies is happening in pockets across the country.
- It has significant health, quality-of-life and economic benefits for individuals, families and the health system.
- How can we do it?

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The Way Forward

We can do it through a Framework that sees a palliative approach to care integrated into:

- all care settings: hospitals, long-term/continuing care, primary care, individuals homes, shelters.
- all programs: cardiac care, renal care, dementia care.
- educational curricula: for professionals across settings of care.

The Way Forward

- The goal is to create a practical, person- and family-centred framework for community-integrated palliative care:
  - Informed by dialogue with key stakeholders
  - For all Canadians – rural, urban, remote
  - Culturally-responsive to the needs of First Nation, Inuit and Métis populations
  - Roadmap for action and implementation

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The Way Forward

- The initiative will address two key objectives:
  - To change the understanding and approaches to aging among key stakeholders as it relates to:
    - chronic, serious and life-limiting illness and dying
    - hospice palliative and end-of-life care and advance care planning
  - To enable stakeholders to move towards community-integration of hospice palliative care across all health and home care settings.

The Way Forward

We can do it through a framework that sees hospice palliative care undertaken by:

- any health care professional
- supported by consultation or referral to a specialist palliative care team when necessary
- building on the best practices from existing hospice palliative care programs and services

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The Way Forward

- Development of *The Way Forward* is a collaborative process; we welcome input and guidance.
- Creating the National Framework is just the first step. The next step will be when organizations, health care providers, leaders and Canadians take action and use the Framework to implement an integrated palliative care approach.

The Way Forward

Thank you to….

Carolyn Tayler, *RN, BN, MSA, CON(C)*
Director Hospice Palliative and End of Life Care,
Fraser Health, BC

…for providing palliative approach information and case studies.

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Questions?

- What questions do you have about the integrated palliative approach to care or The Way Forward?

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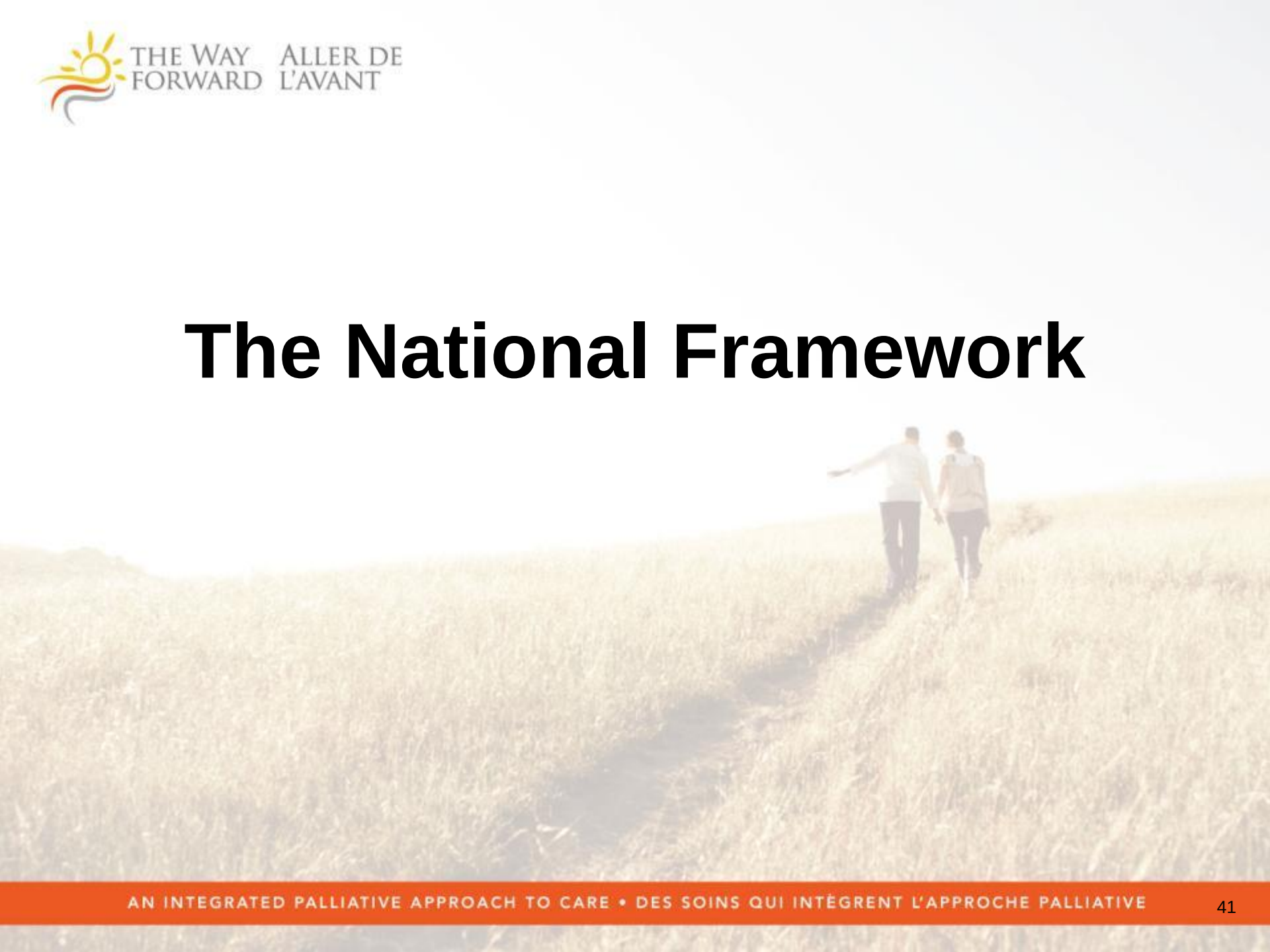
The National Framework



Background

- The National Framework will be an iterative document that will be revised and modified through and with the input of stakeholders.
- It is intended to be a practical, implementable and provide a roadmap for action.
- It will identify action steps across settings and for providers.

Content

- The case for support – describing the gap and the need to integrate a palliative approach to care
- The National Framework
- Vision and principles
- Action steps and opportunities by setting/provider
- Conclusion to follow

The Case

- Describes an integrated palliative approach to care
- Who will benefit from an integrated palliative approach to care?
- What the current gap for Canadians is and how this approach will address this need?
- What it may look like in practice (a system and person-centered view)

The Framework

- Benefits of the Framework
- Key principle:
  - Dying is part of living
  - Person and family driven care

The Framework in action

- Divided into settings/providers so that stakeholders can see themselves in the solution
- Federal/Provincial/Territorial governments
- Regional Programs and Planners
- Long-Term Care
- Home Care
- Primary Care
- Acute Care

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Questions

1) Thinking from a health system perspective, what do you see as the barriers and enablers in the Framework?

2) Thinking about patients and families, what are the barriers and enablers in the Framework?

3) Thinking about your organization, what are there enablers and barriers for engaging in the Framework?

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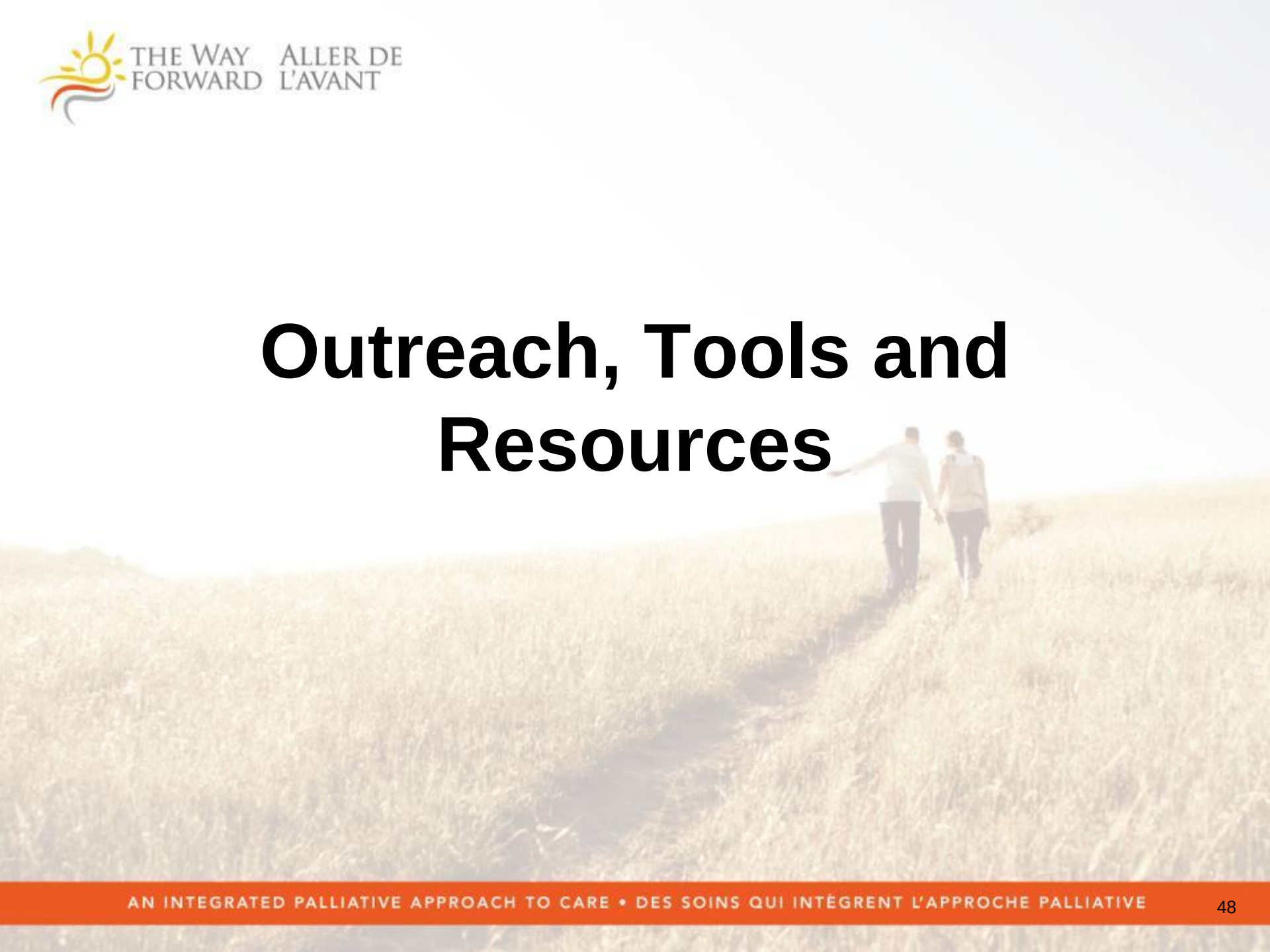
Outreach, Tools and Resources



Outreach to governments

- Since the announcement in June, briefing meetings with provincial and territorial governments and the federal Minister of Health's office, FNIHB
- Strong alignment and focused efforts in palliative care and integration across settings, especially home care and primary care
- Many governments developing provincial frameworks

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Outreach to stakeholders

- Presentations and meetings with CMA, CNA, CHCA Conference, Thunder Bay palliative meeting
- International Palliative Care Congress, Montreal
- Link with CPAC on their HPEOL initiative
- Abstract submitted to Ontario Association of Non-Profit Homes and Services for Seniors conference

Work products to date

- Discussion documents, including one page backgrounders
- The Way Forward website
- One pagers and postcards
- Environmental scan across Canada of existing data in hospice palliative care and a literature review of best practices
- Communications tools – message map, Q&A

Reporting requirements

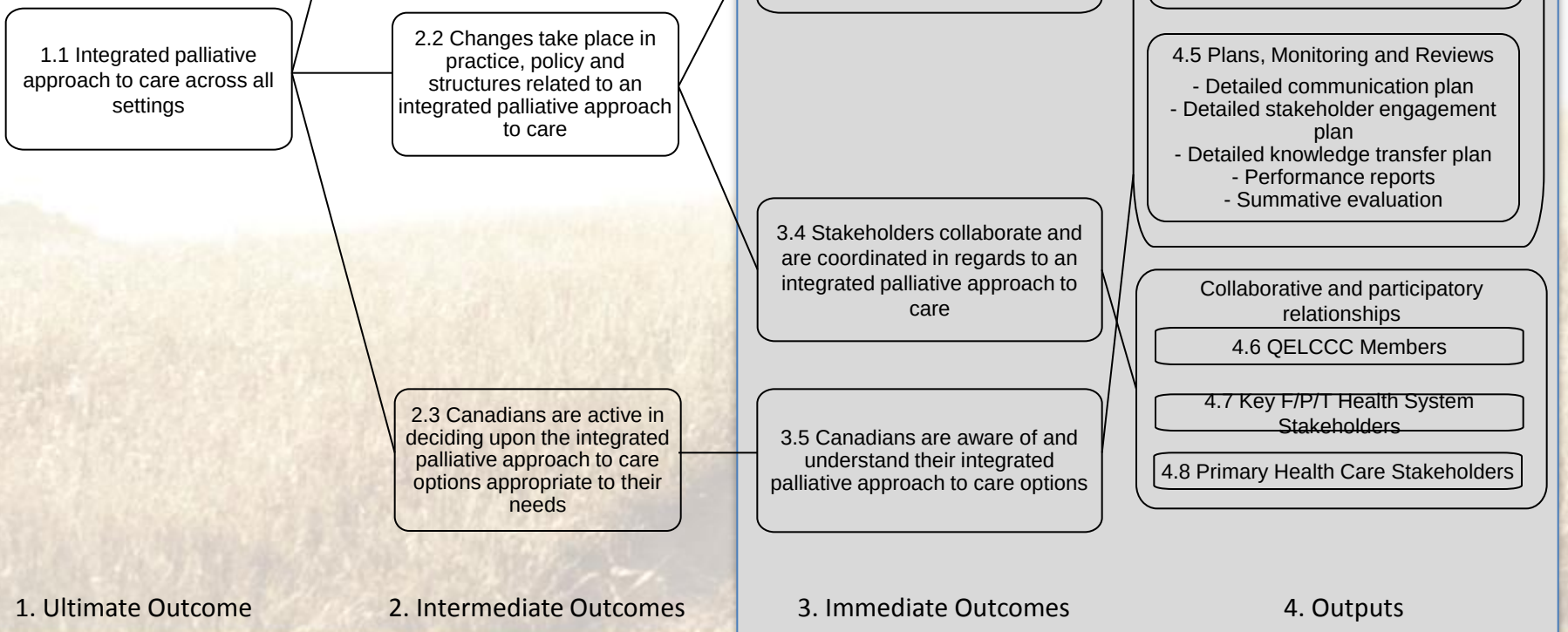
- Quarterly reporting on progress against work plan to Health Canada
- Recipient Reporting and Evaluation Template from Health Canada includes strong focus on KT – dissemination and uptake
  - Project outputs
    - Collaborative work, barriers and enablers, knowledge products
  - Project outcomes
    - Awareness and understanding, application of knowledge products, action on policy and practice

Measuring success

- A logic model for an integrated palliative approach to care has been developed.
- The ultimate outcomes of the initiative will occur well beyond the timing of the three year initiative.
- It is important to measure the outputs and immediate outcomes of the initiative, and that these will contribute to longer-term outcomes.

Draft Logic Model, January 16, 2013

Version 2



Outputs and Immediate Outcomes fall within the window of the 3-year TWF Initiative

Indicators and measures

- The following indicators and measures are part of the performance and evaluation plan for the initiative:
  - Number of QELCCC members participating in the development of the Framework (e.g. participation in on-line forums, direct input)
  - Level of dissemination by QELCCC of the Framework to members/organizations
  - Awareness and understanding of the initiative by QELCCC members based on an annual survey

Website

- Enhancing site and increasing interactivity
- En/Fr

Discussion documents

- A number of discussion documents have been developed to encourage stakeholder dialogue, and inform the development of the Framework
  - The palliative approach to care
  - Integrating the palliative approach into chronic disease management
  - Caregivers
  - Cost-effectiveness of hospice palliative care
  - Innovative models of care
  - Synthesis of Parliamentary & Senate reports

Tools and resources

- A number of resources are available, and others will be developed:
  - One pager about The Way Forward
  - One page Backgrounders on the discussion documents
  - Postcards
  - Message map and Q&A
  - What else is needed?

Questions

1) How can the initiative support the mandate of your organization? Will it be of interest to your members/constituents? If so, what aspects are most relevant?

2) What do you need to help you describe the initiative? Do the messages and Q&A help support your conversations?

3) Who else needs to know about this initiative?

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QELCCC Engagement

Questions

1) Based on what you heard today about The Way Forward, what would success look like at the end of three years – complete the following sentence:
    a. By 2015, The Way Forward will have …..

2) Thinking about your organization and members, what ideas do you have to provide information about The Way Forward and opportunities to shape the Framework?

3) In 2013/14, what could my organization do? (List opportunities) What do I need from the initiative to make this happen?

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Next Steps

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Next steps

- Ongoing outreach with stakeholders about the Framework, and the data and quality indicators
- Survey of Canadians about elements of the Framework and an integrated approach to palliative care, March-May, 2013
- Website revisions and interactive opportunities for feedback
- Satellite symposium on October 30, 2013 in advance of the CHPCA Conference in Ottawa

The Way Forward

For more information:

- Visit: www.hpcintegration.ca / www.integrationdessoinpalliatifs.ca

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