

# Unpacking the Principles of a Palliative Approach to Care Series

## Including Designated Family and Caregiver(s) in the Unit of Care

Teaching Presentation:

Dr. Samantha (Sammy) Winemaker, Associate Clinical Professor, Department of Family Medicine, Division of Palliative Care, McMaster University

Invited Caregiver:

Dr. Lester Krames, Professor Emeritus in the Department of Psychology, University of Toronto

Host: Jennifer Campagnolo, CHCA

Date: June 19, 2024.



Canadian  
Home Care  
Association



# Land Acknowledgement



Turtle Island By Patrick Hunter ([www.patrickhunter.ca](http://www.patrickhunter.ca))

We recognize with humility and gratitude that Canada is located in the traditional, historical and ceded and unceded Lands of First Nation, Inuit and Metis Peoples. On behalf of us all, we acknowledge and pay respect to the Indigenous peoples past, present and future who continue to work, educate and contribute to the strength of this country.

# Learning Objectives

By the end of the session, participants will be able to:

Understand and acknowledge the importance of the role of family or caregiver(s) and community throughout a person's care.

Recognize opportunities to engage family and caregivers in care and decision-making according to the person's wishes.

Identify the needs of family and caregivers to ensure their well-being and support them in role as a carer.

# THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK

**THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK**

A curriculum guide for educators and reference manual for disciplines providing palliative care.

**CANADIAN PARTNERSHIP AGAINST CANCER**  
PARTENARIAT CANADIEN CONTRE LE CANCER

**Health Canada** **Santé Canada**

**THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK**

A curriculum guide for educators and reference manual for disciplines providing palliative care.

**What this framework seeks to achieve, and how to use it**

This framework establishes a minimum national standard for palliative care in Canada.

It is written with several readers in mind:

- Individuals, managers and human resources personnel** will use it to fill skills gaps and guide hiring practices.
- Educators** will use it to identify minimum standards for palliative care competencies, weave the development of essential skills into existing curricula, or build new curricula to teach the competencies.
- National accreditation and regulatory agencies** will use it as a guide for establishing minimum national standards in palliative care.

**Specifically, the disciplines with competencies in the framework:**

- Nurses
- General Physicians
- Social Workers
- Personal Support Workers
- Volunteers

**The framework includes:**

a. Twelve domains of competency:

1. Principles of a palliative approach to care	5. Care planning and collaborative practice	9. Professional and ethical practice
2. Cultural safety and humility	6. Last days and hours	10. Education, evaluation, quality improvement, research
3. Communication	7. Loss, grief, and bereavement	11. Advocacy
4. Optimizing comfort and quality of life	8. Self-care	12. Virtual care

b. Discipline-specific skills self-assessments:

- provide the health care practitioner with a snapshot of their own competencies;
- provide managers with tools to gauge the levels of palliative care competencies within a team;
- can guide professionals and managers as they customize continuing education plans.

c. Education resources

**CANADIAN PARTNERSHIP AGAINST CANCER**  
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<sup>1</sup> Canadian Partnership Against Cancer & Health Canada. *The Canadian Interdisciplinary Palliative Care Competency Framework*. Toronto, ON: 2021.

# Unpacking the Principles of a Palliative Approach to Care



## Domain 1: Principles of a palliative approach to care

Palliative care aims to improve the quality of life of people with life-limiting conditions and their designated families or caregivers. This person-centred care ideally begins at diagnosis, continues into bereavement, and is for people of any age. <sup>1</sup>

# Unpacking the Principles of a Palliative Approach to Care



## **Competency: Including designated family or caregiver(s) in the unit of care<sup>1</sup>**

For Interdisciplinary team members (nurses, PSWs, generalist physicians, social workers and volunteers) this means recognizing, understanding and integrating:

- Asking the person who they consider family and include those individuals if the person wishes
- Respond to the designated family or caregiver's unique needs and experiences
- Respect for the role of family or caregiver(s) and community throughout a person's care, especially for members of underserviced communities
- Appreciation of the impact a life-limiting condition may have on designated familial roles

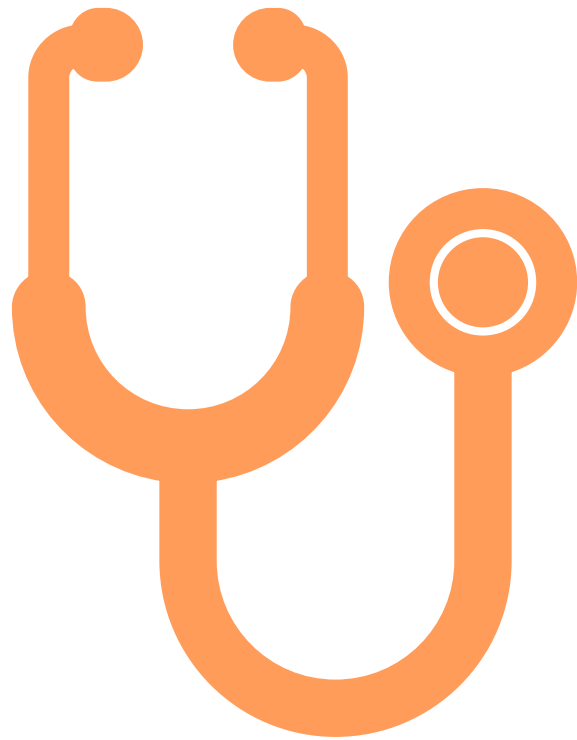
# Introductions



**Dr. Samantha (Sammy) Winemaker**  
Associate Clinical Professor, Department of Family Medicine,  
Division of Palliative Care, McMaster University,  
Author and co-host of the Waiting Room Revolution podcast



**Dr. Lester Krames**  
Caregiver  
Professor Emeritus in the Department of Psychology,  
University of Toronto.



## Including Designated Family & Caregivers In The Unit Of Care

- Dr. Samantha (Sammy) Winemaker
- CHCA Palliative Care ECHO Hub – Canadian Home Care Association
- June 19, 2024



# Conflict Of Interest



I receive funding from Health Canada  
and CIHR for research projects.



I have co-authored a book  
(Page Two, 2023)

# Objective

- Attendees will be able to appreciate the role of the patient's delegated family and/or caregiver(s) in the illness journey.











In the Dark

**REACTIVE**

**UNAWARE**

**UNSURE**

**GENERIC**

**OVERWHELMED**

**FRUSTRATED**

**SCARED**



**PREPARED**

**INFORMED**

**CONFIDENT**

**TAILORED**

**IN CONTROL**

**IN CHARGE**

**HOPEFUL**

In the Know

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



## EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



## CONNECT THE DOTS

Play a central role in navigating the system



## INVITE YOURSELF

Initiate conversations about what to expect

In the Dark



In the Know

# 7 keys for navigating a life-changing illness



## **WALK TWO ROADS**

Hope for the best and plan for  
the rest



## WALK TWO ROADS

Hope for the best and plan for the rest



Reality

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## ZOOM OUT

Understand the big picture  
of your illness



Illness Understanding

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges





## KNOW YOUR STYLE

Reflect on how you cope and face challenges



Character

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



INDIVIDUALITY

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



## EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



## **EXPECT RIPPLE EFFECTS**

Prepare for the family's parallel journey



Delegated Family

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



## EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



## CONNECT THE DOTS

Play a central role in navigating the system



## CONNECT THE DOTS

Play a central role in navigating the system



Shared Management

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



## EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



## CONNECT THE DOTS

Play a central role in navigating the system



## INVITE YOURSELF

Initiate conversations about what to expect





## INVITE YOURSELF

Initiate conversations about what to expect



Partnership

# 7 keys for navigating a life-changing illness



## WALK TWO ROADS

Hope for the best and plan for the rest



## ZOOM OUT

Understand the big picture of your illness



## KNOW YOUR STYLE

Reflect on how you cope and face challenges



## CUSTOMIZE YOUR ORDER

Tailor the care plan to your values and preferences



## EXPECT RIPPLE EFFECTS

Prepare for the family's parallel journey



## CONNECT THE DOTS

Play a central role in navigating the system



## INVITE YOURSELF

Initiate conversations about what to expect

# 7 provider invitations



INVITE REALITY



INVITE ILLNESS  
UNDERSTANDING



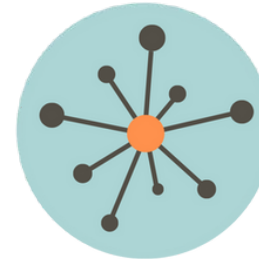
INVITE THEIR  
CHARACTER



INVITE INDIVIDUALITY



INVITE THE FAMILY



INVITE SHARED  
MANAGEMENT



INVITE PARTNERSHIP

In the Dark



In the Know

# 7 KEYS FOR NAVIGATING A LIFE-CHANGING DIAGNOSIS



## 1. Walk Two Roads

Balance staying positive while also seeking honest, accurate information. This helps you stay hopeful and grounded to reality.

### ACTION

Ask yourself what you are hoping for and what you need to plan for just in case?

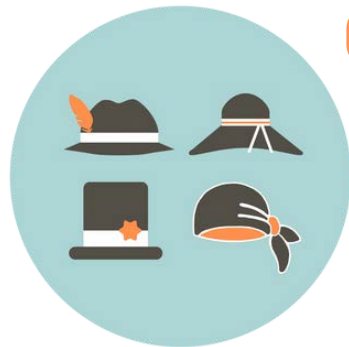


## 2. Zoom Out

Every illness has a known pattern to it. Understanding this storyline gives you a birds-eye view of where you are at in your illness and the long view.

### ACTION

Ask your provider "What will my illness look like over time? What can I expect along the way?"



## 3. Know Your Style

Your unique way of being will have as much impact on your illness experience as the illness itself. Harness information about your style to gain more control.

### ACTION

Reflect on your tendencies when facing stressful situations & how those might apply in your illness.



## 4. Customize Your Order

At times you may want to tailor your care to match your values. Use your values & preferences to guide your decisions throughout your illness.

### ACTION

Ask yourself what do you value most?

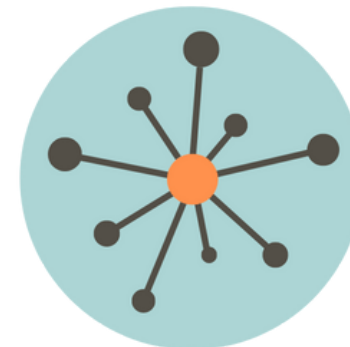


## 5. Anticipate Ripple Effects

Your inner crew (e.g. family and caregivers) will have a parallel illness journey. Their lives will be affected in multiple ways.

### ACTION

Consider what support you need from your inner crew. Encourage them to get information and support too.



## 6. Connect the Dots

You and your inner crew need to play a central role in co-ordinating information. This enhances continuity and safety, especially at transition points

### ACTION

Ask yourself who will be the manager of your journey?



## 7. Invite Yourself

Initiate conversations with your healthcare team. Don't assume no news is good news. Passive, polite patients are encouraged to be respectfully assertive.

### ACTION

Ask questions and seek the information you need so you can make informed decisions.

For more information go to:  
[waitingroomrevolution.com](http://waitingroomrevolution.com)

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# Benefits for Providers

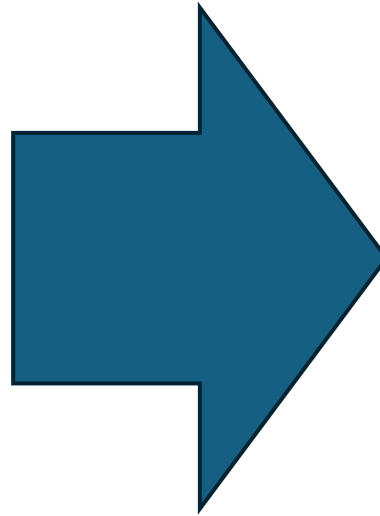
## **Heads Down Care**

- Weary
- Detached
- Reactive
- Helpless
- Hopeless
- Futile
- Frustrated
- Conflicted
- Burnout

# Benefits for Providers

## Heads Down Care

- Weary
- Detached
- Reactive
- Helpless
- Hopeless
- Futile
- Frustrated
- Conflicted
- Burnout



## Heads Up Care

- Caring
- Engaged
- Proactive
- Helpful
- Hopeful
- Meaningful
- Pride
- Satisfaction
- Resilience





**LOST**

**CONFUSED**

**UNSURE**

**UNCLEAR**

**PERPLEXED**

**DISORIENTED**

**BEWILDERED**



Thank You

Dr. Samantha (Sammy) Winemaker

Palliative Care Physician

Co-founder, Waiting Room Revolution

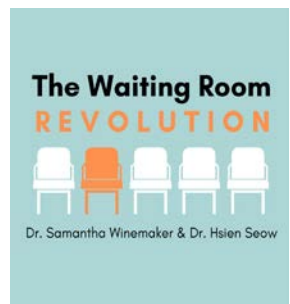
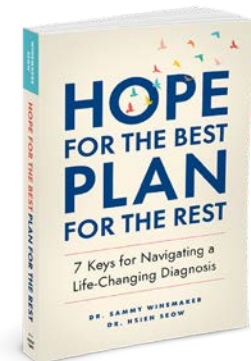
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**Dr. Lester Krames**

Caregiver

# Questions & Discussion



## Project ECHO

All teach, all learn.

Bridging the Knowledge Gap in Home and Community Care.



Through CHCA Project ECHO, we envision a future where all patients receive high-quality care, no matter where they live. Project ECHO's innovative model provides education, spreads best practices, and builds collaborative provider networks in home and community-based care. The outcomes are enhanced skills, increased knowledge, improved care quality, reduced healthcare costs, and greater provider satisfaction.

### ECHO Streams

Each ECHO Stream targets key areas in home and community-based care across the country. Using the renowned Project ECHO model from the University of New Mexico, CHCA Project ECHO connects you with specialists, experts, research, and tools. Here's what you can expect:

- **Virtual TeleECHO Sessions:** Join 1-hour virtual sessions with experts and engage in case-based discussions.
- **Case-Based Learning:** Discuss real-life case studies and share provider insights during every session.
- **Best Practice Protocols:** Learn from evidence-informed practices and protocols tailored to each theme and topic.
- **Continuing Education:** Access resources and tools through the online ECHO Hub to support your continuous learning journey.

Choose an ECHO Stream to enhance your skills, gain valuable insights, and connect with experts and peers.



Home-Based Palliative Care



Integrated Seniors Care



Innovation (Coming Soon)

[cdnhomecare.ca/chca-project-echo](https://cdnhomecare.ca/chca-project-echo)

# CHCA ECHO Hub

[cdnhomecare.ca/chca-project-echo-home-based-palliative-care](https://cdnhomecare.ca/chca-project-echo-home-based-palliative-care)



## **Understanding the Interdisciplinary Team**

**October 9, 2024**

- Dr. Gordon McDonald, Palliative Care Physician, NB
- Elisabeth Antifeau, Regional CNS, Palliative Care, Interior Health, BC

## **Addressing Barriers to Care**

**November 13, 2024**

- Dr. Kelli Stajduhar, RN, PhD, FCAHS, Professor, School of Nursing and Institute on Aging & Lifelong Health, University of Victoria
- Kate Leahy, RN, Nurse Coordinator for the Palliative Outreach Resource Team (PORT)

*Thank  
you!*

For taking a few moments to  
complete the feedback survey