NO "RIGHT PLACE TO DIE"

A PALLIATIVE APPROACH TO SERIOUS MENTAL ILLNESS

Host and Moderator: Amanda Tevelde

Presenters: Julie Leighton-Phelps, RN, BScN, CHPCN(C)

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC

Date: September 24th, 2025

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with:

Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

Stay connected: www.echopalliative.com

Thank You

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada.

Production of this presentation has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Introductions

Host and Moderator

Amanda Tevelde
Communications, Fundraising and Community Relations Specialist
North Simcoe Muskoka Hospice Palliative Care Network

Presenters

Julie Leighton-Phelps, RN, BScN, CHPCN(C)
Palliative Pain and Symptom Management Consultant (PPSMC)
North Simcoe Muskoka Hospice Palliative Care Network

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC
Clinical Educator
Waypoint Centre for Mental Health Care

Thank you for joining us today!

Please remember to complete the satisfaction survey following today’s session.

The following presentation is property of the North Simcoe Muskoka Hospice Palliative Care Network (NSMHPCN) and intended for the attendees of today's session. The presentation may not be duplicated or shared without prior permission from the NSMHPCN. (Reviewed January 2025)

Learning Objectives

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

Understand the unique challenges and disparities in providing palliative and end-of-life care to individuals living with Serious Mental Illness (SMI).

Understand the principles and practices of a palliative approach within psychiatric settings, including symptom management, multidisciplinary collaboration, and ethical considerations.

Apply practical strategies and resources to improve quality of life, support decision-making, and enhance person-centered care for individuals with SMI at end of life.

A BRIEF OVERVIEW

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with:

Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

Host: Amanda Tevelde

Presenters: Julie Leighton-Phelps, RN, BScN, CHPCN(C)

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC

Date: September 24, 2025

SERIOUS MENTAL ILLNESS

- SMI is also known as Serious and Persistent Mental Illness (SPMI).
- Government of Canada defines SPMI as “changes in an individual’s thinking, mood or behaviour and is usually associated with significant distress or impaired functioning in social, occupational and other activities (HPCO).

PALLIATIVE APPROACH

Definition of Palliative Care

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

"World Health Organization" 2018

PALLIATIVE PSYCHIATRY

- Despite this well-established involvement of psychiatrists in palliative care, psychiatry does not currently explicitly provide palliative care for patients with mental illness outside the context of terminal medical illness.
- Palliative psychiatry is based on accepting that aspects of SPMI can be irremediable, such as the presence of certain symptoms, their severity, the risk of relapse, or the risk of a fatal outcome.
- Not end of life care, symptom relief of treatment resistant mental health.

SPECIALIZED PROGRAMS

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with:

Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

Host: Amanda Tevelde

Presenters: Julie Leighton-Phelps, RN, BScN, CHPCN(C)

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC

Date: September 24, 2025

WAYPOINT

- 315 bed academic and teaching hospital,
- Serves patients with serious mental illness,
- One of the largest forensic mental health hospitals in Canada and;
- Recognized internationally for leadership and research.

SPECIALIZED CARE

- Horizon Program for Geriatric Care,
- Specialized addictions programs,
- Dual diagnosis,
- ECT and rTMS and;
- Forensic Programs.

LIMITATIONS

- **Resuscitation Status**
- **Medical Assistance in Dying**
- **Transfers to other facilities**

OUR PATIENTS

- Physical Health Conditions
- Brief overview of mental health conditions
- Mood, psychotic, personality

SMI'S AND COMORBIDITIES

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with:

Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

Host: Amanda Tevelde

Presenters: Julie Leighton-Phelps, RN, BScN, CHPCN(C)

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC

Date: September 24, 2025

What percentage of Canadians do you believe have both a significant mental illness and a physical comorbidity?

A. 30%

B. 10%

C. 20%

D. 5%

CO-MORBIDITIES AND MORTALITY

- Chronic Illness: common illness in those with SMI include diabetes, cancer, CVD, COPD, liver disease and infectious diseases
- Life Expectancy: likely die 10-20 years sooner than those without SMI
- Disability: SMI and substance misuse is the leading cause of disability in Canada

MOOD DISORDERS

- 41% of Canadians aged 18-29 have a diagnosis of anxiety, most treatable disorder but only 36.9% of people receive treatment
- 45% of LTC residents have depression
- 40% of people with physical illness
- 500 000 people call in sick every day in Canada due to stress related symptoms of depression

PSYCHOTIC DISORDERS

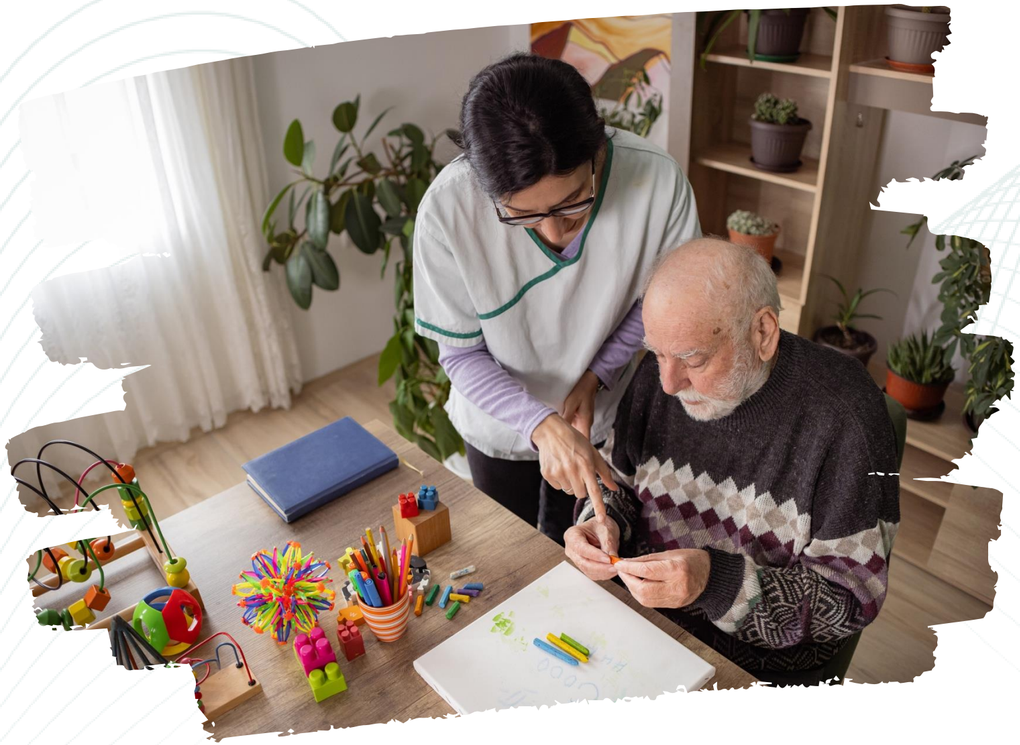
- Schizophrenia = higher prevalence in men, peak onset for men between ages of 15-25, peak onset for women 25-25
- One of the top 10 causes of disability worldwide
- The most expensive, accounts for ¼ of all mental health costs and 1 in 3 beds in psychiatric facilities

PERSONALITY DISORDERS

- Ways of thinking, feeling and behaving that deviate from the expectations of culture, causes, distress or problems functioning overtime.
- Begins late adolescence/early adulthood
- Typically not diagnosed under age of 18 years
- Symptoms or characteristics are dependent on which type of personality disorder

DEMENTIA & DELIRIUM

- 771, 939 people in Canada are living with Dementia
- Not a normal part of aging
- Progressive decline
- Delirium ranges from 8-17% in ER
- Up to 82% in older adults



DUAL DIAGNOSIS

- Term specific to Canada
- 3-6x more at risk for developing a psychotic disorder
- Between 10%-30% of Canadians are thought to have a developmental disability
- Umbrella terminology

TREATMENT & BARRIERS

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with:

Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

Host: Amanda Tevelde

Presenters: Julie Leighton-Phelps, RN, BScN, CHPCN(C)

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC

Date: September 24, 2025

BIAS AND STIGMA

- **Beliefs**
- **Effects**
- **Patient Response**

HOW IS THIS APPLICABLE?

- Understanding who is receiving care
- Recognizing barriers
- Providing appropriate supports

PROVIDING PALLIATIVE CARE

Barriers

Identifying the complex disparities in providing optimal palliative and EOL care in those with SMI.

Multi-disciplinary

Involving several key HCP at Waypoint and community partners. Creating a “unique village”.

Symptom Management

Excellent assessments of physical and psychiatric symptoms and use of appropriate interventions.

Project ECHO Palliative Care - Canada BY Pallium Canada NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with: Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

PHYSICAL SYMPTOMS

PSYCHIATRIC MEDICATIONS

- Medications need to be slowly weened before discontinuing
- Managing side effects
- Antipsychotics are 1 of the top 20 medications prescribed to hospice patients
- Risk of rebound psychosis in the SMI patient population

BREAKING THROUGH BARRIERS

Understanding and acknowledging

- Negative symptoms of mental illness
- Stigma and bias of mental health
- Difficulties in being understood by HCP
- Potential lack of social support
- Challenges providing care, inclusive of access to care

END OF LIFE IN FORENSICS

- Importance of advance care planning and early recognition
- Taking advantage of palliative approaches to care
- Being creative within our limits
- Make workflows less cumbersome
- Have resources readily available

IN YOUR PRACTICE

- **Using non-judgmental language**
- **Validate experiences**
- **Acknowledge and understand symptoms as signals**

CASE STUDY

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with:

Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

Host: Amanda Tevelde

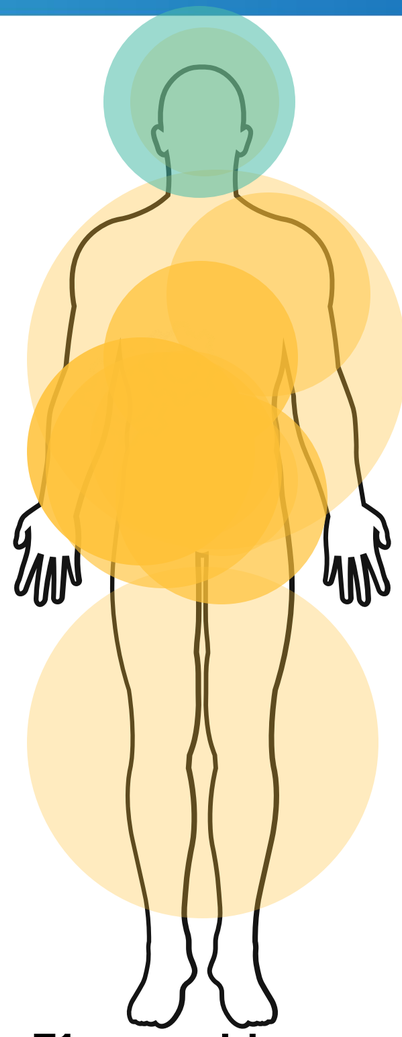
Presenters: Julie Leighton-Phelps, RN, BScN, CHPCN(C)

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC

Date: September 24, 2025

MEET MR. BAGGINS

- Cirrhosis
- Epilepsy
- Cholelithiasis
- Recurrent UTI
- Hypertension
- Pancytopenia
- Hepatitis C
- Urinary Retention
- Dyslipidemia
- GERD
- Diabetes Type 2



71 year-old man

- Schizophrenia
- Major Neurocognitive Disorder
- Cannabis Use Disorder
- Nicotine Use Disorder

SOCIAL HISTORY

Capacity
- PG&T

Goals of Care
- Transfer to Hospital, no CPR

Social
- Divorced with children
- Post-secondary education
- Was retired

Goal of admission
- Medication review
- Address addiction
- Enhance community support
- Discharge

INVESTIGATIONS

On Admission

- CBC
- Electrolytes
- HBAIC
- Liver function test
- FIT Test
- ECG
- Urine
- Valporic Acid
- Hepatitis confirmation

Ongoing

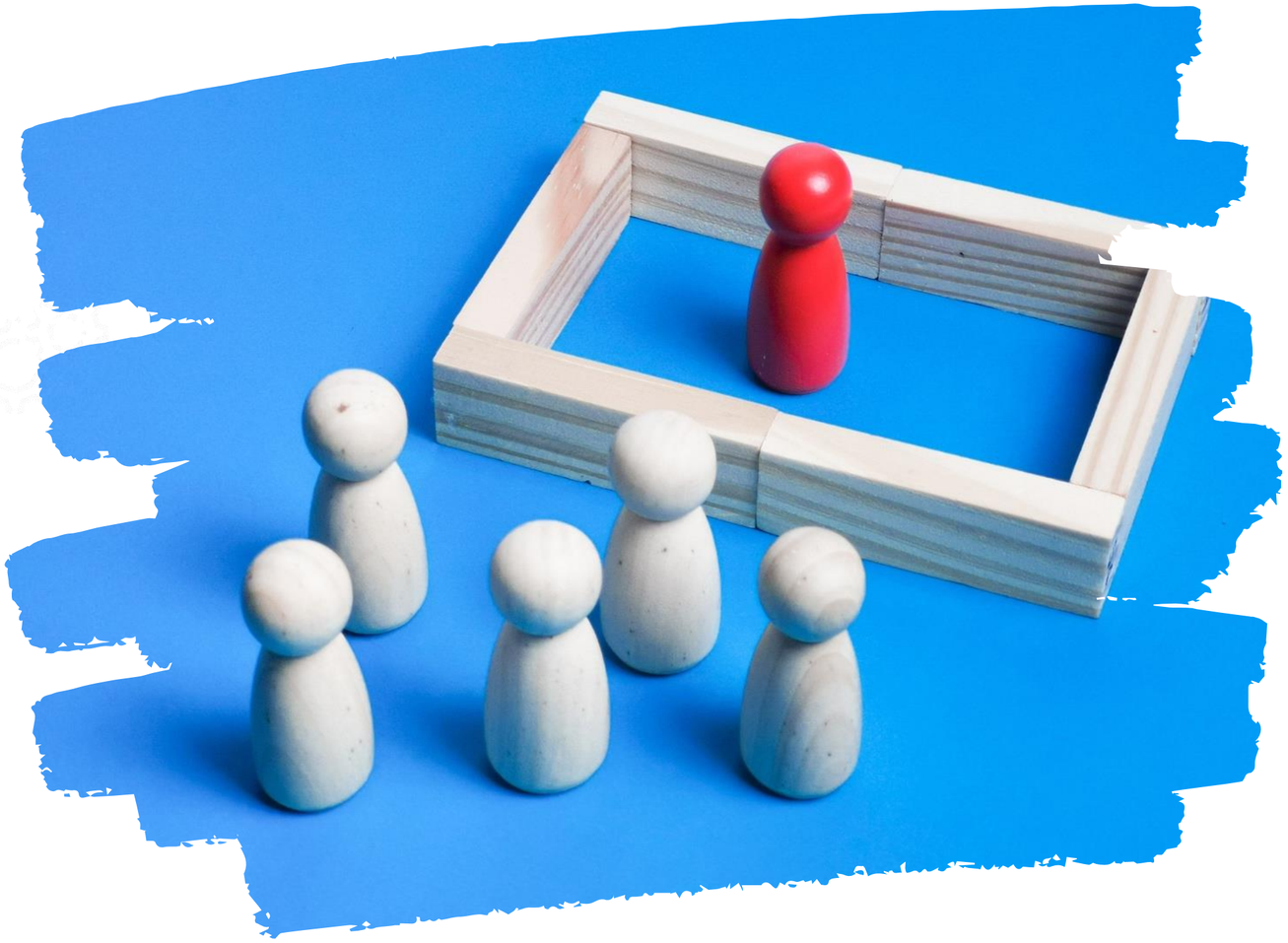
- Urine
- CBC
- Electrolytes
- HBAIC
- Liver function
- Lipid profile

On Transfer

- Sleep clinic
- Chiropody
- Kidney function
- Bladder scans
- x-ray (fecal impaction)
- MRI
- Biopsy of lung nodule

BARRIERS TO CARE

- Patient request for MAiD
- Increase in expressions of risk
- Medical complexity
- Sharp decline in cognitive functioning
- Rebound psychosis



PALLIATIVE APPROACH INTERVENTIONS

Ethics Consult

- Related to change in status and sharp functional and cognitive decline.

Recreation Referral

- Support in providing Mr. Baggins with activities that he enjoyed and increasing quality of life

Occupational and Physiotherapy

- Assist in ensuring safe devices utilized
- Assist in increasing quality of life

Behaviour Support Specialist

- Engaged to help identify precursors to expressions of risk and provide a patient centerd plan
- Also assisting in ensuring patient preferences were utilized

END OF LIFE INTERVENTIONS

Hospice Referrals

- Referral to Hospice x2, declined both times

Medication Titration

- Attempted to titrated off medications to minimize rebound psychosis
- Rebound psychosis occured

Private Room

- Increased nursing monitoring
- Catheter for comfort only
- Minimize use of restraints

Goals of Care

- Changed 4 days before patient death

REVIEW OF CARE IMPROVEMENT

Education

- Needs identified inclusive of, medications, rebound psychosis, expected findings at end of life

Adequate pain control

- No pain medication ordered

Need for a standard approach

- Multiple providers involved in care and orders, need to develop a baseline standardized process

Staff support

- Distraught over death, well known to many staff over many years

RESOURCES

CAMH - Mental Health 101s
www.moodle8.camhx.ca/moodle/
Cost: Free

Equip Health Care - Trauma and Violence Informed Care
https://equiphealthcare.ca/
Cost: Free

CMHA Recovery/Discovery Colleges
www.cmha.ca/find-info/mental-health/online-mental-health-courses/
Cost: Free

NSMHPCN Resource Toolkit
https://nsmhpcn.ca/rtk/mental-health/
Cost: Free

CONCLUSION

Summary

In summary Chantal and I would like to encourage all of you here today to continue on educating yourself and your team members on the importance of incorporating Serious Mental Illness education within your organizations

Call to Action

As a call to action, we are hopeful for new research into a palliative approach to care related to Serious Mental Illness and improved implementation of policies to enhance your palliative and end of life care programs.

Project ECHO Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

In partnership with: Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

CONTACT US

Julie Leighton-Phelps, RN, BScN, CHPCN(C)
Palliative Pain and Symptom Management Consultant (PPSMC)
North Simcoe Muskoka Hospice Palliative Care Network

Phone
705-794-0545

Email
julie@nsmhpcn.ca

Website
https://nsmhpcn.ca

Chantal Byrnes-Leadbeater, RN, BScN, AWCCP, NSWOC
Clinical Educator
Waypoint Centre for Mental Health Care

Phone
705-549-3181 ext 3003

Email
cbyrnes-leadbeater@waypointcentre.ca

Website
https://www.waypointcentre.ca

Project ECHO Palliative Care - Canada BY Pallium Canada NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network In partnership with: Waypoint CENTRE for MENTAL HEALTH CARE CENTRE de SOINS de SANTÉ MENTALE

WHAT WILL YOU TAKE FORWARD?

RESOURCES

Boer, K. den, Veer, A. J. E. de, Schoonmade, L. J., Verhaegh, K. J., Meijel, B. van, & Francke, A. L. (2019, April 3). *A systematic review of palliative care tools and interventions for people with severe mental illness - BMC psychiatry*. SpringerLink. https://link.springer.com/article/10.1186/s12888-019-2078-7#Sec15

Donald, E. E., & Stajduhar, K. I. (2019). A scoping review of palliative care for persons with severe persistent mental illness. *Palliative and Supportive Care, 17*(4), 479–487. doi:10.1017/S1478951519000087

Foti, M., Bartels, S., Merriman, M., Fletcher, K., & Van Citters, A. (2005, May). *Medical Advance Care Planning for persons with serious …* Psychiatry Online. https://ps.psychiatryonline.org/doi/pdf/10.1176/appi.ps.56.5.576

Foti, M., Bartels, S., Van Citters, A., Merriman, M., & Fletcher, K. (2005, May). *End-of-Life Treatment Preferences of Persons With Serious Mental Illness*. Psychiatry Online. https://ps.psychiatryonline.org/doi/epdf/10.1176/appi.ps.56.5.585

Hinrichs KLM, Woolverton CB, Meyerson JL. Help Me Understand: Providing Palliative Care to Individuals With Serious Mental Illness. American Journal of Hospice and Palliative Medicine®. 2022;39(2):250-257. doi:10.1177/10499091211010722-337.

RESOURCES

Hospice Palliative Care Ontario. (2023). Palliative care considerations for patients living with severe mental illness. Hospice Palliative Care Ontario (HPCO). https://www.hpco.ca/palliative-care-considerations-for-patients-living-with-severe-mental-illness/

Jones, S., Popoola, E. O., Ryan, L., Brown, S., & Curtis, M. (2024). 7 getting mental health medicines right when it matters at the end of Life: A Regional Survey of Palliative and Psychiatry Professionals. Oral Presentations. https://doi.org/10.1136/spcare-2024-pcc.7

Launders, N., Dotsikas, K., Marston, L., Price, G., Osborn, D. P., & Hayes, J. F. (2022). The impact of comorbid severe mental illness and common chronic physical health conditions on hospitalisation: A systematic review and meta-analysis. PLOS ONE, 17(8). https://doi.org/10.1371/journal.pone.0272498

Morgan B. D. (2016). "No Right Place to Die": Nursing Attitudes and Needs in Caring for People With Serious Mental Illness at End-of-Life. *Journal of the American Psychiatric Nurses Association*, *22*(1), 31–42. https://doi.org/10.1177/1078390316629960

Mental Health Coordinating Council. (2022). Recovery oriented language guide. https://mhcc.org.au/wp-content/uploads/2022/10/Recovery-Oriented-Language-Guide-3rd-edition.pdf

RESOURCES

ProCare hospicecare. ProCare HospiceCare. (2025). https://www.procarehospicecare.com/

Shaley, D., Fields, L., & Shapiro, P. (2020, June 12). *End-of-life care in individuals with serious mental illness*. Psychosomatics. https://www.sciencedirect.com/science/article/pii/S0033318220301894

Sheridan, A. (2019, November). Palliative care for people with serious mental illnesses - the Lancet public health. https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(19)30205-1/fulltext

Webber, T. (2012, November). End of Life Care for People with Mental Illness. https://jemh.ca/issues/v7/documents/JEMH_Vol7EndofLifeCareforPeoplewithMentalIllness.pdf

Westermair, A. L., Trachsel, M., Kious, B., Buchman, D. Z., & Levitt, S. (2025). Special report: Palliative psychiatry: An innovative approach to caring. Psychiatric News, 60(4). https://doi.org/10.1176/appi.pn.2025.04.4.23

Thank you for joining us today!

Please remember to complete the satisfaction survey following today's session.

The following presentation is property of the North Simcoe Muskoka Hospice Palliative Care Network (NSMHPCN) and intended for the attendees of today's session. The presentation may not be duplicated or shared without prior permission from the NSMHPCN. (Reviewed July 2025)