

# **Palliative Care Discharge Planning for First Nations and Inuit Patients Returning to Remote Communities**

**Winnipeg Regional Health Authority  
(WRHA)**

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**Lori Embleton**, Program Director

WRHA Palliative Care Program

**Dr. Michael Harlos**, Medical Director

WRHA Palliative Care Program

Professor & Section Head, Palliative Medicine,  
University of Manitoba



# Disclosure

The presenters have no  
conflicts of interest to disclose



# Objectives

- Describe challenges in planning discharges to remote communities for palliative First Nations and Inuit people
- Describe factors that need to be considered to facilitate discharges for palliative First Nations and Inuit people



### About Palliative.info

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*Palliative.info* offers an organized, up-to-date collection of links to palliative care resources on the internet, as well as locally developed palliative care material.

*... more info ...*

#### What is Palliative Care? (a personal definition)

Palliative Care is an approach to care which focuses on comfort and quality of life for those affected by life-limiting/life-threatening illness. Its goal is **much more than comfort in dying**; palliative care is about living, through meticulous attention to control of pain and other symptoms, supporting emotional, spiritual, and cultural needs, and maximizing functional status.

The spectrum of investigations and interventions consistent with a palliative approach is guided by goals of patient and family and by accepted standards of health care, rather than being boundaried by preconceptions of what is or is not "palliative".

See also the [World Health Organization's definition](#)

#### Links Grouped by Topic:

- [Aboriginal / Indigenous Peoples](#)
- [Advance Directives \(Health Care Directives\)](#)
- [Advocacy, Govt Policy](#)
- [Assessment/Evaluation Tools](#)
- [Programs](#)
- [Psychosocial Professional](#)
- [Quality of Life](#)
- [Research Sites Related to Palliative Care](#)
- [Specific Diseases/Populations](#)
- [Spiritual / Faith-Based](#)
- [Standards and Norms](#)

#### Teaching Material



- [Manitoba Resources - Lectures/Presentations/Handouts](#)
- [Ian Anderson Modules](#)
- [StopPain.org: Topics in Pain Management - A Slide Compendium](#)

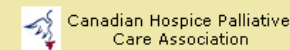
#### Local (Winnipeg) Documents


 Search This Site

#### Manitoba Palliative Care Nurses Association



#### National Canadian Resources



#### Email Discussion Lists and Bulletin Boards

##### 1. [PaedPalCare mailing list](#)

An international email discussion list on pediatric palliative care sponsored by ACT

##### 2. [PalliativeDrugs.com](#)

A bulletin board moderated and maintained by Dr. Andrew Wilcock

#### Palliative Medications



A comprehensive and authoritative resource founded by Robert Twycross and Andrew Wilcock.



Medication compatibilities, subcutaneous administration



To save to your hard drive, right-click on title of the document that you want to download, and choose "Save Target As..." (or similar).

## Events / Conferences



Topic		Author	Click To View Or Download
<b>2015 Canadian Hospice Palliative Care Conference - Ottawa</b>			
1	Discharge Planning for Palliative First Nations and Inuit Patients Returning to Their Home Communities	Lori Embleton, Mike Harlos	PowerPoint® pdf version
2	Related Documents: Discharge Planning Guideline; Care Plan Template; Checklist	Lori Embleton, Mike Harlos	1. Discharge Planning Guideline 2. Care Plan Template 3. Checklist
<b>Palliative Manitoba - 24th Annual MB Prov. Pall. Care Conf. - Sept. 17, 2015</b>			
1	Considerations for end-of-life care in dementia	Mike Harlos	PowerPoint® pdf version
<b>Critical Care Outcomes Improvement Symposium - Critical Care At The End Of Life - May 22, 2015</b>			
1	Symptom Management in Palliative ICU Patients	Mike Harlos	PowerPoint® pdf version
<b>Cropo Educational Session March 11, 2015</b>			
1	Communication and Decision Making in Palliative Care	Mike Harlos	PowerPoint® pdf version

## Resident Teaching Material

Topic (Click On Title To View Or Download)		File Format	Author / Lead
Communication and Decision Making in Palliative Care		PowerPoint®	Mike Harlos
<b>Pharmacy / Medications Introduction</b>			
1	Pharmacy Intro	PowerPoint®	Christian LaRiviere
2	Medication "Cheat Sheet"	pdf	
3	Adjuvant Medications Comparison	pdf	
4	Drug Routes	pdf	

Palliative care is comfort-focused care and support for those affected by life-limiting illness – the patient, their family, their health care providers, *and particularly in small rural and remote settings, the community.*






An anticipated death should be a family and community event with the peripheral support of health care, rather than a medical event with peripheral involvement of family and community.

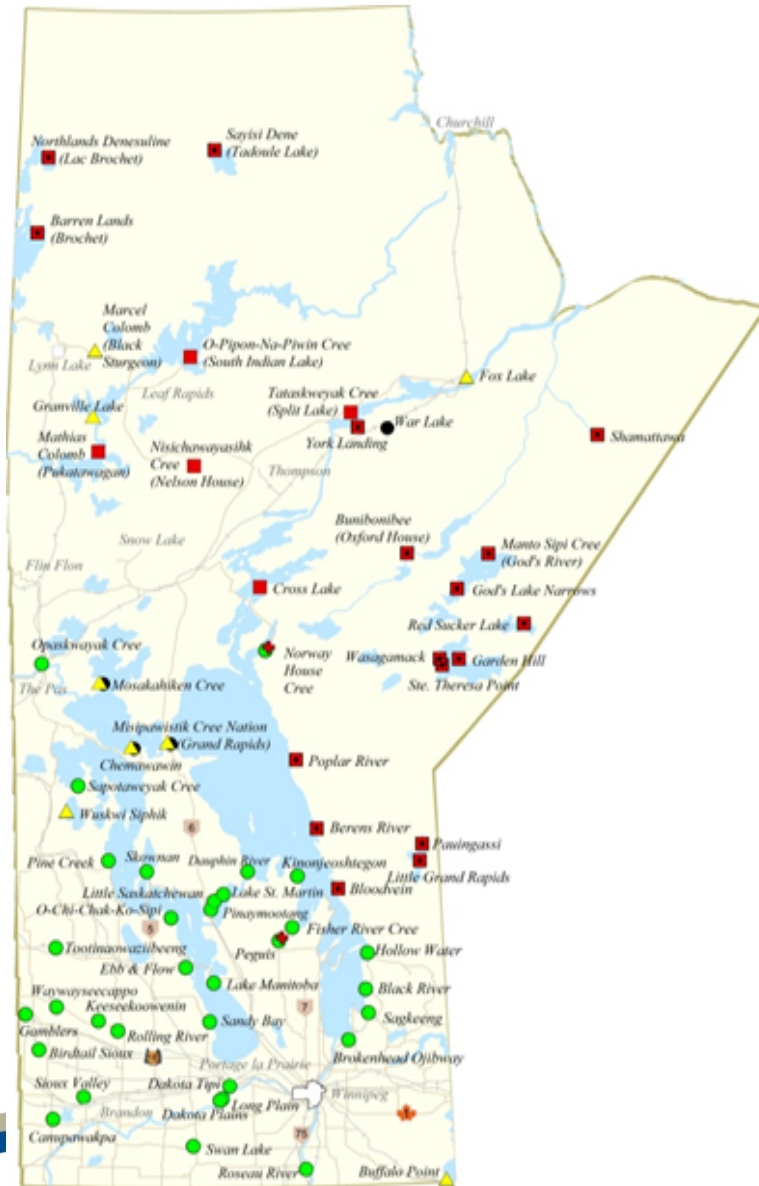




# Manitoba

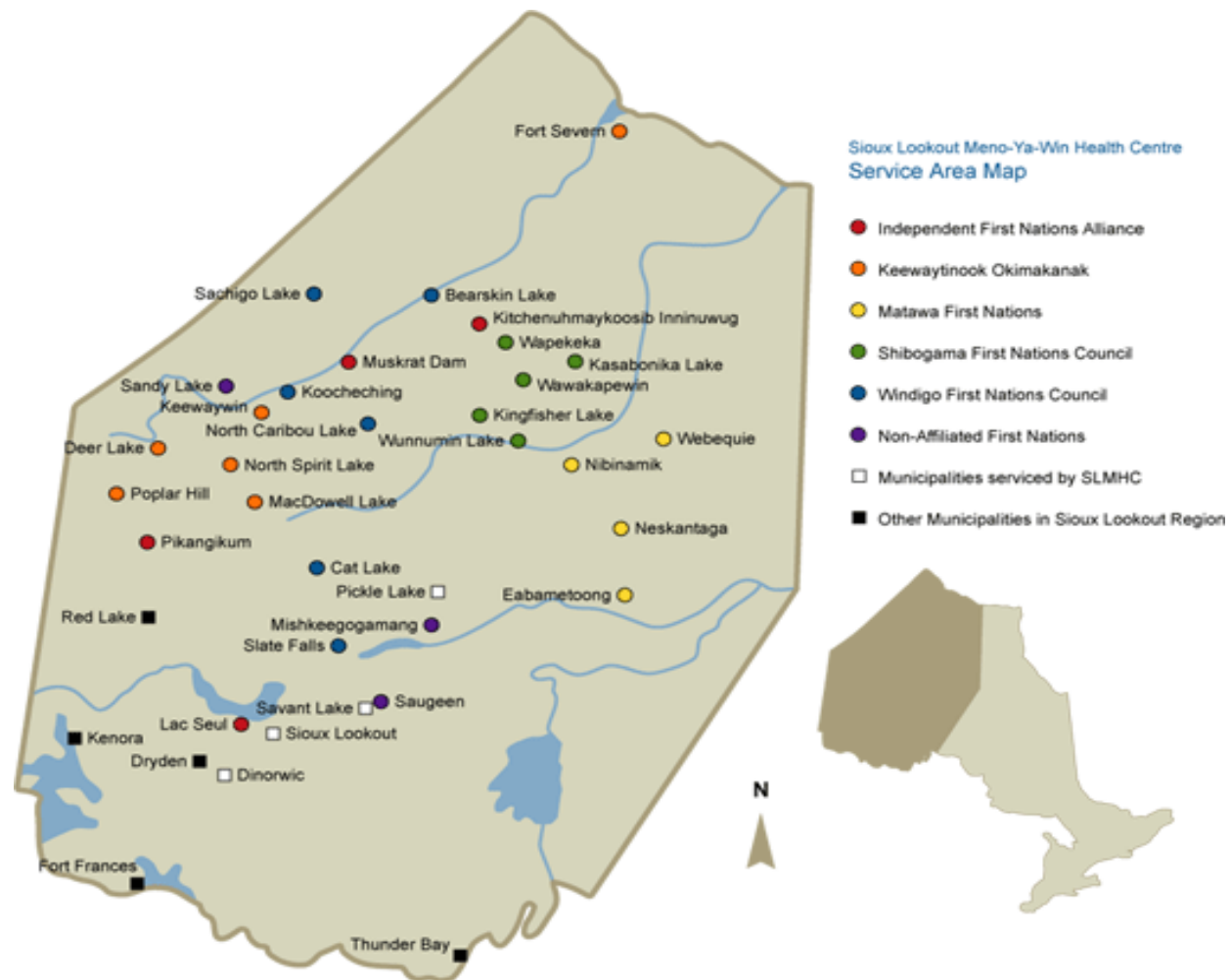
## Health Facilities Legend

-  Green circle is 33 Health Centres
-  Yellow triangle is 8 Health Offices
-  Red box is 22 Nursing Stations)
  - Red box with a dot in the middle is 17 fly in only communities
-  Black circle is 4 Provincial Nursing Stations
-  Red diamond is 2 Federally run hospitals
  - Norway House
  - Percy E. Moore





# NW Ontario



# KIVALLIQ REGION OF NUNAVUT



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# **Regional Discharge Planning Coordinator WRHA Aboriginal Health Programs-Health Services (AHP-HS)**

- assists in the coordination of a safe and appropriate discharge plan that is suitable to patients care needs.
- Provides advocacy, guidance and support to the Multi-Disciplinary Team, the Patient and Family, Community Health Programs, First Nation Programs and other service or supports that may be required to participate in the care plan.



# Palliative Care Discharge Challenges

- Variable availability of community health programs
- Support for Caregiver/s varies
  - Home care workers may be in difficult position of providing care to relatives
- NIHB or Other Coverage – often does not match provincial coverage
- Medication Storage, Management and Administration
- Jurisdictional – uncertainty RE funding responsibilities
- Socio-Economic
- WRHA bed utilization pressures
- Interpretation/Translation



# Working Group

- Working group started in 2011
- Representatives from Palliative Care, Aboriginal Health Services and Home Care
- Began with First Nations people being discharged within WRHA
- Evolved to discuss discharges outside of WRHA
- Built on experience with pediatric patients.



# Tool Development

- Learned from every discharge – shared experiences
- Group had clear vision of what we wanted to see
  - Some of us lacked knowledge about the system and life in remote communities
- Invited to attend meeting with Four Arrows RHA
  - Community members shared stories about caring for residents
  - Shaped our vision and commitment to continue work



# Clinical Considerations As Death Nears

1. Management of existing symptoms and medical conditions in the context of changing priorities, functional capabilities, and ability to take medications
2. Anticipating and addressing new symptoms that might arise in the final days (typically dyspnea, congestion, agitated delirium)
3. Accessing supplies and medications and ensuring availability, safe storage and disposal
4. Anticipating concerns of family and addressing emotional wellbeing and physical capabilities of caregivers
5. After-death details





# Predictable Challenges As Death Nears In Progressive Terminal Illness

- Functional decline – 100%
  - mobility (risk of falls), toileting, hygiene, etc.
- Decreased intake (food, fluids, meds) – pretty much 100%
- Congestion: reported as high as 92%
- Delirium: 80% +
- Families who would be grateful for support and information: must be near 100%

When these issues arise at end-of-life, things haven't "gone wrong"... they have gone as they are inclined to.



# Role of the Health Care Team

1. **Anticipate** predictable challenges
2. **Communicate** with patient/family
3. **Formulate** a plan for care



# Role of the Health Care Team

1. **Anticipate** changes and challenges
2. **Communicate** with patient/family regarding potential concerns:
  - What can we expect? How long can this go on?
  - Not eating/drinking; sleeping too much
  - How do we know they are comfortable?
  - Are medications making things worse?
  - Would things be different elsewhere?
3. **Formulate** a plan for addressing predictable issues, including:
  - Health Care Directive / Advance Care Plan, *particularly addressing*:
    1. artificial nutrition and hydration
    2. treatment of life-threatening pneumonia at end of life
    3. expectations RE: transfer out of community
  - Medications by appropriate routes for potential symptoms



# Specific Considerations in Remote Communities

- ensuring comfort during transportation
- connecting with community health care providers RE care plan
- agreement among family/community members for a palliative approach?
- family/community resources for supporting care in home
- health care providers and home support staff may find themselves having to provide care for dying relatives
- nursing support may not always be available 24/7
- medication availability, refills, safe storage, disposition
- is there a clear plan once death occurs?
- impact of a death on family and community – communal loss



# Tools

3 key components:

1. Guideline
2. Care Plan
3. Checklist



# 1. Guideline

Intended to be a reference when planning discharge for First Nations patients who want to return to their home community for palliative care.

- In cases where death is imminent – not all steps will be followed
- There will be barriers that may make discharge impossible



## Discharge Planning Meeting, including:

- Patient/family
- WRHA care team
  - aboriginal health
  - palliative care program
  - hospital unit staff
- Community team(s)
  - Home and Community Care
  - MD for community
  - Nursing Station/Community Health Centre staff,
  - Band representatives, Elders, RHA Pall Care Coord





# Discharge Planning Meeting

- Prior to meeting- call Nursing Station to see if they are aware of plans to return
- Review of the patient's illness, course of care in facility and approach to care when returning home:
  - Diagnosis
  - Prognosis
  - Whether or not patient/family/community would consider transfer back to WRHA or if goal is to remain in home community



# Discharge Planning Meeting

- If the discharge plan includes withdrawal of life-sustaining treatment – plan of care needs to be reviewed with WRHA Palliative Care Program Directors
- May be factors identified during planning that make discharge home impossible
  - Safety for patient, family and care team
  - Environmental factors that will not support care plan



# Discharge Planning Meeting

## *Review patient's medical condition & goals of care*

- Ensure that everyone is aware of plan as we move forward

## *Equipment*

- Is it available, accessible and who is responsible for obtaining

## *Oxygen*

- Is it available, accessible and who is responsible for obtaining



# Discharge Planning Meeting

## *Medications –*

- Who will primary prescriber be? At discharge and ongoing?
- Which pharmacy provider will be involved?
- How will medications be dispensed? Is nursing station prepared to assist?
- How/where will medications be stored?
- Who will be responsible for administering medications?
- Will there be resources available to help prepare medications? – e.g. syringes
- What will family/caregivers need to know about medications?



# Discharge Planning Meeting

## *Care in the home –*

- What services are available in community?
- Is training required?
- What support is available?

## *Documentation completed –*

- Letter of anticipated death –completed and sent to Medical Examiner and law enforcement agency for community
- Health Care Directive or Advance Care Plan



# Discharge Planning Meeting

## ***Transportation to home community approved and arranged-***

- Arrangements must be made for transportation from “bed in WRHA facility to bed in home community”
- Can patient travel by commercial airline? If not, life flight will need to be arranged.
- If by air – need to discuss transport after landing to home; may need boat ride, stretcher-capable vehicle
- Care needs need to be considered during entire journey including oxygen, medications and contingency plans in case of weather delay



# Discharge Planning Meeting

## *Plans for care after death reviewed-*

- Does the community use a funeral home or is burial on site?
- Notification of law enforcement and Medical Examiner
- How to dispose of/return medications?
- Availability of Nursing Station/Community Health Center staff at time of death?
- What support is available for family, community care team





# Discharge Planning Meeting

## ***Contact information documented and shared-***

- Nursing Station/Community Health Center
- Home and Community Care team
- MD
- Pharmacy
- Other care providers – e.g. oncologist
- Regional Palliative Care Coordinator
- WRHA Palliative Care program
- WRHA Aboriginal Health Services
- Canadian Virtual Hospice



## 2: Care Plan

- Developed & shared with everyone involved in care in the community including patient/family and WRHA staff



# Care Plan

- Template developed that summarizes information discussed in meeting:
  - Patient demographic information
  - Review of medical history
  - Summary of the overall approach to care
  - Scheduled and *prn* medications at time of discharge
  - Potential symptoms, pharmacological and non-pharmacologic management



# Care Plan

- Proposed schedule for:
  - nursing assessments
  - home and community care team
  - family to provide care - *Including specific information about things family can expect to do*
- List of equipment required



# Care Plan

- Information about procedures i.e. dressing changes, line care
  - including frequency, supplies required, how to reorder
- Information about medications and medication safety
- Health care team contact information



## 3: Checklist

- developed to guide team and provide easy reference for steps to follow.



Action	Completed
Meeting held	
Discharge feasible?	
Equipment issues addressed	
Oxygen arranged, if needed	
Medications – all issues addressed	
Care and support in home available	
Transportation arranged, approved	
Documentation - Health Care Directive, Coroner	
Contact information	
After-death plans	
Detailed care plan for anticipated symptoms	
Follow-up meeting / phone call arranged	



# What have we learned?

- Need to have preliminary call with Nursing Station/ Home and Community care before meeting
- Involving FNIHB staff to assist
- Plans may change quickly- keep options open
- Planning takes time
- What if discharge is not possible?
- Engagement of Aboriginal Health Services and Palliative Care Program is essential
- Teleconference with as many parties involved is key
  - Expand use of telehealth for meetings





# Feedback

- Care plans well received – need to make sure families understand to contact nursing station for help
- Developing relationships with teams in communities
- Communities appreciate support from WRHA Palliative Care Program
- Northern Connections (community primary care clinic focused on supporting urban First Nations patients) – want to be involved in supporting discharge plans



# Moving Forward

- Tools have been modified to be consistent with resources available for Nunavut patients
- Education sessions planned to support tool use
  - Regional Utilization team
  - Senior Leadership at Sites
- Model discharge planning so site teams can take the lead
- Share tools
- Learn from our experiences and others

