Winnipeg Regional Health Authority
Caring for Health

Office régional de la santé de Winnipeg
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PALLIATIVE CARE PROGRAM

Discharge / End of Life Planning for First Nations and Inuit Communities Guidelines

Date: January 2023
Approved: April 2024

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Purpose

These guidelines are intended to be a reference when planning discharges for First Nations, Inuit and Metis patients who want to return to their home community for palliative care in a northern remote location. It is recognized:

- In cases, where death is more imminent, all steps in this process may not be followed.
- There can be different barriers in communities, or care needs, that will not allow a home community discharge.
- The process for First Nations, Inuit and Metis patients returning to communities outside Manitoba is affected by differences in provincial and territorial structures, but the guidelines will generally apply. In these cases, it is especially important there is physician to physician discussion about the treatment plan.

If death is not imminent, planning should be as thorough as possible to support a smooth transition home. Teams **must** allow time to engage the patient, their family and community, as well as navigate the jurisdictional hurdles that are inherent in planning (for example, obtaining authorization / accommodations for additional escorts, ensuring pharmaceutical coverage, equipment delivery, etc.). A good plan takes time and effort but it can save a lot of frustration and make the experience less stressful for the patient, their family and the community as a whole.

Procedure

1. **Discussion with Local Community Care Team:**

   Contact the nursing station or local health centre in the home community to make them aware that a discharge home is being considered. The nursing station / health centre staff will have information about services available in the community that the patient and team will need to be aware of to begin planning.

2. **Patient / Family / Community/ Care Team Meeting**:

   Arrange a patient / family / care team meeting to review current and anticipated future care needs, discuss the logistics of planning and explore whether discharge to the home community is possible.

   Explore comfort level of family / community to support required care in the community.

All health care should be provided in a way that supports cultural safety. It is essential the person's wishes and preferences be respected while incorporating practices and traditions that are uniquely important to them as individuals. Using trauma and violence informed approaches to care can help ensure the relationship is meeting the needs of the patient in a manner that is not further perpetuating the trauma.

For more information see:

Cultural Safety Resources | Winnipeg Regional Health Authority (wrha.mb.ca)

It is critical to engage family and community member supports so the care plan reflects the priorities and values of the patient and considers the unique supports and barriers that may be a concern when planning end of life at home.

Opportunities to use virtual platforms (Telehealth, conference call, MS Teams) for these meetings should be considered.

Attendees at the meeting may include, but are not limited to:

- Patient and their escort(s) / family that are with the patient
- Interpreter
- Indigenous Health Services Discharge Facilitator (if returning to a First Nation or Metis community) or Kivalliq Inuit Services Discharge Facilitator (if returning to an Inuit community)
- WRHA Palliative Care Consult Team
- Clinical Unit Staff (Attending Physician, Clinical Resource Nurse, Allied Health Care Team – OT / PT/ HC, social work, pharmacist).
- Extended family / support network in home community
- Home Community Care Team (local physician, home and community services, nursing station / community health center staff, elders, band representative, Regional Palliative Care Program Coordinator)

Discussions should include the resources required in the community to address current and future care needs including anticipated medical changes.

Reconsider the feasibility of home if:

- Family / caregivers feel they are not able to meet care needs and / or manage anticipated changes when they arise
- Consensus cannot be reached among caregivers (professional and family) with care plan and / or goals of care
- Unable to provide an environment where medications can be safely stored and provided

- Environmental factors will not support care needs e.g. space in the home, running water, electricity

If there are concerns regarding the feasibility of the discharge, these must be raised and addressed by members of the care team before proceeding.

Topics that need to be discussed during the meeting include, but are not limited to:

- Clear Communication About Goals of Care:
  - Review course of treatment to date and goals of care moving forward.
  - Discussion should include what care can be provided within the community and strategies that will be used to provide comfort. If there have been interventions used in hospital that will not be available in the community (for example IV hydration, transfusion support) it is important to talk about what alternative strategies (medications) will be used to provide comfort.
  - Clarify ACP status and complete ACP documentation. It should be shared with patient and family, community nursing station / health center and community home care teams
  - Discuss plans to remain within community for end of life when illness progresses and clarify patient / family expectations about being transferred out of community

- Letter of Anticipated Death at Home (LAD):
  - Clarify who will generate and sign the letter and how it is distributed to the parties mentioned under "Communication with Medical Examiner / Law Enforcement"

- Equipment:
  - What equipment is required in the home and who is responsible for arranging delivery? Ensure the family has support for how to use equipment / troubleshooting issues.

- Oxygen (if needed):
  - What is required and who is responsible for arranging delivery? (Including obtaining required approval).
  - Include safety precautions (for example: presence of wood burning stoves, smoking in home)

- Medications:
  - Identify who is responsible for ordering, dispensing, obtaining necessary approval, education, storage and disposal.
  - Patients should be sent to the community with a minimum two-week supply of medication and explicit instructions on how to administer and get more medication when needed. Note: Communities may not have a pharmacy in the community and

there can be delays in obtaining newly prescribed medications (particularly in inclement weather). It is important to plan ahead.

- It is helpful to review list of discharge medications with the community specific pharmacy provider prior to finalizing care plan. This is especially important if the patient requires medications that need to be compounded or are not on the FNIHB End of Life Care Drug Formulary.
  (https://www.sac-isc.gc.ca/eng/1573680460871/1573680491141)
  - If medications are not on the formulary, an application for exceptional drug status form must be completed by the prescriber and sent to FNIHB before medications can be dispensed. Identify a member of the team who will be responsible for obtaining medication approval (for example Ward Clinical Resource Nurse). The pharmacy provider and / or FNIHB Pharmacist can assist with this process and problem solving.
- Safe storage of medications dispensed in the home is important. Explore the ability of the nursing station/ community health centre to store, prepare and dispense medications as needed.
- End-of-life medications, where possible, should be available using the sublingual / buccal route. Not all communities have nursing support to go to the home after hours to insert a subcutaneous line.

- Medical Care:
  - What nursing / physician supports are available in the community? (Including after-hours and weekend coverage)
  - What Home Care Services are available in the community and who will be providing them?

- Transportation Considerations:
  - Determine type of transport that is most appropriate given the patient's clinical condition (i.e. ground vs. commercial airline vs. medivac)
  - Consider the level of care that will be required during transport including i.e. medication administration to maintain comfort, whether or not oxygen is required (note: If oxygen is required on flight, the aircraft may need to be pressurized to conserve oxygen supplies)
  - Transportation services generally only cover the cost of facility to facility transfers and not to the patient's home. In some circumstances, arrangements may need to be made to cover the cost of transportation. Contact the Indigenous Health Services Discharge Facilitator for assistance if required.
  - The timing of transportation to the community is often not predictable. Consider the possibility of a delay or interruption in the transfer of the patient to their community e.g. bad weather, mechanical issues. Confirm who will be responsible for care in such circumstances with the transportation company and the local community.

- In some cases, it will be necessary to discuss the possibility that death could occur during transport. This should to be discussed with the patient, family and the transportation company. The Advanced Care Plan (ACP) should to be in place and reviewed with transport team.
- Travel may not end with arrival at community airport. Patients may have to travel a considerable distance after arrival and discussions need to take place regarding who will provide care, including administration of medications, during this second phase of transport. Clarify who will be responsible for arranging and supporting the patient during air / boat / ground transportation from the airport to the community.

- Care at Time of Death:
  - Who will provide care and handling of the body after death? (I.e. coordinate transfer to the funeral home)
  - What cultural practices are important to consider in caring for the patient after death?
  - How will unused medications and equipment be returned and / or disposed of?
  - What is the availability of Nursing Station / Community Health Centre staff to offer support to the family after death has occurred?

- Communication with Medical Examiner / Law Enforcement:
  - Identify most appropriate law enforcement agency to receive a copy of the Letter of Anticipated Death (LAD) i.e. RCMP or community Indigenous law enforcement agency
  - Letter of Anticipated Death (LAD) once completed should be shared with the following parties:
    - Patient / family
    - Community nursing station / health center
    - RCMP or community Indigenous law enforcement agency
    - Provincial Medical Examiner's office
    - Funeral home
    - EMS services (if in community)

Discussions during meeting should be documented and shared with all involved in meeting.

3. Developing Care Plan:

If discharge to the home community is planned, the WRHA Palliative Care consult team will develop a care plan in consultation with the attending care team in the community (See Care Plan Template)

The care plan should include the following information:

I. Clear communication about goals of care:
   - A review of the course of treatment to date and description of goals of care moving forward

- Clarification of ACP status
- Clarification re: patient / family expectations to remain in the community for end of life care as care needs change.

II. Pharmacologic management of symptoms (current and anticipated):
- List of medications prescribed on discharge
- Instructions about how and when to administer scheduled and as needed medications
- Plans for safe storage, dispensing and preparation of medications.

NOTE: If death is not imminent and there are limited active symptoms, the scope of the final care plan created may not be as detailed. For example, it may not be appropriate to give the patient and their family medications and instructions for their use when they are not currently needed. If returning to a community with limited on-site pharmacy support, consider prescribing a one to two week supply of "stock" medications that may be required at end of life to be stored in the health center or nursing station. This will ensure the medications are available for staff when required in the future to be used as directed by the primary care prescriber in the community. The WRHA Palliative Care Physician group is also on call 24/7 to provide advice as needed (this should be noted in the care plan).

III. Non-pharmacologic strategies for management of symptoms

IV. How to meet other care needs
- Activities of daily living
- Catheters
- Dressings / wound care
- Feeding / hydration / nutrition

V. What to expect as illness progresses and strategy to manage symptoms:
- In particular, any illness specific symptoms that may be anticipated such as seizures, bleeding, bowel obstruction, respiratory obstruction

VI. Contact information for team members including
- WRHA Palliative Care Program – Palliative Care Team will be available for consultation once patient reaches the home community (through St. Boniface paging (204) 237-2053)
- Physician providing care
- Home and Community Care team (home care), Nursing Station / Community Health Centre

May also consider including the following as needed:
- Regional Palliative Care Coordinator
- Band council member(s) as identified by family

Once completed the care plan should be shared with:
- Patient and family
- Nursing station and/or Community Health Centre staff

- Home care agency providing services in the community (home and community services if care provided by on reserve staff, regional home care program if provided by staff off reserve)
- Physician designated to provide care for the community
- A copy of the care plan will be added to the WRHA Community Palliative Care Chart (EMR)

4. Follow Up Plans:

Follow up conference calls / virtual visits can be scheduled to support the community team while care is being provided and after the patient has died. The frequency of calls will vary depending on the condition of the patient but the initial appointment should be made at the time of completion of the care plan.

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CHECKLIST

Discharge of First Nations, Metis and Inuit Patients Returning to Remote Home Communities for End of Life Care

Action	Completed
Patient / Family meeting held with facility care team (including Attending Physician / CRN / Allied Health / Interpreter / IHS Discharge Facilitator or Kivalliq Inuit Services Discharge Coordinator / PC Consult Team) and local community care team (Home and Community, Nursing Station / Community Health Center Staff / Local Physician)	
Discharge to home community determined to be feasible	
Equipment required for care identified, accessible and available	
Oxygen (If needed) – Ordered, approved, available, and safety teaching completed	
Medications – Minimum two week supply ordered, approved, dispensing pharmacy identified, and safety concerns addressed	
Care in Home – Providers identified, training available, and support available	
Transportation to home community arranged and approved	
Documentation Completed: • Letter of Anticipated Death – Faxed to Medical Examiner and local law enforcement • Advance Care Plan + / - Health Care Directive	
Contact information available to facility team members and home community team members	
Plans for care after death reviewed including care and handling of body after death	
Care plan completed including plans for current and anticipated symptoms (e.g. loss of oral route)	
Follow up meeting / phone call arranged	