Winnipeg Regional Health Authority | Office régional de la santé de Winnipeg
Caring for Health | À l'écoute de notre santé

Palliative Care Program
A8024 - 409 Taché Avenue
Winnipeg, Manitoba
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Programme de soins palliatifs
A8024 - 409 Taché Avenue
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Guidelines for Discharge Planning for First Nations Patients Returning to Home Community for Palliative Care

These guidelines are intended to be a reference when planning discharges for First Nations patients who want to return to their home community in Manitoba for palliative care. It is recognized:

- In cases, where death is more imminent, all steps in this process may not be followed.
- There will be different barriers in communities that will make discharge impossible.
- The process for First Nations patients returning to communities outside Manitoba will be altered due to the differences in provincial structures, but the guidelines will generally apply. In these cases it is especially important that there is physician to physician discussion about the treatment plan.

Procedure

1. Contact should be made with nursing station in the home community to make them aware that a discharge is being contemplated. The nursing station 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. A meeting between the facility care team and those providing care in the home community should be held to determine if the plan to discharge to a home community is possible. Opportunities to use Telehealth for these meetings should be explored.

   Attendees at the meeting may include, but are not limited to:
   - Patient and family – interpreter should be arranged Facility care team – clinical unit staff, aboriginal health services discharge coordinator, palliative care, social work, PT, OT.
   - Community team – Home and Community Care services, Nursing Station/Community Health Centre staff, MD for community, Band Representative, Elders

   Discussions should include the resources required in the community to address current and future care needs e.g. potential for bleeding or bowel obstruction.

If the discharge plan includes withdrawal of life-sustaining treatments (in the home community or before leaving WRHA), the plan of care must be reviewed by the Palliative Care Program management team before proceeding with further discussions.

There may be factors identified during discharge planning that may make discharge to home community impossible. These may include but are not limited to:

- Inability to provide an environment where medications can be safely stored
- Family/caregivers are not able to meet care needs and/or problem solve when issues arise
- Consensus cannot be reached among caregivers (professional and family with care plan and/or goals of care
- Environmental factors that will not support care needs e.g 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.

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

- Equipment – what equipment will be required in the home and who will be responsible for arranging
- Oxygen – (if needed) what will be required and who will be responsible for arranging – including obtaining needed approval. Will also need to include safety precautions such as presence of wood burning stoves
- Medications – identify who will be responsible for ordering, dispensing, obtaining necessary approval, education, storage and disposal.
    - Patients should be sent to community with medication and explicit instructions on how to administer and get more medication when needed.
    - It may be helpful to review list of discharge medications with 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 Palliative Care Drug Formulary (http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/provide-fournir/pharma-prod/med-list/palliat-eng.php)
    - If medications are not on the formulary, an application for exceptional drug status form needs to be completed and sent to Ottawa before medications can be dispensed. The pharmacy provider and/or FNIB Pharmacist can assist with this process and with problem solving.

- Safe storage of medications dispensed in the home is important. Team should explore the ability of the nursing station/ community health centre to store, prepare and dispense medications as needed.

- Home care services– what services are available in the community and who will be providing.
- Medical care – which physician or physician organization provides medical care in the community – how to share pertinent information with them
- Law Enforcement Agency - Information about which agency provides law enforcement in the community (RCMP or aboriginal police force)
- Letter of Anticipated Death (LAD) – once completed –identify parties that should receive a copy. e.g. nursing station or Community Health Centre, RCMP and/or aboriginal police service, Band Council, Provincial Medical Examiner's office, funeral home if applicable.
- Health Care Directive-if in place and who should receive copies
- Transportation to home in community
  - Timing of transportation to the community is often not predictable as it will be dependent on the availability of equipment.
  - Transportation arrangements are made through FNIHB. Contact FNIHB Medical Transportation Unit (TRU) @ 1-877-9830911 or 204-984-4773.
    - FNIHB will contact nursing station to make sure they are aware that the patient is returning
    - FNIHB will need information about the physical health status of the patient to determine the most appropriate form of transport.
      - ❖ If patients are able to travel by commercial airlines, FNIHB will make arrangements.
      - ❖ If patient is not able to travel on commercial airline, FNIHB will make arrangements for transfer via Medivac. If Medivac is required –the transport will not be confirmed more than 24 hours in advance. TRU may also require a letter from a physician indicating the need for Medivac services.
    - MTCC will contact the sending facility to confirm the level of care that will be needed during the flight including:
      - ❖ The need to administer medications during transport
      - ❖ If oxygen is required the aircraft may need to be pressurized during the flight to conserve oxygen supplies.

- ❖ Consideration should be given 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 family and the transportation company. HCD/ACP should to be in place and reviewed with transport team.
- ❖ FNIHB will book ground transportation in WRHA using licensed transport providers
- ❖ FNIHB will contact the community once the flight is confirmed.

- 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 to provide care, including administration of medications, during this second phase of transport. If ground transportation is required in the community, FNIHB will be responsible for making these arrangements.

- <u>Transfer to a health care facility in a community</u>
  - FNIHB will not cover transportation costs to a health care facility
  - If patient is returning to a facility within a Rural Health Region, the sending facility should contact the receiving facility. The receiving facility will then contact the Manitoba Transportation Coordination Centre (MTCC) to make arrangements for transportation to facility. Once arrangements are made, the receiving facility will notify the sending facility. The receiving RHA will pay the transportation costs. Negotiations will then take place between the region, province and FNIHB regarding payment.
  - If a patient is returning to a federal facility – Norway House or Percy Moore (Peguis) the sending facility will make transportation arrangements and pay the transportation costs. Once paid, a copy of the invoice should be sent to WRHA Regional Director of Transportation for tracking purposes.

- <u>Care at time of death</u>
  - Who will provide care and handling of body after death

- Does the community use the services of a funeral home or do they have burial on site
- Notification of provincial medical examiner - LAD
- Notification of local law enforcement agency – LAD
- How to dispose/return medications
- Availability of Nursing Station/Community Health Centre staff

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

3. If discharge to the home community planned, a care plan should be developed in consultation with the care team in the community. The care team in the community must include representatives from: Nursing Station and /or Community Health Centre, and Community Care team. If the patient is returning to a community adjacent to a reserve, it will be essential to clarify who is providing services/care in the home – community team or regional health authority home care.

The care plan developed should contain information on the following:

- Pharmacologic management of symptoms (current and anticipated)
  - List of medications prescribed on discharge
  - How and when to administer scheduled medications
  - How and when to administer breakthrough or prn (as needed) medications
  - Plans for storage, dispensing and preparation of medications.
- Non-pharmacologic strategies for management of symptoms
- How to meet other care needs
  - ADLs
  - Catheters
  - Dressings
  - Feeding/hydration/nutrition
- What to expect as illness progresses
  - Potential for symptoms such as seizures, bleeding, bowel obstruction, respiratory obstruction
- Contact information for team members including
  - WRHA Palliative Care Program – palliative care team will be available for consultation once patient reaches the home community.
  - Physician providing care
  - Home and Community Care team, Nursing Station, Community Health Centre,
  - Regional Palliative Care Coordinator
  - RCMP and local law enforcement
  - Band council

Once completed the care plan should be shared with:

- Patient and family
- Nursing station and/or Community Health Centre staff
- Home and Community care staff or Regional Home Care program staff
- Physician designated to provide care for the community
- WRHA Aboriginal Health Services
- WRHA Palliative Care team and Rural Palliative Care Coordinator

4. Follow up conference calls/tele-health should be scheduled to support community teams 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.

5. Physician follow up
   The attending physician should contact the receiving physician (or physician organization) to transition the medical plan of care immediately prior to transfer to the community. Information for ongoing consultation with WRHA Palliative Care program should be included in this transition meeting.

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Date developed:

Name:
Address:
DOB:
PHIN:
MHSC:
Treaty Number:
Substitute Decision Maker / Proxy:
Allergy:

Diagnosis:

History:

Overall Approach to Care: (Include info re: comfort focused approach, Advance Care Plan / Health Care Directive, awareness of life expectancy, whether or not pt/family/community would consider transfer out of community or if goal is to remain at home)

CARE PLAN

Medications at time of transfer:

a) Scheduled Medications:

b) As Needed Medications:

(using generic name with trade name in brackets)

Possible Symptoms and Suggested Care:
Possible symptoms that **may** be experienced and the way to manage them are listed in the chart below.

SYMPTOMS	MEDICATIONS TO HELP	OTHER WAYS TO HELP
Pain or Shortness of Breath	**Scheduled pain reliever:** **Extra pain reliever as needed:** **Comments:** Pain medications are used to relieve pain, improve comfort and/or decrease feelings of shortness of breath. ** If more than three or four extra doses are needed in a day, call your nurse or doctor for advice (dose may need adjusting)	Other helpful ways to relieve pain: - changing positions or moving / turning the person - using hot or cold packs for short periods as tolerated (not to be used over medication patch) - help the person to think about something else (meditation / prayer, telling a story, watching television) - pain medications can slow the bowels and laxatives are often needed to go to the bathroom regularly Other helpful ways to relieve shortness of breath: -raise the head of bed -open window or have a fan to increase air movement -cool cloth on forehead -stay with person – calm soothing voice to help them relax or perhaps help them to think about something else
Pain or Shortness of Breath caused by activity		Plan ahead when preparing to move – give pain medication 30 minutes prior

		to activity so that the medication has time to start working. It will lessen pain or shortness of breath during the activity. Offer help with moving Pace yourself – take rest as needed Use equipment to make movement easier (walker for walking, raised toilet seat) shorten distances (commode at the bedside)
Feeling nervous or worried (which can be made worse by pain or shortness of breath)		Other helpful ways to relieve nervousness: - practice ways to relax (focusing on controlled breathing, meditation, prayer, thinking about something else, music) - talk about what is worrying the person and ask for help if more support is needed - stay with the person to calm him / her - turning / changing position
Confusion (strange thoughts and fears)		Other ways to help confusion and restlessness: - comforting, familiar surroundings - clock and / or calendar to keep track of time - soothing, gentle voice - if the person is confused, they may say or do things that feel hurtful – remember, this is the disease and not in the person's control – acknowledge their fears and use medications to help them feel more calm.

Taking care of bowels		Medications and illness can cause the bowels to move slowly making the stool hard and difficult to pass Bowel medications can help to keep them moving more regularly (a person should have a bowel movement at least every three days)
Feelings of Nausea or vomiting (upset stomach / throwing up)		Other ways to help with upset stomach: - have the person "listen to their body" and eat or drink only what they want - bland foods like rice, bread, and crackers are sometimes easier to take - try many small meals rather than big meals - if sudden vomiting or severe belly pain and not able to pass gas or stool, call your nurse.
Noisy bubbling breathing when too weak to cough		As a person gets weaker it is more difficult for them to clear phlegm. Often they are not aware of this noisy breathing (like snoring) but it can be hard for family to hear. Repositioning can also help.

Care at Home:

Include the following information:

Schedule for nursing assessments at home

Schedule for health care aid personal care / respite care

Schedule for family to be with patient (including specific info re: who, when, things they may be expected to do while caring for the patient – i.e. medication administration, personal care)

Specific information about equipment required (walker, oxygen, hospital bed, etc)

Information about dressing changes, central line care, etc (frequency of care, supplies required, who will provide / re-order supplies as needed)

Information re: medication safety (who will order medications, through what pharmacy, how will meds be dispensed, is nursing prep needed – i.e. drawing medication in syringes, who will administer, how will we keep track of medications given, how will medications be stored)

Any special care needs (sharing of personal health information, safety plans etc)

Limitations / considerations re: care that can be provided in the home:

Health Care Team Contact Information:

Nursing Station / Health Center info

Home and Community Care team info

Primary physician (prescriber) involved in care

Pharmacy

Other providers (oncologist, nephrologist, etc)

Regional Palliative Care Coordinator resource

WRHA Palliative Care Consult Service:
A palliative care physician is available through St. Boniface Hospital paging: (204)237-2053 to provide advice and support to the primary care team 24hr/day, 7 days per week.

Canadian Virtual Hospice: www.virtualhospice.ca for information / written resources

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Checklist for Discharge of First Nations Patients Returning to Home Communities

Action	Completed
Meeting between facility care team (palliative care, aboriginal health services and unit staff) and community team(s) (home and community care, nursing station, community health center) held	
Discharge to home community determined to be feasible	
Equipment required for care identified, accessible and available	
Oxygen(If needed)– ordered, approved and available	
Medications – ordered, approved, dispensing pharmacy identified, safety concerns addressed	
Care in home – providers identified, training available, support available	
Transportation to home community arranged and approved	
Documentation completed • Letter of Anticipated Death – faxed to ME and local law enforcement • Health Care Directive, Advance Care Plan	
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	