Palliative Care

Information for Patients and Caregivers



A philosophy of care

Healthier people.

Healthier communities.

Thriving together.



The Southern Health-Santé Sud Palliative Care Program has put together this information for our patients and their caregivers. This information is intended to introduce you to our team, our services and other services which may be available. We hope you find this helpful.

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This publication is available in alternate format upon request.

What is Palliative Care?

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems 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).

In Southern Health-Santé Sud, palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- will enhance quality of life and may also positively influence the course of illness
- is applicable early in the course of illness



What Palliative Care Services are Available in Southern Health-Santé Sud?

Palliative care is a philosophy of care. A palliative approach to health care is used when a patient's goals of care shift from treatments which are intended to cure to goals which are focused on quality of life and symptom management.

A person does not need to be close to death to take a palliative approach to health care. This approach can be taken in any hospital, personal care home or in the patient's home.

All nurses and doctors receive basic education about a palliative approach and can work with a patient and their caregivers to meet the patient's goals of care.



Regional Palliative Care Team

Our team consists of nurses, palliative care physicians and a social worker. This team provides specialized knowledge to patients, caregivers and other health care providers about palliative matters, such as pain and symptom management.

Nursing If you are referred to the Regional Palliative Care program, you will be contacted by a member of the team. A primary palliative care nurse will be assigned to be your nurse. The nurse may visit you at home or in the hospital or personal care home. You, the patient, may also decline a visit and wait until a later date to see the palliative care nurse.

Once you meet the palliative care nurse, they will be your resource for issues related to your illness. The nurse will:

- do a physical health review
- review your medications
- discuss how you are feeling
- discuss pain and symptom management
- teach you about your medications
- provide information about what can be expected as your condition deteriorates; and
- offer various options to maximize your quality of life

Your palliative care nurse will communicate and work with your health care providers to manage your care and symptoms. This might include your oncologist, your family doctor, a home care case coordinator and other home care providers.

The palliative care nurse may call you to check up on you once in a while.

Doctors If you are referred to the Regional Palliative Care program, you have access to physicians who have taken extra training in palliative care. The palliative care physicians, working with your palliative care nurse and your primary care provider (family doctor, nurse practitioner or physician assistant), can assist with your care.

Social Worker

The social worker can help with:

- Practical Issues information about specific financial resources, such as the Compassionate Care Benefit and the Terminal Illness Application for CPP.
- Psychological Support discussions to help with the multitude of decisions related to end of life care and the personal and familial challenges related to the changes which occur at end of life.
- Exploration of the emotional impact of illness and the effect it has on coping and strategies to manage fear, anxiety, anger and sadness while caregiving.
- Social Support how to communicate with your partner, children, family, friends or colleagues about illness and end of life.
- Bereavement support for spouses, children and families as they journey through the grief process.
- Referral help to find peer and group supports, education and information.

How the Team Works The Regional
Palliative Care Team works as a team. This
means the patient and caregiver may
meet several different team members.
Nurses, doctors and the social worker
communicate with each other regularly
about each patient's needs and status in
order to best help the patient.

The palliative care nurse will start a palliative care record for the patient and record assessments, document notes about visits and record medication changes, for example.

When the Team Works The Regional Palliative Care Team is available to provide services Monday – Friday, from 8:30 am to 4:30 pm. Your palliative care nurse will make you aware of their schedule.

When team members are off duty or away, another team member will cover the other's patients during regular business hours. Covering team members can be reached by phone. Voice mails are updated to reflect who is working and who is covering.

Resources & Information to Help You

Palliative Care Drug Access Program This provincial program is in place to provide medications to you at end-of-life at no cost. You will need to sign an application form to apply for the benefit. Your doctor will also need to sign the form. Once you have signed the form, the Southern Health-Santé Sud Palliative Care program will review your application and determine if you meet the eligibility criteria.

The form is submitted to the Manitoba Pharmacare program and once it has been processed you will no longer be charged for medications that are covered under the program. Please see link below for more information regarding criteria and coverage: https://www.gov.mb.ca/health/pcdap/index.html

Palliative Oxygen if you require home oxygen, the cost of the oxygen is covered by the Home Oxygen Concentrator Program (HOCP). The oxygen company will call to schedule a delivery time and will set up and teach you how to use the oxygen. Once oxygen is no longer needed, the company should be called and they will pick up the equipment. Oxygen concentrators are supplied under this program if you qualify. Oxygen tanks are provided under the Palliative Care Drug Access Program, if you qualify.

Accessing Equipment During your illness, you may need to access equipment to help you manage on a daily basis.

Mobility Aides - such as canes and walkers and/or transport wheelchairs are sometimes available for borrowing for a period from your local Services to Seniors office. If you need a wheelchair for longer term use, you will need to be seen by the Occupational Therapy program for measurements. A wheelchair can be ordered for you at no cost through the Society for Manitobans with Disabilities and delivered to you by mail.

Hospital Beds, Tables or Commodes - if you need other equipment such as a hospital bed, over-bed table or a commode, your Case Coordinator - Home Care can order this equipment and have it delivered to your home. Delivery of equipment can take up to 5-7 business days, therefore; it is important to think in advance about the equipment you may need.

Emergency Response Information Kit (ERIK)

The use of this kit is beneficial for you, your family and the emergency response team should you need their help. This kit contains a Health Care Directive, a list of your current medications and contact information for your primary care provider. Ask your nurse about this kit and s/he will help you to access one and complete it. Once completed, make sure to place the ERIK on your fridge and the red ERIK sticker on your front door. Should the paramedics attend to you at your home, they will locate the ERIK immediately upon arrival and follow the directives in it.

Notification of Anticipated Death at Home (NAD)

The decision to die at home is not always a straightforward or easy one to make. However, this is something you should discuss with the palliative care nurse. S/he can help answer questions about what this might be like for you and your family.

The NAD contains information necessary for all involved parties once death has occurred. The NAD is put in place to ensure your wishes are followed when death happens at home. It is intended to provide the family with a plan for the funeral home to pick up the body directly from the home without involvement from the police or the Chief Medical Examiner.

Whether your wish is to die at home or not, having the document in place does not mean you cannot go to the hospital or that you must stay at home. It would be put in place should circumstances change or should you and/or your family change the plan of care. For the form to

be completed, you will need to provide the name of the funeral director in charge of funeral arrangements. Your doctor will need to sign this document. A copy will be placed in your ERIK.

Accessing Hospital Care If/when care at home becomes difficult or symptoms become unmanageable, a hospital admission may be necessary. Your palliative care nurse may be able to assist you in accessing a bed in a local hospital if you need admission during weekday hours when they are is working. Should your symptoms after hours change and become unmanageable, you will need to access care through the emergency department of your local hospital.

The staff at the hospital will assess you, ask you questions and work with you to help you. If it is decided that an admission to hospital is the best course of action, the staff at the hospital will make arrangements for an admission.

Although staff in the hospitals do their best to place patients in the most appropriate setting, for various reasons, it may not be possible to place you in a private room. If you are admitted to a private room, there is also no guarantee that you will not be transferred out of that room.

Please keep in mind that the palliative care nurses working in Southern Health-Santé Sud do not have the ability to access hospital beds in Winnipeg. Should you wish to receive care in Winnipeg, you will need to access the care through an emergency department of a Winnipeg hospital. There is also the possibility that once your symptoms are stabilized, the Winnipeg hospital may suggest transferring you to a hospital within your region.



Emergency Services If a situation occurs which requires emergency transportation to the hospital, it is important for you to know that any costs incurred from emergency ambulance transportation or any other stretcher/wheelchair transportation is not covered by the palliative care program.

If you call emergency services (911), please remember, when you are leaving your home to go to the hospital, to bring with you;

- all the medications you are currently taking;
- your Health Care Directive; and
- any other information relevant to your care.

Non-urgent Transportation Should you require a hospital admission but are not able to be taken to the hospital in a vehicle, you can book non-urgent transportation through 911. You must tell them that you wish to book non-urgent transportation from your address to the hospital. You will be asked all the usual emergency questions which you must answer and then instruct them that it is non-urgent. You will be charged the usual ambulance fee.

Use of Medications During your illness, you may be prescribed a variety of medications to help control your symptoms. Some of these medications are controlled substances and can be dangerous to others around you. It is important to store all your medication in a safe place. Also be aware not to speak freely about all the medication you have in your home. This could bring about unnecessary risk to you and your loved ones in your home.

Medications may change frequently during your illness trajectory. Sometimes the type of medication will change, sometimes the dosage or strength of the pills and sometimes the route of administration. Be mindful of all the medications in your home. Unless you are specifically asked to keep a medication, once you are no longer using it, return the medication to a pharmacy to have them dispose of the medications appropriately.

Once death has occurred, all unused medications should be taken to a pharmacy for disposal. To find a local pharmacy that will accept unused medications, please visit: http://healthsteward.ca/province/manitoba/.



Questions or Concerns

If patients and caregivers have questions about the program, services, offered, concerns about service provided or want to share positive experiences about your care, please contact:

Kelly Kaleta, Director - Home Care, Palliative Care & Seniors Southern Health-Santé Sud 180 Centennaire Dr Southport MB ROH 1H1 T 431-541-7479 F 204-428-2779

Email: kkaleta@southernhealth.ca

Additional Palliative Care Services Available in Southern Health-Santé Sud

The Regional Palliative Care Team can help you and your caregivers access other services and resources as well. Some of these are listed below:

Bereavement Support

- Bereavement support may be provided by volunteers, professionals, or in a group setting.
- If a patient or caregiver are interested in bereavement support please discuss this with a palliative care team member.

Compassionate Leave

This is a federal government initiative that provides up to 26 weeks of paid leave for caregivers of critically or terminally ill loved ones.



Information about this initiative can be found online at http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml or by contacting your local Service Canada Office, or calling 800-277-9914.

Volunteer Support

- Volunteers provide emotional and practical support to the person who is dying, family, caregivers, or friends.
- Volunteers receive special training. about palliative and end of life care.
- Volunteers are managed in most communities by local community groups who are interested in augmenting the services of the Regional Palliative Care Team.
- Patients and caregivers who are interested in learning more about volunteer services can either speak with a palliative care team member, or contact one of the groups listed on p. 9.

Altona	T 204-324-4480
Boundary Trails	T 204-331-8815
Carman	T 204-745-2021
Emerson	T 204-746-7356
Gladstone	T 204-872-3318
Morris	T 204-746-7356
Pembina Manitou	T 204-242-4461
Portage la Prairie	T 204-857-3746
Rock Lake	T 204-825-4357

Community Palliative Care Volunteers Coordinators



Southern **Health-Santé** Sud **PALLIATIVE CARE PROGRAM**

8 380 Stone Bridge Crossing Steinbach MB R5G 2R1 T 204-346-7034 | F 204-388-2049 Toll Free 800-742-6509

Email: info@southernhealth.ca

Palliative Care Team Contact Information

Manager - Palliative Care Cell 204-905-3302

Southwest Area

Palliative Care Nurse -Boundary Trails Health Centre **T** 204-905-3908

Winkler - T 204-823-0550

Morden - T 204-332-0235

Altona - **T** 204-361-6480

North Area

Palliative Care Nurse Portage District General Hospital

1 204-905-9963

Carman - T 204-823-2162

Portage - T 204-408-8985

Morris - **T** 204-870-7476

Palliative Care Coordinator

Cell 204-392-3115

East Area

Palliative Care Nurse Bethesda Regional Health Centre

1 204-905-9961

Steinbach - T 204-371-7398

Ste. Anne - T 204-905-4234

St. Pierre - **T** 204-371-1497

Social Workers

Southwest - **T** 204-361-6464

North - T 204-371-0554

East - T 204-392-6011

At some time, in some way, we must all face the end of life. And when death comes to us or to a loved one, we hope it will be peaceful and free of pain. We hope to be surrounded by those we love, feeling safe, comfortable and cared for.



Dr. Cornelius Woelk, Medical Director - Palliative Care

T 204-325-4312

F 204-325-4594

Dr. C.W.Wiebe Medical Centre, 385 Main St Winkler MB R6W 1J2

- Responsible for the overall medical direction of the Regional Palliative Care Team.
- Responsible for the provision and/or facilitation of consultation regarding symptom management, support, education, research and evaluation.

Dr. Darren Reimer, Physician, Palliative Care

F 204-388-2049

8 380 Stone Bridge Crossing Steinbach MB R5G 2R1

 Responsible for the provision and/or facilitation of consultation regarding symptom management, support, education, research and evaluation.

Dr. Tanja Borchers, Physician, Palliative Care, Pediatric Palliative Care T 204-331-2332

 Responsible for the provision and/or facilitation of consultation regarding symptom management, support, education, research and evaluation.

After hours, you may go to your local emergency department or call Health Links-Info Santé 888-315-9257 for help.

Culture of Safety

Southern Health-Santé Sud strives for a just culture of safety. A just culture of safety is creating a work environment where everyone feels safe to report any concerns without laying blame for system learning and improvement including patients, residents, clients and families.

Southern Health-Santé Sud encourages patients, residents, clients and families to request the information they need in order to become active participants in their care. If you or your loved one have any questions or concerns relating to a possible safety event, do not hesitate to contact your health care provider to discuss these questions or concerns and steps that can be taken to address them.