

Advanced Cancer Patient Information

Emotional and Practical Aspects of Care

►PART 2 OF 4

Information and resources for
patients living with advanced
cancer in Manitoba.



Changing *FOCUS*

*Living with
Advanced Cancer*



Proudly supported by:

 **CancerCare Manitoba**
FOUNDATION

All funds raised stay in Manitoba.

 **CancerCare Manitoba**
COMMUNITY ONCOLOGY PROGRAM
Community Cancer Programs | Uniting Primary Care and Oncology

Introduction

This booklet is for patients living with advanced cancer as well as family members or caregivers. It will help you think about decisions you may need to make in the future, as well as practical information on programs that can assist you with the financial burden that you may be experiencing. The booklet also contains information about provincial resources and services. It lets you know the programs or people available within CancerCare Manitoba to meet the health care needs you may have related to your advanced cancer.

There are various parts to this booklet and you can use it in the way that works best for you. Not all the information in this booklet will apply to you. You may find information about things that don't affect you or things you don't want to read about at this time.



This booklet may bring up many questions for you. Information in this booklet is provided in a general way. If you have specific questions about your health or cancer treatments, please discuss them with your health care team.



Please go to www.livingwithadvancedcancer.ca for additional information that you may find helpful, such as videos and links to various websites.

This booklet includes information from the Canadian Virtual Hospice (www.virtualhospice.ca).

Slight modifications were made to their content in order to be relevant for patients living with advanced cancer and to provide local information.

Permission was obtained from the Canadian Virtual Hospice to use and modify their content.

©Copyright 2016-2017 CCMB Transitions, Community Oncology

Table of Contents

Learning You Have Advanced Cancer: The Emotional Impact.....	2
What is Palliative Care?.....	3
Health Care Decisions and Considering the Future	7
An Approach to Decision Making and Advance Care Planning	8
Health Care Directives.....	11
Preparing a Will.....	14
Financial Aspects and Concerns.....	15
Medication Coverage Information.....	17
Additional Supports and Resources.....	18

Learning You Have Advanced Cancer: The Emotional Impact

Finding out that your cancer is advanced (has gotten worse), is not something you want to hear. This can be a frightening time filled with many questions.

People living with illness, and their loved ones, often experience emotions like fear, sadness, anxiety, grief and worry. Some people are shocked or angry. Many people have such a rush of emotions that it can be hard to sort out. At Patient and Family Support Services we have experienced people to talk to and programs to help you and your loved ones cope.

PATIENT AND FAMILY SUPPORT SERVICES

PSYCHOSOCIAL ONCOLOGY

Experienced counselors (psychosocial clinicians) are available to talk with you about issues related to living with advanced cancer. The services are:

- Confidential
- Free of charge
- Available to patients and families
- Able to meet with you individually or together with a family member
- Able to link you with resources and support groups
- Able to help you troubleshoot practical issues such as a change in your financial needs

Anyone can request an appointment. Talk to your health care provider or call the Psychosocial Oncology department to arrange an appointment.

204-787-2109

or

toll-free 1-866-561-1026 ext 2109



What is Palliative Care?

Palliative care is a type of health care for patients and families facing life-threatening illness like advanced cancer.

- It is also called comfort care or end-of-life care.
- It provides care that makes patients feel better, but doesn't cure the cancer itself.
- The goal is reducing pain or discomfort caused by treatment or the cancer.
- It addresses social, emotional and spiritual support needs.
- It can include treatment for non-cancer problems such as pneumonia or a bladder infection.

What can I expect?

- The focus of your care is changing. Your health care providers are concerned about your quality of life (helping you feel as well as you can for as long as you can).
- The most important thing is controlling pain or discomfort.
- You may see your family doctor more frequently.
- You may start or increase home care services.
- Palliative care specialists may join the health care team.

Palliative care for people living with advanced cancer

Palliative care isn't just for comforting those dying of cancer. Doctors now offer this care to everyone who is living with advanced cancer. Often people start palliative care as soon as they find out they have cancer. Then they are sure pain and discomfort are always under control. Now pain or discomfort won't stop them from doing things they enjoy.

Choosing palliative care does not mean giving up hope, but rather changing what you hope for. The treatment goals are different now, we want to stop pain or other discomfort.

What is palliative chemotherapy and palliative radiation therapy?

Palliative chemotherapy or radiation therapy has the goal of stopping pain or other discomfort. This treatment:

- might shrink a tumor or slow down a tumor's spread
- may improve a person's quality of life (they will feel better and enjoy activities of daily living)
- does not cure the cancer

Do I need a special doctor or nurse to receive palliative care?

Often your health care team can provide comfort care. Sometimes a palliative care specialist may be the best person to treat some problems.



Ask your doctor or nurse if you would like to meet a palliative care specialist.

What is quality palliative care?

- Listens to the patient and their family
- Meets the patient's and family's emotional, cultural and spiritual needs
- Works to stop or reduce things like pain, upset stomach, feeling like you can't eat and becoming confused
- Helps the patient feel respected, supported and keep a sense of well-being
- The team caring for you may include volunteers, counselors/social workers, nurses, physicians and spiritual leaders

What is Palliative Care?

When is palliative care provided?

Palliative care can be provided to anyone with advanced illness

- at any age
- at any time
- with the ultimate goal of comfort to the patient.

As long as your health care providers are paying close attention to controlling your pain and other symptoms, you are receiving palliative care, even if you aren't registered in an official Palliative Care Program.

Who Provides Palliative Care?

Many health care providers contribute to palliative care teams, depending on the needs of the patient and the family:

- nurses
- oncologists
- primary care providers - family doctors / nurse practitioners
- social workers
- spiritual care providers
- palliative care specialists
- occupational therapists & physiotherapists
- home care and personal support workers
- volunteers
- pharmacists
- others

What is a Palliative Care Coordinator?

Each health region in the province of Manitoba has palliative care coordinators. They are in charge of assessing and planning the care of palliative care patients. The palliative care coordinators contributing to your care will also vary depending on your specific needs and the services available where you live.

Volunteer Visitors

Volunteer support may be provided by some palliative care programs and is also available from Palliative Manitoba (formerly Hospice and Palliative Care Manitoba)

Palliative Manitoba volunteers are carefully screened, selected and trained to offer support to individuals and families living with life limiting illness. Volunteers are matched with clients and their families and are available to talk on the phone or make in home visits.

Palliative Manitoba also provides volunteers who are trained to provide bereavement support over the telephone on a one to one basis.

Palliative Manitoba can be contacted at: 204-889-8525 or through their website at: www.palliativemanitoba.ca



Where is palliative care provided?

The best place to receive care depends on your needs. Many palliative care programs provide services and support for patients wherever they are living – at home, in a residential hospice, in hospital or in a personal care home.

Home

Some people choose to stay at home for as long as they can. Family members, with support from the health care team, may decide that they want to be the main caregivers.

Many communities have supports and services to help patients and families provide care at home, including these:

- **Home Care Program**

The home care program in Manitoba offers palliative care services in the home. Professional nursing care and other home-based support services may be available to assist the family caregivers. Many home care programs offer respite programs that provide short-term patient care for several hours.



Talk to the health care team in your community to find out more about hours of operation and available services.

- **Palliative Care Programs**

Palliative care programs may offer in-home visits from nurses or doctors who are specialists. Even if in-home visits are not available, Palliative Care Program staff are on-call to offer advice by phone to local health care providers.



Talk to your local healthcare team or your team at CancerCare Manitoba to find out about the palliative care resources available in your area.



Palliative Care Programs are available throughout Manitoba. A list of contact numbers is included in the additional supports and resources section on [page 19](#).

- **Private Companies**

Sometimes people will pay for private home care services because they need extra help. Private home care companies supply part-time, as needed or around-the-clock care. However, unless you have insurance, you will have to pay for these costs yourself. Private services may include:

- nursing/medical care
- personal care
- cleaning
- cooking
- companionship
- transportation

If you choose to stay at home, remember that at any point you can change your mind about where care is going to happen. Some families decide they want a home setting for as long as possible. If you eventually choose to leave home, palliative care can be provided in any care setting.

What is Palliative Care?

Residential Hospice

A residential hospice provides full-time palliative care, usually in a home-like setting.

Some hospices will also take care of the person who is ill for a few days at a time so that caregivers can get some rest.

Residential hospices often give priority to people who are nearing the last stages of life and are not expected to live more than a few months. Hospice staff will pay close attention to physical symptoms. Staff will also care for the patient's emotional and spiritual health.

Hospital

Many hospitals have staff with special training in palliative care. These people provide support and work with the patient and the patient's health care providers.

Some hospitals have special palliative care units or wards to help manage symptoms that are more difficult. These units offer privacy and a more home-like environment. Unfortunately these areas aren't meant to be used for long-term stays. Instead, symptoms are brought under control so that patients may be transferred to a place where it's appropriate to stay for a longer period of time such as a hospice, their home or a personal care home.

Sometimes the care provided in a residential hospice is not fully covered by the public health system. In that case, the family will likely be required to pay a daily charge (per diem). Sometimes private or group insurance will cover these costs.

Personal Care Home

Personal care homes, also known as nursing homes, regularly provide palliative care services. You don't have to be a long-time resident to receive palliative care in a personal care home. People with advanced illnesses will sometimes move into a personal care home so that they can receive palliative care.

Personal care homes have access to health care providers with special training in palliative care. The palliative care specialists provide support and work with the patient, the family and the personal care home team. They also offer support for difficult decision making.

Residents in a personal care home are required to pay a daily charge (per diem). This charge is determined based on the amount the resident is able to pay.

Health Care Decisions and Considering the Future

When diagnosed with an advanced cancer, it is important to take some time to think about your wishes related to your health care. As our focus changes from cure to quality of life, aggressive medical action is less helpful and can worsen discomfort. This section includes information about:

- decision making
- advance care planning
- health directives
- legal considerations
- wills

I. Health Care Decisions:

An Approach to Decision Making and Advance Care Planning

Making decisions about health care can seem overwhelming. The issues are often complex and involve subjects that we are not used to thinking about in our day-to-day lives. The intensity of decision making is magnified when living with advanced cancer. The stakes feel very high for every choice that arises.

Where do you start?

Try these three steps to guide the decision-making process:

1. Know all the facts about the topic you are considering.
 - Find out as much as you can about your cancer.
 - Your health care team can help you explore any “what if...?” questions you have.
 - Make sure you know what to expect for each of your choices.
2. Make a list of your goals
 - Writing down clear goals you are hoping to achieve helps you focus your thinking.
 - The question, “should I do this?” can be answered with, “That depends on what your goal is...”
3. Divide your list into “hope for goals” and “goals I can achieve.” Then make a plan accordingly.

STEPS TO GUIDE DECISIONS



Step 1: What are some questions you have about your cancer that you would like answered? Is there anything you want to ask your health care team? Do you have “what if...?” questions? Write them down here.

1. _____
2. _____
3. _____
4. _____
5. _____

An Approach to Decision Making and Advance Care Planning

Step 2: What are your goals? Write them down here.

1. _____
2. _____
3. _____
4. _____
5. _____

Step 3: Which of these goals are hoped for and which are achievable? What do you need to do to achieve these goals? What plans do you need to make?

Avoid assumptions

Unless goals are stated clearly and talked about openly we can make incorrect assumptions about the hopes and expectations of others.

For example:

A patient may be assuming that chemotherapy is being given with the goal of curing a cancer, but the doctor may know the cancer can't be cured but hopes the chemotherapy will slow down the cancer growth. When the doctor uses the word "treatable," the hopeful patient and family interpreted this word to mean "curable." Because of the assumptions the goals of the doctor and the patient are not the same.

Treatable versus Curable

Treatable

Treatments such as chemotherapy or radiation therapy will likely control the cancer. The cancer is likely to stop growing, it might shrink or the patient's blood values might improve. The health care team does not expect the cancer to be cured, or eliminated completely, by this treatment.

Curable

There is a reasonable expectation that with this treatment the cancer can be completely removed from the body.

Health Care Decisions and Considering the Future

The role of the health care team

The health care team will play a key role in providing information.

- They may review and explain test results
- They can help explore treatment options such as medications, radiation treatments, or surgery.

Sometimes patients and families will want to try a particular treatment in hopes that it will improve certain symptoms. The health care team can provide information about whether that goal is medically possible.

The role of the patient and family

1. Give information to the health care team

- Tell the team things that can't be measured because only you know how things feel, such as energy level, difficulty breathing or other things that make you feel better.
- Only the patient and family can voice goals relating to their own values or belief systems.

2. Making decisions about care options

For most people living with advanced cancer, a time usually arises where they would not want further tests or treatments. If someone is not well enough to take part in discussions about their care family members may be asked to help.

Family members might feel it is time to limit certain treatments such as antibiotics or blood transfusions especially when death is near. Making decisions for someone else comes with a tremendous sense of responsibility.

Family might feel like they are deciding whether their loved one lives or dies when this outcome has already been determined by the cancer. If you clearly communicate your goals your family can feel assured that they are making choices that you would make.

Questions about limiting treatments in these situations are focused on how to ensure the best possible quality of life as death nears.

If your goals are clearly communicated, your loved ones don't have to think, "What do I want done?" they can try asking, "What would they want done?"

Determine whether the goals can be achieved

Now that you've set some goals, the next step is to find out whether they can be achieved. There are three potential scenarios for every goal:

- The goal is clearly achievable.
- The goal is not possibly achievable.
- There is uncertainty about whether the hoped-for goal is achievable.

Achievable goals –Goals that might work

Some goals are clearly possible under most circumstances. Using antibiotics to treat a simple infection in an otherwise healthy person is an example of a treatment that will usually result in the hoped-for outcome of stopping the infection.

In such circumstances, when there is informed consent of the patient or a substitute decision maker, the treatment is usually provided.

Health Care Decision and Considering the Future

Unachievable goals –Goals that probably won't work

Sometimes goals are likely not possible. For example, it is not possible to re-start (resuscitate) someone's heart that has stopped beating because of advanced cancer. Advanced cancer is a condition that will progress causing the shutdown of many body systems. When body systems can no longer support life, resuscitation (re-starting the heart) will not work.

Why would I tell the health care team NOT to re-start my heart (resuscitation)?

When the health care team tries to restart your heart, it is an aggressive treatment. They use strong medicines, electricity (a shock) and your body experiences physical trauma due to the chest compressions. If we know your body is too weak to benefit from the things we do to restart your heart it shouldn't be attempted. The health care team's role is to explain your situation to you clearly and openly. Through this discussion, the patient, family and the health care team may decide to set different goals.



If there is conflict about what is the right decision, ask for a second opinion. Some families find that a consultation with someone who specializes in medical ethics or conflict resolution helps all parties involved to find the best solution.

Goals surrounded by uncertainty

There may be uncertainty about whether the hoped-for goals are achievable. Some medical interventions might not help as much as expected. They might not do what is hoped for.

For example, someone may wonder if a blood transfusion will give them more energy, or whether an infection will respond to antibiotic treatment. In these situations it is reasonable to try but it is recommended that the following limits be in place:

1. Clearly state and agree upon hoped-for outcomes.
2. Decide on a time limit. If the hoped-for goal isn't achieved by this time then other options should be considered.
3. Make a plan for an alternative course of action if things don't go as expected.

In conclusion

This approach to making decisions can be time consuming and emotionally challenging. It involves open discussion about things we aren't used to talking about. You'll need to understand the current situation, review your goals, and think about what options are available. Talking openly with your family and your health care team may reduce some of the anxiety and confusion of the decision-making process.

Health Care Directives

What is a Health Care Directive or living will?

- A document anyone can fill out at any time
- States the patient’s decisions about treatment
- Only used by the health care team when the patient can’t speak for themselves
- Recommend filling it out while you are well so you have the energy and opportunity to talk about it with your family if you wish.

Most Canadian provinces and territories have legislation recognizing a person’s right to make decisions regarding their own care and treatment.

Advantages of health care directives	Limitations of health care directives
May encourage people to think about and talk about their values in terms of treatment and quality of life.	A person may change their feelings about treatment options as they become increasingly ill. Solution: health care directives will need to be updated if the patient changes their mind.
People are assured their wishes will be respected when they can no longer make decisions themselves.	All potential situations cannot be anticipated in advance.
Family members feel relieved because they don’t have to make all the difficult decisions. Family is confident they are doing what the person would want.	Sometimes a health care directive will ask for care that is not medically possible. For example, health care teams will not try to restart the heart when it has stopped because the various systems of the body have shut down at the end of a terminal illness. Even though there may be treatment options that are asked for in a health care directive, the health care team cannot be asked to do what is impossible or what is considered a poor standard of health care.
Conflict may be reduced among potential decision makers because many treatment decisions are already written down and decided.	Health care directives often use terms that are too vague and they are unhelpful. For example: “ <i>no heroic measures</i> ” or “ <i>no quality of life</i> ”. These are both phrases that can have different meanings to different people. Solution: Be as clear as possible when stating what you really want to happen if you are nearing the end of your life.



Talk to the health care team about your goals and make sure they are realistic.

No one can anticipate all the decisions that might have to be made over weeks or months of palliative care. A health care directive cannot possibly address every single situation. So, as part of a health care directive, a person can name a proxy they trust.

What is a proxy or substitute decision maker?

Proxy: The person who makes health care decisions on the person’s behalf when the person is unable to speak for himself or herself.

- When choosing a proxy, it is crucial to talk to your proxy about your desires and wishes, so that your proxy can better understand your values. The proxy should understand your wishes and will be ready to act on them, even if those wishes are different from their own personal views or beliefs.
- A proxy only makes decisions related to health care. Being a proxy does not make the person responsible for administering the estate, or making any financial decisions.

Health Care Directives

Power of attorney: You appoint someone to be responsible for your financial decisions.

- Appointing a person to have power of attorney requires another written document that provides legal authority for someone else to manage your legal and financial affairs.

What kinds of things are covered in a health care directive?

It is up to you. Health care directives can be very specific, naming different treatments and stating the person's preferences. Or, they can be general, making a broad statement about the person's values regarding health care treatment.

For example:

- The document may specify that the person does not want to be revived if their heart stops beating. This person does not want the health care team to try to prolong their life when death is near.
- The person may ask to be kept comfortable and free from pain as death nears. This may mean increasing medication to the point where the person is sleeping all of the time. This person is okay with being sleepy as long as they don't feel pain.
- Someone who has an illness that may eventually result in the need to be on a machine to assist breathing might include instructions to guide this decision.

What does a health care directive look like?

Health care directives can be as simple as a handwritten note, but they should be signed and dated. A health care directive in Manitoba does not need to be witnessed or drawn up by a lawyer.



In Manitoba, forms and information can be found on the Manitoba Health website at: <http://www.gov.mb.ca/health/livingwill.htm>. A health care directive form and information is included in this package.

Who can write a health care directive?

Anyone who has what is called decision-making capacity can make up a health care directive.

Who should not write a health care directive?

Someone who is:

- very confused
- doesn't understand the issues being considered
- doesn't understand the consequences of choices being made

Provincial and territorial regulations may require that the writer be of a certain age and be able to understand the contents of the directive.

In Manitoba, a person who is 16 years of age or older has the capacity to make health care decisions.

Health care directives should be reviewed and updated, with the most recent one easily available to family members and the health care team.



A copy of the directive can also be placed within a person's hospital chart.

When does a health care directive take effect?

When the patient loses the ability to communicate or make health care decisions. This would include someone who is:

- Unconscious
- Has lost the mental capacity to make decisions
- Unable to communicate through words, writing or gestures.

What happens if the health care team does not want to follow the health care directive?

Health care professionals have ethical and legal factors to consider when developing a plan for care.

Sometimes a health care directive will ask for care that is not medically possible, such as trying to restart the heart when it has stopped because the systems of the body have shut down after a long illness. Even though there may be treatment options that are asked for in a health care directive, the health care team cannot be asked to do what is impossible or what is considered bad health care. The health care team is not legally obligated to begin interventions that they believe can't work or are the wrong treatment for the patient.

Who should know about my health care directive?

It is the patient's responsibility to make sure that whoever needs to see the health care directive has an up-to-date copy of it. This could include:

- Close family
- Close friends
- Proxy decision maker (if you have chosen one)



Although starting these discussions may feel uncomfortable, sharing this information may help your family or friends to make difficult decisions. It will give you the peace of mind of knowing that your wishes will be respected.

What happens if there is no health care directive?

In the absence of a health care directive, family members often come to a consensus about treatment after sitting down with the health care team to discuss options. If no family member is available to make a decision about care, the health care team will try to act in the best interests of the patient.

If family members cannot come to agreement the province of Manitoba has developed a list identifying who can make decisions on someone else's behalf, starting with the closest adult relatives. These people are called substitute decision makers.

Talk to your health care team

If you are unsure about what should be contained in your health care directive, sit down with the health care team to discuss what might happen as your illness progresses and what kinds of tests or treatments might be offered. Health care directives do not need to cover every medical possibility. If you have specific concerns about receiving certain tests or treatments they should be written down, signed and dated, then given to the health care team.

Even if a person decides against certain life-sustaining treatments they will still be provided with appropriate medical care within the guidelines set out in their health care directive. You won't be abandoned by the health care team. Health care providers will continue to provide treatment to ensure that you are comfortable.

Preparing a Will



What is a will?

- A legal, written document that sets out how you want your property and possessions to be distributed after your death.
- A will also names an executor – the person who will look after your estate after your death and make sure your assets are distributed in the manner set out in your will.
- If you have young children, your will can name a guardian to look after them in the event of your death.
- Provincial and territorial law sets out the requirements for a valid will.
- In Manitoba, a formal will generally has to be signed, dated, and witnessed, and the writer must be of sound mind and be 18 years of age (unless certain conditions are met.)

Why make a will?

A will ensures that your wishes will be carried out with a minimum of expense and delay after your death. Without a will, provincial or territorial legislation will determine how your assets are to be distributed to your family members.

Can a will be changed?

Yes, a will can be changed as often as you like. However, changing a will is not as simple as striking parts out and inserting new text. You will need either to create a new will (making clear that the old will is revoked), or add what's called a codicil that sets out the change.

Codicils must be signed, dated, and witnessed in the same way as a will.

What does an executor do?

The role of the executor is to represent your interests after your death. This person will be responsible for:

- paying outstanding debts
- carrying out the instructions you have left in your will
- file a final tax return after your death

Factors to consider in choosing an executor include the age and the health of the person, where they live, their financial stability and their ability to manage the concerns of others and be impartial.

Are some assets dealt with outside the will?

Yes. If you own property as a joint tenant with someone else, for example, the property will be transferred automatically to the surviving partner after your death. All that is needed is for the provincial or territorial land registry office to receive the death certificate naming the deceased property owner. Then, title of the property is transferred solely into the survivor's name. It is suggested to put all bank accounts in joint status with right of survivorship. In addition, life insurance policies and Registered Retirement Savings Plans (RRSPs) allow you to name a beneficiary in the event of your death and these monies are also transferred directly to the named beneficiary upon proof of death.

How do I prepare a will?



Most people will get help drawing up a will. Common options include using a lawyer or getting help from a standardized will kit. In addition to actually drawing up a will, a lawyer can provide advice on ways to reduce the amount of tax paid out in the process of distributing your assets. It is safest to prepare a will with a lawyer.

Whatever path you decide to follow, there are some basic decisions that you will need to make in order to complete your will. You will need to make a list of your assets and liabilities, determine who your beneficiaries will be (who you will leave your assets to), and choose an executor of your estate.

Financial Aspects and Concerns

Disability Benefits for Patients

Canada Pension Plan

The Canada Pension Plan (CPP) is best known as a retirement pension, but it also provides disability benefits to CPP contributors and their families. If you have children and are receiving a disability benefit, your children may be eligible for the CPP children's benefit. In order to be eligible for this benefit, you must:

- be under 65 years of age;
- have earned a specified minimum amount and contributed to the CPP while working for a minimum number of years;
- have a severe and prolonged disability as defined by the CPP legislation.

Provincial or territorial social assistance

People who are not eligible to receive a disability benefit from the CPP apply for social assistance. Provinces and territories generally require that the applicant's disability be long term and severe enough to prevent the person from working. In addition, the applicant must also complete a needs test to determine the person's total income and whether they qualify for the benefit.

Employment Insurance sickness benefits

Employment Insurance sickness benefits offer income protection from temporary work absences. If the work absence is going to be over a long period of time, employment insurance will not provide benefits.

Employer insurance plans

Some employers provide group insurance packages to their employees as a work-related benefit. These packages may cover costs for prescription drugs, medical expenses and dental expenses. Group insurance may also provide survivors with an income in the event of the employee's disability or death.

It is a good idea to check with your employer or the insurance company providing the group insurance to understand the details of your particular coverage, and how long the insurance will continue in the event that illness forces you to stop working. People who work for companies that do not offer group insurance plans or who are self-employed may have disability coverage they purchased through a private insurer, above and beyond the CPP disability benefit.

Living benefits

Life insurance will often provide for what is known as a living benefit. Such a benefit allows for people who have been diagnosed with a terminal illness to have a portion of their anticipated benefit paid to them in the years before their death. Taking such benefits will reduce the amount of the insurance benefit ultimately paid to the beneficiary of the insurance. A financial advisor can help you make these kinds of decisions.

Tax credits

People who have costs related to health-related goods and services or additional living costs due to disability may be eligible for tax credits. To find out more about tax credits that may be available to you, consult with a financial advisor.

Caregiver benefits through Canada Employment Insurance

Since 2004, the Government of Canada has offered a Compassionate Care Benefit to Canadians who need time off from work to care for a seriously ill family member.

Financial Aspects and Concerns

Caregivers who experience a loss of income as a result of providing care to a seriously ill family member may apply to Human Resources and Skills Development Canada (HRSDC) to receive up to six months of special benefits (following a two-week waiting period).

The six months of compassionate care benefits can be shared among family members who apply and qualify for these benefits.

To qualify for the compassionate family care leave benefit, caregivers must have 600 hours of insured work in the designated qualifying period and their regular weekly earnings must have decreased by more than 40%. To apply, caregivers complete an application form and submit documents which verify that a family member is seriously ill with a significant risk of death in the next 26 weeks (six months) and that there is a need for one or more family members to provide care or support. These documents include:

- **Authorization to Release a Medical Certificate**
This document must be completed and signed by the ill person or their legal representative.
- **Medical Certificate for Employment Insurance Compassionate Care Benefits**
The certificate must be completed and signed by the ill person's doctor.



Further information is available on the internet at:
http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Caregiver benefits through individual employers

Some employers allow employees to take leave without pay for the long-term care of family members. Unpaid leaves can vary in length from three weeks all the way up to five years. Employers set their own policies on when and how a leave will be granted.



For assistance with applying for financial programs or benefits please make an appointment at Patient and Family Support Services

204-787-2109 or toll-free 1-866-561-1026

Medication Coverage Information

Provincial Palliative Care Drug Access Program

Manitoba has a special program to cover the cost of medications and basic medical supplies for terminally ill people registered with a palliative care program. Manitoba's Palliative Care Drug Access Program is designed for people at the end stages of their illness, when the focus of care is on comfort. By covering the cost of eligible drugs for use in the home or in another residence, a major financial burden is removed for the patient and their family.

The Palliative Care Drug Access Program provides deductible-free coverage through Manitoba Health. Once the application has been processed by Manitoba Health, the costs of all eligible drugs prescribed by a physician will be covered. When filling their prescriptions at the pharmacy of their choice, individuals enrolled in the program will no longer be charged for their prescribed eligible medication.

The program is open to residents of Manitoba, with a current Manitoba Health registration number. The patient and physician must agree on palliative care, and that the patient is dealing with an advanced phase of a terminal illness. An application form must be completed and signed by both the patient and a physician. The physician will then send the completed application form to the palliative care coordinator in the local regional health authority. If the patient is eligible for coverage, the form will be forwarded to Manitoba Health for registration.

Application forms are available to physicians through the palliative care coordinator at the regional health authority and also available on the Manitoba Health website. The patient or guardian will receive notification regarding acceptance into the program from their physician or palliative care coordinator.

Patients accepted into the program can be registered with the Palliative Care Drug Access Program and obtain their eligible prescription drugs at no charge at the pharmacy of their choice. Coverage will continue as long as the patient remains registered with the Palliative Care Drug Access Program.



Further information can be found on the Manitoba Health website at: <http://www.gov.mb.ca/health/pcdap/>



If you are a person with **First Nations Status** and have delays or denials with First Nations, Inuit Health Branch's (FNIHB) Non-Insured Health Benefits (NIHB) program, please tell your primary nurse or contact the **Education and Liaison Nurse**.



204-784-2786 or toll-free at 1-855-881-4395

E-mail changingthepath@cancercare.mb.ca

Additional Supports and Resources

CancerCare Manitoba (CCMB) can help you access additional supports and resources. There are a variety of resources available that focus on different aspects of your cancer.



You should continue to see your primary care provider in your community (such as your family physician or nurse practitioner) who is an important link for your day-to-day health care needs.

Don't have a family doctor? Call the Family Doctor Finder 204-786-7111 or toll free 1-866-690-8260.



Counselling and Resource Library: CCMB's Patient and Family Support Services has psychosocial clinicians/counselors who specialize in working with people with cancer and their families/loved ones.

- They can see you individually, as a couple, as a family or any member of your family on their own.
- There are counsellors available at both CCMB MacCharles and St. Boniface sites and some rural sites, and access through Manitoba Telehealth.
- The resource library is located on the first floor at the MacCharles site. It has numerous resources that are helpful for patients, families and caregivers.



Patient and Family Support Services **204-787-2109** or toll-free **1-866-561-1026 extension 2109**.



Support Groups & Community Resources: Professionally lead face-to-face and/or online groups provide an environment for those living with cancer to interact with others in similar situations.

- **CancerCare Manitoba in Winnipeg:** Call the Program Leader or Patient & Family Support Services to find out if there are any support groups for your type of cancer or other groups that might be appropriate for the support that you desire.

Support Groups Program Leader - **Phone: 204-787-4286**

CCMB's Patient & Family Support Services - **Phone: 204-787-2109 or toll-free 1-866-561-1026 ext.2109**

- **Hospice Palliative Care Manitoba:** is a volunteer-based charitable organization which connects people with the palliative care resources they need. They provide services in addition to the formal health care system, such as volunteer visitors, telephone and bereavement support and they also have a resource library.

Hospice Palliative Care Manitoba: **Phone: 204-889-8525** or **website: www.palliativemanitoba.ca**.



There are many other support programs and groups available through CCMB Patient & Family Support Services.

Information is available in the *Navigator* newsletter, CancerCare Manitoba's website www.cancercare.mb.ca or by calling CCMB's Patient and Family Support Services - Phone: 204-787-2109 or toll-free 1-866-561-1026.

Are you are having pain or discomfort because of cancer or treatment?



Cancer Helpline: call 204-787-8900.

Urgent Cancer Care: Located on the main floor of CancerCare Manitoba at 675 McDermot Avenue in Winnipeg, right next to the hematology lab.



Pain and Symptom Clinics: Some patients living with cancer have pain or discomfort that may be difficult to manage. If you are struggling with pain, nausea, shortness of breath, depression or anxiety you might need help from the Pain and Symptom Management Clinic. Your CancerCare Manitoba health care provider, family doctor or nurse practitioner can send a referral.

The Pain and Symptom Clinics work with the primary cancer team.

These clinics are held at both CancerCare Manitoba sites in Winnipeg (McDermot Avenue and St. Boniface) and can also be accessed by Manitoba TeleHealth.



Palliative Care: CancerCare Manitoba has a nurse who is available to answer any questions you may have about palliative care issues or resources.

Call the Palliative Care Clinical Nurse Specialist at Telephone: **204-235-3363 or toll-free 1-866-561-1026.**



Palliative Care Programs in Manitoba: Palliative care programs are available across the province of Manitoba and are organized under each health authority (region). The health care team at CCMB can help to link you with the program that is available where you live. Here is contact information for the programs in Manitoba:

Health Authority – Palliative Care Contact Information		Phone Number
Winnipeg Regional Health Authority		204-237-2400
Southern Health – Santé Sud		204-388-2038
Interlake-Eastern Regional Health Authority		204-785-7739
Northern Regional Health Authority	Western Area	204-623-9661
	Eastern Area	204-778-1450
Prairie-Mountain Health	Southwest Area (West of Hwy#10, South of Riding Mountain National Park)	204-747-1832
	Southeast Area (East of Hwy#10, South of Riding Mountain National Park)	204-578-2307
	Brandon Area	204-578-2340
	Northern Area (North of Riding Mountain National Park)	204-629-3006



Community Cancer Programs Network: The Community Cancer Programs Network (CCPN) enables cancer patients in rural Manitoba (outside of Winnipeg) to receive treatment closer to home. Other cancer support services may be available in your community (e.g. patient navigation, cancer support groups, psychosocial support, spiritual support, nutritional counseling, volunteer drivers and palliative care, etc.)

Centralized number for the CCPN office in Winnipeg is: **204-787-5159**



Cancer Navigation Services: Cancer Navigation Services are available throughout rural Manitoba and include: facilitating timely access to services; providing informational, educational, psychosocial, and practical support; guidance surrounding symptom management, and linking patients and families to appropriate resources offered through CCMB and within local communities. Cancer Navigation teams include Nurse Navigators and Psychosocial Oncology Clinicians. Cancer Navigation Services are available to cancer patients and their families and are provided at no cost.

The Nurse Navigator is an experienced cancer nurse who serves as a linkage between patients and the cancer care system. Psychosocial Oncology clinicians are concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer.

Health Authority - Cancer Navigation Services	Phone Number
Winnipeg Regional Health Authority	1-855-837-5400
Southern Health - Santé Sud	1-855-623-1533
Interlake - Eastern Regional Health Authority	1-855-557-2273
Northern Regional Health Authority	1-855-740-9322
Prairie Mountain Health	1-855-346-3710



Additional Supports and Resources



First Nations, Metis and Inuit Cancer Control:

Many Manitobans experience barriers to care. The goal of this team is to make sure everyone who needs cancer services receives culturally responsive, equitable care.

If you have difficulties getting the right services, resources and support, the education and liaison nurse can help.

Contact the patient access coordinator for assistance with:

- troubleshooting Non-Insured Health Benefits (FNIHB/NIHB)
- ensure interpreters are with you at medical appointments
- connect patient escorts with caregiver support.

Telephone: **204-784-2786 or toll-free at 1-855-881-4395**

E-mail: **changingthepath@cancercare.mb.ca**



Diet & Nutrition: Patients with advanced cancer may have specific problems with eating due to long-term side effects of treatment or the overall impact of cancer on their body. A dietitian may be able to help modify a patient's diet to accommodate the difficulties they are experiencing. You can access a dietitian through CancerCare Manitoba's Patient & Family Support Services. They can also assist in referrals to dietitians in your community.

CCMB Dietitians - **Phone: 204-787-2109 or toll-free 1-866-561-1026 ext. 2109**



Sexuality Counselling: An expert nurse counselor is available at CCMB to meet with you and/or your partner to talk about any concerns you have about sexuality. The nurse is available to meet with you in person or by telehealth.

Call the Clinical Nurse Specialist: **204-787-4495 or toll-free 1-866-561-1026**

If you need assistance, call CCMB's Patient and Family Support Services: **204-787-2109 or toll-free 1-866-561-1026.**



Websites – Cancer & Palliative Care Information: The Web is a great source of information, but it is also full of misinformation. These websites are ones you can rely on to provide you with accurate information:

Living with Advanced Cancer This website includes all of the information given to you in this package as well as links to additional resources.	www.livingwithadvancedcancer.ca
CancerCare Manitoba General Cancer Information and Support	www.cancercare.mb.ca
Canadian Virtual Hospice	www.virtualhospice.ca
Cancerview Canada General Cancer Information	www.cancerview.ca
Canadian Cancer Society	www.cancer.ca
Canadian Hospice Palliative Care Association	www.chpca.net
Canadian Caregiver Coalition	www.ccc-ccan.ca
National Cancer Institute (USA)	www.cancer.gov
American Society of Clinical Oncology "ASCO" Patient Site (USA)	www.cancer.net

Glossary

Medical ethics: the principles of moral and professional conduct, concerning the rights and duties of the physician in relation to patients and fellow practitioners.

Occupational therapist: a specialist in the treatment of physical or mental illness that works to improve a person's ability to perform daily functions.

Oncologist: a physician who specializes in the diagnosis and treatment of cancer.

Palliative care: end-of-life care, with the goal of comfort and the reduction of pain, for patients with a terminal illness.

Pharmacist: a person licensed to prepare and dispense drugs and medicine.

Physiotherapist: a specialist in the treatment of disease and injury who uses exercises to help improve joint movement and to reduce swelling and pain.

Power of attorney: you appoint someone to be responsible for your financial decisions.

Prescription drugs: medicine obtained with a doctor's written directives.

Primary care provider: health care provider who is the patient's principal point of continuing care, typically the patient's family physician.

Proxy: the person who makes health care decisions on the patient's behalf when the patient is unable to speak for himself; chosen by the patient.

Psychosocial clinician: specialists concerned with understanding and treating the social, emotional, and spiritual aspects of cancer.

Radiation treatment: use of gamma rays or high-energy x-rays to damage or destroy cancer cells.

Regional health authority: organization that seeks to improve the quality and delivery of Manitoba's health services by area, for example the Winnipeg Regional Health Authority (WRHA).

Respite program: patient care provided in the home or institution intermittently in order to provide temporary relief to the family caregiver.

Tax credits: an amount of money that a taxpayer is able to subtract from the amount of tax that they owe to the government.

Terminal illness: an incurable illness at the end stage.

Will: a legal, written document that sets out how you want your property and possessions to be distributed after your death.

