



Five-Year Action Plan to Address the

# Financial hardship of cancer in Canada

## A CALL FOR ACTION



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# Bankruptcy. Welfare. Losing the family home.

These are not the outcomes we usually associate with providing compassionate care or surviving the cancer journey. But for some Canadians, the financial impact of cancer can be this devastating.

It's time to rethink how cancer affects Canadians, and what we must do to enhance the quality of life for everyone touched by the disease.

In 2010, the Manitoba division of the Canadian Cancer Society and the Canadian Cancer Action Network joined forces to explore the issue and to find solutions. We conducted a literature review. Then we spoke to people on the front lines – people working in the cancer care system, cancer survivors and those who have provided care to family members. While these interviews were restricted to Manitoba, they echoed the findings of studies from all across Canada.

What we found was a definite and growing pattern of financial hardship that we consider alarming. Ironically, some of the latest advances in cancer treatment and survivorship come with new costs, which are now contributing to the financial impact of a cancer diagnosis.

The good news is that there are more cancer survivors in the population than ever before. Many are living much longer – and with a higher quality of life – than we would have thought possible just a few decades ago. With proper supports, many should be able to remain productive and financially self-sufficient in the long term.

The bad news is that higher survivorship presents additional financial challenges for the affected individuals, their families and the cancer care system as a whole. Many of these survivors may face a second cancer incident, which will in turn lead to repeated disruptions in earning power. As they undergo treatment, they also face many additional expenses that may eventually exhaust their savings.

**1 in 6 Ontario cancer patients said out-of-pocket costs were significant or unmanageable.**

**Lost income may have a larger effect than out-of-pocket costs.**  
(1)

**Nearly half of Canadians will develop cancer in their lifetime. 62% are expected to survive for 5 years or more.**  
(2)

With more than 40 per cent of women and 45 per cent of men experiencing cancer at some point in their lives, many Canadians will find themselves in the position of either patient or caregiver, and will face these financial pressures. However, most Canadians are not even aware that these hardships exist.

Throughout this document, you will find personal stories of Manitobans whose lives have been dramatically changed by the financial impact of cancer. Their stories show that there is no universal experience leading to financial hardship. The contributing factors vary, but the outcome is the same – troubling financial pressure, ranging from mild to crushing.

**In 2009, new cancers resulted in wage losses of up to \$3.18 billion.  
(3)**

In all cases, the common thread is the mounting impact of lost income – by the patient, the caregiver or both.

Government income stabilization programs are a large part of the problem but also a foundation for real solutions. Many of these programs are badly out of step with the needs of Canadians affected by cancer, the realities of today's cancer journey and the changed cancer care delivery system. Until governments make major policy changes to address these issues, the financial hardship of cancer will not be fully resolved.

There are many things that can be done to ease the pressure on Canadians affected by cancer and other serious diseases. There is a role for the federal and provincial governments, regional health care systems, non-profit organizations, clinicians, communities, families and individuals. This document outlines several key challenges that require attention, and we hope the wider community will be inspired to come forward with many more ideas for action.

The ultimate solution is to eradicate cancer from our lives. Until then, let's help cancer patients focus their energy on dealing with their illness, rather than worrying about money. Surviving cancer should be something Canadians celebrate – not the cause of another set of problems.

We invite you to join us in bringing about positive change.

Canadian Cancer Society  
Manitoba Division

Canadian Cancer Action Network  
Manitoba Division

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# Exploring the issues

A study of national wage loss from cancer showed that 91 per cent of households suffer a loss of income or rise in expenses as a direct result of a cancer diagnosis (3). For some, these pressures become a “perfect storm” leading to serious financial distress – hardship so severe that some families never recover.

As we spoke to cancer survivors and health care workers, we uncovered stories of up to three generations being financially devastated by the cancer of a single family member. These findings were backed up by the literature review, which identified factors contributing to the risk among certain groups.

Severe financial hardship can be created by two major factors:

- **Family income may decline dramatically** because of the need to stop working during treatment or while caring for a loved one who is ill. Gaps in our public safety nets leave some people with few financial footholds until they have hit rock bottom.
- **Expenses may skyrocket** at the same time as income is dropping. Gaps and inconsistencies in coverage and services can leave individuals responsible for tens of thousands of dollars in additional costs.



These issues are compounded by a third factor:

- **A lack of awareness and a false sense of security** have left Canadians unprepared to deal with these challenges, both as individuals and as a society. Most Canadians do not know that a cancer diagnosis has caused some people to declare bankruptcy, lose their homes, lose all of their savings, make less than optimal treatment decisions or become dependent on taxpayer-funded programs for the rest of their lives. Until cancer comes into their own lives, they believe the myth that all health care is free. Most never imagined that they could face such difficult challenges at such a vulnerable time of their lives. The reality comes as a shock to many.

## EXPLORING THE ISSUES:

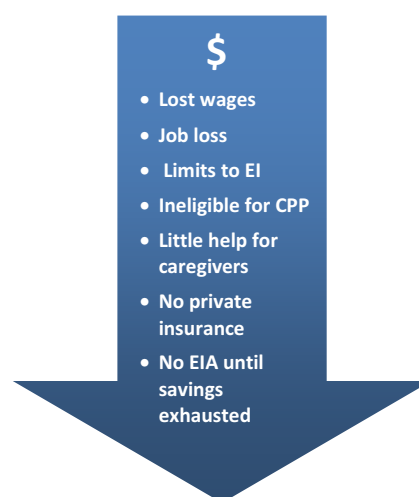
# Loss of income

Lost wages are the single largest contributor to the financial hardship of cancer. For some Canadians, government assistance may be unavailable until nearly all personal savings have been depleted. This huge blow to financial stability and personal spirit makes it extremely difficult for some survivors to get their lives back on track when the cancer journey is over.

## BARRIERS TO MAINTAINING OR RETURNING TO WORK

Canadians that have no contractual or legal right to job security, may be at risk of losing their jobs while being treated for cancer or taking a leave to provide care. They may be capable of working, at least part-time, but:

- **Medical appointments may be so time-consuming and uncoordinated** that holding on to a job becomes impossible.
- **Survivors may be left with conditions that rule out their previous occupations.** For example, facial disfigurement or severe lymphedema might affect the type of work a person can do.



## GAPS IN FEDERAL SAFETY NETS

### Employment Insurance Sickness Benefit for patients

The federal Employment Insurance program will pay sickness benefits of up to 55 per cent of an individual's salary, up to a maximum of \$485 per week. However, there are limitations:

- **The benefit is only paid for 15 weeks**, which is far shorter than the average treatment period for many cancers. A study by the Canadian Breast Cancer Network showed that two-thirds of respondents were away from work for 16 weeks or more during treatment, and the average gap without EI coverage was 23 weeks. (4)
- **Not everyone qualifies for the benefit.** A person must work at least 600 hours in the last 52 weeks before making a claim – a requirement that may be difficult to meet for part-time or

**Given an annual household wage loss from cancer of \$17,729 per person, the national estimate of household wage loss comes to \$2.95 billion. (3)**

seasonal workers, or for those who recently found work after a period of unemployment and were then diagnosed with cancer.

Most self-employed Canadians are also ineligible for this benefit. Although the federal government opened up the EI program to self-employed workers in January 2010, most have not opted in.

- **If your illness recurs or a second round of treatment is required**, you will not qualify unless you have worked at least 600 hours (approximately 16 weeks or four months for a typical full-time job) since your last claim.

### **Canada Pension Plan Disability Program for patients**

All employees and employers pay into the Canada Pension Plan. The purpose of the CPP Disability benefit is to provide coverage for Canadians whose disability prevents them from working at any job on a regular basis – provided they don't qualify for disability benefits from other programs.

However, many cancer survivors and health care workers note that it is extremely difficult to access this benefit – even though most Canadians pay into the plan for decades – because the test for eligibility is so restrictive:

- **The disability must be considered “severe and prolonged” or likely to result in death.** Having cancer, even with metastatic disease, is often insufficient to obtain the benefit and the medical criteria are extremely limited.
- **Any future return to work is ruled out.** If a person with cancer anticipates returning to any job on a regular basis in the future, he or she will not qualify.
- **At least four years of contributions are required.** Before becoming disabled, the individual must have made adequate CPP contributions in at least four of the last six years, or valid CPP contributions for at least 25 years, including three of the last six years.
- **The application process can be long and difficult** unless the person is terminally ill.

### **Lack of direct financial support to caregivers**

Informal caregivers are “the invisible backbone of the health care system,” providing \$6-9 billion in unpaid health care every year (5) and contributing half of the overall costs of home care

**Gaps in income supports can turn a temporary need for assistance into a permanent one.**

**Caregivers typically lose 23% of their workable hours. (3)**



(6). Their role in end-of-life care is on the rise – in part because of restructuring in the health care system, and in part because the need for supportive care has increased as more people are treated for cancer and for a longer period of time (7).

Considering the enormity of their contribution, financial support to caregivers should be seen as a cost-effective investment in managing public health care costs.

And yet, Canada lags behind other nations in terms of financial support to caregivers. One study found that 25 per cent of the cost of end-of-life care falls to the family (8).

The Manitoba tax credit for caregivers, introduced in 2009, and the Canadian Family Caregiver Tax Credit, introduced in 2011, are encouraging signs that governments are beginning to recognize the growing need to provide more financial support.

The Compassionate Care Benefit provided through Employment Insurance may also provide financial support for caregivers. This EI benefit for caregivers is only available to those meeting the eligibility requirements, and it has severe limitations:

- **Only six weeks of benefits** are provided, at 55 per cent of the recipient's average insured earnings.
- **Death of a family member must be imminent** before someone can qualify. A person will not qualify if there is significant need for caregiving but the person is not at risk of death within 26 weeks (six months).
- **There is limited flexibility in how it can be taken.** For example, the six-week benefit can be taken all at once, broken down into one-week periods and/or shared among family members. However, two or more family members can't use it at the same time and partial weeks aren't allowed. All of the benefit must be used within a six-month period.

The federal government recently introduced a tax credit that marks a good first step by recognizing the financial burden that cancer patients face. However there is still work to be done to improve accessibility to and the immediacy of funding.

Other countries have taken a more progressive approach that recognizes the importance of caregivers in our society. In Australia and the United Kingdom, caregivers receive direct payments based on need. The U.K. also recently introduced a state pension for low- or no-income caregivers.

**Nearly 70% of employed caregivers report some sort of adverse impact on their work. (9)**

**41% of family caregivers use their personal savings to survive. (10)**

## ABSENCE OF PRIVATE INSURANCE

Through an employee benefits package, many people are able to draw on sick leave or private health insurance while dealing with cancer.

However, some workers have no private coverage of this kind. While the number is difficult to pinpoint, recent studies have estimated that 20 to 30 per cent of Canadians rely solely on government benefit programs or have no coverage at all.

Several barriers can stand in the way of obtaining adequate private insurance:

- **A person's employer may not offer a benefit package** or the employee may not have worked enough hours to qualify for benefits.
- **A previous diagnosis may make a cancer survivor ineligible for coverage as an individual** if she or he becomes unemployed or self-employed.
- **Premiums may be considered too costly** by self-employed people and others who could opt into group coverage, particularly if they are dealing with other financial challenges at the time.
- **Caregivers are usually unable to recover their lost wages** when they must miss work to provide care to a family member.

Studies also show that Métis and non-status Aboriginals are more likely than non-Aboriginals to be underinsured or have no insurance at all. (12)

Regardless of the cause, up to 30 per cent of working Canadians – or more – may find themselves facing a sudden loss of income because they have no private insurance or employee benefits, or because coverage is denied because of a pre-existing condition. Even if they do have this coverage, **the benefits may run out long before they are able to return to work.**

## THE LONG DROP TO PROVINCIAL WELFARE PROGRAMS

For some cancer patients, the only choice is the low-income support programs for sickness or disability that are provided through provincial “welfare” programs across Canada. A physician must document that the person has a physical or mental incapacity or disorder that is likely to continue for more

**1 in 5 Canadians have no private supplemental health insurance. The percentage is higher in Newfoundland and Labrador (30%) and New Brunswick (32%).**  
(11)

**For people with disabilities, low-income support rates across Canada in 2009 ranged from \$8,665 to \$12,095 a year – consistently below most socially acceptable measures of adequacy.**  
(13)

than 90 days, and a medical panel reviews each case to determine eligibility.

These plans typically cover most medications, medical supplies and medical transportation, and also open the door to social housing. However, they are definitely a last resort after all other options have been exhausted.

Advocates for recipients point to two huge flaws in these programs:

- **The meagre funding does not meet the basic living needs of people who are dealing with a medical crisis.**  
The median provincial welfare payment in 2009 was \$10,881 per year, ranging from a low of \$8,665 in New Brunswick to a high of \$12,905 in Ontario. (Alberta provides up to \$14,297 per year under its Assured Income for the Severely Handicapped (AISH) program.)
- **Recipients must deplete nearly all of their liquid assets, including Registered Retirement Savings,** before they can qualify in most provinces. The rules require the person to basically start over with very little. The amount that an ill or disabled person can retain when applying for provincial welfare ranges from a low of \$500 in Nova Scotia to a high of \$5,000 in Ontario. For cancer patients who may eventually return to work, this requirement to deplete savings imposes far too great of an economic penalty, setting them up for complete financial ruin. (13)

The fact that some people are forced onto these programs by cancer is evidence of the extent to which other programs are failing to support people through the cancer journey in a financially sound way.

## **This is Margaret's story.**

It begins with a lump on her daughter's collarbone. It ends with a life on social assistance.

When Margaret's daughter was diagnosed with Non-Hodgkin's lymphoma, both of them were professionals with good benefit programs and a stable employment outlook. Her daughter's diagnosis changed all of that. It seemed that Margaret's only option was to quit her job and care for her 17-month grandson. They had no one else to turn to.

A stem cell transplant meant her daughter would need to move to Winnipeg for at least six months. Margaret made the three hour trip from their rural home countless times so her grandson and very sick daughter could be together. As a divorced parent herself, she understood the need.

As the illness progressed, costs mounted. Margaret's savings were depleted by fuel costs, hotel stays, restaurant meals and non-covered cancer drugs. She also wanted to bestow occasional treats on a daughter and grandson who would have precious little time together.

When her daughter died at age 27, Margaret took custody of her three-year-old grandson. As a grandmother, she isn't entitled to the support a foster parent would receive. And although she once had a good-paying job, those days are behind her now.

Today Margaret and her grandson live on the \$1,145 per month she receives from provincial welfare. She can see how the rest of her life will unfold, and she worries about the future of her grandson. As he grows up, he misses the things most other kids in the community take for granted – including the love of his mother.

## EXPLORING THE ISSUES:

# Rising expenses

Canadians pride themselves on health care that is free and universal – but when cancer strikes, they find they're on their own for many expenses. At a time when income may be dropping due to inability to work, out-of-pocket costs are rising. The increasing financial pressure sometimes leads to financial collapse.

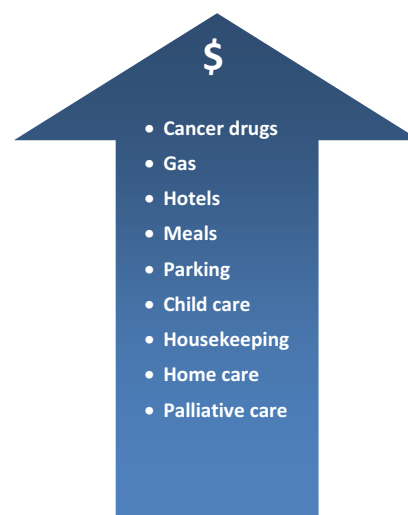
## DRUG COSTS

Most Canadians believe that essential medications are covered by their health care system, particularly when a serious illness like cancer is at stake. However, not all drugs related to cancer treatment are covered by provincial/territorial programs, and the level of financial assistance varies greatly from jurisdiction to jurisdiction.

Since 2004, purchase of cancer drugs (regardless of purchaser) has increased more than five times faster than the growth of cancer incidence (14). Some governments are failing to keep up with new treatments coming on to the market in an attempt to stay within their budgets. This is often to the detriment to cancer patients.

While coverage varies significantly across the country, costs are generally being driven by two factors:

- **Some medications not given in hospitals are not covered by government plans.** *The Canada Health Act* states that only drugs provided for patients in a hospital setting must be provided free of charge. In most provinces, people have to pay all or some of the cost of certain medications that are taken at home, even if they are considered essential as part of internationally accepted treatment protocols. Today half of the newer cancer treatment drugs are taken at home, which means that the burden of drug costs is shifting to the individual (15). Many of these drugs directly treat the cancer, while others are supportive drugs taken at home to deal with the side effects of treatment, such as nausea, pain and increased susceptibility to infection.
- **Drug coverage deductibles are high for many Canadians.** All provinces except New Brunswick and Prince Edward Island provide some sort of cost-sharing for catastrophic drug costs, which are defined as drug costs exceeding three per cent of net



**For 1 in 12 Canadian families, drug costs amount to more than three per cent of their net household income. (15)**

household income. In 2008, 7.6 per cent of Canadian households faced prescription drug costs at this level (16). However, even with those plans in place, six per cent of Canadians pay over \$1,000 a year for drugs (17)

British Columbia, Alberta, Saskatchewan, the Northwest Territories and Nunavut have gone a step further by eliminating all drug costs for people with cancer (15). In April 2012, Manitoba followed through with its promise to provide full coverage with zero deductible for oral cancer treatment and support drugs that patients may need during their treatment regardless of where these drugs are taken. However, the remaining seven provinces and territories have not yet taken action.

The majority of Canadians have private supplemental health insurance to help ease the burden (18), but even this coverage has limits. Plans with co-payments typically require the patient to pay 20 per cent of the cost of their prescription drugs. For newer drugs, the price of an average course of treatment is \$65,000 – therefore the individual may be responsible for up to \$13,000 or more of the cost. Some private plans also have an annual or lifetime cap on costs, which are often well below the costs of newer cancer drugs.

Some provinces – but not all – have programs that will pay some of these high deductible amounts from private plans, often on an income-based scale (provided the drug is on their formulary).

Overall, British Columbia is considered to have the best drug coverage, and Atlantic Canada the worst, based on the range of cancer drugs covered, coverage of oral and parenteral cancer drugs, universal coverage of all residents, and out-of-pocket cost to patients for cancer treatment drugs (18).

Most at risk are the substantial number of Canadians with no private insurance. According to Statistics Canada, nearly seven million Canadians have no private coverage for drugs or medical devices, other than what is provided by government.

**55% of Canadians say they would have to dip into their savings or take out a loan to pay for drugs if they had cancer.**

**Nearly half of this group say this would have a major negative impact on their family finances. (19)**

**Nearly 1 in 5 Canadians have no private supplemental health insurance. In some provinces, the rate is nearly 1 in 3. (19)**

## Public and private payer roles in cancer drug coverage

Area	Public Payer Role	Private Payer Role
<b>British Columbia</b> <b>Alberta</b> <b>Saskatchewan</b>	Coverage of cancer drugs for all residents	Coverage of cancer drugs not approved for public funding for plan members
<b>Manitoba</b>	Coverage of cancer drugs and support drugs that patients may need during treatment for all residents	Coverage of cancer drugs not approved for public funding for plan members
<b>Ontario</b>	Coverage of cancer drugs for residents eligible for the public drug plans	Coverage of cancer drugs for plan members
<b>Quebec</b>	Coverage of cancer drugs for all residents without private coverage	Coverage of cancer drugs for plan members
<b>Atlantic</b>	Coverage of cancer drugs for residents eligible for the public drug plans	Coverage of cancer drugs for plan members
<b>Territories</b>	Coverage of cancer drugs for all residents	Coverage of cancer drugs for plan members

Source: Cancer Drug Access in Canada. 2009. (20)

## Eligibility for public coverage of cancer drugs taken at home

Area	Eligibility for Public Drug Plan	Specific High Drug Cost Program	Gaps in Eligibility
British Columbia	All	N/A	
Alberta	All	N/A	
Saskatchewan	All	N/A	
Manitoba	All	N/A	
Ontario	Seniors Social assistance	All others	
Quebec	All	N/A	
New Brunswick	Low income seniors Social assistance	Limited*	Working families without private coverage Moderate and high income seniors**
Prince Edward Island	Seniors Social assistance	Specific cancer drugs***	Working families without private coverage High income families
Nova Scotia	All	All	
Newfoundland	Seniors Social assistance Low income families	All others	
Yukon	All	N/A	
Northwest Territories	All	N/A	
Nunavut	All	N/A	
Federal	Registered First Nations and Inuit Military RCMP Inmates Refugees	N/A	

Source: Cancer Drug Access in Canada. 2009. (20)

\* New Brunswick residents may apply to the Department of Social Development for “Health Card Only” benefits, which provide 100% coverage for drugs listed on the public formulary. Eligibility for this benefit requires that applicants have high medical expenses relative to income and that they exhaust their personal assets first.

\*\* New Brunswick seniors who do not qualify for the public drug plan may purchase drug insurance through the Medavie Blue Cross Seniors’ Prescription Drug Program.

\*\*\* All Prince Edward Island residents with net household incomes less than \$150,000 per year are eligible to receive some assistance with payments for a selected list of oral cancer drugs.



## Public coverage of high cancer drug costs

Area	Type of Plan	Terms
<b>British Columbia</b>	Cancer agency	100% coverage
<b>Alberta</b>	Cancer agency	100% coverage
<b>Saskatchewan</b>	Cancer agency	100% coverage
<b>Manitoba</b>	Manitoba Pharmacare	100% coverage
<b>Ontario</b>	Trillium Drug Program	100% covered after income-based deductible
	Ontario Drug Benefit	100% coverage for seniors (small co-payment applies) and social assistance recipients
<b>Quebec</b>	Régie de l'assurance maladie du Québec (RAMQ)	Premium + co-payment (maximum out-of-pocket expense based on income)
<b>New Brunswick</b>	Department of Social Development	Residents may qualify for "health card only" benefits once personal assets are exhausted
	New Brunswick Prescription Drug Plan	100% coverage (small co-payment required) for low-income seniors and social assistance recipients
<b>Prince Edward Island</b>	High Cost Drugs Program	7 specific cancer drugs partially covered for net incomes less than \$150,000
	PEI Pharmacare	Coverage for seniors and social assistance recipients (co-payment required)
<b>Nova Scotia</b>	Drug Assistance for Cancer Patients	Gross family income less than \$15,720
	Family Pharmacare	Income-based deductible and co-payments
	Seniors' Pharmacare Program	Premium plus co-payment
<b>Yukon</b>	Chronic Disease Program	100% coverage above deductible
<b>Northwest Territories</b>	Specified Diseases (including cancer)	100% coverage
<b>Nunavut</b>	Full Coverage Plan for Chronic Health Conditions	100% coverage
<b>Federal</b>	Health Canada Veterans Affairs RCMP Correctional Services Canada National Defence Citizenship and Immigration Canada	100% coverage

Source: Cancer Drug Access in Canada. 2009. (20)

## THE COST OF MEDICAL TRAVEL

Travel appears to be one of the biggest indirect costs of cancer, particularly for rural Canadians who must travel to larger centres for highly specialized treatment and services. Studies across Canada show that these costs can quickly surpass all other out-of-pocket expenses. (1)

While some of these expenses can be recovered later, they are nevertheless up-front costs for the patient. The money must be found and paid immediately, sometimes long before reimbursement is received.

These travel expenses take many forms, and hit rural people the hardest:

- **Lost wages** are an additional challenge for people who must take travel long distances for medical treatment.
- **Fuel** is a significant and growing expense for rural people.
- **A more reliable vehicle** may need to be purchased for the many hours of highway travel.
- **Accommodation** may be difficult to find at an affordable price. Some patients need to be away from their home community for several months – for example, if they are undergoing a bone marrow or stem cell transplant.
- **A companion** may need to travel with a person who is weakened by illness and treatment, leading to additional expenses and lost wages for a spouse, friend or family member.
- **Child care** may be needed, sometimes with little advance notice. If parents have no family support nearby, paid child care will be required.
- **Parking** can be a significant expense around major treatment centres, where people may spend several hours waiting to see a specialist.

**There are also inconsistencies in how travel assistance is applied.** For example, Canadian Blood Services will pay the cost of travel and accommodation for unrelated donors of bone marrow or stem cells, but not for donors who are family members.

**Health care professionals worry that these costs may dissuade some rural patients from getting optimal care –** perhaps even convincing them to opt for a more radical form of treatment.

While rural people seem to accept travel costs as a part of their lifestyle, **many people are frustrated by travel expenses that could have been avoided.** It's common to hear stories of rural

**81% of Canadians are unfamiliar with the cancer drug regimen in their province. 35% are not familiar at all. (19)**

**Women with breast cancer who must travel for weeks of radiation therapy are more likely to choose a mastectomy over breast-conserving surgery to save the costs of travel and accommodation. (21)**

**In Newfoundland and Labrador, rural residents are nearly twice as likely as urbanites to report that travel costs are important considerations in their treatment decisions. (22)**

people staying overnight at a hotel because of a 9:30 a.m. appointment—which didn't actually occur until late afternoon. These people feel appointments could be better co-ordinated to make more efficient use of their travel time and expenses. Sensitivity to this issue could significantly reduce the financial burden borne by rural and northern residents.

### **Urban cancer patients also face mounting transportation**

**costs.** One alternative to parking and fuel expenses is the Canadian Cancer Society Manitoba Division's subsidized transportation program, which takes patients to treatment centres in many parts of the province for just \$6.00 per ride. While this is a vital service for many people, not everyone's needs can be accommodated. For example, there are some restrictions on the program's ability to serve people with oxygen tanks or wheelchairs, and the reliance on volunteers means that hours of service may be limited.

## **PARKING COSTS ACROSS CANADA**

While medical travel is a big expense for rural Canadians, even urban residents can face significant costs when visiting treatment centres. Parking fees can quickly add up to hundreds of dollars.

Rates can vary considerably across Canada and even within the same city, as the chart below shows. A cancer patient in Charlottetown could pay nothing for parking, while a patient in Toronto could pay as much as \$28 per day. Some hospitals provide special rates for people undergoing treatment, but others do not.

<b>CITY</b>	<b>Hourly Rate</b>	<b>Daily Rate</b>
<b>GREATER VANCOUVER, British Columbia*</b>	\$3.50-\$4.50	\$14.00-\$17.25
<b>CALGARY, Alberta</b>	\$3.50	\$13.00
<b>EDMONTON, Alberta</b>	\$3.50	\$15.00
<b>REGINA, Saskatchewan</b>	\$2.00	\$5.00 **
<b>SASKATOON, Saskatchewan</b>	\$3.00	\$15.00-\$18.00
<b>WINNIPEG, Manitoba</b>	\$3.00-\$3.50	\$12.00-\$17.00*
<b>TORONTO, Ontario</b>	\$8.00-9.00	\$23.00-\$28.00
<b>MONTREAL, Quebec</b>	\$14.00	\$19.00*
<b>CHARLOTTETOWN, Prince Edward Island</b>	Free when receiving cancer treatments	

\* Special rate passes are available at some hospitals for patients or people undergoing chemotherapy.

\*\* Special rate for people undergoing chemotherapy.

## ONE RURAL FAMILY'S TRAVEL COSTS

One Manitoba farm family added up the expenses when their daughter was diagnosed with Hodgkin's lymphoma. This is how their costs stacked up over a six-month period as the parents and their child traveled to Winnipeg and Brandon for multiple tests, surgery and chemotherapy.

<b>Transportation</b>	22 trips to Winnipeg = 12,452 kilometres 4 trips to Brandon = 576 kilometres TOTAL = 13,028 kilometres 13,028 x 40.5 cents/kilometre (rate used by the Manitoba government) =	<b>\$5,276.34</b>
<b>Parking</b>	\$20 x 44 days =	<b>\$880.00</b>
<b>Accommodation</b>	24 nights at Ronald McDonald House* = \$240.00 One night at hotel = \$129.00 TOTAL =	<b>\$369.00</b>
<b>Food</b>	Average of \$75/day for 68 days =	<b>\$5,100.00</b>
<b>Incidentals</b>	44 days x \$17.30/day (rate used by the Manitoba government) =	<b>\$761.20</b>
<b>Lost wages</b>	44 work days at \$350/day =	<b>\$12,320.00</b>
<b>TOTAL</b>		<b>\$24,706.54</b>

\* Not an option if the sick person is over 16.

# This is Bob's story.

It ends in a lonely place, far from everything fond and familiar.

Bob's story began in happier times, when he and his wife lived in a small northern community that was their home for 22 years.

Each of them had jobs, and together they owned a small business. It was a comfortable life, with summers spent at their cottage on a nearby lake.

When Bob's wife was diagnosed with leukemia, their world was suddenly shattered. Within hours, she was flying to Winnipeg for tests and prolonged treatment.

Bob rode to Winnipeg every weekend so he could be with her during chemotherapy. He paid up-front for his \$140 round-trip bus tickets, \$50-per-night accommodations and meals. Meanwhile, his wife had lost her income and had no insurance plan to fall back on.

Because the chemotherapy was available only in Winnipeg, the couple decided it made sense to leave the north. Bob took an early retirement. They sold their home and cottage, closed their business and left their friends behind. The move cost \$7,000 in all.

The couple couldn't find an affordable home in Winnipeg so they moved to the outskirts. Their fuel costs added up as they drove into the city for treatments – but because they lived in the region, they could no longer claim these costs on their income tax.

When Bob's wife left the hospital, they discovered additional costs, like oral medications, dressings and supplies. One course of drugs alone was \$1,000.

After two years of chemotherapy, Bob's wife died. He hasn't made many friends in the south and still feels very unsettled. As he remembers his experience, he wonders why no one was there to give them financial advice when they needed it most.

## CHILD CARE AND HOUSEKEEPING

Parents with cancer may need additional help with child care and household responsibilities while they attend medical appointments or when they aren't well enough to handle these tasks. This is more of a problem for single parents, but it can also be an issue for two-parent families if both parents are unable to work because one is sick and the other must take care of the children. If a friend or family member can't step in, it may be difficult to find immediate, affordable help.

Child care can also be a significant family expense **if it is a child who has cancer, and there are other siblings needing care**. The parent may need to pay someone to stay with the other children while the sick child is taken to medical appointments.

**These expenses can be particularly burdensome when either a child or parent with cancer needs to be away from home for an extended period** to receive cancer treatment. A parent may need to be hundreds of miles from home for several months of treatment. If parents in this situation wish to have their children visit them, they are responsible for most of those costs, as well.

**In extreme cases, the only option may be temporary foster care**. Some parents needing long-term help have no partner, friend or family member to turn to and can't afford to pay for child care. During a medical emergency, he or she might have to approach a child and family services agency and enter into a voluntary agreement to place the child in a licensed foster home or child care facility. (Guardianship would not be transferred on the understanding that the parent would resume care of the child when able.)

**If a parent with cancer dies, the family faces a new set of challenges**. If there is no surviving parent, the financial burden may shift to another family member – a grandparent, an aunt, an uncle or perhaps an adult sibling. However, **in some provinces a family member is not entitled to the same financial assistance that would be offered to an unrelated foster parent**. Grandparents taking on this responsibility face additional financial pressures at a time when their income-earning years may have already ended, and their own health problems and medical expenses may be increasing.

## HOME CARE EXPENSES

The growing need for home care, particularly during the palliative stage of illness, can greatly add to the out-of-pocket costs of dealing with cancer.

While most provinces provide a certain amount of “free” home care to qualifying families, **there is no national standard for home care.**

Even if a family qualifies for provincial home care assistance, a **shortage of home care staff** may prevent them from taking full advantage of these services. If their need exceeds what the provincial service can provide, the family may need to pay for private home care. These shortages are often more acute in rural areas.

People receiving care at home may also require **supplies not covered by provincial health plans**, including:

- Supplies for gastric feedings
- Digital thermometers (needed by all children with cancer and adults with low immune status)
- Electric razors (needed by adults predisposed to bleeding)
- Bath stools, walkers and canes

People may delay replacement of these items because of cost.

## **UNIQUE CHALLENGES FOR THE MÉTIS, FIRST NATIONS AND INUIT**

The literature review confirms that cancer is linked to huge challenges for Aboriginal people.

- **The Métis and non-status Aboriginals are more likely than non-Aboriginals to be underinsured or have no insurance at all** (14). At the same time, this population has higher mortality rates from cancer and a lower mean income (23).
- **Jurisdictional issues present additional challenges for First Nations and Inuit people.** They are covered by Health Canada’s Non-Insured Health Benefits program – however, if they live on reserve, they are often ineligible for provincial programs available to the rest of the population, such as home care and palliative care. As a result, health care providers and First Nations/Inuit people often struggle with jurisdictional problems on a regular basis.

The most well-known example of these problems is the story of Jordan River Anderson, a boy with complex medical needs who spent his entire short life in hospital in Winnipeg because the federal and provincial governments could not agree on who should pay for his care if he returned home to his northern Manitoba reserve. While governments continued

**The federal, provincial and municipal services provided to the average Canadian are almost 2 ½ times greater than the services received by First Nations citizens.**  
(24)

to squabble over jurisdiction, Jordan spent two years in hospital unnecessarily. He died at the age of five without ever having spent a day in a family home. In his memory, First Nations across Canada are asking the federal and provincial governments to adopt a child-first policy called “Jordan’s Principle.” For more information, visit <http://www.fncfcs.com/jordans-principle>.



## This is Sue's story.

### Her cancer is gone, but so is her sense of financial security.

The clock is ticking down and Sue needs to make a tough decision. Should she return to a stressful job that she fears may hurt her health, or should she risk having no insurance benefits?

It's a difficult choice for a 30-something breast cancer survivor, still weak from difficult chemotherapy and barely able to make the minimum payment on her credit card.

With her insurance benefits running out, Sue's employer is pressuring her to return to her demanding job. Meanwhile, her doctor has increased her heart medication and told her to avoid undue stress.

Health-wise, her best option might be to find a new, less-stressful job. But if she moves to a different employer, her new group insurance plan may not cover her for a pre-existing condition. That means she could find herself without any benefits if her cancer returns.

Tapped-out financially, Sue can't delay her decisions about returning to work. Within six months of her surgery, her savings were exhausted and she was starting to move into debt.

Even though she had drug coverage, she still had to pay a portion of expenses like \$40 anti-nausea pills.

In the midst of her ordeal, Sue's car broke down and she was assessed a \$4,000 fee for condo renovations. All she could do was cry. Now she owes money to her parents and can't even begin to think about when or how she will pay it back.

Today she's running out of options. During a difficult recovery, she's used up sick time, holiday time and short-term disability benefits. Her long-term disability will run out soon.

The future looks much different to Sue today than it did two years ago. What a difference two years can make, when cancer comes into a young life.

## EXPLORING THE ISSUES:

# Lack of awareness and understanding

The financial hardship of cancer is an invisible problem to many Canadians, including those who could be in a position to help.

**A false sense of security seems to cloud Canadians' understanding of these issues.** As voters, taxpayers, potential cancer patients and future caregivers, all Canadians should be demanding better long-term solutions. However, most do not know that a cancer diagnosis has caused some people to declare bankruptcy, lose their homes, lose all of their savings, make less than optimal treatment decisions or become dependent on taxpayer-funded programs for the rest of their lives.

**Part of the problem is that many people are reluctant to speak out about their personal financial crises.** When they have a life-threatening illness like cancer, they may also hesitate to complain about the cost of treatments that have the potential to extend the length and quality of their lives.

**Consequently, most Canadians are unprepared for the financial crisis that may follow a medical crisis.** "We didn't see it coming" is a common comment from families financially devastated by cancer.

**The lack of awareness may also explain the scarcity of community programs addressing this issue.** Canadians generously donate to cancer research and charities that provide special vacations for sick children, but seem unaware of the everyday financial crises of many families dealing with cancer. One health care worker noted that toys and books are the most common donation to their department, while a more useful donation might be grocery store gift cards or hospital parking vouchers.

**Nearly half of Canadians under the age of 35 say they haven't given much thought to the cost and availability of cancer drugs.**  
(19)

## EXPLORING THE ISSUES:

# Who is at greatest risk?

A combination of factors can push a family over the financial precipice when a medical crisis strikes.

People can be at greater risk of financial devastation because of where they live, their stage of life and their access to family and community supports. Based on the literature review and feedback from health care workers, higher-risk groups include:

- **Canadians facing high expenses due to cancer, relative to their income.** This group includes rural and northern residents who need to travel for treatment and Canadians with no private health insurance.
- **People with low income and/or no disability insurance** -- a group that includes a higher proportion of seasonal, part-time or self-employed workers, Métis and non-status Aboriginals.
- **Parents with children who have cancer** face higher loss of income and out-of-pocket costs – in part because parents must accompany the child to hospital or appointments.
- **Family caregivers**, who may number up to five million in Canada. In 2002, nearly one-quarter of households with a caregiver reported a combined annual income of less than \$20,000.
- **Adolescents and young adults with cancer** because they are at risk of long-term financial instability.
- **People receiving multiple forms of treatment**, which can lead to higher out-of-pocket costs and greater loss of income.
- **People lacking strong support systems**, such as reliable family and friends and supportive employers.

**When cancer strikes, the costs are most burdensome for lower income groups.**  
(25)

**Families of children with cancer incur an average of more than \$28,000 in costs in the first three months following a child's diagnosis.**  
(27)

## **This is Brenda's story.**

It began with hopes for a better life, before cancer and a lack of child care split her family apart.

Brenda was new to her rural community when she discovered she had breast cancer. She had just left a difficult marriage and was now facing a mastectomy and aggressive chemotherapy. She also had three young children and no real friends in her new community.

Brenda knew she would be too sick to take care of her kids as she underwent intensive treatment, and there was no one she could rely on to do it for her. She certainly couldn't afford to pay someone on her income. Her only choice was to temporarily send her children into the care of a family services agency – a move that was terribly upsetting for the whole family.

Brenda's difficulties continued as she underwent post-surgery treatment. With no well-organized community care sites in the area, she often had to travel long distances for treatments and follow-up. The cost of travel, accommodation and meals piled up.

At the same time, Brenda was dealing with intense feelings of isolation. A stranger to her neighbours, she was given no help from community fundraisers and service clubs. She received none of the support and kindness that can ease financial and spiritual burdens at such a difficult time.

Twenty years later, Brenda still feels the hurt of those lonely, desperate days. She reunited with her children after recovering, but their relationship has always been strained. Although she remarried several years ago, she lives with feelings of guilt that her ongoing battle with cancer has been an unfair financial burden to her husband.

Today, Brenda hopes she may finally be getting back on her feet, emotionally and financially. However, as she waits for a biopsy on her lung, she knows that further challenges may be ahead.

# A Framework for Change

Based on the literature review and personal interviews, a grassroots steering committee of consumers of cancer services in Manitoba identified three key challenges that require attention. All segments of society can become part of the solution as we work toward these goals.

## THREE KEY CHALLENGES

Income stabilization	Cancer drugs and medical equipment	Transportation and accommodation
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### CHALLENGE:

## Income stability for patients and caregivers

There are many causes of financial hardship, but there are also many opportunities to reduce the possibility of severe income loss following a cancer diagnosis through improvements to the social safety net.

For all Canadians, the bottom line should be better financial support in times of serious illness – at a level adequate to support their needs during such a stressful and exceptional life event. Income stability would greatly offset the increased costs for patients and caregivers – making cancer expenses less of a burden and reducing the anxiety of individuals and families during a very difficult time.

While improving these programs may seem like a monumental undertaking, a handful of decisive program improvements to stabilize income may accomplish more than could be achieved by scores of incremental changes to address cancer-related expenses.

Canada needs to mend these gaps in our government safety nets:

**WE RECOMMEND**  
**Programs be aligned with today's cancer journey**

Certain federal safety net programs are increasingly unable to meet the needs of cancer patients. Some rules are out of step with the increasing survival rate following a cancer diagnosis, and today's dynamic economy, where job displacement and career interruptions are more common.

These limitations prevent support programs from fulfilling their ultimate mandate, which is to carry people through tough times so they can become financially independent in the long term. Providing people with a leg-up and a foothold at the right time could potentially save taxpayer dollars in the long run.

**Nearly 130 countries provide a higher wage replacement rate than Canada. Some even offer 100% for part of the leave.**  
(29)

# This is Mary's story.

It's the tale of two cancers, a broken marriage, bankruptcy...and the drive to overcome.

In the year 2000, Mary was separating from her husband and supporting four daughters on her own. It was a difficult break-up and she knew there would be rocky times ahead. She couldn't have imagined just how difficult the next 10 years would be.

While Mary and her husband battled over property and child support, she received the devastating news that her youngest daughter had cancer of the spinal cord. It soon became clear that the family was going to be in big financial trouble – and there was nothing she could do about it.

Mary was self-employed with a successful accounting practice, but as her daughter's illness worsened, she had to drastically scale back her business. Meanwhile, the family's expenses were growing. Many of her daughter's medications weren't covered by government plans, and quickly became a significant cost. As they began spending more and more time at the hospital, the cost of meals and parking consumed more and more of Mary's greatly reduced income.

Within a year, the financial strain became so great that Mary declared bankruptcy.

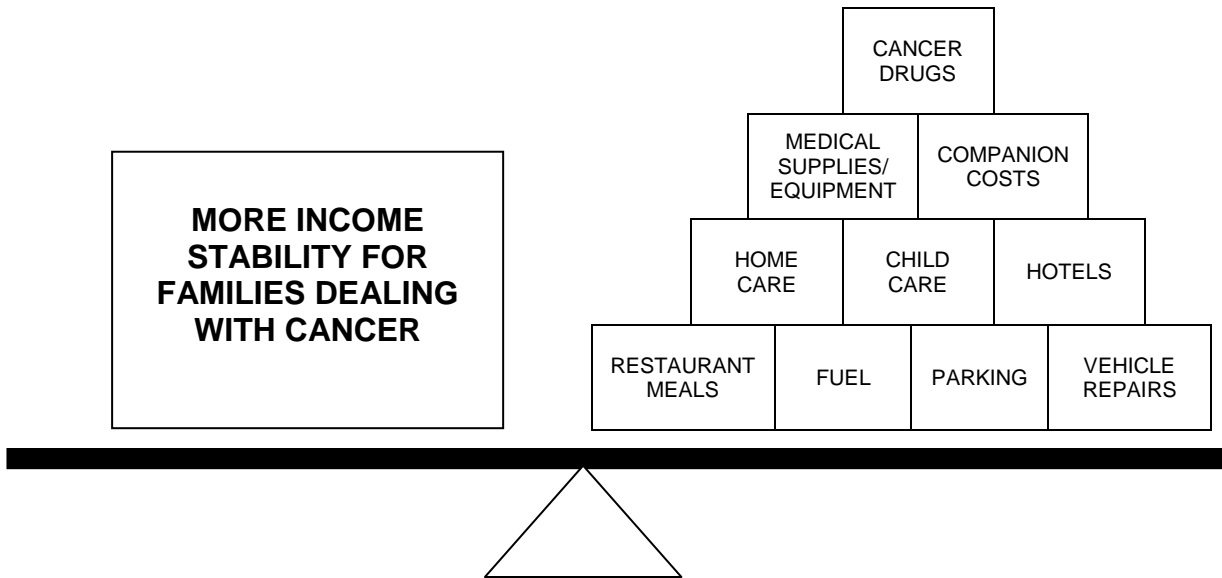
The following year, Mary herself was diagnosed with chronic lymphocytic leukemia, which her oncologist said could be brought on by stress. At that point, she made the decision to stop working completely. She was one of the lucky few able to avoid going on welfare by qualifying for CPP Disability payments.

Unable to pay the mortgage, Mary had to sell the family home – and for a while, she and her daughters had no place to call their own. At one point, the five of them split up and bunked in with family and friends until they could find a cheap place to rent.

In time, things began looking up – in part because of Mary's own illness. A new law allowed her obtain part of her ex-husband's pension for her own care, and regular child support was finally coming in. She also began planning for a bone marrow transplant, which might make her strong enough to work once again.

Sadly, her daughter died just as Mary was starting to get re-established.

It's been a difficult 10-year struggle for Mary, yet it could have been much worse. Her financial background helped her navigate the system and fight for every bit of assistance available. Today she wants to use those skills to make the system better for others.



*On the surface, addressing income loss may seem like a monumental challenge. However, income security may actually be the simplest and easiest way for governments to remedy this complex problem. A few decisive improvements on the income side of the equation would balance the impact of countless and widely varying factors that cause cancer-related expenses to rise.*

There are many opportunities for governments to ensure that a cancer diagnosis does not compromise financial security and push people onto welfare – perhaps for the rest of their lives.

- **Increase the Employment Insurance sickness benefit** by extending the length of the benefit to 52 weeks
- **Expand access to the CPP disability benefit** by broadening the interpretation of the eligibility criteria during the screening process
- **Increase access to other federal entitlement programs**, such as Old Age Security, as a means of providing interim financial support.

**90 countries provide benefits for 26 weeks or until recovery, compared to 15 weeks in Canada. (29)**

## **WE RECOMMEND More support for caregivers**

The economic contribution of family caregivers was estimated at more than \$25 billion for 2009, and one in four Canadians cared for a loved one with a serious illness in the last 12 months. It's time to provide better support to this important and growing segment of the population.



The ideal solution is to create a Canadian Family Caregiver Strategy that addresses the critical issues of job and income stabilization as well as financial support. As a first step, we encourage the federal government to:

- **Improve the Compassionate Care Benefit** provided by the federal Employment Insurance program by:
  - Increasing the benefit period to 26 weeks, accessible during a 52-week period
  - Building more flexibility into how the program can be used – for example, allowing partial weeks over a longer period rather than blocks of weeks at a time
  - Softening the eligibility criteria from “significant risk of death to “significant need for caregiving due to a life-threatening illness”
  - Allowing more than one family member to use the benefit at the same time
- **Introduce direct financial support to caregivers** in the form of a Family Caregiver Tax Benefit, which would be:
  - A way of providing income to family caregivers with lower incomes or no income at all (unlike a tax *credit*, which only benefits those who have sufficient income to cover additional expenses)
  - Based on revenue and place of residence
  - Easy for government to manage
  - Not demeaning for the claimant.

**Financial compensation should include tax relief and a labour policy, as well as an approach that makes a value statement on time spent caregiving. (30)**

## **WE RECOMMEND**

### **Provincial welfare programs respect the needs of people who are sick**

Provincial welfare programs are the only option for many sick Canadians who do not qualify for EI or CPP benefits. The creation of new income support programs could offer a solution, to the financial hardships that many cancer patients are facing. These programs could provide temporary financial relief for families faced with financial hardship.

- **Allow recipients to keep a larger portion of their Registered Retirement Savings** and still be eligible for support

# This is Jenn's story.

It's a cautionary tale for anyone who thinks a job means benefits when illness strikes.

When Jenn learned she had breast cancer, she was in her early 40s and working as a health care aide in a private home. She hadn't thought much about what would happen if she became ill. After all, she had a job. That meant she had sick benefits, didn't it?

Jenn soon learned that not all jobs come with sick benefits, and she was one of the unlucky ones. During the next year, she would find out just how quickly a person can end up bankrupt and living on welfare if they're too sick to keep working.

When Jenn began chemotherapy, she was able to collect Employment Insurance. However, she soon discovered that she could collect EI for only 15 weeks – the maximum sickness benefit, regardless of how long a person has been paying EI premiums.

At that point, provincial welfare was Jenn's only option.

Still sick and stressed out, Jenn found it impossible to make ends meet on her meagre welfare payments. Soon the debts started to mount, and before long, she had maxed out her credit card and line of credit. Next she gave up her car, and in time she filed for bankruptcy.

Now Jenn is working again, although any savings she once had are gone. As soon as she felt able, she bought a second-hand van and started working as a driver for children and families. It doesn't pay much and her doctor suggested it was too early to go back to work, but she just couldn't live on welfare any longer.

Looking back, Jenn wonders whether she would have gone ahead with chemotherapy if she'd known about the financial strain heading her way.

- **Increase payments** for sick people so they are more in line with basic living costs and respectful of the need for good self-care and nutrition during cancer treatment
- **Administer these programs separately** from welfare programs for able-bodied people to reduce the stigma of accessing these programs due to illness

## **WE RECOMMEND**

### **More opportunities to maintain employment**

More people might be able to keep their jobs and earn income during cancer treatment if there were more flexibility within the workplace and better co-ordination within the cancer treatment system. Many segments of the community can play a role in making it easier for people to go in and out of treatment or take on the role of caregiver without facing long-term unemployment. Here are some examples:

- **Bring more flexibility to employment insurance programs** so that people can work part-time during treatment or while providing care, if they are able.
- **Build on cancer survivorship programs** to include approaches that help people keep their jobs during treatment, such as more co-ordinated scheduling of diagnostic testing, treatment and follow-up, and an increase in the availability of services outside of normal working hours.
- **Encourage employers to be understanding** of how workplace policies and job displacement could compound the complex financial pressures faced by people dealing with cancer, either as patients or caregivers, and how a lack of flexibility could contribute to financial devastation.
- **Help survivors find new occupations** through a combination of education, retraining and support that prepares them for suitable employment after treatment.

## **WE RECOMMEND**

### **New programs to fill the gaps**

There are many other approaches federal and provincial governments can consider to prevent people from falling through financial cracks when dealing with cancer. Some of these include:

- **Support programs for adolescents and young adults with cancer.** For many of these people, their cancer diagnosis may preclude them from purchasing insurance as individuals if they become unemployed or self-employed. They may need additional sources of health care funding, insurance debt relief and disability income.
- **Flexible support for low-income people with cancer or other illnesses that would follow the individual throughout all phases of treatment and rehabilitation.** This could be in the form of a tax benefit or welfare payments and should ensure that all Canadians have adequate funding for care – whether they are assisted by family members, friends or professionals, and regardless of whether they remain in the home or move to a care facility.
- **Assistance for relatives who provide long-term child care,** for example, by ensuring that they are entitled to the same compensation as foster parents who aren't related to the children in their care.

## CHALLENGE:

# Affordable cancer drugs and equipment

The rapidly rising cost of cancer drugs is a systemic cost that can and should be borne by the public system. Canadians deserve the kind of drug coverage that most people assume they already have – fair, comprehensive and in tune with current treatment protocols.

## WE RECOMMEND

### **Government coverage of all cancer drugs**

- Individually, all provinces should embrace the policy of the western provinces by **ensuring that all cancer treatment and support drugs are available at no cost to cancer patients** in all parts of Canada – regardless of whether the drugs are IV, oral or self-injectable, and regardless of whether they are used within or outside of a hospital.

## WE RECOMMEND

### **A pan-Canadian drug purchasing program**

- All provinces should work together so that all Canadians have equal access to more affordable cancer drugs. Provinces should use the new pan-Canadian Oncology Drug Review process to achieve greater uniformity of cancer drug formularies across Canada, and should also pursue options for increasing affordability, such as through bulk purchasing discounts for cancer drugs.

## CHALLENGE:

# Easing transportation / accommodation costs

Travel for medical care can exceed even drug costs as the largest single out-of-pocket expense borne by cancer patients and their families (26). The cost of fuel, accommodation, vehicle repair and lost wage can quickly add up to tens of thousands of dollars. Because costs can be higher in rural areas, rural people face inequities based solely on where they live.

The public, private and not-for-profit sectors can all play a role in reducing these tremendous costs.

## WE RECOMMEND

### More sources of assistance

Governments can:

- **Examine their role in reducing travel and accommodation costs** for cancer treatment, regardless of the person's location of residence

Corporate sponsors, community organizations and individual donors can:

- **Expand volunteer community services** to help drive people to and from appointments
- **Provide direct assistance** in the form of gas, parking and restaurant vouchers
- **Channel more donations toward family essentials,**

## WE RECOMMEND

### More efficient use of patient time and travel

There are many ways healthcare system can reduce travel time and costs. Some examples include:

- **Patient-centred coordination of healthcare services.** For example, appointments for out-of-town patients could be scheduled for the middle of the day to reduce the need for overnight stays. When possible, multiple appointments could be strategically scheduled to reduce the need for multiple trips.

**“Provide care closer to home through regional clinics or tele-oncology.”**  
(22)

- **Greater use of Tele-Health services within cancer agencies**
- **Continued development and expansion of community cancer programs in rural areas**

## **WE RECOMMEND**

### **Affordable options for accommodation**

Governments, corporate sponsors and community organizations can:

- **Explore opportunities to increase the range of affordable accommodations** near large treatment centres
- **Support not-for-profit efforts** to build affordable accommodations for rural people who must travel for medical treatment

## This is Donna's story.

Would it have a happier ending, if cancer and expenses hadn't separated Donna from her daughter?

As a single mother in a small northern community, Donna took pride in providing for her daughter. In 2006 she was working three part-time jobs to make ends meet. Life wasn't always easy, but all things considered, life was good.

Then Donna found a lump in her breast. Without sickness benefits, it was clear that social assistance would be the only way she and her daughter could survive while she was ill.

Suddenly, life became very difficult Donna was expected to pay up-front for her medical travel costs, and for prescriptions that could total more than \$700 at a time.

Even worse were the long and frequent separations from her daughter, who was just 12 years old at the time. When Donna travelled to Winnipeg and Flin Flon for treatment, there was rarely enough money for her daughter to join her. Although Donna's own travel costs were covered through social assistance, the extra board and meals for her child were not.

After finishing treatment, Donna regained her footing and went back to work. Soon she was working almost full-time, and an employee benefit program was on the horizon. But while Donna waited for these benefits, cancer struck again – this time as a brain tumour.

One again, Donna returned to social assistance, and once again, treatment kept her away from her daughter.

In time, Donna put illness behind her. She began working full-time as a janitor, and did some cleaning on the side to earn extra cash. Things seemed to be going well.

Then in 2010, the worst disaster struck, when her daughter committed suicide in the basement of their home.

Looking back, Donna asks whether there was something she could have done to avoid this final tragedy. She continues to wonder what might have been, had cancer and poverty not kept them apart during those important years.



# 5 Years, 9 Measures of Success

We aim for significant improvements to be made by 2017 and will use the following measures to track our success:

- Canadians will have access to substantially improved **federal support programs** that provide all seriously ill people and their caregivers with an adequate level of income, longer duration of coverage and greater flexibility of use. This goal will be achieved through improvements to existing programs, as described on pages 28-31, or through innovative new programs that accomplish the same objectives.
- **Caregivers' jobs** will have better statutory protections.
- **Provincial welfare programs** will respect the unique circumstances of sick people by allowing them to retain a greater portion of their savings, and by providing adequate payments to meet their needs.
- Across Canada, all **cancer treatment and support drugs** will be available at no cost to patients, regardless of where and how they are administered.
- All valid out-of-pocket expenses for **medical supplies and equipment** will be reimbursed.
- Patients will receive substantial relief from the cost of **medical travel**.
- **Access to cancer treatment will be less time-consuming and costly** – particularly for rural residents – because additional measures such as coordinated scheduling, increased use of Tele-Health and expanded community cancer centres will reduce the need for travel.
- **More community assistance** will be focused on relieving the financial pressures of cancer and other serious illness.
- **The wider community** – including financial services and human resources professionals – will receive more information on what they can do to help prevent the financial devastation of families dealing with serious illness.

# Potential Partners

It will take a collective effort, demonstrating broad public support, to convince governments and agencies of the very real and urgent need for change. The size of the challenge makes it all the more important for organizations to join forces as we advocate for improvements.

Together, the Canadian Cancer Society – Manitoba Division and the Canadian Cancer Action Network will reach out to many other groups that are well-positioned to influence change.

- **Other health advocacy organizations** dedicated to improving quality of life for Canadians affected by cancer and all other types of life-limiting, chronic and serious illnesses and diseases, at either the national or local level
- **Elected representatives** of the federal, provincial, territorial and municipal governments, who can show their support for Canadians fighting cancer by supporting the changes to government programs identified in this report, and by lobbying their colleagues and leaders to do the same
- **Government departments** dealing with issues related to health care, social services, community development, seniors and women at the federal, provincial and municipal level have a role to play in making these issues a priority for their departments, and in ensuring that the programs they administer meet the needs of Canadians with cancer
- **Health care organizations**, including regional health authorities, clinics, hospitals and professional organizations for those on the front lines of the patient experience
- **Labour organizations** with an interest in improving employment security for all Canadians
- **Anti-poverty organizations** advocating on behalf of financially challenged Canadians
- **Aboriginal organizations** representing First Nations, Inuit, Metis and non-status Aboriginals
- **Professional organizations** representing people working in financial planning, insurance and human resources
- **Service clubs, charitable organizations and foundations** that can facilitate non-government forms of assistance, such as corporate sponsorships and charitable donations

# Timeline for Change

A coordinated approach to relieving the financial burden of cancer needs to start now. The following goals provide focus and will guide our efforts to bring about change.

## SHORT-TERM GOALS

### YEAR 1

- Brief key partners and government decision-makers on the issues and potential solutions
- Build partnerships with like-minded organizations
- Establish a provincial working group
- Establish a national steering committee
- Share lessons learned so all jurisdictions can evaluate needs in each province
- Encourage public use of the CCS Cancer Information Service to find information on existing assistance programs
- Provide all Canadians with access to simple tools for assessing their personal risk
- Provide cancer survivors with new tools and opportunities to make their voices heard
- Expand the CCS Manitoba transportation program to include new communities
- Secure provincial governments' commitment to advocate for national solutions
- Begin building broad public awareness of the need for change

## MEDIUM-TERM GOALS

### YEARS 2-3

- Provide Canadians with an annual interprovincial report card on the adequacy of policies, programs and services addressing financial hardship
- Continue to educate governments and monitor their progress in addressing priorities
- Carry out targeted, co-ordinated advocacy and awareness activities with key partners
- Educate employers and workplace advisors in partnership with the Canadian Partnership Against Cancer
- Bring together stakeholders, experts and influencers in a national think-tank to find practical, far-reaching solutions at every level
- Initiate further research to increase our understanding of key issues and the financial needs of cancer patients and caregivers

- Achieve further expansion of CSS transportation program in co-operation with community sponsors
- Encourage the expansion of community-based assistance programs to offset transportation and accommodation expenses

## **LONG-TERM GOALS**

### **YEARS 4-5**

- Continue to monitor and report on Canada's progress in addressing priorities
- Secure partners' support for a broad, high-profile public awareness campaign focusing on unaddressed issues, particularly regarding government income support programs and cancer drug coverage
- Provide Canadians with a final report and recommendations for the future

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# How You Can Be Part of the Solution

## **Educate yourself and others**

Find out whether your family is adequately prepared for the financial impact of a cancer diagnosis. Help others see the risk and find the help they need. Introduce the issue of financial burden and cancer into your education curricula for health care workers, counsellors, financial planners, lenders and human resource professionals.

## **Contribute to community programs**

Donate to programs that provide emergency funding to breast cancer patients in need. Encourage your community or service club to donate volunteer drivers, gas or parking vouchers to rural families who need to travel for cancer treatment.

## **Make this a personal cause**

Would you like to see changes in government policies and programs? Do you believe the health care should address financial need? Let your government and regional health system know.

## **Tell your story**

Have you suffered financial hardship because of cancer? Submit your story to [infor@mb.cancer.ca](mailto:infor@mb.cancer.ca).

## **Join the conversation**

Bring forward additional solutions to address these important issues. We welcome your input.

**For more information, visit [www.cancer.ca/manitoba](http://www.cancer.ca/manitoba) and [www.ccanceraction.ca](http://www.ccanceraction.ca).**