

# REPORT CARD

## ON CANCER CARE IN CANADA 2002

# S

## till racing against cancer

*Political leadership is urgently needed to make cancer care Canada's number one priority*

Cancer today is the leading cause of premature death in Canada, responsible for almost 30 per cent of all potential years of life lost. Based on current incidence rates, 38 per cent of women and 41 per cent of men will develop cancer during their lifetimes (*Canadian Cancer Statistics 2002*). Because cancer is primarily a disease of older people, an aging population and the fact that people live longer are expected to drive up incidence and mortality rates.

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VOLUME 5  
WINTER 2002-03

## ARE WE PREPARED?

### *Preventing cancer*

Cancer control is about prevention, finding a cure and managing the disease. In 80 per cent of cases the known causes of cancer are related to lifestyle. At present, only a small percentage of funding is allocated to prevention, despite its importance. More research and new approaches to prevention are needed to stave off the looming increase in cancer cases. A clearly enunciated and well-funded plan is required now to help people stop smoking, eat a healthy diet, remain active, avoid excessive sunlight, and reduce their exposure to other agents, such as cancer-producing viruses spread through sexual activity.

### *Managing cancer*

The recent Romanow and Kirby reports point to serious shortcomings in our healthcare system. Though the state of cancer care was not specifically under the microscope, the deficiencies in the general healthcare system, such as lack of equipment, shortage of professionals, high costs of drugs, and inconsistencies in care across the country, have a significant effect on people with cancer. The volume of new and existing cases, the complexity of treatment and the lethal nature of the disease put unique pressures on cancer patients and the system that is meant to care for them.

The Romanow and Kirby reports confirmed that Canada is at the bottom third of Organization for Economic Cooperation and Development (OECD) countries in the availability of diagnostic equipment, such as MRIs and CT scans. This affects waiting times for treatment across the spectrum of patients in Canada, but since both types of machines are crucial in the detection and management of cancer, the impact on cancer patients is significant. Lack of diagnostic equipment and technicians is but one aspect where the system is failing patients in providing optimum care. The shortage of oncology professionals is another factor causing waiting times to rise.

# Report Card on CANCER CARE in Canada

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## **Publisher**

Cancer Advocacy Coalition of Canada

## **Editors-in-Chief**

Pat Kelly

Colleen Savage

## **Board of Directors**

Dr. Jack Chritchley

*Former Vice-President of the Communities  
Oncology Network at the BC Cancer Agency*

Dr. William Hryniuk

*Former Director, Breast Cancer Clinical  
Program, Karmanos Cancer Institute, Detroit*

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*Author, cancer survivor and advocate*

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*Co-founder of the New Brunswick Breast  
Cancer Network*

Colleen Savage, Co-Chair CACC

*Toronto-based health policy analyst and  
public affairs consultant*

Barry Stein

*Montreal-based attorney, President of the  
Colorectal Cancer Association of Canada*

Jan Capen, MBA

*Victoria-based cancer survivor and advocate*

Dr. Stefan Glück

*Medical oncologist, Tom Baker Cancer Centre,  
Calgary, Alta.*

## **Contributing editors/writers**

Laura Eggertson

Marja Hughes

## **Design**

The Armadillo Design Company

Cancer Advocacy Coalition of Canada

180 Bloor Street West, Suite 904

Toronto, Ontario M5S 2V6

Tel.: (416) 538-4874, Toll Free: 1 877-472-3436

E-mail: canceradvocacy@on.aibn.com

Web site: www.canceradvocacycoalition.com

## **IS IT ENOUGH TO FIX THE SHORTAGE OF DIAGNOSTIC EQUIPMENT AND CANCER CARE PROFESSIONALS?**

Prevention, early detection and timely treatment are important factors in the fight against cancer. An equally important facet of cancer control is surveillance. Up-to-date and reliable data on cancer incidence and mortality rates is vital in tracking trends and identifying whether prevention, screening, and treatment efforts are reducing deaths and increasing survival rates. Very little information is currently available about the long-term outcome for patients treated with various forms of chemotherapy drugs. This information is critical to helping patients make knowledgeable choices, to help plan for appropriate resources and to enable us to benchmark our efforts against other jurisdictions.

Our annual effort to chart the state of cancer care in Canada includes a search for up-to-date statistics. Without this data we do not know how many people have cancer or will get cancer, how long they are waiting for diagnosis and care, and how much cancer care costs and will cost, which means we cannot adequately track the disease and our efforts to control it. We cannot manage what we cannot measure.

Our survey of provincial and territorial cancer registries and agencies reveals an uneven ability to respond to our inquiries about incidence and mortality trends, prevalence and survival rates. Despite the best efforts of cancer care agencies and professionals we still have a patchwork of statistics and a lack of standardized definitions and methodologies for collecting and analyzing data.

Combined with varying degrees of access to diagnostic equipment, specialists and treatments, as well as different provincial decisions about funding for health services, new programs and research, your chances for surviving cancer might depend on where you live in Canada.

## **WHAT DOES THE FUTURE HOLD**

Although we have made considerable progress in the fight against cancer,

### **WHY SHOULD YOU CARE ABOUT CANCER?**

- *One in three Canadians will be diagnosed with cancer some time in their lives*
- *Every day, 375 people in Canada are diagnosed with cancer, and 181 people die from the disease (Canadian Cancer Statistics 2002)*
- *Incidence rates of cancer in Canada are expected to increase by 70 per cent by 2015, because of an aging and growing population (Health Canada)*
- *In a few short years, mortality counts for cancer will outstrip those of cardiovascular and respiratory disease, mental disorders and injuries (Health Canada)*
- *Every Canadian family has a cancer story to tell*
- *Despite sweeping studies of Canada's healthcare system in the past few months, Canadians are still waiting for political commitment to a comprehensive national strategy for cancer care and control*
- *A deadly silence surrounds the national plan to address growing cancer problems: Where is the Canadian Strategy for Cancer Control?*

we need to overcome a number of challenges if we are to continue to make progress in cancer control. Where you live should not determine your standard of care or your chances for survival. Our report makes it clear that further advances are needed in the full range of cancer control activities.

The biggest shortcoming of the current state of cancer care in Canada is the lack of a comprehensive program capable of providing national standards in cancer care and control. Canada has had an unofficial national cancer plan for more than a year. But this critical strategy has yet to gain government commitment. Our political leadership has failed us in implementing the Canadian Strategy for Cancer Control at the same time as the number of new cases of cancer is rising.

Our system is already under strain when the number of people living with cancer is increasing by about seven per cent a year. That percentage will grow as the population ages. We urgently need political commitment for the strategy, including prevention, detection, treatment and palliative care with equal and timely access for all Canadians. The time for “watchful waiting” is past. The time to act is now—before the full impact of a cancer epidemic is upon us.

Failure by our governments to heed this advice, provide the required leadership and establish an effective national cancer control strategy, means that fewer and fewer Canadians will get optimal cancer care.

Canadians could have the best cancer care in the world – we have a publicly funded healthcare system, we have first-rate cancer care professionals, we have renowned research facilities, and—most importantly—Canadians consider cancer control a national priority.

We need to rekindle the spirit of an unforgettable young advocate who brought us together in the fight against cancer more than 20 years ago. Terry Fox’s singular courage put Canada on the map as a global leader in the fight against cancer. Finance Minister John Manley recently spoke with great pride about participating in the 2002 Atlanta, GA, Terry Fox Marathon of Hope. But it will take more than political speeches to keep Canada in the forefront of cancer control.

It’s time for our politicians and healthcare managers to feel the same urgency for cancer care as those who are living with the disease.

It’s time for Canadians and our political leaders to get back into the race against cancer.

***FIND OUT WHAT YOU CAN DO TO GAIN POLITICAL COMMITMENT TO IMPLEMENT THE CANADIAN STRATEGY FOR CANCER CONTROL. SEE THE BACK COVER OF THIS ISSUE OF THE CACC REPORT CARD ON CANCER CARE IN CANADA TO GET INVOLVED IN THE FIGHT AGAINST CANCER.***

## **Acknowledgement**

The Cancer Advocacy Coalition of Canada wishes to extend a note of appreciation to the following sponsors for their generosity and support in 2002:

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- Provide a demonstrable benefit to people with cancer
- Demonstrate accountability and transparency about the way in which collaborative efforts will be undertaken
- Have clearly identified goals and objectives that are compatible with CACC’s mission
- Assure that the CACC maintains final control over all editorial content, design and dissemination of information, products and services
- Bring a strong commitment to the success of the alliance through agreement on the terms and conditions and demonstrable support from each partner’s key leaders.

These guidelines are developed and unanimously supported by the Board of Directors of the CACC.

## CROSS-CANADA CHECKUP

To get beyond the 1998 figures that form the basis for *Canadian Cancer Statistics 2002*, the Cancer Advocacy Coalition of Canada surveyed provincial and territorial cancer agencies and registries and asked the following:

1. Can you provide your most up-to-date statistics on cancer incidence and mortality for the most prevalent cancers (breast, lung, colorectal, prostate)? Do you have five- and ten-year survival rates?
2. Can you tell us how long patients have to wait to receive radiation, chemotherapy or for diagnostic tests?
3. What does your province or territory spend each year on cancer care services?

The responses showed that pressed for resources, most provinces and territories referred to *Canadian Cancer Statistics 2002*. In some instances, statisticians or staff responsible for surveillance data were not available, or had other pressing deadlines, or the position was vacant. Others had data beyond 1998, including Newfoundland and Labrador, Nova Scotia, Quebec, Ontario, Manitoba, Saskatchewan and British Columbia.

Prince Edward Island's response exemplified the problem on waiting times. The province would not release the information it tracks, saying that each province measures waiting times differently. A case-by-case evaluation in some instances would be necessary for the data to be correctly interpreted, a spokesman for the Prince Edward cancer care agency said.

Quebec and Saskatchewan also cited the issue of standardized definitions. Each institution—much less each province—measures the time differently (e.g., the point at which one starts to count).

Cancer care agencies were for the most part able to provide budgets figures for cancer services. But these figures do not represent all the money a province spends on cancer care. For example, acute care hospitals or other organizations provide many services. Because no province seems to have a global cancer figure, it is impossible to compare budgets.

Here are specific answers to our questions, per province, where they were provided:

### NEWFOUNDLAND AND LABRADOR

#### INCIDENCE AND MORTALITY:

Data on actual cancer incidence for 1999 is being collected and should be available shortly.

# Aggressive national cancer control strategy needed to meet rising cancer rates

Worldwide, there are 20 million people living with cancer. By the year 2020, the World Health Organization estimates this figure will have increased to more than 30 million. An aging population and the rising incidence of lung cancer (the most common cancer) and skin cancer (the fastest growing cancer) are driving this projected increase.

Despite scientific and technological advances in the search for cures, and even with increased emphasis on prevention, cancer remains one of the most deadly diseases in the world. Cancer accounts for 12 per cent of all deaths today, or about six million cases worldwide (World Health Organization). By 2020 cancer deaths are estimated to rise to 10 million a year. In the developed world, cancer is the second most common cause of death, after cardiovascular diseases.

Every day, 375 people in Canada alone are diagnosed with cancer, and 181 people die from the disease. (*Canadian Cancer Statistics 2002*). By 2010 those figures are expected to skyrocket to 602 people diagnosed with cancer and 295 people dying from the disease each day (Health Canada).

Estimates of mortality counts for cancer, cardiovascular, respiratory, mental disorders, and injuries for 1998 to 2010 predict that cardiovascular deaths are declining and by about 2006 will intersect (at about 75,000 death per year) and then fall below cancer deaths, which are rising (Health Canada's Surveillance and Risk Assessment Division).

A concerted effort focused on prevention, early detection, speedy diagnosis and improved treatment (including advanced drugs and technologies) is imperative to manage, and hopefully stave off, the coming epidemic of cancer cases.

The World Health Organization believes national cancer control programs are the best hope to fight cancer. "A well-conceived, well-managed national cancer control programme is able to lower cancer incidence and improve the lives of people living with cancer," the WHO says in *National Cancer Control Programmes: Policies and Guidelines* (May 2002).

## ***A GROWING PROBLEM***

**R**ising incidence rates, escalating costs of health care and the physical, emotional and financial strain that a cancer diagnosis causes, makes cancer care one of the most serious crises Canada will face in the next two decades.

Overall, mortality rates for cancer have been declining since the late 1980s, says Dr. Howard Morrison, Health Canada's interim director of chronic disease control and management. But an aging population "and the fact that we haven't seen the big improvements that we'd like to have seen" means incidence rates have been increasing slightly, he says. Screening programs are likely responsible for some of that increase—but not all. And the fact that new cases are on the rise, even slightly, speaks to the issue of prevention.

One of the worrisome trends in cancer care for Morrison is the increase in non-Hodgkins lymphoma in Canada. "It used to be quite rare and now it's quite common. We don't really understand what's driving that," says Morrison.

The most comprehensive cancer report available today to help decision-makers set priorities for cancer control is *Canadian Cancer Statistics 2002*. The report presents the incidence and mortality of the most common types of cancer by age, gender, time period and province or territory. It includes actual rates and frequencies up to 1998, and estimated values for the years up to 2002. (More recent actual rates and frequencies were not available at the time of publication.)

Those estimates show 136,900 new cases of cancer and 66,200 deaths for 2002, with men outnumbering women for new cases (by 3.9 per cent) and deaths (by 12.9 per cent).

Breast cancer continues to be the most frequently diagnosed cancer in women. One in nine women are expected to develop the disease. Prostate cancer is the most frequently diagnosed cancer in men. One in eight men are expected to develop the disease. Lung cancer remains the leading cause of cancer death for men and women. Colorectal cancer is the third most common cancer for both sexes.

Cancer is primarily a disease of older Canadians: men 60 years and older constitute 71 per cent of new cases and 83 per cent of cancer deaths; women 60 years and older make up 63 per cent of new cases and 79 per cent of cancer deaths.

Together with incidence and mortality rates, survival rates are an important indicator of the burden of cancer and the success of cancer control. The report includes five-year relative cancer survival rates in eight provinces, based on 1992 incidence, for the four most common cancer sites: breast, prostate, lung and colorectal. Survival rates were highest for prostate cancer at 87 per cent, followed by breast cancer at 82 per cent, colorectal cancer at 56 per cent for men and 59 per cent for women, and lung cancer at 14 per cent for men and 17 per cent for women.

While mortality rates have been declining overall, rising incidence rates,

The 2002 annual report for the Newfoundland Cancer Treatment and Research Foundation indicates new patient referrals over the past five years have increased 24 per cent. During the fiscal year 2001-2002, the number of new patients and follow-up visits increased by 7.8 per cent and 4 per cent respectively, compared with the previous year. Consultations increased by 233 per cent, which may be directly related to a clinical policy requiring all new and reoccurring patients to be evaluated by both medical and radiation oncologists.

### **WAITING TIMES:**

New patient referrals to the cancer program are assessed weekly and patients are prioritized according to disease staging. Patients with advanced cancer are seen within one week. The maximum waiting time for non-urgent patients is approximately 4-6 weeks. Waiting periods for chemotherapy are relatively short and do not generally exceed one week. The maximum waiting period for routine radiation therapy is six weeks.

No answer was available on waiting times for diagnostic services. Patients who are in active treatment and follow-up programs, have a "minimal" wait time for diagnostic imaging services. Cancer patients are given priority by most diagnostic imaging departments of acute care hospitals.

## **PRINCE EDWARD ISLAND**

### **INCIDENCE AND MORTALITY:**

This registry says it cannot produce survival and age-adjusted statistics. Only *Canadian Cancer Statistics 2002* data is available.

## **NOVA SCOTIA**

### **INCIDENCE AND MORTALITY:**

Incidence rates are available for 2000. In a report released on October 25, Cancer Care Nova Scotia says the provincial cancer rate will rise by more than 40 per cent over the next eight years, with an estimated 19 people being diagnosed every day. The study analyzed cancers from 1995 to 1999. It found 11,000 people died during that five-year period and 5,000 new patients were diagnosed each year. The figure is expected to rise to 7,000 a year by 2010.

### **WAITING TIMES:**

No systematized information on waiting times is available, according to the Nova Scotia cancer care agency.

## **NEW BRUNSWICK**

The provincial Department of Health and Wellness has established a Cancer Care Steering Committee to improve care for cancer patients in New

Brunswick—the province does not have a cancer care agency or cancer registry. The committee will develop a comprehensive, integrated, patient-centred community cancer care program, together with regional health authorities.

The Committee will review the 1998 Cancer Services Action Plan and identify priorities for the development of a continuum of cancer care services, including prevention, screening and detection, education, treatment and support. It also will monitor data on trends in cancer morbidity and mortality in the province, and identify ways to make the most efficient use of all available resources in meeting the Action Plan's objectives.

## QUEBEC

### INCIDENCE AND MORTALITY:

The most recent incidence rates available are for 1999. Projections are available for 2001.

A comprehensive report released in May, *La survie au cancer pour les nouveaux cas déclarés au Québec en 1992* (Cancer survival for new cases diagnosed in Quebec in 1992), includes comprehensive five-year survival rates (based on 1992 cases) for the principal cancer sites. Survival rates are compared with other provinces in Canada (they were not higher or lower than elsewhere).

### WAITING TIMES:

Waits of more than eight weeks exist at some regional cancer centres, because patients refuse transfers between institutions, according to Quebec's Ministry of Health. When institutions have waiting times approaching eight weeks, patients can be transferred, arranged by the ministry at no cost to the patient (food, lodging, and transportation are paid for). As of January 31, 2002, transfers to the U.S. for treatment have ceased.

Quebec notes that waiting time comparisons in Canada are difficult with no standardized definition. This is also a problem between institutions within the province. Quebec is trying to develop a standard definition to give patients better access to relevant data.

There is now a plan in place for radiation oncology from 2002 to 2009, which focuses mostly on delays in breast and prostate cancer treatment. Since the plan has been implemented, delays have diminished. As of February 2003, a pilot program called SGAS (Management System for Access to Services), will be launched at two of the nine radiation oncology centres. It will include standardized definitions. If all goes well, the other radiation oncology centres will be added to the system later in 2003.

### HUMAN RESOURCES:

Quebec has increased recruitment of radiation oncologists, radiation therapists and physicists but

the fact that people live longer, and an aging population make it imperative for those who collect cancer data to sound the alarm on the upcoming need for cancer care and control.

## A WORRISOME TREND

Cancer is a complex, highly lethal, costly disease to manage and the number of new cases is rising. Some of the biggest problems in managing the disease lie in waiting times for detection and treatment, and surveillance.

### DIAGNOSIS

According to a recent Ipsos-Reid poll, conducted for the *Globe and Mail* on CTV news, 63 per cent of those surveyed believe reducing waiting times for diagnostic services such as an MRI or a CT scan should be the top priority for increased health spending (*Globe and Mail*, November 25, 2002).

This would corroborate an earlier report by the Ontario Association of Radiologists, released in early October. The association says that waiting times for common diagnostic examinations are “overwhelmingly in excess of the recommended two weeks.” These examinations include mammograms used to detect breast cancer, ultrasounds used to detect a wide range of cancers, and x-ray barium enemas used to detect colorectal cancer. The other alarming fact that emerged from this survey of 60 Ontario communities is that the level of access fluctuates drastically across the province for the same diagnostic examination.

Ontario's radiologists say years of provincial funding freezes and cutbacks have resulted in outdated equipment, lack of funding for overhead expenses to deliver the services, shortages in radiologists and technologists, and no ability to introduce important new diagnostic examinations.

The Fraser Institute's 12<sup>th</sup> annual survey *Waiting Your Turn: Hospital Waiting Lists in Canada*, released September 2002, also reported significant waiting times for diagnostic and therapeutic technology—computed tomography (CT), magnetic resonance imaging (MRI), and ultrasound scans. The median wait across Canada for a CT scan was 5.2 weeks; 5.0 weeks for an MRI; and 3.2 weeks for an ultrasound. Compared to other OECD countries, patient access to medical technology in Canada ranks in the bottom third, says the report.

### TREATMENT

The Fraser Institute's survey found waiting times for surgical and other therapeutic procedures grew in 2001-02. For Canada as a whole, waiting time between referral by a GP and consultation with a specialist is 7.3 weeks, up from 7.2 weeks in 2000-01.

There was some good news. The report identified the shortest waiting times in radiation oncology (2.6 weeks) and medical oncology (3.3 weeks). The survey also found actual waiting times in most cases exceed what are considered clinically reasonable. Medical oncology was among the specialties that most often met or exceeded the “reasonable” standard.

For Canada as a whole, though, time between seeing a specialist and treatment rose to 9.2 weeks, up from 9.0 weeks in 2000-01. Medical oncology showed one of the shortest intervals with 2.2 weeks, just after urgent cardiovascular surgery (1.9) weeks.

However, our cross-country survey (see sidebar) seems to be at variance with the institute's report. As our survey indicates, waiting times vary, from a low of 1-2 weeks in British Columbia for radiation treatment, to as much as eight weeks in some parts of Quebec.

Variations in definitions and methods, as well as data sources make the result of waiting time studies seem contradictory, says the 2002 edition of *Health Care in Canada*, published by the Canadian Institute for Health Information and Statistics Canada. The report also says that "while most studies using administrative data include all patients who received care, coverage for physician surveys varies. For example, only about one quarter of doctors contacted by the Fraser Institute in 2001 responded to the survey."

Comparable data about who is waiting for what and for how long is still scarce and only pockets of information exist across the country.

## **SURVEILLANCE**

Up-to-date information on cancer incidence and mortality rates is vital in tracking trends and whether disease detection and treatment are successful in reducing deaths and increasing survival rates.

Information on cancer incidence and mortality is provided by provincial and territorial cancer registries and collected by Statistics Canada. But as the *Canadian Cancer Statistics 2002* report indicates, variations exist between geographic regions in screening and early detection technologies, patterns of diagnosis, availability and access to cancer treatment, and variation in reporting methods by registries.

The North American Association of Central Cancer Care Registries (NAACCR) tracks incidence and mortality rates among U.S. states and Canadian provinces and territories. The association develops and promotes uniform data standards for cancer registration and encourages the use of cancer surveillance in cancer control.

The most recent report, *Cancer in North America 1995-1999*, includes only seven Canadian cancer registries—The Northwest Territories, British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick and Prince Edward Island. Data from the other cancer registries did not meet the association's criteria to be included, says the report. Each registry was asked to provide five years of data (1995-1999). Figures from each year had to pass criteria for completeness of reporting, non-duplication of records, internal consistency of data, and a low percentage of death-certificate-only cases and cases with missing or unknown information on sex, race and age.

The seven registries included in the report only make up one third of Canada's population, which makes it difficult, if not impossible, to extrapolate any kind of trend in cancer incidence and mortality or comparison between Canada and the U.S. Although experts agree that

has the added problem of needing them to speak French.

## **ONTARIO**

### **INCIDENCE AND MORTALITY:**

The Ontario Cancer Registry has both incidence and mortality rates up to and including 2001. The registry also can provide five- and ten-year survival rates.

## **MANITOBA**

### **INCIDENCE AND MORTALITY:**

Cancer Care Manitoba has incidence and mortality rates for 1999, incidence figures for 1990-1996, and prevalence numbers for 1996 in Manitoba's Regional Health Authorities.

### **WAITING TIME:**

The average waiting time for radiation therapy is currently 4-5 weeks. Urgent cases are seen sooner. There are no waiting lists for systemic therapy, except for some waiting time for first appointments for more common cancers.

## **SASKATCHEWAN**

### **INCIDENCE AND MORTALITY:**

Incidence and mortality data for the years 1999 to 2001 are available. Five- and ten-year survival rates could be generated, but not in time for this publication.

### **WAITING TIMES:**

The Saskatchewan Cancer Agency currently does not collect provincial waiting times for radiation and chemotherapy. But data could be extrapolated from date of diagnosis to start of treatment. However, if these figures are for comparison purposes, standard definitions would be needed, the agency says.

## **ALBERTA**

### **INCIDENCE AND MORTALITY:**

Alberta cites incidence and mortality rates from *Canadian Cancer Statistics 2002*. Alberta's cancer registry reports on its Web site that the province's population of about three million is growing and aging. The number of cancer cases is increasing each year. It is estimated that by 2010 the number of new cases will increase from just under 4,500 cases per year to more than 15,000.

### **WAITING TIMES:**

The Alberta Cancer Board says standard waiting times for radiation is four weeks maximum and they are largely on track, except for prostate cancer, which is a little over four weeks. According to Dr. Stefan Glück, medical oncologist at the Tom Baker Cancer Centre in Calgary, director of the South

Alberta Breast Cancer Program and professor in the department of oncology at the University of Calgary, waiting times for breast and lung cancer are longer. The aim is to bring these times back to less than two weeks by the end of the year.

## BRITISH COLUMBIA

### INCIDENCE AND MORTALITY:

Incidence and mortality rates are available for 1999. Survival rates by tumour group are being compiled.

### WAITING TIME:

British Columbia cancer agencies have provincial standards for medical oncology (systemic therapy) care. There is a maximum of two weeks waiting time for an oncology appointment (certain urgent referrals are seen within a day or two). This standard is met most of the time, except when dealing with temporary shortages of medical oncologists, in which case patients are triaged for appointments according to medical need, or referred to another cancer centre. In those few circumstances there may be a delay of up to four weeks.

Waiting times are monitored for all centres, according to diagnostic category (e.g., breast cancer, lung cancer, etc.).

There is also a maximum of two weeks waiting time from a physician writing a chemotherapy treatment order and treatment. Urgent cases are treated within days. Data is not collected, but agencies are notified if there is a problem and endeavor to resolve it. There have been difficulties recruiting and retaining chemotherapy nurses, but at present, appropriate staffing levels are in place.

The median waiting time for radiation therapy in British Columbia for radiation therapy once a decision is made to treatment is between 1-2 weeks.

## NORTHWEST TERRITORIES

### INCIDENCE AND MORTALITY:

The most recent figures are included in *Canadian Cancer Statistics 2002*. Information is available on survival times from the registry.

### WAITING TIMES:

The registry has no means of collecting and analyzing waiting times. They would be similar to Alberta's waiting times (especially Edmonton), where most cases are referred, unless they can be processed in the territory, which would reduce wait times.

## NUNAVUT

No information provided.

the NAACCR data is the best benchmark for comparing different populations trends, without the inclusion of all provinces and territories. Canadians lack much-needed evidence on our progress in fighting one of our nation's major causes of death.

## WHERE ARE WE FAILING?

To fully understand the need for a comprehensive strategy, Canadians must understand the prevalence of cancer. They must understand that where you live may affect your chances of survival and the time it might take you to receive a diagnostic test or begin radiation treatment. The lack of adequate data to track these issues is a problem many cancer care professionals acknowledge. It remains a key issue for those trying to ensure that Canadians receive the best care for cancer, no matter where they live.

Cancer care professionals, who are managing an increasing number of patients, also are active in research into prevention and treatment. They help train students, participate in advisory and professional committees, monitor progress on research, and participate in developing appropriate evidence-based guidelines.

But regional disparities exist. Cancer agencies face increasing pressure to be more accountable to the public, have access to better information and track the effectiveness and efficiency of their programs faster. The last dependable figures for comparison across the country date from 1998, as presented in the *Canadian Cancer Statistics 2002* report, with estimates for 2002.

We need up-to-date, standardized numbers. Without these we do not know how many people have cancer or will get cancer and how much cancer care will cost, which means we cannot adequately track the disease and our efforts to control it.

One of the medical advisors at Quebec's Co-ordination Centre for Cancer Control, Linda Cote-Brisson, explained that the centre is a new body, created to co-ordinate cancer care. It is part of Quebec's cancer control strategy, which has been in place since 1998 and is similar to the national strategy on cancer control. What we need, she says, is "better data and a means for evaluating leading indicators."

The causes of cancer may still hold some mysteries, but we do know a lot about the means of control. And there is no better way to exploit that knowledge than through a national cancer control program, as the WHO has concluded. We need to implement a well-funded, well-organized program capable of providing national standards, and a comprehensive and systematic approach to prevention, detection, treatment and surveillance. We need political commitment for a program that is equitable, sustainable and effective. Without government commitment an effective national cancer strategy, fewer and fewer Canadians will get optimal cancer care.

The Cancer Advocacy Coalition of Canada has long promoted the need to implement an active, aggressive cancer control strategy here. (See story p. 10). The coalition believes that we know enough about treatment and the ingredients of a sound cancer control strategy. Canada could be the global leader in cancer control—taking stronger steps to prevent, cure and relieve suffering—if only we had the political will, as a nation and a people, to do so.

Province/ Territory	Total expenditure on professional cancer services	Capital investment in equipment 2001-02	Cancer agency annual budget	Population 2002
<b>British Columbia</b>	Not readily available	Not readily available	The BC Cancer Agency's 2001-02 operating budget: \$216,814,758, including \$172,925,064 from the province.	4,060,133
<b>Alberta</b>	Not readily available	\$13.3 million (\$4.2 million from internal resources, \$9.1 million from external sources).	Alberta Cancer Board 2002-03 budget: \$151.5 million, including \$142.1 million from the province.	3,009,860
<b>Saskatchewan</b>	Not readily available	\$3.5 million to acquire two new linear accelerators.	Saskatchewan Cancer Agency annual operating budget: \$46 million, most of it provided by the province	1,021,963
<b>Manitoba</b>	Not available	Investment in capital assets totalled \$1.8 million.	Cancer Care Manitoba operating budget: \$47.9, including \$38.1-plus from the province.	1,146,444
<b>Ontario</b>	A December 2001 provincial government report suggests \$1.5 billion is spent on cancer care	\$60 million has been provided to the cancer system over 2 years: \$40 million to CCO and \$20 million to Princess Margaret hospital.	Cancer Care Ontario annual budget: \$312 million (according to province). In 2001-02 province contributed \$266 million.	11,697,569
<b>Quebec</b>	Not available	Not available	No Cancer Agency	7,381,766
<b>New Brunswick</b>	Not readily available	Not available	No Cancer Agency	755, 617
<b>Nova Scotia</b>	Not readily available	Not available	Cancer Care Nova Scotia 2001-02 budget: \$4,359,024	942,315
<b>PEI</b>	Not available	Not available	Not available	138,341
<b>Newfoundland and Labrador</b>			Newfoundland Cancer Treatment and Research Foundation 2002-03 operating budget: \$15,498,509	537, 877
<b>Territories</b>	Not available	Not available	Not available	40,849
<b>Nunavut</b>	Not available	Not available	Not available	27,503

For more financial information on cancer care across Canada visit the CACC Web site: [www.canceradvocacycoalition.com](http://www.canceradvocacycoalition.com)

*A bill that would increase federal spending on cancer care is making its way through the United States legislative system. Senator Edward Kennedy was joined in September 2002 by three-time Tour de France champion and cancer survivor Lance Armstrong to introduce the Quality Of Care For Individuals With Cancer Act. Legislative suggestions include money to expand cancer registries, development of*

*comprehensive data systems and implementation of case-manager programs.*

*Canada's publicly funded national healthcare system, combined with a more manageable population base, affords our country a distinct advantage in implementing a made-in-Canada Quality Of Care For Individuals With Cancer Act.*

# *Advocacy is key to putting cancer care crisis on top of political agenda*

**Advocacy groups need to bring more pressure to bear if a national cancer control strategy is to get more funding to battle the disease, says a senior Health Canada bureaucrat.**

“We think cancer’s a huge public health problem that hasn’t had near the focus that it should have had, particularly given the demographics,” says Dr. Howard Morrison, interim director of chronic disease control and management for Health Canada.

“The take-home message is that the squeaky wheel gets the grease,” Morrison said in an interview for this publication. “Governments listen to citizens, to externals. They’re much more likely to listen to the extent that there are advocates who are actively and aggressively campaigning with appropriate facts. Governments respond to political pressure.”

Morrison was commenting on the Canadian Strategy for Cancer Control. Launched almost four years ago, the strategy is currently financed at \$600,000 a year—\$500,000 from Health Canada and \$100,000 from the National Cancer Institute of Canada (the funds are for planning and do not include research). When the strategy was devised, participants were hoping for a budget of \$20 million a year. That is less than half of what the national AIDS strategy receives (\$42 million this fiscal year). While cancer killed 58,703 people in 1997, compared with 626 from HIV and 5,699 from diabetes, the other disease control strategies are more fully funded. The diabetes control strategy, for example, receives \$115 million over five years. Even though

these funds include implementation over a number of years, it is fair to say that despite the huge number of Canadians affected by cancer, a dedicated fund to implement—not plan—has not been established.

“While the national strategy has substantial support across both the patient and professional cancer communities, it suffers incredible underfunding when compared with other disease-based strategies,” wrote the Cancer Advocacy Coalition of Canada’s Board of Directors in a letter to the Romanow Commission. during its examination of the state of health care in Canada.

“This inequity underlines the importance of using evidence-based medical criteria to fund strategies.”

The coalition called on the Romanow Commission to recommend that the cancer control strategy achieve priority status among other disease control initiatives. That priority is critical given that by 2010, the number of people suffering from cancer will have jumped by 70 per cent, according to Health Canada.

“We have a crisis in cancer care—we know there will be a 70-per cent increase in the number of new cancer patients, while half of the professional cancer care providers will retire,” says Pat Kelly, chair of the Cancer Advocacy Coalition of Canada. “Canadians consider cancer a high priority—it is the disease Canadians fear the most. Yet none of our elected provincial or federal officials has taken a stand on fixing cancer care.”

“We need political leadership now, first of all at the national level, for what we’re going to do for cancer care in this country.”

**T**HE CANCER CARE CRISIS is manifest in human resources—a shortage of key cancer care professionals (see story page 17)—and in the strains an increasing volume of cancer patients is

placing on the underfunded healthcare system, says Kelly. She points to a caseload of about 130,000 new cancer patients each year. No one approach will solve the problem, but a creative, forward-thinking strategy that will exist beyond the life of one individual minister of health or provincial government is critical, she insists. Canadians need to know that, like the Canada Pension Plan, a cancer control strategy will be in place throughout their lifetime.

So far, the political leadership Kelly and the coalition are seeking has not materialized. The number of cancer cases is gradually increasing at a rate of seven per cent per year. But Morrison and other Health Canada officials charged with implementing the cancer control strategy are not hopeful that this spring's federal budget will deliver the millions necessary to boost the strategy to the top of the priority list.

"I don't think there's any anticipation of funding it at the levels that many of the individual council members would like to see it funded at," says Morrison. "It's a legitimate debate for Health Canada to say, 'where do we get the most bang for our buck, and is this where we want to put it, as compared to all other line-items and groups that want the money.' But it should at least be on the agenda for discussion," he says. "You can do more with more money. That is the ultimate bottom line."

The federal government could learn from the experience of Ontario's Conservative government under then-Premier Mike Harris, says the coalition's Kelly. After taking office in 1995, the Harris government rejected the advice of Cancer Care Ontario and cancelled plans for new cancer centres across the province. The result was that just before the 1999 election, waiting times for radiation therapy had soared to more than 20 weeks. The resulting political debacle forced the Ontario government to finance treatment for patients travelling to the United States for radiation therapy—a problem Kelly suggests the federal government could avoid by longer-term planning.

The federal government has sent some signals that more funding might be available in this fiscal year, says Dr. Barbara Whiley, the Canadian Cancer Society's representative to the strategy's governing council.

The Kirby Report recommended in October that the federal government come up with \$5 billion to finance the public health care system, including paying the cost

of large or "catastrophic" drug bills. The committee, headed by Liberal Senator Michael Kirby, recommended that Canadians who pay more than \$5,000 a year in drug costs should get some help. Under the committee's plan, once patients reached the \$5,000 mark, the government would pay up to 90 per cent of the additional costs. (See sidebar "patient welcomes idea for federal funding," p. 13.)

Nevertheless, more funding for this or other related initiatives does not appear high on Health Minister Anne McLellan's agenda—at least not for discussion with the Cancer Advocacy Coalition of Canada, representing cancer patients. McLellan's press secretary declined an interview for this article, citing scheduling problems. Ontario Health Minister Tony Clement was similarly busy, his media spokesman said.

Without a political push at either the national level, or from strongly motivated provinces, the Canadian Strategy for Cancer Control will falter, says Kelly. That means Canadians have to push the politicians, she urges—unless they want cancer care to deteriorate.

"Anyone running for public office should be prepared to say what they plan to do about the shortage of cancer care professionals, the lack of planning and resources and the failure to fund primary cancer prevention efforts," says Kelly. "Candidates should also be prepared to talk about researching links between the environment and cancer—that's what Canadians want and expect."

Every day, an estimated 375 Canadians learn they have cancer, and another 181 die from the disease, says Kelly, citing *Canadian Cancer Statistics 2002*. "Canada needs cancer leaders every day."

Lacking that leadership, members of the Canadian Strategy for Cancer Control's governing council say they are pushing forward with a cancer control plan. The council, charged with implementing the strategy, consists of representatives from the Canadian Cancer Society, Health Canada, the Canadian Institutes of Health Research, the National Cancer Institute of Canada and the Canadian Association of Provincial Cancer Agencies. Members also include five cancer patients nominated by the Canada Cancer Advocacy Network (not affiliated with the Cancer Advocacy Coalition of Canada). The network is funded by Health Canada and the Canadian Cancer Society, and is managed by Cancer Society staff.

The council has so far held two meetings, and established working groups in six priority areas: standards, guidelines, human resource planning, prevention, strategic research and rebalance focus. The latter group is looking at the need to improve systems and resources for supportive and palliative care, rather than putting all of the emphasis on treatment.

**O**VER THE NEXT SIX MONTHS, the council and working groups will develop proposals on how to spend whatever resources federal and provincial governments decide to devote to the strategy, says Morrison. During that time, he expects politicians—and Canadians—to be wrestling with the recommendations for reforming the healthcare system tabled by Romanow.

“The question is, is there the political will to fund these (cancer control) activities, and can these activities deliver something meaningful?” Morrison asks. Given what cancer care experts already know about the disease, appropriate control strategies could make “sizeable differences in how many people get cancer.”

That is because about 30 per cent of all fatal cancers in Canada, and the major cause of lung cancer, is attributable to cigarette smoking (Health Canada). The federal government’s activities on tobacco control have begun to bear fruit, with a corresponding reduction in the number of men getting lung cancer, Morrison says. Close to another third of cancer cases can be linked to unhealthy diets and obesity, related to colon and endometrial cancer, he adds. One missing piece of the cancer control agenda is an effective strategy to influence people’s behaviour around physical activity and diet, says the Health Canada bureaucrat.

“It goes beyond social marketing. It goes beyond just running ads. We have to think about what actually influences people’s behaviour and what we can realistically do to influence that.”

Finally, Canadians deserve better screening for colorectal and other cancers. Despite good evidence from clinical trials indicating that screening cuts mortality rates, it is not being applied systematically in Canada, says Morrison. On the treatment side, he says, Canada also needs to do better surveillance to know who is getting what diseases and to ensure that there is equity of treatment across the country.

“Many of these activities are going to (need to be) provincially co-ordinated. We can’t be talking in isolation,” he says.

It is unrealistic to expect a massive influx of funds into the cancer control strategy, says the Cancer Society’s Whiley, given the stresses on the health care system as a whole. She believes a national cancer control strategy should be about using the money already in the system more effectively. Increasing the focus on prevention, centralizing components that can be delivered more centrally, such as the development of national standards and guidelines, and more effective human resources planning are all initiatives that will make cancer control more efficient and effective, Whiley says.

But Whiley also acknowledges the work that remains to engage politicians at the provincial and federal level as “this huge challenge” of cancer control. “The progress so far is encouraging,” she says of the strategy. “People are beginning to come together in a way that I don’t think they ever have before. The best opportunity we have to really move things forward in a more expeditious manner is through this collaborative model.”

Strangely, both Health Canada and the Canadian Cancer Society rejected a *Grassroots Action Plan* that the Cancer Advocacy Coalition of Canada put forward to mobilize public support around a national cancer control strategy. The plan would have involved individual Canadians, service and non-profit organizations, corporations, communities, and politicians in getting federal government commitment for the national strategy for cancer control.

“We didn’t ask Health Canada and the Canadian Cancer Society to fund it—just to support it,” says Kelly, who recalls everyone agreeing that grassroots support would be vital to the success of the national strategy.

Dr. Andrew Padmos, commissioner of Cancer Care Nova Scotia, heads the council’s human resources working group. Like Whiley, he is pleased at the way the strategy has developed momentum and has become an effective instrument of policy development and promotion. Still, says Padmos, he understands the desire to see the strategy move ahead in political priorities.

“Are the people affected by cancer and working with cancer satisfied at the pace or the dimensions of change or improvement? I’d say No. We’re appropriately impatient about getting better faster and getting bigger.”

# PATIENT WELCOMES IDEA OF FEDERAL FUNDING FOR DRUGS

Tammy Young is not only battling metastatic breast cancer – she is battling the Ontario health care system.

Young, 38, is already living with the knowledge that she will not likely survive to see her three children grow up. The financial burden her illness has created, because the drug she needs to keep her out of a wheelchair, has added an extra layer of distress.

Young has used up the lifetime cap of \$25,000 in drug payments that is all her husband's group insurance plan, Maritime Life, will cover. She didn't even know the plan had a lifetime cap – until she needed expensive drugs. She is currently taking Zolendrenic acid to prevent hypocalcemia, which causes bones to fracture easily. But neither the province nor the Trillium Drug Plan, which covers some drugs, will cover the \$849-a-month bill unless Young actually had hypocalcemia, she says.

Paying for the drug would be a huge drain on the family income, since Young's husband, Steve, is a truck driver who earns \$58,000 a year. But having the medicine is critical for Young's quality of life in the time she has left with her family, she says.

"If I don't have the drug then my bones are just going to start breaking all over the place and fracturing and then I'm going to be in a wheelchair," says Young, who worked as a secretary before her cancer metastasized.

That's why Young welcomes recommendations made by the Kirby Report in October that the federal government cap an individual's out-of-pocket expenses for prescription drugs. The remaining costs for catastrophic illnesses requiring expensive medication would be paid out of a special fund the federal government would establish.

If the Youngs received that kind of financial

help, they wouldn't have to take out a second mortgage on their home, says Tammy Young.

"When I became metastatic I said to myself that I wouldn't become a financial burden on my family, and that's something I'm trying really hard to stick to," Young says. "Obviously my husband's going to need whatever money he has once I'm gone. For me to use whatever money should be used to pay the mortgage for drugs doesn't make sense. It's bad enough to know that I'm sick, but to know that it's causing financial burden on the family—it's huge."

Young's plight illustrates the ethical questions Canadians need to debate and the values they need to impress upon political leaders and bureaucrats, says Pat Kelly, chair of the Cancer Advocacy Coalition of Canada. She quotes Dr. Margaret Somerville, founding director of the Centre for Medicine, Ethics and Law at Montreal's McGill University:

*"Whose values should be given priority in deciding the very sensitive and difficult issue of whether giving people an additional period of life merits the costs involved?" Somerville asks in a 1999 article she wrote for the journal Current Oncology.*

*"If the life of a young, single mother with advanced breast cancer can be extended by an average of five months by a very expensive treatment and she says this extension is of the utmost value to her and her children, should this mean that cost should be irrelevant? Apart from the other ethical issues raised, such decisions confront us directly with costing individual human life and the ethics of doing so."\**

\* Somerville quote from Excerpts from The Ethics and Law of Access to New Cancer Treatments – M.A. Somerville, *Current Oncology*, Vol. 6 Number 3, 1999

Anyone wishing to help Tammy Young can make a donation through any branch of the TD bank. An account has been set up for the Youngs, in trust. Make a donation to the TD Canada Trust Account #6235836, Transit #0545.

*Your money or your life:*

# ACCESS TO CANCER DRUGS

**A**NNIE KING\* HAS A CHOICE. She can either come up with \$30,000 a year, every year, for the rest of her life—or she can discontinue taking the genetically targeted cancer drug Imatinib that has commuted her death sentence into a life sentence.

It is a choice King does not think she should have to make. But it is one an increasing number of cancer patients in Canada are facing, as some provincial health insurance plans decline to cover the full cost—or to cover any of the cost—of new cancer medications.

King has a rare form of cancer that has been stabilized by Imatinib, an expensive new drug that targets the molecules affecting the formation of tumors in her liver. Because of the cost of the drug—\$2,400 to \$3,000 a month—the Province of Ontario does not cover it. King has been told that if she wants to keep taking the medication after January, when her clinical trial ceases, she will have to pay for it herself.

“There are numerous arguments about what kind of drug insurance coverage Canada should have, but it is clear that that we need to re-evaluate the present system,” said Pat Kelly, chair of the Cancer Advocacy Coalition of Canada, in the coalition’s submission to the Romanow Commission about pharmacare.

“The Canada Health Act is supposed to ensure Canadians have coverage for medically necessary treatment. By any reasonable standard, Canadians

would believe cancer drugs are medically necessary treatment—no matter that the bureaucrats may say otherwise.”

**O**NE OF THE PROBLEMS for cancer patients is where they live, says the coalition. If King lived in Quebec, her drug costs would be covered. The patchwork of coverage across the country means that a patient from one province may get financial coverage and access to an important drug, while a patient in a neighbouring province is denied.

The good news for King is that Imatinib can help her—an option that did not exist when she became ill. The drug was fast-tracked by the U.S. Federal Drug Agency in 2001 and is touted as the first of a new breed of molecularly targeted cancer agents. In 1993, King was diagnosed with a rare kind of cancer characterized by tumors in the gastrointestinal tract, stomach or intestines. Even if the tumors are removed by surgery, the cancer eventually spreads to the liver.

Despite surgery and radiation, doctors could not treat King successfully. In September 1998, her oncologist told her to go home and put her affairs in order. She had about six months to live.

But King would not give up. Seeking a second opinion at the Mayo Clinic in New York, she paid about \$5,000 for tests and was told she had GIST—gastrointestinal stromal tumor—and not a Leiomyosarcoma as she had previously been told. Still, there was nothing doctors in New York could do either. Returning to her southern Ontario home, King began to research treatments and doctors who specialized in liver cancer. In 1999, she found a liver surgeon in London, England, who thought he could help.

Taking her scans with her, King flew to London. Nagy Habib did not promise a cure, but the London surgeon told King that by operating to remove the largest tumors on her liver, he could buy her time—and the hope that in that time, researchers would find a cure.

The operation and her stint in hospital in London cost \$25,000, an immediate out-of-pocket expense. OHIP later reimbursed most of those bills. A second operation a year-and-a-half later to remove tumors that had grown back cost King another \$25,000.

The operations bought King time. In May 2001, her Ontario oncologist told her that a drug he thought could help her—Imatinib—was undergoing clinical trials in Canada.

Since starting on the drug, King's cancer has stabilized. Her tumors are shrinking. The medication is not a cure, she cautions—but it has turned her illness from a terminal condition into a chronic one.

“This drug isn't going to just help me for a year and then I'm going to be told I'm cured,” says King. “This drug is something I may have to take for the rest of my life.”

“It could be that I'm basically cancer-free,” adds King, who has been told she would need a PET-scan to confirm the status of her tumors. Since PET-scans are in short supply in Canada, she has opted simply to live with the knowledge that she has stabilized.

“I've come from being told that you have six months to live—and now I've got hope. I feel fine. If you saw me you'd never believe that I'm sick,” says King.

She is living, though, with bad news of a different kind. Since Imatinib has now been approved in Canada for the treatment of GIST, the clinical trials are ending. Ontario cancer centers and government drug plans are not providing Imatinib—cancer centers because it is an out-patient treatment they do not have to cover within their budgets, and government drug plans because Imatinib is not listed in the provincial Formulary. This fragmented system leaves King facing an extraordinary drug cost next year, a cost that Senator Kirby would call catastrophic (see article page 10.)

King, who is 54, is a self-employed management consultant. Her income is not low enough to qualify for the Ontario Drug Benefit Plan. She has applied to the Trillium Drug Plan, a special fund that sometimes covers extraordinary drug costs. She does not yet know if the fund will pay for the drug. But she is not rich enough to be able to afford the medication without great financial hardship. She did, however, get her doctor to fill out the application for Ontario

coverage, even though she does not believe she will qualify. Her doctor, she says, complains that he had to do the paperwork.

As of January 2002, Ontario has financed the drug for four patients with GIST who qualify under what is known as Section 8 provisions, says Jason Jacobs, director of communications for Novartis Pharmaceuticals Inc. (Canada). So far, only Quebec is reimbursing all GIST patients who need Imatinib. B.C. and other provinces are assessing patients' need on a case-by-case basis, says Jacobs. “For the provinces, it's a budgetary decision,” he says. But for the patients, “it's life or death.”

**K**ING DOES NOT EXPECT her provincial government to pay for everything associated with her treatment. But since Imatinib would be covered if King was a patient admitted to a hospital for chemotherapy, she does not think her costs are fair.

***The patchwork of coverage across the country means that a patient from one province may get financial coverage and access to a life-saving drug, while a patient in a neighbouring province is denied.***

“I'm not saying they should pay for everything—they should pay for some of it,” she says. “I'm obviously paying a lot more taxes than a lot of people, so I should be getting something for my tax dollars. My tax dollars should be a kind of medical insurance.”

The *Canada Health Act*, passed in 1984, is intended to make sure all Canadians have “reasonable access to

medically necessary insured services without direct charges,” according to Health Canada. The Act sets out national standards—including portability and universality of health care—that each province must meet in order to qualify for transfer payments from the federal government. But the Act is outdated and has not kept pace with advances in modern medicine, such as drug delivery, says the coalition's Kelly. For instance, the Act only mandates that drugs delivered in hospital must be covered. Other prescription drugs—such as Imatinib—are covered at the discretion of each province.

Imatinib is not the only drug that cancer patients have difficulty accessing. Cost is clearly a barrier for patients needing access to many drugs, especially for

those, like King, who do not have any health benefits because they are self-employed, or whose insurance companies may have life-time limits on coverage.

Provinces, according to the Romanow Commission's pharmacare discussion paper, evaluate cost-effectiveness before recommending coverage. The coalition is concerned that cost containment will take precedent over the potential to save a life.

"If the number one mandate of the healthcare system is to save money, then the logical conclusion would be not to provide care for anyone," says Kelly. "Clearly this cannot be the case, and the evaluation of new medication must give greater weight to the benefits of the treatment (reduced mortality, morbidity, pain) than the costs."

The Canadian health care system should instead be concerned with putting people first, says Kelly. "We need medical care that is governed by first principles that recognize the priority is a timely response to the needs of the patient."

Dr. Margaret Somerville is the founding director of the Centre for Medicine, Ethics and Law at McGill University, and is an internationally renowned expert in medical ethics. In a 1999 article published in the journal *Current Oncology*,\*\* she argues that Canadians also have a legal right to drugs that could prolong their life, whether or not those drugs will ultimately save them:

***"People with a serious illness and potentially fatal illness such as cancer would seem to have a strong argument that decisions of a government body which prevented their access to life-prolonging treatment, interfere with their rights to life and security of the person. Whether they can win such an argument will depend on how a court interprets the situation in which they claim their constitutional rights are infringed.***

***If the action of the government body is seen to interfere with their access to health care, and thereby creates risks to their life or security of their person (i.e., their constitutionally protected Charter rights), their claim will likely succeed."***

As King awaits a decision from Ontario about coverage for herself, she wonders about the fate of other cancer patients. Many do not have the advocacy skills to navigate a health care system she describes as increasingly strewn with obstacles.

"I do feel that we live in a wonderful society here, where we are taken care of a lot. However, when things don't go right, however rich you are, \$30,000 is a lot of money to be having to spend on a drug," says King.

*\* Annie King is a pseudonym.*

*\*\* Somerville quote from Excerpts from The Ethics and Law of Access to New Cancer Treatments – M.A. Somerville, Current Oncology, Vol. 6 Number 3, 1999.*

## APPROVAL TIME AN ADDED BURDEN

*The length of time it can take to approve a new drug in Canada is another barrier to effective drug treatment, according to an analysis obtained by the Cancer Advocacy Coalition of Canada.*

*The average approval time for new drugs in Canada in 1999-2001 was 648 days, compared with 508 days in the United States, says Dr. Nigel Rawson, senior researcher at the Center for Health Care Policy and Evaluation in Minneapolis. That is a difference of four and a half months—a lifetime for some cancer patients.*

*The median approval times were 645 days in Canada and 371 days in the United States, which*

*means 50 per cent of new drugs approved in Canada have approval times of 645 days or less. In the United States, 50 per cent of its new drug applications are approved within 371 days, says Rawson.*

*Health Canada's priority approvals program aims to respond to the urgent need for a new drug therapy within 180 days. But as Rawson's analysis points out, that target is rarely met.*

*"We look forward to the time when 180 days is as long as Health Canada ever needs to review cancer drugs," says Pat Kelly, chair of the Cancer Advocacy Coalition of Canada.*

# Cancer professional shortage equals

## longer waiting lists

**A**FTER 27 YEARS as a radiation oncologist in Edmonton, Dr. Alan Lees should be retiring from his medical career with the satisfaction of a job well done and confidence that his patients are in the hands of a qualified replacement. Instead, Lees, 65, says he is entering retirement “baffled and frustrated.”

That is because Lees, who was scheduled to leave Edmonton’s Cross Cancer Institute in mid-December 2002, knows he is also leaving his patients in a precarious position. So far, the institute has been unable to recruit a replacement.

“If there’s no one to replace me, the people (doctors) who are left here are going to be stretched even further than we are at the moment,” says Lees. “Inevitably, waiting lists will increase.”

The shortage of professionals in radiation oncology and other cancer care disciplines is not unique to Edmonton. Overall, there is a 15 per cent vacancy rate in key disciplines across the country, says Dr. Andrew Padmos, who chairs the Canadian cancer control strategy’s working group on human resources.

At the Cross Institute, there are four radiation oncologists who treat breast cancer patients, says Lees. But in recent months, two oncologists, including Lees, have been handling the workload of all four. One of the doctors is on maternity leave, another has been ill. There is no slack in the system to accommodate illnesses, maternity leaves or even vacations. Unexpected or even predictable increases in new cases turned up by, for example, screening programs, are not planned for by those hiring the professionals.

“We are on the recruiting path,” says Rick Boyd, vice-president of finance and administration for the Alberta Cancer Board. “If recent past history is any

indication, we will be successful, but right now it’s hard to say that, because we haven’t got any candidates just yet.”

Lees believes the reason the Alberta Board has not been able to recruit doctors is because they did not move fast enough and put balancing the board’s budget ahead of filling his spot. But Boyd says Alberta is

simply in a competition for the best professionals, and the competitors are hospitals and institutes around the world.

**A**CROSS THE COUNTRY, provinces are competing to attract the doctors, nurses and other cancer care therapists they need to fill vacancies, replace retirees and keep up with the growing volume of cancer patients. The demographic bulge of the baby boom generation is affecting the numbers of people getting cancer, and the age of those treating them. The average age of oncologists in Canada is 58, according to the Canadian Association of Radiologists (2000). The average age of oncology nurses is 48, according to the Canadian Association of Nurses in Oncology (2000).

The number of people living with cancer in Canada is increasing by about seven per cent a year, says Dr. Andrew Padmos, who is also commissioner of Cancer Care Nova Scotia. So as professionals near retirement, caseloads grow.

“Seven per cent per year is a substantial increase in people who are eligible for additional or successive treatments. If 20 years ago you had a type of cancer, you might get one course of a treatment of a certain type, and if that failed there might have been nothing else for you,” he explains. “Now there are two, three or more types of treatment which can be offered in each

case, and thus there are more people needing more treatments at the same time.”

The human resources working group that Padmos chairs for the Canadian Strategy for Cancer Control surveyed provincial cancer agencies, excluding Quebec, in January and October 2001 and again in October 2002. (Quebec was excluded because the province defines its disciplines differently and has devised a plan to cope with the shortage of professionals in the radiation therapy disciplines, a strategy which “is making a difference,” Padmos says.)

The goal was to determine the number of positions provincial agencies have filled and to document vacancies in the areas of medical oncology, radiation oncology, radiation therapy and medical or clinical physics.

“What we found in our three surveys is that there still are serious shortages reported in those key categories,” says Padmos. “Fifteen per cent of the positions in this complement are vacant.”

For Padmos, the human resources challenge in cancer care needs to be one of the top priorities in any national cancer control strategy. “It probably would win a vote as to the highest priority,” he said in an interview from Halifax.

**CANADA IS NOT ALONE** in facing human resource shortages. When Lees returns to England, for example, he will likely take up a part-time job because his home country is also short of oncology specialists, he says. The reasons for the shortages vary from country to country. Canada is having problems training enough doctors in radiation and medical oncology, says Padmos, in part because of the difficult type of work and because the specialties are viewed as having a heavy workload.

“It may also be that they’re not specialties that are actively promoted at the level of university training programs for different medical groups and divisions. Programs do have a popularity and some of them have a compelling business case,” he says. “We’re not sure in recent years if that’s applied to oncology training.”

Current shortages in Canada also are aggravated by a lack of planning. In the early 1990s, universities and colleges were not filling enough spots to keep up

with today’s demand—one of the reasons members of the Canadian Strategy for Cancer Control believe human resource planning must be co-ordinated amongst provinces and other key players, including educational institutions.

Shortages of cancer care professionals vary across the country—a picture that can change quickly if one province recruits from another, says Padmos. No region was reporting particular “hot spots” when the working groups did his survey, he says, adding that the figures can of course be considered outdated as soon as they are printed if jobs open up or oncologists leave one jurisdiction for another.

“You get two oncologists moving from B.C. to Saskatchewan and that can solve Saskatchewan’s problem,” Padmos says by way of illustration.

To attract more students, oncologists must be sure they are doing everything they can to showcase the disciplines, says Padmos. “It is an exciting and worthwhile field, and it’s a great career. The second thing we need to do is to campaign at the post-graduate dean’s level in medical schools for additional training posts that would be available for specialists in oncology.”

Since the provinces fund both education and training and clinical posts, it is essential that they become partners in any plan to increase the number of specialists who are trained, says Padmos.

That view is echoed by Boyd at the Alberta Cancer Board.

“The more we co-ordinate our training and our certification and our planning, the better off Canada will be,” he says. “You do get provinces working at odds with each other, recruiting from each other or having training programs which wouldn’t be suitable in another province. The more we can chase those out, the better.”

Another possible solution is to extend the contracts of oncologists who might like to continue to work past 65, even if only on a part-time basis, suggests Lees. Unless there is some co-ordinated effort to solve the shortages, it is the patients who will suffer, he says.

“Patients can’t get care. There are delays. They don’t get to see you when they should. They wait extra weeks for treatment,” Lees concludes. “This is not a good way to end a career.”

# Cancer is everybody's business!

## What You Can Do to Gain Political Commitment to Implementing the Canadian Strategy for Cancer Control

**F**ind out what you can do to ensure political commitment to the Canadian Strategy for Cancer Control and to affect public policy on cancer prevention, research and control.

Note: The Cancer Advocacy Coalition of Canada does not support or oppose political candidates. Communications to current elected representatives are intended to gain support for cancer control efforts. This is not intended to support or oppose any individual's candidacy.

### *SEND A LETTER TO YOUR REPRESENTATIVES*

Your political representatives know that you, the constituent, are the key to their understanding of the Canadian Strategy for Cancer Control and issues important to you, not to mention their political futures. They want and need to hear from you on issues you consider important.

### *MAKE A PHONE CALL*

When you need to get in touch with your political representative immediately and do not have time to craft a letter or other written message, resort to the most common and effective method of communicating with your elected officials—make a telephone call. Ask them for an update on their party's efforts to implement the Canadian Strategy for Cancer Control.

### *CALL RADIO AND TALK SHOWS*

Calling the television or radio talk shows in your area is a great way to help get your message to thousands of listeners. They will be looking for ideas about what matters to Canadians—talk to them about the need for a Canadian Strategy for

Cancer Control. April is cancer month—pitch your ideas about the need for political commitments to cancer control.

### *MEET IN PERSON*

By far the most effective way to articulate your views to your elected officials and positively affect the outcome of legislation and policy debates is to speak with political representatives face-to-face. Call your provincial and federal officials and arrange a convenient time to meet with them and discuss how they can help implement the Canadian Strategy for Cancer Control.

### *WRITE A LETTER TO THE EDITOR*

Studies show that people read the letters to the editor section more than they read the editorials by journalists. Moreover, letters to the editor are widely read by community leaders to gauge public sentiment about current issues in the news. Talk about you or your family's experience with cancer and the need for urgent political commitment to the Canadian Strategy for Cancer Control.

# CANCER ADVOCACY COALITION OF CANADA

## Join the CACC for better cancer care in Canada Cancer is everybody's business!

### What is the CACC?

The Cancer Advocacy Coalition of Canada was formed in 2000 by cancer survivors, advocates and healthcare professionals concerned about the state of cancer care in Canada. The CACC is a national, non-profit organization open to individuals who want to join the effort to make cancer control an urgent healthcare priority for every level of government. The CACC is the only grassroots, non-profit organization representing all cancer sites and devoted exclusively to cancer advocacy. Members advocate through public consultations, publications and reporting on cancer issues, legislative forums, targeted political strategies, networking with other grassroots and professional cancer organizations and the media.

The CACC is an established, outspoken and insightful public watchdog on cancer-related policies at all government levels. The CACC represents the concerns of citizens, survivors and advocates in all aspects of cancer public policy.

The CACC Web site provides a clearinghouse for members, the public and the media about emerging issues in cancer control:  
[www.canceradvocacycoalition.com](http://www.canceradvocacycoalition.com)

### A Call for Members:

#### *Individuals and Organizations!*

The CACC welcomes Canadians across the country to become involved in the community of cancer advocates. When you join the CACC you are helping

to build a strong, grassroots community dedicated to making cancer control in Canada a national priority.

Membership in the Cancer Advocacy Coalition of Canada is open to individuals (\$25/year) and organizations (\$100/yr). Membership includes:

- Subscription to all CACC publications, including *Cancer Care in Canada* and CACC's annual *Report Card on Cancer Care in Canada*
- Invitation to attend the CACC Annual General Meeting and the right to nominate candidates for election to the Board of Directors
- Opportunities to be involved in CACC Working Groups on cancer-related issues and development of policy and position statements
- Information and discounts on CACC-sponsored workshops and conferences

### How to join CACC:

Join online: [www.canceradvocacycoalition.com](http://www.canceradvocacycoalition.com)

or

Call our toll-free number: 1-877-472-3436

Email us: [canceradvocacy@on.aibn.com](mailto:canceradvocacy@on.aibn.com)

or

Write to: **Cancer Advocacy Coalition of Canada**  
**180 Bloor St West, Suite 904**  
**Toronto, ON M5S 2V6**

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### MEMBERSHIP FORM

Name: \_\_\_\_\_ Organization: \_\_\_\_\_ Title: \_\_\_\_\_

Tel. work: \_\_\_\_\_ Tel. home: \_\_\_\_\_ E-mail address: \_\_\_\_\_

Street address: \_\_\_\_\_ City: \_\_\_\_\_ Prov/Terr: \_\_\_\_\_ Postal Code: \_\_\_\_\_

VISA number: \_\_\_\_\_ Expiry date: \_\_\_\_\_ Signature: \_\_\_\_\_

Or cheque: \_\_\_\_\_

Please make cheque payable to Cancer Advocacy Coalition of Canada

Specific areas of volunteer interests: \_\_\_\_\_