Health State Descriptions for Canadians

Health State Descriptions for Canadians: Cancers

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Recommended citation:

This document is one of a series that covers the major disease groupings that affect Canadians. The series is primarily intended to document the disease classifications used in the Population Health Impact of Disease in Canada (PHI) research program and help researchers to understand how the PHI estimates were calculated. It is also of interest to health professionals, advocacy groups, and individual Canadians who are looking for an overview of how living with cancer affects day-to-day functioning throughout its various stages of progression and treatment.

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This work contributes to the Population Health Impact of Disease in Canada research programme, a collaboration of Statistics Canada, the Public Health Agency of Canada, and researchers from McGill University, the University of Ottawa, the University of Manitoba, the Institute for Clinical Evaluative Sciences (ICES) and l’Agence de développement de réseaux locaux de services de santé et de services sociaux de la Montérégie. The PHI is funded by Statistics Canada and the Public Health Agency of Canada.
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Cancers

William K. Evans, Sarah K. Connor Gorber, Selene T. Spence and B. Phyllis Will

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August 2005

Catalogue No. 82-619-MIE, No. 001
Frequency: Occasional
ISSN 1715-3026
ISBN 0-662-40695-8

Ottawa

La version française de cette publication est aussi disponible (n° 82-619-MIF au catalogue, n°001).

Note of appreciation

Canada owes the success of its statistical system to a long-standing partnership between Statistics Canada, the citizens of Canada, its businesses, governments and other institutions. Accurate and timely statistical information could not be produced without their continued cooperation and goodwill.
Context: Health state descriptions for Canadians

This document provides standardized descriptions for the main health states associated with the progression and treatment of a disease. These descriptions are the first step in measuring how living with a disease and its treatment affects health-related quality of life in terms of physical, mental, and social well-being.

Underlying this approach is a new tool to measure functional health. Among other attributes, pain, limitations to physical functioning, or anxiety can limit an individual’s ability to participate in day-to-day activities. We use the Classification and Measurement System of Functional Health (CLAMES), with eleven such attributes that span physical, social and mental well-being. For each of these, there are four or five levels ranging in severity from no limitations in the attribute to severe limitations. Level 1, for instance, represents no limitations; for the attribute describing pain and discomfort it would read “generally free of pain and discomfort.” Table 1 shows the complete list of levels for each attribute.

For each health state from initial diagnosis to remission or palliation, we describe a “typical” case based on literature review and clinical experience. Although each individual will have a unique experience, these general descriptions are needed to measure health at the population level.

These descriptions were used to elicit preference scores from panels of Canadians based on techniques grounded in utility theory. Preference scores, which indicate the relative preference for a health state compared with full health, help us understand how Canadians view the various aspects of functional health. Along with data on incidence and duration, preference scores contribute to estimates of the impact on the Canadian population of both disease and risk factors that contribute to them.

Measured in terms of years of life lost and year-equivalents of reduced functioning due to the disease these estimates allow us to determine how many years of life—and how many years of healthy living—are lost due to specific diseases and risk factors. They provide answers to questions such as “what would be the impact of reducing obesity on the health of Canadians?” both in terms of lives saved and in terms of increased health over their lifespan.

This document is one of a series that covers the major disease groupings that affect Canadians. The series is primarily intended to document the disease classifications used in the Population Health Impact of Disease in Canada (PHI) research program and help researchers to understand how the PHI estimates were calculated. It is also of interest to health professionals, advocacy groups, and individual Canadians who are looking for an overview of how living with cancer affects day-to-day functioning throughout its various stages of progression and treatment.

More information on the Population Health Impact of Disease in Canada (PHI) research program and the development of these estimates is available at http://www.phac-aspc.gc.ca/phi-isp/index.html.
Table 1
Classification and Measurement System of Functional Health (CLAMES)

Core attributes

Pain or discomfort
1 Generally free of pain and discomfort
2 Mild pain or discomfort
3 Moderate pain or discomfort
4 Severe pain or discomfort

Physical functioning
1 Generally no limitations in physical functioning
2 Mild limitations in physical functioning
3 Moderate limitations in physical functioning
4 Severe limitations in physical functioning

Emotional state
1 Happy and interested in life
2 Somewhat happy
3 Somewhat unhappy
4 Very unhappy
5 So unhappy that life is not worthwhile

Fatigue
1 Generally no feelings of tiredness, no lack of energy
2 Sometimes feel tired, and have little energy
3 Most of the time feel tired, and have little energy
4 Always feel tired, and have no energy

Memory and thinking
1 Able to remember most things, think clearly and solve day-to-day problems
2 Able to remember most things but have some difficulty when trying to think and solve day-to-day problems
3 Somewhat forgetful, but able to think clearly and solve day-to-day problems
4 Somewhat forgetful, and have some difficulty when trying to think or solve day-to-day problems
5 Very forgetful, and have great difficulty when trying to think or solve day-to-day problems

Social relationships
1 No limitations in the capacity to sustain social relationships
2 Mild limitations in the capacity to sustain social relationships
3 Moderate limitations in the capacity to sustain social relationships
4 Severe limitations in the capacity to sustain social relationships
5 No capacity or unable to relate to other people socially

continued on next page...
Supplementary attributes

Anxiety
1. Generally not anxious
2. Mild levels of anxiety experienced occasionally
3. Moderate levels of anxiety experienced regularly
4. Severe levels of anxiety experienced most of the time

Speech
1. Able to be understood completely when speaking with strangers or friends
2. Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know you well
3. Able to be understood partially when speaking with strangers and people who know you well
4. Unable to be understood when speaking to other people

Hearing
1. Able to hear what is said in a group conversation, without a hearing aid, with at least 3 other people
2. Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but require a hearing aid to hear what is said in a group conversation with at least 3 other people
3. Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but unable to hear what is said in a group conversation with at least 3 other people
4. Unable to hear what others say, even with a hearing aid

Vision
1. Able to see well enough, with or without glasses or contact lenses, to read ordinary newsprint and recognize a friend on the other side of the street
2. Unable to see well enough, even with glasses or contact lenses, to recognize a friend on the other side of the street but can see well enough to read ordinary newsprint
3. Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint but can see well enough to recognize a friend on the other side of the street
4. Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint or to recognize a friend on the other side of the street

Use of hands and fingers
1. No limitations in the use of hands and fingers
2. Limitations in the use of hands and fingers, but do not require special tools or the help of another person
3. Limitations in the use of hands and fingers, independent with special tools and do not require the help of another person
4. Limitations in the use of hands and fingers, require the help of another person for some tasks
5. Limitations in the use of hands and fingers, require the help of another person for most tasks
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Note to reader

How to read the classification:

Health states are classified using eleven attributes, each with 4 or 5 levels. Level 1 indicates no limitations, while level 4 or 5 are the most severe limitations. Please note that these levels are a shorthand for the classification: they are not measurements on an interval scale.* A complete list of the attributes and levels appears as Table 1.

As an example, we can look at two health states, the first describing the health state at diagnosis for cancers with very good prognosis and the second describing the health state for a more advanced cancer during the last month of life, during terminal care.

Individuals with early stage breast cancer (a very good prognosis) could be described by the following:

- Somewhat unhappy (level 3 of Emotional State)
- Mild limitations in the capacity to sustain social relationships (level 2 of Social Relationships)
- Moderate levels of anxiety experienced regularly (level 3 of Anxiety)

By contrast, the following describes terminal care:

- Severe pain or discomfort (level 4 of Pain or Discomfort)
- Severe limitations in physical functioning (level 4 of Physical Functioning)
- Very unhappy (level 4 of Emotinal State)
- Always feel tired, and have no energy (level 4 of Fatigue)
- Somewhat forgetful, and have some difficulty when trying to think or solve day-to-day problems (level 4 of Memory and Thinking)
- Severe limitations in the capacity to sustain social relationships (level 4 of Social Relationships)
- Moderate levels of anxiety experienced regularly (level 3 of Anxiety)
- Limitations in the use of hands and fingers, require the help of another person for some tasks (level 4 of Use of Hands and Fingers)

This is represented by

Classification of the major health states in the progression and treatment of cancer are provided in the Summary table.

*For instance, the difference between level 1 and level 2 is not the same as between level 3 and level 4. In addition, attributes are not equally important in terms of health state preferences. For more information on health state preferences developed from these scores, please see http://www.phac-aspc.gc.ca/phi-isp/index.html.
### Summary table:
**Classification of health states related to cancer**

#### Attribute and level

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<th>Fatigue</th>
<th>Memory and thinking</th>
<th>Social relationships</th>
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Introduction

Cancer cells are characterized by abnormal, uncontrolled and progressive growth. Malignant tumours tend to infiltrate the surrounding tissues and to give rise to distant metastases (spread of disease to other parts of the body away from the primary site).

Most cancers are classified using a staging system based on tumour size, extent of lymph node involvement, and evidence of distant metastasis. Generally, treatment options for early stage cancers (localized disease) are designed to achieve local control. Therapy for more advanced regional cancers aims at local-regional control, with a lower probability of “cure.”* Cancers diagnosed at the most advanced stage have already metastasized to other parts of the body and, with a few exceptions, are treated with palliative intent to increase length of survival, maintain quality of life and treat cancer-related symptoms, when curative intent is not possible.

The psychosocial impact of a diagnosis of cancer cannot be underestimated. “Acute psychological distress is to be expected as a patient confronts the implications of cancer: possible death, pain, dependence on others, disability, disfiguring changes in the body, and loss of function, all of which endanger his or her relationships with others.”1 From this description, we can assume that for most cancers, patients experience the emotional impact created by the initial diagnosis, as well as the knowledge that they may have months of therapy ahead of them.

There is likely to be uncertainty and anxiety experienced while the cancer is “in remission,” until the individual is “cured” or relapses. Upon relapse, the patient is faced with more diagnostic and therapeutic options and more uncertainty. Patients who are told that there is no longer a way of curing the cancer must come to terms with the finality of their lives and with months of palliation and terminal care.

This document examines the functional limitations—physical, emotional and social—experienced by patients at the time of diagnosis of cancer and as they undergo the most common therapeutic modalities used, such as surgery, radiotherapy, chemotherapy and hormonal therapy (for prostate cancer). The long-term effects of these treatments are also examined, as are the functional limitations related to palliative and terminal care.

The document starts with an overview of progression and treatment for the three most frequently diagnosed cancers in each of three prognostic groups: bladder, breast, prostate (very good prognosis); colorectal, non-Hodgkin’s lymphoma, renal (fairly good prognosis); lung, pancreatic, and stomach cancer (poor prognosis). These nine cancers represent almost 72% of all (estimated) cases diagnosed in

* While it is generally acknowledged that cancer patients are not “cured,” clinicians approach therapy with curative intent.
Two types of leukemia are also described: chronic lymphocytic leukemia (most common leukemia among adults) and acute lymphoblastic leukemia (most common leukemia among children).

The remaining sections provide descriptions and classifications for health states at diagnosis; while receiving treatment; and while in subsequent health states, including remission, palliation and terminal care. Readers should bear in mind that an individual will progress through various health states.
The cancers

This section provides an overview of the symptoms and usual treatment path for nine cancers frequently diagnosed in Canada. International Classification of Disease (ICD-9) coding is provided for each cancer type. Literature on these cancers was used to develop generic descriptions for three prognostic categories; these descriptions are provided in the next section (page 17). These nine cancers are the three most common cancers in each prognostic category. An overview of two types of leukemia is also provided.

Stomach (gastric) cancer (ICD-9 151)

In 2002, an estimated 1,800 men and 1,000 women were diagnosed with stomach cancer in Canada. The ratio of deaths to new cases was 70%, making this type of cancer the third worst in terms of overall prognosis, after pancreatic and lung cancer. Most cases are diagnosed at an advanced stage, with a high likelihood of spread to adjacent organs, such as the spleen or pancreas. The tumour can also spread directly into the esophagus or the duodenum. In approximately half of the resected cases, invasion into the lymphatic system is seen.

Stomach cancer incidence has been decreasing in North America, although it is considered epidemic in Japan, Eastern Europe and South America. During the last two decades, even with the overall decrease, there has been an increase in proximal gastric cancers (those in the upper part of the stomach), which generally have a poorer prognosis than cancers in the body or outlet of the stomach. Stomach cancer has been associated with salted or smoked meat and fish, nitrates in the drinking water, smoking cigarettes and diets low in animal protein and fat. In addition, there is an increased risk of gastric cancer for those who have undergone partial removal of the stomach (subtotal gastrectomy) for ulcer disease and for those who have pernicious anemia.

Patients may present with a variety of symptoms, including weight loss, fatigue, loss of appetite and epigastric discomfort, at which time, a barium study or flexible upper endoscopy (with biopsy) is generally performed. For the small proportion with localized disease (less than 10%), curative surgery is the treatment of choice, but there is considerable debate as to the benefits of total versus subtotal gastrectomy and the degree of lymph node dissection (lymphadenectomy) required. Post-gastrectomy symptoms can include difficulty swallowing, bloating, diarrhea, flushing after eating and weight loss. Those who have only part of the stomach removed experience fewer of these symptoms and thus report having a better quality of life than patients who undergo a total resection. Chemotherapy (5-fluorouracil plus cisplatin) has become the standard treatment for advanced gastric cancer. Palliative surgery is considered when patients...
suffer from pain, hemorrhage, perforation or obstruction, but is associated with a high level of post-operative morbidity.

**Colorectal cancer (ICD-9 153 and 154)**

In 2002, an estimated 17,600 new cases (9,500 men and 8,100 women) were diagnosed in Canada making colorectal cancer (CRC) the third most common cancer for each gender. In that year, there were an estimated 6,600 colorectal cancer deaths, with a ratio of deaths to new cases of 37% (fairly good prognosis).

Environmental factors, and especially dietary intake, may cause or promote colorectal cancer, which usually occurs in men and women over 40 years of age. Diets high in calories, cholesterol and fat and low in fibre appear to place individuals at higher risk of developing this disease. High alcohol consumption and certain occupational exposures can also increase the risk, in addition to inherited syndromes.

Many patients with CRC exhibit no symptoms, which highlights the importance of early detection programs and screening. Cases detected through screening are more likely to be treated at an earlier stage, with greater likelihood of cure. Approximately one-third of cases are diagnosed at each of three stages: localized stage, with regional nodal involvement or with distant metastatic disease. The liver is frequently the site of colorectal cancer metastasis. Symptomatic colon cancer presents with intermittent abdominal pain, nausea or vomiting, whereas symptomatic rectal cancer is more likely to present with rectal bleeding. Generally, rectal cancer, which represents almost one-third of all CRC cases, has a worse prognosis than colon cancer.

Surgery is the major treatment for those diagnosed with non-metastatic colon cancer. Lymph node dissection assists staging and can be therapeutic. Sphincter-sparing surgery for patients with early rectal cancer should always be considered before radical resection. The treatment objective for patients with locally advanced rectal cancer is to resect (remove) the tumour completely while attempting to minimize functional impairment and morbidity, such as impotence, urologic dysfunction and the need for a permanent colostomy (the surgical creation of an opening between the colon and the surface of the abdominal wall). Whereas almost one-third of rectal cancer patients will require a permanent colostomy, most colon cancers can be treated without one. Physical symptoms exhibited prior to surgery, such as loss of appetite, rectal bleeding, urgency of bowel movement and psychological distress, diminish following treatment.

For rectal cancer, adjuvant radiation therapy and chemotherapy can reduce the risk of local recurrence, but have associated toxicities. Depth of bowel-wall invasion and nodal status are used as indicators of the risk of local failure. There is a synergistic effect between combined radiotherapy and chemotherapy (chemoirradiation) in the treatment of rectal cancer. The combination reduces the risk of local failure and distant extrapelvic recurrence.

Some colon cancer patients can benefit from adjuvant chemotherapy following surgical...
The standard therapy for advanced systemic colorectal cancer is combination chemotherapy (particularly 5-fluorouracil or 5-FU and folinic acid with or without another drug). Since the majority of patients who recur do so within two years of their initial treatment, routine follow-up, preferably with colonoscopy, is generally initiated.

Patients managed successfully by surgery may live normal lives. However, if a colostomy is necessary, patients may limit their social activities for fear of embarrassment. Sexual relations are frequently impaired. Metastatic colorectal cancer is commonly associated with weight loss, loss of appetite, pain and progressive loss of strength and general well-being.

**Pancreatic cancer (ICD-9 157)**

The pancreas is located behind the stomach and in front of the first and second lumbar vertebrae, in the upper abdomen. In 2002, an estimated 1,550 men and 1,700 women were diagnosed with pancreatic cancer in Canada. The median age at diagnosis was 70 years of age. The ratio of deaths to new cases for pancreatic cancer was 99%, making it the cancer with the poorest prognosis for survival. This is partially explained by the inability to diagnose this cancer until after it has become locally advanced (40% of cases involve invasion of the duodenum or peripancreatic soft tissue and regional lymph nodes) or has metastasized (40% of cases have visceral involvement, usually to the liver). Fewer than 20% of cases are confined to the pancreas at the time of diagnosis and are potential candidates for resection.

The risk of pancreatic cancer rises as the amount and duration of cigarette smoking increase. Diets high in fat or meat consumption and with low intakes of fruits and vegetables add to the risk of this type of cancer. In addition, increased incidence appears to be associated with chronic pancreatitis, diabetes mellitus and some occupations that involve long-term exposure to solvents and petroleum compounds. Data on the impact of coffee and alcohol consumption are inconclusive. Recently, obesity and physical inactivity have also been shown to be associated with pancreatic cancer.

Patients with pancreatic cancer generally present with obstructive jaundice and upper abdominal or back pain. Marked loss of appetite, glucose intolerance, weight loss and fatigue are also common symptoms. Since so few patients are surgical candidates, accurate preoperative assessment of resectability is critical. Surgery generally involves removal of the pancreas, duodenum, gallbladder and bile duct (pancreaticoduodenectomy). This is generally followed by gastrointestinal reconstruction, which can be associated with various complications, including delayed gastric emptying and wound infection. In addition, patients may experience post-operative weight loss, thirst, frequent urination, fatigue and diabetes. Almost all patients experience pain, often described as gnawing, persistent, intense and devastating, during the course of their disease, to the point where some patients’ will to live may be undermined. Patients with locally advanced and metastatic disease may benefit from chemotherapy, particularly from the drug gemcitabine.
Lung cancer (ICD-9 162)

In 2002, an estimated 12,000 men and 8,800 women were diagnosed with lung cancer in Canada, making this disease the second most common form of cancer for both genders. Almost 80% of all cases diagnosed were over 60 years of age. The estimated 18,400 deaths from lung cancer in 2002 (10,700 men and 7,700 women) represent almost 28 per cent of all cancer deaths in Canada, making this disease the leading cause of cancer death. The ratio of deaths to new cases for lung cancer was 88%, compared with 48% for all cancers, placing it in the “poor prognosis” category.

The predominant risk factor contributing to lung cancer is the number of cigarettes smoked and the duration of smoking. In addition, exposure to carcinogens such as asbestos, radon, passive smoke, hydrocarbons, chromium and nickel all appear to increase lung cancer risk. The choice of therapy for lung cancer is determined by the histological cell type—small cell or non-small cell—and the extent of disease at diagnosis. Non-small cell lung cancer accounts for over 80% of cases diagnosed. Almost two-thirds of all lung cancers are diagnosed at advanced stages, which limits therapeutic options.

Early stage non-small cell lung cancer is usually treated surgically, by lobectomy (removal of a lobe of the lung) or pneumonectomy (removal of the whole lung). Many of those diagnosed with locally advanced non-small cell lung cancer disease will receive radiotherapy in combination with chemotherapy. Patients diagnosed with metastatic disease are often dealing with high levels of comorbidity due to concomitant smoking-related illness and receive palliative chemotherapy and terminal care.

Small cell lung cancer cases are generally treated with chemotherapy and radiotherapy. Most with limited disease small cell lung cancer also receive prophylactic cranial irradiation, which is associated with a transient increase in fatigue, nausea and vomiting.

Lung cancer patients often present with a persistent cough, dyspnea (difficult or laboured breathing), decreased appetite and pain from pleural or chest wall involvement. Over 80% of those diagnosed with inoperable non-small cell lung cancer complain of fatigue, depressed mood and decreased energy. Reduced lung capacity as a result of surgery, radiation or underlying lung disease due to smoking often leads to reduced physical and role functioning.

Breast cancer (ICD-9 174)

Breast cancer is the most common malignancy affecting Canadian women (male breast cancer is uncommon and is not reviewed here). In 2002, an estimated 20,500 women were diagnosed with breast cancer and 5,400 died of the disease. The ratio of deaths to new cases was 26%, making this cancer among those with the best prognosis. Whereas incidence rates have leveled off since the early 1990s, mortality rates have been declining for over a decade.2

Risk factors that contribute to breast cancer are early age at menarche, nulliparity or late age at the time of first full-term pregnancy, late menopause, exposure to environmental toxins, genetic predisposition, and the use of...
hormone replacement therapy. Evidence of the impact of diet and excessive use of alcohol are inconclusive.

In approximately 80% of cases, patients present with a palpable breast mass and have the diagnosis confirmed with a fine needle biopsy. Because of improved screening programs such as mammography, early stage breast cancer now represents almost 90% of all incident cases (small-to-medium-sized tumour, no or limited nodal involvement and no evidence of distant metastasis). Therapeutic options are dependent upon the stage of the disease at presentation, the age (almost 80% of cases occur in women aged 50 and older) and menopausal status of the patient, and the hormone receptor status of the tumour.

The majority of early stage breast cancers are treated surgically with breast-conserving surgery (excision of the primary tumour and adjacent breast tissue), followed by radiotherapy. Women diagnosed with loco-regional disease generally receive a modified radical mastectomy (excision of the breast with axillary node dissection) and many are now treated with pre-operative chemotherapy and post-operative radiotherapy. Standard therapies for metastatic breast cancer include hormonal therapy or chemotherapy.

Because breast cancer is among the more slow-growing tumours, life expectancy is often measured in years or decades, rather than in months. The quality of life of individuals with breast cancer is greatly influenced by the self-esteem issues experienced by the patient due to changed body image and altered sexual functioning. Following surgery, many women experience considerable arm morbidity due to arm swelling (lymphedema), as well as fear of cancer recurrence. Those undergoing chemotherapy and radiotherapy often exhibit chronic fatigue, nausea or pain, hot flashes and mood alterations, which interfere with well-being.

**Prostate cancer (ICD-9 185)**

Prostate cancer is the most frequent form of cancer diagnosed among Canadian men. In 2002, an estimated 18,200 cases were diagnosed, and 4,300 men died of the disease. Almost one-third of men over 50 years of age who die of other causes are found to have prostate cancer at autopsy. However, this type of cancer should not be considered a benign disease, since, if left untreated, it continues to progress slowly, but steadily. Incidence increases more rapidly with age for prostate cancer than for any other cancer. Almost half of new cases and about 85% of deaths occur in men over 70 years of age.

The rise in the number of cases detected in the early 1990s can partially be explained by the increased use of screening techniques, such as the measurement of prostate-specific antigen (PSA) levels and transrectal ultrasonography (TRUS). Because tumour growth is promoted by androgens, men with high testosterone levels are at greater risk of developing prostate cancer. Diets with high monounsaturated fat intake, exposure to cadmium and genetic predisposition are also risk factors.

Because the prostate gland surrounds the urethra, patients with prostate cancer often have difficulty urinating, with symptoms such as hesitancy, incomplete bladder emptying or blood in the urine. They may also experience
pain or sudden impotence. The decision to manage early prostate cancer by treatment or by careful observation is controversial, since the two most common treatments for localized cancer, radical retropubic prostatectomy (removal of the prostate) or radiation therapy can result in urinary incontinence and/or erectile dysfunction.

Locally advanced prostate cancer is usually treated with external-beam radiation therapy and androgen ablation therapy (chemical castration). Treatments with curative intent are often unsuccessful, since many patients already have occult metastases.

When prostate cancer metastasizes, it spreads to lymph nodes and bone in over 80% of cases, which may require palliative radiation therapy for bone pain as well as androgen ablation therapy. Side effects include hot flashes, increased fatigue, loss of libido, impotence and weight gain.

Complications of long-term treatment are osteoporosis, depression and loss of muscle mass. Patients who have undergone prostatectomy may restrict social activities because of their concern over urinary incontinence. “Prostate cancer patients perceive pain, fatigue, impaired sexual life, urinary frequency and incontinence, and reduced professional life as having the greatest impact on the quality of their lives.”

The emotional and cognitive burden of prostate cancer can affect self-esteem, self-image, masculinity and sexuality.

**Bladder cancer (ICD-9 188)**

In 2002, an estimated 5,000 new cases of bladder cancer were diagnosed (3,700 men and 1,300 women, most of whom were age 70 and over), making this the sixth most common cancer in Canada. It is considered a preventable disease since most cases result from exposure to environmental carcinogens. Both amount and duration of cigarette smoking have been shown to be correlated with bladder cancer incidence. There is also a high occupational risk for people exposed to aryl amines, such as those used in the paint, rubber and dye industries. The male to female ratio of bladder cancer is approximately three to one, but, in areas where cigarette smoking is common amongst women, this gap can narrow. Because the ratio of deaths to new cases for bladder cancer is 30%, compared with 48% for all cancers, this site is classified as one that has a very good prognosis. It should be noted that the ratio for women with bladder cancer is less favourable, at 36% (fairly good prognosis).

Hematuria (blood in the urine) and irritative symptoms such as urinary frequency are the most usual indicators. Cystoscopy and biopsy are the common methods of diagnosis. On presentation, almost 80% of all bladder cancers are considered to be superficial (limited to the mucous membrane lining, submucosa or connective tissue below). While low grade tumours rarely progress, bladder carcinomas are frequently multifocal (multiple areas of cancer) and can affect the entire urothelial tract. Higher grade muscle-invasive tumours are much more likely to metastasize. Transurethral resection (TUR) can offer local control for most superficial bladder lesions, but cannot prevent recurrence.

While bladder preservation is always desirable, cystectomy (partial or complete removal of the bladder), high-dose local
irradiation, intravesical (within the bladder) immunotherapy and/or chemotherapy are often used to treat locally invasive, non-metastatic bladder cancer. For men, radical cystectomy involves not only removal of the bladder, but part of the urethra, the prostate and regional pelvic lymph nodes, which can lead to sexual dysfunction when nerve-sparing surgery is not performed. For women, radical cystectomy generally includes removal of the bladder, ovaries, uterus, entire urethra, lymph nodes and a segment of the vaginal wall. Following cystectomy, the patient must undergo the installation of a bladder substitute or urinary diversion, which may be associated with incontinence, impotence in men, and recurrent infection. For those with regionally invasive disease who are not considered good candidates for cystectomy, radiotherapy alone is a treatment option, but combined modality therapies can also be considered.

Patients with advanced cancer may experience hemorrhage, pelvic or flank pain, or rectal obstruction with constipation. Radiotherapy or chemotherapy can reduce symptoms and the administration of combination chemotherapy can extend survival for some patient populations.

**Renal (kidney) cancer (ICD-9 189)**

In 2002, an estimated 2,500 men and 1,500 women were diagnosed with renal cancer, the seventh most frequently diagnosed cancer in Canada. Renal cell cancer is the most common type of kidney cancer, representing approximately 85% of all cases. The ratio of deaths to new cases was 36% (fairly good prognosis), compared with the average of 48% for all cancers. Most cases are diagnosed between the ages of 50 and 70 years. Risk factors include living in an urban setting, cigarette smoking, analgesic abuse, obesity and exposure to environmental toxins (asbestos and cadmium).

Approximately 45% of patients present with localized disease, 25% have locally advanced cancer and 30% present with metastatic disease (generally in the lung, bone, or brain). In many cases, renal cancers are discovered incidentally during radiographic procedures such as ultrasound or computed tomography. Often, patients are asymptomatic until the disease has become more advanced, at which time, they may present with pain, hematuria (blood in the urine) and flank mass.

Either radical or partial nephrectomy (complete or partial removal of the kidney) is the standard treatment for localized renal cancer. Removal of the lymph nodes (regional lymphadenectomy) is generally performed at the same time. While lymph node dissection is useful for staging, there is ongoing debate as to whether it prolongs survival. Radical surgery includes removal of the kidney and surrounding tissues, including the adrenal gland. When both kidneys are involved, one is removed and a partial nephrectomy is performed on the remaining organ, if possible. Radical surgery and dialysis with possible later renal transplantation is a less favoured option.

While localized kidney cancer is often cured by surgery, treatment for metastatic disease is generally unsuccessful. Palliative surgery for metastatic renal cancer rarely cures the disease but may increase survival. Palliative radiotherapy may relieve pain, but renal cell carcinoma appears to be chemotherapy-
resistant and not responsive to hormonal therapy.

Many patients with renal carcinoma develop systemic symptoms: anemia due to loss of blood in the urine, fever, fatigue, malnutrition, wasting and weight loss.

**Non-Hodgkin’s lymphoma (ICD-9 200 and 202)**

In 2002, an estimated 6,300 Canadians (3,400 men and 2,900 women) were diagnosed with non-Hodgkin’s lymphoma (NHL), the fifth most frequently diagnosed cancer in Canada. The ratio of deaths to new cases was 45% (fairly good prognosis). The median age at diagnosis is 65 years, but incidence peaks in the 80 to 85 year age group.

NHLs are a diverse group of cancers originating in the lymphoid system, which includes the lymph nodes as well as extranodal sites such as the stomach, small intestine, skin and brain. Lymphocytes are produced by the lymph nodes to provide immunity against infection: B cell lymphocytes produce antibodies and T cell lymphocytes provide cell-based immunity. Exposure to environmental toxins, viruses and congenital or acquired immunosuppression can cause lymphocytes to develop into malignant lymphomas, with B cell lymphomas being more common than T cell. NHLs develop in up to 30% of those infected with human immunodeficiency virus (HIV) and almost half are associated with the Epstein-Barr virus infection. Patients undergoing organ transplantation and receiving immunosuppressive drugs are very likely to develop NHL.

NHLs are somewhat paradoxically divided into “indolent” ( incurable) and “aggressive” (potentially curable) lymphomas. Indolent lymphomas usually present with widespread involvement of the lymph nodes, spleen, liver or bone marrow and are considered incurable. However, they tend to grow slowly and as many as half of those diagnosed may have their initial therapy deferred for several years (“watch and wait”). For some patients, this lack of treatment may create stress and anxiety. For most patients with indolent NHL, the primary goal of therapy is to achieve lengthy survival with a good quality of life. When typical lymphoma symptoms such as weight loss, fever and sweating appear, treatment becomes necessary. Weakness, malaise, poor appetite, decreased stamina, in addition to uncomfortable lymphadenopathy (swelling of the lymph nodes) are commonly present.

Early stage indolent NHLs are treated with either chemotherapy or localized radiation therapy. Those with advanced stage symptomatic disease are often treated with either a single chemotherapy agent or a combination of drugs, with almost three-quarters achieving a complete remission. However, the vast majority will become resistant to treatment and will eventually relapse. Approximately 40% of indolent cases will convert to diffuse aggressive lymphoma.

Approximately three-quarters of patients with “aggressive” NHL present with advanced stage disease, which can progress rapidly. However, if a patient achieves a complete response, cure can still be achieved. The treatment standard is single agent chemotherapy, with or without involved field
radiation for early stage cancer, and combination chemotherapy alone for advanced stage. Combination chemotherapy is known to produce many toxicities, including hair loss, nausea, fatigue, constipation and bone marrow suppression. For patients who relapse after achieving a remission, salvage chemotherapy followed by autologous bone marrow transplantation is the only treatment that can produce long-term remission.

**Leukemia (ICD-9 204)**

Leukemia is a cancer of the body’s blood-forming tissues, including the bone marrow and lymphatic system. The word means “white blood” in Greek, since the blood takes on a whitish tone as abnormal white blood cells (lymphocytes) accumulate and block the production of normal blood cells in the bone marrow. Leukemia is categorized according to the type of white blood cell that is involved (lymphoid or myeloid) and how rapidly it develops (acute or chronic). In this disease, the production of red blood cells and platelets is also affected, which can lead to fatigue from anemia or bleeding or easy bruising due to impaired ability to form blood clots.

In 2002, an estimated 3,650 new cases of leukemia (2,100 men and 1,550 women) were diagnosed in Canada. In adults, there are four major types of leukemia: acute lymphocytic (ALL), acute myeloid (AML), chronic lymphocytic (CLL) and chronic myeloid (CML). Although there is a perception that leukemia is a disease of children, adults are ten times more likely to develop it. In 2002, it was estimated that fewer than 350 children were diagnosed with leukemia in Canada. Little is known about the causes of leukemia, although post-natal exposure to radiation (therapeutic doses for medical conditions or military radiation exposure) has been suggested as a risk factor for acute leukemias. Leukemia develops more frequently in men, Caucasians and those in higher socio-economic groups and has been linked to exposure to benzene and other toxins, radon, cigarette smoke and certain viruses. Those born with Down’s syndrome have a twenty-fold risk of developing leukemia.

Chromosome damage due to the administration of chemotherapeutic agents has been linked to the development of secondary leukemias.

While leukemia can present in a variety of ways, anemia, thrombocytopenia (low blood platelets) and severe and persistent fatigue are common presenting signs and symptoms. An enlarged liver and spleen and swollen lymph nodes may also be present. A bone marrow aspiration and biopsy are required to establish a definitive diagnosis of leukemia. As the name implies, acute leukemias tend to have a more sudden onset of symptoms, whereas chronic leukemias are more gradual in their onset and run a more indolent course. This chapter includes two types of leukemia: chronic lymphocytic leukemia (CLL), the most common leukemia among adults, and acute lymphoblastic leukemia (ALL), the most common leukemia among children.

**Chronic lymphocytic leukemia (CLL)**

Chronic lymphocytic leukemia (CLL) is the most common adult leukemia in the western world. CLL is considered a disease of the elderly; it is rarely diagnosed before the age...
of forty (90% of cases of all chronic leukemias are over fifty). The low incidence of CLL in Asian countries is thought to be due to genetic differences, rather than environmental factors.

CLL is always suspected when there is an excess of lymphocytes in the blood, as well as the bone marrow. Many cases of CLL are diagnosed during a routine blood test. Because patients with early stage CLL are often asymptomatic, and can live for long periods without requiring therapy, it is often difficult to determine when to initiate treatment. As an example, early stage indolent or “smoldering” CLL has a survival equivalent to an age-and sex-matched healthy population. However, the natural history of CLL can be extremely variable.

Chronic leukemia cells are often slow to multiply and are therefore less sensitive to chemotherapy. However, it is generally believed that symptomatic CLL (fever, unintended weight loss, profuse night sweats and enlarged lymph nodes) should be treated with systemic therapy usually consisting of alkylating agents, sometimes combined with purine analogues or monoclonal antibodies. Those diagnosed with more aggressive, advanced disease (approximately 25% of CLL cases) are at high risk for rapid progression and lower survival.

There is no evidence that long term systemic therapy is beneficial. Because of the advanced age of most CLL patients, only about 10% of them qualify for bone marrow transplantation. It is generally offered to those who are less than fifty-five years of age. Patients with CLL are thought to be at higher risk of developing second malignancies, such as lung cancer or cancer in the gastrointestinal tract. The most frequent cause of death for CLL patients is severe systemic infections, such as pneumonia or septicemia.

**Childhood acute lymphoblastic leukemia (ALL)**

Leukemia is the most common form of childhood malignancy, accounting for 30% of all childhood cancer. The incidence of leukemia is increased in children with certain chromosomal abnormalities. Over three-quarters of the cases of childhood leukemia are acute lymphoblastic leukemia (ALL). The peak incidence of ALL is between three and six years of age and the disease is more common in boys. Twenty per cent of cases are acute myeloid leukemia and less than 5% are chronic myeloid leukemia (CLL is rarely diagnosed in children).

Children with leukemia are generally symptomatic one to six weeks prior to diagnosis. The symptoms reflect the degree to which the bone marrow has been infiltrated with leukemic white cells. Anemia and thrombocytopenia (reduced platelet count) are present in more than two-thirds of patients; these lead to easy fatigability, headache and malaise, as well as bruising and bleeding from the gums and nose. Skin pallor, fever, bone tenderness and enlarged lymph nodes are common.

In the 1950s, when children were diagnosed with leukemia, there were few treatment options and those therapies available were intended to palliate the symptoms, not cure the disease. Today, as a result of extensive basic and clinical research, therapy commonly achieves a complete remission, which implies a return to normal in the blood
counts and bone marrow. “Remission induction therapy” generally includes several chemotherapy drugs, which can induce complete remission within four weeks of initiation of therapy. More than ninety percent of children with ALL achieve complete remission after three to four weeks of induction therapy, compared with 60% to 80% of adults. With timely, adequate and intensive treatment, over 70% of children with ALL are now cured. Infections, organ dysfunction and hair loss are common adverse events during remission induction therapy.

A complete remission is followed by high doses of postinduction chemotherapy, which is designed to kill any remaining leukemia cells in the bone marrow, lymphatic system or blood stream. Prophylactic chemotherapy and/or radiotherapy is routinely directed to the central nervous system; otherwise, this would be a common site of spread. After complete remission is achieved, a period of “maintenance therapy” is begun to eliminate all residual leukemia cells and prevent relapse. Maintenance therapy consists of a variety of chemotherapeutic regimens, and can last from two to four years.

During induction chemotherapy, severely low blood cell counts result in most patients experiencing fever, thus requiring broad spectrum antibiotic treatments and red blood cell and platelet transfusions. Despite prophylactic antibiotics and platelet transfusions, induction chemotherapy can still result in death from infection and hemorrhage. The prognosis of those who fail to achieve remission, or relapse after achieving remission, is poor. Approximately one-third of patients who relapse will achieve a second remission, which is generally of shorter duration than the first. While controversial, bone marrow transplantation is often attempted for selected patients in first remission.
At diagnosis

This section presents the context and descriptions for 21 health states that cover the course and treatment of cancer. These health states were developed based on the cancers presented in the previous section.

For the purposes of this document, most cancers were classified according to their likely prognosis, as well as therapeutic intent. These prognostic groups are from Canadian Cancer Statistics. This classification was used on the assumption that cancers with similar prognoses would have similar effects on individuals, in terms of limitations to their functional capacities. (Descriptions for two types of leukemia are provided separately.)

The prognostic category “very good” (ratio of deaths to new cases [d/c] of 30% or less) includes the following cancers: breast, prostate, bladder, testicular, uterine, thyroid, cervical, melanoma* and Hodgkin’s disease. These cancers would generally be diagnosed at an early stage (almost 90% of breast cancer patients are diagnosed at an early stage) and would be treated with curative intent.

Cancers with a “fairly good” prognosis (d/c of greater than 30% but less than 50%) include colorectal, renal, oral and laryngeal, non-Hodgkin’s lymphoma, and bone and connective tissue.** These are often diagnosed at a later stage, or behave in an aggressive fashion, which implies less chance for cure.

Finally, cancers classified as having a “poor prognosis” (d/c 50% or greater) include lung, pancreatic, stomach, ovarian, brain, liver,** gall bladder,** esophageal and multiple myeloma. These are usually not diagnosed until the disease has progressed (approximately 70% of lung cancers are diagnosed at an advanced stage), and are treated with palliative intent.

This classification approach applies to most, but not all, the cancers listed above. Under certain circumstances, cancers which are considered “curable” are diagnosed at an advanced stage, but highly effective therapy is available. On the other hand, “poor prognosis” cancers are sometimes diagnosed early enough to be treated with curative intent.

This section provides generic descriptions based on a literature review of the three most common cancers in each prognostic group. The patients’ physical and emotional states at the time of diagnosis of local or regional disease are expected to apply to any of the cancers in the category (as indicated in the descriptions). One health state at the time of diagnosis of metastatic disease is also described.

* Non-melanoma skin cancers are excluded from this classification and from Canadian Cancer Statistics because they are usually successfully treated without requiring hospitalization and because reporting procedures vary across the country, making consistent registration of these cancers difficult.

** These cancers were omitted from Canadian Cancer Statistics and have been classified based on case fatality data from the Surveillance, Epidemiology, and End Results (SEER) Program.
## Cancers with a very good prognosis

| Description | This description applies to the health state at diagnosis of local or regional
disease, prior to the commencement of treatment. It describes patients diagnosed
with breast, prostate and bladder cancer, but also applies to cancer of the uterus,
thyroid, cervix and testis, melanoma and Hodgkin’s disease. Patients report
depression, impotence, urinary difficulties (for bladder and prostate cancers) and
impaired sexual functioning as well as decreases in self esteem and self-image.
Duration of this phase is estimated to be 37 days.6 |
| Classification | Core | Supplementary |
| | 1 | 1 | 3 | 1 | 1 | 2 | 3 | 1 | 1 | 1 | 1 |

## Cancers with a fairly good prognosis

| Description | This description applies to the health state at diagnosis of local or regional
disease, prior to the commencement of treatment. It describes patients diagnosed
with colorectal cancer, non-Hodgkin’s lymphoma and renal (kidney) cancer, but
also applies to oral and laryngeal cancer and cancer of the bone and connective
tissue. Many patients with these cancers experience general malaise, fever, fatigue,
loss of appetite, decreased stamina, psychological distress (including stress and
anxiety) and impaired social and sexual relations. Duration of this phase is
estimated to be 37 days.6 |
| Classification | Core | Supplementary |
| | 2 | 2 | 3 | 2 | 1 | 2 | 3 | 1 | 1 | 1 | 1 |

## Cancers with a poor prognosis

| Description | This description applies to the health state at diagnosis of local or regional
disease, prior to the commencement of treatment. It describes patients diagnosed
with lung, pancreatic and stomach cancer but also applies to cancer of the ovary,
brain, esophagus, gall bladder, liver and multiple myeloma. Marked loss of appetite,
weight loss, chest, abdominal or back pain, fatigue, depressed mood and decreased
physical functioning are common symptoms. In addition, lung cancer patients often
present with a persistent cough and dyspnea. Duration of this phase is estimated to
be 37 days.6 |
| Classification | Core | Supplementary |
| | 2 | 2 | 3 | 2 | 1 | 3 | 3 | 1 | 1 | 1 | 1 |
Metastatic disease

**Description**

This description applies to any cancer that is diagnosed after it has metastasized (spread to other parts of the body), generally referred to as Stage IV disease. It also applies to any cancer that is initially diagnosed at an earlier stage, but has metastasized at the time of recurrence.

While radiotherapy and chemotherapy are viable therapeutic options for treating metastatic disease, the treatment objective is palliative, rather than curative. Surgical interventions may be necessary to manage tumour-induced obstruction of the esophagus, bowel, bladder or other structures, or to repair bones weakened by cancer that have fractured. The functional limitations of patients living with metastatic disease will be dependent on the site of metastasis.

Patients complain of pain severe enough to compromise daily functioning, as well as progressive loss of strength and weight loss. Sadness, grief and depression are also common in life-threatening illness. Fatigue is a serious and disabling side effect of metastatic disease. Many patients experience confusion and have difficulty concentrating. In addition, social impairment, marital and relationship stress and direct interference with sexual functioning can lead to high levels of anxiety and feelings of helplessness and hopelessness. Duration of this phase is estimated to be 37 days.

**Classification**

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Chronic lymphocytic leukemia (CLL)

**Description**

This description applies to chronic lymphocytic leukemia at diagnosis and before treatment. Many individuals with early stage CLL are asymptomatic, but may be identified during a routine blood test when they present with infections, fatigue, or lymphadenopathy. Individuals may live in this health state for long periods without requiring therapy.

Patients with CLL suffer from the discomfort of enlarged lymph nodes and/or, liver and spleen, recurring infections, persistent fatigue and night sweats. In addition, they may experience more frequent hospitalizations, uncomfortable medical procedures, decreased social interaction, stress over their chronic illness and fear of death.

**Classification**

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Childhood acute lymphoblastic leukemia (ALL)

Description
This description applies to childhood acute lymphoblastic leukemia at diagnosis and before treatment. Children with ALL may experience swollen lymph nodes, easy bruising, nosebleeds, frequent infections and fever, and excessive sweating. In addition, they frequently suffer from persistent fatigue due to anemia, emotional strain, and anxiety; they experience separation from their family when hospitalized, disrupted schooling and limitations to their social lives. Children with leukemia are generally symptomatic one to six weeks prior to diagnosis.

Classification

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**Therapeutic options**

When cancer occurs, the common therapeutic options are surgery, radiotherapy, and chemotherapy. These may be administered alone or in various combinations. Hormonal therapy is commonly used as a first line therapy for prostate cancer. The choice of treatment depends on the size and location of the tumour, the extent of tumour spread, the patient’s age and general health. Each therapeutic option can have an impact on any or all of the functional abilities of the individual. The level of dysfunction that patients experience will depend on the type of therapy they undergo and their own coping skills.

These descriptions apply to the health state experienced during cancer therapy (or following therapy in the case of surgery) and the following considerations should be noted:

- only the short-term impact of the therapy is included, for example, the description for “after surgery” includes only the three to five weeks following the surgical procedure; the descriptions for radiotherapy and chemotherapy apply to the time during which the therapy is being administered;

- many cancer patients receive more than one therapeutic modality. To understand their true emotional and physical state, the cumulative effects of the diagnosis of cancer, as well as administration of the various therapies, would have to be considered.

**Surgery**

Surgery is the most frequently used cancer therapy and cures more patients than any other single treatment modality. Surgery is necessary to determine whether a growth is benign or malignant and to obtain tissue that can determine the type of cancer and extent of spread at the time of diagnosis. For small, localized, easily accessible tumours, a complete resection (removal) of the tumour and surrounding margins (tissue around the tumour and perhaps nearby lymph nodes) can be performed with curative intent. For more advanced disease, total removal of the cancerous organ might be necessary.
Following in-patient surgery

Description
The majority of surgical procedures for cancer are performed in-hospital. For the nine cancers studied (other than leukemia), the common procedures performed are complete or partial resection of the organ (resection is indicated by the suffix “ectomy”). They are mastectomy or lumpectomy for breast cancer, prostatectomy for prostate cancer, cystectomy for bladder cancer, colostomy or resection of rectum for colorectal cancer, nephrectomy for kidney cancer, gastrectomy for stomach cancer, lobectomy or pneumonectomy for lung cancer, and pancreaticoduodenectomy for pancreatic cancer.

This description includes the post-operative effects of any surgery that requires an overnight stay in hospital, even if just for one night and typically lasts between 3-5 weeks. For many patients, the surgical procedure confirms the diagnosis of cancer, resulting in uncertainty and fear about the future, not only in terms of survival, but also about additional therapies that might have to be undergone. Side effects following surgery can range from mild to severe. Some patients experience minor discomfort for a few days, whereas those treated with more radical procedures may endure long-term discomfort and dysfunctionality. Common experiences are arm morbidity following mastectomy for breast cancer; incontinence and/or impotence after prostate cancer surgery; difficulty breathing after removal of a lung; or the psychological impact of a colostomy after colorectal cancer. In addition, many breast, prostate, bladder and colorectal cancer patients experience problems with sexuality and self-esteem following surgical treatment. Post-operative fatigue is generally quite significant and of long duration.

Classification
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Supplementary: 3 1 1 1 1

Following out-patient surgery

Description
The only surgery consistently performed on an out-patient (ambulatory) basis is lumpectomy or breast conserving surgery for early stage breast cancer. Patients may experience pain and discomfort (due to the insertion of drains) and some arm morbidity following the surgery. They may also be quite anxious and uncertain about future recurrences and potential adjuvant therapies.

Classification
Core: 2 2 3 2 1 2
Supplementary: 3 1 1 1 1
Radiotherapy (radiation therapy)

Radiotherapy uses high-energy radiation from a linear accelerator or other radiotherapy machine to damage or kill cancer cells. The treatment objective is to target a specific cancerous area, while minimizing damage to surrounding healthy tissue. Radiotherapy may be administered pre-operatively to shrink the tumour to facilitate surgery (e.g., for rectal cancer), or may be given as adjuvant therapy post-operatively to reduce the probability of local recurrence (e.g., of breast cancer, following breast conserving surgery). It is sometimes combined with chemotherapy (chemoirradiation) (e.g., for locally advanced lung cancer).

Radiotherapy may be used to “cure” some cancers (radical radiotherapy), but it can also effectively palliate symptoms and improve quality of life when “cure” is not possible. While radiotherapy is most often administered on an out-patient basis, hospitalization may be required if the patient has co-morbid conditions, or if radioactive sources are being implanted directly into the area of the tumour.

While receiving curative radiotherapy

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<td>Local radical or curative radiotherapy may be used as the sole therapeutic agent for a number of potentially curable cancers. It is generally provided at a hospital or clinic five days a week for five or more weeks. Side effects of radiotherapy depend on the treatment dose and the part of the body being treated. Patients experience mild discomfort and moderate levels of anxiety while undergoing radiotherapy. Fatigue appears to be the most common side effect and one which has the most profound impact on quality of life. Local skin changes (itching, tenderness, swelling or soreness), nausea and vomiting, diarrhea and ulceration of the radiated area may also occur.</td>
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While receiving palliative radiotherapy

**Description**
Palliative radiotherapy is used to provide pain relief and improve quality of life when curative therapy has failed or is not an option. It is usually administered in low doses and with a short duration (less than four weeks) and is sometimes given only once.

Patients may experience mild discomfort while undergoing palliative radiotherapy and most experience fatigue. As patients recognize that the treatment is non-curative, they are often very anxious and uncertain about their future and may withdraw from social relationships at this time.

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Chemotherapy

Chemotherapy is the term used to describe a variety of drugs that kill or inhibit the growth of cancerous cells. Unlike surgery or radiotherapy, chemotherapy is systemic, meaning that the drugs are usually injected into a vein and flow through the bloodstream to almost every part of the body. The drugs damage newly forming cells. Patients usually receive their treatments at intervals of every three to four weeks in an out-patient environment, such as a clinic or at home, often over a period of six months. However, because of the toxicity associated with some chemotherapy combinations, a short hospital stay may be necessary.

Chemotherapy may be used to cure, control or palliate cancer. Pre-operative or neoadjuvant chemotherapy may be used to reduce the size and extent of the primary tumour, to facilitate complete surgical excision. Chemotherapy is commonly used as adjuvant therapy after local treatment with surgery or radiotherapy to eradicate or suppress minimal residual disease, decrease the rate of relapse or improve survival. In cases where a cure is not possible, chemotherapy is often administered to relieve symptoms, prolong life and enhance quality of life.

Depending on the specific drugs used, chemotherapy can produce mild, moderate or severe side effects. The most common reactions, nausea and vomiting, are now being treated more successfully with anti-emetics (stemetil, ondansetron or related medications), which can prevent or relieve these symptoms. The type of cancer and stage at diagnosis will determine which health state applies during chemotherapy.
While receiving chemotherapy (mild toxicity)

Description
This description is based on the regimens of chemotherapeutic agents used to treat loco-regional colon cancer (5-fluorouracil [5FU] with folinic acid) and metastatic pancreatic cancer (gemcitabine [Gemzar]).

When individuals receive chemotherapeutic agents that have mildly toxic side effects, they generally experience mild nausea (anti-emetics are usually administered), some diarrhea and a relatively low risk of hospitalization for fever or dehydration. Fatigue is a commonly reported side effect.

Duration of treatment is estimated to be six months.

Classification
Core Supplementary
2 2 3 3 2 3 3 1 1 1 1

While receiving chemotherapy (moderate toxicity)

Description
This description is based on the regimens of chemotherapeutic agents used to treat loco-regional and metastatic breast cancer (anthracycline based regimens), lung cancer (cisplatin with other agents), metastatic bladder cancer (gemcitabine with cisplatin), loco-regional non-Hodgkin’s lymphoma (CHOP—cyclophosphamide, doxorubicin [Adriamycin], vincristine [Oncovin] and prednisone, with or without rituximab [Rituxan]), and metastatic stomach cancer (doxorubicin [Adriamycin] plus cisplatin).

Individuals receiving chemotherapeutic agents that have moderately toxic side effects generally experience moderate to severe nausea and vomiting (the effects of which are lessened with anti-emetics), weakness, hair loss, neuropathy (nerve damage), risk of infection and a moderate risk of being hospitalized for fever or neuropathy. Patients describe their side effects as including discomfort, fatigue and anxiety. Social relationships can be disrupted due to decreased sexual desire and mood swings and some patients experience paraesthesia (an abnormal touch sensation, such as burning or prickling in their fingers or toes) which can create difficulty buttoning clothes or tying shoes.

Duration of treatment is estimated to be six months.

Classification
Core Supplementary
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While receiving chemotherapy (severe toxicity)

Description

This description is based on the regimen of chemotherapeutic agents used to treat metastatic colon cancer (irinotecan with 5-fluorouracil and folinic acid), which may require the administration of anti-emetics, as well as anti-diarrheal medicines.

Patients generally experience severe nausea and vomiting (the effects of which are lessened with anti-emetics) and very severe diarrhea, with a high risk of hospitalization for neutropenic fever and dehydration. They may also complain of sensitive skin, cough, sore muscles, severe mouth sores, moderate epigastric distress, shortness of breath (dyspnea), weakness and dizziness. Some patients experience paresthesia in their hands and feet. Patients’ capacities to sustain social relationships can be compromised during the administration of chemotherapeutic agents which have severely toxic side effects, due to fatigue, anxiety, depression and irritability.

Duration of treatment is estimated to be six months.

Classification

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Hormonal therapy

Some types of cancer, including most breast and prostate cancers, depend on hormones to grow. Hormonal levels can be reduced by surgically removing the organs that produce them (testes or ovaries) or by administering drugs that stop hormone production or block their effects. This health state is based on hormonal therapy, which is routinely used as a first-line therapy for prostate cancer.
While receiving hormonal therapy

**Description**

Generally, hormonal ablation therapy (chemical castration) is used as the standard treatment for the management of symptomatic metastatic prostate cancer, which usually presents with bone pain. While the pain decreases in the majority of cases, important side effects are impotence or loss of sexual desire, which can be temporary, long lasting or permanent. Many men also experience hot flashes, breast tenderness, loss of muscle mass, increased fatigue and weight gain, which compromises their self-esteem and masculinity.

While the duration of treatment depends on the stage of disease at diagnosis, the average duration of hormonal therapy is three months for local or regional diagnosis and eighteen months for metastatic disease.

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Bone marrow transplantation

Bone marrow transplantation is a treatment for leukemia during which malignant cells are eliminated through the use of high-dose chemotherapy and/or radiation. This is followed by bone marrow or peripheral blood stem cell rescue in order to restore hematological and immunological function. The objective of bone marrow transplantation is to provide a healthy stem cell population that will differentiate into blood cells to replace deficient or pathologic cells of the host. Autologous bone marrow transplantation involves using an individual’s own bone marrow which has been purged of cancer through chemotherapy and/or radiotherapy. In allogeneic bone marrow transplantation, healthy bone marrow from a compatible donor is used.

Following bone marrow transplantation

**Description**

This description is for the immediate post-surgery recovery period, which lasts four to six weeks. The first two to three weeks after bone marrow transplantation has been performed are critical, as the establishment of the new graft takes 10 days to three weeks. During this time, patients are without marrow function, making them susceptible to infection and vulnerable to bleeding. In addition, they may experience shortness of breath, wheezing, flank or back pain, fever, mouth ulcers and diarrhea. Patients must undergo long periods of hospitalization, isolation from friends and family and high levels of stress.

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Subsequent health states

Remission

Patients are considered in remission after treatment when there is no clinical evidence of cancer; more generally, remission refers to the period following treatment. Patients may remain in this state until they die from some other cause or they may have a recurrence of their cancer. While in remission, patients do not exhibit any signs of cancer, but might experience residual physical or psychological effects, most commonly from the treatments received. In addition, many cancer patients “in remission” live with the concern and fear that their cancer may recur. These definitions were developed from literature and are based on three of the most common cancers in each prognostic group. Individuals often undergo two or more types of treatments and may experience the combined long-term effects of multiple treatments.

Remission after surgery

| Description | This description includes the long-term effects of having had surgery only, not in combination with any other therapy. Fatigue, insufficient sleep and insomnia are reported following surgery. Patients requiring radical surgery frequently report severely restricted social and sexual activities. Breast cancer patients experience numbness, pain and swelling in the affected arm; lung cancer patients complain of dyspnea; those having surgery for colorectal or prostate cancer can experience persistent bowel and/or bladder problems. Anxiety and psychological distress can result from follow-up visits. |
| Classification | Core | Supplementary |
|  | 2 2 2 2 1 3 | 2 1 1 1 1 |
Remission after radiotherapy

**Description**
This description includes the long-term effects of having had radiotherapy alone, not in combination with any other therapy. Chronic fatigue and distress are frequently reported following radiotherapy. While most side effects are temporary, there are some long-term chronic reactions to radiotherapy that are permanent, such as radiation-induced scarring of the tissues (e.g., lung fibrosis) or within the abdomen, leading to bowel obstruction. Bladder and bowel cancer patients report irritative bladder or bowel symptoms and rectal cancer patients may experience inflammation of the rectum. Rarely, radiotherapy can lead to the late induction of second malignancies.

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Remission after chemotherapy

**Description**
This description includes the long-term effects of having had chemotherapy alone (at any level of toxicity), not in combination with any other therapy. Many patients exhibit chronic fatigue (referred to as off-treatment fatigue), energy loss, sleep dysfunction, problems with memory and attention. Some women experience hot flashes and mood alterations as well as sexual dysfunction (due to menopausal symptoms, painful intercourse, poor body image or low libido) following chemotherapy. Other side effects reported are employment and marital problems, familial disruptions and anxiety. Damage to the reproductive system can result in short- or long-term infertility and sexual problems for both men and women. Second malignancies may occur years later as a result of the chemotherapy administration.

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Remission after hormonal therapy

**Description**
This description includes the long-term effects of having had only hormonal therapy for prostate cancer, not in combination with any other therapy. Patients may experience hot flashes and breast tenderness, fatigue, lethargy, loss of libido and sexual impotence, which can be temporary, long lasting or permanent.

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Recurrence

Cancer may recur after the initial treatment. A specific health state for recurrence is not provided here. Cancer that recurs either locally at the original cancer site or regionally is assumed to have similar effects on the patient’s functional and emotional state as the initial diagnosis. Recurrent cancer after an initial “curative therapy” may, however, have a greater emotional impact because it represents a failure to totally eradicate the tumour. If the cancer has metastasized to other parts of the body at recurrence, the diagnosis of recurrence is likely to have a far greater impact on the patient’s psychological state, since metastatic disease is considered incurable. Some patients move between remission and relapse several times. This most typically occurs with metastatic breast cancer, but is becoming more common with other tumours for which there are moderately effective therapies.

Palliative and terminal care

When cancer has advanced to the point where it is not considered curable, the treatment approach is described as palliative. The objective of palliative care is to provide the best possible quality of life and to extend survival, if possible. This includes the use of any therapeutic option to relieve pain or discomfort, as well as the provision of psychological, social and spiritual support. Many patients experience a long period of palliative treatment during which their tumour is controlled (breast cancer being the best example); however, palliative care is defined here as the five months of life prior to the terminal care phase (the last month before death). The goal of terminal care is to provide supportive care when no active anti-cancer therapy is available or suitable.

Palliative care

This health state is defined as the five months before the terminal care phase. Existential, physical, and psychological well-being is generally improved following admission to a palliative care unit. Patients may experience pain and fatigue of varying degrees while in palliative care, as well as the side effects of the administration of morphine (constipation, nausea, vomiting, sleep disturbances, mental clouding and confusion). Many express concern that they can no longer fulfill their roles in the family and cannot perform household duties. Sadness, grief, anxiety and depression are common, as well as feelings of isolation.

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Terminal care

Description

The health state of patients in the last month of life is similar to that in the palliative care state, except for the severity of the functional limitations experienced. For example, many patients experience severe pain or discomfort during this phase. Generalized weakness and fatigue can make even simple acts, such as feeding oneself, difficult.

“The last weeks of life are especially dramatic, with increased dependency, weakness, confusion, and inability to manage simple functional and personal tasks such as bathing, walking and continence.”

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References


The following references were used as general sources to describe the cancers, their main symptoms and treatment courses:


Unless otherwise specified, estimates of the number of new cancer cases and deaths were taken from:


The following references were used for the health state descriptions:


Baird AD, Woolfenden KA, Desmond AD, Fordham MV, Parsons KE. Outcome and survival with nonsurgical management of renal cell carcinoma. BJU Int 2003; 91(7):600-602.


The following websites were also consulted:

<table>
<thead>
<tr>
<th>Website</th>
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<td>American Cancer Society</td>
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