





Health Care Use at the End of Life in Atlantic Canada



## Who We Are

Established in 1994, CIHI is an independent, not-for-profit corporation that provides essential information on Canada's health system and the health of Canadians. Funded by federal, provincial and territorial governments, we are guided by a Board of Directors made up of health leaders across the country.

## **Our Vision**

To help improve Canada's health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.

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# About the Canadian Institute for Health Information

The Canadian Institute for Health Information (CIHI) collects and analyzes information on health and health care in Canada and makes it publicly available. Canada's federal, provincial and territorial governments created CIHI as a not-for-profit, independent organization dedicated to forging a common approach to Canadian health information. CIHI's goal: to provide timely, accurate and comparable information. CIHI's data and reports inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health.

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The project team responsible for the development of this report included the following:

Jeremy Collins, Special Projects Lead (Lead Analyst/Writer)

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This report is dedicated to the steadfast commitment of health professionals, researchers, government and community service staff and volunteers who strive to provide the most appropriate services and support to end-of-life patients in their remaining days. A special thank you goes to the researchers and staff who provided valuable information and advice throughout the development and analysis of this report.

Please note that the analyses and conclusions in the present document do not necessarily reflect those of the individuals or organizations mentioned above.

## **Executive Summary**

Providing appropriate and comprehensive health care services for all patients is an ongoing goal for health care organizations in Canada. This is the basis for our universal health care system. But as Canadians are living longer and often with one or more chronic diseases or conditions, the system is being increasingly challenged due to the complex needs of this growing patient population.

This report provides an overview of the 2007–2008 end-of-life population in Atlantic Canada, according to population profiles, location of death and hospital usage during the last year of life. The intent of this report is to provide health program managers, ministerial staff, policy-makers and other related service delivery groups with additional information to help with the assessment and delivery of the most appropriate end-of-life care for their residents. Vital statistics and hospital administrative data from each province were used to perform the analyses in this report; where appropriate, the two data sources were linked.

The decedent population in this report includes 18,427 adults (age 19 and older) in Atlantic Canada; this accounts for approximately 90% of the Atlantic Canada decedent population in 2007–2008. The Atlantic provinces share very similar demographic profiles. For example, provincial decedent populations were largely made up of seniors (age 65 and older), the sexes were almost equally distributed and most decedents had a marital status of *not married/unknown* (including widowed) at the time of death.

The leading causes of death in the three provinces<sup>i</sup> where data was available for analysis were consistent with national rates and were similar across the provinces: neoplasms (28% to 31%) and circulatory diseases (29% to 34%). A cross—age group comparison found that external causes of death were most common in younger populations; as the population aged, neoplasms and circulatory disease became more prevalent as the underlying causes of death. To aid analysis, decedents were categorized into trajectory groups<sup>ii</sup> based on underlying causes of death. Four trajectory groups were analyzed: frailty, organ failure, sudden death and terminal illness. Organ failure accounted for the highest proportion of decedents, followed closely by terminal illness, frailty and sudden death.

Decedents in Newfoundland and Labrador were excluded from leading cause of death and trajectory group assignment, as underlying cause of death was unavailable at the time of analysis.

ii. See page 6 for trajectory group definitions.

Understanding where individuals die is important when planning and providing care at the end of life. Analyzing location of death of Atlantic Canada decedents found that 63% (11,591) of all decedents died in hospital. Hospital deaths were most common in New Brunswick (67%) and least common in Prince Edward Island (54%).

This study also analyzed in-hospital palliative care in Atlantic Canada. Approximately 59% of the 9,507 decedents who died in an acute hospital received palliative care during their last hospital admission. New Brunswick reported the highest rate, at 64% of acute hospital deaths, and P.E.I. reported the lowest (13%). Patients with a terminal illness were found to be almost twice as likely as those in any of the other groups to have received palliative care.

Hospitalizations in the last year of life were also common: 45%, 65% and 71% of the Atlantic decedent population were hospitalized at least once within the 30, 180 and 360 days prior to death, respectively. Nova Scotia decedents were the least likely to be hospitalized in any of the three time periods, while New Brunswick decedents were the most likely. Terminally ill patients were the most likely to be hospitalized in all three time periods.

The 2007–2008 decedent population of Atlantic Canada spent just more than 475,900 days in hospital, with an adjusted average of 26 days spent in hospital in the last 360 days of life. Hospitalized patients in Newfoundland and Labrador and Nova Scotia reported lower-than-average hospital day rates (34 and 35 days, respectively) in the 360-day time period, while patients in New Brunswick reported the highest average hospital day rate (37 days) in this time period. Terminally ill patients saw the highest hospital day average.

Identifying patterns of hospital use and location of death can help to better tailor health care services for end-of-life patients. There are, however, limitations. Reporting on end-of-life care in Atlantic Canada would ideally include all aspects of the patient's experience—from pain and symptom management to social, cultural and psychological needs during the patient's final days. Additionally, reporting on the health care experience would preferably involve analyses of continuity of care across all health care settings (including home, community and hospice care). Unfortunately, our story of end-of-life care in Atlantic Canada is only a partial narrative, limited by the availability of data on the full spectrum of care.

## Introduction

Death is a phenomenon that, obviously, affects each and every one of us. Before our own death, most of us experience death through the passing of grandparents, parents or close friends. We would all like to experience a death that is characterized by dignity and comfort, without pain or unwanted life support, and with little emotional, psychological and spiritual distress.<sup>1–4</sup> Endof-life patients and their caregivers have indicated the need for a coordinated care environment where care is provided by trusted and knowledgeable health care providers, and patients are involved in decision-making processes.<sup>2</sup> For many patients, there is a wish to die at home,<sup>3,5</sup> yet the majority of Canadians die in provincially, territorially or federally run hospitals. According to Statistics Canada, in 2007, two-thirds (67%) of Canadians died in hospital.<sup>6</sup>

## End-of-Life Care and Palliative Care

There is some confusion between the terms "end-of-life care" and "palliative care." Some use the two synonymously.

According to the World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual). Specifically, palliative care

- · Provides relief from pain and other distressing symptoms;
- · Affirms life and regards dying as a normal process;
- · Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness; and

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## End-of-Life Care and Palliative Care (cont'd)

 Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

End-of-life care refers to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future. End-of-life care tends to be broader than palliative care, in that it includes any type of care—respite, home care, etc.—but in the context of this study, both terms are used.

#### Source

World Health Organization, WHO Definition of Palliative Care, accessed on June 10, 2010, from <a href="http://www.who.int/cancer/palliative/definition/en/">http://www.who.int/cancer/palliative/definition/en/</a>.

For most end-of-life patients, death comes gradually as the consequence of one or more chronic diseases or conditions. This, however, makes it difficult to know exactly when the patient may die; hence, medical care may be inadvertently focused on curative interventions instead of palliative care in the patient's remaining days. Almost all end-of-life patients need a palliative care program that maintains quality of life, handles reduced capacity/function, facilitates dying with dignity and comfort, provides symptom and pain management, and also provides information on bereavement programs for friends and families. 19, 10

## What Is a "Good Death"?

The idea of a "good death" seems like an oxymoron. But to those facing terminal illness, where death is a reality in the near future, the idea can hold promise. The notion that death is possible without overwhelming or uncontrollable pain or crushing anxiety can provide a new perspective on these patients' final days; it can empower patients and their families at a pivotal point in time.

According to one author, there are 12 key principles of a good death:

- To know when death is coming and to understand what can be expected.
- To be able to retain control of what happens.
- · To be afforded dignity and privacy.
- To have control over pain relief and other symptom control.
- To have choice and control over where death occurs (at home or elsewhere).
- · To have access to information and expertise of whatever kind is necessary.
- · To have access to any spiritual or emotional support required.
- To have access to hospice care in any location, not only in hospital.
- To have control over who is present and who shares the end.
- To be able to issue advance directives that ensure wishes are respected.
- To have time to say goodbye and control over other aspects of timing.
- To be able to leave when it is time to go and not to have life prolonged pointlessly.

These principles are good ones to incorporate into health care services, professional codes and care plans or missions for end-of-life care organizations and institutions, according to the author.

#### Source

R. Smith, "A Good Death," BMJ 320, 7228 (January 15, 2000): pp. 129-130.

Physiological conditions are not the only significant concern for end-of-life care; psychological and spiritual issues also play a significant role as patients approach death. Clinical depression and anxiety, feelings of helplessness and hopelessness, and concerns about possibly becoming a burden to family caregivers and decision-makers are very common issues for palliative patients. 9, 11 Left unchecked, these issues can lead to increased desires for a quick death, suicide ideation and suicide, thereby having a profound impact on the quality of life for those with little time remaining. 5, 9

There have been advances in developing palliative care programs in recent years, both within and outside of the hospital setting. A large number of health, social and community workers, family members and volunteers strive to help patients in their remaining days. Yet, for policy-makers, planners and medical and government department staff, meeting the needs of end-of-life patients with quality care presents a significant challenge. One of the reasons for this is the medical, psychosocial and spiritual diversity of the patient population. 9, 10

End-of-life care requires significant investment in resources, funding and coordination of health system and community-based services. Senator Sharon Carstairs noted in *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*<sup>1</sup> that the manner in which palliative care is currently structured and provided across Canada requires change:

Since 1995 there have been some significant improvements in public policy regarding end-of-life and in the delivery of palliative care services. Yet, we need to raise the bar . . . We need a culture of care that recognizes death as a natural part of life, responds to the reality that death trajectories are changing, and that incorporates palliative care services sooner for those who have a life-threatening illness.<sup>1</sup>

Senator Carstairs warned that, due to the aging population, we will face a "tsunami" of palliative patients in the near future. The baby boomer generation will soon hit the age of seniority. We will need to assess the health and social systems' capacity to accommodate the baby boomer cohort in future end-of-life care planning and service delivery.<sup>6</sup>

Adding to this is the fact that people are living longer. In July 2010, those age 65 and older were estimated to represent 14% of the overall Canadian population.<sup>12</sup> Projections for the future suggest that Canadians age 65 and older will make up 26% of the population by 2061.<sup>12, 13</sup>

The proportion of those age 65 and older is estimated to be higher in Atlantic Canada when compared to the national average. This is true in all four provinces, with senior populations ranging from 15.2% in Newfoundland and Labrador to 16% in Nova Scotia, according to the July 2010 population

estimates. More remarkable are the projections: by 2026, three of the four Atlantic provinces will surpass the 25% mark projected for the national average, and in 2031, seniors will make up a full quarter of the population in all four Atlantic provinces. This will effectively put Atlantic Canada 25 years ahead of the rest of the country, with a full quarter of the population made up of seniors. (See Figure 1.)

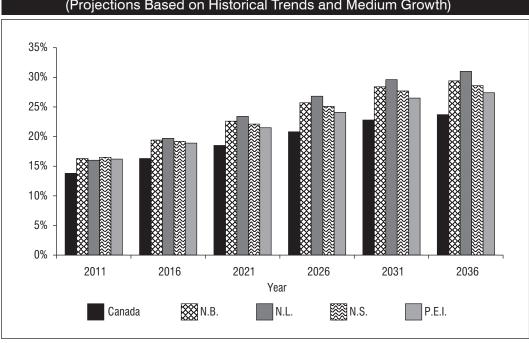


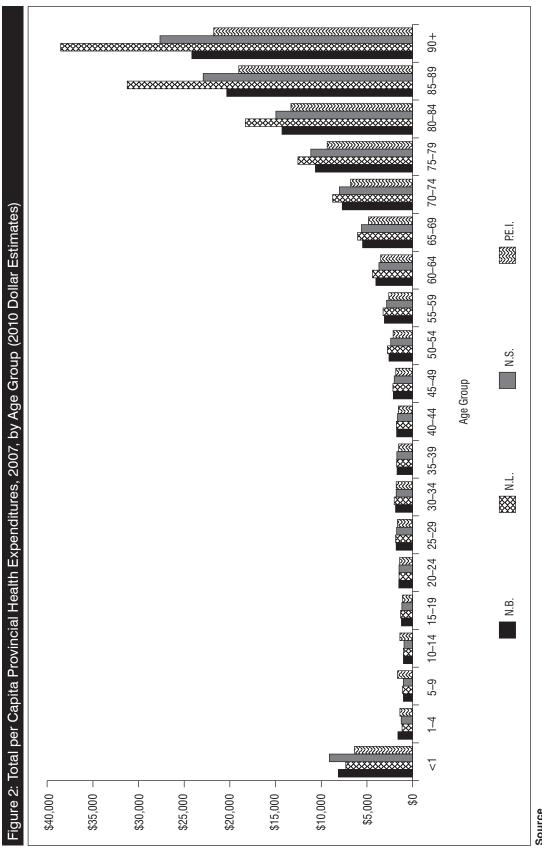
Figure 1: Percentage of Canadian Population Age 65 and Older, 2011 to 2036 (Projections Based on Historical Trends and Medium Growth)

Source

Statistics Canada, *Population Projections for Canada, Provinces and Territories, 2009–2036* (Ottawa, Ont.: Statistics Canada, 2010), catalogue no. 91-520-X.

This will have health system implications. Considering that an estimated 80% of seniors have one chronic disease, and about 70% have two or more conditions that may limit life expectancy,<sup>1</sup> the aging population in Atlantic Canada may need additional funding, as well as more health resource planning for end-of-life care and related programs.

The impact of the aging population is reflected in per capita spending for each Atlantic province (Figure 2). In terms of spending, those age 65 and older are second only to the neonatal/infant population. Both groups surpass the \$5,000 per capita spending level and, after the age of 65, these levels increase. Indeed, Figure 2 demonstrates that spending increases dramatically with each successive age group. Those age 85 to 89 surpass \$19,900 in per capita spending in all Atlantic provinces, for example. Assuming the Atlantic Canada projections are correct, the baby boomers may have a large impact on the end-of-life programs and services in the future.



Source Canadian Institute for Health Information, National Health Expenditure Trends, 1975 to 2010 (Ottawa, Ont.: CIHI, 2010).

Figure 2 also underscores the fact that older Canadians should be a population of interest when planning health programs and service delivery for the future. The Atlantic provinces will require flexible and innovative approaches to managing their growing population of older patients—a population that will likely have complex medical, psychological, social and spiritual needs. A study on Canadian palliative care costs<sup>14</sup> found that the public health system paid for approximately 71% of overall costs, while families absorbed approximately 27% of these costs. Approaches to end-of-life care must also take into account the financial burden incurred by caregivers and families.

## **About This Report**

In this report, we profile health care use at the end of life in Atlantic Canada. We illustrate how the aging population could substantially affect Atlantic Canada. The current health care system's structure and methods of providing end-of-life care may be ill prepared to handle the projected volume of patients with complex chronic conditions—patients who require specialized palliative care in the final days and months of life.

The intent is to better understand end-of-life care in these provinces. The goal of this report is to help support health service and program planning and policy development aimed at meeting the current and future needs of end-of-life patients in Atlantic Canada.

The report focuses on the decedent population profile, location of death and use of acute hospital services in all four provinces. In this way, this study is comparative; it compares the patterns of hospital utilization among the four Atlantic provinces, with particular focus on those 65 and older, who made up the majority of the decedent population in 2007.

Table 1 illustrates the economic importance of hospital use in Atlantic Canada. Hospitals accounted for the largest portion of total health expenditures, ranging from approximately 29% in Prince Edward Island to just below 38% in Newfoundland and Labrador.

Table 1: Percentage Distribution of Total Provincial Health Expenditures,	
2010 Dollars (Forecast)	

Expenditure	N.B.	N.L.	N.S.	P.E.I.
Hospitals	35.4	37.8	32.8	28.7
Other Institutions	10.8	15.2	12.1	13.7
Physicians	12.3	12.4	12.3	12.5
Other Professionals	9.3	5.6	8.5	7.2
Drugs	17.0	15.0	16.5	14.5
Capital	2.5	4.5	5.0	6.3
Public Health	3.3	3.3	3.4	4.3
Administration	3.1	3.1	4.1	8.3
Other Spending	6.3	3.0	5.2	4.6
Total	100	100	100	100

#### Source

Canadian Institute for Health Information, *National Health Expenditure Trends*, 1975 to 2010 (Ottawa, Ont.: CIHI, 2010).

## Methodology

In this study, the Canadian Institute for Health Information (CIHI) received vital statistics (mortality) data from all four provinces for 2007–2008. This data was linked to hospital discharge data.

Table 2: Summary of Study Methodology						
Population	This study included residents from the four Atlantic provinces who died in the most recent year (2007–2008) for which vital statistics death data was available from all four provinces. The study focused on the adult (age 19 and older) population. Excluded from this study were non-residents and persons not eligible for provincial health coverage (invalid or missing health card numbers) at the time of death. This study also excluded members of the military and RCMP and registered First Nations individuals, whose members may not have been captured in the provincial hospital discharge data.					
Data Sources	Provincial vital statistics (death) and hospital discharge abstracts were used. Data years included 2006–2007 and 2007–2008 hospital discharge records within 365 days of the patient's death, as determined by date of death and hospital discharge date.					
Data Linkage	Each provincial data or research unit linked death certificate data to hospital databases using unique identifiers (health care numbers as assigned by each province). Data for the year preceding the decedent's death was extracted to create a one-year retrospective health services use record. Once linked, the data was de-identified and forwarded to CIHI's Atlantic office for analysis and report development. For New Brunswick, CIHI performed the linkage between vital statistics data and CIHI's Discharge Abstract Database.					

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Table 2: Summary of Study Methodology (cont'd)							
Coverage of Health Services	The focus of the study is on health (hospital) services that are comparable across the four participating provinces. Excluded were physician services, formal home care and continuing care, and informal care received from family members or other means. This study also excluded hospital services provided by Health Canada.						
Limitations	Due to privacy legislation and data release standards, not all data elements were available. In certain cases, the data may have been suppressed due to small cell sizes.						

## A Note About Variations

Variations among provinces are not necessarily a reflection of accessibility or quality of care but an indicator that populations, health programs and systems differ in Atlantic Canada. Understanding the variation in programs, in addition to the collection and analysis of standardized data (elements or fields), is key for developing comprehensive, flexible palliative care programs to meet the needs of end-of-life patients in Atlantic Canada, both individually and as a whole.

## Report Structure

This report focuses on results for Atlantic Canada.

Chapter 1 describes the demographic characteristics of the decedent cohort.

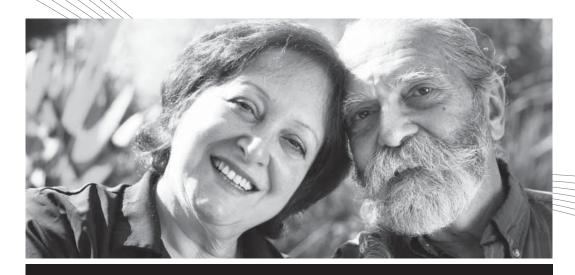
Chapter 2 looks at death in hospitals and other locations. It presents findings related to the type of care received (palliative and non-palliative).

Chapter 3 focuses on hospital use, illustrating variations across provinces in hospital admissions and use of hospitals in the last year of life.

Appendix A provides a concise but comprehensive summary of end-of-life and palliative care programs and services available in Atlantic Canada.

**Appendix B** provides a summary of hospitalization by location of death.





**Chapter 1**Describing Atlantic Canada Decedents

"The focus of palliative care is on preserving the quality of the recipient's life so that their suffering is minimized but their experience of life is not. Palliative care is not about dying, it is about living well until the very end."

**Senator Sharon Carstairs** 

## Introduction

The experiences of end-of-life patients often vary according to condition or disease, sex, marital status and age. Table 3 illustrates the demographic characteristics of each Atlantic province in July 2007. The provinces had a strikingly similar composition across age, sex and marital status. The greatest differences were seen in marital status: Newfoundland and Labrador had the highest percentage of married people (54%), while Nova Scotia had the lowest percentage (50%).

Table 3: Profile of Atlantic Canada Population (Mid-Year Estimates, July 1, 2007) <sup>15</sup>										
	Atlantic Pro	vinces	N.B.	N.B.		N.L.			P.E.I	
	N	%	N	%	N	%	N	%	N	%
Age Group										
<19	487,300	21.0	156,300	21.0	103,400	20.4	195,900	20.9	31,700	23.0
19–64	1,496,100	64.3	478,600	64.2	332,000	65.5	599,500	64.0	85,900	62.2
65+	342,600	14.7	110,500	14.8	71,000	14.0	140,600	15.0	20,500	14.8
Gender										
Female	1,189,100	51.1	379,500	50.9	257,600	50.9	481,500	51.4	70,500	51.0
Male	1,136,800	48.9	365,900	49.1	248,800	49.1	454,500	48.6	67,600	49.0
Marital Status	S									
Married*	1,192,854	51.3	380,012	51.0	273,175	53.9	468,795	50.1	70,872	51.3
Not Married	1,133,146	48.7	365,388	49.0	233,325	46.1	467,205	49.9	67,228	48.7
Total Population	2,326,000	100	745,400	100	506,500	100	936,000	100	138,100	100

#### Note

Statistics Canada, *Annual Demographic Estimates: Canada, Provinces and Territories, 2008* (Ottawa, Ont.: Statistics Canada, 2008), catalogue no. 91-215-X.

The similarities between the provincial populations were also reflected in decedent populations in this study. In Table 4, the demographic profiles of the decedent populations show that

- The majority of patients were seniors, comprising 80% of the total Atlantic decedent population in 2007–2008;
- Sex was almost equally represented in the patient population; and
- Approximately 60% of patients were unmarried (or had unknown marital status) at death.

<sup>\*</sup> Includes persons who are legally married, legally married and separated, and living in common-law unions.

Table 4: Adult Decedents (Age 19+), Atlantic Canada, 2007–2008										
	Total		N.E	N.B.		N.L.			P.E.I.	
	N	%	N	%	N	%	N	%	N	%
Age Group										
19–44	612	3.3	215	3.5	125	3.1	246	3.3	26	2.9
45–64	3,070	16.7	995	16.2	718	18.0	1,206	16.4	151	16.6
65–74	3,306	17.9	1,075	17.5	760	19.0	1,313	17.8	158	17.4
75–84	5,329	28.9	1,789	29.1	1,220	30.5	2,085	28.3	235	25.9
85+	6,110	33.2	2,072	33.7	1,176	29.4	2,523	34.2	339	37.3
Total 65+	14,745	80.0	4,936	80.3	3,156	78.9	5,921	80.3	732	80.5
Gender										
Female	9,150	49.7	3,057	49.7	1,960	49.0	3,687	50.0	446	49.1
Male	9,277	50.3	3,089	50.3	2,039	51.0	3,686	50.0	463	50.9
<b>Marital Status</b>										
Married	7,509	40.7	2,456	40.0	1,668	41.7	3,020	41.0	365	40.2
Not Married/ Unknown*	10,918	59.3	3,690	60.0	2,331	58.3	4,353	59.0	544	59.8
Total	18,427	100	6,146	100	3,999	100	7,373	100	909	100

#### Sources

Vital Statistics Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

## Causes of Death

In 2007, the Maritime provinces (New Brunswick, Nova Scotia and P.E.I.) had mortality rates similar to 2007<sup>i</sup> national levels<sup>16</sup> for neoplasms (31%), circulatory diseases (30%) and external causes of death (6%). (See Table 5.) External causes include trauma and accidents in general; examples include falls, motor vehicle accidents, drowning, electrocution, homicide, poisoning and suicide. Neoplasm death rates were highest in Nova Scotia and New Brunswick, while P.E.I. had the highest rates of circulatory, respiratory and external causes of death. New Brunswick had the highest rates of other causes of death. Other causes include infectious disease (like HIV), endocrine or metabolic conditions (diabetes), neurological diseases (Alzheimer's, amyotrophic lateral sclerosis) and digestive diseases (such as cirrhosis of the liver).

<sup>\*</sup> Widowed decedents made up 66% of not married/unknown and 39% of the Atlantic population (n = 7,253). The proportion of widowed decedents in each province was as follows: New Brunswick, 39% (n = 2,403); Newfoundland and Labrador, 39% (n = 1,551); Nova Scotia, 40% (n = 2,954); Prince Edward Island, 38% (n = 345).

 <sup>2007</sup> was the most current year available for data on leading cause of death at the time of publication. Newfoundland and Labrador decedents were excluded from this analysis, as this information was unavailable, based on the data sources (vital statistics) used in this study at the time of analysis.

Table 5: Cause of Death, Adult Decedents, Maritime Provinces								
	Maritime Provinces		N.B		N.S.		P.E.I.	
Cause of Death	N	%	N	%	N	%	N	%
Circulatory	4,344	30.1	1,776	28.9	2,257	30.6	311	34.2
Neoplasms	4,397	30.5	1,882	30.6	2,260	30.7	255	28.1
Respiratory	1,334	9.2	520	8.5	721	9.8	93	10.2
Endocrine, Metabolic and Nutritional Diseases	572	4.0	262	4.2	279	3.8	31	3.4
External Cause	873	6.1	348	5.7	459	6.2	66	7.3
Other	2,908	20.2	1,358	22.1	1,397	18.9	153	16.8
Total	14,428	100	6,146	100	7,373	100	909	100

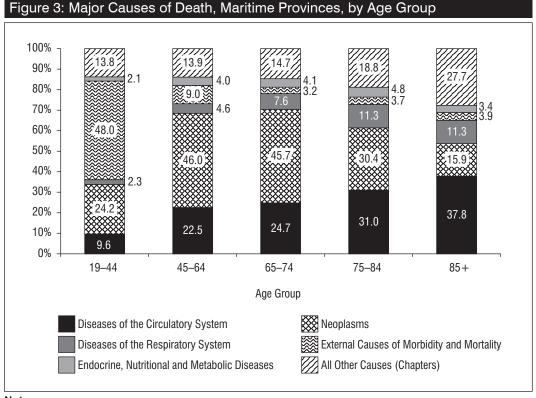
Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

#### Sources

Vital Statistics Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island.

# Age-Based Pattern

When examining the leading causes of death, a distinct pattern emerges among age groups. As shown in Figure 3, the leading cause of death among those age 19 to 44 was external causes (48%). By comparison, neoplasms were the leading cause of death for those age 45 to 64 and age 65 to 74 (46% for both) and circulatory diseases were the leading cause of death for those age 75 to 84 and age 85 and older (31% and 38%, respectively).



Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

#### Sources

Vital Statistics Data, 2007-2008, New Brunswick, Nova Scotia and Prince Edward Island.

# Trajectories: Categories for Causes of Death

There are five distinct categories (also known as groups or trajectories) for causes of death: sudden death, terminal illness, organ failure, frailty and other.<sup>17</sup> These are used to help identify patterns of health resource use. Decedents were assigned to a category or group based on the underlying cause of death code (ICD-10-CA diagnosis code) found in the vital statistics records.

It is noteworthy that "frailty" is an unusual term for those age 19 to 64, as it is typically associated with advanced age. It may help to consider that frailty is not a disease but a general state of weakness, and it can be caused by many things. Frailty includes Alzheimer's, acute myocardial infarctions (AMIs or heart attacks), influenza and pneumonia.

Table 6: Cause of Death Trajectory Groupings*				
Sudden Death (for example, accidental death, falls, trauma)	Decedents in this group are likely to be in good health or to display normal functional ability before the incident that causes death. While it is possible that a condition associated with one of the groups below is present, the underlying cause of death is one of trauma, accident or other unintended causes. Typically, these decedents display low health care costs relative to the other groups.			
<b>Terminal Illness</b> (for example, cancer, chronic renal failure, HIV-related diseases)	Typically, decedents in this group who are diagnosed with some form of cancer show substantial physician billing for cancer-related treatment in the last year of life. Functional status information demonstrates a terminal phase for this group. Typically, these decedents demonstrate a short period of evident decline.			
Organ Failure (for example, congestive heart failure and chronic obstructive pulmonary disease)	Organ failure decedents are typically diagnosed with either congestive heart failure or chronic obstructive pulmonary disease. Decedents in this group are likely to experience long-term limitations that are exacerbated by acute episodes (with high costs or long hospitalizations) followed by recovery. Episode severity may gradually increase while post-episode recoveries subside, eventually leading to death.			
Frailty (for example, neurological decline and other frequent causes of death among the elderly)	Typically, due to their advanced age, decedents in this category may display lower functional status relative to other decedents in the year before death. The pattern of decline over time is typically more gradual, characterized as prolonged dwindling in functional ability.			
Other (those not elsewhere categorized)	These are the remaining decedents whose conditions are not classified into any of the other four categories. They may not exhibit specific patterns in functional decline or service utilization.			

\* The ICD-10-CA codes used for trajectory group assignment are available upon request.

#### Sources

- J. Lunney et al., "Patterns of Functional Decline at the End of Life," *JAMA* 289, 18 (May 14, 2003): pp. 2387–2392.
- J. Lunney, J. Lynn and C. Hogan, "Profiles of Older Medicare Decedents," *Journal of the American Geriatric Society* 50 (2002): pp. 1108–1112.
- J. Lynn and D. Ádamson, Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age (Santa Monica, California: RAND Corporation, 2003).

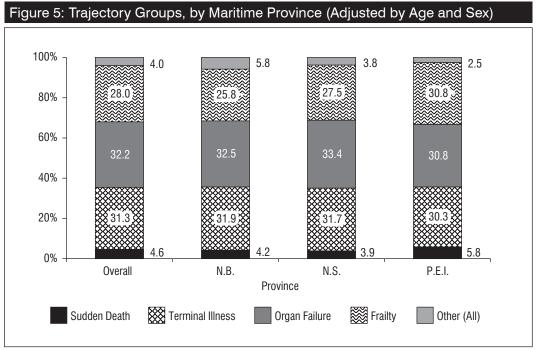
Figure 4: Four Main Theoretical End-of-Life Trajectories Terminal Illness Sudden Death High High Function Function Deaţh Deaţh Low Low Time Time Organ Failure Frailty High High **Function Function** Death Death Low Low Time Time

Figure 4 shows the patterns of decline experienced in the four main categories described above.

## Source

J. Lunney, J. Lynn and C. Hogan, "Profiles of Older Medicare Decedents," *Journal of the American Geriatric Society* 50 (2002): pp. 1108–1112.

In the total decedent population in the three provinces where data was available, 32% succumbed to organ failure, 31% to terminal illness and 28% to frailty. Sudden death and other causes accounted for 5% and 4% of the total cases, respectively.



Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island.

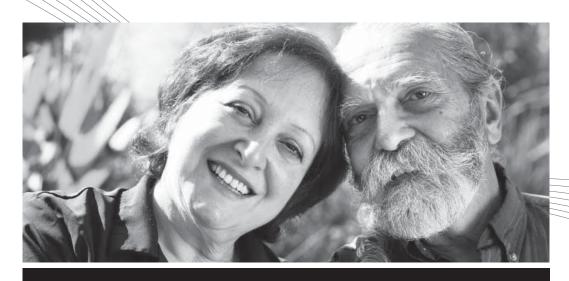
# Summary

The decedent population in this report includes 18,427 adults (age 19 and older) in Atlantic Canada and accounts for approximately 90% of the decedent population in 2007–2008. The analysis revealed strong demographic similarities in terms of age, sex and marital status across the provinces. The majority of deaths were among seniors, and the sexes were almost equally distributed. Marital status of *not married/unknown* was consistently higher in all provinces.

The leading cause of death in the three Maritime provinces was fairly consistent with 2006 national patterns: neoplasms and circulatory disease accounted for the majority of deaths. Across age groups, external causes were most common in younger populations, while neoplasms and circulatory disease became more pronounced as the leading cause of death as patients aged.

In this study, the combined maritime population had slightly higher percentages of organ failure, followed closely by terminal illness and frailty. Sudden death and other causes accounted for the smallest proportions of the decedent population.





Chapter 2
Death in Hospitals and Other Locations

## Introduction

Historically, the place to die was at home, surrounded by loved ones.<sup>14</sup> Change and a shift away from this ideal began in the mid-20th century. Factors such as the reduction of the extended family and increased longevity led to greater numbers of people entering long-term care facilities. Today, the majority of patients are no longer dying in the traditional family home but are instead dying in hospitals, nursing homes and other facilities.<sup>6, 18, 20</sup> Home is still the preferred location of most end-of-life patients,<sup>2, 4</sup> yet it may not be the most appropriate location if sufficient support is not available to caregivers.<sup>14, 19</sup>

Where death occurs is contingent on a number of issues. While personal preferences are a strong indicator of the location of death,<sup>18</sup> the characteristics of illness, availability of services and type of services are important influences on the location of end-of-life care and death.<sup>5</sup> There are also differences between sexes; for example, men have a shorter expected lifespan and would likely have family and spousal support. By comparison, women are more likely to be single (including widowed) and residing in a long-term care facility at the end of life.<sup>6, 18, 20</sup>

This chapter examines location of death, according to vital statistics and hospital discharge data for the Atlantic region. Table 7 shows the various locations of death by province as recorded on vital statistics records. Location categories such as *private home* or *home* allow for direct comparisons between provinces. Other categories, such as *hospital*, are not as straightforward. In New Brunswick, for example, *hospital* refers to all provincially subsidized hospitals, while in Nova Scotia *hospital* refers to any acute care facility, rehabilitation facility or forensic hospital. Another category, *other health (care) facility*, is also heterogeneous, pertaining to nursing, community and special care homes in all provinces, but also referring to rehabilitation or palliative care facilities in P.E.I. and rehabilitation and chronic care in Newfoundland and Labrador.

Definitions for locations of death were provided by department/ministry of health staff from each of the four Atlantic provinces.

Table 7: Location of Death	Codes on Death	Certificates,	by Province
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N.B.*	N.L.	N.S.	P.E.I.
Private Home	Private Home	Home	Home
Hospital	Hospital	Hospital	Hospital
Other Health Care Facility	Other Health Care Facility	Other Health Facility	Other Health Facility
Other	Other	Other	Other
Unknown/Not Stated	Unknown	Unknown	Unknown
Nursing Home			
ER/Outpatient			
Correctional Institution			

#### Sources

Vital Statistics Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

## Methodology

In this study, three methods were used to determine location of death in the four Atlantic provinces.

**Method 1**: Use location of death as specified on the death certificate (vital statistics only).

**Method 2:** (a) Match the location of death as *hospital* between the death certificate and the discharge data, but **exclude** palliative care patients (non-palliative care). (b) Match the location of death as *hospital* between the death certificate and the discharge data, but **include** palliative care patients (palliative care).

**Method 3**: Use only the discharge data location of death as *hospital* to identify patients.

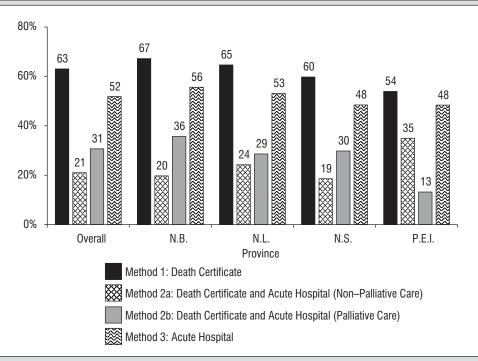
As shown in Figure 6, Method 1 consistently returned the highest estimate of in-hospital deaths; estimates ranged from 54% in P.E.I. to 67% in New Brunswick. Method 2 yielded significantly reduced estimates compared to Method 1, as a consequence of excluding or including palliative care.

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<sup>\*</sup> *ER/outpatient* was included in the hospital category, under the premise this is where ER/outpatient services are found in New Brunswick. *Nursing home* was included as *other health facility*, as this location is frequently captured for other provinces. *Correctional institution* was grouped to *other*.

## Methodology (cont'd)

Figure 6: Methods of Assessing In-Hospital Deaths, by Province and Data Sources



#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

The discrepancies between the proportions determined by methods 1 and 2 (a and b) indicated the in-hospital death populations in Atlantic Canada (in 2007–2008) had a large number of patients receiving some manner of palliative care during their final admission.

The difference between methods 1 and 2 (a and b) may be the result of patients dying in emergency departments, or it may be attributed to the difference in the types of hospital facilities included in the designation of *hospital* on the death certificate. Methods 1 and 2 (a and b) will be used, as indicated, for the remainder of the analyses.

In this report, some tables and figures include age- and sex-adjusted analyses (as indicated); adjustments were based on the decedent cohort age 19 and older. In addition, Newfoundland and Labrador decedents were excluded from cause of death and trajectory analyses, as the underlying cause of death was unavailable at the time of analysis.

## Provincial Variations for In-Hospital Deaths

The majority of decedents in Atlantic Canada died in hospital, as indicated by the death certificate (Method 1). Table 8 shows that 11,591 (63%) Atlantic Canadians in this study, age 19 and older, died in hospital. At the provincial level, P.E.I. had the lowest estimate (54%) of in-hospital deaths, and New Brunswick had the highest estimate (67%). A comparison of age groups indicates that the proportion of hospital deaths was higher for those age 19 to 64 in New Brunswick and Newfoundland and Labrador, while proportions between the age categories remained fairly consistent in Nova Scotia and P.E.I.

Table 8: In-Hos	pital Deaths, b	v Province and	Age Group

	Age 19–64			Age 65+			Age 19+		
		In-Ho	ospital		In-Ho	ospital		In-Hospital	
Province	Total # of Decedents	#	% of Total Deaths	Total # of Decedents	#	% of Total Deaths	Total # of Decedents	#	% of Total Deaths
N.B.	1,210	850	70.2	4,936	3,283	66.5	6,146	4,133	67.2
N.L.	843	563	66.8	3,156	2,023	64.1	3,999	2,586	64.7
N.S.	1,435	841	58.6	5,899	3,541	60.0	7,334	4,382	59.7
P.E.I.	177	95	53.7	732	395	54.0	909	490	53.9
Overall	3,665	2,349	64.1	14,723	9,242	62.8	18,388	11,591	63.0

#### Sources

Vital Statistics Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (Method 1).

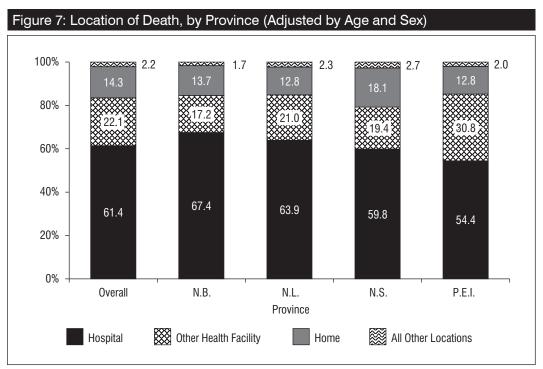
P.E.I. decedents age 19 to 64 were the least likely to have died in hospital, followed by Nova Scotia decedents in the same age category. Decedents from New Brunswick in this age category, by comparison, were most likely to have died in hospital.

Those patients 65 and older in New Brunswick had the highest percentage of in-hospital deaths, compared with decedents from the other three Atlantic provinces.

## Deaths in Other Health Facilities and Homes

Deaths in other health facilities accounted for 22% of all deaths in this study. This category was highest in P.E.I. (31%), which may be explained by the inclusion of all non-acute facilities in this group, such as palliative care, community care facilities, nursing homes and so forth.

Home deaths accounted for 14% of all decedents. Nova Scotia had the highest percentage (18%) of home deaths, and Newfoundland and Labrador and P.E.I. had the lowest (13%).



## Sources

Vital Statistics Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (Method 1).

## Further Analysis by Health Region

More detailed analyses of acute in-hospital deaths by health region are found in Table 9. A total of 9,507 Atlantic decedents died in an acute hospital in 2007–2008. Central health region in Newfoundland and Labrador and Queens region in P.E.I. had the highest levels of non-palliative hospital deaths. By comparison, the lowest percentage of non-palliative hospital deaths was found in Nova Scotia's district health authority (DHA) 4.

Nova Scotia's DHAs 4 and 9 had the highest rates of palliative care acute hospital deaths in Atlantic Canada in 2007–2008. New Brunswick's regions 3, 5, 6 and 7 also had high rates. These findings are consistent with New Brunswick having the highest proportion of palliative care acute hospital deaths among the Atlantic provinces. The lowest regional percentage was found in the Queens region in P.E.I. (9%), which was substantially less than the next-lowest percentage, which was in Newfoundland and Labrador's Central region (32%).

Table 9: Acute Hospital Deaths, by Province and Health Region/District (Adjusted by Age and Sex)

Province and	# of Acute Hospital	Acute H % Non–Pall			lospital: tive Care
Region/District	Decedents	Actual	Adjusted	Actual	Adjusted
N.B.	3,408	35.6	35.6	64.4	64.4
Region 1	850	36.1	35.8	63.9	64.2
Region 2	790	42.8	42.7	57.2	57.3
Region 3	759	32.8	32.8	67.2	67.2
Region 4	219	35.2	35.2	64.8	64.8
Region 5	166	27.1	27.0	72.9	72.1
Region 6	384	31.0	31.0	69.0	69.0
Region 7	240	32.9	33.1	67.1	66.9
N.L.	2,114	45.8	46.3	54.2	53.7
Central	442	67.9	70.4	32.1	32.1
Eastern	1,181	36.7	37.4	63.6	63.3
Labrador-Grenfell	90	52.9	53.7	48.9	47.1
Western	401	48.8	51.1	51.9	51.2
N.S.	3,547	38.4	38.4	61.6	61.6
DHA 1	297	42.1	41.8	56.9	57.9
DHA 2	329	58.6	59.9	40.7	41.4
DHA 3	306	37.2	38.5	62.7	61.8
DHA 4	267	22.8	24.1	76.4	77.2
DHA 5	171	49.2	53.3	49.1	48.8
DHA 6	236	57.9	59.1	40.7	42.1
DHA 7	198	55.7	56.5	45.5	44.3
DHA 8	621	39.2	41.0	61.8	60.8
DHA 9	1,122	26.1	27.1	74.2	73.9
P.E.I.	438	72.6	71.8	27.4	28.2
Kings	85	57.9	62.6	38.8	40.1
Prince	157	54.0	57.0	45.2	45.1
Queens	196	91.5	90.7	8.2	8.5
Overall	9,507	40.6	48.0	59.4	52.0
Note					

### Note

The population used to adjust the rates was the entire in-hospital (acute) population.

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (methods 2a and 2b).

Analyses of location of death (using Method 1) at the regional level are shown in Table 10. The results show P.E.I.'s Queens region had the lowest rate of hospital deaths (44%); the highest rates were found predominantly in New Brunswick regions. Of the remaining locations of death, the highest percentage of other health facility deaths was found in Queens (41%) in P.E.I. Queens accounted for more than 57% of the total decedent population in P.E.I.; this high regional proportion helps explain why P.E.I. had the highest proportion of other health facilities deaths in Atlantic Canada.

Table 10: All Locations of Death, by Province and Health Region/District (Adjusted by Age and Sex)

				% in Other				% in Other	
Province and	# of	% in I	-lospital		Facility	% at	Home		cation
Region/District	Decedents	Actual	Adjusted	Actual	Adjusted	Actual	Adjusted	Actual	Adjusted
N.B.	6,146	67.2	67.4	17.4	17.2	13.6	13.7	1.8	1.7
Region 1	1,523	65.5	66.2	19.6	18.9	13.1	13.5	1.8	1.4
Region 2	1,531	64.3	64.3	16.3	16.2	17.4	17.5	2.0	2.1
Region 3	1,352	67.2	67.5	17.7	17.1	13.2	13.4	1.8	1.9
Region 4	422	67.1	66.3	23.0	24.3	8.1	7.8	1.9	1.7
Region 5	283	74.9	74.1	11.7	11.9	12.4	13.2	*	*
Region 6	622	74.6	74.6	13.0	13.1	10.9	10.8	1.4	1.4
Region 7	413	68.8	69.0	16.7	17.0	13.1	12.6	1.5	1.4
N.L.	3,999	64.7	63.9	20.1	21.0	13.1	12.8	2.2	2.3
Central	838	65.8	65.0	22.2	22.4	9.9	10.1	2.1	2.6
Eastern	2,267	62.2	61.8	21.8	22.2	13.9	13.7	2.1	2.2
Labrador-Grenfell	186	64.5	61.7	15.6	19.4	16.7	17.1	3.2	1.9
Western	708	71.2	69.8	13.1	15.3	13.3	12.5	2.4	2.4
N.S.	7,334	59.7	59.8	19.6	19.4	17.9	18.1	2.7	2.7
DHA 1	598	59.2	59.6	20.7	19.6	17.2	17.9	2.8	2.9
DHA 2	602	63.1	63.4	19.3	18.4	14.5	14.9	3.2	3.3
DHA 3	624	59.5	59.3	21.3	20.5	16.5	17.3	2.7	2.9
DHA 4	543	60.2	60.5	15.5	16.2	21.0	20.3	3.3	3.0
DHA 5	308	63.3	61.9	19.8	19.1	14.0	15.3	2.9	3.7
DHA 6	481	57.8	57.7	19.8	19.1	19.5	20.1	2.9	3.1
DHA 7	419	59.2	60.9	22.4	20.1	15.8	16.4	2.6	2.6
DHA 8	1,247	62.0	61.7	17.0	17.8	19.1	18.7	1.9	1.7
DHA 9	2,512	58.0	58.1	20.7	20.7	18.6	18.4	2.7	2.7
P.E.I.	909	53.9	54.4	31.6	30.8	12.5	12.8	2.0	2.0
Kings	133	65.4	65.2	15.8	16.0	16.5	15.3	*	*
Prince	254	72.4	71.1	16.9	17.1	9.8	9.8	*	*
Queens	522	42.0	43.8	42.7	40.7	12.8	13.0	2.5	2.5
Overall	18,388	63.0	61.4	19.6	22.1	15.2	14.3	2.2	2.2

#### Note

#### Sources

Vital Statistics Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (Method 1).

<sup>\*</sup> Results suppressed because of small cell sizes (n<5).

## A Focus on Palliative Care

As shown in Table 11, of the 9,507 decedents who died in an acute hospital, 5,644 received some form of palliative care during their last hospital admission. P.E.I. had the lowest proportion (27%) and New Brunswick the highest percentage of in-hospital palliative care decedents (64%). The average for all four Atlantic provinces was 59.4%.

Table 11: Acute In-Hospital Palliative Care Deaths, by Province and Age Group

		Age	Age 19–64		65+	Age 19+	
Province	# of Acute Hospital Deaths	# of Decedents	% of Total Acute In-Hospital Deaths	# of Decedents	% of Total Acute In-Hospital Deaths	# of Decedents	% of Total Acute In-Hospital Deaths
N.B.	3,408	437	65.6	1,757	64.1	2,194	64.4
N.L.	2,114	289	62.8	856	51.8	1,145	54.2
N.S.	3,547	475	69.8	1,710	59.7	2,185	61.6
P.E.I.	438	31	38.8	89	24.9	120	27.4
Overall	9,507	1,232	65.3	4,412	57.9	5,644	59.4

### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (Method 2b).

## Identifying Palliative Cases by Most Responsible Diagnosis

Palliative care decedents in this report include anyone receiving any type of palliative care during their last admission leading to an in-hospital death. But what about patients admitted as palliative care patients—patients deemed palliative as their most responsible diagnosis according to their main patient service?

Table 12 shows the number of people who died in each province in 2007–2008 versus the number of patients who came into the hospital specifically for palliative care and then died. As the table indicates, the percentage of decedents admitted for palliative care was substantially less than the percentage of decedents receiving palliative care after admission to hospital.

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## Identifying Palliative Cases by Most Responsible Diagnosis (cont'd)

Table 12: Acute In-Hospital Deaths, Decedents Admitted for Palliative Care

		Palliative Care Patients				
Province	# of Decedents	% of Acute In-Hospital Deaths	% of All Deaths			
N.B.	1,070	31.4	17.4			
N.L.	596	28.2	14.9			
N.S.	1,050	29.6	14.3			
P.E.I.	115	26.3	12.7			
Overall	2,831	29.8	15.4			

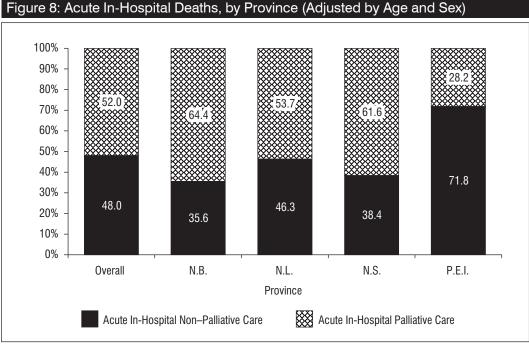
#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (Method 2b).

Broken down by age, a high percentage of Nova Scotia decedents age 19 to 64 received palliative hospital care during their last admission. By comparison, fewer P.E.I. decedents in this age group received palliative care in their last hospitalization leading to in-hospital death.

Of decedents age 65 and older, New Brunswick decedents had the highest percentage of those receiving in-hospital palliative care, compared with their counterparts in the other Atlantic provinces who also received palliative care during their last hospital admission. There was a twofold or more difference for P.E.I., with fewer patients receiving palliative care during their last admission than in New Brunswick.

Comparison of non-palliative care and palliative care acute in-hospital deaths (adjusted rates) are shown in Figure 8. Overall, patients receiving palliative care during their last admission accounted for 52% of all acute in-hospital deaths, with the highest adjusted rate in New Brunswick (64%) and the lowest adjusted rate in P.E.I. (27%).



#### Note

The population used to adjust the rates was the in-hospital (acute) population.

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island (methods 2a and 2b).

## Palliative Care in Prince Edward Island

P.E.I. palliative care rates are notably lower than those in any other province in Atlantic Canada. When consulted, Health P.E.I. indicated that when patients have been deemed to require palliative care they are often transferred out of acute facilities to the provincial palliative care unit (in Prince Edward Home), chronic care facilities, nursing homes or other facilities. P.E.I.'s higher proportions of deaths in other health facilities (see below) reflect the transfers out of acute facilities. Furthermore, palliative care is often not coded in patient records at P.E.I.'s largest facility, Queen Elizabeth Hospital in Charlottetown; palliative care was recorded for only an adjusted rate of 9.2% of acute in-hospital deaths in 2007–2008. When palliative service transfers (code 58) were added to the palliative care analysis, Queen Elizabeth Hospital's proportion increased to an adjusted rate of 16.4% of deaths, and P.E.I.'s overall adjusted rate increased to 35.4% (results not shown).

## **Trajectory Group Comparisons**

As discussed in Chapter 1, there are five distinct trajectories based on the underlying causes of death: sudden death, terminal illness, organ failure, frailty and other. Four of these trajectories (all except the *other* category) were analyzed in this report. This analysis looked at in-hospital non-palliative and palliative deaths for the three provinces for which data was available.

Overall, terminal illness decedents had the highest in-hospital deaths (74%), followed by patients in the organ failure group. Terminal illness, organ failure and frailty groups saw higher percentages among those age 19 to 64, compared with both those age 65 and older and the overall population.

Table 13: Hospital Deaths, by Trajectory Group										
	Ag	Age 19–64		Ag	Age 65+			Age 19+		
		In-H	ospital		In-H	ospital		In-Hospital		
Trajectory Group	Total # of Decedents	#	% of Total Deaths	Total # of Decedents	#	% of Total Deaths	Total # of Decedents	#	% of Total Deaths	
Frailty	424	226	53.3	3,456	1,668	48.3	3,880	1,894	48.8	
Organ Failure	656	460	70.1	4,048	2,706	66.8	4,704	3,166	67.3	
Sudden Death	418	95	22.7	175	85	48.6	593	180	30.4	
Terminal Illness	1,222	933	76.4	3,326	2,409	72.4	4,548	3,342	73.5	
Overall	2,720	1,714	63.0	11,005	6,868	62.4	13,725	8,582	62.5	

## Note

Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

#### Sources

Vital Statistics Data, 2007-2008, New Brunswick, Nova Scotia and Prince Edward Island (Method 1).

To understand the extent to which patients in each trajectory group received palliative care, we looked at patients in each group who received palliation at one point during their final hospital stay. Overall, terminal illness decedents had the highest percentage of palliative care (83%). This was much greater than the next group, organ failure, at 48%. Terminal illness palliative decedents had a higher proportion of decedents age 19 to 64 than age 65 and older. All other trajectories had the opposite pattern when comparing those age 19 to 64 and age 65 and older: all rates increased as decedents aged.

ii. In chapters 2 and 3, the other group was excluded from analysis because that population did not have a discernable pattern of decline or service usage. A small number of invalid causes of death/ trajectories were also excluded.

Table 14: Palliative Care In-Hospital Acute Deaths, by Trajectory Group							
	A	ge 19–64	Д	ge 65+	Age 19+		
Trajectory Group	#	% of Total Deaths	#	% of Total Deaths	#	% of Total Deaths	
Frailty	41	35.0	527	43.4	568	42.6	
Organ Failure	147	40.7	1,106	49.8	1,253	48.4	
Sudden Death	11	28.9	28	41.8	39	37.1	
Terminal Illness	725	85.0	1,761	81.7	2,486	82.6	
Overall	924	67.5	3,422	60.4	4,346	61.8	

## Note

Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

## Sources

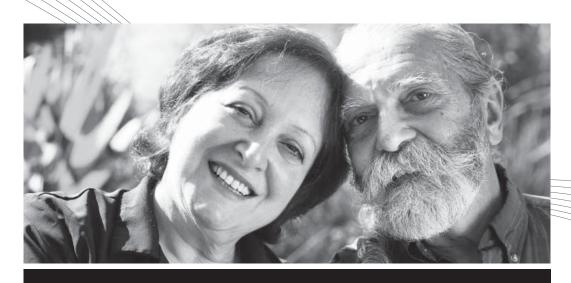
Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island (Method 2b).

## Summary

The majority of decedents in Atlantic Canada died in hospital in 2007–2008, according to death certificate information. In-hospital deaths were most common in New Brunswick and least common in P.E.I. When examining categories of death, such as terminal illness or sudden death, terminal illness patients were the most likely to die in hospital. The second most common cause of death was organ failure. Frailty and sudden death were the least common causes of death.

Of the 9,507 patients who died in an acute hospital, half of them (approximately 52%) received palliation during their final hospital stay. New Brunswick had the highest percentage of palliative patients (64%) and P.E.I. had the lowest (27%). There was a notably higher rate in terminal illness patients receiving palliative care during their last hospital admission, compared with the next group (organ failure).

P.E.I. experienced the highest percentage of patients who passed away in facilities categorized as *other health facility locations*. These include all non-acute facilities in the province, including palliative care institutions. At-home deaths occurred in Nova Scotia more frequently than in all of the provinces.



Chapter 3
Use of Hospital Services

## Introduction

Hospitals accounted for the highest percentage of total provincial health expenditures for each of the Atlantic provinces (see Table 1). For every health care dollar spent, hospitals accounted for 30 cents (P.E.I.) to 37 cents (Newfoundland and Labrador).<sup>21</sup> The extent to which the decedent population of Atlantic Canada was in hospital, in part, reflects the breadth and complexity of the care required to treat these end-of-life patients, although, of course, hospital expenditures are not solely related to the decedent population. These costs reflect overall hospital expenditures per province.

This chapter focuses on the patterns of hospital use in the final year of the decedents' lives. Hospitalizations occurring within 1 month, 6 months and 12 months prior to the date of death are considered.

## Measuring Hospital Use by Time Frames

Hospital use analysis spans the last year of a patient's life, from the date of death to one year (360 days) prior to death, to fully represent the hospital use in the last year of a patient's life. Three units of time were used to report hospital use: 30 days, 180 days and 360 days prior to the date of death. (See Table 15.)

Table 15: Rationale for Using Specific Periods of Time Before Death					
Within 1 Month (≤30 Days Before Death)	Within 6 Months (≤180 Days Before Death)	Within 1 Year (≤360 Days Before Death)			
Within 30 days of death, health care use typically increases substantially, particularly in hospital and drug use, which tend to peak in the last week of life.	Within 180 days of death, individuals may be determined to be in need of palliative care.	Examining hospital use within one year of death permits analysis of the period of increase in health care use and variations in patterns of care over an extended time period.			

#### Source

Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada* (Ottawa, Ont.: CIHI, 2007).

Analyses of the number of hospitalizations and total hospital days that patients spent in hospital were determined from the hospital discharge abstracts. The total number of hospital days included only the total hospital days for decedents with one or more hospitalizations in the given time period.

## **Provincial Variations**

In the last 30 days prior to death, approximately 45% of the Atlantic Canada decedent population were hospitalized. (See Table 16.) The rate of hospitalization increased to 65% for 180 days and 71% for 360 days prior to death.

Table 16: Decedents Hospitalized in Acute Facilities Within Selected Time Periods Prior to Death, by Province (Adjusted by Age and Sex)

	≤30 Days	Before Death	≤180 Day	s Before Death	≤360 Days Before Death		
Province	#	% (Adjusted)	#	% (Adjusted)	#	% (Adjusted)	
N.B.	2,963	48.3	4,165	67.9	4,478	73.0	
N.L.	1,907	47.1	2,633	65.1	2,817	69.8	
N.S.	3,138	42.9	4,512	61.7	4,929	67.3	
P.E.I.	392	43.4	598	66.4	646	71.7	
Overall	8,400	45.4	11,908	65.3	12,870	70.5	

#### **Sources**

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Provincial comparisons in Table 16 indicate that decedents in Nova Scotia had fewer hospitalizations in the 30, 180 or 360 days prior to death. Conversely, New Brunswick patients had higher rates of hospitalization in all time periods. These differences varied by age group. Across all provinces, the rate of hospitalization varied less than 7% between the lowest and highest rate in a given time period.

Time-period analysis is useful for summarizing hospital use at specific points in the final year of decedent life, yet it does not portray the trends of use. Figure 9 shows the percentage of each provincial decedent population hospitalized each day in the last 180 days of life. Overall, the range of hospitalization varied slightly between the Atlantic provinces, especially when looking at days less than 90 and greater than 10 prior to death. New Brunswick patients consistently had the highest hospital usage in the last 180 days, while Nova Scotia and Newfoundland and Labrador patients had the lowest. P.E.I. counterparts were more variable, particularly around the 90- to 30-day range. Regardless, all provinces increased in hospital usage as decedents approach their date of death.

30% 20% 10% 0% 90 60 30 0 Days Prior to Death ···· N.B. N.L. ••• N.S. P.E.I.

Figure 9: Daily Percentage of Provincial Acute Hospitalizations Within the Last Three Months of Life (Adjusted by Age and Sex)

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

## Further Analysis by Health Region

Analysis by health region is shown in Table 17. Nova Scotia's DHA 9 had the lowest rate of hospitalization for all three time periods, and New Brunswick's health regions 5, 6 and 7 consistently had the highest rates of hospitalization in the three time periods—the top five, if not the top three. P.E.I.'s Kings and Prince health regions also tended to have higher hospitalization rates, especially in the 180- and 360-day time periods.

Table 17: Decedents Hospitalized in Acute Facilities Within Selected Time Periods Prior to Death, by Province and Region/District (Adjusted by Age and Sex)

		≤30 Days Before Death			0 Days e Death	≤360 Days Before Death	
Province and	Total # of	%		%		%	
Region/District	Decedents	Actual	Adjusted	Actual	Adjusted	Actual	Adjusted
N.B.	6,146	48.2	48.3	67.8	67.9	72.9	73.0
Region 1	1,523	45.6	46.1	67.0	68.0	71.9	72.7
Region 2	1,531	44.6	44.6	63.2	63.1	69.6	69.5
Region 3	1,352	49.7	49.9	68.7	68.9	73.7	73.9
Region 4	422	48.8	48.7	69.9	69.3	73.7	73.2
Region 5	283	54.8	54.6	73.9	74.0	77.4	77.3
Region 6	622	54.3	54.5	72.7	73.0	76.7	77.0
Region 7	413	52.1	52.5	70.5	71.2	76.0	76.7
N.L.	3,999	47.7	47.1	65.8	65.1	70.5	69.8
Central	838	46.9	46.1	66.5	65.4	70.8	69.7
Eastern	2,267	49.2	48.8	65.6	65.3	70.2	69.9
Labrador-Grenfell	186	44.1	44.6	68.8	69.1	72.6	72.9
Western	708	44.6	44.4	65.1	63.9	70.3	69.3
N.S.	7,334	42.8	42.9	61.5	61.7	67.3	67.3
DHA 1	598	43.3	43.8	61.0	61.9	65.9	66.4
DHA 2	602	46.5	46.7	66.6	67.0	72.1	72.5
DHA 3	624	43.1	43.3	60.4	60.5	67.0	66.7
DHA 4	543	47.3	47.4	64.8	64.7	71.5	71.2
DHA 5	308	44.8	44.0	65.3	64.1	69.2	68.4
DHA 6	481	49.5	49.4	66.3	65.9	73.0	72.5
DHA 7	419	41.8	42.5	63.2	64.9	68.3	70.0
DHA 8	1,247	42.7	42.6	64.1	64.1	70.2	70.2
DHA 9	2,512	39.4	39.5	57.0	57.1	62.5	62.5
P.E.I.	909	43.1	43.4	65.8	66.4	71.1	71.7
Kings	133	49.6	48.7	73.7	72.9	76.7	75.8
Prince	254	48.8	47.8	72.8	72.2	76.0	75.4
Queens	522	38.7	40.1	60.3	62.4	67.2	69.3
Overall	18,388	45.7	45.4	64.8	65.3	70.0	70.5

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

The pattern described above is reflective of the provincial differences in hospitalization rates, as all regions in New Brunswick (except Region 2) and Kings and Prince regions in P.E.I. were above the overall (average) hospitalization rate in each time period, and most Nova Scotia DHAs were below the overall (average) hospitalization rate in each time period. In Newfoundland and Labrador, the health regions varied above and below the overall average across time periods.

## Days in Hospital

The Atlantic decedent population spent a total of 152,949 days in hospital in the 30-day time period (Table 18), with an average stay of 8.4 days. For the 180- and 360-day time periods, a total of 364,535 days (average 20 days) and 475,917 days (average 26 days), respectively, were spent in hospital by Atlantic decedents in 2007–2008.

Provincial comparisons of hospital days indicate that New Brunswick had the highest rates across all time periods. Nova Scotia experienced the lowest rates for the 30-day time period. In the 180-day time period, Nova Scotia and Newfoundland and Labrador had the lowest rates. Newfoundland and Labrador saw the lowest average for the 360-day time period.

Table 18: Total Acute Hospital Days	or Selected Time Periods Prior to Death, by Province
(Adjusted by Age and Sex)	

	≤30 Days Before Death			≤180 Days Before Death			≤360 Days Before Death		
	Hospital	Average Hospital Days		Hospital Average		ospital Days	Hospital	Average Hospital Days	
Province	Days Actual Adjusted	Days	Actual	Adjusted	Days	Actual	Adjusted		
N.B.	55,432	9.0	9.1	132,125	21.5	21.5	171,890	28.0	28.0
N.L.	33,329	8.3	8.2	76,119	19.0	18.8	98,963	24.7	24.4
N.S.	56,498	7.7	7.7	137,338	18.7	18.8	180,517	24.6	24.7
P.E.I.	7,690	8.5	8.6	18,953	20.9	21.1	24,547	27.0	27.2
Overall	152,949	8.3	8.4	364,535	19.8	20.0	475,917	25.9	26.1

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Two hospital day values are presented for each time period in this report. The total hospital days are show in Table 18. Total refers to the hospital days that decedents spent in acute facilities, regardless of any hospital admission occurring in the reported time period. By contrast, Table 19 shows only the hospital days of decedents with at least one hospitalization in the specific time period. This table indicates that the Atlantic provinces are fairly uniform in the number of hospital days per hospitalized patient. The average hospital day rates for hospitalized decedents show only a moderate difference between the highest and lowest rates. For the 30-day time period, there was less than a 1% difference between the lowest and highest averages. The pattern for the 180-day and 360-day time periods indicates that Newfoundland and Labrador had the lowest average rates (27 and 34 days in hospital, respectively) and P.E.I. the highest average rates (31 and 37 days in hospital, respectively).

Table 19: Acute Hospital Days, Decedents Hospitalized Within Selected Time Periods Prior to Death, by Province (Adjusted by Age and Sex)

	≤30 Days Before Death			≤180 Days Before Death			≤360 Days Before Death		
	Hospital	Average Hospital Days		Hospital	Average Hospital Days		Hospital	Average I	Hospital Days
Province	Days	Actual	Adjusted	Days	Actual	Adjusted	Days	Actual	Adjusted
N.B.	32,838	11.1	11.0	122,521	29.4	29.2	165,763	37.0	36.8
N.L.	20,798	10.9	10.8	71,080	27.0	26.6	96,921	34.4	33.9
N.S.	33,363	10.6	10.6	121,493	26.9	27.0	173,251	35.1	35.3
P.E.I.	4,363	11.1	11.0	18,405	30.8	30.6	24,224	37.5	37.1
Overall	91,362	10.9	10.9	333,499	28.0	28.3	460,159	35.8	35.8

### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

## Further Analysis by Health Region

The total and average number of hospital days for each region can be found in Table 20. P.E.I.'s Queens and Prince health regions consistently had among the highest averages across all time periods. There is a similar pattern as observed in the decedent hospitalizations. The average hospital day rates were higher than average in each time period in all New Brunswick regions and in Kings and Prince in P.E.I. By comparison, most Nova Scotia DHAs had less than the average number of hospital days in each time period. Newfoundland and Labrador regions varied across the time periods.

Acute hospital days, number of hospitalizations and average days per hospitalization for decedents hospitalized within selected time periods prior to death, by province, can be found in Table B3 in Appendix B.

Table 20: Total Hospital Days Within Selected Time Periods Prior to Death, by Province and Region/District (Adjusted by Age and Sex)

	≤30 Days Before Death		≤180 Days Before Death		≤360 Days Before Death	
Province and Region/District	Hospital Days	Average Hospital Days (Adjusted)	Hospital Days	Average Hospital Days (Adjusted)	Hospital Days	Average Hospital Days (Adjusted)
N.B.	55,432	9.1	132,125	21.5	171,890	28.0
Region 1	13,915	9.3	33,623	22.4	43,169	28.6
Region 2	12,663	8.3	32,014	20.8	42,335	27.6
Region 3	12,395	9.2	28,463	21.1	36,629	27.0
Region 4	3,680	8.7	8,940	21.0	12,190	28.4
Region 5	2,588	9.2	6,154	22.2	7,962	28.7
Region 6	6,332	10.3	14,241	22.9	18,433	29.7
Region 7	3,859	9.4	8,690	21.2	11,172	27.2
N.L.	33,329	8.2	76,119	18.8	98,963	24.4
Central	7,303	8.6	15,894	18.7	20,709	24.3
Eastern	17,093	7.5	38,059	16.7	49,672	21.7
Labrador-Grenfell	2,024	10.3	4,547	22.6	5,612	27.9
Western	6,909	9.5	17,619	24.3	22,970	31.7
N.S.	56,498	7.7	137,338	18.8	180,517	24.7
DHA 1	4,398	7.5	10,300	17.6	13,462	22.9
DHA 2	5,520	9.2	13,178	22.1	16,703	27.9
DHA 3	4,551	7.3	11,080	17.4	14,397	22.6
DHA 4	4,043	7.3	8,182	14.9	10,425	19.0
DHA 5	3,131	10.0	6,749	21.4	8,619	27.3
DHA 6	3,473	7.2	8,282	17.0	11,793	24.2
DHA 7	3,110	7.7	8,262	20.4	11,179	27.1
DHA 8	10,375	8.3	26,177	21.1	33,672	27.2
DHA 9	17,897	7.1	45,128	18.0	60,267	24.0
P.E.I.	7,690	8.6	18,953	21.1	24,547	27.2
Kings	1,440	10.9	3,866	29.7	5,277	40.7
Prince	2,742	10.7	6,335	24.7	7,966	31.0
Queens	3,508	7.0	8,752	17.5	11,304	22.6
Overall	152,949	8.4	364,535	20.0	475,917	26.1

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

## Comparing the Cause of Death Categories

As noted, this report examined the distinct trajectory groups or categories based on cause of death: sudden death, terminal illness, organ failure and frailty. Analysis of trajectory group hospitalizations in the Maritime provinces indicated that the terminal illness group had higher rates of hospitalizations in all three time periods (Table 21). In the last month of life, 55% of terminal illness patients were hospitalized. The group with the next-highest rate of hospitalizations within 30 days of death was those in the organ failure group (49%).

Table 21: Decedents Hospitalized Within Acute Facilities Within Selected Time Periods Prior to Death, by Trajectory Group

			≤30 Days Before Death		≤180 Days Before Death		≤360 Days Before Death	
Trajectory Group	Total # of Decedents	#	% of Total Trajectory Group	#	% of Total Trajectory Group	#	% of Total Trajectory Group	
Sudden Death	593	107	18.0	173	29.2	207	34.9	
Terminal Illness	4,548	2,507	55.1	3,748	82.4	3,961	87.1	
Organ Failure	4,704	2,308	49.1	3,105	66.0	3,352	71.3	
Frailty	3,880	1,241	32.0	1,825	47.0	2,067	53.3	
Overall	13,725	6,163	44.9	8,851	64.5	9,587	69.9	

#### Note

Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island.

The average number of hospitalizations for decedents hospitalized at least once, within each time period and by trajectory group, is shown in Table 22. In the 30 days prior to death, the average number of admissions was the same for all trajectories. In the 180- and 360-day time periods, terminal illness continued to exhibit a higher total and average number of hospitalizations.

Table 22: Hospitalizations, Decedents Hospitalized Within Acute Facilities at Selected Time Periods Prior to Death, by Trajectory Group

		≤30 Days Before Death	≤180 Days Before Death	≤360 Days Before Death
Trajectory Group	Total # of Decendents	Average # of Hospitalizations	Average # of Hospitalizations	Average # of Hospitalizations
Sudden Death	593	1.1	1.4	1.7
Terminal Illness	4,492	1.1	1.9	2.4
Organ Failure	4,760	1.1	1.6	2.0
Frailty	3,880	1.1	1.5	1.8
Overall	13,725	1.1	1.7	2.1

#### Note

Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island.

The average number of hospital days, as indicated in Table 23, was highest for the terminal illness trajectory group and lowest for the sudden death group overall.

Terminal illness had the highest rate of hospitalization in all three time periods, yet the differences among the terminal illness, frailty and organ failure hospitalized decedents were minimal at 360 days prior to death. The pattern in the average number of hospital days for hospitalized decedents was consistent with the average hospitalizations indicated in Table 22.

Table 23: Hospital Days, Acute Hospitalized Decedents Within Selected Time Periods Prior to Death, by Trajectory Group

		≤30 Days Before Death	≤180 Days Before Death	≤360 Days Before Death
Trajectory Group	Total # of Decendents	Average Hospital Days	Average Hospital Days	Average Hospital Days
Sudden Death	593	7.3	18.6	22.5
Terminal Illness	4,548	12.3	31.3	38.3
Organ Failure	4,704	10.3	27.6	36.5
Frailty	3,880	9.7	25.1	33.8
Overall	13,725	10.9	28.5	36.3

#### Note

Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island.

A comparison of the average hospital days of the entire trajectory population with only hospitalized patients, within the given time periods, yielded noticeable differences when comparing trajectory groups. The average hospital days of patients hospitalized at least once, for example, was less varied (with the exception of sudden death).

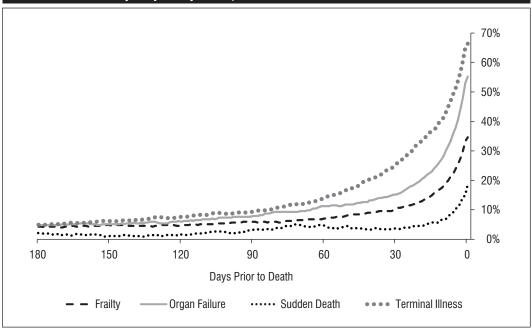
Daily percentage of hospitalizations within the last six month of life, by trajectory group (frailty, organ failure, sudden death and terminal illness), is shown in Figure 10. Sudden death remains relatively low until near the date of death; the percentage hospitalized only surpasses the 10% mark around six days prior to death, which likely relates to hospitalization for fatal trauma or accidents.

With the exception of sudden death, the trajectory groups have a similar pattern of hospital usage in the 30 to 60 days prior to death, although terminal illness has higher proportions than organ failure and frailty. It is helpful to remember that in cases of sudden death, the underlying causes of death are trauma, accident or other unintended causes. Decedents in this group are likely to be in good health or to display normal functional ability before the incident that causes death, and typically these decedents display low health care costs relative to the other groups.

The proportion of terminal illness hospitalizations starts to increase around 60 days (14% hospitalized) prior to death, and by the day of death, almost two-thirds (66%) of terminal illness patients were in hospital. The organ failure group starts increasing its percentage of hospitalizations around 30 days (16% hospitalized) prior to death and rises to 55% by the day of death. The percentage of hospitalizations for frailty decedents also increased around day 30 (10%), although it is shown to be increasing at a slower rate than that of terminal illness and organ failure. Thirty-five percent of frailty patients were in hospital by the day of death.

ii. In Chapter 2, 74% of terminal illness decedents died in hospital (Table 13), compared to 66% in Figure 10. The difference in values results from using Method 1 (death certificate only) to derive the 73.8% value and Method 2 (linking death certificate and hospital discharge data) to determine the days the decedent was hospitalized prior to death.

Figure 10: Daily Percentage of Acute Hospitalizations Within the Last Six Months of Life, by Trajectory Group, Maritime Provinces



## Note

Newfoundland and Labrador decedents were excluded, as underlying cause of death was unavailable at the time of analysis.

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Nova Scotia and Prince Edward Island.

## Summary

Hospitalizations in the last year of life were common for Atlantic Canadians at the end of life. Three distinct time periods (30, 180 and 360 days from date of death) were analyzed in this chapter. The decedent population of Atlantic Canada spent 475,917 days in hospital, with an average of 26 days in the last 360 days of life. Newfoundland and Labrador and Nova Scotia had similarly low rates of average hospital days. New Brunswick had the highest rates.

Approximately 45%, 65% and 70% of the Atlantic Canada decedent population were admitted to hospital in the 30-, 180- and 360-day time periods, respectively. Nova Scotia decedents were hospitalized the least and New Brunswick decedents the most during any of the time periods. New Brunswick consistently had the highest percentage of hospital usage, while Newfoundland and Labrador and Nova Scotia had lower rates that were similar to each other. P.E.I. varied at different points in the time periods. Breaking it down by region, most New Brunswick regions were above the overall Atlantic rate for hospitalization, along with Kings and Prince health regions in P.E.I. By comparison, most Nova Scotia regions were below the overall Atlantic hospitalization rate for each time period.

As expected, there were dramatic increases in hospital usage in all provinces as patients approached their date of death. For all trajectory groups, there was a progressive increase in hospital usage as decedents were in their final days of life. The percentage of hospitalizations increased dramatically for all trajectory groups starting around 30 days prior to death.

Across all time periods, a higher percentage of terminal illness patients were hospitalized, followed (in order) by organ failure, frailty and sudden death cases. Similarly, the terminal illness patients had the highest average number of hospitalizations in all three time periods. Terminal illness decedents were hospitalized earlier and with greater percentages throughout. Sudden death had the lowest, as expected.

## Conclusions

The adult decedent population profiled in this report accounted for 18,427 deaths in Atlantic Canada in 2007–2008, or approximately 90%. Analysis of the general and decedent populations indicated very similar demographics in age, sex and marital status across provinces. In the three Maritime provinces (New Brunswick, Nova Scotia and P.E.I.), the leading causes of death in 2007–2008 were fairly consistent with national patterns, with neoplasms (28% to 31%) and circulatory diseases (29% to 34%) making up the majority. Trajectory analysis indicated that organ failure accounted for the highest proportion of decedents, followed closely by terminal illness, frailty and sudden death.

The majority of decedents in Atlantic Canada died in hospital in 2007–2008; 11,591 (63%) deaths in Atlantic Canada occurred in hospitals. Hospital deaths were most common in New Brunswick (67%) and least common in P.E.I. (54%). Analysis of other locations of death found P.E.I. had the greatest proportion of other health facility locations, and Nova Scotia decedents were the most likely to die at home. Trajectory group analysis indicates that individuals with a terminal illness had the highest percentage of death in hospital (74%), while individuals succumbing to a sudden death accounted for the lowest percentage of deaths in hospital (30%).

In-hospital palliative care was discussed in this report. The in-hospital death population was divided into decedents receiving palliative care and those not receiving this type of care. There were 9,507 end-of-life patients who died in hospital in acute care. Just more than half (52%) of these patients received palliative care during their last hospital stay. New Brunswick had the highest percentage of palliative patients (64% of acute hospital deaths) and P.E.I. had the lowest (27%). Terminally ill patients received palliative care at a rate that was double the next closest group (organ failure).

Hospitalizations<sup>i</sup> during the last year of life were common for the Atlantic Canada decedent population, with 45%, 65% and 71% of these patients being hospitalized at least once within 30, 180 and 360 days, respectively, of their day of death. Of the four Atlantic provinces, more Nova Scotia decedents were hospitalized and fewer New Brunswick decedents were hospitalized in any of the three time periods. Terminally ill patients had higher rates of hospitalizations, followed by those with organ failure, frailty and those experiencing a sudden death.

Summary statistics for hospitalizations according to location of death are available in Appendix B.

Days spent in hospital were also examined. The 2007–2008 decedent population of Atlantic Canada spent 475,917 days in hospital in 2007–2008, with an adjusted average of 26 days in the last 360 days of life. Hospitalized decedents in Newfoundland and Labrador and Nova Scotia had the lowest average hospital day rates, while New Brunswick decedents had the highest average hospital day rate in the 360-day time period. Those patients with a terminal illness had the highest hospital day average, followed (in order) by those with organ failure, those with frailty and those experiencing sudden death.

## Reflections on the Parameters of This Report

In this report, we examined only hospital deaths at the end of life in Atlantic Canada. The intention was to give health program managers, ministerial staff, policy-makers and other related service delivery groups additional information to help with the assessment and delivery of end-of-life care for their residents.

In-hospital death is of particular interest given the stated desire of many end-oflife patients to die elsewhere (not in a hospital). It is an analysis that helps those planning service delivery for these patients.

In our inquiry, we did not take a comprehensive approach to analyzing the endof-life care experience. One reason was data limitations. For example, we did not have pharmaceutical, primary care or home care usage data for these patients. Other reasons were more practical and related to time and capacity. Regardless, we believe this report adds value.

Palliative care is an area that comes to light in this report as needing further study. It is a complex field, particularly since variations in where patients die and hospital usage depend on a number of factors, some of which are harder to measure, such as

- Geography, population, culture and demographics;
- The patient's condition and personal characteristics; and
- The availability of health, social and community programs. 2, 3, 5, 10

Ideally, a number of health information sources would help to provide a comprehensive view of the palliative care population and their health care needs. Having such information would help inform the discussion on appropriateness of care. Through comprehensive collection of information, we would meet all or most of the complex and diverse needs of end-of-life patients. One size does not fit all; each patient's needs are different. Services need to adapt to the patient's condition and to the needs and preferences of the patients, their families and caregivers to provide the best possible care during the final days.<sup>4, 7, 10, 26</sup>

What matters most for palliative care patients at the end of life is having trust in, and open communication with, their service providers; being treated with dignity; the provision of continuous care; and pain/symptom management.<sup>3, 4, 8, 10</sup> Furthermore, end-of-life patients are concerned with the spiritual, psychological and social aspects of their life, including life completion and the satisfactory resolution of outstanding issues.<sup>4, 9, 11</sup> The vast majority of this information is currently captured in various forms of clinical and administrative data, survey results and qualitative research results. Developing indicators from these information sources to assess the quality of care, quality of life and quality of death are crucial to palliative patients and their attainment of a good death.

## For Further Information

Canadian Cancer Society—Cancer Statistics 2010 (Special Topics: End-of-Life Care) www.cancer.ca

Canadian Hospice Palliative Care Association www.chpca.net/home.html

Canadian Virtual Hospice www.virtualhospice.ca

Hospice Palliative Home Care in Canada: A Progress Report www.qelccc.ca/uploads/files/hphc-progress\_report/Hospice\_Palliative\_Home\_Care\_Progress\_Report-final.pdf

Network for End-of-Life Studies, Dalhousie University, Nova Scotia http://nels.schoolofhealthservicesadministration.dal.ca

Quality End-of-Life Care Coalition of Canada www.chpca.net/qelccc.htm

Raising the Bar: A Roadmap for the Future of Palliative Care in Canada http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare e.asp

# Appendix A: Summary of End-of-Life and Palliative Care Programs and Services in Atlantic Canada

## Palliative Care Programs

## New Brunswick<sup>28-30</sup>

The Extra Mural Program (EMP) in New Brunswick is responsible for providing a wide range of health services in home and community settings, taking the provision of care outside the hospital setting. Established in the regional health authorities, the EMP is available to New Brunswick residents with a valid medicare number, an identified need for care outside the hospital and referral to the program. The EMP includes acute care, rehabilitation and palliative care services (among other services).

The Extra Mural Palliative Care Program provides total care to patients with diseases or conditions that no longer respond to curative treatment. For palliative patients, pain and symptom management, along with psychological, social and spiritual support is essential. The goal of the program is to ensure the best quality of life is achieved at the end of life for patients and their loved ones.

Palliative care services are provided by a wide variety of health and community service professionals ranging from nurses to social workers and pastoral care. Services include assessment, interventions, service planning and coordination with medical and external agencies across government programs. End-of-life care is provided to qualified, physician-recommended palliative patients who are classified as palliative by an EMP team. Patients remain under the care of their attending physician, who retains the responsibility for changing patient care as required.

The multifaceted, integrated palliative care services are intended to make care accessible close to where patients live. EMP can provide 24-hour health services and assistance with medications, a wide range of equipment and home service. Palliative care includes community-based hospice services in a number of communities. In fall 2010, the Hospice Greater Saint John opened as the first residential hospice in Atlantic Canada, providing 24-hour medical and non-medical care to patients and support for family members. The 10-bed facility is anticipated to provide service to up to 150 end-of-life patients each year.

## Newfoundland and Labrador<sup>30, 31</sup>

Palliative care services in Newfoundland and Labrador are provided through the regional health authorities, with funding from the provincial government. Certain acute facilities in the province have designated palliative care beds to provide in-hospital care to palliative patients. Furthermore, community health nurses in remote locations and nursing stations provide palliative care to local patients.

Regional end-of-life coordinators help coordinate care with a wide range of health service providers (physicians, nurses, pharmacists and so on) and community and social support staff. The palliative care coordinator ensures patient information is up to date, tracks the meetings between providers and patients, and ensures patients are informed of the services available to them.

Home palliative services are available for qualified Newfoundland and Labrador residents. Home care services are prioritized for palliative patients, who may receive up to four weeks of home care services; at the end of four weeks, patients are reassessed for need of service. Patients receiving this service also have 24-hour access to case management services and to medical supplies and equipment. Home care and end-of-life program recipients are eligible to apply for coverage under the Newfoundland and Labrador Drug Prescription Plan.

## Nova Scotia<sup>32</sup>

Palliative care programs and services include a wide range of services available to end-of-life inpatients and outpatients. The types of services available vary across the province but include palliative care consultation, case management and assessments (in community and hospital settings), pain and symptom management, volunteer support and bereavement services.

In Nova Scotia, palliative care (or hospice palliative care) is defined as care that relieves suffering and improves the quality of life for individuals living with progressive life-threatening diseases or conditions, or for the bereaved. Hospice palliative care involves active and compassionate therapies that address the physical, psychological, social, spiritual and practical needs of individuals living with a life-threatening illness and their families. Finally, all palliative or end-of-life patients are provided with free home care support.

Palliative care programs are situated in all nine DHAs and in the Pediatric Palliative Care Service at the IWK Health Centre (providing outreach to the Maritime provinces). The DHAs vary in terms of availability and access to palliative care, as regional programs have developed independently of one another. Regardless of differences between the regional programs,

palliative services focus on improving the quality of living and dying for individuals at the end of life. The aim for all programs is to ensure all Nova Scotians requiring end-of-life care have access to appropriate palliative care services at the appropriate time. Common themes and goals resonate with all programs:

- A holistic approach to provide support (physical, emotional, social and spiritual), comfort and improved quality of life for individuals, caregivers and families:
- Collaboration with partners such as health care and community services
  providers, volunteers, hospice palliative care societies and family members.
   Palliative care services coordinate patient care with health care providers
  including VON, continuing care and the primary health care team;
- An integrated palliative care approach to service delivery—multiple organizations work closely to coordinate services to meet the needs of palliative patients;
- A focus on ongoing education, advocacy and research to promote excellence in the delivery of palliative care services;
- Bereavement support as an important component of the palliative care service; and
- An emphasis on evidence-based decision-making and effective use of available resources.

## Prince Edward Island<sup>33</sup>

The P.E.I. Provincial Integrated Palliative Care Program is guided by the principle that all islanders have the right to quality end-of-life care that allows for a dignified death, free of pain and surrounded by loved ones in their preferred setting. This philosophy is transparent throughout the different components of the program: the Provincial Palliative Care Unit, the Integrated Palliative Care Program, the Palliative Home Care Drug Pilot Project and other related programs.

The Provincial Palliative Care Unit is an eight-bed unit that serves patients from across the island requiring pain and symptom management. The unit is staffed with one registered nurse and one licensed practical nurse on every shift. Supportive services are shared with other services or facilities and include hospice, dietary services, physiotherapy, occupational therapy, spiritual care, social work and a number of other services.

P.E.I.'s integrated approach to palliative care involves a network of services providing comprehensive and coordinated care to address the physical, psychological, social and spiritual needs of individuals and their families in their preferred care setting by the most appropriate team members. Home-Based Care manages the client registry, houses the client information,

provides case management and coordinates the delivery of services to clients at home. There is a full-time provincial palliative care resource nurse and a full-time provincial palliative care medical consultant who support the program.

The Palliative Home-Based Care Drug Program started in the fall of 2008 and provides drug coverage for pain and symptom management to eligible residents in their preferred location. This project is an extension of the Provincial Integrated Palliative Care Program, which aims to enhance client and family palliative care options through access to trained, qualified health care teams in the most appropriate setting.

As of November 2010, 158 patients have registered and have been able to remain at home for a total of 7,764 days. Patients in this program have been able to remain at home for 80% of their palliative care, corresponding to a 25% increase in time spent at home in comparison with patients receiving care prior to the pilot. This program has successfully enabled islanders to receive increased care in the comfort of their own homes while improving system flow and a resulting decreased net cost to the health care system.

## Home Care/Support in Atlantic Canada

## New Brunswick<sup>29</sup>

Home care services provided by the EMP are described (in process and eligibility) in the palliative care section above. EMP home care services include care, medical supplies and equipment from the EMP Equipment Loan Bank. In-home support services consist of non-professional assistance with daily personal care needs (dressing or bathing) and housekeeping tasks (cleaning and meal preparation) in their home. Home support services required for a long term are accessed through the single entry point assessment program and funded by the Department of Family and Community Services.

## Newfoundland and Labrador<sup>34, 35</sup>

Newfoundland and Labrador has three generic programs that provide home care support services to qualified patients at the regional health authority level. The Special Assistance Program provides basic medical supplies (including oxygen) and equipment to qualified patients to assist with daily living activities. The provincial Home Support Program provides respite care and personal and behavioural support to allow individuals to maintain their independence. Home support services are provided by private companies as a supplement to family and other support sources. Services are either purchased by the individual or may be subsidized if functional and financial assessments recommend support, up to a set amount.

Palliative care is an example of the third group called home and community care. Eastern Regional Health Authority, for example, provides home and community care to help all patients and families achieve an optimal level of well-being. Residents are offered a wide range of services, including clinical intervention, rehabilitation, chronic disease management and palliative/end-of-life care. Services are provided on a referral and assessed-need basis and include service providers such as nurses, social workers and occupational therapists, among the other providers who work to meet patient needs to help self-management of chronic diseases and support client independence.

## Nova Scotia<sup>36</sup>

Home care services are offered through the Continuing Care Branch of the Department of Health and Wellness. Home care services aim to allow people to remain as independent in the community for as long as possible and include home oxygen, nursing (dressing changes, intravenous therapy and catheter care) and home support (light housekeeping and respite care).

Home care is intended as a supplement to community and personal care resources. Residents requiring home care are first contacted and assessed (in person) by a care coordinator to determine eligibility for each required home service. If nursing services are required, there is no charge; other services, such as home support or home oxygen, are fee-based, depending on the income of the individual. The care coordinator may also help the individual connect with external social programs such as Meals on Wheels.

Services are monitored and adjusted by the care coordinator if the needs of the individual change. In the event the individual requires more service than the home services provided, the care coordinator will provide the necessary information to help make decisions about choices available. If required, the care coordinator will provide an application for placement in long-term care and help place the individual in a location to best fulfill his or her needs.

## Prince Edward Island<sup>37, 38</sup>

Home care and support services are provided to individuals based on assessed need. Services are intended to provide help for individuals to achieve and maintain health and personal independence in the community and to supplement the care and support available from family and friends. The P.E.I. Home Care Program provides health care and support services, including the following assistance:

- Adult protection;
- Assessments (nursing home admissions);
- Care coordination;

- · Community-based dialysis;
- Community support services;
- · Integrated palliative care;
- Nursing;
- Occupational therapy;
- · Personal care;
- Physical therapy; and
- · Respite care.

Improving and expanding home care is one of the strategic initiatives in P.E.I. to help reduce acute care admissions and premature admission to long-term care. The new system is aimed at providing quality care to aid residents who have chosen to stay at home.

## Long-Term Care in Atlantic Canada

## New Brunswick<sup>39</sup>

The long-term care (LTC) system in New Brunswick aims to provide the appropriate LTC services when and where they are needed during the continuum of care. Services are provided for all residents age 19 and older and are intended to complement and supplement informal caregivers to provide individuals with the capacity to function independently where possible. LTC consists of three components: in-home services, special care homes and nursing homes.

LTC services are provided to individuals with limited capacity to perform daily activities. Individuals are assessed to determine the level of care (measured by the degree of independence in daily life and/or supervision needed) the patient requires in approved residential facilities. Level 1 care, for example, is intended for the mostly mobile individuals who require 24-hour supervision to help in their personal care. By comparison, Level 4 care is intended for individuals with cognitive and/or behavioural issues who require 24-hour supervision in all daily activities and personal/medical care. Special care homes (level 1 or 2) provide a residence with services for those requiring low to moderate levels of care on a regular basis; nursing homes provide service to individuals who are assessed as needing Level 3 and Level 4 care.

Clients using the LTC system are generally responsible for paying for the service; if clients are not financially capable of paying full costs, assistance is provided by the government. For individuals requiring government subsidies, client costs are determined by family or client income, the services provided and whether a spouse or dependent(s) lives at home.

## Newfoundland and Labrador<sup>40, 41</sup>

LTC facilities in Newfoundland and Labrador provide residential care and accommodations to residents who have high care needs and require on-site professional nursing services. Residents are assessed for their care needs, and accommodations may be subsidized by the Department of Health and Community Services. LTC refers to both LTC homes (nursing homes) and hospital/health centres with combined long-term and acute care services.

Services provided by LTC facilities generally consist of the following:

- 24-hour nursing, medical, social work and personal care services;
- Nutritional services to meet nutritional, therapeutic and social needs;
- Pharmacy services, including storage, administration and record keeping;
- Therapeutic rehabilitative and restorative services to meet assessed needs; and
- Pastoral care services for the spiritual needs of residents and families.

LTC facilities provide high-quality holistic, resident-centred care with an emphasis on providing for the spiritual, psychosocial, cultural and physical needs of residents. Every effort is made to foster independence and freedom of choice to maximize personal well-being to the extent of their abilities. Residents retain the right to access medical and community services designed to meet their holistic needs. Admission to a long-term bed is carried out by regional health authority staff. If required, financial assessments are included to determine if, and to what extent, an individual pays for services. Long-term care services are also available through privately owned and operated personal care homes.

## Nova Scotia<sup>42, 43</sup>

LTC provides accommodation, supervisory care, personal care and nursing services to individuals who can no longer live independently in the community, regardless of family and other available support. To be eligible for LTC, the individual must be a legal resident of Nova Scotia, age 19 and older, who is registered in the Nova Scotia health insurance plan.

The Department of Health and Wellness licenses and approves three types of LTC facilities, all of which are inspected by the department:

- Community-based options—accommodation, supervision and non-nursing personal care for one to three people in each home.
- Residential care facilities—homes for people who need supervision and limited help with personal care.
- Nursing homes or homes for the aged—homes for people who need help with personal care and professional nursing care.

A care coordinator performs an assessment of an individual's LTC needs, which may include assessments from other professionals; recommendations are reviewed by a specialist for final approval. Residents who qualify for a given level of care provided by specific facilities can be placed on a wait list. The care coordinator tries to ensure the best accommodations are found to meet the needs of the individual.

LTC is paid for jointly by the provincial government and residents. The Department of Health and Wellness pays for the health care costs, and residents pay their accommodation costs and personal expenses. The department sets standard accommodation charges for the three types of LTC homes. Individuals able to pay the charge do not undergo a financial assessment, while residents unable to pay the standard charge may have rates reduced through an income-based, financial assessment.

## Prince Edward Island<sup>44-46</sup>

Nursing homes provide residents access to appropriate nursing care (24 hours a day, 7 days a week) and provide accommodation, personal care and medical services. Nursing homes include public nursing manors, licensed private nursing homes and licensed nursing beds in private combined nursing/community care facilities. There are nine public nursing facilities and eight private nursing homes in P.E.I.

Most nursing home residents have multiple complex diagnoses and require nursing care that can no longer be provided at home or by community health care. Residents are normally age 60 and older when admitted to the facility, yet those younger than 60 may be admitted if the level of nursing care is required to meet daily health care requirements.

Admission to long-term nursing care is based on a coordinated priority needs assessment conducted by committees with representatives from hospitals and home care, housing and LTC programs. Individuals undergo a standard health needs assessment review; if daily nursing care is required and the individual is medically stable, he or she is eligible for nursing home admission. For those admitted, costs are determined by an assessment of financial income; if the patient cannot afford care costs, care is subsidized by Health P.E.I. as the payer of last resort.

# Appendix B: Hospitalization by Location of Death Summary

The following tables provide a high-level overview, to complement the results of Chapter 3, of the number of decedents hospitalized and the number of hospitalizations and hospital days by location of death. The tables are based on hospitalization within 180 days prior to death. There are two general comparison groups of location of death: acute versus palliative in-hospital death (as totals of in-hospital deaths) and all locations of death.

## Comparing In-Hospital Deaths

Table B1: Hospital Usage for Non–Palliative Care Hospital Death Decedents Hospitalized Within 180 Days Prior to Death (Age 19+)

Province	# of Decedents	Total # of Hospital Days	% of All In-Hospital Days	Average Hospital Days
N.B.	1,199	28,832	28.8	24.1
N.L.	960	23,869	36.5	24.9
N.S.	1,341	36,067	29.7	26.9
P.E.I.	317	9,293	53.0	29.3
Overall	3,817	98,061	32.1	25.7

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Table B2: Hospital Usage for Palliative Care Hospital Death Decedents
Hospitalized Within 180 Days Prior to Death (Age 19+)

Province	# of Decedents	Total # of Hospital Days	% of All In-Hospital Days	Average Hospital Days
N.B.	2,170	74,836	60.5	34.5
N.L.	1,135	33,768	51.0	29.8
N.S.	2,157	66,596	59.1	30.9
P.E.I.	120	4,532	26.7	37.8
Overall	5,582	179,732	56.3	32.2

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Table B3: Acute Hospital Days, Number of Hospitalizations and Average Days per Hopitalization Within Selected Time Periods Prior to Death, by Province

	≤30 Days Before Death			≤180 Days Before Death			≤360 Days Before Death		
Province	Hospital Days	# of Hospital- izations	Average Hospital Days	Hospital Days	# of Hospital- izations	Average Hospital Days	Hospital Days	# of Hospital- izations	Average Hospital Days
N.B.	32,838	3,260	10.1	122,521	7,038	17.4	165,763	9,492	17.5
N.L.	20,798	2,104	9.9	71,080	4,381	16.2	96,921	5,816	16.7
N.S.	33,363	3,485	9.6	121,493	7,604	16.0	173,251	10,460	16.6
P.E.I.	4,363	424	10.3	18,405	943	19.5	24,224	1,261	19.2
Overall	91,362	9,273	9.9	333,499	19,966	16.7	460,159	27,029	17.0

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

## Comparing All Locations of Death

Table B4: Hospital Usage of New Brunswick Decedents Hospitalized Within 180 Days Prior to Death (Age 19+), by Location of Death

Location of Death	# of Hospitalized Decedents	% of All Hospitalized Decedents	Total Hospital Days	% of Total Days	Average Hospital Days
Hospital	3,586	86.1	109,243	89.2	30.5
Other Health Facility	250	6.0	6,937	5.7	27.7
Home	317	7.6	6,226	5.1	19.6
Other	12	0.3	115	0.1	9.6
Overall	4,165	100	122,521	100	29.4

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Table B5: Hospital Usage of Newfoundland and Labrador Decedents Hospitalized Within 180 Days Prior to Death (Age 19+), by Location of Death

Location of Death	# of Hospitalized Decedents	% of All Hospitalized Decedents	Total Hospital Days	% of Total Days	Average Hospital Days
Hospital	2,226	84.5	61,111	86.0	27.5
Other Health Facility	232	8.8	6,129	8.6	26.4
Home	164	6.2	3,649	5.1	22.3
Other	11	0.4	191	0.3	17.4
Overall	2,633	100	71,080	100	27.0

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Table B6: Hospital Usage of Nova Scotia Decedents Hospitalized Within 180 Days Prior to Death (Age 19+), by Location of Death

Location of Death	# of Hospitalized Decedents	% of All Hospitalized Decedents	Total Hospital Days	% of Total Days	Average Hospital Days
Hospital	3,651	80.9	106,117	87.3	29.1
Other Health Facility	303	6.7	6,705	5.5	22.1
Home	514	11.4	8,071	6.6	15.7
Other	44	1.0	600	0.5	13.6
Overall	4,512	100	121,493	100	26.0

#### Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

Table B7: Hospital Usage of Prince Edward Island Decedents Hospitalized Within 180 Days Prior to Death (Age 19+), by Location of Death

Location of Death	# of Hospitalized Decedents	% of All Hospitalized Decedents	Total Hospital Days	% of Total Days	Average Hospital Days
Hospital	449	75.1	14,098	76.6	31.4
Other Health Facility	120	20.1	3,773	20.5	31.4
Home	26	4.3	525	2.9	20.2
Other	*	*	*	*	*
Overall	595	*	18,396	100	30.9

## Notes

Overall excludes the other values.

## Sources

Vital Statistics and Hospital Discharge Data, 2007–2008, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.

<sup>\*</sup> Results suppressed because of small cell sizes (n<5).

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