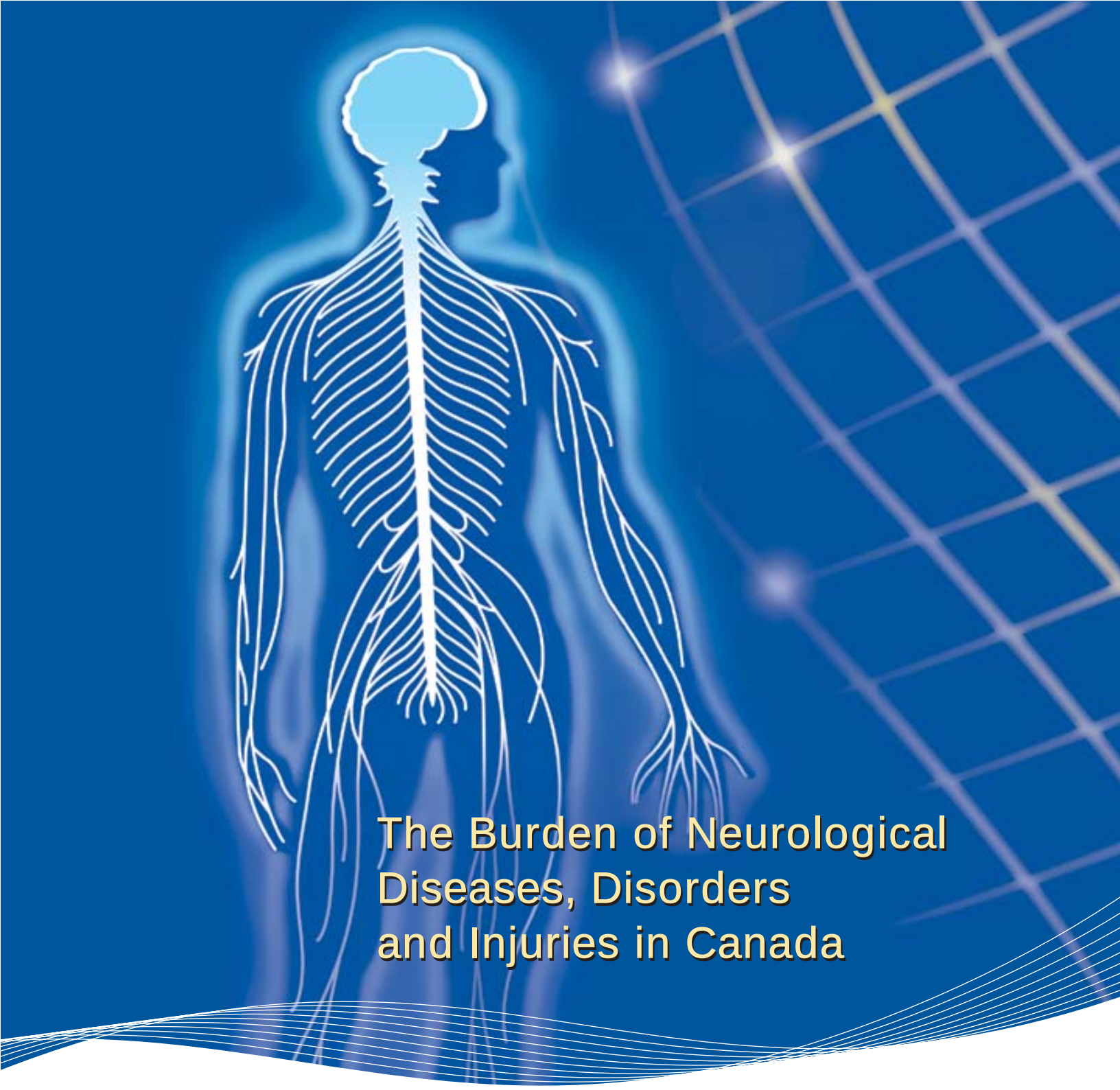

The Burden of Neurological Diseases, Disorders and Injuries in Canada

CANADIAN NEUROLOGICAL SCIENCES FEDERATION
FÉDÉRATION DES SCIENCES NEUROLOGIQUES DU CANADA

CANADIAN BRAIN AND NERVE HEALTH COALITION

Canadian Institute for Health Information
Institut canadien d'information sur la santé

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About the Canadian Neurological Sciences Federation

The Canadian Neurological Sciences Federation (CNSF), formerly the Canadian Congress of Neurological Sciences (CCNS), is an organization representing four member societies: the Canadian Neurological Society, the Canadian Neurosurgical Society, the Canadian Society of Clinical Neurophysiologists and the Canadian Association of Child Neurologists. CNSF's mission is to enhance the care of patients with diseases of the nervous system through education, advocacy and improved methods of diagnosis, treatment and rehabilitation.

For more information, visit CNSF's website at www.cnsfederation.org.

About the Canadian Brain and Nerve Health Coalition

The Canadian Brain and Nerve Health Coalition (CBANHC), established by the former CCNS, is a coalition of several voluntary health organizations and practitioners with an interest in neurological disorders. CBANHC is committed to improving the quality of life of Canadians by promoting access to cost-effective treatments, supporting research and education and promoting public and government awareness of the incidence and impact of nervous system disorders and injuries.

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 editorial committee for this report included Charles Tator (CBANHC), Garth Bray (CNSF), Dan Morin (CNSF), Greg Webster (CIHI), Heather Dawson (CIHI) and Aleksandra Jokovic (CIHI).

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  Nurse Coordinator, Canadian Association of Neuroscience Nurses
- Charles Tator
  Chair, CBANHC

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PHAC is an agency of Health Canada and works closely with provinces and territories to improve and protect the health of Canadians, and to help reduce pressures on the health care system. The Agency is focused on more effective efforts to prevent chronic diseases, prevent injuries and provide leadership on emergency preparedness and response to public health emergencies and infectious disease outbreaks. For more information, visit PHAC's website at www.phac-aspc.gc.ca.

It should be noted that the analyses and conclusions in this report do not necessarily reflect the views or opinions of the individual members of CBANHC, CNSF or their affiliated organizations.

Highlights

- The total cost of the 11 neurological conditions highlighted in this report was estimated to be $8.8 billion, representing 6.7% of the total attributable cost of illness in Canada in 2000–2001.
- The 11 highlighted neurological conditions accounted for 2.4% of the total direct cost of illness in Canada in 2000–2001.
- Nine of 11 highlighted neurological conditions (for which data were available) accounted for 8.3% of the total indirect cost of illness in Canada in 2000–2001.
- Six of 11 highlighted neurological conditions (for which data were available) accounted for 10.6% of the total disability-adjusted life years in Canada in 2000–2001.
- Just over 9% of acute care hospitalizations and 19% of patient days in acute care hospitals in Canada in 2004–2005 were for patients with one of the 11 highlighted neurological conditions as a primary or secondary diagnosis.
- 20% of patients receiving inpatient rehabilitation in 2005–2006 had one of the following conditions: head injury, multiple sclerosis, Parkinson’s disease, spinal injury or stroke.
- 50% of complex continuing care (CCC) stays and 65.1% of CCC patient days in Ontario in 2005–2006 were for patients with Alzheimer’s disease, ALS, cerebral palsy, epilepsy, head injury, multiple sclerosis, Parkinson’s disease or stroke.

Report Overview

The World Health Organization (WHO) reported in 2006 that "a large body of evidence shows that policy-makers and health-care providers may be unprepared to cope with the predicted rise in the prevalence of neurological and other chronic disorders and the disability resulting from the extension of life expectancy and ageing of populations globally."[1]

Neurological diseases, disorders and injuries represent one of the leading causes of disability in the Canadian population. Very few neurological conditions are curable, and many worsen over time. They produce a range of symptoms and functional limitations that pose daily challenges to individuals and their families. In addition, neurological conditions pose an economic burden to society. Because the incidence of neurological conditions increases with age, this burden may magnify as Canada's population ages.

To date, there has been little focus on the burden of neurological diseases, disorders and injuries in Canada. Recognizing this, the Canadian Brain and Nerve Health Coalition partnered with the Canadian Institute for Health Information and the Public Health Agency of Canada to create this report.

This report is intended to improve understanding of the epidemiology of neurological conditions and the economic impact on the Canadian health care system and society. Using available data sources, estimates of the economic burden, disability-adjusted life years (DALYs) and hospital utilization associated with 11 neurological conditions are provided in the report. The report serves as a baseline of information about the burden of neurological conditions across the country and provides a foundation for future research in this area.

The neurological conditions highlighted in the report are:

- Alzheimer's disease
- Amyotrophic lateral sclerosis
- Brain tumours
- Cerebral palsy
- Epilepsy
- Head injury
- Headaches
- Multiple sclerosis
- Parkinson's disease
- Spinal injuries
- Stroke

The report also provides a short summary of current literature provided from CBANHC-affiliated voluntary health organizations for an additional 20 neurological conditions.

Economic Burden Associated With Neurological Diseases, Disorders and Injuries in Canada

Estimates of the economic burden including total cost, indirect and direct costs presented in this report were generated by the Public Health Agency of Canada (PHAC) for 2000–2001.

Components of Total Cost: Direct Costs and Indirect Costs

Direct Costs

Direct costs include both public- and private-sector spending. Public-sector spending includes payments made by governments and government agencies. Private-sector spending includes out-of-pocket expenditures made by individuals and health insurance claims paid to individuals by commercial and not-for-profit insurance firms.

- Hospital care expenditures are composed of payments for hospital operations (including staffing and capital expenditures), physician remuneration through hospital payroll and the cost of drugs dispensed in hospitals.
- Physician care expenditures are professional fees paid by provincial/territorial medical care insurance plans to physicians in private practices, professional fees paid by alternative payment plans to physicians (such as salary, capitation and sessional fees) and fees for services rendered in hospitals when paid directly to physicians by the plans.
- Drug expenditures are composed of payments for prescribed and non-prescribed drug products purchased in retail stores, including dispensing fees, mark-ups and taxes.
- Additional expenditures include all other expenditures (health research, long-term care facilities, other health care professionals, etc.).

Indirect Costs

Indirect costs consist of mortality and morbidity costs.

- Mortality costs represent the dollar value of production lost due to premature death caused by the neurological conditions under study.
- Morbidity costs are the dollar value of production lost due to activity days lost because of long-term disability resulting from the neurological condition under study. Short-term disability costs are not included in the estimates of morbidity costs.

Data sources and methods used to estimate direct and indirect costs are described in Appendix B.

Total Costs

The total cost of all illnesses in Canada in 2000–2001 was estimated by PHAC to be $176.4 billion. This included $97.9 billion (55.5%) in direct costs and $78.5 billion (44.5%) in indirect costs.

One-quarter (25.7%) of the total costs were unattributable; in other words, it was not possible to allocate specific costs to a specific diagnostic category.

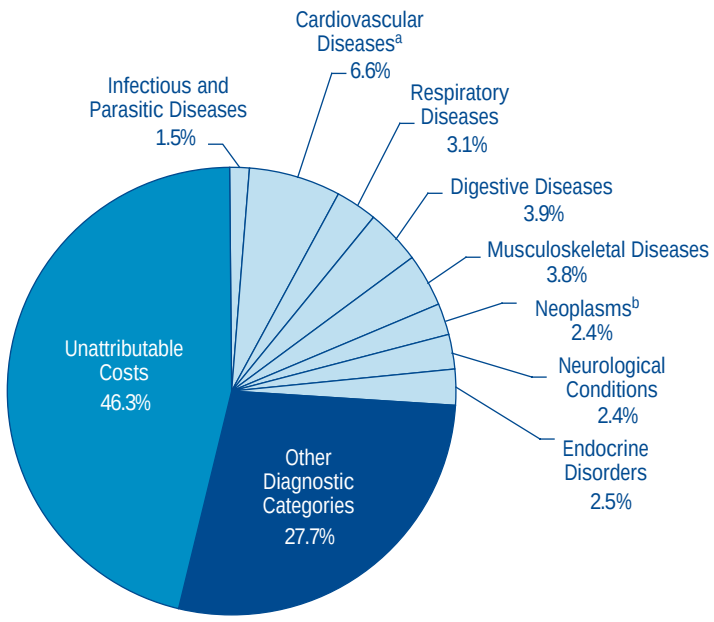
The total cost of the 11 neurological conditions highlighted in this report was estimated by PHAC to be $8.8 billion, representing 6.7% of the total attributable cost of illness in Canada in 2000–2001.

Direct Costs

Direct costs for all illness in Canada in 2000–2001, as estimated by PHAC, were $97.9 billion. This is composed of $30.6 billion in hospital care expenditures, $13 billion in physician care expenditures, $15.1 billion in drug expenditures and $39.3 billion in additional expenditures. Of the direct costs, 46.3% were unattributable, or could not be allocated to a specific diagnostic category.

1

Direct Costs of All Illness in Canada by Diagnostic Category, 2000–2001



Notes: **a** Excludes stroke.
b Excludes tumours of the brain and other related parts of the nervous system.

Source: PHAC, economic burden of illness custom tabulations, May 2007.

In 2000–2001, the direct costs associated with the 11 highlighted neurological conditions in Canada were estimated by PHAC to be $2.3 billion, representing 2.4% of the direct costs of all illness. The neurological conditions made up 5.3% of hospital care expenditures, 1.8% of physician care expenditures and 3.1% of drug expenditures for all illness in Canada.

Hospital care expenditures accounted for just over two-thirds (69.7%) of the total attributable direct costs for the 11 highlighted neurological conditions. Drug expenditures comprised 20.4%, and physician care expenditures made up 9.9%, of the total attributable direct costs.

Highlights of direct costs for the individual conditions:

- Stroke had the largest total direct costs (28.7%) among the 11 conditions, followed by Alzheimer's disease (18.7%) and headaches (17.8%).
- Hospital care expenditures represented the largest component of the direct costs for Alzheimer's disease, ALS, brain tumours, cerebral palsy, head injury and stroke—ranging from 73.7% to 99.3%—and almost half of the direct costs for epilepsy, multiple sclerosis and Parkinson's disease.
- Physician care expenditures made up the highest proportion of direct costs for epilepsy (25.7%), brain tumours (24.9%) and headache (18.1%).
- Drug expenditures accounted for about half of the direct costs for headaches, multiple sclerosis and Parkinson's disease.

PHAC notes the following limitations for drug expenditure estimates:

- Projected patterns of prescriptions by diagnostic category are based on sample data collected during patient visits to physicians,[ii] and do not track whether or not prescriptions are actually filled. As a result, this distribution may not reflect exact prescription drug usage patterns that contribute to expenditure estimates.
- Expenditures for the non-prescribed products could not be allocated to diagnostic categories since many of these over-the-counter drugs and personal health supplies could easily be allocated to more than one disease category.
- Existing data do not include information on the number of non-prescription products being purchased in a given year in Canada.

Due to these limitations, drug expenditures for some of the neurological conditions may be underestimated.

i These samples are based on reporting periods of two consecutive days for four consecutive quarters by five regions (Ontario, Quebec, the Maritimes, British Columbia and the Prairies) and eight physician specialities (general practice/family medicine, internal medicine, psychiatry/neurology, obstetrics/gynecology, otolaryngology/ophthalmology, surgery, pediatrics and dermatology).

2

Direct Costs Including Hospital Care, Physician Care and Drug Expenditures for Highlighted Neurological Conditions in Canada, 2000–2001

	Hospital Care Expenditures		Physician Care Expenditures		Drug Expenditures		Total Direct Cost
	$ (Million)	Percentage of Total	$ (Million)	Percentage of Total	$ (Million)	Percentage of Total	$ (Million)
Alzheimer's disease	398.66	92.4	7.66	1.8	25.05	5.8	431.37
ALS	13.63	98.8	0.16	1.2	N/A	N/A	13.79
Brain tumours	72.53	73.7	24.50	24.9	1.36	1.4	98.38
Cerebral palsy	37.05	93.2	2.69	6.8	N/A	N/A	39.74
Epilepsy	44.82	45.0	25.63	25.7	29.11	29.2	99.56
Head injury	150.71	99.3	0.31	0.2	0.71	0.5	151.73
Headache	106.54	25.9	74.19	18.1	230.29	56.0	411.03
Multiple sclerosis	58.40	42.0	12.09	8.7	68.73	49.4	139.22
Parkinson's disease	89.21	44.2	13.35	6.6	99.30	49.2	201.86
Spinal injuries	61.62	100.0	N/A	N/A	N/A	N/A	61.62
Stroke	579.53	87.2	67.55	10.2	17.79	2.7	664.86
Total	1,612.70	69.7	228.13	9.9	472.33	20.4	2,313.16

Note: N/A = Data not available.

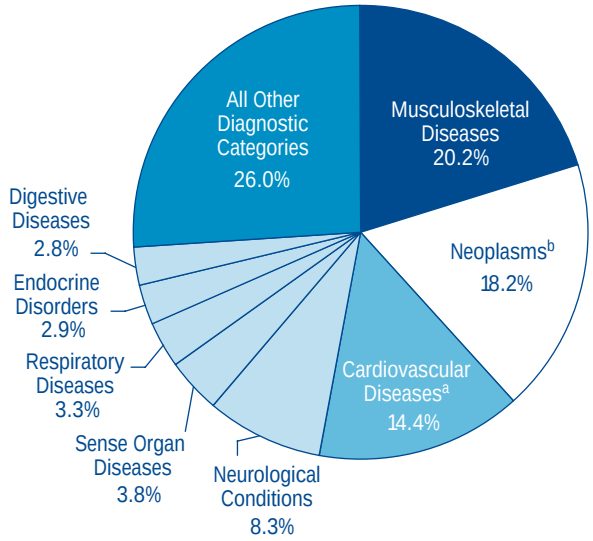
Source: PHAC, economic burden of illness custom tabulations, May 2007.

Indirect Costs

In 2000–2001, indirect costs for all illness in Canada, as estimated by PHAC, were $78.5 billion. This comprises mortality costs of $44.1 billion and morbidity costs of $34.9 billion. There are no unattributable indirect costs.

3

Indirect Costs for All Illness in Canada by Diagnostic Category, 2000–2001



Notes: **a** Excludes stroke.
b Excludes tumours of the brain and other related parts of the nervous system.

Source: PHAC, economic burden of illness custom tabulations, May 2007.

In 2000–2001, the indirect costs were available for nine of the highlighted neurological conditions. These were estimated by PHAC to be $6.5 billion, representing 8.3% of the indirect costs of all illness.

Morbidity and mortality costs were available for 7 of the 11 conditions highlighted in the report: Alzheimer's disease, cerebral palsy, epilepsy, headache, multiple sclerosis, Parkinson's disease and stroke. In addition, mortality costs were available for ALS and brain tumours.

Highlights of indirect costs for the individual conditions:

- Stroke had the largest indirect costs (32.2%), followed by Alzheimer's disease (15.4%), multiple sclerosis (12.4%) and brain tumours (12.3%).
- Morbidity costs made up a larger component of the indirect costs for Alzheimer's disease, cerebral palsy, epilepsy, multiple sclerosis and Parkinson's disease, ranging from 61.7% to 78.7%.
- Of the indirect costs for stroke, 63.2% was associated with mortality.

4

Indirect Costs (Mortality and Morbidity) by Highlighted Neurological Conditions in Canada, 2000–2001

	Mortality Cost		Morbidity Cost		Total Indirect Cost
	$ (Million)	Percentage of Total	$ (Million)	Percentage of Total	$ (Million)
Alzheimer's disease	383.47	38.3	618.35	61.7	1,001.82
ALS	168.57	100.0	N/A	N/A	168.57
Brain tumours	805.06	100.0	N/A	N/A	805.06
Cerebral palsy	90.11	26.3	252.02	73.7	342.13
Epilepsy	162.54	23.3	535.55	76.7	698.09
Headache	0.00	0.0	351.17	100.0	351.17
Multiple sclerosis	172.80	21.3	638.45	78.7	811.25
Parkinson's disease	93.80	38.3	151.14	61.7	244.94
Stroke	1,327.33	63.2	772.35	36.8	2,099.68
Total Cost	3,203.68	49.1	3,319.03	50.9	6,522.70

Note: N/A = Data not available.

Source: PHAC, economic burden of illness custom tabulations, May 2007.

Disability-Adjusted Life Years (DALYs) Associated With Neurological Disease, Disorders and Injuries in Canada

The Global Burden of Disease study conducted in 2002 by the WHO, the World Bank and the Harvard School of Public Health determined that neurological and psychiatric conditions accounted for 38.3% of the DALYs worldwide.[2] This proportion was higher in developed countries, such as Canada.[2] According to the WHO 2006 report, in 2005, neurological conditions[iii] contributed to 6.3% of the global burden of disease as measured by the DALYs, compared to slightly over 5% for HIV/AIDS and malignant neoplasms, and around 4% for ischemic heart diseases and respiratory diseases.[1] In the grouping of countries including Canada, neurological conditions constituted 10.9% of the DALYs for all illnesses and were found to be a major cause of lost years of healthy life (YDL).[1]

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.[3]

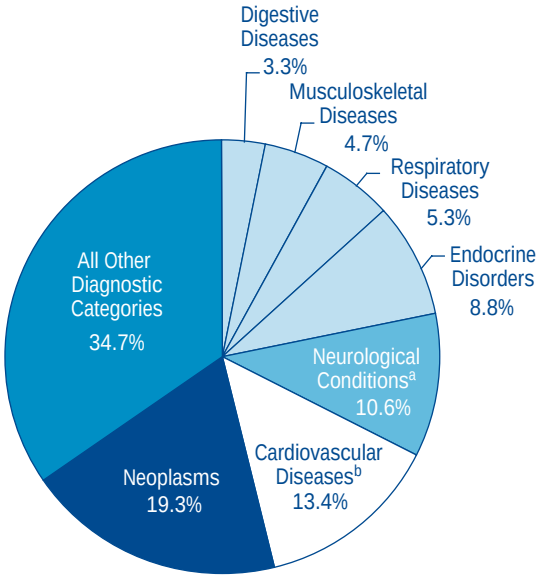
ii Included in this estimate are Alzheimer's disease and other dementias, epilepsy, migraine, multiple sclerosis, Parkinson's disease, stroke, traumatic brain injuries, neuroinfections (poliomyelitis, tetanus, meningitis, Japanese encephalitis) and neurological conditions associated with malnutrition.

Estimates of the DALYs for all illnesses in Canada and the highlighted neurological conditions were generated by the PHAC for 2000–2001. Data sources and methods used to estimate DALYs are provided in Appendix B.

The DALYs were available for 6 of the 11 highlighted conditions in this report: Alzheimer's disease, epilepsy, headache, multiple sclerosis, Parkinson's disease and stroke. These six neurological conditions alone accounted for 10.6% of the total DALYs for all illnesses in Canada in 2000–2001.

5

Disability-Adjusted Life Years for All Illness in Canada by Diagnostic Category, 2000–2001



Notes: **a** Includes Alzheimer's disease, epilepsy, headache, multiple sclerosis, Parkinson's disease and stroke.
b Excludes stroke.

Source: PHAC, custom tabulations, May 2007.

6

Disability-Adjusted Life Years by Highlighted Neurological Condition in Canada, 2000–2001

	YLL[a]		YLD[b]		DALYs[c]	
	Number	Percentage of YLL for All Illness	Number	Percentage of YLL for All Illness	Number	Percentage of YLL for All Illness
Alzheimer's disease	88,718	3.4	87,210	3.6	175,927	3.5
Epilepsy	5,782	0.2	9,545	0.4	15,327	0.3
Headache	0	0.0	36,959	1.5	36,959	0.7
Multiple sclerosis	7,809	0.3	5,867	0.2	13,677	0.3
Parkinson's disease	14,735	0.6	38,243	1.6	52,978	1.1
Stroke	149,263	5.7	88,873	3.7	238,136	4.7
Total	266,307	10.2	266,697	11.0	533,004	10.6

Notes: **a** Years of life lost because of premature mortality.
b Years of healthy life lost as a result of disability.
c YLL + YLD.

Source: PHAC, custom tabulations, May 2007.

The six neurological conditions made up 10.2% of the YLL and 11.0% of the YLD for all illnesses in Canada in 2000. Stroke had the largest DALYs (4.7%), followed by Alzheimer's disease (3.5%).

Years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD) contributed equally to the total DALYs of the six neurological conditions and the total DALYs for Alzheimer's disease. The number of the YLD was higher than the number of the YLL for the DALYs of epilepsy and Parkinson's disease.

Hospital Utilization Associated With Neurological Diseases, Disorders and Injuries in Canada

This report provides data on utilization of hospital-based services by patients with the 11 highlighted neurological conditions. Data sources, definitions and methods used to calculate hospital utilization for these conditions are included in Appendix B. The associated codes used to define patients with the conditions for purposes of this analysis are listed in Appendix C.

Because this report does not include utilization statistics for services provided in settings such as primary care physicians' offices, private clinics, patients' homes or residential care facilities, data provided represent only a partial burden that these diseases, disorders and injuries represent to the health care system in Canada.

Hospital Emergency Department and Urgent Care Centre Utilization

Just over 4% of all emergency department (ED) and urgent care centre (UCC) visits in Ontario and 10 hospitals in other parts of Canada in 2004–2005 included patients with one of the 11 highlighted neurological conditions as a primary or secondary diagnosis. With the exception of patients with headaches and head injury, the acute care hospital admission rate via the ED was consistently higher among patients with neurological conditions, compared with the overall ED/UCC patient population.

7

ED and UCC Utilization by Patients With Highlighted Neurological Conditions, 2005–2006

	Number of Patients[a]	Number of Visits[a]	Percentage Admitted to Acute Care via the ED[a]
Alzheimer's disease	4,733	5,371	50.0
ALS	158	205	55.6
Brain tumours	1,526	2,036	58.7
Cerebral palsy	527	665	37.3
Epilepsy	4,487	5,553	29.6
Head injury	80,970	89,870	10.4
Headache	75,320	98,659	3.9
Multiple sclerosis	1,190	1,758	28.9
Parkinson's disease	1,216	1,436	39.5
Spinal injuries	5,163	6,448	48.0
Stroke	15,011	16,766	81.6
Total[b]	113,248	191,185	

Notes: **a** Based on primary or secondary diagnosis for the condition of interest.
b Total: patients with multiple conditions were only counted once.

Source: National Ambulatory Care Reporting System, CIHI.

Acute Care Hospitalizations

Just over 9% of acute care hospitalizations and 19% of patient days in acute care hospitals in Canada in 2004–2005 included patients with one of the 11 highlighted neurological conditions as a primary or secondary diagnosis.

The number of hospitalizations was highest for patients with Alzheimer's disease and stroke, representing 3.4% and 2.2%, respectively, of all hospitalizations in 2004–2005. These two conditions also contributed to the largest number of patient days among the 11 conditions and comprised 8.8% and 5.3%, respectively, of the total acute care patient days in 2004–2005.

The median length of stay (LOS) was 7 days, ranging from 11 days for patients with Alzheimer's disease to 3 days for patients with head injury. With the exception of cerebral palsy, headache and head injury, the median LOS was consistently higher for patients with neurological conditions than the median LOS of four days for all acute care inpatients.

8

Acute Care Hospitalizations for Patients With Highlighted Neurological Conditions, 2004–2005

	Number of Patients[a]	Number of Hospitalizations[a]	Total Patient Acute Care Days[a]	Median Length of Stay (Days)[a]
Alzheimer's disease	56,384	67,238	1,494,866	11
ALS	1,107	1,374	30,398	8
Brain tumours	6,529	9,122	128,317	7
Cerebral palsy	3,109	4,173	38,824	4
Epilepsy	18,604	23,374	259,161	5
Head injury	23,609	24,354	240,467	3
Headache	15,239	16,598	132,057	4
Multiple sclerosis	4,922	6,486	81,328	6
Parkinson's disease	11,714	14,543	291,055	10
Spinal injuries	10,400	10,706	188,322	9
Stroke	46,570	49,135	941,184	9
Total[b]	179,147	209,337	3,399,533	

Notes: **a** Based on primary or secondary diagnosis for the condition of interest.
b Total: patients with multiple conditions were only counted once.

Source: Hospital Morbidity Database, CIHI.

Inpatient Rehabilitation Services

Data on inpatient rehabilitation services were available for the following conditions: head injury, multiple sclerosis, Parkinson's disease, spinal injury and stroke.

In 2005–2006, 6,405 patients with these five conditions received inpatient rehabilitation services in Ontario and 17 hospitals in other parts of Canada. They required a total of 271,524 patient days, which represented almost a third (31.7%) of the total rehabilitation patient days.

Sixty-six percent of the total rehabilitation days coded as "waiting for discharge" included patients with one of the neurological conditions (with the exception of those with Parkinson's disease). In other words, this group of patients tended to wait longer for discharge to an appropriate care setting, once they had completed their rehabilitation goals, than other types of rehabilitation patients (for example, patients recovering from joint replacement therapy). In 2005–2006, the total amount of time waiting for discharge to a more appropriate setting (once their rehabilitation treatment was complete) was 28 days for patients with multiple sclerosis, 93 days for patients with spinal injury, 273 days for patients with head injury and over two years for patients with stroke.

The median total LOS of these patients was 1.3 to 3.3 times that for all patients, and was longest for patients with spinal injuries (56 days) and shortest for patients with Parkinson's disease (23 days). Almost a quarter (23%) of the total patient days in inpatient rehabilitation services in 2005–2006 included patients with stroke.

9

Inpatient Rehabilitation Services for Patients With Selected Neurological Conditions, 2005–2006

	Number of Patients	Total Patient Days[a]		Active Patient Days[b]	Patient Days Waiting for Discharge
		Total	Median	Total	
Head injury	732	39,620	35	39,347	273
Multiple sclerosis	188	7,898	35	7,870	28
Parkinson's disease	97	2,670	23	2,670	0
Spinal injuries	333	22,816	56	22,723	93
Stroke	5,060	198,520	33	197,648	872
Total	6,410	271,524		270,258	1,266
All rehabilitation patients	32,114	857,704	17	855,787	1,917

Notes: **a** Patient days from admission to discharge (excluding service interruptions).
b Difference between total patient days and patient days waiting for discharge.

Source: National Rehabilitation Reporting System, CIHI.

Total Function Score is a measure of the rehabilitation clients' overall functional ability obtained by adding scores on the 18 items (13 for motor disability and 5 for cognitive disability) in the Functional Independence Measure (FIM™) that are on a scale from 1 (dependent function) to 7 (independent function). Total Function Score can range from 1 to 126 (higher score indicates higher overall level of functioning).

Total Function Score

In 2005–2006, patients with the five conditions had consistently lower mean Total Function Scores at admission than the overall rehabilitation patient population (85.9), ranging from 70.1 for patients with spinal injury to 81.6 for patients with multiple sclerosis. At discharge, mean Total Function Scores were higher than mean Total Function Scores at admission, indicating improvement in the overall functional ability of these patients. Changes in the Total Function Score ranged from 13.2 for patients with MS to 23.4 for patients with head injury. However, the mean discharge Total Function Score of patients with all these conditions was lower than that for all inpatients in rehabilitation services in that year.

10

Total Function Scores for Patients With Selected Neurological Conditions, 2005–2006

	Number of Patients	Total Function Score[a]		
		At Admission (Mean)	At Discharge (Mean)	Change[b]
Head injury	732	80.2	103.5	23.3
Multiple sclerosis	188	81.6	94.9	13.3
Parkinson's disease	97	77.5	94.5	17.0
Spinal injuries	333	70.1	93.7	23.6
Stroke	5,060	76.9	98.4	21.5
Total	6,410			
All rehabilitation patients	32,114	85.9	105.5	19.6

Notes: **a** Possible range 18 to 126 (higher scores signify better overall functioning).
b Difference between mean Total Function Score at discharge and mean Total Function Score at admission.

Source: National Rehabilitation Reporting System, CIHI.

Complex Continuing Care

Data related to complex continuing care (CCC) utilization were available for the following conditions: Alzheimer's disease, ALS, cerebral palsy, epilepsy, head injury, multiple sclerosis, Parkinson's disease and stroke.

Between 2001–2002 and 2005–2006, 33,335 patients with these neurological conditions received CCC services. Over the five-year period, these patients had 47.3% of CCC stays and 69.3% of patient days in CCC. The median LOS for these patients was 52 days, and 13% of their stays were longer than one year. Patients with either Alzheimer's disease or stroke had the largest proportion of CCC patient days over this time period: 38.1% and 36.6%, respectively.

In 2005–2006, 10,100 patients with at least one of the eight neurological conditions had 10,961 stays in CCC with a total of 1.3 million patient days, which represented 50.1% of CCC stays and 65.1% of CCC patient days during that year. Their median LOS was 50 days, compared with 40 days among the overall CCC patient population. As in the time period from 2001–2002 to 2005–2006, Alzheimer's disease and stroke were the neurological conditions that were associated with the largest proportion of the number of stays and patient days in CCC.

11

Complex Continuing Care Utilization by Patients With Selected Neurological Conditions, Ontario, 2005–2006

	Number of Patients[a]	Number of Stays[a]	Percentage of All Stays by CCC Patients[a]	Number of Patient Days[a]	Percentage of Total Patient Days for All CCC Patients[a]
Alzheimer's disease	5,646	5,940	27.2	740,452	36.5
ALS	136	143	0.7	28,559	1.4
Cerebral palsy	226	257	1.2	51,754	2.6
Epilepsy	176	200	0.9	41,781	2.1
Head injury	601	673	3.1	129,456	6.4
Multiple sclerosis	507	601	2.7	120,364	5.9
Parkinson's disease	984	1,041	4.8	118,757	5.9
Stroke	4,941	5,356	24.5	666,172	32.9
Total[b]	**10,100**	**10,961**	**50.1**	**1,319,196**	**65.1**

Notes: **a** Based on a CCRS code for one or more of the conditions of interest.
b Total: patients with multiple conditions were only counted once.

Source: Continuing Care Reporting System, CIHI.

The Way Forward: Understanding the Burden of Neurological Conditions in Canada

Using the most current data from existing data sources, new information and analyses to illustrate the economic burden, DALYs and hospital utilization associated with neurological diseases, disorders and injuries in Canada have been presented in this report. However, there are some limitations to this analysis:

- The direct costs of the neurological diseases, disorders and injuries in this report include only expenditures for hospital care, physician care and drugs. By excluding other direct costs, such as costs for transportation and medical devices such as braces, splints, walkers and wheelchairs, the economic burden associated with these conditions is underestimated.
- Limitations to the way drug expenditures are calculated may underestimate true prescription drug expenditures, and costs for over-the-counter drugs and personal health supplies, for some of the neurological conditions.
- The indirect costs presented in the report may be a conservative estimate of the morbidity and mortality costs associated with neurological conditions because cost data were available for only 7 of the 11 conditions. Only mortality costs were provided for ALS and brain tumours, and morbidity costs include only long-term disability costs.
- Indirect costs do not include the value of time lost from work and leisure activities by family members or friends who help care for the person with the neurological condition of interest.
- The DALYs were estimated for only 6 of the 11 highlighted conditions, and therefore the information that the report provides is a partial picture of the impact of these conditions based on this measure.

The health system utilization information is limited to hospital-based care and does not reflect utilization associated with community-based care, such as care provided in general practitioners' offices, private clinics and patients' homes. This is partly due to the limited scope of this report and partly due to the lack of comprehensive information about community-based care for the conditions examined in the report. Considering this and that the data for the ED/UCC visits, inpatient rehabilitation services and CCC are primarily limited to hospitals in Ontario, the report provides only a partial picture of the burden that neurological diseases, disorders and injuries represent to the Canadian health care system.

Possible Areas for Future Study

The burden of the 11 highlighted neurological diseases, disorders and injuries presented in the report is not the full picture of the impact that these conditions have on individuals, communities, society and the health care system in Canada. Nevertheless, the report provides information that will serve as a baseline in future research involving these conditions, as well as insight about the data gaps and the improvements required to establish a comprehensive picture. The information provided for the 11 highlighted conditions is an important indication of the likely magnitude of the total burden of neurological diseases, disorders and injuries in Canada.

Areas for future study that could provide additional information to support discussion around the burden of neurological diseases, disorders and injuries include the following:

- Explore continuity and pathways of care (for example, acute care hospitalization and transfer to rehabilitation or CCC) for patients with neurological conditions.
- Examine how factors such as severity of illness, comorbidities and quality of care influence the patterns of health care utilization by patients with neurological conditions.
- Understand the health outcomes associated with the care received by patients with neurological conditions (for example, Total Functional Scores of patients who have and have not had inpatient rehabilitation).
- Measure more comprehensively the economic burden of neurological conditions and the effects they have on the quality of life of these patients.
- Explore the effect of timely access to care and early diagnosis and treatment on the onset of neurological conditions and the development of disability.
- Explore gaps in data and potential solutions that would lead to more comprehensive information about the burden of neurological conditions outside of those examined in detail in this report.

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Highlights

- Alzheimer's disease and other dementias accounted for $431.4 million in direct costs and $1 billion in indirect costs in Canada in 2000–2001.
- 50% of patients with Alzheimer's disease visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations across Canada for patients with Alzheimer's disease increased by 38% between 2000–2001 and 2004–2005.
- Almost 9% of patient days in Canadian acute care hospitals for patients aged 19 and older included patients with Alzheimer's disease as a primary or secondary condition in 2004–2005.

Alzheimer's Disease

What Is Alzheimer's Disease?

Alzheimer's disease (AD) is a progressive degenerative disease characterized by a general decline in mental abilities involving memory, language and logical thinking.[1] Accumulations of dense, irregular deposits (called "plaques") in certain regions of the brain and thread-like "tangles" within individual neurons are the pathological hallmarks of AD.[1,2]

According to the Alzheimer Society of Canada, AD is more common than any other type of dementia (64% of all cases in Canada).[3] The Society also estimates that there are approximately 280,000 Canadians over the age of 65 with AD.[3] A study by the Canadian Study of Health and Aging Working Group estimates that 60,000 new cases of dementia occur each year.[4]

The prevalence and incidence of dementia increase with age.[2] Women are at a higher risk of developing AD, partly because they live longer than men.[5] AD has also been associated with previous head injury, high cholesterol and family history.[2] In addition, there are risk factors (such as smoking, lack of exercise, poor nutrition, genetic predisposition and lower social status) that are less firmly established.[6,7]

Signs and Symptoms

The signs and symptoms of AD gradually worsen over time.[1] Symptoms may include confusion and memory loss, disorientation and changes in mood and behaviour.[1] As the disease progresses, patients usually develop difficulty with activities of daily living, agitation and depression, difficulties recognizing family and friends, loss of speech and, eventually, total dependence on others.[1]

Diagnosis and Treatments

AD is diagnosed with fair certainty through medical history, blood and urine tests (to rule out other forms of dementia), neuropsychological tests for memory and problem-solving and brain imaging.[1] However, post-mortem examination of the brain is required for a definitive diagnosis of the disease.[1]

There is currently no cure for AD. However, several medications are available that can delay the progression of the disease and improve the symptoms of depression, agitation and sleep problems.[1] Cognitive rehabilitation, during which individuals are taught new strategies to recall important information and go about their daily tasks, is also used as part of treatment.

Economic Burden

The PHAC estimates that total costs associated with AD in 2000–2001 were $1.4 billion.

- Direct costs were $431.4 million: $398.7 million (92.4%) for hospital care, $7.7 million (1.8%) for physician care and $25.1 million (5.8%) for drugs.
- Indirect costs were $1 billion: $383.5 million (38.3%) in mortality cost and $618.4 million (61.7%) in morbidity cost.

Disability-Adjusted Life Years (DALYs)

The PHAC estimates that in 2000–2001, AD and other dementias were associated with almost 176,000 DALYs, accounting for 3.5% of the DALYs for all illnesses in Canada. The years of life lost due to premature mortality and the years of healthy life lost due to disability represented almost equal parts of the DALYs for AD and other dementias: 50.4% and 49.6%, respectively.

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.

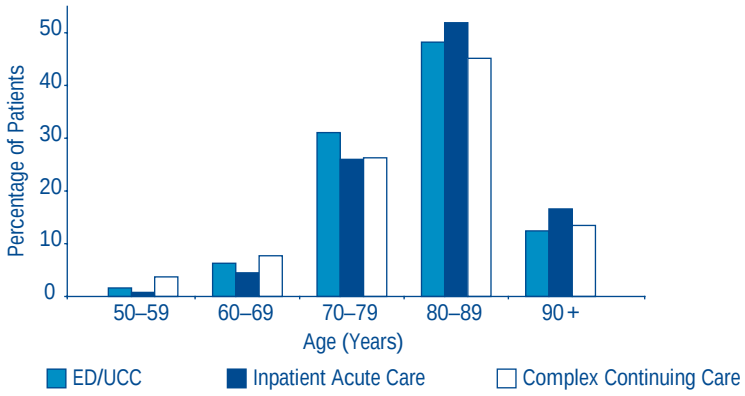
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, and acute care and complex continuing care (CCC) hospitalizations for patients with AD.

12

Age Distribution of Patients With Alzheimer's Disease Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care and Complex Continuing Care

The majority of patients with AD who used hospital-based services were 70 years of age or older.



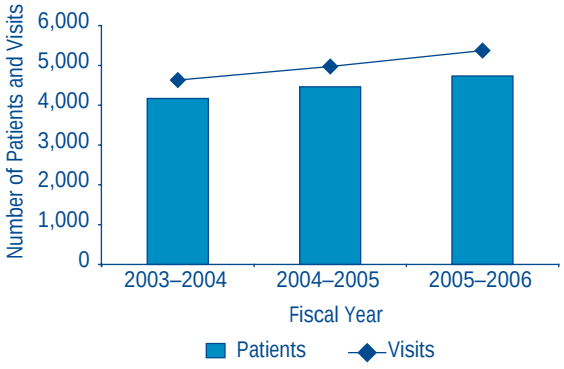
Note: Patients with AD: ED and UCC, n = 4,733; inpatient acute care, n = 53,384; complex continuing care, n = 5,646.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

13

ED and UCC Visits by Patients With Alzheimer's Disease, 2003–2004 to 2005–2006

Between 2003–2004 and 2005–2006, both the number of patients with AD visiting EDs and UCCs and the number of visits increased. In 2005–2006, on average, patients with AD made 1.1 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population 19 years of age and older.



Note: Based on patients 19 years of age and older.

Source: National Ambulatory Care Reporting System, CIHI.

14

ED and UCC Visit Disposition of Patients With Alzheimer's Disease, 2005–2006

In 2005–2006, just over half (52.4%) of patients with AD as a primary diagnosis and 54.6% of patients with AD as a secondary diagnosis were admitted to acute care hospitals via EDs. In comparison, the overall admission rate via the ED was 12.6% in 2005–2006.

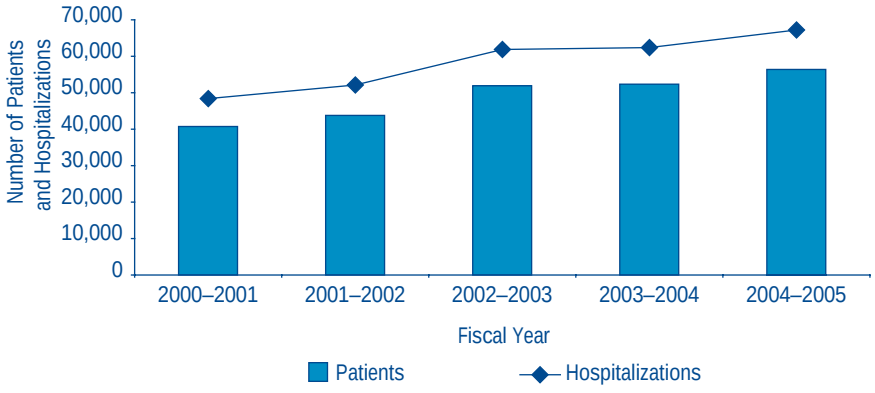
	Patients With AD Aged 19 and Older		
	AD as Primary Diagnosis (%)	AD as Secondary Diagnosis (%)	All ED/UCC Patients Aged 19 and Older (%)
Discharged home	52.4	42.8	83.3
Admitted to acute care hospital	46.2	54.6	12.6

Source: National Ambulatory Care Reporting System, CIHI.

15

Acute Care Hospitalizations for Patients With Alzheimer's Disease in Canada, 2000–2001 to 2004–2005

Between 2000–2001 and 2004–2005, the number of patients with AD in acute care hospitals increased 39%, from 40,720 in 2000–2001 to 56,384 in 2004–2005. The number of hospitalizations for these patients rose by 38% (from 48,390 to 67,238) during this same time. In 2004–2005, 56,384 patients with AD had a total of 1.5 million patient days, which represented 8.8% of patient days in acute care hospitals for patients 19 years of age and older. The average number of hospital stays per patient with AD was 1.2, compared with 1.4 for all acute care inpatients aged 19 and older.



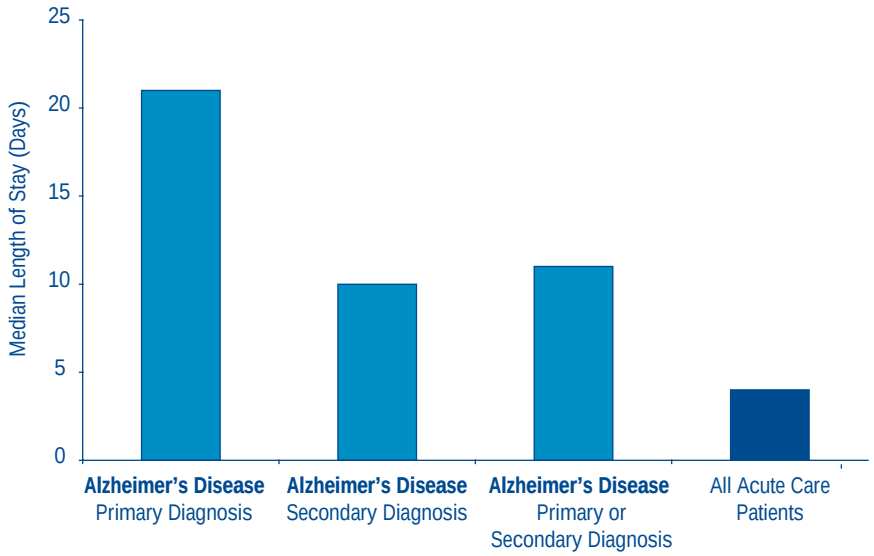
Note: Based on patients 19 years of age and older.

Source: Hospital Morbidity Database, CIHI.

16

Median Length of Stay for Patients With Alzheimer's Disease in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with a primary diagnosis of AD was 21 days; this is more than five times longer than the median LOS for all acute care patients (4 days) 19 years of age and older.



Note: Based on patients 19 years of age and older.

Source: Hospital Morbidity Database, CIHI.

AD was the primary diagnosis in 19.8% of hospitalizations for patients with AD in 2004–2005. When AD was not the primary diagnosis, the most common reasons for hospitalization included diseases of the circulatory system (19%), diseases of the respiratory system (17%) and injury and poisoning (14%).

The readmission rate for patients with AD was 4.3% within 7 days and 10.9% within 30 days of discharge. This compares with readmission rates of 3.8% and 9.0%, respectively, for all acute care inpatients 19 years of age and older.

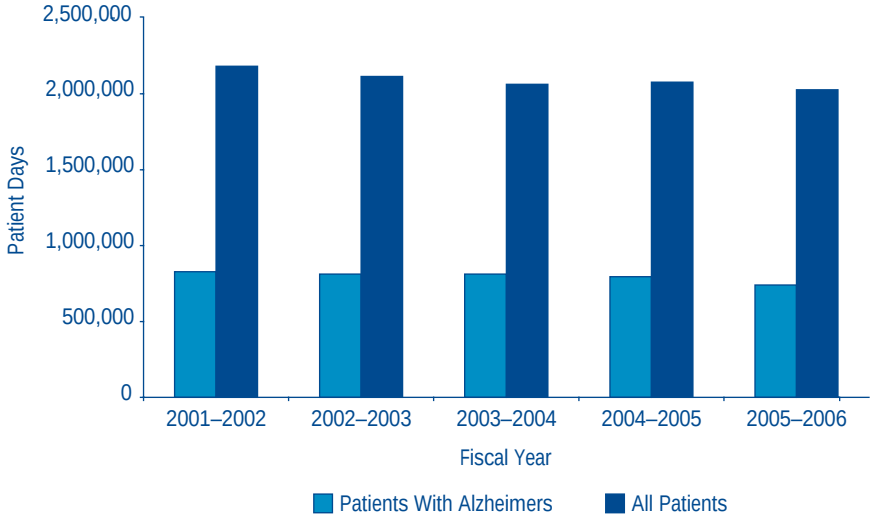
Complex Continuing Care

Thirty-eight percent of patient days in CCC between 2001–2002 and 2005–2006 included patients with AD. The median LOS for discharged patients with AD was 50 days, compared with 41 days for CCC patients 19 years of age and older over these years. In these two patient groups, 14% and 8% of stays, respectively, were longer than one year.

17

Patient Days for Patients With Alzheimer's Disease and All Patients in Complex Continuing Care, Ontario, 2001–2002 to 2005–2006

The number of patient days for patients with AD declined by 10.5% from 2001–2002 to 2005–2006. In 2005–2006, 5,646 patients with AD had 5,940 stays in CCC beds, for a total of 740,452 patient days, which represented 36.5% of the CCC patient days during that year.



Note: Based on patients 19 years of age and older.

Source: Continuing Care Reporting System, CIHI.

18

Discharge Disposition of Patients With Alzheimer's Disease From Complex Continuing Care, Ontario, 2005–2006

Just over one-third of patients with AD discharged from CCC were transferred to a residential care setting and 15% were transferred to acute care hospitals in 2005–2006. Sixteen percent of patients were discharged home, compared with 29% among all CCC patients 19 years of age and older. More than a quarter of patients with AD died during their stay in CCC during 2005–2006.

	Patients With AD Aged 19 and Older (%)	All CCC Patients Aged 19 and Older (%)
Discharged home[a]	16	29
Discharged to residential care[b]	39	25
Admitted to acute care hospital	15	17
Died	29	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

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Amyotrophic Lateral Sclerosis

Highlights

- Amyotrophic lateral sclerosis accounted for $13.8 million in direct costs and $168.6 million in indirect costs in Canada in 2000–2001.
- More than half of patients with ALS visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations across Canada for patients with ALS increased 5.8% between 2000–2001 and 2004–2005.
- In 2004–2005, the median LOS for patients with ALS in acute care hospitals in Canada was eight days, compared with four days for all inpatients 19 years of age and older.
- The median LOS for patients with ALS discharged from CCC in Ontario in 2005–2006 was 120 days, compared with 40 days for all patients 19 years of age and older.

Amyotrophic Lateral Sclerosis

What Is Amyotrophic Lateral Sclerosis?

Amyotrophic lateral sclerosis (ALS), also called Lou Gehrig's disease, is a rapidly progressing disease characterized by destruction of motor neurons—the pathways by which the brain sends messages to voluntary muscles.[1] The cause of these changes, which lead to paralysis of most of the body's voluntary muscles (that is, muscles of the extremities and muscles that control breathing, speaking, chewing and swallowing), is not known.[1] While physically devastating, ALS may also affect a patient's mental abilities.[2]

The results of a Canadian research study estimate that there are approximately 2,000 Canadians living with ALS.[1] Causes of ALS are not yet understood.[1] According to the ALS Society of Ontario, ALS generally appears between the ages of 45 and 65 years.[1] Research indicates that most individuals with ALS die within three years of onset.[3]

Signs and Symptoms

Establishing a diagnosis of ALS is often complex, since early symptoms and signs are frequently vague.[1] They can include muscle cramping, weakening and twitching, tripping, dropping things, slurred speech and difficulty breathing and swallowing.[1]

Diagnosis and Treatments

To diagnose ALS, it is required that both upper and lower motor-neuron abnormalities be present, that symptoms steadily worsen and that other diseases that cause similar symptoms be ruled out.[1] There is presently no cure for ALS. An ALS-specific drug currently available may prolong life by a few months.[4] Symptoms can also be controlled through occupational and physical therapy, exercise, nutritional management and the use of assistive devices.[5] These treatments help individuals maintain independence and quality of life for a period of time.

Economic Burden

The PHAC estimates that the total costs associated with ALS in 2000–2001 were $182.4 millon. This estimate does not include drug expenditures or morbidity costs because data were not available.

- Direct costs were $13.8 million: $13.6 million for hospital care and $0.2 million for physician care.
- Mortality costs were $168.6 million.

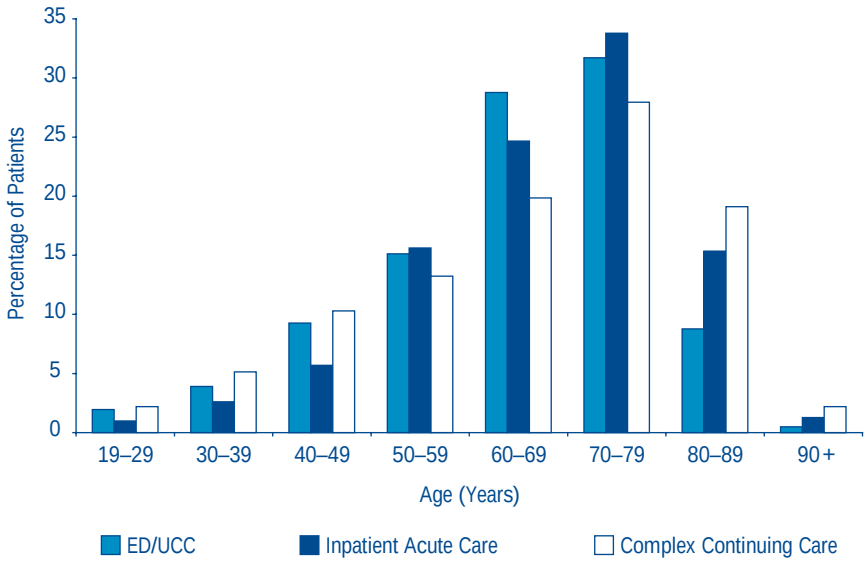
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations and hospital-based continuing care for patients with ALS.

19

Age Distribution of Patients With Amyotrophic Lateral Sclerosis Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care and Complex Continuing Care

The majority of patients with ALS who used hospital-based services were 60 years of age or older.



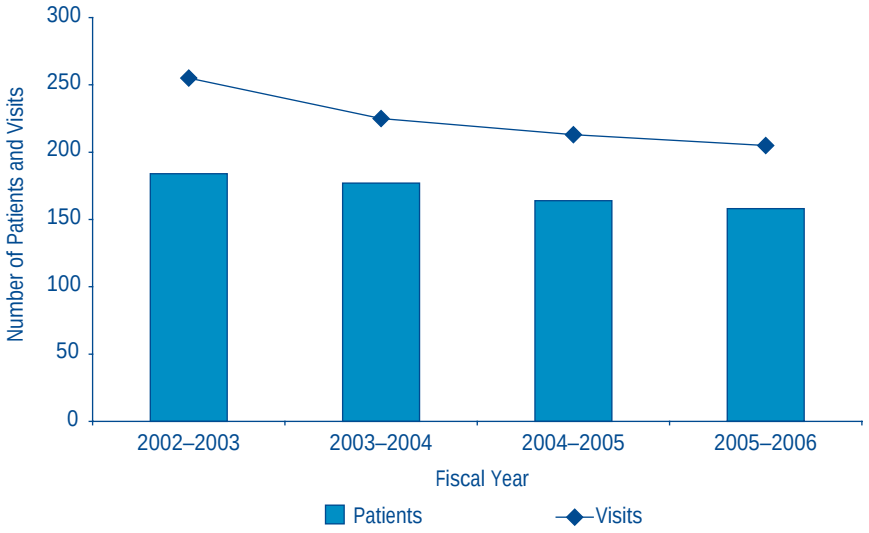
Note: Patients with ALS: ED and UCC, n = 158; inpatient acute care, n = 1,107; complex continuing care, n = 136.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); Continuing Care Reporting System, 2006–2006, CIHI (includes only Ontario).

20

ED and UCC Visits by Patients With Amyotrophic Lateral Sclerosis, 2002–2003 to 2005–2006

Between 2002–2003 and 2005–2006, the number of patients with ALS visiting EDs and UCCs decreased slightly from 184 in 2002–2003 to 158 in 2005–2006. The number of ED/UCC visits by these patients also decreased (from 255 to 205) between these years. In 2005–2006, on average, persons with ALS made 1.3 ED/UCC visits, compared with an average of 1.8 visits made by the overall ED/UCC patient population 19 years of age and older during this year.



Note: Based on patients 19 years of age and older.

Source: National Ambulatory Care Reporting System, CIHI.

21

ED and UCC Visit Disposition of Patients With Amyotrophic Lateral Sclerosis, 2005–2006

In 2005–2006, over half (58.3%) of the patients with ALS as a primary diagnosis and 52.6% of the patients with ALS as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall admission rate via the ED for patients 19 years of age and older was 12.6% in 2005–2006.

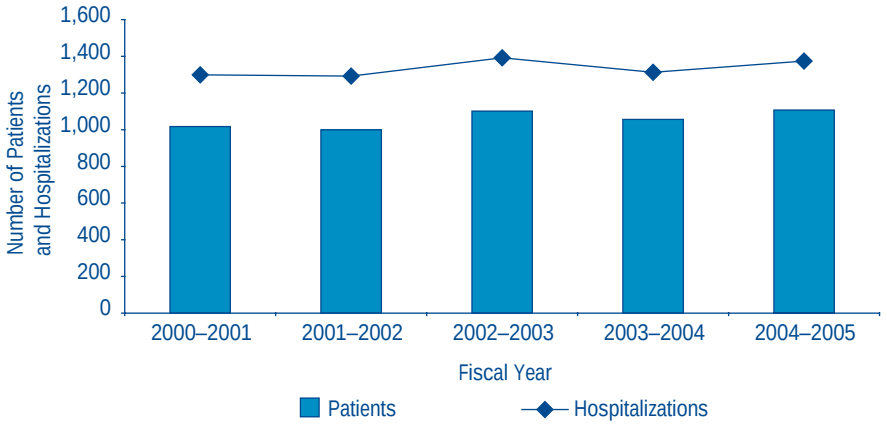
	Patients With ALS Aged 19 and Older		
	ALS as Primary Diagnosis (%)	ALS as Secondary Diagnosis (%)	All ED/UCC Patients Aged 19 and Older (%)
Discharged home	38.9	43.3	83.3
Admitted to acute care hospital	58.3	52.6	12.6

Source: National Ambulatory Care Reporting System, CIHI.

22

Acute Care Hospitalizations for Patients With Amyotrophic Lateral Sclerosis in Canada, 2000–2001 to 2004–2005

Both the number of patients with ALS in acute care hospitals and the number of hospitalizations for these patients fluctuated in the period from 2000–2001 to 2004–2005. Overall, the number of patients increased by 8.8%, from 1,017 in 2000–2001 to 1,107 in 2004–2005, and the number of hospitalizations rose 5.8% (from 1,299 to 1,374) during the same time. In 2004–2005, patients with ALS had a total of 30,398 patient days. The average number of hospital stays for patients with ALS was 1.2, compared with 1.4 for all acute care inpatients aged 19 years and older.



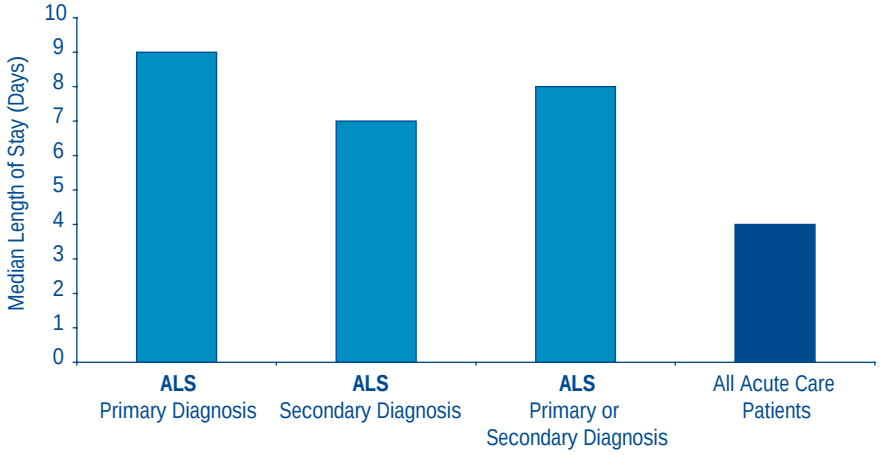
Note: Based on patients 19 years of age and older.

Source: Hospital Morbidity Database, CIHI.

23

Median Length of Stay for Patients With Amyotrophic Lateral Sclerosis in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with ALS was eight days; this is twice as long as the median LOS (four days) for all acute care patients aged 19 years and older.



Note: Based on patients 19 years of age and older.

Source: Hospital Morbidity Database, CIHI.

ALS was the primary diagnosis for 40.4% of hospitalizations for patients with ALS in 2004–2005. When ALS was not the primary diagnosis, common reasons for hospitalization included diseases of the respiratory system (32%), reasons other than specific health conditions (for example, observation, follow-up care) (15%) and symptoms, signs and ill-defined conditions (12%).

The readmission rate for patients with ALS was 4.8% within 7 days and 13.0% within 30 days of discharge. This compares with readmission rates of 3.8% and 9.0%, respectively, for all acute care inpatients 19 years and older.

Complex Continuing Care

In 2005–2006, 136 patients with ALS had 143 stays in CCC beds, with a total of 28,559 patient days, which represented 1.4% of CCC patient days during that year. The number of patient days for patients with ALS declined by 12.5% from 2003–2004 to 2005–2006.

In 2005–2006, the median LOS for discharged patients with ALS was 120 days, compared with 40 days for all CCC patients 19 years of age and older. Twenty-four percent of patients with ALS had stays in CCC that were longer than one year. This compares to the overall CCC patient population aged 19 years and older, among whom only 6% of patients had stays of over one year.

24

Discharge of Adult Patients With Amyotrophic Lateral Sclerosis From Complex Continuing Care, Ontario, 2005–2006

One-quarter of the patients with ALS discharged from CCC were transferred to acute care hospitals, and 13% were transferred to residential care in 2005–2006. Only 10% were discharged home, compared with 29% among all patients in the same age group discharged from CCC. More than half (53%) of the patients with ALS died during their stays in CCC, in contrast to 28% in the overall CCC patient population 19 years and older.

	Patients With ALS Aged 19 and Older (%)	All CCC Patients Aged 19 and Older (%)
Discharged home[a]	10	29
Discharged to residential care[b]	13	25
Admitted to acute care hospital	24	17
Died	53	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

References

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Highlights

- Brain tumours accounted for $98.4 million in direct costs and $805.1 million in indirect costs in Canada in 2000–2001.
- The number of patients with brain tumours visiting EDs and UCCs in Ontario increased 16% from 2002–2003 to 2005–2006.
- 66.7% of patients with brain tumours visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- More than 6,500 patients with brain tumours were hospitalized in acute care across Canada in 2004–2005.
- In 2004–2005, the median LOS for patients with brain tumours in acute care hospitals across Canada was seven days, compared with four days for all inpatients.
- Readmission rates for patients with brain tumours were 2.1 times higher than for all acute care patients within both 7 days and 30 days of discharge.

Brain Tumours

What Are Brain Tumours?

Brain tumours can be classified as non-aggressive (benign) or aggressive (malignant). Benign brain tumours usually originate from coverings of the brain (meningiomas) or cells associated with nerves coming from the brain (schwannomas and neurofibromas). There are two main types of malignant brain tumour: primary (arising from brain cells) and metastatic (having spread from tumours elsewhere in the body).[1] The most common form of malignant brain tumours are gliomas.[2] The occurrence and growth of brain tumours are likely to be associated with a combination of genetic and environmental factors.

According to the Brain Tumour Foundation of Canada, there are 55,000 Canadians surviving with a brain tumour, and approximately 10,000 new cases are diagnosed each year.[3] The Foundation also reports that the incidence increases with age and that brain tumours are now one of the most common types of pediatric cancer.[3] In 2002, Statistics Canada reported that nearly 1,600 Canadians died of malignant brain tumours.[4]

Signs and Symptoms

The signs and symptoms of brain tumours depend on their location and size.[5] They include headache, nausea and vomiting, seizures, blurred vision, weakness in the extremities, slurred speech and decreased memory and concentration.[1,5]

Diagnosis and Treatments

Diagnosis and identification of tumour type usually require brain imaging—computed tomography (CT) or magnetic resonance imaging (MRI)—and a tissue sampling.[1] Although benign tumours can be cured by surgical removal, there is currently no cure for most malignant brain tumours. Treatment is often difficult because of the location of brain tumours, but usually involves some form of surgery, radiation therapy or chemotherapy, or a combination of all three.[1]

Tumour type, as well as the age of the patient and level of functioning, will dictate the type and order of treatment. Steroid medications are sometimes used to decrease brain swelling. Antiseizure medication may be given to treat or prevent seizures associated with brain tumours.[1]

Because brain tumours and their treatment affect functioning of the brain and the body, rehabilitation and psychosocial services are crucial. In the absence of a cure, maintaining independence and quality of life for as long as possible are paramount for both patients and their families.[2]

Economic Burden

The PHAC estimates that the total costs associated with brain tumours in 2000–2001 were $903.5 million.

- Direct costs were $98.4 million: $72.5 million (73.7%) for hospital care, $24.5 million (24.9%) for physician care and $1.4 million (1.4%) for drugs.
- Mortality costs were $805.06 million.
- Morbidity costs were not available for brain tumours.

The Canadian Alliance of Brain Tumour Organizations notes that “in addition to the limitations related to estimates for drug expenditures identified by PHAC, it should be noted that physicians practicing in the specialty of neurooncology, who prescribe the majority of medications for those people diagnosed with brain tumours, are not included in the list of physicians for which the data for drug estimates was gathered. Thus, given the numbers of patients with malignant brain tumours in Canada and the known high cost of the chemotherapeutic agents used to treat such tumours, the estimates of drug costs for the brain tumour population are considered to be underestimated.”[6]

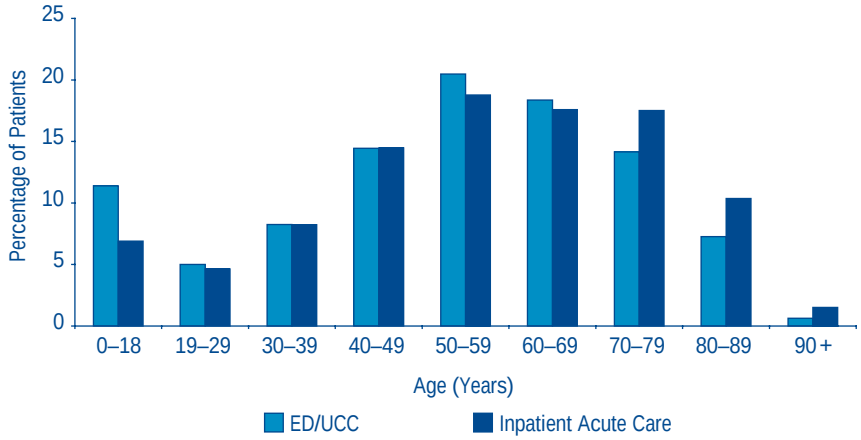
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, and acute care hospitalizations for patients with brain tumours.

25

Age Distribution of Patients With Brain Tumours Using Hospital Services, Including EDs and UCCs and Inpatient Acute Care

The majority of patients with brain tumours who used hospital-based services were 50 years of age or older. Children (18 years of age and younger) comprised 11.4% of the patients visiting EDs and UCCs and 6.9% of the acute care inpatients.



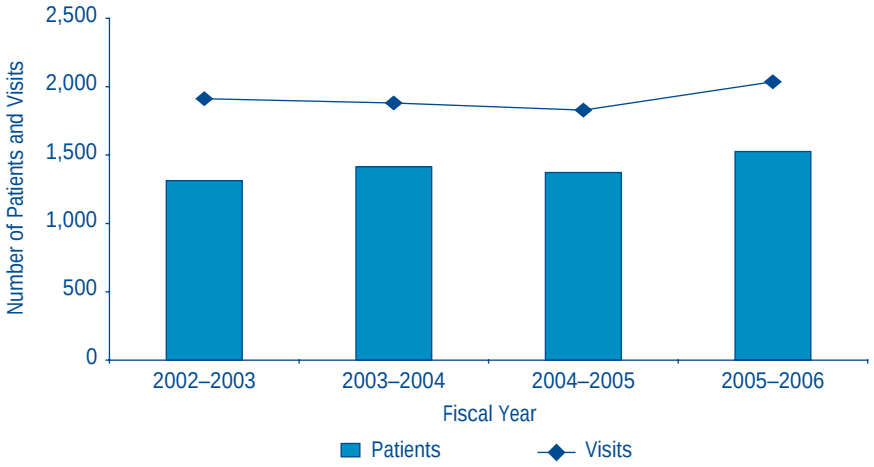
Note: Patients with brain tumours: ED and UCC, n = 1,526; inpatient acute care, n = 6,529.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories).

26

ED and UCC Visits by Patients With Brain Tumours, 2002–2003 to 2005–2006

Both the number of patients with brain tumours visiting EDs and UCCs and the number of ED/UCC visits by these patients fluctuated over the four years. Overall, the number of patients increased 16% from 2002–2003 (n = 1,312) to 2005–2006 (n = 1,526), and the number of visits rose 6.5% (from 1,912 to 2,036) between these years. In 2005–2006, on average, persons with brain tumours made 1.3 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this year.



Source: National Ambulatory Care Reporting System, CIHI.

27

ED and UCC Visit Disposition of Patients With Brain Tumours, 2005–2006

In 2005–2006, two-thirds (66.7%) of patients with brain tumour as a primary diagnosis and 42.8% of patients with brain tumour as a secondary diagnosis were admitted to acute care hospital. In comparison, the overall admission rate via the ED was 10.6% in 2005–2006.

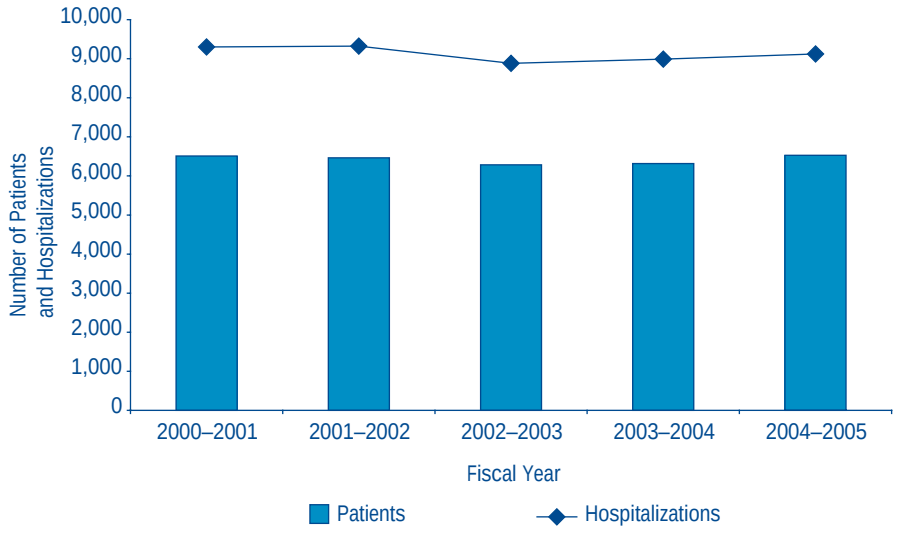
	Patients With BT (Brain Tumour)		
	BT as Primary Diagnosis (%)	BT as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	31.8	55.3	85.3
Admitted to acute care hospital	66.7	42.8	10.6

Source: National Ambulatory Care Reporting System, CIHI.

28

Acute Care Hospitalizations for Patients With Brain Tumours in Canada, 2000–2001 to 2004–2005

Both the number of patients with brain tumours in acute care hospitals and the number of hospitalizations fluctuated minimally between 2000–2001 and 2004–2005.



Source: Hospital Morbidity Database, CIHI.

In 2004–2005, 6,529 patients with brain tumours were hospitalized in acute care, with a total of 128,317 patient days. The average number of hospital stays for patients with brain tumours was 1.4, compared with 1.3 for all acute care inpatients. The median length of stay (LOS) for patients with brain tumours was seven days, compared with four days for all patients in acute care.

Brain tumour was the primary diagnosis in 62.3% of hospitalizations for patients with brain tumours in 2004–2005. When brain tumour was not the primary diagnosis, the most common reasons for hospitalization included reasons other than specific health conditions (for example, observation, follow-up care) (30%), diseases of the nervous system and sense organs (11%) and diseases of the circulatory system (11%).

The readmission rate for patients with brain tumours was 7.5% within 7 days and 18.4% within 30 days of discharge. These are twice the readmission rates of 3.6% and 8.5%, respectively, for all acute care patients.

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Highlights

- Cerebral palsy accounted for $39.7 million in direct costs and $342 million in indirect costs in Canada in 2000–2001.
- 37.3% of patients with cerebral palsy visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations across Canada for patients with cerebral palsy decreased by 16.7% from 2000–2001 to 2004–2005.

Cerebral Palsy

What Is Cerebral Palsy?

Cerebral palsy (CP) is a group of disorders of body movement and posture resulting from damage to the brain that occurs during fetal development, birth or in early childhood.[1] Some risk factors for CP include very low birth weight, multiple births, placental damage, infections and head injury.[1, 2]

Researchers report that CP is the most common physical disability among children.[1] According to the Cerebral Palsy Association, it is estimated that there are over 50,000 Canadians living with CP.[3]

Signs and Symptoms

The signs of CP (except in its mildest forms) usually become obvious as early as 12 months of age.[4] Babies with CP are slow to reach their developmental milestones, such as rolling over, sitting up, crawling and walking.[2]

CP is not progressive and its common symptoms include muscle tightness or spasm, difficulty with gross and fine motor skills and abnormal perception and sensation.[2, 3] However, individuals with CP may also develop seizures, learning difficulties, behavioural problems and difficulties in communicating, swallowing and breathing.[2, 5] CP varies widely in its severity.[1] In its mildest form, it manifests in a slight awkwardness of movement or hand control; in its most severe form, there may be virtually no muscle control and profoundly compromised movement and speech.[1]

Diagnosis and Treatments

Diagnosis of CP is often delayed until a period of observation, extensive physical examinations and brain imaging (CT or MRI) are completed to rule out other neurological conditions.[1] There is no cure for CP. However, there is much that can be done to promote independent living through enhancing functional abilities.[2] This might include surgery, occupational therapy, speech and physical therapy and adaptive equipment.[1] Medications may also be used to control spasticity and seizures.[1]

Economic Burden

The PHAC estimates that total costs associated with CP in 2000–2001 were $381.8 million.

- Direct costs were $39.7 million: $37.1 million (93.2%) for hospital care and $2.7 million (6.8%) for physician care. Drug expenditure estimates were not available.
- Indirect costs were $342.1 million: $90.11 million (26.3%) in mortality cost and $252.02 million (73.7%) in morbidity cost.

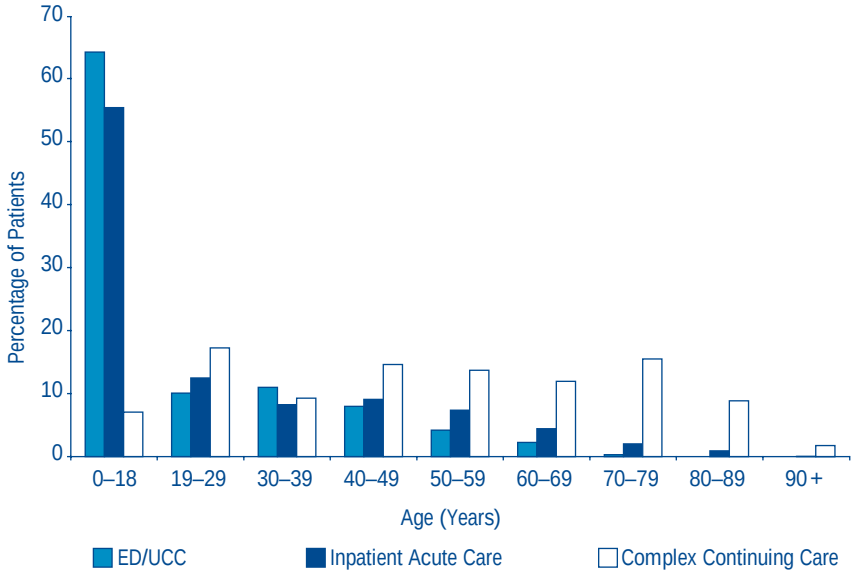
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations, inpatient rehabilitation services and complex continuing care (CCC) for patients with CP.

29

Age Distribution of Patients With Cerebral Palsy Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care and Complex Continuing Care

The majority of patients with CP who used hospital-based services were children (18 years of age and younger).



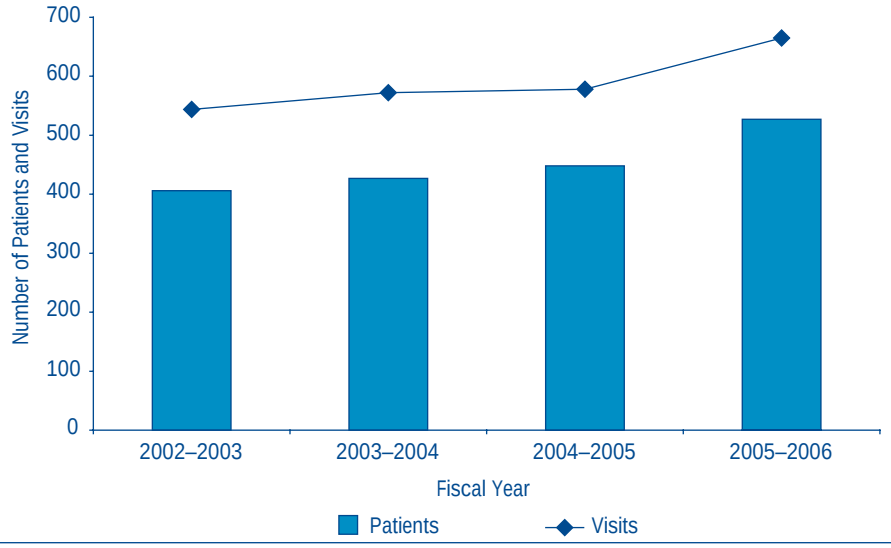
Note: Patients with CP: ED and UCC, n = 527; inpatient acute care, n = 3,109; complex continuing care, n = 226.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

30

ED and UCC Visits by Patients With Cerebral Palsy, 2002–2003 to 2005–2006

Over the four years, the number of patients with CP visiting EDs and UCCs increased from 406 in 2002–2003 to 527 in 2005–2006. The number of ED/UCC visits by these patients also increased (from 544 to 665) between these years. In 2005–2006, on average, persons with CP made 1.3 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this same time period.



Source: National Ambulatory Care Reporting System, CIHI.

31

ED and UCC Visit Disposition of Patients With Cerebral Palsy, 2005–2006

In 2005–2006, 17% of patients with CP as a primary diagnosis and 39.5% of patients with CP as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall admission rate via the ED was 10.6% in 2005–2006.

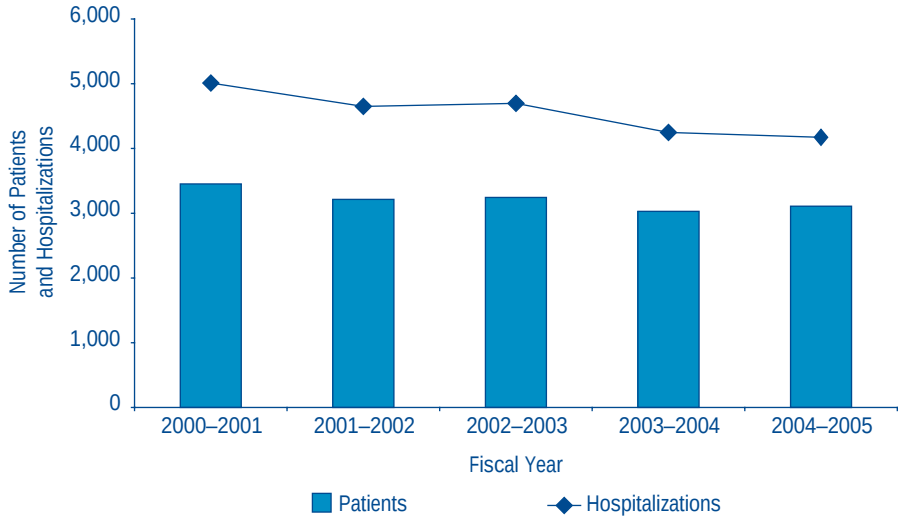
	Patients With CP		
	CP as Primary Diagnosis (%)	CP as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	81.5	58.5	85.3
Admitted to acute care hospital	16.9	39.5	10.6

Source: National Ambulatory Care Reporting System, CIHI.

32

Acute Care Hospitalizations for Patients With Cerebral Palsy in Canada, 2000–2001 to 2004–2005

During the period from 2000–2001 to 2004–2005, both the number of patients with CP in acute care hospitals and the number of hospitalizations for these patients fluctuated. Overall, the number of patients decreased 9.9% from 2000–2001 (n = 3,452) to 2004–2005 (n = 3,109), and the number of hospitalizations decreased 16.7% (from 5,011 to 4,173) between these years.



Source: Hospital Morbidity Database, CIHI.

In 2004–2005, patients with CP had a total of 38,824 patient days. The average number of hospital stays for patients with CP was the same as for all acute care inpatients: 1.3. The median length of stay (LOS) for patients with CP was four days, the same as it was for all inpatients in acute care.

CP was the primary diagnosis in 5.0% of hospitalizations for patients with CP in 2004–2005. When CP was not the primary diagnosis, the most common reasons for hospitalization included diseases of the respiratory system (21%), diseases of the digestive system (14%) and diseases of the musculoskeletal system and connective tissue (14%).

The readmission rate for patients with CP was 4.2% within 7 days and 10.5% within 30 days of discharge. This compares with readmission rates of 3.6% and 8.5%, respectively, for all acute care inpatients.

Complex Continuing Care

In 2005–2006, 226 patients with CP had 257 stays in CCC in Ontario, with a total of 51,754 patient days, which represented 2.6% of the CCC patient days during that year. The number of patient days for patients with CP declined by 38.8% from 2001–2002 to 2005–2006.

In 2005–2006, the median LOS for discharged patients with CP was 150 days, compared with 40 days for all CCC patients. In these two patients groups, 34% and 6% of stays, respectively, were longer than one year.

33

Discharge Disposition of Patients With Cerebral Palsy From Complex Continuing Care, Ontario, 2005–2006

Among the patients with CP who were discharged from CCC in 2005–2006, more than a third (34%) were transferred to acute care hospitals, 23% were transferred to residential care and 26% were sent home. The proportion of patients with CP who died was 17%, compared with 28% among all CCC patients in 2005–2006.

	Patients With CP (%)	All CCC Patients (%)
Discharged home[a]	26	29
Discharged to residential care[b]	23	25
Admitted to acute care hospital	34	17
Died	17	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

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Highlights

- Epilepsy accounted for $99.6 million in direct costs and $698.1 million in indirect costs in Canada in 2000–2001.
- The number of visits to EDs in Ontario by patients with epilepsy decreased 11.9% from 2002–2003 to 2005–2006.
- Around 30% of patients with epilepsy visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations across Canada for patients with epilepsy increased 7.2% from 2000–2001 to 2004–2005.

Epilepsy

What Is Epilepsy?

Epilepsy is a group of neurological disorders characterized by sudden, brief and recurrent seizures resulting from abnormal discharges of electrical activity in the brain.[1] There are two main types of epilepsy: partial (affecting part of the brain) and generalized (affecting the whole brain).[1] While all forms of epilepsy are characterized by some form of seizure, not all seizures are indicative of epilepsy.[1]

A national study estimates that epilepsy affects approximately 0.6% (175,000) of Canadians, and that the incidence is highest during childhood and among the elderly.[3] Approximately 15,500 new cases are diagnosed each year, according to Epilepsy Canada.[1] According to the World Health Organization, epilepsy is a growing worldwide public health problem.[4]

Signs and Symptoms

Signs and symptoms of seizures vary:

- Simple partial seizures are divided into four main categories (motor, sensory, autonomic and psychic) and are not associated with alterations of consciousness or amnesia.[1]
- Complex partial seizures involve altered behaviour and awareness and some change in consciousness, followed by amnesia.[1]
- Generalized absence seizures (formerly called “petit mal seizures”) are characterized by a complete loss of awareness lasting usually less than 10 seconds and are not preceded by a warning.[1]
- Tonic-clonic seizures (formerly called “grand mal seizures”) are a generalized convulsion, which occur in two phases: tonic (manifested in muscle stiffening and loss of consciousness) and clonic (manifested in jerking and twitching of the body extremities). After the seizure, consciousness returns slowly and the individual is often confused or disoriented.[1]

Because the symptoms of seizures are often dramatic, those with epilepsy may encounter social limitations and experience poor quality of life.[5]

Diagnosis and Treatments

Since there is no specific diagnostic test, a detailed medical history is essential in deciding whether seizures are epileptic, and if so, whether they are partial or generalized.[6] Electroencephalograms (EEGs) and brain imaging—computed tomography (CT) and magnetic resonance imaging (MRI)—help in identifying the type of epilepsy and determining the presence of structural lesions causing seizures.[3,6]

Epilepsy may be treated with drugs, surgery or diet.[7] Drug therapy is effective in about two-thirds of patients.[8] Among these, appoximately 70% become seizure-free using a single anti-epileptic drug.[8] However, medication side effects (fatigue, allergies, weight gain or loss, changes in mood and memory problems) are common and can be disruptive.[6] Some types of epilepsy, especially those that affect only one area of the brain, can be treated with surgery.[9] In a recent clinical trial, about half of the participants with temporal lobe epilepsy became seizure-free following surgery, compared with 8% of participants in the drug-therapy group.[7]

Economic Burden

The PHAC estimates that total costs associated with epilepsy in 2000–2001 were $797.7 million.

- Direct costs were $99.6 million: $44.8 million (45%) for hospital care, $25.6 million (25.7%) for physician care and $29.1 million (29.2 %) for drugs.
- Indirect costs associated with epilepsy were $698.1 million: $162.5 million (23.3%) in mortality cost and $535.6 million (76.7%) in morbidity cost.

Disability-Adjusted Life Years (DALYs)

In 2000–2001, PHAC estimates that epilepsy was associated with more than 15,000 DALYs, accounting for 0.3% of the DALYs for all illnesses in Canada. The years of healthy life lost due to disability represented a larger part (62.3%) of the DALYs for epilepsy than the years of life lost due to premature mortality (37.7%).

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.

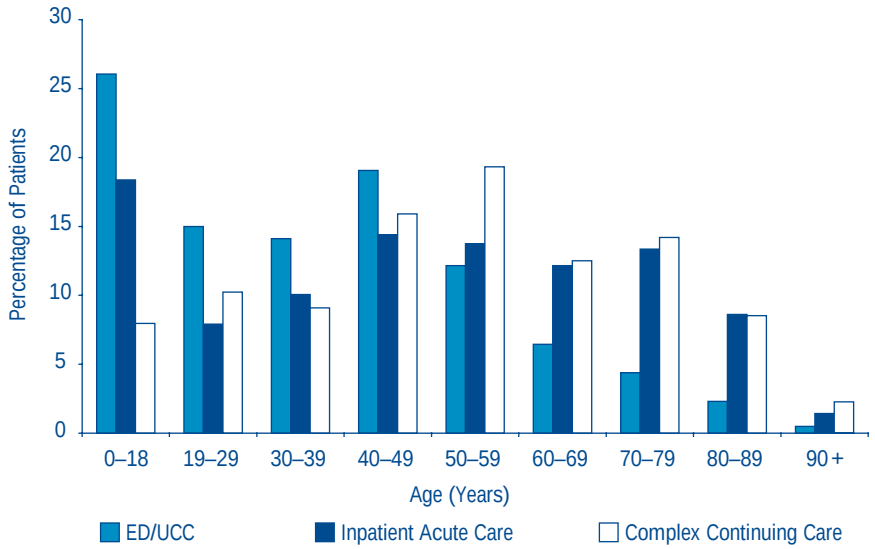
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations and complex continuing care for patients with epilepsy.

3 4

Age Distribution of Patients With Epilepsy Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care and Complex Continuing Care

The majority of patients with epilepsy who used hospital-based services were in the age group of 19- to 59-year-olds. Children (18 years and younger) comprised 26.1% of patients visiting EDs and UCCs and 18.4% of acute care inpatients.



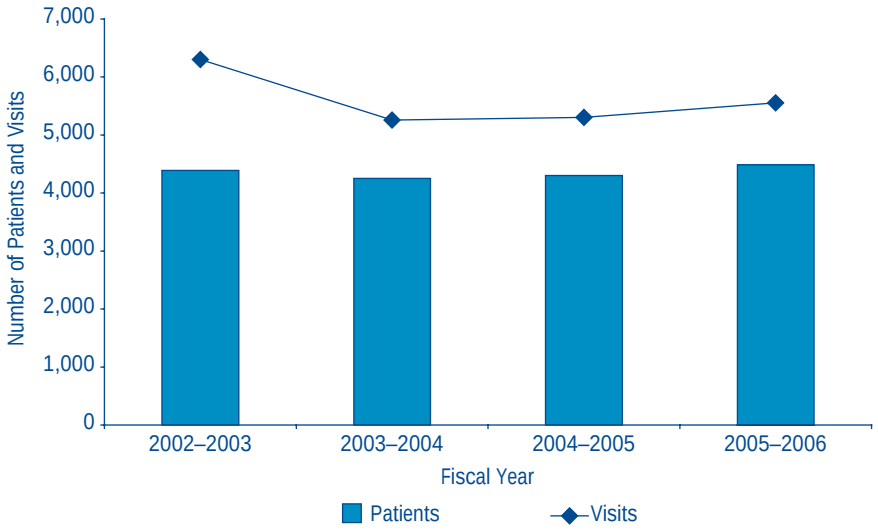
Note: Patients with epilepsy: ED and UCC, n = 4,478; inpatient acute care, n = 8,604; complex continuing care, n = 176.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

3 5

ED and UCC Visits by Patients With Epilepsy, 2002–2003 to 2005–2006

Both the number of patients with epilepsy visiting EDs and UCCs and the number of ED/UCC visits by these patients fluctuated over the four years. The number of patients increased 2.3% from 2002–2003 (n = 4,388) to 2005–2006 (n = 4,487). The number of visits decreased 11.9% (from 6,303 to 5,553) between these years. In 2005–2006, on average, patients with epilepsy made 1.2 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this year.



Source: National Ambulatory Care Reporting System, CIHI.

3 6

ED and UCC Visit Disposition of Patients With Epilepsy, 2005–2006

In 2005–2006, 29% of the patients with epilepsy as a primary diagnosis and 33% of the patients with epilepsy as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall admission rate via the ED was 10.6% in 2005–2006.

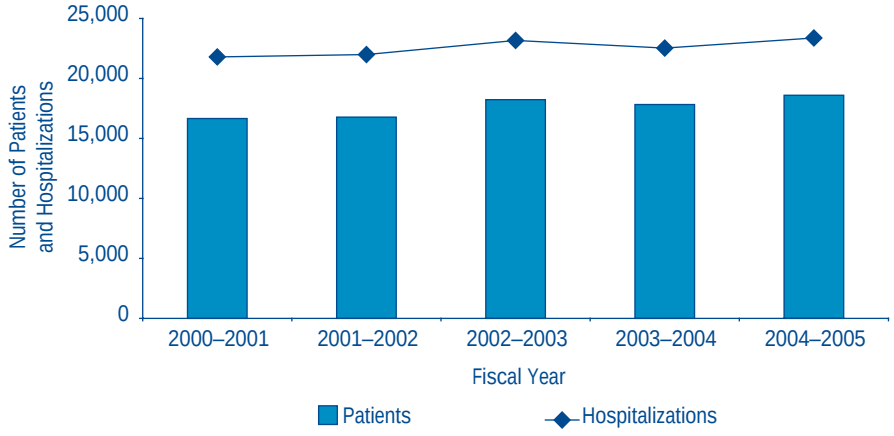
	Patients With Epilepsy		
	Epilepsy as Primary Diagnosis (%)	Epilepsy as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	68.3	63.7	85.3
Admitted to acute care hospital	29.1	33.0	10.6

Source: National Ambulatory Care Reporting System, 2005–2006, CIHI.

3 7

Acute Care Hospitalizations for Patients With Epilepsy in Canada, 2000–2001 to 2004–2005

Both the number of patients with epilepsy in acute care hospitals and the number of hospitalizations for these patients fluctuated during the period from 2000–2001 to 2004–2005. The number of patients increased 11.7% from 2000–2001 (n = 16,659) to 2004–2005 (n = 18,604), and the number of hospitalizations increased 7.2% (from 21,794 to 23,374) between these years. In 2004–2005, 18,604 patients with epilepsy were hospitalized in acute care and had a total of 259,161 patient days, which represented 1.5% of patient days in acute care. The average number of hospital stays for patients with epilepsy was the same as for all acute care inpatients: 1.3.

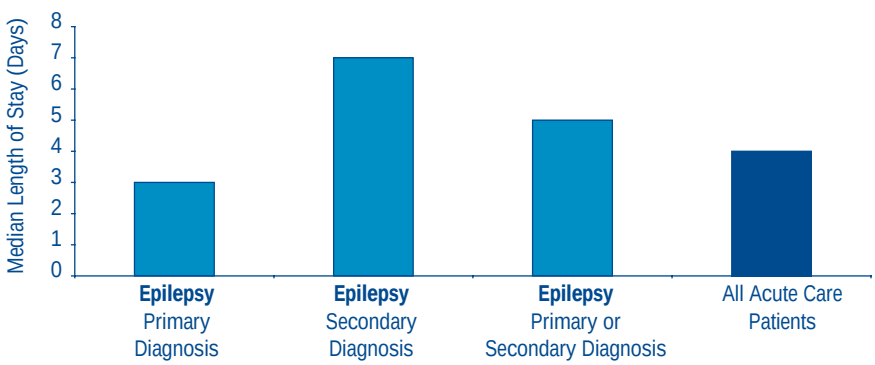


Source: Hospital Morbidity Database, CIHI.

3 8

Median Length of Stay for Patients With Epilepsy in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with epilepsy was five days, compared with four days for all acute care inpatients. The median LOS was three days when epilepsy was the primary diagnosis and seven days when epilepsy was the secondary diagnosis.



Source: Hospital Morbidity Database, CIHI.

Epilepsy was the primary diagnosis in 39.3% of hospitalizations for patients with epilepsy in 2004–2005. When epilepsy was not the primary diagnosis, the most common reasons for hospitalization included diseases of the circulatory system (13%), injury and poisoning (12%) and diseases of the respiratory system (12%).

The readmission rate for patients with epilepsy was 4.1% within 7 days and 9.8% within 30 days of discharge. This compares with readmission rates of 3.6% and 8.5%, respectively, for all acute care inpatients.

Complex Continuing Care

Between 2001–2002 and 2005–2006, 359 patients with epilepsy had a total of 465 stays in a complex continuing care (CCC) bed in Ontario. They had a total of 206,448 patient days, which represented 2% of the patient days in CCC during this same time period.

In 2005–2006, 176 patients with epilepsy had 200 stays in a CCC bed, with a total of 41,781 patient days, which represented 2.1% of CCC patient days during that year. The median LOS for discharged patients with epilepsy was 109 days, compared with 40 days for all CCC patients. In these two patient groups, 25% and 6% of stays, respectively, were longer than one year.

39

Discharge of Patients With Epilepsy From Complex Continuing Care, Ontario, 2005–2006

Almost half of the patients with epilepsy discharged from CCC were transferred to acute care hospitals, and more than a quarter (26%) were discharged to residential care in 2005–2006. Only 18% were discharged home, compared with 29% among all CCC patients.

	Patients With Epilepsy (%)	All CCC Patients (%)
Discharged home[a]	18	29
Discharged to residential care[b]	26	25
Admitted to acute care hospital	48	17
Died	7	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

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Highlights

- Head injuries accounted for $151.7 million in direct costs in Canada in 2000–2001.
- More than 10% of patients with head injury visiting EDs in Ontario in Canada in 2005–2006 were admitted to acute care hospitals.
- Just over 2% of all patients in inpatient rehabilitation services in Ontario in 2005–2006 had head injury.
- 6.4% of CCC patient days in Ontario in 2005–2006 included patients with head injury.
- Patients with head injuries visiting EDs and UCCs in 2005–2006, and hospitalized in acute care in Canada in 2004–2005, were predominantly male: 60.6% and 67.3%, respectively.

Head Injury

What Is Head Injury?

The term “head injury” includes any trauma to the scalp, skull or brain. Head injuries, including traumatic brain injuries (TBI), vary in severity.[1] Mild TBI (concussion) may cause a temporary loss of brain function, while severe TBI may involve fracture of the skull and result in contusions (bruising of the brain) and/or hematomas (bleeding in the brain).[1]

While the prevalence of head injury in Canada is unknown, recent studies have estimated that the annual incidence of severe TBI is 11.4 per 100,000,[2] and of mild TBI 600 per 100,000.[3] According to research, a disproportionate number of head injuries occur in males aged 15 to 24, mostly related to motor vehicle accidents, and head injuries among young children and the elderly are mostly due to falls.[4] About half of deaths from all causes of trauma are due to head injury.[5]

Signs and Symptoms

Any blow to the head should be treated seriously. While severe head injury can cause death and considerable morbidity, even mild head injury can result in long-term disability.[6] Head injury may affect memory, mood, communication, mobility, concentration and problem-solving, and cause impulsivity, loss of control of anger, emotional instability and depression.[1,7,8] Individuals with head injury may have physical disabilities, such as paralysis of the limbs or loss of vision and/or hearing, while some may lose the sense of smell, suffer from headaches or have seizures.

Treatments

The treatment options for head injury are drug therapy and surgery, depending on the type of injury and associated neurological deficits. Drug therapy is used to prevent or treat seizures, decrease brain swelling and control agitation.[1] Surgery may be indicated to relieve increased pressure on the brain and to remove blood clots. After the acute phase of treatment, rehabilitation or continuing care is often required.[6] Psychosocial support is often needed to help patients cope with accompanying problems like depression and anxiety, and to ease the burden on families and/or caregivers.

Economic Burden

The PHAC estimates that the total direct cost associated with head injury in 2000–2001 were $151.7 million: $150.7 million (99.3%) for hospital care, $0.3 million (0.2%) for physician care and $0.7 million (0.5%) for drugs. Indirect cost data were not available.

Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations, inpatient rehabilitation services and complex continuing care for patients with head injury.

Patients with head injuries visiting EDs and UCCs in 2005–2006, and hospitalized in acute care in Canada in 2004–2005, were predominantly male: 60.6% and 67.3%, respectively.

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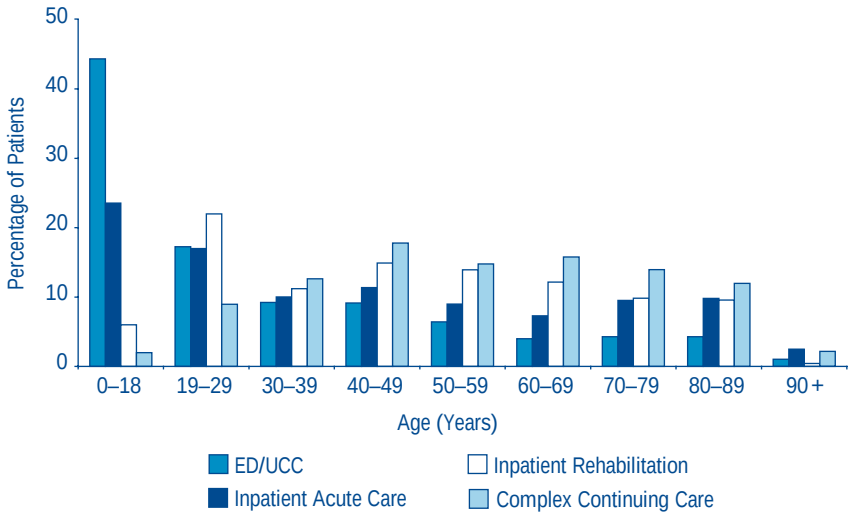
Age Distribution of Patients With Head Injury Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care, Inpatient Rehabilitation and Complex Continuing Care

Children (18 years and younger) represented almost 45% of the patients with head injury visiting EDs and UCCs, and almost 25% of the patients with head injury, hospitalized in acute care. Patients with head injury who were in the age group of 19- to 29-year-olds accounted for almost a quarter of the patients with head injury who received rehabilitation services.



Note: Patients with head injury: ED and UCC, n = 80,970; inpatient acute care, n = 23,609; inpatient rehabilitation, n = 732; complex continuing care, n = 601.

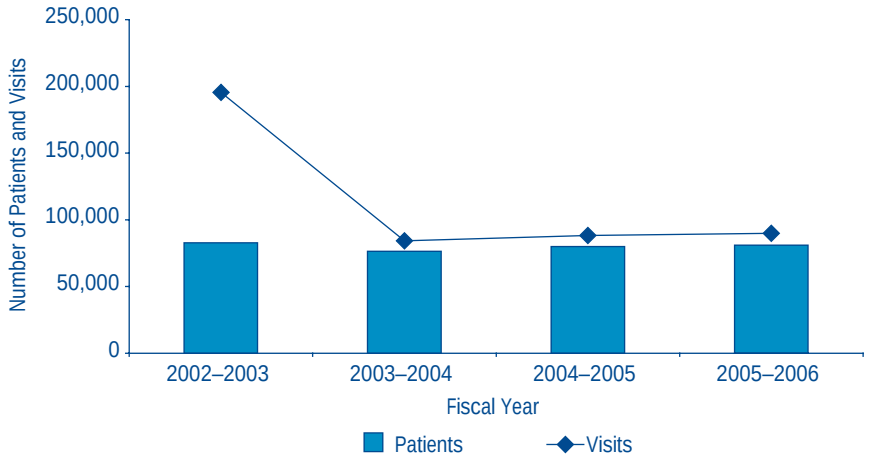
Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); National Rehabilitation Reporting System, 2005–2006, CIHI (includes Ontario and 17 facilities outside of Ontario); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

Head injury was the primary diagnosis in 74.5% of hospitalizations for patients with head injury in 2004–2005. When head injury was not the primary diagnosis, the most common reasons for hospitalization included injury and poisoning (51%), diseases of the circulatory system (8%) and mental disorders (7%).

41

ED and UCC Visits by Patients With Head Injury, 2002–2003 to 2005–2006

Both the number of patients with head injury visiting EDs and UCCs and the number of ED/UCC visits by these patients fluctuated between 2002–2003 and 2005–2006. The number of patients decreased by 2.2% from 2002–2003 (n = 82,831) to 2005–2006 (n = 80,970). The reduction in number of visits between 2002–2003 and 2003–2004 cannot be fully explained at this time. In 2005–2006, patients with head injury, on average, made 1.1 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this year.



Source: National Ambulatory Care Reporting System, CIHI.

42

ED and UCC Visit Disposition of Patients With Head Injury, 2005–2006

In 2005–2006, 8.5% of the patients with head injury as a primary diagnosis and almost one-quarter (22.7%) of the patients with head injury as the secondary diagnosis were admitted via the ED to an acute care hospital. In comparison, the overall admission rate via the ED was 10.6% in 2005–2006.

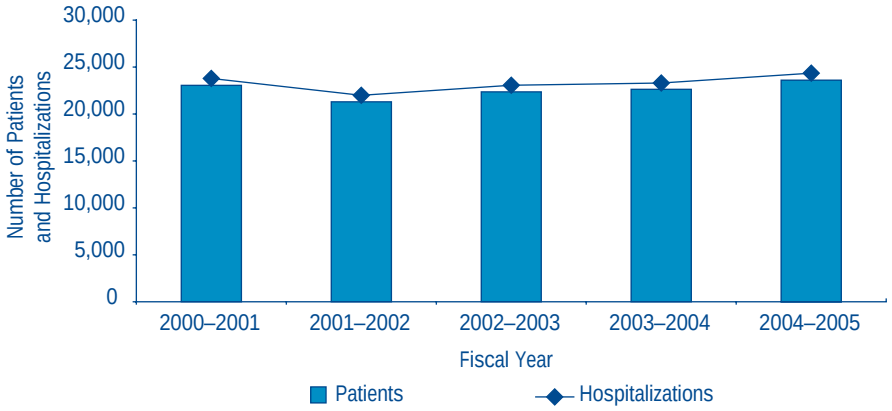
	Patients With HI (Head Injury)		
	HI as Primary Diagnosis (%)	HI as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	86.0	75.4	85.3
Admitted to acute care hospital	8.5	22.7	10.6

Source: National Ambulatory Care Reporting System 2005–2006, CIHI.

4 3

Acute Care Hospitalizations for Patients With Head Injury in Canada, 2000–2001 to 2004–2005

Both the number of patients with head injury admitted to acute care hospitals and the number of hospitalizations for these patients fluctuated during the period from 2000–2001 to 2004–2005. Both the number of patients and the number of hospitalizations increased by 2.4% between 2000–2001 and 2004–2005.



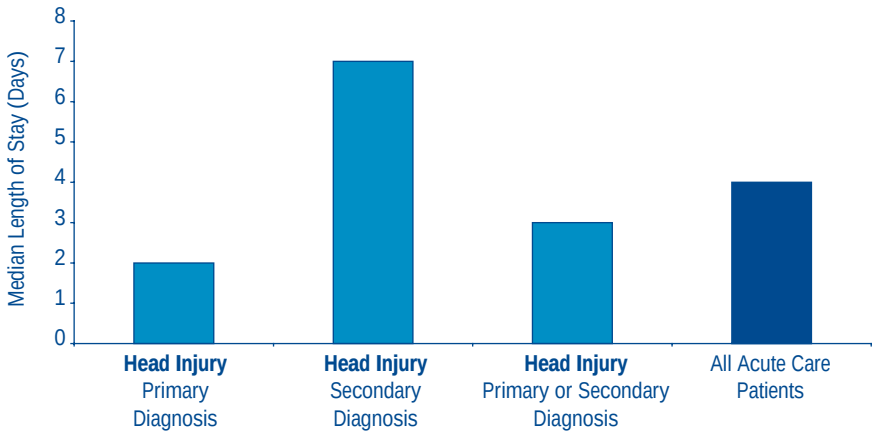
Source: Hospital Morbidity Database, CIHI.

In 2004–2005, 23,609 patients with head injury were hospitalized in acute care and had a total of 240,467 patient days, which represented 1.3% of patient days. Patients with head injury averaged 1 hospital stay in that year, compared with 1.3 hospital stays for all acute care inpatients.

4 4

Median Length of Stay for Patients With Head Injury in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with head injury was three days, compared with four days for all patients in acute care. The median LOS was two days when head injury was the primary diagnosis and seven days when head injury was the secondary diagnosis.



Source: Hospital Morbidity Database, CIHI.

The readmission rate for patients with head injury was 3.0% within 7 days and 5.3% within 30 days of discharge. This compares with readmission rates of 3.6% and 8.5%, respectively, for all acute care inpatients.

Inpatient Rehabilitation Services

In 2005–2006, 732 patients with head injury received inpatient rehabilitation services in Ontario and 17 facilities in other parts of Canada. They had a total of 39,620 patient days, which represented 4.6% of patient days in inpatient rehabilitation services during that year. The active LOS for these patients was 39,347 days. The median LOS for patients with head injury was more than two times that for all patients: 35 days versus 17 days, respectively.

The mean Total Function Score at admission was lower for patients with head injury (80.2) when compared to all rehabilitation inpatients (85.9). At discharge, the mean Total Function Score for patients with head injury was 103.5, indicating a Total Function Score change of 23.4. In contrast, the average Total Function Score change for all rehabilitative patients was 19.6.

Total Function Score is a measure of the rehabilitation clients' overall functional ability. It was measured using the Functional Independence Measure (FIM™)[i] instrument, which assesses disability and caregiver burden associated with the disability. The FIM™ is composed of 18 items (13 for motor disability and 5 for cognitive disability) rated on a scale representing gradation from dependent (1) to independent (7) function. Scores on these items are added to obtain the Total Function Score, which can range from 1 to 126 (higher Total Function Score indicates higher overall level of functioning).

Complex Continuing Care

Seven percent of the patients in CCC between 2001–2002 and 2005–2006 included patients with head injury. The number of patient days for patients with head injury declined by 20.2% from 2001–2002 to 2005–2006.

In 2005–2006, 601 patients with head injury had 673 stays in a CCC bed, with a total of 129,456 patient days, which represented 6.4% of the CCC patient days during that year. The median LOS for patients with head injury was 92 days, compared with 40 days for all CCC patients. In these two patients groups, 28% and 6% of stays, respectively, were longer than one year.

i Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

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Discharge Disposition of Patients With Head Injury From Complex Continuing Care, Ontario, 2005–2006

Almost half (44%) of the patients with head injury discharged from CCC were transferred to acute care hospitals and almost one-quarter (23%) to residential care in 2005–2006. Only 16% were discharged home, compared with 29% among all CCC patients.

	Patients With Head Injury (%)	All CCC Patients (%)
Discharged home[a]	16	29
Discharged to residential care[b]	23	25
Admitted to acute care hospital	44	17
Died	16	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

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Highlights

- Headaches accounted for $411 million in direct costs and $351.2 million in indirect costs in Canada in 2000–2001.
- The number of patients with headaches visiting EDs in Ontario increased 8.2% from 2002–2003 to 2005–2006.
- The number of acute care hospitalizations across Canada for patients with headaches decreased 19% from 2000–2001 to 2004–2005.

Headaches

What Are Headaches?

Headaches can be classified into two main types: primary headaches (tension, migraine or cluster) and secondary headaches caused by other medical conditions and medication overuse (for example, for treatment of primary headaches).[1]

Tension headaches occur in up to 80% to 90% of individuals, according to published reports.[1,2] Researchers estimate that the annual prevalence of migraines is 18% to 33% in women and 6% to 13% in men, and that cluster headaches affect 0.1% of the population.[3,4] Reports indicate that migraines are more prevalent among those 20 to 50 years of age.[1] All primary headaches can be associated with considerable distress, disability, diminished quality of life and financial costs.[1]

Signs and Symptoms

Typical symptoms of tension headaches are mild to moderate pressure and tightness, often like a band around the head.[1] Migraine headaches involve a moderate to severe throbbing or pulsating pain, usually on one side of the head, often accompanied by nausea, vomiting and sensitivity to light or sound.[1] Menstruation, stress, anxiety and head and neck trauma may predispose patients to migraine attacks.[1,5] Cluster headaches are usually excruciating, with a penetrating quality.[1] They are frequently recurrent, short-lasting and always occur on one side of the head, accompanied by tearing, redness of the eye, nasal congestion and swelling.[1,2] Medication-overuse headaches are often more frequent upon awakening, and tend to be exacerbated by physical exertion.[1]

Diagnosis and Treatments

Primary headaches can usually be diagnosed with a detailed clinical assessment and symptom diaries.[1] To diagnose secondary headaches, a comprehensive neurologic examination and tests are required to determine the underlying cause of the headache.[1]

There are currently no cures for primary headaches, but a variety of drugs are available for symptom management.[1] For secondary headaches, the best approach is to treat the underlying cause.[1]

Economic Burden

The PHAC estimates that the total costs associated with headaches in 2000–2001 were $762.17 million.

- Direct costs were $411 million: $106.5 million (25.9%) for hospital care, $74.2 million (18.1%) for physician care and $230.3 million (56%) for drugs.
- Morbidity costs of $351.2 million made up 100% of the indirect costs. There were no mortality costs associated with headache.

Disability-Adjusted Life Years (DALYs)

The PHAC estimates that in 2000–2001, headaches were associated with almost 37,000 DALYs, accounting for 0.7% of the DALYs for all illnesses in Canada (includes years of healthy life lost due to disability and not life lost due to premature mortality).

Hospital Utilization

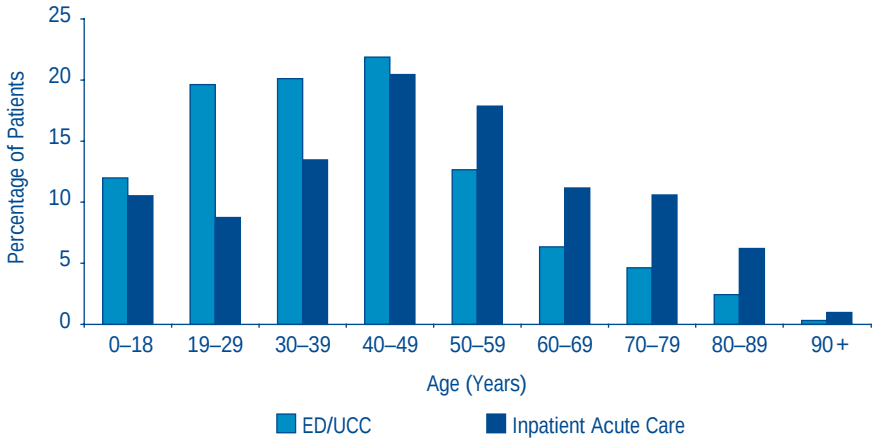
CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, and acute care hospitalizations for patients with headaches.

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.

4 6

Age Distribution of Patients With Headaches Using Hospital Services, Including EDs and UCCs and Inpatient Acute Care

The majority of adult patients with headaches who used hospital-based services were in the age group 19 to 59 years. Children (18 years of age and younger) represented 12.0% of patients with headaches who visited EDs and UCCs and 10.5% of patients with headaches who were hospitalized.



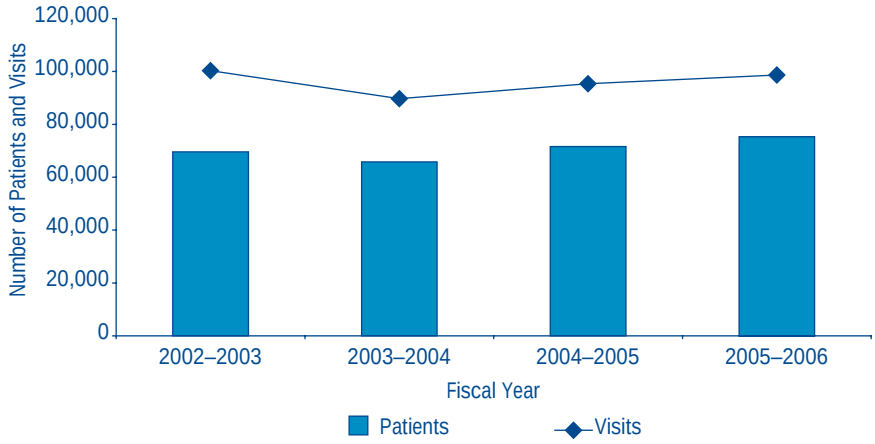
Note: Patients with headache: ED and UCC, n = 75,320; inpatient acute care, n = 15,239.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories).

47

ED and UCC Visits by Patients With Headache, 2002–2003 to 2005–2006

The number of patients with headaches visiting EDs and UCCs and the number of ED/UCC visits by these patients fluctuated over the four years. Overall, the number of patients increased by 8.2% from 2002–2003 (n = 69,627) to 2005–2006 (n = 75,320). In contrast, the number of visits decreased 1.7% (from 100,322 to 98,659) between these years. In 2005–2006, on average, persons with headaches made 1.3 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this same time period.



Source: National Ambulatory Care Reporting System, CIHI.

48

ED and UCC Visit Disposition of Patients With Headaches, 2005–2006

In 2005–2006, 3% of the patients with headaches as a primary diagnosis and 11% of the patients with headaches as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall admission rate via the ED was 10.6% in 2005–2006.

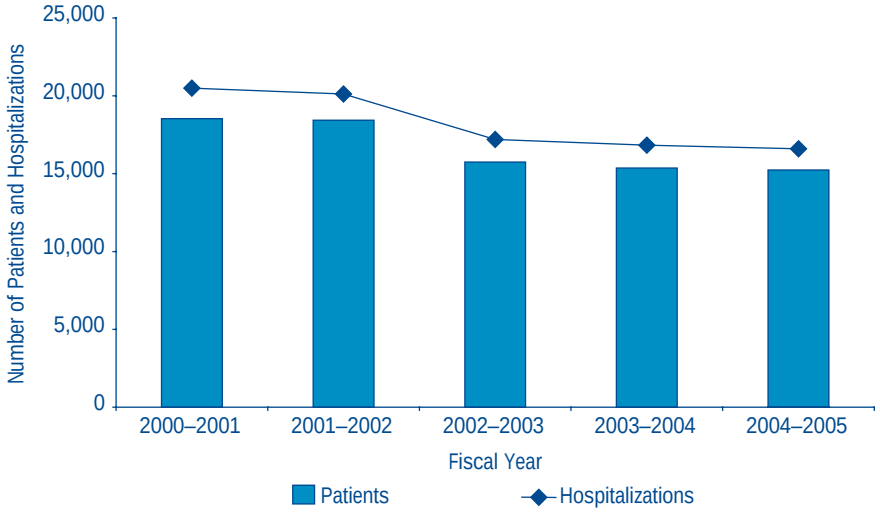
	Patients With Headache		
	Headache as Primary Diagnosis (%)	Headache as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	89.3	84.9	85.3
Admitted to acute care hospital	3.0	10.8	10.6

Source: National Ambulatory Care Reporting System 2005–2006, CIHI.

49

Acute Care Hospitalizations for Patients With Headaches in Canada, 2000–2001 to 2004–2005

Both the number of patients with headaches in acute care hospitals and the number of hospitalizations for these patients decreased during the period 2000–2001 to 2004–2005. The number of patients decreased by 17.8% from 2000–2001 (n = 18,534) to 2004–2005 (n = 15,239), and the number of stays declined 19% (from 20,497 to 16,598) between these years.



Source: Hospital Morbidity Database, CIHI (includes all provinces and territories).

In 2004–2005, patients with headaches had a total of 132,057 patient days. The average number of hospital stays was 1.1, compared with 1.3 for all acute care inpatients.

The median length of stay (LOS) for patients with headaches was the same as for all acute care inpatients: four days. The median LOS was two days when headaches were the primary diagnosis and five days when headaches were the secondary diagnosis.

Headache was the primary diagnosis in 26.1% of hospitalizations for patients with headache in 2004–2005. When headache was not the primary diagnosis, the most common reasons for hospitalization included diseases of the circulatory system (15%), symptoms, signs and ill-defined conditions (13.3%) and mental disorders (10%).

The readmission rate for patients with headaches was 3.5% within 7 days and 7.3% within 30 days of discharge. This compares with readmission rates of 3.6% and 8.5%, respectively, for all acute care inpatients.

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Highlights

- Multiple sclerosis accounted for $139 million in direct costs and $811.3 million in indirect costs in Canada in 2000–2001.
- The number of visits to EDs in Ontario by patients with multiple sclerosis increased 15.7% from 2002–2003 to 2005–2006.
- Almost 30% of patients with multiple sclerosis visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- In 2004–2005, almost 5,000 patients with multiple sclerosis were hospitalized in acute care across Canada.

Multiple Sclerosis

What Is Multiple Sclerosis?

Multiple sclerosis (MS) is a disabling disease resulting from the inflammation and damage of nerve cells of the brain and spinal cord.[1,2] There are two main types of MS: relapsing-remitting MS (characterized by episodic relapses and remissions) and primary-progressive MS (characterized by a steady, slow progression).[1] The relapsing-remitting MS is more frequent, occurring in 85% of patients.[1] The cause of MS is not known, but probably involves genetic, viral and environmental factors.[2]

According to research, MS is the most common disabling neurological condition in young adults worldwide.[1] It affects up to three times as many women as men, with a typical age of onset between 20 and 50 years, according to a published report.[2] The Multiple Sclerosis Society of Canada estimates that there are currently 55,000 to 75,000 patients with MS in Canada; this is one of the highest prevalence rates of MS in the world.[3]

Signs and Symptoms

The first symptoms of MS may be the disruption of vision in one eye and change of sensation.[1] New symptoms occur months or years later, and can include vision difficulties, muscle weakness, loss of balance and coordination, pain, extreme fatigue, bladder and bowel problems and changes in cognitive functions.[1,2] These symptoms tend to vary in severity. Approximately 15% of people with relapsing-remitting MS experience minimal disability 15 years after diagnosis. This form of MS is referred to as benign MS.[1] However, many patients with relapsing-remitting MS eventually enter a phase of steady worsening known as secondary-progressive MS.[1]

Diagnosis and Treatments

MS is diagnosed on the basis of evidence of two disease episodes, and is achieved through a detailed medical history and neurological examination.[1,2] Diagnosis is confirmed by brain and spinal cord imaging (magnetic resonance imaging or MRI).[2]

The treatment of MS is aimed at relieving symptoms, preventing disease relapse and patient rehabilitation.[1,4] The disease-modifying medications mainly benefit patients with the relapsing-remitting MS and are more effective when introduced early.[1] These medications reduce the frequency and severity of relapses and thus slow the progression of disability.[4] Patients with MS also require therapies for accompanying conditions, such as pain, fatigue, depression and bladder/bowel problems.[1,2] Occupational therapy, rehabilitation services and psychosocial support are often needed to help with activities of daily living and diminished quality of life.[2]

Economic Burden

The PHAC estimates that the total costs associated with MS in 2000–2001 were $950.5 million.

- Direct costs were $139.2 million: $58.4 million (42%) for hospital care, $12.1 million (8.7%) for physician care and $68.7 million (49.4%) for drugs.
- Indirect costs were $811.3 million: $172.8 million (21.3%) in mortality costs and $638.45 million (78.7%) in morbidity costs.

Disability-Adjusted Life Years

The PHAC estimates that in 2000–2001, MS was associated with 13,677 DALYs. The years of life lost due to premature mortality represented a larger component (57.1%) of the DALYs for MS than the years of healthy life lost due to disability (42.9%).

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.

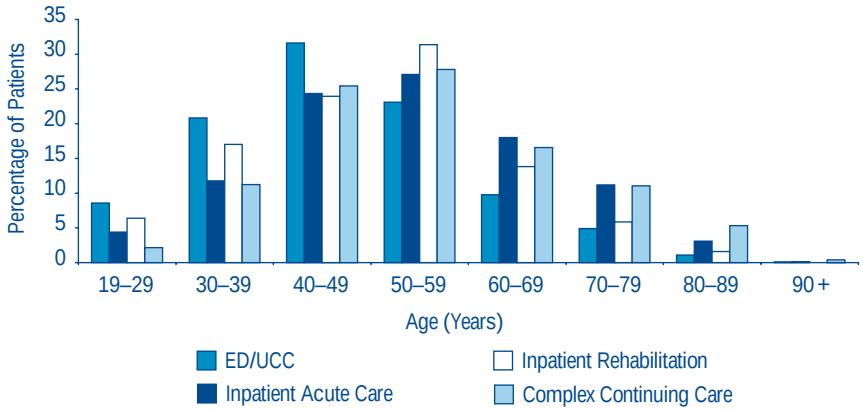
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations, inpatient rehabilitation services and complex continuing care for patients with MS.

50

Age Distribution of Patients With Multiple Sclerosis Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care, Inpatient Rehabilitation and Complex Continuing Care

The majority of patients with MS who used hospital-based services were in the age group 40 to 59 years.



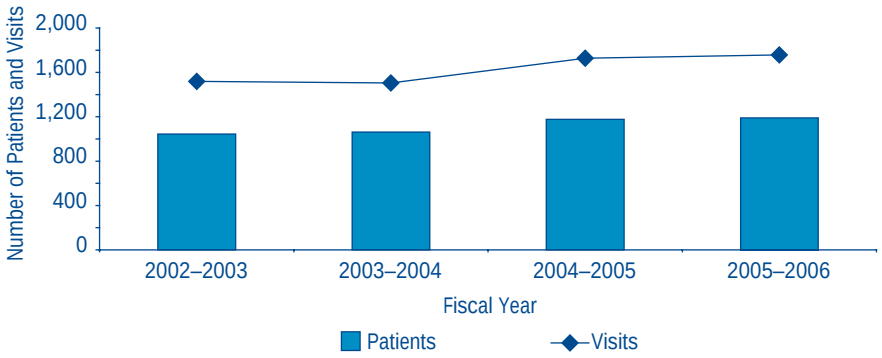
Note: Patients with MS: ED and UCC, n = 1,190; inpatient acute care, n = 4,922; inpatient rehabilitation, n = 188; complex continuing care, n = 507.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); National Rehabilitation Reporting System, 2005–2006, CIHI (includes Ontario and 17 facilities outside of Ontario); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

5 1

ED and UCC Visits by Patients With Multiple Sclerosis, 2002–2003 to 2005–2006

Both the number of patients with MS visiting EDs and UCCs and the number of ED/UCC visits by these patients increased over the four years. The number of patients increased by 14%, from 1,044 in 2002–2003 to 1,190 in 2005–2006, and the number of visits increased by 15.7% (from 1,519 to 1,758) between these years. In 2005–2006, on average, persons with MS made 1.5 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population 19 years of age and older during this year.



Note: Based on patients 19 years and older.

Source: National Ambulatory Care Reporting System, CIHI.

5 2

ED and UCC Visit Disposition of Patients With Multiple Sclerosis, 2005–2006

In 2005–2006, 28% of the patients with MS as a primary diagnosis and 30% of the patients with MS as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall admission rate via the ED for persons 19 years of age and older was 12.6% in 2005–2006.

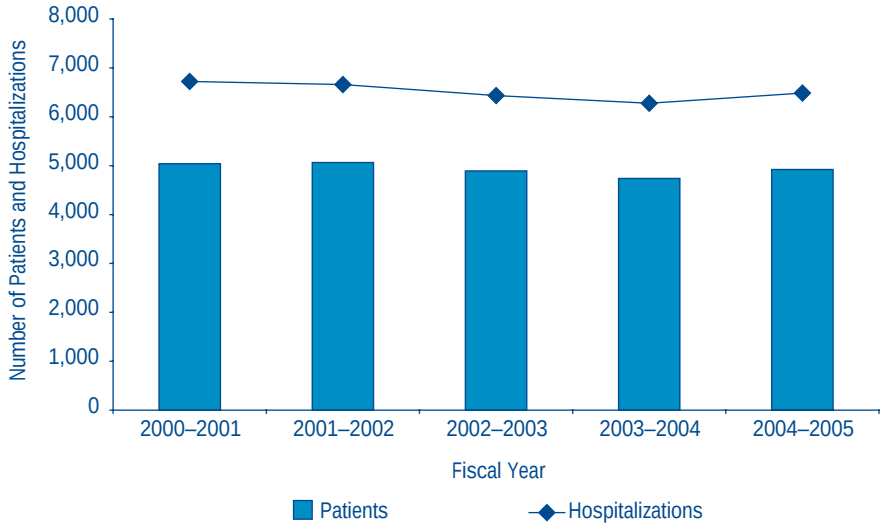
	Patients With MS Aged 19 and Older		
	MS as Primary Diagnosis (%)	MS as Secondary Diagnosis (%)	All ED/UCC Patients Aged 19 and Older (%)
Discharged home	70.4	69.0	83.3
Admitted to acute care hospital	28.0	29.8	12.6

Source: National Ambulatory Care Reporting System, CIHI.

5 3

Acute Care Hospitalizations for Patients With Multiple Sclerosis in Canada, 2000–2001 to 2004–2005

Both the number of patients with MS in acute care hospitals and the number of hospitalizations for these patients fluctuated slightly during the period from 2000–2001 to 2004–2005. The number of patients with MS decreased 2.3% from 2000–2001 (n = 5,039) to 2004–2005 (n = 4,922), and the number of hospitalizations decreased 3.5% (from 6,723 and 6,486) between these years.



Note: Based on patients 19 years of age and older.

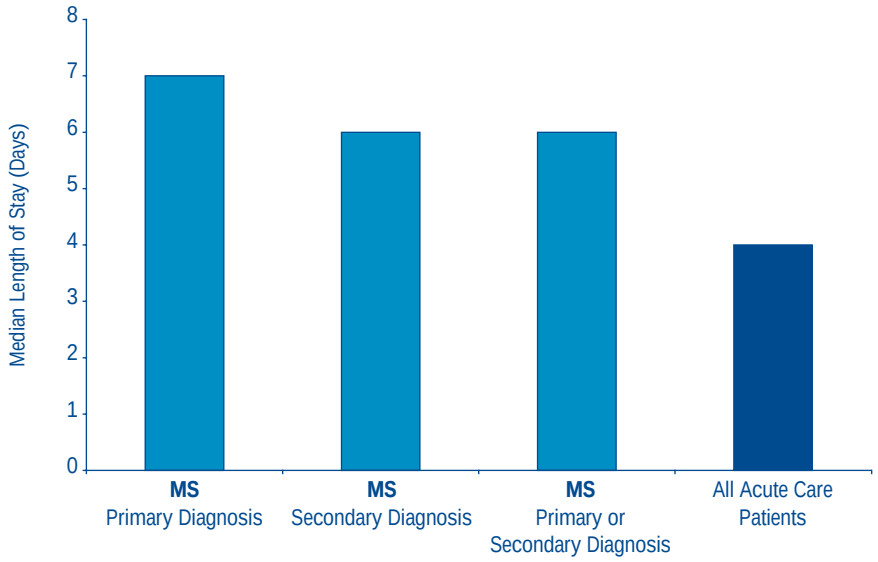
Source: Hospital Morbidity Database, CIHI.

In 2004–2005, patients with MS had a total of 81,328 acute care patient days. The average number of hospital stays was 1.4, compared with 1.3 for all acute care inpatients 19 years and older.

5 4

Median Length of Stay for Patients With Multiple Sclerosis in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with MS was six days, compared with four days for all patients in acute care aged 19 years and older. When MS was the primary diagnosis, the median LOS was seven days.



Note: Based on patients 19 years of age and older.

Source: Hospital Morbidity Database, CIHI.

MS was the primary diagnosis in 23.8% of hospitalizations for patients with MS in 2004–2005. When MS was not the primary diagnosis, the most common reasons for hospitalization included diseases of the genitourinary system (16%), diseases of the respiratory system (13%) and diseases of the digestive system (10%).

The readmission rate for patients with MS was 3.1% within 7 days and 8.3% within 30 days of discharge. This compares with readmission rates of 3.8% and 9.0%, respectively, for all acute care patients 19 years and older.

Total Function Score is a measure of the rehabilitation clients' overall functional ability. It was measured using the Functional Independence Measure (FIM™)[i] instrument, which assesses disability and caregiver burden associated with the disability. The FIM™ is composed of 18 items (13 for motor disability and 5 for cognitive disability) rated on a scale representing gradation from dependent (1) to independent (7) function. Scores on these items are added to obtain the Total Function Score, which can range from 1 to 126 (a higher Total Function Score indicates a higher overall level of functioning).

Inpatient Rehabilitation Services

In 2005–2006, 188 patients with MS had a total of 7,898 inpatient rehabilitation patient days in Ontario and 17 hospitals in other parts of Canada. Their median LOS was 35 days, compared with 17 days for all patients 19 years of age and over.

The mean Total Function Score at admission for patients with MS (81.6) was lower than the mean Total Function Score for all rehabilitation patients 19 years of age and over (85.9). At discharge, the mean Total Function Score for patients with MS was 94.9, indicating a Total Function Score change of 13.2 points. In contrast, the Total Function Score change for all rehabilitation patients 19 years and over was 19.6.

i Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

Complex Continuing Care

Between 2001–2002 and 2005–2006, 1,256 patients with MS had 1,856 stays in Ontario. These patients had a total of 750,913 patient days, which represented 7.2% of the patient days in CCC. The median LOS for discharged patients with MS was 131 days, compared with 41 days among the overall CCC patient population 19 years of age and older over these years. In these two patient groups, 34% and 8% of stays, respectively, were longer than one year. The number of patient days for patients with MS declined by 33.2% from 2001–2002 to 2005–2006.

In 2005–2006, 507 patients with MS had 601 stays in a CCC bed, with a total of 120,364 patient days, which represented 5.9% of the CCC patient days during that year.

55

Discharge Disposition of Patients With Multiple Sclerosis From Complex Continuing Care, Ontario, 2005–2006

More than a third of the patients with MS discharged from CCC in 2005–2006 were transferred to acute care hospitals, and 17% were transferred to residential care. One-fifth of these patients died during their stays in CCC in that year, compared with 28% among all CCC patients 19 years of age and over. Patients with MS were as likely to be discharged home as an average CCC patient.

	Patients With MS Aged 19 and Older (%)	All CCC Patients Aged 19 and Older (%)
Discharged home[a]	28	29
Discharged to residential care[b]	17	25
Admitted to acute care hospital	34	17
Died	20	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

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Highlights

- Parkinson’s disease accounted for $201.9 million in direct costs and $245 million in indirect costs in Canada in 2000–2001.
- The number of visits to EDs in Ontario by patients with Parkinson’s disease increased 10.5% between 2002–2003 and 2005–2006.
- Almost 40% of patients with Parkinson’s disease visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations across Canada for patients with Parkinson’s disease decreased 10.6% from 2000–2001 to 2004–2005.

Parkinson's Disease

What Is Parkinson's Disease?

Parkinson's disease (PD) is a slowly progressing neuro-degenerative disease that affects muscle movement and control, leading to severe limitations in daily activity and quality of life.[1] PD results from the loss of nerve cells in the part of the brain called the substantia nigra.[2] These nerve cells supply the neurotransmitter dopamine, which acts as a messenger between the cells of the brain that control the body's movements.[2]

According to the Parkinson Society Canada, nearly 100,000 Canadians have PD, and it affects 1% of the population over age 65 and 2% of those aged 70 and older.[2,3] Because it is more common among the elderly, the numbers of new cases of PD are expected to rise as the population ages.[2]

Signs and Symptoms

Symptoms and signs of PD often appear around the age of 60, but can occasionally present in much younger people.[3] Symptoms tend to fluctuate and intensify over time.[2] Individuals often experience significant disability 10 to 15 years after they have been diagnosed with PD.[2]

Common indications of PD include tremors on one side of the body when at rest, bradykinesia (slow movements) and stiff or rigid muscles.[2] Two of these must be present to make the diagnosis.[2] In addition, a person with PD may experience depression and anxiety, handwriting difficulties, diminished voice volume, fatigue and sleep disorders, numbness and pain.[2] Typically, the symptoms and signs move from one to both sides of the body with a decrease in mobility, leading to reliance on others for activities of daily living.[2]

Diagnosis and Treatments

PD is diagnosed through clinical assessment based on a medical history and a complete neurological examination.[2] There are no blood or diagnostic imaging tests that can definitively diagnose PD at this time.[2]

Though there is no cure for PD, various pharmaceutical and surgical treatments can help manage symptoms and improve quality of life.[2] Some drugs help to improve symptoms such as tremors and rigidity and some drugs help to slow the progression of the disease.[1,4] However, due to side effects, drugs tend to be prescribed only when symptoms are significantly affecting a person's daily activities and quality of life.[2] There are various surgical options (such as deep brain stimulation) that can be used when drug treatment is unsuccessful or causing intolerable side effects.[1] Because of the risks involved, surgery may not be an option for all persons with PD.[1]

Economic Burden

The PHAC estimates that the total costs associated with PD in 2000–2001 were $446.8 million.

- Direct costs were $201.9 million: $89.2 million (44.2%) for hospital care, $13.4 million (6.6%) for physician care and $99.3 million (49.2%) for drugs.
- Indirect costs were $244.9 million: $93.8 million (38.3%) in mortality cost and $151.14 million (61.7%) in morbidity cost.

Disability-Adjusted Life Years (DALYs)

The PHAC estimates that in 2000–2001, PD was associated with almost 53,000 DALYs, accounting for 1.1% of DALYs for all illnesses in Canada. The years of healthy life lost due to disability represented a larger component (72.2%) of the DALYs for PD than the years of life lost due to premature mortality (27.8%).

Hospital Utilization

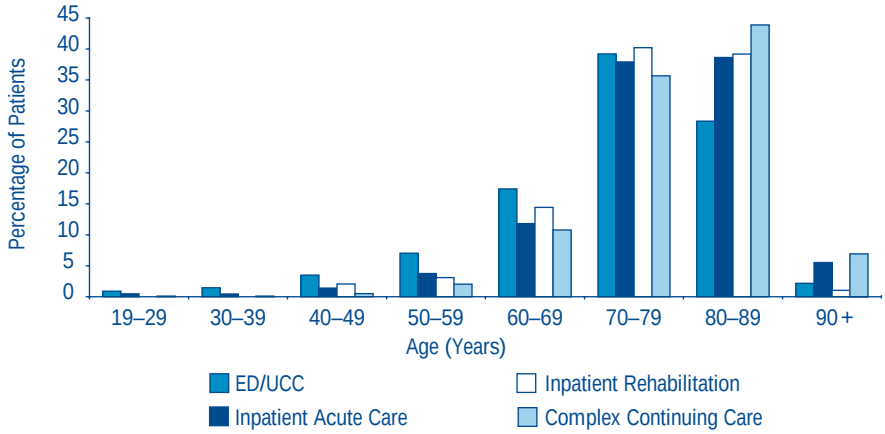
CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits and acute care, inpatient rehabilitation and complex continuing care (CCC) hospitalizations for patients with PD.

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.

5 6

Age Distribution of Patients With Parkinson's Disease Using Hospital Services, Including ED and UCC Visits, Inpatient Acute Care, Inpatient Rehabilitation and Complex Continuing Care

The majority of patients with PD who used hospital-based services were 70 years of age or older.



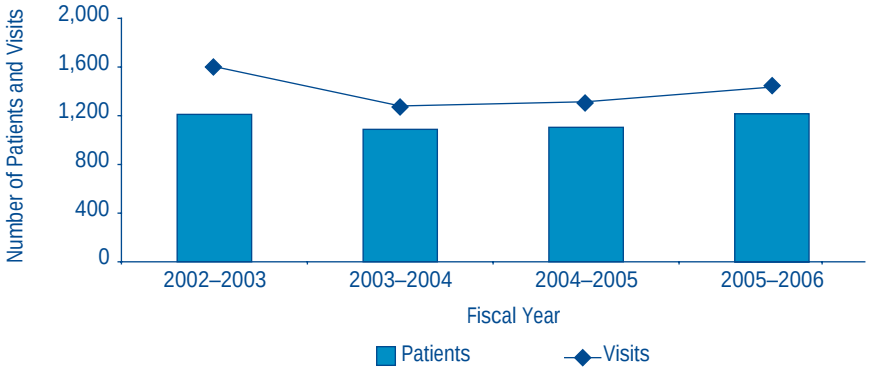
Note: Patients with PD: ED and UCC, n = 1,216; inpatient acute care, n = 11,714; inpatient rehabilitation, n = 97; complex continuing care, n = 984.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); National Rehabilitation Reporting System, 2005–2006, CIHI (includes Ontario and 17 facilities outside of Ontario); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

5 7

ED and UCC Visits by Patients With Parkinson's Disease, 2002–2003 to 2005–2006

The number of patients with PD visiting EDs and UCCs during the period from 2002–2003 to 2005–2006 fluctuated slightly. The number of visits decreased by 10.5% (from 1,604 to 1,436) between these years. In 2005–2006, 1,216 patients with PD visited EDs and UCCs and, on average, made 1.2 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this year.



Note: Based on patients 19 years of age and older.

Source: National Ambulatory Care Reporting System, CIHI.

5 8

ED and UCC Visit Disposition of Patients With Parkinson's Disease, 2005–2006

In 2005–2006, one-third (33.5%) of the patients with PD as a primary diagnosis, and almost half (46.6%) of the patients with PD as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall admission rate via the ED was 12.6% in 2005–2006 for patients 19 years of age and older.

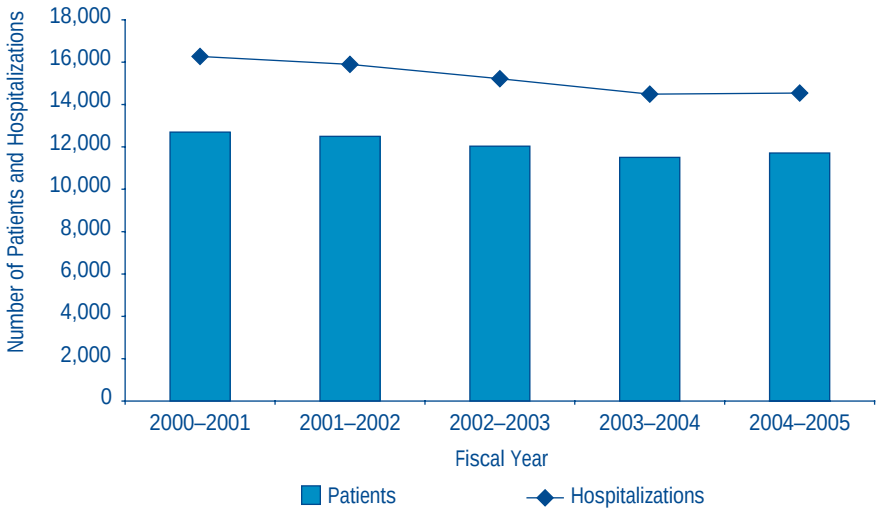
	Patients With PD Aged 19 and Older		
	PD as Primary Diagnosis (%)	PD as Secondary Diagnosis (%)	All ED/UCC Patients Aged 19 and Older (%)
Discharged home	65.0	51.6	83.3
Admitted to acute care hospital	33.5	46.6	12.6

Source: National Ambulatory Care Reporting System, CIHI.

5 9

Acute Care Hospitalizations for Patients With Parkinson's Disease in Canada, 2000–2001 to 2004–2005

Both the number of patients with PD in acute care hospitals and the number of hospitalizations for these patients decreased over the five years of this study. The number of patients decreased by 7.8% from 2000–2001 (n = 12,700) to 2004–2005 (n = 11,714), and the number of hospitalizations declined by 10.6%, from 16,271 in 2000–2001 to 14,543 in 2004–2005.



Note: Based on patients 19 years of age and older.

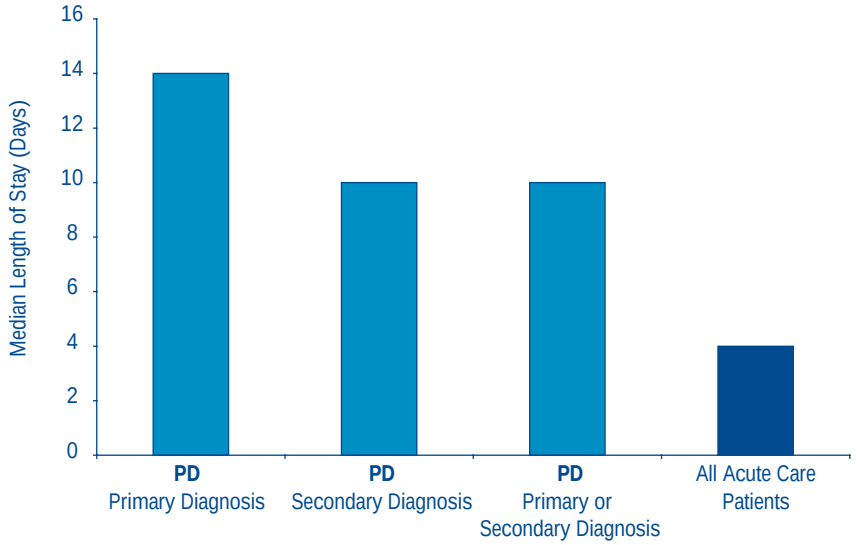
Source: Hospital Morbidity Database, CIHI.

In 2004–2005, patients with PD had a total of 291,055 patient days. The average number of hospital stays for patients with PD was 1.2, compared with 1.3 for all acute care inpatients 19 years and older.

60

Median Acute Care Length of Stay for Patients With Parkinson's Disease in Canada, 2004–2005

The median length of stay (LOS) for patients with PD was 10 days, compared with 4 days for all patients in acute care aged 19 and older. When PD was the primary diagnosis, the median LOS was 14 days.



Note: Based on patients 19 years of age and older.

Source: Hospital Morbidity Database, CIHI.

PD was the primary diagnosis in 15.1% of hospitalizations for patients with PD in 2004–2005. When PD was not the primary diagnosis, the most common reasons for hospitalization included diseases of the circulatory system (16%), diseases of the respiratory system (14%) and injury and poisoning (12%).

The readmission rate for patients with PD was 4.4% within 7 days and 11.7% within 30 days of discharge. This compares with readmission rates of 3.8% and 9.0%, respectively, for all acute care patients of the same age.

Inpatient Rehabilitation Services

In 2005–2006, there were 97 patients with PD receiving inpatient rehabilitation services in Ontario and 17 hospitals in other parts of Canada. They had a total of 2,670 patient days and their median LOS was 23 days, compared with 17 days for all patients.

The mean Total Function Score at admission was lower for patients with PD (77.5) compared with all rehabilitation patients 19 years of age and older (85.9). At discharge, the mean Total Function Score for patients with PD was 94.5, indicating a Total Function Score change of 17.0 points. In contrast, the Total Function Score change for all rehabilitation patients 19 years of age and older was 19.6.

Complex Continuing Care

In 2005–2006, 984 patients with PD had 1,041 stays in a CCC bed, with a total of 118,757 patient days, which represented 5.9% of the CCC patient days during that year. The median LOS for discharged patients with PD was 47 days, compared with 40 days for all CCC patients 19 years of age and older. The number of patient days for patients with PD declined by 18.2% from 2001–2002 to 2005–2006.

Total Function Score is a measure of the rehabilitation clients' overall functional ability. It was measured using the Functional Independence Measure (FIM™)[i] instrument, which assesses disability and caregiver burden associated with the disability. The FIM™ is composed of 18 items (13 for motor disability and 5 for cognitive disability) rated on a scale representing gradation from dependent (1) to independent (7) function. Scores on these items are added to obtain the Total Function Score, which can range from 1 to 126 (a higher Total Function Score indicates a higher overall level of functioning).

61

Discharge of Patients With Parkinson's Disease From Complex Continuing Care, Ontario, 2005–2006

One-third of the patients with PD discharged from CCC were transferred to a residential care setting, and 16% were transferred to acute care hospitals in 2005–2006. Almost one-quarter of these patients died during their stays in CCC in that year, compared with 28% among all CCC patients aged 19 years and older.

	Patients With PD Aged 19 and Older (%)	All CCC Patients Aged 19 and Older (%)
Discharged home[a]	27	29
Discharged to residential care[b]	33	25
Admitted to acute care hospital	16	17
Died	23	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

i Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

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Highlights

- Hospital costs for spinal injuries accounted for $61.6 million in Canada in 2000–2001.
- Almost 50% of patients with spinal injuries visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations across Canada for patients with spinal injuries increased 8.7% from 2000–2001 to 2004–2005.

Spinal Injuries

What Are Spinal Injuries?

There are two main types of injury to the spine: spinal injuries and spinal cord injuries. Spinal injuries involve only damage to the bones or ligaments of the spine (vertebrae), while spinal cord injuries involve damage to the spinal cord. The spinal cord may be damaged by bone fragments or disc herniations that result from fracture or dislocation of the vertebrae. The incidence of spinal injuries without neurological involvement is unknown. Both spinal injuries and spinal cord injuries are most frequently caused by motor vehicle crashes, falls and sports or recreational activities.[1] According to the Canadian Paraplegic Association, motor vehicle crashes account for 35% of all spinal cord injuries.[1]

The Canadian Paraplegic Association estimates that about 900 Canadians sustain a spinal cord injury each year, 80% of whom are male and between the ages of 15 and 34 years.[1,2]

Signs and Symptoms

Since the spinal cord is the primary neurological pathway conducting messages from the brain to the body parts, spinal cord injuries are often disabling due to the paralysis that occurs.[1] The degree of paralysis depends upon the level and severity of injury.[1] Patients may experience pain, loss of sensation, partial or total paralysis of arms or legs, and loss of control of bladder and bowel function.[1] Injury in the thoracic part of the spine or below results in paraplegia (that is, paralysis of the legs and trunk, and usually loss of bladder control and sexual function).[1] Injury in the cervical part of the spine (neck) results in quadriplegia (that is, paralysis of all four limbs and the trunk).[1] Approximately 50% of persons with spinal cord injuries are paraplegic and 50% are quadriplegic.[1]

Diagnosis and Treatments

Spinal injuries are diagnosed by a neurological examination that measures motor and sensory functions and by X-ray and digital imaging—computed tomography (CT) and magnetic resonance imaging (MRI).[3]

Although there is no cure for spinal cord injuries, early treatment can reduce the severity of injury and improve prospects of recovery.[3] After resuscitation, the initial treatment involves bracing and/or surgery directed toward preventing further injury of the spinal cord, and pain management. Surgery may be required to relieve compression of the spinal cord and to stabilize the spine.[3] Steroid medication may be administered to reduce swelling and optimize neurological function. Once the patient and the spine are stable, intensive rehabilitation (including physical and occupational therapy) is initiated. Counselling and support groups are also helpful for patients and families in coping with limitations in daily activities and diminished quality of life.

Economic Burden

The PHAC estimates that in 2000–2001 the hospital costs associated with spinal injuries were $61.6 million. Direct hospital costs were the only category of cost estimates available for spinal injury.

Hospital Utilization

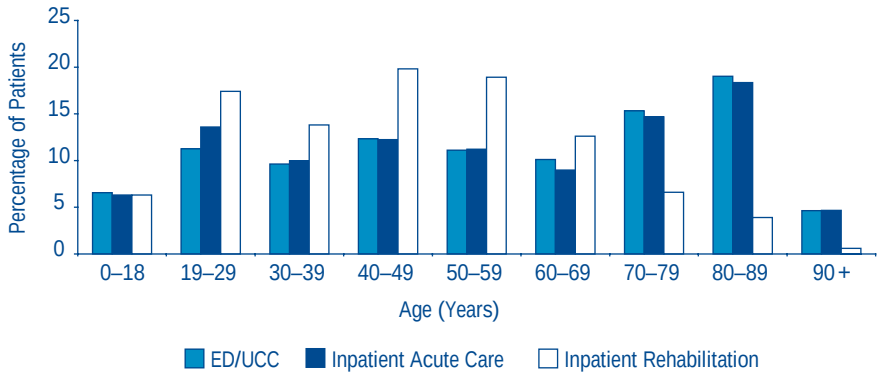
CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations and inpatient rehabilitation services for patients with spinal injuries.

In 2005–2006, 48.4% of patients with spinal injuries visiting EDs were male, and males represented 56.1% of patients with spinal injuries hospitalized in acute care. Almost three-fifths (58.4%) of male patients with spinal injuries visiting EDs and UCCs were in the 19-to-59 age group, while female patients with spinal injuries visiting EDs and UCCs were predominantly in the 60-and-over age group (63.3%).

6 2

Age Distribution of Patients With Spinal Injuries Using Hospital Services, Including EDs and UCCs, Inpatient Acute Care and Inpatient Rehabilitation

Children (18 years and younger) comprised 6.6% of patients with spinal injuries visiting EDs and UCCs, 6.3% of acute care inpatients and 6.3% of rehabilitation inpatients. The majority of adult patients with spinal injuries receiving rehabilitation services were in the 19-to-59 age group.



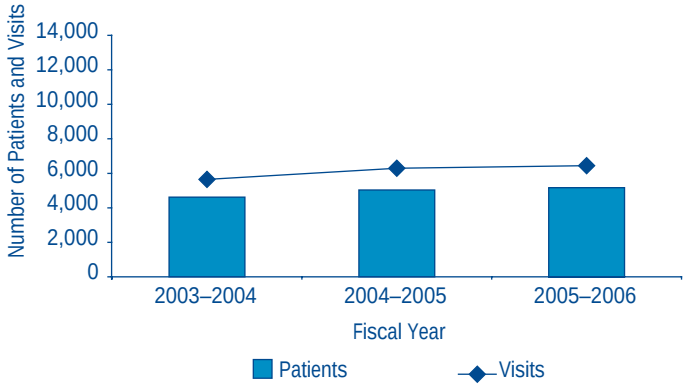
Note: Patients with spinal injuries: ED and UCC, n = 5,163; inpatient acute care, n = 10,400; inpatient rehabilitation, n = 333.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); National Rehabilitation Reporting System, 2005–2006, CIHI (includes Ontario and 17 facilities outside of Ontario).

6 3

ED and UCC Visits by Patients With Spinal Injuries, 2003–2004 to 2005–2006

Between 2003–2004 and 2005–2006, both the number of patients with spinal injuries visiting EDs and UCCs and the number of ED/UCC visits increased. In 2005–2006, on average, persons with spinal injuries made 1.1 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during this year.



Source: National Ambulatory Care Reporting System, CIHI.

64

ED and UCC Visit Disposition of Patients With Spinal Injuries, 2005–2006

In 2005–2006, 41.7% of patients with spinal injury as a primary diagnosis, and 67.9% of patients with spinal injuries as a secondary diagnosis, were admitted to an acute care hospital via the ED. In comparison, the overall rate of admission via the ED was 10.6% in 2005–2006.

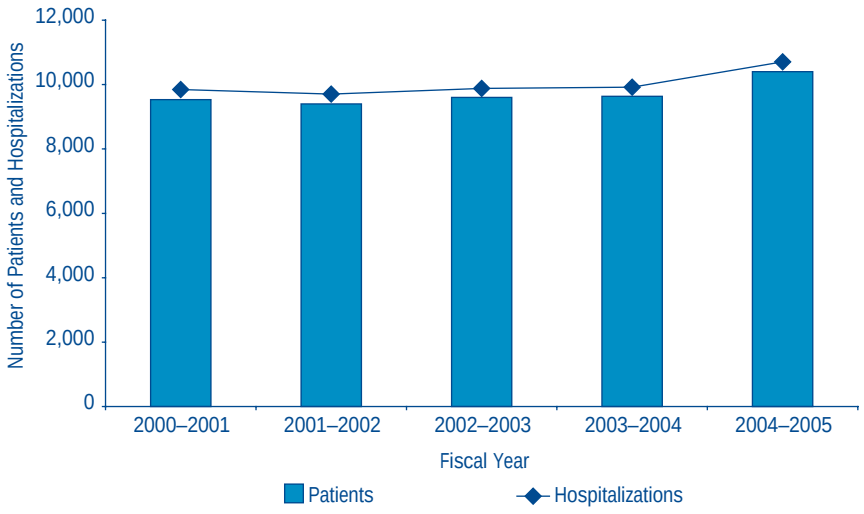
	Patients With Spinal Injuries		
	SI as Primary Diagnosis (%)	SI as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	57.6	31.4	85.3
Admitted to acute care hospital	41.7	67.9	10.6

Source: National Ambulatory Care Reporting System, CIHI.

65

Acute Care Hospitalizations for Patients With Spinal Injuries in Canada, 2000–2001 to 2004–2005

Both the number of patients with spinal injuries in acute care hospitals and the number of hospitalizations for these patients fluctuated slightly between 2000–2001 and 2004–2005. Overall, the number of patients increased by 9.1% from 2000–2001 (n = 9,533) to 2004–2005 (n = 10,400), and the number of hospitalizations increased 8.7% (from 9,847 to 10,706) between these years.



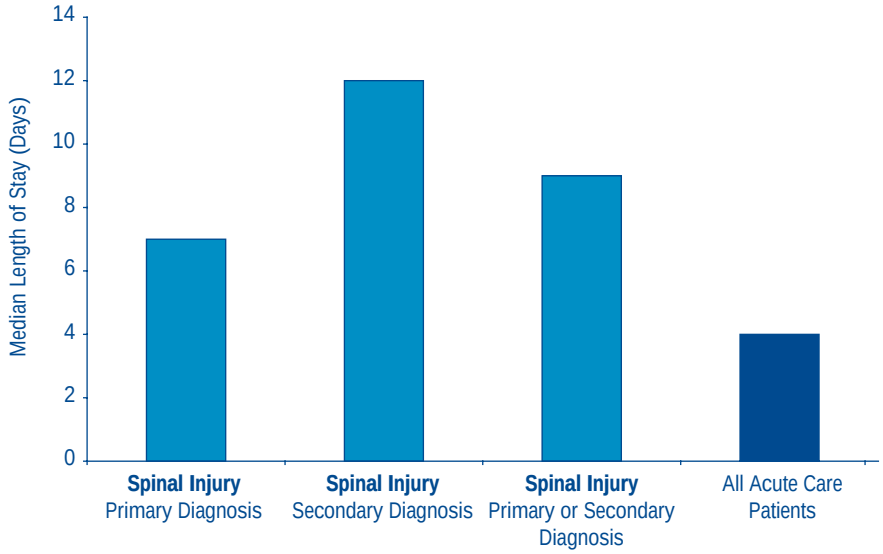
Source: Hospital Morbidity Database, CIHI.

In 2004–2005, patients with spinal injuries had a total of 188,322 patient days. Patients with spinal injuries averaged 1 hospital stay a year, compared with 1.3 hospital stays for all acute care inpatients.

6 6

Median Length of Stay for Patients With Spinal Injuries in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with spinal injuries was nine days, compared with four days for all acute care inpatients. The median LOS was 7 days when spinal injury was the primary diagnosis and 12 days when spinal injury was the secondary diagnosis.



Source: Hospital Morbidity Database, CIHI.

Spinal injury was the primary diagnosis in 59.3% of hospitalizations for patients with spinal injuries in 2004–2005. When spinal injury was not the primary diagnosis, the most common reasons for hospitalization included injury and poisoning (61%); reasons other than specific health conditions (for example, observation, follow-up care) (7%); and symptoms, signs and ill-defined conditions (5%).

The readmission rate for patients with spinal injuries was 3.2% within 7 days and 6.8% within 30 days of discharge. This compares with readmission rates of 3.6% and 8.5%, respectively, for all acute care patients.

Inpatient Rehabilitation Services

In 2005–2006, 333 patients with spinal injuries received inpatient rehabilitation services in Ontario and 17 hospitals in other parts of Canada. They had a total of 22,816 patient days, which represented 2.7% of patient days in inpatient rehabilitation services during that year. The active LOS for these patients was 22,723 days, meaning that they had to continue their stays in rehabilitation services for 93 days in total after being ready to be discharged. The median LOS for patients with spinal injuries was 56 days, compared with 17 days for all patients.

Total Function Score is a measure of the rehabilitation clients' overall functional ability. It was measured using the Functional Independence Measure (FIM™)[i] instrument, which assesses disability and caregiver burden associated with the disability. The FIM™ is composed of 18 items (13 for motor disability and 5 for cognitive disability) rated on a scale representing gradation from dependent (1) to independent (7) function. Scores on these items are added to obtain the Total Function Score, which can range from 1 to 126 (a higher Total Function Score indicates a higher overall level of functioning).

The mean Total Function Score at admission was lower for patients with spinal injuries (70.1) compared with all rehabilitation patients (85.9). At discharge, the mean Total Function Score for patients with spinal injuries was 93.7, indicating a Total Function Score change of 23.6. In contrast, the Total Function Score change for all patients was 19.6.

i Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

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1 Canadian Paraplegic Association, *Spinal Cord Injury* (Ottawa: Canadian Paraplegic Association, 2000), [online], cited October 31, 2005, from <http://www.canparaplegic.org/national/level2.tpl?var1 = story&var2 = 8.00>.

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3 S. DeCorwin et al., *Life After a Spinal Cord Injury* (Montréal: Association des paraplégiques du Québec, 2002), p. 15.

Highlights

- Stroke accounted for $665 million in direct costs and $2.1 billion in indirect costs in Canada in 2000–2001.
- Stroke accounted for 4.7% of the DALYs for all illnesses in Canada in 2000–2001.
- The number of visits to EDs in Ontario by patients with stroke decreased 7.2% from 2002–2003 to 2005–2006.
- More than 80% of patients with stroke visiting EDs in Ontario in 2005–2006 were admitted to acute care hospitals.
- The number of acute care hospitalizations in Canada for patients with stroke decreased 6.2% from 2000–2001 to 2004–2005.
- Just over 5% of patient days in Canadian acute care hospitals in 2004–2005 included patients with stroke as a primary or secondary diagnosis.
- 23% of inpatient rehabilitation days in Ontario and 17 hospitals elsewhere in Canada in 2005–2006 included patients with stroke.
- Among the five conditions in the report, the largest proportion of CCC patient days in 2005–2006 was associated with patients discharged with stroke (32.9%).

Stroke

What Is a Stroke?

A stroke is a sudden loss of brain function ("brain attack") caused by either a blockage of an artery to the brain, usually by a blood clot (ischemic stroke), or bleeding in or around the brain caused by a ruptured blood vessel (hemorrhagic stroke).[1] The majority of strokes (80%) are ischemic.[1]

Stroke is one of the leading causes of death and disability in Canada, according to Statistics Canada.[2] According to the Heart and Stroke Foundation, each year, approximately 50,000 Canadians have a stroke, and Statistics Canada reports that more than 15,000 died in 2002 due to cerebral vascular disease (including stroke).[2,3] Research indicates that up to one-third of survivors are left with permanent disability.[4] According to the Heart and Stroke Foundation, men have a higher lifetime risk of having a stroke, but more women die from stroke.[3] The Foundation also reports that in 2001, 8.4% of all deaths among women in Canada were due to a stroke, compared with 5.7% for men.[3]

Signs and Symptoms

Strokes may start with sudden disturbances of vision or speech, unsteadiness of gait, headache and/or numbness or weakness of an arm, leg or an entire side of the body.[1] The effects of a stroke depend on which part and how much of the brain is affected. They can include paralysis on one side of the body, communication problems, vision difficulties, cognitive impairments (such as memory lapses or difficulty in problem-solving), disorientation, difficulty swallowing, trouble walking and behavioural changes.[5]

Diagnosis and Treatments

Diagnosis of stroke requires a careful medical history and physical examination. Brain imaging—magnetic resonance imaging (MRI) or computed tomography (CT)—can help to determine the type and severity of stroke.[6]

Appropriate emergency management during the first few hours after a stroke can substantially improve health outcomes and limit functional disability.[6] If identified immediately, some patients with ischemic stroke will receive clot-dissolving drugs.[6] In patients with blockages of the carotid arteries, which supply blood to the brain, medicines to prevent clot formation are given and surgery can be done to remove the obstruction.[7] Most patients can benefit from an interdisciplinary approach, such as that provided in a dedicated stroke unit.[8]

Economic Burden

The PHAC estimates that total costs associated with stroke in 2000–2001 were $2.8 billion.

- Direct costs were $664.9 million: $579.5 million (87.2%) for hospital care, $67.6 million (10.2%) for physician care and $17.8 million (2.7%) for drugs.
- Indirect costs were $2.1 billion: $1.3 billion (63.2%) in mortality costs and $772.4 million (36.8%) in morbidity costs.

Disability-Adjusted Life Years

The PHAC estimates that in 2000–2001, stroke was associated with more than 238,000 DALYs, accounting for 4.7% of the DALYs for all illnesses in Canada. The years of life lost due to premature mortality represented a larger component (62.7%) of the DALYs than the years of healthy life lost due to disability (37.3%).

Disability-adjusted life years (DALYs) is a summary measure of years of life lost because of premature mortality (YLL) and years of healthy life lost as a result of disability (YLD). One DALY can be thought of as one lost year of healthy life due to a specific disease, disorder or injury.

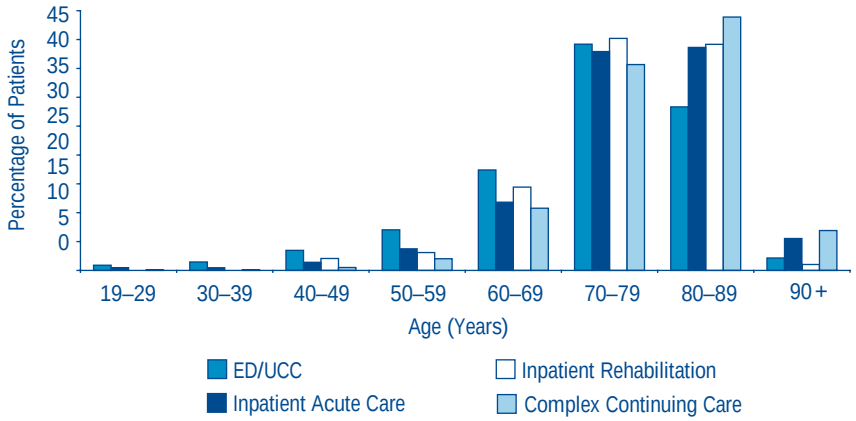
Hospital Utilization

CIHI data were used to provide information on emergency department (ED) and urgent care centre (UCC) visits, acute care hospitalizations, inpatient rehabilitation services and complex continuing care (CCC) for patients with stroke.

6 7

Age Distribution of Patients With Stroke Using Hospital Services, Including EDs and UCCs Inpatient Acute Care, Inpatient Rehabilitation and Continuing Care

The majority of patients with stroke who used hospital-based services were 70 years of age or older.



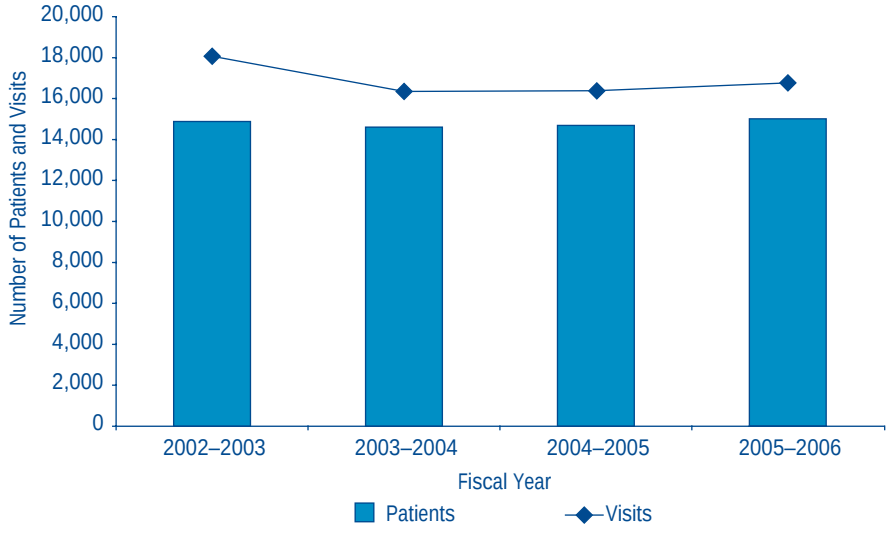
Note: Patients with stroke: ED and UCC, n = 15,011; inpatient acute care, n = 46,570; inpatient rehabilitation, n = 5,060; complex continuing care, n = 17,001.

Sources: National Ambulatory Care Reporting System, 2005–2006, CIHI (includes Ontario and 10 EDs outside of Ontario); Hospital Morbidity Database, 2004–2005, CIHI (includes all provinces and territories); National Rehabilitation Reporting System, 2005–2006, CIHI (includes Ontario and 17 facilities outside of Ontario); Continuing Care Reporting System, 2005–2006, CIHI (includes only Ontario).

6 8

ED and UCC Visits by Patients With Stroke, 2002–2003 to 2005–2006

The number of patients with stroke visiting EDs and UCCs remained relatively stable during the period from 2002–2003 to 2005–2006. The number of visits decreased 7.2% (from 18,069 to 16,766) between these years. In 2005–2006, on average, persons with stroke made 1.1 ED/UCC visits, compared with 1.8 visits made by the overall ED/UCC patient population during the year.



Source: National Ambulatory Care Reporting System, CIHI.

6 9

ED and UCC Visit Disposition of Patients With Stroke, 2005–2006

In 2005–2006, over three-quarters (82.4%) of patients with stroke as a primary diagnosis and two-thirds (66.3%) of patients with stroke as a secondary diagnosis were admitted to an acute care hospital via the ED. In comparison, the overall rate of admission via the ED was 10.6% in 2005–2006.

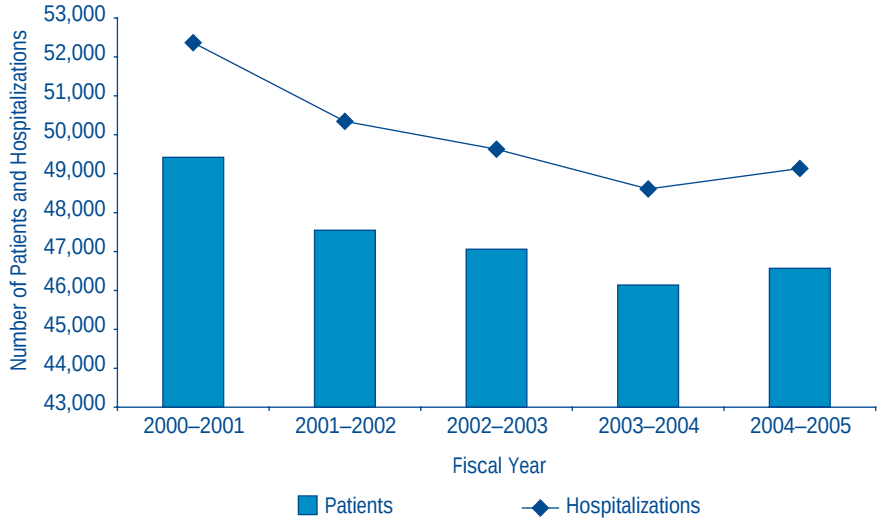
	Patients With Stroke		
	Stroke as Primary Diagnosis (%)	Stroke as Secondary Diagnosis (%)	All ED/UCC Patients (%)
Discharged home	16.1	30.0	85.3
Admitted to acute care hospital	82.4	66.3	10.6

Source: National Ambulatory Care Reporting System, CIHI.

7 0

Acute Care Hospitalizations for Patients With Stroke in Canada, 2000–2001 to 2004–2005

Both the number of patients with stroke in acute care hospitals and the number of hospitalizations for these patients decreased between 2000–2001 and 2004–2005. The number of patients decreased 5.8% from 2000–2001 (n = 49,422) to 2004–2005 (n = 46,570), and the number of hospitalizations decreased 6.2% (from 52,366 to 49,135) between these years.



Source: Hospital Morbidity Database, CIHI.

In 2004–2005, 46,570 patients with stroke were hospitalized in acute care across the country. They had a total of 941,184 patient days, which represented 5.3% of patient days in acute care hospitals. The average number of hospital stays for patients with stroke was 1.1, compared with 1.3 for all acute care inpatients.

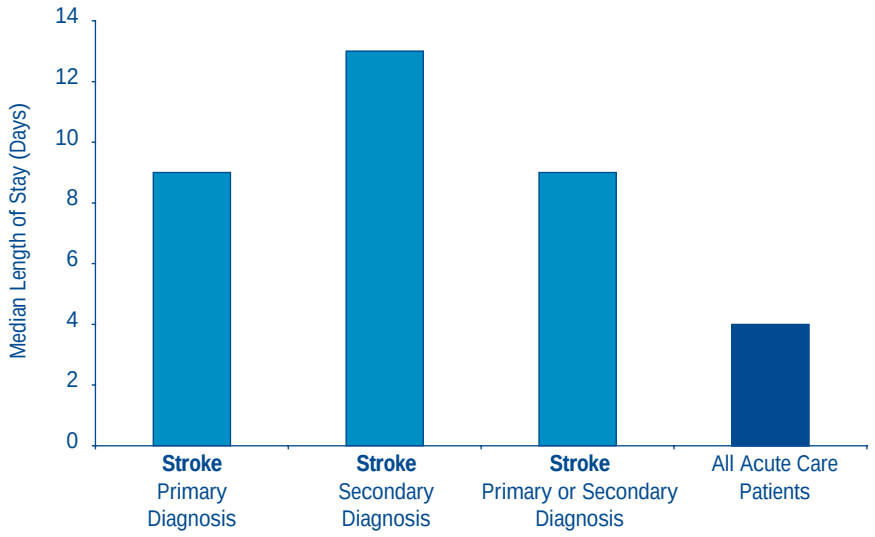
Stroke was the primary diagnosis in 74.7% of hospitalizations for patients with stroke in 2004–2005. When stroke was not the primary diagnosis, the most common reasons for hospitalization included diseases of the circulatory system (22%), reasons other than specific health conditions (for example, observation, follow-up care) (16%) and diseases of the respiratory system (9%).

The readmission rate for patients with stroke was 3.5% within 7 days and 8.7% within 30 days of discharge. This compares with readmission rates of 3.6% and 8.5%, respectively, for all acute care inpatients.

71

Median Length of Stay for Patients With Stroke in Acute Care Hospitals in Canada, 2004–2005

The median length of stay (LOS) for patients with stroke as either primary or secondary diagnosis was nine days, compared with four days for all acute care inpatients. The median LOS was 9 days when stroke was the primary diagnosis and 13 days when stroke was the secondary diagnosis.



Source: Hospital Morbidity Database, CIHI.

Total Function Score is a measure of the rehabilitation clients' overall functional ability. It was measured using the Functional Independence Measure (FIM™)[i] instrument, which assesses disability and caregiver burden associated with the disability. The FIM™ is composed of 18 items (13 for motor disability and 5 for cognitive disability) rated on a scale representing gradation from dependent (1) to independent (7) function. Scores on these items are added to obtain the Total Function Score, which can range from 1 to 126 (a higher Total Function Score indicates higher overall level of functioning).

Inpatient Rehabilitation Services

In 2005–2006, stroke patients comprised 15.6% of all rehabilitation patients in Ontario and 17 hospitals in other parts of Canada. These 5,060 patients had a total of 198,520 patient days, which represented 23.1% of patient days in inpatient rehabilitation services during that year. Their median LOS was 33 days, compared with 17 days for all patients.

The mean Total Function Score at admission was lower for patients with stroke (76.9) than for all patients (85.9). At discharge, the mean Total

i Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

Function Score for patients with stroke was 98.4, indicating a Total Function Score change of 21.5. In contrast, the Total Function Score change for all patients was 19.6.

Complex Continuing Care

Between 2001–2002 and 2005–2006, the median LOS for discharged patients with stroke was 57 days, compared with 41 days for the overall CCC patient population during this time period. In these two patient groups, 14% and 8% of stays, respectively, were longer than one year. The number of patient days for patients with stroke increased 22.2% from 2001–2002 to 2005–2006.

In 2005–2006, 4,941 patients with stroke had 5,356 stays in CCC beds, with a total of 666,172 patient days, which represented 32.9% of the CCC patient days during that year. The median LOS for discharged patients with stroke in that year was 57 days, compared with 40 days among the overall CCC patient population. For patients with stroke who were younger than 45 years, the median LOS was 186 days.

7 2

Discharge Disposition of Patients With Stroke From Complex Continuing Care, Ontario, 2005–2006

Almost a quarter (23%) of the patients with stroke discharged from CCC in 2005–2006 were transferred to acute care hospitals, and 28% to residential care. Nearly one-quarter (24%) of these patients died during their stay in CCC in that year.

	Patients With Stroke (%)	All CCC Patients (%)
Discharged home[a]	24	29
Discharged to residential care[b]	28	25
Admitted to acute care hospital	23	17
Died	24	28

Notes: **a** Includes with or without home care.
b Includes nursing home or long-term care facility.

Source: Continuing Care Reporting System, CIHI.

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Other Neurological Conditions

The previous chapters illustrate the economic costs and health services utilization associated with 11 neurological conditions in Canada. The main determinant in the selection of these conditions was the availability and comprehensiveness of data. Many other neurological conditions cause significant disability and therefore represent a burden to individuals, communities, society and health care in Canada. In this chapter, 20 of these other conditions are reviewed briefly to acknowledge their importance. However, additional data would be required to quantify their social and economic burden, as well as their impact on the health care system.

Attention Deficit Hyperactivity Disorder

Attention deficit hyperactivity disorder (ADHD) is a condition that involves three related sets of symptoms that impair development, including inattention, hyperactivity and impulsiveness, and is further sub-classified based upon these symptoms.[1] ADHD most likely results from a chemical imbalance in the brain, possibly due to a deficiency of dopamine or noradrenaline.[2] For children who meet the diagnostic criteria of ADHD, the treatment of choice is a combination of medication, special education and psychosocial interventions, including individual, group and family counselling.

ADHD is the most commonly diagnosed health condition in children, affecting 3% to 9% of school-aged children, and is more common in boys than in girls.[2,3] ADHD affects up to 4% of adults worldwide.[2]

Autism

Autism is defined behaviourally, with difficulties in social communication, interaction and imagination.[4] Children with autism often exhibit a restricted range of interests and have commonly recognized repetitive behaviours and mannerisms.[4] They are often hypersensitive or hyposensitive to the environment.[4] Symptoms vary from mild peculiarities to a severe developmental disorder. The manifestations of autism also tend to change over time.[4]

The diagnosis of autism is based on the individual's history, focusing on development and core behaviours, and observation of the individual in different settings.[4] Treatment strategies usually require a multidisciplinary child development team.[4] Pharmacotherapy is used to control comorbid conditions such as obsessive-compulsive disorder, seizures or ADHD.

Recent estimates suggest that the incidence of autism is 30 to 60 cases per 10,000.[5] There has been an increase in the prevalence of autism over time, which may be due to improvements in diagnosis and a broadening of the definition of the various autism disorders.[5]

Bell's Palsy

Bell's palsy is the most common facial paralysis.[6,7] It is an abrupt, isolated weakness of one side of the face.[6] The etiology of Bell's palsy remains controversial, but the most common cause is understood to be an infection of the facial nerve by herpes viruses (herpes simplex or herpes zoster).[6] Diagnosis of Bell's palsy relies mainly on clinical information and examination.[6] Although many patients recover without treatment, the best outcomes are achieved when cortico-steroids and anti-viral medications are given within 72 hours of the onset of symptoms.[6]

In the United Kingdom, the incidence of Bell's palsy is estimated at 20 cases per 100,000.[6] While Bell's palsy can occur at any age, studies have shown that it often occurs among persons between the ages of 10 and 45.[6,7] Men and women are affected equally, although pregnant women experience a higher incidence (45 cases per 100,000).[6]

Complex Regional Pain Syndrome

Complex regional pain syndrome (CRPS) is a chronic condition of intense pain in an arm or leg that usually develops following trauma or immobilization.[8] There are two types: CRPS type I (also called reflex sympathetic dystrophy), which does not have obvious nerve lesions, and CRPS type II (causalgia), which occurs after a defined peripheral nerve injury.[9] Like most chronic pain conditions, the best treatment is a combination of functional restoration and medications, along with a multidisciplinary approach.[9] Limited information is available about the epidemiology of CRPS.[10]

Congenital Anomalies of the Central Nervous System and Spine

Congenital anomalies of the central nervous system and spine include neurological conditions such as neural tube defects and hydrocephalus, which develop during the growth of the fetus and are present at birth. Other anomalies, such as syringomyelia, may not be seen at birth and may not produce symptoms until adulthood. More sophisticated technology for prenatal screening and genetic counselling and increased prenatal intake of folic acid have led to a

decline in births with neural tube defects.[11,12] For example, in Canada, the rate of neural tube defects (which produce anencephaly and various forms of spina bifida) declined from about 11.1 to 5.6 per 100,000 live births between 1989 and 1999 as a result of these preventative measures.[13]

Creutzfeldt-Jakob Disease

Creutzfeldt-Jakob disease (CJD) is a rare, degenerative and fatal brain disease.[14] It is caused by alterations in prions, which are proteins normally present in the brain and other tissues.[14] There are three main types of CJD: sporadic, hereditary and acquired.[14,15] In sporadic CJD, accounting for 85% of patients, no preventable risk factors have been identified, although recent evidence has suggested a possible genetic predisposition.[14] In hereditary CJD, making up 5% to 10% of patients, the patient has a family history of the disease and/or a genetic marker for the disease shows up in tests. In acquired CJD (1% of patients) the disease is spread through exposure to brain or nervous tissue, usually via a medical procedure.[14] New variant CJD, which has occurred in Great Britain and other parts of Europe, may result from human ingestion of contaminated beef.[14] This form of the disease begins primarily with psychiatric symptoms, affects younger people and has a longer duration.[14]

There is currently no specific diagnostic test for CJD other than brain biopsy.[14] The diagnosis is inferred from the clinical course of the disease and investigations such as cerebrospinal fluid (CSF) examination, electroencephalogram (EEG) and magnetic resonance imaging (MRI).[14] Because there is no cure or treatment for CJD, these investigations are also important to rule out treatable forms of dementia.[14]

CJD affects one person per million worldwide.[14] It usually affects people later in life and runs a rapid course; 90% of patients die within one year.[14]

Degenerative Disorders of the Spine

Degeneration of the spine is common at any age, but is most frequent among those over 60 years old. An estimated 80% of adults experience back pain at some point in their lives.[16] Degenerative processes affecting intervertebral discs and joints of the spine can be accelerated by overuse or injury. This can result in acute herniation or arthritic disorders of the spine.

Degenerative disorders of the spine are usually treated with rest in the acute stage, exercise for strengthening of the spinal, abdominal and limb muscles, non-steroidal anti-inflammatory medication, muscle relaxants, analgesics and relevant life style changes.[17]

Global Developmental Delay

Global developmental delay is a set within a broader category of developmental disabilities. It is defined as a significant delay in two or more of the following developmental areas: motor, speech and language, cognition, social/personal and activities of daily living.[18] Significant delays are defined as performance that is two standard deviations or greater below the mean on age-appropriate, standardized testing.[18]

Global developmental delay can affect up to 1% to 3% of children under five years of age.[18]

Treatment strategies for children with global developmental delay are based on the etiology of the delay. This is determined by brain MRI, metabolic and genetic testing, EEG and exploration for toxic exposure.

Huntington's Disease

Huntington's disease (HD) is a genetic brain disorder that causes progressive physical, cognitive and emotional deterioration.[19] HD causes the death of cells in specific parts of the brain: the caudate, the putamen and, eventually, the cerebral cortex.[19] As the disease progresses, people with HD have more difficulty controlling their movements, remembering the recent past, making decisions and controlling their emotions.[19]

A diagnosis of HD is determined after neurological and psychological tests, brain imaging—computed tomography (CT) or MRI—and genetic testing.[19] There are currently no treatments that will slow down or stop the progression of HD.[19]

The Huntington Society of Canada estimates that 1 in every 10,000 Canadians has HD, and approximately 5 in every 10,000 are at risk of developing HD.[19] The HD gene is dominant, meaning that parents with HD have a 50% chance of passing it on to each child, who is considered to be "at risk." Both male and female children are at the same risk of inheriting the gene.[19] Symptoms usually start to manifest between 30 and 45 years of age, but can appear as early as 5 years of age or as late as 70 years of age and older.[19]

Hydrocephalus

Hydrocephalus is a disease characterized by enlargement of the ventricles of the brain.[20] Cerebrospinal fluid (CSF), which is produced in the ventricles, normally circulates into the space outside the brain and spinal cord, where it acts as a cushion and plays a role in both supplying nutrients to the nervous system and removing waste materials.[20] Hydrocephalus occurs when the normal flow of CSF is blocked or CSF reabsorption is impaired.[20] Symptoms and signs, including head enlargement in infants, are caused by the pressure of the enlarged ventricles on the brain.[21] Hydrocephalus is most commonly

a congenital disorder (often associated with other neurological disorders such as spina bifida), but it can also be caused by brain hemorrhage, meningitis or head trauma.[21,22]

Hydrocephalus is diagnosed by brain imaging—ultrasound (in infants), CT scanning or MRI.[21] The most effective treatment is surgical insertion of a shunt to divert the CSF into another body cavity, such as the peritoneal cavity, where it can be reabsorbed.[21]

According to the Hydrocephalus Association, hydrocephalus occurs in 2 out of every 1,000 births.[20] A 1998 study suggests that the total annual cost of care of hydrocephalus, excluding outpatient and community-based care, is $3.5 million in Manitoba alone.[22]

Hypoxic-Ischemic Encephalopathy (Anoxic Encephalopathy)

Hypoxic-ischemic encephalopathy, also known as anoxic encephalopathy, is a clinical state that occurs when the brain is severely deprived of oxygen for five minutes or longer. Hypoxic-ischemic encephalopathy is usually caused by cardiac arrest, but can also result from birth injury, drowning, severe hemorrhage, suffocation, carbon monoxide poisoning and diseases that paralyze the respiratory muscles.

Although MRI and electrophysiological testing can detect changes that correlate with anoxic encephalopathy, the diagnosis is mainly based on clinical criteria. Following cardiac resuscitation, the level of supportive care provided depends on the clinical state of the patient.

Hypoxic-ischemic brain damage is the leading cause of morbidity and mortality among patients with cardiac arrest who are initially resuscitated.[23] Perinatal hypoxic-ischemic encephalopathy occurs in between 1 and 8 of every 1,000 births of more than 34 weeks of gestation.[24] Of full-term infants showing hypoxic-ischemic encephalopathy, about a fifth die during the newborn period and 25% of those who survive have permanent neuropsychological deficits.[25]

Idiopathic Intracranial Hypertension

Idiopathic intracranial hypertension (previously known as benign intracranial hypertension or pseudotumour cerebri) involves increased intracranial pressure of an unknown cause.[26]

The overall incidence of idiopathic intracranial hypertension is estimated to be about 1 per 100,000.[27] It occurs most commonly in overweight women and those with excessive intake of vitamin A and the use of certain medications (for example, endocrine drugs or tetracycline).[26] Among overweight women aged

20 to 44, the incidence of this condition in the United States is estimated to be 15 to 19 per 100,000.[26] The incidence tends to be higher in people with arterial hypertension and polycystic ovary syndrome.[26]

Diagnostic criteria require that other causes of intracranial hypertension (such as brain tumours) be excluded.[26] Evidence-based management strategies for idiopathic intracranial hypertension are not available. The main aim of treatment is to prevent the loss of vision, since this condition leads to blindness in 10% of patients.[26] Surgery may be needed to remove pressure on the optic nerve and weight reduction is often indicated.[26]

Muscular Dystrophies

The muscular dystrophies represent a heterogeneous group of disorders that involve muscle wasting and weakness.[28] They are all inherited and are classified into three main groups: Duchenne-type, facioscapulohumeral and limb girdle.[28] Duchenne-type, the most common muscular dystrophy, primarily affects boys and occurs in 1 per 3,500 live male births.[29] Diagnostic tests for muscular dystrophies usually include measuring creatinine kinase levels, electromyography, ultrasonography, muscle biopsy and genetic testing.[28]

Myasthenia Gravis

Myasthenia gravis is an autoimmune disease that causes the gradual loss of muscle strength and function.[30] In myasthenia gravis, antibodies are generated that destroy the receptors in the neuromuscular junction, the area where nerve transmission causes a muscle to contract.[30] This results in exercise-induced muscle weakness and fatigue.[30] Myasthenia gravis affects everyone in its own way, and each patient could have weakness in a different group of muscles.[30]

The prevalence of myasthenia gravis in the U.S. is approximately 14 per 100,000.[31] Among women, the incidence is highest in the age groups 20 to 30 years and 70 years and older.[31,32] On the other hand, among men, it is highest in the age group 60 to 70 years.[31] A variety of treatment modalities are used to control the symptoms of myasthenia gravis.[30]

Peripheral Neuropathy

Peripheral neuropathy can be inherited or acquired, but always involves damage to the peripheral nervous system, which transmits information concerning motor, sensory or autonomic functions between the central nervous system (brain and spinal cord) and other parts of the body. There are more than 100 types of peripheral neuropathy, each with its own set of symptoms and prognosis. Inherited peripheral neuropathy is caused by genetic mutations or errors in the genetic code. The most common cause of acquired neuropathy is diabetes mellitus; other causes are alcoholism, nutritional deficiencies, physical injury, toxins, tumours, autoimmune responses and vascular and metabolic disorders.[33,34,35,36]

The estimated prevalence of peripheral neuropathy ranges from 2,400 to 8,000 per 100,000.[34] It has been estimated that more than 17 million people in the U.S. and Europe have diabetes-related polyneuropathy.[37]

The symptoms in acute neuropathies (for example, Guillain-Barré syndrome) are characterized by symptoms that appear suddenly, progress quickly and fade slowly as the damaged nerves recover.[33] Chronic neuropathies involve symptoms that manifest gradually and develop slowly.[33]

The diagnosis of peripheral neuropathy is usually based on clinical history, physical examination and neurophysiological tests, including nerve conduction studies and electromyography (EMG).[35] These tests help to determine the part of the nerve that is affected and the extent of damage.[35] In some instances, nerve biopsy is necessary to establish a diagnosis.[35] Treatment of peripheral neuropathy depends on the cause of the disorder.[36]

Sleep Disorders

The sleep disorders are a group of conditions that share the symptom of excessive daytime sleepiness. There are two main types of sleep disorder: narcolepsy and sleep apnea. Narcolepsy is characterized by “recurrent attacks of irresistible sleep” that are variably associated with cataplexy (loss of muscle tone in response to laughter or other emotion) and episodes of transient paralysis or hallucinations at the onset of sleep (hypnogogic paralysis or hallucinations).[38] Narcolepsy is associated with decreased levels of sleep-related chemicals called hypocretins.[39] The incidence of narcolepsy in a U.S. study was estimated to be 1.4 per 100,000.[39,40]

Sleep apnea, which may be caused by neurological disorders (central sleep apnea) or upper airway obstruction (obstructive sleep apnea or OSA), is a condition in which there are abnormal interruptions in breathing during sleep. Depending on the definition criteria, the prevalence of OSA ranges from 1% to 4% and is more common in men than in women.[41] The incidence of central sleep apnea is about one-tenth of that of OSA.[42]

Nocturnal polysomnography is important for determining the type of sleep disorder. The management of narcolepsy involves pharmacologic, educational and lifestyle interventions. Moderate to severe sleep apnea is often treated with nasal continuous positive airway pressure.

Spinocerebellar Ataxias

Spinocerebellar ataxias (SCAs) are hereditary degenerative disorders characterized by unsteady gait and poor coordination of hands, speech and eye movement.[43] At least 24 different types of SCA are recognized, and in 12 of these, gene mutations have been identified.[44] A study in the Netherlands estimated the prevalence of SCA to be 3 per 100,000.[43]

Clinical assessment, including a detailed family history and genetic testing, is required for the diagnosis of SCA. There is currently no therapy available to prevent SCA, but management by a multidisciplinary team can help patients and their families deal with the effects of these disorders.[44]

Syringomyelia

Syringomyelia is a disorder in which a cyst forms within the spinal cord that usually contains cerebrospinal fluid and can expand over time, causing damage to neurons and nerve fibres in the spinal cord.[45] It is classified as "primary" (unrelated to any other disease state) or "secondary" to another disorder, such as spinal injury, meningitis, congenital anomalies or spinal cord tumours.[45,46] According to the Canadian Syringomyelia Network, the disease is less common than multiple sclerosis.[47] Early diagnosis of syringomyelia can be established with MRI. Treatment may require surgical intervention.[48]

Tourette Syndrome

Tourette syndrome is an inherited neurological or neurochemical disorder characterized by motor and phonic tics, which are involuntary, rapid, sudden movements or vocalizations that occur repeatedly at irregular intervals.[49] Tics usually appear around age 3 to 8 years, with a mean age of onset of 6 years.[50,51] The cause of Tourette syndrome is unknown, although there is strong evidence that genetic factors may play a role.[50,52] Comorbid conditions include ADHD, obsessive-compulsive disorder or both.[50] About 16% of patients with Tourette syndrome have insomnia, and 26% of patients have anger-control problems.[50] Once considered a rare condition, the prevalence of Tourette's syndrome is now estimated to be between 31 and 157 per 1,000 children aged 13 to 14 years.[50] The male-to-female ratio is about 4 to 1.[51] If the tics are serious enough to interfere with function, medications can alleviate the symptoms.[50]

Trigeminal Neuralgia

Trigeminal neuralgia is a disorder of the trigeminal nerve (the nerve of the face), characterized by severe, intermittent pain in the face.[53] The cause of this disorder is believed to be compression of the trigeminal nerve root by blood vessels where the nerve exits the brain stem.[54] Trigeminal neuralgia can also be secondary to multiple sclerosis or benign lesions at the base of the brain.[53]

Trigeminal neuralgia is rare before the age of 50. Its prevalence increases with age and is highest after the age of 70.[54,55] The age-adjusted incidence of trigeminal neuralgia is approximately 6 per 100,000 for women and 3 per 100,000 for men in the U.S.[55]

Anti-epileptic medications control the symptoms of trigeminal neuralgia in most patients. However, surgery is sometimes necessary for pain relief. It involves either moving the blood vessel that causes nerve compression or destroying nerve fibres.[55]

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Appendix A
CBANHC-Affiliated Voluntary Health Organizations

The Canadian Neurological Sciences Federation (CNSF) would like to thank the following agencies and voluntary health organizations for their participation in the Canadian Brain and Nerve Health Coalition (CBANHC).

- Acoustic Neuroma Association of Canada
- ALS Society of Canada
- Alzheimer Society of Canada
- Autism Society Canada
- Brain Injury Association of Canada
- Brain Injury Association of Alberta
- Brain Tumour Foundation of Canada
- Canadian Alliance of Brain Tumour Organizations
- Canadian Association for Neuroscience
- Canadian Association of Neuroscience Nurses
- Canadian Brain Tissue Bank
- Canadian Congress of Neurological Sciences
- Canadian Continence Foundation
- Canadian Down Syndrome Society, National Office
- Canadian Institutes of Health Research
- Canadian Paraplegic Association
- Canadian Psychiatric Research Foundation
- Canadian Reflex Sympathetic Dystrophy Network
- Canadian Spinal Research Organization
- Canadian Syringomyelia Network
- Canadian von Hippel–Lindau Family Alliance
- Central Okanagan Brain Injury Society
- Cerebral Palsy Association of British Columbia
- Epilepsy Canada
- Heart and Stroke Foundation of Canada
- Heart and Stroke Foundation of Ontario
- Huntington Society of Canada
- Institute of Neurosciences, Mental Health and Addiction
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- Myasthenia Gravis Coalition of Canada

- NeuroScience Canada Foundation
- Ontario Brain Injury Association
- Parkinson Society Canada
- Regroupement des associations de personnes traumatisées cranio-cérébrales du Québec
- Rick Hansen Foundation (Man in Motion)
- Spina Bifida and Hydrocephalus Association of Canada
- ThinkFirst Foundation of Canada
- Tourette Syndrome Foundation of Canada
- Tuberous Sclerosis Canada

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- Feri Dehdar, Cerebral Palsy Association of British Columbia
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- Heidi Bernhardt, Canadian ADHD Resource Alliance
- Dr. Derek Fewer, CNSF
- Dr. Manouchehr Javidan, CNSF
- Ean Robertson, Huntington Society of Canada
- Rosie Wartecker, Tourette Syndrome Foundation of Canada
- Dr. Jerome Yager, CNSF

Appendix B
Data Sources and Methods

Hospital Utilization

Hospital utilization was assessed through analyses of CIHI data related to emergency department (ED) and urgent care centre (UCC) visits and acute care, inpatient rehabilitation and complex continuing care (CCC) hospitalizations.

ED and UCC Visits

Data Source

ED/UCC visits and patient characteristics were determined based on CIHI's National Ambulatory Care Reporting System (NACRS), which includes demographic, diagnostic and procedural information from hospital EDs and UCCs in Ontario and selected hospitals in other parts of Canada (in 2005–2006, five from Nova Scotia, three from British Columbia, one from Prince Edward Island and one from the Yukon Territory). Submission to NACRS is mandatory in Ontario.

Inclusion Criteria

- Records of patients with a valid health card number for 2001–2002 to 2005–2006 with the following conditions of interest:
  - Alzheimer's disease, amyotrophic lateral sclerosis, multiple sclerosis and Parkinson's disease records of patients 19 years of age and older; and
  - Brain tumours, cerebral palsy, epilepsy, head injuries, headaches, spinal injuries and stroke for patients of any age.

Conditions of Interest

- Conditions are identified using the ICD-9 or ICD-10 codes submitted to CIHI (Appendix C).
- Conditions were categorized as either:
  - Primary diagnosis: when the condition of interest was recorded in the patient chart as the main reason for the visit; or
  - Secondary diagnosis: when the condition of interest was recorded in the patient chart but it was not the main reason for the visit.
- As such, in one visit, a patient record may reflect that the patient has more than one condition of interest.

Acute Care Hospitalizations

Data Source

Acute care hospitalizations and patient characteristics were determined based on CIHI's Hospital Morbidity Database (HMDB), which includes demographic, diagnostic and procedural information for patients discharged from acute care hospitals in all provinces and territories.

Inclusion Criteria

- Records for patients with a valid health card number for 2000–2001 to 2004–2005 with the following conditions of interest:
  - Alzheimer's disease, amyotrophic lateral sclerosis, multiple sclerosis, and Parkinson's disease records of patients 19 years of age and older; and
  - Brain tumours, cerebral palsy, epilepsy, head injuries, headaches, spinal injuries, and stroke for patients of any age.

Conditions of Interest

- Conditions are identified using the ICD-9 or ICD-10 codes submitted to CIHI (Appendix C).
- Conditions were categorized as either:
  - Primary diagnosis: when the condition of interest was recorded in the patient chart as the main reason for the hospitalization; or
  - Secondary diagnosis: when the condition of interest was recorded in the patient chart but it was not the main reason for the hospitalization.
- As such, for one hospitalization, a patient record may reflect that the patient has more than one condition of interest.

Hospitalization Characteristics

- Length of stay (LOS) was determined for hospitalizations in 2004–2005. In the case of multiple visits where the neurological condition of interest was the primary diagnosis, LOS was based on the final hospitalization in the year.
- Readmission following an index discharge was determined for 2003–2004. It was based on the first record of hospitalization in the year, when the neurological condition of interest was either the primary or the secondary diagnosis. When a patient was readmitted or transferred to another acute care hospital within 24 hours, this was considered the same hospitalization. A same-day readmission was not considered to be a new episode of care.

Inpatient Rehabilitation Services

Data Source

Inpatient rehabilitation patients were identified using CIHI's National Rehabilitation Reporting System (NRS), which includes administrative, sociodemographic, clinical and functional status information for patients in a designated general or specialized inpatient rehabilitation bed in an acute care hospital, or a rehabilitation hospital in Ontario and selected hospitals in the other parts of Canada (in 2005–2006: five in British Columbia, six in Alberta, three in Saskatchewan, one in New Brunswick, two in Nova Scotia and one in Newfoundland). Submission to NRS in Ontario is mandatory.

Inclusion Criteria

- Records for patients with a valid health card number in 2005–2006.
- Records for patients with planned discharges.
- Records with discharge Functional Independence Measures (FIM™)[i] scores.

Conditions of Interest

- Conditions for which data are available include head injury, multiple sclerosis, Parkinson's disease, spinal injuries and stroke.
- Conditions were identified using the Rehabilitation Client Group (RCG)[ii] codes (Appendix C), which best describe the primary reason for the admission.

Hospitalization Characteristics

- Length of stay (LOS) was calculated in two ways: total LOS excluding service interruptions, and active LOS (total LOS excluding days waiting for discharge).
- Total Function Score[iii] was determined from the admission and discharge records.
- Total Function Score is a measure of the rehabilitation patients' overall functional ability. It was measured using the Functional Independence Measure (FIM™) instrument,[iv] which assesses disability and caregiver burden associated with the disability. The FIM™ is composed of 18 items (13 for motor disability and 5 for cognitive disability) rated on a scale representing gradation from dependent (1) to independent (7) function. Scores on these items are added to obtain the Total Function Score, which can range from 1 to 126 (higher Total Function Score indicates higher overall level of functioning).

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i Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

ii Adapted with permission from the UDSMR impairment codes. Copyright Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc., all rights reserved.

iii Based on data collected using the FIM™.

iv Property of Uniform Data System for Medical Rehabilitation, Division of UB Foundation Activities, Inc.

Complex Continuing Care

Data Source

CCC patients were identified using CIHI's Continuing Care Reporting System (CCRS) database. Data from CCC hospitals in Ontario (where submission to CCRS is mandatory) were used.

Inclusion Criteria

- Records for patients with a valid health card number from all submitting CCCs in Ontario for 2001–2002 to 2005–2006.
- Records with a complete assessment, including diagnostic information. (The assessment is mandatory if the patient stays in the facility 14 days or more; in 2005–2006, 18% of residents did not receive assessments and therefore were not included in the analysis).

Conditions of Interest

- Alzheimer's disease, amyotrophic lateral sclerosis (ALS), cerebral palsy, epilepsy, head injuries, multiple sclerosis, Parkinson's disease and stroke. Data for ALS were available starting in 2003–2004.
- Conditions were identified using the coding scheme specific to CCRS (Appendix C). In one CCC stay, a patient record may reflect more than one condition of interest.

Hospitalization Characteristics

- Bed days (that is, days of care provided to patients in CCC beds) were based on individual episodes of care. In the case where a patient left for a short visit to acute care and then came back, two separate visits were recorded. They were also based on patients who had complete episodes (that is, were discharged from CCC). If a patient had more than one complete episode, bed days were based on the last visit.
- Discharge information was based on the last visit if a patient had more than one complete episode.

Estimates of Economic Burden and Disability-Adjusted Life Years (DALYs)

Estimates of economic burden (including direct costs and indirect costs) and the DALYs were calculated by the Public Health Agency of Canada for 2000–2001.

Direct Costs

Data Source

CIHI's *National Health Expenditure Trends 1975–2004,* Table C.1.1, *Total Health Expenditures by Use of Funds,* was used.[1]

Methods

Cost components were distributed by diagnostic category using additional data sources. Specific details regarding cost distribution are available from PHAC.

Indirect Costs

Data Source

Labour market data were used.

Methods

Included in calculations were the following economic variables: the average annual income[2] and the average value of unpaid work[3] (both take into account the employment and unemployment rates); the average supplementary income[4] and the value of labour income (added to account for wage supplements such as Canada/Quebec Pension Plan or CCP/QPP, workers' compensation, employment insurance funds); the average annual labour productivity growth rate[v] in the Canadian business sector.[5] Indirect costs do not include value of time lost from work and leisure activities by family members or friends who help care for the person with the neurological conditions of interest.

Estimates of the Disability-Adjusted Life Years

Data Source

DALYs were determined based on the WHO (World Health Organization) workbook, which includes data for North America on incidence, distribution and duration associated with the different stages of disease, when available.[6]

Methods

The WHO workbook data were updated to include Canadian preference scores, which indicate the relative preference for a health state compared with full health. These scores help understand how Canadians view the various aspects of functional health (for example, pain, discomfort, physical functioning, fatigue).

v The 2.2% average annual productivity growth rate reflects the economic performance for Canadian businesses for the last five years.

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Appendix C
Neurological Condition Codes

The following table lists the codes used to identify patients with the neurological conditions presented in the report. Records of patients visiting emergency departments/urgent care centres and of those discharged from acute care hospitals were identified using the ICD-9, ICD-9-CM and ICD-10-CA codes. Records of patients receiving inpatient rehabilitation services were identified using the Rehabilitation Client Group codes and those receiving complex continuing care services were identified using the codes from the Continuing Care Reporting System coding scheme.

Neurological Condition	Codes				
	ICD-9	ICD-9-CM	ICD-10-CA	Rehabilitation Client Group	Continuing Care Reporting System Coding Scheme
Alzheimer's disease (records of patients aged 19 and older)	290.0, 290.1, 331.0	290.0, 294.1, 331.0	G30.0, G30.1, G30.8 + F00.2, G30.0 + F00.0, G30.1 + F00.1, F03, F05.1, G30.8, G30.9 + F00.9	-	I1R_ALZHEIMERS I1V_DEMENTIA_NOT_ALZHEIMERS
Amyotrophic lateral sclerosis (records of patients aged 19 and older)	335.2	335.2	G12.2	-	I1Q_AMYOTROPHIC_LAT_SCLEROSIS
Brain tumours (malignant and benign)	191, 192, 225, 237.5, 239.6	191, 192, 225, 237.5, 239.6	C70-C72, D32, D33, D43.0, D43.1, D43.2, D43.4	-	-
Cerebral infantile palsy	343	343	G80	-	I1T_CEREBRAL_PALSY
Epilepsy	345	345	G40, G41	-	AB10D_EPILEPSY
Head/brain injury	310.2, 800–804, 850–854, 925	310.2, 800–804, 850–854, 925, 959.01	F07.2, S02, S06, S07, S09, T02.0	02.2	I1EE_TRAUMATIC_BRAIN_INJURY
Headache (including migrane)	307.8, 346, 784.0	307.8, 346, 784.0	F45.4, G43, G44.0, G44.2, R51	-	-
Multiple sclerosis (records of patients aged 19 and older)	340	340	G35	03.1	I1Y_MULTIPLE_SCLEROSIS
Parkinson's disease (records of patients aged 19 and older)	332	332	G20–G22	03.2	I1AA_PARKINSONS_DISEASE
Spinal injuries	805, 806, 952	805, 806, 952	S12.0-S12.7, S12.9, S14.0, S14.1, S24.0, S24.1, S34.0, S34.1, S22.0, S22.1, S32.0-S32.2, T08	04.2	-
Stroke	430–432, 434, 436	430–432, 434, 436, 997.02	I60-I64, I66	01	I1U_CEREBROVASC_ACCIDENT