Ontario

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Motor Neuron Disease

Brain Health in Ontario Project

ONTARIO BRAIN INSTITUTE
INSTITUT ONTARIEN DU CERVEAU

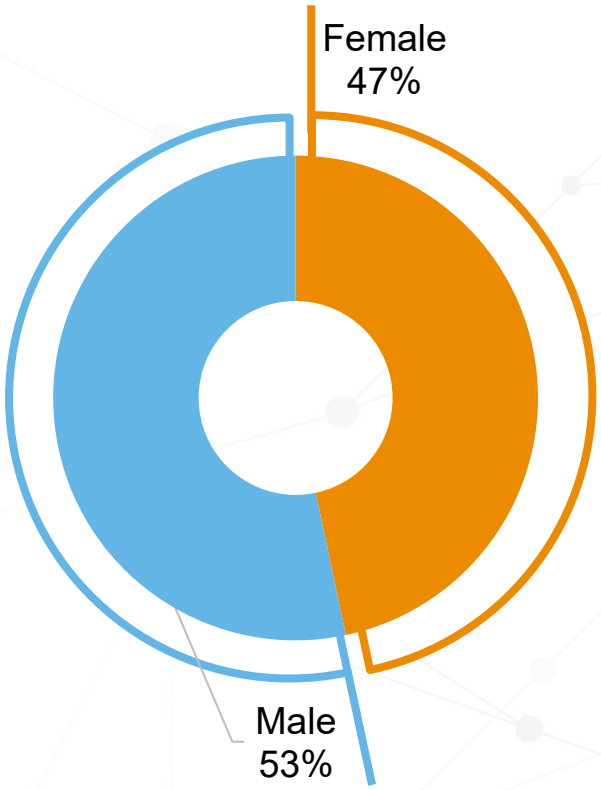
WELCOME TO BRAIN CENTRAL

Motor Neuron Disease

- Motor neuron disease is a category of disorders characterized by degeneration of motor neurons that results in progressive weakness and deterioration in swallowing, speech and breathing. Two common forms of motor neuron disease are spinal muscular atrophy and amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease).

- Spinal muscular atrophy is a hereditary disease which affects individuals as young as six months of age. A loss of lower motor neurons creates weakness in skeletal muscles of the torso, upper arms and upper legs.
- Amyotrophic lateral sclerosis (ALS) typically presents in those between 40 and 70 years of age. ALS causes progressive weakness of the muscles in the mouth, throat, arms and legs. Affected persons may also develop cognitive difficulties or dementia.
- ALS is associated with premature mortality, with death often occurring within three to five years of symptom onset. While 5% of ALS cases are hereditary, the definitive cause of the disease remains unknown for the other 95% cases.
- ALS has no cure, and effective treatment for motor neuron disease remains elusive. Currently, only one drug has been approved for the treatment of ALS, and it has only modest effectiveness – it can only slow the progression of the disease and extend the lifespan by a few months. Without a cure or viable drug therapies, the best available treatment for persons with ALS is supportive care (respiratory care, medical symptom management, rehabilitative therapy, lifestyle modification and palliative care).
- Persons with ALS can benefit from an interprofessional team approach to health care. Expertise among the care providers pertaining to the many dimensions of living with ALS – including expertise in nutrition, breathing, communication, exercise and physical activity, occupational therapy, social work, interpersonal relationships, and legal counselling especially in addressing end-of-life decisions – can assist in promoting the best possible quality of life for the affected person.

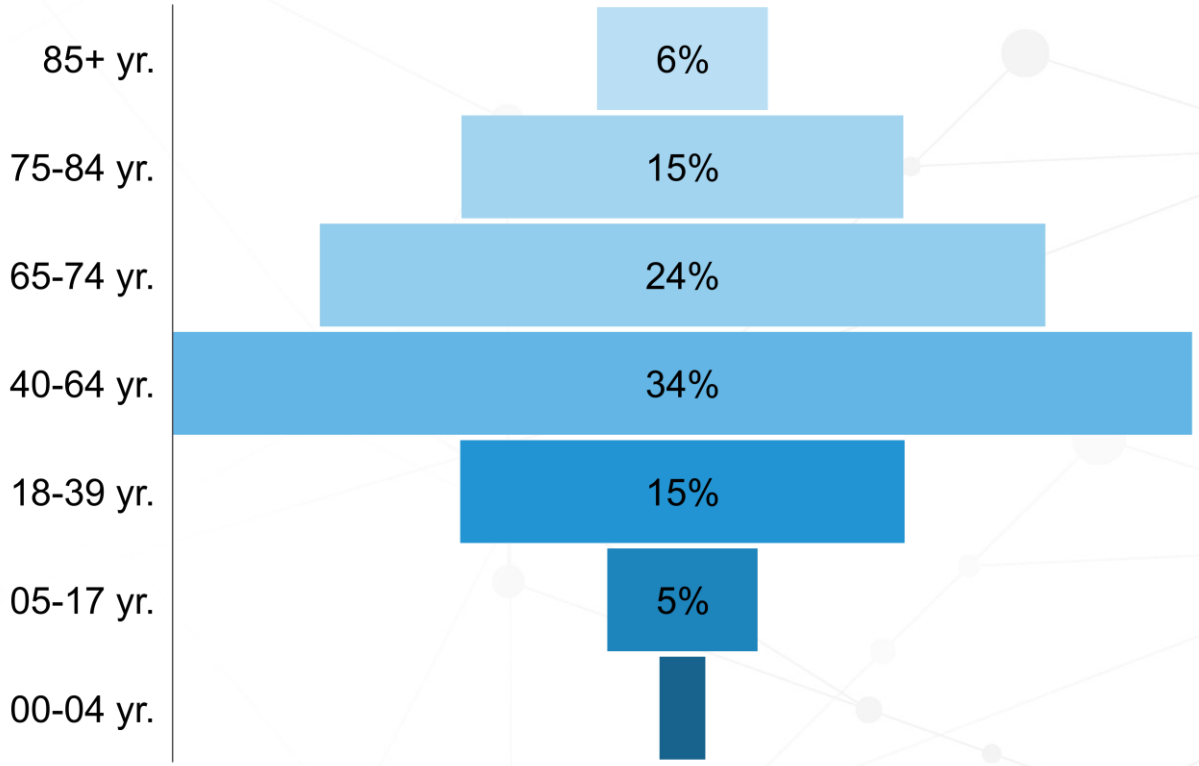
Demographics: Sex distribution



On April 1, 2019 males accounted for 53% of the 1,174 Ontarians identified with a motor neuron disease.

*Note, years represent the fiscal year. For example, 2019 is from April 1, 2019 to March 31, 2020.

Demographics: Age distribution



On April 1, 2019 the majority of people with a motor neuron disease were between the ages of 40 and 64 years, with 55% of people being under the age of 65. The mean age of a person with a motor neuron disease was 57 ± 22 years.

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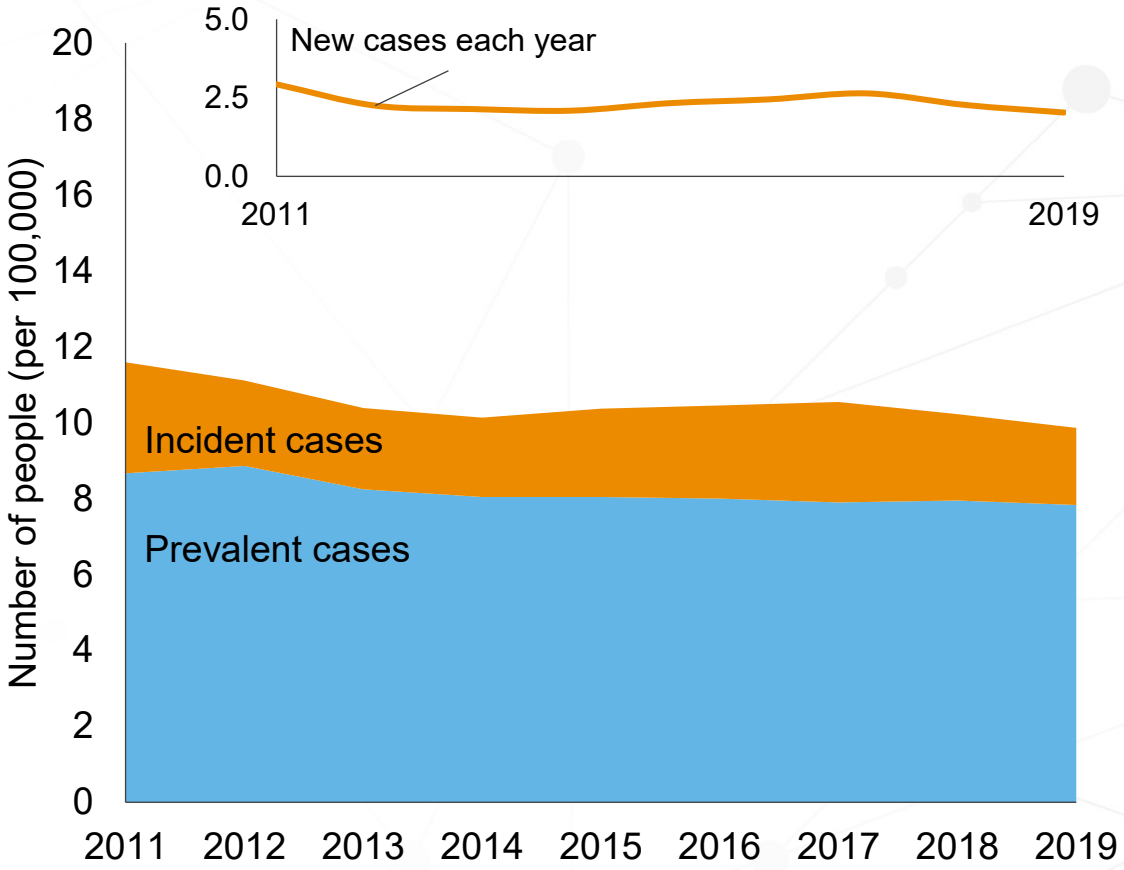
Prevalence and incidence over time



Incidence is the number of people newly diagnosed with a disorder within a given time period while prevalence is the number of people existing with the disorder at a given time.

The incidence and prevalence of Ontarians with a motor neuron disease are depicted in orange and blue, respectively. Between 2011 and 2019, incidence changed from 2.93 to 2.03 per 100,000 people and prevalence decreased from 8.66 to 7.83 per 100,000 people.

In total, the number of people with a motor neuron disease changed from 1,144 in 2011 to 1,174 people in 2019.

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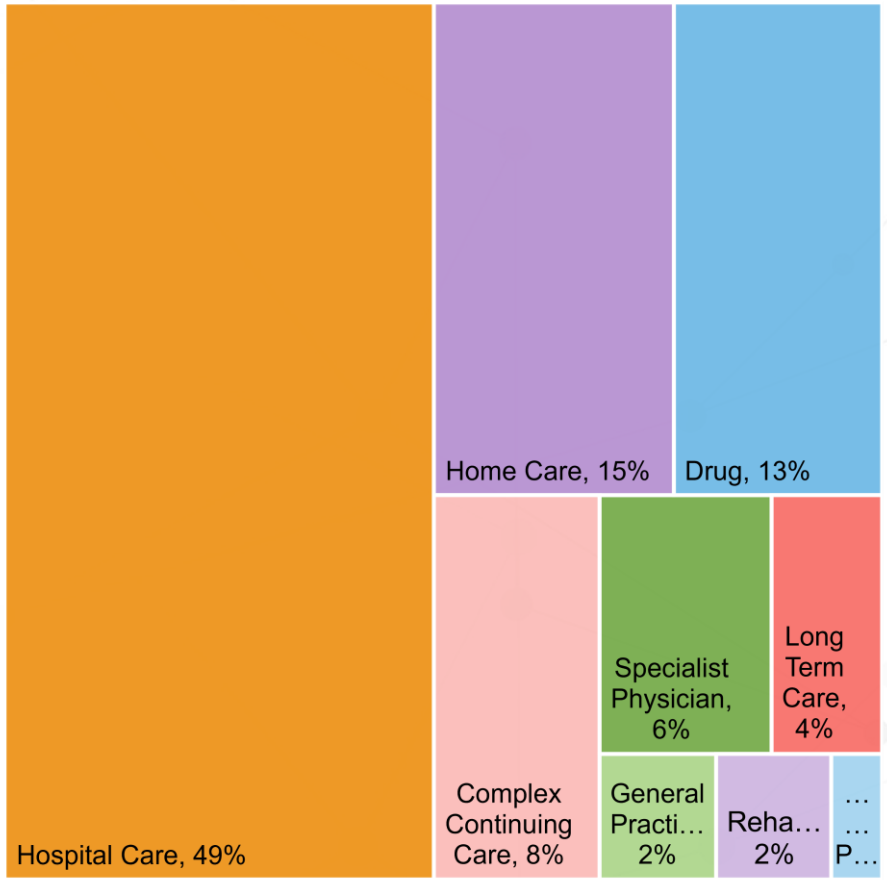
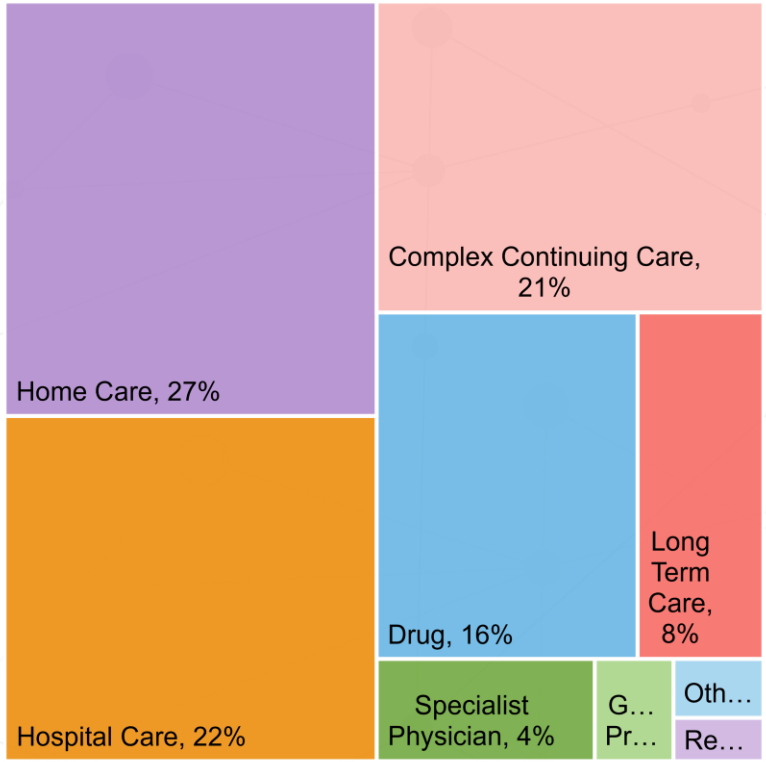
Cost Drivers: Incident vs. prevalent

Incident case cost drivers



Prevalent case cost drivers



*Cost drivers examined include: Hospital care, home care, general practitioner, specialist physician, other health professional, drug cost, rehab, complex continuing care, and long term care.

Cost Drivers: Incident vs. prevalent

In 2019, the average total cost to the health system for an Ontarian with a motor neuron disease was 1.3X more for an incident case than a prevalent case. Cost relationship is indicated by total box size. The largest cost driver of incident cases was attributable to hospital care (49%), while home care (27%) and hospital care (22%) had the highest costs for prevalent cases.

The average total health care costs for a person with a motor neuron disease (prevalent case) for 1 year are 24X higher for adults (18 - 64) and 5X higher for seniors (65+) compared to the average Ontarian.

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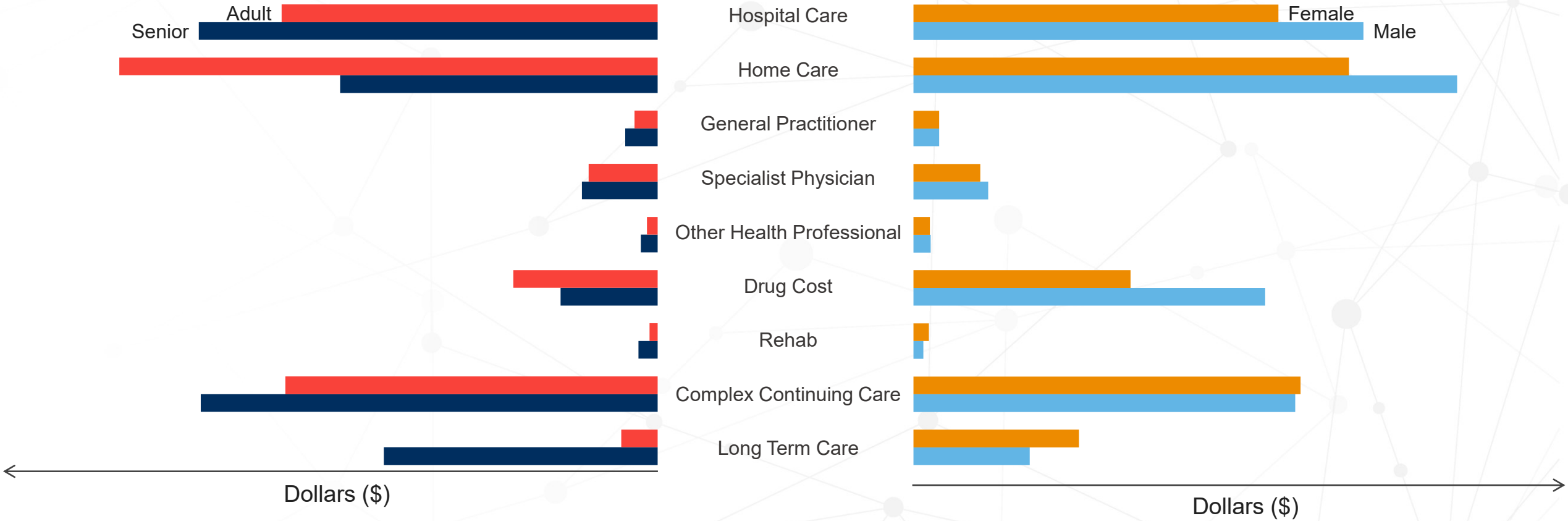
*Cost drivers examined include: Hospital care, home care, general practitioner, specialist physician, other health professional, drug cost, rehab, complex continuing care, and long term care.

Cost Drivers vary by age and sex for prevalent cases



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Cost Drivers vary by age and sex for prevalent cases

Overall, health care costs (in Canadian dollars, 2019) for people with a motor neuron disease are higher for the senior (65+ years) population compared to adults (18 - 64 years) and are also higher for males than females. The cost drivers, those services that drive health care costs, vary depending on age and sex. Amongst adults, home care accounts for the largest cost driver at 34% of all costs, while hospital care and complex continuing care drives costs in the adult population at 26% each. Home care is the largest cost driver in both females and males representing 26% and 28% of the health care costs respectively.

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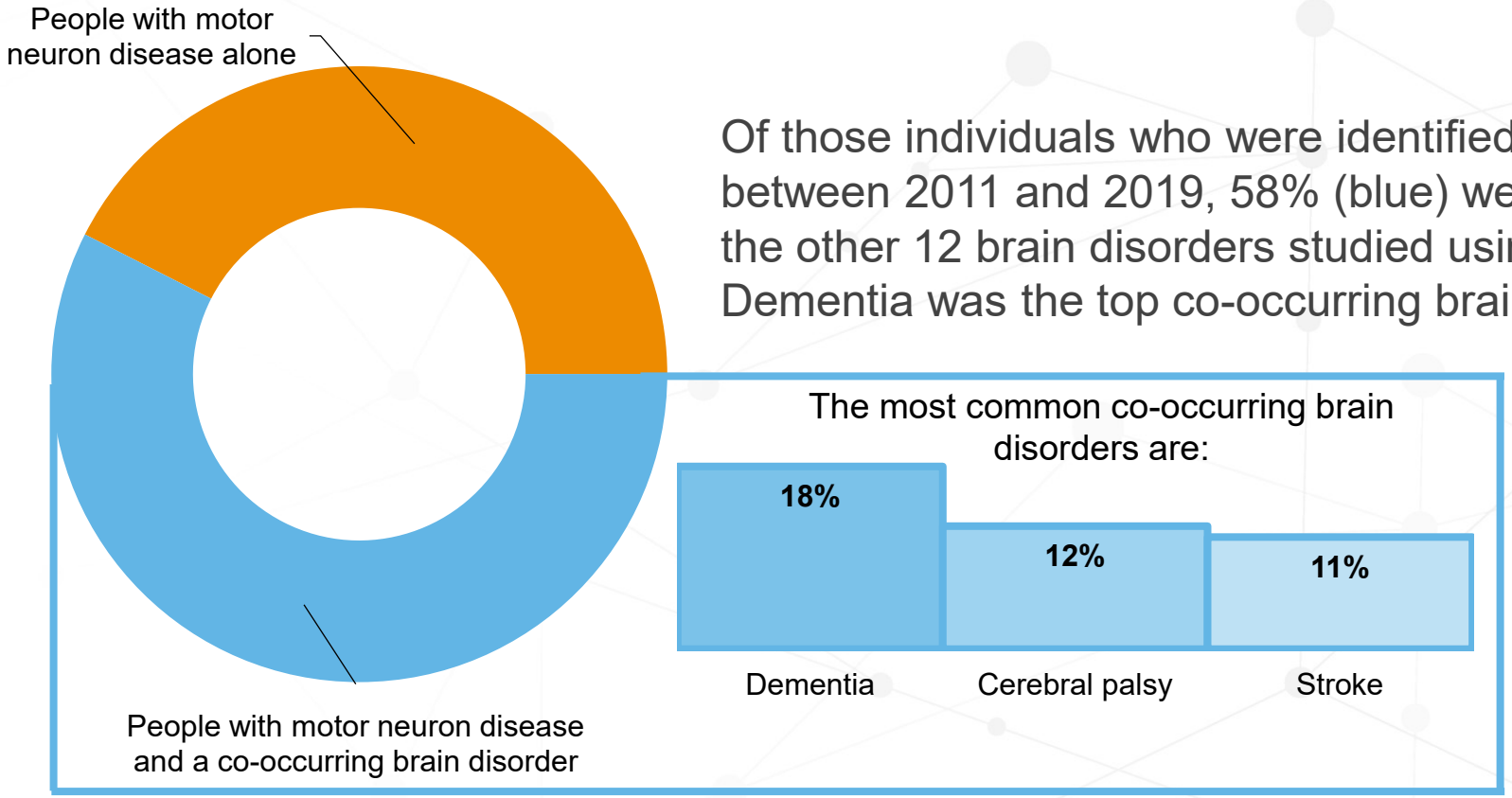
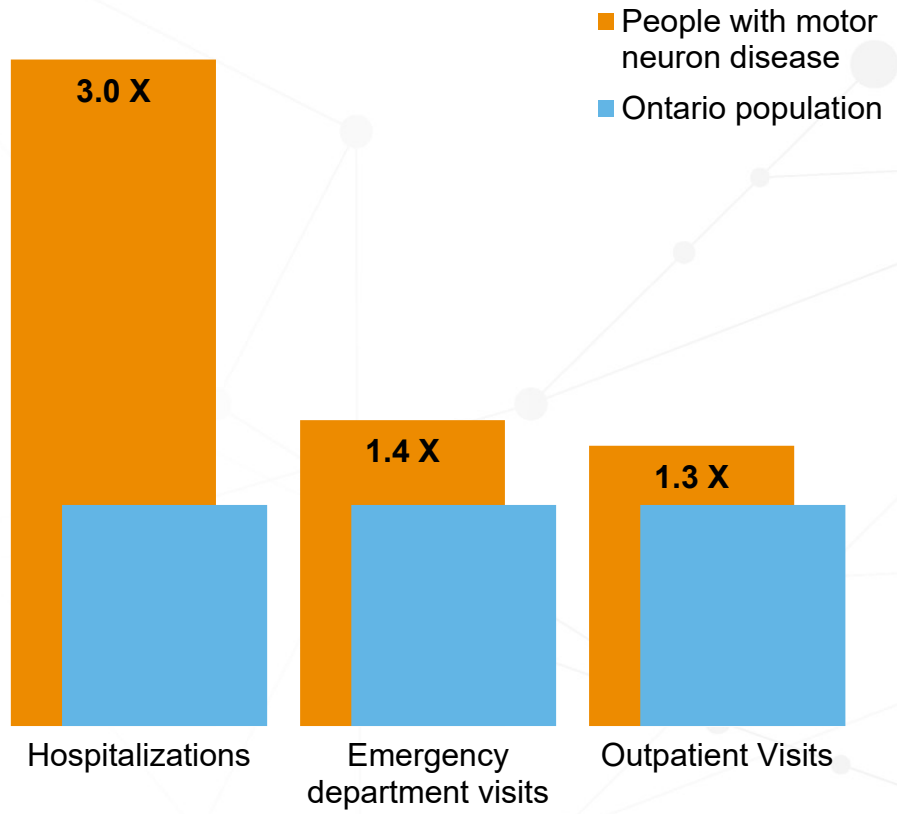
Co-occurring brain disorders



Of those individuals who were identified as having a motor neuron disease between 2011 and 2019, 58% (blue) were also identified as having one of the other 12 brain disorders studied using health administrative data. Dementia was the top co-occurring brain disorder, with 18% of those with a motor neuron disease also having dementia, followed by 12% with cerebral palsy, and 11% having had a stroke.

*Note, years represent the fiscal year. For example, 2019 is from April 1, 2019 to March 31, 2020.
*Note, other brain disorders studied include: non-malignant brain tumour, benign brain tumour, dementia (incl. Alzheimer's disease), epilepsy, motor neuron disease, multiple sclerosis, parkinsonism, schizophrenia, spina bifida, spinal cord injury, stroke, and traumatic brain injury & concussion.

Mental Health and addictions service use



Of those individuals who were identified as having a motor neuron disease in 2019, their visit rates for mental health and addictions related services were between 1.3X to 3.0X greater than the general Ontario population, depending on visit type.

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Additional study information

Brain Disorder	Evidence Grade	Reference	Algorithm	ICD-09 (CM) codes	ICD-10 codes	OHIP Dx codes	ODB drugs name	OMHRS codes	Age Restriction
Motor neuron disease	II	Accepted algorithmc	1 hospitalization record or 1 physician claim record	335	G12	335	N/A	N/A	None

Brain health in Ontario project main page: www.braininstitute.ca/BrainHealth
Methods and Considerations: www.braininstitute.ca/brainhealth-methodology

Publication information