



ALS SOCIETY OF CANADA

ALS FACT SHEET

SOCIÉTÉ CANADIENNE DE LA SLA

FACTSHEET #1

“ALS is clearly the most common cause of neurological death on an annual basis.”

– Dr Michael Strong, *clinician scientist at the Robarts Research Institute, London, Ontario.*

ALS FACTS

- Two to three Canadians a day die of ALS.
- Between 1,500 and 2,000 Canadians currently live with ALS.
- In at least 90% of cases, ALS strikes individuals with no family history of the disease.
- ALS can strike anyone, regardless of age, sex, or ethnic origin.
- The usual age of onset is 55 – 65, but some have been younger than 20.
- Ninety percent of people with ALS die within five years of diagnosis. While some live longer, others die within a few short months.
- An ALS diagnosis affects the whole family.
- ALS is costly – economically, physically, and emotionally.
- June is ALS month. Friends, family, and supporters of those with ALS dedicate June to raising awareness of this disease and to raise funds for a cure.
- WALK TO D’FEET ALS is our national signature event raising funds for research and local services for those affected by ALS.
- The cornflower is the ALS Society floral emblem because despite its fragile appearance, it is a hardy wildflower found throughout Canada. Like the cornflower, people with ALS show remarkable strength in coping with this devastating disease. Like the cornflower, awareness of ALS and funding for care and a cure is growing across Canada.

FREQUENTLY ASKED QUESTIONS

WHAT IS ALS?

ALS is a rapidly progressive fatal neuromuscular disease. It is characterized by degeneration of a select group of nerve cells and pathways in the brain and spinal cord. This leads to progressive paralysis of the body’s voluntary muscles, particularly in the limbs and respiratory system.

ALS is a form of Motor Neuron Disease, and is sometimes called Lou Gehrig’s disease. Lou Gehrig was a famous New York Yankees baseball player who died of ALS in 1941. ALS was first identified by the famous French neurologist, Dr Jean-Martin Charcot in 1874.

WHO GETS ALS?

In 2001, 1423 Canadians died of ALS, including Tim E. Noël, Deputy Governor of the Bank of Canada, Ottawa, and Dr. Barry Smith, former Dean of Medicine at Queen’s University, Kingston.

Hundreds of others live with ALS – many, like Elizabeth Grandbois, Burlington, ON.; Suzanne Bourassa, Sudbury, ON.; Bert Weir, Roddickton, NE.; Marcel Bertrand, Winnipeg, MN.; and Dan Maloney, Nelson, BC give some of their energy to raise awareness and funds for support services for those with ALS and for research for a cure.

ALS can strike anyone. ALS is not contagious, does not discriminate, and can strike at any age. While the usual age of onset is between 55 and 65, young adults and even teenagers have been diagnosed.

Regardless of age, ALS is a devastating disease for the individual and their family.

WHAT ARE THE SYMPTOMS?

The first symptoms of ALS usually occur either in the legs, the arms, the throat, or the upper chest area. Along with muscular weakness, one may also experience excessive muscular fatigue or aching fatigue. Some individuals begin to trip and fall, some lose the use of their hands and arms, some find it hard to swallow, and some begin to slur their speech. Fasciculation – or muscle twitching – may also be an indication of ALS. There is no precise order in which the symptoms may appear and any one of them could be a possible indication of the disease.

HOW IS ALS DIAGNOSED?

ALS symptoms, which are similar to many other conditions, must be investigated before an ALS diagnosis is determined.

Continued overleaf /...

ALS SOCIETY OF CANADA • LA SOCIÉTÉ CANADIENNE DE LA SLA

To connect with your local ALS Society, call toll free 1-800-267-4257 or visit <http://www.als.ca>

We can live without ALS.

SEPTEMBER 2002



.../ Continued from page 1

There is no single clinical test to identify ALS. Before a diagnosis is made, the person should be given a thorough medical evaluation – including a complete health history, a physical examination, a neurological assessment, and diagnostic tests such as an MRI and blood studies.

WHAT ARE THE EFFECTS OF ALS?

Because ALS frequently takes its toll before being positively diagnosed, many people with ALS are debilitated before learning they have ALS. As the disease progresses, there is increasing paralysis of the limbs and respiratory system. The senses – taste, touch, sight, smell and hearing – remain unimpaired and the intellect is usually unaffected.

In addition, ALS has a devastating affect on the family. The caregiver burden is high as the person with ALS needs greater and greater support. Resources of all sorts are consumed – financial, physical, emotional – and depleted. In the later stages it can be particularly costly, demanding both expensive equipment and extensive nursing care in assisting with daily living tasks. While the Canadian health system covers some of these expenses, families must bear any remaining costs.

ECONOMIC IMPACT

As ALS progresses, household modifications, equipment, and supplies are necessary for quality in-home care. During the later stages of the disease when there can be extensive paralysis, home and nursing care are required in order to assist with the tasks of daily living. This type of care can be costly. While the Canadian health system covers some of these expenses, people with ALS and their families must bear any remaining costs, including some equipment purchases and private nursing.

STATISTICS CANADA DEATH RATE DATA

		1994	1995	1996	1998
ALS	Males	493	567	520	592
	Females	503	489	590	460
	TOTAL	996	1056	1110	1052
CYSTIC FIBROSIS	Males	35	24	24	31
	Females	38	33	23	26
	TOTAL	73	57	47	57
MULTIPLE SCLEROSIS	Males	129	129	105	133
	Females	184	212	189	221
	TOTAL	313	341	294	354
AIDS	Males	1489	1637	1198	1245
	Females	139	127	108	210
	TOTAL	1628	1764	1306	1455

- According to the latest Statistics Canada data, 1,052 people died of ALS in 1998. (This is a conservative number, as ALS may not always be listed as the primary cause of death.)
- According to Statistics Canada, from 1994 to 1996 deaths due to ALS were:
 - 94% higher than deaths from cystic fibrosis,
 - 70% greater than deaths from multiple sclerosis, and
 - only 15% less than deaths from AIDS.
 These statistics show that twice as many people a year die of ALS than cystic fibrosis and multiple sclerosis combined.

IS THERE HOPE FOR PEOPLE WITH ALS?

Increasingly, ALS is being seen as a treatable disease with medications to assist in managing the symptoms and with technology being employed to aid in communication.

However, there is no treatment yet that significantly prolongs life. Some drugs are now available and others are being tested and developed that will soon offer new treatment options.

Many people with ALS say that they live life more fully now, with much joy, even knowing what is to come. In the meantime, good planning – and medical and social management – can ease the burden for both those with ALS and their family.

WHAT IS BEING DONE?

The cause of ALS is unknown. Possible causes currently under investigation include genetic predisposition, viral or infectious agents, environmental toxins, and immunological changes. Although recent research has resulted in significant breakthroughs, much more is needed to find a cure.

WHAT IS THE ALS SOCIETY OF CANADA?

Our mission is to support research towards a cure for ALS and to support ALS Partners in their provision of quality care for persons affected by ALS.

The ALS Society has partner units in every Canadian province. The ALS Society of Canada is a national voluntary organization founded in 1977.

The ALS Society of Canada web site – www.als.ca – has the latest information about activities of the Society, ALS research, and services for those affected by ALS.