



ALS Society of Ontario
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10 FACTS ABOUT ALS

- 1 ALS is a fatal, rapidly progressive neuromuscular disease. Common symptoms include muscle weakness, wasting and cramping, difficulties swallowing and problems with speech. Most people with ALS become immobile and many are robbed of their ability to speak. Respiration also becomes increasingly difficult, and some people eventually rely on ventilation to assist with breathing.
- 2 Average equipment and care costs are \$130,000 per person over the course of the disease. Most of these costs are not covered by government funding or private insurance.
- 3 Ninety per cent of caregiving is shouldered by family caregivers, usually a spouse, child or parent. Caregivers are often forced to quit their jobs, leaving the family with no income. Some families lose their homes and are forced into bankruptcy.
- 4 The average age of diagnosis is 55 to 65 years of age. One-third of those diagnosed are younger than 45.
- 5 ALS is a death sentence. There is no known cause, cure or treatment.
- 6 Eighty per cent of people with ALS die within two to five years. Some die within a few months while others live longer than five years.
- 7 Nationwide, 2,500 to 3,000 people have ALS, with close to half living in Ontario.
- 8 ALS is five times more prevalent than Huntington's disease, four times more prevalent than muscular dystrophy, and has a similar incidence rate as multiple sclerosis. The number of people with ALS is smaller than people with these other neurological diseases because people with ALS usually die so rapidly.
- 9 ALS is hereditary in five to 10 per cent of cases. The other 90 to 95 per cent of cases strike people with no family history of ALS.
- 10 ALS strikes regardless of age, sex or ethnicity.

About the ALS Society of Ontario

The ALS Society of Ontario is a charitable organization dedicated to providing the necessary equipment and support services to people with ALS, and to funding research toward a cure or effective treatment.

The ALS Society of Ontario remains committed to providing the following services:

- ◇ Assisting with the loan and purchase of essential medical equipment
- ◇ Peer support for people with ALS, their caregivers and family members
- ◇ Staff or volunteer home visitors (where available)
- ◇ Information and referral to community and health services for people with ALS, caregivers and families
- ◇ Referrals to counseling and support groups (where available)
- ◇ Educational materials about ALS and the support needed by people with ALS provided to healthcare providers, students, people with ALS and their families, employers, etc.)
- ◇ In-service training about ALS and the ALS Society of Ontario to the healthcare community

Providing independence, dignity, hope and choice to people living with ALS