



# WHEN SPEAKING ABOUT ALS

| Fact Sheet #2

## LANGUAGE GUIDELINES

If you are speaking on behalf of the ALS Society, please prepare by carefully reviewing this information.

### WHAT TO CALL THIS DISEASE

ALS - as simple as that

ALS, sometimes called Lou Gehrig's disease

No need to say "amyotrophic lateral sclerosis". It is a mouthful, easy to stumble over or mispronounce.

Using ALS builds stronger recognition of the acronym.

### WHAT IS ALS?

ALS is a fatal neuromuscular disease.

Nerve cells degenerate.

Voluntary muscles weaken and become immobile.

The senses are unimpaired and the intellect may remain unaffected.

### PREFERRED LANGUAGE

It is preferable to say:

Canadians with ALS...

People living with ALS...

Those affected by ALS...

The ALS Society serves those living with ALS

The ALS Society serves those affected by ALS (which includes the wider circle of family and caregivers)

### DO NOT USE PALS (person with ALS)

Many people with ALS do not like this reference.

However, if a person with ALS wishes to use PALS in referring to themselves, that is, of course, their choice.

### NOT OUR PATIENTS

People with ALS are patients, but they are not **OUR** patients. The ALS Society does not provide medical care.

Suggested alternative:

People with ALS

Clients of the ALS Society

### INACCURATE STATEMENT

"The mind remains intact" is inaccurate.

### ACCURATE STATEMENT

"The mind may remain unaffected" is accurate.

"The intellect may remain unaffected" is accurate

(Research is showing that an element of dementia is often present in those with ALS.)

### ADJECTIVES FOR ALS

devastating

catastrophic

### THE ALS SOCIETY

**PROVIDES** information to build awareness

**SUPPORTS** people affected by ALS to serve immediate needs

**FUNDS** research for a cure.

### SOME MORE FACTS ABOUT ALS

Approximately 3,000 Canadians currently live with ALS

Every day two or three Canadians die of ALS

ALS is the most common cause of neurological death in Canada

ALS can strike anyone

- Male or female
- Any ethnic origin
- At any age
- Some have been diagnosed as teens
- Usual onset is in middle age

90% die within three to five years of diagnosis

- Some will die within a few short months
- Some will live longer than five years

Some cases are hereditary

- Less than 10% are familial ALS
- ALS is not contagious

ALS affects the whole family

- 90% of care is shouldered by family caregivers
- ALS is a costly disease - emotionally, physically and financially

Ten Provincial ALS Societies provide quality care to those affected by ALS

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