New ALS guideline establishes national standard for managing neurodegenerative disease

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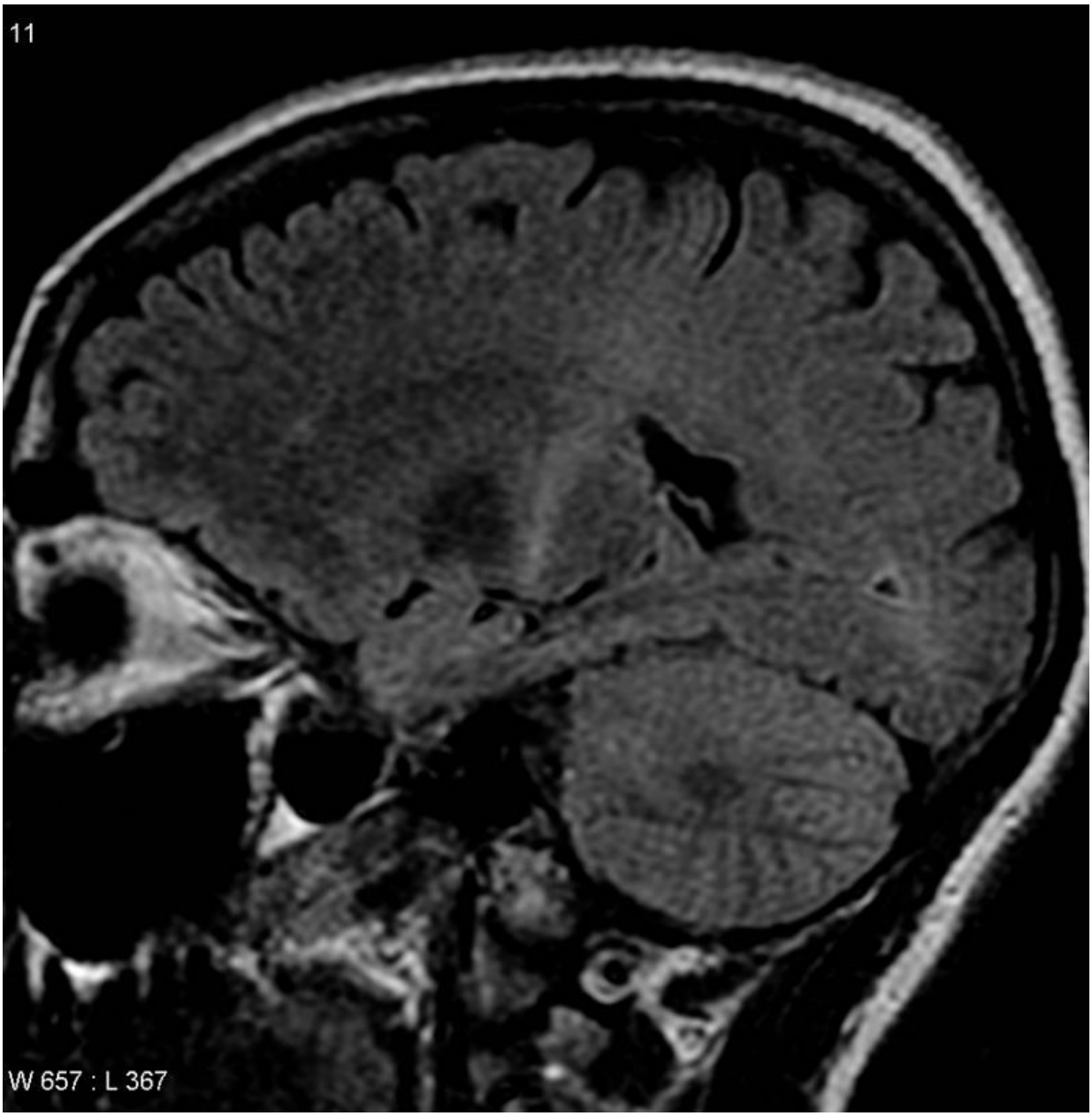

An MRI with increased signal in the posterior part of the internal capsule which can be tracked to the motor cortex consistent with the diagnosis of ALS. Credit: Frank Gaillard/Wikipedia

The first Canadian guideline for the care and management of patients with amyotrophic lateral sclerosis (ALS)—Lou Gehrig's

disease—recommends a patient-focused approach, with attention to holistic and emotional aspects of well-being.

The guideline, published in *CMAJ (Canadian Medical Association Journal)*, is intended for ALS clinicians, allied health professionals and primary care providers, and contains an easy-to-reference table with comprehensive recommendations. As new evidence may change management, the guideline will be updated every 5 years.

"These best practice recommendations are an important step forward in improving the lives of people living with ALS across the country and supporting their caregivers by addressing important issues," says Dr. Christen Shoesmith, neurologist and Motor Neuron Diseases Clinic director at London Health Sciences Centre in London, Ontario, and chair of the ALS guideline working group. "The emphasis on expert consensus relative to evidence-based recommendations highlights the need for more research in ALS management and underscores the challenges ALS clinicians face in managing patients with this complex and devastating disease."

About 3000 Canadians live with ALS, a debilitating degenerative disease affecting the brain and spinal cord that ultimately results in paralysis. ALS has no cure, and four out of five people with ALS will die within five years of being diagnosed.

The guideline is based on the best available evidence as well as expert consensus when evidence is lacking. It is intended to guide Canadian clinicians through issues unique to Canada and to update previous guidelines published in the United States and Europe.

- Communications—tailor the initial discussion about diagnosis to the patient's needs; information about ALS prognosis does not need to be provided at the time of diagnosis

- Disease-modifying therapies—have an open discussion with patients about the potential risks and benefits of both approved and unapproved therapies
- Multidisciplinary care—refer patients to specialized ALS multidisciplinary clinics for optimized health care delivery
- Caregivers—be attentive to the needs of caregivers and involve them in care planning

The guideline provides detailed recommendations for managing symptoms including pain, cramps, sleep disturbances, depression and anxiety as well as recommendations for respiratory management, nutrition, exercise, medication alignment, palliative care and more.

The authors emphasize the need for more research into ALS treatment and the challenges in caring for people with this disease.

Funding for the guideline was provided by the ALS Society of Canada and the Canadian ALS Research Network (CALS).

"This guideline will enable ALS clinics across Canada to meet a common national standard, and to adapt as this standard continues to evolve over time. In doing so, ALS clinicians can offer the best possible care to their patients and help them to navigate this exceedingly complex and devastating disease," conclude the authors.

"Canadian best practice recommendations for the management of amyotrophic lateral sclerosis" is published November 16, 2020.

More information: *Canadian Medical Association Journal* (2020). www.cmaj.ca/lookup/doi/10.1503/cmaj.191721