



McMaster University
Medical Centre

Dear Community Health Care Professional,

You are currently treating a patient who was referred to you by the ALS Clinic at McMaster University Medical Center. We are a team of health care professionals dedicated to the treatment of ALS. We know first hand how difficult it can be to treat patients with ALS and so we want you to know we are here to help you ---the health care professionals in the community---anyway we can. We know we cannot do this work without you and as such see ourselves as part of the community team. We hope to have open communication and ongoing interactions with you. Please feel free to contact any of our team members and let us be a resource for you so we can all work together to provide the highest level of care for patients with ALS. Thank you in advance for your time, skill, knowledge and care.

MAIN LINE: 905 521 2100

DR. JOHN TURNBULL: Neurologist & Director

Oversees the care of patients (initial assessment and follow-up consultations) and conducts ALS research.
extension 76365

ISHTAR GABRIEL: Clinic Coordinator

Coordinates patient care and clinical team, organizes clinical trials and oversees education and support services
extension 76870, email: gabrieli@hhsc.ca

SHELLEY CURRY: Administrative Assistant:

Oversees new patient referrals, books patient appointments, arranges EMGs and MRIs and assists the ALS Clinic Team Staff.
extension 76365, email: currys@mcmaster.ca'

JODEE NAYLOR: Respiratory Therapist Provides information to patients about respiratory care, techniques and equipment and arranges airway and breathing support.
extension 73731, pager 1222, email: naylorj@hhsc.ca

MAUREEN HILLS: Social Worker

Arranges community services and financial assistance, provides counseling for patients, caregivers and their families and advocates on behalf of patients and their families.
extension 73257, pager 4053, email: hills@hhsc.ca

NANCY HUBBARD: Speech and Language Pathologist, KIM WILLIAMS: Occupational Therapist & JAMES LESLIE: Rehabilitation Technologist

Available to discuss augmentative and alternative communication strategies (AAC) and electronic aids to daily living (EADL). If you do not live in the Hamilton region, they can help you register with an expanded level ADP-designated communication centre in your home region.

(Nancy) extension 77466, email: hubbard@hhsc.caextension

(Kim) extension 77459, email: careyk@hhsc.ca

(James) extension 77025, email: leslie@hhsc.ca

JANE ALLAN: Regional Manager ALS Society of Ontario

The ALS Society provides "*A Resource Guide for People with ALS*", offers support groups for people with ALS and their caregivers, and help with equipment requirements through financial assistance and a loan pool. FOR MORE INFORMATION PLEASE refer to: www.alsont.ca

Phone: (289) 313-0619 email: jane@alsont.ca

What is Amyotrophic Lateral Sclerosis:

Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's disease," is a progressive neurodegenerative disease that attacks nerve cells (motor neurons) for voluntary movement in the brain and the spinal cord. The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With all voluntary muscle action affected, patients in the later stages of the disease become totally paralyzed. Yet, through it all, for the vast majority of people, their minds remain unaffected.

As motor neurons degenerate, they can no longer send impulses to the muscle fibers that normally result in muscle movement. Early symptoms of ALS often include increasing muscle weakness, especially involving the arms and legs, speech, swallowing and breathing. When speech and swallowing issues are the first noted, it is called "Bulbar" type.

Both upper motor and lower motor neurons are affected with ALS (unlike many other neuromuscular diseases). Losses of upper motor neurons can result in muscle weakness, stiffness, slowness of movement, tightness and spasticity. Lower motor neuron losses result in muscle weakness, atrophy, cramping and twitching. Since both are lost with ALS, all these symptoms may occur, but not necessarily at the same time or to the same degree in each muscle.

Sensation remains intact, although some people will complain of tingling/numbness at times. Sexual function generally remains normal, although physical limitations can require adaptation. Bowel and bladder control usually remains intact. Most autonomic reactions remain normal.

The rate at which ALS progresses can be quite variable from one person to another. Although the mean national survival rate with ALS is three to five years. In any case the focus should **always** be proactive, and on maintaining independence, function and quality of life.

On a final note: it is important to remember that ALS is a devastating disease, which takes a huge EMOTIONAL, PSYCHOLOGICAL AND FINANCIAL toll on the person with ALS as well as their families. One of the BIGGEST obstacles for patients and families is accepting the diagnosis and coming to terms with all the physical and social changes (and for some patients this never happens). A good sense of humour, kindness, honesty and thoughtfulness go a long way and you would be amazed how receptive patients and families will be when they know they can trust and rely on us/you. We look forward to hearing from you.

Sincerely,

The ALS Clinic Team
McMaster University Medical Centre