ALS SYMPTOM ROADMAP

Understanding Your Symptoms and Illness Impacts

WHAT IS THIS FOR

ALS looks and feels different for everyone, but understanding common symptoms experienced is key to getting the right types of support, feeling prepared, and having more choice and control.

This tool allows for open conversations between patient, family, and health care teams to talk about where things are at and what to expect later.

HOW TO USE THIS

Use the space below to take notes and discuss these topics with your healthcare team:

1. **Your current symptoms and illness impacts.**
2. **What can we do to maximize quality of life?**
3. **Who needs to be involved in my care team?**
4. **When my illness is changing, what do I need to know?**

MAJOR ILLNESS IMPACTS

INDIVIDUAL SYMPTOMS MAY VARY FROM MILD (1) TO SEVERE (4)

SPEECH

1. Noticeable changes in speech, but still readily understood
2. Increased difficulty being understood by others
3. May use gestures, writing, or aids to supplement speech
4. Loss of speech, reliance on communication aids

SWALLOWING & SALIVATION

1. Difficulty chewing and/or coughing during eating and drinking
2. Increased difficulty with chewing/swallowing; needing longer meal times and/or modified food texture
3. Use of tube feeding as well as oral intake
4. Loss of swallowing function, dependent on feeding tube for nutrition

LOWER EXTREMITY (LEGS)

1. Slight changes in walking or balance
2. Trouble climbing stairs; limited endurance; falls
3. Use of mobility device most of the time (e.g. walker, wheelchair)
4. Use of wheelchair 100% of time

UPPER EXTREMITY (HANDS/ARMS)

1. Less strength in hands and/or arms
2. Trouble with writing, dressing, and grooming
3. Needs assistance with daily activities due to hand/arm weakness
4. Total dependence for all personal care and activities of daily living

BREATHING

1. Shortness of breath/fatigue with active exertion (e.g. walking, stairs)
2. Shortness of breath/fatigue with mild exertion (e.g. speaking, lying down); Discussing use of BiPAP.
3. Shortness of breath/fatigue all the time. BiPAP use ≥16 hrs/day
4. Dependence on BiPAP 24 hrs/day. Considering invasive mechanical ventilation.

NOTES ON YOUR EXPERIENCE

Financial contribution:

Health Canada Santé Canada

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ALS PLANNING ROADMAP

Prepare for Key Life Changes - Page 1

How to Use: Review this table to understand what key life changes to expect and things to think about.

	Key Life Changes	Things to Think About
POST DIAGNOSIS	**Manage symptoms and maximize quality of life**	· Explore access to and eligibility for medications and therapies · Investigate intervention options and research studies · Obtain psychosocial and emotional support **Relevant providers:** family doctor, nurse, neurologist, social worker, occupational therapist
	Bring my values, wishes, and goals forward	· Ensure wishes and preferences are expressed with key people · Explore supports to maintain daily routine (e.g. cleaning, meals, etc.) · Review legal, financial, and other affairs · Find creative ways to participate in things that bring joy · Identify substitute decision-maker/power of attorney for personal care · Assess and revisit long-term goals and values regularly · Explore options for end-of-life (e.g. Do Not Resuscitate, Ventilator, etc.) **Relevant providers:** social worker, palliative care clinician, nurse practitioner, home care workers, lawyer, financial planner, genetic counsellor
LIVING WITH ALS	**Manage swallowing and speech challenges**	· Explore strategies for swallowing safety · Explore voice banking · Discuss strategies and tools to optimise speech clarity · Explore use of non-verbal strategies, communication aides or assistive tech · Explore ways to assist with secretion clearance · Optimise nutrition, manage weight loss · Investigate feeding tubes, food modifications, and nutrition **Relevant providers:** speech-language pathologist, swallowing specialist or registered dietitian, neurologist, palliative care
	Manage respiratory issues	· Learn ways to cough effectively (e.g. cough assist) · Explore ways to manage shortness of breath · Explore ways to assist secretion clearance (e.g. medication, suction) · Discuss options to support breathing (e.g. BiPAP, mechanical ventilation, strategies without equipment) **Relevant providers:** respiratory therapist, respirologist, palliative care
	Manage mobility issues	· Discuss exercises and strategies for energy conservation, pressure relief, and activities of daily living · Explore mobility devices, home accessibility, and adaptive aids · Have proactive conversations about changing abilities, supporting safety and accessing equipment · Engage early with public or private personal care workers · Explore medication for stiffness, twitching, and cramping **Relevant providers:** occupational therapist, physiotherapist, psychiatrist, personal support worker

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ALS PLANNING ROADMAP

Prepare for Key Life Changes - Page 2

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	Key Life Changes	Things to Think About
LIVING WITH ALS (CONTINUED)	**Manage mental health**	· Access mental health supports to help process and manage emotions · Engage with family, friends, and community · Discuss concerns and wishes about later and end stages of the illness **Relevant providers:** family and palliative care doctor, psychologist, social worker, psychiatrist, spiritual/faith leader, ALS support groups
	Support caregivers	· Obtain caregiving support, resources and respite · Activate your informal helping network or hire professional support · Learn about home and community care supports **Relevant providers:** social worker, personal support worker, homecare services, ALS caregiver support groups, hospice programs
	Monitor for changes in cognition, behaviour, and mood	· Because 10%-50% of ALS patients experience a range of mild to moderate changes in their thinking, mood and or personality, you should: · Monitor for changes in judgement, impulsivity, and difficulty with words · Monitor for changes in social engagement and with activities previously enjoyed **Relevant providers:** neurologist, social worker, mental health practitioner
POTENTIAL BIG DECISIONS	**BiPAP and long term mechanical ventilation**	· Investigate benefits of BiPAP and long-term mechanical ventilation; if appropriate, explore access options (e.g. private, publicly funded) **Relevant providers:** neurologist, respirologist, respiratory therapist
	Feeding tube	· Investigate feeding tubes to help when you cannot swallow safely and to maintain adequate nutrition orally **Relevant providers:** neurologist, dietitian, speech language pathologist
	Place of care	· Plan for where care is best managed as needs increase · Identify needed adaptations to your current residence and funding supports · Ask about caregiver benefits that may be available · Explore alternative living arrangements (e.g. long-term care, supportive living, palliative care unit) **Relevant providers:** social worker, care coordinator, occupational therapist
NAVIGATING LATE PHASE	**Prepare for end of life and decisions**	· Review which medications and interventions are appropriate · Focus on treatments that optimise comfort and quality of life · Reassess where care can be provided (home, hospice, palliative care unit) · Revisit goals of care · Revisit additional support and end-of-life options **Relevant providers:** family doctor/nurse practitioner, neurologist, palliative care practitioner

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