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.

MAJOR ILLNESS IMPACTS

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

SPEECH

- 1. Noticeable changes in speech, but can be readily understood
- 2. Increased difficulty being understood by others
- 3. May use gestures, writing or other communication aids to supplement natural 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 and swallowing, resulting in prolonged meal times and/or changes in the texture of food and/or
- liquids 3. Use of tube feeding in addition to oral intake
- 4. Loss of swallowing function, depend on feeding tube for nutrition

LOWER EXTREMITY (LEGS)

- 1. Small changes in walking or balance
- 2. Trouble climbing stairs, limited endurance, falls
- 3. Using mobility device most of the time (walker, wheelchair)
- 4. Using 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 (dressing, food prep, eating) due to hand/arm weakness
- 4. Total dependence for all personal care and daily living activities

BREATHING

- 1. Shortness of breath/fatigue with exertion (walking, transferring, etc.)
- 2. Shortness of breath/fatigue with mild exertion (eating, speaking, and/or when lying). Discussions about starting BiPAP
- 3. Shortness of breath/fatigue all the time. BiPAP use more than 16 hrs/day

Santé

Canada

4. Dependance on BiPAP 24 hrs/day and/or consideration of invasive mechanical ventilation





The views expressed herein do not necessarily represent the views of Health Canada.

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?

NOTES ON YOUR EXPERIENCE



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	 Access and eligibility for potential medications and therapies Latest intervention options, research and research participation 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 people important to me Discuss diagnosis with those important to me and supports needed to maintain daily routine (cleaning, groceries, meal preparation, banking, transportation, etc.) Prepare for future decision-making and review legal, financial, and other affairs Find creative ways to continue participating in things that bring you joy Support for substitute decision-maker/power of attorney for personal care Assess and revisit long-term goals and values regularly Explore concerns and choices for end-of-life (e.g. Do Not Resuscitate, Ventilator) 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 as speech and voice changes Explore voice banking as speech changes occur Discuss tools and strategies to optimize clarity of speech, use non-verbal strategies, and explore communication aides (e.g. assistive technology) Explore ways to assist with secretion clearance (saliva, phlegm, mucus) Optimize nutrition, manage weight loss Learn about 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 make a cough more effective, considering cough assist Understand how to manage shortness of breath Explore strategies to assist secretion clearance, including medication and suction Discuss options for supporting breathing with your healthcare provider (e.g. BiPAP, invasive mechanical ventilation, symptom management without equipment) Relevant providers: respiratory therapist, respirologist, palliative care
	Manage mobility issues	 Discuss mobility devices, home accessibility, adaptive aides, energy conservation, exercises, strategies for activities of daily living and pressure relief Have proactive conversations about changing abilities and how to support your safety and avoid delays in accessing home equipment Engage early with public or private personal support worker assistance Explore medication for stiffness, twitching, and cramping (neurologist, psychiatrist) Relevant providers: occupational therapist, physiotherapist, psychiatrist, personal support worker



Canada

Santé

Canada

The views expressed herein do not necessarily represent the views of Health Canada.







ALS PLANNING ROADMAP

Prepare for Key Life Changes - Page 2

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
	Manage mental health	Access mental health supports to help process and manage emotions
10 -	rianage meritar nearth	 Engage in your community and spend time with friends and family
ALS Ver		• Talk about concerns and wishes related to disease progression, later stages of
EE		the illness, and end of life
1 ≥ĕ		Relevant providers: family and palliative care doctor, psychologist, social worker, psychiatrist,
		spiritual/faith leader, ALS support groups
	Support consistent	Plan for caregiving support/resources and respite
	Support caregivers	Assess who can provide care or seek professional support
		Learn about homecare to increase comfort and preparedness
		Relevant providers: social worker, personal support worker, homecare services, ALS caregiver support
		groups, hospice programs
	Monitor for changes	Note: 10%-50% of ALS patients may experience a range of mild to moderate
	in cognition, behaviour,	changes in their thinking, mood and or personality
	and mood	\cdot Monitor for changes in insight, judgement, impulsivity and word finding difficulty
		• Monitor for changes in social engagement and with activities previously enjoyed
		\cdot Monitor for increased or out of context crying/laughter that impacts day to day
		Relevant providers: neurologist, social worker, mental health practitioner
S	BiPAP and long term	• Assess appropriateness of BiPAP and long-term mechanical ventilation and if so,
AL	mechanical ventilation	how to obtain and get support (family, private/publicly funded assistance)
POTENTIAL BIG DECISIONS		Relevant providers: neurologist, respirologist, respiratory therapist
DE		
PC BIG	Feeding tube	• Learn about feeding tubes for when you can no longer swallow safely and
		maintain adequate nutrition orally
		Relevant providers: neurologist, dietitian, speech language pathologist
	Place of care	 Plan for where your care can best be managed as your needs increase
		• Identify needed adaptations to your current residence and funding supports
		\cdot Ask about caregiver benefits that may be available to loved ones
		\cdot Explore alternative living arrangements within your community (long-term care,
		supportive living, respite, palliative care unit)
		Relevant providers: social worker, care coordinator, occupational therapist
	Prepare for end of	Review which medications and interventions are needed
NG SE	life and decisions	 Focus on treatments that optimize comfort and quality of life
АТІ РНА		• Reassess where care can be provided (home, hospice, palliative care unit)
NAVIGATING LATE PHASE		\cdot Revisit goals of care to ensure they inform treatment/intervention decisions
NA LAT		Explore additional support options
		Relevant providers: family doctor/nurse practitioner, neurologist, palliative care practitioner
		receiver provider of a many doctor, harde practicioner, heardologist, painative care practicioner







