## 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?

NOTES ON YOUR EXPERIENCE

### 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**

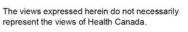
- 1. Shortness of breath/fatigue with active exertion (e.g. walking, stairs)
- 2. Shortness of breath/fatigue with mild exertion (e.g. speaking, lying down); Discussing use of BiPAP.
- 3. Shortness of breath/fatigue all the time. BiPAP use ≥16 hrs/day
- 4. Dependence on BiPAP 24 hrs/day. Considering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

Financial contribution:

















# **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
	Manage symptoms	• Explore access to and eligibility for medications and therapies
δ	and maximize quality	· Investigate intervention options and research studies
ST	of life	Obtain psychosocial and emotional support
POST DIAGNOSIS	c	Relevant providers: family doctor, nurse, neurologist, social worker, occupational therapist
	Bring my values,	• Ensure wishes and preferences are expressed with key people
	wishes, and goals	• Explore supports to maintain daily routine (e.g. cleaning, meals, etc.)
	forward	· 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
	Manage swallowing	• Explore strategies for swallowing safety
S	and speech	• Explore voice banking
LIVING WITH ALS	challenges	· Discuss strategies and tools to optimise speech clarity
ĬĬĔ	chaneriges	• 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	• Learn ways to cough effectively (e.g. cough assist)
	issues	• 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	· Discuss exercises and strategies for energy conservation, pressure relief, and
	issues	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













# **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
LIVING WITH ALS (CONTINUED)	_	• 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	Because 10%-50% of ALS patients experience a range of mild to moderate
	in cognition, behaviour,	changes in their thinking, mood and or personality, you should:
	and mood	· 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
(0)	BiPAP and long term	· Investigate benefits of BiPAP and long-term mechanical ventilation; if
A Š	mechanical ventilation	appropriate, explore access options (e.g. private, publicly funded)
POTENTIAL BIG DECISIONS		Relevant providers: neurologist, respirologist, respiratory therapist
CDE		. Investigate feeding tubes to help when you sappet swallow safely and
, m	Feeding tube	<ul> <li>Investigate feeding tubes to help when you cannot swallow safely and to maintain adequate nutrition orally</li> </ul>
		to maintain adequate nutrition orany
		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
	Prepare for end of	Review which medications and interventions are appropriate
NG \SE	life and decisions	· Focus on treatments that optimise comfort and quality of life
₽¥ ₽¥		· Reassess where care can be provided (home, hospice, palliative care unit)
N N		· Revisit goals of care
NAVIGATING LATE PHASE		· Revisit additional support and end-of-life options
		Relevant providers: family doctor/nurse practitioner, neurologist, palliative care practitioner













