



# 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	<b>Manage symptoms and maximize quality of life</b>	<ul style="list-style-type: none"> <li>• Access and eligibility for potential medications and therapies</li> <li>• Latest intervention options, research and research participation</li> <li>• Psychosocial and emotional support</li> </ul> <p><b>Relevant providers:</b> family doctor, nurse, neurologist, social worker, occupational therapist</p>
	<b>Bring my values, wishes, and goals forward</b>	<ul style="list-style-type: none"> <li>• Ensure wishes and preferences are expressed with people important to me</li> <li>• Discuss diagnosis with those important to me and supports needed to maintain daily routine (cleaning, groceries, meal preparation, banking, transportation, etc.)</li> <li>• Prepare for future decision-making and review legal, financial, and other affairs</li> <li>• Find creative ways to continue participating in things that bring you joy</li> <li>• Support for substitute decision-maker/power of attorney for personal care</li> <li>• Assess and revisit long-term goals and values regularly</li> <li>• Explore concerns and choices for end-of-life (e.g. Do Not Resuscitate, Ventilator)</li> </ul> <p><b>Relevant providers:</b> social worker, palliative care clinician, nurse practitioner, home care workers, lawyer, financial planner, genetic counsellor</p>
LIVING WITH ALS	<b>Manage swallowing and speech challenges</b>	<ul style="list-style-type: none"> <li>• Explore strategies for swallowing safety as speech and voice changes</li> <li>• Explore voice banking as speech changes occur</li> <li>• Discuss tools and strategies to optimize clarity of speech, use non-verbal strategies, and explore communication aides (e.g. assistive technology)</li> <li>• Explore ways to assist with secretion clearance (saliva, phlegm, mucus)</li> <li>• Optimize nutrition, manage weight loss</li> <li>• Learn about feeding tubes, food modifications, and nutrition</li> </ul> <p><b>Relevant providers:</b> speech-language pathologist, swallowing specialist or registered dietitian, neurologist, palliative care</p>
	<b>Manage respiratory issues</b>	<ul style="list-style-type: none"> <li>• Learn ways to make a cough more effective, considering cough assist</li> <li>• Understand how to manage shortness of breath</li> <li>• Explore strategies to assist secretion clearance, including medication and suction</li> <li>• Discuss options for supporting breathing with your healthcare provider (e.g. BiPAP, invasive mechanical ventilation, symptom management without equipment)</li> </ul> <p><b>Relevant providers:</b> respiratory therapist, respirologist, palliative care</p>
	<b>Manage mobility issues</b>	<ul style="list-style-type: none"> <li>• Discuss mobility devices, home accessibility, adaptive aides, energy conservation, exercises, strategies for activities of daily living and pressure relief</li> <li>• Have proactive conversations about changing abilities and how to support your safety and avoid delays in accessing home equipment</li> <li>• Engage early with public or private personal support worker assistance</li> <li>• Explore medication for stiffness, twitching, and cramping (neurologist, psychiatrist)</li> </ul> <p><b>Relevant providers:</b> occupational therapist, physiotherapist, psychiatrist, personal support worker</p>

Financial contribution:



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## 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
LIVING WITH ALS (CONTINUED)	<b>Manage mental health</b>	<ul style="list-style-type: none"> <li>• Access mental health supports to help process and manage emotions</li> <li>• Engage in your community and spend time with friends and family</li> <li>• Talk about concerns and wishes related to disease progression, later stages of the illness, and end of life</li> </ul> <p><b>Relevant providers:</b> family and palliative care doctor, psychologist, social worker, psychiatrist, spiritual/faith leader, ALS support groups</p>
	<b>Support caregivers</b>	<ul style="list-style-type: none"> <li>• Plan for caregiving support/resources and respite</li> <li>• Assess who can provide care or seek professional support</li> <li>• Learn about homecare to increase comfort and preparedness</li> </ul> <p><b>Relevant providers:</b> social worker, personal support worker, homecare services, ALS caregiver support groups, hospice programs</p>
	<b>Monitor for changes in cognition, behaviour, and mood</b>	<ul style="list-style-type: none"> <li>• Note: 10%-50% of ALS patients may experience a range of mild to moderate changes in their thinking, mood and or personality</li> <li>• Monitor for changes in insight, judgement, impulsivity and word finding difficulty</li> <li>• Monitor for changes in social engagement and with activities previously enjoyed</li> <li>• Monitor for increased or out of context crying/laughter that impacts day to day</li> </ul> <p><b>Relevant providers:</b> neurologist, social worker, mental health practitioner</p>
POTENTIAL BIG DECISIONS	<b>BiPAP and long term mechanical ventilation</b>	<ul style="list-style-type: none"> <li>• Assess appropriateness of BiPAP and long-term mechanical ventilation and if so, how to obtain and get support (family, private/publicly funded assistance)</li> </ul> <p><b>Relevant providers:</b> neurologist, respirologist, respiratory therapist</p>
	<b>Feeding tube</b>	<ul style="list-style-type: none"> <li>• Learn about feeding tubes for when you can no longer swallow safely and maintain adequate nutrition orally</li> </ul> <p><b>Relevant providers:</b> neurologist, dietitian, speech language pathologist</p>
	<b>Place of care</b>	<ul style="list-style-type: none"> <li>• Plan for where your care can best be managed as your needs increase</li> <li>• Identify needed adaptations to your current residence and funding supports</li> <li>• Ask about caregiver benefits that may be available to loved ones</li> <li>• Explore alternative living arrangements within your community (long-term care, supportive living, respite, palliative care unit)</li> </ul> <p><b>Relevant providers:</b> social worker, care coordinator, occupational therapist</p>
NAVIGATING LATE PHASE	<b>Prepare for end of life and decisions</b>	<ul style="list-style-type: none"> <li>• Review which medications and interventions are needed</li> <li>• Focus on treatments that optimize comfort and quality of life</li> <li>• Reassess where care can be provided (home, hospice, palliative care unit)</li> <li>• Revisit goals of care to ensure they inform treatment/intervention decisions</li> <li>• Explore additional support options</li> </ul> <p><b>Relevant providers:</b> family doctor/nurse practitioner, neurologist, palliative care practitioner</p>

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