



Minimizing Fatigue in Amyotrophic Lateral Sclerosis (ALS)

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Although the course of ALS is unpredictable, fatigue is one outcome that is predictable, resulting from muscle weakness and spasticity. Fatigue can range from mild lassitude to extreme exhaustion. People often complain of tiredness, dwindling strength or lack of energy. Untreated breathing problems can also aggravate fatigue. Despite the adverse effects of fatigue, symptoms can be minimized through effective management. By recognizing the signs of fatigue, knowing which factors worsen symptoms, and learning how to conserve energy, persons with ALS can greatly enhance their strength, tolerability of activities, and emotional stamina. Strategies for minimizing fatigue can markedly improve quality of living.

Noticeable signs of fatigue include:

Slower body movement, slower speech responses, shorter answers, lower voice volume, dull tone of voice, shortness of breath, increased sighing, anorexia, irritability, anxiety, episodes of crying, decreased smiling, lack of enjoyment of previously enjoyed experiences, de-

creased caring about things that were previously important, deterioration in appearance and grooming, increased forgetfulness, increased preference for being alone, and disinterest in decision-making in daily plans.

Factors that may aggravate fatigue include:

Immobility, overexertion, sleep disruption, pain, excessive weight loss, malnutrition, breathing weakness, stress, anxiety, hopelessness, grief, too hot or cold weather, certain medications (such as tranquilizers, sedatives, pain relievers, anti-histamines, muscle relaxants). Alcohol, smoking, the unavailability of people when help is needed, the lack of financial resources to provide for needs to make life easier, and an inaccessible home environment, such as a home with steps and long distances between rooms.

Anti-Fatigue Strategies

1. Learn methods to make tasks easier. Use assistive devices when needed. See a physical or occupational

therapist for determining what is best for your needs. If you have trouble walking, get a wheelchair. A motorized wheelchair will spare you the exertion of manually wheeling around in a standard model.

2. Make your home environment accessible for daily activities. Remove barriers to conserve energy. For example, moving your bed to the first floor of your home may spare the exertion of using the stairs.
3. Pace yourself. Move slowly and easily. Stop and rest often, and take a few breathers before you start again. If you become breathless during a task, it is time to stop. Schedule heavier tasks during predicted times of higher energy. Plan your activities and gather everything you need before you start. Don't stand when you can sit. Utilize possible short-cuts. Obtain assistance in completing tasks if you need help. Always allow enough energy to enjoy at least one valued experience each day.
4. Rest when you are tired. Alternate periods

of activity with periods of rest. Schedule regular rest periods each day, perhaps a half an hour after morning care and an hour in the early afternoon. Rest before going away. The goal is to always avoid overexertion.

5. Obtain an accessible parking permit. Your local Bureau of Motor Vehicles has a form that your physician will need to complete to obtain permission to park in accessible lots.
6. If you have problems waking up at night, determine why and what to do about it. Successful use of nasal ventilation helps prevent disrupted sleep. Try to establish a regular sleeping pattern.
7. Avoid becoming too hot or too cold since this may worsen muscle fatigue, aggravate breathing and compound fatigue further. Use an air conditioner in your home or vehicle if the climate is warm. Also avoid prolonged bathing in water that is too

warm, hot Jacuzzis and steam baths.

8. Maintain your nutritional requirements each day to help prevent excessive weight loss, resulting in muscle loss that can cause increased fatigue. Seek nutritional counseling if necessary. People with swallowing impairment may benefit from insertion of a feeding tube into the stomach, a minor surgical procedure for optimal management of nutrition, weight and fatigue.
9. Avoid stressful situations as much as possible. Implementing methods for making tasks easier will help reduce physical and emotional stress. By understanding fatigue, family members may cope better with emotional upsets and realize they are not personal attacks, but normal responses to fatigue.
10. If you feel noticeably weaker or have difficulty breathing after taking a medication, notify your physician. Perhaps your

medication needs to be substituted for another one or the dosage may need to be altered. Trouble breathing, however, may be related to respiratory muscle weakness, resulting in hypoventilation or the inability to take a deep breath. This may warrant a pulmonary evaluation and treatment of symptoms.

11. Nasal or mouthpiece ventilation helps alleviate fatigue and boosts energy in people with respiratory impairment. Shortness of breath signals the need to use nasal ventilation or to discuss the option with your physician.

Failure to manage fatigue can result in rapid physical deterioration, inability to cope, unexpected respiratory failure and dying prematurely. However, effective management of fatigue will promote optimal wellness in living, the desire to keep living, the strength to carry on and prolong survival. Although in ALS you cannot take away fatigue, you can learn ways to overcome fatigue and not let it overcome you.

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