Minimizing ALS Fatigue

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, and lack of energy. Despite the adverse effects of fatigue, symptoms can be minimized through effective management. Be recognizing the signs of fatigue, knowing which factors worsen symptoms, and learning how to conserve energy, persons with ALS can greatly improve their quality of living.

Noticeable signs of fatigue include: Slower body movement, slower speech responses, short answers, lower voice volume, dull tone of voice, shortness of breath, increased sighing, anorexia, irritability, anxiety, crying episodes, decreased smiling, lack of enjoyment of previously enjoyed experiences, decreased caring about things that were previously important, deterioration in appearance and grooming, increased forgetfulness, increased preference for being alone, and disinterest in decision making daily plans.

Factors which may aggravate fatigue include: Immobility, overexertion, sleep disruption, pain, excessive weight loss, protein malnutrition, breathing weakness, stress, anxiety, hopelessness, grief, too hot or cold weather, certain medications (such as tranquilizers, sedatives, pain relievers, antihistamines, 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 which has steps and long distances between rooms.

Anti-Fatigue strategies are:

1. Learn methods of making every task easier. Use assertive devices when needed. See an occupational therapist for determining what is best for your needs. If you have trouble walking, don’t resist getting a wheelchair. A motorized wheelchair will spare you the exertion of manually wheeling around in a standard model.

2. Pace yourself. Move slowly and easily. Stop and rest often and take a few breathes before you start again. If you become breathless during a task, it is time to stop. Schedule heavier task 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 shortcuts. Obtain assistance in completing tasks if you need help. Always allow enough energy to enjoy at least one valued experience each day.

3. Alternate activities with periods of rest. Schedule regular rest periods each day, perhaps a half hour after morning care and an hour in the early afternoon. Rest before going away.

4. Get a handicapped parking sticker. Your local department of motor vehicles has the form that your physician will need to fill out.

5. Try to establish a regular sleeping pattern. If you have problems waking up at night, determine why and what to do about it.
6. Avoid prolonged bathing in warm water, as it may worsen muscle fatigue. Be cautious of extreme outdoor temperatures.

7. Maintain your nutritional requirements each day, and prevent unnecessary weight loss. You may need to consult with a dietitian.

8. Avoid stressful situations as much as possible. Understanding fatigue will help family members cope better with emotional upsets, realizing they are not personal attacks, but normal responses to fatigue.

9. If you feel noticeably weaker or have difficulty breathing after taking a medication, let your doctor know. Perhaps your medication needs to be substituted for another one or the dosage altered. Trouble breathing, however, may be related to breathing fatigue and may warrant an evaluation by your doctor for a breathing remedy.

10. Make your living environment accessible for daily activities, and promote energy conservation. Moving a bed to another location or relocating personal items are some examples.

Failure to manage fatigue can result in unnecessary suffering, social isolation and rapid physical deterioration. However, effective management will maximize your wellness and abilities, giving you the desire to keep living and the strength to carry on. Although in ALS you can’t take away fatigue, you can learn to overcome fatigue and not let it overcome you.

Excerpted from an article by Pamela A. Cazzolli, R.N.

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