



Although not all people with amyotrophic lateral sclerosis

(ALS) are affected exactly alike, progressive muscle weakness is a hall mark of the disease, resulting in problems with immobility. Weakness usually begins in a group of muscles and gradually spreads to other muscles, causing gradual loss of muscle movement. While some people continue to maintain use of their arms or legs, others may slowly lose the ability, and therefore, activities become increasingly difficult, or perhaps not possible as muscle weakness progresses. People with limited mobility are at risk for complications, as prolonged immobility or inactivity may cause changes in the muscles and joints and affect every system in the body, as well as impact one's psychological well being.

Complications of immobility include:

- **Disuse atrophy** is muscle wasting caused by inactivity or disuse of the "good" muscles, those that are unaffected by motor neuron degeneration. Although the disease causes muscle weakness that may result in trouble walking or performing daily

Preventing and Treating Complications of Immobility in People with ALS

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activities, people who do not use their limbs, if they have the ability to move, will lose muscle mass more rapidly. Thus, immobility will compound weakness of the working muscles. Although they say, "if you don't use it, you'll lose it," overexertion should be avoided. People with ALS should also know that if any muscles are unable to contract because of motor neuron damage, then exercise will not restore the strength of those muscles.

- **Joint stiffness and pain** can occur if weak limbs are not stretched and if joints are not given adequate full range of motion. The stiffness is due to tightness of the muscles and tissues surrounding the joints. Limitation of motion of the shoulder joint may also cause inflammatory thickening of the tissues enclosing the joint, resulting in adhesive capsulitis, often referred to as a "frozen shoulder." Unresolved joint stiffness and pain can hamper activities and lead to premature disability if symptoms are not reversed. People who do have

use of their arms or legs are a risk for contractures of the joints.

- **Contractures** are shortenings of muscle or connective tissue around the joints that prevent the normal range of movement of joints. The tightening of these muscles and tissues are due to immobility and cause deformities or joints to become bent in a fixed position that is resistant to stretching to a straight position. Contractures can occur in the finger, hand, wrist, elbow, shoulder, ankle, knee, and hip joints, including flexion contractures of the neck. Weak limbs can lead to an unending cycle of decreased range of motion, increased muscle and tissue tightness of the joints, development of contractures, further impaired mobility, resulting in more joint tightness and contractures.
- **Pressure sores or ulcers** can result from pressure to an area of the body from a bed or chair. Any surface that presses against the skin and underlying tissues

decreases circulation to the area, as the pressure collapses capillaries, interrupting the tissue's supply of oxygen and nutrients. When a person remains in one position for too long, the pressure obstructs the blood flow, causing tissue to break down. The first sign of this is redness.

Unrelieved pressure, however, can lead to ulcer development, beginning with a red mark that won't blanch and then ends with deep tissue destruction. Thus, a red mark that won't go away is the first sign a pressure sore is developing. Many pressure sores go unnoticed for long periods because they begin at the bone or muscle and progress upward. This means underlying tissue can be severely damaged before the skin turns red. Although pressure sores can develop over any bony prominence pressing against the mattress or chair, the areas that are the most prone to tissue breakdown are the bony prominence of the vertebrae in the lower spine, tailbone and hipbones.

- **Poor circulation** can result from lying or sitting in one position for too long. Improper positioning can also hamper blood flow to any body part. Prolonged sitting on an unpadded surface can obstruct the large blood vessels behind the knees, as well as damage the nerves, causing loss of sensation. Impaired

blood flow can also lead to blood clot formation. Lack of fluid intake may increase the risk of clotting of the blood. Although serious, this complication is usually preventable. Inactivity can also cause fluid retention and swelling of extremities.

- **Urinary tract infections** are another risk for people who may spend long periods of time on their back. This can promote urinary stasis or stagnation in the flow of urine from the kidneys to the bladder, and thus, lead to infection. Prolonged immobility also causes an increase of minerals and salts to circulate in the blood that can promote the formation of kidney stones.
- **Constipation** is a common problem that may result from decreased physical activity. Other factors may aggravate bowel evacuation. These include loss of privacy and embarrassment if toilet assistance is needed; uncomfortable positioning while using the commode; excessive delay in elimination because of the inconvenience in going to the bathroom; and the unavailability of caregiver assistance if help is needed to use the commode. Bowel irregularity may produce abdominal discomfort, as well as cause loss of appetite.
- **Aggravation of respiratory problems** may also result from immobility. Being confined to a chair or

bed for long periods in one position may suppress lung expansion and the ability to take a good breath that is needed for an effective cough force to clear the airways. Consequently, secretions in the lungs may accumulate and thicken, causing mucus plugs that may aggravate breathing. Secretions in the lungs also harbor bacteria that may multiply and possibly result in pneumonia.

- **Depression** is a normal response to progressive loss of muscle function and impaired mobility. People who are homebound because of trouble leaving their homes, or who are embarrassed about their disability, may have infrequent contact with people. As a result, they can become victims of social isolation that may compound feelings of depression. Emotional responses to immobility vary widely and may include such feelings as helplessness, despair, irritability, anger, outbursts of rage, constant sadness, frequent crying, listlessness, and social withdrawal.

Key Interventions For Preventing And Treating Complications

1. **Continue with daily activities that you are able to perform safely and as tolerated, while avoiding overexertion.**

Exercise helps maintain optimal function of the muscles that helps

prevent disuse atrophy. The general rule is to "do as much as you can for as long as you can, and rest when you are tired." Overexertion may aggravate breathing. Therefore, shortness of breath is a sign to stop activities and rest. Also, avoid lifting weights since that is too strenuous. Weight lifting will not strengthen muscles weakened by the disease.

2. Do stretching and range-of-motion exercises to each of the joints everyday, and several times a day.

(a) to maintain joint mobility (b) to help prevent joint stiffness and pain (c) to stretch tightened joints and help prevent or reduce joint contractures or deformities. Active exercises are done without assistance, but passive exercises are done with assistance, as this is usually required to achieve a full range-of-motion of each joint. Exercises should first be demonstrated by a physical therapist or a trained registered nurse to assure the proper technique and to avoid injury.

3. Maintain proper body alignment, and change positions at least every two hours.

Repositioning helps prevent continuous pressure on any body part. People who are immobile should be turned or moved regularly and properly supported by pillows or

foam to provide maximum comfort and to prevent pressure sores and deformities.

A mattress overlay, such as an alternating pressure pad, protects against pressure sores, but not a two-inch foam overlay that provides only comfort. Variable-pressure mattresses composed of air pockets and spongy material are also available for optimal protection against pressure points, particularly the bony prominences. When sitting, use air, gel or foam seat cushions. Proper limb positioning helps prevent joint stiffness and contractures.

To help prevent ankle contractures or deformities of the feet in a footdrop position, place a footboard at the end of the bed to support the feet at a right angle. Placing pillows at the bottom of the feet or wearing padded footdrop protection boots can support the feet when in bed. To help prevent flexion contractures of the neck, try to promote an upright head posture to keep the head and shoulders from slouching forward. Good body alignment and regular repositioning also promotes circulation; enhances lung expansion for optimal breathing and coughing; promotes gastrointestinal function; and reduces the risk of urinary tract infections and blood clot formation. Since the calf

is a risk site for a clot, call your physician if you experience pain in the calf and notice localized warmth, redness and swelling.

4. Maintain an adequate fluid intake.

To help prevent thick secretions in the airways; to help prevent or relieve constipation; and to protect against urinary tract infections and kidney stones. A sufficient fluid intake also prevents dehydration that can also lead to increased viscosity of the blood that can lead to blood clot formation.

5. Focus on abilities and not disabilities.

Find methods to enhance mobility through the use of assistive devices and making the home accessible. This will help minimize feelings of helplessness, depression and giving up.

6. Maintain regular contact with people and do not allow immobility or embarrassment to be a barrier to interacting with others.

Participate in activities with family, friends or caregivers. This will minimize feelings of loneliness, boredom and the effects of social isolation. If possible, attend sporting events, church or group activities, and take trips or go outdoors. People who have trouble leaving the home can invite family and friends

in to visit. By using a computer, anyone can also keep in touch with family and friends through the Internet. In fact, through advanced technology and the development of switches to activate the computer, the whole world is only one "click" away. People with ALS

who have social interaction and an effective means of communication can achieve life satisfaction despite immobility.

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