



Managing Depression in Amyotrophic Lateral Sclerosis (ALS)

Pamela A. Cazzolli, R.N.
www.alscareproject.org

People with amyotrophic lateral sclerosis (ALS) face ongoing changes and losses as the disease progresses, resulting in unavoidable grief and depression. Struck by shock and disbelief at first, awareness of losses eventually becomes a reality. Some persons are overwhelmed by thoughts that life will never be the same, thoughts that may lead to hopelessness, helplessness and despair.

Grief and depression are normal reactions to functions that are permanently lost. Each new loss is usually experienced as a first. Sadness and crying commonly follow awareness of changes. Although ALS individuals may perceive that crying is a loss of control or weakness, crying is a therapeutic strategy, an important emotional release. Grieving allows one to "let go" of what can no longer be. Lingering grief and depression, however, can lead to chronic sorrow, a pervasive sadness that never goes away.

Because depression can slow bodily movement, producing fatigue (similar to symptoms of ALS), signs of depression may be overlooked. If undetected, depression will remain unmanaged, compounding life's misery. Furthermore, depression is like a

contagious disease, infecting an entire household. By recognizing signs of depression, strategies can be implemented for alleviating unbearable grief, enhancing the ability to adapt to losses.

Common signs of depression include: loss of energy, disinterest in activities, lack of desire to interact with family and friends, wishing not to be bothered, crying spells, slowed thinking, forgetfulness, difficulty concentrating and making decisions, sleep disturbances, unkempt appearance and loss of appetite.

Signs of severe depression include: staring into space for long periods, no desire to do anything, communicating only to answer a question, poor concentration or memory, confusion, refusal to eat, weight loss, gastric disturbances, difficulty sleeping or excessive sleep, feeling that there is no reason to go on living and thoughts of suicide.

STRATEGIES FOR MANAGING DEPRESSION

1. **Express your feelings.** Talking about losses is very important in working through grief precipitated by loss. If speech is impaired, find an effective means of communication.

2. **Focus on your abilities rather than your dis-abilities.** Use assistive devices to enhance mobility. Do not resist a wheelchair if needed. Modify your home environment for easier accessibility.
3. **Set new goals which are achievable.** Maintain a purpose in living, despite physical limitations.
4. **Have something to do and to look forward to everyday.** Keep your mind busy. Plan for pleasurable experiences and achievements.
5. **Maintain social inter-action with others.** Avoid loneliness. Plan enjoyable activities with family or friends. Find accessible methods for leaving your home, going in and out of your vehicle, and visiting others. If traveling is difficult, encourage family and friends to visit with you at home.
6. **Maintain control of your life and decision-making.** Being in control reduces feelings of powerlessness and helps to prevent

giving up.

7. **Strive to maintain a positive self-concept.** Getting dressed daily and looking one's best can help people to overcome a negative self-image.
8. **Seek spiritual care.** Faith in God, scriptural meditation and prayer provide peace of mind, joy and hope for tomorrow, despite trials and tribulations.

Signs of unresolved depression may warrant treatment or professional counseling. Seek help if needed. By understanding strategies that may assist in adjusting to loss, people with ALS may help overcome agonizing grief and depression. The goal is to change from focusing on what was lost in the past to focusing on what is here to enjoy now and the days ahead.

References:

1. Messner R L, Lewis S. Double trouble: managing chronic illness and depression. Nursing 95; 1995; Vol. 25, No. 8:46-49.
2. Kahn AM. Coping with fear and grieving. Chapter Eleven, in: Chronic Illness: Impact and Interventions (I.M. Lubkin, Editor), Jones and Bartlett Publishers(1995); Boston; pages 241-260.

© 2000 Pamela A. Cazzolli, R.N., Canton, Ohio USA. All Rights Reserved.
www.alscareproject.org D7 Uhc`JF B4 Uc`Wta
Toll Free: 866-TEAM-ALS

ALS Care Project, 4450 Belden Village St NW, Suite 206, Canton, OH 44718 USA

"Improving the care of people with ALS through research and education in the community"