

Gregory W. Fulton ALS Center

Mood and Behavior Changes



Anxiety and Depression

It is natural for individuals to experience grief and sadness following a new diagnosis of ALS. As the disease progresses and patients experience changes in their independence, grief may come in waves. Continued grief and difficulty coping with the diagnosis can lead to depression and anxiety. Financial concerns, family dynamics and values regarding dying may contribute to this. Some signs of depression include: difficulty sleeping at night, difficulty leaving home or participating in activities someone once enjoyed, sleeping too much during the day, hopelessness, mind-racing, and fatigue. ALS impacts the entire family and it is common for caregivers to experience grief, depression, anxiety, or burnout as well. Discussing these changes with the ALS team is crucial since treatment options are available and can improve quality of life.

Management of Anxiety and Depression

- **Counseling** can be beneficial for patients and their caregivers. Counselors do not need to be familiar with ALS but rather able to assist with the coping and grieving process. Many counselors offer services through telehealth.
- **Support groups** can provide a sense of community and allow individuals with ALS to share their concerns, resources, and tools while navigating this illness. Support groups can ease feelings of loneliness. The ALS Association provides support groups for both patients and their caregivers.
- **Antidepressants** can be helpful for the management of depression and anxiety. It may take four to six weeks to notice the positive benefits of antidepressants, so they should be taken consistently and not on an as-needed basis. Discussing medication options should be done with a provider.
- **Psychiatrists** can be helpful since they specialize in the medical management of anxiety and depression.

If you have any questions regarding counseling or other community resources available to you contact:

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Pseudobulbar Affect (PBA)

PBA is a condition that occurs in ALS when there is damage to the area of the brain that is responsible for expressing emotion. Patients may experience uncontrollable or inappropriate laughing, crying, or both. Often this doesn't align with the individual's actual feelings. The level of severity can differ from person to person but, if it impacts daily function or ability to socialize then medication can be prescribed for this.

Frontotemporal Dementia

FTD is a form of dementia that can occur in ALS. Some genes are highly associated with FTD, such as C9orf72. Patients with FTD can exhibit behavioral changes and difficulty processing language. Some examples include lack of judgment, obsessive or repetitive tendencies, and difficulty understanding/processing language.

Frontotemporal Degeneration Support Group

The (FTD) Support Group is a space where care partners connect and share with others who understand the unique experiences of those affected by the disease. This support group is held virtually via Zoom by the Barrow Memory Disorders program and not specific to patients with ALS.

To register, please contact:

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