

GRIEVING PROCESS AFTER DIAGNOSIS: STRATEGIES TO COPE WITH THE DISEASE

Discovering you're diagnosed with ALS can bring about a whole lot of complex emotions. Many people speak of a feeling of mourning after receiving the initial diagnosis. Some grieve about a feeling of lost time, physical functions, control or other things that we think of as self-evident in our lives.

But while grief is a normal, usual response to the diagnosis, it can be one of the most difficult emotions to deal with in a healthy way.

Rebecca Axline, LCSW-S, supervising clinical social worker in the Houston Methodist Neurological Institute, has given advice to people with chronic diseases including chronic diseases that have lasted for over 35 years. She emphasizes that, while the experience of grief is different for everyone, there are some strategies that can help you to navigate the grief you might feel, whether they've just given you the diagnosis or if you've lived with ALS for years.

Give yourself permission

Tell yourself it's okay to mourn. "Mourning is about changing," Axline says. "It's healthy to let yourself be conscious of what you feel that was changed or lost. If you experience sadness and other emotions related to your diagnosis, find ways to express these emotions without wreaking havoc to yourself or someone else." Axline says that she encourages people to "develop skills to experience emotions that work for them, instead of trying to push them down or bottling it up."

Pay attention to Wellbeing

Rest enough and eat adjusted food, said Axline, but also think about the fact that Wellbeing goes beyond satisfying your physical needs. Make up the balance in terms of how well you care for your emotional, intellectual,

occupational and social needs, and look for support in family, friends or caregivers when you need it.

Look for professional help

This is especially important when your feelings of sadness or loss become overwhelming. A graduate therapist can help you work through your emotions, connect you with sources for added support if you should need it and enable strategies after your diagnosis. In case you wish to look for help but aren't sure where to start, contact the ALS Liga for help.

Allow yourself to feel joy and look for a purpose

Keep in mind: ALS defines you. Embrace the joyful moments. You have the power to live your own life. Search a goal and accept the love and support of others. Some people find joy and goals in helping others, or learning something new, or spending time with friends and family. Whatever gives you joy and a purpose, do it – and allow yourself to experience these good feeling, just like you allowed yourself to "lean in" any kind of sadness you may experience.

Find your own support system

A supportive circle of friends and family, combined with an informed and experienced caregiving team, can provide a huge comfort. When you feel you have a need for extra support, there are many resources available to you. As a start you can go to the ALS Liga for more information about hospitals in your surroundings. If you want to get to know others living with ALS, you can find support groups in your local neighborhood or in online forums or on social media sites such as Facebook.

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