

WHAT IS ANTICIPATORY GRIEF?

We can feel sad about losing someone before they have died. This is called anticipatory grief.

When someone you love has an illness like ALS, life changes a little at a time. Maybe they can't talk the same way, walk like they used to, or do certain activities anymore. You may miss the way things were — even while your loved one is still here.

That sadness, worry, or confusion you feel has a name. And it is okay to feel it.

Why does anticipatory grief happen?

As illness changes your loved one, lots of “little losses” can happen, like:

- not getting big hugs anymore
- not being able to play the same games
- hearing a machine instead of their voice
- seeing them get tired more easily

Each change can feel like losing something important. These losses can stack up and feel heavy.

You may miss the past.

You may worry about the future.

You may feel lots of things at once.

That doesn't make you strange — it makes you human.

Feelings you might have

Anticipatory grief can show up in many ways. You might feel:

- sad or like you want to cry for no clear reason
- worried about what will happen next
- mad that life feels unfair
- guilty for wanting things to feel “normal” again
- confused because your loved one is still alive

You might also notice changes like not sleeping well, having trouble in school, or wanting to be alone more. All these feelings and more are normal — and they won’t last forever.

Talking about it helps

You do not have to carry these feelings by yourself. You can talk to:

- a parent, guardian, or other family member
- a counselor or therapist
- a teacher, coach, or school counselor
- a faith leader
- another trusted adult

You can also draw, write, listen to music, or play to help your feelings come out. Sometimes adults feel sad too. When they share their feelings, it shows you it’s okay to share yours.

It’s okay to ask questions

You might wonder:

- “Will my loved one be okay?”
- “What will happen later?”
- “Why did this happen to our family?”

It’s okay to ask. It’s also okay to not be ready to ask yet. If adults don’t know the answer, they can help you find someone who does or sit with you while you talk through it.

You are not to blame

Nothing you did, thought, said, or didn’t do caused the illness. And it is never your job to fix it. Your job is to be you — to learn, play, laugh, rest, feel, and keep being a kid. These feelings mean you love deeply. They mean your heart notices change. And even when things feel hard, you do not have to go through it alone.



Our Mission: To unite and empower the ALS community through a collaborative approach of providing comprehensive care and support to individuals and families affected by ALS, advancing national and state advocacy, and fostering bold research initiatives.



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