

# UNDERSTANDING GRIEF BEFORE DEATH:

## THE IMPACT OF ANTICIPATORY GRIEF



Grief isn't a singular event that only occurs after a loved one dies. It's a complex process that often begins long before, especially for families facing a progressive illness like ALS. This is known as anticipatory grief, and it's a profoundly important aspect of the emotional journey for children and youth.

### The Cumulative Losses of Illness

Anticipatory grief encompasses all the losses associated with illness. For a child or youth, this means a constant disruption of their sense of "normalcy." Each new symptom or progression of the disease brings another loss. It could be the inability to receive a "bear hug" from grandpa, cook with mom, or ride bikes with dad. These aren't just minor changes; they are significant losses that alter relationships and accumulate over time. This ongoing accumulation of losses can be even more painful than the final one, leaving children feeling confused, sad, and deeply grieving while their loved one is still alive.

**“[the machine] makes communication a lot harder... I think it’s just that it isn’t her voice. Because that’s all you really want to hear. And all you hear is that... machine. My dad’s old phone has my mom’s voice message on it. And we call so we can listen to it.”**

~18-year-old

This teen grieved the loss of her mother's voice and the "normal" associated with it, highlighting how incremental losses can be profoundly impactful yet often overlooked.

Examples of Anticipatory Grief in Children and Youth:

- Grieving the loss of shared activities: A child might grieve that they can no longer play sports with a parent who is losing mobility, or that bedtime stories are no longer read in the same way because a parent's voice has changed. These aren't just minor inconveniences; they're losses of significant bonding experiences.
- Missing a loved one's presence while they're still alive: A teenager might feel a deep sadness about their parent becoming less responsive or unable to participate in family discussions as they once did. Even if the parent is physically present, the "person they knew" might be fading, leading to feelings of loneliness and isolation.



- Worrying about future milestones without the loved one: A child might start to anticipate and grieve missing out on future events with their parent, like graduations, weddings, or the birth of their own children. They're grieving the loss of a future they envisioned.
- Anxiety about the process of dying: Children may become preoccupied with what the death will "look like," whether their loved one will suffer, or what will happen to them after the death occurs. This can manifest as increased anxiety, fear, or difficulty sleeping.
- Changes in behavior and mood: Anticipatory grief can show up as irritability, anger, withdrawal from friends or activities, difficulty concentrating in school, changes in appetite or sleep patterns, or even regressive behaviors in younger children (like bed-wetting or thumb-sucking). These are often expressions of their internal struggle to process the impending loss.

Guilt or self-blame: Children might irrationally feel responsible for the illness or their parent's decline, or they might feel guilty for wishing the suffering would end, even if that means the death of their loved one.

## Acknowledging and Addressing Anticipatory Grief

It's crucial to acknowledge these early and incremental losses with your child. Here are some suggestions for initiating conversations about these difficult feelings:

- Check in regularly: Ask your child how they feel about the changes and progressions they're witnessing.
- Identify what they're grieving: Encourage them to articulate what they miss about the parent or loved one with ALS. For younger children, art or play can be powerful outlets for expressing feelings without words. Older children might prefer to write.

Share your own emotions: It's important to let your child know that you, too, are sad and grieving the loss of how things were, how they are now, and what they might become. Children learn how to process emotions by observing adults, so it's okay to emote and share your feelings with them.

## Seeking Professional Support

These conversations can be incredibly emotional and challenging. Don't hesitate to seek professional help from a social worker, faith leader or mental health therapist. They can provide invaluable guidance and support to help your family navigate the complexities of anticipatory grief and the difficult journey ahead.



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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