

Anticipatory Grief Guide

UNDERSTANDING YOUR FEELINGS



Grief is an emotional, cognitive, physical, and spiritual response to loss. We tend to associate grief with what we expect to experience in the future. But, actually, concerns about loss begin as soon as we recognize that a loss may occur.

“Anticipatory grief” is the name for what people experience when they know that they will likely face a profound loss. For parents of a child with a serious illness, it includes all the losses along the illness journey—not just the prospect of death. It means grappling with and grieving the loss before it completely unfolds.

Anticipatory grief takes up a lot of room in a parent’s mind and heart. It can take many forms: sadness, tearfulness, anger, irritability, loneliness, guilt, anxiety, a desire to talk or to withdraw. It may manifest itself with physical problems such as sleep or memory difficulty, headache or other physical pain. It may include a mental rehearsal of the death and the hours/days following the death. It may include a need to engage in immediate decision-making around preparation for the death. It could also be complete avoidance of these issues.

Understanding that this is what you are feeling and experiencing can go a long way toward helping you stay functional and accept your feelings as normal. Anticipatory grief is not often discussed, so parents don’t always understand what it is that they’re experiencing. This can be confusing and scary, and make you doubt your ability to cope.

So many parents have these thoughts alone, in their own heads, and feel guilty or ashamed. They worry that they are going a little mad. Know that anticipatory grief is a natural and common part of the process.

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Your loved one does not need to have died already for you to seek support—the better the Before, the better the After. Grief support and counseling—either one-on-one with a trained counselor or in a support group—can be very helpful to you during this time. Here, we offer the expert guidance of [Dr. Nancy Frumer-Styron](#) and the voices and experiences of other parents to shine some light on what you're experiencing and help you see that you are not alone.

<https://courageousparentsnetwork.org/video-library/provider/nancy-frumer-styron>

From Letters to a Young Poet
by Rainer Maria Rilke

...if a sadness rises before you
larger than any you've ever seen,
if an anxiety like light and cloud shadows
moves over your hands and
everything that you do. You must
realize that something has happened
to you. Life has not forgotten
you, it holds you in its hands
and will not let you fall. Why do
you want to shut out of your life
any uneasiness, any miseries, or
any depression? For after all, you
do not know what work these conditions
are doing inside of you.

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