What is Anticipatory Grief?

Grief is an emotional, cognitive, physical, and spiritual response to loss. It is a natural byproduct of receiving a life-threatening diagnosis for a loved one. “Anticipatory grief” is the name for what people experience when they know that someone they love may possibly die. It includes all the losses along the illness journey. It means grappling with and grieving the loss before it completely unfolds. For parents caring for children with a life-limiting illness, anticipatory grief is very common. It takes up a lot of room in a parent’s mind and heart.

Anticipatory Grief 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. 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.

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. Parents associate grief with what they will experience in the future, rather than recognizing that their concerns about loss have already begun.

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. 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, but it’s a natural and common part of the process.

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. Your loved one does not need to have died already for you to seek support—the better the Before, the better the After. 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.
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.