Information for Parents and Caregivers

Diagnosis Related Grief

About Diagnosis Related Grief:

Even when a parent/caregiver has a strong feeling that something is going on with their child that they don't quite understand, a diagnosis can be really difficult to accept. Often this time is full of conflicted feelings. We hear things like:

- *"I knew it! I told them something was wrong!"* **Vindication.**
- Or, *"No! Not my baby. This is not happening."* **Denial.**
- *"Why me? Why us? Why them?"* **Anger.**
- Or even, *"Oh, thank goodness, now we can get the help we need!"* **Relief.**
- Sometimes we hear, *"Nothing will ever be okay again."* **Deep sadness.**

All of these feelings are normal and expected. All of these feelings will be heard and accepted by your provider. Processing the grief associated with a diagnosis can be a very challenging path for families and can lead to frustration, miscommunication, and hurt feelings. It's important to remember that everyone handles shifting dreams through grief differently, and everyone needs space and support through this process. It's also helpful to remember that the day after your child's diagnosis he/she/they are the exact same child as they were the day before the diagnosis. We use labels (diagnoses) to help us categorize symptoms to create treatment plans and provide services through insurance. Your child is so very much more than just their diagnosis.

In the past, the grief process was referred to as stages, but current research shows that these same stages are often more helpfully understood as tasks. As you move from the feeling of shock around diagnosis toward acceptance and actively advocating for your child, many parents cycle through feelings of denial, anger/rage, confusion/powerlessness, and deep sadness/depression. These emotions are a necessary part of preparing you to be a warrior for your child.

Parent/Caregiver Tips:

- **Take time.** Give yourself grace and space. You are allowed to react any way you need to to process this information. Do not make any decisions at this point, and recognize that your body and brain need time to absorb this information. If it is helpful to talk to people, talk. If it feels helpful to sit in the quiet, do that.
- **When you experience denial, use that energy to learn.** If you need some time to research all of the reasons why this diagnosis can't be true, that's okay. Build your knowledge base and find out more information about options. It is likely that there is no "magic pill," but the more information you have, the better.
- **Feel angry!** You have every right to be. But don't shoot the messenger. It's very likely that the provider that talked to you about the diagnosis had their own grief process about giving you the information. Use your anger to fuel the pursuit of services you want for your child and your family. Maybe your path will be taking on systems that don't serve your child well or advocating for appropriate reimbursement for necessary treatments. Get your feelings out on paper/email, and then pause. Wait a few days, read them again, and then send if you still are committed to your words.

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Parent/Caregiver Tips: (cont.)

- **Find a "translator."** What would you do if you suddenly woke up in a different country? You don't understand when people speak. You aren't sure which direction you should go to get what you need. Many parents experience this same feeling of living in the unknown after diagnosis. Finding someone who understands the landscape to walk with you would be our first recommendation. Connect with others who know the terminology, treatment options, and how to navigate this new world. These people will teach you and become your biggest source of support. These connections will help to minimize feelings of isolation and connect you and your child with others. Your providers can often help you access these connections through local or online parenting or diagnosis-specific support groups.
- **Take a break!** Many parents are tempted to completely immerse themselves in learning what they need to learn about their child's diagnosis, but even your favorite food or activity gets old after a while. There will be time to get where you need to be to support your child, but you have to take care of yourself in order to get there safely. For some parents, that might mean having a silent cry through a loud action movie, or spending time watching the waves roll in at the beach. Do some shopping, take a walk outside, or have lunch with a friend. Whatever fills your cup, do it.

Next Steps:

If you start to feel like you need additional support to manage this process in appropriate ways, it may be helpful to contact your pediatrician, a local therapist, or talk to the counselor at your child's school.

Additional Resources:

Processing Grief Over a Loved One's Autism Diagnosis: https://www.goodtherapy.org/blog/processing-grief-over-autism/

The Advice I Didn't Know I Needed After An Autism Diagnosis: https://www.scarymommy.com/autism-diagnosis-advice-parents/

Relief. Obsession. Resentment. Then Appreciation.: https://www.additudemag.com/stages-of-grief-after-an-adhd-diagnosis/