

Feeling Guilty When Raising a Child with Special Needs

When Annalise* was born, Patricia knew immediately that something wasn't right with her daughter. The doctors kept saying everything was fine, but Annalise had low muscle tone, could barely move her arms and legs, and had a weak cry. By Annalise's second day of life, she was in the hospital's intensive care unit.

Although she wasn't correctly diagnosed with Prader-Willi syndrome until she was eleven, Patricia and her husband, James, were proactive in addressing Annalise's diagnosis: signing her up for physical therapy, instilling a love of reading, and encouraging her to participate in sports as she grew.

Twenty years ago, when Annalise was growing up, medical knowledge of Prader-Willi was in its infancy, so although Patricia and her husband noticed that Annalise had a very large appetite, it wasn't until she reached puberty that they recognized the full impact of the constant hunger that was a core feature of the disability.

"She was just getting more and more obese and it was shocking," Patricia recalls. She didn't think about locking up food, or how important it was to maintain a rigid schedule of mealtimes.

"We just didn't have enough training," she says of their lack of education on the disability. "It's our fault."

All of us feel guilt at points in our lives. For parents of children with special needs, guilt is often more pronounced. Parents like Patricia often feel guiltier about what they *didn't* do, than what they *did* do.

Patricia is a parent, like many others, who genuinely put her child first and tried to anticipate her daughter's needs, yet interwoven throughout her personal story is a sense of perceived failure and self-disappointment that results in a feeling that she hasn't done enough.

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Parents also may encounter feelings of guilt when they mentally determine that the needs of their child are more than they can adequately support in the home. In many inter-

views, parents expressed regret that they didn't have enough specialized knowledge to address the problems associated with their child's disability. Most parents, whether their child has special needs or not, feel it is their inherent role to nurture and protect their child. But when a child has a disability and does not make gains over time, parents may feel they failed to do their job.

When Holly enrolled her son, Will, in a residential school for children with autism spectrum disorder, she felt guilty despite objectively knowing it was the best choice for his safety. A common theme for parents of children with special needs who require out of home care is the inherent conflict, or struggle, between rationally understanding what is best for their child and family at this time, and the feelings of failure and guilt associated with this decision. For many parents, this feels like a no-win situation, and one that they may have to constantly defend to other family members and supporters that may not understand.

"Basically, we left him with strangers," Holly says. "It was just really difficult for us to have him away."

She also felt guilty for actually enjoying the calmness in the house during Will's absence. "Without him being home, for the first time our other two kids have really gotten to feel loved; to have Mom and Dad both come to their functions," she said. "For a long time, we all felt very guilty feeling good about that."

As Holly and her family saw Will thrive and make progress in the new, more structured therapeutic environment, the feelings of guilt began to subside.



Many parents find they feel guilty about what they did, and also about what they did not do—so simultaneously beating themselves up for errors of commission and omission—and that feeling may last for years. However, parents don't have to sink in this morass of guilt. Instead, they can re-examine their perspective and ask if they can forgive themselves for not being all-knowing and all-powerful—and the answer is “well, of course”—as we are all human.

Some parents ask—Is there a way to live without extreme guilt as a parent of a child with special needs? Yes, there is. First, recognize that it is absolutely normal to want a sense of peace and quiet in your home. We also know through research that the presence of long-term stress in the living environment can become toxic and often has a negative impact on the entire family system.

Parents of special needs children are typically under such long-term stress that the idea of a change in living environment, even if it is short-term and makes great therapeutic sense, can bring tears to their eyes. Parents need to remember that this does not mean they are not good, loving parents. Parents do well if they can. It only means that their child's needs are above and beyond what can currently be met in the home, and that the impact of their child's disability is at this point affecting the entire family in a negative manner. It means parents need help.

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No parent wants to see a child struggle because of a disability, but extreme guilt is not only hard to stop, but also counter-productive and damaging. One approach is to self-monitor your thoughts and feelings during times when you feel guilt. First, identify what specifically you feel guilty about. Put it in words as if it were a thought or sentence in your mind. What are you thinking? Just get it out—don't judge it—accept it as “there” and not as right or wrong. Is it something you feel you didn't do perfectly—or at least as well as what others expect of you? Or perhaps that a good parent would have recognized their child's disability earlier or done something sooner? Are you admitting that you struggle with the

responsibilities of taking care of your child? Or admitting that you mourn the loss of the parenting and family life you anticipated when you were younger?

Then ask yourself some questions about what you were thinking:

1. As you look back in time—try to remember what guided your thinking. Did your decisions make sense at the time? They probably made a lot of sense and were guided by your love for your child.
2. Given what you knew at the time—did you do your best for your child and the rest of your family? Parents do well if they can—and give tons of energy to helping their child.
3. Were you trying to juggle a thousand things at once? Did that take a toll? Yes, it would take a toll on us, as it would on anyone.
4. Is there anything you can do right now, in the present, not to correct the past, but to accept that it happened and focus on the future? What can you do in the here and now to make your child more successful in the future? Remember—he or she needs your continued support and advocacy to navigate the world.
5. What did you do well? When we feel extremely guilty we tend to focus on what we did not do well and forget, or have reduced awareness and attention, about what we did do well. You did a lot of things very well—you genuinely did—list some and say them out loud.
6. Emotions can be like a snowball rolling down a hill. They can gain energy. So we need to also remember that just because we feel a certain way does not mean we should feel that way. For example, ask yourself—“just because I feel guilty, does it necessarily mean I am guilty?” The answer is often “no” and that our decisions at the time made sense given the circumstances.
7. Have you noticed that sometimes you feel less guilt? That maybe at times you don't feel guilty at

all? What does that mean? Remember that emotions are like thoughts—and that they come and they go—like clouds. Pay attention to them—and just let them go. Everything changes.

8. What would you say to your best friend or sibling if they were in the same situation? Would you judge them as harshly as you judge yourself? Probably not. We tend to be harder on ourselves. Pretend they are sitting in a chair across from you. What would say to them after they tell you the same words you tell yourself? Would you be reassuring? Would you tell them they did the best they could at the time?

9. Can you give yourself permission to not be the perfect parent? The perfect person? Of course you can—otherwise you'd be the first ever. Parents feel guilty because they care, want to do better, and expect a lot of themselves. However, feeling extremely guilty over situations or circumstances that cannot be changed is a form of self-punishment that takes us away from being present for our children—now and in the future. Learning how to put aside the guilt over the past, accepting that it happened, and ultimately moving forward may be the best gift you can give yourself *and* your child. And never forget, the better we do, the better the child does.

This article was written by Pamela DeLoatch and can be found at <http://www.orplibrary.com/posts/feeling-guilty-when-raising-a-child-with-special-needs>.