



Transcending Loss While Parenting High Needs Children

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The Downward Spiral of Loss

I am not convinced that "simple loss" exists. However for those of us parenting high needs children, our sense of loss can feel like a never-ending bottomless pit of sorrow that is continually reactivated. Not only do expected milestones and family rituals trigger our multiple losses and feelings of isolation, but even a simple outing to the grocery store evokes layers of pain anchored to our decimated dreams. The crushing weight of judgment leveled at us by community bystanders, as we accompany our children on these outings, only adds to our feelings of being misunderstood and alone. In 2009, researchers at the University of Wisconsin found that mothers parenting children with autism had stress levels comparable to war veterans and I am sure this dynamic exists while parenting many high needs kids. While we are in the midst of continual crisis management, there is little

or no time for us to process our ongoing experience of grief and sorrow. Jane Taylor McDonnell's honest and arresting memoir, *News From The Border*, hauntingly depicts the pervasive atmosphere of loss that is the backdrop to her life with Paul, diagnosed with autism.

[Mine] is a story of grief, yes and of loss. But it is a different kind of grief from the one brought by the death of a child. For one thing the child isn't gone; he or she is *right there* flooding the backyard, screaming from the top of a tree, or pouring maple syrup all over the carpet and vacuuming it up. And the terrible extra burden that befalls parents of [disabled] children is that they have no time to grieve. They are caught up from the beginning in a perpetual crisis

that leaves them no time to reflect, no time to even feel their feelings for themselves. They must always be rushing to attend to a child in distress.

Dr. Pauline Boss, a marriage and family therapist and researcher examining complicated, unrelenting grief, coined the term *ambiguous loss* to capture exactly what Jane McDonnell so eloquently describes above. Dr. Boss asserts that ambiguous loss is the most devastating type of loss that exists because the long-range consequences of our losses remain unclear and indeterminate. According to Dr. Boss, this type of loss shatters our belief in a fair, orderly, manageable world, while it simultaneously erodes our confidence to control and master circumstances. In the case of autism, the child's body is still

present but his or her developmental trajectory has drastically careened off course. As parents, whom can we appeal to in order to insist that our delightful, cherished, idealized children that we invested so much promise into -- be returned forthwith?

Ambiguous loss is typically a long-term situation that traumatizes and immobilizes, not a single event that later has flashback effects. The outcomes of PTSD are similar, though not identical to outcomes of long-term ambiguous loss. Both can result in depression, anxiety, psychic numbing, distressing dreams, and guilt. But ambiguous loss is unique in that the trauma goes on and on in what families describe as a rollercoaster ride, during which they alternate between hope and hopelessness... Hopes are raised and dashed so many

times that psychically people no longer react. Just as animals lay down in their cages and no longer tried to avoid the pain in early experiments of erratically placed electric shocks, people experiencing trauma out of which they can't make sense feel helpless and no longer act. *Pauline Boss*

The Rebuilding Process

The first step forward entails completely and totally embracing yourself exactly as you are in this very moment. If your house is a mess, you haven't showered in days, you eat on the run, your husband is a roommate of sorts, and you no longer remember what it feels like to relax with friends -- all is not lost. Love yourself unconditionally in this very moment, *without expectations.*

As *hard* as it maybe for you to believe and surrender to --**from the spiritual perspective** --there are *no mistakes* in a perfectly evolving Universe. Make peace with the fact that you are exactly where you are supposed to be, doing exactly what you are supposed to be doing for your own and your child's highest good, even when it doesn't look and feel that way. Know that you are not alone as you struggle to accept the above tenet; that you are part of a tsumani of mothers who are ushering high needs children through life. This responsibility is a **Divine Calling**. If you feel hopeless and stuck, validate that any mother would feel the same if she had lived through the exact same set of circumstances. Just stop for a moment and breathe. Speak to yourself as though you are you own

best friend. Would you tell your best friend to buck up and go put in a load of laundry? No, instead you would listen to your friend's painful story and offer compassion and kindness. And yet, as mothers we somehow believe that we need to keep pushing ourselves through every obstacle with a battering rod. Now is the time to end this practice.

Validate Your Feelings Tied to Your Experiences

Validation means to give value to **ALL** of your uncomfortable feelings with well-grounded evidence as to why you have the right to feel exactly as you do. There are no right or wrong, good or bad feelings. When you validate your personal truth and the feelings attached to your truth, in a non-judgmental manner, your mind

has nothing to deny, repress, or minimize about your painful experiences. You will immediately become lighter and freer.

Begin by closing your eyes and breathing slowly, while deeply inhaling through your nose and exhaling through your mouth. Scan your body and ask yourself where you notice stuck, dense energy. Is it a pressure over your chest, a pounding in your forehead, queasiness in your stomach, etc? Begin by filling in the following sentence stem as quickly as you can..."*I give myself permission to feel [this queasiness in my stomach] because*"... Repeat this sentence stem and fill in the blank for six to eight responses. Next, grant yourself permission to go back in time to another experience that carries a similar emotional resonance and see yourself exactly as you were in

that moment. Go back in time by decade and it's preferable to locate your earliest memory that shares a similar emotional vibration. Complete this sentence as rapidly as possible, "*I validate that this still bothers me because*"... Repeat this sentence completion six to eight times. For example, I validate that this still bothers me because I felt humiliated when Mrs. Strands brought me to the blackboard to decipher a math problem that I didn't know how to compute. I validate that this still bothers me because I felt alone with my pain as I do today. I validate that this still bothers me because I kept my pain a secret, just as I am today. Always repeat the beginning part of the sentence before filling in the blank and it is vital to go as quickly as you can to prevent your mind from sabotaging the process.

Ask yourself, how old you were when you first experienced this resonate pain? Try to remember what grade you were in or where you worked? Try to remember where you lived and how much you weighed? Remind yourself that whatever choices you made "BACK THEN" were enacted as a survival mechanism. Rapidly finish this sentence completion, "*BACK-THEN, it wasn't my fault because*"...

Validation does not mean that you are excusing anyone else's behavior. You are merely observing what happened in the *THEN* and the *NOW* with discernment, knowing that the truth will invariably set you free. As a mother, you now hold the power to nurture yourself by releasing these painful emotional anchors. Close your eyes and visualize, while breathing white light into any part of your body that still hold a heavy energetic

imprint. Exhale any remaining energy out of your mouth or down through the bottom of your feet. Complete the process by giving six to eight answers to, *"What I just learned about myself is"...*

Know that validation prevents you from slipping into self pity; it averts you from staying glued to a painful storyline; it stops you from identifying yourself as a victim; it blocks you from slipping into intellectualization to explain away your pain; it allows you to live your authentic truth; and over time, it gives you back your vibrancy and resiliency for life!

To be walked through validation and other core healing tools for empowerment, contact Karen Hasselo at spiritfirstcoaching@gmail.com