

The Day I “Truly” Received My Son’s Diagnosis of Autism: How Acceptance Led to Resilience

by Shoshana Shea, Ph.D.

Daniel Gottlieb was a young, burgeoning psychologist, husband, and father when quadriplegia entered his life. He was driving on the freeway when he was struck by a giant wheel that unhitched from a tractor-trailer, flew across the freeway, and crushed his car. He was instantly paralyzed from the neck down. As he lay in the hospital contemplating how he could end his pain and suffering, one of his night nurses, who suffered from depression and had heard that Gottlieb was a psychologist, shared that she felt suicidal. Unaware that he had been contemplating that very idea himself, they talked through the night. Now, a prominent writer, therapist, and radio talk show host, he acknowledges that by listening to her experience, Gottlieb may have not only saved her life, but she likely saved his: Why? Gottlieb says that was because the nurse saw him as a person. *We become identified with the waves and we forget that we are the ocean* (Brach, 2012). When the waves thrash us around, we suffer. Gottlieb later shared in two of his books, *Letters to Sam* and *The Wisdom of Sam* that he stopped striving to be the man he always wanted to be and finally realized the man he was.

I will never forget when one of those waves came into my life on a crisp, fall day in November. When picking up my son from preschool, his teacher told me to call his pediatrician because there was “something wrong” with him. Those words numbed me; I wondered out loud, “And what should I tell the doctor? That something was just wrong?” Indeed, when I spoke with the doctor, I catatonically echoed the preschool teacher’s words, “There’s something wrong with my son.” I might have said what I feared, “I did something wrong”. The doctor responded by saying, “Well, we all worry about the big ‘A,’ ... autism, that is.” I don’t remember much more of that day; the specifics are a blur to me now. I was completely submerged under the wave, being dragged along the ocean floor. Coming up for air was a long way off. This felt like a tsunami to me, and I had already counted myself a casualty.

To use a metaphor from Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999), picture a man trapped in a deep hole, with only a shovel by his side. In despair and desperation, he picks up the shovel and begins to dig. Not being one who

quits, he puts all his effort into digging his way out. He toils through the night and as the sun rises, he takes stock of his progress. He is not only still stuck in his hole, but it is deeper than he ever would have imagined. He is baffled; why was the shovel there if it was not a means to get out of the hole? He thinks, “This is all I have...” Tara Brach, clinical psychologist, author, meditation teacher and dedicated leader in training therapists to integrate mindfulness into their practice of psychology, calls this a “false refuge”; a tool that is seemingly helpful and certainly available, but which is not. The first thing the man must do is drop the shovel, and yet he fears he cannot because what would he do then? Sit in the darkness and the pain of being in a terrifyingly deep hole?

In her book, *When Things Fall Apart*, Pema Chodron writes, “Reaching our limit is not some kind of punishment. It’s actually a sign of health that, when we meet the place where we are about to die, we feel fear and trembling. A further sign of health is that we don’t become undone by fear and trembling, but we take it as a message that it’s time to stop struggling and look directly at what’s threatening us...How we stay in the middle between indulging and repressing is by acknowledging whatever arises without judgment, letting the thoughts simply dissolve, and then going back to the openness of this very moment. That’s what we’re actually doing in meditation. Up come all these thoughts, but rather than squelch them or obsess with them, we acknowledge them and let them go... We can meet our match with a poodle or with a raging guard dog, but the interesting question is – what happens next?”

When I initially received my son’s diagnosis, I did more than my fair share of shoveling; I went through shock, anger, guilt, shame, reasoning, begging, pleading, bargaining, blaming, rage, numbing, and most of all, rigorous inquisitions of myself. If the shovel had not worked before that point, I was not going to let my son down, so I shoveled harder, with more gusto than ever before. It would take me six months until I finally stopped digging when the RAIN began to fall. The RAIN soaked my body and I bathed in my pain and tears.

I attended a workshop led by Tara Brach as part of a conference on Mindfulness (FACES, 2009). Dr. Brach led us through an exercise where she asked us to take something we were struggling with in our lives and say “Yes” to what we were experiencing. She elaborated, “Saying ‘Yes’ does not get rid of the pain; it actually allows the experience to be freed and unfold itself; a space opens up. Some people notice fear, however, and do not get that sense of freedom. When we get stuck, it usually means we have not looked deeply enough into the nature of our experience...”

The acronym RAIN has been used in mindfulness to engage in a progressively deepening process:

R stands for *recognize*: “What is going on? What are we noticing?” “They say there is something wrong with my child, or, maybe not?” “He seems alright...” This process involves also recognizing equivocation.

A stands for *acceptance*, wherein we allow the situation to simply be. Without knowing it, we often say, “This can’t be happening.” With acceptance, we say “Yes,” and allow it to be. But I didn’t want to say “Yes.” I was saying “No! This can’t be happening; this can’t be happening; this can’t be happening...” It was like if I admitted there was “something wrong,” I was signing up my son for never having a “normal” life. I was giving up on him. If I truly accepted his diagnosis, maybe it didn’t have to be that something was “wrong”; maybe it just was.

Another ACT metaphor is that of a ball and chain attached to our ankle. Burdens are cumbersome, often shameful, their weight unbearable. So we tend to act like they do not exist, and valiantly try moving forward in our lives. We try and drag our ankle but it just won’t budge. We tell ourselves, “I can’t be having this pain; more importantly, I won’t allow it!” So we stay stuck. Acceptance is bending down and picking up the ball and holding it close to our bodies. This way, we will likely move at a very slow pace, but at least we are moving. Jack Kornfield reminds us of the Zen Buddhist saying in his book, *The Wise Heart*, “If you understand things are just as they are. And if you don’t understand things are still just as they are.”

I stands for investigate our inner experience with heart, with kindness, with compassion. We use the *Four Foundations of Mindfulness* to further deepen this investigation (Mind, Body, Feelings, and Dharma, Kornfield, 2008).”

- 1) Mind: We ask, “What am I believing? What am I really afraid of? What is most distressing to me?” “What stories or judgements do I have about this?”, “I failed him.”
- 2) Body: “Where do I feel this in my body?” My head aches. My chest is tight. My stomach is churning.
- 3) Feelings: Agitation, sorrow, and fear.
- 4) Dharma: “The elements and the patterns that make up experience” (from *The Wise Heart*), “How locked in are we?” “What would I see if I were to go beyond this small self?” But I *can’t* come into my present moment because *it* won’t be OK;

he won't be OK. *I* won't be OK. Pema Chodron says, "We can meet our match with a poodle or a raging guard dog, but the interesting question is – What happens next?"

This leads us to the final step of RAIN.

N stands for non-identification or non-attachment. We see our thoughts as thoughts, and not as who we are as a person. In ACT, this is called "defusion." Tara Brach ended the exercise with the following words: "We unhitch ourselves, and we come home to who we really are. We are fully present. No longer identified with the small self. Back to natural loving presence. And we are then able to really ask ourselves, 'So what am I needing in this moment?'"

Before going through these steps of RAIN, I *really* thought I was accepting the situation. I had taken my son for a private evaluation. I was calling professionals to figure out whether I really needed to intervene. I was fighting against well-meaning friends and family, by telling them that he needed to be assessed, and they would push back and tell me to just leave him alone and that he would grow out of it. They would then contradict themselves by looking worried at other times, and asking me if I noticed he was doing something that other kids don't normally do. I would persevere, equivocate, and hide in silence and drown in self-pity. In the end, I came to realize that I was *completely* unwilling to accept that this was indeed happening. This lack of acceptance was impeding my process of resilience, and the ability to truly help myself and my son. I was never going to drop that shovel, and then, I did.

Resting in my awareness, I was able to let go of the struggle; my exit strategies had become defunct, and the tears flowed freely. At the next break, I stepped out and called the school district to schedule an evaluation to arrange for intervention. I haven't looked back since. It is not that I haven't indulged in self-pity or other avoidance strategies since then; it is that I always return to the truth and come back home to natural, loving presence. I *am* willing, and I have dropped the shovel. My son has been one of my greatest teachers and remains so.

If you can rest in the ocean, you are not afraid of the waves (Tara Brach).

References

Brach, T. (Producer). (2012, March 7). *Freedom in the Midst of Difficulty*. Retrieved from URL <https://www.tarabrach.com/freedom-in-the-midst-of-difficulty-audio/>.

Brach, Tara. (2012) *True Refuge: Finding peace and freedom in your own awakened heart*. New York, NY: Random House Publishing Group.

Chodron, Pema. (1997) *When Things Fall Apart: Heart advice for difficult times*. Boulder, CO: Shambhala.

FACES Conference (2009, April 2-4) *Awakening to Mindfulness*. La Jolla, CA.

Gottlieb, Daniel. (2006) *Letters to Sam: A Grandfather's lesson on love, loss, and the gifts of life*. New York, NY: Sterling Publishing Co.

Gottlieb, Daniel. (2010) *The Wisdom of Sam: Observations on life from an uncommon child*. Carlsbad, CA: Hay House.

Hayes, S. C., Strosahl, K. D., Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change*. New York: Guildford Press.

Kornfield, Jack. *A Wise heart: A guide to the universal teachings on Buddhist psychology*. New York, NY: Bantam Dell.