



# Complex Child E-Magazine

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## My Anti-Stress Toolkit

by Kristen Davis

The definition of stress is:

A mentally or emotionally disruptive or upsetting condition occurring in response to adverse external influences and capable of affecting physical health, usually characterized by increased heart rate, a rise in blood pressure, muscular tension, irritability, and depression.<sup>1</sup>

Stress is a palpable, uninvited third party in our family system, that permeates the spaces where there used to be quiet, calm, uninterrupted life.

We live in somewhat-rural southern Maine, and I am blessed to have two children (ages eight and 11 years), a husband who is also my best friend, one dog, three cats and four fabulous, brown egg-laying hens. Riley (age eight) is our child who is complex. She is diagnosed with an uber-rare disorder called CLOVES syndrome, which affects about fifty people worldwide. CLOVES stands for Congenital, Lipomatous, Overgrowth, Vascular Malformation, Epidermal Nevi and Skeletal/Spinal Anomalies/Scoliosis. It's a syndrome that affects multiple body systems and body parts, and the spinal lesions involved can cause significant neurological damage and/or death. For more information, see this link: <http://www.clovessyndrome.org/forums/viewtopic.php?f=9&t=38>

At a recent physical, my doctor told me that providing care for with a loved one with several chronic conditions raises my baseline stress levels higher than normal. Based on my experiences with stress, and the almost constant ache in the muscles in my back and neck, I agree with my doctor's assertion. After twelve years of being a social worker, I made the decision to stop working in that field. I've been happily unemployed for three months now, and I'm loving it. However, I'm not loving paying \$1500 for COBRA each month, but here we are.

There are many reasons for stress in our home. The biggies for us are money (see COBRA payment above), caregiving responsibilities, relationships with each other in the home, and future worries about Riley's health and quality of life. Stress is with us at all hours. Sleep is disrupted when the oxygen hose for BiPAP comes unhooked, or the pulse oximeter goes off with its all too familiar beeping when Riley de-sats. Lack of sleep makes me stressed.

Doing the “have-to’s” of Riley’s care stresses me out, because she is physically, emotionally and verbally opposed to most of the tasks. Tasks like testing blood sugar, cathing, bathing, going to doctor and other appointments and taking meds. These “have to’s” can often become power struggles as Riley picks up on my stress. Stress is cumulative, creates a constant flow of cortisol in my system, wears me out, and makes me cranky and whiny.

On the flip side, stressful experiences and effects have pointed me to what is important in life, and have helped me to gain clarity with what I want/need. Life’s stressors helped me to realize that social work was no longer a healthy profession for me. Avoiding stress can be extraordinarily motivating for me, and can help me get the job--whatever the job of the moment is--done. All of these exhausting and depleting experiences have helped me to learn how to take better care of myself and, in turn, take better care of my family.

However, I have no interest in being a victim to stress, and have spent much time and energy in figuring out how to see these experiences as blessings in disguise.

My personal stress busters include:

- Time to myself, when I’m not doing anything, except what I want. Examples for me are reading, creating, painting, writing, time outside to be in nature, watching birds, going to the beach and listening to music.
- Being grateful for the abundance in my life. I do this as often as I am able, and I benefit from writing these down and looking at them thru the day.
- I have started meditating recently and greatly enjoy listening to the free iPhone apps for meditation, as well as Jon Kabat-Zinn’s Mindfulness for Beginners. The breathing exercises are so helpful to me!
- Spending time with animals.
- Date night out (rare but very needed) or bringing take-out in, for the grown ups after the kids go to sleep.
- Having a predictable routine for the day, so that I am able to have some control over what is happening around me.
- Continuing to learn about and practice patience, forgiveness, care and compassion with myself, along this path.
- A long hot, bubble bath.
- Smelling flowers.
- Medication and therapy. YEARS of both have kept me sane!!

I could go on and on about my personal toolbox of stress busters, and all the ways I can be less stressed in my day. The catch for me is carving out tiny increments of time throughout the day to pause, regroup and de-stress. I have been guilty of going about my day like a robot, just getting through the day to get the kids into bed. It's quite a challenge for me to stop and take a break, before moving on to the next big thing.

*For more information, see the [CLOVES website](#) and Riley's CarePage, [www.carepages.com](http://www.carepages.com) Page ID = WeLoveRiley.*

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<sup>1</sup> <http://www.thefreedictionary.com/stressed>