Volume 3, Issue 7

MOTIVATED

THE MAGAZINE THAT MOVES YOU!

Through the Eyes of a Special Child

Preventing Caregiver Burnout

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I want my money back...

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FROM THE **EDITOR**

For those of you who are caregivers of children, the chronically ill, or elderly, I am sure you will agree that providing care for anyone is a challenge. Giving care to someone with special needs, however, presents an additional set of challenges, and at times, can seem overwhelming.

How do I know? I have been caring for a young, exceptional child for the past five years. He is a beautiful child, and such a joy. I treasure this time I have with him. Still, he has his "challenging" days, which can include meltdowns and demanding behavior that can test my patience and grand-parenting skills to the limit.

When this happens out in public, we are sometimes met with disapproving looks and stares, and yes, every so often with comments. I have learned to either ignore those, and quietly explain that this child faces special challenges, or give out a little card that explains the same. At difficult times like that, meeting someone who understands or sympathizes is very encouraging and makes a big difference.

Therefore, knowing first-hand how much greater awareness and understanding are needed, this issue of *Motivated* is dedicated to all those who sacrificially and lovingly care for others, and to all the beautiful exceptional people, both young and old, who deserve the best care we can possibly give them.

Christina Lane
For *Motivated*

A Blue Rose

Author Unknown

As I made my way around the store, and headed for the checkout counter, a young man, who appeared to be about sixteen-years-old, blocked me in the narrow aisle. I wasn't in a hurry, so I patiently waited for the boy to realize that I was there. He waved his hands excitedly in the air and declared in a loud voice, "Mommy, I'm over here."

It was obvious that he was intellectually challenged, and he startled as he turned and saw me standing so close to him, waiting to squeeze by. His eyes widened and surprise exploded on his face as I said, "Hey Buddy, what's your name?"

"My name is Denny and I'm shopping with my mother," he responded proudly.

"Wow," I said, "that's a cool name; how old are you Denny?"

"How old am I now, Mommy?" he asked his mother as she slowly came over from the next aisle. "You're fifteen-years-old Denny; now be a good boy and let the man pass by."

I acknowledged her and continued to talk to Denny for several more minutes about summer, bicycles, and school. I watched his brown eyes dance with excitement, because he was the center of someone's attention. He then abruptly turned and headed toward the toy section.

Denny's mom had a puzzled look on her face and thanked me for taking the time to talk with her son. She told me that most people wouldn't even look at him, much less talk to him.

I told her that it was my pleasure, and then told her that there are plenty of red, yellow, and pink roses in God's Garden; however, blue roses are very rare and should be appreciated for their beauty and distinctiveness. Denny is a blue rose and if someone doesn't stop and smell that rose with their heart and touch that rose with their kindness, then they've really missed a blessing.

She was silent for a second, then with a tear in her eye she asked, "Who are you?" Without thinking I said, "Oh, I'm probably just a dandelion, but I sure love living in this beautiful garden."

She reached out, squeezed my hand and said, "God bless you!" Then I had tears in my eyes.

Next time we see a blue rose, may we all take the time to smile and say hello. A kind word or a moment of our time can make all the difference and be just what that person or their family needs. ◀▶

PEOPLE WILL FORGET WHAT YOU SAID, PEOPLE WILL FORGET WHAT YOU DID, BUT PEOPLE WILL NEVER FORGET HOW YOU MADE THEM FEEL!—Anonymous

Through The Eyes of a Special Child

Author Unknown

Each exceptional child is different, of course, but here's something that one such child might want to tell you—if they could.

Spend time getting to know me.
Please have patience with me. I may not be able to do the things another child can.
Enjoy learning about my special needs so that you will understand.
Care about what my parents or caregivers tell you about how I communicate.
Imagine your child having problems, then realize what my parents feel.
Always be kind to people who are disabled. We are just like you.
Listen to me. I may be hard to understand, but if you take the time, you can understand me.

Never blame my parents. They didn't do anything wrong or cause me to be the way I am.
Encourage my parents and caregivers. They need it.
Entertain me, so that my parents or caregivers can have some time off.
Distraction is part of my daily life. I can't sit still. I try, but I can't.
Screaming is what I sometimes do when I can't handle what is going on around me. I want to tell you what is wrong, but I can't. ◀▶

PREVENTING CAREGIVER BURNOUT

Tips and support for family caregivers
By Melinda Smith, M.A. and Gina Kemp, M.A.,
Web Reprint from www.helpguide.org

Outside the world of paid work, the people most prone to burnout are caregivers—people who devote themselves to the unpaid care of the chronically ill or family members with disabilities. The demands of caregiving can be overwhelming, especially if we feel we have little control over the situation or that we're in over our head.

If we let the stress of caregiving progress to burnout, it can damage both our physical and mental health, so if we are caring for a family member, it is essential that we get the support we need. The good news is that we're not alone. Read on to find that help for caregivers is available. ◀▶

WHAT WE SHOULD KNOW ABOUT BURNOUT

Providing care for a family member in need is a centuries-old act of kindness, love, and loyalty, and as life expectancies increase and medical treatments advance, more and more of us will participate in the caregiving process, either as the caregiver, the recipient of care, or possibly both.

Unfortunately, caregiving can take a heavy toll if we don't get adequate support. Caregiving involves many stressors: changes in the family dynamic, household disruption, financial pressure, and the sheer amount of work involved. The rewards of caregiving—if they come at all—can be intangible and far off, and often there is little hope for a happy outcome.

As the stress piles up, frustration and despair take hold, and burnout becomes a very real danger. But we can prevent caregiver burnout by following a few essential guidelines:

- Learn as much as you can about a family member's illness or disability and about how to be a caregiver. The more we know, the more effective we'll be, and the better we'll feel about our efforts.
- Know your limits. We need to be realistic about how much of our time and ourselves we can give. Set clear limits, and communicate those limits to doctors, family members, and other people involved.
- Accept your feelings. Caregiving can trigger a host of difficult emotions, including anger, fear, resentment, guilt, helplessness, and grief. As long as we don't compromise the well-being of the care receiver, we should allow ourselves to feel what we feel.
- Confide in others. We should talk to people about what we feel and not keep our emotions bottled up. Caregiver support groups can be valuable, but trusted friends and family members can help too. We may also benefit from seeing a therapist or counselor.

Once we burn out, caregiving is no longer a healthy option for either us or the person we're caring for. So it's important to watch for the warning signs of caregiver burnout and take action right away when we recognize the problem. ◄►

10 TIPS FOR FAMILY CAREGIVERS

Taken from the National Family Caregiver's Association's website

- Caregiving is a job, and respite is an earned right. Reward yourself with respite breaks often.
- Watch out for signs of depression, and don't delay in getting professional help when you need it.
- When people offer to help, accept the offer and suggest specific things that they can do.
- Educate yourself about your loved one's condition, and about how to communicate effectively with doctors and professionals.
- There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- Trust your instincts. Most of the time they'll lead you in the right direction.
- Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
- Grieve for your losses, and then allow yourself to dream new dreams.
- Seek support from other caregivers. There is great strength in knowing you are not alone.

COMMON WARNING SIGNS OF CAREGIVER BURNOUT

- You have much less energy than you used to.
- It seems like you catch every cold or flu that's going around.
- You're constantly exhausted, even after sleeping or taking a break.
- You neglect your own needs, either because you're too busy or you don't care anymore.
- Your life revolves around caregiving, but it gives you little satisfaction.
- You have trouble relaxing, even when help is available.
- You're increasingly impatient and irritable with the person you're caring for.
- You feel overwhelmed, helpless, and hopeless.

THE VALUE OF CAREGIVER SUPPORT GROUPS

Remember that old adage, "Trouble shared is trouble halved?" A caregiver support group is one way to share your troubles. Seek out people who are going through the same experiences that you do each day. If you can't leave the house, many Internet services are available. In most support groups, you'll talk about your problems and listen to others talk; you'll not only get help, but you'll be able to help others, too. Most important, you'll find out that you're not alone. You'll feel better knowing that other people are in the same situation, and their knowledge can be invaluable.

PREVENTING CAREGIVER BURNOUT TIP 1: GET THE HELP YOU NEED

The first strategy for preventing caregiver burnout is: Don't try to do it all alone. Taking on all of the responsibilities of caregiving without regular breaks or assistance is a surefire recipe for burnout. Ask for help when you need it. Enlist friends and family who live near you to run errands, cook a meal for you, or take a turn with the care-receiver so you can take a well-deserved break.

PREVENTING CAREGIVER BURNOUT TIP 2: SEEK EMOTIONAL SUPPORT

Pablo Casals, a world-renowned cellist, said, "The capacity to care is the thing that gives life its deepest significance and meaning." Although caregivers are often isolated from others, it's essential that you receive the emotional support you need, so you don't lose that capacity.

Share what you're going through with at least one other person. Turn to a trusted friend or family member, join a support group, or make an appointment with a counselor or therapist. You can also draw strength from your faith. Other believers can provide the encouragement you need to feel good about your caregiving role, and may also be able to provide a break from time to time.

PREVENTING CAREGIVER BURNOUT TIP 3: TAKE CARE OF YOURSELF

When you are a caregiver, finding time to nurture yourself might seem impossible, but you owe it to yourself to find the time. Without it, you may not have the mental or physical strength to deal with all of the stress you experience as a caregiver. Give yourself permission to rest and to do things that you enjoy on a daily basis. You will be a better caregiver for it.

IN THEIR OWN WORDS

I WANT MY MONEY BACK…

Autism Speaks blog post by John Scott Holman, adapted

At the tender age of fifteen, I saw my first psychologist, a stern, elderly man who smelled like a secondhand bookstore. His full, wiry beard was speckled with white and gray, as if it had caught the contents of an overturned ashtray. It fell past his chest, disappearing beneath the edge of his massive, oak desk. I wondered if it reached his toes, and leaned forward awkwardly, hoping for a revealing glimpse.

"Young man," he said, startling me. "Tell me why you're here."

"Do you shampoo that beard?" I asked.

"Excuse me…"

"You look like Charles Darwin."

He leaned back and stared at me, mildly annoyed, as if I was a fly he had noticed swimming in his coffee. "Your family is concerned by your behavior. I believe…"

"I commend you, sir!" I interrupted. "The world is experiencing a shortage of truly magnificent facial hair; you've got the best beard I've seen all year! You know who else had a good beard? Sigmund Freud. Are you a Freudian psychologist?"

"Young man, let's try to stay on topic."

"Right, beards… Nobody could beat Tolstoy's beard. Now that dude had a beard!"

TIPS FOR TAKING CARE OF YOURSELF

- Incorporate activities that you enjoy, even when you don't really feel like it. Listen to music, work in the garden, engage in a hobby—whatever it is that you enjoy.
- Pamper yourself. Take a warm bath and light candles. Read a nice book, or go out for dinner with family or a close friend.
- Eat balanced meals to take care of your body. Find time to exercise even if it's a short walk every day. Do the best you can to sleep at least 7 hours a night.
- Laughter really is the best medicine. Buy a light-hearted book or rent a comedy. Whenever you can, try to find some humor in everyday situations.
- Keep a journal. Write down your thoughts and feelings. This helps provide perspective on your situation and serves as an important release for your emotions.
- Arrange a telephone contact with a family member, a friend, or a volunteer so that someone calls each day to be sure everything is all right. This person can help by contacting other family members with status updates, or to let them know if you need anything.
- Try to set a time for afternoons or evenings out. Seek out friends and family to help you so that you can have some time away from the home. If it is difficult to leave, invite friends and family over to visit with you. Share some tea or coffee. It is important that you interact with others.

"Young man!" he bellowed, startling me again.

"Humph… Young man," I muttered. "Just 'cause I can't grow a big fancy beard…"

The psychologist lifted a notepad from his desk and began scribbling absentmindedly. "I'm afraid," he said, "that you have a very serious case of Bipolar Disorder."

"Huh? How do you know? I've only been here for five minutes!"

"Trust me; I've been around a long time."

"But… I've never had a manic episode, and the DSM-IV clearly states…"

"You, my dear boy, are an upstart!" the psychologist fumed, a fat, blue vein trembling in his forehead.

"Ok, chill dude… I'm bipolar. Whatever you say… Beethoven was bipolar. I don't think he had a beard though…"

For as long as I can remember, people have been trying to figure me out. Other parents told my mother and father that I was clearly lacking discipline. Teachers refused me an education unless I was prescribed enough Ritalin to keep the Rolling Stones touring for another century.

Hyperactive, precocious, and more than a little odd, I was truly a handful. Snakes, snails, and puppy dog tails? If only my mother was so lucky. Someone must have littered my gene pool with pixie sticks, happy meals, mountain dew, and an Encyclopedia Britannica.

"There's something wrong with him," my mother would sob. "He's allergic to people! He won't sit still, he won't listen, he's always hurting himself, and he's smarter than my whole graduating class put together!"

I treated other children like overgrown action figures, ordering them about, an infantile Cecil B. Demille directing a playground epic.

"C'mon Tina, say that line again, and this time, say it with feeling! Put down the Polly Pocket and explain your character's motivation!" Eventually, my peers developed their own interests, and I was left to wander the playground alone, thinking of Ghostbusters, Power Rangers, and… existential motifs in Russian literature.

"Scotty's latest obsession," was a phrase used regularly to describe the most current of my all encompassing interests. At twelve-years-old, I had forgotten more randomly collected information than most people will learn in college. My obsessions gradually became less and less age appropriate as my focus narrowed; retired barbiturate and amphetamine combinations used as antidepressants in the 50s and 60s; and the impact of synesthesia on the literature of Vladimir Nabokov; to name a select few.

I wasn't interested in girls, or boys, for that matter. My parents bought me a Mustang for my sixteenth birthday–I drove it all of three times. I wore the same few outfits day after day. I was diagnosed with ADHD, Generalized Anxiety Disorder, Borderline Personality

Disorder, Major Depressive Disorder, and, of course, Bipolar Disorder. I spent time in hospitals and treatment centers.
At 24 years-old, my girlfriend suggested that I might have Asperger Syndrome.

"Huh?"

"Scott," she said, "you can recite every line of the movie Cabaret, yet you haven't seen it since you were thirteen. You just listed every currently marketed benzodiazepine in alphabetical order, apparently for my entertainment.

"So…?"

"You're a walking dictionary, but you can't remember your own address. Not only can you not drive, you can't figure out which of the three cars parked in your driveway is mine. I think you should see a doctor."

"I've seen them all."

"Scott…"

"Ok… ok… Wait, I'm autistic? I want my money back…"

How did I manage to live a quarter of a century without being properly diagnosed. I'm autistic–duh!

Discovering my autism has been my saving grace. I will never forget the overwhelming emotions that poured over me when I first read about Asperger Syndrome in the DSM-IV. I'm not broken. I'm not bad. I'm just autistic and that is alright! Since being formally diagnosed, I've come to understand and embrace myself for the remarkable person I am. In a few short months, I've become a prolific autistic writer, with a column appearing this week on www.wrongplanet.net, a potential contract with a publishing company, public speaking engagements, and an opportunity to travel to San Francisco to help Alex Plank and crew film a documentary on Hacking Autism.

Somebody pinch me!

Even when I had given up on myself, God had a plan for my life. I now have the opportunity to use my gifts to spread awareness of autism spectrum disorders. If sharing my experiences spares other autistics from going through the pain of living undiagnosed, my struggles will not have been in vain.

My diagnosis has been my vindication and my inspiration. I want to shout it from the rooftops; "I'm autistic!"

Well, better late than never.

Seriously though, I want my money back…◀▶

PARENTING FROM THE HEART

I'm only Human

By a father of three exceptional children

I have been a special needs parent for over a decade and something that I learned along the way is that despite my very best efforts, at the end of the day, I'm only human. I get frustrated, overwhelmed, and on occasion say and do the wrong thing.

One of the things that happens quite often to special needs parents is that the demand on us simply exceeds the resources we have available, be it emotional, physical, or financial. This demand is constant in many cases, and the strain over time becomes more and more difficult to carry. The stress can really take its toll.

I feel that as special needs parents, we often don't give ourselves enough credit or cut ourselves enough slack. Speaking for myself only, I have a tendency to be overly critical of myself, especially when I feel I'm failing at something, which is honestly, quite often. However, in reality, I'm failing to remember that I'm doing or trying to do things every day that most people simply couldn't handle. We tend to become so accustomed to everything that we often focus more on our perceived losses or defeats than we do on our successes and victories.

One of the things that I have always encouraged people to do is share their feelings. Venting, or expressing what we are going through, is something that is extremely important in special needs parenting. Again, speaking only for myself, I'm under constant and unforgiving pressure. These pressures can range from health or behavioral issues to simply trying to make ends meet.

Some of this pressure I put on myself, but most of it is inherent to special needs parenting in general.

There are times that my kids drive me crazy and I swear that my head is going to explode. For a long time this was like a double-edged sword. I would be so incredibly stressed out, overwhelmed, and frustrated. On top of that, I would feel an extreme sense of guilt for being stressed out, overwhelmed, and frustrated. The kids had no control over most of their behaviors, but I had this idea that, as their father, I was supposed to have this never-ending supply of patience. Instead I was always "a day late and a dollar short."

There were times that I was so far gone that I would go through a drive-thru to pick up dinner and when asked, "Can I take your order?", I would answer, "I'll take some sanity with a side order of patience and some peace and quiet for desert…oh…and…supersize that." Apparently, this kind of stuff is not on the menu…anywhere! Trust me, I've tried everywhere. You can ask my wife. She was always mortified when I would place my order.

Then one day, it hit me. I'm not sure how or why this happened, but I realized that I didn't have to feel guilty for being frustrated, overwhelmed, and stressed out by my kids or their behavior. I guess I had felt like if I admitted that I was frustrated or overwhelmed by the challenges associated with raising three boys with special needs, that it somehow reflected poorly on them, or that I loved them less. I didn't want anyone to think that about my kids because, while challenging, they are totally awesome, and I wouldn't trade them for anything in the world.

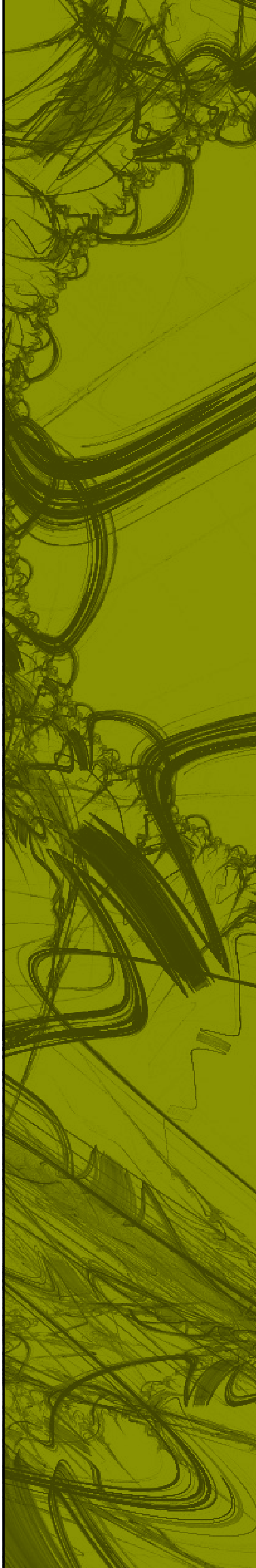
Admitting frustration with those challenges, or even with any or all of my kids, doesn't mean they are bad and it certainly doesn't mean that I somehow love them any less. What admitting this did mean however, was that I was human. I learned that not only was it normal to feel these things, but it was also healthy.

This was such a powerful realization for me, and it changed my perspective considerably. I discovered that acknowledging these feelings, and even embracing them, provided a much-needed sense of relief. The relief really kicked in when I became comfortable enough with these feelings to not only admit them to myself, but share them publicly as well. While that may not appeal to everyone, and understandably so, it helped me to keep myself centered.

I think that this is something particularly difficult for fathers. Society tells us that we are supposed to be almost emotionless and not feel these things and if as a man, you actually do have these feelings, God forbid you ever admit it.

Look, we are human beings living in very difficult situations. These situations very often require sacrifice to the nth degree. Feeling frustrated, overwhelmed, or even resentful is completely normal, at least in my opinion. I also think that admitting these things is not a sign of weakness or even bad parenting. In fact, I would argue that it shows great courage and a deep unconditional love for our kids. Honestly, no one likes admitting things like this, but in doing so we get a better understanding of our limitations and ourselves.

As far as I'm concerned, this helps to make me a better parent, and speaking for myself, I need all the help I can get. ◄►



EMPOWERMENT FOR CAREGIVERS

All problems become smaller if we don't dodge them but confront them.
—William F. Halsey

Out of difficulties, grow miracles.
—Jean De La Bruyere

A difficult time can be more readily endured if we retain the conviction that our existence holds a purpose, a cause to pursue, a person to love, and a goal to achieve. —John Maxwell

Laughter and tears are both responses to frustration and exhaustion. I myself prefer to laugh, since there is less cleaning up to do afterward.
—Kurt Vonnegut

Remember sadness is always temporary. This, too, shall pass.
—Chuck T. Falcon

The greatest weapon against stress is our ability to choose one thought over another. —William James

Sometimes it helps to know that I just can't do it all. One step at a time is all that's possible—even when those steps are taken on the run. —Anne W. Schaef

Strength means recognizing that it is impossible to be strong all the time.
—Sally Franser

Love cures people—both the ones who give it and the ones who receive it. —Karl Menninger

We make a living by what we get, but we make a life by what we give.
—Norman Macewan

The love we give away is the only love we keep. —Elbert Hubbard

Those who bring sunshine into the lives of others, cannot keep it from themselves.—Sir James M. Barrie