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Issue Editor Motivated Vol 7, Issue 12 Christina Lane

awexdesign

Design

Contact Us: Email Website

motivated@motivatedmagazine.com www.motivatedmagazine.com

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Stories of caring are all around us. Parents take care of children, teachers take care of students, doctors and nurses take care of patients, adult children take care of aging or ailing parents, siblings take care of each other, and yet others take care of those with special needs.

Every caregiver has a story, and every story touches family members, friends, coworkers, and more.

We care for others out of love and outgoing concern, but that doesn't mean that it is always easy. Caregiving brings challenges and burdens with it that can tax our resilience, patience, and endurance.

Someone once said that it's important to remember that you cannot feed others from an empty cupboard. I found this to be true myself when I cared for a young grandson on the autism spectrum for several years. I needed regular times of respite, to refill and re-strengthen myself for the task at hand. I also needed support and understanding from others who found themselves in similar situations.

I hope you will benefit from reading this issue of *Motivated*, and that the stories from other caregivers will encourage you that you're not alone on this caregiving journey. If you're anything like me, you may just heave a sigh of relief and think, "I know just how that feels" and "Thank goodness I'm not the only one!"

Christina Lane For *Motivated*

6 Things I Wish Someone Told Me When I **Became** a **Special Needs Parent**

By Kirsty Russell, adapted

When you receive a diagnosis for your child, your life completely and irrevocably changes. I can still vividly remember all the overwhelming feelings that hit me. There was shock, disbelief, anger, guilt, dismay, panic, denial, and confusion. Over the following weeks, months, and years, those feelings remained, in one form or another.

Over 10 years later, I now know these feelings will never completely go away, and I have learned to manage them better. But for someone new to the special needs parenting world, it can be a huge shock.

So I want to give them the advice I wish I had received when my journey began:

- 1. Don't be afraid of your emotions. Recognize and accept that everything you feel at first is natural. In order to move forward, you need to acknowledge your feelings and move through the stages that will follow. Don't fight your feelings. Find a professional counselor if your emotions overwhelm you.
- 2. Know that you are not alone. There are other families out there with special needs, and it's important to connect with those facing similar challenges. It was only after seeking professional help that I felt more at peace with the diagnoses, and was able to connect with others.

- 3. Find a support group and have the courage to join up. If it's too raw and confronting to meet with others in person, find an online group to join. There are countless support groups online that offer a wealth of information, personal experience, and support. Join them and take in information at your own pace.
- 4. Make time for yourself and your partner. You will not be an effective caregiver for your child if you are mentally and physically exhausted. You need to look after yourself, and that means trying to find some time away together with your partner, or you may lose yourself and your relationship.
- 5. Regardless of the diagnosis, your child is still the same precious person he or she was yesterday. Do not let a diagnosis or a name or a label change how you love, cherish, and protect your child. Your child is more than just a condition or a diagnosis. Celebrate their achievements, recognize their strengths, and support their efforts.
- 6. Believe in vourself. Never forget that you know your child best, and that you will always be their best advocate throughout your journey. Believe in yourself and trust your instincts when it comes to making decisions for your child. You may not be an expert in your child's condition, but you are an expert in who they are, which is just as important.

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That February night, like most nights, I was exhausted. I couldn't wait to get into bed, where I could finally relax for a minute and thank God for getting me through another day. Like many women my age, I was juggling a lot. Raising a 10-year-old son with special needs, helping my 83-year-old mom, working part-time as a college writing teacher and keeping the household running.

My husband, Steve, did all he could, but he had a high-pressure job with long hours, so most of the work around the house fell to me. The stresses of the sandwich generation!

Good thing all I had left was to throw a load of clothes in the dryer and let the dog out. I hurried down the stairs to the laundry room. My right foot hit something wet on the tile floor and flew out from under me. Wham! I landed hard, my ankle twisting with a sickening crunch.

I yelped. In seconds, my son, Tommy, was at my side. The same Tommy who obviously hadn't remembered to stomp

the snow off his boots before he came into the house and left a puddle on the floor. If I'd told him once I'd told him a thousand times...

"Daddy, Mommy fell down!" he yelled. Tommy had autism and was prone to anxiety. I patted his arm. "I'm okay," I said, trying not to gasp in pain. "It's just a sprain."

Steve ran downstairs and helped me to my feet. I leaned against him and hobbled to our bedroom. I couldn't afford to be laid up. Tommy depended on me for so much, even just picking out his clothes and pouring his cereal for breakfast. He didn't do well if his routine was disrupted. And I had to take Mom grocery shopping. I'll be better tomorrow, I told myself.

Steve got a pillow to elevate my leg, an ice pack and some ibuprofen.

"The dog needs to go out," I said.

"Got it," he said. "Just lie still. Let me take care of you for a change."

The next morning I managed to get Tommy dressed, fed and on the bus.

But each step I took was excruciating. I had no choice but to call my mother. She drove right over. One look at me, and she declared, "I'm taking you to the hospital." She'd taught school for more than 30 years, and her tone of voice told me it was pointless to argue.

X -rays showed I'd broken my fibula. "I'm going to put your leg in a boot and give you crutches," the doctor said. "But I don't want you walking on it more than absolutely necessary for six weeks."

"Six weeks?" I cried. "That's not possible! I have a job and a special-needs son. My mother's in her eighties. My family. They depend on me!"

"I mean it," the doctor said. "If you put too much stress on your leg, it won't heal. Then you'll be looking at surgery and an even longer recovery."

I protested all the way home. "Laura, relax," my mom said. "I can help around the house, and with Tommy. I may be old, but I'm not dead."

I had to press my lips together to keep from blurting, "This is a disaster in the making!"

Tommy loved his grandma, but I couldn't see her taking care of him every day. Both of them were strong-willed, and they would butt heads. The slightest change in Tommy's routine, and he'd have a meltdown. I didn't want him getting so anxious that he reverted to reciting video-game scripts and not being able to carry on a conversation. Besides, did Mom have the stamina?

When Tommy came home, he ran to me and gave me a big hug.

"Does it hurt?" he asked, pointing to my boot.

"A little," I said.

Tommy nodded, then went to the kitchen for his snack as usual. Mom had an apple and a bag of pretzels waiting for him.

Mom came over every day to get Tommy on and off the school bus. In between she cleaned, did laundry, grocery shopped, cooked. I spent most of the day at the computer, researching story ideas, filling out school paperwork for Tommy, catching up on e-mail, stuff I rarely found time to do.

Still, I felt guilty about burdening my family, especially Mom. One day I caught her organizing my closets. "You don't have to do that," I told her. "You're going to tire yourself out."

"Laura, I'm fine," she said. "I have so much more energy these days. I like being needed. I feel more like an important part of the family and not just some old lady who has to be looked after."

"Mom, I don't know how to thank you," I said.

"For what?" she asked. "For how you've helped Tommy. And me. For everything."

"I didn't do anything you wouldn't have done for me," Mom said. "What are families for?"

I had been so sure that my family would fall apart without me at the helm. But thinking I needed to do everything was why I was so stressed out, wasn't it? I'd underestimated my husband, my son, my mom, the family God had blessed me with. No one person makes a family. It takes everyone working together, all in.

I looked at my walking boot, feeling a surge of gratitude. It wasn't just my leg that was growing stronger. Our whole family was.



TRAGEDY HAS TWICE visited the Woodiwiss family. In 2008, Anna Woodiwiss, then 27, was working for a service organization in Afghanistan. On April 1, she went horseback riding and was thrown, dying from her injuries. In 2013, her younger sister Catherine, then 26, was hit by a car while biking to work. She has endured, and will continue to endure a series of operations. The recovery is slow.

A victim of trauma, as Catherine writes in a remarkable blog post, experiences days "when you feel like a quivering, cowardly shell of yourself, when despair yawns as a terrible chasm, when fear paralyzes any chance for pleasure." Her mother, Mary, talks about the deep organic grief that a parent feels when he or she has lost one child, and seen another badly injured, a pain felt in bones and fiber.

But suffering is a teacher. Through their own experiences, the Woodiwisses drew a few lessons about how those of us outside the zone of trauma might better communicate with those inside. There are no uniformly right responses, but their collective wisdom, some of it contained in Catherine's piece, is quite useful:

Do be there. Some people think that those who experience trauma need space. Assume the opposite. Most people need presence. The Woodiwisses say they were awed after each tragedy by the number of people, many of whom had been mere acquaintances, who showed up and offered love from across the nation and



the continents. They were also disoriented by close friends who simply weren't there, who were afraid, or too busy. Catherine's father, Ashley, says he could detect no pattern to help predict who would provide the ministry of presence and who would fumble

Don't compare, ever. Don't say "I understand what it's like to lose a child. My dog died, and that was hard too." Even if the comparison seems suitable, don't make it. Each trauma should

be respected in its uniqueness. "From the inside," writes Catherine, comparisons "sting as clueless, careless, or just plain false."

Do bring soup. Nonverbal expressions of love are as healing as eloquence. When Mary was living with Catherine during her recovery, a friend noticed she didn't have a bath mat. He went to buy her one. Mary says she will never forget that.

Do not say "You'll get over it." "There is no such thing as 'getting over it," Catherine writes. "A major disruption leaves a new normal in its wake. There is no 'back to the old me."

Do be a builder. The Woodiwisses distinguish between firefighters and builders. Firefighters drop everything and arrive at the moment of crisis. Builders

are there for years and years, walking alongside as the victims live out in the world. Very few people are capable of performing both roles.

Don't say "It's all for the best" or try to make sense of what has happened. Catherine and her parents speak with astonishing gentleness and quiet thoughtfulness, but it's pretty obvious that these tragedies have stripped away their tolerance for pretense and unrooted optimism.

Ashley also warned against those who over-interpret and try to make sense of the inexplicable. Even the deeply religious should not take theology beyond its limits. Faith is a grounding in ultimate hope, not a formula to explain away each individual event.

I'd say that what these experiences call for is a sort of passive activism. We have a tendency, especially in an achievement-oriented culture, to want to solve problems and repair brokenness. But what seems to be needed is the art of presence: to perform tasks without trying to control or alter the elemental situation. Allow nature to take its course. Grant the sufferers the dignity of their own process. Sit simply through moments of pain and uncomfortable darkness. Be practical, mundane, simple, and direct.

Ashley and Mary went to Afghanistan a few months after Anna's death. They remember that as a time out of time. They wept with Afghan villagers and felt touched by grace. "That period changed me and opened my imagination," recalls Ashley. "This thing called presence and love is more available than I had thought. It is more ready to be let loose than I ever imagined."

Care for Caregivers

By Sara Altshul, adapted

Valuable advice that will help you stay well while looking after your loved one.

When you're responsible for an adult loved one who's battling a debilitating illness, it's easy to feel alone.

But of course, you're not. You're part of a vast, caring army: Millions of people offer daily support to a chronically ill, disabled, or aging family member or friend.

Generally speaking, that army consists of middle-aged adult children or older spouses, who sacrifice their own health to care for a loved one who is battling a debilitating disease.

These caregivers bear a heavy load helping loved ones manage the details of living, as well as assist them with their most intimate daily needs, including toileting, feeding, and simply getting around.

Caregiving impacts everyone's life. Today, one in eight people have a family member with some form of dementia; 70 percent of these people live at home.

But dementia-related conditions are just the tip of the iceberg; millions more people with diabetes, heart disease, injuries, and arthritis also rely on family or friends for help.

As a caregiver, it's vital to look after yourself as tenderly as you look after your loved one. Put yourself last, as many caregivers do, and eventually your health will suffer.

In addition to experiencing higher than normal rates of stress and depression, caregivers have mortality rates that are 63 percent higher than non-caregivers.

What's more, research has shown that stress impacts your immune system for up to three years after caregiving duties end, which increases your chances of developing a chronic illness.

Caregivers are at risk for emotional, mental, and physical health problems that arise from complex caregiving situations, but when caregivers learn to identify and deal with stress, their levels of anxiety, depression, anger, and hostility plummet.

Here are 10 tips for family caregivers that can help you stay well, physically, mentally, and emotionally:

- 1. Do something just for yourself every day. Read, listen to music, phone friends, work at a craft, exercise. Anything that gives you pleasure and a little respite will also help lower your stress levels.
- 2. Watch for signs of depression. If you begin to feel listless or low in energy, if you're having trouble sleeping or can't concentrate as well as you once could, you might be clinically depressed. If you feel helpless or hopeless, don't delay in getting professional help.
- **3.** When people offer to help, accept. Suggest specific things they can do, such as prepare a meal, spend an hour with your loved one so you can go out, or even walk the family dog.

- **4. Eat healthy foods.** Don't skip meals or snack mindlessly. See food as both fuel and medicine; choose balanced and nutritious meals.
- **5.** Be open to technologies and ideas that promote your loved one's independence. Having a person dependent on you may be stressful, but it's also stressful to be dependent. Encourage your loved one to do as much as they can for themselves when they can.
- **6. See your doctor annually.** Tell your doctor you're a caregiver so that they are aware of the particular stress you experience. They may offer a specific treatment plan for you based on your particular situation.
- **7. Be good to your back.** Caregivers often do a lot of lifting, pushing, and pulling. Ask your doctor or chiropractor for practical ways of protecting yourself against back injuries. If you have a bad back, know what your limitations are and get help with chores that could lead to an injury.
- 8. Grieve for your losses and then allow yourself to dream new dreams. If you're caring for a spouse with Alzheimer's disease or another permanently debilitating condition, you need to grieve for the person who is now lost to you. Find reasons to be hopeful, and seek support through a faith or community center.
- **9. Seek support from other caregivers.** No one knows better than other caregivers what you're going through. What's more, other caregivers can be realistic about your situation and help you problem-solve.
- **10. Take care of your health.** Eat right, sleep right, and exercise right. This protects you and your loved one. Here's why: If you're sick, you can't be a good caregiver.

Help and hope is all around you.





aregiving can be draining at times, but there are also surprising benefits.

You may know that taking care of someone long-term can be challenging and even tax one's overall wellbeing. Studies bear this out, showing that caregiving often increases stress, thus potentially harming immunity and contributing to depression. There's a term among doctors—"caregiver burden"—to describe the pressure the role can bring.

But what's lesser known is that caregiving has some benefits—and there's even a term for that too: "caregiver gain," or the "healthy caregiver hypothesis." Researchers studying caregivers have been surprised to discover these boons, attributing some of the benefits to the extra physical and mental activity involved with caregiving.

Taking care of someone can require literal heavy lifting as well as intensive thought concentration. Those two things alone may keep your brain and body in better shape—and thus your emotions lifted as well. In fact, according to one poll, 83 percent of caregivers considered the work they do a positive experience.

Though caregiving can be a strain—especially for those who tend loved ones with dementia—discover (and be inspired by) some of the specific benefits lent by serving someone in need.

1. Improved Memory and Thinking

All of that time spent navigating insurance claims, scheduling appointments, timing medications, and more, may be good for a caregiver's brain. You know that saying about the brain's health—"use it or lose it?" Caregiving is an example of using it—a lot.

One study published in *The Journal of Aging and Health* in 2011, found that older women who cared for someone long-term had significantly sharper memory and better thought processing speed than their non-caregiving peers.

2. Increased Lifespan

Though the stress of caregiving has been found in some studies to trigger an earlier death, a 2010 study found that some caregivers actually experience the opposite. Researchers tracking women over several years found that the caregivers lived longer than those who weren't taking care of anyone.

Another study's findings support that the positive aspects of caring have been underreported. The bottom line: Nobody talks about the fact that caregiving may be good for you.

3. Enhanced Sense of Purpose

There's a quality that cannot be described or named easily to the reasons for "caregiver gain." Some speculate that this may have something to do with a sense of purpose. Studies have found that once people retire, cognition may decline. Not using the brain and body as much is part of that, but many also attribute that to a lost sense of reason for being.

Having a strong sense of purpose is correlated with a lower occurrence of cardiovascular disease, according to a recently published meta-analysis. Humans need to feel like we have a reason for being here in order to thrive—and though caregiving may cause stress, it does mean we're needed, and that matters a lot when it comes to how we feel.

4. Physical Strength

Not all caregiving requires bathing or moving the care recipient, but some of it does. And all of it requires at least some action—getting glasses of water, making food, or generally walking around, which potentially adds up to a lot of activity.

The same researchers cited above found that caregivers had a stronger grip, and could walk faster than non-caregivers. Physical strength is generally great news for blood sugar levels, muscle tone, joint flexibility, mood, and overall mental health.

Each caregiver's situation is unique, but if you find yourself noticing the upside of caregiving, you're not alone. In fact, there's science to support your experience.

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Caring



There are four kinds of people in the world: Those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.—Roselyn Carter

Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.

—Leo Buscaglia

Never believe that a few caring people can't change the world. For, indeed, that's all who ever have.—Margaret Mead

The simple act of caring is heroic.

—Edward Albert

Caring for our seniors is perhaps the greatest responsibility we have. Those who walked before us have given so much and made possible the life we all enjoy.—John Hoeven

A smile is the light in your window that tells others that there is a caring, sharing person inside.—Denis Waitley

Live so that when your children think of fairness, caring, and integrity, they think of you.—H. Jackson Brown, Jr.

From caring comes courage.—Lao Tzu

Without a sense of caring, there can be no sense of community.—Anthony J. D'Angelo

Caregiving often calls us to lean into love we didn't know possible.—Tia Walker

We can all make a difference in the lives of others in need, because it is the most simple of gestures that make the most significant of differences.—Miya Yamanouchi

No one cares until someone cares; be that one!—Ken Poir

