

# THE RESILIENT CAREGIVER

BY LAUREN AGORATUS, M.A.



## **TAKING CARE OF YOURSELF WHILE CARING FOR ANOTHER**

Did you know that November of each year is National Family Caregivers Month by presidential proclamation? In part the proclamation reads:

“Whereas, the primary source of community-based services and the cornerstone of our long-term care system are care recipients’ family members, friends and neighbors who help their loved ones maintain their independence and their quality of life; and...according to the National Alliance for Caregiving, there are roughly 67 million family or informal caregivers in the United States...”. This means you’re not alone!

## **AM I A CAREGIVER?**

Not a caregiver you say? Many parents of children with special needs suddenly realize, “How many other parents are still

diapering their five year olds, or feeding them baby food? How many of us may even be lifetime caregivers?” While it’s the responsibility of parents to take care of their children, they need to recognize that they are doing more than other parents, and so are also caregivers.



## **BUT I DON'T WANT TO BE A CAREGIVER!**

Parents of children with disabilities, like all parents, love their children and want the best for them. They understand that there are challenges in raising all children. But the reality is that parents of children with disabilities and special healthcare needs face both the reality of raising any child, and the reality of the additional responsibilities that come from raising children with special needs.

An article in the *New York Times*, “The Reluctant Caregiver,”<sup>1</sup>



**BUILDING THE FUTURE:** The CDC's Building Healthy Inclusive Communities initiative recognizes that "creating opportunities for healthy, active living by people of all abilities is a priority as we plan our communities."

mentally weary of the constant changes, lifting, medications, paperwork, insurance denials, treatments. They may be tired of deciding if it's safe to maintain their child at home or do they need to go to the emergency room, and of worrying if they guess wrong as their child's life can literally be in their hands.

### **IMAGINE BEING THE CARE RECIPIENT**

Families may wonder what it must be like for their child going through the many challenges they face. Research has shown that some children can actually suffer PTSD<sup>2</sup> (Post Traumatic Stress Syndrome) post hospitalization and also that 1 in 3 (even adults) suffer PTSD after being on a ventilator.<sup>3</sup> The child may not feel safe when returning home from the hospital. Families can use bedrails, baby monitors, a bedtime routine, and regular relaxation techniques like reading, soothing music or sounds, etc. to help address these fears.

Parents can think about what it must be like to have to depend on someone to hear you even if you just need a glass of water. Or what if the child can't get to the bathroom or needs help with personal care. Families can think about how their child might feel if they're hooked up to medical equipment. The child may be scared of being sick, going through uncomfortable or painful medical procedures, and does not know what to expect. Parents can think what it must feel like for the child to depend on other people for things the child used to do for him/herself, or that other children can do for themselves.

### **BEHAVIOR IS COMMUNICATION**

When a child acts out, it is most likely that they can't help it. Behavior may be the worst when the child is in pain, hungry, etc. Their behavior is how they're communicating. They feel like they have no control over anything in their world. By remembering this, then it helps parents *not* be "The Reluctant Caregiver."

### **THE TOLL OF CAREGIVING**

It is commonly acknowledged that caregiving affects the caregiver's health. This is true for caregivers across the lifespan whether they are parents of children with special needs, "well-spouses", or involved in eldercare. There can be a physical toll, for example back problems lifting a care recip-

ient. There is also an emotional toll and stress affects health. There are also publications from caregiver organizations on avoiding medication errors, how to talk to doctors or deal with hospitalization, their own health, etc. (*See Resources*). In addition, caregiving can affect employment. Parents may need to use the Family Medical Leave Act ([www.dol.gov/dol/topic/benefits-leave/fmla.htm](http://www.dol.gov/dol/topic/benefits-leave/fmla.htm)) and some states have paid leave.

### **HOW TO TAKE CARE OF YOURSELF (SO YOU CAN CARE FOR YOUR CHILD)**

Parents need to make sure that they go to their own doctor appointments for regular physical checkups, dental, vision, etc. They get so caught up in their child's appointments, they often neglect their own. Here are some practical tips:

- *Do preventive care like annual physical, flu shot, vitamins, etc.*
- *If parents are depressed (up to 75% of caregivers have this happen) get help. Asking for help is a sign of strength, not weakness.*
- *Relieve stress through exercise, respite, etc.*
- *Parents shouldn't feel guilty for taking breaks because it'll give them more energy to be a better caregiver.*
- *Get support. Parent-to-Parent matches trained volunteer parents to families of children with the same condition. Finding out about their child's condition helps parents know what they're dealing with and they can partner with medical and educational professionals in making decisions. Parent Training Centers can help parents with schools and the early intervention system. Parents Anonymous support groups can also help (the majority of parents who participate in these groups are parents of children with special needs).*

Sometimes the hardest thing about being a family caregiver of a child with special needs is not knowing what to expect or just needing a listening ear. Sometimes just finding someone "who's been there" will help parents of children with disabilities get information on their child's condition and also talk to other families. This way they won't feel so helpless or hopeless. Parents can talk to other families for information and support, making their family unit stronger.

explained that families may feel a sense of reluctance for many reasons. Most families didn't plan on being "special parents," or caregivers of children with special needs, some of whom may need lifelong care.

Sometimes special parents are reluctant caregivers because they just want to be mom or dad, and enjoy time with their child. They're tired of being a teacher, behaviorist, physical therapist, case manager, nurse, etc. Sometimes parents are just tapped out with round-the-clock care. Or they don't want to go to the hospital out of state, and live apart from their spouse for who knows how long, again.

Parents may be physically, emotionally,



**DOUBLE DUTY:** Parents of children with disabilities love their children and want the best for them. They understand that there are challenges in raising all children, but the reality is that parents of children with disabilities face both those challenges and the reality of the additional responsibilities that come from raising children with special needs.

### **RESPIRE & OTHER STRESS RELIEVERS FOR FAMILY CAREGIVERS**

Parents need to take care of themselves so they can take care of their child. Sometimes families may be able to involve their child, which is always best if possible, such as going on walks or doing yoga together. Even if the child doesn't participate, there may be a way for a parent to try to do healthy things while supervising their child. For example, the child could read or play a videogame while the parent does an exercise video in the same room.

Parents may just need some downtime, rather than "doing something." Sometimes families can read, do puzzles, etc. alone or together while their child is engaged in another independent activity. Or sometimes reading to the child, or just being in the same room reading together, is calming. Music or meditation can also be helpful. Even having a "quiet corner" that the parent uses to regroup with candles, aromatherapy, etc., could give the parent the relaxation that s/he needs. If both parents are present, one parent can watch the child while the other takes a mini-break, even if it's just for five minutes.

Ultimately, parents of children with disabilities may just need to get away for a bit. Parents have to feel comfortable with the person who will be with their child, so it may be a gradual process. Families may want to stay home the first time, and then increase the time away. Even a few hours a month is beneficial. In some states, children with developmental disabilities or other conditions,

receive respite services. The source of respite will differ from state to state. Many times, the Title V (Maternal/Child Health) Program can give families leads on how to find care. Family Voices/Family-to-Family Health Information Centers and Parent-to-Parent programs can also give parents helpful resources. There is also a national respite locator for families (see Resources.)

There are many ways that parents can de-stress, for either a short time period or hours. Parents of children with special needs can talk to other families, take care of their physical/mental health, or just get away for a bit and come back refreshed.

### **WHEN A FAMILY CAREGIVER IS "OUT OF COMMISSION"**

Parents may worry who would take care of their child if something happens to them temporarily. Family caregivers need to have a backup plan in case anything changes with the primary caregiver of the child with special needs. There are ways to get backup plans in place and people who can help families do that (see Resources.)

### **HELP FOR FAMILY CAREGIVERS AFTER THEIR CHILD IS HOSPITALIZED**

**Medications:** Parents should have the information they need to care for their child at home after hospitalization. Even during hospitalization, families can ask what prescriptions their child is getting instead of waiting until they get the list to go home. Find out

if medications cause side effects. Also, if the child has other issues, such as high blood pressure, thyroid disease, diabetes, cardiac problems, cholesterol, etc. parents can ask if new medications will affect other conditions. Families can also check if new medications will interact with current meds and give them at different times. A great resource is the PDR (Physician's Desk Reference [www.pdr.net](http://www.pdr.net)) listing medications and side effects. A tool for families, which includes medication, uses and a checklist for a pill organizer is found at [www.mymedschedule.com](http://www.mymedschedule.com).

**Daily Routine:** Parents will need to check if their child can resume their usual routine. After hospitalization, some children may have special diets, need dressing changes, or may not be able to bathe/shower as usual. Families should be taught how to use any equipment or administer medications, including shots, before heading home.

**Complications:** Sometimes, besides obvious medication side effects, other conditions may surface. Even if a child may not have had a condition like high blood pressure, sometimes meds. can *cause* them. Parents can ask if they should check vital signs like weight, blood pressure, temperature and when to call the doctor. Families may want to check if the pediatrician or specialist have after hours contacts.

**Extra Helping Hands:** It's possible that a child could need more care once home. If so, families should contact nursing/home health agencies before discharge to make sure that the insurance covers it and that there is a schedule set up before the child is home. Parents can also set up home instruction with their school district if their child can't return to school immediately. If their child stays in the hospital for an extended period, hospital instruction should also be arranged.

**What Do Families Need?** Quite simply it depends on where they are in the process of caring for their child. If the parent is just getting a diagnosis, they need information on the condition and emotional support. For detailed information including research, databases, literature etc. the Maternal & Child Health Bureau has "Knowledge Paths" on some conditions. The American Academy of Pediatrics also has a website for families for general health information, including special needs.

**Long-term Caregiving:** Some children may need lifelong care. Strength is definitely needed. But to maintain that strength, caregivers need to take care of themselves in order to take the best care of their loved ones. Strength and self-care come from various sources:

**Physical:** Even when a child is in the hospital, families may be able to bring food to store in the family lounge and

microwave instead of going to the cafeteria. This way, they're actually spending more time with their child and eating better. Families will find that hotels and Ronald McDonald Houses have gyms because they know how important this is for parents. If staying nearby, families can walk to the hospital and use stairs instead of elevators. Parents may be able to do quiet yoga, Tai Chi, or qigong in the room while the child sleeps. If possible, it is good for the child to walk the hallways, or even go in a wheelchair rather than staying in bed.

**Mental/Intellectual:** Parents can find out as much as they can about their child's condition and treatment options so they know they're making the best decisions for her care. Many hospitals have in-room computers or family libraries. Parents can attend daily doctor's rounds to get the most up-to-date information and ask questions. It may help to keep a notebook with a medication list updated with changes and notes on unusual vital signs, test results, treatment, and what to resolve before returning home.

**Emotional/Spiritual:** This may be the most difficult area as there may be no time to process information and parents have to act like everything was fine in front of their child. It is particularly hard for single parents on their own. Professionals may not ask families how they are when they watch their child being rushed to the emergency room, transported by ambulance to another hospital, or intensive care unit, not sure if the child's going to make it. Parents may need to be reminded when they feel like they can't do anything for their child that they just need to be mom or dad, not a doctor or nurse. Hospital social workers are also available for parents.

Practically speaking, parents can make a "phone tree" where they call one family member who updates others. Parents need to keep their cellphone line open at all hours so doctors can reach them. For those who struggle spiritually, "At the Heart of the Matter: A Spiritual Journey for Caregivers" by Dr. Green is a good read.<sup>4</sup> The book gives caregivers the "opportunity to personalize his or her caregiving journey based on their individual needs." Remember that spirituality doesn't necessarily mean religion; it's whatever the personal transformation means to the individual. The book has inspirational quotes, poems, thinking points, caregiver assessments and short chapters as time is limited for caregivers. For those in the hospital, many have chapels or quiet meditation rooms for families.

### **FAMILIES CAN SEE THEIR CHILD WITH SPECIAL NEEDS IN A NEW WAY**

Family caregivers of children with disabilities can be encouraged by "reframing" how they see their child. Reframing "is a way of viewing and experiencing events, ideas, concepts and emotions to find more positive alternatives."<sup>5</sup>

**Getting a Better Understanding of the Child:** Dr. Ross Greene, the developer of Collaborative Problem Solving, says "children will do well if they can." What this means is children are doing the best they can with the skills that they have. It is important for family caregivers to realize that all behavior is communication and sometimes the only way children can communicate is by "acting out." This doesn't mean the temper tantrums seen in

**CAREGIVING/DISABILITY RESOURCES**



**CAREGIVER ACTION NETWORK-RESOURCES**  
<http://caregiveraction.org/resources>  
**CAREGIVER ACTION NETWORK - CAREGIVER TOOLBOX**  
<http://caregiveraction.org/resources/toolbox>

**INSURANCE & MEDICAL HELP**



**NATIONAL MEDICARE OFFICE**  
[www.medicare.gov](http://www.medicare.gov) or 24 hr. Hotline (800) 633-4227



**SHIP**  
(STATE HEALTH INSURANCE ASSISTANCE PROGRAM)  
**COUNSELORS FOR MEDICARE**  
[www.medicare.gov/contacts/search-results.aspx?customresult=AllSHIP](http://www.medicare.gov/contacts/search-results.aspx?customresult=AllSHIP)



Centers for Medicare & Medicaid Services  
**CENTERS FOR MEDICAID/MEDICARE**  
"Who Pays First" guide on insurance (private/Medicaid/Medicare)  
[www.medicare.gov/Publications/Pubs/pdf/02179.pdf](http://www.medicare.gov/Publications/Pubs/pdf/02179.pdf)

**MENTAL HEALTH HELP FOR CHILDREN AND FAMILIES**



**FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH**  
[www.ffcmh.org/chapters](http://www.ffcmh.org/chapters)  
or Spanish <http://translate.google.com/translate?hl=en&sl=en&tl=es&u=www.ffcmh.org>



**NATIONAL ALLIANCE ON MENTAL ILLNESS**  
<https://www.nami.org/Find-Support/Family-Members-and-Caregivers>  
or Spanish [www.nami.org/Find-Support/Diverse-Communities/Latino-Mental-Health/La-salud-mental-en-la-comunidad-latina](http://www.nami.org/Find-Support/Diverse-Communities/Latino-Mental-Health/La-salud-mental-en-la-comunidad-latina)

**FAMILY SUPPORT**



**PARENT-TO-PARENT**  
<http://www.p2pusa.org/parents/>



**PARENT CENTER HUB**  
Find your Parent Center [www.parentcenterhub.org/find-your-center](http://www.parentcenterhub.org/find-your-center)  
or Spanish [www.parentcenterhub.org/lista-espanol/](http://www.parentcenterhub.org/lista-espanol/)  
**PARENT CENTER HUB - SPECIFIC CONDITION RESOURCES**  
[www.parentcenterhub.org/topics/disability/](http://www.parentcenterhub.org/topics/disability/)



**PARENTS ANONYMOUS SUPPORT GROUPS**  
<http://parentsanonymous.org/programs/parents-anonymous-groups/network-map/>

**RESPIRE AND OTHER RESOURCES**



**TITLE V (MATERNAL/CHILD HEALTH)**  
[www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx](http://www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx)  
**MCHB KNOWLEDGE PATHS ON CONDITIONS**  
[www.ncemch.org/knowledge-base.php](http://www.ncemch.org/knowledge-base.php)



**FAMILY VOICES**  
[www.familyvoices.org/states](http://www.familyvoices.org/states)  
**FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS**  
[www.fv-ncfpp.org/f2fhic/find-a-f2f-hic](http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic)



**AMERICAN ACADEMY OF PEDIATRICS (FAMILY SITE)**  
[www.healthychildren.org](http://www.healthychildren.org)



**ARCH NATIONAL RESPITE LOCATOR**  
<http://archrespite.org/respitelocator>

**REFRAMING PERSPECTIVE**



**ROSS GREENE'S WEBSITE "Kids will do well if they can!"**  
[www.livesinthebalance.org](http://www.livesinthebalance.org)

typically developing children. This is a “meltdown” in which the child is so overwhelmed that they either lash out or shut down.

Family caregivers need to recognize if their child’s behavior is a “skills vs. a compliance” issue. Is it that the child won’t do something, or that they can’t? Maladaptive behavior may be the only thing that has worked for the child in the past. The child needs to learn appropriate replacement behaviors and skills. It doesn’t go from “zero to sixty.” If the child is overwhelmed in class, for example, the goal may not initially be to get him/her to sit still for an entire class. The child can learn to ask for breaks, or if nonverbal, use a picture card. At first, reinforce the request every time. Then work towards asking appropriately. Remember that if the child acts out and then is removed from class, he/she learns that this allows “escape/avoidance.” Even negative attention is reinforcing!

**“Just Walk a Mile in His Moccasins”:** As frustrating as it may be for parents to deal with their child’s behavior, parents should think about what the child is going through. While it’s true that some things take longer and it would be easier for parent to do rather than the child, if *anyone* had those special needs it would take them longer too. Families can think of how frustrating it would be if they couldn’t hear well and needed things repeated multiple times or used alternative methods of communication. Or how hard it would be if they had poor muscle tone, just to put on a pair of socks. Parents can think how it would feel to walk into a store if all the lights seemed brighter, sounds seemed louder, smells seemed stronger and they all hit at once causing sensory overload. There is a difference between “disability awareness” and “disability sensitivity.”<sup>6</sup>

**“THERE ARE MANY WAYS FAMILY CAREGIVERS CAN HAVE MORE POSITIVE INTERACTIONS WITH THEIR CHILD WITH SPECIAL NEEDS. “CATCH THEM BEING GOOD” MEANS TO REINFORCE THE CHILD WHEN HE/SHE IS DOING SOMETHING PARENTS WANT TO BE REPEATED. ”**

**Then Reimagine:** Just like taking a picture and placing it in a new frame, parents can reframe their child’s special needs. This is especially true for children with mental health issues. Just like physical conditions, mental illness is physiologically based. The organ affected just happens to be the brain in which symptoms manifest as behavior. No one would blame someone with diabetes who needed insulin.

There are also positive ways to describe characteristics for all children. Some examples are...

Instead of:	vs.	Reframing:
Disabled		Differently abled
Fearful		Cautious
Hyperactive		Full of energy
Stubborn		Determined
Learning Disabilities		Learning Differences
Persistent		Committed
Loud		Exuberant

There are many ways family caregivers can have more positive interactions with their child with special needs. “Catch them being good” means to reinforce the child when he/she is doing something parents want to be repeated. Rather than telling the child “don’t” do something, families can tell the child what they do want them to do. For example, instead of saying “don’t throw your clothes on the floor” say “please put your clothes in the hamper.” Although it may be more polite to ask, rather than tell a child to do something, some children interpret things literally and if parents ask if the child can do something they may simply reply no. They’re not being defiant; the child is simply expressing a preference as he/she thought it was a choice.

By reframing how they see their child through a more positive lens, family caregivers can better help their child with special needs.

## FINALLY, GRATITUDE

Family caregivers may have a variety of reasons to be grateful. Perhaps doctors have literally saved their child’s life on multiple occasions. Families need to have backup plans.

Maybe there are local hospitals that can stabilize the child, but not admit, before transporting to a children’s hospital. Families can also check with current doctors to make sure they can consult with whichever local hospital. Pediatricians may also offer to facilitate a discussion between the local hospital specialists as the primary care physician.

Family caregivers may also have gratitude for little things. If the child doesn’t have much energy or strength, things like just watching TV, iPad, videogames help but it’s also an opportunity to spend more time with the child. If the child isn’t up to walk around the block, parents can start small, like walk to the end of the driveway, then walk to the corner. Families can read together, do puzzles, do word searches, listen to music or play instruments. Even for special occasions, if the family can’t get out, perhaps they can make a gift wish list, shop online, and have gifts delivered home. Parents can even feel grateful that their child is home and well enough again to keep them up at night.

By taking care of themselves in all of these areas, families can truly become “resilient caregivers.” •

## ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a child with multiple disabilities. Her daughter Stephanie has five life-threatening conditions, plus autism, just to keep it interesting. Lauren serves as the Coordinator for Family Voices-NJ and as the central/southern coordinator in her state’s Family-to-Family Health Information Center (F2FHIC). New Jersey’s PTI, F2F, and Parent to Parent program are all housed at the SPAN Parent Advocacy Network (SPAN), found at [www.spanadvocacy.org](http://www.spanadvocacy.org). Family Voices/F2FHICs in other states can be found at <http://www.familyvoices.org/states>.

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- Caregiver Support Services –Dr. Eboni Green [www.caregiversupportservices.org](http://www.caregiversupportservices.org) & radio broadcasts/playback [www.blogtalkradio.com/caregiversupport](http://www.blogtalkradio.com/caregiversupport)
- [https://en.wikipedia.org/wiki/Cognitive\\_reframing](https://en.wikipedia.org/wiki/Cognitive_reframing)
- <https://www.aaanativearts.com/native-american-poetry/walk-a-mile-in-his-moccasins>