

PARENTS ARE NOT SUPER HUMAN

"...it is not the child's disability that handicaps and disintegrates families; it is the way they react to it and to each other" (Dickman & Gordon, 1985, p. 109).



JANICE FITZGERALD
EXECUTIVE DIRECTOR
PARENT TO PARENT OF NYS

Parent to Parent of NYS is a statewide organization with 13 regional offices throughout NYS
Serve approximately 9,000 people annually



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What Does John want?
The same things everyone else wants.



- Meaningful relationships
♥ to be valued
- Economic resources - enough \$
- Peace of mind - freedom from fear, abuse and ridicule
- Friends - to belong



Realities and Challenges Faced by People with Chronic Illness or Disability

- Prejudice
- Intolerance of differences
- Social isolation – less opportunities for learning
- Social exclusion
- Teasing and bullying



Challenges Faced by People with Chronic Illness or Disability

- Access to quality and appropriate education
- Budget cuts – balancing budgets on the backs of kids and elderly who need assistance
- Lack of expectations
- Sensory impairments
- Communication challenges




Uncomfortable Interacting with People with Disabilities?

- People feel sorry for people with disabilities
- Assume that they are bitter about their disabilities – people with disabilities are generally comfortable and ok with their disabling conditions
- Afraid you will say the wrong thing - What is appropriate terminology, for example, disability, impairment, or handicap? When you're working with someone, you can ask what terminology he or she prefers.

**How do families manage?
How do we keep doing the things we
need to do?**

Extraordinary Parenting Responsibilities Create
Extraordinary Pressures on Parents



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**Parents of Children with Special Needs
are called upon to act as their child's:**


- Case manager
- Nurse
- Therapist
- Advocate
- Teacher
- And be a mom or dad



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At the same time, parents often...


- Have no formal training to prepare them
- Lack quality childcare
- Have limited employment
- Feel homebound and isolated



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At the same time, parents often...

- Have little time to maintain their own health
- Have limited time for other children
- Have limited time to maintain healthy relationships



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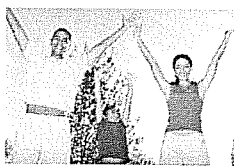
**RESILIENCE
How Can We Be
Resilient Families?**



- Opening up channels of communication
- Prioritize time together – family and also separate time as partners
- Counseling, support group
- Support Network
- Respite

Resilience

- Dynamics Within a Family
 - Child with a Disability
 - Brothers and Sisters
 - Partners



Strain on Relationship



- If a relationship is unstable, the added stress of disability or special health care needs can cause a relationship to collapse.
- If a relationship is stable and non-stressed, the disability may increase closeness and strength.

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Strain on Family



Problem: When child is diagnosed, ALL the attention is focused on helping the child.

Parents also need assistance in coping with additional stresses related to parenting a child with special needs.

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Strain on Family



Brothers and sisters may experience the same emotions that parents feel.

Brothers and sisters also have their own fears and their own emotions.

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Strain on Partners & Family



To avoid dealing with marital problems, some parents will turn most of their attention to the affected child to avoid dealing with their spouse or other children. This can make things worse by creating an unhealthy bond between the parent and child taking the focus off their relationship and placing it on the child's illness or disability (Lavin, 2001).

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Strain on Family Strength of Family



Brothers and sisters will model the actions, words and attitudes of others.

*If children live with encouragement,
They learn confidence.
If children live with tolerance,
They learn to be patient.
If children live with praise,
They learn to appreciate.
If children live with acceptance,
They learn to love.*

*Children Learn What They Live
By Dorothy Law Nolte*

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HOW CAN WE MAKE IT WORK?

RESILIENCE – FINDING WAYS TO

- Handle the added stresses in our lives
- Minimize stresses
- Overcome the stresses
- Have coping mechanisms
- Use coping mechanisms as their family's safety net



**The Message We Give Ourselves
Change Your Perceptions to Focus
on the Positive.**



- Focusing on the positive makes you feel better about yourself, more in control of your life, and provides greater meaning to your life.
- Viewing events as challenges rather than threats reduces stress.

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**Challenge Beliefs That Lead To Internal Stress
Challenge the Messages You Tell Yourself**



- *"The success or failure of my children depends entirely on me."*
- *"Other people must see me as a good parent, able to handle everything."*
- *"It's selfish of me to spend time and energy on myself."*
- *"I can't really change my life; I just am who I am."*

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**Catch Yourself Making Negative
Statements and Challenge Them**



Pay attention to your self-talk

- Stop putting yourself down for mistakes and imperfections that are just part of being human.
- You're adding additional stress in what you're telling yourself.
- Talk positively to yourself. Tell yourself "Good job" or "You handled that tough situation well."

"The trouble with most people is that they have no invisible means of support."

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RESILIENCE



COMMUNICATION

- Successful relationships = communication
- Avoid assumptions
- Share emotions
- Share information with partner
- Share information with children when possible

**Be Assertive
Stand Up for Your Decisions!**

Assertiveness simply means expressing your feelings and letting others know your beliefs and opinions.



To become more assertive:

- Speak up.
- Disagree with others when you believe differently.
- Say no to unreasonable demands.
- Learn about your child's needs so you can be an active participant in meetings, etc.

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**External Stressors Often Involve
Relationships With Others**

Keys to managing external stressors.

- Strong communication
- Problem solving
- Organization skills




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Problem Solving & Strategies for Coping with External Stress


5 Steps to Help Sort Out Problems

1. Describe the problem with a specific statement.
2. State how it could be better.
3. Determine what is keeping it from getting better.
4. Propose solutions for the things over which you have control.
5. Plan action with specific, achievable goals.



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Recognize What You Can and Cannot Control



The only real control you have is the choice of your own thoughts, your own words, and your own actions.

“You can’t push a wave onto the shore any faster than the ocean brings it in.”

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Be Assertive

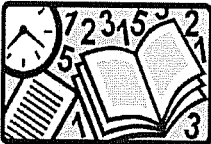
Stand Up for Your Decisions!

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Time Management

“So much to do, so little time.”




- Define your limits, it is ok to say no
- Simplify your life
- Develop routines
- Set short-term goals and prioritize them
- Delegate
- Become an expert organizer
- Live by lists

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Strategies for Coping with Physiological Stress

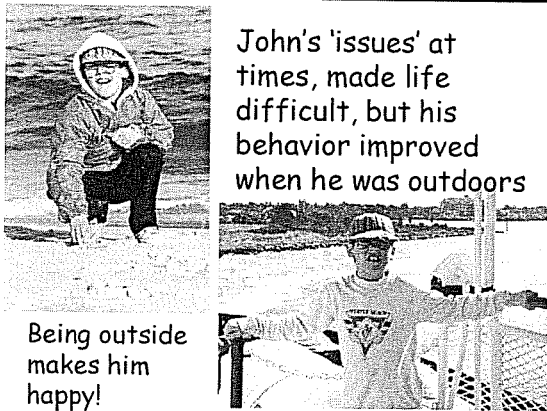
- Get physical.
- Get rest.
- Have a good laugh.
- Play.
- Give yourself permission to take time off.
- Relax – deep breathing, guided imagery, meditation.



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How do we make life work for everyone in our family? Play!







John's 'issues' at times, made life difficult, but his behavior improved when he was outdoors


Being outside makes him happy!

All parents share one thing in common: they all want what is best for their child.

- The best teachers
- The best therapists
- The best doctors
- The best support staff




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How often do we stop to consider if our child deserves a parent who is at their best?

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When we are able to effectively manage stress in our lives, then we have something to give to our important role of parenting.

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The better we are emotionally, physically, and spiritually, the better our family will be.

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By C. Amber Havens
National Center on Accessibility

"...it is not the child's disability that handicaps and disintegrates families; it is the way they react to it and to each other" (Dickman & Gordon, 1985, p. 109).

Today's parents face a world of challenges with everything from keeping themselves healthy and happy to providing their children a safe environment that fosters the physical, emotional and social growth of their children in today's society. Sometimes the everyday demands of life seem too great to overcome and families will experience stress and/or crisis as they try to survive. Often families will fall apart or choose to split up the family unit in response to money struggles, addictions, abuse, health, or just plain unhappiness. It is no surprise then to learn that having a child with a disability can also drive families apart or into a state of chronic stress or crisis. This does not have to be the case. This article addresses not only how having a child with a disability can impact the family system, but also how families can use their circumstances to become a more resilient and healthy family.

CHILD DISABILITY

According to Dr. Robert Naseef (1997) one of every ten children is born with a disability. An individual is considered to have a disability if they have a physical or mental impairment that substantially limits one or more major life activities such as: seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working (U.S. Department of Justice, 1992).

In addition to the stress of the disability itself, financial strain due to medical bills or quality care, lack of control, egos, attitudes, isolation, anger, embarrassment, grief, and protectiveness all merge to bombard the family of a child with a disability. Without a safety net in the family...crisis may loom. These types of certain continuous challenges can be a reaction to the disability itself, the stress and strain the disability creates within the family unit or a family member's reaction to the child with the disability. Regardless of the type of disability, parents must learn to cope with the fact that their child will never fulfill the life they had hoped and dreamed of for them. The journey is long and many families will not make it together.

Keys to Resilient Families

- Communication
- Making time a priority
- Keeping perspective
- Building a support network
- Seeking professional assistance
- Respite
- Play!

INTERNAL DYNAMICS OF THE FAMILY SYSTEM

Marital Strain

In a marriage relationship that is unstable, the stress of dealing with a child's disability can cause the family system to collapse; on the other hand, in a relationship that is strong and relatively non-stressed, a child's disability may develop increased closeness and strength in the parent's marriage. While there is a general impression that parents who have a child with a disability are more likely to split up than parents of "normal" children, there has been limited research in this area and it is inconclusive.

Although several studies have documented stress in families of children with disability (Hodapp & Krasner, 1995; Innocenti & Kwisun, 1992; McCubbin & Huang, 1989; Singer & Farkas, 1989; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981; Wallander & Noojin, 1995; and Ziolko, 1991) and stress is often a factor in divorce, none have conclusively linked disability or chronic illness of children to parental divorce. There are different reports concerning divorce rates of parents who have children with disabilities, but most studies agree that there is a high level of marital discord in these families and that divorce or separation is more likely in families of children with more severe and impacting types of disabilities (Hodapp & Krasner, 1995).

Hodapp and Krasner (1995) found in their study that families of eighth grade students with disabilities in a large, nationwide sample had higher rates of divorce and separation as compared to families of non-disabled children. Singer and Farkas (1989) in a study of the impact of infant disability on maternal stress perceptions found that 85% of their respondents reported that despite problems the family experienced as a result of the disability, their families were closer because of their shared experience.

When people decide to have children there is typically great joy at the impending life they are bringing into the world. That elation and hope for the future can come to a crashing halt when a baby is born with a disability. For many this is too much to bear and sorrow and grief begin as the realization of lost hopes and dreams sets in. Often parents of newborns with severe disabilities are advised to institutionalize their baby or risk destroying their marriage (Dickman & Gordon, 1985). The parents of older children who acquire a disability or become chronically ill also deal with grief and sorrow of lost hopes and dreams. Parents will often feel a deep sense of guilt as if they have caused the disability or disease and will begin the long process of coming to terms with not only their child's disability but with their personal emotions and those of other family members such as siblings, grandparents, aunts, and uncles.

A family who has a child with a disability will experience many challenges such as "repeated physical and emotional crises, interactive family issues, ruined schedules, and additional expenses which can create financial burdens for a family," (Lavin, 2001, p. 21). It may be during these times of physical and emotional stress that parents will take out their frustrations on each other, the other children or even the child with the disability or illness. This can lead to marital problems as well as issues of sibling rivalry, parentification, and even child abuse.

Sibling Strain

Siblings may share the same emotions that parents feel (i.e. grief, anger, and guilt) and some of these arise from fear and misunderstanding (Batshaw, 1991). Siblings may be afraid that they can "catch" the disability or that they even caused their sibling's disability by wishing mom was not going to have a new baby or that it would just go away (Batshaw, 1991). Siblings may also feel jealous and left out as the child with the disability will require more attention to attend to everyday needs (Pearson & Sternberg, 1986). Other parents and sometimes siblings may be embarrassed about having a child or sibling with a disability; they may lash out at the child with the disability or illness in harmful abusive ways for disrupting their families and adding stress to the family situation.

To avoid dealing with marital problems, some parents will turn most of their attention to the affected child to avoid dealing with their spouse or other children. This can make things worse by creating an unhealthy bond between the parent and child taking the focus off their relationship and placing it on the child's illness or disability (Lavin, 2001).

FAMILY RESILIENCE

Irving Dickman and Dr. Sol Gordon (1985, p. 109) share in their book *One Miracle at a Time*, that "it is not the child's disability that handicaps and disintegrates families; it is the way they react to it and to each other." Finding a way to deal with the added stresses, minimize them, overcome them – by sharing them – can glue a marriage (and a family) together more firmly than ever." Dickman and Gordon (1985) also share that all families need to have a coping mechanism and those families who utilize these as their safety net are more likely to survive as an intact family unit.

"By taking care of each other and your relationship you are not only working toward the future you really want, you are giving your children the benefit of a stable, loving home to grow up in. Build on what you already have. Know that seeking the support of professionals and other parents who have lived through what you are experiencing is a sign of strength, not weakness. However, if your family unit separates, you can each still go on to

build full and productive lives” (Albrecht, 1995, p. 24). This is the key to becoming a special family; providing the children with a stable family system.

According to Winslow, Wolchik, and Sander (2004) most children will adapt well to the transition of divorce, but nearly 20% to 25% will develop mental health or adjustment problems later in life. For the child who has a disability and already struggles with self-esteem and identity issues (Lavin, 2001) not to mention the daily challenges of their disability, this transition may overload them. This makes it critical for families of children with disability to pull together. So what can families of a child with a disability do to thrive in a situation of chronic stress?

Walsh (1998) and Boss (2002) both suggest that strategies for facilitating resilience in families experiencing chronic stress situations include opening up channels of communication, seeking professional help (counseling or support groups), making time for each other (spouse and other children) a priority, keeping perspective, developing a support network, and embracing respite. While this list is pretty comprehensive, there is something else that families can do to be resilient...Families can play

Communication

One of the most important aspects of any human relationship is communication. Communication is the giving and receiving of information for understanding between two or more people. If parents are trying to hang on to their marriage, this is key to coping as a couple. They should share their feelings with one another, so that the other partner does not have to make assumptions or guess as to what the other is feeling. Holding in emotions, thoughts and feelings will protect no one and will more likely make both partners feel isolated when they are already hurting (Albrecht, 1995).

Communication is also the sharing of information. You should share the child's disability, illness, diagnosis, doctor's report, and other important information with family members. This is important for all family members who are involved in the child with the disability's life to be on the same page as how to best meet and understand the needs of the child.

Since siblings may feel jealous, embarrassed and naturally left out due to the extent of attention given to the child with the disability or chronic illness, it is important to educate siblings and other family members so that they may increase their understanding and acceptance of the sibling with the disability or illness. Although educating family members can seem like a challenging task it can be a fast, easy, and painless process. It is important to note that education should be an ongoing process; as a child naturally grows and changes, so might their disability or illness.

In the beginning, many family members may be overwhelmed by the diagnosis and need to hear it directly from the family doctor. Many physicians are open to meeting with families and addressing any questions members might have about the child's disability or illness. If the parents are not comfortable in taking their entire family along to the next doctor's appointment, they might request family members to write down all the questions they have, and once the parents have the answers they can call a family meeting and share the new information with all interested.

Parents can also encourage family members to educate themselves through reading materials. For many parents, this might be readings suggested by their physician. The local library is always a great place to start for readings related to disability and family. When sharing new readings with family members, make sure that it is age-appropriate material. There are many children's books that relate the specifics of disability in a way that is understandable and non-frightening to children. This may be key in helping siblings grasp what they are dealing with.

Seek Professional Help

Counseling for individuals or groups may be beneficial to the family unit regardless of marital status. Counseling can offer comfort in knowing that the emotions, attitudes and feelings of the family members are all "normal" to have (Dickman & Gordon, 1985). Counseling can offer family members the opportunity to redirect their emotions into something positive for the family unit and the best interest of the children.

Individual and group counseling can take place with psychiatrists, psychologists, or within a support group of people who have similar experiences. Parents may need assistance deciding what level of support they need from counseling. Doctors, nurses, school officials, other helping professionals, and friends are all good resources to determine where support can be found that has potential to meet the needs of a particular family.

Support groups can be beneficial to the husband-wife team as they meet with other husband-wife groups who have lived their current experience and can provide valuable insights or just listen to what a couple is dealing with. Support groups can also be a valuable tool for the single parent or the sibling who needs someone to listen to them and give them emotional support as they deal with their families situations. Listings of support groups can often be found in healthcare settings (i.e. doctor's office, hospital, clinic, and counseling facilities), schools, churches, bookstores, and the internet.

Making Time a Priority

For parents of a child with a disability, time is a rare gift. Making time for each other, as man and wife not just mom and dad, should be a priority in parenting a child with a disability and key for keeping the marriage intact and healthy. It does not have to be anything fancy, but always make time for each other. Go for a walk in the park, hole up in the bedroom for a few hours, visit a library, go to a movie, etc...just spend time together. Parents should think about what they really need to take care of their relationship and plan ahead to make it happen (Albrecht, 1995).

Making time for the other children should be a priority also. Siblings need to know that they are special, valuable, loved and don't always come second. Encourage them to embrace their childhood, thank them for all the help they give around the house, and acknowledge their feelings (Albrecht, 1995; Dickman & Gordon, 1985; and Lavin, 2001).

Keep Perspective

As a parent of a child with a disability or chronic illness, the emotions experienced are likely to be the strongest they will ever have and these feelings may be confusing (Albrecht, 1995) as they juggle feelings of anger, grief, protectiveness, and love all jumbled together. If the strain of crumbling relationships is added into this already challenging mix it may be too much stress for individual family members to handle causing the family system to collapse. It is important to recognize personal feelings and emotions, try to find a balance, and remember it can always be worse.

Develop a Support Network

As parents of a child with a disability the most valuable resource available is the family's support network (Dickman & Gordon, 1985; Walsh, 1998). Family members, medical and helping professionals, friends, support groups, trained baby-sitters, etc... In trying times the social network can step in when parents, siblings, or caregivers need a break or help fill in the gaps of the family to meet the needs of other family members.

Embrace Respite

Respite is time away from the disability and or stress of family, where individual or group family members can focus on themselves or other family members who are affected by the child's disability. Respite may also be

needed by the child with the disability or the siblings, time away from the family who is so focused on providing for all the "special" needs that they overlook the child's need for time away from focusing on their disability (Naseef, 1997). There are two types of respite experiences: 1.) formal respite experiences through state programs or camp environments; or 2.) non-formal respite utilizing the support network.

Formal respite :

Formal respite is created through using organized programs such as state programs, camps, and special recreation programs. Today, many states offer waivers for respite care. This varies from state to state and is tied up with Medicaid programs. Basically, this program pays a qualified and trained caregiver to look after the person with the disability, giving all parties needed time away from each other. Many organized camping programs offer specialized respite weekends where the child with a disability can go to camp for the weekend. The American Camp Association (www.aca.com) is a resource for accredited camps in the United States . Specialized recreation programs can be found by contacting the local Recreation and Parks Department or special services agencies. The National Respite Locator service (www.respitelocator.org/index.htm) is also a great online resource for finding respite programs.

Non-formal respite :

Non-formal respite is created through utilizing the support network. This can be having a family member stay with the children while the parents take a vacation, shopping trip, etc... Be creative.

Play

Through recreation and leisure experiences families have opportunities to experience self-actualization, creatively express themselves, build family unity, be healthier, build esteem of the individual members and of the collective family, reduce stress, conquer boredom, and socialize with each other while extending their social network by making new friends outside of the family (New York State Recreation & Park Society, 2004).

Leisure, recreation and play should be an important component of any child's life, this should be no different for the child with a disability. Children learn important life skills through play. Parents teach children important lessons in recreation and leisure times.

For the family of a child with a disability, some may think that due to the nature of the child's disability that their child cannot or should not participate in leisure activities for fear of them getting hurt physically or emotionally. For other families, parents may not know how or where to get their child involved in these types of activities. The healthy family knows that "those who play together stay together".

Families in need of assistance in planning or partaking of recreation activities can often find great resources through community institutions such as the local Recreation and Parks Departments, day care centers, human service agencies and even their personal physicians. Other recreation resources can be found at the National Center on Accessibility (www.ncaonline.org), the National Center on Physical Activity and Disability (www.ncpad.org), and other online resources such as Family Village (www.familyvillage.wisc.edu/Leisure/information.html) and Disability and Business Technical Assistance Centers (www.adata.org/centers.htm).

In conclusion, having a child with a disability is not a catastrophe for a family system and does not have to be devastating for the parents, siblings or child with a disability. With the right mindset, support system, and a little fun the family of a child with a disability can learn ways to deal with and overcome chronic stress in order to not only survive but thrive.

About this Monograph

These materials were developed by the National Center on Accessibility for the National Center on Physical Activity and Disability under sponsorship of the Centers for Disease Control and Prevention.

About the Author

C. Amber Havens is a doctoral student at Indiana University specializing in leisure behavior. She received her undergraduate degree in therapeutic recreation from Arkansas Tech University and her graduate degree from Indiana University .

Recommended Reading for Adult Family Members:

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John Wiley & Sons, Inc.

- Batshaw, M.L. (1991). *Your child has a disability: A complete sourcebook of daily and medical care*. Boston , MA : Little, Brown and Company.

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Caregiving: A Personal Story

By Janice Fitzgerald

Parents, spouses and other caregivers of individuals with illnesses and disabilities do not have special gifts. We are very average people who tap into our superhuman strengths that everyone has, but don't always need to draw on.

27 years ago this Fall my life changed forever. My son, John, who was six-months old at the time, became very ill. He was admitted to the medical center in Burlington, VT and diagnosed with Infantile Spasms, a rare and violent seizure disorder. It is also referred to as West Syndrome. We left Burlington on Christmas Eve in 1985 not knowing if he would survive, and if he did live through this period, there was no prognosis of what his future would hold. He did survive, the seizures did stop, but his mental development was delayed.

When John was a youngster, his behaviors were a challenge to be around. Regularly, his outbursts sent me, my husband and our other two sons running for cover. Between 1 and 5, he had an attention span of less than 10 seconds; he required constant and intensive monitoring. We live in a rural wooded area and John would wander off into the woods with no concept of danger. He would wake up during the night, climb out of his crib and wander in our house. He would climb to the top of a playground slide, out of my quick reach and grab a handful of hair from another child's head. It was impossible to leave him unsupervised for a second.

Through all of this, we were also trying to be good parents to our other two sons. For several years we were a house divided – one parent staying home with John, and one parent going to school functions, scouts, parties or picnics.

We never gave up and John did progress. He started to talk when he was 5 and eventually he learned that there were consequences to his behavior and there were privileges to be earned when that behavior was kept in line. He learned to ride a bike and to downhill ski at 8.

When John was young his assaultive behaviors were disruptive. As he got older, we could no longer "wrap him up" or pick him up and get him to his room. Butting the back of his head into my face sent me reeling. When he was 8 1/2, we were connected to a physician who was able to prescribe medication that worked for John. Once his behavior was under control, he was able to learn and be more involved in activities. Gradually he learned accountability for his actions. He learned and

understood that as he got older, he could be arrested for being violent.

Today, John is a responsible 27 year old citizen who works hard and continues to learn and mature. He is an assistant Scout Master, an Eagle Boy Scout and works full time as a dishwasher in a dining hall at a local private college. He has his driving license and drives to work. He is a responsible, cautious driver.

Twenty years ago, I would not have been able to write about all of this. It took a long time to reconcile myself with the fact that one of our children had special needs. There was bitterness and anger about missing many of the things my other children were a part of. There was the guilt of not being able to share an equal amount of time with our other sons. There was exhaustion, lots of exhaustion. There were times when we did not have childcare; the doors of day care providers' homes don't open so easily for children with behavior challenges. When there was no childcare, I could not maintain a job, and therefore we went into debt.

We experienced long periods without a break in the care giving.

There were times that I wanted to give up and walk out of my house and never look back. I didn't walk out, I couldn't. When I think of those times now, I know they are the times that my inner strength had another growth spurt.

We had things to adjust to through the years. The acceptance of that first illness, and then the acceptance of the ongoing extra care that lasted beyond the terrible two's of a baby. Acceptance has come to us, but it took time and a lot of compromise and working together.

Caregiver burnout can happen at any age. It is often seen when a spouse becomes ill, when caring for an elderly spouse or parent, or, as in our case, when we faced exceptional parenting challenges of a young child.

Take a few seconds to think about what it would be like for you if suddenly you were so physically ill or injured that you could not take care of yourself. Think about the people you know. Who are your friends, your relatives, your spouse and your children? Think very seriously about who you would want to have taking care of you? Who is it that you would want to depend on? Think about

the qualities of the person you would need to depend on.

Next, think about the possibility that the person caring for you has moved into your house with you. They've given up their job and their friends. They do this out of LOVE, *the ultimate love of another person*.

Now, let's say your illness or recovery time takes 10 times longer than anyone predicted. Or, you learn that you are never going to fully recover. And for the entire time, the same kind, compassionate person has been your caregiver. Doing your laundry, helping you bathe, cooking your meals, and taking you to doctor appointments, helping you go to the bathroom.

Two years have passed and this wonderful person has not had a vacation. In fact, they haven't even been away from you for a day in two years. They have not met up with their own friends for even a few minutes because they worry that you will not be ok. They worry that no one else can understand what you need. This may sound wonderful to have someone so totally committed to you, but guess what? It can't go on forever. Burnout inevitably comes along. It will manifest itself as depression, constant fatigue, or a declining interest in pursuing any outside activities. It might be withdrawal from social contacts, or maybe an increase in the use of stimulants or alcohol. Those are some of the symptoms.

And along with those symptoms the quality of care will diminish. Impatience, anger and abuse can happen in extreme cases.

Caregivers won't see or admit these symptoms in themselves. If you are a caregiver, think long and hard about what other people are telling you. Think about the possibility of burnout. If enough people start saying the same thing to you, it's probably true. "Take a break, get out of the house..." Two difficult things to do are to admit that you do need a break and to reach out for the help.

For your own mental health, develop a network of friends and colleagues and attend a support group. I found it very difficult to reach out.

I used to think it was a weakness to not be able to handle all that I was dealing with. A caregiver support group has benefits. Even a group that does not match the diagnosis or care you are giving will be a help. Talking to other people who understand what you are experiencing can be a tremendous relief. They can also assist you in tapping into resources that you didn't know were around... a good doctor, a source of respite help.

Somehow, some way, get a break – respite is what we call it. Guilt free time out is essential. We do not have to be all things to all people. We may be essential and irreplaceable to the person we love and care for so dearly, but.... they will survive some time without our help. It is ok to let someone else give his or her best care so that we can take some time for ourselves.

We need time to regroup, to rest, to come back somewhat refreshed. We cannot continue with superhuman powers forever. It is important to understand that it is ok to take a break. It is necessary to get a break in order to keep yourself physically and emotionally healthy.

If we become sick or have a medical emergency, who will provide the care we've been giving? Who will take our place? Ask any caregiver who has been at it for any length of time and they will tell you that their own health has suffered when the focus was on another person and they neglected to take care of themselves.

Remember that guilt is a self-made emotion. We do it to ourselves. We internalize our actions and reactions. Guilt is wasted energy and it is energy that we desperately need to conserve.

It would be nice if there was some magical way to avoid illness, to avoid dementia, to avoid disabilities, but that's not going to happen, and denial isn't going to work for very long when faced with a challenging situation.

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