

Caregivers Do Not Have Special Gifts and Talents

By Janice Fitzgerald, Executive Director, Parent to Parent of New York State

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.

Eighteen 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. 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 assaultive 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.

Today, John is a responsible 18 year old citizen who works hard and continues to learn and mature. He is an Eagle Boy Scout and had a part-time job this past summer.

Ten years ago, I would not have been able to write about all of this. My emotions were so jumbled and I was a bundle of nerves. It took a long time to come to grips with and accept 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 because I stayed home with John. There was the guilt of not being able to share an equal amount of time with my other boys. 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 special needs. 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. All of the 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.

We will be changed forever and we will make an amazing difference in another person's life when we can draw on our inner strengths, and combine it with good care for ourselves and the person we love.

To all of the parents who are caregivers, we commend you for your dedication and hard work. Remember that our Parent to Parent staff are here to offer a listening ear and to help you find resources (www.parenttoparentnys.org).

Additionally, below are links to a few caregiver websites that offer support and may be of help to you.

www.nfcacares.org/

www.aoa.gov/prof/aoaprof/caregiver/caregiver.asp

www.caregiving.org/

www.caregiver.com

www.cyfernet.org/hottopic/famcaregivers.html

©2004 Parent to Parent of New York State. Permission is granted to copy and distribute this article as it is here without alteration. For permission to reprint, all or in part, please contact Janice Fitzgerald, Executive Director, Parent to Parent of New York State, PO Box 1296, Tupper Lake, NY 12986; (518) 359-3006; Email: Parent2par@aol.com

Parent to Parent of New York State is a nonprofit organization that connects and supports families of individuals with special needs. For more information, please visit our website at www.parenttoparentnys.org or call 1-800-305-8817.