

## **How to survive in a Special Needs family**

### **Overview**

How many of you remember the show “Leave it to Beaver” or the “Brady Bunch”? In each of these and others, the Dad is shown working hard, raking the leaves. Mom is in the kitchen making the perfect meal. While there might be some little snags in life, everything gets worked out and it seems warm and complete.

This we know is not reality – even for families without special needs. However, many of us still seek this ideal and compare our marriages and family functioning against this false reality.

I’d like to talk with you about what “the reality” is in terms of the family, marriage, sibling relationships, and the impact to one’s self. Although I’m thinking about families with “special needs,” in particular, many of the suggestions and issues exist in families without family members with special needs.

Before we begin, it’s important to let you know how I am defining “special needs.” In my definition, I am incorporating those families that have members with a learning disability, mental illness or physical disability. By design, I’m intending this definition to be very broad and takes in an estimated 35 million adult Americans afflicted by severe brain disorders, as reported by the National Institute of Mental Health.

### ***When will things feel normal? – Impact on the family***

All families have normative and transitional life event stressors such as birth, adoption, graduations, weddings and moving. Parents generally take pride in their children’s accomplishments and can be hurt when they do not succeed. A family with a special needs member has the “usual” stressors that all parents have. But in addition to helping a child develop and grow, they have to act as:

- Mediator
- Advocate
- Referee
- Negotiator

This is very difficult and parents frequently become exhausted. What happens in the family affects each child, and what happens to each child affects the family. Just as in a mobile, if one piece of the mobile changes, is disturbed, or removed, the family has to

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find a new “homeostasis.” This requires change, which a lot of people have difficulty dealing with alone.

Children with special needs can provoke forbidden feelings that are too painful and shocking to talk about:

- Wanting to abandon one’s own flesh and blood,
- Hoping they will die,
- Wishing they had never been born,
- Repulsion, and
- Even hatred.

In adoption, parents may think about “giving the child back.” If the child was created through IVF, donor sperm or donor eggs, the parents’ feelings may be guilt, anger and self-hatred for “pushing the limits” of technology.

Other feelings that are common are:

- **Anger:** Anger at God, your partner, society, schools, professionals. The question asked is “Why us?” A counter question to ask yourself is “Why not us?”
- **Guilt:** About previous health issues (STD’s), abortions, waiting a long time to have children, what you did during the pregnancy (or didn’t do).
- **Embarrassment:** By the behavior of the special needs member.
- **Loneliness:** As the time increases to advocate for the member, energy is depleted and one’s social circle gets smaller. Family events may be difficult to endure because of insensitive relatives or the stress involved in managing the situation. Many feel like they are the only one going through the stress.
- **Envy:** Of those “normal” families, other parents, or those who just seem to be handling it better.
- **Confusion:** We do not understand the illness, behavior or how “it happened.”
- **Sadness and joy:** Tears reflect your feelings of disappointment, fear and anger.

In response to their thoughts, families may bend over backwards to prove they care; this obsessive dedication to the disabled neutralizes the desire to neglect or destroy them.

Parents who embrace care-taking with a vengeance typically expect their unimpaired child (especially daughters) to do the same. This might be in the form of baby-sitting, physically attending to the other children in the family, at the expense of their own social lives. They have responsibility but no authority. Helping the mentally or physically handicapped is always presented as a family project – to participate with less than 100% enthusiasm is unthinkable.

All children care about what their parents think of them. If their perception is that they are a disappointment to their parents, these children may give up all hope. They may feel that they may never be able to meet their father’s and/ or mother’s expectations, whose

criteria of success are well beyond them. This may manifest itself by the child trying to punish or embarrass the parents whose standards are too high.

### ***Tips for the family***

1. Confronting and learning to tolerate hostility makes authentic compassion for oneself as well as for the ill person possible. Naming and accepting the banished emotions takes away their power. Accepting hatred leaves room for love. This means that talking about the forbidden feelings has to take place; otherwise those forbidden feeling just gain power. This can be done through family meetings and/or therapy.
2. Education is one of the most important interventions for the family. Each parent, grandparent and sibling needs to understand the difficulties and behavior of their brothers or sisters. Information puts fears into perspective.
3. Support groups: SEPTA, CACLD, CHAD, ACOA, Al-anon all will provide support and understanding. You will find that you are not alone.
4. Gain acceptance. This is the hand you have been dealt. You and your family may not like the situation, feel like you deserve it, but the reality is you have a special needs child. Some people ask, "Why me?" You might change your thinking to "Why not me?"
5. Identify your internal stressors, which are each person's attitudes, perceptions, assumptions and expectations. Have each member gain realistic expectations of the family, parents and special needs member.
6. Identify your external stressors: Those friends, neighbors and relatives who don't understand your situation. Sometimes we have to create a family of choice, versus the one we are related to. Some members may just be too toxic to be with.
7. Focus on what is going right, for each member of the family. Sometimes we lose sight of what is going on right in our lives.
8. Develop financial plans for future care, if applicable.

### ***Impact on the marriage***

No one in the family is exempt from the chronic crisis that an ill child creates. The personality and history of both you and your partner will determine how you each deal with the trauma. Challenging children can hold together a bad marriage and they also destroy many good ones.

The demands may include recognizing the problem, seeking help, dealing with the diagnosis, communication with the school and coordinating with service providers. Very often, one parent remains in denial about the situation while the other is forced to fight their partner, as well as the school system. It is imperative that parents act as a team.

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Depending on each partner's vision of what their child would do professionally or socially (their expectations for the child as the mother and father), the response to the diagnosis may pull couples together, or plunge them into mourning and they feel like a dark cloud is over them. When we have children, we all begin to have dreams of what they will be like when they grow up. The disappointment and grief we feel when this vision is shattered is permanent, and will be revived whenever you witness the rituals and achievements of ordinary life – graduations, weddings, birth of grandchildren, professional successes. Expect to go through the grief cycle each time one of these events take place. Some describe this has a “hole in my heart” that will never be completely healed.

To cope with the stress, fathers may bury themselves in work, to bury their own sense of failure and disappointment. Mothers may become over-involved with the difficult child. Either parent may demand perfection and obedience from the “normal” children.

Be aware that it might be difficult for fathers to acknowledge their child has a problem because many children have two behavior patterns- one for the person who is with them all day, (usually the mother), and another for the father who may see them for much shorter periods of time.

Parents may envy the “healthy” children because they will some day leave or “escape.”

Be aware of common coping mechanisms to exit relationships:

- ⇒ affairs,
- ⇒ alcohol and drugs,
- ⇒ over/under eating,
- ⇒ workaholism, or
- ⇒ sports.

Researcher John Gottman found that certain interactional patterns can predict divorce.

The two main ones were:

1. Verbal expression of contempt of the wife. This can be in the form of sarcasm.
2. The husband's defensiveness exhibited by “stonewalling” which is a form of withdrawal. The wife may pursue in anger. It may be the husband's way of indicating that he can not take in any new information. Gottman found that when this occurs, physiologically the man's heart rate increased dramatically.

Gottman recommends that couples:

1. Use Cognitive Behavioral Therapy to replace negative self talk and phrases with positive ones.
2. Learn non-defensive listening.
3. Validate each other

### ***Tips for couples***

1. Share in the education of the issue. Some partners deal best by watching videos versus reading books or going to meetings.
2. Allocate at least 15 minutes each night - with the TV and phone off - to talk about the day's events.
3. Share responsibility for decision-making and child management. Realize that what you model sets the tone for family functioning. This includes trying to schedule team meetings when both parents can attend.
4. Agree on a consistent approach to address expectations, discipline, homework and after school activities.
5. Create a jar with slips of paper with things each one of you would like i.e. a hug, smile, flowers, back rub. Each day pick one thing out and deliver by the end of the next day.
6. Use respite services to take a break.
7. Practice "Sensate Focus" to bring back the sexual feelings you once had for each other.
8. Consider couples therapy to talk about the myriad of feelings you may be having. You can also use this time to talk about each partner's family history to understand if anyone else had the problem in the family, and if so, how was it handled?
9. Set up caring days:

### ***Caring days***

- ⇒ Hit my care button: the things you do now that hit my care button that make me feel loved and cared about are: \_\_\_\_\_ (Don't assume your partner can read your mind).
- ⇒ You don't send me flowers anymore – or give me hugs/kisses when I come home from work. The things you used to do that "hit my care button" and made me feel loved and cared about are:
- ⇒ Go ahead make my day: things I always wanted to ask you to do that would make me feel cared for and loved but I'm afraid to ask because I fear looking needy, extravagant, selfish...).

### ***Impact on siblings***

Siblings have two life tasks (Safer) when living with a special needs member: to recognize the impact a damaged sibling has on them, and to forge an identity in which that sibling is peripheral. The sibling relationship is the child's first social network and can be the basis for his or her interaction with people outside the family. Their siblings

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are playmates first, and then take on new roles as they mature such as teacher, friend, companion, protector, competition, confidant, or role model.

The sibling of the special needs child also wants the child to be normal and might be in denial and not accept him for who he is. The sibling may challenge you that the special needs child is spoiled and gets away with too many things.

Older siblings may want to parent the special needs child. This makes the hierarchy unbalanced and does not allow the sibling sub-system to grow and strengthen.

Siblings usually compare themselves to each other. The child with the special needs who struggles in school and has a sibling who is high achieving may release his frustration through hostility, revenge and distaste.

Dr. Jeanne Safer coined the term the “Caliban Syndrome” to describe the “abnormal; sibling in the normal one’s life and an image in the normal one’s psyche.” She further describes the impact of being “the normal one” in a family where the brother Caliban is “damaged.” This comes from Shakespeare’s “The Tempest.” No one in the family is exempt from the consequences of being related to Caliban – the father is disillusioned and puts down Caliban for his illness, while the daughter is idealized and is the bearer of his destiny. As children do, Caliban lives out the role his family assigns to him; when one child is preferred over another- either because of illness or being the intact child, their sibling relationship can become poisoned. Children may also become estranged from their parents because their parents failed to acknowledge or protect them from a sibling’s outbursts.

The “normal one” will also want to assure him/herself they are different than the ill child. They may do this by not having any difficulties, not making any demands, not holding grudges; being perfect and prematurely mature are the signs of the “Caliban Syndrome.” They also experience “survivor guilt

We can also look at the “function of the symptom.” In the case of Caliban his presence is essential because he permits father and daughter to maintain their idyllic, un-ambivalent bond. I frequently ask clients, what would change if your child were to get better? Many answer that they would then have to focus on their marriage or themselves. Now is the time to do this.

Siblings who return from home after being away are shocked at the intensity of the distress they endured every day – having a sibling in crisis. Some realize all their life they have had to “arrange life” around the illness.

They grieve, feel guilty, and they struggle to compensate by achieving for two. If they do not know their sibling's diagnosis, ambiguity may increase their anxiety and they may grow up with a feeling of vague depression and some nameless dread that they keep to themselves.

Feelings many siblings have are:

- **Fear** – that “it” might happen to them.
- **Jealousy** – They don't understand why parents have to spend so much time with their sibling. They may resent this time and view as if rejection.
- **Sadness** – They may wonder what is wrong with them that their parents love their sister or brother with the illness more. They may act out or become the perfect one to gain this perceived loss of love.
- **Embarrassed** – They have to explain to friends why their sibling is behaving a certain way.
- **Anger** – They find they have to spend much of their time helping a sibling with an issue. They can lose their own childhood caring for their brother or sister.

### ***Tips for siblings***

- Parents should carefully explain the difficulties to all the children. This is not being disloyal to the child with the illness. It helps their brothers and sisters understand what is happening and gain empathy for them. It also helps them not make incorrect assumptions.
- Help each child understand what is “fair” – when everyone gets what he or she needs, not necessarily what he or she wants. A child who is ill has greater needs.
- Help them learn how to get their needs met through healthy ways of asserting themselves. This will be a life skill that will help them forever.
- Parents should give them special understanding, attention, support and recognition of their unique contributions to the family.
- Parents should understand that a sibling may be able to rationally explain their ill sibling to friends or neighbors, but may have temper tantrums over the sibling's actions in the home.
- Resist the temptation to put the burden for care giving on the shoulders of an older sibling. This is especially true if the older sibling is a sister.
- Schedule a special time with the non-disabled sibling.
- Require the disabled sibling to do as much for him or herself as possible.

## ***Dealing with the hand life has dealt you – protecting the “self”***

From all that we have talked about, it’s probably obvious that members in a family with special needs children have a tendency to have a lot of stress and be prone to burn out.

### ***Signs of Caregiver Burn Out***

1. **Denial**- about the disease and its effect on the person who has been diagnosed. It sounds like “I know he will get better....”
2. **Anger** – at the person with the illness or others; about the treatment options; feelings that people don’t understand what is going on. “If she tells me to just get tougher and the kid will improve I will scream!”
3. **Social withdrawal**- from friends and activities that once brought pleasure. “I don’t care about getting together with the neighbors anymore.”
4. **Anxiety** – about facing another day and what the future holds. “What happens when he needs more care than I can provide.” Take a day at a time.
5. **Depression** – begins to break your spirit and affects your ability to cope. “I just don’t care anymore.”
6. **Exhaustion** – makes it nearly impossible to complete necessary daily tasks. “I’m too tired for this.”
7. **Sleeplessness** – caused by a never-ending list of concerns. “What if she explodes at the wrong person?”
8. **Irritability** – leads to moodiness and triggers negative responses and reactions. “Leave me alone.”
9. **Lack of concentration** – makes it difficult to perform familiar tasks. “I was so busy. I forgot we had an appointment.”
10. **Health problems** – begin to take their toll, both mentally and physically. “I can’t remember the last time I felt good.”

The reality is if you don’t take care of yourself, you cannot be there for anyone else. Much like in an airplane crash, parents are advised to make sure that their oxygen masks are on first, then to help the child.

So how can you survive?

***Tips for the individual***

1. Take time for yourself. This can be 1-3 hours a week. It doesn't have to be 1 hour EVERY day.
2. Support groups: i.e. SEPTA, CACLD, CHAD.
3. Know your feelings and when you have had enough. Describe the anger rollercoaster. Gain self awareness.
4. Don't be afraid to ask for help. You don't have to be strong and perfect.
5. Not all advice will be helpful, but don't take it personally.
6. Share providers: OT, PT, advocates, and social skills.
7. Rotate playgroups allowing one parent to leave.
8. Build a faith in a higher power.
9. Don't blame yourself.
10. Hire advocates to help bridge the family's and the child's needs with the school's abilities.
11. Anticipate that with each life cycle transition, grief and sadness will tend to come back, with a possibility of depression, i.e., if everyone is talking about where their child is going to college and yours is not, you might tend to begin blaming yourself and isolate.

As we educate ourselves, find support, and take care of ourselves, new feelings emerge:

- Joy: you celebrate your child's achievements as well as your own.
- Serenity: acceptance brings this feeling forward.
- Strength: at handling the adversity that hits each one of us.

Until finally, we see that life's reality is like the old Buddhist saying, "A family has 10,000 joys and 10,000 sorrows."