

SPECIAL Parenting Matters of Westchester

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A Resource For Parents Of Children With Special Needs
And The Professionals Who Work With Them

Self Care Edition

Are You Recharging Yourself?

Roberta R. Omin, CSW-R

Special needs children are likely to be high maintenance children. Whether a disability is developmentally, neurologically or medically based, these children require significant time, attention, planning and support. They are sensitive on many fronts. Their emotions, behaviors, likes and dislikes are often intensified. Their health, learning and/or social needs are vast. These sensitivities necessitate that parents adjust their usual style in order to suit their child's unique needs and ways of responding.

Parents often have a range of experiences and feelings: worry, burden, inadequacy, frustration, and exhaustion (emotional and physical). Over time, this may bring about depression, isolation, resentment and guilt.

While there is no fixed rule, women and men have different styles and beliefs regarding self care. Women have been socialized as caregivers and may find it difficult to claim time for themselves due to an inner notion that it is "selfish." Men, on the other hand, are socialized to be providers and often overwork. For both, self care can seem elusive or inconceivable and for some, even unacceptable.

While there is no magic cure to relieve some of the realities of having a high main-

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Asking For Help And Support

Jenny A. Frank, CSW

A rarely discussed and frequent experience of special needs parents is wanting and needing to ask for help from other family members and friends. Many reasons may impede you from enlisting assistance: fear of disappointment, letting go of control, not knowing how your child's behaviors may play out or self-limiting pride. This article outlines some ideas to get you started.

If asking for help is not easy:

⟨ Be honest with yourself regarding why you are not asking for help.

⟨ Ask other parents about techniques they use in asking for support.

⟨ In considering who to approach, ask yourself: What are those person's unique qualities and gifts? Have they been supportive of your parenting and how do they relate to your children? What are their attitudes toward exceptionalities?

⟨ Prepare to handle different responses. Some will deny or minimize your child's difficulties: "don't worry; he'll outgrow it." Others may offer unrealistic responses such as "we're only given what we can handle." ⟨ Ascertain how a person can be most helpful. Not all people can fill *all* purposes.

Some areas of support can include occasional baby-sitting, after school care, going on a field trip, accompanying you on visits to doctors and other specialists, tutoring

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Parents' Perspectives

Interviews With Parents

Special Parenting Matters (SPM) asked several parents to share their self care strategies. We started with Mike, a father of a chronically disabled child.

SPM: Our experience in working with parents is that fathers have a difficult time taking emotional care of themselves. As a husband and father of two girls what's been your experience?

Mike: It begins with having a relationship with my wife where we can talk about and hear each others fears and feelings. We support each other in creating respite and have a mutual commitment to define some area outside of being parents of a disabled child. My wife has renewed her interest in sculpture, pottery and art and I support her by coming home so she can go to her class. She allows me to really pursue my career and doesn't complain. When I am home I am fully involved.

We have a clear division of labor and have refined our teamwork to make it balanced. In addition to the daily needs, we share the ball concerning my daughter's many doctors, medical suppliers, educational program, school meetings, pharmacy, and therapists. When one of us is doing more than our share over time then we know we are in trouble. Each of us has to do 100%. I couldn't live with myself if my wife was doing more than her share.

SPM: That's quite unusual. Caregiving is usually placed on the woman's shoulders. How have you both worked out sharing responsibility and having time and space for self care?

Mike: We had a pivotal experience. When our daughter was diagnosed with a severe chronic disability, we were reeling with shock. We took time to come to terms with what our future was going to be. We went out to lunch and both became tearful and acknowledged this is life changing. We said out loud "this will either break us apart or we'll pull together and make this work."

We had to make a decision because we were faced with terrible uncertainty about her future and still had no idea what we would be facing. If we hadn't put it out there, we'd have been adrift.

Looking back, my wife is in a new stage of being a parent of a chronically disabled child. After 11 years she has come out of her cocoon, gone into therapy and she is being transformed. If I can show her my support it will help us be free to be ourselves.

Several other parents shared their thoughts:

"I am fortunate to not have to work during the day. However, I have a girls' night out once a month on a Friday night." *Lori, mother of two*

"I have recently started to go to church on Sundays with my child and every time I go I feel so much better. This is really for me." *Anita, single mother of an adult son and child*

"I try to model myself after my husband who is more proactive at taking time and not feeling guilty. I, on the other hand, feel intense guilt and anxiety over leaving my children. Slowly I am adapting to the idea that not only do I need time, I have earned it." *Emily, mother of two*

"Seeking out counseling in the early phase really helped me. Another strategy is to not schedule my time so tightly doing things back to back. It gives me breathing room." *Lisa, mother of two*

"When a friend offers to stay with the children, I don't do laundry and household chores, although it is extremely tempting with all that needs attention. In my heart I know I need to get out of the house and do for me." *Sheila, mother of three*

"I encourage my wife to go to the city overnight on occasion. She is from there; she has some old friends and seems to get invigorated from the city's energy. I work there so coming home has that effect on me." *Edward, father of one*

**"...this will either
break us apart
or we'll pull
together..."**

tenance child, taking time for yourself helps. A good place to start is for couples to talk with each other about their self care needs and then co-create nourishing and re-energizing opportunities for them as individuals and as a couple.

Below are ideas that make caring for yourself a manageable reality.

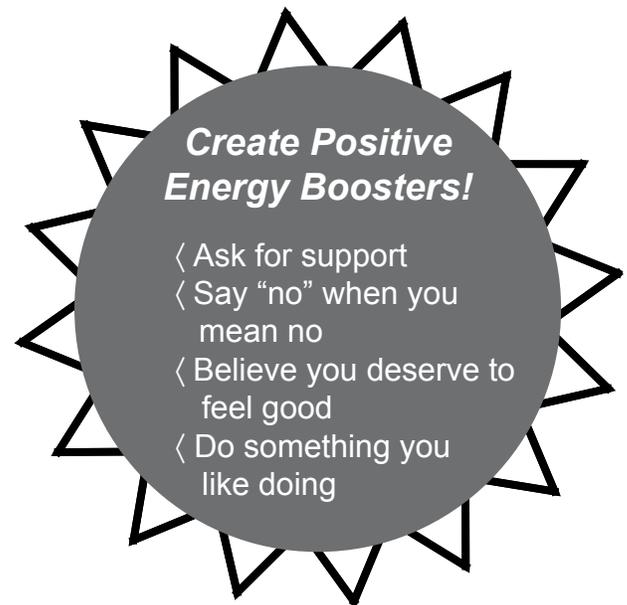
- < Remind yourself that you and that your couple relationship require attending. Find your “us.”
- < Let go of the notion you have to do it all by yourself.
- < Identify what is extraneous and depletes your energy.
- < Practice saying “no” on occasion.
- < Learn to share responsibility with your spouse.
- < Ask for help from family/friends (see Jenny’s article).
- < Overcome being intimidated by others who seem to do this effortlessly.
- < Find professionals who work respectfully with you.
- < Broaden your parenting skills to better handle taxing behaviors or circumstances.
- < Find environments that fit your child and yourself (e.g. don’t go to supermarkets with your child if it creates tension).
- < Network with parents whose children are older and have similar profiles to learn what lies ahead. Ask about their coping strategies and techniques.

Meeting your own needs can come in a variety of forms, depending on what would be fulfilling at a given time. Perhaps your internal batteries can be recharged with quiet reflection and other times rejuvenated by having contact with people whom you feel close and understood. Ideas to consider for revitalization are:

- < Develop a relationship with a sitter whom you can trust; who can be trained to work with your child.
- < Block out non-negotiable time for you and your spouse on your calendar.
- < Go out on dates with your spouse...something interesting, novel and fun.
- < Find a form of exercise you like to do; designate time, even if for short periods - it will be invigorating.

- < Meditate, learn relaxation techniques.
- < Get involved in something you thought you would never do and things you like to do. It builds up your reserves.
- < Start or join a book club, support or discussion group.
- < Attend the theatre, lectures, movies, music and/ sporting events.
- < Get good rest, including power naps.
- < Keep a private journal to pour out your dark thoughts and negative feelings.
- < Create a space for a safe haven in your home; make it your special retreat.
- < Have lunch with a friend or a close family member.

By challenging your attitudes about self care and not abandoning your needs, you will gain new perspectives about renewal and energy. More often, by making your-self do some of these things, you’ll discover you cope more effectively, minimizing the risk of burnout. You deserve to claim time and space for yourself and each other. In being creative, your possibilities are endless.



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and or helping with a certain specialized project, internet research or monetary relief.

Now that you are prepared:

- ⟨ Try to meet at a time when you can be at your best and can minimize interruptions and distractions.
- ⟨ Articulate your needs clearly being mindful not to impart too much information early on. For instance, talking about obstacles or the immense effort you put into planning your child's educational or health program.
- ⟨ Don't lose sight that friends and family will have reactions and feelings about your situation. Encourage them to ask questions, express feelings and allow them time to digest what you asked of them.
- ⟨ Elicit their useful ideas for you and/or your child.
- ⟨ Try not to take a lack of positive or delayed response personally or as a resounding NO. Consider setting up another time to talk or inviting that person to one of your child's related services or meetings (such as doctor, IEP, or speech therapy) as a beginning to further involvement and deeper understanding of your child.

Parents of high maintenance children face many challenges. A practical means of inoculating against the pressures is to ask for assistance. Support can come in many forms - emotional, recreational, logistical, or financial. The adage "it takes a village to raise a child" is even more relevant with special needs children. Eliciting help will lessen feelings of isolation and stress and may enrich your relationships in ways you would not have otherwise known.

SPECIAL ParentingMatters of Westchester offers:

- ⟨ Workshops designed for Schools, SEPTA's and Parent Organizations
 - ⟨ Inservice Staff Trainings
 - ⟨ Consultations with Professionals
- (914) 939-6557 or (914) 941-8179

Parent Coaching

Child-friendly behavioral strategies to suit your family's needs



- Discover the influence of your parenting style on your children's behavior
- Expand your repertoire for positively impacting their emotional growth
- Support spouses to work together for the benefit of your marriage and family
- Restore fair parenting with all your children

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