

Compassion Fatigue, Self Care and Moms of Special Needs Children

A summary of what I am learning

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4/10

More than the regular mom

Being a Special Needs Caregiver:

Being a Caregiver is not a role people usually choose. It seems to choose us most of the time. It's a role that comes at us from events and circumstances beyond our control. For some of us, the news comes when we are our most excited waiting for the arrival of the gift of a new baby. Even when we chose a profession in caregiving or choose to adopt a special needs child, there is no way we can understand all the demands that will daily roll over us.

Who is ever prepared for the constant demands, the emotional reaction and fall out of loving another human being with all your heart and learning to come to terms with what that will need to look like for this child as she grows and matures. The needs and responsibilities are daily, 24/7. They cannot be skirted and can't always be delegated. While caring for loved ones can be enormously satisfying, there are days that the work offers little reward, but lots of pain, frustration, disappointment and feelings of not being up for the challenge. When it is your child, you internalize every success and every failure. You are responsible for getting to the right helpers, and understanding and educating yourself and others.

Many times you are called to be a warrior advocate for your child. The battles can be brutal and exhausting. You wonder if anyone gets it. Does anyone understand? You love every inch of this child and every possibility lying in them for the future. You dream for them and grieve for them and for yourself. You pray for them and make deals with God about them. You lose sleep.

All while dealing with the dailyness of their special needs and for all the other demands of being a mom, wife, friend and maybe even a career worker. The more significant the needs of your special little ones and your family as a whole, the easier it is to lose yourself in caring for them.

As caregivers, the moms, dads and grandparents who care for special needs children and grandchildren whom they love dearly, you deserve to be recognized and supported for the vital part you play in bringing love, care and dignity to the lives of your treasured children everyday!! I wish I could give each of you a "mother, father, grandparent, aunt or uncle of the year" trophy and throw a parade in your honor. But I can encourage you, cheer you on and help you better yourself physically, emotionally and spiritually as you walk your marathon of a journey in supporting your special needs child, yourself and your whole family grow to reach their potential and move in their life purposes.

It is important that you, as a special caregiver connect with others like you to gain strength from each other and to **KNOW THAT THEY ARE NOT ALONE**. It is essential that you know about tools, products and resources that might make your lives easier. It is also important that you are aware of community and public resources that offer assistance. You especially need to know about respite help services and support, because you need to stay healthy and be aware of your own needs for well-being.

It is so easy to be overwhelmed and stressed by all that it takes to care for your family and deal with the systems that provide services, help, and resources. It is important to take in all the help you can and build a support system within your family, your community and your friends. Places to build in support include extended families, neighborhood communities of faith, local schools, parks and recreation programs, early intervention and other specialized programs developed for the child with special needs.

Stress factors build on stress factors for those of us who are doing special caregiving and are also single moms, aging grandparents, have our own health issues, live in rural areas or with no family nearby, not having a church family for support, being asked to remove your child from a church program, feeling that school personnel are against you, not having specialized programs available in your area or being placed on long waiting lists or not being able to afford them. Of course, caring for more than one child with special needs raises the stakes. ***If you fit one or more of these categories, planning for yourself and what you need to stay centered and healthy must be a priority!***

Sleep deprivation is one of the most common problems with the most devastating consequences! In the best of circumstances, most moms' of special needs children are chronically sleep deprived.

Somehow, we believe we can do this job indefinitely. We believe we can keep punishing our own bodies and we will somehow miraculously keep functioning optimally. Sleep deprivation or lack of respite time for caretakers gets overlooked by almost all professionals who focus on your child. This is a gross oversight. Long term planning in this area is necessary for everyone's success. Don't take your personal sleep plan for granted.

I know and you know that as parents and caregivers for children and adult children with special needs, we are not especially gifted or equipped in these skills. We learn and make mistakes on the job. Even if we have had experience as a teacher or nurse or some other helping professions before being gifted with our special needs children, none of those experiences equip you to on the other side of the desk or the table. It does not prepare you for being the one others give lectures to about exactly what your child needs or does not need. We are average people who at times have to tap into superhuman strengths for short term spurts.

Adrenaline is a gift from our bodies to get us through crises, but this system in our bodies was not meant to be depended upon for the long haul. The system can shut down and start causing problems. It seems for some of us inevitable that our own emotional, physical and spiritual care must be overlooked or denied, because caring for others must take center stage. Here is a reality check for you: you would not expect this of anyone else and it is unrealistic to expect it of yourself. You are probably getting so good at care taking that you could spot warning signs of fatigue and burnout in others and want to help them. It is time to stop and take a look at yourself, to listen to your body, mind and spirit and take inventory. How are you?

Superhuman daily powers cannot and will not continue forever. As caretakers, we need time to regroup, to rest, and to return filled with love and empathy: refreshed. It is important to understand that it is okay to take a break. It is actually **necessary** for physical, emotional and spiritual health.

Compassion Fatigue and who it impacts:

Stress is your body's response to a challenge, whether it is a threat to your life, or the pressure to take care of your loved one, or being trapped in a traffic jam when your 8 year old needs picked up from soccer practice and you had to be down town for an occupational therapy meeting. We think of stress as all bad, but our bodies actually respond to change and challenge whether it is positive or negative. A promotion, a wedding, a new baby, a surprise birthday party – they all produce a stress reaction. And some of us like the feelings of adrenaline more than others! Personally, I am not an adrenaline junkie. The impact of all this stress (good and bad) is cumulative over time. That needed boost of energy under stress will run out if not managed and refueled.

Reserve energy must build up like a savings account in your body over time by rest, quiet moments, times of less demanding activity. Relentless work turns excitement and enthusiasm to anxiety, guilt and anger and then to burnout. Studies confirm that people who work for a living as long-term caretakers are at high risk for high levels of compassion fatigue. I think that more studies would show that moms who under more typical circumstances are under high levels of stress are even more vulnerable than those who work at it as their paying job. Our jobs as moms never end. They are 24/7 and we are never done being moms no matter how old our children get.

Compassion fatigue first described those working to help in crisis situations like natural disasters and war. It was then applied to health care, social workers and mental health workers who deal day in and day out with deep problems and our most fragile members of society. Dealing with hopelessness, callousness and painful realities can cripple one's passion and energy to keep helping over time.

So, not only does the idea of compassion fatigue impact you and your roles at home, but it impacts your interactions with all the professional helpers who are part of your child's therapeutic team. Remember, compassion fatigue was first described in doctors and nurse and those who give “bad news” multiple times per day. When you run across “helpers and experts” with negative attitudes and incredibly unrealistic lists of interventions for you to do with no emotion for what they are asking you to do, stop and be aware that while very knowledgeable, they may be dealing with some level of compassion fatigue as well. When you have choices of helpers (which is not always the case) pick someone you are comfortable with who leaves

you feeling heard and who at least occasionally gives you positive feedback, support and hope. It makes a huge difference to have some one on your team who celebrates the small things with you and your child.

Your risk for compassion fatigue also increases with your own level of anxiety, past hurts and traumas. If there was a traumatic event associated with your child's special needs that can increase your risk. **AWARENESS IS KEY.** Heightened awareness leads to quicker insight, so you can increase your self-care faster. Simple things we all know about can really make a difference: regular exercise, healthy eating habits, stopping to enjoy a social activity, journaling, sleeping, praying and more. You can practice prevention by adding these healthy practices before you feel worn out.

The term Compassion Fatigue is slowly replacing the term "burn-out". It refers to a physical, emotional and spiritual exhaustion that takes over a person and causes a decline in one's ability to experience joy or to feel and care for others without overriding negative feelings or numbness. Compassion Fatigue comes from a constant output of care and time without getting enough back to reassure yourself and continue to feel hopeful about the future. Remember, it also impacts doctors, nurses, mental health workers, clergy, teachers, etc.

It doesn't happen all at once. It's a process. It's not a matter of one day you are fine and the next totally exhausted. It can take weeks to years to appear depending on the amount of stress and the condition you were already in when you began the extra helping. Basically, it's a low level, chronic, clouding of caring and concern for others in your life due to overuse of your skills of compassion. You may also feel numb and blunted or feel emotional pain or any combination. A very common response is to not know what else to do but to pour yourself back into the responsibilities until there is even further damage which takes longer to heal.

The Warning Signs of Compassion Fatigue

- Anger
- Blaming
- Chronic lateness
- Depression
- Diminished sense of personal accomplishment
- Exhaustion
- Frequent headaches (a change in headaches)

Gastrointestinal complaints
High self-expectations and then feelings of failure
Hopelessness
Hypertension
Distorted objectivity
Less ability to feel joy
Low self-esteem
Sleep difficulties
Irritability
Trouble breathing
Use of alcohol, drugs, sex or food to comfort
Feelings of being overwhelmed with someone
elses' pain or perceived pain
Intrusive thoughts
Desire to avoid the person needing care
Backaches
Increased marital stress

Caretaking can be overwhelming. The challenge is to refuel and maintain your resilience so that you can keep doing the work of caring with energy and compassion. Financial stress like sleep deprivation and unrealistic expectations adds to compassion fatigue, but money and resources hardly ever get discussed, addressed or planned for in a helpful way. These are all important areas for which to discuss, seek counsel and plan.

Another area that adds to all of this is the herculean effort needed to try to work within systems – medical, insurance, educational, disability benefits, mental health, etc. Dealing with your feelings of blame and guilt when you don't feel you measure up to the expectations of professional helpers can be devastating. Difficulty trying to understand all the different vocabularies and acronyms is frustrating at best. In your grief, you must learn these new vocabularies and the hoops of paperwork and phone calls needed to get the help you are seeking. These issues cut deeply and sharing them with others going through the same difficulties helps and gives you clearer perspective and more realistic expectations.

Spouses who are not the primary caretaker also pay a high emotional price, as do siblings. The whole family and each new additional member must come to their own terms with the "new normals" that can keep changing to meet special needs. Each "new normal" involves lifestyle changes and priority shifts for every family member even when you do your best to minimize it. You may be expanding huge amounts of extra energy to keep things "normal" for your spouse and other children. You need to be aware that all of it impacts all of you. Plan for it and for the adjustments.

This great load of stress has been shown to greatly increase the risk for divorce and further emotional damage to the whole family. It's vitally important, even during a crisis to make marriage a priority. Even short times spent ALONE together focused on neutral themes are helpful. Siblings feel the stress of being left out and vying for attention. They may later have guilt over any bad feelings they had toward their brother or sister with special needs. Reality is that equal amounts of time with each child may not be a regular event, but each child needs to know they are very loved and very special. Do not assume they know this.

With all this talk of stress, I need to mention that some of the symptoms listed above can go to levels above chronic stress and lead to other health and medical problems. If you are having significant difficulty dealing with the tasks of life for more than 2 weeks straight, please check with your doctor and follow through those recommendations. Chronic stress can change brain chemistry and lead to many stress related medical problems including depression and anxiety disorders among others. If you already have existing medical conditions, know that chronic stress can make managing them more difficult.

Tools that help

Reducing Stress one step at a time

One of my biggest fears in putting together a "list of things to do that help" is that you will feel more stress, shame or guilt about not being able to make all these things happen in your already overloaded, overwhelming days. That is not my heart or intention at all! May I suggest that if you are trying to prevent compassion fatigue or burnout or when you take self-inventory, you see a few budding signs, that you skim /read through the things that help and see what "speaks" to you. What sounds heavenly? What would you love to have 20 minutes to do once in awhile? Start there. Baby steps, girlfriends. Baby steps.

I am going to interject a scripture reference for helping guide you in choosing ways to heal and reduce stress. The verse is also a wonderful way to try to break out of negative thinking patterns that are fueling your stress. Here it is:

Phillipians 4:8 (The Message)

Summing it all up, friends, I'd say you'll do best by filling your minds and meditating on things that are true, noble, reputable, authentic, compelling, gracious – the best, not the worst, the beautiful, not the ugly, things to praise, not things to curse.

There is so much out there in the literature about how to reduce stress. Much of it comes from a variety of world views. I happen to be clear on my world view. My view is God centered and biblically based. So as I gather information, I can't help but filter it all through that lens. One of my favorite Christian authors for women is Barbara Johnson. We lost her to cancer in 2008, but she left a legacy of wisdom, joy and laughter despite personal deep pain. I recommend any of her books. In her book, Splashes of Joy in the Cesspools of Life, she has chapter on stress and brilliantly cuts through it all to put every tool into one of two categories. I am borrowing it for us here.

Barbara Johnson writes, "As I sort through them all, there seem to be two main approaches to dealing with stress:

1 **DO SOMETHING.** Be efficient, set priorities, use time wisely, etc.

2 **DO NOTHING.** Relax, escape, let go, let God."

So let's start with what sounds best: **DO NOTHING!** Oh, for a few hours to do nothing!

Barbara Johnson has her own life affirming list of DO NOTHING, relaxing ways to deal with stress. Here is her list:

"Following are 20 ways to deal with stress that can help you relax and try to "go with the flow" rather than getting tense or uptight.

Tickle a baby... Pet a friendly dog or cat... Don't know all the answers ...Look for the silver lining... Say something nice to someone... teach a kid to fly a kite...walk in the rain...schedule play time into everyday...take a bubble bath... read a poem...listen to a symphony...play patty cake with a toddler...take a different route to work

...remember that stress is an attitude...remember you always have options...have a support network of people, places and things...quit trying to fix other people...get enough sleep...talk less and listen more...relax, take each day at a time, you have the rest of your life to live!"

Now it's my turn to sort through all the 100s of suggestions and find the one's I think are worthy and fall under DO NOTHING.

Relaxation Techniques

Deep breathing

Music therapy

Massage – from self massage of your head or hands to full body massages:)

Spending time in nature – you can combine this with other stress busters and get 2 for 1

Laughing – finding humor

Gentle Stretching or beginning yoga

Meditation

Prayer

journaling

mindfulness meditation

Here is my version of a mindfulness meditation exercise. In a quiet, calm place, with or without soothing music (just instrumental), with or without water therapy (you can do this in a hot bath or whirlpool). Once you begin to transition to relaxing, clear your mind and breath deeply a few times. Good clean oxygen does wonders and concentrating distracts an over busy mind. Now, here is the technique: read or repeat to yourself the truth of God's Word about who you really are in Him.

Here are some good ones to start with, but feel free to find your own in the Bible. They are truth and hope and freedom to your soul. Just tell yourself the statement, not the reference on where to find it.

I am a child of God (Romans 8:16)

I am forgiven (Colossians 1:13,14)

I am saved by grace through faith (Ephesians 2:8,9)

I am kept safe wherever I go (Psalm 91:11)

I am casting all my cares on Jesus (I Peter 5:7)

I am doing all things through Christ who strengthens me
(Phillipians 4:13)

I am bringing every thought into captivity

(II Corinthians 10:5)

I am filled with laughter and rejoicing (Job 8:21)

Emotional and Mental Health

Practice Awareness – take time to check in with yourself

Practice Acceptance

Be kind to yourself

Express your needs and feelings verbally and in writing.

Journaling, however, you use the paper space, helps

Quiet times

Personal space and boundaries

Take help/Seek help

Stay connected to spouse, friends and family

Reach out to encourage others

Pay attention to your feelings

(I would add share all of them with God)

Learn to say NO

Avoid blaming and complaining over & over.

It makes things worse and fuels the negativity
and stress by replaying it over & over

Avoid making any life changing decisions while
very stressed

Avoid quick fixes – look for sustainable lifestyle
changes

DO SOMETHING!

Here is Barbara Johnson's list of **DO SOMETHING!**

“Following are twenty ways to cope with stress that involve taking decisive action, doing something to deal with whatever may be causing stress in your life. Get up fifteen earlier... Prepare for the morning the night before... Set appointments ahead...Make duplicate keys...always make copies of important papers... repair anything that doesn't work properly...Ask for help with jobs you dislike...Have goals for yourself... Stop a bad habit... Ask someone to be your “vent” partner...Do it today... plant a tree...feed the birds... stand up and stretch... memorize a joke... exercise everyday...learn the words to a new song...get to work early... clean out one closet...write a note to a far away friend.”

Healthy Habits

Plan healthy meals and snack and don't skip them
Keep healthy snacks in the car for you and the kids.
Drink lots of water. Headaches and exhaustion are magnified when we are dehydrated.
Make sure you plan to visit your doctor and dentist regularly.
Increase your sleep and rest
Exercise
Vary your activities
Take breaks and vacations – USE any respite you have available

Support

Connect with people with similar struggles
Find someone else to encourage and support
You need a place to take and receive
Find at least a few emotionally healthy people who leave you happier and more hopeful
ASK FOR HELP – keep asking when necessary
Educate yourself on the special needs you are dealing with and what changes are normal or concerning.
Make yourself an expert on your kid. That means you know what is normal, what is a change and what is concerning.

Organization

Find a calendar that works for you
Use one calendar
Use the 168 hour a week calendar to check your life balance. (see attached). You are only one person!
To do lists are good, but never end
Take time to list what you do get accomplished!
Use a giant notebook to make a health notebook for your special needs child. All information should be in one place. There are examples on line. Give yourself a month to finish it.
Be proactive. Plan for stress.
Check into monthly planning of frozen meals
Make a household notebook kind of like the health notebook.
Include all the info you need on all the other family members as well as all \$ and household needs, warranties, upkeep, etc. The initial investment seems big, but the long term ease outweighs it!

The more organized you can be, the more easily someone can step into help.

As long as you are keeping lists, keep one on simple tasks around the house or errands you never seem to get to, but would make your life easier. Then pull it out when a friend, co-worker, family member says "How can I help?" There really are little things they can do easily for you! Let them help.

Life Principles and Legacy thinking

So many times we are hit with the responsibility of parenting a special needs child before we have ever thought through what that means, what we want our family values to be and what kind of legacy we want to leave for our special needs child, our entire family and our own life. This kind of reflection takes some time and starts with the end in mind. It is a type of value clarifying exercise. Sometimes they are called "principles of living" or our spiritual compass. Having a solid idea of what is important in your family and in your own life can relieve a lot of stress and anxiety, because you can look at each decision and each time you add something to your life or take something out of your life, you can look at it through the lenses of your life principles, values and legacy commitments.

Does it line up with what you and your spouse want for your lives or not. If not, it is easier to say NO and not 2nd guess yourself. What adds love, life, joy and meaning to your family and yourself? Take time to reflect. This is a great topic to journal.

Seek spiritual counsel when you are unsure. Pray about your choices. This is a great couples' exercise, but can be done alone if it currently adds stress to your marriage. I believe that being aware of the legacy you want to leave and building into it brings hope.

This topic of self-care is so huge, it could be a week long conference! I want to at least give you a short list of family based activities.

Your Family:

Vacations together near or far – there are even suggestions now on at home vacations

Keep everyone involved at their level with helping. Helping the child with special needs and helping the family by contributing what they can. You are all in this together.

Anticipate stressful times and prepare everyone, again, to their level of understanding. Unexpected stress is more difficult to manage than anticipated stress. Know your family and what each needs in this area.

Practice strong, healthy communication and repeat frequently. Get help for communication if needed.

Be flexible

Give all family members as many choices as possible. Any choices give us a sense of control and independence.

This is just as true for the child with special needs!

Plan time away for everyone. In other words, support their friendships and interests.

Anything you add to your life to make it less stressful will probably help other family members as well.

Be hopeful! You can recognize and address worries without dwelling on them. Pray about things as a family.

HOPING INCREASES COPING!

My best advice for couples is to talk to each other about what you need most. Listen. Plan for each others needs. Make the time to laugh together, play together and pray together. If your spouse isn't comfortable praying with you, there is nothing keeping you from praying for your marriage and your spouse!

Reducing your stress is a gift to your spouse, especially for our husbands. They are by nature problem solvers and not being able to change anything or fix it for his family and the woman he loves the most may be one of his greatest stressors.

Now, I am back to my original dilemma. I feel slightly overwhelmed myself just putting all this information down in one place like this. I can think of 20 things I could be, should be, shouldn't be doing to take better care of myself and those entrusted to me. So, I am going to step back and think about what God is helping me do right for myself and my family and what

would add love, life, joy and peace to my family and to my days. And I will start there with you in baby steps!

Barbara also has this life long perspective on stress. I believe she was in her 60's or early 70's when she wrote this:

"When I speak for women's groups, I say, " You may think you have it all together, but then something will come along to remind you that you will never have it all together, no matter how old, no matter how much experience you have. The older you get, the more you realize that you get one wall up and the other walls fall down. If it's not a physical problem, it will be emotional or mental. The point is that you have to accept what life hands you. You'll never have all the walls up at the same time - at least not on this earth anyway. We live in a broken world. That is why Proverbs 3:5&6 makes so much sense.

TRUST IN THE LORD WITH ALL YOUR HEART,
AND LEAN NOT ON YOUR OWN UNDERSTANDING
IN ALL YOUR WAYS ACKNOWLEDGE HIM
AND HE SHALL DIRECT YOUR PATHS (NKJV)

The stress will always be there, but God will
always be there, too, and that gives you the edge!"

YOU ARE NOT ALONE!

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laurie@coachingforward.com

On line resources

<http://www.caregivers-domain.com/caregiverburnout.html>

<http://www.specialkidstoday.com/articles/general/parent-coaching-3826/>

<http://www.compassionfatigue.org/pages/compassionfatigue.html>

National Family Caregiving Association (NFC A)

10400 Connecticut Avenue Suite 500

Kensington, MD 20985

(301) 942-6430

(301) 942-2302 (fax)

www.thefamilycaregiver.org

www.nfcacares.org

info@nfcacares.org

Family Caregiver resources

American Red Cross

Family Caregiving Program

National Headquarters

2025 E. St NW

Washington DC 20006

(202) 303-4498

www.redcross.org

or contact your local chapter

<http://www.pspinformation.com/caregiving/thecaregiver/compassion.shtml>

<http://www.aafp.org/fpm/20000400/39over.html>

<http://www.cnn.com/2009/LIVING/personal/08/28/o.have.compassion.fatigue/index.html>

<http://www.livesinthebalance.org/compassion-fatigue-0>

<http://www.livesinthebalance.org/collaborative-problem-solving-radio-dr-ross-greene>

<http://www.livesinthebalance.org/about-lives-in-the-balance-and-collaborative-problem-solving>

<http://www.doh.state.fl.us/demo/php/PDFs/CompFatigue.pdf>

<http://depts.washington.edu/fadu/Gelo2003.pdf>

<http://www.imaginif.com.au/the-cost-of-caring-vicarious-trauma-compassion-fatigue-burn-out/>

<http://www.caregivers-domain.com/specialneedschildren.html>

<http://www.caregivers-domain.com/laughter-is-the-best-medicine.html>

<http://www.disaboom.com/children-with-disabilities>

<http://www.bellaonline.com/articles/art55033.asp>

The Effect of a Child's Illness on Maternal Sleep and Function

<http://womens-health.jwatch.org/cgi/content/full/2006/1130/1>

Chronic Illness in Children May Cause Chronic Partial Sleep Deprivation in Mothers

<http://www.medscape.com/viewarticle/545019>

<http://www.parenttoparentnys.org/Library/Caregiving/CaregiversNoSpecialGifts.htm>

- When Your Child Has a Disability: The Complete Sourcebook of Daily and Medical Care, Revised Edition, by Mark Batshaw.

A really useful book to read and keep as a reference. Covers a wide range of medical and educational issues, as well as daily and long-term care requirements of specific disabilities. Discusses parent concerns like behavior, medication, and potential complications. Also addresses issues such as prematurity, early intervention, legal rights, attention-deficit/hyperactivity disorder, learning disabilities, genetic syndromes, and changes in health.

- Coping With Your Child's Chronic Illness, by Alesia T. Barrett Singer.

A good introduction and general guide to coping for parents of a newly diagnosed child.

- Whole Parent, Whole Child: A Parent's Guide to Raising a Child With a Chronic Illness, by Patricia M. Moynihan and Broatch Haig.

This book helps you answer the questions: "What kind of parent am I now? What kind of parent do I want to be? How can I help my child with a chronic illness lead the fullest life possible?" This book aims to help you keep your perspective, and will remind you that you are not alone.

<http://www.med.umich.edu/yourchild/topics/chronic.htm>

<http://itunes.apple.com/us/podcast/family-caregivers-unite/id351243463>

http://caringforfamilymembers.suite101.com/article.cfm/parents_and_secondary_traumatic_stress_disorder

<http://seniorliving.about.com/od/lifetransitionsaging/a/caregivercare.htm>

http://seniorliving.about.com/od/caregivers/a/caregivers_hope.htm

http://www.triwest.com/corporate/frames.aspx?page=/unauth/newContent/newBehavioralHealth/prov_dep_selfcare_faq.asp

<http://ptsd.about.com/od/selfhelp/qt/Self-Care.htm>

<http://mothershaveneedstoo.blogspot.com/2007/08/emotional-self-care-husbands-support.html>

<http://createabalance.com/>

<http://www.circleofmoms.com/mothers-of-special-needs-children>

<http://www.azspecialneeds.com/resources/assets/Mom%20and%20Dad%20need%20to%20find%20a%20loving%20balance.pdf>

<http://www.specialkidstoday.com/articles/illnesses-diseases--disorders/special-needs-children-and-grandparents-4510/>

<http://www.childrentoday.com/articles/illnesses-diseases--disorders/children-with-multiple-special-needs-683/4/>

link for how to make a hospital crisis more comfortable

<http://www.onlineorganizing.com/BlogEntry.asp?id=716>

links for help with making a health notebook/record keeping

<http://cshcn.org/planning-record-keeping/care-notebook>

http://specialchildren.about.com/gi/o.htm?zi=1/XJ&zTi=1&sdn=specialchildren&cdn=parenting&tm=24&f=21&tt=13&bt=0&bts=1&st=24&zu=http%3A//www.providence.org/Oregon/Programs_and_Services/ChildCenter/e15swindells.htm

http://www.medicalhomeinfo.org/Tools/care_notebook.html

<http://www.partoparvt.org/CareNotebook.html>

<http://www.medicalhomeportal.org/living-with-child/caring-for-children-with-chronic-conditions/managing-and-coordinating-care/care-notebook>

<http://www.squidoo.com/care-notebook>

Coping with medical care and diagnosis

www.coping.org/specialneeds/coping.htm

Making a Household Organizational Notebook

<http://organizedhome.com/household-notebook>

<http://tipnut.com/make-a-household-organizer-notebook-buncha-links/>

168 Hours in My Week

Each time I move something into my time schedule, I have to move something out. No two things can occupy the same space.

	MON	TUES	WED	THUR	FRI	SAT	SUN
4:00 a.m.							
5	Example: Sleep (7 hours)						
6							
7							
8							
9							
10							
11							
NOON							
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							
11	Example: Sleep (11:00 p.m.- 6:00 a.m.)						
Midnight							
1							
2							
3							

Fill in this chart for a day, or several days, to see if your time schedule reflects your desired lifestyle. Look for time slots in your week to make changes.