

Taking Care of Yourself

Expect some difficulties.

We get them in greater share than most. If we keep telling ourselves how unfair it is, we will only become bitter. Of course, it is unfair, very unfair, but what in life is fair? Life gives us a full deck of cards; we get some good hands and some bad ones. Some are easier than others, but we have no choice but to play them all. Play as best you can with the hand you have. It is not the load that breaks us down, but the way we carry it. Remember that no matter how hard you may try, there may be some days that just get you down. It's part of the territory.

Talk about it.

Talk about how you feel. Things that we try to keep inside always come out later - after they have gone painfully inward. Find someone who will listen. The more we talk, the less we hurt. Other special parents are a wonderful resource, because they can lend support, encouragement and practical help. Most of all, they can identify with our joys and sorrows. If you have a computer, join the RettNet, where sorrow is divided and joy is doubled.

Be gentle with yourself.

Some days, we feel like you can take on the world, and other days, we want to disappear from the world. It's part of normal adjustment to a difficult situation. Life has its ups and downs. When you're having a down day, try to remember that you won't stay down forever. And the best thing is, the good days will be so much better.

Learn how to ask for help.

You probably think you shouldn't have to ask, especially when it is your spouse. Do it anyway. Asking for help is a skill we need to cultivate, because it doesn't come naturally. We're called "special parents" and we think that means we have to do everything in a special way. We're really just ordinary people called upon to do extraordinary things. Many people would help if we would just ask. Basically, we have two choices. We can give in and get help, or we may reach the point where we give out or give up. Ask for help, even if it kills you.

Once in awhile, practice incompetence.

People never want to help when they think they can't do it as well as you or when they know you expect perfection. Be willing to settle for less once in awhile when you need a break. She can be dressed in stripes and polka dots and the fashion police won't arrest you. She can even have a different feeding or sleep schedule now and then and she'll survive.

Learn to let go.

Sometimes we want to shelter our kids forever. We think others couldn't possibly care for her as we do. Perhaps they can't ever love her as we do, but they can help and care for her. It takes some work to find the right

caregiver, but it can be done. Start out with little getaways until you develop confidence in the caregiver. Make a notebook of all of her likes and dislikes, her routines and favorite activities. You can even make a care video showing how things are done at your house.

Take it easy.

Try not to dwell on decisions that are well in the future. One decision at a time is enough. Trying to figure it all out and plan for the rest of our child's life will paralyze us. Many of the things we worry about may never come to pass -- she may never have seizures or breathing problems. There may be good treatments for some of the other effects of RS in the very near future. And we're lucky to be led by a team of scientists dedicated to finding the cure for RS. Learn to live one day at a time. Today is a gift...that's why we call it the present.

Variety is the spice of life.

Remember that your child is a very important part of your life, but not all of it. Develop interests outside your special parent role. Studies have shown that burnout doesn't come from our frantic schedules; it comes from doing too much of the same kind of stuff. Get away from the routine. Find a healthy outlet. Do something physical if you can. And going to the library looking for RS stuff or going to a RS meeting definitely do not count!

Just do it.

Make some time every day to do something for yourself. Take a short walk, jog around the back yard in the dark, call a friend, soak in the tub, read the comics.

Get away alone.

We need some time together for the 3 Rs --- respite, regrouping and rejuvenation. Many parents say they can't get away because 1) caregivers are hard to find, and 2) they can't afford it anyway. But let's face it, can we afford not to get away? After all, we will pay one way or the other, either now or later. If we pay now, we may sacrifice some material things to afford time away. If we pay later, we may sacrifice a marriage or our sanity. So, we're faced with the choice to pay the babysitter now, or pay the divorce lawyer or the shrink later. It doesn't have to cost a lot. Time away can be an afternoon or an evening a week -- it doesn't have to be elaborate. On those days when we really can't arrange to go away, we can plan for a night time movie date in front of the TV or a game of Scrabble - something far removed from care giving.

Accept what you cannot change.

There are many things in life which we can change -- where we live or work, how we dress or who we choose for friends. We cannot change the fact that our daughters have RS. We can, however, change many aspects of our lives and hers that will make life easier. Often, it is helpful to marshal the energy which might be spent grieving into making things better. It may not be easy at times, but in those times of struggle you will find a stronger sense of who you are and you will find that doing something positive helps your outlook.

Keep in touch.

Find time to talk and play with your spouse or significant other. The average American couple spends only two minutes each day in meaningful conversation. Your child is a very big part of your life. She can bring you closer together, but the many demands on your time can pull you apart. Find time for each other, even if it is just a short time. Make it a priority. Our daughters need us, but we need each other just as much and maybe more.

Listen and learn.

While you're talking, don't assume that your partner feels as you do. People grieve and cope in different ways. Listen in the same way you want to be heard.

Toss the guilt out the window.

Having a handicapped child is the only situation when we feel guilty not because of what we did, but because of what we didn't do. We often feel that we can never do enough. There are never enough hours in the day to get it all done, to be fair to everyone, to give as much as is needed. We may say we can't live with regret if we didn't give it every chance, try every strategy, therapy or medicine known to man. These are admirable goals, but impossible ones. We are only human. We can only do our very best.

Learn how to say "no" with gusto.

We can choose to say "no" once in awhile. We don't always have to be the ones in charge of Little League or the carpool. Try saying, "It's my year to say "no." When asked to run for PTA office, say, "This year, I'm only running for my life." Don't take on more than you can realistically do. Keep the demands in balance.

Forgive and forget.

Taking care of ourselves means taking care of our hearts, too. Have patience with those who stare. Usually they stare not to be unkind, but because they are curious. They may not understand, but they can't understand if they haven't lived our lives. Don't expect them to. For each person who is unkind, there are dozens of people who are doubly kind. Remember that. Don't expect everyone to understand how you feel. Most have not walked in your shoes and they can't possibly identify with your many emotions. They can't begin to know how much work it is to raise a child with special needs. Try to remember that you may not have had as much insight before you became a special needs parent yourself.

Make your hero a sandwich.

Society tells us that since we have special kids, we're special parents and most of us take that to heart. We think that everything we do has to be heroic - and after all, the world keeps reminding us what saints we are. How many times have you been told how patient and heroic you are? We have to give ourselves permission to be human, to be unspecial and to have the same ordinary gripes and make the same everyday mistakes as the rest of the world. Give yourself a break.

Choose your hats carefully.

The number of roles we have as caregivers can be unlimited. We have to decide which are the most important ones -- in which areas we will seek help. Our choices may differ from others. Just remember that we can't wear all of the hats at once. We look pretty silly and one by one, the hats will fall off. They're heavy and too hard to balance. In fact, some days we choose to wear no hat at all!

Trust your instincts.

As your child's parent, you know her better than anyone. You are the best expert. So when the days come that are filled with frustration and unexpected responsibilities, remember to believe in yourself and your ability to make the best decisions on her behalf. Trust your own judgments and opinions.

Laugh a lot.

Throughout it all, we need to never lose our precious sense of humor. Laughter is internal jogging.

Find your own stress busters.

It may be different ways on different days. Look at what gives you peace and comfort and then find a way to make it happen.

Spend time with your other children.

Try to carve out special "time alone" with the other kids. They need your undivided time and attention sometimes.

Attitude is everything.

Situations may be out of our control, but we choose our attitudes. It's not what happens to us, but what we do with what happens to us that counts. We can't change RS, or how others will act. We can only change ourselves.

Give it some time.

While it seems like a cliché, the passage of time does help the healing process. It may seem very difficult to accept at first, but as time passes, the grief process moves us from panic, fear, helplessness, disappointment, anger and bewilderment to acceptance.

You will make new dreams.

We go through a process of mourning for our lost dreams of the child we wished for. The grieving is no less than death. It is a sad and hurtful time, as we imagine that our lives are so desperately changed forever. In the beginning it is hard to understand, but with time and experience, we learn profound lessons of love. We find that we can survive, and even thrive.

Celebrate life.

We've been to places we'd rather not visit on this journey, had situations we'd surely trade. But there is always a lot to Recognize that while it probably is the biggest issue at your house, RS is not the only issue. Find some time to notice the good things that are happening all around. They help us recognize that on the balance, life is good. We have many things to be thankful for. We have all learned a new definition for heartache, but we've also learned the most important and profoundly simple lessons in life. We've be thankful for, if you take the time to look. In the end, we've learned that family, health and well being, making a difference, are all that really count.

Making Time for Yourself

by Kathy Hunter

Throughout the years, we've almost always made time for a short vacation during the summer months. Even when the bills were high and time was short, we managed to pile the kids into the station wagon and head off for a couple of days "away from it all".

Most of our vacations were spent in a six-man tent which we shared with some pesky mosquitoes and other crawling critters. Our unlimited entertainment budget included fishing, swimming, shell hunting, cooking marshmallows by the fire and relaxing in damp sleeping bags by the light of the Coleman lantern. Most people don't understand why it is that we almost always come back from vacation tired. I never wondered why!

Keeping Stacie happy and occupied was always a challenge, even in familiar surroundings. Pushing a wheelchair in the sand is work, if not impossible. We always felt like gypsies because we had to take so much stuff. Most of us have The Plan and The Back-up Plans I and II for everywhere we go with our girls. R & R (rest and recreation) can all too easily change to W & W (work and work).

As I look back, however, I remember that Stacie has had many good experiences with us and we all benefited in a number of ways. Even considering all the vacation time hassles, there were many precious memories in the making and I wouldn't trade any of them. But there is one thing I would change: as hard as it might seem, I would find, borrow, or make time to have a vacation without the work.

I say this with a glow of confidence after just returning from two glorious sun-filled weeks at the beach. It was our very first vacation without kids and without work in 26 years. It was a genuine revelation. It took me one day to figure out that this is what Webster had in mind when he gave a definition for "vacation". Strolling on the beach one night, I was struck

with the thought that most of the folks we met at the shore did not have any idea what it was like to provide for a child with handicaps. They did not realize how much of our time goes into cultivating an ordinary life in spite of some extraordinary stressful circumstances. Not to mention, balancing our energies to meet the demands of caring for our girls and their brothers and sisters. We all need time away - real vacation time. And that's what I would change if I could do it all over.

I would still go camping in the tent that leaks. I would still include Stacie in our activities and outings most of the time. But I would make it a priority to plan some time alone without her to restore, refresh, and revitalize. This might include taking a caregiver along or finding a baby-sitter during vacation time, or it might mean leaving her alone in someone else's competent hands. It might be hard to arrange, but it is not impossible.

I have found that the families who do the best are those who make time for themselves, while still managing to provide the very best for their child. When we overextend ourselves we end up tired and resentful. Our girls will have very special needs for all of their lives, and we need to best preserve ourselves for the long haul if we're going to endure. We may have to make some trade-offs - Stacie may not be as happy while we are gone and she may wear stripes with polka dots, but she'll survive. It will take some extra energy (for years this was my excuse) and some creativity (inquire at your church, club, school, swap kids with a friend or neighbor). It might cost something, but consider the cost of not doing it. Give yourselves permission to be special to yourselves for a time. It is possible - and wonderful. Make it happen. You'll be glad you did.

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