

Helpful Hints/Words of Wisdom

The advice I received from many people when Edie was diagnosed a little over two years ago was to hang in there, that things would get easier as she gets older, and the hurt never goes away but it gets easier. I didn't believe any of that at the time, but now that some time has passed, I know that this is right.

~ Ashley Hagg

I'm not sure it ever gets easier; I just think we learn to change our expectations. Instead of dwelling on what Carol lost in skills, I praise all she has accomplished. Instead of taking giant steps, we take small but firmer steps. I notice how I view everyday life as far different from my neighbors and from most of my family...I think everyone walks a far different path in life from the one we had planned. But, you will love this daughter deeper than anything you've ever experienced. You'll be so proud the day she takes that first step, because you know just how hard it was to take. There'll be days you'll sink to incredible lows, but the highs will be higher than anything you thought possible. You'll survive Rett Syndrome because you won't allow your daughter to see sadness. Only complete and unselfish love will be in your eyes! Tread firmly, know the meaning of having fun and don't lose yourself.

~ Kathy Pryor

I let myself have days off to veg out. I let myself give in to the tired days and enjoy the sparkly days. I read, knit, garden, sew and sit on the internet for hours on end if I need to. I have realized that life is not a competition.

~ Leita Boltwood.

I think that sometimes we moms just do it all without thinking, like we would our babies or our "typical" children, and we forget to ask for help, or our husbands feel like maybe they wouldn't do it right if they did step in.

~ Kandy Hallstrom

We have a caretaker who has 3 little kids, one being the same age as Jess, and she feels so important when she goes there. Since we have no family members close enough to visit, this is her chance to be with her adopted family. She might stay with them overnight once every 6 weeks or so and then visit for an afternoon every other week. How exciting for Jess! As soon as we can find the help we are going to have someone come and help on the weekends, and the help is there to do just that -- by doing things like trips to the bathroom, reading and playing with Jess. It would give me a chance to make her the healthy meals she needs, wash clothes, take a shower, find my mind and put it in order, or take the dogs for a walk. That doesn't mean that this person is now taking over and I am cruelly abandoning my lil angel. It means I am being wise and taking all the preventive measures to avoid a total nervous breakdown.

~ Kristina Kelley

Who is to say that she wouldn't enjoy interacting with another person anyway? Especially as she gets older, perhaps she would enjoy the company of another caregiver as well as you and other family members? Maybe she would prefer a fresh and enthusiastic person who appears in the evening to read her a story and get her ready for bed. She is human, maybe she gets tired of you and needs her space too.

~ Rachel Dine

Just as our children go through various emotional, physical and developmental stages we as parents continue to do so also. Growing into "letting go" over time is probably the most realistic assessment of this than anything. It isn't something that happens overnight; it evolves. We all do things as we need to. Relax and enjoy your little one but find someone you trust her with to allow her small amounts of time away from you, to give you a break, and to open her world to the love of others. The rest will develop as is necessary in your and your daughter's lives.

~ Patti Peery

We each take time during the week to do our own thing. I go to weight watchers and almost never miss a meeting. It is only a half hour, but it's my time. We also get five respite days quarterly so we use those when we need a break. At first I didn't like to leave Danni, but now it is old hat. Some days can be overbearing, but my theory is it's only a few more hours, and this day will be over and we can start fresh tomorrow.

~ Ellen Ayer

We get one weekend a month of respite care. I love my girl more than anything, but I also need that one weekend a month for my sanity. I find that I appreciate Kayla more when I've had a break from her. I went through a period where I hated having to do everything for her. I wanted so much for her to walk, talk, feed herself, bathe herself, dress herself. I was so tired and so worn out I just felt like I couldn't do it anymore. It was at this point that I begged for the respite hours. I got special funding (until our DDA funding is approved) which allows for that one weekend a month. The first weekend she went, I was nervous and worried and paranoid, but when she came home I realized that changing her diapers and feeding her and all the stuff I do for her, isn't the end of the world. It's just part of being Kayla's mom. I am a much better mother because I get a little bit of me time each month. Such a small thing, but it makes such a big difference.

~ Beth

I've been through many caregivers and school helpers. I can't say as an older parent I feel that burned out. I feel energized by good care I managed to secure for my daughter. It was tough, but who said life is easy for anyone? Some of my caregivers in the home have been bad, too, but I learned how to get rid of them quickly and be more selective in the beginning. I also have a big respect for those who have stayed with us. It's a hard job to provide care for someone like my daughter who in very many ways is totally dependent on others. It's also important to like those you hire, however, and feel they're competent or else resentment can take over. It takes a lot of work to make a relationship that is beyond the money I'm paying for my daughter's care. I think we're in the same boat as our caregivers, anyway, and it helps me deal with their concerns over money. It's also harder than ever for anyone working to feel as if they are getting paid enough for what they do...I do get tired of the endless cycle of finding and keeping good caregivers: but that's the reality of providing care for my daughter- and if I look at her, I get re-energized and keep on. I don't think the parents of younger girls need to lose their optimism; it just helps to start out with a good dose, enough to keep things going.

~ Jane George

The important thing for us as a family at the moment is that we are surviving and that every day Jennifer teaches us something new and wonderful. We know that hard times are ahead but I hope we have left our darkest days behind.

~ Matthew Moss, Wahlsay, Shetland Islands, UK

I found that I was looking too far ahead and living everything a dozen times in my head before it actually happened or didn't happen as the case may be. I was completely exhausted when I actually had to do what I had been thinking about over and over. I just let things 'happen' now. When things do happen there is always something new to take its place.

~ Leita Boltwood

When I am to the maximum stress limit, it is always nice to go out, to have time with friends, to go to a movie and relax or go for a bike ride with our oldest daughter and get a huge scoop of ice cream. But when I become completely consumed and stressed with the daily life of Rett syndrome and all the accompanying aspects, I sneak into Ashley's room and stare at her...at the perfectly round face with beautiful eyes and lips. I think of how hard the regression time was, and the learning about Rett, the many supportive messages from others when the reality was hitting the hardest. I remember crying twenty times a day (coming from a person who cried only at my great Aunt's funeral). I remember how I thought there could never be anything that could hurt more in the world than learning that a part of me, something so little had something I could not fix! To sneak in Ashley's room at night and be thankful for having been able to have five minutes with her. To have her smile at me, to have her kiss me with a big open sloppy kiss and know that it was meant for me. To picture her unconditional smile when her sister wakes her up in the morning. I watch her lying still with no seizures and no stress and think that if she was not to wake in the morning, I would have benefited the most from knowing her.

~ Stephanie Sexton

I hold my daughter all I can, I hug her, I tell her I love her. She knows it, and she is "The Princess" of our household. But, my husband and my son are just as important to me. And in order for them to feel that love too, we take breaks from the day in day out Rett thing. We all have our limits. I know mine, but I also know that no one totally knows how much love I have for this child of mine.

~ Kandy Hallstrom, Idaho

I don't feel guilty for getting respite, and letting my son have some normal down time, some good sleep, some quiet mornings with just me. Katie is so loved in this family I cannot even begin to describe it. She is my world. But my gosh, I don't know what I would do if I didn't get time away, if I didn't get my son all to myself once in awhile, if I could never help him with his homework, if I could never have a quiet evening with my husband...

~ Kandy

As I learn more, Rett syndrome presents some challenges that draw out the creative side of me. As I work together with Angela's kindergarten team at school to figure ways she can be an active participant next year in a regular kindergarten class, I am energized. This is a huge challenge, and I feel the same kind of exhilaration as someone might feel climbing Mt. Everest as we figure ways to make it workable. But it admittedly has taken lots of work and researching and learning new skills on my part, which was a bit overwhelming at first.

~ Rose-Marie Gallagher

My wife and I have restarted to exchange a massage, with nice music and scented oil. I like to take an extended walk in the hills just behind the house. It is a perfect way for me to get grounded. We try to create a memorable day once in a while; we ask someone to take care of Tanja and her sister, and we go for a day hike, or to a very special restaurant, or to the spa, or into the city to see a performance. We only manage to do this once or twice a year, but I find it very important to have the feeling that we can have something like a normal life.

~ Rudi/ Heidelberg

Sometimes when my husband and I can get away alone together, we'll agree beforehand not to mention RS or anything related, and those times are very refreshing. There's also a key to that "beforehand" business. If I know my kids are going to spend the afternoon with Grandma at the end of the week, I can get through most anything because I know there is a light at the end of the tunnel. It's when there is no promise of a break in sight that I tend to get overwhelmed. I adore my kids, but we all know how intense the Rett stuff gets. Just knowing you can eventually--and hopefully regularly--expect a break from the intensity is very stress-reducing.

~ Rose-Marie Gallagher

I have the most trouble with relatives who subconsciously want to keep reminding me that I should be sad. It's very hard to see them anymore because they just don't get it that I'm happy from day to day and that everything Amanda does is magic. It seems that I cannot explain it to them either, because I have tried and they just don't see. When we go different places, I find that some people just automatically "get it" and some people never will.

~ Joy Maner

At first, because she was so little and our lives hadn't always been "special needs," people were sad for us...which reminded me that we had experienced a loss. It kind of fed into my sadness. As Angela gets older, people tend to forget that our lives haven't always included wheelchairs, feeding tubes, clinic days, therapy appointments, and on and on. That has become the norm for our family in their eyes, so they no longer express sadness. When they don't feel sad for us anymore, I don't have external reminders to be sad. There are family members and good friends who hold our pain tenderly, recalling the early normal days, and we still share good healing tears...but it isn't everyone we encountered, like in the early days.

~ Rose Marie Gallagher

I work at a group home part time and spend a lot of time helping an atypical Rett woman. The thing that really helps my stress level is that I have the choice to choose my own hours. I can decide when I want to go to the home and spend time with the woman and when I'm too stressed out in my life to log in some hours. Although, I try to be somewhat consistent with some kind of schedule. The other week, I was caught in a big snowstorm at the group home for two days straight by myself, taking care of four developmentally disabled adults. By the time I got home, I was practically in a comatose state! It took me about couple of days of lying on a couch and vegging out on television to get my energy back! This gave me a glimpse into the challenges that families who care for their disabled children every day deal with.

~ Leslie Johns

Frankly I don't care if people stare as long as they don't gawk. They are probably in awe of my daughter's beauty! I always hold my head high and look right at them and they usually smile like "our heart goes out to you" and I smile right back and think, "my heart goes out to you, too, because you have no idea what a gift I have been given!"

~ Shelley Schmidt

If you catch someone staring or glaring, take a deep breath, smile and say "hello." You may find they didn't realize they were being rude. I've caught myself seeming to stare at people -- non-handicapped -- when I'm really not staring at them but staring into space deep in thought but appearing to look in their direction. If this is what the person is doing, your greeting will bring them back to earth and you will be relieved to find out the stare had nothing to do with you or your angel. If the person was intentionally staring or glaring, your greeting will most likely embarrass that person and make him/her feel really small. And who knows, maybe they will watch their own behavior next time. People are social creatures. We can shape others' behavior by acknowledging rude behavior, but doing so in a way which embarrasses them, and not ourselves.

~ Johanna Billings

One time I got really mad at someone that was just staring and staring at Amber and was just about to blow a fuse at the person, when they commented on how beautifully mesmerizing she is! My dad thought this was hilarious as I was regularly complaining about people and how rude and ignorant they are. Now when I see someone staring I don't assume what they are thinking/they may not be thinking anything at all!

~ Rachael WA Mom to Jasmine

I go through phases of wishing for different behaviors from the people we encounter, but one wish seems to be constant: I want people to see Ellie as another human being who has all the same needs as anyone else in this world. I have never encountered a person who didn't have a basic need for compassion. That doesn't mean pity Ellie for having RS, or pity me for being the mother of a daughter who happens to have a disability. Just offer kindness. A kind smile. A greeting. Eye contact without fear or sorrow.

I do not mind questions, because I see questions as an opportunity to teach, even when some questions are in poor taste (i.e., "what's wrong with her?" or "is she retarded?"). As for children, I teach them that Ellie is exactly the same as they are on the inside. When I had to explain to my nieces and nephews how they should talk to Ellie and interact with her, I asked them to let me try to show them. Then I told them to hold their hands together and not let go for anything. They had to sit on one place on the floor. And they couldn't use their voice for anything but laughing and smiling if they liked what we were saying, or crying if they didn't. They had to imagine what it would be like to understand what was going on without being able to use their voice or move much. Then we had them imagine if no one talked to them just because they couldn't talk back, etc. The whole time, Ellie was sitting right there and smiling at them.

~ Mickie McCool

I think we never know how we will react until it really happens to us personally. Sometimes I think that some of the people who think they could never handle it when they look at us just would if it happened to them. They just don't

realize it because they never get the "opportunity" to step outside of themselves and serve another little human being in that way.

~ Joy Maner I was losing the essence of "my daughter" to the syndrome, to other caregivers, with everybody trying to tell me what I should be doing for/about her. I should do everything the teachers told me without comment or input. Even when I told them I knew her better than they did, they said surely I did not because they were trained/experts. I should keep my house spotless because it "looks" better to everyone like those who have their lives together. I should make her mind me! I should take her to the 30th doctor because surely he would know what to do. I should make her perfect for them so they'd be more comfortable with her around. She'd be better they all said. I was frazzled, nervous, sick, controlling, crying, and running around trying to fix everything from her IEP to her seizures to her walk to her hands. Finally I couldn't take it anymore and simplified my life. I simply made Amanda the person my number 1 priority with nobody else, except Joe. Eventually she began to come around, started eating better, became more affectionate, healthier and just a more wonderful centered human being, despite the things she still cannot do for herself.

~ Joy Maner

I have a very mobile daughter who we love dearly, but there are times that we needtime out, so I put a board across the hallway, which is close to the recreation room and her bedroom. I put her stereo on and she is happy to listen to it. She is so mobile and will jump on her brothers and sister as well as stand in front of the television or tread on their games...I do not feel guilty about doing this as I have to think of my other kids, too. They all deserve to have some time out from her...She does not mind going up the hallway and when she has had enough she will open her door and walk down hallway and climb over the board.

~Wendy Morris, Gillian, 13

If you collapse from exhaustion or simply have a nervous breakdown, your child with Rett has no one else who will help them with the same vigor and determination and love as you. We owe it to our children, to give ourselves a regular break to avoid getting to that point. It is also important to remember that you are entitled to a life, to other interests, to fulfil your dreams and so are your other children. Achieving this does not mean you are neglecting your child in some way; in fact you are serving her best by being content yourself and giving her a contented atmosphere to live in. This requires that you give yourself and your other kids time, which can easily be totally consumed with the practicalities of caring for your child with Rett.

~ Rachel Dine

Each family has to find the balance that's right for them. Some will take comfort in having their girls close at all times, and even having them sleep in the same room. Others will feel best if they can engineer some quiet time or privacy for themselves and/or their other children. It's not up to any of us to say that one way is right and another is wrong. But please, be absolutely sure you consider all of your children as you explore ways to find the balance that works for you.

~ Johanna Billings

My husband and I have a standing deal. Each one of us gets one weekend to do whatever we want, per month. For me the time is easy,.....shop, estate sales, flea markets, meet friends, movies or go to concerts. There's a chocolate factory not far away....that's always reserved for High Stress Alert Days. Diamondback Baseball Games....nothing like a screaming your head off while drinking a few beers. Or, driving to top of SouthMountain to watch the incredible sunsets. I love to explore the back roads of Arizona, in search of the perfect Margarita. Or best of all.....getting an inner tube and

floating down the Salt River with an ice chest tied and towed....just watching the world go by when it's 110! Life doesn't get much better than that! Think of an adventure!

~ Kathy Pryor

Depending on the nature of the stress, there are lots of alternatives. A lot of the time I take walks alone in the beautiful outdoors and I often pound the ground and send my stress through my feet right into the earth. It feels so good! I also love to go work out with weights at the gym. Because I write for a local paper, I often write when I am stressed...it fuels the creativity and gets it done, then I am not stressing on the deadline. I think we should do stuff that puts us in control over things; it makes the world less overwhelming. Working in the garden can definitely replace stress with a great kind of exhaustion, and I can bring bounty to my home with it. And yes, sometimes I even hang out with my goofy husband and watch a movie..... whatever it takes, and I am so thankful for every day that I am blessed with a good attitude.

~ Kristina Kelley

When I start feeling really stressed out, I know it's time to turn to others for help. I do not have family in the area and my mother-in-law cannot lift McKenna so I had to look for other resources. First, my husband and I went through the budget and made some adjustments so that we can have a woman clean our house every other week. I love coming home to a spanking clean house! Well worth the money if you ask me! Next, I applied for additional respite hours so that I can have time away with my husband to just go dancing, go to a movie or out to dinner or even by myself. I joined a reading club so that one night a month I can get away to talk with a group of strangers who don't know anything about me. I always try to schedule time away one night a week so I can relieve the stress and McKenna loves it because the sitters adore her and play, play, play. I think the key is to take care of yourself because when you are happy and rejuvenated, you will be a better parent to your angel.

~ Shelley Schmidt

It feels really good sometimes just to forget about the outside world. I have been trying to take one day a week and just doing what I want to do. Sometimes, I read, (then fall asleep!). Sometimes, I end up finding something in the house that really needs to be done and just start it. Then my mind is off the bad stuff, and really into what I'm doing. Some days, I volunteer at a local food pantry/kitchen. You will find that you don't have it that bad after you see what others are going through. And it really feels good to help others, even if it's sweeping their floors.

~ Brenda Sutton

I laugh to myself when people tell me they unwind with hobbies--HOBBIES? I have to choose between brushing my teeth and flossing them. There's no time for both, let alone a hobby! But you know, when I can sneak in a few minutes of sewing at naptime I do come away feeling amazingly refreshed. Something completely UNrett seems to be rejuvenating. There is so much with RS that is outside our control that sometimes just digging in where we do have some control can be a real stress reliever. So in addition to the physical benefits of exercise, there's some mental benefit of knowing we have control over that aspect of our lives during that moment. Cleaning can give that same feeling of putting something under our control again. Hobbies, if one can work out the time factor, could do the same.

~ Rose-Marie Gallagher

Any time I snatch for myself always brings me back to Jess...a happier, healthier and more refreshed mom. If I am weary, weepy, grouchy, and bitter, you can bet the best of vibrations are not flowing into my household and of what benefit would that be to anyone? I am so adamant about taking advantage of caregivers if you have them, because I regularly do not have that leisure. I love to do everything and anything with Jess...I just love being her mom. But in order to be the mom she needs I can't be a martyr and pretend I wouldn't love some help. The complete joy of Jess's love makes me strongbut...Rett is sooooo tough, it stabs every part of my heart, gnaws at my emotions, and often makes me cry.

~ Kristina Kelley

You cannot change the circumstances, the seasons, or the wind, but you can change yourself. That is something you have charge of.

~ Jim Rohn

For us, it has indeed gotten easier...slowly. I heard at a parenting-for-special-needs class that it takes about 3 years to come to terms with grief, and you know, I think that was really pretty true for me. Part of what makes special needs grief so hard is that you have to be strong for your kids, to be so present for them, when what you feel like doing is going away for a good long month and crying it all out of your system. But we can't do that, so the grief kind of lays dormant. It rears up its head in waves, constantly at first but less and less frequently as time goes on. Right now I don't feel sad every day, and I don't cry very often any more, though I still have some sad and teary moments...I have had to find creative ways to work that sadness out--when I'm driving alone, I tend to let it all pour out, and I usually feel lots better afterward.

~ Rose Marie Gallagher

I think that we will never truly come to terms with Rett. Sure, we love our Rett family members and friends, we can function well, be good people, get things done, and work to help our Rett loved ones be all they can be., etc. But the pain of the loss -- and their pain that we feel too -- will always remain with us and be a part of us. It's less important now that we've come this far, but it's always going to be there and feeling it is a normal part of life.

~ Johanna Billings

I will always have the unanswered questions of what her life would have been if not for Rett. But right now I have Chelsea as she is with Rett and every day I see her smile. I sit totally amazed at how she can wring her hands with just the right tilt and her fingers in extraordinary ways that I cannot duplicate. I watch her laugh and her eyes glow and then watch her manipulate everyone in her presence to do what she wishes. Then I have to decide maybe her little life isn't so terribly bad after all. She is happy and she has no chores or responsibilities. She has her way on everything about 99.9% of the time. So I mourn for me, not her. For the lost first date, and the prom dress shopping and never being mother of the bride. But I do not mourn for Chelsea, because other than illnesses which she might have had anyway, she has the life of a queen.

~ Andrea Parris

Give yourself time. You will be amazed at the life your family will lead. Yes, it will be very different from your friends and

other family. But the joy you and your family can have is unimaginable. My daughter Kimberly is 15 now, she has never walked and is a hand mouther. To me she is the sweetest angel ever sent to earth. Her giggles and laughter are music to my ears. No, she has never said, "I love you, Mom," out loud. But, she says it everyday with her beautiful all-knowing eyes. She gives me, my husband and her brother and sister those looks that just scream, "Oh I Love You So Much!" Yes, we still have days that are very hard, and the routines of medicine and feeding schedules can be wearying. But I would never trade my life with her for any other. Take care of yourself and give yourself time to grieve for the perfect child that is not to be. Then, you will see that what you have is a big blessing in disguise. Your daughter will be will be your angel here on earth.

~ Shelley Schmidt

This is not what I had planned. None of us did. But then I look at my 15 year-old daughter and she looks up at me and she smiles. She smiles with her whole being. She lights up her entire body with her smile. You know that smile, the one that money could not buy. The one that my "normal child" cannot give me. The one that touches my soul. And so I know that tomorrow will be another day, probably no better than today. But with it will come that smile. The one that makes me go on. My advice is to go lie with your daughter and watch her sleep. Touch her face so that you memorize it with your fingers. Thank the Lord that you can smell her breath as she sleeps. And when everything else in life gets so bad that you wish it would all just stop, think of her at this moment. How soft her skin is. How beautiful she was at birth. Her laugh. Her sigh. And her smile. That is what our lives are now about. And I don't know why, but it is.

~ Andrea Parris

As a Human Resource Director, every day, I subtly remind people that while their issues in the workplace appear to be of a great magnitude, there are most definitely bigger issues than a co-worker's snide remark or their direct deposit not going through. I observe the stress of 50 -100 people a day and wonder how they deal with the stress of their issues. I can only hope it is as easy for them as it is for me to find peace.

~ Stephanie Sexton

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