

## Caring and Coping

As parents of children with Rett syndrome, we face challenges - mentally, spiritually, emotionally and physically. We know that out of sight is never out of mind.

It takes strength and energy to pursue the diagnosis, make an appropriate treatment plan and find others who will support it, in addition to all of the many physical aspects of direct care giving.

Emotionally, we must cope with lost dreams for our beloved child, silent stares from an insensitive public and screaming spells that might last for hours, lost sleep we can't recover and relatives and friends who do not always support us.

We face financial challenges we never would have thought possible. It's a brave new world in this club we never wanted to join.

But having joined the club, we soon find that knowing that we're not alone is a big step toward coping.

We may look to family for support, or to professional counseling, community groups or religion, but may still feel isolated and misunderstood.

We often find that other families, those who live in our skin, provide the best cushion for the devastating emotions that accompany the diagnosis of Rett syndrome.

All parents take on the role of caregiver, but the special parent role is a more demanding one.

The difference is that in the typical situation, the need for so much attention diminishes after the first couple of years of a child's life. In RS, the need lasts forever and that's a very long time.

Someone said that raising teenagers is like nailing Jello to a tree. If that is true, I think we could safely say that raising a child with RS is like nailing the Jello before it gels.

The very basics of care giving include what we do every day -- feed, bathe, shampoo, put on deodorant, brush teeth, style hair, toilet, diaper, dress, and give medicine.

We may have to lift and carry her, help her walk, put on braces, reposition her for comfort frequently or change a bib for drool.

We might have to program and reprogram a communication device. We most definitely must know how to operate a VCR and have ESP for when it's ready to rewind or replace.

We have to learn to find the right professionals, schedule appointments and therapies, search for the right school and provide special equipment.

In time, we learn how to bargain for a shorter route with the bus driver, negotiate to increase therapy on the IEP when they're trying to convince us that less is more, listen to the advice and opinions of family members and friends who know a little but say a lot, convince the insurance company that yes, she really is handicapped (we're not making this stuff up), and keep our wits in public places when she screams, throws up or has a seizure.

It's no wonder we get tired. Taking care of all of someone else's needs for a lifetime is a task. No matter how much we love her, no matter how strong we are, no matter how good an attitude we may have -- it is a task. It's a labor of love for sure, but it can be a lot of work.

Most of us do what we can to provide for others' needs first, because there is little time for everything. The other kids need time and attention and there is not enough of either for all.

So we divide it up as best we can and leave ourselves what is left over, usually nothing. Then, while we're not looking, we may become resentful and tired.

All too often, we find ourselves at the bottom of the care list. And then we find that our cope runneth over. We may become exhausted, discouraged and depressed.

That's when we need to take a really hard look at how we're doing things and the effect it has on us. We learn that to be really good caregivers, we must first take good care of ourselves.

The passage of time helps us better understand that we can't take the RS away and our possibilities of changing it are limited. We can't erase it, so we have to face it.

It is important to do all that we can, but at the same time to recognize that we can't do it all. We can, however, find ways to maximize what we do and minimize the challenge. While we can't take away the RS, we can make important changes that will make a difference like better therapies, new communication methods, or environmental modifications.

We can find ways to manage the stress of care giving, beginning with being good to ourselves. Here are some ways to do just that.

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