

Finding Rest

By Marla G. Nowak

At twelve months my little fellow with Down syndrome put a donut in the VCR. This was a foreshadowing of things to come. Whatever curiosity gene possessed my boy to experiment at age 1 has followed him to age 13.

Today's summertime lazy morning had me feeling good with a song in my heart. Then I went upstairs. Daddy's shirt was arranged neatly on the ironing board, the hot iron face down on top of it. My "helpful" son had contemplated ironing, and then walked away. Now, the song in my heart should have stayed. After all, the fire I instantly imagined did not happen. God allowed me this discovery, and I'm grateful.

Parenting a special needs child can be, among other things, wearying. Exhausting. Overwhelming. The fatigue factor packs a hard punch because the effort is so constant. Some of our children do not outgrow behaviors or mature like typical children. Many of our children lack good reasoning skills and impulse control. Until you encounter a fairly trustworthy child who can in a heartbeat make a very careless decision, you may not quite understand the level of responsibility felt by the parents of some children. Parents of toddlers experience this for a season, but some of us might for a lifetime. Time and experience do not teach us to mellow. While we put our children in God's loving hands, we'd also better pay attention.

If ...

You have three door locks to keep someone in,
Your clock is set nightly so you can wake and monitor your child,
You hold your adult child's hand in public because he wanders,
Your 17-year-old still occasionally colors the walls with a marker,
Your son needs help blowing his nose or using the pottie at 19,
An entire stick of butter might be spread on one piece of bread,
Obsessive behaviors control your child,
Self-injurious behaviors or violent outbursts are a constant threat,
You cannot run to the store without packing the meds,
You are brushing someone else's teeth for 16 years,
You send your 27-year-old to her room,
Your child sobs but cannot communicate or generalize pain,
Your son can't go to Sunday school because there is no helper for him,
Your daughter could be very easily physically taken advantage of,
... then you, friend, may be able to relate to the fatigue encountered by some parents of special needs children.

Some parents whose children are very young may not have yet dealt with ongoing issues. Parents whose children are high functioning, or who have a good support system, may not experience the depth of the disability that others do. Some parents may struggle daily.

Many days, “inconveniences” are met with strength, grace, and even humor. We love and cherish our children for who they are. All children, all people have weaknesses and are demanding. Our children may have a different set of demands sometimes. We deal with it. We love them. We find joy. Most days.

Other days we are weary.

Fatigue may come from the need to advocate medically and educationally. Staying on top of the health issues with therapies, stethoscopes, needles, G-tubes, oxygen, and appointments gets tiresome. As our children progress through home education, we may, like many mothers, struggle with doubt. Doubt is draining. We encounter seasons when our children do not seem to make much progress or when they have setbacks. One year they amaze us; the next they struggle with some basics. Day after day after day, we keep plugging away. We listen to ourselves and realize we are not encouraging and cheery. Instead we hear ourselves saying things like, “Try harder! Why can’t you get this?” Then the guilt of our impatience drains us. Lord, we are sorry.

Discouragement tires us. Your 10-year-old son wets himself at a sporting event. You have a very messy eater, and the other children scoot over and stare. Maybe your child refuses to speak because he knows he is not easily understood. Maybe your child is extremely anxious. Maybe her friends outgrow her. Maybe she is too outgoing, huggy, and touchy. Maybe your relatives think you don’t try hard enough. Maybe other children giggle behind her back or tease him to his face. Maybe someone cruelly told you, “You didn’t have to have him.” Maybe your typical children feel forgotten at times because of the demands of your special needs child. Maybe your children are never invited anywhere like other children are. And worse, maybe they ask you why.

Maybe you’ve been approached about your child’s behavioral problems and the need for “discipline.” The easy “solution” is offered. You already know there are issues. You try. You dread another incident where you overhear whispers. Maybe your medical bills are so high that you are broke. Some parents have personalities that advocate well, maybe even push. Some tire of pushing and some say no, this is mine to deal with—alone.

Fatigue makes everything worse. Not all days are difficult, but when they come, they are heavy. You hate feeling like the martyr, the victim, but some days you are not a cheerful person of faith. Your entire family suffers from your discouragement. There are many problems with your fatigue. Find solutions.

Find Rest in God

We must remember our children are equipped to do all God has called them to do. And so are we.

When we are weary like David, we remember his lament:

“I am weary with my groaning; all the night make I my bed to swim; I water my couch with my tears” (Psalm 6:6).

God will give us rest as He promised:

“Come unto me, all ye that labour and are heavy laden, and I will give you rest” (Matthew 11:28).

We are weary, but He is not:

“Hast thou not known? Hast thou not heard, that the everlasting God, the Lord, the Creator of the ends of the earth, fainteth not, neither is weary? There is no searching of his understanding” (Isaiah 40:28).

He will enable us to be refreshed:

“But they that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles; they shall run, and not be weary; and they shall walk, and not faint” (Isaiah 40:31).

“Thou wilt keep him in perfect peace, whose mind is stayed on thee: because he trusteth in thee” (Isaiah 26:3).

He will strengthen and keep us.

Jesus is truth, and the enemy is a liar. We must abide in God, because the enemy will come to us without invitation. He will come at the most opportune time as he did to a hungry, tired, weary Jesus. If we possessed the ability to always stay “up,” Jesus would not tell us, “Do not be weary.” The implication is that we will be weary. We are going to be tired, or He wouldn’t need to give us rest.

It's easy to feel depressed and frustrated. It's hard to be patient. Patience is not a carefree personality. Patience is hard work, tiring work. We need to learn to abide for rest, for peace, for hope. We must hear Hebrews 4:16: *"Let us therefore come boldly unto the throne of grace, that we may obtain mercy, and find grace to help in time of need."*

Find Physical Rest

Sleep well, exercise, eat healthfully, relax. Bitterness can be disguised exhaustion. Rest will optimize your coping ability.

Find Rest with Others Who Understand

Find a friend or a group whose child or children have similar disabilities. Understanding can bring courage, laughter, solutions, and ideas. One parent said, "With these families, I feel normal." My son agonizes over high-pitched sounds. One Sunday a solo at church unnerved him. He sat curled up, tense, fingers in his ears. Some will criticize. A person who understood approached me, saying, "Your son was really in pain. Look how he sat, quiet, tried to deal with it." Instead of feeling uncomfortable, I felt pleased that my son did not leave the service running, and I felt God's grace and encouragement. People who have experienced a particular difficulty are often best at comforting and encouraging those with similar difficulties.

Find Rest in Christian Community

The feeling of isolation is not uncommon for families with special needs, even in church. The parents whose autistic son cannot attend Sunday school because "He doesn't follow directions" can explain it. On the other extreme, you find a child sitting on the floor in the corner, biting her nails, not moving or speaking, for two hours. Smiling, the VBS teacher says, "She was no trouble." Parents have been told, "Your child is no different from any other child and needs to be treated the same way." Tell that to the parents of the 11-year-old who left Sunday school class to go to the bathroom and was found walking down the road a quarter mile away.

Special needs ministry is overlooked in many churches. Some families stop attending church. They don't expect others to take their child for the weekend or even an evening. They would like more than "Your family is a blessing. God knew you could handle this," and a smile.

Many parents do not want to ask for special help. They know their child is different and may cause "extra work." As "ambassadors for Christ," as God's fellow workers, church family should be able to minister to all children and adults. Jesus seemed to go out of His way to find what the world considers weak. The brain of the most profoundly impaired individual and the most brilliant human mind are both far removed from God's wisdom

and brilliance. In comparison to God, I'm not sure you could measure the difference in the two. All people need to be ministered to.

Value and ministry should not be performance-based. Special needs people need to hear the truth and experience Christian love. Though the mind and body may be racked with profound disability, the spirit can thrive. If your child cannot be part of your church family, you may want to pray that God provides such a church family.

As homeschoolers, most of us have learned to dismiss weak socialization arguments. However, special needs children may have less opportunity. Some have personalities, abilities, or conditions that allow lots of interaction. Many don't. Parents must be careful since many special needs children are at high risk for abuse. Yet parents should find some community for their child (especially those with little extended family). Many special needs individuals are lonely, especially as they age. Seek trusted community.

As parents, we sometimes worry about today and even more about tomorrow. I know I do. My children have wonderful siblings who are devoted to them. Still, none of us knows what the future holds. Who will ultimately care for our children? Let's seek to find rest in the Lord. He will care for them.

Marla is delighted to have accomplished her childhood dream of being a wife and mommy. Originally from the Shenandoah Valley, Marla is still a small-town girl at heart and cherishes her family and faith. Presently in their eleventh year of homeschooling, she and her husband are the parents of seven children, including two children with Down syndrome and two children in Heaven lost to a rare pulmonary disease.

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Originally appeared in The Old Schoolhouse® Magazine, Summer 2007. Used with permission. www.TheHomeschoolMagazine.com