



Complex Child E-Magazine

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Saving Your Sanity through Respite Care by Dawn Hoskins

Over five years ago, we were blessed with a beautiful little girl who is the definition of high maintenance. Our little blessing has A LOT of special needs. However, because of all the respite care we receive, we survive and continue to thrive.

At first, we had no idea about the wonderful world of respite care. All we knew was that our little girl's monitors were constantly going off, and her feeding pump needed lots of attention, especially at night, which meant that we just didn't sleep. Our routine was to feed and medicate baby, fix the pump, take her vitals, try to do the laundry, clean syringes, continue to hold the family together, and feed the rest of the family. Repeat eight times a day.

At around the three month mark we collapsed. We kept it going, but we were running thin. My mother-in-law suggested that we hire a nurse and she would pay for the nurse. This was an offer we couldn't refuse. I called around and found a wonderful lady and she started the next week. She would come in the mornings so I could finally sleep and my husband could drop our other daughter at school and head to work. Life was now doable again.

Finding Respite Care

At the six month mark, my mother-in-law, a teacher, asked why our county Regional Center, our local agency responsible for assisting young children with special needs, was not involved. I didn't even know what a Regional Center was! She gave me the name and number of the Director of the Regional Center of her county. I called the number and spoke with the first person who truly understood the gravity of our situation. She promised that someone would be contacting me the next day.

The Early Intervention case manager from our county's Regional Center called the next day. She wanted to come to our house and evaluate our younger daughter and to "see how we coped." She was stunned, to say the least, that no one in the hospital had told us that services were available for a child with such extensive needs. She arranged for an evaluation for physical therapy, occupational therapy, speech (feeding) therapy, and respite care vendored through a local nursing agency.

The next week this evaluation took place. We found out that our daughter qualified for

every service they had. We, however, being firmly middle class, decided to only accept those things we could not supply ourselves. Our main interest was the respite care. In our daughter's case, her respite care was provided by a skilled nurse due to the magnitude of her medical needs. Many other children, however, receive respite care from a lay provider, a home health aide, or even a trained and paid family friend or relative. As is typical, we were allotted a certain number of hours a month, and no, they don't roll over if we don't use them.

We could have never have known what a HUGE blessing respite care would be. It turned a home that revolved around the care of one member into a home that revolved around the entire family. It gave us back the most important part of our lives.

Adapting to Respite Care

Initially, it was a bit rough. I have a very high bar for anyone who wants to care for our younger daughter. I had the first right of refusal, was initially responsible for training each nurse who cared for our daughter, and could fire a nurse on the spot. I started as a harsh task master because these nurses were, of course, handling my most precious treasure.

We talked our current nurse into applying to the nursing agency that was vended through our Regional Center. She was hired and became our first respite nurse.

We set up a training schedule with the agency for any nurse they sent to us. The first day, the new nurse shadowed the current nurse. On the second day, the new nurse worked with the old nurse supervising. The third day, the new nurse shadowed me. And on the fourth day, the new nurse worked alone with me available to answer any questions. At that point, I could usually tell if the nurse was a good fit, or better suited for a different type of child.

We have had to let several nurses go for various reasons, but currently we have two regular nurses and one fill-in nurse. We have had the two nurses for three years now and our families are good friends. I understand that being friends with the families is not normal, but we do live in a very small town and one of our nurses is our Pastor's wife.

Positive Changes

To say that respite care has changed our lives would be an understatement. We are now confident that if we are not home, our younger daughter will be well taken care of. We can participate in our older daughter's schooling. We can do volunteer work. My husband can go to work at a normal time and not fall asleep at his desk. I have time to cook dinner, do laundry, and walk the dogs. I can occasionally get out to lunch with old friends as well. Respite care has brought some normalcy to our family.

Each month I do have to come up with the nurse's schedule and submit it to the nursing agency. They usually accept it as is, but occasionally, changes need to take place. Flexibility is an asset with respite care.

If a child needs respite care, and her insurance only covers two hours a month like ours did, calling the local agency responsible for services is a good place to get information. Local pediatricians, the nursery at the hospital, and local special needs organizations are good sources of information on what is available in your area.

Respite Resources:

- ARCH Respite Locator: <http://chtop.org/ARCH/National-Respite-Locator.html>
- Your local Early Intervention Program
- Your state's Medicaid/HCBS waivers
- Your state's program for people with developmental disabilities
- Your local Easter Seals: <http://www.easterseals.com>
- Your local UCP: <http://www.ucp.org>
- Your local ARC: <http://www.thearc.org>
- Local religious organizations such as Jewish Children's Services or Lutheran Children's Services