

# FINfacts



A publication of the Family Information Network of Ohio  
for families with young children.

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## Yes, It's Stress

By David Whitehurst, Editor

**W**hat exactly is stress? As defined by *The Merriam-Webster Medical Dictionary*, stress is “a state of bodily or mental tension resulting from factors that tend to alter an existent equilibrium.” How does this definition apply to families and parents? A family or household has developed a set of day-to-day routines and behaviors that keep it in a state of equilibrium, a kind of normal balance. Bringing a major change, say a newborn baby, into the house will naturally disturb this balance, and all members of the household will feel the “tension” (stress) of adjusting to the needs of the new arrival. When the new arrival has a set of special needs which members of the household do not expect or do not fully understand, the stress is magnified.

Deanna Albrigo, a mental health therapist at Akron Children's Hospital Medical Center, has worked closely with parents of children with special needs, and she knows that these parents feel great stress. Albrigo also knows the causes of this stress very well.

“Stress begins immediately with the diagnosis,” she notes. “While she is pregnant, a mother may find out from her doctor that her child has Down syndrome. She begins to worry, ‘How am I going to care for this child?’” As she learns more about the medical problems her child may face—for example, heart and feeding issues—her stress increases and deepens.”

Very soon after the birth, parents of a child with disabilities may begin to grieve the loss of the expected child—the typically-developing child—and begin to face the unanticipated and often unique demands of raising a child with un-typical needs. Many of these children

require a kind of medical assistance which is unfamiliar to the parents. Many of the children also develop typical behaviors - eating, walking, playing, and talking - in different ways and at different rates. The new family situation requires more thinking, more decision-making, more uncertainty, and, therefore, creates more stress.

Telling family and friends about the diagnosis is in itself problematic. A parent may wonder: “How much will others understand about my child with special needs without my providing them medical details? How many of these details should I tell? Do I feel comfortable explaining my child's condition? Do I feel comfortable not explaining my child's condition?” Because parents have entered what might be termed “unknown territory,” all of these decisions are difficult and unfamiliar.

Even after the nuclear family becomes more comfortable with the new realities, parents face challenges in the larger community. “Sometimes family or friends will make negative comments without thinking. It can be very hurtful... Every new parent wants to be congratulated, and that may not happen in the same way.” Albrigo adds, “And it may be difficult to find reliable caregivers. Often even loving family members are not comfortable caring for a grandchild or nephew with special needs... Although these parents have more need for help and support, they often have fewer people willing or able to provide it.”

In a public setting, a parent may worry that other people will not accept her child's behavior, especially when that child is not able to express himself in an easily-understandable way. Albrigo adds, “A parent may wonder, ‘Will my child be made fun of?’ And when the

child acts in an unexpected way, will others think, ‘Why can't you control your child?’” These concerns may lead a parent to limit the number of trips outside the home, further isolating the family and reducing the child's important contact with the larger community and its benefits.

Not only is home and public life changed, but work life is also affected. “Often children with special needs may have multiple doctors' appointments, physical therapy, occupational therapy, speech therapy. Who takes them to these appointments? If the parents take off work, they may not be getting paid.” Because of these often-increased care demands for the child and limited help from others, a mother or father may not be able to return to work as planned. “A parent who enjoyed his or her career and had an identity based on it, now must adjust to the very different role of a stay-at-home parent.” The result? Stress.

Once the child with special needs enters a day-care, pre-school, or play setting, other stressors emerge. Albrigo notes, “Parents of children with special needs may not engage easily in conversations with parents of typical children about their child's growth and development. Often teachers and helpers in these settings may not be adequately prepared for the particular needs of a child with special needs, leading a parent to wonder if her child will be educated appropriately.” In a school setting where the staff is well-prepared to teach the child and meet her special needs, parents can be overwhelmed by the educational planning meetings. “Often the language used and the process followed are unfamiliar and confusing.”

The combination of changes at home, in the community, at work, and at

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school creates strains in the marital relationship. Each parent may feel both overworked and underappreciated. Each may feel that she or he has made the most sacrifices for the family, or that he or she is working harder than his or her spouse to support the family's needs. At this uncertain yet demanding time, when cooperation and collaboration are needed most, the necessary gathering of forces and coming together by spouses may become even more difficult.

A grim picture? It can be, but according to therapist Albrigo, there are many healthy and effective ways for parents to reduce stress. In her work as a provider of the Positive Parenting Program (Triple-P) at Akron Children's Medical Center and teaching the Stepping Stones curriculum for children with disabilities (ages 0-12), Albrigo has developed several good recommendations:

- Talk with other parents who have children with similar disabilities. These parents, especially if they have been raising their children for a longer time, can provide you with practical ideas about how to handle everyday situations (dressing, eating, riding in the car, communicating, taking medicines, defusing upsets, among many others). In addition to this information, these parents can offer you emotional support not provided by those who haven't experienced the demands of raising such a child. They will be willing to communicate honestly and completely about the challenges and joys of raising a differently-abled child.

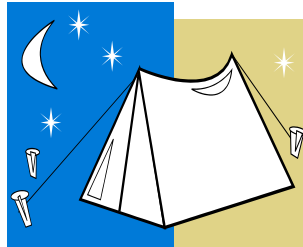


- Join a support group. These groups also help with information and support. In

addition, they plan fun social activities for both parents and their children. Importantly, they also monitor and report about the research on medical and adaptive advancements which could be helpful to parents as

the years progress. Examples of these groups are Upside of Downs and Autism Speaks, but many other good support groups can be found by searching on-line.

- Use available community resources. County Boards of Developmental Disabilities



often run camps for kids during different seasons, and community centers host adaptive sports programs for kids with special needs (baseball, swimming, bowling). Some theaters help families by sponsoring a movie night with lights on and volume down for kids with extra-sensitivity to sensory stimuli.



- Use the Internet to get necessary information on treatment, medications, adaptive equipment, and advice about how to manage various life activities.

Help is just a click away!

- Make friends with a parent of a child with special needs like your child's. This friend can be a very helpful and experienced child care helper. Take turns babysitting with each other's children to gain some valuable time for yourself and your spouse.
- Be sure to take care of yourself and your needs. Carefully plan sleep, exercise, and recreation, and don't forget activities with your spouse and friends.
- A child with special needs often relies on routines and schedules. Prepare your child for any changes to



that normal routine. If you are going to visit Uncle John, show your child photos of him and talk about what he or she can expect at Uncle John's house.

- In addition, tell your relatives what to expect when you visit them with your child. If necessary, tell them, "I may have to come early" or "I may have to leave early." Good communication helps!
- When going out of the house for some reason, carry a "Bag of Tricks" with food, drinks, toys, and other things which may provide comfort or distraction for your child. This precaution may help to prevent unwelcome behaviors at unexpected times.



- Plan shopping trips wisely. It might be better to go to smaller stores or to shop at less busy times. When you are in a store, know the exits and the best places to take your child if you need privacy to handle common or uncommon needs.
- Take "comfort" foods for your child when eating at a restaurant to avoid problems with food selection.
- Set realistic expectations. If you encounter a challenge with your child, don't fret. All children are challenging!

A final thought: Parents of children with special needs will feel stress. Adjusting to this natural stress will create a new equilibrium, a new balance, in the life of the family. And it is this new balance, and this new strength, which many parents value most.

**Check out the new  
Webinars listed  
on Page 4!**

## The Aldoys' New Normal

By David Whitehurst, Editor

In early 2008, when John and Jennifer Aldoy planned their summer move from North Ridgeville, a Lorain County town west of Cleveland, to Findlay, Ohio, they knew it would take some time to adjust to their new surroundings and their new family situation. After all, John was starting a new job at the Ford Motor Company in Lima, and Jenn was leaving her job as an office assistant in downtown Cleveland, a job she really enjoyed. But those were not the only big changes they faced. Along with their 3-year-old daughter Audrey, the Aldoys would be taking a baby, not yet born, to their new home in northwest Ohio. As the move approached, they felt both the hope of good things to come and the stress of leaving the family's normal routines, their comfort zone.

But even with the best planning and preparation, events can overtake us. To paraphrase the Scottish poet Robert Burns, "The best-laid plans of mice and men often go awry." The Aldoys know this truth well.

Jenn gave birth to their son Jonah on February 25, 2008 after a typical labor and a full-term delivery (38 weeks). But when Jenn was holding her newborn a short time after his birth, she noticed that he was not breathing. The doctors rushed to Jonah's aid and saved his life, but the lack of oxygen to his brain had caused serious damage. Jenn was told by the hospital staff that brain injury in a child begins after four minutes without oxygen, and they estimated that Jonah was without oxygen for about 25 minutes.

Jonah was transferred to the Level III Neonatal Intensive Care Unit where he was placed in a chemical coma until the doctors were able to stabilize his condition. Because of Jonah's fragile health, Jenn and John were at the hospital nearly round the clock during their son's stay.

Fortunately, John was able to use his Family Medical Leave (FMLA) benefits to take time off from his job. Jenn recalls, "We saw Audrey only in the mornings for nearly two months. I told myself that she was too young [age 3] to remember all of this, but I felt terrible about not spending much time with her." Jonah spent 41 long days in the hospital under-

going numerous tests, treatments, and medications before he was finally able to go home to his family on April 5th. Those six weeks (and the months following) were very stressful for the Aldoys. They met with specialists and hos-

moving all of your earthly possessions to a new house in a new city! The Aldoys were overwhelmed.

They completed their move on July 7, 2008. Jenn sums up their situation on that day. "We were in a new town with no family, no friends, NO HELP. And we were dealing with Jonah's doctors' visits and all of his physical challenges and delays. We were exhausted." Back at his job, John worked long days, and Jenn stayed home all day to care for Audrey and Jonah. "When John came home, I needed a break. But he needed a break too. At times I was jealous that he could have a life separate from our home... It was hard. At times I didn't think we could keep it all together."

But they did keep it together, and

they found ways to reduce the stress they were feeling. Doctors clarified Jonah's diagnosis. Although his general health is good, the early injury, possibly caused by persistent pulmonary hypertension of the newborn (PPHN), had damaged his brain's cor-

text. Jonah has cerebral palsy and cortical vision impairment. (The optic nerve does not send its signal properly.) Jonah can see shadows, high contrast, and bright colors. Other effects are significant delays in other developmental tasks--speaking, eating, moving, and even smiling. [During these days Jenn worried that her son would never smile.] Clearly, not all of the medical news was positive, but clearing up the uncertainty made Jonah's daily needs more understandable and manageable for Jenn and John.

In mid-July 2008, the Aldoys met and spoke with Cindy Bregel of the Family Information Network (FIN); later Jenn and Jonah began working with a Help Me Grow (HMG) service coordina-

pital staff nearly every day to get updates on Jonah's complex brain injury. Jenn

remembers thinking, "How do you know if the decisions you've made for your child are the right ones? I assume many parents of special needs kids ask themselves these questions often. Am I taking him to the right doctor? Is he getting the right therapy? Do the benefits outweigh the side effects of medicine? Am I doing what's best for him?"

At the same time, while their son Jonah was being "poked and prodded" by the hospital's nurses and doctors, the Aldoys were also busy moving their belongings to an apartment (and a storage unit) while they worked on their Findlay house -- cleaning, painting, hanging blinds. Imagine taking care of a tiny newborn with serious medical needs--not to mention a three-year-old-- and simultaneously attending to all of the details of



Jonah Aldoy



Audrey, John, Jonah & Jenn Aldoy

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tor, Bailey Anderson. Soon HMG was providing specialists who came to Jonah's house to give him the physical, occupational, and speech therapy he needed. They also provided information about adaptive equipment to help Jonah stand, sit, and travel in the car. The therapists and consultants helped to move the Aldoys from "no help" to "good help." Jenn believes, "Had I not found Cindy on that night, I don't know where we would be now."

In November of 2011, another major family stress—financial stress—was lessened. Jonah was approved for an Ohio Home Health Care Waiver. "Jonah now has two wonderful nurses who care for him while I work a few hours during the day," Jenn remarks. "This allows me to

be at home at night with my family. I remember being a kid and having dinner as a family every night. It is a staple I wanted for my own family." The Aldoys are developing their new comfort zone.

Family and friends also began to respond to the family's changed dynamics. "Our neighbors and coworkers also offered their constant understanding, care, and support. John and I connected with other parents of special needs kids and shared our concerns and triumphs, no matter how small! Through this experience with others, Jenn learned a key, stress-reducing lesson: "If you are offered help, TAKE IT!"

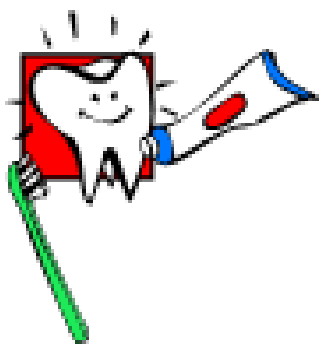
Jenn has special praise for husband John. "When I started working nights in 2009, he did most of the 'mom' duties: dishes, laundry, homework, playtime,

bath time, Jonah's medical needs, Girl Scouts, soccer. Seriously! Who could be so lucky? ... And he didn't complain about having to do these things. He just provided!"

Jenn also found another way to reduce her stress. She expressed her feelings—her fears and successes and worries and joys—by posting comments at [www.caringbridge.org](http://www.caringbridge.org), a site devoted to people with medical needs. (See her posts by using the website name *jonahaldoy!*)

Now the Aldoys enjoy "a new normal." Jonah, a soon-to-be-four-year-old, attends the Blanchard Valley Center Preschool in his Ohio-State-inspired, scarlet and gray wheelchair. And although Jenn and John were not always sure it would ever happen, their special son Jonah often can be seen with a big smile on his face.

## FIN Webinars



### "Don't Leave Dental Out of Developmental Assessment"

Wednesday, February 22, 2012

10:00 – 11:00 a.m.

**Speaker:** Paul S. Casamassimo, DDS, MS, Professor and Chair and Chief of Dentistry, The Ohio State University College of Dentistry and Nationwide Children's Hospital, Columbus

#### Session will help us:

- Understand what families need to know about dental care for children birth through five
- Understand what to look for in choosing a dentist for children with disabilities
- Recognize common dental problems that young children with disabilities may have
- Understand the physician's and dentist's role in caring for young children

#### Upcoming Topics

Down syndrome - Wednesday, March 14, 2012 at 1:00 p.m.

Hearing - Wednesday, April 18, 2012 at 1:00 p.m.

Please check our website, [www.akronchildrens.org/fin](http://www.akronchildrens.org/fin), frequently for updated information on upcoming educational Webinars.