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to live in the present and taking one day at a time; reassessing priorities and refocusing their energies accordingly; sustaining their own emotional well-being by staying calm and taking time to reflect and meditate; practicing good health habits including exercising, eating nutritious meals, and getting enough rest; and finding supportive others for emotional and practical help. Many families draw sustenance, hope, and an acceptance of their circumstances from their religious beliefs, which often are deepened or renewed following their child's diagnosis.

Mind matters

One of the most remarkable features of how many families cope is related to how they *think* about their circumstances, their family, and life in general. This is sometimes referred to as "appraisal" coping. It relates to how families define specific stressors and strains as well as available resources. In other words, rather than seeing the sources of stress as too big to be surmountable, they are reduced by focusing on only part of the problem (for example, "one day at a time"), or seeing their child's needs as much less demanding or difficult than those of another family's child.

Similarly, parents pay attention to what they have for managing the situation. This means acknowledging the strengths in their spouse, their other children, as well as community resources, such as health care providers and educators. Given the overwhelming chronic demands these families face and the real limits they encounter in finding more resources to help them, they are left with changing the way they think about their situation as a way to achieve balance and reduce distress.

In addition to appraising their circumstances in a way that makes them manageable, many families seem to find new meaning for their life. Having a child with such severe medical needs and such a tenuous hold on life shatters the expectations of most parents for how life is supposed to be. It leads to a search for meaning as a way to accept their circumstances. When families get to this place, they not only accept their child and their family's life, but they often experience a kind of gratitude that those of us who have never faced this level of hardship can't really understand.

Joän M. Patterson, Ph.D.

A sense of coherence

In his description of Holocaust survivors, Aaron Antonovsky called this orientation to life "a sense of coherence." This is an abiding belief that life is meaningful, comprehensible, and manageable and that things will work out the best that they can under the circumstances. In contrast to our Western preference for always having personal control over our lives, coherence is a balance between internal and external control. Many of these parents are able to accept what cannot be changed, while simultaneously working to make the best life they can for their child and their whole family.

Medically fragile children represent the extreme end on the continuum of children with special health needs. The impact on the life course of the family and its members as well as the financial and emotional costs are enormous. Some of this burden and cost could be lessened if we, as a society, committed the resources needed to support these families. Collectively, we already have committed resources to the research and development that has enabled medicine and technology to save the lives of these children. Now we must commit the resources needed to ensure that they and their families can have a decent quality of life.

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Change and Perspective

by Cynthia Bissell, R.N.

Seventeen weeks into my pregnancy, an ultrasound revealed that our first "child" would be twins! Our excitement and anticipation were short-lived, however. Eric and Aaron were born at 26 weeks gestation–three and a half months too soon.

Our lives as parents certainly got off to a rough start, as did the lives of our boys, who were immediately whisked off to the neonatal intensive care unit (NICU). When we finally got to visit them, it was difficult to see our babies among all the tubes and wires. They looked like tiny albino monkeys, covered with fine blond hair.

The Bissells: Eric, Aaron, and Anthony, with parents, Richard and Cynthia.

A roller coaster ride

The boys spent the next three months in the NICU, a stressful roller coaster ride that can be truly understood only by other parents of "preemies." Both boys had many of the problems common to prematurity, including hypotension (abnormally low blood pressure), respiratory distress syndrome, intracranial hemorrhages (bleeding in or around the brain), retinopathy of prematurity (an eye disorder), patent ductus arteriosus (a condition in which oxygenated blood flows back into the lungs rather than circulating to the rest of the body), hyperbilirubinemia (jaundice), and anemia.

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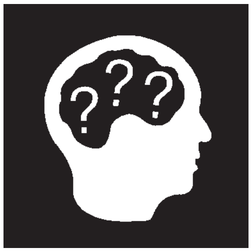
Sudden Health: The Experience of Families with a Member who has Surgery to Correct Epilepsy



by David B. Seaburn, Ph.D., Assistant Professor of Psychiatry and Family Medicine; and Giuseppe Erba, M.D., Professor of Neurology and Pediatrics, University of Rochester School of Medicine and Dentistry

Over 2.5 million Americans and their families are currently affected by epilepsy and an additional 150,000 are newly diagnosed each year. Persons with epilepsy may lose their faculties numerous times each day, speak incoherently, and become incontinent. They may not be able to go for a walk alone or boil water, not to mention hold a job, complete an education, drive a car, or maintain intimate relationships. The diagnosis itself carries a stigma that may force persons with epilepsy to maintain secrecy about their condition, withholding such information from employers, insurance providers, and friends.

Treatment for epilepsy may also present challenges. Side effects from anti-epilepsy drugs (AEDs) can have a dramatic impact on the person's quality of life. Person's taking medication for seizure control may experience tremors, sedation, poor concentration, mood alteration, headache, dizziness, ataxia, and sexual dysfunction. Unfortunately, despite aggressive medical treatment, approximately 31 percent, or about 360,000, of all persons with epilepsy live with intractable seizures that cannot be controlled through AEDs. These individuals and those who are close to them face the uniquely difficult situation of trying to manage the unmanageable. For many persons whose seizures are intractable, treatment options may involve more invasive procedures such as surgery.

Eligibility for surgery depends on the nature of the epilepsy—that is, how well it can be located as a lesion in the brain. For those who are eligible, though, surgery is remarkably successful, with

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Eric's most serious problem was bilateral periventricular leukomalasia (PVL), a brain injury in which tissue around the ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen. Eric has spastic quadriplegic cerebral palsy as a result of his PVL. Aaron needed a tracheostomy because of acquired subglottic stenosis (a narrowing of the area beneath the vocal cords and the opening between them), an unfortunate complication of his earlier need for a breathing tube. Because of damage to his lungs and airways, he also had bronchopulmonary dysplasia, a chronic condition that would always affect his breathing. Aaron has more recently been diagnosed with asthma, attention deficit hyperactivity disorder (ADHD), and learning disabilities.

An amazing journey

The twins are now 9 years old and the trauma of the NICU has gradually faded. We are amazed at where the twins have taken our family over the past nine years. When the boys first came home from the hospital, I was often housebound caring for two sick, fragile infants. I turned to the Internet for information and support. My computer became my link to the outside world.

I began building web pages as a way to network with other families and share our experiences. Since my husband Richard and I are both RNs, we had a bit of an advantage caring for sick babies. One of my web pages, Aaron's Tracheostomy Page (www.tracheostomy.com) has become the leading tracheostomy resource on the Internet. I have also published a *Pediatric Tracheostomy Home Care Guide,* which is currently in its second edition. Networking with other parents around the world who are dealing with similar issues as our family was extremely therapeutic, and it not only helped us to work through our past experiences, it also is helping us face the many challenges ahead.

> We are amazed at where the twins have taken our family over the past nine years.

The twins' hectic schedules of therapies, doctors' appointments, and surgeries made it difficult to work a regular job. I have gradually moved away from nursing and now build Internet resources. This enables me to work at home with a more flexible schedule.

Benefits of networking

Once the boys' health began to stabilize, Richard and I were able to begin networking in our own community. We attended our first Family Leadership Series in 1997. The Leadership Series is sponsored by Families Organizing for Change (FOC). FOC is a statewide, grassroots coalition of families with children and adults who have disabilities or chronic illness. The Leadership Series is a six-day series, which teaches families about leadership and advocacy. Richard served as FOC Regional Coordinator for two years and is now an employee of the State of Massachusetts, working with individuals who have developmental disabilities.

Through networking with other families, we found our third son, 9-year-old Anthony. Anthony has severe cerebral

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70 percent of patients being completely cured. We became interested in this population of patients and their families. We wondered what their post-surgery experience was since in most cases the families had lived with epilepsy for an extended period of time, often decades.

Six families

To explore the experience of these patients and families we conducted a qualitative pilot study in which six families were examined in depth. The family member with epilepsy in each of these families had suffered from the disease for an average of more than fifteen years. The study included a married father with three children; a single mother with one son and a supportive father; a wife with two teenaged children; a single woman living with her aunt and a friend; an adult daughter living with her parents; and a young man in his twenties who moved back home to live with his mother, stepfather, and siblings.

Each of these families agreed to be interviewed and videotaped in their homes twice, once just before the surgery and a second time six to eight months after the surgery. We learned that epilepsy has a profound effect on families in the long period before surgery. Many family roles are organized around epilepsy, with seizures being significant events that are seldom discussed. Families struggle with the stigma of epilepsy and try to establish a sense of “normal” life even though they readily admit that their lives don’t feel normal.

> Families had to deal with a new set of challenges brought on by their experience of “sudden health.”

Family responses to epilepsy

We found that families in the study responded to epilepsy in one of two primary ways. Families with a member whose onset of epilepsy was in late adolescence or early adulthood responded to the seizure disorder like trauma teams who saw the seizures as out-of-the-ordinary events that must be addressed so that they could return to their normal daily living. The epilepsy was often experienced as more emotionally upsetting in large part because the families could remember a time when the person was not afflicted.

In families in which the onset of epilepsy was in childhood, long before the person married or had children, we found a nesting phenomenon in which the family organized themselves in such a way that they could hold and protect the member who had epilepsy. Unfortunately, communication and relationships were also often woven around the member with epilepsy, leaving him or her more isolated and less involved in family life.

Dealing with “sudden health”

The post-surgery interviews revealed that each of these families had to deal with a new set of challenges brought on by their experience of “sudden health.” In each case, the surgery was successful, with only one patient reporting a single seizure. That was the good news. But what was unexpected was the difficulty that several families had in making the adjustment to the absence of seizures from their daily life. This was particularly challenging for the nesting families because much of their structure was organized around epilepsy as a normative experience in their lives. For them, the transition to having a “new” person in their midst was often difficult.

In one family, the father had surgery. He had been emotionally absent throughout his marriage. His wife reported that she didn’t like the fact that now he was “barking orders at my kids.” This family also struggled with personality changes in the father who was known as taciturn at best. Now he talked all the time, something that was annoying to several family members. He also began to parent his adolescent daughter in ways that would have been more appropriate for a

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palsy and was at risk of institutionalization. We were so happy to be able to adopt him and avoid that outcome.

A matter of perspective

Richard and I are often asked how we manage having three children with special needs. Well, we have learned that “problems” are all a matter of perspective. We discovered this back in the NICU when we were told that Eric had PVL and Aaron would need a tracheostomy. We were paralyzed with worry and fear, but gained some insight on our own situation by observing two other mothers. One woman was upset because one of her twins was temporarily under an oxygen hood; the other was despondent because one of her twins had died. All of us were grieving from different perspectives. We realized that although things could be better, they could also be much worse.

In less than a decade, our children have completely changed our lives. We have changed careers, met new friends, and become advocates for people with disabilities. We have also developed different philosophies and new perspectives. The boys have taught us about strength, endurance, patience, and what is truly important in life.

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