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## Mom and Dad need to find a loving balance

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From the time she was in second grade, Stephanie Hock has been an advocate for people with autism.

"We had to bring something special to school, and so I brought Louie," said the 24-year-old Paradise Valley woman, referring to her severely autistic younger brother.

"Kids asked about why doesn't he talk, and I just said, 'He was born that way.' "

Stephanie and her two other siblings, Adrienne, 25, and Richard Hock Jr., Louis' 22-year-old twin, say their upbringing was enriched, not ruined, by a young man who has never slept through the night and who demanded trips to McDonald's every two hours on weekends for the things he found most soothing: car rides and vanilla ice cream.

Their parents, Dana and Richard Hock Sr., took a team approach from the time Louis was diagnosed at age 2, spending one-on-one time with each sibling and taking separate vacations with them. They used relatives and paid help to stay home with Louis so they could attend their other kids' sporting events and school activities, and they remembered what a doctor had advised.

"Give him a lot of love, and remember you have three other kids and you need to get on with your lives," Richard Sr. said. "We decided Louie's handicap was not going to define our whole family."

In a world where parents of healthy kids usually struggle to achieve a work/life balance, parents of children with developmental disabilities and chronic illnesses are hit even harder.

Consumed by worry and overwhelmed by endless trips to doctors' offices and hospitals, these parents may be too spent physically and emotionally to fulfill their other responsibilities. They unwisely suspend the house rules for an ill child and are not in tune with the fears of the offspring who are well.

Experts say it's important for parents to take care of themselves as a couple first, to spend individual time with each child and to be as honest and open as possible, imparting as many facts about the disability or illness as their children can understand.

"Typically, parents are acutely aware that they're trying to spread themselves thin enough to cover everyone in the family," said Sue Levine, co-author of a report on siblings of children with Down syndrome, published Wednesday in the *American Journal of Medical Genetics*.

"The danger with a disabled child, especially where there are severe behaviors . . . (is that) they become the whole center of the family, and that makes everyone else take a more minor role."

Levine, a social worker at Family Resource Associates Inc. in New Jersey, said many children in her study said their parents are too lenient with brothers and sisters with Down syndrome. Siblings want parents to set limits on behavior and follow through with consequences.

Michelle and Stacy Tetschner's son Raymond knows he can't jump on the couch. But the 3-year-old tries it anyway, especially when *Barney* is on TV. So his brothers patiently collect him and redirect his attention.

Raymond, who has Down syndrome, was left at a Phoenix hospital by his birth mother. He came to live with the Tetschners, originally his foster family, when he was 2 weeks old, and they adopted him about seven months later.

Before making the decision, Michelle and Stacy consulted their sons, Stephen and Mitchell, now 15 and 12, because they knew it would impact everyone's comfortable routine.

"Their reaction was, 'Duh, we already knew that (he would be staying),' " Michelle Tetschner said.

The boys have benefited from having Raymond around. At Stephen's 15th birthday party, the toddler was the only boy who could get the girls dancing.

Stephen appreciates his parents' focusing on someone other than him, and Mitchell admits it's a good thing to learn to care for a baby, diaper changes notwithstanding.

"He makes us smile, smiles that we wouldn't have had without him," Michelle said.

The older boys put up with Raymond shuffling through their CDs - and usually licking them, too - and having to listen to the toddler's songs in the car. They have baby-sitting horror stories, like the time their parents were out and the police came to the door after Raymond speed-dialed 911.

For parents, that alone time is critical, said Janet Kirwan, family services director at Southwest Autism Research & Resource Center in Phoenix.

"Parents have to make sure they have their oxygen masks on before they deal with their children," Kirwan said, using the airline-passenger analogy.

"It's very difficult to provide your child with special needs (with) the sort of resources it takes if you are totally exhausted and strung out."

The Tetschners make it work by spending time alone with the older boys. They also insist the boys attend support groups and events for kids with siblings who have Down syndrome. The activities are part fun, part therapy for kids who often have concerns and questions but don't know how to talk about them.

Communication with siblings is key, said Wendy Pauker, a child life specialist in the intensive care unit at Phoenix Children's Hospital.

"Keep them in the loop as much as possible, bring them to visit, or if they can't come to visit, have them draw a picture or call," Pauker said.

## **A brother's battle**

Stephen Arias knows more about cancer than most 10-year-olds do. His older brother, Michael, was diagnosed with neuroblastoma in 1997 at age 3. For 2 1/2 years, his parents, Carla and Joseph Arias, exhausted their medical options, including a bone-marrow transplant in Los Angeles.

During the six months the couple and Michael were in California, Stephen, then 2, lived with his grandparents in Texas. The Ariases called and read him stories over the phone, and once, he flew with his grandma to visit.

"I expected him to run to me," Carla said, "and he just clung to his grandmother and that was it - I've got to spend more time with him."

As Michael's battle with cancer was nearing an end, his parents brought him home to die. Stephen learned to ask his mother about Michael's red-blood-cell counts, because if they were high enough, the boys could wrestle with their dad when he came home from work.

For two weeks in fall 1999, Michael was well enough to go to kindergarten. When Michael died Oct. 6 of that year, Stephen's parents told Stephen that Michael's body had stopped working and that he had gotten a new angel body.

But as the months passed, Stephen's mood began to change.

"He was fearful, cranky, angry and acting out, and we didn't know what was happening, and he couldn't tell us," Carla Arias said. "And he kept asking to sleep with scissors."

Stephen and his parents joined a support group, and a therapist figured it out: Stephen had been dreaming of Michael with his angel wings, and he rationalized that if he had scissors to cut them off, Michael would have to stay.

As the time came for Stephen to start kindergarten, he began to worry that he would get cancer and die, too, because that had happened to Michael the year he started school. Stephen, who had never had a relative or pet die, simply didn't understand the permanence of death, his mother said.

Pauker, whose duties include explaining to children that their siblings with cancer are dying, said the plainer, the better.

"We say the word 'dying,' not 'going to sleep' or 'passing away,' to avoid any confusion," she said. "We also make sure they know no one did anything wrong, that no one's at fault. We have to say, 'We don't know why this happened.' "

Stephen and his sister Gabrielle, 8, will go later this month to the American Cancer Society's Sunrise Sidekicks Camp near Payson for siblings of children with cancer. Carla said the ACS has filled a void left by the doctors and nurses who moved on after Michael died.

Gabrielle doesn't remember Michael, and Caroline, 6, was born after he died, but Stephen has his memories.

"He was almost always in the hospital, and we went to Toys 'R' Us a lot when he was finished with something," Stephen said. "He was always cheerful, he almost never went to timeout, he made a lot of friends."

## **Rewarding relationship**

Louis Hock never stood in the way of his siblings making friends. In fact, if you weren't willing to be Louis' friend, his brother and sisters could do without you as their friend, too.

"It was never, 'Keep it down' because of Louis, or only one parent can go to your recital because someone has to stay with Louis," said Stephanie Hock, who has a master's degree in special education and hopes one day to open a vocational center for autistic adults.

The Hock children feel they've gotten more from Louis than they've given to him.

"It grounds you," Stephanie said. "If you get upset about whatever, you look at him, and he gets excited about a cup of juice, and it puts life into perspective."

Both the Tetschner boys and Stephanie and Richard Hock Jr. argue about who gets to care for their brothers when their parents no longer are able to. The parents admit it's a nice problem to have.

"She's better with behavior modification and technical aspects," Richard Jr. allowed, referring to Stephanie. "But I *am* his twin brother."

## **Tips for helping siblings understand**

These suggestions on helping typical children grow up with siblings who have developmental disabilities or illnesses are from Sue Levine and Brian Skotko, authors of the report, "What Children are Thinking: Brothers and Sisters of Persons with Down Syndrome," published this week in the *American Journal of Medical Genetics*:

**Be open and honest.** Encourage your children to ask questions, and answer on their level. If they don't ask, periodically check in with them on their concerns.

**Allow siblings to express negative feelings.** Acknowledge it's sometimes hard to live with a child with a disability. Allow them private space and time.

**Recognize the difficult moments siblings may be experiencing.** Be aware they may be more sensitive in certain situations, and that always including the child with the disability may be uncomfortable.

**Limit caregiving responsibilities.** Kids need to be kids. Allow them to be brothers and sisters, not extra parents.

**Recognize the individuality of each child.** Point out what makes them special, and schedule special time with each.

**Be fair.** Listen to both sides of the story, and remember it's not always the oldest or most capable sibling who starts disagreements.

**Take advantage of supports for siblings.** Contact local and national groups for meetings, events and resources.

**Seek support for yourself.** Parents with support tend to be better equipped for the journey, and children often mirror how their parents are coping.

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