

CONNECTING PEOPLE WITH SPINAL CORD INJURIES

FacingDisability.com is an interactive website that connects people with spinal cord injuries (SCI) and members of their families with the real-life experience of others.

BY STEPHANIE D. LOLLINO

Forever is a long time – especially for a child. And when parents find out their child has sustained a spinal cord injury that is likely to result in permanent paralysis, the child's future seems to hang in the balance. Now families of recently injured children—as well as those with any other member facing spinal cord injuries—have a new resource from which to draw information and support that encourage new beginnings, and the probability of strong, bright futures.

FacingDisability.com is an interactive website that connects people with spinal cord injuries (SCI) and members of their families with the real-life experience of others. It is a first-of-a-kind portal into the world of SCI families and the circle of information and support surrounding it. Connecting the life experiences of others that have been down the same path often helps people find their own strength and support. The comprehensive website has more than 1,400 videos of family members, medical experts and children answering real-life questions about how they cope with a spinal cord injury. Much of the information on the website is helpful to any family member or caregiver who is dealing with a disability.

The good news about SCI and children is they grow up to live successful, happy lives. “Even though paralyzed children need lots of extra encouragement from parents, teachers and caregivers, there are many new programs available that offer help,” says Thea Flaum, president of the Hill Foundation and creative leader of the website.

WHAT CAN PARENTS DO

Parents who are suddenly thrust into the world of hospitals, rehabilitation and their new roles as caregivers, can begin to feel a sense of normalcy when they view these videos. In one FacingDisability



video Sue, who's also a nurse, explains her concern after her 10-year-old son became quadriplegic following an auto accident.

“We immediately just started trying little things to see what he could do, and not what he couldn't do,” Sue explains. “Once my son realized he could do these little things, he wanted to do more and more. One of the things that he cried about was not being able to ride his horse anymore. I told him he could – that we would find a way.”

But first, Sue had to encourage her son to talk, and sit up again. It was very difficult and he began to show signs of giving up. Sue decided to show him his horse – and that was all he needed. He got out of the facility and after that day, Sue's son decided he wanted to work really hard in physical therapy. Miraculously, Sue's quadriplegic son eventually was able to sit on his horse.

Sarah Klass, director of spinal cord injury service at Shriners Children's Hospital in Chicago, is a national leader in the field of pediatric spinal cord injuries. “Children truly are very resilient, and they adjust extremely well to a traumatic injury,” Klass says. “We're always very excited to see a young child who progresses so well after they sustain their spinal cord injury. And, I think that there's a lot of hope for parents—to know if their child does sustain an injury, they will have a high quality of life, and can do so many things in the world that they always had hoped

they could do.” Sara Klass goes on to explain that one of the most important things a parent can do is to encourage a child in rehabilitation and to continue maintaining a positive outlook. “Attitude can be everything during rehabilitation. It's not always easy, and there are going to be difficult days both for



FacingDisability was specifically created to connect families who suddenly have to deal with a spinal cord injury with other people like them. Their website has more than 1,000 videos of family members answering real-life questions about how they cope with a spinal cord injury.

the parent and for their child. It helps to let them know that through hard work and persistence they will be able to come out on the other end feeling the way they felt before, and doing just as many things as they did prior to their spinal cord injury.”

Adults who sustained spinal cord injuries as children also speak out on FacingDisability.com. They share success stories – as well as their worst fears.

Marzet, who was injured at age 15, said he worried most about making a comeback at school. “One of the main things I worried about when they told me I wasn’t going to be walking again, was going back to school, I was kind of wondering, how was everybody going to start looking at me now.”

Joey, who became quadriplegic at age 13, shared his thoughts on making new friends after the accident. “After I was home for two years, one of my best friends learned how to take care of me. And once he learned how to take care of me, he would bring me outside. If he would go to the store or something and it was time for me to use the bathroom, then I would tell my friend, ‘hey man, I need to use the bathroom,’ and he’d say, ‘Okay, it’s nothing nasty, you’re my boy, what do I have to do?’ After he learned, all my friends learned.”

Megan, who was injured at age 18 talks about dating after SCI.

“I had a boyfriend at the time, that didn’t last very long. We broke up a month after I got back to school. I think eventually you have to be comfortable with yourself, and be comfortable with your disability and how it affects you for anyone else to be interested,” Megan says. “It’s much more important with intimate partners; that if you’re comfortable with yourself, then they can be too.”

COPING WITH FEELINGS

All parents worry about their child’s state of mind after a life-altering injury. But many are uncertain about what to do. “Anxiety and depression are very treatable illnesses, but with spinal cord injuries they’re often minimized because people think, ‘well of course you’re depressed, or of course you’re anxious.’ You don’t have to be depressed or anxious because you’re going through a spinal cord injury,” says Dr. Robin Dorman, clinical health psychologist at Northwestern University Medical Center, Chicago. “In terms of feelings of depression, anxiety, and really intense levels of stress in children, for the most part, you can expect those to get better. Because more is known, more is learned. Adaption is a process, just like grieving is a process.”

Parents frequently experience shock and sadness of their own after their child sustains an injury. Dr. Dorman adds it is very important that both parents and children are evaluated during the rehabilitation process.

“I think the most important thing that parents can do to promote emotional well-being for their child is just to listen, and be good communicators,” says Dr. Lawrence Vogel, Medical Director, Spinal Cord Injury Program, Shriners Hospital for Children, Chicago. “Our findings are that children and adolescents with SCI probably don’t have any greater amount of anxiety or depression compared to the general population. But I think that it’s still behooves parents and health care providers

just to be a bit more aware of the potential for emotional issues and adjustment issues.”

GOING TO COLLEGE

Molly – who became quadriplegic at age 15 says, “My college experience was great. It was a really hard transition, I think especially freshman year. I felt like I spent a lot of time just taking care of myself and getting through the day. I had a lot less time to spend on my classes and being social. After I got through that first year, things got a lot easier. And in the end, I feel like I had a really normal or better than normal college experience. I made great friends, and I was in clubs, and went abroad and took all sorts of normal things like that. I graduated from Stanford in June, and I’m going to work as a teaching assistant this year at Stanford, and then I’m thinking probably medical school or maybe a Ph.D.”

MARRIAGE AND FAMILY

“Adults who sustain spinal cord injuries as children absolutely can marry and have wonderful relationships, and if they want, choose to have and raise a wonderful family,” says Sara Klaas. “It’s very exciting for us, working in pediatrics to be able to see someone who was injured at a young age develop very well through all of their teenage years, and then transition into adulthood, and even get married and come back and visit us with their first-born child.”

NEW VIDEO APP

FacingDisability is making it easier for more family members dealing with spinal cord injuries to share their stories. A video app, launched in May 2014, allows users to do just that, using an iPhone or iPad. “It’s easy to use. Just download the app, choose a question and record your answer and then upload it directly to FacingDisability.com. We will let you know when your video is up on the website. “Everybody is welcome to share – and every bit helps,” says Thea Flaum.

Facingdisability.com is an important new resource offering education and support to families facing spinal cord injuries. It allows individuals to view a collection of more than 1,400 videos of family members answering real-life questions about how they have coped with SCI. Interviews are with experts in the medical community that offer information families need to know right away. The website offers resources, forums and peer counseling. FacingDisability.com currently averages 2,400 unique visitors per week.

The website is funded by the Hill Foundation for Families Living with Disabilities, a 501(c)(3) non-profit, created by Vicki’s parents, Robert Hill and Thea Flaum, in an effort to help other families like theirs. 737 N. Michigan Ave., Suite 1560, Chicago, IL 60611. Phone: 312-284-2525; Fax: 312-284-2530; info@facingdisability.com •

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