

EASING A CHILD'S PAIN AFTER
STROKE STRIKES MOM

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Matthew Filstead was one day old when his mother suffered a stroke.

While Matthew slept in the nursery, his mother was clinging to life in the Intensive Care Unit at Chicago's Prentice Women's Hospital, hooked up to machines and IVs, unable to roll over or focus her vision. Most painful of all, she could not hold her newborn son.

Susan Filstead, then 38, underwent four brain surgeries, including an emergency surgery to repair a massive intracerebral hemorrhage — a stroke caused by bleeding within the brain.

"It was very terrifying," she recalled. "But it was because of him that I had the will to live — the will to be his mom."

Susan, a picture of health with low-blood pressure before her pregnancy, developed pre-eclampsia during her third trimester, resulting in high blood pressure and Matthew's early delivery at 35 weeks.

Nineteen days after his birth, Matthew went home without his mother.

A month later, Susan got a pass from the rehabilitation center, where she was learning how to walk again, to be home with her son on his first Christmas. The stroke had left her with little movement on her left side, and it was the start of seizures she continues to suffer daily. When Matthew was three-and-one-half months old, Susan finally returned to the family's home in the Chicago suburb of Arlington Heights to be a mom.

"My heart was aching the whole time I was in the hospital. I would call home and hear him crying in the background and couldn't wait to get home,"



Susan, Bill and Matthew Filstead

said the former health-care manager.

"Then, when I got home, I had to deal with the fact that someone else — a caretaker we hired — was taking care of him and me. That tore me apart."

In the aftermath of her stroke, Susan learned she had developed epilepsy. Today, she suffers more than 20 seizures a day that alter her consciousness or vision or

leave her with involuntary movement on her left side. She's had two unsuccessful surgeries to treat the epilepsy. She holds hope that new treatments or surgeries will someday work.

"Matthew was three when I had

my surgeries, and he went up to the neurosurgeon and said, 'Are you going to make my mommy better?'" said Susan. "The surgeon looked down at him and said, 'I'm going to try.'"

Matthew, who is now eight, knows how to call for help when his mother suffers a seizure. Susan's parents, Viola and Otto Eik, moved to a home just 15 minutes away, and her husband, Bill, is always nearby.

Even Hans, the family dog, is part of her fight, intuitively detecting the onset of Susan's seizures — possibly through a scent her skin emits — and moving to her side to help her brace against a fall.

"He's an amazing guy," said Susan. "There were times when he'd help me by coming up to me and pushing his whole body against me so I wouldn't fall. He sleeps by my side and has nudged me a few times to make sure I was OK."

Matthew added, "Hans cries and

SEASING A CHILD'S PAIN AFTER STROKE



Susan gets a pass to be home for Matthew's first Christmas, Dec. 1992



Matthew has his first taste of cake, Spring 1993

"I am going to make you better," Matthew says. November 1997

other people and kids to Susan and is not pleased by the attention she draws," said Bill. "But we tell him it's only natural that people are curious, and if we talk about it and provide them with information, it might be helpful."

Matthew hangs out with school friends and does all the things eight-year-old boys do. Susan's eyes fill with tears when she recalls him giving her a hug not long ago, saying, "Mom, you're OK just the way you are."

His parents embrace his optimism, vigilantly insisting their family life be as normal as possible.

"We told Matthew this is our life, and this is the way we adjust," said Bill Filstead. "If you spend time thinking about it, you waste energy. Occasionally we have a bad moment, but not a bad life."

Two years ago, Susan and Bill, a health-care consultant, founded the Susan Eik Filstead Stroke & Epilepsy Foundation Inc.

"There wasn't anything we could do to change the way things are in our lives, but we could try to make it better," said Susan. "I wanted to create the foundation to give Matthew hope - to give us all hope."

Bill administers the foundation that has raised \$20,000 and has two fund-raisers planned for November.

"At the heart of our mission is to find a cure for epilepsy and reverse the damage of stroke," Bill said. "Initially, we want to use the money we've raised to fund a conference in which we get the best and the brightest to think outside the box about what has to happen for us to cure it."

Even Matthew, who is reluctant to talk about his mother's illness, rallies behind the foundation.

"We're looking for a cure," he said. "It's great. We may end up saving people's lives in the future."

As they strive to someday make a difference in the lives of others, the Filsteads remain determined to build a normal daily life for themselves.

In July, the family braved a crowd of 70,000 people to attend an 'NSync concert at Soldier Field. "We rented a limo to drop us off at the door so we didn't have to worry about walking

so far," said Bill. "It's a simple choice for us — you can either take off, or you can fight. We choose to fight."

When school pals visit, Matthew asks Susan matter-of-factly to make brownies. When they go to the park to play soccer, Susan plays goalie while in the scooter and with cane in hand.

"To Susan's credit, never has she said she couldn't go somewhere because of her illness even though there were times when she should have said no," said Bill.

And while some days in the Filstead household are better than others, Susan insists she'll never give up.

"On those bad days, I just take one look at Matthew and there's no way I'd give up," she says. "My hope is much stronger than any fear or sadness I ever have."



For more information on Susan Eik Filstead Stroke and Epilepsy Inc.: 126 East Wing Street, Suite 290, Arlington Heights, Ill. 60001. Web site: www.sefef.org.

MY HOPE IS MUCH STRONGER THAN ANY FEAR OR SADNESS I EVER HAVE.



Susan finally is discharged from the rehabilitation center. Dec. 31, 1992



First mother/son outing when Matthew is 4 years old. May 1997



Matthew at a Filstead Stroke & Epilepsy Foundation fundraiser.

OCCASIONALLY WE HAVE A BAD MOMENT, BUT NOT A



Mom and Matthew take a field trip to pick apples. gets upset when he sees you're having a seizure."

But his mother knows better. Matthew is projecting his own feelings about her illness onto the 11-year-old family dog.

"Matthew has broken down crying that he wishes he had never been born because then my life wouldn't

be ruined," Susan admitted painfully. "It would break my heart when I heard him say things like that."

When Matthew was as young as three, his parents would take him to Chicago's lakefront and tell him that they used to jog together on the shore of Lake Michigan.

"That was before you had me," Matthew said, according to Bill Filstead.

"But our mantra has been 'It wasn't your fault. We wanted to have you.'"

Matthew makes similar remarks today. Susan deals with the situation head-on saying, "I can't tell him I love him enough; how lucky and happy I am to have him and it is absolutely not his fault that this happened to me. It's important that he knows it is not his fault."

As Matthew grows older, Susan finds it gets easier to address his concerns, such as the possibility of more



Hans, the family's loyal dog, stays at Susan's side.

BAD LIFE.

surgeries and trips to the emergency room. But some attempts to ease the way aren't always smooth.

"I sent a video to school dealing with differences and people with disabilities, and the other kids in the class weren't very open to it and were laughing," said Susan. "But we were able to talk to him about it."

When Matthew was younger, he and his mom were often left out of pre-school activities with other children and parents because of her illness. Today, with some minor adjustments, their lives include school field trips and other activities. Bill takes Susan's motorized scooter in the family car, while Susan rides with her son on the school bus to the zoo and other attractions around Chicago. She was a "room mom" for Matthew's first- and second-grade classes.

"He's conscious of the reaction of

WHEN YOUR CHILD HAS EXPERIENCED THE TRAUMA OF STROKE

When a child experiences the trauma of a family medical emergency, such as a stroke, it is important for parents to understand that the child is going through a normal grief and loss cycle, says Carole A. McKelvey, MA, a licensed professional counselor specializing in family and trauma-recovery issues.

"Many adults try to protect a child from grief and to downplay the emotions the child is having, especially if the adult is having trouble acknowledging what has changed," said McKelvey, the author of six books on families and children.

Accepting the stages of the grief cycle — denial, anger, guilt, despair, detachment and resolution — is a healthy way to begin resolving the loss, said McKelvey, whose Littleton, Colorado, practice is called the Family Preservation Center.

"When a family faces a tragedy, it is often difficult to understand the impact that the medical emergency of an adult or other family member can have on the children," said McKelvey. "Each member is an integral part of the family, so when something affects one family member it influences every other member."

An unexpected result of the trauma is that the child can act out behaviorally, said McKelvey.

"It can't be emphasized more that children act out their emotions in behaviors," she said. "You may see fighting, school problems, temper tantrums and negative attitudes when a loss has occurred."

Children also may demonstrate their emotions through physical problems, such as stomach pains, chest tightness, headaches,

nightmares, bed-wetting and regression.

Parents can help a child resolve issues around a stroke or other medical emergency by:

- Reassuring the child that even though the family has changed, the child is treasured and the family will survive.
- Helping the child with the guilty feelings he or she has. Children believe they are the center of the universe and that everything that happens revolves around them. When something bad happens, they believe they have caused it to happen.
- Explaining the situation in terms that are easy to understand. Using books written for children about medical traumas and hospitalizations is often helpful.
- Allowing the child to play out feelings by providing toys that can be healing, such as a child's medical kit or toy hospital set.
- Giving children permission to be sad. Allow them to cry. Don't downplay their feelings. When children are going through the grief cycle, they need permission to feel their grief and loss. Crying can be healing.
- When a child enters the angry stage, allow and encourage him or her to express this emotion and accept the expression.
- If a child is having a particularly rough time getting through the grief and loss cycle, consult a specialist, such as a professional counselor or psychologist who specializes in working with children who have been traumatized.