



I'm Not the Me I Remember: Fighting Encephalitis

A special report from Inspire and Encephalitis Global
in recognition of Rare Disease Day 2012

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Introduction

Welcome to *I'm Not the Me I Remember: Fighting Encephalitis*, a special report co-authored by Inspire and Encephalitis Global in recognition of Rare Disease Day 2012.

In online patient communities, patients and caregivers reach out to each other to gather information to use in multiple ways—to research further online, to use as background materials in broaching topics with their clinicians, and to help explain their disease to loved ones and friends. We see deep connections made by members of online communities. These connections are particularly profound in groups devoted to those affected by rare diseases.

I'd like to thank Encephalitis Global's leadership—particularly co-founders Wendy Station and Ingrid Guerci, Dr. H. Gordon Deen of the Mayo Clinic, psychologist Dr. Steven W. Sliwinski, and all of the Encephalitis Global members who contributed to this report.

Inspire provides a number of online communities for people affected by rare diseases. A list of these communities can be found on [page 30](#). We are grateful to all the rare disease patient advocacy organizations that partner with us.

Recently we received a note from one of our partners, Joyce Graff, founder of the [VHL Family Alliance](#) and a former board member of the [National Organization for Rare Disorders \(NORD\)](#). Joyce, a tireless patient advocate, wrote:

"We were contacted by a young woman in Denmark who clearly has been getting the wrong advice since 1998. I was able to connect her with the geneticist in Denmark who thought she was coordinating care for everyone with VHL in Denmark, but this young woman was not in touch with her. We connected her with the patient support group in Denmark. I passed to her a presentation from our recent symposium that talks about her very problem. We are helping her get a second opinion on her case from that speaker, a doctor in Texas, with the Danish geneticist in the loop. Within days, this young woman in Denmark has gone from feeling totally alone with pain and multiple surgeries since 1998 to having a team around her in her own country and around the world, working with her to get her better care. That's phenomenal."

It is phenomenal. Together we're better.



Brian Loew

Founder and CEO

Inspire

Foreword

Wendy Station and Ingrid Guerci

Encephalitis is an inflammation of the brain often caused by a viral infection. Types of infectious (viral) encephalitis include herpes simplex encephalitis and mosquito-borne encephalitis. Other types of encephalitis include autoimmune encephalitis (Hashimoto’s encephalitis, Rasmussen’s encephalitis and acute disseminated encephalitis, known as ADEM), HIV encephalopathy and postvaccinal encephalitis. Patients require urgent care due to rapid development of fever, headache, seizures, and neurological issues. This rare disease can be fatal.



Wendy Station

Ingrid Guerci

The public has little knowledge of the impact of encephalitis on the family—people who are struggling to face life itself after surviving this horrible disease. Issues include memory loss, where a fiancée is heartbroken when her future spouse really does not remember her or the promise that they shared. A man’s anger with himself, when his spouse is now the solo family breadwinner. Children who now face their education with frustration, as their peers move ahead and leave them behind. A farmer, who can no longer return to his fields. Or families who experience the worst impact of all, when a loved one loses their struggle post-encephalitis.

Many of the lingering effects of encephalitis (sometimes referred to in this report as “E”) are not visible. These invisible disabilities may include problems with learning, memory, attention, problem solving and behavior. Comprehensive therapy, including cognitive therapy, is important to obtain optimal recovery results. An encephalitis survivor may have permanent cognitive dysfunction in the form of decreased short-term memory, decreased attention span, and decreased concentration abilities. Many are not able to work due to these ongoing cognitive deficits that can leave them permanently disabled. (See pages 8-17 for a detailed look at this and related topics.)

This report references the two-year mark as a milestone, but it is not a recovery deadline. This two-year mark is merely a measurement milestone in the lifelong potential for improvements post-encephalitis. When I (Wendy) was diagnosed with encephalitis in 1999, my family was told that the extent of my recovery and improvements would be measured at the two-year point post encephalitis; few, if any improvements would occur after that date. In recent years, the medical community has studied the plasticity of the brain, confirming that recovery from brain injury has no timeline.

Encephalitis Global, Inc. has teamed up with Inspire to gather data for a first-of-its kind encephalitis research survey project, as part of International Rare Disease Day 2012. We hope this report, *I’m Not the Me I Remember: Fighting Encephalitis*, will raise awareness of a cruel and little-understood disease, and help medical professionals better understand encephalitis and its impact.

“Like other rare diseases, it is difficult for the medical profession to study encephalitis using traditional research methods, because so few cases are seen at even the largest medical centers,” said H. Gordon Deen, M.D., professor of neurosurgery at Mayo Clinic, who has treated encephalitis survivors and has studied encephalitis. “Internet support groups are starting to play an increasing role in rare disease research. These groups are able to assemble large numbers of patients with the disease in question, and present themselves to medical researchers as potential study participants.”

Deen added, “Having a large pool of readily available study participants will eliminate one major barrier to research on encephalitis and other rare diseases.”

As co-founders of the Encephalitis Global support organization, we thank board members Becky Dennis, Dale Hunter and Bob Morris for their invaluable assistance. Thanks also to Dr. Deen, who reviewed the findings of this survey, and who also assisted in the making of a five-minute educational video about encephalitis, “[Fighting Encephalitis](#),” which was produced on behalf of Encephalitis Global. We are also grateful to psychologist Dr. Steven W. Sliwinski for his insights and support. Finally, thanks to all those members of the [Encephalitis Global Support Community](#) on Inspire who took the time to complete this survey.

Wendy Station of Vancouver, Canada, and Ingrid Guerci of New York are both encephalitis survivors. They founded the nonprofit patient advocacy organization Encephalitis Global, Inc. in 2004.

I'm Not the Me I Remember: Fighting Encephalitis Executive Summary

Board members of Encephalitis Global—Wendy Station, Ingrid Guerci, Becky Dennis, Dale Hunter and Bob Morris—wrote this summary, with editing by John Novack of Inspire.

Encephalitis survivors share “silent suffering” even after two years from the initial onset of the illness, according to a recent survey of members of [Inspire’s Encephalitis Global Support Community](#). In the survey, many survivors cited lingering symptoms that plague them, such as short-term memory loss and aphasia, that is, a communication disorder. Yet these ailments often go undetected by their families, friends and colleagues, creating a feeling of isolation.

“Survivors often have undiagnosed memory loss and other residual neurological symptoms, which are frustrating to the patient, family, and friends,” said H. Gordon Deen, M.D., professor of neurosurgery at Mayo Clinic, Jacksonville, FL. “The situation is all the more frustrating because the patient may appear to be superficially normal.”

One caregiver, in responding to the survey, wrote, “Even doctors can be incredibly dismissive about this very, very serious illness and the long shadow it casts into the lives of patients, caregivers, families, friends and loved ones.”

“Dealing with this sudden and dramatically life-altering illness is overwhelming enough, but when a healthcare provider or family member dismisses the patient’s experience, it can be traumatic and lead to painfully isolating and shaming conclusions for the patient,” said psychologist Steven W. Sliwinski, Ph.D., past president of the Collin County Psychology Association in Dallas, TX.

An encephalitis survivor wrote, “I look normal and act normal but it’s a very hard thing to have as people don’t know of it. Even if they have heard of it, they still don’t know about it. I tell friends and family but they seem to be thinking that it’s two years now and I should be better, which is of course what I feel, so it makes it very hard, but as my family keeps telling me, I am still here, just not quite the me I remember.”

Key findings of the Encephalitis Global/Inspire survey revealed the emotional impact that survivors share, the difficulty in diagnosing the illness, what treatments proved more effective, and the importance of online communities.

Other survey findings

- About one-quarter (24%) of survivors said they never experienced headaches
- About half of survivors had no rehabilitative therapy, other than prescription medications
- More than 90% found Internet searches for information about encephalitis helpful, compared to 66% finding medical doctors helpful
- Common residuals are problems multi-tasking (60%) and problem solving (56%)
- Nearly half of respondents said online communities reduce feelings of isolation and neurosis

According to the survey, encephalitis creates a negative psychological impact on the patient due to its invisibility and often the misdiagnosis of it altogether.

- Survivors and caregivers share a high degree of torment and anger about the frequency of misdiagnosis and the lack of adequate follow-up care after proper diagnosis. This includes caregivers of those who did not survive. More than 20% of survivors responding to the survey say they were misdiagnosed, sometimes as long as two years later. Feelings of being dismissed (often stemming from misdiagnosis) can significantly complicate a survivor's recovery, especially those whose doctors suggested they were mentally ill.

"The initial diagnosis is often incorrect, as symptoms may be attributed to another diagnosis, such as the flu or even a psychiatric disorder," said Deen, who described encephalitis as a "devastating" rare disease.

- Although neuropsychological exams were not always ordered, about half of the patients who did take one benefited from doing so. This, perhaps, is from discovering the root causes of "issues" experienced. For example, one survivor indicated that the exam concluded that her problem-solving abilities were significantly compromised from the impact of encephalitis. Seeing those results helped her understand her limitations better and develop adaptive skills.

"When a patient understands their residuals from this cruel illness, they are better equipped to incorporate strategies and coping mechanisms into their daily activities," said Sliwinski. "Without this information, a patient is more likely to develop the feeling of despair and a sense of being damaged goods. These feelings are likely to hinder progress at repairing the damage and may lead to co-morbid disorders such as depression."

- Because encephalitis is often not recognized as an acquired brain injury, this impacts the degree to which aftercare and therapy is recommended, thus slowing recovery. Unfortunately, even though aftercare and therapy have significant evidence as being beneficial to recovery, health insurers often deny this treatment. The lack of research and frequency of misdiagnosis likely contributes to the denial of insurance coverage.

The lack of research and frequency of misdiagnosis likely contributes to the denial of insurance coverage.

- Deen cited that, like other rare diseases, it is difficult for the medical profession to study encephalitis using traditional research methods because so few cases are seen at even the largest medical centers. Groups such as Encephalitis Global, Inc. are using Internet support groups to assemble themselves in large numbers (1,500 to date) and present their own statistics to increase awareness among medical researchers.

“Having a large pool of readily available study participants will eliminate one major barrier to research on encephalitis and other rare diseases,” Deen said.

- Support is vitally important to successful recovery: the support of family and friends, of psychotherapy, and of online communities. Online communities serve a critical role to encephalitis survivors because there is such a lack of available information about the disease, about its lasting effects, and about recovery and effective aftercare. More than half of respondents said that communication via online communities reduces their feelings of isolation and neurosis. More than half learn coping strategies for dealing with the illness and its residuals from online communities.

Methodology

Encephalitis Global and Inspire teamed up to create an online survey in early 2012 for members of the [Encephalitis Global Support Community](#), an online support group. The survey, hosted on Inspire.com, serves as one of several efforts by Encephalitis Global to raise awareness of the rare disease, and help medical professionals better understand encephalitis and its impact on patients and families. Encephalitis Global also produced a video as another tool to educate the medical community and public. It can be viewed at <http://www.youtube.com/watch?v=M5cfl2Rwze4>.

For the survey, Inspire emailed a link to the online survey to members of the support group. More than 250 people responded to the survey, 57% of whom identified themselves as having had encephalitis, with the balance being caregivers or those left behind due to the loss of a loved one with encephalitis. Respondents had the opportunity to write short narratives to describe the impact that encephalitis has had on them and their loved ones. Excerpts from those narratives are on [page 27](#).

Long-term residuals and how they are viewed

The biggest variance between survivors' and caregivers' perspectives centered on the impact from long-term residuals; that is, issues that continued beyond two years. In particular, survivors perceived themselves as much more impacted over the long term than did caregivers. Despite this difference, the two groups were surprisingly consistent on their overall assessments. See chart on [page 13](#).

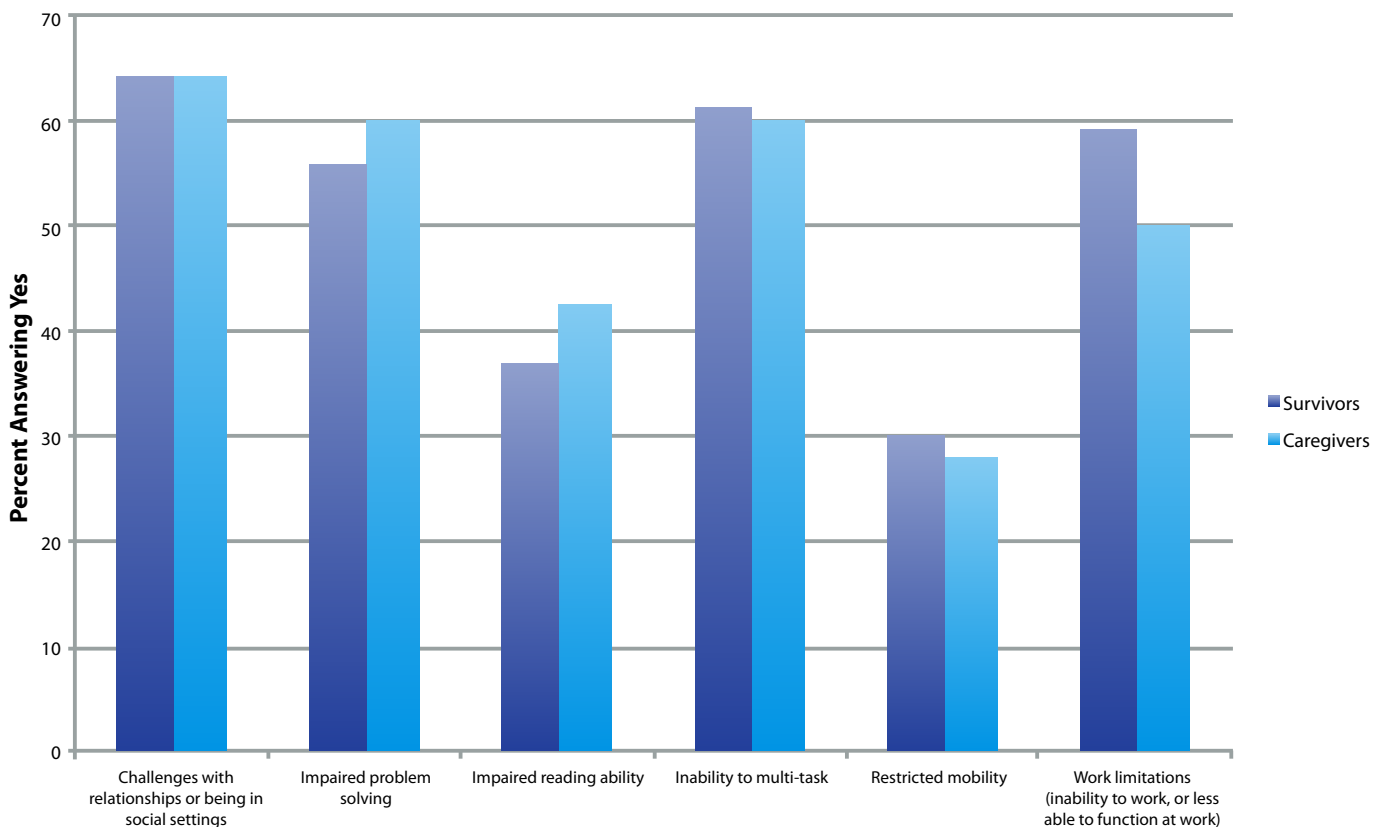
"When you consider the dismissive feeling that patients encounter when talking about symptoms that aren't visible to others, it's no surprise that they tend to keep it to themselves over time to avoid that isolating demeaning feeling," Sliwinski said. "This lack of visibility may give a false impression that the patient is no longer suffering from symptoms such as lack of concentration, fatigue and feelings of disorientation."

For survivors and caregivers, more than half cited challenges with relationships, impaired problem-solving, inability to multi-task and work limitations. They attribute these difficulties to their disorientation, lack of concentration, language issues and memory issues.

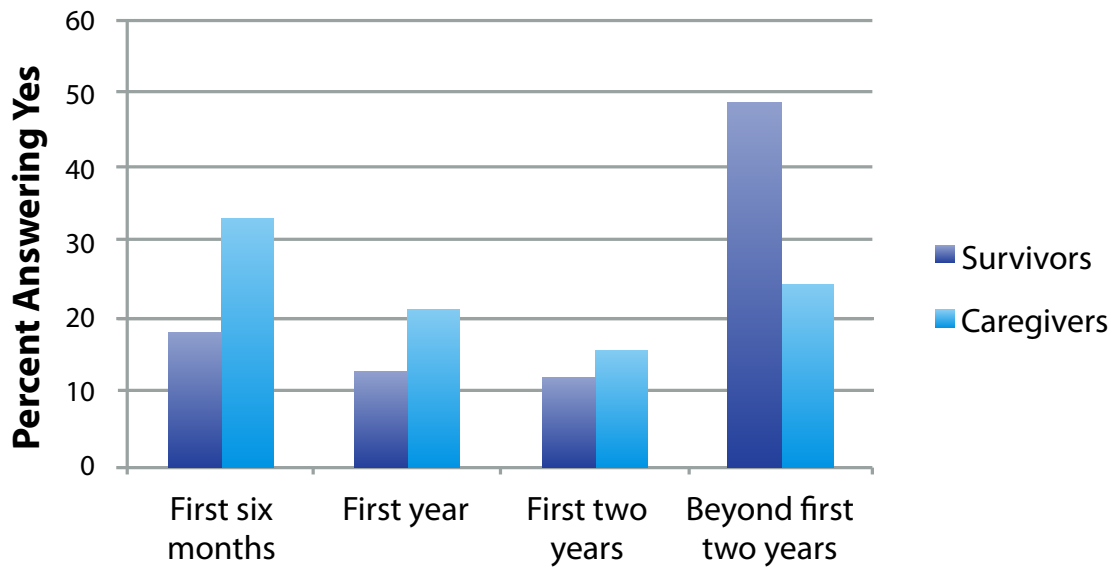
Dr. Deen of the Mayo Clinic noted, "In order to maximize recovery, encephalitis survivors should be viewed as having an acquired brain injury and have access to comprehensive rehabilitation. . . Neuropsychological testing can be very helpful to identify the nature and extent of any residual intellectual dysfunction, and help with ongoing therapy and adaption strategies."

Specifically, although survivors and caregivers both reported similar large changes due to residuals, survivors felt much more affected by difficulties in finding words (aphasia), body temperature changes, balance problems, fatigue, disorientation, inability to concentrate, short-term and long-term memory lapses, and personality changes (see charts on [page 14](#)). Particularly striking were survivors' perceived residuals that continued beyond two years, including aphasia, disorientation, inability to concentrate, and long- and short-term memory lapses.

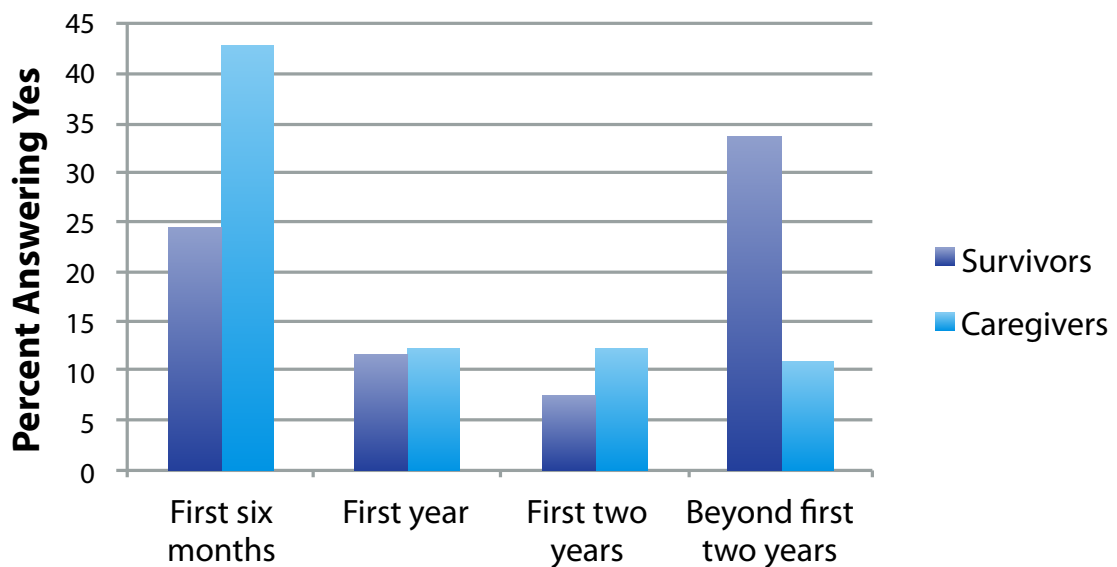
Changes Due to Residuals



Lack of Concentration



Aphasia

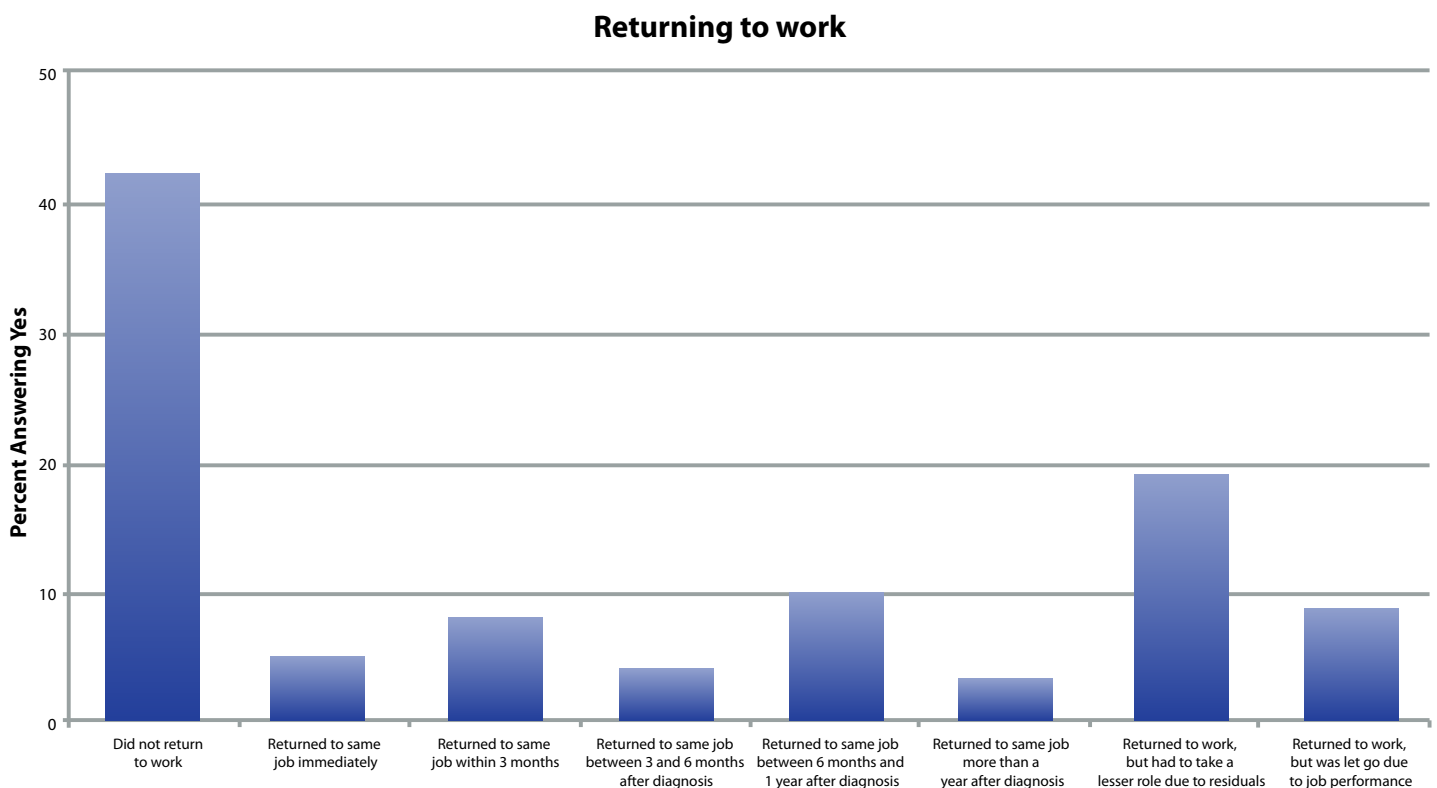


Difficulties in returning to work

Another striking finding is the extreme impact on ability to work after contracting encephalitis.

Of the 150 people who were working before falling ill to encephalitis, 43% said they could not return to work at all. Roughly 20% returned to a lesser role due to residuals, and 8% returned to work but were let go due to job performance.

About 17% of respondents said they returned to the same role at work within six months of diagnosis, and another 10% said they returned to the same employment role between six months and a year after diagnosis (See chart below).



* Includes responses from patients and caregivers. Percentages are rounded.

One survivor cited their early diagnosis and comprehensive therapy as the two keys of giving them the best “shot” at a full and rich life. “I experience much of what others experience, but I don’t seem to have the degree of struggle, for the most part.” This survivor noted several coping strategies that helped in the workplace:

- One conversation at a time.
- Don’t ask me a question when I am concentrating.
- Don’t have the TV or radio on when trying to communicate with me.
- Have complete notes/manuscript when speaking publicly.
- Create/keep notes/lists of things to do.
- Closed office door with white noise to shut out general office noise.
- Working late at night when there are no interruptions.
- Take extensive notes on laptop in a meeting or conversation.
- My workweek is divided into two parts: Tuesday thru Thursday and Saturday and Sunday. I have Monday and Friday off.
- A smart phone with access to a dictionary, voice memos and email/calendar.

The power of online resources

Both patients and caregivers deemed Internet searching an important tool for learning about encephalitis and post-diagnosis care: 92% of survivors and 90% of caregivers found Internet research somewhat or very helpful. Online communities and forums shared similar results: 78% of survivors and 85% of caregivers found these somewhat or very helpful.

One survivor, a woman from the UK, wrote, “I (educated) myself about Encephalitis by doing a lot of research on the Internet and other sources of information, in order to understand the problem and the therapies given to me. It allowed me to tailor my therapies and to guide my doctors into giving me therapies that were more adapted to me.”

Both groups said that family was an important part of patients' well-being: 80% of survivors and 100% of caregivers felt family was somewhat or very helpful. Perhaps the comfort of family attributes to this high percentage.

In contrast, fewer respondents found the medical community helpful: doctors were somewhat or very helpful for only 65% of survivors and 73% of caregivers; medical journals were somewhat or very helpful for only 50% of survivors and 51% of caregivers.

"This underscores a need for the medical community to be more aware of encephalitis so they can more swiftly diagnose it and so they can become a stronger resource about this type of acquired brain injury," said Becky Dennis, a director on the Encephalitis Global board who wrote a book titled, "Brain Wreck," about her encephalitis journey. The board will leverage the book as another tool to educate the public about this illness that attacks 20,000 people a year in the U.S. alone.

78% of survivors and 85% of caregivers found online communities and forums to be somewhat or very helpful.

"Like the group psychotherapy model, there is a power in knowing others who are struggling with the same issues," Sliwinski, the psychologist, explained. "Actively participating in support groups or online communities will lead to recognition of shared experiences and feelings among group members. This shared experience will remove a group member's sense of isolation, validate their experiences, and raise their self-esteem."

"Interacting with members at different stages of recovery, especially with those who have overcome the problems with which they are still struggling almost always instills hope. When patients tell their story to a supportive listener who knows not to dismiss them almost always leads to relief from isolation, shame, and guilt. Some," Sliwinski added, "even get practical advice about treatments they may not have discovered on their own or through their healthcare provider."

In the survey, over half the patients learn new coping strategies and benefit from commiserating with survivors who understand. Nearly half indicated that it reduces their feelings of isolation and neurosis.

The journey to diagnosis: A dozen doctors, 2.5 years

Becky Dennis

My career spiraled upward at 38 years old. As the new senior vice president for a publicly traded global company, I celebrated a challenge to test my skills further.

On Feb. 6, 2008, I delivered a presentation at a meeting in Southeast Asia, feeling confident and full of life. Two hours later, fatigue stung me, nearly paralyzing my speech. My vision blurred. My lips and limbs tingled, then fell numb. Walking required so much effort that my body yielded to a wheelchair.

Accustomed to leading organizations, my mind raced for answers in this compromised state. A company car raced me to the hospital. I thought: "Maybe I haven't acclimated to my Eastern location yet? Did I forget one of my medications? What in the world is wrong with me when colleagues 10 years and more my senior are just fine with the same travels?"

Colleagues and medical professionals talked in the emergency room. Words bounced in my head, then vacated, leaving me unable to respond. Despite my intense fear, I laid motionless, unable to express my experience. I recall shivering. A fog overcame my ability to communicate. A cardiologist determined that my fatigue and stress level contributed to my condition, so he dismissed me six hours later.

Back in the U.S. a week later, a neurologist diagnosed me for stroke based on my symptoms. After months of testing, however, MRIs and blood work lacked conclusive evidence of this diagnosis, so he recommended psychotherapy, leaving me with no other explanation for my constant headaches, tingling sensations, slurred speech, and short-term memory loss. Loss of taste attributed to losing 20 pounds in just a few weeks. My inability to concentrate plagued my work. I required five naps a day, often drooping my head down



on my desk rather than taking the short 20 steps to my bedroom. My once hectic travel schedule trapped me in my home office, unable to navigate the complexities of globetrotting.

I refused a “crazy” theory.

All the while, fear of another, more debilitating episode distracted me, making me feel like a time bomb. Complicated migraines—another diagnosis, didn’t seem to fit with such long-lasting symptoms. After 2.5 years and 12 doctors, I pushed again for answers.

In May 2010, I visited Massachusetts General Hospital. Prior to my visit, I gathered notes from every doctor visit and medical test from the previous 30 months to present at my appointment. I met with a neurologist who examined each symptom, such as short-term memory loss, loss of taste and smell, aphasia, loss of peripheral vision, and fatigue. He confidently concluded encephalitis, likely from a mosquito bite. For two-plus years, I fought to conceal my illness in absence of a diagnosis that fit, not wanting to sound “crazy,” as suggested by the first couple of doctors.

With this diagnosis that finally “fit,” I felt vindicated. Validated. My spirits lifted just knowing that a doctor—someone degreed and other than me—looked closely enough to understand me. Such complex symptoms were not, could not, be stress.

“With this diagnosis that finally “fit,” I felt vindicated. Validated. My spirits lifted just knowing that a doctor—someone degreed and other than me—looked closely enough to understand me.”

Committed to helping others, her own life is cut short

This essay is excerpted from the book, "Brain Wreck," written by Encephalitis Global board member Becky Dennis.

While in her late teens, Jesseca Morey's life focused on collecting food for the homeless, earning 50+ community service Girl Scouts patches, and working at a nursing home to earn money to pay for her own car. Since she was 10, Jesseca thrived on being in healthcare to help others, which was amplified by her father losing a leg in a car accident six years earlier.

Within months after college graduation, Jesseca started her new career as an occupational therapy assistant at a rehabilitation center near her Tacoma, WA home. At 21, she enjoyed a healthy life, dashing through the house with excitement each time snow blanketed her neighborhood.

Jesseca's first week on the job excited her. She was so happy about having her first patients, and providing them the skills they needed to return to a productive life.

But just days after starting her job, on Wednesday, Nov. 15, 2006, headaches and stomachaches riddled her body. She told her mother, Cheri, "Must be symptoms related to my new job. If I'm not feeling better by the end of the week, I'll see a doctor."

Two days after talking to her mother, Jesseca came home from work and said she wanted to see a doctor. She lay down on the couch, comforted by her mom. A few hours later, Cheri awoke to the sounds of Jesseca having a seizure. Cheri called 911. An ambulance whisked Jesseca away, and she suffered another seizure in route to the hospital. Blurred vision, confusion, numbness, hallucinations, fever and vomiting ensued.

Jesseca's first week on the job excited her. She was so happy about having her first patients, and providing them the skills they needed to return to a productive life.

different ER, where they performed a lumbar puncture. The results confirmed she had contracted herpes simplex encephalitis and meningitis. An infectious disease doctor and neurologist were assigned and they administered Acyclovir to treat her herpes-induced symptoms.

On Nov. 22, a week after her first headache, doctors put Jesseca on life support. The next day, Jesseca lost her battle. Snow sprinkled her grave. Her first paycheck from her new employer arrived two days later.

Doctors ran a CT scan, chest X-ray and blood work. They decided Jesseca suffered from a seizure disorder and the flu. They recommended she see a neurologist in two months. They sent her home, but her headaches intensified.

On Saturday, Nov. 18, Jesseca's family drove her to a clinic, which retrieved her records from the hospital. They ran blood work, reinforcing a flu diagnosis. The clinic administered a shot for her headache, then released her.

That evening, Jesseca's fever increased. Her headaches became unbearable. An ambulance rushed her to a

Quick treatment creates lifeline

This is another excerpt from Becky Dennis' book, "Brain Wreck." Bob Morris is a board member of Encephalitis Global.

Always in good health and full of energy, Bob Morris enjoyed putting others first. An Episcopal priest in his early 60s, he practiced what he preached, looking for opportunities to serve others. His congregation enjoyed his leadership, charismatic persona and an unconventional sense of humor. In April 2010, Bob and his wife, Cathleen, left their Florida home for South America and their first-ever sabbatical.

During the trip, Bob suffered a sudden onset of severe diarrhea and vomiting. A headache nearly incapacitated him. Ailments seemed foreign to Bob, especially given his exercise regimen and resistance to getting sick. For 24 hours Cathleen nursed his symptoms, presuming food poisoning. But when this accomplished clergyman began hallucinating as he chewed handfuls of antibiotics, claiming they were "his M&Ms and you can't have them," Cathleen sought medical help, fearful of something much more severe. Bob sunk into a child-like state, trembling uncontrollably, with visions of flying fish in his hair and blood dripping from his limbs. He poured with sweat from a high fever.

Twelve hours later in the hospital, Bob slipped into a coma. With scant resources on a holiday weekend, the available staff administered IV antibiotics and oxygen. Four days later, a neurologist discovered a shadow on Bob's CAT scan, indicative of head injury from a fall. A spinal tap and MRI revealed viral meningoencephalitis (meningitis and encephalitis), showing significant damage to the frontal and temporal lobes. The presumed cause was the herpes simplex virus. Doctors immediately put him on Acyclovir.

Bob regained consciousness six days later. Sensitivity to light forced him to wear sunglasses. Vertigo nauseated him with any slight movement. Food and water terrified him, accelerating a weight loss of 25 pounds in only 10 days.

Inflammation of his brain slowly dissipated. After two weeks of bed rest, the hospital released him, but didn't clear him for travel back to the U.S. His first journey out of bed was an assisted walk of just a few yards. He collapsed, completely drained from fatigue.

Two weeks later, Bob returned to his Florida home, where he underwent comprehensive rehabilitation including cognitive therapy, physical therapy, biofeedback and psychological counseling. Most encephalitis patients never have access to such optimal medical care and insurance coverage.

With a relatively quick diagnosis and extensive rehabilitation efforts, Bob returned to work part time four-and-a-half months later. After almost two years, Bob went back to work full-time, traveling again to see his daughters in New York City and Washington, DC, and enjoying walks on the beach with Cathleen. Not even his lingering fatigue, short-term memory loss or aphasia can extinguish his passion for serving others. He is immensely grateful to Cathleen, his advocate throughout this ordeal. He knows she saved his life by getting swift medical attention.

Most encephalitis patients never have access to such optimal medical care and insurance coverage.

“He is coming back to me”: Caring for a loved one after HSE

Lola Slingluff

My life as a caregiver to my husband, Dick, began 18 days after the onset of herpes simplex encephalitis (HSE) when we moved into rehab. Dick could go to the bathroom, dress himself and shower on his own, but I never left him alone in case he would fall. We attended six therapy sessions a day. He has Wernicke’s aphasia but was doing very well, even wrote, “I love Lola,” one day in speech therapy. After 10 days of therapy we were released.

On our hour-long ride home, however, he had a seizure, and would not squeeze my hand or speak. My first time alone with him, what started out with so much to be happy about, ended in fear. He didn’t recognise his house or speak for several hours. This seizure left him unable to dress himself, and when I got him into bed he told me, “I guess you’re leaving now.” My heart sank--he didn’t know me either.

Physically, things improved rather quickly, but memory, not so fast. He didn’t know our names and I was not sure how much he remembered of me. After that last seizure I lived in fear of the next one. I never touched Dick or kissed him because I wasn’t sure if he knew me enough. It was a strange, very sad feeling when all I wanted to do was hold him and make him better. Dick is a very shy man and I didn’t want him to feel molested. One thing he never forgot was that he smoked, and one day he was trying to light his cigarette without a lighter, just his thumb. We did give him a lighter, after a little laugh.

We got right back into therapy three times a week. Dick didn’t like to go, so I would take him out to eat or to the casino after to give him something to look forward to. The day his brain remembered pain, what a sad day. Up to that point he always said he didn’t hurt, and he showed no signs of pain, walked perfect like a young man. But all his pain came back double.

Three weeks after we got home from the hospital, my sister was murdered. I had to go through the worst grief of my life without Dick to comfort me. He did say, "That's sad," but he had very little emotion at this point. Now I started worrying, "What if something happens to me? Who will take care of Dick?" I don't want Dick to have to go to a nursing home. I made my son promise to get in home health care for Dick if something did happen.

We had a nurse/friend live with us for four months. Dick could never be left alone and I have a part time job several blocks from our house in our small town in Iowa. I don't like to leave him, but I can run home to him when he needs me. I've had to do so, and maybe always will.

The paperwork was never ending. I had to get power of attorney for everything. I had to deal with medical bills, retire him out of the factory and set up his pension. Our son did all the paperwork for his SS disability, thank God for him. We got home April 15, and I finally got all the paperwork done by September.

Three months post-HSE

Dick didn't connect well with his therapist so I found him a new one. Dann was so much better, of course Dick still didn't want to go because it was like school to him and he called himself stupid. Dick still didn't know the names of his children, couldn't name body parts, cars or his or my full names. With Dann he started to show some emotions, and we even laughed. These were the best times for me, because this was pretty much the only time Dick talked. We stayed in therapy with Dann for three more months, and Dick still needs to be there, but he wanted to quit. Our friend who was helping me at home moved out and I cried for a couple of days. The thought of being alone if he had a seizure was overwhelming. I was afraid I would forget to give him his meds. Sleep didn't come easy because my brain would not shut up and let me rest.

Six months post-HSE

The neurologist lowered his Keppra, but we had to add a depression med. Dick would sleep 16 hours a day unless I took him somewhere and the only place he would go was out to eat or the casino. We spent some money and gained some weight. It was still my job to trim his beard, remind him to shower, fix his plate and give him his medication. He never talked about what happened to him and he doesn't like for me to do so either.

Ten months post-HSE

In the last four months Dick has improved a little at a time, my fear of him having seizures has lessened to the point that I lowered his Keppra again. He smiles more often, and I know he actually listens to the television because the neighbors can hear it again. He still has trouble with the remote, and names are very hard for him, even his children's names. I help him talk, but the hardest part is being responsible for his happiness. E causes too much depression and mood swings. Things will never be the same, but you learn to accept and be grateful for any improvement.

Everyone dealing with encephalitis hears the same things: "He looks so good," or, "You're so lucky to have him." What no one knows, but us, is it's not them at first.

We've been together more than 40 years. We got married when I was 16 and he was 17. On Jan. 26, 2012, nearly a year after the onset of HSE, Dick gave me a kiss. I cried and thanked him. I got two kisses the next day. He is coming back to me. I am one of the lucky ones because he was diagnosed correctly on the third day.

Other voices: Perspectives of patients and caregivers

The following are excerpts from responses to the Encephalitis Global/Inspire survey. We asked respondents to tell us in their own words about the impact of encephalitis, which they often referenced only as “E.” Many comments focused on the anguish of the disease (“I feel like I am on a tightrope in a windstorm.”) Others expressed hope and resolve (“I am happy and intend to live whatever life I have left to the fullest.”) These excerpts have been edited slightly for grammar and space.

I actually thought I was going nuts and was giving up until I talked with a doctor who knew someone who had E and understood exactly what I was going through. He told me exact symptoms and what I could expect for the coming years. He was a blessing. He was amazed that I had been able to go as far in my career that I had. I shared my tricks that I used to stay organized, such as recording meetings and carrying journals of all my notes so I could remember them.

As the acquired brain injury is an invisible disability, people, even doctors, can be incredibly dismissive about this very serious illness and the long shadow it casts into the lives of patients, caregivers, families, friends and loved ones; the level of ignorance about the condition is so frustrating and unhelpful. It really helps to know that there are people who are going through the same thing out there who can compare notes with you. Having close friends to rely on and share insights on the illness and recovery process is vital—I’d be lost without my support network of friends and family.

The “invisible-ness” of encephalitis makes it difficult, sometimes impossible, to have the public show true compassion of what we are coping with, every day.

I have just been diagnosed within the last two months but have been having the symptoms for at least two years. I have Hashimoto’s Encephalitis (HE). I have learned to cope with this all by finding friends that share the same disease/disorder as I do that can relate to what I am going through. It makes me know I am not making up some of the weird symptoms that one experiences with the HE. It also helps me recognize some that I never even thought of mentioning to my neuro. I do not talk to family very much about this, as I do not like to scare them or sound like I am complaining, it is easier to complain to someone on the web that does not know you.

Once they found I’d live, I felt very abandoned. Not once was it mentioned that I’d have residual problems from the swelling and scarring. Nor was I told it was called a brain injury. I thought I’d go back to being me and that never happened. However, I’m a happier and better person now from it. It gave me the drive to succeed in what made me happy, which is working with the homeless. I’ve won many awards and may possibly be featured in a documentary. Without encephalitis, I don’t know that it would have happened! There is happiness in the end.

My husband saw two doctors and made two hospital visits. They concluded he just had a virus. He complained of a pain in his neck and back followed by disorientation and confusion. We returned and they conducted a spinal tap, revealing herpes simplex encephalitis. He was a very bad case and I did not expect him to live. He had to learn everything again, just like a baby. How to walk, talk, eat, find words. He is still incontinent, confused, and disoriented. He spent six months in the hospital and two months in rehab. I am giving up my job to give him direction in basic living skills such as washing, dressing and shaving.

My daughter was diagnosed with viral encephalitis at 9 weeks of age. She is now 26. She is now working but she lacks social interaction as she has significant residual issues, especially in social situations. I worry about how she will cope and care for herself when we, her parents, are gone.

At first I grieved for the person I used to be and even thought of suicide. Now, after nearly six years, it has taught me what really is important in life and I wake up everyday with a smile on my face. My mantra is, "I still remember to eat, drink and shop." The little things like forgetting to put my knickers on, or taking my glasses off before a shower, putting my pants on backwards or forgetting what day it is are just an everyday occurrence in my life now and give me the beautiful uncertainty of life. Acceptance is a wonderful thing and I am happy and intend to live whatever life I have left to the fullest.

Inspire rare disease communities

ALS Advocacy Support Community

<http://www.inspire.com/groups/als-advocacy/>

Amyloidosis Support Community

<http://www.inspire.com/groups/amyloidosis/>

CARES Foundation Support Community

<http://www.inspire.com/groups/cares-foundation/>

Charcot-Marie-Tooth (CMT) Support Community

<http://www.inspire.com/groups/charcot-marie-tooth-cmt/>

Ehlers-Danlos National Foundation Support Community

<http://www.inspire.com/groups/ehlers-danlos-national-foundation/>

Encephalitis Global Support Community

<http://www.inspire.com/groups/encephalitis-global/>

Fibromuscular Dysplasia Society of America Support Community

<http://www.inspire.com/groups/fibromuscular-dysplasia-society-of-america/>

Lysolife Community

<http://www.inspire.com/groups/lysolife/>

Myelin Repair Foundation Multiple Sclerosis Community

<http://www.inspire.com/groups/mrf-multiple-sclerosis/>

National Adrenal Diseases Foundation Support Community

<http://www.inspire.com/groups/national-adrenal-diseases-foundation/>

National Fabry Disease Association Support Community
<http://www.inspire.com/groups/national-fabry-disease-foundation/>

National Organization for Rare Disorders (NORD) Support Community
<http://www.inspire.com/groups/rare-disease/>

Nephrotic Syndrome and FSGS Support Community
<http://www.inspire.com/groups/nephrotic-syndrome-and-fsgs/>

Neurofibromatosis, Inc. Support Community
<http://www.inspire.com/groups/neurofibromatosis-inc/>

Organic Acidemia Association Support Community
<http://www.inspire.com/groups/organic-acidemia-association/>

Pseudomyxoma Peritonei (PMP) Support Community
<http://www.inspire.com/groups/pseudomyxoma-peritonei-pmp/>

Scleroderma Foundation Support Community
<http://www.inspire.com/groups/scleroderma-foundation/>

Stop Sarcoidosis Support Community
<http://www.inspire.com/groups/stop-sarcoidosis/>

Tuberous Sclerosis Alliance Support Community
<http://www.inspire.com/groups/tuberous-sclerosis-alliance/>

United Leukodystrophy Foundation Support Community
<http://www.inspire.com/groups/united-leukodystrophy-foundation/>

VHL Family Alliance Support Community
<http://www.inspire.com/groups/vhl-family-alliance/>

Wilson Disease Association Support Community
<http://www.inspire.com/groups/wilson-disease-association/>

About Inspire



Princeton, N.J.-based Inspire creates safe, moderated online communities, organized by medical condition, for patients to share information and to support one another.

Inspire builds and manages these communities in partnership with more than 75 national patient advocacy and support organizations. For more information, go to www.Inspire.com, or email team@inspire.com. Follow Inspire on Twitter at www.twitter.com/teaminspire, and on Facebook at www.facebook.com/Inspiredotcom.

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