



# BRAIN INJURY

## WHEN THE CALL COMES

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A Congregational Resource

Brain Injury Association  
of New Jersey, Inc.  
The Elizabeth M. Boggs Center  
on Developmental Disabilities

This publication is a collaborative product of The Elizabeth M. Boggs Center on Developmental Disabilities, UMDNJ-Robert Wood Johnson Medical School, the Brain Injury Association of New Jersey, Inc. (BIANJ) and the New Brunswick Theological Seminary. It has been guided by a task force of chaplains and pastoral counselors, staff of BIANJ and The Boggs Center, persons with brain injury and family members.

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#### **Publication Editors:**

Rev. Bill Gaventa, M.Div., serves as Coordinator of Community and Congregational Supports and Assistant Professor of Pediatrics at the Elizabeth M. Boggs Center on Developmental Disabilities.

Wendy Berk, LCSW, TBI Outreach Specialist, Brain Injury Association of New Jersey, Inc.

#### **Editorial Assistance:**

Rev. David Cotton, Karen Lewis, Jane Lowenstein

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For additional copies, contact:

**Brain Injury Association of New Jersey, Inc.**

1090 King George Post Rd., Suite 708

Edison, NJ 08837

Phone: 732-738-1002

Fax: 732-738-1132

Email: [info@bianj.org](mailto:info@bianj.org)

*Design and production: Ron Toelke Associates, Chatham, NY 12037*



Brain Injury Association of New Jersey, Inc.



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17 Seminary Place  
New Brunswick, NJ 08901



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## The Challenge of Brain Injury to Pastoral and Congregational Care

*by Rev. Bill Gaventa, M.Div.*

**B**rain injury, in its many forms, does not easily fit into any category. It can be traumatic, caused by accident. It can be acquired, a part of birthing a new life or the aging of an older one. It can happen to anyone, of any culture or any socioeconomic background. It can happen anywhere: highway, home, hospital, church, synagogue, mountain, pool and school. Thus, it doesn't "fit" into any one area of pastoral and congregational care.

Brain injury is an **acute** crisis, which can often bring out the best in a congregation and clergy. But brain injury is also usually a long haul, with **chronic** implications, where "rehab" does not mean the same as "recovery," where the real struggle of faith may be when things are not "fixable," and when initial overflowing support is too often replaced with a long range sense of abandonment.

It happens to an **individual**, but it impacts a **whole family**, including close friends, co-workers, and congregations. All need support.

It is sometimes an **accident** and other times clearly someone's **fault**.

It is a **physical** trauma, but, because of the brain, often has profound **cognitive, psychological, and emotional** implications.

It is sometimes a **visible** condition, when a long-term impact leads to a visible disability or support device (e.g.,

a cane or wheelchair), but it is often, over time, **invisible**. People can look the same, but, in profound ways, not feel or be the same.

From the perspective of pastoral and congregational care, brain injury can impact all the parts of the congregation: worship, religious education, the building, community outreach, and ministry. Again, you name it. The person with a brain injury could be a child in your church school or the chair of your board of trustees or the homeless person down the street.

These same people are the reason for this booklet and guide. People with brain injury and their families told the Brain Injury Association of New Jersey about the importance of faith, clergy, and congregational care, in either its presence or absence. That led to a project that involves people with brain injury and their families, trauma center chaplains, community clergy, social workers, advocates, seminary faculty, educators and other professionals. This booklet comes from our conversations together. It is meant to give witness to the stories and faith journeys of people with brain injury and their families, and the critical roles that can be played by pastors, priests, rabbis, imams and congregations.

We hope you never have the occasion, as clergy or congregation, to use this short, introductory guide. But we also hope it is a first resource for pastors and congregations who find themselves called to

reach out to a person or family whose lives may be profoundly impacted by this unwelcome visitor. Brain injury often calls for incredible courage and perservance from those it touches. It likewise calls for the best from congregations and clergy as communities of faith and care. When that call comes, we hope you find this guide useful.

*Bill Gaventa serves as Coordinator of Community and Congregational Supports at The Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School, UMDNJ. He is a supervisor in Clinical Pastoral Education, and Co-Editor of the Journal of Religion, Disability, and Health.*



time  
one  
place  
faith  
age

## Brain Injury... An Overview

by Wendy Berk, LCSW

Brain injury surrounds us, and yet it is an epidemic that is widely unrecognized and unknown. It is estimated that approximately 1 in 10 individuals will have their life touched by a brain injury. Brain injury not only affects the identified patient, but also the family, friends, and community of the injured individual. There are two types of brain injury. A Traumatic Brain Injury (TBI) is an insult to the brain, caused by an external physical force such as a fall or car crash. An Acquired Brain Injury (ABI) is an injury that is caused by a medical condition such as a stroke, brain tumor, near suffocation, infections in the brain, etc.

### CONSIDER THESE NATIONAL STATISTICS:

- Brain injury is the leading cause of death and disability among young children.
- An estimated 5.3 million Americans currently live with disabilities resulting from brain injury.
- Each year 80,000 Americans experience the onset of long term disability following a traumatic brain injury.
- Every year 1.5 million people sustain a brain injury.
- Every 21 seconds an infant, teenager, or adult sustains a traumatic brain injury.
- Each day more than 4,000 individuals sustain a traumatic brain injury.
- Each year 230,000 people are hospitalized with traumatic brain injury and survive.

### In New Jersey:

- Each year approximately 9,500 people are admitted to the hospital with traumatic brain injury.
- Each day 26 people are hospitalized with traumatic brain injury.
- Each day approximately 3 people die as a result of a traumatic brain injury.

### OTHER IMPORTANT FACTS:

- Motor vehicle crashes are the leading cause of brain injury. Other causes include falls, use of firearms, sports/recreation injuries, bicycle accidents, too little blood flow in the brain (i.e., heart attack, stroke), infections of the brain (i.e., meningitis), shaken baby syndrome, and others.
- While no one is immune from brain injury, the highest incidence is among persons 75 years of age or older and among persons 15-24 years. The rate among males is twice that of females.
- The cost of traumatic brain injury in the United States is estimated to be \$48.3 billion annually. Brain injury accounts for more years of lost productivity than any other injury.
- The consequences of brain injury are unpredictable. A brain injury can affect who we are and the way we think, act, and feel. It can change everything in a matter of seconds. The effects of brain injury depend on factors such as cause, location and severity. It is important to note that no two brain injuries are exactly the same, and that the effects of a brain injury are complex and vary greatly from person to person.

## *Coping with a brain injury is difficult and can create many hardships.*

Brain injury can cause an individual to develop cognitive, physical and emotional changes. The following are some possible consequences of brain injury:

### **Cognitive:**

- Short and/or long-term memory loss
- Slowed ability to process information
- Trouble concentrating or paying attention
- Communication difficulties such as word finding and/or keeping up with a conversation
- Organizational problems, impaired judgment, decision-making difficulties
- Inability to do more than one thing at a time

### **Physical:**

- Seizures
- Muscle spasticity and tremors
- Problems with balance and motor coordination
- Fatigue and/or weakness
- Hearing and visual changes
- Loss of ability to smell and taste
- Speech impairments such as slow or slurred speech

### **Emotional:**

- Increased anxiety, stress and frustration
- Depression and mood swings
- Impulsive behavior
- Reduced self-esteem

Recovery from a brain injury may last weeks, months, or years. Recovery is slow and often incomplete. The individual with a brain injury, as well as family, friends, and other community supports often must adapt to incorporate these changes into everyday life. Unlike other injuries, the effects of a brain injury are not always visible, which is why brain injuries are sometimes unrecognized.

Scars from a brain injury are frequently more severe on the inside and very difficult to heal. The individual and the family often go through a bereavement process, as they mourn the life they previously had. Experiencing feelings of anger, depression, guilt, and anxiety are common, normal, and healthy for both the individual and family.

Coping with a brain injury is difficult and can create many hardships. Those affected by brain injury often need support from somebody who understands the complexities of brain injury.

With the support of family, friends, community, and rehabilitation professionals, many individuals with brain injury are able to be active members of society, return to work or school, and continue in loving family relationships. Often, long-term supports are needed to accomplish these goals. The Brain Injury Association of New Jersey, Inc. (BIANJ) assists individuals with brain injury and their families to achieve these goals.

The Brain Injury Association of New Jersey, Inc. was founded in 1981 by family members and friends of individuals with brain injury.

BIANJ is a charter member of the national Brain Injury Association, and is a statewide membership organization dedicated to providing education, outreach, prevention, advocacy, and support services to all those affected by brain injury and to the general public. BIANJ offers many programs and services to families, including:

- Information and resources
- Support groups
- Family support
- Toll-free Family Helpline: (800) 669-4323 within New Jersey
- TREK, a week-long summer respite and independent skills-building program for individuals with brain injury
- PACE, a supported employment program
- TBI Family CARE, a mentoring program for families and individuals recently affected by brain injury

The Brain Injury Association of New Jersey can be reached at (732) 738-1002, or by visiting their website at <http://www.bianj.org>.

*Wendy Berk, MSW, LCSW, is a licensed clinical social worker with an extensive background in the health field. She has clinical experience in both acute hospital and residential care. She is currently a TBI Outreach Specialist for the Brain Injury Association of New Jersey, Inc.*



## I Don't Know What to Pray For

*Rev. David Cotton, M. Div.*

"I don't know what to pray for!" This anguished cry is heard frequently from the loved ones of a person with brain injury. The challenge to the spiritual caregiver is to acknowledge and address the spiritual conflict so often present in those faced with a friend or family member with a brain injury.

In other types of traumatic injury the prayer pathway is clear: repair—rehab—return to life as usual. With brain injury, however, the route is not nearly so well-marked, and the conflict is intensified. The ability of medical science to "fix" the brain is so limited that often the chances of recovery are slim, and the possibility of a return to one's previous life even slimmer. When faced with the choice of death or a life of confinement to a body which may no longer hear or interpret commands from the brain, the pray-er's choice is both confusing and confounding. What about the quality of life? What about a life of institutionalization? What about suffering? What about finances?

These questions loom large and must be asked. The spiritual caregiver can help by providing a non-judgmental, listening ear as persons work through the range of issues and choices which rush through their minds and hearts—especially the most complicated issue. Even the slightest notion that a spiritual person might utter the cry found at the

beginning of the article—that one might actually entertain the notion to pray for someone to die rather than to live—is simultaneously unavoidable and unthinkable.

This thought, when it comes, leads to tremendous stress and almost certain feeling of guilt. The family, friends, and caregivers could have a spiritual crisis on their hands. And into this complex situation walk the spiritual caregivers, attempting to discern what situation awaits them.

"Where is their hope?" It is often enlightening to ask this question when assessing how far persons have come in dealing with the trauma of a loved one's brain injury. The miracle-working power of medical science and technology is the first stop for hope. But this source of hope fades quickly when the medical community often can offer no better promise than support for the rest of the body while waiting anxiously to discover to what extent the brain heals itself.

With medical hope diminished, the object of hope often shifts to the personality—the perseverance and "spunk"—of the injured person. "He/she's a real fighter!" This type of hope, too, often wanes rapidly. With brain injury the psychological qualities which would give family and friends reason to hope are the very functions which have been severely altered or even wiped out by the injury they seek to combat.

Having worked their way through the technology of

medicine and the power of personality, for many the focus of hope at some point turns to faith. Whether found in the arms of traditional religion or in the refuge of individual spirituality, they seek solid footing where all else seems to be giving way, comfort where all else is pain.

Now is the time, having journeyed with the family, that the spiritual caregiver has the opportunity to offer companionship and compassion, presence and prayer. Even when the cure may not be realistic, care is never optional. "I don't know what to pray for!" The essence of spiritual care is found in just this situation—when faith cries out its question, and someone comes alongside—even when there may be no answer.

*Rev. David Cotton is Coordinator of Pastoral Care at Jersey Shore Medical Center in Neptune, New Jersey. He is an ordained Presbyterian minister.*

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## Seeing the Unseen: The Person Behind the Patient

*Robert Lee,  
a person who has brain injury*

Medicine is based on learning the various diseases, old and new, as well as the many accidents that occur to the body, and how they can be controlled and repaired. Historically doctors have learned how the body fights diseases and how the bones of the body can repair themselves with physicians' assistance. However, there appears to be a factor that is overlooked or not considered while the physician is caring for the diseases, the broken bones, and the "patient." That is the person himself or herself. This "patient" is alive and does have a mind, an attitude, and a mental outlook. This understanding is probably most important in the patient who has suffered a brain injury.

I say this because of my own story. The healing time following my accident consisted of five weeks of being in various stages of coma. The neurosurgeon who cared for me was an excellent physician and a nice guy. But he overlooked one thing — me — the patient as an individual! He did not know how to respond to my questions about the pain and its possible effect on the brain. At times, his response made me very angry. I would say, "Doctor, you have no right to say that. Have you ever been here?" He responded with an apology and said, "No, I'm sorry. You are right."

The basic problem comes from the visual knowledge that

we all take for granted. If a friend walks into a room on crutches, you normally say, "I'm sorry to see that you broke your leg. How and when did it happen?" But if I walk into a room, people only say, "Hello." My injury is invisible. The conversation then goes to problems at hand. Others do not see the brain injury, nor do they detect any inner swelling or the pain that exists. I have had doctors say that the pain might be there forever or that I might wake up one morning and it will be gone. The outside world cannot relate to the problems I have in thinking and the associated pain. They cannot relate to my thought processes and how I search for and think about words.

Don't tell me what to do

or what is happening. I am awake, and I can think and feel almost everything. Why not ask me what I feel...or ask me how I feel?

All people who have had the terrible experience of a brain injury due to an accident or to brain surgery due to cancer or other diseases understand the inner feelings of being such a patient. Thank God other people have not had that experience! But those who have not — including families, friends, and even doctors — cannot truly understand what is going on in the patient's brain. We are not only affected physically, but also emotionally. We attempt to present ourselves to the outside world as we were before the accident or surgery. However,

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*What does a person with brain injury look like? Go look in a mirror. It could be a person who looks just like you. Many people with brain injury look perfectly "normal"; others have more visible long term disabilities. "Hidden" does not mean "imagined". "Unseen" does not mean "unreal".*

we cannot truly do that. Then we become emotionally upset and depressed when we attempt to face the world today the way we faced it yesterday.

I would like to share with you an experience I had with a doctor. One of the results of my bicycle accident is that I have developed seizures. Thus, I have been told that I will have to take anti-seizure medication for the rest of my life. To the person with brain injury, this is a very depressing thought because it seems to interfere with daily living. Therefore, it is important that those who speak to the patient understand the emotional problems that he/she is experiencing. Physicians should deal with the patient's total being—not just the medical portion.

When one of my physicians indicated that seizure medication was required, I asked if the medication would control the seizures. "It should," he responded. I said that was the wrong answer, and he replied, "That's the best I can do..." Professionally (I was a pharmaceutical researcher), I understood what he was saying, but emotionally I could not. It would have been better if he had said something like, "We hope that it will." I probably could have dealt with that in a much better way. But being told that "it might" left me very vulnerable and in constant fear. Patients need to be supported, not to be left hanging and alone.

Another aspect of the person with brain injury is their relationship with family

members. Families can be very helpful or present many difficulties. It is important for the entire family to understand the capabilities of the injured family member. Injured persons not only lose physical abilities, but also lose feeling abilities, as though they had lost their role within the family. As an example, both my grown children came to me and individually said that I should try to relax, get better, take care of myself, and not worry about other factors in life such as money.

It was a wonderful thing for them to say, but in its own way, it hurt very much. I was no longer the father. Not only couldn't I take care of them, but I also couldn't take care of myself.

The frustration of having been a professional and wanting very badly to be one again was my most difficult issue. I don't remember this, but I was told that I had to be introduced to my wife and children. My son had to help me with simple words such as "spoon," "knife", and "fork," and I also had to be reminded to take medications three times a day.

I remember being taken to a psychologist's office for testing, being questioned about simple acts, and not being able to complete the answers. This led to fighting back in the only way I knew, a child-like attack. I told the doctor, "I hate you!" when he asked how I was feeling at my second visit. I remember that he was very compassionate and said, "That's okay, but why do you hate me?" I answered as only a child could, "Because

you make me feel like a dummy." Please understand that even though we might be unable to answer many questions, we are very much aware that we can't. The rehab staff knew how to play the game as we went along, and slowly but surely my half brain learned things all over again.

When one family member is hurt, many others are injured as well. Since we can never be the same, as we would like to be, that frustration is felt by the injured person and by the family who really wants things to be the way they were before. Everyone has to go slowly so that the injured one feels that he/she has permission to go slowly. It is important not to make corrections when they speak, but rather, as my son said, "Try again, Dad."

It is important to understand that our thinking processes are very different from other people's and quite different from the way we used to be. My wife recently said, "You'll find whatever you need in my left-hand upper dresser drawer." I couldn't remember exactly where and in which drawer. "You're not listening to me," she said, but in fact I couldn't remember. It was as simple as that. I realize it was frustrating to my family, but believe me, it was twice as frustrating to me.

*Robert Lee is the author's pen name, but the story is a real one.*

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one family  
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## Two Mothers, Two Sons, Two Faith Journeys

Sally Jankowsky

My name is Sally Jankowsky, and the following is my experience with faith and churches in my family's time of desperate need. For several years prior to my son Michael's injury, I was involved in the Charismatic movement in my church. When Mike was injured, the first place my husband and I turned was to God. We went to our church and spoke to our priest. The very next day, a Sunday, Mike's name was brought to the pulpit and the congregation was asked to pray for him. This went on for at least a year.

When Mike was better and able to come home, our parish priest came to our home several times to visit with Mike and to give him communion. He also went to the trauma hospital several times to see Mike. At the trauma hospital, we met the chaplain and requested that he be with Mike and us. He came every day to the ICU. His presence was very important to us. He listened and stayed with us. I don't remember him saying much, but his mere presence was a comfort.

I don't know if I think of God every day. However, my involvement in Mike's care and the volunteer work I do in the disability arena, make me feel that God has given me a mission. In this way I feel that I am connected to God. I guess in a strange and tragic way, there is a blessing here.

Now Mike wants nothing to do with church or God. He tells me it is God's fault that this happened to him. When

he was home after the injury, however, he did go to church with us. Mike also told us that while he was dying (as a result of the initial injury), he saw a light. It was God, and God told him to go back. HE told Mike HE was not ready for him yet. *Sally Jankowsky lives in Toms River, New Jersey, has been married for 37 years to her husband Ron ("a great guy," she says), and is the mother of 3. Michael, the oldest, sustained a brain injury at age 19. She has 4 grandchildren. "My family" says Sally, "is the joy of my life, and I am driven by my dream and my heart." She has also been a close friend for many years of Muriel Overmars, author of the other article in this pair. They met through their sons, both named Michael, when they were at Children's Specialized Hospital, Mountainside, New Jersey.*

Muriel Overmars

Our son sustained a traumatic brain injury sixteen years ago as a result of an automobile accident. After arriving at the hospital and being told he was on life support, I went to the hospital chapel to pray. I have always been an active member of our church, and I taught religion for many years. My faith in God has always been very strong. But during this time of crisis our family needed comfort and support, and it just was not there.

Our son's accident had occurred just before Ash Wednesday, and he now lay in a coma with numerous broken bones and with machines to sustain his breathing. After I received ashes at our church, I asked one of our parish priests to please visit our son in the hospital

and to bless him with holy ashes. I was told that there was a Chaplain at the hospital to do that, and I was left on the church steps feeling emotionally upset and alone.

This was the church our family had attended for almost twenty years! This was the church where our children had made their Communion and Confirmation. Mindful of the fact that the clergy have busy lives and hectic schedules, I still wanted to know, "Where was everyone when we needed them so badly?"

There were some positives. When our son awoke from his coma after four months, I called our church and asked if a mass could be said in our home. The Pastor was very apologetic about the manner in which our family had been treated. He came to our house and said a mass for our son.

As our son progressed, we tried to take him to church in his wheelchair. But because of impulsivity problems related to his injury, the uneasiness of the parishioners around us was obvious and he no longer belonged. He was different.

I believe people wanted to reach out but were uncomfortable with the situation. Even close friends and relatives found it difficult and still do. It is as if they feel "there but for the grace of God go I," and so they avoid getting involved.

Even with my deep faith, I had to draw away from the church and re-evaluate my beliefs. It took a lot of soul searching, but after a period of time I came back to my church — but with a different attitude.

I have found that there is a big difference between religious persons who feel as long as they go to church on Sunday they are guaranteed a place in heaven and Christian persons who try their best to follow the teachings of Jesus Christ. I believe I am blessed to have been given the insight to know the difference.

Our son now attends a church where he and other persons with disabilities are accepted for who they are. The parishioners even helped to build him a ramp so that he could enter the front door in his wheelchair. Our son's faith in God has never wavered. Although he is angry at times, he still believes that God has a purpose for him.

As for me, I have weathered the storm and have come through with my faith in God intact. It must show because my daughter now teaches religion for our church, and her children are receiving their sacraments in the same church as she did.

I like to believe my family has come through our crisis accepting the fact that we are all only human and that it is faith in God that gets us through life.

*The Overmars family live in Northern New Jersey. Along with other families, Muriel and Sally have started a not-for-profit group called "Advocacy Consulting and Education (ACE) for Families with Traumatic/Acquired Brain Injury. They have spoken at conferences about their experience, and are active members of the Brain Injury Association of New Jersey.*

## A Personal Story: A Journey of Discovery

*Ray Vigano,  
an individual with brain injury*

I would like to share my experience with a brain injury, which I incurred in 1996.

In June of that year I began to experience some unusual and discomfoting events and feelings over a period of about two weeks. On several occasions I became light-headed and somewhat disoriented, and I also had occasional difficulty controlling my thoughts. These episodes prompted me to consult my doctor. The diagnosis was one of vertigo, and I received medication for it. This didn't help, so I saw a neurologist who couldn't make a diagnosis but wanted to observe me for several more days. Unfortunately, several days later I had to be taken to the ER and admitted to hospital when I became very disoriented, experienced slurred speech, and went into seizures. I was hospitalized several days, put on antibiotics and given a battery of tests including EEG and MRI and a spinal tap, but still the doctors could not tell us what happened to me.

Somewhere in my seizure, in a comatose state, I remember a vision which I believe was of God. It was a state of perfect peace. I came home from the hospital and on the surface appeared fine. However, my brain was not functioning properly. I quickly realized that I had significant memory loss, including what I did at work, the names of my neighbors

and co-workers, my neighborhood street names and locations, and also many significant life events.

But most upsetting for me was that I had short-term memory lapses and could not concentrate on anything for more than a few minutes. I became easily confused and very frustrated when faced with the simplest of decisions. I began to become depressed because I could not be comfortable when several people were around me carrying on a conversation, since I could not keep up with the changing thoughts and flow. I would become exhausted trying to stay there and usually had to leave to get away and be alone and try to relax and compose my racing mind. I also could not understand why I left out words or letters when I tried to write but not when I spoke.

I remained home from work several months and began a slow healing and recovery process including individual and group therapy and psychological counseling. I know that this was a very difficult and scary time for my wife as it was for me. She stood by me and supported me. Not all my family members could understand or appreciate what we were going through because to the untrained observer, I appeared fine. Why wasn't I putting what happened to me behind and just moving ahead with my life? Believe me, I was desperately trying to do just that. During therapy, especially group therapy where I was with

others who had experienced different sorts of brain injury and were struggling with hidden disabilities, some for years, I became more determined to overcome or live with my problems. I also thanked God for what I still had and prayed for His help. Over time I have recovered most of my thought processes and functions, and I have returned to work.

I have recovered from what the medical center later diagnosed as an uncommon type of viral encephalitis, and I consider myself quite fortunate. I was only left with some vision and hearing problems and a story to tell. Many others with brain injury are not so fortunate. Relearning about and uncovering experiences that lay buried in my mind has been a joy, as I suddenly get glimpses of past places or people or events like an explorer on a voyage of discovery. But isn't that what a voyage through life is—a discovery and rediscovery of ourselves and what is around us? And yes, we are not alone.

*Ray Vigano is married and has four children. He works for a corporation in Northern New Jersey and values family support very highly.*

*Not all  
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## Pastoral Issues of Note in Different Types of Brain Injuries

by Fr. Bill Cramer

*Denial,  
anger,  
bargaining,  
depression,  
acceptance  
are all  
emotions  
that will be  
touched upon  
by coping  
family  
members.*

The trauma of brain injury to a patient creates a crisis in any family system. Each family brings a set of emotions and coping patterns based on their family history, the nature or cause of the brain injury, the status or role of the family member with a brain injury in the family unit and the family's "faith" system.

A brain injury is a loss. The five stages of loss that Elisabeth Kubler-Ross explains in her book, *On Death and Dying*, can really apply to all those losses. Denial, anger, bargaining, depression, acceptance are all emotions that will be touched upon by coping family members.

Is there a difference in the way families will cope based on the incident/accident that caused their loved one to sustain a brain injury?

I think the answer is "Yes" and "No." Look at these examples: your grandfather falls down the basement stairs and suffers a brain injury. Your 9-year-old niece, who is not wearing a helmet, falls off her bicycle and hits her head. She suffers a brain injury. A single mother of two young children crosses the street, is hit by a car and suffers a brain injury. On a city street, two gangs battle over turf and your 16-year-old son is hit with a bat; he suffers brain injury. Your husband left a party, had too much to drink, lost control of his car, caused an accident which killed the driver of the other car; your husband is now in the hospital uncon-

scious with a brain injury.

Now let me ask the question again—is there a difference in the way families cope based on the incident/accident that caused their loved one to become brain injured?

The similarities—whether a brain injury is caused by an accident, a natural event or an act of violence, families will go through shock, denial, anxiety, anger, guilt, depression, acceptance, and hope. They will go through these emotions in various degrees and at different times, sometimes simultaneously.

The differences—the family of the husband with a brain injury whose drinking and driving caused the death of someone else, finds they are now dealing with new fears—police investigation, legal ramifications by the family of the other party, questions concerning the family's income if the husband does not fully recover and cannot return to work. The family of the single mother of two, injured crossing the street, deals with the uncertainty of how to raise these two children if the deficits from the brain injury are permanent. Thus, the status and role of the family member with the brain injury can shape a family's response. The disability of a wage earner or parent has a very different impact on a family than the disability of an elderly grandparent. A natural cause, an accident, or someone's fault and responsibility: all impact the way an individual and family might respond.

The family of the 16 year old injured in the gang vio-

lence and the family of the 9 year old girl who fell off the bike both feel the shock and despair of losing the "future" hopes and dreams of their child if the brain injury recovery process is not complete. Thus, the stage of the family life cycle makes a significant difference in how families respond.

The various causes of brain injuries involve similar but also unique responses by family members. An appropriate pastoral response should include the realization that there are many issues that affect family dynamics. How has the family dealt with previous crises? What is the family's pattern of relation to each other and the status and role of the family member with the brain injury? What are the coping resources of the family?

Pastoral care always has a significant role. All those may be part of the mix of spiritual, pastoral and emotional issues being raised by the family. Spending time with the family, allowing them to share their emotions, allowing healing tears to flow, and offering appropriate prayers all give immense pastoral support to coping family members.

*Father Bill Cramer is Director of the Pastoral Care Department at St. Joseph's Hospital and Medical Center, Patterson, New Jersey and Vice Chairman of the ethics committee.*



## A Son's Story: The Power of Faith

by Michael Jordan Segal,  
LMSW, LMFT  
Victim of a gunshot wound  
resulting in TBI

On February 17, 1981, I thought my life was set. I was a happy, athletic, pre-med honors student at the University of Texas at Austin, well on my way to fulfilling a life long dream of becoming an orthopedic surgeon. Within five minutes that beautiful life was shattered forever.

After a long evening of studying for a chemistry exam, my beautiful girlfriend Sharon (who six years later became my wife) asked me to take her back to the dorm. I pulled into a nearby convenience store when I noticed my gas gauge registered empty.

Upon entering the store, I was immediately accosted by three robbers who forced me at gunpoint into the cooler, pushed me down, and shot me in the back of my head execution-style, hoping to eliminate any witness. By some miracle I was still alive when the paramedics arrived.

Several hours later the neurosurgeon painted a very bleak picture for my family when he said I would either die on the operating table, or if I survived, never be able to lead a productive life. However, weeks after major neurosurgery, being comatose, unable to move my right side or speak, I was alive and on my long, hard road to recovery. Believe me, it was not an easy task having to learn to walk, talk, and think again.

Once, while in therapy, a neuropsychologist tested me and said, "Mike, you must give up your dream of returning to the University of Texas and be more realistic." I thought, "Who is she to tell me what I can and cannot do? She doesn't even know me."

I've often thought about what kept driving me to excel and to never give up and accept my fate. After much soul searching, I knew it had to be the way I was raised and the influence my father had on my life. By profession, my father is a Rabbi, and he always instilled in me such great faith. He told me that if I worked hard enough I could achieve anything and that he always believed in the proverb, "After the darkest night the sun always rises." Now it was my chance to erase the darkest night in my life and let the sun shine through.

After almost two years of never-ending therapy (12-14 hours per day), I finally returned to the University of Texas and four years later graduated with highest honors.

Life was not easy at University of Texas. In addition to attending classes, I had to continue therapy. Life will never be easy for me. However, I believe that life is not supposed to always be easy. I feel that in order to experience the beauty in life, one must also taste some bitterness. Perhaps I have experienced a great share because, up to this day, I still have many residual disabilities from the shooting that almost took my life. I am partially

paralyzed on my right side. I have difficulty with my vocal cords, causing my voice to sound constantly hoarse. I have a slow rate of speech, and I suffer from other physical problems.

In the early days of my recovery, I was constantly dwelling on my losses. Now I concentrate on the activities I can achieve and accentuate the positive rather than dwell on the negative.

Because of that outlook, upon graduation, I decided to earn a Master's Degree of Social Work and am now employed at Memorial Hermann Hospital. I primarily work in the Neuro-Critical Care Unit, helping families of survivors of head injury learn to cope. The most important skill I learned from school and my father is that of listening. My father lives by the famous maxim; "God gave human beings two ears but only one mouth. Therefore, the most important thing one can do is listen." Listening, rather than speaking, is such a vital skill in counseling and in life itself.

Whether you are a friend, a member of the clergy, a social worker, or a doctor, listening to someone who has suffered a crisis is vital. It can help the sun rise for that individual as it did for me and my family after experiencing the darkest night.

Michael is currently a Social Worker at Memorial Hermann Hospital, Houston, Texas. He is married to Sharon, his high school sweetheart who dropped

out of school to be with him when he was injured. Together, they have a daughter, Shawn. Mike has written an autobiographical manuscript entitled *Never Say Quit* and is currently looking for a publisher. Mike was a recent contributing author in *Chicken Soup for the Christian Family Soul*. Mike is available for public/keynote speaking. He can be reached via email at [msegalhope@aol.com](mailto:msegalhope@aol.com).

▼

*I've often  
thought  
about  
what kept  
driving me  
to excel  
and to  
never give  
up and  
accept my  
fate.*

## His Father's Perspective: A Path Over the Mountain

by Rabbi Jack Segal,  
Father of Michael Segal,  
previous article

Nineteen years ago, when Toby and I were called in the middle of the night and told that our second son, Michael, a pre-med student at the University of Texas, had been shot in the head by three thugs during a robbery, I felt as if my entire world had quickly and abruptly ended. Michael's future had been so bright. His love for people had been so warm. His desire to help humankind had been so strong. But now he was barely hanging on to life by a thin thread.

We quickly drove to Austin and noticed that there were scores of his fellow students at the hospital waiting for some information about Michael. That night, several of the students said to me, "Rabbi Segal, we've decided that we are going to have a prayer service for Michael at Hillel. We would like you and Mrs. Segal to be present."

About one hundred students attended the service that evening, and one of them rose and asked me to say a few words to those who had assembled there. It was a surprise to me because my mind was a million miles from Austin. I was merely thinking of Michael and what had happened to him. However, I rose and briefly spoke to the group.

I said, "Michael has been dealt a severe and bitter blow, but there is a great difference between being 'knocked down'

and 'knocked out.' True, Michael has been 'knocked down,' but Toby and I will not allow him to be 'knocked out,' and if you know Michael, you know that he will arise off the canvas to fight the biggest battle of his life—survival—and he will return to normalcy. He will *not* remain down for the count of ten."

I hesitated for a minute and then continued, "Remember what the angels told Lot and his family when God was about to destroy the city of Sodom. They told them (*Genesis 19:17*) 'Do not look backward...escape to the mountain (that is before you).'

God was telling Lot and his family that there was nothing they could do about the past, but there was much they could do about the present and the future. God was telling them *not* to concentrate on what *was*. God was telling them to give heed to what was *before them*. That is why they were told that they should look toward the mountain that was before them. Yes, it was tall. It was high and difficult to climb. It would take much effort and exertion and toil to reach the top—but it was attainable."

I paused for a moment, but then I went on, "Yes, Michael has a gigantic mountain before him that he now has to scale, but with an excellent medical team and with the help and assistance of his family and friends, Toby and I *know* that he shall overcome."

And as a postscript I added, "When the Israelites

entered the Holy Land after wandering forty years in the desert, Joshua thought that the task presented to him, conquering the land, was an impossible one. But God said to him the same two Hebrew words on three separate occasions (*Joshua 1*): '*Chazak V'emetz*.'—'Be strong and have courage.' They are the ingredients of success in every venture.

Yes, the future looks bleak. The day appears to be dark. But this is not the time for pessimism. It's the time for sweat and perspiration. It's the time for support and help. It's the time for helping him and aiding him to convert the impossible into the possible, the hopeless into the hopeful, and the unachievable into the achievable."

We then gathered to pray for Michael as Moses had done for his sister Miriam when she had become seriously ill in the desert (*Numbers 12:13*), and we hoped that he would recover as King Hezekiah had regained his strength and health when prayers were recited on his behalf. As the Bible states, (*II Kings 20:5*): "I have heard thy prayer; I have seen thy tears; behold, I will heal thee..."

Since that day 19 years ago Michael has exerted himself and labored to regain his strength and health. He has always believed in Benjamin Franklin's statement (*Poor Richard's Almanac*, 1734): "God helps them that help themselves." With faith in God, confidence in himself, and a

magnificent support group of physicians, therapists, teachers, friends, and family, Michael was able to return to the University of Texas. He graduated Phi Beta Kappa and then went on to the University of Houston to receive a Masters Degree in Social Work. Today Michael is married, has a daughter, and works as a social worker at Memorial Hermann Hospital in Houston.

True, Michael still has to do therapy every day, but he refused to be knocked *out* when he was knocked *down* 19 years ago. He insisted on looking *forward* and not *backward*, even though a tall mountain loomed before him. However, he believed that over every tall mountain there was a path and it was his duty to search for and find that path.

*Rabbi Jack Segal, M.Ed., M.A., D.H.L., Ed.D is currently Rabbi Emeritus of Congregation Beth Yeshurun in Houston, Texas, where he had served as the Senior Rabbi for 31 years. He has degrees in physics, mathematics, and counseling, and has been active in interfaith ministries and a variety of community services and boards.*



## Transitions for People with Brain Injury and Those Who Journey with Them

by Karen Lewis, M.Div.

Hospital, rehab, home. For many with brain injury, this is the path they follow. Others may not require hospitalization, or are discharged directly home without the transition to a rehabilitation facility. Some are never able to return to their own homes. Still others may not be aware they have sustained a brain injury until they begin to notice “changes.” This article will focus on those individuals whose injury takes them on the path of hospital, rehab, home.

Stated another way, before the brain injury, during the treatment, and life hereafter. A person and family may receive good care and support in all those places, or maybe not. The important thing for clergy and congregations to remember is that they may be one of the few constant supports in someone’s life, and, if a person was a member of the congregation before the injury, they remain a clear point of reference, stability, and encouragement.

At onset, a person with a brain injury is considered an emergency. The person will be sent to an intensive care unit in an acute care hospital where their life may be saved and their condition stabilized. In this kind of emergency, congregations are often at their best, and at the hospital people may be surrounded by care. A trauma center may have a chaplain who can work in real part-

nership with the person’s pastor and congregation. The chaplain may be more familiar with the hospital and acute care, but never underestimate the power of the visit from one’s “home church.”

The focus of acute care is often to “get the patient to rehab.” It can be an acute or sub-acute rehabilitation center, depending on the degree of injury. The kind of rehab and location may be also be a function of the specialized programs needed and the insurance available. Here patients will spend several hours a day in a structured rehabilitation program. There will be a team of professionals supporting and assisting the person with occupational, physical, and recreational therapy; they will even learn tools for housekeeping tasks. The focus is on attitude and activity. There may not be a chaplain, and a rehab center may be a long way from home. Cards, calls, and visits may be more difficult for pastor and congregation, but may be even more needed than before. Through both of these transitions the person is usually surrounded by a lot of support. Typically, friends and family were present in the hospital cheering during the first awakenings after a coma. There were countless professionals aiding every step in rehab. Through rehab, the hope is often “getting someone back home.” However, at both rehab centers and at home, just as the long term adjustment of life with brain injury becomes apparent, the support can taper off.

Many families may be very accepting of the medical stage and



### Crashes and Brain Injury

It could be a car or bike crash that causes (or leads to) a brain injury. But there are other “crashes.” Crashes when long term changes and losses become clear. Crashes of hope when “rehab” does not “fix.” Crashes when dreams and hopes and memories meet new realities. Pastors... be on the lookout for crashes.

*...it becomes crucial for God's people to support those with brain injury through a complex and long journey.*

subsequent relearning of basic skills and activities of daily life; however, very few recognize or are prepared for the changes affecting cognition. A typical scenario finds the person returning to the household with everyone expecting life to go on as before. Once individuals have mastered the more physical problems, expectations of resuming a pre-injury lifestyle are common but can be very disappointing.

With time there can be an improvement in cognition, but this leads to an increased awareness and insight, which may contribute to new problems with unpleasant emotional reactions. Here's when another crash comes, when hopes of complete recovery flounder, and when everyone realizes the difference between "life before" and "life now and here after." Family members are confused as to why the person seemed so pleasant and worked hard to get better through rehab—but now is angry, abusive, and depressed. The support systems in place up to this time have gradually been reduced. This can coincide with the time the family members have begun to relax the ongoing support they've been providing and are hoping to "get back to normal."

This is a pivotal time in the lives of persons with brain injuries and their families because they are finding out that life has forever changed. More importantly, they are learning that there is no point at which one is pronounced "cured" after a brain injury.

New questions, problems, or setbacks sometimes kick up the emotional and spiritual trauma of the journey all over again. This is when it is crucial to remember that there is life after a brain injury. It may be a different life, but it is a life worth living. This is when pastoral and congregational care can be so crucial, when both faith and people can be mobilized to deal with what is and what can be, while also mourning the loss of what was.

Support groups can play a vital role in discovering this. Support groups enable the person to identify with others who have similar problems, and together solutions are often found. Also, as a result of group interaction, the individual can feel less alone, and a sense of belonging is very important to those whose lives have been dramatically changed. Many support groups extend services into social areas, sponsoring activities outside the regular meeting times, picnics, dinners out in the community, dances, volunteer opportunities and other ways members can be productive and fulfilled. Clergy can help find support groups, open the church or synagogue to them, and both encourage and bless the involvement of individuals and families in them. Families find support groups very helpful in gaining insight into the long-term consequences of brain injury and the ways to recognize problems in advance of their becoming difficult issues. Sharing practical management strategies with other

families is a real source of coping skills. Support groups, like hospital chaplains, can be crucial, but remember there are no substitutes for "down home care from one's congregation."

The journey home thus may not be a life back to normal. It may be a journey with spontaneous signs of hope, hard-fought achievements, physical and emotional setbacks, highs and lows, peaks and valleys. "Yea, though I walk through the valley." As people of faith affirm that God goes with us, so it becomes crucial for God's people to support those with brain injury through a complex and long journey.

*Karen is United Methodist and a graduate of Princeton Theological Seminary. She has worked as a chaplain at Kessler Rehabilitation Institute and at the Boggs Center on Developmental Disabilities as Assistant Coordinator of the New Jersey Coalition for Inclusive Ministries and the project that produced this booklet.*



## Lightening the Load: Finances and Care

by Wendy Berk, LCSW

A brain injury can often be a devastating and life-altering event which affects many aspects of everyday living. In addition to dealing with the medical and emotional burdens of a brain injury, many families face increased financial burdens as well. At a time when it feels like the whole world has stopped, the need to pay bills has not.

There are many reasons why financial problems may arise at the time of a brain injury, including:

- The individual who sustained brain injury may have been the family bread-winner.
- Family members may take time off from work or stop working completely to be at hospital, rehab, or at home to provide care.
- Inadequate insurance may leave the family with enormous medical bills.
- Family may need to pay out of pocket for certain medical care, equipment, medications, and/or therapies.

Financial problems after brain injury can affect anyone, and families may be unsure of where to get help and uncomfortable asking for it. When addressing their financial needs, it is important to recognize the sensitivity of this subject.

There are federal and state programs in place to assist in providing possible sources of income, medical insurance, housing, nutritious meals, etc. Some of these programs include State Disability, Social Security, Medicare, Medicaid, Homeless Prevention Programs, and Food Stamps. The eligibility criteria for each program vary, and families will need to contact their local Board of Social Services or Social Security Office for specific information. Please refer to the listing of additional resources included within this booklet. The Brain Injury Association of New Jersey, Inc. (BIANJ) can also answer questions regarding available resources through their Family Helpline, (800) 669-4323.

In addition to these programs, many townships have informal supports in place to help members of their community. Some of these supports come from merchants who are willing to donate time or supplies, or through local agencies and service clubs such as the Red Cross, or Salvation Army. For example, they may help families build a ramp onto their house for wheelchair accessibility.

Many families look to their place of worship after a brain injury, not only for spiritual and emotional support, but also for community assistance. Families may have difficulty asking for assistance, and congregational members and friends may want to help but not know how to offer or what to do. As a pastor or congregational leader, you can have an important role in helping families identify specific needs, and then pulling members of the congregation together to help, both initially and long-term. Some ideas for congregational support include:

- **Fundraisers** for medical expenses, specific kinds of equipment, or joining together to build a ramp, and/or remodel a home.

- **Day to day supports** such as meal preparation, transportation, child care, home repairs and maintenance. Think of the ways that congregations so often respond in a crisis, such as a death. While it is difficult to maintain that level of response long term, think about some ways and at what level assistance can be sustained over the long haul. Loneliness and abandonment have a much higher spiritual and emotional cost than the fairly simple strategies a congregation can employ to combat those feelings.
- **Respite care** is a real help for families and others who are providing care on a full time basis. Caregivers need a chance to get away to recharge their bodies and spirits. People receiving care also need other friends, visitors, and people involved. This kind of help is almost priceless. These “non-medical” services are often not covered through insurance and can be very costly. It can also be difficult to find a caring, trusted person with whom the family is comfortable leaving their loved one. This often creates added stress and guilt for the caregiver.

Think about developing a circle of support, a network of people through the congregation, who would pledge to come over on a periodic basis, and be both a visitor and helper while a caregiver gets time away. Families and other professional caregivers can provide any training and guidance which may be needed.

- **Advocacy** from pastoral and congregational sources might be crucial. If families are looking for services, fighting with an insurance company, or involved in bureaucratic jungles, a pastor, priest or rabbi can be a very valuable ally — one who listens but also acts on behalf of others. Clergy may also know other members of their congregation whose specific skills can be of service.
- **Inclusion** within the congregation is important when a person with a brain injury is past the initial trauma, and begins to think about returning to the community. A congregation can help find ways for them to contribute and use their gifts for the life of the congregation or other volunteer opportunities. It may also include using congregational networks to help find an employer who would be willing to give somebody the chance to work.

There are many personal hurdles the individual with brain injury and the family may go through, including the onset of financial burden. As members of the spiritual community, you can help by becoming familiar with available resources, advocating for their needs, and organizing community and congregational supports. For additional information about community resources, please contact BIANJ at (732) 738-1002. If you are willing to help, they are willing to help you.

## This or That

by Rebecca Libutti

*This is something I wrote for the insurance company that came to examine whether I truly was damaged in any form or fashion.*

They came to tell me cautiously today  
That they really feel I'm okay  
They came with notepads and pens  
in hand  
To see for themselves if I could sit  
or stand  
They asked me awkwardly, "So how  
do you feel?"  
A question that makes my whole  
head reel  
How do I answer a question like that?  
Well...I feel just fine...except for  
this or that

There's a pain in my head that won't  
go away  
So I must take a nap nearly every day  
There's a problem with balance and  
My depth perception  
My joints won't bend, 'cept for that  
Rare exception  
Muscle spasms in my legs and back  
My scalp is recovering from a  
shingles attack  
Years of weight-watching but I  
still fight fat  
But I feel just fine...except for  
this and that

I had frozen shoulder for a year or two  
Shin splints and heel spurs...what  
else is new?  
Nails are brittle, skin is dry

Welts, rashes, brown age spots don't lie  
My bladder is weak, incontinence  
embarrassing  
Bleeding hemorrhoids are simply  
harassing  
Constipation is problematic  
Various infections are syndromatic  
So ask me again a question like that  
'Cause I feel just fine...except for this  
or that

My cholesterol's up to four hundred  
and ten  
Elevated triglycerides may cause  
my end  
My thyroid stopped working and is  
under suppression  
And now I am battling severe  
depression  
I think I am due for a panic attack  
But I feel just fine...except for  
this or that

Except for this twitching here or there  
And the fact that I'm losing much  
of my hair  
Short-term memory is in short supply  
I forget where I am, and I don't  
know why  
So all in all it seems quite plain  
But what is the use to cry or complain  
I'll tell you again, it's as simple as that  
I feel just fine...except for this or that.

*Rebecca is a survivor of a glioblastoma brain tumor, which is a stage IV malignant brain tumor. She is a strong advocate in the brain tumor community, and has written a book, That's Unacceptable, which outlines her battle with this disease.*

## A Time to Pray and A Time to Laugh: Positive Approaches to Coping with Life After Brain Injury

by Carolyn Rocchio

Founder, Brain Injury

Association of Florida

*Mother of a son with brain injury*

Brain injury is a major public health problem worldwide and when it occurs, it intrudes upon the lives of every member of an extended family. Just as the person who is injured is changed, all others who are about that individual are affected in a variety of ways, some positively while others, negatively. What are some of the forces at work that help people with these inevitable changes? When speaking with survivors of brain injury and their families, I found that there are many commonly shared ideas about getting through catastrophic situations emotionally and physically healthy. Some recommendations worth considering follow.

Many families immediately respond that faith helped them through the recovery of a loved one. Some families with no religious affiliation and little or no experience with prayer found that when faced with tragedy involving a family member or dear friend, they found themselves praying, possibly for the first time.

The healing power of prayer is universally accepted as the first line of defense for “believers” and recent studies support the theory that faith influences the body. “The mind and body used to be considered separate realms,” says S. Bryant Kendrick,

associate professor of internal medicine at Bowman Gray School of Medicine, Wake Forest University in North Carolina. (Goodwin, p. 83). Just as stress increases the production of hormones that affect the immune system, so also does the mind over body hold true when dealing with other life events.

*The federal government has funded 43 medical studies on spirituality and religion as therapy, and even the prestigious Journal of the American Medical Association has shown interest in the subject by asking its readers if prayer or participation in religious observances should be recommended when prescribing for patients. A think tank, the National Institute for Healthcare Research (NIHR) has initiated a project called “Faith and Medicine” to educate medical students in the value of spirituality in patient care and promote additional research in this area. Thirty of our 126 medical schools now offer courses in faith and medicine. We are coming closer to a time when the two previously diverse subjects are becoming recognized as equal components for improving health and well being.*

An interesting statistic compiled by the Gallup poll in 1994 indicates that 96 percent of Americans believe in God; however, the American Psychiatric Association published a report in 1989 indicating that only 43 percent of therapists believe in God. *The Journal of Family Medicine* in 1990 reported that 50 percent of the

individuals polled wanted their doctors to pray with them.

In addition to faith as a major component promoting healing, many families talked about humor and a positive attitude as a force that sustained them through difficult times. There is certainly nothing funny about brain injury, but finding reasons to smile each day is a factor in health and raises the level of optimism. Experts in child behavior agree that laughing and having fun with your kids increases their self esteem, teaches them social skills, and helps them establish positive peer relationships. (Ford) If, in fact, that statement is true, then it stands to reason that finding ways to approach our problems with humor and greater optimism should reduce their negative impact and allow us to deal more effectively with them.

I know that humor is a significant factor in my son’s ability to cope with his life changes after brain injury. Always a laid-back casual guy, he found many opportunities to laugh at himself during his recovery and throughout the last fifteen years of living with brain injury.

He was the family comedian with knack for the ridiculous; he was an uninhibited show-off but also very manipulative. For example, in the midst of having the riot act read to him for some indiscretion, he would envelop me in a bear hug and plant a sloppy kiss on my forehead. It was hard to stay mad at him for any

length of time, even while being manipulated.

As he lay in a coma after his brain injury, I tried to find ways to stimulate him and coax him into consciousness, but most of all to maintain my own sanity by feeling I was fulfilling an important mission at his bedside. I told him jokes, read “MAD Magazine”, and told him about the latest skit from “Saturday Night Live”, a show he faithfully watched with his sisters. Once he moved out of ICU and could have visitors, I made sure his friends were prepared for his appearance: (trach, G-tube, and a variety of other unfamiliar trappings) and that they came often and always with an upbeat attitude. Whether or not the atmosphere we created changed the course of Tim’s recovery remains to be seen because there is little evidence that persons can be awakened from coma by external means. However, we were rewarded when he smiled for the first time on the 71st day post injury. The smile gradually took shape as he thumb wrestled with a visiting friend. We played finger games frequently to keep his hands and fingers contracting. I recorded this event in my daily journal as a red-letter day. Although no sound accompanied the smile, it encouraged us immensely. We hoped it was the beginning of the return of the Tim we knew best—always smiling.

One of the most talked about examples of the healing quality of humor is the story of Fulton Oursler, a former

## A Time to Pray and A Time to Laugh: (continued)

editor of *Reader's Digest* who, when diagnosed with an incurable illness, simply decided that he wasn't ready to die. He rented a suite at a hotel, assembled all the films of the Marx Brothers, Abott and Costello, Ritz Brothers, Charlie Chaplin, and other comedians, shut himself off from the rest of the world, and laughed and put all his cares of the world aside—and his health gradually improved. Over the years I have been amazed at the ways families manage catastrophic events. Those whose energies are spent in more positive and upbeat ways, such as praying for survival and hopeful

outcomes, viewing life from the perspective of the glass half full instead of half empty, seem to survive with less emotional scars than others whose negativity seems to sabotage efforts to improve outcome. In the 15 years I have dealt with my son's brain injury and in my 14-year involvement with the Brain Injury Association, I have been privileged to meet and form friendships with some of the most optimistic and fulfilled people I have ever known. They are the movers and shakers of the brain injury movement; they are the backbone of support group develop-

ment and advocacy. You won't find sad faces at a Brain Injury Conference. You'll find people from all walks of life pursuing their goals in a positive and forward-thinking mode.

It's not to say that all prayers are answered or that feeling the need to act happy when you're not will result in the good life. However, the "whatever works for you" strategy does make one an active participant in the outcome. Problems will accompany us wherever we go, but it's a less rocky road if we tread it with faith and find ways to laugh off the heartaches we experience.

*This article was adapted from one originally printed in the Family News and Views Newsletter of the Brain Injury Association. Reprinted with permission of the author.*

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## Parish Life and People with Brain Injuries

by Rev. Elizabeth Waid, M.Div.

Probably every parish has one or more members who are living with brain injury.

Sometimes they are undiagnosed. There are youngsters whose families thought they were "OK" after a fall or a car crash and who are later said to have attention deficit disorder. There are adults whose erratic behavior is a symptom of an unrecognized brain injury rather than the mental illness we suspect. There are those whose alcoholism masks the results of such an injury. Being misunderstood and treated for the wrong disability is a frequent result of brain injury.

There are others in our congregations who are rightly diagnosed. We knew about the crash, the attack, the fall, the sports accident, the brain

surgery. We were at the hospital, sent meals to the family and prayed for them in church. We were glad that the patients survived. Often we give thanks that they have "recovered." But there we are mistaken. People do get better, often miraculously so. But things are never the same again. It is important for the pastor to know that and to think of people as "living with" their injuries, rather than to speak of their injuries as something in the past, something they once had.

Of course, if the injured person remains in a coma or has long term visible disabilities such as paralysis, the permanency of the injury is forced upon us. But many have no scars to point to, so they seem well. Their struggles to cope and their family's efforts to adapt may be hidden from us. They and their families may drop

from sight. Sometimes there is a divorce. Adults with brain injury are sometimes abandoned or forced from home when others become exhausted or irritated by what is seen as willful misbehavior. Always there is a need for understanding and support, both for the injured person and for the caregivers.

### The Pastor as Support

To be helpfully supportive, pastors need knowledge. Read. Get on the Internet. If possible, talk to physicians and therapists. Many are very eager to communicate their patients' needs to others. Alas, some of them are also limited in knowledge and experience with brain injuries. Their help to the patient, caregivers and pastor will be limited as well. Knowing that support must be long term will make the need for more information obvious

and the time spent getting it well worth while.

Listen to the person who has been injured. Listen to the caregivers. Try to avoid telling them how much they have to be thankful for. Grieve with them for what is lost. There will also be times to rejoice. They will tell you about them.

Coming to know the areas where society's ignorance makes life hard for those with brain injury and their families is the first step to becoming a support, and later an advocate. Finding medical care for ordinary health problems in the future will be difficult if the patient's injury causes a lack of cooperation with hospitals and physicians. Issues surrounding the return to work or school—or the lack of opportunity for such a return—and ongoing support in the work and school environment are

## Parish Life and People with Brain Injuries (continued)

important. Helping people to reconnect or stay connected to the life of the congregation is important and difficult. It takes constant involvement with the person and family, not only to offer transportation, programs, etc., but also to keep them using what is being offered or adapting the offering to their real and current needs.

Many caregivers and some individuals with brain injury become extremely knowledgeable and quickly connect with others in similar situations. They become advocates and educators for others in similar situations. Other families, in shock or denial or just overwhelmed, will need help in making these connections. For most individuals with brain injury that role will come, if at all, after long rehabilitation.

Obviously the pastor can't be the only, or even the chief support. Helping people connect with others who are knowledgeable, or who can offer care or information, is important. Supplying congregational support in the form of a Stephen minister, parish nurse, or other sustaining, dependable connection would be helpful. Respite care would be a blessing, but it isn't easy to develop people with skill, caring and the time involved to give it. Helping families to find good professional care and ways to pay for it is often the only alternative.

### The Pastor as Advocate

Advocacy comes as an outgrowth of knowledgeable support. Helping to interpret the situation of the individual with brain injury and caregiv-

er is only useful if the pastor has it right—and keeps up with changes that develop. Sometimes the pastor can help caregivers and individuals with brain injury “hear” what physicians and therapists are saying. Sometimes they can be helpful at meetings with school officials and even with employers and co-workers. Helping to establish programs or make those in place function effectively is an advocacy role in which a pastor can be aided and sometimes bested by members of the congregation's social ministry committee.

Issues of housing, ongoing medical care, recreation, transportation and caregiver support need to be addressed on a broad scale in most communities. Discovering and drawing together those who might work jointly in those areas is an important task. Aiding media awareness, even getting useful books into the public library are areas of local advocacy. Advocacy within the congregation is also important.

Advocacy in areas of prevention—“Buckle up for Safety!” “It's Cool to Wear Your Bike Helmet—Sports Helmet—Skating and Scooter Helmet,” support of groups like MADD and SADD, are examples of the advocacy that comes with awareness.

### The Pastor in the Congregation

The individual with brain injury and the care givers have the same needs as others in the congregation—to be included, to have their spiritual needs met, to find avenues of service, to be assured of God's

love for them in the midst of their suffering.

Sometimes this will involve beginning new support or Bible study groups, providing space and publicity for recreation programs, and reevaluating the ways in which volunteers serve. A person who before an injury read lessons and assisted in the distribution of Holy communion at church, but who is now no longer able to read and has full use of only one arm, may be a cup bearer, carry the bread plate, sing in the choir, offer prayer or even give a temple talk about brain injury and its challenge to people of faith. Seeing them continue, or begin, as leaders in public worship not only involves them, but also gives the congregation a powerful message of shared gifts and baptismal inclusion.

### One Congregation's Experience

In our congregation, Apostles' Lutheran Church in Turnersville, New Jersey, a community member introduced herself and her disability as she asked for space for a recreation program. Slowly she led many of us to new understanding and awareness of problems associated with brain injury. We found that it was the underlying situation of several of our neighborhood food distribution clients. We began hearing of relatives and acquaintances of our members. We became aware of difficulties faced daily with housing, work, transportation, medical care and the hardships experienced because of the long waiting periods common in settling injury cases.

We were a little bit knowledgeable and ready to learn more when one of our own youth was seriously injured, and he and his family began the long road of recovery and redirection. We have enjoyed the growing recreation program and the varied group who come. We have employed a gifted staff member whose brain surgery took nothing away from his ability to serve. Our original “teacher” has become involved in the congregation in ways that fit her limitations and remarkable abilities.

Some of us have been able to take part in seminars and workshops to make us more effective and aware. We are looking into a project to provide housing for individuals with brain injury who need more independence than a traditional group home affords and yet require some support for successful community living. God knows where we will be led next.

We believe that neither our previous lack of awareness nor our present opportunities are unique. Neither do we expect that we will outgrow or complete our involvement with those who have brain injuries or with their families and other caregivers.

*Rev. Elizabeth Waid is the Pastor of Apostles Lutheran Church in Turnersville, New Jersey.*



## When Shepherding Leads to Referral

by *Nunzio Gubitosa,*  
*M.A., M.Phil.*

Ministering to a person in need takes great skill. One aspect of that is recognizing when the person needs services that you cannot provide. Being acquainted with different therapies allows the minister to be more effective in his or her direction or assistance.

Often the person with brain injury needs more than the patient, caring listening of a clergy person. Some form of psychotherapy may be needed. It can be group, ego-supportive, or others. The clergy person is a perfect conduit to persons with brain injury in helping them pick up the pieces of their lives after the trauma.

Persons with brain injury often suffer from feeling alone, misunderstood, and ill at ease in the world. They have trouble reorienting themselves in society and may feel rejected. The recommendation for therapy will provide the person with a safe environment to explore these problems. The clergy person can provide the “sanctuary” where persons with brain injury can catch their breath and articulate their needs. While therapy may be called for, the minister and congregation can continue to provide the spiritual support and “spiritual sanctuary” that support an individual and family in their work.

People with brain injury may have trouble communicating. If the problems they

have are of a physical nature, perhaps speech therapy is needed. However, communication problems can stem from feeling different and out of place after the trauma. Then a group therapy experience might be helpful. Perhaps the person is dealing with unresolved anger—anger from being put in this new and vulnerable position. Then, individual therapy may be in order. Family counseling may be needed to help cope with the stresses placed on a family that is adjusting to relationships impacted by the brain injury.

The clergy person can help a person decide what therapy may help with specific and individual needs, and also consult with appropriate professionals on his or her behalf. For referral assistance, the Brain Injury Association is a good place to start for information about available services. (See the resource section of this booklet.)

Clergy can best view themselves as facilitators of healing. As a shepherd leads his or her flock to water when thirsty, so too the clergy person can lead the person to the kinds of therapy that will address psychological and emotional needs.

*Nunzio Gubitosa is a psychotherapist at Grace Counseling Center in Madison, New Jersey. He did a post graduate residency in psychotherapy at the Blanton-Peale Graduate Institute in New York City, and is certified in individual and group psychotherapy.*

*The clergy person can provide the “sanctuary” where persons with brain injury can catch their breath...*



## Recommended Bibliographic Resources for Clergy and Congregations

This booklet is a companion to *Acute Brain Injury: A Guide for Family and Friends*, available from the Brain Injury Association of New Jersey, 732-738-1002.

*At the Will of the Body: Reflections on Illness*. Arthur Frank. Houghton Mifflin Company, 215 Park Ave., South, New York, NY 10003. 1991. Not about brain injury per se, but an excellent book about the experience of illness and being a patient. His second book is *The Wounded Storyteller: Body, Ethics, and Illness*. The University of Chicago Press. 1995.

*Cultivating Wholeness: A Guide to Care and Counseling in Faith Communities*. Margaret Kornfeld. Continuum Publishing, 370 Lexington Ave., New York, NY 10017. 1998. \$24.95. Excellent book for pastors about pastoral care and counseling in a community perspective.

*Living with Brain Injury: A Guide for Families*. Richard Senelick MD and Cathy Ryan, MA. 1998. 145 pp. book available for \$10.95 from the national Brain Injury Association. Order online at [www.biusa.org](http://www.biusa.org). or order by credit card from (800) 321-7037. A video, *Living with Brain Injury*, based on the book, is also available for \$19.95. The national Brain Injury Association has many more publications for families, professionals, and other caregivers. Call them for their Catalogue of Educational Resources.

*On the Road to Congregational Inclusion: Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families*. A bibliography and address listing for clergy, laypersons, families, and service providers. 2000 Edition. 125 pp. \$10.00 plus \$5 shipping and handling from the Boggs Center-UAP, P.O. Box 2688, New Brunswick, NJ 08903. Resources for congregational ministries with people with disabilities and their families

from many religious and secular sources.

*Resource Guide for Children and Adolescents with Brain Injuries*, and many other booklets on specific topics for children, adolescents, and young adults with brain injuries are available from Lash and Associates Publishing/Training, 708 Young Forest Drive, Wake Forest, NC 27587. Visit their Web site at [www.lapublishing.com](http://www.lapublishing.com) or call 919-562-0015 for a catalogue.

*Supportive Care in the Congregation*. Dean Preheim Bartel and Alfred Neufeldt. A booklet from the Mennonites on a model for a congregational care plan providing a supportive care network for persons who are disabled or dependent. \$3. From MMA, 1110 Main St., P.O. Box 483, Goshen, Indiana 46527.

### Organizational Resources for Inclusive Ministries

The New Jersey Coalition for Inclusive Ministries is a network of clergy, congregations, and organizations who are committed to developing and strengthening inclusive ministries for people with disabilities and other special needs and their families. Benefits of membership include networking and conference events, a quarterly newsletter of ideas, resources, and models for creative ministries, consultation and referral, speakers, and access to a collection of resources and videos for use in your congregation. Membership is \$25 for a congregation, \$10 individual, and \$100 for an organization. Organization members receive ten copies of the newsletter, which they can send or designate to congregations, staff, or others. To join, send a check made payable to the Coalition for Inclusive Ministries, c/o the Boggs Center, P.O. Box 2688, New Brunswick, NJ 08903.

## Resources in the Public Sector

There are many resources that may be helpful as you support a person with a brain injury or their family and friends. The following are resources for information, support and services. This list is not meant to be comprehensive, but to serve as an introductory guide. For information about Brain Injury Programs, Rehabilitation Facilities, and Professionals working with individuals with brain injury, contact the Brain Injury Association of New Jersey. The first step to information is the Brain Injury Association of New Jersey, Inc.

### Brain Injury Association of New Jersey, Inc. (BIANJ)

800.669.4323 (Family Helpline) 732.738.1002 [www.bianj.org](http://www.bianj.org)  
BIANJ provides a number of services to assist the individual with a brain injury and his/her family.

#### Call the Family Helpline for:

- Information about brain injury
- Resources and services available in your area
- Brain Injury Support Groups
- Family Support Programs
- Return-to-Work Program

### Brain Injury Association (BIA)

800.444.6443 (Help Support Line)  
703.236.6000 [www.biausa.org](http://www.biausa.org)

BIA provides information about brain injury and resources throughout the United States. The web page provides dozens of links to brain injury information sites.

### New Jersey State Office on Disability Services

222 South Warren Street  
Trenton, NJ 08625  
888.285.3036  
[www.state.nj.us/humanservices](http://www.state.nj.us/humanservices)

The State Office on Disability Services is an excellent resource for disability-related information. Call for a free resource guide of public and private agencies that provide services for individuals with disabilities.

**SOCIAL SECURITY:** After a brain injury, many people face significant financial struggles. Early contact with the Social Security Administration can help identify possible sources of income replacement and medical benefits for your loved one.

#### **Social Security Administration**

800.772.1213 [www.ssa.gov](http://www.ssa.gov)

SSA provides general information and will set up an appointment with your local Social Security office.

#### **State Help Insurance Assistance Program (SHIP)**

800.792.8820

SHIP provides information and assistance with Medicare related problems.

**LEGAL:** Legal issues and concerns can be complicated. Involvement of an attorney may be necessary to advocate for the rights of your loved one.

#### **BIANJ Family Helpline**

800.669.4323 [www.bianj.org](http://www.bianj.org)

BIANJ maintains a database of attorneys with experience representing individuals with brain injuries.

#### **New Jersey Protection and Advocacy**

800.922.7233 [www.njpanda.org](http://www.njpanda.org)

This program protects and advocates for the rights of citizens with disabilities.

#### **Education Law Center**

973.624.1815 [www.edlawcenter.org](http://www.edlawcenter.org)

This agency provides help for families related to the education system.

#### **Community Health Law Project**

609.392.5553

This project advocates for the health care needs of individuals with disabilities.

**EDUCATION:** Participating in a successful education program is the right of all children. The following resources can help you advocate for your child's needs.

#### **Statewide Parent Advocacy Network (SPAN)**

800.654.7726 [www.spannj.org](http://www.spannj.org)

This program provides information, training, and advocacy for parents of children with disabilities.

#### **Office of Special Education Programs**

609.292.0147 [www.state.nj.us/njded/specialed](http://www.state.nj.us/njded/specialed)

This state office is responsible for providing special education and related services.

#### **Association of Schools and Agencies for the Handicapped— New Jersey**

877.287.2724 [www.asah.org](http://www.asah.org)

This organization provides information about private schools in NJ which provide specialized services for children and adults with special needs.

**TRANSPORTATION:** Many people with brain injury are unable to drive and must rely on public transportation. The following resources can help with finding suitable transportation.

#### **New Jersey Transit-Office of Special Services**

973.491.7385

[www.njtransit.state.nj.us/accesvcs.htm](http://www.njtransit.state.nj.us/accesvcs.htm)

This office provides information about accessible buses and rail stations.

#### **Access Link**

800.955.2321

This is a service of NJ Transit for those who are not able to use a regular fixed-route bus.

#### **NEW JERSEY STATE SUPPORTED ASSISTANCE PROGRAMS:**

[www.state.nj.us](http://www.state.nj.us)

Funding is available to assist with the personal care, housing, and work needs of people with disabilities. Contact the following agencies for information.

#### **New Jersey TBI Medicaid Waiver Program**

609.588.2733

This program provides services in the home and community for those injured after the age of 16 who qualify financially and medically.

#### **Personal Assistance Services Program**

609.292.7800

Provides assistance with daily living to people with disabilities in the community.

#### **Commission for the Blind and Visually Impaired**

973.648.2324

This program provides vocational rehabilitation services for people who are blind or visually impaired.

#### **Division of Vocational Rehabilitation Services**

609.292.2919

DVRS provides services to individuals with work-related disabilities to help those individuals become employed.

#### **Division of Developmental Disabilities**

609.292.7260

This organization provides services for households that include an individual with a developmental disability or brain injury sustained before the age of 22.

#### **Division of Housing and Community Assistance**

Housing Assistance

609.633.6150

Section 8 Housing Voucher Program

609.633.6151

**INFORMATION AND ADVOCACY:** After a traumatic brain injury, the family and the person with the injury often feel alone and overwhelmed. Support and information are available through a number of organizations.

#### **Brain Injury Association of New Jersey, Inc. (BIANJ)**

800.669.4323 (Family Helpline) 732.738.1002

A source for information on brain injury, rehabilitation services and a wide range of resources.

### Family Support Center

800.372.6510 [www.efnj.com/efnjsvcs.htm](http://www.efnj.com/efnjsvcs.htm)

This is a clearinghouse of information on national, state, and local family support programs and services for persons with disabilities.

### New Jersey Technology Assistive Resource Program

800.342.5832

[www.njpanda.org/NJPAhome.html](http://www.njpanda.org/NJPAhome.html)

This program is a source of assistance for individuals with disabilities needing to obtain assistive technology through advocacy, referral and legal representation.

### New Jersey Coalition for the Advancement of Rehabilitation Technology

609.392.4004 [www.ucpanj.org/services.htm](http://www.ucpanj.org/services.htm)

This program evaluates individuals with disabilities and recommends assistive technology to improve functional abilities at home, work, and school.

### New Jersey Self Help Clearinghouse

800.367.6274 [www.njshc.org](http://www.njshc.org)

This clearinghouse provides information on self-help support groups.

### Special Needs Advocate for Parents

888.310.9889

[www.snapinfor.org](http://www.snapinfor.org)

This organization provides information, education, advocacy, and referrals to families with special needs children.

### GOOD WEBSITES FOR INFORMATION ON TRAUMATIC BRAIN INJURY:

There are many good websites on TBI. Here are a few that provide information and links to other sites.

#### Brain Injury Association of New Jersey:

[www.bianj.org](http://www.bianj.org)

#### Brain Injury Association (national):

[www.biausa.org](http://www.biausa.org)

#### Missouri Traumatic Brain Injury

Demonstration Project:

[www.tbimo.org](http://www.tbimo.org)

#### Head Injury Hotline:

[www.headinjury.com](http://www.headinjury.com)

#### National Resource Center for TBI:

[neuro.pmr.vcu.edu](http://neuro.pmr.vcu.edu)

#### Traumatic Brain Injury—Information for Caregivers:

[Members.tripod.com/gobrowns/Health/brain.htm](http://Members.tripod.com/gobrowns/Health/brain.htm)

#### The Brain Injury Information Network:

[www.tbinet.org](http://www.tbinet.org)

#### Links on TBI:

(Marilyn Lash, LA Publishing)

[www.lapublishing.com/links.html](http://www.lapublishing.com/links.html)

#### Coma Recovery Association:

[www.comarecovery.org](http://www.comarecovery.org)

#### Care Guide:

[www.careguide.com](http://www.careguide.com)

### COUNTY OFFICES FOR THE DISABLED:

The offices function as a central clearinghouse for information about programs and services, advocate on behalf of people with disabilities and provide technical assistance at a local level.

Atlantic County	609.343.2389
Bergen County	201.336.6500
Camden County	856.225.5232
Cumberland County	856.825.8707
Essex County	973.228.8230
Gloucester County	856.384.6980
Hunterdon County	908.788.1372
Mercer County	609.989.6468
Middlesex County	732.745.4013
Monmouth County	732.431.7399
Morris County	973.285.6855
Ocean County	732.506.5062
Salem County	856.881.6200
Somerset County	908.231.7168
Sussex County	973.579.0560
Union County	908.527.4840
Warren County	908.869.6000

Residents of counties with no office listed can contact the Office on Disability Services, at 888-285-3036, for information.

### CRISIS INTERVENTION AND REFERRAL SERVICES:

These are county-based organizations, usually affiliated with the United Way, that provide support and information about a variety of services and community resources.

Atlantic County	609.343.2305
Bergen County	201.646.3676
Burlington County	856.234.8888
Camden County	856.663.2255
Cape May County	609.729.2255
Cumberland County	609.935.4357
Essex County	973.746.4040
Gloucester County	800.648.0132
Hudson County	201.434.2628
Hunterdon County	908.325.4357
Mercer County	609.896.4108
Middlesex County	732.418.0200
Monmouth County	732.938.2250
Morris County	800.435.7555
Ocean County	732.240.6105
Passaic County	973.279.8900
Salem County	856.881.6200
Somerset County	908.725.6640
Sussex County	973.209.4357
Union County	908.353.7171
Warren County	908.689.7335

# So What's A Pastor to Do?

by Rev. Bill Gaventa

In this booklet you have read facts, examined statistics, heard stories, looked at possible resources, and seen some ideas. Whatever speaks to you may depend on your personal or pastoral experience with the impact of brain injury. If you have not had that experience, know that many in your community and/or congregation have.

What's expected of pastors and congregations varies from congregation to congregation and from one faith tradition to another. But brain injury calls for some pastoral and caregiving roles that are common to many faiths:

## **Presence:**

Being there at the time of crisis, transitions, and over the long haul. If someone has been a member of your congregation, it is your presence, and that of the congregation, that can be a living reminder of a God who does not abandon but journeys with us. Abandonment, for some people and families, is the worst side effect of brain injury. Presence is also making room, welcoming back, and including someone in the ongoing congregational life of prayer, praise, and service. It is a double process of "re-membering," i.e. helping the congregation remember people who may be in hospital, rehab, or home; and helping those persons become members again.

## **Counsel:**

Through information, prayer, reflection, listening, sharing, helping people (and yourself) to understand the meaning of an injury for a person and his/her family, friends, and congregation. Why did this happen? What does it mean, for me and my loved ones, for self image, for understandings of God? With the long rehab process, there is the even longer process of reshaping and reframing understandings of the past, possibilities in the present, and hope for the future. Counsel also means learning when to refer and helping to look for resources that you may not have.

## **Advocacy:**

Pastor Waid talks about it in her article. Think of the "shepherd," who journeys with others through the valleys and mountains, leads to new resources, fights off predators, and, in a new world, cuts through jungles of red tape, speaks when others are overwhelmed, and searches when others are lost. Sometimes clergy and lay leaders feel powerless in the face of health and human service systems, but your roles as advocates could be the voices that make the difference. When an agency gets a call, or a visit, by someone advocating for another because of their care as a faith community, it makes a difference.

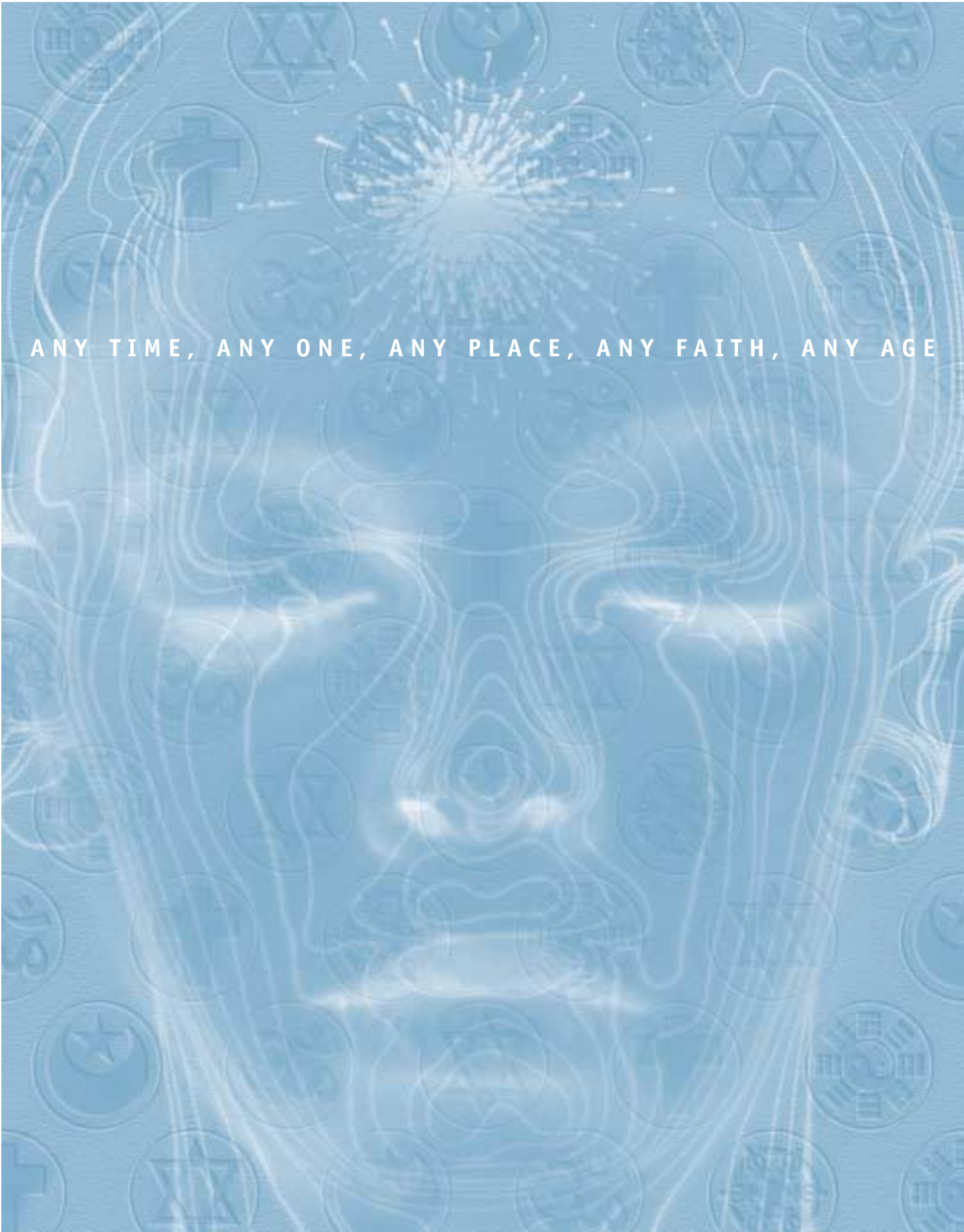
## **Organizing:**

Brain injuries can happen by accident; a caring community and congregation does not. The possibilities of what can be done, even when an injury is not "fixable," are as many as the possible needs. Congregations can organize circles of support and visitors and can develop a plan for the "little things" that add up over time, like meals and cards. Volunteers or others can build accommodations to homes or sanctuary. Support groups can be sponsored and/or welcomed to use the building. Education can include awareness events for the congregation about disabilities or preventive programs about brain injury. And everyone can look for ways that a person with traumatic brain injury can contribute to the life of the congregation.

So... The resources are there and the possibilities are there. The key, as people with brain injury and their families in this booklet have said, is first to be there and listen, and then let their questions, needs, and gifts join with your commitment to guide the journey and process of mourning, hoping, and rebuilding.

On their behalf, thanks for being there.

## **Local Numbers and Notes:**



ANY TIME, ANY ONE, ANY PLACE, ANY FAITH, ANY AGE



## **Brain Injury Association of New Jersey, Inc.**

**1090 King George Post Road, Suite 708**

**Edison, New Jersey 08837-3722**

**Phone: (732) 738-1002 Fax: (732) 738-1132**

**FAMILY HELPLINE: (800) 669-4323**

**[www.bianj.org](http://www.bianj.org)**



## **The Elizabeth M. Boggs Center on Developmental Disabilities**

**335 George Street, P.O. Box 2688**

**New Brunswick, New Jersey 08903-2688**

**Phone: (732) 235-9300 Fax: (732) 235-9330**

**[www.rwjms.umdj.edu/boggscenter](http://www.rwjms.umdj.edu/boggscenter)**

