

12th ISSUE: September 2024 Brain Injury Recovery Issue: Caregiver Perspective

Resource Facilitation: What is Alexithyma?

Book Review: Surviving Head Trauma

Picnic Recap

Telling of the Tail: Sheri Krahn's Family (BI Survivor)

Information Request

FEARURES

This photographer wants to remain annonyumus and wanted to share this photo to show nature at its finest.

Message from the Executive Director

Hello Everyone!

This summer has sure been full of surprises! Our first surprise came with our picnic location being donated by Wisc Pact, followed by our deck creation (see page nine), the funding for the deck was sponsored by Water Stone Bank Foundation, and to cap off our wonderful summer we were so very generously donated our location for our Christmas Party from the Muskego Circle Community Center. **Until next time God Bless! Lois York-Lewis**







In the Beginning

Our Mission:

Middle

Gary and Ted's hard work!

To offer assistance, provide resources and information and reassure survivors that they are not walking this journey

alone.

Who we are:

We are all volunteer and run by brain injury survivors and their support persons.

We are a 501C3, Registered Charity 27-4483622, Tax Exempt Organization, and are 100% funded through the

generosity of people like you!

BI-INSIDE Magazine Team:

Bari L. Rieth (Co-Founder, TBI Survivor who inspired our organization, Daughter, Grand-daughter and Wife to Brain Injury Survivors, Board Secretary, Layout-Editor and Contributor)

Lois M. York-Lewis (Co-Founder, Mother of the TBI Survivor who inspired this organization, Mother in-law, Wife and Daughter to Brain Injury Survivors, Pres. of Board of Directors for the BIRCofWI, and Contributor)

Kathy Richardson, C.B.I.S.T, (Resource Facilitator, TBI Survivor, Vice President of the Board of Directors for the BIRCofWI and Contributor)

Linda Scherwinski (Mother to a Brain Injury Survivor, Board Member for the BIRCofWI and Contributor)

Katie Marshall (Resource Facilitation Assistant Contributor and Editor)

Scott Daul (Office Assistant and Editor)

Sheri Krahn (Editor & Contributor)

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Your Donation will go a Long Way! THANK YOU!!

In Honor of...

Castellion, Kyle **Dudzik**, Mark Erickson, Reneé Franke, Rick Fromader, Tony Gerum, Timothy* Koenig, Robert **Kraemer**, Noelle Krahn, Sheri Lee, Grace **Marshall**, Katie Rieth, Bari*** Rieth, Gary*** Scherwinski, Micki Schillinger, Joe Schmitt, Mark*

*Indicates additional recognition

In Memory of ...

Eckholdt, Vickie Foster, Donna Franke, Rick *** Gebert, Elliot Hiekkanen, Bee Kasprzak, Loraine Koehler, Lois(Lois Ann) Kozak, Margaret (Peggy) Krebs, Lucille* Krebs, Richard W. Sr.* Malueg, Mark Niebuhr, Matthew Marvin Rieth, Bethany* Robinson, Derek*

Make your Donation today!

Visit: https://www.bircofwi.org/donations-link/





Kathy Richardson, BS, CBIST Resource Facilitator Alexithymia is a disorder characterized by:

- The inability to identify
- process
- describe and work with one's own feelings

It often includes a lack of understanding of the feelings of others, difficulty distinguishing between feelings and physical sensations of emotional arousal, restricted imagination (few dreams or fantasies) and logical thinking.

There are two types of alexithymia: trait and state.

- State alexithymia has a specific cause, such as a traumatic event and is often a temprary condition.
- Trait alexithymia is believed to be a chaacteristic inherent in a person's personalpersonality. Trait alexithymia may be caused by genetics or events in early childhood development

Resource Facilitation: What's the Buzz What is Alexithyma?

such as neglect or abuse.

Approximately 60% of traumatic brain injury survivors experience "state" alexithymia. Alexithymia occurs when a brain injury causes disruption to brain regions and neural networks.

It is responsible for processing emotions, which can lead to disconnections between emotional responses and whether an emotion can be identified and expressed appropriately.

Alexithymia frequently co-occurs with multiple disorders ranging from neurological to anxiety disorders and physical illnesses.

The symptoms of alexithymia are:

- Difficulty identifying different types of feelings
- Limited understanding of what causes feelings
- Difficulty expressing feelings
- Difficulty recognizing facial cues in others
- Limited or rigid imagination
- Constricted style of thinking
- Hypersensitive to physical sensations



- A lack of impulse control
- Violent or disruptive outbursts
- Detached or tentative connection to others
- Difficulty identifying feelings and distinguishing between feelings and the bodily sensations
- Difficulty describing feelings to other people
- Limited imagination and, therefore, little or no fantasies and limited dreams
- An unawareness of what is happening in their own mind and a very concrete way of thinking

Disorders that may cause or present with alexithymia, include: State Alexithymia can have a devastating effect on relationshps if left untreated.

But, treating this condition can be very challenging as survivors are not likely to seek emotional support from family, friends or a professional.

Once in therapy, they may not be able to accurately describe their emotions or have any insight into their emotions, making it harder to benefit from therapy. Some therapies that have sho-

wn promise are short Term Interpersonal Therapy, **Dialectical Behavior** Therapy, and Cognitive Mindfulness Training.

In addition, you can work on expanding your emotional awareness and vocabulary on your own. If you think you're feeling angry, ask yourself what two other emotions you might be feeling and then consider why you are feeling that way.

You can also start journaling your emotions. Participating in a formal emotional self-awareness treatment program can also help.

New apps have been developed to expand emotional vocabularies and emotional awareness:

1. My Emotional Compass

*Available for purchase March 1st on Amazon

(\$3.99) by Create Ability Concepts, Inc. This app was developed by Dawn Neumann, PhD, Indiana University School of Medicine and Rehabilitation Hospital of Indiana. It helps people navigate their emotions by breaking them down into pleasant vs. unpleasant and levels of emotional arousal.

2. The Mood Meter(free) by **Emotionally Intelligent Schools** LLC. This app was developed by The Yale Center for Emotional Intelligence. This app uses colors to label your feelings and emotions and teaches effective strategies to help you regulate your feelings.

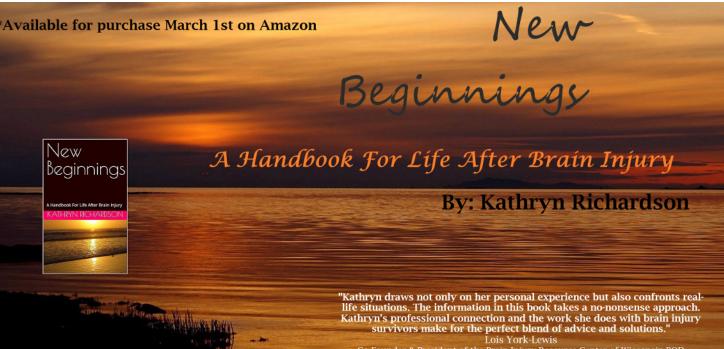
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Co-Founder & President of the Brain Injury Resource Center of Wisconsin BOD

Book Review: Surviving Head Trauma

Surviving Head Trauma was written by a Traumatic Brain Injury Patient*, Terry Smth. These exact words are used for the description of the front cover.

While reading this book we came to discover information about Terry's accident as well as information about some of the negative decisions he made after he sustained his brain injury as well as some positive ones. In the following paragraphs we will be reviewing *Surviving Head Trauma*.

First off, we noticed that it was a bit difficult for us to follow Terry. He seems to jump around a lot, quickly transitioning from one time to another without much explanation.

We found this aspect of the book very difficult to understand where he was in time. We almost received whip lash from all of the fast changes in time.

A specific time that is mentioned throughout the book is when and how he sustained his TBI. Terry was involved in a roll over truck crash while on a military base.

This crash ended up killing some of the marines who were on this truck. Fortunately, this was not his fate.

Next, Terry talks about some of the negative decisions that were made after he sustained his brain injury. These decisions include: two failed marriages, self medicating with drugs and alcohol, and being arrested for being inappropriate in a yard while being under the influence.

Thankfully Terry brightens up this book, when he talks about some of the good choices he made. He was an academic achiever, he started regularly taking prescribed medication to help better cope with life and different issues, and the books mentions about how through it all he "managed" to keep a positive attitude which lead him to find his third wife.

In the end, believe in yourself, follow your





Katie Marshall & Scott Daul

Sheri Krahn



Bari Rieth

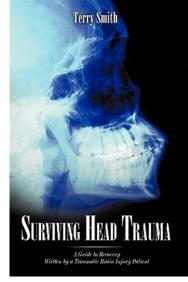
dreams, work hard, finish what you start, everyone will have ups and downs, but keep moving forward and keep your head high.

Overall we would give the following grades, based on an A-C scale:

Organization: C

Positive and Negative Balance: **B**

Overall: C



*In order be considered a traumatic brain injury, TBI, there needs to be a traumatic event and normally a person goes to a hospital at some point, which gives them the title of a "patient." We have chosen to not be referred to as patients, but as survivors.



BIRCOFWI PICNIC: Blue Lotus Center

Our picnic wouldn't have been possible if it weren't Wispace,Inc. who sponsored us being able to use the Blue Lotus Center.

Thank you also to KwikTrip for your donation of a gift card, which helped us bring the Unmasking Brain Injury Display along.





The day of the picnic was a perfect one and instead of writing about it, these pictures will give you an idea of the wonderful day we all had!

Grill Master in training





Bari Rieth

The world of brain injury is like a club, one that I thought I would never have to join. I did not know anything about brain injury before I sustained one, but now I can't get out of this club.

When it chooses you, you are suddenly thrust into this club that you didn't ask to join. You are shipped off to war without

<u>Wisconsin (bircofwi.org)</u> Say what?

Resource Facilitation - The Brain Injury Resource Center of

having any knowledge of how to fight.

If you are lucky you learn along the way to defend yourself and to become numb to the battery of tests, blood transfusions, therapies and losing friends. If you are even luckier you will meet others who have gone through a similar experience as you, not the same but similar and they can relate.

Contact our Resource

Facilitator, Kathy Richardson, today to join our Social and Skills Program. Everyone that is part of this program is also part of our resource facilitation program. Click this link to learn more.

Kathy Richardson, BS, CBIST Resource Facilitato



Information Request

Written by: Bari Rieth and Druis (Eighth Grade student) Information shared by: Lois York-Lewis

The following email was written to us by an eighth grade student asking Lois about comas. The following is the email and her response:

Dear BIRCofWI, I am an 8th grade student at Neenah Middle School. Currently we are doing a research project for English, and mine is on the effects of a coma.

We are required to interview or email questions to someone, and your website seems to apply. Therefore I was hoping you could take the time to answer the questions I have listed below?

- What impact does a coma put on one individual's life?
- How does suffering patients have an impact on a healthcare worker's life?
- How long does a person need care for after waking up?

Thank you for your time, I hope you will take these questions into consideration and reply if possible.

Sincerely, Druis A Middle School in Wisconsin

Lois responded to these questions by emailing these answers back:

Greetings Druis I would be happy to help. The answers to your questions are a bit complicated and the extent of a brain injury plays a key role. First, it is best to understand what the scale tells us about measuring the severity of TBI. "Severity of injury" refers to the degree or extent of brain tissue damage.

The degree of damage is estimated by measuring the period of loss of consciousness, the depth of coma, and the level of amnesia (memory loss), and through brain scans.

The Glasgow Coma Scale (GCS) is used to measure the depth of coma. The GCS rates three aspects of functioning: eye-opening, movement, and verbal responce.

Individuals in deep coma score very low on all these aspects of functioning, while those less severely injured or recovering from coma score higher.

A GCS score of 3 indicates the deepest level of coma, describing an unresponsive person.

A score of 9 or more indicates that the person is no longer in a coma, but is not fully alert.

The highest score (15) refers to a fully conscious person. **What impact does a coma**

put on one individual's life?

A person does not just "wake up" from a coma. The early stages of recovery are a gradual process of becoming more responsive and aware of people and suroundings.

Rarely does a person progress directly through the different levels of consciousness. It is common to experience overlap (or a back and-forth) between stages.

The individual may become confused, not recognize people, and behave strangely, they could

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swear, become angry, and even be violent.

Interestingly, noise, touch, light, and movement may either calm the individual or upset them. How they respond is unknown until it happens.

Post-traumatic amnesia is also very common during the early phases. Some may not remember being hurt or even what may have happened to cause the brain injury. But it is important to

remember, the severity of the injury drives the process of recovery. How does suffering patients have an impact on a healthcare worker's life?

Each of us poses some very powerful human emotions. However, the individual's personality traits are the driving force for how a person is affected.

It can also depend on whether the patient is a child or >> an adult. Many employers now offer Mental Health services that can assist healthcare workers who become affected by the environment they work in.

How long does a person need care for after waking up?

Unfortunately, there is no "one size fits all" answer. Every brain injury is unique and as a result, every individual will regain consciousness from a coma at a different rate.

Generally, the more severe the brain damage, the longer it will take for the individual to recover.

I hope this information is helpful. Wishing you great success with your project.

> God Bless, Mrs. Lois M. York-Lewis

Intimacy, Sexuality, and Sex After Brain Injury

What do you think of when you hear intimacy, sexuality, and sex after brain injury? Do you imagine your relationship returning to its' preinjury state?

Do you envision your relationship ending, as you know it? Are you ready to accept the person post-injury?

Can you change your expectations to fit the new life that is emerging? There is no right or wrong answer when it comes to being a caregiver to someone with a brain injury; there is only the reality of this new situation.

We are the choices we make and must accept our abilities and limitations when brain injury damages not only the survivor, but the marriages, partnerships, and relationships of those involved. Not every marriage, partnership, or relationship will survive, but for those that do, there is a light at the end of the tunnel. Written by: Lois York-Lewis

Going from a husband/wife, partner, lover, and best friend to a caregiver comes at a great price. According to Stejskal, T. (2011), "when we care for someone through acts of daily living (such as showering, toileting, and eating) our brains often shut off the sexual attraction aspect as our internal protective mechanism.

This psychological response (a strong incest prohibition) is quite normal and expected since we equate this task closer to parenting than marriage."

It may take years for your relationship to show signs of recovery. Not just from an emotional sense, but from the sense of loss that comes after the injury has occurred.

Your patience, your tolerance, your compassion will all be put to the test. Your family will not always be able to understand the choices you make.



Executive Director

Your whole world, unwillingly, will be shaken and turned upside down. You will doubt your ability to keep going and this is only natural.

A new story is just beginning: It may not be possible or realistic to recapture the love that once was. It will be more important to accept that the past is just one chapter from the book of your_life that is closed and if not, then how can a new one begin?

There is more to a relationship than sex, there is more to a marriage than intimacy, there is more to a person than their sexuality.

*Deck creation continued from page 2.

Call it a labor of love or two guys just having a good time and wanting to make a difference in the lives of brain injury survivors. Whatever you call it, Ted **Meagher** and Gary **Rieth** were dedicated **and** very carefully and flawlessly put together the deck shown on page two.

How the BIRCofWI has benefited from this is now we can conduct **and have a space for** outdoor art classes like the

one that we held on September 19th and we are having another pop-up **outdoor** art class on Thursday October 3rd from 1-4 p.m.

Individuals will be guided through the creation of a *canvas painting of a fall/sunflower art scene* and then paint the word "Thankful" (artfully).

Make sure you save your spot by registering today!



Discontinuing Print Version

As of March 2024 we will no longer be offering the print version of the BI-INSIDE Magazine. This is a great opportunity to break isolation by visiting your local library to use their computer and to view this magazine!

Take this opportu-

nity to catch up with a friend and take a look together!

We value our readers and want to encourage **survivor** to keep reading! Each issue has fascinating articles that

cover brain injury awareness as well as brain injury recovery.

We sent out a letter to everyone who received the BI-INSIDE Magazine in print and got no indication back that anyone wanted to continue.

Look below to view instructions on how to access the BI-INSIDE Magazine online!



Telling of the Tale: Sheri Krahn Written by: Bari L. Rieth

"Something is very wrong Steve." This was what Sheri's oldest son Steve heard while he talked to her on the phone.

All of a sudden, Steve had lost all communication with his mom, until five or seven minutes later when he called her to learn that she had driven herself to the emergency room. They preformed many tests, but it wasn't until they preformed the spinal tap that they could even begin to understand what was going on.

The spinal tap revealed the massive aneurysm that was located inside Sheri's head next to her brain. Even though this was all taking place no one ever explained what "it" was, Steve recalled.

"Of course, these doctors had ideas from their books and everyone understands "aneurysm," but there were many explanations." Steve continued his thought by writing that "words like aneurysm and brain bleed where used the most."

Just to review quick, according to the Mayo clinic, "an aneurysm is an abnormal bulge or ballooning in the wall of a blood vessel." (2024) The website continues this information by stating that "if the brain aneurysm leaks or ruptures, it causes bleeding in the brain."

Similar to Steve, Sheri's niece Erin has been very involved with her both before and after her brain injury, but she also stated that Sheri's situation explained to her. By "it" she means the brain aneurysm, which erupted and caused the brain to bleed. This is what the true cause of her brain injury was.

"I knew Auntie needed help with new things, but I don't know if I knew why." Erin further explained that "I knew that I would get off the bus at Auntie's so that she could shower with someone home."

Not wanting to be alone is a common feeling amongst brain injury survivors as well as everyday people, but this is intensified by the brain injury. Survivors tend to be, at least initially, very dependent upon at least one other person.

According to Brainline.org, "many survivors find themselves unable to work, drive, live alone, manage their finances, and do things alone" (2009). The loss of independence can lead to feeling frutrated and lonely.

Brain injury can rob you of the confidence you once had in yourself and as we just read Sheri lost confidence in herself. More than likely, she didn't even realize it.

Brain Injury can play with your memories, which can cause you not to remember certain aspects of a conversation to not remembering a period or length of time all together.

Erin gives us a glance into the person Sheri used to be right after the brain injury ocurred when she states that "My auntie was never really the "adult," she wanted to play games, go to the park and rollerblade."

It was almost as if Sheri was a child again and was growing up alongside her niece. During a conversation Sheri relayed to me that she remembers being very angry when Erin got her first boyfriend.

"He was taking away my best friend, she would spend more time with him and not me," Sheri told me. She continued this thought by saying she had these feelings even though she already had a husband and three grown-up children.

These emotions are justified to Sheri, because at this time she felt that she was only a teenager even though she knew she was an adult.

Steve and his wife Laurie are very involved with Sheri. They make the trip, 28 miles away, every week.

With arriving on Monday and going back to their home early Thursday morning, not only do they provide transportation and go shopping with her, they take her to doctor appointments, they also work on her house, watch her dog and cat from time to time, provide lawn care, and the biggest help comes by them just being there.

Erin considers herself full-filling more of a "supportive" role.

The greastest support comes from Sheri's loving grandchildren who learned that "Meme has an ouchie inside

Continued from page 11

her head." "We know that we need to over explain things and help by answering her questions," Sheri's grandchildren wrote to me.

Being understood is great and is what we strive for at the Brain Injury Resource center of WI.

Sheri has been working with the ADRC of Sauk County

and they help her with providing transportation to the BIRCofWI in Waukesha, where she comes every Wednesday. We have so enjoyed getting to know Sheri and truly value her as part of our team!

Sheri relayed to me that "as a BI survivor, I know not everyone you know can take on this task." She continiued her thought by saying that people who know you may try to deny anything is wrong, but what they are doing is a dis-service to the survivor.

Sheri put her final thoughts into words by saying that "there are many reasons, coming from their heart or from their logic that can make it difficult to understand," but at the end of the day we are all people.

Watch your mail/email for more information on upcoming events! If you are not on our mailing list, complete the information below to get started!

Contacts First Name:	Contacts Last N	Contacts Last Name:	
Mailing Address:	I		
City:	State:	Zip Code:	
Cell # (including area code):	I		
Home # (including area code):			
(Choose One) Call me on this pł	none in case of cancellatior		
Email:			
I am a brain injury survivor and	d I would like to receive a birthd	lay post card from BIRC!	





Sheri Krahn with her sister and niece and the new puppy at our picnic this past summer!