

November 2021

# BrainStorming



## BIAIA Virtual Events and Support

While much of our communities continue to meet virtually, the Brain Injury Alliance of Iowa would like to remind you that we continue to work to deliver virtual support groups, webinars and other web-based learning. Opportunities are highlighted on our social media pages in addition to the [BIAIA events](#) tab on our website. If you are unable to attend live webinars watch them on our [YouTube Page](#). If you are unsure how to access event information, reach out to us at [info@biaia.org](mailto:info@biaia.org) or contact your Neuro Resource Facilitator.

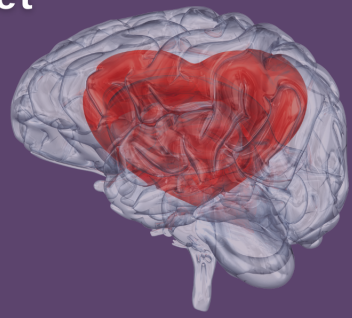


### "Note to Self: It's OK to Set Boundaries"

1. Why boundaries are important.
2. Signs of unhealthy vs. healthy boundaries.
3. How to create a "Caregiver Bill of Rights."
4. How to create a "Not-To-Do List."
5. How to set and protect your boundaries with others; more specifically, how to communicate your needs and expectations to others in a calm, confident way.

**Caregiver Webinar**  
**November 19th, 2021 12pm-1pm CST**

Register and learn more by scanning the code or going to our website [www.BIAIA.org](http://www.BIAIA.org) and click on **Events**



The development of this project is supported through the Brain Injury Services Program (BISP) of Iowa, through contract 58828106 with the Iowa Department of Public Health (IDPH). The contents are the sole responsibility of the authors and do not necessarily represent the official views of IDPH.



# Call for Presenters

30th Annual Best Practices in Brain Injury Conference March 3rd-4th, 2022 VIRTUAL

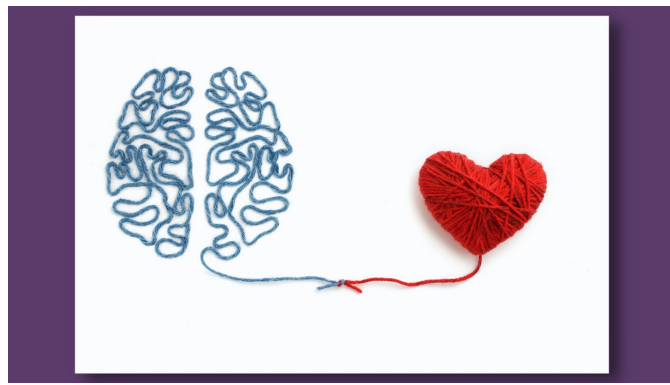
We welcome compelling session proposals regarding best practices in the following key topic areas:

- Long term Services and Supports in Iowa: Rights, Advocacy and Knowledge of Levels of Care for Brain Injury
- Intimacy and Relationships after Brain Injury
- Understanding the loss of the person with brain injury
- Assistive Technology
- Stroke
- Sleep after Brain Injury
- Responding to Concentration and Attention Challenges
- Service Planning for Substance Use Disorder Treatment and Brain Injury
- Brain Injury and Employment Services
- Service Planning for Pediatric Brain Injury
- Implementation of Screening for Brain Injury
- Equity, Inclusion, and Diversity in Brain Injury Services
- Emerging, Promising, Best, and Evidence-Based Practices for Brain Injury Services and Supports

Presentation proposals need to be submitted by Tuesday, December 7, 2021. BIAIA will make decisions by Tuesday, December 21, 2021.

Contact the Brain Injury Alliance of Iowa with questions. 855-444-6443 or [info@biaia.org](mailto:info@biaia.org)

**Having But Not  
Having: Navigating  
Ambiguous Loss**



November is National Family Caregivers Month. As such, raising awareness of and normalizing the caregiver's experience of ambiguous loss after brain injury is deserving of time and attention.

Ambiguous Loss. Whether or not you've heard of ambiguous loss before, if you're living in the "after" of brain injury, if your life has been touched by it, you are all too familiar with how ambiguous loss feels.

Most find learning about what ambiguous loss is to be enormously validating. While your experience is a deeply personal and unique one, how you're feeling and what you're going through, is normal and expected. Knowing this doesn't change the hurt, but knowing that you aren't alone in this journey can be very profound, very healing.

Ambiguous loss is a unique kind of grief that is specific to brain injury, referred to as "having but not having," where an individual is physically present, yet, not...things have changed and in an earth-shattering way. The person you love and care for is still here, but he or she is cognitive and emotionally changed. The person you once knew, in "the before," that version of them, is gone. Ambiguous loss is referred to as "frozen sadness," as it leaves one feeling frozen in time and paralyzed with grief.

Pauline Boss, the researcher who coined the term said of ambiguous loss, "You've lost trust in the world as a fair and rational place." Life doesn't feel fair. What's happened to your loved one, and how it's impacted everything, everything around them, including you, isn't fair. Nothing makes sense anymore.

We are, to a large extent, defined by the relationships that we have with others. We are a certain way with them. They are a certain way with us. We are a certain way together. As a caregiver living with ambiguous loss, you grieve who the survivor was before the brain injury, as well as who YOU were in relation to them. Your identity has been shaken to its core.

Sadly, a caregiver's experience of ambiguous loss is often a less obvious impact to the people around them. Caregivers live with constant, paralyzing uncertainty. There are no guarantees when it comes to brain injury recovery.

As a result, caregivers fluctuate between hope and hopelessness. Having mixed, conflicting emotions is another secondary impact of ambiguous loss. Caregivers experience a range of mixed, conflicting emotions about this “new” person in their life, as well as their ability and desire to love and care for him or her. Feelings like confusion, gratitude, resentment, betrayal, anger, guilt, hope, hopelessness. Confusion because you grieve who he or she was, but you are also grateful that they are still here.

There is hope, however. You can and deserve to live well with ambiguous loss. There are specific goals for treatment that are identified in the literature for how to support individuals in navigating ambiguous loss. Specialized therapy and support can be very beneficial. You don’t have to figure this out on your own.

For more information on what ambiguous loss is and how to navigate it, please consider Pauline Boss’ book *Ambiguous Loss: Learning to Live with Unresolved Grief* and/or her website at [www.ambiguousloss.com](http://www.ambiguousloss.com). Additionally, please don’t hesitate to reach out to me at [csand@biaia.org](mailto:csand@biaia.org) with any questions and/or needs related to ambiguous loss.

Courtney Sand, MS, LBA, BCBA, CBIST  
Neuro Resource Facilitator, Brain Injury Alliance of Iowa

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**November is also  
Epilepsy  
Awareness Month!**  
#NEAM2021  
#RemoveTheFilter



Brain injury is a leading cause of Epilepsy

According to Jeffrey Englander MD, David X. Cifu MD, and Ramon Diaz-Arrastia MD, Model Systems Knowledge Translation Center:

"Early post-traumatic seizures: A seizure in the first week after a brain injury is called an early post-traumatic seizure. About 25% of people who have an early post-traumatic seizure will have another seizure months or years later.

Late post-traumatic seizures: A seizure more than seven days after a brain injury is called a late post-traumatic seizure. About 80% of people who have a late post-traumatic seizure will have another seizure (epilepsy).

Epilepsy: Having more than one seizure is called epilepsy. In some people this will be a problem they have for their whole lives. The cause of your brain injury can help doctors figure out how likely you are to have seizures.

- 65% of people with brain injuries caused by bullet wounds have seizures
- Bleeding between the brain and the skull, which is called a subdural hematoma, also may cause a seizure.
- Over 60% of people who need 2 or more brain surgeries after a brain injury experience seizures."

*Posted on BrainLine June 10, 2014. Reviewed July 26, 2018*

**Learn more and access resources through**

[Epilepsy Foundation Iowa](#)



**Brain Injury Alliance**  
I O W A

## INJURY PREVENTION DAY NOVEMBER 18TH, 2021

According to the CDC  
[www.cdc.gov/transportationsafety/mc/index.html](http://www.cdc.gov/transportationsafety/mc/index.html)

- Helmets saved an estimated 1,859 lives in 2016
- Helmets reduce the risk of death by 37%.
- Helmets reduce the risk of head injury by 69%.



**Learn more**

[Center For Disease Control CDC "Motorcycle Safety"](#)

**National Institute of Neurological Disorders and Strokes (NINDS) allocated \$16 million toward a seven-year, multicenter research project**

NINDS Awards Research Project to TBIMS on Inpatient Rehabilitation for Patients with TBI. Last month, the National Institute of Neurological Disorders and Strokes (NINDS) allocated \$16 million toward a seven-year, multicenter research project led by The Ohio State University Wexner Medical Center and College of Medicine that will compare inpatient rehabilitation treatments for traumatic brain injuries (TBI). More than \$2.5 million has been awarded for the first year of the project, with the remainder expected to be awarded as the project progresses. Although a wide range of rehabilitation interventions are used, clinicians still grapple with determining which specific interventions are best for their patients. [LEARN MORE](#)

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**November 30th, 2021 is Giving Tuesday!**  
**We appreciate your support!**



**Brain Injury Alliance**  
I O W A

The mission of the Brain Injury Alliance of Iowa is to create a better future through brain injury prevention, advocacy, education, research, and support.

- DONATE or BECOME A MEMBER  
Scan to learn how



**#GIVING TUESDAY™**

WWW.BIAIA.ORG - 855-444-6443 - INFO@BIAIA.ORG

“Thank you so much for your help, you were a blessing to me when I thought there was no way through the tunnel” – Anonymous NRF client



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**Stroke Highlight:**  
**Understanding**  
**Types of Stroke**

**F.A.S.T.**

Face  
Drooping

Arm  
Weakness

Speech  
Difficulty

Time to  
Call 911

There are 3 types of strokes that people can encounter. The first type is Transient Ischemic Attack. TIA's usually only last a few minutes and may reoccur or sometimes happen just once. People usually recover fully and scans are normal but also have an increased risk of stroke with in next 5 years. The second kind is an Ischemic Stroke. Quick treatment is key with this. Ischemic strokes can be caused by plaque clot at site or embolism that breaks off and travels to the site. The third type is a Hemorrhagic stroke and this can be caused by intracerebral hemorrhage or a subarachnoid hemorrhage. Up to 80% of strokes can be prevented so work with your doctor on a plan. The Brain Injury Alliance of Iowa also can provide resources and support.

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**Iowa Department of Education wants to hear from families. Now is the time to use your story to help create change!**



ASK Resource Center and the Iowa Department of Education are partnering

to collect family input about special education. What is going well? What should be changed? What ideas do you have for the future? [LEARN MORE](#)

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**Review and submit your application by  
December 15th, 2021**

**HealthCare.gov**

Due to new laws passed earlier this year, many people who buy health insurance through the Marketplace are now eligible for more savings and lower monthly premiums. In fact, 4 out of 5 who enroll in a health plan through HealthCare.gov can find a plan for \$10 or less per month, with financial assistance.

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## **Neuro Resource Facilitation**

Neuro Resource Facilitation is a fee-free service offered by the Brain Injury Alliance of Iowa to support people with brain injury, their family members, caregivers and community navigate life after brain injury.



- To reach a Neuro Resource Facilitator please contact 855-444-6443 or email [info@biaia.org](mailto:info@biaia.org)
  - The Brain Injury Alliance of Iowa desires to share your success stories in various publications such as newsletters, website or social media accounts. **Click [HERE](#) to share your story!**
  - Consider a donation to the Brain Injury Alliance of Iowa, as we continue to support Iowans to "live well" after brain injury. **Click [HERE](#) to make a donation today.**
  - Iowans affected by brain injury, family and caregivers are invited to our support group communities. **Click [HERE](#) to learn more, register to join and share.**
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**Thank you to our corporate members!** Click [HERE](#) to learn more about our corporate members and corporate membership benefits.

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Our mission at the Brain Injury Alliance of Iowa is to create a better future through brain injury prevention, advocacy, education, research and support. Join us on our platforms to obtain the latest and most relevant information pertaining to brain injury.



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