

Pseudobulbar Affect (PBA) Self-Advocacy Toolkit



All About PBA

Learn the science behind PBA, why it is so frequently misunderstood, and what to do about it.

Your Journey

Tips and tools to track your PBA journey, speak with medical providers and insurance companies, and access the right care.

Resources

Download helpful materials for you and others and discover an entire community of others living with PBA.

Preface

Pseudobulbar Affect (PBA) Self-Advocacy Toolkit

Individuals with neurological diseases, including traumatic brain injury and stroke, often have trouble obtaining an accurate diagnosis and appropriate treatment for the secondary conditions they experience because of their brain injuries.

Pseudobulbar affect, or PBA, is an example of this type of secondary condition.

Pseudobulbar affect is a neurological condition that causes sudden, frequent, uncontrollable crying and/or laughing that does not match how the person feels. PBA is often misdiagnosed. It may be hard to find a clinician who understands PBA or to get insurance coverage for the right treatment. Many people must advocate for themselves or on behalf of a loved one.

The Brain Injury Association of America (BIAA) produced this toolkit to provide self-advocacy information and resource materials. The toolkit is available for free at biausa.org/PBA now.



The condition is more common than you think. According to a 2011 online survey of people with neurological disorders, the number of individuals in the United States with PBA ranges from 1.8 to 7.1 million. It is estimated that as many as 48 percent of individuals who sustain traumatic brain injury and 28 percent of individuals who have a stroke experience PBA symptoms.¹

PBA is sometimes called emotional lability, emotional incontinence, inappropriate or labile affect. It is also referred to as forced crying and laughing, pathological crying and laughing, and involuntary emotional expression disorder (IEED). These labels incorrectly suggest PBA is a psychological problem. Outbursts have little relationship to the individual's actual emotions.

PBA can take a toll on individuals as well as their families and friends. In a study on the impact of patient education, individuals with PBA reported "bullying," "funny looks," and embarrassed laughter from family members. The study authors noted PBA disrupts family communication patterns and is frustrating for everyone. One study participant said:



"I've gone through bullying because of it because people don't understand. They assume that you're being—have emotional problems when you don't. They don't realize that it's a neurological—it's a physical condition, not an emotional condition."²

It is important to understand PBA comes about because of injury to one's central nervous system. Mood disorders, such as depression, are psychological and related to a person's mental state. The stigma, anxiety, and stress of PBA may cause situational depression, but medication or other therapies designed to treat psychological conditions will not treat PBA.

Key Concepts

- PBA is a neurological condition causing uncontrollable laughing or crying.
- An existing, or primary, neurological disease or disorder causes PBA.
- PBA is common among individuals who have sustained brain injuries.
- Psychological medication and/or therapies do not treat PBA.
- Identifying and understanding PBA helps to reduce feelings of stigma, embarrassment, or isolation.

[1]Work SS, Colamonic JA, Bradley WG, Kaye RE. Pseudobulbar affect: an under-recognized and under-treated neurological disorder. *Adv Ther.* 2011;28:586-601.

[2] Turell W, Roc A, Pioro E, Howson A. Living with the burden of pseudobulbar affect: a qualitative analysis of the effects of education on patient experience. *J Patient Experience.* 2020; 1324-1330. DOI: 10.1177/2374373519899597.

Identifying the Signs and Symptoms of PBA

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According to the Mayo Clinic, pseudobulbar affect differs from depression in that “PBA episodes tend to be short in duration, while depression causes a persistent feeling of sadness. Also, people with PBA often lack certain features of depression, such as sleep disturbances or a loss of appetite.”³

Just as no two brain injuries are alike, no two individuals will show PBA in the same way. You or your loved one may have triggering events that cause a laughing or crying response that is disproportionate to the situation in duration or expression. You or your loved one may feel embarrassed or confused. There may be a noticeable display of frustration during an episode. For example, facial expressions or body movements may appear to be spasms.

Feeling overwhelmed, stressed, or anxious is a normal response to the challenges of life, especially when living with a brain injury or other neurological disorder. As PBA can mimic other conditions, it can be difficult to diagnose. That is why it is frequently mistaken for depression. If you suspect you or your loved one has PBA, you can take action.

The Center for Neurologic Study-Lability Scale (CNS-LS) is a short questionnaire that can help individuals with neurologic illness or injury identify the presence of PBA symptoms and their frequency. A CNS-LS score of 13 or higher may suggest PBA, but low and high scores can occur in persons with and without PBA. After a week of tracking, patients can share the questionnaire with their physician. Similarly, keeping a detailed journal is helpful when talking with health care providers about PBA symptoms. Keeping track of episodes is important to assist in communicating with your healthcare provider. The PBA Episode Journal is a great resource to make sure you capture specific information.

Key Concepts

- PBA is not depression, but it can cause someone to become depressed.
- Different people show PBA in different ways.
- The CNS-LS quiz may help your medical provider diagnose PBA.
- A PBA Episode Journal can help you track your experience with this neurological condition.

[3]Pruthi S, Ed. Pseudobulbar affect. Accessed on 08/10/2022 from <https://www.mayoclinic.org/diseases-conditions/pseudobulbar-affect/symptoms-causes/syc-20353737>.

PBA Episode Journal



Instructions: Complete a journal entry each time you or your loved one experiences a PBA episode. You may also download this form by clicking the link above.

Date:

D D M M Y Y Y Y

Time of Episode:

What symptoms did you experience?

Sudden Crying Sudden Laughing Crying that turned to Laughing

How long did the episode last?

What were you doing at the time of the episode? What triggered the outburst?

Did you feel the episode was consistent with your emotions at the time?

Yes No

How do you feel about the episode? (Select all words that apply.)

Silly Angry Sad Tired Embarrassed Worried Sick Disappointed Dizzy

Shy Scared Confused Frustrated Other (Describe)

What did you do in response to the episode?

How have your daily activities changed because of PBA?

What questions do you have for your health care provider?

PBA Episode Journal Notes

Additional Notes

Center for Neurologic Study-Lability Scale (CNS-LS)

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Using the scale below, please circle the number that describes the degree to which each item applies to you during the past week. Save the results to share with your health care provider.

<i>Patient Assessment</i>	<i>Applies Never</i>	<i>Applies Rarely</i>	<i>Applies Occasionally</i>	<i>Applies Frequently</i>	<i>Applies Most of the Time</i>
There are times when I feel fine one minute, and then I'll become tearful the next over something small or for no reason at all.	1	2	3	4	5
Others have told me that I seem to become amused very easily or that I seem to become amused about things that really aren't funny.	1	2	3	4	5
I find myself crying easily.	1	2	3	4	5
I find that even when I try to control my laughter, I am often unable to do so.	1	2	3	4	5
There are times I won't be thinking of anything happy or funny at all, but then I'll suddenly be overcome by funny or happy thoughts.	1	2	3	4	5
I find that even when I try to control my crying, I am often unable to do so.	1	2	3	4	5
I find that I am easily overcome by laughter.	1	2	3	4	5

Score: _____

Date: _____

Talking with Health Care Providers

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Getting an accurate diagnosis is the first step in managing pseudobulbar affect. Usually PBA is diagnosed during a neurological evaluation. Often the health care provider who treated brain injury can diagnose PBA. If that clinician is no longer available or you are now under the care of another health care provider, seek a referral to one of the following specialists:

Neurologists are doctors who specialize in how the nervous system functions following brain injury.

Physiatrists are doctors of physical medicine and rehabilitation who work with the patient, family, and rehabilitation team to develop the treatment plan.

Primary care physicians, such as internists and geriatricians, as well as neuropsychologists are able to diagnose PBA, as are psychiatrists, but they may mistake the condition for depression. Neurologists and physiatrists tend to have the best understanding of PBA and may be more familiar with insurance requirements pertaining to PBA treatment. As you prepare to discuss PBA with your health care provider at your appointment, it is a good idea to bring along:

- A loved one or caregiver who has observed your laughing/crying episodes
- Records pertaining to you or your loved one's primary neurological condition
- CNS-LS assessment results
- PBA Episode Journal entries

Share all of the above with your provider and be sure to discuss what episodes feel like from your point of view and from your caregiver's point of view. While some details may be uncomfortable, your physician wants to understand and help.

In 2021, the Brain Injury Association of America (BIAA) conducted an online survey of 110 individuals who experienced PBA. About 75 percent of respondents discussed their symptoms with their physician, but they did not always get an answer on the first try. As one respondent explained:



"It took 4 different doctors before being referred to a psychiatrist, who then properly diagnosed me with PBA. Other doctors just kept trying me for depression, even though I explained I was not depressed... There is not enough awareness & understanding about how debilitating PBA can be. PBA is more than laughing & crying; it affects my ability to organize, remember things, multitask, or control emotional outbursts."

Living With PBA

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Living with PBA does not have to be burdensome, embarrassing, or frustrating. The right treatment is available.

Even with treatment, you or your loved one may still experience outbursts. This is not a cause for alarm or a reason to feel guilt. You are living with a neurological condition that is out of your control. Some situations may be more likely to bring on an episode. These can include certain times of day when you are tired, when you are in a hurry, or when sensory overload makes you feel anxious. For example, your trigger may involve furry pets while someone else's relates to scary movies. Your PBA Episode Journal is a great way to identify and track your triggers so you can avoid them, prepare to face them, and/or to identify what helps calm you after an episode. If you feel an episode coming on, try taking slow and deep breaths, changing your posture or, if possible, moving locations.

Be open and honest about your PBA diagnosis. Explaining your condition will help others understand it and be supportive of you. Your friends and family do not want to see you isolate yourself, so making it a point to live while managing your condition is worthwhile. If you find it difficult to explain PBA, the PBA Explained Card found at the back of this toolkit is a simple way to explain your episode to others.

KEY CONCEPTS

It is important to stay connected and refrain from isolating. If you have not found a support group, check for one that is affiliated with the Brain Injury Association in your area, join a virtual support group, or share your story with others on BIAA's website.



[State Brain Injury Association](#)



[Virtual Support Groups](#)



[BIAA's Personal Stories](#)

Caring for Someone With PBA

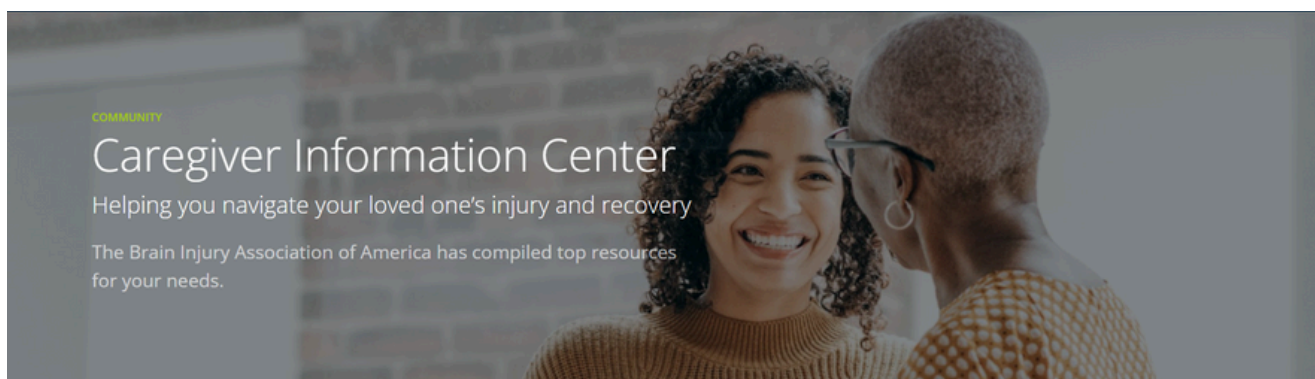
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Caring for a loved one with a neurological disorder such as a stroke or traumatic brain injury can be difficult. Watching your loved one struggle with pseudobulbar affect, particularly undiagnosed or untreated, compounds this difficulty. It is important to remember the PBA is not a psychiatric disorder. It is a secondary neurological condition resulting from a brain injury. You must be a champion when your loved one loses hope, isolates himself or herself, or appears depressed.

Caregiving can be a tough job because of the many roles you play: researcher, teacher, interpreter, recorder, and advocate. Here are some tips for being a caregiver to a loved one with PBA:

- Be informed and unafraid to speak up on their behalf.
- Maintain medical records pertaining to the primary neurological disorder.
- Attend all medical appointments and report your experience and observations of outbursts.
- Keep your own PBA Episode Journal.
- Discuss PBA outbursts with your loved one to help identify any triggers and make a plan for dealing with them. For example, come up with a “keyword” to use when you or your loved one suspects an outburst is about to happen. Identify a signal when your loved one wants help vacating an area or distributing the PBA Explained Card.
- Show your loved one that you are not embarrassed or ashamed when episodes occur.
- Most important, care for yourself and remain positive.

The Brain Injury Association of America’s Caregiver Information Center is an excellent tool for coping with the consequences of brain injury. Family, friends, neighbors, and coworkers can also offer support. You can help others by sharing your story.



PBA Explained Card

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Downloading, printing, and laminating the message below is a great tool to explain PBA to others. You can also save and share the QR code from your phone, which will link directly to this card on BIAA's website.



Notes

Additional Notes



Brain Injury Association of America
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Fairfax, VA 22031-1931

www.biausa.org
1-800-444-6443

The Pseudobulbar Affect (PBA) Self-Advocacy Toolkit and online PBA Resource Hub were made possible by a generous bequest from the estate of Mark W. Davis and our corporate sponsor.

