

# 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.

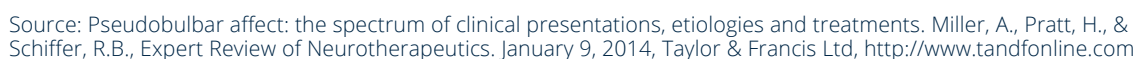
Pseudobulbar affect is a neurological condition that causes sudden, frequent, uncontrollable crying and/or laughing that does not match how the person feels. PBA is often misdiagnosed. It may be hard to find a clinician who understands PBA or to get insurance coverage for the right treatment. Many people 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](https://biausa.org/PBA) now.

## Pseudobulbar Affect (PBA) Self-Advocacy Toolkit

- Acquired or Traumatic Brain Injury (ABI/TBI)
- Stroke
- Amyotrophic Lateral Sclerosis (ALS)
- Multiple Sclerosis (MS)
- Parkinson's Disease
- Alzheimer's Disease

Figure 1. Proposed brain circuitry involved in emotional expression and its hypothesized dysfunction in pseudobulbar affect (PBA).





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.<sup>1</sup>

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."*<sup>2</sup>

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, Colamonico 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.”<sup>3</sup>

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?

<input type="checkbox"/> Sudden Crying	<input type="checkbox"/> Sudden Laughing	<input type="checkbox"/> Crying that turned to Laughing
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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?

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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How do you feel about the episode? (Select all words that apply.)

<input type="checkbox"/> Silly	<input type="checkbox"/> Angry	<input type="checkbox"/> Sad	<input type="checkbox"/> Tired	<input type="checkbox"/> Embarrassed	<input type="checkbox"/> Worried	<input type="checkbox"/> Sick	<input type="checkbox"/> Disappointed	<input type="checkbox"/> Dizzy
<input type="checkbox"/> Shy	<input type="checkbox"/> Scared	<input type="checkbox"/> Confused	<input type="checkbox"/> Frustrated	<input type="text"/> 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."*

# PBA Treatment

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The U.S. Food and Drug Administration (FDA) approved Nuedexta® for the treatment of pseudobulbar affect in 2010. Nuedexta is a combination medication made up of two drugs: dextromethorphan and quinidine. Dextromethorphan attaches to receptors in your brain that affect your mood and behavior, while quinidine raises the levels of dextromethorphan in the body. Typically, Nuedexta is taken by mouth, starting with one capsule per day and working up to two capsules per day. It may take a few weeks or months for the medicine to take effect. As with all drugs, there can be side effects.

**Fact: *Nuedexta is the first and only medication approved for the treatment of PBA.***

Some clinicians will prescribe antidepressants before prescribing Nuedexta. This happens when there is an incorrect diagnosis of depression. It also happens when insurance companies require patients to fail to improve from an alternative – often less expensive – medication or therapy.

As part of BIAA's 2021 survey, 80 people reported talking to their doctor about the condition. Among that group, 21 percent were referred to psychological counseling, but most said the treatment did not work. About 55 percent said they were prescribed an antidepressant for their PBA. The majority of people still take that drug even though it does not fully eliminate PBA episodes. About 25 percent of survey respondents discontinued the antidepressant because it did not work or because the side effects were intolerable. Many individuals who advocated for themselves or their loved ones to get the right treatment received appropriate care:



*"When I was taking Nuedexta, my brain felt more clear - clarity and focus, not overtaken by the desire to cry or laugh or even my depression and severe anxiety. It enabled me to act, to move, to execute plans and trust my brain, which had been unreliable and very noisy until then.*

*Nuedexta lowered the noise and improved my confidence and tolerance, which also improved the suicidal ideation."*

# Navigating Insurance

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The [Patient Protection and Affordable Care Act of 2010](#) brought many positive changes to the U.S. health care system. Today, more than 90 percent of Americans have health insurance. Health insurance pays for medical care, including prescription drugs, and is intended to protect people from financial ruin.

There are two primary sources of health insurance in the United States – private and public. Approximately 60 percent of insured Americans are covered under a private health plan, such as those purchased from an insurance broker, via the Affordable Care Act's [Healthcare Exchange](#), or through a group plan provided by an employer.

Medicare is the public program that provides health coverage for people age 65 and older and persons under age 65 who have a qualifying disability. The federal government administers the Medicare program. Medicaid is the health coverage plan for people with low income. State government agencies, such as state health departments, administer Medicaid plans. If you do not have health insurance or can no longer afford your insurance, you will want to investigate [Medicare](#) or [Medicaid](#) insurance programs as soon as possible.

Unfortunately, navigating the maze of insurance coverage can be frustrating. In this section, we will discuss various aspects of health insurance to ensure you are equipped with the knowledge to protect and receive your benefits.

## Key Concepts

Maintaining health insurance coverage is important for your treatment and overall well-being. The buttons below will direct you to viable options to receive answers on coverage and affordability.



# Prescription Drug Coverage

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The U.S. Food and Drug Administration (FDA) puts new medications through a rigorous process to determine their safety and effectiveness before they become available to the public. Once approved, health insurance plans assess the cost of a new drug and the availability of a generic version. The insurance plan might also explore alternative treatments, such as counseling or therapy.

Public and private health plans contract with pharmacy benefits managers (PBMs) to determine which medications are covered and under what circumstances. Medical providers develop the approved list, known as a formulary, based on an assessment of the drug's effectiveness, safety, and value. The insurance company also creates an approval process for the medication. Insured persons can contact their health plan to learn what the approval requirements are for a specific medication.



*When you are considering insurance plans, ask to see each plan's Explanation of Benefits and Prescription Drug Formulary. The formulary provides guidelines on how the cost of the drug is split between you and the health plan, if manufacturer rebates are passed to you or your health plan, as well as the requirements for approval of a specific medication.*

If your insurance company denies the medication prescribed for you or your loved one, review the written explanation of benefits to understand why the prescription was denied. If you do not receive a written statement, contact your insurance company using the phone number on the back of your insurance card or a number provided on the company's website. The reason for denial may vary. For example:

**Prior authorization.** Health plans and their PBMs frequently require an insured person to obtain a prior authorization before approving insurance coverage for a medication. The insured person must meet certain requirements by providing:

- Medical records to prove the original neurological disease or injury
- Neuropsychological tests or case notes to prove the accuracy of the diagnosis
- License, board certification, or other credentials to confirm the prescriber is a specialist
- Frequent re-evaluations to prove the medication remains effective

If coverage of a previously approved medication is suddenly denied, appeal the decision immediately. Frequently, a second prior authorization will be enough to get the prescription started again. If not, send a complaint letter to your health plan with a copy to your [State's Insurance Commissioner](#).



**Medical Necessity.** Your physician – likely a neurologist – may be required to explain to your health insurance plan why treatment for PBA is medically necessary. Typically, your doctor sends a letter explaining your medical history, current symptoms, and the rationale for prescribing Nuedexta.

**Step Therapy.** In some instances, the health insurance company will require insured patients to try alternative – often less expensive – medication or therapy. The insurance company will cover the medication only after all other options have failed. Individuals with PBA are often required to try psychological counseling and/or antidepressant medication before coverage for a prescription for Nuedexta is approved.

Keep in mind that your health plan's PBM works for the insurance company, not you. The three largest PBMs in the U.S. control approximately 80 percent of the prescription drug market and own standalone and mail order pharmacies of their own. To date, more than 40 states have passed laws to improve access to medications and curtail PBM practices deemed harmful to patients. For example, you or loved one may receive a letter urging you to fill prescriptions through a mail order pharmacy affiliated with the PBM. This practice is called patient steering and is banned in some states. If you believe your health plan or its PBM is acting outside of the law, contact an attorney. You can find a list of [BIAA Preferred Attorneys](#) on BIAA's website.



Finally, if your health plan refuses to cover the medication you need, your co-pays are unaffordable, or if you lack health insurance altogether, look for drug manufacturer coupons or saving programs. You can find these online, through your medical provider, or by asking a pharmacist. Remember to check pharmacy prices from wholesale retailers like Amazon, Costco, and Sam's Club and to use SingleCare and GoodRx when possible.

# Sample Complaint Letter to Commissioner

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Alert your [State's Insurance Commissioner](#) if you feel you are being treated unfairly with this sample letter:

Date

Name of State Insurance Commission

Address

City, State Zip

Dear Insurance Commissioner:

I have filed the attached insurance claim with \_\_\_\_\_(insert name of your insurance company) on \_\_\_\_\_(insert date[s]). My physician has deemed this therapy/procedure/drug/etc. medically necessary for my medical condition. However, my insurance company has denied me access to the standard of care.

I have had the following specific problems with this insurance company: (List all of your problems, such as refusal to cover physician-prescribed therapy, claim has not been paid or has been denied, etc.)

Please accept this letter as a formal written complaint against \_\_\_\_\_(insert name of your insurance company).

Sincerely,

Your Name

Your Address

Your Telephone Number

CC: Insurance Company Name  
Insurance Company Address  
Insurance Company Telephone

CC: Your Physician's Name  
Physician's Address  
Physician's Phone



# Living With PBA

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Living with PBA does not have to be burdensome, embarrassing, or frustrating. The right treatment is available. Once you are receiving treatment, be sure to keep your doctor informed about your improvements, side effects, or any other changes in your life.

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

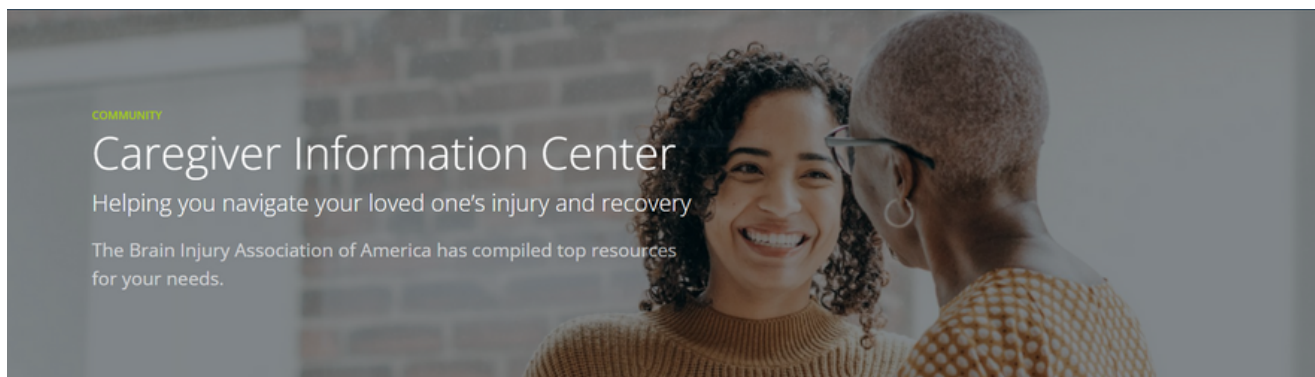
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Caring for a loved one with a neurological disorder such as a stroke or traumatic brain injury can be difficult. Watching your loved one struggle with pseudobulbar affect, particularly undiagnosed or untreated, compounds this difficulty. It is important 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

Pseudobulbar Affect (PBA) Self-Advocacy Toolkit



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*

# Download the PBA Toolkit

Pseudobulbar Affect (PBA) Self-Advocacy Toolkit



In addition to downloading the complete PBA Toolkit, you can save the QR code on your phone to link directly to the Toolkit on the PBA Voices website.



*The Pseudobulbar Affect (PBA) Self-Advocacy Toolkit was made possible by a generous bequest from the estate of Mark W. Davis and these corporate sponsors:*





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