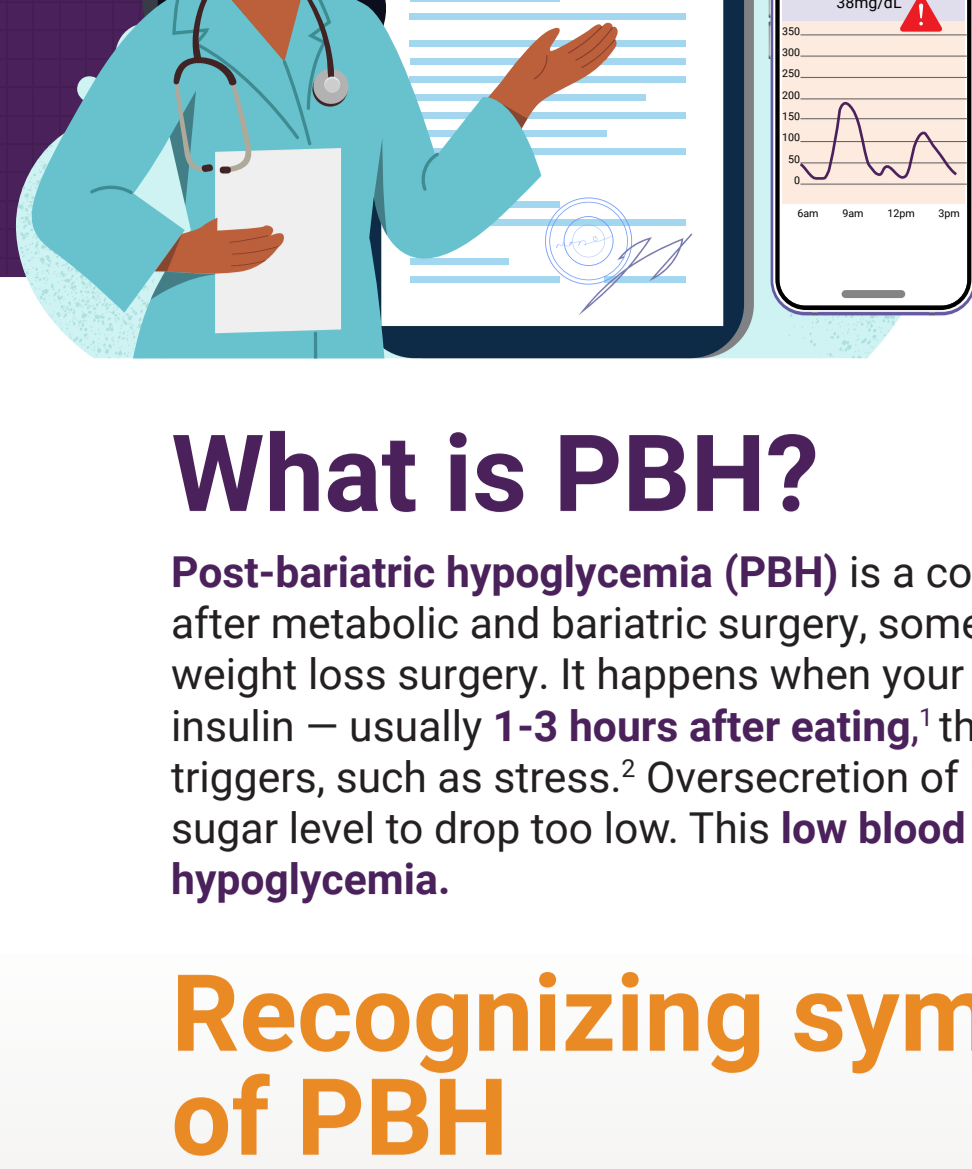


Understanding PBH

A Community Guide to Education and Support

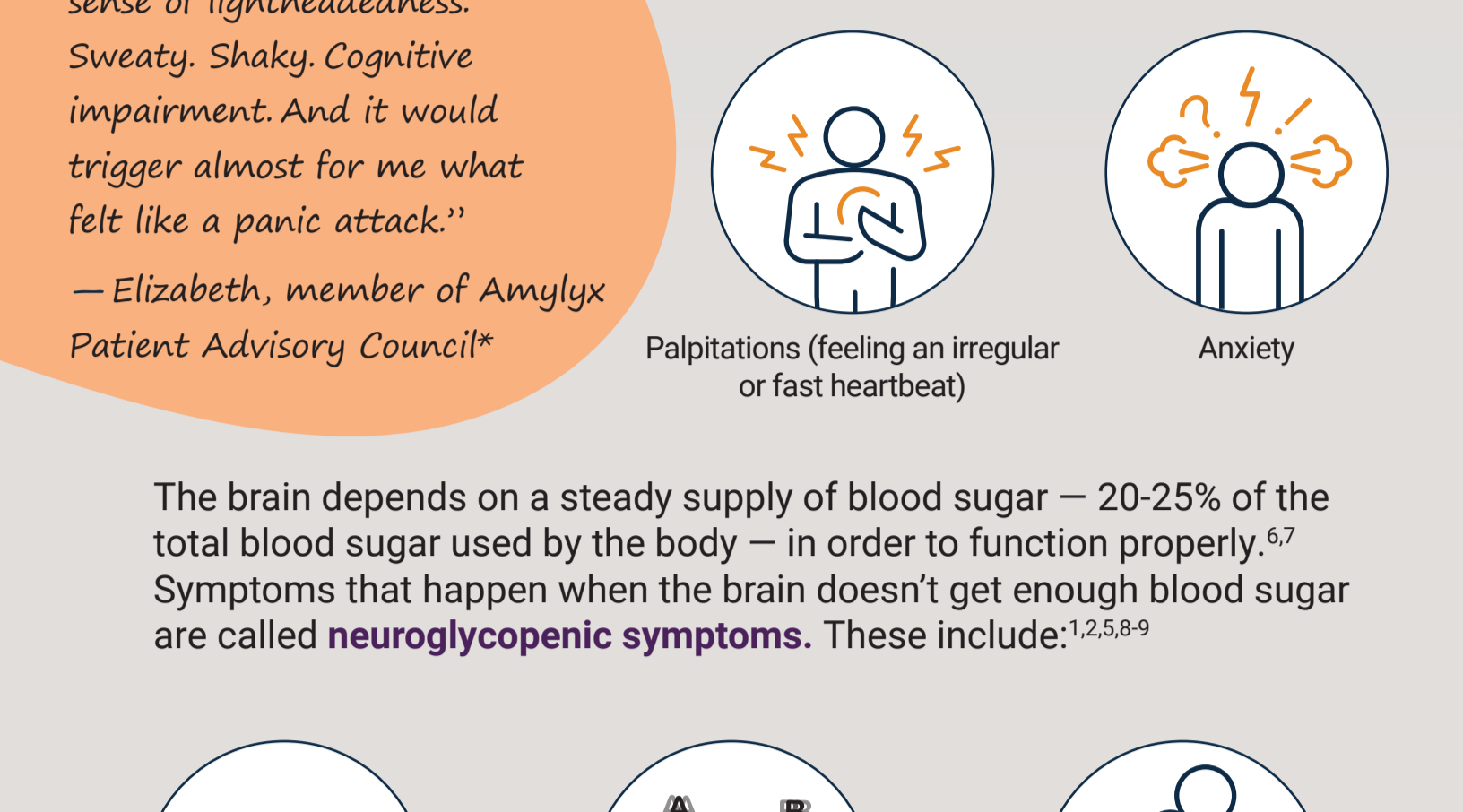


What is PBH?

Post-bariatric hypoglycemia (PBH) is a condition that can occur after metabolic and bariatric surgery, sometimes referred to as weight loss surgery. It happens when your body releases too much insulin – usually 1-3 hours after eating,¹ though there can be other triggers, such as stress.² Overeating of insulin causes your blood sugar level to drop too low. This low blood sugar state is also called hypoglycemia.

Recognizing symptoms of PBH

As your body responds to rapid changes in blood sugar levels, a cycle of sharp rises and drops (or highs and lows), resembling a rollercoaster, may occur. This leads to a range of symptoms as the body struggles to stabilize blood sugar.³



Some symptoms happen when the body tries to raise blood sugar levels.⁴ Doctors sometimes call these **autonomic symptoms**. These include:⁵



Sweating



Tremors (shaking)



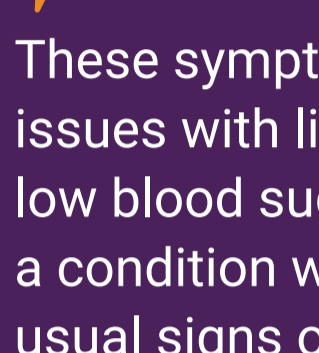
Palpitations (feeling an irregular or fast heartbeat)



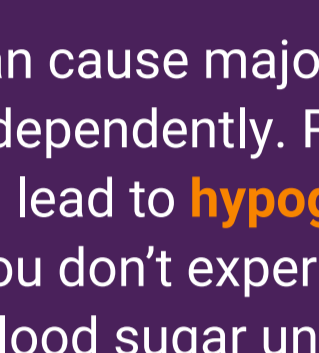
Anxiety

“Initially, when I hadn’t identified that it was hypoglycemia, what I experienced was this sudden sense of lightheadedness. Sweaty. Shaky. Cognitive impairment. And it would trigger almost for me what felt like a panic attack.”
—Elizabeth, member of Amylyx Patient Advisory Council*

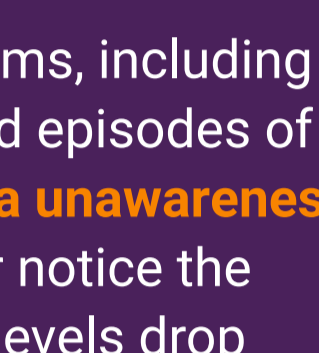
The brain depends on a steady supply of blood sugar – 20-25% of the total blood sugar used by the body – in order to function properly.^{6,7} Symptoms that happen when the brain doesn’t get enough blood sugar are called **neuroglycopenic symptoms**. These include:^{1,2,5,8-9}



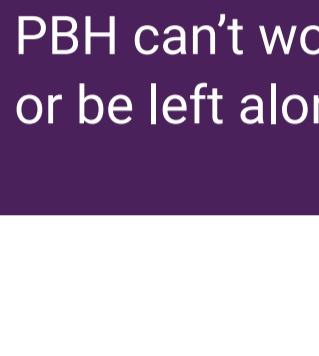
Confusion, disorientation, or odd behavior



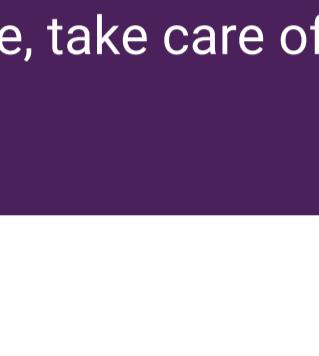
Blurred vision



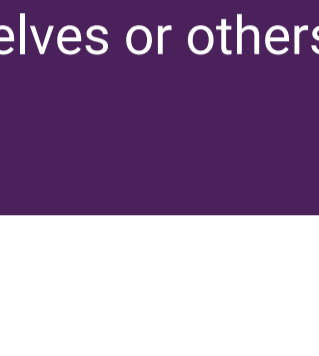
Persistent fatigue and exhaustion



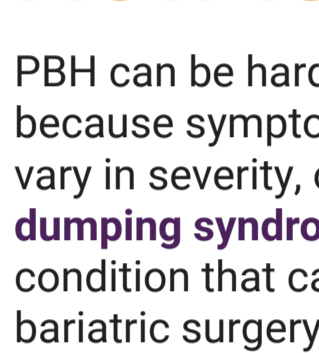
Difficulty speaking



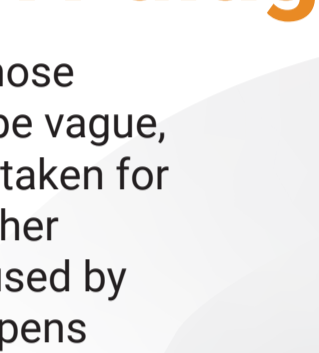
Dizziness



Poor coordination



Impaired cognition (trouble thinking, learning, and remembering)



Weakness



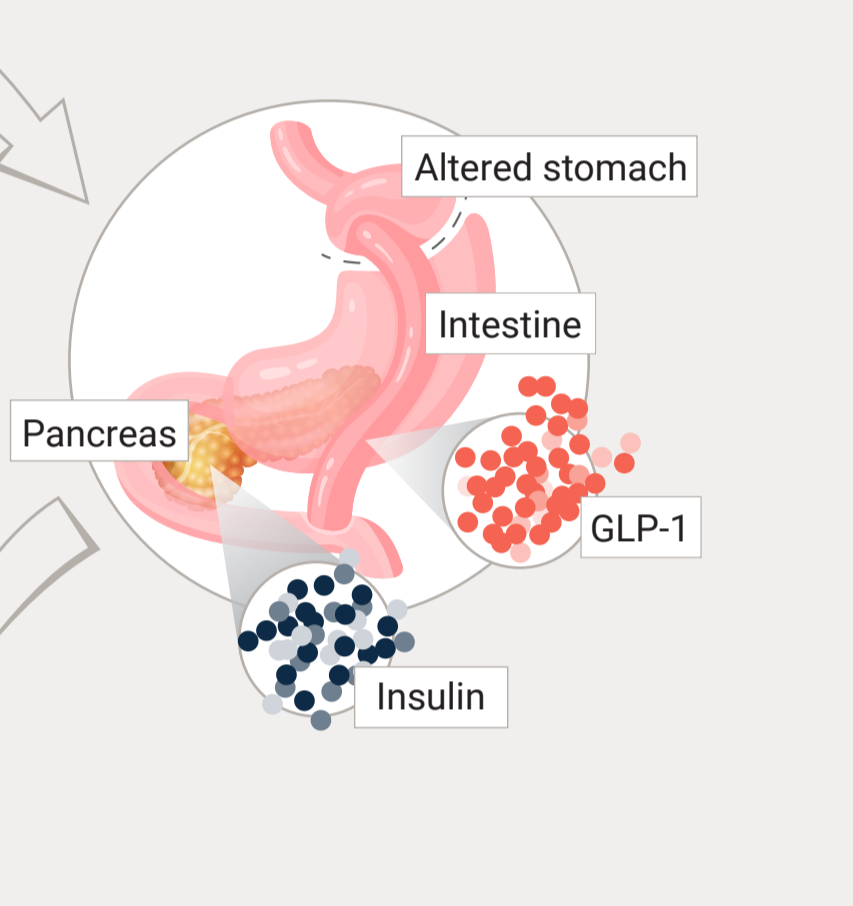
Loss of consciousness

These symptoms can cause major problems, including issues with living independently. Repeated episodes of low blood sugar can lead to **hypoglycemia unawareness**, a condition where you don’t experience or notice the usual signs of low blood sugar until your levels drop dangerously low.¹⁰ Because of this risk, many people with PBH can’t work, drive, take care of themselves or others, or be left alone.^{2,9}

How is PBH diagnosed?

PBH can be hard to diagnose because symptoms can be vague, vary in severity, or be mistaken for dumping syndrome, another condition that can be caused by bariatric surgery and happens when food moves too quickly from the stomach to the small intestine.²

Speak with your primary care provider or endocrinologist to see if you have PBH or may have another condition.



Causes of PBH and who it impacts

The exact cause of PBH is not known, but research suggests the overactivity of a hormone called **glucagon-like peptide-1 (GLP-1)** is a central cause.¹¹



GLP-1 is normally released after a meal and causes the release of **insulin** from the pancreas.

A key role of insulin is moving **glucose** from the bloodstream into cells. In people living with PBH, **GLP-1 is overproduced** after eating, leading to abnormally **high insulin levels** and, as a result, **low blood sugar levels**.¹¹



Low blood sugar levels

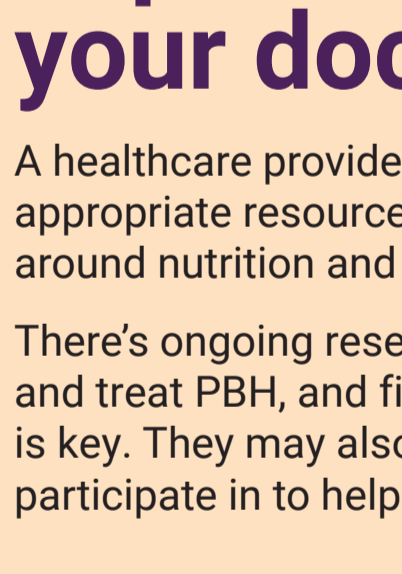


It is estimated that **PBH affects 160,000 people** in the U.S., or 8% of people who have received the two most common surgeries, **Roux-en-Y gastric bypass (RYGB)** or **sleeve gastrectomy**.¹²⁻¹⁵

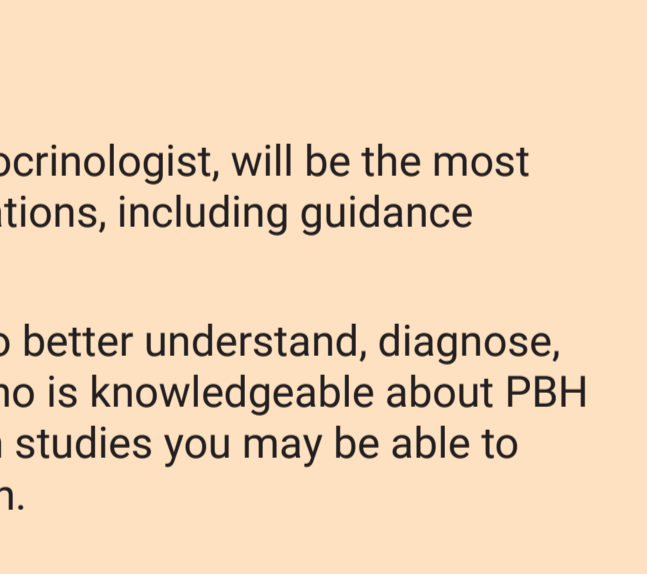
COMMUNITY SPOTLIGHT

How one person navigates PBH

Maggie experienced a long journey to her PBH diagnosis, and she also had trouble getting help and finding answers for living with this condition. This added yet another difficult layer to managing her often debilitating symptoms. To raise awareness of PBH and counter some common misconceptions about her condition, Maggie shared her story, which can be viewed at www.amylyx.com/community or by scanning the QR code.



Watch Maggie's video here



Current challenges in managing PBH

Care for and management of PBH are still evolving, and there are no approved treatment options. Many people face challenges in getting the right diagnosis, care, and support. PBH is often not properly recognized as disabling and serious, and there is a lack of PBH education and awareness.

One common misconception is that dietary changes alone are sufficient and can work for everyone. Even when dietary recommendations are rigorously followed, **sudden and unpredictable crashes** can still occur.²



Because of this, people often develop **coping strategies** like drastically cutting back on food or carbs to avoid crashes – especially during work or important events – only to end up dealing with malnutrition or fatigue.²

Others do the opposite, continually snacking on carbs to keep blood sugar up, which can lead to weight gain and repeated crashes throughout the day. **Fear of and intolerance to food** can be real struggles.²

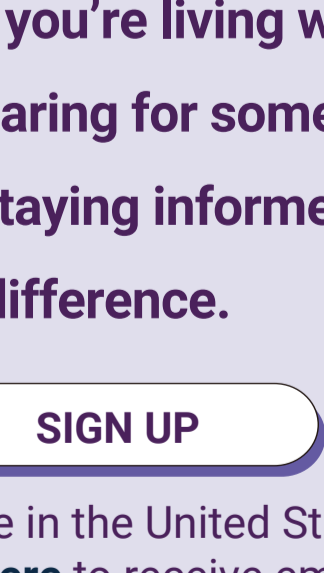
Topics to discuss with your doctor

A healthcare provider, such as an endocrinologist, will be the most appropriate resource for recommendations, including guidance around nutrition and care options.

There's ongoing research helping us to better understand, diagnose, and treat PBH, and finding a doctor who is knowledgeable about PBH is key. They may also have insights on studies you may be able to participate in to help advance research.

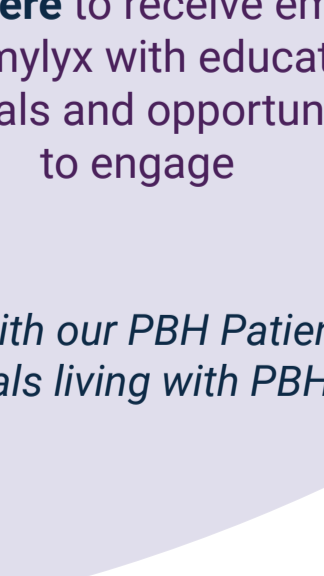
Blood sugar tracking

Monitoring blood sugar patterns is one way to understand your crashes. A glucometer or continuous glucose monitor (CGM) can give you insights into how different foods, activities, and stress levels impact you.⁹ Talk to your doctor about whether this type of tracking could help you.



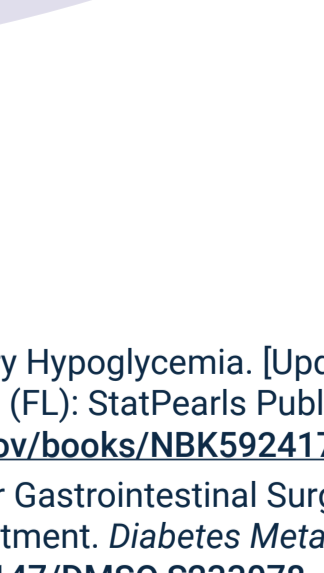
Preparing for the lows

When a low blood sugar event happens, it's important to be prepared. While food-based interventions are often the first step, some situations may require medication,² which is something to discuss with your doctor. It's also a good idea to educate your family and close friends about your symptoms and how they can help if you ever have a severe low.



Stress management

It's understandable that chronic conditions can create mental health challenges. In addition, stress can directly affect blood sugar regulation.² While it can be challenging, finding ways to reduce stress may help stabilize your blood sugar over time.



The bottom line? PBH is complex, and no two people experience it exactly the same way. If you're struggling, reach out to your doctor.

PBH advocacy and how to stay informed

At Amylyx, our mission as a clinical-stage pharmaceutical company is to develop new treatments for diseases with high unmet needs. To shift the trajectory of these diseases and conditions, our team must first learn what changes will make meaningful differences for those most affected.

As collaborators who value connection, we ask for input from the community early and often and strive to be partners of choice. Our ultimate vision is for the communities we serve to see us as credible champions for listening to and meeting their needs.

If you'd like to support raising PBH awareness or amplifying the patient voice, please email advocacy@amylyx.com.



Whether you're living with PBH or caring for someone who is, staying informed can make a difference.

SIGN UP

If you're in the United States, [click here](#) to receive emails from Amylyx with educational materials and opportunities to engage

* Amylyx developed this guide in collaboration with our PBH Patient Advisory Council, which is made up of individuals living with PBH

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