



Make the most of your conversation with your doctor if you suspect Bardet-Biedl syndrome

If you have experienced constant, hard-to-control hunger and weight gain from an early age, they may be signs of a rare condition

Bardet-Biedl (pronounced BAR-day BEED-el) syndrome, or BBS, is a rare genetic disease that has a wide range of symptoms. Some symptoms may include vision impairment, kidney problems, or learning disabilities.

There are also two key symptoms of BBS related to weight: obesity and constant, hard-to-control hunger.

Obesity due to BBS has a unique cause, which means that standard weight management methods may not work. That is why it's important to discuss symptoms with your doctor. They may help lead to a specific diagnosis, which is a positive first step to managing it.



Unlike general obesity, obesity due to BBS requires different management and treatment.

Use your voice

It's important to have an open and honest conversation with your doctor to receive a diagnosis sooner rather than later. The more you share about your medical history and daily life, the more your care team can help.



Talk to your doctor about whether genetic testing for BBS may be right for you. Genetic testing may aid in diagnosis.



Tips to support a productive conversation



Prepare for your appointment by collecting your full medical history and documenting your symptoms.

Use the checklist below to summarize your symptoms

- ☐ Continuous weight gain that led to obesity at an early age
- ☐ Weight gain that doesn't respond to a calorie-restricted diet and regular exercise plan
- ☐ Constant, hard-to-control hunger

Behaviors around food, including:

- ☐ Hiding eating behavior from friends and family
- ☐ Planning your day around food
- ☐ Waking up at night to eat
- ☐ Feeling sadness or frustration when food isn't available

Other seemingly unrelated symptoms, including:

- ☐ Vision loss or impairment
- ☐ Kidney problems
- ☐ Born with extra toes or fingers
- ☐ Developmental issues or learning disabilities
- ☐ Hormonal problems/delayed puberty

Consider keeping a food diary for at least a week before your next appointment. This can help your doctor understand your eating patterns.



Ask questions to guide the conversation. Some suggestions are included on the next page.



Repeat the doctor's answers in your own words to make sure you are understanding them correctly.



Don't be afraid to be open with your doctor. You are your best advocate. The more information you share with your doctor, the better they will be able to help you.



Act early: A BBS diagnosis is a positive first step to managing it.

Remember: Obesity due to BBS requires tailored management.



Ask your doctor about BBS

Starting the conversation

- 1 Based on my symptoms and medical history, do you think I could have BBS?
- 2 Could it be another rare condition that causes obesity?

How to confirm BBS

- 1 Would I need to go to a specialist?
- 2 Should I consider genetic testing for BBS?

If you are diagnosed with BBS

- 1 What might I expect after a BBS diagnosis?
- 2 How should I expect to change/tailor how I manage my weight and hunger?
- 3 Are there treatments that can help with obesity due to BBS?
- 4 Are there other doctors that should be added to my care team to help manage obesity due to BBS?

To learn more about rare conditions that cause obesity, visit DifferentObesityBBS.com or scan the QR code to the right.

