HYPOPARATHYROIDISM AFFECTS THE WHOLE YOU

Your guide to understanding hypoparathyroidism. Read on for answers to your questions about this lifelong condition.
If you have been living with hypoparathyroidism (hypopara) for a while, or have just been diagnosed, you probably want to know more. Asking questions, such as what it means for how your body functions, is a normal part of understanding your condition. This guide is designed to help actively manage your hypopara.

What is hypoparathyroidism?

It is a rare, complex condition where you have no or very low levels of parathyroid hormone (or PTH for short). This happens when your parathyroid glands are missing, damaged, or not working like they should and they do not produce enough PTH.

Hypopara can make you feel invisible… like you’re not really “there.”

Without PTH, your body cannot regulate certain minerals, including calcium and phosphate, which are important for keeping your body healthy. As a result, people with hypopara can have low blood calcium (hypocalcemia), high blood phosphate (hyperphosphatemia), and other mineral imbalances.

Approximately 75% of all cases of hypopara are a result of surgery on or near the parathyroid glands. Hypopara can also be caused by an autoimmune or genetic condition. Sometimes there is no known cause of hypopara.
WHAT ARE THE SIGNS AND SYMPTOMS OF HYPOPARATHYROIDISM?

Hypopara can affect many systems in the body, including those that control the brain and nervous system, the heart, and the muscles.

Low blood calcium because of hypopara can lead to symptoms that you may not know are connected to your condition. Knowing the signs and symptoms is important so you can be active in managing your hypopara.

Here are some of the signs and symptoms that can occur when you have hypopara.

- Brain fog, depression, irritability, confusion or disorientation, seizures
- Throat tightness
- Fast, slow, or uneven heart rate, symptoms of heart failure
- Shortness of breath, wheezing
- Stomach cramps
- Numbness and tingling in fingers
- Muscle weakness, spasms, twitches, cramps
- Numbness and tingling in toes

It’s important to keep your doctor up to date about the symptoms you feel to make sure your hypopara is well controlled.

On page 15 of this brochure, there is a symptom tracker you can use to keep track of symptoms to share with your doctor.
WHAT QUESTIONS CAN I ASK MY DOCTOR?

Taking an active role in managing your condition is important. Asking questions will help you find the information you need to make sure you are getting the most appropriate care for your hypopara. Although there is no cure for hypopara, you can ask your doctor questions to determine how best to manage this lifelong condition. Below are a few examples.

**How is hypopara managed?**

**What possible complications can happen because of my hypopara?**

**How many patients with hypopara do you have?**
WHAT IS THE IMPACT ON MY DAILY LIFE?

Living with hypopara can be challenging. Knowing what to expect and how it may impact your daily life can help you be prepared. From working, to personal relationships, and even self-image, hypopara can put a strain on you.

Below are some of the different ways that hypopara may affect daily life.

PHYSICAL ABILITIES

Muscle spasms, twitches, cramps, pain, weakness can impact:
- Strenuous activities (lifting heavy objects, running)
- Moderate activities (vacuuming, playing golf)
- Carrying groceries
- Climbing stairs
- Bending or kneeling
- Walking moderate to long distances
- Bathing/dressing

SOCIAL AND FAMILY LIFE

Physical and emotional symptoms can impact your ability to:
- Spend time with family and friends
- Play an active role in your spouse’s and/or children’s life
WHAT IS THE IMPACT ON MY DAILY LIFE?

ABILITY TO WORK

Your ability to work, either outside or inside your home, may be affected by physical and emotional symptoms. You may:

• Need to work fewer hours
• Have reduced ability to accomplish all tasks
• Be limited in the type of work you can do
• Have reduced ability to concentrate or pay attention
• Experience memory loss

MOOD

You may feel:

• Nervous
• Depressed or “down in the dumps”
• Tired or worn out
• Unhappy or unfulfilled
• Isolated, lonely, or “invisible”
HOW CAN I MANAGE MY HYPOPARATHYROIDISM SYMPTOMS?

It may seem daunting at first, but life with hypopara can be managed. Having the right information about your condition and a good healthcare team to help you manage symptoms to prevent any long-term complications is important.

Hypopara can affect many systems in your body. For that reason, your healthcare team may include an endocrinologist (a doctor who specializes in mineral and hormone imbalances). You may also see a nephrologist (kidney doctor) in addition to a primary care doctor. Don’t forget, you are also an important member of the team.

What are your doctors’ goals when managing your hypoparathyroidism?

Professional medical organizations have created guidelines that help your doctor develop a management plan. The guidelines for hypopara have the following goals:

- Preventing symptoms of low blood calcium
- Keeping your blood calcium level slightly below normal or in the low normal range (see picture below)
- Keeping your blood calcium and phosphate levels balanced
- Avoiding extra calcium in your urine and blood
- Keeping calcium from collecting in your kidneys and other soft tissues throughout the body

Calcium ranges

<table>
<thead>
<tr>
<th>Calcium Range</th>
<th>Target Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOW BLOOD CALCIUM</td>
<td>&lt;8.4 mg/dL</td>
<td>Low blood calcium</td>
</tr>
<tr>
<td>NORMAL BLOOD CALCIUM</td>
<td>8.4-10.6 mg/dL</td>
<td>Normal blood calcium</td>
</tr>
<tr>
<td>HIGH BLOOD CALCIUM</td>
<td>&gt;10.6 mg/dL</td>
<td>High blood calcium</td>
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</tbody>
</table>

TARGET RANGE
For people being treated for hypopara
8.0-9.0 mg/dL
WHAT ARE THE COMMON LAB TESTS FOR HYPOPARATHYROIDISM?

When first diagnosed, your doctors will determine the calcium levels in your blood and urine. Based on these levels and any changes in your symptoms, your doctors will talk with you about how to manage your condition.

You will also have regular blood and urine tests to help your doctor continue managing your hypopara and make sure it is controlled. Some of the tests you may have include:

- **Total Serum Calcium**: Measures the total amount of calcium in your blood because hypopara can lower your calcium levels.

- **Ionized Calcium**: Provides more information about the balance of calcium in your body.

- **Urinary Calcium**: Measures the calcium in your urine by collecting it over a 24-hour period.

- **Phosphate/Phosphorus**: Measures the level of phosphorus in your blood because hypopara may increase your phosphate levels.
WHAT ARE THE COMMON LAB TESTS FOR HYPOPARATHYROIDISM?

<table>
<thead>
<tr>
<th>Test</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Creatinine</td>
<td>Creatinine levels, obtained by a blood or urine sample, show how well your kidneys are functioning</td>
</tr>
<tr>
<td>Vitamin D</td>
<td>Measures the levels of vitamin D in your blood and shows how well your kidneys can process vitamin D</td>
</tr>
<tr>
<td>Parathyroid Hormone</td>
<td>Measures the levels of PTH in your blood to see how your parathyroid glands are working</td>
</tr>
<tr>
<td>Magnesium</td>
<td>Measures the level of magnesium in your blood because hypopara may lower your magnesium levels</td>
</tr>
</tbody>
</table>

Always talk with your doctor about your medical condition or treatment. This information does not take the place of talking to your doctor.
WHAT ELSE CAN I DO ON MY OWN TO MANAGE MY HYPOPARATHYROIDISM?

Even though living with hypopara can make you feel isolated or overwhelmed at times, you do have options. Below are some helpful tips and information that you can use to manage your hypopara and ensure you are on the best path forward.

EATING A CALCIUM-RICH DIET

A diet rich in calcium can be helpful for people with hypopara. Milk, yogurt, and cheese are rich natural sources of calcium. Other foods that provide calcium include:

• Vegetables (broccoli, kale, Chinese cabbage)
• Calcium-fortified orange juice
• Breakfast cereals
• Sardines
• Tofu (made with calcium sulfate)

Your doctor may also ask that you make other changes to your diet:

• If you have high blood phosphate levels, reduce phosphate in your diet by avoiding carbonated soft drinks and eating fewer eggs and less meats
• If you have high urine calcium levels, a low-salt diet may be advised

EXERCISE AND ACTIVITY

Some people with hypopara may experience depression and/or anxiety. If you feel depressed or anxious, try to be active and exercise, as tolerated. The National Institute of Mental Health recommends participating in activities, including exercise, to help relieve depression. Staying as active as you can may help you feel less depressed or anxious. Always talk with your doctor about which activities may be right for you.
WHAT ELSE CAN I DO ON MY OWN TO MANAGE MY HYPOPARATHYROIDISM?

MEDICATION LIST

Keep a list of all the medicines you take in your purse or wallet. Note any changes in your medicine that you may have made since your last visit. This information should be reviewed with your healthcare team at every appointment. Having this information with you is also very helpful if you need to visit the emergency department at the hospital.

EXPLAINING HYPOPARATHYROIDISM

Many friends, family members, and coworkers may not be familiar with hypopara. They may not understand the symptoms that you face or how your condition affects your daily life, mood, or well-being.

Take some time to explain to those around you what it’s like to live with hypopara. For example, you may want to help them understand that not all the symptoms are easy to see from the outside. Cognitive and emotional symptoms like brain fog and depression can be hard to “see.”
WHAT ELSE CAN I DO ON MY OWN TO MANAGE MY HYPOPARATHYROIDISM?

CONNECT WITH OTHERS
Talking with other people who are affected by or living with hypopara can be very helpful in dealing with a rare disease. Communities made up of other patients or caregivers can offer information, support, and encouragement.

Check out the Hypopara Answers™ Facebook page or YouTube channel to connect with others, read their stories, and share your own. You can also visit the HypoPARAthyroidism Association website to learn about educational conferences designed to support those touched by hypopara.

facebook.com/HypoparaAnswers/
youtube.com/user/HypoparaAnswers
hypopara.org

OTHER HELPFUL TIPS
• Wear a medical ID bracelet specifically for “hypocalcemia” to ensure you get the right care in case of an emergency
• If your hypopara causes you to visit the hospital often, make sure your doctors know; be sure to also get a copy of your hospital records to share with your doctor
WHAT DO DOCTORS RECOMMEND TO MANAGE HYPOPARATHYROIDISM?

Calcium and active vitamin D are two of the main tools used to manage hypopara, which limit symptoms and reduce the risk of complications.

Managing hypoparathyroidism can be a balancing act

- Some people may require very high doses of calcium and active vitamin D, which can lead to concerns for potential complications
- Even when people take very high amounts of calcium and active vitamin D, some can still experience wide swings in serum calcium
- Increased or new symptoms could be a sign that blood calcium levels and phosphorus levels are out of balance

If your hypoparathyroidism is not properly controlled, you may experience:

- Symptoms of low blood calcium
- The need for larger doses of supplements to control your blood calcium level or prevent symptoms
- Extra calcium in your urine, kidney stones, buildup of calcium salts in your kidneys or other soft tissues, or poor kidney function
- Phosphate or calcium-phosphate levels in your blood that are out of balance
- A problem with your gastrointestinal system that makes it hard to absorb calcium and vitamin D
- Symptoms such as brain fog, depression, muscle weakness, cramps, and shortness of breath

Ask your doctor if there are other things that can be done to help control your hypopara.
WHAT ELSE SHOULD I KNOW ABOUT MY HYPOPARATHYROIDISM?

Throughout your hypopara experience, you may want to discuss other important issues with your healthcare team. Below are some questions that you can ask to better understand and manage the process.

• What is my target blood calcium level?
• How often should I have my blood calcium level checked?
• Is it necessary to monitor my phosphate and vitamin D levels?
• What are my long-term goals?
• Why do I continue to experience symptoms like twitching, cramping, or abnormal excitability of nerves and muscles that cause leg or arm spasms (also called tetany)?
• Are there other symptoms I should watch for?
• If I have severe symptoms and need emergency care, what should I tell the emergency staff about my condition?
• Why might I still experience symptoms if my lab values are in the normal range?
• If I am still experiencing symptoms, even though I take my medicines, are there other things I can do?
It’s important to keep your doctor informed about the symptoms you feel to make sure your current plan is working. The more your doctor knows about your symptoms, the more that can be done to manage your hypopara.

You can use the diagram below to tell your doctor if you have been experiencing symptoms since your last visit. Circle ALL of the symptoms that you remember feeling. Then, using a number from 1 to 3, write down next to it how often each occurs (1=only once in a while, 2=sometimes, 3=all the time).

*Shortness of breath, swelling, feeling tired, coughing, confusion or memory loss, rapid weight gain.

**Throat tightness**
- Muscle twitches
- Muscle spasms

**Muscle weakness**
- Depression
- Brain fog, confusion, or disorientation

**Shortness of breath, wheezing**
- Fast, slow, or uneven heart rate

**Numbness and tingling in fingers and toes**

**Symptoms of heart failure**
- Stomach cramps

**Irritability**

**Seizures**

*Shortness of breath, swelling, feeling tired, coughing, confusion or memory loss, rapid weight gain.*
Routine monitoring with lab tests may help your doctor manage your hypopara and monitor how well your hypopara is controlled. Keeping track of your levels is very important because you and your doctor may be able to spot when levels rise or fall. Using the chart below, write down your lab values for each test every time your doctor checks them. You may need to share this information with your other doctors.

**Name:**

<table>
<thead>
<tr>
<th>Test</th>
<th>Date:</th>
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Notes: 

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HYPOPARATHYROIDISM AFFECTS THE WHOLE YOU

When you have the right information, support, and resources, you can learn how to best navigate your life with hypopara. Playing an active role in managing your condition will also help ensure that your hypopara is controlled.

Hypoparathyroidism community support

Don’t forget, there are others out there just like you who are living with hypopara. Connect and find support from others in the community.

hypopara.org

facebook.com/HypoparaAnswers/   youtube.com/user/HypoparaAnswers

If you would like more information about hypopara, talk with a member of your healthcare team and visit hypoparaanswers.com

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