CHOOSING YOUR BEST HEALTHCARE PARTNERS

A guide to finding an endocrinologist that can develop a management plan for your hypoparathyroidism
Hypoparathyroidism (hypopara) is a rare, complex condition of the endocrine system where you have no or very low levels of parathyroid hormone (or PTH for short).

The **endocrine system** is a network of glands in your body that secrete hormones that are used to regulate many different bodily functions.

Endocrine conditions are usually managed by an endocrinologist, a doctor who specializes in mineral and hormone imbalances. Because hypopara is such a rare condition, some endocrinologists may have more experience with it than others. You may need to talk with more than one endocrinologist to develop a management plan that’s right for you, since everyone’s symptoms can vary. Having a good healthcare team to help you manage symptoms and prevent any long-term complications is important.

Because hypopara can affect many systems in your body, your healthcare team may also include a nephrologist (kidney specialist) and a primary care doctor. Don’t forget, you are also an important member of the team, which is why you need to be actively involved in your care plan.
WHAT ARE YOUR ENDOCRINOLOGIST’S GOALS WHEN MANAGING YOUR HYPOPARATHYROIDISM?

Professional medical organizations have created guidelines that help your endocrinologist develop a management plan. These guidelines for hypopara include 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

**TARGET RANGE**
For people being treated for hypopara
8.0-9.0 mg/dL

<table>
<thead>
<tr>
<th>Condition</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOW BLOOD CALCIUM</td>
<td>&lt;8.4 mg/dL</td>
</tr>
<tr>
<td>NORMAL BLOOD CALCIUM</td>
<td>8.4-10.6 mg/dL</td>
</tr>
<tr>
<td>HIGH BLOOD CALCIUM</td>
<td>&gt;10.6 mg/dL</td>
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</tbody>
</table>

Confirm with your healthcare team that they are considering these guidelines when creating your care plan to manage your hypopara.
COMMON LAB TESTS FOR HYPOPARATHYROIDISM

Endocrinologists rely on several blood and urine tests to manage hypopara. Using the list below of some recommended tasks, ask your doctor about these tests and find out how often they will be performed.

- Total serum calcium
- Ionized calcium
- Urinary calcium
- Phosphate/phosphorus
- Creatinine
- Vitamin D
- Parathyroid hormone
- Magnesium

For more information on each of these tests, including what they measure and why, go to www.hypoparaanswers.com/pdf/living-with-hypopara.pdf.
GETTING THE CONVERSATION GOING

Talking with your endocrinologist about your symptoms is one of the most important things you can do to play an active role in managing your hypopara. Here are some examples of questions that may help start the conversation.

**How many patients with hypopara have you managed?**

*Note:* Don’t be too concerned if the answer is only a few; after all, this is a rare condition. If you are not comfortable with their experience level, you can consider seeking their help in recommending another specialist.

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

*Note:* Ask them to be open with you and to discuss potential long-term issues, as well as more immediate concerns.

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**What medicines are used to manage hypopara?**

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**Are there any side effects from my medicine I should be aware of? Can they be managed?**

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**What is my target blood calcium level?**

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**What are the long-term goals of my care plan?**
Throughout your hypopara experience, your endocrinologist may make changes to your care plan. Here are some additional questions that you can ask to better understand and manage this process.

**Why do I continue to experience symptoms?**
(List all your ongoing symptoms)

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**How do my most recent lab values compare with previous results?**
What does this mean for me?

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**Why might I still experience symptoms if my lab values are in the normal range?**

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**If I am still experiencing these symptoms, even though I take my medicines, are there other things I can do?**

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WHAT IF MY HYPOPARATHYROIDISM IS NOT PROPERLY CONTROLLED?

Increased or new symptoms could be a sign that blood calcium levels and phosphorus levels are not where they should be. It’s important to talk with your endocrinologist about all of your symptoms and how they make you feel, both physically and emotionally.

Visit www.hypoparaanswers.com/pdf/living-with-hypopara.pdf for a downloadable symptom tracker. Fill it out each week between appointments and share it with your endocrinologist to ensure that your symptoms are discussed. The more he/she knows about the symptoms you are experiencing, the more that can be done to manage your hypopara.

If your hypopara 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

These are possible signs that more may need to be done to improve your current care plan.

Ask your endocrinologist if there are other things that can be done to help control your hypopara.
Remember, since hypopara is such a rare condition, not all endocrinologists have the same level of expertise. You may find that you need to talk with more than one endocrinologist before you find one that has experience managing hypopara.

Need help finding an endocrinologist?
You are not alone! The American Association of Clinical Endocrinologists can help you find an endocrinologist in your area. Go to aace.com/resources/find-an-endocrinologist to begin your search.

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

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.