Hypopara Answers™

LIVING WITH HYPOPARATHYROIDISM

Takeda

Living with Hypoparathyroidism

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What happens after diagnosis?

As hypoparathyroidism is a rare condition, nurses and healthcare workers may never have heard of it. Doctors may only diagnose a few cases in their careers. Therefore, diagnosis can take time, and misdiagnoses can also occur. An endocrinologist may make the diagnosis and be a primary point of contact throughout treatment. If you have had recent thyroid surgery, it is also possible that a diagnosis may come from a surgeon.

Initially, meetings with your physician will be fairly regular, when working out a management plan. During this time, blood calcium levels will be checked regularly, to monitor the effectiveness of treatment. Once a stable dose is achieved, your blood calcium should be monitored every 3–6 months. If the hypopara medication or dosage changes, blood calcium will have to be checked again more regularly.[1]

As well as blood calcium, your physician may also want to check for other things including 24-hour urinary calcium annually, blood phosphate, magnesium and creatinine, as these can all be used to indicate disease progression, commorbidities and effectiveness of treatment.[1]

Diagnosis with hypopara can be an isolating and frightening experience. The symptoms of hypopara can be difficult to manage and this can often impact your mental health and quality of life. Therefore it is important to receive support, either from a doctor or nurse, family members, or other individuals affected by the disease. With support, hypopara can feel more manageable.

Managing hypopara

Managing my symptoms

Management of the disease itself is done through a combination of self-management techniques and evaluations and assessments performed by your doctor or endocrinologist. Your doctor or endocrinologist will be the focus for your care when just starting on your disease journey, during any crises, and if you need to adjust your medication or the dosage of said medication. For all of the stages in between, care is mainly performed by you and your friends and family.

KEEPING A DIARY: Try keeping a diary of test results, doses of current medications, and symptoms. This will help you be aware of symptoms and understand high and low calcium warning signs, so you can adjust your calcium supplementation accordingly. This can also be useful for a physician so they can monitor hypopara and tailor treatment to your needs.

MANAGING DIET AND FLUID INTAKE: It is important for hypopara patients to have food which is high in calcium. Dairy is the most common high-calcium choice, but other non-dairy products are high in calcium, such as spinach and broccoli, nuts, legumes such as lentils, peas, beans and soya products, bread and anything made with fortified flour, and all types of fish.[2] Maintaining adequate hydration by drinking the recommended amount of water is also important, especially for those at risk of developing kidney stones.

CARRY SPARE MEDICATION: Always carry spare medication with you. Try to maintain a month's supply in reserve. If you go on holiday, carry an extra supply of medication; ensure it is kept in your hand luggage with prescription labels visible, and carry any documentation required to show to security if asked.

SEEK SUPPORT: As a rare disease, hypopara can be isolating. It is important to seek support when you need it and share any issues. This can be with a doctor, friends and family or other patients.

Management by a physician

Your physician may perform some physical tests and ask some questions relating to your symptoms, e.g. if you are experiencing flank pain (kidney stones), vision loss (cataracts) or neurological symptoms (such as seizures, disorientation, memory loss etc, which could be indicative of brain calcifications).

Long-term complications of hypopara

Hypopara can have long-term complications, which is why it is so important for you to visit your physician if your symptoms are not being managed. Complications of hypopara can arise as a result of hypocalcaemia and hypercalcaemia.

Hypocalcaemia primarily causes tingling and twitching in muscles, anywhere in the body.

Hypercalcaemia, as a result of calcium supplementation, can lead to calcium being deposited across the body (known as extraskeletal calcifications). Calcifications can occur in the kidney, leading to kidney stones, in the eyes, causing cataracts, or in the brain, causing neurological symptoms such as seizures. Calcifications are rare, but very serious, so doctors and endocrinologists must monitor blood and urinary calcium, phosphate, and calcium phosphate product closely to minimise the risk.

Renal dysfunction is another complication of hypercalcaemia. Renal dysfunction is associated with patient age, duration of disease, and duration of hypercalcaemia during treatment.

Doctors may check for the following complications

- Calcifications by using CT imaging
- Cataracts through ocular testing
- Neuromuscular irritability can be monitored through physical examination

The impact of hypopara

Quality of life and hypopara

The physical symptoms and complications of the hypopara can often impact daily life. Often people find it more difficult to do day-to-day activities because their physical ability is reduced, and find cognitive tasks more difficult due to symptoms such brain fog or fatigue. Mental health symptoms can often arise because of this reduced ability to live life “normally”. People with hypopara report feelings of depression and anxiety, emotional sensitivity, and isolation.

It is important to seek help from your physician if you are experiencing mental health issues, as they may be able to refer you to a mental health specialist. It may also help to seek support from family, friends and other patients.

How life changes with hypopara

Hypopara symptoms can often disrupt daily life, with many people reporting that hypopara impacts their careers, relationships and ability to do day-to-day tasks. Symptoms of hypopara may have a direct influence on these factors, such as brain fog and fatigue impacting the ability to focus at work, or tetany and muscle spasms reducing physical ability. Telling a doctor how symptoms are impacting daily life can be important, as they may be able to suggest a better way to manage symptoms and this may reduce the interruption to daily life.

Patient stories

Natalie's story

"My life's circumstances, while difficult, have introduced me to a brand new perspective. Hypoparathyroidism is often misunderstood, which makes the journey for people with this condition much harder than what most believe."

"During one of my routine thyroid checks, the nodules I'd had for years were found to have doubled in size and could be cancerous. My endocrinologist decided it was time to have my thyroid removed."

"During the first 24 hours after surgery, I had tingling in my fingers, but other than that, everything seemed fine. But, during the next 48 hours, despite the calcium and active vitamin D they had been giving me, the tingling got a lot worse, eventually spreading to my entire body—and I mean, my entire body! I was told this was only a result of the surgery and would pass in time."

"My endocrinologist did a blood test and checked my PTH – which was at 0 – and diagnosed me with hypoparathyroidism. She explained to me what was happening with my body and that, if I felt brain fogged, could no longer concentrate, had anxiety, or felt tired, it was because of the low calcium."

"I tried to go back to work full-time, but each time hypopara caused me to be put back on sick leave. My duties had become far too demanding for the 'new me'. My company rated me insufficient, and I feared being laid off, so I asked for a demotion, and they accepted. My new job no longer required the travelling that I loved, but I could work part-time from home. I was finally put on partial disability, but I could tell the disability committee could not understand what I was going through."

"There is still so much I cannot do because of hypopara, but the difference now is that I've accepted it. I see my daily struggles for what they are in the grand scheme of things and focus on the positive."

Patient stories

“Hypoparathyroidism forced me to grow up. I have become a way better mother, and I’m much more patient. I have taught my children to focus on being happy and enjoying life, as you never know what tomorrow will bring. Both of my children are studying to become doctors, and I couldn’t be more proud of them. It seems my health condition helped them choose their destinies. They have come to fully understand what a rare disease like hypoparathyroidism can do to a person’s life. They respect the strength it requires to manage this condition and refuse to see our struggles as a weakness.”

Conor’s story

“What I can remember from my childhood and dealing with the complications of hypopara is being in hospital for treatment more than I was at home – simply because my body could never decide how much calcium it needed. Instead of playing outside or making friends at school, I was running away from my mum up hospital wards trying to avoid taking my medication, crying my eyes out because I hated the taste of it. Hugging me, she’d tell me that she had put the medicine in strawberry-flavoured yogurt to get rid of the taste. This was my childhood.”

“Puberty was a particularly turbulent time for me and my family. Looking back, I must have been in hospital every two weeks at least by the time I was 14. For me, this was quite like a tease—to be given a taste of what a normal life would be like, only to have it snatched away by a low calcium attack and hospital admission for treatment again, and again, and again. It was the same frustrating routine every time.”

“Honestly, in my early teenage years, I didn’t really know what my illness was, why I had to take my medicines every day, or even what the specific tablets did. It seemed that no matter what I did, my calcium would just drop. Managing my disease was nothing but a chore, and I didn’t understand why all the medicines I was taking weren’t making me ‘better.’”

Patient stories

“The consultant I have today wasted no time in learning about my disease when he was handed my case. He had nine or 10 files full of information by the time he met me. On top of that, he’s friendly and talks to me on a personal level, rather than about me. Our working relationship has solidified my opinion of hypopara being a manageable disease, which in turn, has calmed some of my anxieties.”

“People have asked me how my illness has changed my life, but because I’ve been living with hypopara since such a young age, I don’t really know any other way to live. It has shaped me into who I am today—probably a lot more patient, understanding, and generally okay being on my own.”

“I have lived with this illness my whole life. Anybody on the outside looking in might never guess what I have to deal with on a daily basis, but no matter what life throws at me, I believe that, with time, and with my family’s support, I can get through it.”

Support networks

Talking to your doctor

Being well informed about hypopara can be helpful in monitoring the condition and knowing when to seek help, as well as for explaining symptoms effectively to a doctor.

Patient support networks

Whether you are a patient, a carer, or a concerned family member, you should not feel alone in living with hypopara. There are more sufferers than you think, and plenty of online communities to share stories, tips and advice. A range of informative resources are available online. There are a number of hypopara patient associations which provide support, including:

Hypopara Europe Network

Nordic Hypopara Organisation

Danish Hypopara Association

Swedish Hypopara Association

InSeNSU (Germany)

Hypoparathyroidisme France

Italian Association
for Patients with
Hyperparathyroidism (APPI)

Hypoparathyroidism Australia

Netswerk Hypopara Germany

These are by no means exhaustive, please research your local support network online.

References

[1] Bollerslev J et al. Treatment of chronic hypoparathyroidism in adults. Europ. Soc. of Endocrin. Clinical guideline. 172 (2)

[2] Omidvar N et al. Calcium Intake, Major Dietary Sources and Bone Health Indicators. Iran J Pedriatr. 2015 February; 25(1) pg 177

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