

A Quick Guide To Understanding Hypoparathyroidism



Together Growing Stronger-Together Making A Difference



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A QUICK GUIDE TO UNDERSTANDING HYPOPARATHYROIDISM

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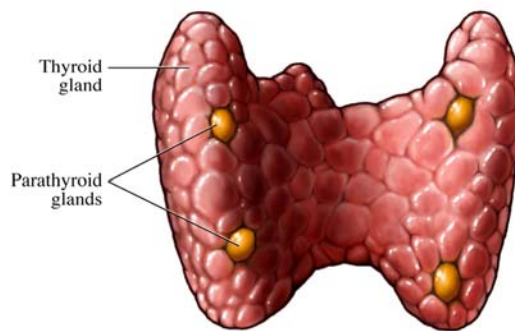
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WHAT IS HYPOPARATHYROIDISM?

Hypoparathyroidism or “hypopara” (“HPTH”), is a rare medical condition which is characterized by hypocalcemia (low blood calcium), hyperphosphatemia (high phosphate levels), and low or inappropriately normal levels of parathyroid hormone (PTH).

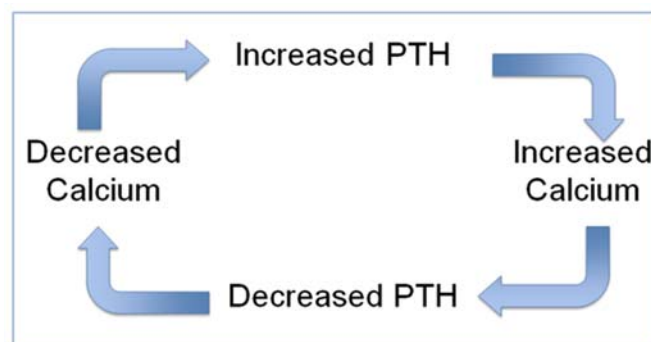
The parathyroid glands are located in the neck, on the back side of the thyroid gland. There are approximately 4 of them, each about the size of a grain of rice.



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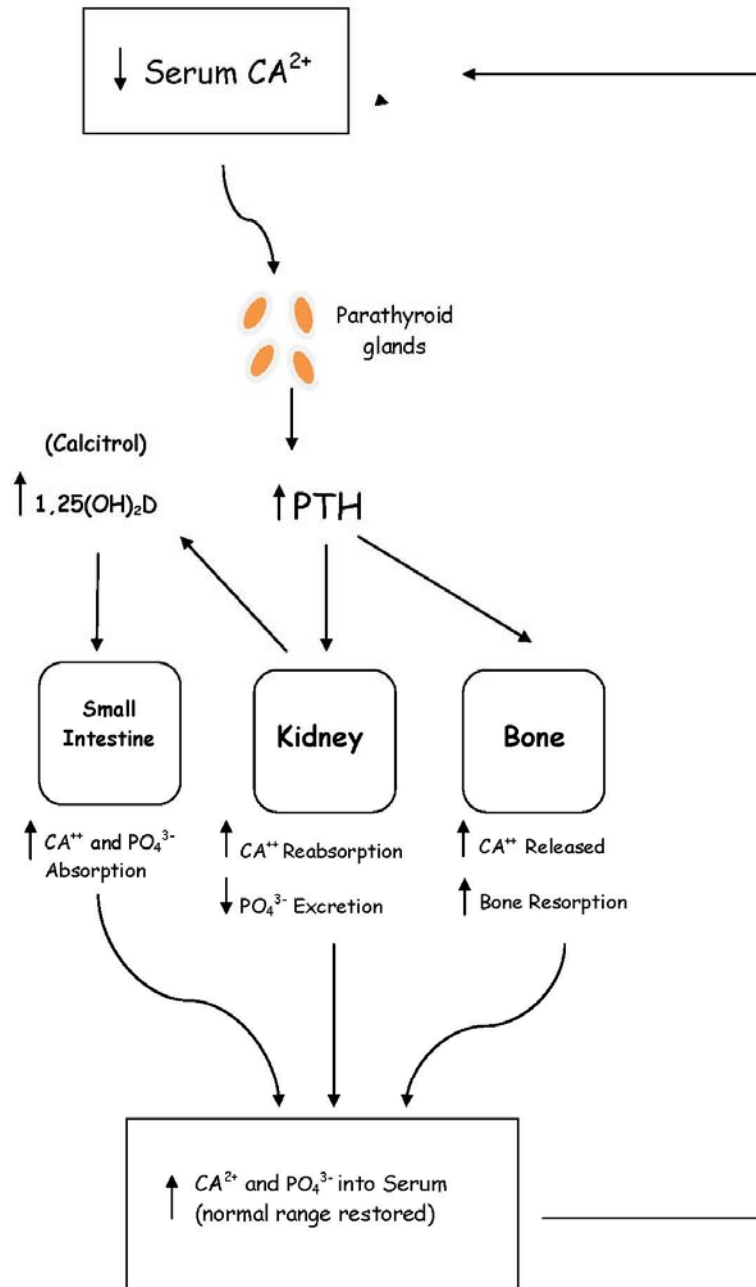
WHAT DO PARATHYROID GLANDS DO?

When calcium levels in the blood drop the calcium sensing receptors (“CaSR”) signal the parathyroid glands to produce parathyroid hormone (PTH). The PTH signals the skeleton to release some of its calcium it keeps in storage and guides the kidneys and intestines to give back some of the calcium they would otherwise get rid of, thus increasing the amount of calcium in the bloodstream. Once the calcium levels normalize, parathyroid hormone excretion also returns to normal. This sensitive balancing act occurs many times during the course of a day for all humans.



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Calcium Homeostasis Feedback Loop



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WHAT HAPPENS WHEN PARATHYROID HORMONE IS MISSING?

When calcium levels begin to drop and there is no functioning parathyroid hormone to correct it, calcium levels will continue to drop. If calcium drops far enough, the level will be too low to perform its usual duties. This is a state called hypocalcemia, which means “not enough calcium in the blood”.

WHAT IS THE ROLE OF CALCIUM IN OUR BODY?

Calcium is essential because it plays a key role in conducting electricity in our bodies. When calcium is out of balance it has bad effects on the nervous system. Calcium also plays a role in muscle contractions, including the contractions of the heart muscle. Calcium is also a building block of healthy bones and teeth and is involved in the clotting process of our blood.

WHAT IS SO BAD ABOUT HYPOCALCEMIA?

Calcium is a key element of the conduction of electricity in the body. When calcium levels are too low the electrical signals in the nervous system do not function properly. This can have effects such as:

- ◆ Paresthesia (pins and needles or numbness) in the extremities or around the mouth
- ◆ Mood changes (such as anxiety, depression, and irritability)
- ◆ Cognitive dysfunction (“brain fog” and an inability to concentrate)
- ◆ Memory problems
- ◆ Tetany (muscle spasms)
- ◆ Muscle/bone pain
- ◆ Difficulty swallowing or speaking (raspy voice)
- ◆ Fatigue or weakness
- ◆ Dizziness

Long term effects of hypoparathyroidism may include:

- ◆ Dental problems
- ◆ Dry hair and/or brittle nails
- ◆ Psoriasis (dry, red, flaky patches of skin)
- ◆ Cataracts (cloudy vision)
- ◆ Reduction in bone turnover (necessary for healthy bones)
- ◆ Kidney disease: kidney stones or hardening of the kidneys (nephrocalcinosis)
- ◆ Soft tissue calcification

In severe cases hypocalcemia has been associated with:

- ◆ Seizure
- ◆ Heart attack
- ◆ Laryngospasm (seizure of the voice box)

**IF YOU EXPERIENCE ANY OF THESE SYMPTOMS YOU SHOULD
SEEK ADVICE FROM YOUR DOCTOR.**

WHAT ARE SOME OF THE TRIGGERS OF HYPOCALCEMIA?

- ◆ Insufficient calcium or vitamin D levels
- ◆ Strenuous exercise
- ◆ Anxiety or stressful situations
- ◆ Diarrhea, constipation or other intestinal conditions that keep a person from absorbing their calcium effectively
- ◆ Changes in medications for other conditions
- ◆ Changes in diet that reduce your calcium or vitamin D intake
- ◆ Any illness that causes diarrhea, vomiting or loss of appetite
- ◆ Abnormalities to your magnesium and/or phosphorus levels
- ◆ Menstruation

TREATMENT OPTIONS FOR HYPOPARATHYROID PATIENTS

Recombinant Parathyroid Hormone (rPTH)

The FDA recently approved the use of a recombinant parathyroid hormone (rPTH), used with calcium and vitamin D to control hypocalcemia in people with hypoparathyroidism. For more information about this hormone replacement option, talk with your doctor.

VITAMIN D

TYPES OF VITAMIN D

- ◆ Vitamin D2 (ergocalciferol) comes from the effects that ultraviolet light has on fungus and can be found in a rare group of foods including mushrooms.
- ◆ Vitamin D3 (cholecalciferol) comes from ultraviolet light directly. This is the vitamin D animals make from exposure to the sun. Generally, if something includes “vitamin D” but doesn’t specify what kind, it refers to vitamin D3.
- ◆ Both vitamin D2 and D3 are also called “native” vitamin D.

WHAT VITAMIN D DOES AND HOW MUCH YOU SHOULD TAKE

A very important role of native vitamin D is to increase the intestines’ ability to absorb calcium. The Daily Recommended Allowance (DRA) for Vitamin D is 400IU (International Units, 400IU = 10 micrograms) per day for all ages and genders, however hypoparathyroid patients may need more than this. Be sure to work with your doctor to figure out how much is right for you.

SOURCES OF VITAMIN D

- ◆ Sun exposure: 10-15 minutes at least twice a week of direct sun onto your skin usually provides adequate amounts of vitamin D. Limit exposure to sunlight as excess may cause skin cancer.
- ◆ Food: Fortified cereals or milk, cod liver oil, eggs, fish (oysters, salmon), dark leafy vegetables (spinach, kale), mushrooms.

CALCIUM

TYPES OF CALCIUM

Calcium comes in several different forms, but the two primary ones are:

- ◆ Calcium carbonate
- ◆ Calcium citrate

HOW MUCH CALCIUM SHOULD I TAKE?

The Daily Recommended Allowances (DRAs) for Calcium is:

- ◆ Children 1-3 years old: 500 mg/day, Children 4-8 years old: 800 mg/day
- ◆ Males and females 9-18 years old: 1,100 mg/day,
- ◆ Males and females 19-50 years old: 800 mg/day
- ◆ Males 51-70 years old: 800 mg/day, Males greater than 70 years old: 1,000 mg/day
- ◆ Females 51 years old and older: 1,000 mg/day

However, hypoparathyroid patients may need more (sometimes significantly more) calcium than is recommended by the DRA. Be sure to work with your doctor on how much is right for you because too much or too little can both have serious consequences.

Recombinant parathyroid hormone replacement is now available for the treatment of hypoparathyroidism. Talk with your doctor about this option.

CALCITRIOL

Calcitriol (also called Rocaltrol) is a prescription form of “activated” vitamin D. “Active” vitamin D is the type the body makes when “native” vitamin D and parathyroid hormone join forces. Hypoparathyroidism patients cannot make activated vitamin D because they do not make parathyroid hormone, which is why it is provided to hypoparathyroid patients in prescription form.

THE CAUSES OF HYPOPARATHYROIDISM

Post–Operative Hypoparathyroidism

The most common form of hypoparathyroidism is post-operative (a.k.a. post-surgical) hypoparathyroidism. This is where a surgery in the neck has either removed the parathyroids or damaged them, or damaged their blood supply. Thyroidectomy is a very common surgery in that region. The parathyroids rest against the thyroid so there is greater chance of their being damaged or removed during the course of a thyroidectomy.

Another surgery that can lead to hypoparathyroidism is parathyroidectomy. The parathyroids can sometimes become overactive and must be removed. Full or partial parathyroidectomy can lead to removal of the glands or damage to their blood supply. Regardless of the reason for the neck surgery, any such procedures run the risk of leading to transient hypoparathyroidism.

It is not uncommon that following neck surgery a patient might experience transient hypoparathyroidism in which the parathyroids do not function normally for anywhere from hours to several months. If the period of transient hypoparathyroidism exceeds six months the common thinking is that the hypoparathyroidism is no longer transient but permanent.

Idiopathic Hypoparathyroidism

The term Idiopathic Hypoparathyroidism is used when the cause for the hypoparathyroidism is unknown. Anyone wishing to start a family should try to determine the cause since some forms of this disease are inheritable or familial.

Congenital Hypoparathyroidism

Congenital hypoparathyroidism is a disorder that exists at or before birth usually through heredity or acquired at birth or during uterine development usually as a result of environmental influences. Congenital disorders are varied and can effect PTH production or secretion, parathyroid gland development or even cause the destruction of the parathyroid tissue itself.

Some congenital forms are:

Familial Isolated Hypoparathyroidism: Where there is a genetic mutation unique to a family. The cause has been determined by genetic testing.

Familial Isolated Idiopathic Hypoparathyroidism: Where there is a genetic mutation unique to a family but the cause has not been determined.

Autoimmune Disorders: autoimmune disorders are those in which the body treats a part of itself as an invader. In autoimmune hypoparathyroidism, the body attacks and destroys the parathyroid tissue or some part of its functionality (for instance, the Calcium Sensing Receptor).

While Autoimmune Hypoparathyroidism is a valid diagnosis, further investigation into the cause of the antibody production could lead to any of a number of genetic conditions which are listed here:

- ◆ APS (Autoimmune Polyglandular Syndrome) is a condition in which several endocrine glands are affected. APS has also been called "polyglandular failure syndrome", or "polyglandular autoimmune disease", the commonality being the autoimmune effects on at least two different endocrine glands. There are two primary subtypes:
- ◆ PAS1/APECED (Autoimmune Polyendocrinopathy, Candidiasis and Ectodermal Dystrophy), also known as PAS Type 1 (polyglandular autoimmune syndrome type one) manifests before the age of 20 and usually between the age of 3-5 years, which gives it its other name "juvenile autoimmune polyendocrinopathy". This condition includes a persistent fungal infection (candidiasis), Addison's disease (adrenal failure) and hypoparathyroidism.
- ◆ PAS2 (polyglandular autoimmune syndrome type two) is more common than PAS1/APECED and involves Addison's Disease, autoimmune thyroid disease (Schmidt's syndrome) but also involves type 1 diabetes. PAS 2 can also include a host of other problems including autoimmune gastritis, pernicious anemia, and alopecia areata (hair loss which can be spotty or diffuse on the scalp or even the entire body).

Calcium Sensing Receptor (CaSR) mutation: another disorder of genetic origin. In this condition antibodies are developed against the CaSR, whose job it is to sense and report low serum calcium levels to the parathyroid gland so that it in turn can produce parathyroid hormone which will increase calcium levels. The antibodies against CaSR, like in any autoimmune disorder, neutralize or destroy the receptor so that vital calcium signals are not received by the parathyroid gland. So autoimmune CaSR disease does not involve a malfunctioning parathyroid gland, but rather, results in a communication breakdown between calcium and the gland designed to correct its lack.

Multiple Endocrine Neoplasia (MEN): in this family of disorders the defective genes cause excessive growth of certain glands. Unlike the autoimmune grouping that stops function of a gland the neoplasia grouping leads to overproduction or unstable production of the effected gland's hormone. Rather than causing hypopara directly, MEN usually results hyperparathyroidism and subsequent surgical dissection which can result in post surgical hypopara.

- ◆ MEN1 (Multiple Endocrine Neoplasia Type One), also called Wermer's Syndrome,

usually presents as tumor of the pituitary gland and parathyroid gland. Parathyroid tumors present between the ages of 20 and 50 or so. MEN1 can also involve pancreatic tumors which are often malignant.

- ◆ MEN2A (MEN Type Two A) is sometimes called "Sipple Syndrome", is a rare disease, and is associated with medullary thyroid carcinoma and parathyroid tumors which commonly develop in adolescents or young adults. MEN2A can also involve tumors of the adrenal glands (pheochromocytoma).
- ◆ MEN2B (MEN Type Two B) is more rare than MEN2A and stands apart from MEN2A in that it usually manifests in children before the age of 10 and includes multiple tumors on the mouth, tongue, eyelids, and mucosal membrane in addition to a high likelihood of medullary thyroid cancer and adrenal cancer (pheochromocytoma) as well as parathyroid tumors. This condition tends to include other physical traits such as joints that bend in the opposite direction, scoliosis of the spine and clubbed foot.
- ◆ FMTC (Familial Medullary Thyroid Carcinoma) does not usually involve parathyroid problems except in so far as there is a risk of damage or excision during thyroidectomy. Though not technically a "multiple endocrine" issue, it is part of the same genetic grouping.

DiGeorge Syndrome (aka, 22q11 Deletion Syndrome): this complex condition includes hypoparathyroidism at birth, underdevelopment of the thymus gland, congenital heart defects, cleft palate, poor kidney function and some common facial characteristics. The acronym CATCH-22 is often used as a learning tool and refers to Complex of Abnormal facies, Thymic hypoplasia, Cleft palate and Hypocalcemia with 22q11 chromosome deletion.

Apart from these various congenital disorders there is another field of disorders that cause something that acts like hypoparathyroidism but technically is not a failure of the function of the parathyroid gland or hormone. We are referring to pseudo-hypoparathyroidism.

Pseudo Hypoparathyroidism (PHP): is characterized by hypocalcemia and hyperphosphatemia. Unlike hypoparathyroidism, however, it is not a defect in the PTH production, but rather, peripheral resistance to the PTH hormone. Another way PHP varies from HPTH is in its effects on the skeleton. In PHP the breakdown and rebuild cycle of bone tissue (called "bone turnover") is increased, while in HPTH it is decreased. This suggests that the PHP patient can be prone to low bone density while the HPTH patient is prone to high (sometimes very high) bone density.

Some subtypes of pseudohypoparathyroidism include something called Albright Hereditary Osteodystrophy, a syndrome of physical features and effects that include round face shape, shortened or stubbed fingers, forehead bossing, and bone formation in places bone is not designed to grow ("ectopic ossification").

Pseudo-Pseudohypoparathyroidism ("PseudoPHP"): this congenital disorder leaves one with normal calcium, PTH, active vitamin D and phosphorus levels (unlike classic hypopara). What it does have in common with hypoparathyroidism is the effect on the skeleton, namely, low bone turnover leading to dense or very dense bones[4]. Bit of trivia: at 30 letters long, this is one of the longest words in the English language[4]. Though postsurgical hypopara is the most common etiology, and of the non-surgical types most are part of the APS or MEN disorders which involve multiple glands, there are some other types of hypoparathyroidism that involve only the parathyroid glands. These can be called "isolated hypoparathyroidism", which simply means it only effects the parathyroid and not other glands.

Some types of isolated hypoparathyroidism could be an autoimmune type, or can involve dysfunction of the CaSR. However hypoparathyroidism can, in rare cases, be caused by the presence of some other diseases:

- ◆ Wilson's Disease: a genetic disorder in which copper accumulates in various tissues.
- ◆ Thalassemia: a genetic disorder in which the person makes insufficient hemoglobin, the iron carrying-cells in blood.
- ◆ Hemochromatosis: a genetic disorder in which the body absorbs too much iron. In both thalassemia and hemochromatosis there is too much iron that is not being managed by iron-carrying cells hemoglobin) in the blood.

DIAGNOSTIC TESTING

BLOOD TESTS

SERUM CALCIUM: This is a single-tube blood test that looks at how much calcium there is in your blood. You do not have to be fasting for this blood test. Avoid calcium supplements or calcium rich food prior to your blood test since these can elevate your serum calcium levels.

IONIZED CALCIUM: This is a measure of the free unbound calcium in your blood. Ionized calcium testing is useful especially when a serum calcium result does not seem to explain the symptoms a patient is experiencing.

MAGNESIUM & PHOSPHORUS: Two common blood tests done on hypoparathyroid patients. Since both magnesium and phosphorus levels can impact your calcium levels, they are commonly checked. They may be tested separately or as part of a blood test called an Electrolyte Panel. These tests don't usually require fasting (but be sure to ask). Both of these tests can be run from the same single tube of blood.

INTACT PTH: Most hypoparathyroid patients only get this test done once. A PTH blood test is only one tube of blood. Though the time of day is probably less important for hypoparathyroid patients most others will usually get this done very early in the morning. You do not have to be fasting for a PTH test.

URINE TEST

24-HOUR URINE CALCIUM: This test measures the amount of calcium excreted in your urine during a 24-hour period. The amount of calcium contained in a 24-hour sample of urine is important for determining how much calcium your body is getting rid of versus how much your body holds onto. Typically, this amount ranges from 50 to 300 mg per day and is suggested to be less than 250 mg per 24-hour-period for females and 300 mg per 24-hour-period for males; although, these values are suggested and vary from person to person. If the amount of calcium excreted in your urine is high, your body may not be adequately absorbing your dietary and supplemental calcium. It is not uncommon for a 24-hour urine calcium test to be run once every six months.

HOW OFTEN WILL I NEED TO HAVE ALL THESE TESTS DONE?

Opinions vary about how often blood and urine should be tested or what other tests will be useful. Once you and your doctor manage to get your calcium stable it is not uncommon to have your serum calcium checked once every other month. If you are experiencing any health problems or symptoms associated with decreases or increases in your calcium you will want to get tested as soon as possible. Work with your doctor to figure out how often to get your blood and urine tests done and consider arranging a “standing lab order” with your doctor so you can get tested without having to first have an appointment or get a referral.

MY BLOOD TESTS ARE NORMAL BUT I’M STILL SYMPTOMATIC?

Patients with hypoparathyroidism who have normal corrected calcium but who are still having chronic symptoms of hypocalcemia may have a low ionized calcium level. Work with your doctor to correct to get the right balance. It might be worthwhile to check magnesium, phosphorus, potassium or an electrolyte panel since those chemistries can impact how you feel even when your calcium is in the expected range.

DOCTOR AND PATIENT: A PARTNERSHIP

When you have identified a potential doctor call the doctor's office and ask if they have had experience with hypoparathyroidism. Experience varies and hypoparathyroidism is a rare disease. It's important to think of your doctor as part of a team – a team that includes you and your loved ones and maybe even this Association, all of whom are working together to get you well and support you.

WHY IS IT NECESSARY TO BE SEEN REGULARLY BY MY DOCTOR?

Hypoparathyroidism can be life threatening if it is not adequately treated. It is very important to be seen by both your endocrinologist and your primary care doctor so that you can be properly monitored and any problems you are experiencing can be addressed before they become major. How often you are seen is set by your doctor and depends on how stable your condition is.

WHAT SHOULD I TELL MY DOCTOR?

- ◆ What medicines you are taking: include when you are taking them, and what doses and strengths they are.
- ◆ What signs and symptoms you have experienced: For instance, if you are having tingling in your fingers, and pain in your limbs, your doctor should be informed. It's important to remember that many signs and symptoms are a natural part of having hypoparathyroidism and your doctor may not be able to make them go away though it is reasonable to expect that, working together, you can make them less frequent or intense.
- ◆ It is expected that you and your doctor will focus on what your "chief complaint" is, in other words, the thing that bothers you more than other things.

MAKING THE MOST OF YOUR APPOINTMENTS

If you are making an appointment to see your doctor it might be helpful to try to get tests he or she want done BEFORE your appointment so that you and your doctor can review them together.

Additionally, if you have a question that you can't find the answer to, write it down and bring it to your doctor appointment. You'll be surprised how willing your doctor is to answer your questions when you come prepared.

KEEPING A DIARY

It will be helpful to keep a diary that tracks when you experience certain symptoms. Diary entries might also help you keep better track of taking your supplements. A review of your diary before a visit with your doctor could be very beneficial.

EXAMS THAT CAN ASSESS YOUR STATE

CHVOSTEK'S SIGN

This exam involves tapping the facial nerve at a specific point just in front of the ear. If your calcium is low the muscles may twitch with an intensity related to how low your calcium is. This exam tests the neuromuscular excitability associated with hypocalcemia.

TROUSSEAU'S SIGN

This exam involves putting a blood pressure cuff on the upper arm, inflating it and keeping it inflated for two minutes. If calcium is low this will cause the hand to cramp into "the claw" and cause mild discomfort. This exam tests the tetany (muscle seizing) associated with hypocalcemia.

TEST RESULTS AND TREATMENT IN GENERAL

Everyone's metabolism is uniquely different and in the condition of Hypoparathyroidism what works for one person may not necessarily work for another. 'Normal' is individually relative to you. Treatment for hypocalcemia is individualized and your doctor will tailor your treatment regimen with a consideration for your medical history, any current symptoms of hypocalcemia and any recent laboratory results of blood calcium and kidney function tests. Although blood tests can give a good indication of blood calcium levels, they can only be a snapshot of your blood calcium levels at the time of your blood test and may not be indicative of the overall hypocalcemia symptoms you may be experiencing throughout the day.

Commonly your endocrinologist will maintain your calcium levels high enough that you don't experience any of the physical symptoms associated with hypocalcemia and low enough to reduce the long term risks of kidney problems.

It is very difficult to say what the right amount of supplemental calcium or vitamin D is that you should take. You and your doctor will need to work this out together, but your feedback, about how you feel on different doses, is vital information.

EDUCATING YOURSELF

Finding credible and reliable information can be both time consuming and frustrating. The HypoPARAthyroidism Association seeks to address this through their website, www.hypopara.org. Founded by Jim Sanders, who together with his five sons are all fellow hypoparathyroid patients, the HypoPARAthyroidism Association is dedicated to improving the lives of people with Hypoparathyroidism.

The HypoPARAthyroidism Association website not only offers a worldwide network of family support it also provides access to many articles, online classes, research written by doctors or other medical professionals, and treatment or management suggestions for healthcare professionals. The Association is a repository for links to other groups and associations as well as websites maintained by medical organizations.

The *HypoPARA-Post*, the Association's quarterly newsletter, is written by HypoPARAthyroidism Association and includes contributions from columnists, researchers, doctors and Association members from around the world.

**Knowledge is the key to successfully
understanding and managing
hypoparathyroidism**

SUPPORT GROUPS

Being a hypoparathyroid patient can be very demanding sometimes leaving you and your family members feeling isolated and alone. You can make contact with others who have hypoparathyroidism using online support groups where you can post questions or share insights with others who need support.

DIETARY INFORMATION

Our food supply provides a unique balance that cannot be duplicated by taking any combination of supplements. It is important to maintain adequate nutrition in order to optimize your treatment plan. Generally, a diet high in calcium and vitamin D is suggested.

Here are some general nutritional tips that may make a positive contribution to your overall health. Do not take supplements or make adjustments to your diet without your doctor's supervision.

General suggestions for maintaining adequate nutrition¹:

- ◆ Be as lean as possible without becoming underweight
- ◆ Eat a calcium optimal diet (see next section for high sources of calcium)
- ◆ Limit foods high in phosphates (carbonated beverages, hot dogs) which can leach calcium from your bones
- ◆ Eat a variety of vegetables, fruits, whole grains and legumes (beans), and dark leafy vegetables
- ◆ Limit consumption of red meats, avoid processed meats, and eat more lean meats and fish
- ◆ Reduce or eliminate trans-fatty acids found in processed foods
- ◆ Avoid refined foods, such as white breads, pastas, and sugar
- ◆ Limit consumption of salty foods and foods processed with salt (<2300 mg/day daily)
- ◆ Do not smoke or chew tobacco
- ◆ Limit alcohol and coffee consumption
- ◆ Eliminate all potential food allergens, including dairy, gluten (wheat, rye, barley and some oats), corn, soy, preservatives, and food additives. Your health care provider may want to test for food sensitivities.
- ◆ Be aware of the content/ingredients in all foods and medicines as they may contain calcium or vitamin D and could affect your calcium stability

Overall, strive to achieve a combination of a healthy diet, regular physical activity and a healthy body weight.²

HOW TO AID IN PROPER ABSORPTION OF CALCIUM SUPPLEMENTS THROUGH YOUR DIET:

- 1) Take calcium supplements with food, it is better absorbed that way. Some health care providers may recommend you take your calcium supplements with a glass of orange juice. Some forms of calcium are better absorbed in an acidic environment. Some acidic-type foods include molasses, prunes, tomatoes, and lemons.

- 2) Take 500 mg or less of calcium at one time. Your body can only absorb 600mg of calcium within a 3 hour period. "Absorption is highest in doses ≤500 mg" (National Academy Press, 2010)
- 3) Divide your total daily calcium dose into equal amounts and take several times a day with meals. For instance, if you are on 2000mg daily, take 500mg four times a day. This will aid in proper absorption and help keep calcium levels stable throughout the day.
- 4) Maintain normal vitamin D levels. Vitamin D aids in calcium absorption. Insufficient amounts of either Native vitamin D or Active vitamin D (Calcitriol), either in the diet or in supplements could contribute to poor absorption of calcium.
- 5) Drink 6-8 glasses of water daily (preferably filtered). Staying hydrated helps facilitate proper digestion of nutrients such as calcium, vitamin D, and magnesium.

HOW DO I KNOW IF MY DIET IS APPROPRIATE?

A dietitian can help plan an appropriate menu for hypoparathyroid patients. Your health care provider can provide recommendations for registered dietitians specializing in this area.

Foods providing 20% or more of the DV are considered to be high sources of a nutrient, but foods providing lower percentages of the DV also contribute to a healthful diet. The U.S. Department of Agriculture's Nutrient Database web site lists the nutrient content of many foods. It also provides a comprehensive list of foods containing calcium. You can take it upon yourself to access your nutrient intake and track your diet and physical activity at www.mypyramid.gov which uses the USDA's "SuperTracker". As always consult with your physician when making dietary changes.

¹American Institute of Cancer Research, American Accreditation HealthCare Commission

²American Institute of Cancer Research

CHALLENGES FOR HYPOPARATHYROID PATIENTS

I'M HAVING TROUBLE KEEPING MY CALCIUM ELEVATED

First thing you should do is discuss this with your doctor, who can help you figure out what is going on.

Here are some common reasons people have trouble keeping up their calcium level:

- ◆ Illnesses which induce vomiting or diarrhea can deplete calcium and electrolyte levels. If you have a chronic medical condition such as Celiac or Crohn's disease or Irritable Bowel syndrome talk to your doctor about a long term strategy in the management of your calcium treatment.
- ◆ Medicines that reduce stomach acid in the treatment of reflux or taking ant-acids which contain aluminum may interfere with the absorption of some types of calcium so check with your doctor or pharmacist as to which one yours is.
- ◆ As a person ages, the amount of stomach acid reduces. If you are over 50, it has been suggested that you switch from calcium carbonate to calcium citrate. Again work with your doctor to find the right form of calcium for you.
- ◆ Physical exertion beyond what an individual is accustomed to. Going on vacation for instance, and walking all day long, uses muscles and body moisture much more than our normal daily activities do. Increased exercise is not discouraged, but taking extra calcium and fluids could help offset calcium loss significantly.
- ◆ Any surgery can affect calcium levels, it is suggested that you have your levels monitored before, during and after.

HOW DO I KNOW IF I'M HAVING SYMPTOMS?

First of all, it's worth saying that not every health problem is going to be related to hypoparathyroidism. Colds, thyroid problems, stress, anxiety, pain in your joints, headaches - normal everyday life can present you with a variety of health challenges. However, if you learn to listen to your own body and recognize how you feel on a good day (when your calcium levels are stabilized) versus how you feel when your calcium levels are dropping you might be able to take steps to avoid a "calcium crash" situation.

We discussed the signs and symptoms of hypocalcemia up on Page 5, but what does high calcium feel like?

SYMPTOMS OF HIGH BLOOD CALCIUM LEVELS (HYPERCALCEMIA)

Hypercalcemia (too much blood calcium) is not a common problem for hypoparathyroidism patients but you should know what to look out for:

- ◆ Headaches or dizziness
- ◆ Stomach ache, nausea or vomiting
- ◆ Extreme thirst
- ◆ A need to pass more urine than usual
- ◆ Restlessness or confusion

TIMING OF MEDICATION AND CONFLICTS

Read all the patient literature given with each prescription or over the counter medication. Be aware of the recommended time span between taking doses of medications that conflict with calcium absorption or medications which calcium will bind to and prevent from being absorbed properly. Examples include thyroid hormone replacements, Iron, Estrogens, diuretics or steroids. If in doubt seek advice from your doctor or pharmacist.

If you experience any of these symptoms you are advised to consult your own doctor for advice and to discuss a treatment plan in the event of any future calcium emergency.

LOOKING AFTER YOURSELF

VISIT THE DENTIST REGULARLY

As calcium can have an effect on the condition of your teeth. Inform your dentist about your hypoparathyroidism and ask for advice on the maintenance of your teeth and gums.

STRESS AND LIFESTYLE

Stress and anxiety can be among the symptoms of hypoparathyroidism. Develop your own strategy for dealing with any stress such as meditation, yoga or reflexology. Listening to relaxation tapes or soothing music can lighten the mood and relieve stress. Take time out every day for yourself or take up a new hobby that you find relaxing.

ALWAYS carry some form of calcium and/ or vitamin D when you are away from home even for a short time.

VACATION PREPARATIONS

In the summertime, especially if you intend to vacation in a hot climate or to sunbathe, the vitamin D naturally formed by our bodies from the ultraviolet rays of the sun may affect your calcium and make you feel unwell. Discuss any worries with your doctor before you go on vacation and make a plan for any calcium emergency while you are on holiday. A good rule of thumb is to stay very well hydrated and have some fast-acting calcium with you at all times and take some at the first sign of symptoms.

DEHYDRATION

Strenuous exercise or dehydration can deplete or upset calcium balances. Carry some form of fast-acting calcium for any symptoms of tingling or numbness you may experience, only after discussing this with your physician beforehand.

MEDICAL ALERT

Invest in medical alert jewelry to make medical staff aware in an emergency situation that you have a rare calcium disorder. To ensure that the seriousness of your medical condition is more readily understood by the medical staff; have the words "Hypocalcemia" engraved on your medic alert item as opposed to the term "Hypoparathyroidism", which is not so easily understood.

CALCIUM EMERGENCY PLAN

You and your doctor should make a plan of action for treatment in the case of any calcium emergency.

GLOSSARY OF TERMS

24 Hour Urine	A collection of ALL urinations during a 24 hr period; used to determine kidney health
acquired	arising in response to an act of the environment on an organism
Albumin	the most abundant protein in human blood plasma. It is produced in the liver. Albumin constitutes about half of the blood serum protein. It is soluble and monomeric. Albumin transports hormones, fatty acids, and other compounds, buffers pH, and maintains osmotic pressure, among other functions.
autoimmune	a state in which the body produces an inappropriate immune response against its own tissues
basal ganglion	any of the four deeply placed areas of grey matter in each hemisphere of the brain
bone turnover	the process of existing bone being broken down to free up calcium then new bone being built up to replace it and that bone becoming calcified
calcilytic	over-reduces the effect of calcium sensing receptors; increases parathyroid hormone function
calcimimetic	over-increases the effect calcium sensing receptors; reduces parathyroid hormone function
calcitonin	the hormone responsible for decreasing levels of calcium in the blood
Calcitriol	"1,25 dihydroxycholecalciferol", "Vitamin D 1,25", "activated Vitamin D" - Calcitriol increases blood calcium levels ([Ca ²⁺]) by promoting absorption of dietary calcium from the gastrointestinal tract and increasing reabsorption of calcium from the kidneys, thus reducing the loss of calcium in the urine. Calcitriol also stimulates release of calcium from bone.
Calcium	A mineral stored in the teeth and bones. Calcium is necessary for nerve function, muscle contraction and elasticity of blood vessels. Calcium levels in the blood are regulated by calcitonin and parathyroid hormone.
CaSR	Calcium Sensing Receptor - in the parathyroid gland, the CaSR receives the messages that tell the gland if there is not enough calcium in the blood, which then triggers the parathyroid gland to release parathyroid hormone (PTH).
cataracts	a clouding of the lens of the eye that obstructs light
Chvostek's sign	an abnormal spasm of the facial muscles elicited by light taps on the cheek to stimulate the facial nerve in patients who are hypocalcemic. It is a sign of tetany.
comorbidity	more than one condition occurring simultaneously in one individual (e.g., having hyperten-
eGFR	estimated Glomerular Filtration Rate or eGFR is a blood test that estimates the kidneys' abil-
electrolytes	Substances vital to the conduction of electricity in the body, such as the brain. Some exam-
elemental calcium	the amount of a calcium compound that is made of actual calcium
enamel hypoplasia	under formation of the enamel of teeth; seen as white or yellow spots or other deformities on
endocrine	referring to hormones and the glands that secrete them
etiology	the science of cause or causation
goiter	swelling of thyroid tissue causing a visible mound on the throat
homeostasis	the body's directive to maintain a stable internal environment in the face of factors that
hormone	a messenger cell whose role is to cause a change in another cell, group of cells, or an organ
hypercalcemia	high levels of calcium in the blood
hypercalciuria	high levels of calcium in the urine
hypermagniuria	high levels of magnesium in the urine
hypocalcaemia	low levels of calcium in the blood

GLOSSARY OF TERMS CONT.

hypomagnesaemia	low levels of magnesium in the blood
hypomineralization	insufficient or not enough mineralization eg not enough minerals supporting or hardening a structure such as bone
idiopathic	rising from an unknown cause
ionized calcium	calcium in your blood that is not attached to proteins. It is also called free calcium.
laryngospasm	an uncontrolled/involuntary muscular contraction (spasm) of the laryngeal cords (vocal cords) temporarily making speaking and breathing difficult
magnesium	a mineral in the body responsible for muscle contraction and nerve function. Low magnesium increases the likelihood of tetany
MCG	microgram/one millionth of a gram
MG	milligram/one thousandth of a gram
nephrocalcinosis	calcification of kidney tissue
nephrolithiasis	the condition of having kidney stones
osteoblast	cells that built bone
osteoclast	cells that chew up bone
osteopenia	a reduction in bone volume, below normal, but less severe than osteoporosis
osteoporosis	porous bone'; a state in which bone is brittle or porous and thus more prone to fracture
parathyroid hormone	PTH; hormone responsible for increasing levels of calcium in the blood
paresthesia	a sensation of tingling, prickling or numbing in the extremities and around the mouth (aka pins & needles)
phosphate	Phosphate is a charged particle (ion) that contains the mineral phosphorus; the amount of phosphate in the blood affects the level of calcium in the blood
phosphorous	is a mineral the body needs to build and repair bones and teeth, help nerves function, and make muscles contract
PTH	parathyroid hormone
PTH 1-34	a synthetic hormone featuring the first 34 segments of the PTH molecule. An example is Forteo (teriparatide) FDA approved for osteoporosis
PTH 1-84	a synthetic hormone featuring the all 84 segments of the PTH molecule. An example is Natpara, FDA approved for hypoparathyroidism
renal calculi	kidney stone
serum calcium	measurement of blood calcium; differs from ionized calcium
teriparatide	PTH 1-34
tetany	involuntary contractions of muscles; muscle spasms; usually resulting from imbalance of calcium, phosphorous or magnesium
thyroid	butterfly shaped endocrine gland located low in the neck in front of the trachea (windpipe)
thyroid hormone	acts throughout the body, influencing metabolism, growth and development, and body temperature
Trousseau's sign	An indication of latent tetany in which carpal spasm occurs when the upper arm is compressed, as by a tourniquet or a blood pressure cuff; can also occur naturally with hypocalcemia
urinary calcium	amount of calcium in the urine; a means of determining kidney health
urinary citrate	amount of citrate (citric acid) in the urine; low levels can increase the chance of kidney stones

Website References:

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HypoPARathyroidism Lab Tracking Form

Patient Name: _____

DATE								
LAB USED								
INTACT PTH								
SERUM CAL- CIUM								
IONIZED CALCIUM								
MAGNESIUM								
PHOSPHO- RUS								
SERUM CREATININE								
24 HR URINE CALCIUM								
TSH								
T4								
T3								

DATE								
OTHER _____								
OTHER _____								
OTHER _____								
OTHER _____								
OTHER _____								

QUESTIONS FOR DOCTOR:

FOLLOW -UP NOTES:

HypoPARathyroidism Medicine Tracking Form

Patient Name: _____

DATE							
CALCIUM ___ Carbonate ___ Citrate ___ _____							
CALCITRIOL							
VITAMIN D							
PTH (1-34)/ PTH (1-84)							
HCTZ							

OBSERVATIONS/QUESTIONS FOR DOCTOR:

FOLLOW-UP NOTES:

NOTES:

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