Ascendis®

Seeds of Change



Understanding **Hypoparathyroidism**

Patient Information Booklet

September 2026 I UK-COMM-2600013

ascendis pharma

CONTENTS

1. What is hypoparathyroidism? 04

2. Symptoms 06

3. Diagnosis 08

4. Potential complications 09

5. Recognising emergency situations 11

6. Daily life with hypoparathyroidism 13

7. Pregnancy and breastfeeding 21

8. Helpful resources 22

Hello,

Being diagnosed with chronic hypoparathyroidism (also known as hypopara or HPT) can feel overwhelming, and it's natural to have questions about what your diagnosis means for you and your day-to-day life.

This booklet has been designed to help you understand and navigate life with hypopara. It provides information about the condition, including the symptoms you may experience, what to expect following diagnosis, and practical guidance on topics such as diet, travel and ongoing management.

In addition, you'll find useful tips for everyday life, guidance on handling emergency situations, and signposts to further information and support.

We hope this brochure will be a helpful companion on your hypoparathyroidism journey.

The Ascendis Pharma Team



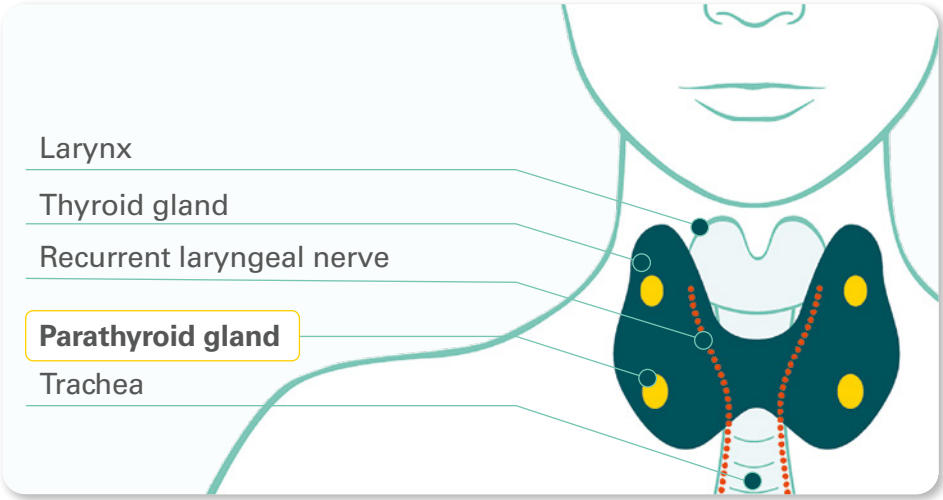
1. What is hypoparathyroidism?

Definition

Hypoparathyroidism is a condition in which the **parathyroid glands do not produce enough parathyroid hormone**. If left untreated, this can lead to low calcium levels (hypocalcaemia) and high phosphate levels in the blood (hyperphosphataemia), which may have health consequences.[1] If symptoms persist for **12 months or more**, this is referred to as **chronic hypoparathyroidism**.[2]

Parathyroid hormone (PTH) is a hormone that normally plays a crucial role in **regulating calcium and phosphate levels in the blood**. Calcium is important for healthy bones and teeth, muscle function, nerve signalling and heart function, while phosphate helps to keep bones and teeth strong and plays a key role in how the body's cells produce and use energy. PTH helps to maintain the right balance of these minerals so that the body can function properly.[1]

The parathyroid glands are four small glands that sit behind the thyroid gland, a butterfly-shaped organ located at the front of your neck. Each parathyroid gland is about the size of a grain of rice.[3]



Prevalence

- **Hypoparathyroidism** is a rare condition affecting approximately 6 to 37 people per 100,000 population, which is approximately between 3,400 and 20,900 people across England.[4,5]
- **Women** are affected more frequently than men, likely due to the higher number of thyroid surgeries performed in women.[6]

Causes

Hypoparathyroidism can occur for a number of reasons. It most commonly develops following surgery to the neck or head, where the parathyroid glands may be removed or damaged. However, it can also be caused by autoimmune conditions, genetic conditions, or other factors that affect the function of the parathyroid glands.[7]



2. Symptoms

There are no symptoms caused by hypoparathyroidism (low parathyroid hormone levels). The symptoms you feel are caused by hypocalcaemia (low calcium levels) or hypercalcamia (high calcium levels).[8] People with hypoparathyroidism may experience a variety of symptoms. These can be divided into three main categories:[1,9,10]

Physical symptoms



- Fatigue
- Muscle pain/cramps
- Tingling (paresthesia) in the fingers, toes and face
- Muscle spasms (tetany)
- Joint or bone pain
- Nausea

Cognitive symptoms



- Brain fog (mental lethargy)
- Difficulty concentrating and thinking through complicated/multiple tasks
- Memory loss/forgetfulness
- Sleep disturbances

Psychological symptoms



- Anxiety/fear
- Sadness
- Feeling misunderstood
- Irritability/overcritical behavior
- Social withdrawal

How the parathyroid hormone helps regulate calcium levels

Parathyroid hormone (PTH) helps maintain healthy calcium levels in the blood by acting on different parts of the body.[1] When PTH levels are too low, calcium regulation can be disrupted, which may lead to symptoms associated with hypoparathyroidism.



Bones

Parathyroid hormone helps maintain the balance of calcium in the blood and bones.



Kidneys

Parathyroid hormone helps the body keep calcium levels within a healthy range. It does this by helping the kidneys retain calcium and supporting the activation of vitamin D, which helps the body absorb calcium from food.



Intestine

Parathyroid hormone activates vitamin D, which helps the intestine absorb calcium from food.

3. Diagnosis

If hypoparathyroidism is suspected, a number of blood tests are usually carried out. These may include tests to measure the levels of calcium and parathyroid hormone (PTH) in your blood, as well as other tests to help rule out other possible causes of your symptoms. Urine tests and X-rays may also be performed, although these are less common.[7,12]

A deficiency of parathyroid hormone can lead to disruption of the calcium balance in the body. A **low calcium level** is therefore a **typical feature of hypoparathyroidism.**

Blood test



Blood tests are commonly used to **measure calcium and parathyroid hormone** in people being investigated for hypoparathyroidism. If necessary, additional testing for creatinine, magnesium, phosphate and vitamin D can be performed.

Urine tests



Calcium and creatinine levels in the urine provide information about how well the kidneys are working and if there are any problems with the balance of calcium and phosphate.

Imaging examinations

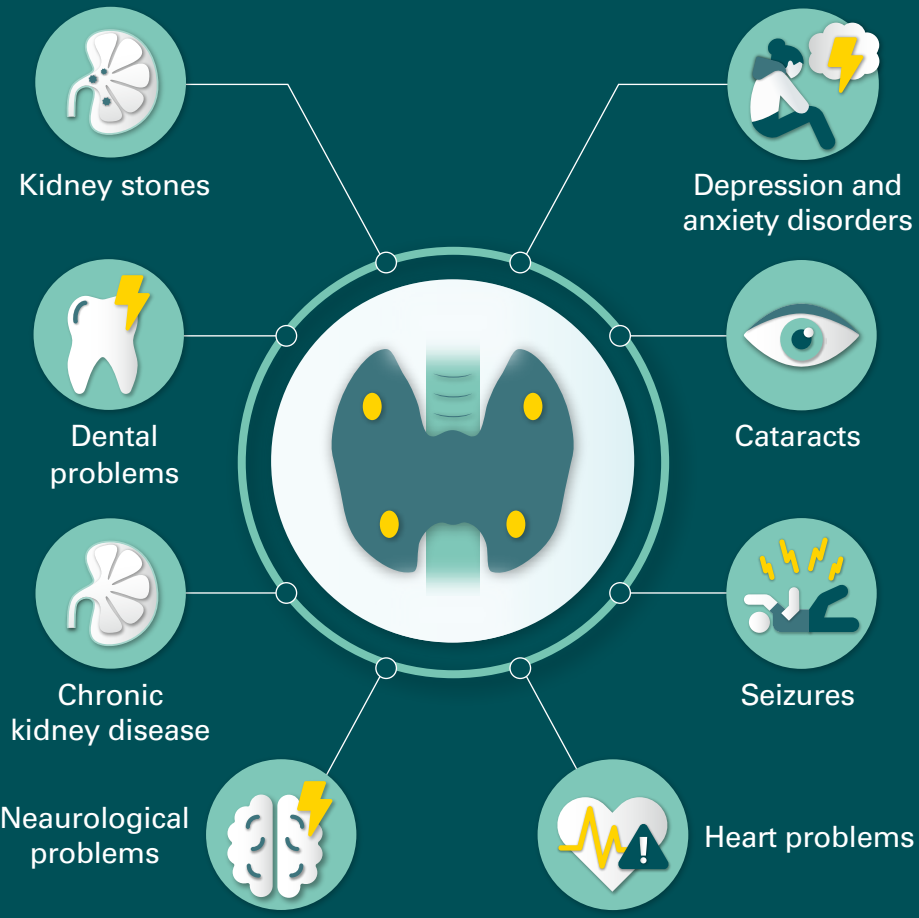


An x-ray of the kidney may be performed to look for signs of calcifications or deposits.

4. Potential complications

Chronic hypoparathyroidism can lead to additional health problems over time.

Possible long-term complications:[1]



Course of treatment

With appropriate medical care and careful treatment interventions, patients can experience **improved wellbeing and quality of life**.

Regular **follow-up appointments**, including blood tests, are usually needed **every 3 to 6 months** to monitor your condition and review your treatment. Changes can be made if needed. The frequency of these appointments will be determined by your healthcare team.



5. Recognising emergency situations

Changes to your treatment, overall health, or daily routine can sometimes affect your calcium levels. This may lead to hypocalcaemia (low calcium levels in the blood) or hypercalcaemia (high calcium levels in the blood), which may require medical attention.

Informing family and friends about your condition and symptoms associated can help ensure quick action in emergency situations.

Symptoms of hypocalcaemia[14] (too little calcium in the blood)



- Tingling and numbness around the mouth, in the hands and feet
- Abdominal cramps and/or muscle cramps
- Tightness in the throat
- Shortness of breath and/or wheezing
- Irritability
- Confusion and/or disorientation
- Depression
- Unusually fast, slow, or irregular heartbeat

Symptoms of hypercalcaemia[14] (too much calcium in the blood)

- Increased thirst and/or dry mouth
- Frequent urination
- Nausea, vomiting, loss of appetite
- Abdominal pain and/or constipation
- Muscle weakness
- Drowsiness and/or headache
- Memory, concentration, and orientation problems
- High blood pressure, unusually fast, slow, or irregular heartbeat



If you notice any of these symptoms, you should seek **medical advice**. In an emergency, call an ambulance or attend your nearest Emergency Department.

Emergency Medical Assistance

Non-life threatening urgent healthcare service: **111**

Life threatening emergencies: **999**

6. Daily life with hypoparathyroidism

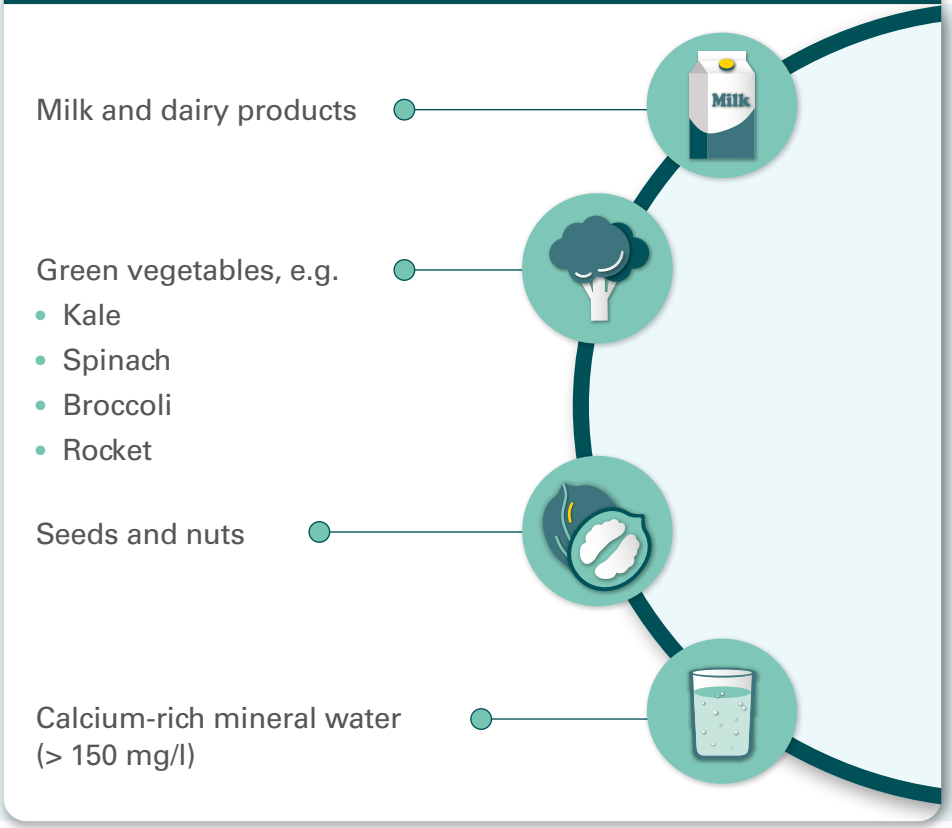
Nutrition

For people with hypoparathyroidism, a diet that provides adequate calcium, includes magnesium-rich foods, and limits foods high in phosphate may be recommended. If prescribed, calcium supplements are often taken in smaller doses throughout the day.

Eating calcium-rich foods throughout the day helps prevent calcium from dropping too low.

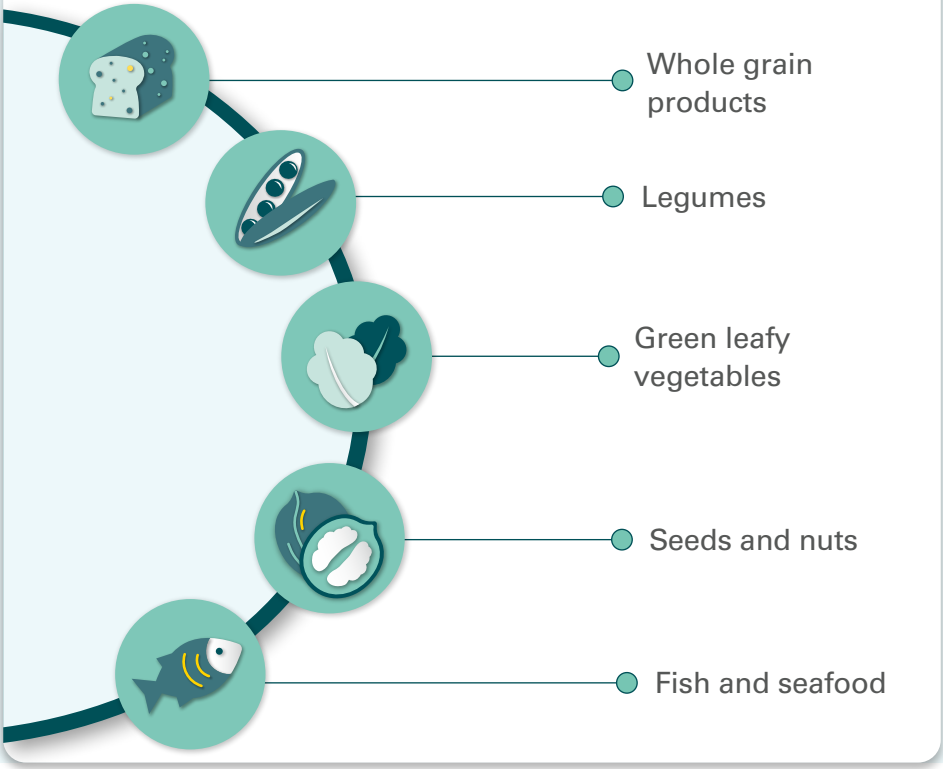
To keep your calcium levels stable, consider incorporating these options into your daily meals:

Calcium-containing foods[15]



Magnesium helps your body absorb calcium from food. Consider incorporating these magnesium-rich foods into your diet:

Magnesium-rich foods[16]



Nuts, seeds and legumes also contain higher amounts of phosphate; however, the positive health-promoting properties of these foods often outweighs this, and consumption in moderation is generally recommended.

More information on diet and hypopara can be found via the Parathyroid UK website here.



Travelling with hypoparathyroidism

Travel should be only be undertaken when your health condition is stable and in discussion with your GP/Consultant. Always seek medical advice prior to starting your trip.

With careful preparation, it is possible to travel with hypopara. **Medical care** in other countries differs from that provided at home, and **language barriers** can make communication difficult if you require medical attention when abroad.

It is advisable to gather information about your travel destination in advance. The GOV.UK website provides helpful information about travel destinations worldwide.

When travelling by air, you may want to carry a **medical certificate** (also called a **customs certificate**) for your medications and medical supplies. This certificate usually lists your prescribed medications, including active ingredients and dosage forms.

Further information on carrying medications can also be found on airline websites.

Tip: Always carry one or two daily doses of your medication in your hand luggage while travelling so that you have them readily available in an emergency.

Health-related checklist for a trip

Documents

- [ ] Passport
- [ ] Driving licence
- [ ] Travel documents
- [ ] Insurance documents
- [ ] Vaccination record

Tip: Check the validity of your documents early and save photos of them on your mobile device

Health-related items

- [ ] Sufficient hypopara medication (+ possibly reserve doses as sensible)
- [ ] Other long-term medications
- [ ] Travel first aid kit
- [ ] Customs certificate completed by your healthcare professional, depending on destination
- [ ] Emergency ID card
- [ ] If necessary, cooler bag for medications – always follow storage requirements for your medication

Personal notes

Additional tips for daily life with hypoparathyroidism

- **Keeping a diary** can be a useful way to track your symptoms, treatment, and overall wellbeing over time. Recording how you are feeling day to day may help you identify patterns and can provide valuable information to discuss with your healthcare team, particularly if your appointments are spaced far apart.

Ascendis has developed a patient diary designed to support people living with hypoparathyroidism. You can access and download it by scanning the QR code or by visiting the Seeds of Change support materials page.

- **Consider discussing your symptoms** and any emotional or psychological impact of the condition with family and friends, if you feel comfortable doing so. This can help you feel supported and better understood.
- If your mental health concerns become more severe, **seek medical support** via your GP or mental health services.
- Exchange experiences **with other people living with hypoparathyroidism**, e.g. via support groups such as Parathyroid UK. [https://parathyroiduk.org/]

- Attend your scheduled **healthcare appointments** and contact your healthcare team if you feel you need additional support or more frequent reviews.
- Bring a **trusted person** to medical appointments and treatment discussions, who can listen, take notes, and ask questions if needed.
- **Prepare for medical appointments** by writing down questions and symptom experiences in advance and bringing them with you.
- **Integrate taking medications** into daily routines or set up a reminder system



7. Pregnancy and breastfeeding

During pregnancy, in addition to the usual prenatal check-ups, close medical monitoring, particularly of calcium levels in the blood and urine, is required. Calcium levels should also be monitored regularly when breastfeeding. Treatment may be **adjusted during pregnancy and breastfeeding based on medical assessment.**[11]

If you are pregnant or breastfeeding, think you may be pregnant or are planning to become pregnant, seek advice from your consultant and gynaecologist.



8. Helpful resources

Seeds of Change UK

https://seeds-of-change.com/uk/

Parathyroid UK

https://parathyroiduk.org/hypoparathyroidism/

NHS - Hypoparathroidism

https://www.nhs.uk/conditions/hypoparathyroidism/

GOV.UK - Travel advice

https://www.gov.uk/foreign-travel-advice

References

1. Mannstadt, M., Bilezikian, J., et al. Hypoparathyroidism. Nat Rev Dis Primers 3, 17055 (2017). https://doi.org/10.1038/nrdp.2017.55.

2. Bollerslev, J. Buch, O. et al. Revised European Society of Endocrinology Clinical Practice Guideline: Treatment of Chronic Hypoparathyroidism in Adults, European Journal of Endocrinology, Volume 193, Issue 5 (November 2025) https://doi.org/10.1093/ejendo/lvaf222.

3. Parathyroid UK. Your Parathyroid Glands. Available at https://parathyroiduk.org/hyperparathyroidism/your-parathyroid-glands/. Accessed August 2026.

4. Bjornsdottir S, Ing S, Mitchell DM, et al (2022). Epidemiology and financial burden of adult chronic hypoparathyroidism. Journal of Bone and Mineral Research, 37 (12) (2022): 2602-2614.

5. Office for National Statistics (2022). Population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2021. Available at https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2021. Accessed March 2024.

6. Parathyroid UK. Hypopara: A quick guide. Available at https://parathyroiduk.org/hypoparathyroidism/. Accessed August 2026.

7. NHS. Hypoparathyroidism. Available at https://www.nhs.uk/conditions/hypoparathyroidism/. Accessed August 2026.

8. Parathyroid UK. Symptoms of hypoparathyroidism. Available at https://parathyroiduk.org/hypoparathyroidism/symptoms-of-hypopara/. Accessed August 2026.

9. Gafni RI, Collins MT. Hypoparathyroidism. N Engl J Med. 380(18) (2019) 1738-1747. doi: 10.1056/NEJMcp1800213. PMID: 31042826.

10. Bilezikian JP, Khan A, et al. Hypoparathyroidism in the adult: epidemiology, diagnosis, pathophysiology, target-organ involvement, treatment, and challenges for future research. J Bone Miner Res. 26(10) (2011) 2317-37. doi: 10.1002/jbmr.483. PMID: 21812031; PMCID: PMC3405491.

11. Bollerslev J, Rejnmark L, et al. European Expert Consensus on Practical Management of Specific Aspects of Parathyroid Disorders in Adults and in Pregnancy: Recommendations of the ESE Educational Program of Parathyroid Disorders. Eur J Endocrinol. 186(2) (2022):R33-R63. doi: 10.1530/EJE-21-1044. PMID: 34863037; PMCID: PMC8789028.

12. Brandi ML, Bilezikian JP, et al. Management of Hypoparathyroidism: Summary Statement and Guidelines. J Clin Endocrinol Metab. 101(6) (2016):2273-83. doi: 10.1210/jc.2015-3907. Epub 2016 Mar 4. PMID: 26943719.

13. Khan AA, Bilezikian JP, et al. Evaluation and Management of Hypoparathyroidism Summary Statement and Guidelines from the Second International Workshop. J Bone Miner Res. 37(12) (2022):2568-2585. doi: 10.1002/jbmr.4691. Epub 2022 Nov 14. PMID: 36054621.

14. Bollerslev J, Rejnmark L, et al. European Society of Endocrinology Clinical Guideline: Treatment of chronic hypoparathyroidism in adults, European Journal of Endocrinology, 173 (2) (2015) G1–G20, https://doi.org/10.1530/EJE-15-0628.

15. Parathyroid UK. Diet in Hypoparathyroidism Part 1: Calcium. Available at https://parathyroiduk.org/living-with-hypopara/self-help-guide/diet/diet-in-hypoparathyroidism-calcium/. Accessed August 2026.

16. Parathyroid UK. Diet in Hypoparathyroidism Part 2: Phosphate. Available at https://parathyroiduk.org/living-with-hypopara/self-help-guide/diet/diet-in-hypoparathyroidism-part-2-phosphate/. Accessed August 2026.