Hypoparathyroidism

Prevalence, Symptoms and Impact on Quality of Life

What is Hypoparathyroidism?

Hypoparathyroidism (also known as hypopara) is a **rare endocrine disease**, caused by **insufficient levels of parathyroid hormone (PTH)** in the body.[1]

The **parathyroid glands lie behind the thyroid gland in the neck**. They produce PTH, which is the primary regulator of calcium and phosphate in the body by acting directly on bones and kidneys and indirectly on the intestine.[2,3] If the parathyroid glands are removed, destroyed, or defective, this may lead to insufficient levels of PTH.[2,4]

75%

Hypopara can arise from genetic causes, autoimmune causes and other causes. Most commonly, hypopara results following neck surgery constituting approximately 75% of all cases.[2,5]

6 months

Hypopara is considered chronic if it persists over 6 months following surgery per the 2016 Endocrine Society Guidelines, 2019 Canadian and International Consensus Statement, and 2022 European Society of Endocrinology.[1,2,6]

In the EU, the number of individuals living with hypopara is estimated to be 3.2/10,000[7]

Symptoms and complications

Hypopara affects numerous systems in the body and is associated with a range of short-term symptoms and long-term complications.[2,4,8]

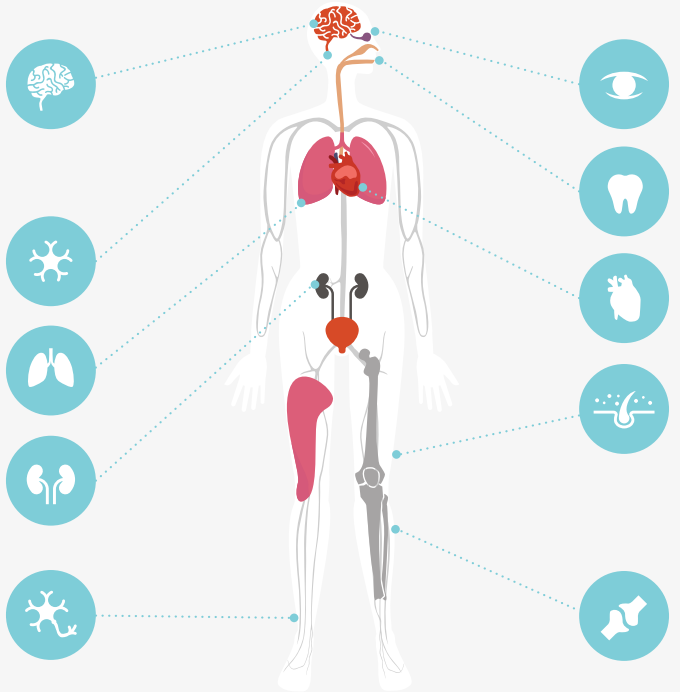
Brain
- Symptoms of anxiety and depression
- Fatigue
- Cognitive impairment, 'brain fog'

Central nervous system
- Seizures
- Calcifications
- Parkinsonism or dystonia

Lungs
- Laryngospasm

Kidneys*
- Nephrocalcinosis
- Kidney stones
- Chronic kidney disease

Peripheral nervous system
- Paresthesia
- Muscle cramps
- Tetany



Eyes
- Cataracts
- Papilledema

Teeth
- Altered tooth morphology

Heart
- Cardiac arrhythmias
- Hypocalcaemia associated dilated cardiomyopathy

Skin
- Dry skin
- Pustular psoriasis
- Brittle nails and prone to onycholysis
- Coarse, thin hair

Musculoskeletal
- Myopathy
- Spondyloarthropathy

*These manifestations are mostly the result of management with calcium and active vitamin D rather than the disease itself.

Impact of Hypoparathyroidism on Quality of Life

The burden of hypopara negatively impacts health-related **quality of life**, **physical functioning**, and **psychological well-being**, regardless of serum calcium levels.[2,9,10]

In a survey* of people living with hypopara, the respondents reported the following impacts on their daily life, mental health, activity and social life and relationships.[9]

Daily life[9]

79%
were not able to do as many things around the home

43%
said that hypopara interferes with their ability to work

67%
were unable to do as much as they used to/wants to

Mental health[9]

81%
felt anxious or had anxiety

64%
felt frustrated

62%
felt depressed or sad

Activity[9]

76%
were not able to exercise in the same way

52%
are less active than they used to be/ want to be

50%
were not as mobile (including ability to walk)

Social life and relationships[9]

79%
were less able to engage in social activities

57%
were more limited in the types of social activities they could do

43%
said this affected their relationships with family

*Survey conducted of 42 adults with hypoparathyroidism.

1 Bollerslev et al. European Society of Endocrinology Clinical Guideline: Treatment of chronic hypoparathyroidism in adults. Eur J Endocrinol. 2015 Aug;173(2):G1-20. **2** Brandi ML et al. Summary Statement and Guidelines. The Journal of Clinical Endocrinology & Metabolism. 2016 Jun 1;101(6):2273–83. **3** Chen K et al. Clinical burden and healthcare resource utilization among patients with chronic hypoparathyroidism, overall and by adequately vs not adequately controlled disease: a multi-country chart review. Journal of Medical Economics. 2019 Jun 17;22(11):1141–52. **4** Mannstadt M et al. Hypoparathyroidism. Nat Rev Dis Primers. 2017 Aug 31;3:17055. **5** Clarke BL, et al. Epidemiology and Diagnosis of Hypoparathyroidism, The Journal of Clinical Endocrinology & Metabolism, Volume 101, Issue 6, 1 June 2026, Pages 2284-2299. **6** Khan AA, et al. Standards of care for hypoparathyroidism in adults: a Canadian and International Consensus. Eur J Endocrinol. Mar 2019;180(3): P1-p22. doi:10.1530/eje-18-0609. **7** Karpf D, et al. Prevalence of hypoparathyroidism in the EU: A systematic review and meta-analysis. Endocrine Abstracts (2020) 70 AEP140 | DOI: 10.1530/endoabs.70. AEP140. **8** Shoback DM et al. Presentation of Hypoparathyroidism: Etiologies and Clinical Features. J Clin Endocrinol Metab. 2016;101(6):2300-12. **9** Brod M, et al. Living with hypoparathyroidism: development of the Hypoparathyroidism Patient Experience Scale-Impact (HPES-Impact). Qual Life Res. 2021 Jan;30(1):277-291. doi: 10.1007/s11136-020-02607-1. Epub 2020 Aug 24. PMID: 32833143; PMCID: PMC7847873. **10** Kontogeorgos G, et al. Low health-related quality of life in hypoparathyroidism and need for PTH analog. Endocrine Connections. 2022 Jan 10;11(1). doi: 10.1530/EC-21-0379.