

Tips for explaining hypoparathyroidism to your work colleagues

Recently, a study looking into the day-to-day life of people living with hypoparathyroidism showed that the condition affected 75% of people's ability to work.¹ Hypopara is a rare and complex disease² which means it can be hard to explain what it feels like to other people, especially new employers or colleagues who are likely to be unfamiliar with the condition.

Here are 5 suggestions that might help guide your conversations:

1. Don't be shy about hypopara:

When starting a new job, it's always good to be upfront about your condition from the start and set guidance on what this might mean for you and for your employer. For example, if you experience debilitating tiredness then flag that there may be days when you are unable to work. Remember, it is completely up to you whom you tell about your hypopara but, in the workplace it is best to start with your manager. We have created the below information guide for you to print and share with your manager/ colleagues to help provide them with more knowledge about hypopara.

2. If you feel comfortable, explain your symptoms to your employer, so they know what to do in an emergency:

Before starting a new job, or even if you have been in a job for a while and have not discussed this before, it might be useful to write down all the symptoms you may experience and the emergency signs to look out for. Share these with your employer and close colleagues and explain what it feels like, only if you feel comfortable in doing so. It is also important to explain what to do in an emergency and to make sure your colleagues know what is required.

3. If you can, try and wear a medical alert bracelet or keep an emergency card on you:

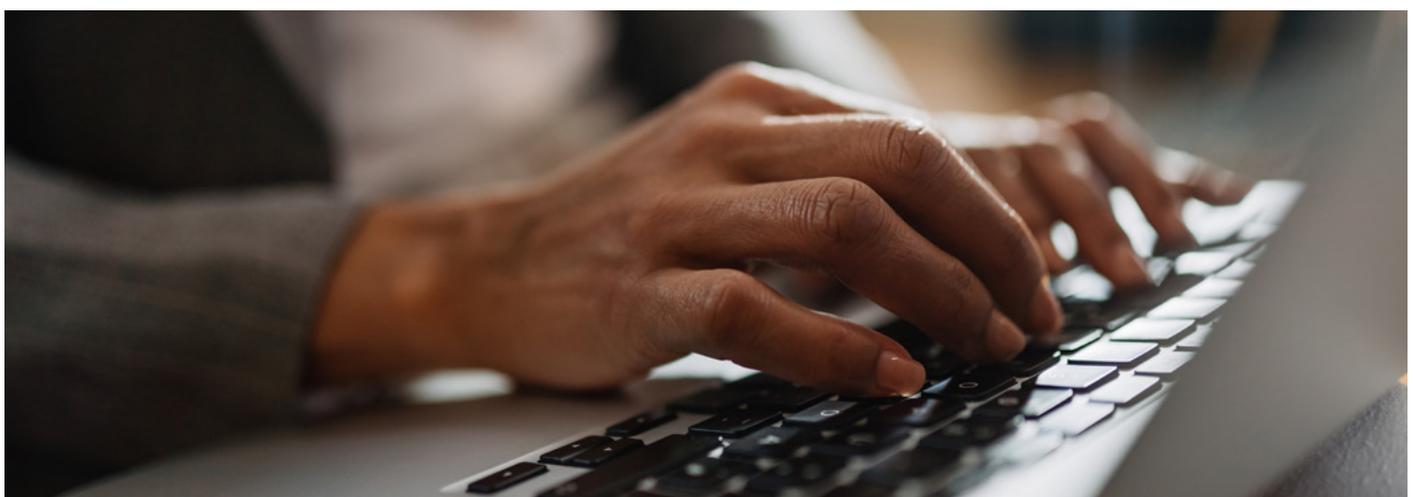
Wearing a medical alert bracelet could help indicate to your colleagues that you live with a chronic condition. This could help when trying to start a conversation about hypopara for the first time. Some patient organisations also have emergency cards available to personalise and print off.

4. Introduce a family member or carer to some key work colleagues, to help explain hypopara:

Having a family member or carer by your side when talking about hypopara for the first time may help when explaining the signs and symptoms of the condition. They can also provide insight about the condition from a caregiver perspective, which may help with any questions asked by your employer.

5. Explain some simple tips to your employer/colleagues which may help you during your working day:

It is important to take regular breaks to help with productivity and mental wellbeing. Staying hydrated is key whilst working, remember to drink 6-8 glasses of water throughout the day.³



This article was developed in collaboration with Professor Ketteler MD, FERA, professor of medicine and Director of the Department of General Internal Medicine and Nephrology at the Robert-Bosch-Hospital in Stuttgart, Germany.

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1. Sigglekow H et al. Burden of illness in not adequately controlled chronic hypoparathyroidism: Findings from a 13-country patient and caregiver survey. *Clinical Endocrinology (Oxf)*. April 2020. Issue 2 92:159-168

2. Hadker N et al. Understanding the Burden of Illness associated with Hypoparathyroidism Reported Amongst Patients in the Paradox Study. *Endocrine Practice*. July 2014; 20 (7): 617-679

3. Associazione Per I Pazienti Con Iparatiroidismo. Dietary advice and suggestions in case of hypoparathyroidism. 3rd Aug 2020. Accessed: <http://www.associazioneappi.it/consigli-su-alimentazione-e-ricette.html>

Information card for your manager/colleagues

We have created the below Q&A guide for you to print and share with your manager or colleagues, to help explain hypopara in further detail.



This is an information card explaining the rare disease, hypoparathyroidism.

The aim of this leaflet is simply to help you help a colleague or an employee who lives with this condition by understanding their symptoms, which they might experience whilst in the workplace or at home. It also includes several suggested adjustments that could be considered to support your employee.

1. What is hypopara?

Hypoparathyroidism (or 'hypopara' for short) is a rare endocrine disorder.¹ It is caused when the parathyroid glands in your neck don't produce enough parathyroid hormone (PTH) so your PTH level drops too low.¹ Damage to the parathyroid glands typically happens because of neck surgery, such as thyroidectomy (partial or total removal of the thyroid), as these glands are small and are located on the thyroid. Hypopara, in some cases, can also be inherited.¹

The parathyroid hormone is responsible for regulating normal blood calcium and phosphorus levels in the body¹, an absence of the hormone can result in low concentrations of calcium in your blood called hypocalcaemia.² If left untreated, hypocalcaemia can be a serious condition, so calcium levels need careful management and regular monitoring.¹

Typical treatments for hypopara include taking doses of oral calcium, as well as Vitamin D and magnesium supplements as needed.¹

2. What are common symptoms of hypopara and how can they impact an employee?

People with hypopara have a high burden of illness and experience a broad spectrum of symptoms, with a multidimensional impact on their lives.³ It is an individual condition and not everyone experiences the same symptoms or in the same way.³

Common symptoms, which are usually caused by low blood calcium levels, known as hypocalcaemia, may include fatigue, muscle spasms and muscle pain, such as cramps or heaviness in limbs and paresthesia, a tingling sensation of the skin.³ This means that your colleague may have difficulty sitting or standing for long periods of time, lifting heavy objects, and undergoing repetitive tasks such as typing. Please be mindful that these tasks, may also cause fatigue, which may influence their overall productivity.

Those living with hypopara may also experience a lack of concentration and mental lethargy sometimes referred to as brain fog,³ which can seriously impact a person's ability to function. These cognitive symptoms may influence their ability to focus and affect their memory.³ This could impact tasks which require your colleague to concentrate for long periods of time or where they must retain large amounts of information. Please be mindful, brain fog could cause your colleague confusion, which they are unable to control.

As an employer of someone living with hypopara, it's important that you're aware of these possible symptoms. Find out more information here and don't be afraid to ask your colleague/employee about their condition and how they experience it: www.hypoparaanswers.eu/home/signs-and-symptoms-public

3. What adjustments could you make as a manager to support your colleague? Please note – these are only suggestions

When an employee is experiencing symptoms of hypopara – and this is not all the time – there are some simple adjustments that could be considered to the working day, see below:

Possible symptoms ³	Suggestions for an employer
Fatigue	Consider this when setting tasks, or even think about reducing working hours
Muscle spasms	Provide a supportive chair and ensure the desk set up is comfortable
Joint/bone pain	Allow for limited manual labour if required
Headaches	Ensure water is always available and nearby
Confusion (brain fog) /memory loss	Allow for regular breaks, as well as breaks to take medication
Depression/anxiety	Provide a mental health support programme
Feeling isolated	Make time for social events for everyone in your team
Management of hypopara (ongoing)	Allow time off for your colleague to go to medical appointments and be flexible with the amount of sick days they may require

4. What should you do in an emergency?

At times, patients can experience severe episodes, and then they have to visit emergency care.³

If your colleague is experiencing a hypo (hypocalcaemia), some of the symptoms they may incur are tingling, spasms and cramp. If they are experiencing a hyper (hypercalcaemia) they may be extremely thirsty, experience headaches, tiredness, and lethargy.⁴

Dairy foods which contain calcium, particularly yoghurt is best in an emergency, ensure there is some available for your colleague.⁵ Please be aware that a severe episode may occur when at work and that you may be required to call your local emergency services on behalf of your colleague.

5. What else can you do as a colleague of someone living with hypopara to better understand their condition?

The resource page on hypoparaanswers.eu have a list of useful tools for you to check out, these include:

- Living with hypoparathyroidism: the first worldwide survey of daily life for patients and carers, results infographic
- HypoparaExchange Podcast Series
- Hypopara eBooks and in-depth articles

Check out: www.hypoparaanswers.eu/home/resources

1. Abate EG and Clarke BL (2017). Review of Hypoparathyroidism. Front. Endocrinol. 7:172.
2. Bilezikian et al. Hypoparathyroidism in the Adult: Epidemiology, Diagnosis, Pathophysiology, Target Organ Involvement, Treatment, and Challenges for Future Research J Bone Miner Res. 2011 October; 26(10): 2317–2337
3. Hadker et al. Understanding the Burden of Illness associated with Hypoparathyroidism Reported Amongst Patients in the Paradox Study. Endocrine Practice. 2014; 20 (7): 617–679
4. Parathyroid UK (2020) Coronavirus and parathyroid conditions FAQs: <https://parathyroiduk.org/news/coronavirus-advice-for-people-with-hypoparathyroidism/>
5. Parathyroid UK (2021) Diet: <https://parathyroiduk.org/living-with-hypopara/self-help-guide/diet/>