

Tips for visiting your healthcare professional

Hypoparathyroidism (hypopara) is a rare and complex disease¹ which means it can be a difficult condition to understand once diagnosed and explaining it to others can be challenging. Healthcare professionals (HCPs) might only encounter one rare disease case per year.² Therefore, when visiting your HCP, it is best to attend as prepared as possible.

You may find it useful to bring along a carer when visiting your HCP at pre-arranged medical appointments. In the [fifth episode](#) of the HypoparaExchange podcast series, we heard from Liz who lives with hypopara, and her husband Bill, who regularly attends Liz's doctor appointments when allowed. Bill explained, *"if Liz is not very well on the day that we have to go to a pre-arranged appointment, I can explain how Liz has been recently, and I just try and talk for her really during the appointment."*

To help make the most out of your pre-arranged medical appointments, please find seven useful questions to support your conversation with an HCP below:

1. **What happens when parathyroid hormone is missing?**
2. **What are some of the triggers of hypocalcaemia?**
3. **What are the potential treatment options available for hypoparathyroidism?**
4. **What tests should I be given to monitor my hypoparathyroidism?**
5. **On average, how often are tests carried out?**
6. **Is it possible to still be symptomatic when my blood tests show within the recommended range?**
7. **Why can't I keep my calcium elevated?**



Additionally, Bill shared another top tip for supporting Liz during these appointments, *'I usually make notes too, so that Liz can look at it afterwards and ask me about what was said, if she wasn't totally aware of what was going on.'* Therefore, if possible, take a note pad and pen with you to your medical appointments so that you don't miss or forget anything important.

For more information, feel free to contact your national patient organisation.

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.

1. 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

2. Engel P et al. Physician and patient perceptions regarding physician training in rare diseases: the need for stronger educational initiatives for physicians. J Rare Disord (2013) 1(2):1–15