Think Calcium, Think Long-Term: Bridging the Gaps in the Hypoparathyroidism Care Pathway

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While hypoparathyroidism (hypopara) is a rare disease, it may affect more people than the healthcare system currently accounts for. There are an estimated 14,000 people living with hypopara in the UK, yet, the majority of patients are not under an endocrinologist's care.[1] It is possible that some patients are therefore falling through the cracks. These "missing patients", who are either living undiagnosed, or without access to a hormone specialist, represent a critical care gap – one with significant implications both for patient outcomes and quality of life, and healthcare resources.

Identifying the Gaps in the Hypopara Patient Pathway

There are three main points in the care pathway where I believe there may be patients who require closer attention:

Undiagnosed in primary care: Given that hypopara is rare and has many non-specific symptoms, GPs are unlikely to encounter the condition on a regular basis so unfamiliarity may lead to underdiagnosis. There is also a lack of calcium testing during routine investigations due to the decline of multi-track analysers.[2] This is particularly true of hypopara patients who have not had thyroid surgery, who may experience a more gradual onset of symptoms.

Under-monitored in endocrinology: Most diagnosed patients receive conventional therapy – oral calcium and active vitamin D – to manage symptoms.[3] However, some people who have good symptom management may not be being regularly monitored for long-term complications, leading to over-treatment risks and long-term renal concerns.

People who are no longer receiving specialist care: Especially since the Covid-19 pandemic, some patients are no longer accessing specialist services and are instead being managed in primary care. They are therefore not being regularly reviewed, despite ongoing treatment which could have long-term complications.

Optimising the hypopara pathway requires a multi-pronged approach across primary care professionals (from GPs to pharmacists), endocrinologists (specialist bone and calcium experts and more general endocrine doctors and nurses), and patients and carers themselves. Addressing the following areas is essential to helping more people living with hypopara navigate the care pathway and access effective, holistic care.

Taking Action to Reduce Calcification Risks

Amongst endocrinologists, we need to raise awareness that therapies for hypopara carry potential complications which are often under-monitored. Training and guidelines for endocrinologists should highlight the importance of regular calcium assessments, renal imaging, and monitoring for calcification risks.

Embedding Ongoing Monitoring into Hypopara Management

We need to improve the systematic review of long-term medication use to ensure that proactive monitoring is embedded and therefore over-treatment is flagged early. Other chronic conditions, like diabetes, offer a useful comparison. Diabetes care is supported by well-established, wrap-around care models that include structured reviews, multidisciplinary teams, and routine long-term monitoring. Hypopara patients would similarly benefit from a more comprehensive approach, including proactive monitoring frameworks that go beyond biochemical targets and actively seek indicators of over-treatment.

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It is recommended that a baseline assessment for the presence of renal calcification or stones with renal imaging is completed for chronic hypopara patients, on top of regular monitoring for serum calcium and phosphorus.[4] Regular monitoring of urine calcium levels should also be part of an optimal monitoring strategy.[4] Embedding these reviews into standard practice will reduce preventable harm and ensure more balanced, responsive treatment regimens.

Pharmacists: An Essential Link in Multidisciplinary Long-Term Hypopara Care

One group particularly well-positioned to support a multidisciplinary clinical approach in hypopara is pharmacists. Pharmacists, both in community and hospital settings, often have the clearest visibility of long-term medication use. They are well placed to spot patients who are regularly prescribed activated vitamin D analogues, calcium supplements, or other metabolites associated with hypopara management. These prescriptions should act as clinical flags. Anyone on long-term metabolite therapy ought to be under periodic review by a specialist, and pharmacists can play a pivotal role in triggering this process. In the context of a rare disease like hypopara, where conventional treatment can potentially carry long-term risks, pharmacists can play a role in optimising treatment plans and support proactive care management.

Empowering Patients as Partners in Hypopara Care

Sitting across all of this is patient empowerment. Given the rarity of the condition, patients are often required to become their own advocates – and, in many cases, can be very knowledgeable about hypopara. Self-management is a critical tool that can help improve both the physiological and psychological manifestations of hypopara. It is therefore essential that healthcare professionals not only support but actively encourage patient engagement and self-advocacy. Empowering individuals to ask informed, timely questions about their monitoring, treatment, and long-term side effects – helps create a truly collaborative care model. Patient advocacy should be a central part of clinical conversations, and we need to ensure that patients feel empowered to question approaches by healthcare professionals to ensure they are receiving the care they need. Ultimately, listening to lived experience must be recognised as a vital source of insight in shaping care decisions.

Closing the Gaps Through Vigilance and Collaboration

Although hypoparathyroidism is rare, it is not insignificant. Delays in diagnosis, gaps in follow-up, and limited action around long-term risks may contribute to avoidable complications. Systematic monitoring and multidisciplinary collaboration are essential – not only for improving outcomes but also for reducing healthcare costs associated with disease/complications. These are all too commonly not optimally managed leading to emergency admissions and renal complications. When patients, primary care providers, specialists, and pharmacists work together, we can close the gaps, reduce risk, and deliver a model of care that is truly fit for purpose.

Healthcare professionals across primary and secondary care must remain vigilant: **think calcium, think long-term.** Whether through a simple addition to a blood panel or a timely medication review in a pharmacy, every step counts toward finding and supporting people living with hypopara.

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[1] Ascendis Data on File.

[2] Parathyroid UK. Hypopara: A quick guide. Available at https://parathyroiduk.org/hypoparathyroidism/. Accessed October 2025.

[3] Parathyroid UK. Current treatment. Available at https://parathyroiduk.org/hypoparathyroidism/current-treatment-of-hypopara/. Accessed October 2025.

[4] Khan, A., Bilezikian, J., et al. Evaluation and Management of Hypoparathyroidism Summary Statement and Guidelines from the Second International Workshop. JBMR. Available at https://www.endocrinology.org/media/txbkbhvb/jbmr_4691.pdf. Accessed October 2025.