Lack of treatment solutions intensifies problems for **hypoparathyroidism**

Like many others, patients with hypoparathyroidism around the UK are now experiencing difficulties accessing the essential medication that keeps them alive.

Hypoparathyroidism is rare, serious and affects all ages. Insufficient parathyroid hormone leads to low calcium levels in the blood which cause distressing symptoms and, without treatment, can be fatal.

It is a challenging condition to manage as there is no readily available replacement parathyroid hormone. Treatment relies on high-dose One Alpha (alfacalcidol) — an oral active vitamin D.

Patients can't access drugs

Patients around the UK are having difficulty accessing their essential medication. Switching brands often destabilises calcium levels leading to urgent hospital admissions and restoring stability can take several months.

One of the 2022 key priorities of the UK Rare Disease Framework Action Plan is 'improving access to specialist care, treatment and drugs.' Instead, we are seeing the withdrawal of existing medication.

Immediate action

Parathyroid UK and their medical advisers have recommended immediate action to the DHSC and called upon the Society for Endocrinology to highlight the matter to its members. Hypoparathyroidism should be recognised as a rare condition requiring protected access to essential medicines for patients with this condition.

This medication needs to be added to the Medicines Repurposing Programme. We need a secure supply and the NHS is ideally positioned to make these drugs for itself.

Long-term needs

In the long term, new ways to prevent and treat the condition and access drugs are needed. Cases are likely to rise as thyroid operations (currently 10,000 pa) increase, so efforts to optimise surgical outcomes and reduce the risk of post-surgical hypoparathyroidism are crucial and include restricting work to key centres, improving surgical techniques and adopting new intraoperative technologies.

Parathyroid UK is involved in a UK-wide multicentre trial (the NIFTy trial) of one such technology and awaits a new device being tested in a clinical setting that will allow patients to check their calcium blood levels at home.

Research takes time and requires funding. In the meantime, patients who are already struggling to manage a rare and underserved condition find themselves more at risk.

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Paid for by **Parathyroid UK**

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