

Pancreatic enzyme replacement therapy national shortage

Mary Phillips

Advanced Clinical Practitioner (Hepato-pancreatico-biliary dietetics)

Royal Surrey County Hospital, UK

Post Graduate Researcher, University of Surrey, UK



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Declaration of interests – Honoraria received for teaching from Abbott, Viatrix, Nutricia Clinical Care and Nordmark Pharma.

Pancreatic enzyme replacement therapy (PERT)

- Essential medication for patients with pancreatic exocrine insufficiency (PEI)
- PEI is a failure of the pancreas to secrete sufficient enzymes to allow normal digestion
- Untreated PEI results in malnutrition, diarrhoea, faecal urgency and incontinence, bloating, reflux, colicky abdominal pain, micronutrient deficiency, erratic blood glucose control, fatigue and reduced performance status.
- The osmotic diarrhoea caused by untreated PEI could influence the absorption of other medications
- Fat malabsorption due to untreated PEI can impact Vitamin K uptake (caution for patients on anti-coagulation)

The impact on the patient

- Insufficient PERT will cause malnutrition, uncontrolled diabetes, significant abdominal symptoms and poor quality of life
 - Less likely to tolerate chemotherapy.
 - Declining nutritional status prior to major surgery.
 - Unable to work.
 - Potentially life-threatening hypoglycemia.
 - Long term impact of hyperglycaemia.
 - Impact on psychological, social and financial status.
 - Poor absorption of other medications.
- **The only real alternative to PERT is artificial feeding.**





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Medicine Supply Notification: Pancrease® HL gastro-resistant capsules

Dispensing & Supply | Shortages

Thursday 12th October 2023



February 2019

Dear

Re: Important Information About Creon (Pancreatin) 40,000

As you have been prescribed Creon, we would like to inform you that Mylan the marketing authorisation holder for Creon, has decided to voluntarily discontinue the manufacture and distribution of Creon 40,000 from June 2019. It's important to note that this decision is not associated with any safety or efficacy findings.



Shortage of Pancreatic enzyme replacement therapy (PERT)



Supply constraint of Creon® 10000 Creon® 25000 (Pancreatin) 26th April 2024



Department
of Health &
Social Care



Medicine Supply Notification

MSN/2024/089

Creon® Micro Pancreatin 60.12mg gastro-resistant granules

Tier 3 – high impact*

Date of issue: 23/08/2024

Link: [Medicines Supply Tool](#)

Summary

- Creon® Micro Pancreatin 60.12mg gastro-resistant granules are in limited supply until late September 2024.



Department
of Health &
Social Care

Medicine Supply Notification

Pancreatic enzyme replacement therapy (PERT)

Tier 2 – medium impact*

The situation now

- Ongoing shortages predicted into 2027
 - Supplies released to wholesalers 3 x month
 - Supplies only 90-95% of normal demand (Creon 25,000 only)
 - Prioritise Creon[®] Micro for infants and those with dysphagia who are unable to open the capsules
 - Prioritise Creon[®] 10,000 and Pancrex[®] capsules (5,000 and 8,000) for children & those unable to swallow large capsules
 - Prioritise Nutrizym 22[®] for those unable to tolerate Creon[®]
 - Prioritise Pancrex[®] powder for tube fed patients – not usually suitable for oral use.
 - Import PERT to meet deficit in demand





Position Statement: Pancreatic enzyme replacement therapy (PERT) shortage – advice for the management of adults with pancreatic exocrine insufficiency

Phillips M.E^{1,3}, McGeeney L.M¹, Watson K-L², Lowdon J².



Desperation....

- “I’ve given up, I spend hours each week trying to track down a supply, I just can’t take that much time off work, so I only have one meal a day, and snack on jelly babies to keep my blood sugars up, my diabetes control is rubbish 😞.”
- “My neighbour died, so I have been using his Creon, he got his from a friend of a friend on facebook”
- “My bowels are so erratic without my PERT, I had to call in sick”
- “The drinks are not great, but just having those is easier than the stress of trying to find any Creon”
- “I got upset with the surgery when they wouldn’t give me any other prescriptions and I have run out, now I’ve been labelled as rude, can you talk to them and explain?”
- “My surgery said they can’t prescribe any imports”



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I’ve tried everywhere local and nothing

██████████ have 2 boxes left and said they don't think they can get anymore

I’ve now had to pay £178 for 5 boxes that my sister is sourcing in ██████████ OBJ

It makes me worry sick that his going to have none and be so ill 😞

tablets and for the last month our pharmacy have told us they cannot source them. He has now ran out and the surgery have told us that there is no alternative?! He is already extremely underweight and without these tablets he will loose even more. I'm not sure if it's just the pharmacy and the doctors being too busy to sort out an alternative or do some research, so wondering if anyone else is also on these tablets and if they are still receiving their medication? Tia

About

I've created this group as a resource to help those struggling to get their vital medication.

I too have been impacted by this having had pancreatic cancer.

I can offer true alternatives (to Creon) that work.

POLL

What do you think are the main issues preventing the prescription of imported PERT? (allow multiple answers)

- I don't know how to do it
- It's too expensive
- I'm not comfortable prescribing an unlicensed medicine
- No time to organise a special prescription
- Creon will come in if we just wait a bit

What do patients need

- There is a 10% deficit in supply across the UK – **we need to import**
- This is due to continue until 2027, so we need a long-term plan
- Supplies are intermittent, please do not be reassured when you get stock in, this does not mean the problem is over
- Patients “going without” is not an acceptable option
- Patients are scared and frustrated – avoid “misinformation”
- Imports are more expensive, but less than the cost of a GP appointment or 30 minutes of Pharmacists time.



Conclusion

- This is a long-term issue: Supply does not meet demand; we need to establish imported medicines to regulate supply for patients
- Clinical impact on patients is significant – consider not only abdominal symptoms and malnutrition, but fitness for surgery, tolerance of chemotherapy, absorption of other medications, glycaemic control, falls
- Associated costs/impact – multiple prescriptions, pharmacy time, patients unable to work, quality of life, some patients may not ever get to curative treatment as a result.
- Patients are petrified and receiving incorrect advice – we need to ensure a consistent message




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Position Statement: Pert Shortage

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