

## Advice to Help Patients with the PERT Medicine Supply Disruption

### What is PERT?

- Pancreatic enzyme replacement therapy (PERT) is prescribed for people with pancreatic exocrine insufficiency (PEI) commonly caused by pancreatic cancer, pancreatitis, or cystic fibrosis (CF). PERT capsules are taken with food to help replace the enzymes the pancreas would normally make. PERT helps food be digested and then the body absorbs all the calories and nutrients from it. If someone with PEI is unable to take enough PERT, they are at risk of not absorbing nutrients and becoming malnourished. The brands of PERT that are commonly available on the NHS and are affected by a supply disruption are Creon<sup>®</sup>, Nutrizym<sup>®</sup>, and Pancrex<sup>®</sup>.

### What is the issue?

- Supply disruptions in the UK mean some people prescribed PERT are unable to obtain it or are experiencing difficulties or delays in accessing it. The supply chain to community pharmacies is erratic and stock is not readily available every day, so there may be a delay in your pharmacy obtaining the medication you need. Because less stock than usual is available in the UK it has made routine supply more challenging.

### Advice for patients

We understand the anxiety the current supply disruptions are causing and are working to help everyone who needs PERT to get the medications they need. Below is some guidance to help you manage the current shortage.

- We recommend placing your prescription requests as soon as your previous one has been dispensed. Check with your GP that it is appropriate for you to do this because of the supply disruption - some automated systems will reject a request if it is requested again too soon.
- We recommend leaving your prescription with your usual pharmacy while they attempt to obtain stock. Even if it is out of stock ask them to order it anyway so the order is logged and can be filled when the next shipment of PERT arrives in the UK.
- Whilst the supply disruption is ongoing, please do not stockpile these medicines, as this will worsen the shortage for everyone.

- It may be necessary to call community pharmacies in your area or use online stock checkers on pharmacy websites to check stocks of PERT if your usual pharmacy is not able to obtain despite giving it time.
- You may be prescribed with an alternative PERT to your usual brand due to the shortages. Your pharmacist or dietitian can guide on the doses of the alternative PERT if you are unsure.
- The Department of Health and Social Care has recommended that only a 1-month supply is provided at a time to try and regulate supplies, so you may need to collect your prescriptions more frequently.
- Taking PERT throughout your meal rather than all at once at the start middle or end improves how well it digests your food and drinks.
- Swallow capsules with a cold drink and keep the capsules at room temperature, so they aren't damaged by high temperatures.
- Taking other medicines called proton pump inhibitors (omeprazole/ pantoprazole/ lansoprazole) or H2-receptor antagonists (Famotidine/ Nizatidine) will reduce the acid in your stomach and make PERT more efficient. This means you may find a lower dose of PERT effective. If you are not on one of these medicines speak to your specialist team at your next hospital appointment or contact your GP.
- Contact your dietitian, nurse specialist or doctor if you are struggling with symptoms of malabsorption such as pale/oily/greasy poo, or bloating/getting full quickly when you eat, or are consistently losing weight.

### What next?

- Healthcare professionals in Cheshire and Merseyside are continuing to work together to try and ensure everyone who needs PERT obtains a supply. We are exploring solutions to ensure patients have ongoing access to the medicines they need.
- Our efforts are directed at trying to support local community pharmacies to obtain a PERT supply for you where possible. If you are an adult with cystic fibrosis under the care of Liverpool Heart and Chest Hospital they will contact you to discuss support with treatment. If you are currently receiving your PERT treatment from your specialist hospital team, please discuss with them around your ongoing supply.

## Useful contacts

- Contact your usual community pharmacy initially.
- If you need to contact your specialist we recommend calling the number on your most recent letter. Below are some general contact details if you can't find this.
- Royal Liverpool University Hospital contact number: **0151 706 2120**
- Aintree University Hospital contact number: **0151 529 3473** (dietitian's secretary)
- Liverpool Heart and Chest Hospital (LHCH): if you are a CF patient looked after by the LHCH CF team, contact your designated CF nurse(s).
- Wirral University Hospitals – **0151 678 5111**
- Alder Hey Children's Hospital – **0151 228 4811**
- Mersey and West Lancs Hospitals - **0151 426 1600**
- Countess of Chester Hospital - **01244 365000**
- East Cheshire Hospitals - **01625 421000**
- Mid Cheshire Hospitals - **01270 255141**
- Warrington and Halton Hospitals - **01925 635911**
- The Clatterbridge Cancer Centre - **0151 556 5000**

More information from the national bodies can be found by scanning this QR code:



Or visiting this website:

<https://www.psgbi.org/position-statement-pert-shortage/>

Viatrix UK has initiated a free Creon® customer service line dedicated to patients and healthcare professional affected by Creon® supply issues. The service can provide information on the nearest pharmacies which have recently received supply.

The Creon® customer service line can be reached on **0800 808 6410**. Operators will respond from UK and handle enquiries in real time. The service will be active from Monday to Friday from 9:00 to 17:00.