PERT shortage
Guts UK patient survey results

The survey was open to people who use Pancreatic Enzyme Replacement Therapy (PERT), as well as the family members, friends and carers of people who use it.

280 people responded to the survey and children and adults of all ages were affected.

Most people who took the survey had exocrine insufficiency, followed by chronic pancreatitis and acute pancreatitis.

People all across the UK have been impacted by the shortages.

Most people who responded told us they usually take Creon 25,000 capsules, followed by Creon 10,000 and Nutrizym 22,000.

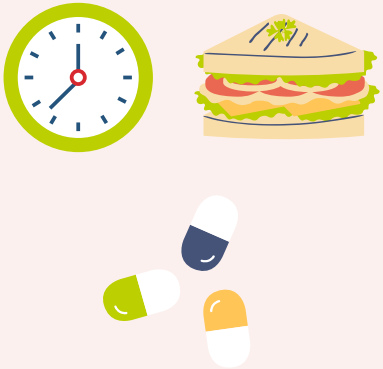
Around **8 in 10 people** told us that they usually get their prescription from a GP or primary care team, with most collecting a one-month supply from a pharmacy.

Most people had experienced problems with the supply of their usual PERT brand or dose on more than one occasion, in the 3 to 6 months before taking the survey.

Most people told us they'd tried alternatives, including:

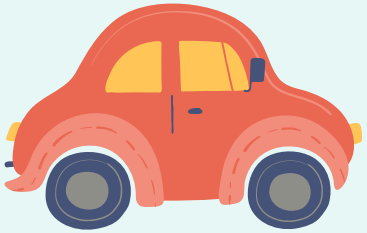
- Changing dose or type of enzyme taken
- Using a different pharmacy
- Getting a prescription from a hospital or specialist centre
- Altering their diet
- Altering when and how much PERT they took

Just **over half of people** surveyed had no supply and were not offered alternatives or additional advice.



1 in 10 people had resorted to alternatives that aren't advised by Guts UK, other organisations, or the NHS, including:

- Using out of date stock
- Buying PERT online supplied from outside the UK
- Buying PERT by travelling outside the UK
- Buying non-prescription enzymes from a health food store or other supplier
- Taking medicine given by another person who uses PERT



Almost three quarters of people had to get PERT from somewhere other than their usual stockist.

Whilst most travelled within a 30 mile radius or less, some people travelled more than 100 miles to get a supply of PERT.

Of those who'd experienced shortages in supply, most people were left without supply for between one and four weeks.

However, some people experienced significant supply issues and were without medication supplies for weeks and months at a time.

Of those who were without supplies, only 7 in 50 were offered and able to access supplies of pre-digested (peptide or fat free) nutritional drinks.

Of those surveyed, more than half thought that the healthcare professional that they spoke to was aware of the current NHS statement on supply problems, which provides guidance on what to do.

Almost everyone surveyed told us that they'd experienced at least one or more of the below in most cases:

Symptoms

- Feeling sick
- Bloating
- Indigestion
- Diarrhoea
- Increased pain
- Pale greasy poo
- Urgency to use the toilet

Dietary factors

- Poor control of diabetes
- Weight loss
- Having to take more tablets with meals, affecting appetite
- Increased levels of hunger

Quality of life factors

- Worry over how having no medicine will affect me
- Increased time taken to manage my condition
- Reduced quality of life
- Reduced ability/unable to work
- More expense in finding medicines
- Had to use other added medicines to reduce symptoms resulting in higher prescription costs

Of those surveyed, 18 people had been admitted to hospital due to issues caused by the supply problems.

You can find more information about the PERT supply problems at www.gutscharity.org.uk
Search 'PERT' for the latest updates