UK and Ireland Neuroendocrine Tumour Society

UKINETS Bitesize Guidance for the Management of Pancreatic Exocrine Insufficiency (PEI)

Patients should be screened for malnutrition using a validated nutrition risk screening tool e.g. MUST, SGA, NRS-2002. Patients at risk should be referred to a dietitian. Specialist dietitian or clinical nurse specialist input is recommended alongside this.

PEI is defined as a reduction of pancreatic exocrine activity, at a level that prevents normal digestion. Early recognition of PEI is vital as it negatively impacts patients' quality of life, nutritional status, and clinical outcomes.

Risk Factors

- NET in pancreas, particularly in head of pancreas and/or in presence of pancreatic duct dilatation
- Treatment with somatostatin analogue therapy
- Pancreatic resection, particularly head of pancreas
- Gastric or lower gastrointestinal surgery

Symptoms

- Diarrhoea
- Urgency
- Steatorrhoea (pale, yellow, orange and/or greasy stools or oil in the pan, stools which float or are difficult to flush away)
- Wind
- Bloating
- Otherwise unexplained hypoglycaemia
- Weight loss or difficulty gaining weight not in line with oral intake

Testing

A faecal elastase (FE1) stool test may be used to confirm or exclude PEI, however the reliability of this in NETs is unclear. Commencing pancreatic enzyme replacement therapy (PERT) therefore may be beneficial. The use of PERT will not affect the accuracy of FE1 and clinicians may choose to do both.

Treatment

In the presence of PEI, patients should be treated with PERT e.g. Creon 25,000, Nutrizym 22, Pancrease HL. This should be started at a dose of at least 44,000-50,000 units of lipase with meals and 22,000-25,000 units of lipase with snacks, supplement drinks or milky drinks. Patients should be encouraged to adjust their dose if this is ineffective.

PERT should be taken at the beginning of meals and split dose at intervals throughout the meal if taking longer to eat or having multiple courses.
There is no maximum dose of PERT in adults, however, where doses exceed 100,000 units lipase with meals, comorbidities such as small intestinal bacterial overgrowth, bile acid diarrhoea, infection, coeliac disease, IBD, IBS and lactose intolerance should be excluded.

All PERT is porcine derived with no alternative available. Patients should be counselled on this upon commencement.

Troubleshooting if symptoms persist

- Check PERT is being taken at appropriate timings
- Is the patient taking with milky drinks, snacks and nutritional supplement drinks?
- Is PERT being stored at <25°C?
- Check capsules are being swallowed whole with a cool drink
- Introduce a PPI if ongoing symptoms at higher doses
- Trial an alternative brand of enteric coated PERT

Patients with PEI are at risk of vitamin and mineral deficiencies. Consider vitamin and mineral monitoring and supplementation.

Please consider referring to local or national guidance for more detailed management advice.

UKINETS Bitesize Guidance for the Management of Pancreatic Exocrine Insufficiency (PEI)

References

1. Panzuto F, Magi L, Rinzivillo M. (2021) ‘Exocrine pancreatic insufficiency and somatostatin analogs in patients with neuroendocrine neoplasia’. Expert Opin Drug Saf. 20(4):383-386. doi: 10.1080/14740338.2021.1881478. Epub 2021 Feb 2. PMID: 33530760.
2. Phillips ME, Hopper AD, Leeds JS, et al (2021) ‘Consensus for the management of pancreatic exocrine insufficiency: UK practical guidelines’ BMJ Open Gastroenterology; 8:e000643. doi: 10.1136/bmjgast-2021-000643
3. Saif MW, Romano A, Smith MH, Patel R, Relias V. (2020) ‘Chronic Use of Long-Acting Somatostatin Analogues (SSAs) and Exocrine Pancreatic Insufficiency (EPI) in Patients with Gastroenteropancreatic Neuroendocrine Tumors (GEP-NETs): An Under-recognized Adverse Effect’. Cancer Medical Journal. 3(2):75–84.

V.1 27/11/2023

Authors: Charlotte Dowd, Elizabeth Bradley, Ruth Lee, Susan Vyoral, James Wimbury, Tak-Wai Ho and Yasmin Chotai De Lima
Preparation date 27 November 2023. Review date November 2025