

Sharon Gallagher
Health and Social Board
Headquarters
12-22 Linenhall Street
Belfast BT2 8BS

Dear Mrs Gallagher,

We are writing to share our serious concerns about the low rates of prescription of a vital medicine for people with pancreatic cancer in Northern Ireland, and to request an urgent meeting to discuss how we can work together to tackle this problem.

As you'll know, pancreatic cancer is the deadliest common cancer in Northern Ireland. 230 people are diagnosed with pancreatic cancer every year in Northern Ireland, with three in five diagnosed at a late stage.

Most people will receive no treatment, and one in two will die within three months. These three short months are extremely distressing, with people often unable to digest their food, leading to rapid weight loss and unpleasant nutritional and digestive symptoms. But Pancreatic Enzyme Replacement Therapy (PERT), already a widely available prescription, can make a significant positive impact on the most debilitating of symptoms.

As you will know, PERT replaces the digestive enzymes that people with pancreatic cancer can no longer produce, allowing food to be digested and absorbed by the body. It helps people gain the strength to undergo treatment, and gives them a better quality of life for the precious time they have left.

Yet despite clinical consensus that PERT is crucial for people with pancreatic cancer, and 2018 NICE guidelines clearly recommending PERT for all pancreatic cancer patients, new research shows that **only 47% of people with pancreatic cancer in Northern Ireland are being prescribed PERT**. This problem needs to be urgently addressed.

Pancreatic Cancer UK has launched a new campaign, **Transform Lives: Prescribe**, to do just that. We are working in partnership with the clinical community to improve PERT prescription rates, whilst developing resources and training to support the healthcare community in understanding and prescribing PERT.

But we can't do this alone. To truly solve this problem, there must be a system-wide approach, addressing the issue through three key steps:

1. PERT must be made a priority in pancreatic cancer care across Northern Ireland through the implementation of national targets. To achieve this:

- **Northern Ireland Cancer Registry** should **establish** a baseline for PERT prescription in Northern Ireland, through auditing and publishing more data on PERT prescription.
- **The Department of Health in Northern Ireland** should **introduce** a national target to ensure that PERT is prescribed to all pancreatic cancer patients as set out in the NICE guidance. The implementation of the new **10-year Northern Ireland cancer strategy** presents a timely moment to set such a target, as well as offering a key mechanism to focus on nutritional support to deliver on the strategies focus on prehabilitation, rehabilitation and supported self-management.

2. Health and Social Care Boards and Trusts must act to ensure the effective prescription of PERT.

From the endorsement of NICE guidelines in Northern Ireland in 2018, Health and Social Care Boards and Trusts had a responsibility to ensure that the NICE guidelines are implemented within 9 months. To ensure that the NICE guidelines on PERT have been implemented, Health and Social Care Boards and Trusts should:

- Audit their services in line with the NICE guidelines and ensure that they are prescribing PERT to all pancreatic cancer patients. Where NICE guidelines are not being met, an action plan should be implemented to ensure that Health and Social Care Boards and Trusts are prescribing PERT.
- Highlight the NICE guidance and share and promote Pancreatic Cancer UK PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.

3. Healthcare professionals should prescribe PERT to people with pancreatic cancer as standard, at the point of diagnosis.

There is currently a responsibility vacuum for nutritional care, with no one person having responsibility – particularly outside of specialist centres.

To ensure that all patients receive PERT:

- Every health professional involved with the care of people with pancreatic cancer needs to be aware of PERT.
- All health professionals involved with the initial pancreatic cancer diagnosis need to pro-actively prescribe PERT.
- To improve local awareness and training, healthcare professionals should access Pancreatic Cancer UK's online PERT hub with training and resources on PERT.
- To ensure that no one falls through the gaps, there should be a nominated local health professional to champion PERT, who can ensure that colleagues are aware and trained to prescribe PERT and track that every person in the MDT has been considered for PERT.

Ultimately, there is no good reason why so many people in Northern Ireland are missing out on a life-changing treatment such as PERT. Everyone with pancreatic cancer should have the opportunity to live the time they have left with the greatest possible comfort and dignity.

We would welcome a meeting with you to discuss how we can ensure all people with pancreatic cancer get access to the best possible treatment. Please contact Emily Waller, on emily.waller@pancreaticcancer.org.uk, who will be happy to make the suitable arrangements.

Yours sincerely,

Pancreatic Cancer UK and our undersigned supporters