

Dr Andrew Goodall CBE  
Cathays Park  
Cardiff CF10 3NQ

Dear Dr Goodall,

We are writing to share our serious concerns about the low rates of prescription of a vital medicine for people with pancreatic cancer in Wales, 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 Wales. 500 people are diagnosed with pancreatic cancer every year in Wales, 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 63% of people with pancreatic cancer in Wales 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 Wales, through the implementation of a national target.** To do this, NHS Wales should:

- **Establish** a baseline for PERT prescription in Wales, through auditing and publishing more data on PERT prescription.
- **Introduce** a national target to ensure that PERT is prescribed to all pancreatic cancer patients as set out in the NICE guidance. This baseline and target is consistent with the **Wales National Optimal Pathway** for suspected pancreatic cancer, which recommends nutritional screening and consideration of PERT at the first CT scan suspicious of pancreatic cancer, along with referral to dietitian.<sup>31</sup>

2. **Welsh Health Boards must take action to ensure the effective prescription of PERT**

The NICE guidelines and NICE quality standards are recognised in Wales.<sup>32</sup> To ensure that the NICE guidelines on PERT have been implemented, Health Boards 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 Boards 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 Wales 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 appreciate 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](mailto:emily.waller@pancreaticcancer.org.uk), who will be happy to make the suitable arrangements.

Yours sincerely,

Pancreatic Cancer UK and our undersigned supporters