

Russell George MS  
Chair of the Health and Social Care Committee  
Welsh Parliament  
Cardiff Bay  
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Dear Mr George,

I'm getting in touch in the hope that the Health and Social Care Committee will formally recognise Pancreatic Cancer Awareness Month this November.

As you will no doubt be aware, pancreatic cancer is the deadliest common cancer. It affects more than 500 people a year across Wales.

Sadly, awareness of the symptoms of pancreatic cancer is devastatingly low – only 1 in 3 people can name a symptom of pancreatic cancer. This is one of the reasons why three in five people will be diagnosed at a late stage, when curative surgery is no longer possible – and why, in turn, **over half of all people diagnosed will die within three months.**

This low symptom awareness, and its catastrophic impact, make clear how hugely important Pancreatic Cancer Awareness Month is.

This year, to mark the month, we're focussing on the importance of a simple tablet – Pancreatic Enzyme Replacement Therapy (PERT) – which can help stop people with pancreatic cancer starving.

The symptoms of pancreatic cancer can have a very serious and distressing impact. People are often unable to digest their food, ultimately starving the body of nutrients and calories – leading to rapid weight loss, malnutrition and loss of muscle mass. But PERT can help with these symptoms, help people keep on weight, and even help make them eligible for life-saving surgery.

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 are running a 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 act 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 proactively 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 the noting of this letter and the consideration of the recommendations above, as well as any action the Committee might be able to take to ensure their adoption.

Yours Sincerely,



Diana Jupp  
**Chief Executive  
Pancreatic Cancer UK**