

**Pancreatic  
Cancer  
UK**



# **Transform lives: Prescribe**

**Improving access to Pancreatic Enzyme Replacement  
Therapy (PERT) for people with pancreatic cancer**

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**May 2021**

# Executive Summary

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**Pancreatic cancer is the deadliest common cancer, with half of people dying within three months. In these short months, people are likely to experience extremely distressing symptoms. In particular, people are often unable to digest their food, ultimately starving the body of nutrients and leading to rapid weight loss and malnutrition.**

**But a simple, widely available prescription can change this. That simple prescription is Pancreatic Enzyme Replacement Therapy (PERT).**

PERT replaces the digestive enzymes that many people with pancreatic cancer can no longer produce, allowing food to be digested and absorbed by the body. As a result, people have a better quality of life and can gain the strength to undergo treatment, which can in turn extend survival.

**NICE guidelines clearly recommend that PERT should be considered for people with both operable and inoperable pancreatic cancer. Yet despite this, only half of people with pancreatic cancer are being prescribed PERT.**

This injustice is not felt equally by all with pancreatic cancer. Those whose cancer is operable are more likely to be prescribed PERT than those whose cancer is inoperable, and PERT is more likely to be prescribed in specialist surgical centres than in non specialist care.

This variation in PERT prescription rates is largely driven by differences in awareness, nutritional expertise, and ultimately, the stage that people with pancreatic cancer are diagnosed. As a result, there are low levels of awareness about nutritional care within non-specialist care settings, where people with inoperable pancreatic cancer are cared for.

This problem needs to be urgently addressed. Currently, diffusion of knowledge and expertise about nutritional care spreads far too slowly for people with the quickest killing cancer. We need to now urgently drive and spread improvements in pancreatic cancer care – particularly where quick, easy, well established solutions, such as PERT, already exist.

Pancreatic Cancer UK is doing its part: we are working in partnership with clinicians, and developing resources and training, to support the healthcare community to drive up PERT prescription rates. But we can't do this alone.

To truly solve this problem, there must be top down national prioritisation. As currently, system-wide barriers are blocking PERT prescription, primarily due to a lack of expertise and prioritisation about nutritional care.

# Recommendations

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## **1. PERT must be made a UK-wide priority in pancreatic cancer care through the implementation of national targets.**

PERT needs to be clearly outlined as a national priority within pancreatic cancer care to overcome the system-wide barriers to prescription. Without setting this national focus, and without corresponding leadership from national and local health bodies, diffusion of knowledge and expertise will continue to spread far too slowly for people with the quickest killing cancer.

## **2. Local health bodies must take action to ensure the effective prescription of PERT**

We need to ensure there is no variation in PERT prescription for pancreatic cancer. Where you are treated, and the stage of your cancer, must have no bearing on your likelihood of getting this crucial prescription. To ensure the effective prescription of PERT, local health bodies should:

- Audit their services in line with national guidelines and ensure that they are considering PERT for all pancreatic cancer patients from the point of diagnosis.
- Highlight national guidance on pancreatic cancer and share and promote Pancreatic Cancer UK's tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.
- Integrate PERT into the pancreatic cancer care pathway from the point of diagnosis, as a central component of best supportive care and cancer prehabilitation.

## **3. Healthcare professionals must consider PERT for people with pancreatic cancer, at the point of diagnosis**

- To ensure that all patients are considered for PERT, every healthcare professional involved with the care of people with pancreatic cancer needs to be aware of PERT.
- All healthcare professionals involved with pancreatic cancer care need to pro-actively prescribe PERT where appropriate, at the point of a patient's diagnosis.

# Introduction

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**Pancreatic cancer is the deadliest common cancer. Most people will receive no treatment and more than half will die within three months. [1] In these short months, people are likely to experience extremely distressing physical and psychological symptoms and half will not get the help they need. [2]**

The most common symptoms that people with pancreatic cancer need support with are digestion problems. This includes bloating, wind and bowel problems, and is often combined with weight loss, difficulty eating and loss of appetite. [2]

These symptoms are primarily caused by the pancreatic tumour reducing the pancreas' ability to produce enzymes for digesting food – a condition known as Pancreatic Exocrine Insufficiency (PEI).

PEI can be caused by the pancreatic tumour obstructing the supply of enzymes to the digestive tract, or by the removal, partial removal or reconstruction of the pancreas during surgery. PEI is common in both people who have received surgery for pancreatic cancer and in those with inoperable disease [3] [4].

A key function of the pancreas is to produce enzymes to digest food, however, PEI reduces these digestive enzymes. As a result, people are unable to digest food, ultimately starving the body of nutrients and leading to malnutrition, muscle loss and rapid weight loss. [5]

Despite the high burden of nutritional and digestive issues caused by pancreatic cancer, there is a widespread lack of healthcare professional awareness about nutritional care. As a result, a diagnosis of PEI is commonly missed. The Pancreatic Cancer UK patient and carer survey recently found that nearly a third of people with pancreatic cancer reported that healthcare professionals had not discussed ways to manage nutritional or digestive symptoms with them and 3 in 4 people reported that they didn't get all the support they needed with nutritional and digestive symptoms. [6]

Despite nutritional support being essential for everyone with pancreatic cancer, there is not equal access to this support. People with inoperable pancreatic cancer are more likely to report a lack of support with digestive symptoms, compared to people with operable pancreatic cancer. [2] As a result, people with the poorest chance of survival are receiving the least support with their digestive symptoms.



# The impact of Pancreatic Exocrine Insufficiency (PEI)

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**Pancreatic Exocrine Insufficiency (PEI) can lead to loss of appetite, rapid weight loss and malnutrition. A recent Pancreatic Cancer UK patient and carer survey recently found that 8 in 10 people had lost more than a stone, with 1 in 3 people losing over three stone, as a result of pancreatic cancer. [6]**

This is clinically important as people experiencing malnutrition and weight loss have reduced physical fitness, reduced response to treatment, and lower survival. [7] [8] [9]

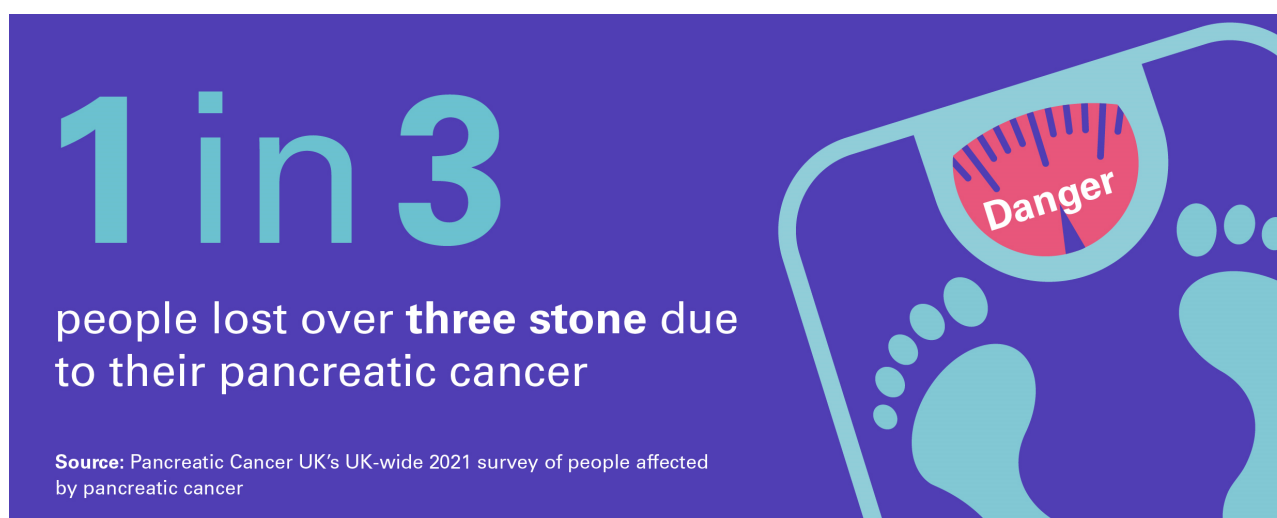
Untreated PEI has also been shown to increase people's length of hospital stay and post-operative complications. [10]

Therefore, addressing nutritional symptoms and treating PEI is essential to help people gain the fitness and strength to undergo and recover from treatment, and is a key part of cancer prehabilitation and rehabilitation. [11]

PEI also commonly causes distressing nutritional and digestive symptoms for people with pancreatic cancer. These distressing nutritional and digestive symptoms lead to a worse quality of life and can prevent people from enjoying everyday activities. [12] [6]

The Pancreatic Cancer UK survey found that for 3 in 4 people, digestive and nutritional symptoms had a significant impact on their enjoyment of hobbies, interests and social activities. [6]

The impact also extended to people's ability to leave the house. Considering that people with pancreatic cancer have very limited survival, such a reduction in the ability to enjoy daily activities in the final months of life has the potential to be devastating.



# The benefits of Pancreatic Enzyme Replacement Therapy (PERT)

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**Pancreatic Enzyme Replacement Therapy (PERT) is an oral, readily available and low-cost supplement that replaces the digestive enzymes that people with pancreatic cancer are no longer producing. These enzymes allow food such as protein, carbohydrates and fats to be digested and the nutrients and calories to be absorbed by the body.**

PERT is not a new medicine. Replacement enzymes have been used since the 1800s and PERT was first recognised in national pancreatic cancer guidance over 15 years ago. [13] In 2018 the NICE guidelines for pancreatic cancer recommended that both people with operable and inoperable pancreatic cancer are prescribed PERT. [14]

PERT is beneficial for all stages of pancreatic cancer. PERT has been associated with improved median survival in both people who have surgery and those who cannot have surgery. [15] [16] [17]

It has even been associated with improved survival for people with late-stage disease who are receiving no other active treatment. [18] This is emphasised in the NICE Quality Standard for pancreatic cancer, which highlights the prescription of PERT for inoperable patients as a priority area in pancreatic cancer care. [19]

Ultimately, PERT is a simple, cost-effective, well-established and readily available prescription, with strong clinical evidence about, and consensus for, the widespread benefits for pancreatic cancer patients. Yet despite this, the usage and uptake of PERT remains inadequate.

-  **PERT allows food to be digested and absorbed, helping people to increase their calorie intake and gain weight. [20]**
-  **PERT can reduce distressing symptoms, such as diarrhoea, pain, fat in stools and bloating. [21] [6]**
-  **PERT can improve people's quality of life, with 74% of people affected reporting that PERT improved their quality of life. [6]**
-  **PERT can improve people's ability to tolerate and recover from treatment and nutritional care is a key component of cancer prehabilitation [11] [22]**
-  **PERT is safe, has few side effects and is low cost compared to other cancer treatments. [23] [24] [25] [5]**



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I had a blockage in my bowel and my appetite disappeared altogether. I was revolted by the idea of food and lost four stone very quickly. After the bypass operation I needed to digest my food to stay alive.

I was prescribed Pancreatic Enzyme Replacement Therapy, also known as Creon, and once I'd learned to take it during meals, it really worked. In two months I've put on nearly half the weight I lost.

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James, who was diagnosed with pancreatic cancer in November 2020

# Who's missing out on PERT?

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**A recent study has revealed that only 55% (736 out of 1350) of people with pancreatic cancer in the UK were prescribed PERT in 2018. [26]**

Even within that figure, further variation in PERT prescription rates exist between centres and even within the same centre. This variation is largely driven by differences in expertise, clinical pathways and ultimately, the stage at which people with pancreatic cancer are diagnosed.

People who can not have surgery are less likely to receive PERT compared to people who have surgery. 98% of people who had curative surgery were prescribed PERT, compared to only 45% of people with inoperable pancreatic cancer. [26]

The same study also found that people treated in non-specialist centres were less likely to receive PERT compared to people who are treated in specialist surgical centres – known as hepato-pancreatobiliary (HPB) centres.

This variation has a significant impact on overall PERT prescription rates as most people with pancreatic cancer are diagnosed at a late stage and treated outside of specialist surgical centres in non-specialist care.

It also suggests that knowledge and expertise about optimal nutritional care often spreads too slowly outside of the specialist surgical centres.

A recent study showed that only

**50%**

of UK-wide  
pancreatic cancer  
patients **were  
prescribed PERT**

**Source:** The RICOCHET Study Group, West Midlands Research Collaborative. Pancreatology, May 2021.





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We were all quite stunned at mum's diagnosis of pancreatic cancer. The pancreatic cancer stopped mum's pancreas from making the enzymes the body needs to digest food. She was unable to eat, drink – or even take medication without vomiting.

We were never told about Pancreatic Enzyme Replacement Therapy (PERT) – inexpensive tablets that could have helped her digest food and build strength for treatment.

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Marie, whose mother died of pancreatic cancer in 2020.



# Why isn't PERT being prescribed?

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The failure to prescribe PERT has been well-documented, but until now, there has been limited understanding as to why it is happening. To fill these gaps in knowledge, Pancreatic Cancer UK commissioned Savanta ComRes to undertake 17 qualitative in-depth interviews of healthcare professionals involved in the care of people with pancreatic cancer across a range of settings and roles, aiming to gain a richer understanding of the perceptions, barriers and solutions to prescribing PERT. The following were found to be three key barriers to prescription:

## 1. Low awareness and expertise

Healthcare professionals reported that a central reason for low PERT prescription was lack of awareness and expertise. Awareness of PERT was reported to arise through sporadic and informal training while others reported that knowledge of PERT was self-taught or through experience. Both of these factors mean that healthcare professionals who have less exposure to people with pancreatic cancer are less likely to be aware of PERT and its benefits. Supportive care and PERT are also not routinely discussed at MDT meetings, with PERT prescription relying on informal patient discussions raised on a case-by-case basis.

The lack of a formal process for PERT prescription combined with a widespread lack of awareness means that people with pancreatic cancer are often sent home without ever being made aware of PERT. As a result, the most common patient-reported barrier to accessing PERT was simply 'not being told about PERT'.

## 2. Variation in access to specialists

People who are treated in specialist pancreatic cancer centres are more likely to be treated by healthcare professionals with higher levels of expertise in treating pancreatic cancer, who are aware of PERT and its benefits. Therefore, in these settings, PERT is often considered as standard. However, the majority of pancreatic cancer patients are treated in non-specialist care where there is less awareness and expertise of PERT and where there is also less contact with specialist pancreatic cancer healthcare professionals. This variation in nutritional expertise has a significant impact on overall PERT prescription rates as most people are diagnosed with pancreatic cancer at an inoperable stage and are treated in non-specialist care.

People with a terminal diagnosis may be cared for by palliative care teams, who may not have expertise on cancer-specific treatments such as PERT. Likewise, in primary care, GPs only see limited numbers of people with pancreatic cancer and as a result tend to rely on the guidance of specialists. However, as many people with pancreatic cancer may not see a pancreatic/HPB specialist, gaps in symptom management begin to appear.

Access to a dietitian is also essential for optimal management of PERT. Dietitians have a crucial role in prescribing PERT and delivering wider nutritional support. Patients who have access to a dietitian are more likely to be prescribed PERT. [26] However, a Pancreatic Cancer UK survey found that only 45% of people with pancreatic cancer had had an appointment with a dietitian. [6]

### 3. Misconceptions around PEI

Under-diagnosis of PEI was reported by healthcare professionals to be another reason for PERT prescriptions being missed.

The main reasons for under-diagnosis include the symptoms of PEI being mistaken for the underlying cancer or patients not reporting symptoms. The poor sensitivity of the diagnostic test (faecal elastase) is also a perceived barrier to diagnosing PEI. However, a diagnosis of PEI can often be determined without the need for the faecal elastase test.

There are also misconceptions around the diagnostic symptoms of PEI. Excess fat in stools (steathorrhoea) is the most visible symptom of PEI and is often thought to be the cardinal symptom of PEI. However, often PEI can present more subtly. For example, people with pancreatic cancer may subconsciously move to a low fat diet to self-manage digestive symptoms. As a result, there would be less excess fat in the stools and the diagnosis of PEI can be missed, despite the presence of other underlying symptoms of PEI such as weight loss and malnutrition.

# 1 in 3

people with pancreatic cancer reported that healthcare professionals had not discussed ways to manage their nutritional or digestive symptoms with them



**Source:** Pancreatic Cancer UK's UK-wide 2021 survey of people affected by pancreatic cancer

# What needs to happen now?

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To ensure everyone with pancreatic cancer is considered for PERT, the institutional barriers to PERT prescription which have led to the low awareness and expertise we are currently facing must be addressed.

## **PERT must be made a UK-wide priority in pancreatic cancer care through the implementation of national targets.**

The first step towards setting targets and driving quality improvement is better data. Without this, we cannot begin to understand or improve services. National public health bodies and cancer data registries in all nations need to publish more and better data on PERT prescription and efficacy in pancreatic cancer.

NHS targets must then be created across the UK for PERT prescription, supported by clear and strong leadership from both national and local health bodies. Without this national focus, diffusion of knowledge and expertise will remain too slow and overly dependent on local healthcare professionals with an interest in nutritional care, championing and driving PERT in their area.

People living with the quickest killing cancer, where 1 in 4 people die within a month, cannot afford to wait for a gradual change in practice. National top down prioritisation is needed now to urgently drive and spread improvements in pancreatic cancer care – particularly where quick, easy, well established solutions, such as PERT, already exist.

In England, Wales and Northern Ireland, the NICE guidelines and NICE Quality Standards are recognised. Therefore, for these nations a national target should be introduced to monitor and enforce the existing NICE Quality Standards. The NICE Quality Standard, and the five quality statements within it, highlight the priority areas for improvement in pancreatic cancer, where there is currently significant variation in care.

The NICE Quality Statement 4 for pancreatic cancer, aligns with the current inequality in PERT prescription for people with inoperable pancreatic cancer and states that 'Adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin [PERT]'. [27]

These quality statements should be used by national and local health bodies to plan quality improvement, to commission high quality services and used as an evidence-based quality indicator.



# England

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NHS England should set a top down national focus and prioritisation on PERT use within pancreatic cancer care.

## **NHS England should:**

- Establish a baseline for PERT prescription in England, through auditing and publishing more data on PERT prescription. Pancreatic Cancer UK will collaborate with NHS Digital to publish a baseline on PERT prescriptions for people with pancreatic cancer, however, moving forward NHS Digital should publish this data annually, to track progress and compliance with the NICE guidelines.
- Introduce a target or quality indicator for the prescription of PERT for people with pancreatic cancer, aligned with the NICE Quality Statement four.
- Include a target or quality indicator for PERT as part of the pancreas service specification for specialist centres.
- Prioritise PERT as a national pancreatic cancer priority for Cancer Alliances and encourage Cancer Alliances to promote Pancreatic Cancer UK's training and resources to drive up prescription rates.

## **Local Health bodies:**

- Cancer Alliances should highlight the NICE guidance and share and promote Pancreatic Cancer UK's PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.
- Clinical Commissioning Groups (CCGs) should audit local services and ask local providers in secondary care to review their guidance on PERT to ensure that they are commissioning care in line with the NICE guidelines.

# Scotland

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Scotland is leading the way in transforming the UK's PERT prescription rates. It has already committed to a number of actions to rectify low prescription levels:

- Redesigning the first six weeks of the diagnostic pathway for pancreatic cancer, including prescribing PERT
- Developing a checklist to ensure that all elements of pancreatic cancer care, including nutrition and PERT, are discussed with patients and delivered
- Undertaking a retrospective baseline audit to measure PERT prescription
- Measuring PERT prescription from diagnosis onwards, as part of a new 'best care package' pathway
- Investing £1.15 million into a prehabilitation programme, with access to timely treatment being a key priority.

**But we still need a concerted, long-term, system-wide effort to effect the greatest change.**

## **NHS Scotland should:**

- Introduce a national PERT target through a Quality Performance Indicator (QPI) in the 2022 review, to consolidate and track progress of the recent commitments and ensure a Once for Scotland approach.

## **Local Health Boards should:**

- Review their current guidance on PERT and share and promote Pancreatic Cancer UK's PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.

# Wales

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The NICE guidelines and quality standards for pancreatic cancer are recognised in Wales [28] and the Wales National Optimal Pathway for pancreatic cancer recommends the consideration of PERT at the first CT scan suspicious of pancreatic cancer [29].

To ensure that these national guidelines and optimal pathways are implemented.

## **NHS Wales should:**

- Establish a baseline for PERT prescription in Wales, through auditing and publishing more data on PERT prescription.
- Introduce a target for the prescription of PERT for people with pancreatic cancer, aligned with the NICE Quality Statement four.

## **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 considering PERT for all pancreatic cancer patients from the point of diagnosis. 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's PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.

# Northern Ireland

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The implementation of the new 10-year Northern Ireland cancer strategy presents a timely moment to set a national focus on PERT prescription for pancreatic cancer. PERT and nutritional support should be a key delivery of the strategy's focus on prehabilitation, rehabilitation and supported self-management.

## **The Northern Ireland Health and Social Care Board should:**

- Introduce a target for the prescription of PERT for people with pancreatic cancer, aligned with the NICE Quality Statement four.

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 nine months. [30]

## **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 considering PERT for all pancreatic cancer patients from the point of diagnosis. 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's PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.

# Healthcare professionals

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Healthcare professionals must consider PERT for people with pancreatic cancer, 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 are considered for PERT:**

- Every healthcare professional involved with the care of people with pancreatic cancer needs to be aware of PERT.
- All healthcare professionals involved with pancreatic cancer care need to pro-actively prescribe PERT, where appropriate, at the point of a patient's diagnosis.
- 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 healthcare 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.

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Doctors wouldn't leave heart, lung or kidney failure untreated, but far too often we leave pancreas failure untreated. This leads to weight loss, abdominal cramps and lack of ability to undergo treatment. PERT is simple and corrects this.

There should be an automatic association when treating pancreatic cancer patients. Think pancreatic cancer, think pancreas failure, think PERT.

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**Keith Roberts, Consultant pancreas surgeon at University Hospitals Birmingham**



# Conclusion

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Ultimately, there is no good reason why so many people with pancreatic cancer are missing out on PERT, a simple, well-established and readily available prescription. Nearly half of people with pancreatic cancer are needlessly experiencing distressing symptoms which could be easily alleviated to significantly improve the quality of their life. PERT could help them tolerate treatment, which may in turn extend life.

The solutions to resolve this problem are clear, but they will require focused and collaborative work by healthcare professionals, commissioners and service providers across the United Kingdom. At Pancreatic Cancer UK, our work to improve outcomes is already underway. We now need to work together to ensure that PERT is urgently made a national focus in the care of people with pancreatic cancer.

For more information on this issue, or to discuss working together to drive up outcomes for people with pancreatic cancer, please contact [policy@pancreaticcancer.org.uk](mailto:policy@pancreaticcancer.org.uk).

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Pancreatic Cancer UK  
Westminster Tower  
3 Albert Embankment  
London SE1 7SP

**[policy@pancreaticcancer.org.uk](mailto:policy@pancreaticcancer.org.uk)**  
**[pancreaticcancer.org.uk](http://pancreaticcancer.org.uk)**

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