

Introduction to our Transform lives: Prescribe campaign

Diana Jupp

CEO

Pancreatic Cancer UK

#TransformLivesPrescribe



“My mum deteriorated pretty quickly. The flesh would hang off her. She experienced regular bouts of explosive diarrhoea, which meant that she didn’t want to socialise with people.

These symptoms were devastating and destroyed normal family life for all of us.”

Marie

Pancreatic Enzyme Replacement Therapy (PERT)



PERT is also known
by the brand names:
Creon®
Pancrease®
Nutrizym®
Pancrex®

- ✓ Alleviates debilitating symptoms and improves quality of life
- ✓ Builds tolerance to life-extending treatments
- ✓ Inexpensive to the NHS
- ✓ Recommended by NICE

"As a GP, whenever I see a diagnosis of pancreatic cancer, I check to see if the person has a repeat prescription for PERT.

These replacement enzymes are so important for digesting food and improving quality of life and outcomes."



Dr Ruth Corbally
Macmillan GP Cancer Lead, Powys Teaching Health Board

"As soon as our investigations detect pancreatic cancer, that's when we consider PERT. This replaces enzymes used for digestion and is vital to keep up the patient's strength and support with debilitating symptoms.

It should be prescribed from the point of diagnosis."



Dr Andrew Millar
Consultant Gastroenterologist and Hepatologist
North Middlesex University Hospital

"The sooner our pancreatic cancer patients are put on pancreatic enzyme replacement therapy (PERT), the sooner we can support them with their symptoms, or give them the strength they need for surgery."



Nigel Jamieson
CRUK Clinician Scientist and Consultant Pancreatic Surgeon
Glasgow Royal Infirmary

The problem with PERT prescription rates

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.

Why isn't PERT being prescribed?

- Low awareness and expertise about nutritional care - particularly in **non-specialist care settings**
- Patients with a **poorer prognosis** being **disproportionally impacted**

People who've had surgery are **twice as likely** to be prescribed the capsules they need to digest food again than people whose pancreatic cancer is too advanced to operate on

Operable

98%

Inoperable

45%

% of people prescribed PERT

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





Transform lives: Prescribe

Right now, half of pancreatic cancer patients are not getting the prescription they need to be able to digest their food. Together we can change this.



Transform lives: Prescribe

1. Working with **NHS decision makers**
2. Working with **health professionals**
3. Supporting **patients**

1. Working with NHS decision makers

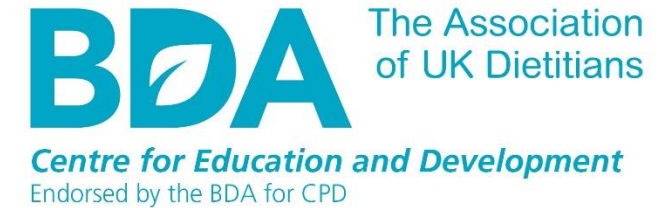
- The NHS across all four nations should **implement national targets** to make sure people with pancreatic cancer are prescribed PERT
- Local health bodies should **take action to ensure the effective prescription** of PERT

2. Working with health professionals

- Healthcare professionals should **consider PERT for people with pancreatic cancer as standard**, at the point of diagnosis.
- There should be a **nominated local healthcare professional to champion PERT**, who can ensure that colleagues are aware and trained to prescribe PERT.

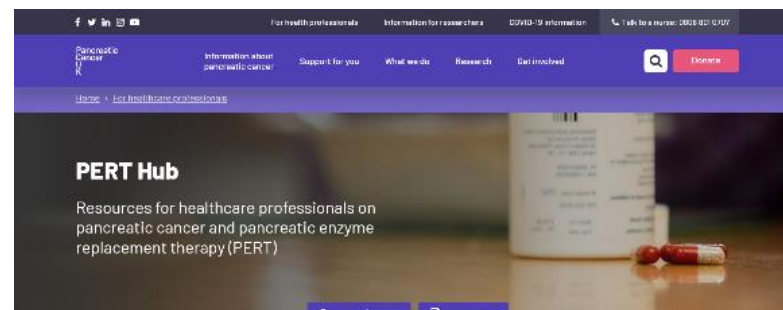
2. Working with health professionals

- Online course about PERT endorsed by the British Dietetic Association and Pancreatic Society of Great Britain & Ireland
- PERT quick reference guide
- Virtual PERT educational session with specialist dietitian Mary Phillips – October 2021



PERT Hub

www.pancreaticcancer.org.uk/health-professionals/pert-hub/



Right now, half of pancreatic cancer patients are not getting the prescription they need to be able to digest their food. Together we can change this.

When cancer affects the pancreas, it can reduce the number of enzymes it produces to break down food. The body begins to starve – unless pancreatic enzyme replacement therapy (PERT) is prescribed. PERT enables food to be digested, building tolerance to treatment. It reduces debilitating digestive symptoms and improves the quality of patients' lives. It's vital that all healthcare professionals consider PERT for their pancreatic cancer patients.

[Manage consent](#)

Join our online Breakfast Briefing on 16th June to find out more about our Transform lives: Prescribe campaign and what you can do to support

[Sign up now](#)

PERT training – Online course

A health professional's guide to pancreatic cancer and PERT, endorsed by the British Dietetic Association and Pancreatic Society of Great Britain and Ireland.

Free | 30 – 45 minutes

[Take our short course](#)



Quick guide on PERT

A two-page info sheet covering the key things you need to know about PERT and pancreatic cancer to advise your patients. Content references are available [here](#).

[Download your free guide](#)



Information for your patients

Download and order our PERT fact sheet, digestive symptoms leaflet, diet booklet and more.

[Get resources for your patients now](#)



“PERT really has changed my life. The one thing that's changed my life, [taking PERT is] a small price to pay for having a virtually symptom free life now.”

Stuart, pancreatic cancer patient

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

Keith Roberts, Consultant Pancreas Surgeon, University Hospitals Birmingham

Check out our [Transform lives: Prescribe](#) campaign.

Sign up to our Health Professional Support and Information Bulletin

[Health Professional Support and Information Bulletin](#)

Get in touch

If you have any questions or comments, please get in touch with us at hnnetwork@pancreaticcancer.org.uk

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Pancreatic Cancer UK, a registered charity in England & Wales (1132252) and Scotland (SC049522), is a guarantee, registered in England and Wales, company number 15558451.

3. Supporting patients

www.pancreaticcancer.org.uk/diet

Do you have problems digesting your food?

The pancreas makes enzymes which help to break down food. This is part of digestion. Pancreatic cancer and surgery to remove the cancer can cause problems with digestion. You might get some of these symptoms:

- losing your appetite
- losing weight, or struggling to put weight back on
- indigestion or heartburn
- runny poo (**diarrhoea**)
- problems emptying your bowels (**constipation**)
- pale, oily, floating poo (**steatorrhoea**)
- tummy pain or discomfort
- bloating or wind
- feeling full up quickly
- needing to poo urgently, especially after eating



If you have pancreatic cancer and have these symptoms, you may need to take capsules. These replace the enzymes your pancreas normally makes.

These are called **Pancreatic Enzyme Replacement Therapy (PERT)**. Common brands are **Creon®**, **Pancrease®**, **Nutrizym®** and **Pancrex®**.


You take these capsules when you eat and they help digest your food.

They can:

- help manage your symptoms
- help you to cope better with treatments, such as chemotherapy or surgery
- make a big difference to how you feel.

If you have these symptoms but haven't been told about PERT, ask your doctor, nurse or dietitian about it.

You could show them this leaflet.



Right now thousands of people with pancreatic cancer don't have access to a simple prescription that could stop them starving. **That's unacceptable.**

When cancer attacks the pancreas, it stops it from breaking down food. The body literally begins to starve. Readily available tablets called Pancreatic Enzyme Replacement Therapy (PERT) can change that. But, shockingly, half of people with pancreatic cancer are never prescribed them.

We're calling on the NHS to prescribe what people with the quickest killing cancer urgently need to live the time they have left to the fullest.

Take a stand with us today.

"Mum was skeletal. She couldn't eat, she couldn't sit at the table."

Marie, whose mum died from pancreatic cancer.

Sign our open letter to make sure people get the prescription they urgently need.

9,382 have signed. Help us get to 65,000.

First name*

Last name*

Email address

Postcode*

Telephone

Why does this matter to you?

- I have a personal connection (myself, family, friend)
- I don't have a connection but I want to help

If you have your email address and/or phone number we'll use these to keep you updated on our news and how you can get involved through petitions, campaigning, volunteering, fundraising and donating. If you're an existing supporter and haven't provided contact details above, we'll keep contacting you in the same way.

Our Privacy Notice has further details on how we use and store your data. It explains how we use data to make our communications relevant and effective.

Add your support now →

Cancer patients can starve when NHS fails to give pills

BY GEMMA BRADLEY

HALF of pancreatic cancer patients are at risk of starvation because the NHS does not prescribe the necessary tablets, a charity has warned.

Watchdog NICE recommends pancreatic enzyme replacement therapy tablets for sufferers.

The PERT pills help patients tolerate treatment and manage pain, diarrhoea, and weight loss. Birmingham

WARNING Charity's Diana Jupp

University researchers found, without the tablet, patients cannot digest food. Marie Morris, 44, who lost her mother to the disease in April 2020, said by the end her mother was "skeletal".

Study author Richard Wilkin said: "Despite national guidance, there is a wide variation and under-treatment with PERT."

Diana Jupp, chief executive of Pancreatic Cancer UK said: "Proven, inexpensive medication is available."



NI woman on surviving rare cancer after doctors found mango-sized tumour

Claire Scott, now 30, is backing Pancreatic Cancer UK's new campaign to ensure people with the disease are prescribed tablets they need to stop them from starving

SHARE     COMMENTS By Sarah Scott 05:00, 28 MAY 2021 **NEWS**



📷 Claire with mum Terri



Transform Lives: Prescribe | Marie's Story

Watch on  YouTube



My mum, Josephine, unfortunately died of pancreatic cancer in April 2020.



U^W LIVE **DIANA JUPP**
Pancreatic Cancer UK



Transform lives: Prescribe

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

May 2021

Executive Summary

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.

Transform Lives: Prescribe

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.

3 in 4

people with nutritional or digestive
symptoms of pancreatic cancer
didn't get all the support they
needed with their symptoms



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



Transform lives: Prescribe



Transform lives: Prescribe

- *Transform lives: Prescribe* is a long-term campaign to improve PERT prescription rates
- Initial target to increase prescription rates from **50 to 75% by 2024**
- Monitoring progress

Together we can transform lives

- **Are you a health professional?** Please share our PERT hub among your networks
- **Are you someone affected by pancreatic cancer?** Please share our petition among your networks
- **Are you a government or NHS policy maker?** We'd love to meet with you to discuss ways to drive up PERT prescription rates nationally
- **Do you represent a local health body?** We'd love to meet to discuss ways to drive up PERT prescription rates in your local area
- **Are you a parliamentarian?** Please help us raise awareness of the importance of PERT by asking an oral or written question in Parliament.

Thanks for joining and helping us
spread the word about PERT!