

Transcript of 'Taking pancreatic enzyme replacement therapy' information video

Title slide: Taking pancreatic enzyme replacement therapy (PERT)

Jeni Jones, Specialist Nurse: My name is Jeni. I'm one of the specialists nurses working on the [Support Line](#) at Pancreatic Cancer UK.

The pancreas plays an important [role in digestion](#). It makes enzymes which help us to break down our food so that the nutrients can be used by the body. If a person has a pancreatic cancer, this can affect how many enzymes are made. It can also stop them from getting to where they need to be in the body.

If your pancreas is not producing enough enzymes, you may have the following [symptoms](#).

- Losing weight even though you're eating.
- Losing your appetite.
- Feeling full up even after a few spoonful's of food.
- Diarrhoea or constipation.
- Cramps, or bloating in your tummy.
- You may also have pale oily poo which smells horrible and doesn't flush very well.

The main way that these are managed is providing [pancreatic enzyme replacement therapy](#). These are capsules which are taken which replace the enzymes produced by the pancreas. They can make a big difference to how you feel and can help to control some of the symptoms. Some of the main types are Creon, Nutrizym, Pancrease and Pancrex.

Carol, in recovery from pancreatic cancer: When I was first prescribed the enzymes, I thought this is epic. It's something I've got to take every time I eat for the rest of my life. But being an asthmatic as well, I thought well I have to take my pump every day. It's just something I've got to do. Something I've got to do.

Stuart, living with pancreatic cancer: Creon really has changed my life. It's the one thing that's changed my life. Unfortunately, they're kind of ungainly pills to swallow and I have to take six or seven or eight every meal. But that's a small price to pay for having virtually a symptom free life now.

Jeni: Some types of pancreatic enzymes have a number after the name. This relates to the amount of enzymes in the capsule. For example, Creon 25,000 means there are 25,000 units in this capsule. Or

Nutrizym 22 means 22,000 units. The dose of enzymes which you need will depend on your symptoms and what you're eating.

You might start with a dose of at least 50 to 75,000 units for a meal, and 25 to 50,000 units for a snack. This may sound like a lot of enzymes, but it isn't as many as your pancreas would normally make. Don't worry about taking too many enzymes. Most people will need to increase their dose of enzymes. Your doctor, nurse or dietitian will be able to help you manage this.

If you're still having symptoms and are taking good doses of pancreatic enzymes, then speak to your doctor or nurse and maybe they will be able to help you manage this. You may need to increase the dose of your pancreatic enzymes. There may be other causes of your symptoms, which your doctor or nurse can also discuss with you.

Stuart: First of all, it had no effect at all, I was still getting the symptoms. My doctor told me take one pill with every meal. Turns out this was way, way, inadequate – not enough at all. One of the team said that I should up it to four or five pills per meal, that's 60,000 or 80,000 unit. Again, this proved to be too little and I was almost going to give up because it was having no effect at all. The symptoms are still there, the bloating, the diarrhoea, the vomiting, the nauseousness. And then one of the nurses said, no, no, no, you can't take too much. Just keep on taking it until it has an effect. It's different for every person. I took her advice and now I have six to eight with a meal. I have maybe one or two with a snack, I have one when I have a cappuccino because that's got calories milk in it that needs digesting. And so I take them throughout the day. And that's had the effect of just making me feel relatively normal. And my diets not restricted at all now, because I take the enzymes,

Jeni: Pancreatic enzymes should be [taken with all meals](#), all snacks, and any milky drinks that are more than 50% milk. If you're having a meal which is lasting for a long period of time, or you're having food that is more fatty than normal do remember to increase the amount of enzymes you take.

Pancreatic enzymes should be taken with cold water and not with hot drinks. If you struggle to swallow the capsules, do speak to your [dietitian](#) or nurse and they may be able to help you to find other ways to take them.

Carol: Taking the enzymes and the [nutrition shakes](#) that I have is helping me to maintain a steady bodyweight. It's been able to maintain my physical abilities. I've still got a long road to go, but I'm getting fitter and stronger every day. And it thanks to the availability and taking these things that I am where I am.

Jeni: It's really important to speak to your doctor, nurse or dietitian about pancreatic cancer and how it is affecting your digestion. They can help you to take pancreatic enzyme replacement capsules and give you advice on diet and nutrition.

For more information about pancreatic enzyme replacement therapy, please visit pancreaticancer.org.uk/diet. You can call us on **0808 801 0707**. You can also email us on **nurse@pancreaticcancer.org.uk**