

# What I tell my patients about **encapsulating peritoneal sclerosis**

**Encapsulating peritoneal sclerosis (EPS) is an uncommon but serious condition that affects the bowel, meaning that it becomes partially or even completely blocked. EPS is most commonly a result of receiving peritoneal dialysis (PD), usually for several years, although in some cases it can occur after just a few months.**

The peritoneum is the membrane that lines the inside of the abdomen and covers most of the organs inside the abdominal cavity, including the bowel. Normally, the peritoneum is very thin and allows the loops of the bowel to slide around easily as food passes through (see Figure 1A). However, in many patients receiving PD, this membrane becomes thickened over time. This may not cause any problems, but in some cases the bowel can become covered in a sheet of fibrous tissue, which can constrict the bowel and stop it moving easily (see Figures 1B and 1C). When this happens, food can no longer pass through the bowel.

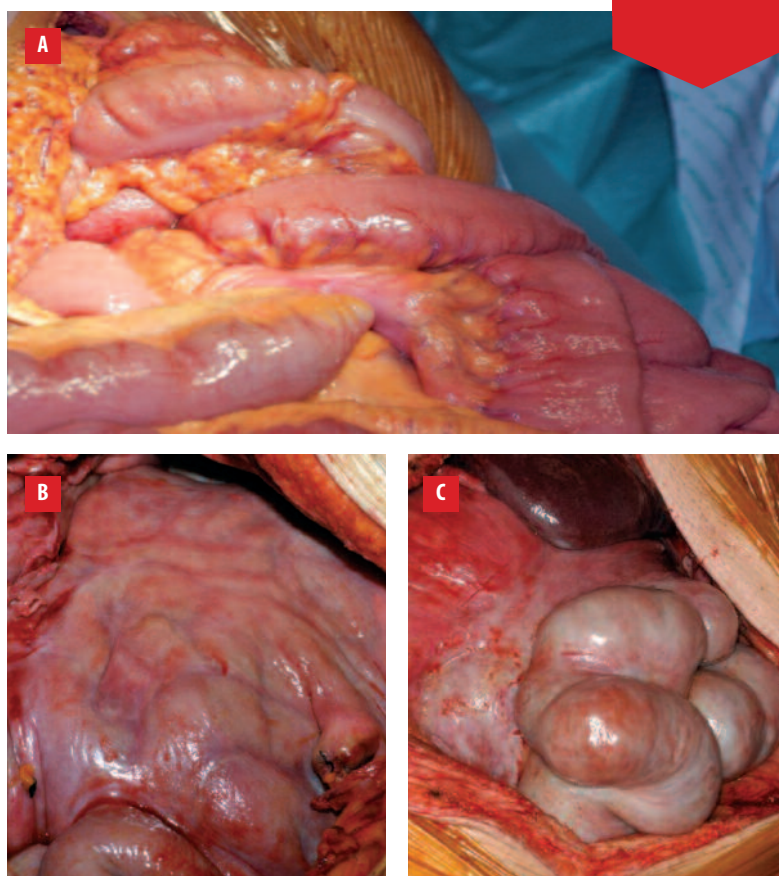
## **Causes of encapsulating peritoneal sclerosis**

The exact cause of EPS is not known but there are some risk factors that make EPS more likely:

- Prolonged time on PD: most people with EPS have been on PD for more than five years, and it is uncommon in patients with less than two years on PD
- Recurrent peritonitis or a single case of severe peritonitis caused by bacterial or fungal infections
- Use of many strong glucose dialysis bags to remove fluid.

However, there are many patients who do not develop EPS even though they have been on PD for many years, have used strong glucose dialysis bags and have had episodes of peritonitis. It is not known exactly why some people experience severe problems with EPS while others do not.

EPS usually develops shortly after stopping PD. Patients may stop PD because they have swapped to haemodialysis or because they have had a kidney transplant.



■ **Figure 1.** Normal bowel (A), fibrous sheet covering the bowel (B) and the bowel encased in a cocoon of fibrous tissue (C)

## **Symptoms of encapsulating peritoneal sclerosis**

As the bowel becomes encased in the thickened sheet of fibrous tissue, food cannot easily pass through the small bowel and can cause a blockage. The build-up of food causes nausea and vomiting, which makes it difficult to eat, so patients often experience dramatic weight loss and, consequently, can become very weak. Patients may also experience watery diarrhoea, as some liquid may be able to get past the blockage, but more solid food cannot. This may be accompanied by bouts of abdominal pain. It is also very common for fluid to collect in the abdomen, which causes bloating.

A CT scan (Figure 2) of the abdomen is used to identify any blockages in the bowel, show fluid build up in the abdomen and see if the bowel is trapped (see Figure 3). A CT scan can sometimes also show that the bowel wall has become thickened. Before

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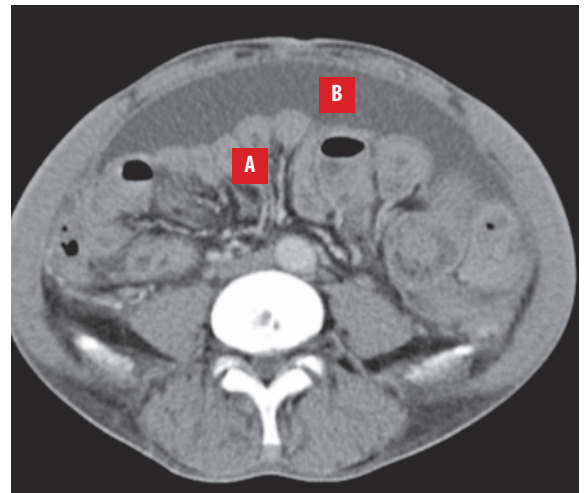
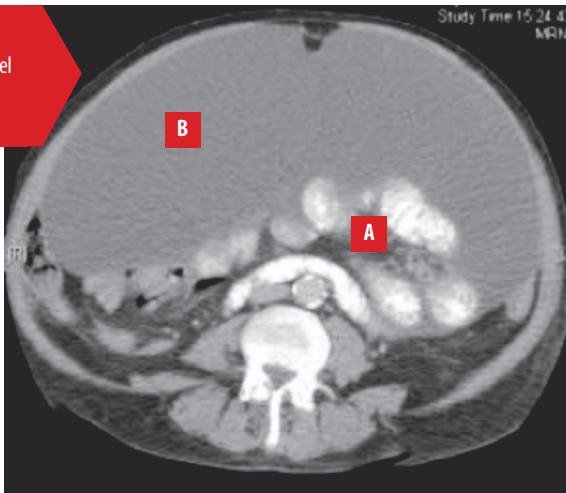
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■ **Figure 2.** A patient undergoing a CT scan



■ **Figure 3.** CT images showing encapsulated bowel (A) and fluid collections (B) causing bloating



having a CT scan, patients are asked to drink a liquid, or have an injection, which highlights the bowel on the CT pictures.

### **Treatment of encapsulating peritoneal sclerosis**

Once EPS has developed, it will not go away without surgical treatment. The severity of symptoms varies, so some patients will need hospital treatment and urgent surgery, while others can remain at home and manage symptoms by modifying their diet until they can have surgery.

Surgery involves carefully removing the fibrotic membrane to allow the bowel to move more freely, enabling food to pass through. The surgery can take a long time, typically four to eight hours and occasionally much longer. As most hospitals do not

have experience of operating on patients with EPS, patients are referred to one of two nationally designated hospitals with surgical experience of this condition; Cambridge and Manchester.

Patients must be as fit as possible before surgery. If a patient is experiencing frequent vomiting, they will need to have a nasogastric tube placed in hospital. This is a long thin tube, which is passed through the nose and into the stomach, to keep the stomach empty and stop vomiting. This prevents a dangerous complication called aspiration pneumonia, which is the result of inhaling stomach contents into the lungs during a vomiting episode, making a general anaesthetic unsafe.

Because patients with EPS become malnourished and lose a lot of weight, it is usually necessary to feed patients for one to two weeks with a special



intravenous feed called parenteral nutrition (PN). This type of feeding is necessary because patients cannot eat enough to get the necessary calories and nutrients to maintain their weight without vomiting. PN is usually given as an inpatient, and involves having a line inserted into one of the large neck veins to administer the PN fluid. Unless the patient has had a kidney transplant, and is able to pass out the extra fluid as urine, daily dialysis is needed.

If left untreated, patients can get increasingly ill over time, and up to 50% of those affected may die as a result of the condition. Without treatment, patients may require hospitalisation to manage the pain, provide PN or drain fluid from the abdomen or from around the lungs. In some cases, the bowel can perforate (develop a hole), which will require emergency surgery.

### Benefits of surgery

Approximately 70% of people who have had surgery are well one year later.

If the surgery is successful, patients should be able to eat normally and will not need further PN once they have recovered from the surgery. Nausea, vomiting and abdominal pain should stop, and weight should return to normal, although this may take some months. However, even after successful surgery, some patients may still experience frequent stomach rumbling or have to change eating habits, such as eating smaller meals more frequently and eating less fibre.

### How long do patients stay in hospital?

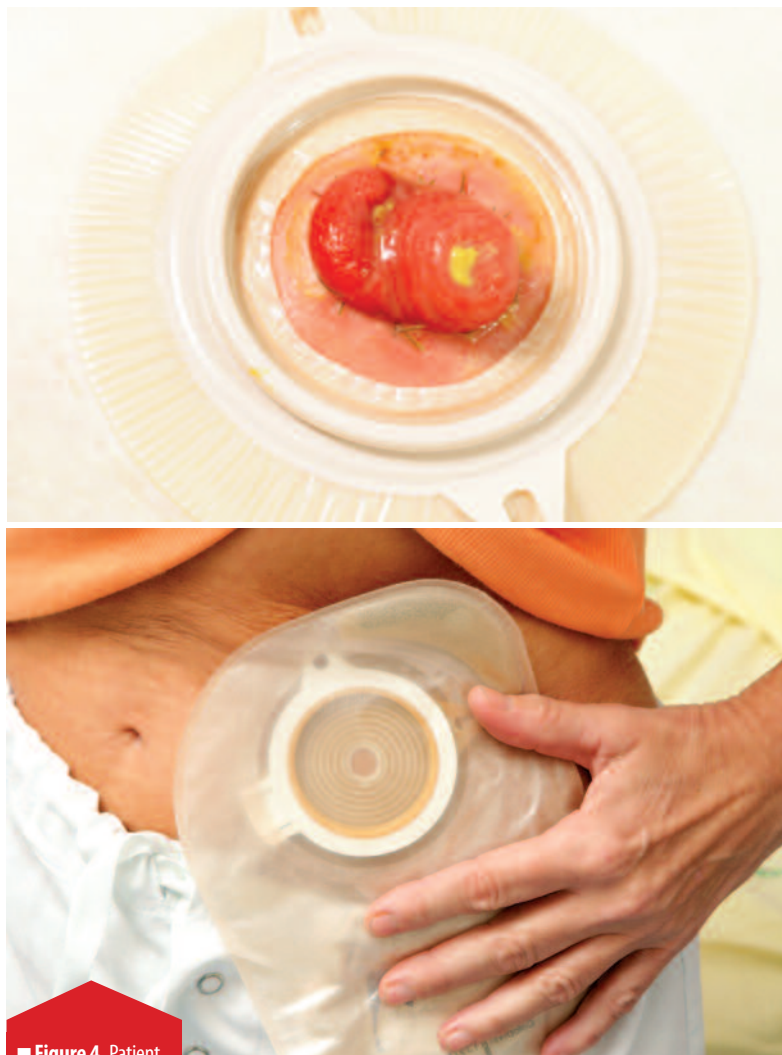
The recovery time after surgery for EPS is very variable and the average total length of stay in hospital is around 4–5 weeks. Patients will be admitted 1–2 weeks before the operation, so that they can receive PN to improve fitness for surgery. Most patients stay in hospital for about three weeks after the operation; some patients are discharged after 1–2 weeks, but others will have to stay longer, occasionally a few months.

For patients admitted for emergency surgery due to a perforation, there will be no time to give PN before surgery. As a result, the recovery time is often longer for these patients.

### Risks and complications of surgery

The surgical treatment for EPS is not without risk and we estimate that 10% of patients may die shortly after surgery, as a consequence of the treatment and its complications, although this depends on the level of fitness before surgery.

The risks are lowest if the patient is fit enough to be on the transplant waiting list or has just had a transplant; the risks are highest in those who have been considered unfit for a transplant.



■ Figure 4. Patient with a stoma (top) and bag (bottom)

### Stoma

If the fibrotic tissue is very difficult to remove and the bowel wall is very weak, it is possible that the bowel may tear during surgery. If this happens, or if the patient already has a hole in the bowel, an ileostomy (stoma) will be needed, where the bowel is brought out to the surface of the abdomen (see Figure 4). A stoma looks like a small spout and is similar in colour and texture to the inside of the mouth. It does not hurt or have any feeling. The bowel contents (faeces) will drain out into a bag, which is stuck securely to the skin around the stoma. About 10% of patients will require a stoma, although it is usually possible to reverse the stoma with another operation after a few months, allowing faeces to be passed as normal.

### Infection

Patients are given antibiotics to help prevent infection. However, some will already have infected fluid or tissue in the abdomen and some may develop an infection after the operation. Most of the time, the infections can be treated with antibiotics but in some cases the infection may be difficult to eradicate. Patients may develop a chest infection or an infection in the blood (septicaemia), which will need to be treated with intravenous antibiotics.

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### Re-operations

About one third of patients will need a second operation soon after the first. This may be due to bleeding, infection or to inspect the condition of the bowel if extensive surgery was required.

### Is it possible to have a kidney transplant after encapsulating peritoneal sclerosis?

It is not usually possible to remain on the kidney transplant waiting list if you have EPS, because you will not be well enough for the surgery or be able to take the necessary immunosuppression medication after a transplant. However, many patients will be able to go back onto the transplant list once they have recovered from the surgery and go on to have a successful transplant.

### Can encapsulating peritoneal sclerosis return?

Although most patients will be successfully treated by the first operation, 25% of patients will get at least one recurrence. This usually happens within 3–6 months of the first operation, and requires a second operation to remove the encapsulating fibrous membrane. Occasionally, a third or fourth operation may be required for more recurrences, but eventually the patient should be free of the condition and be able to eat normally.

### Is it possible to have peritoneal dialysis again?

Once EPS has occurred, it will not be possible to have PD again. EPS usually occurs in patients for who the peritoneum is no longer working properly for PD ■

#### Declaration of interest

The authors declare that there is no conflict of interest.

## Key points

- Encapsulating peritoneal sclerosis (EPS) is an uncommon but serious condition that affects the bowel. The exact cause is unknown, but it is most commonly a result of being on peritoneal dialysis.
- Symptoms of EPS include nausea and vomiting, weight loss, weakness, and abdominal pain and/or bloating.
- Treatment involves having surgery to free the bowel from the encapsulating fibrous membrane.
- Surgery is not without risks, but 70% of people who have had surgery are well one year later; patients may be able to eat normally again, should no longer have pain, their weight should return to normal, and they may be able to go back onto the kidney transplant waiting list.



## The proposed changes to dialysis commissioning

**T**he Government has been forced into a u-turn in the face of a campaign by 27,000 very sick, frightened and distressed kidney patients.

In a statement issued on 27 January 2015, NHS England said that it has listened to patients and clinicians and would continue national commissioning of specialist renal and morbid obesity services in 2015/16. The decision to transfer responsibility to clinical commissioning groups will be kept under review, but any changes will not happen before April 2016.

This decision comes after a ferocious battle waged by the National Kidney Federation (NKF) over a six-month period, ever since it learned of the intention to transfer the commissioning of dialysis services from NHS England to GP-led clinical commissioning groups. No proper consultation had taken place before the decision to move dialysis reached Ministerial level, and the NKF struggled to find anyone who had even been informed. There was no evidence to support the move and the timescale was widely thought to be hurried and dangerous, putting lives at risk.

NKF issued a briefing paper to its patients in November 2014, followed by a consultation paper in December. While the NKF consultation could not identify anyone in favour of the proposed changes, or who felt that the changes could be carried out safely in the timescale proposed, the consultation did find that the proposal had terrified many patients whose lives depend on dialysis provision. NKF's findings were conveyed to Earl Howe in a special meeting hosted by the All Party Parliamentary Kidney Group in the House of Commons on 7 January 2015.

The news released on 27 January is of immense relief to all dialysis patients. NKF wishes to congratulate the patients, kidney patient associations, charities, professional associations and others involved for their support during this campaign, which has reversed the Government's plans to alter the way dialysis services are commissioned, for at least another year. Together we have turned the almost overwhelming tide ■

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