

Complete cytoreduction for pseudomyxoma peritonei

Understanding NICE guidance –
information for people considering the
procedure, and for the public

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About this information

This information describes the guidance that the National Institute for Clinical Excellence (NICE) has issued to the NHS on a procedure called complete cytoreduction for pseudomyxoma peritonei. It is not a complete description of what is involved in the procedure – the patient's healthcare team should describe it in detail.

NICE has looked at whether complete cytoreduction is safe enough and works well enough for it to be used routinely for pseudomyxoma peritonei.

To produce this guidance, NICE has:

- looked at the results of studies on the safety of complete cytoreduction and how well it works
- asked experts for their opinions
- asked the views of the organisations that speak for the healthcare professionals and the patients and carers who will be affected by this guidance.

This guidance is part of NICE's work on 'interventional procedures' (see 'Further information' on page 10).

About complete cytoreduction for pseudomyxoma peritonei

Pseudomyxoma peritonei is an abnormal growth (tumour) that starts in the appendix or bowel. It grows slowly in the abdomen and produces lots of mucus (jelly-like material). When it becomes very big, it can block the intestine and cause other problems.

The usual treatment for pseudomyxoma peritonei is an operation to remove as much of the tumour as possible. Patients may need to have this repeated, as the tumour usually grows again. Medicines are also used that aim to stop the tumour from growing (this is called chemotherapy). If a patient isn't having any particular problems as a result of the tumour, their doctor may just keep a check on them and delay treatment until problems start. This is called 'watchful waiting'.

The aim of complete cytoreduction is to remove all traces of the tumour so that there are no bits left that could start to grow again. It's a major operation that involves removing:

- a large section of bowel
- the spleen
- the gallbladder
- two fatty layers in the abdomen known as the greater omentum and lesser omentum

- the uterus (womb) and ovaries if the patient is a woman.

The delicate membrane covering some of the inside surfaces of the abdomen is stripped off (the membrane is called the peritoneum). And tumour that's attached to the surface of the liver is removed. The lowest part of the bowel (the rectum) is also sometimes taken out.

During the operation, a heated liquid containing chemotherapy medicines is put into the abdomen. Chemotherapy medicines are also put into the area after the operation.

This whole procedure is sometimes called the Sugarbaker technique after the doctor who developed it.

How well it works

What the studies said

There have not been any good studies looking at what happens to patients who have complete cytoreduction for pseudomyxoma peritonei. In one of the studies NICE looked at, 86% of patients with a less aggressive type of tumour were alive 5 years after the operation (86% is nearly nine out of ten patients). Half of the patients with a more aggressive type of tumour were alive 5 years after the operation. In another report, around three-quarters of

patients who had a second operation were alive 5 years later (another operation to remove more tumour may be done if it continues to grow).

What the experts said

The experts said that complete cytoreduction for pseudomyxoma peritonei was controversial because it was a major operation for a condition that got worse only gradually. One expert commented that it was difficult to diagnose pseudomyxoma peritonei without opening up the patient, so it was difficult to find a group of patients who hadn't had surgery to compare with those who had.

Risks and possible problems

What the studies said

In one study of what happened in 46 patients who had the operation:

- nearly all the patients had a long period afterwards where their stomach was weak and didn't empty properly
- 22 patients had neutropenia, which is a low level of the white blood cells called neutrophils that are needed for protection against bacterial infections

- 10 patients had damage to the stomach or the remaining bowel
- an opening (called a fistula) formed in the intestine in 6 patients
- the nerves in the area were affected in 5 patients, which can cause problems such as numbness.

Eleven patients needed another operation to help with one or more of the problems caused by the complete cytoreduction.

What the experts said

The experts said that some patients could die as a result of having the operation. According to the experts, the possible problems were:

- losing a lot of blood
- developing an infection that affects breathing
- inflammation of the remaining peritoneum
- damage to the bowel
- blockage of the bowel
- the development of abnormally joined areas (adhesions)
- problems with the site of the opening used for the operation.

One expert said that such a long and involved procedure would be more likely to result in problems and deaths than a shorter operation.

What has NICE decided?

NICE has decided that complete cytoreduction for pseudomyxoma peritonei should only be carried out in hospitals and centres that receive funding from the National Specialist Commissioning Advisory Group, which is a body that watches over the funding of very specialised services for the NHS. If a doctor in one of these hospitals or centres wants to carry out complete cytoreduction for pseudomyxoma peritonei, he or she should make sure that the patient understands what is involved and that there are still uncertainties over the safety of the procedure and how well it works. There should be special arrangements in place so that the patient only agrees (consents) to the procedure after this discussion has taken place.

What the decision means for you

Your doctor may have offered you complete cytoreduction for pseudomyxoma peritonei. NICE has considered this procedure because it is relatively new. NICE has decided that there are uncertainties about the benefits and risks of the procedure. Because of these, NICE has recommended that complete cytoreduction for

pseudomyxoma peritonei should be carried out only by specialist medical teams. Your doctor should discuss the benefits and risks with you before you agree to have the procedure. Some of these benefits and risks may be described above.

Further information

You have the right to be fully informed and to share in decision-making about the treatment you receive. You may want to discuss this guidance with the doctors and nurses looking after you.

You can visit the NICE website (www.nice.org.uk) for further information about the National Institute for Clinical Excellence and the Interventional Procedures Programme. A copy of the full guidance on complete cytoreduction for pseudomyxoma peritonei is on the NICE website (www.nice.org.uk/IPG056guidance), or you can order a copy from the website or by telephoning the NHS Response Line on 0870 1555 455 and quoting reference number N0539. The evidence that NICE considered in developing this guidance is also available from the NICE website.

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