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Percutaneous endoscopic colostomy

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



Ordering information

You can download the following documents from www.nice.org.uk/IPG161

- this booklet
- the full guidance on this procedure.

For printed copies of the full guidance or information for the public, phone the NHS Response Line on 0870 1555 455 and quote:

- N1000 (full guidance)
- N1001 (information for the public).

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About this information

The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. One of NICE's roles is to produce guidance (recommendations) on whether interventional procedures are safe enough and work well enough to be used routinely in the NHS in England, Wales and Scotland.

This information describes the guidance that NICE has issued on a procedure called percutaneous endoscopic colostomy. 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 percutaneous endoscopic colostomy is safe enough and works well enough for it to be used routinely for the treatment of problems affecting the bowel (see below).

To produce this guidance, NICE has:

- looked at the results of studies on the safety of percutaneous endoscopic colostomy 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 the procedure

Percutaneous endoscopic colostomy is a procedure to make an opening in the bowel and abdomen (called a colostomy), so that the contents of the bowel can be collected outside the abdomen. This procedure avoids having to do this as a major operation and is a possible option for people who have tried conventional treatments that haven't worked or people who are unsuitable for surgery. This procedure is often carried out in people who get repeated episodes of twisting in the section of bowel above the rectum. This is known as recurrent sigmoid volvulus.

Sigmoid volvulus can be life threatening and may need emergency treatment. Surgery may be needed to try to stop it from happening again. There are a number of different operations that can be used. Some are more likely to be successful than others. Those that involve major surgery may be unsuitable for elderly people and those whose immune system is not working properly.

Percutaneous endoscopic colostomy is also a possible option for people with colonic pseudo-obstruction. A person with this has the signs and symptoms of a blockage in the bowel, but doctors cannot find a blockage. Finally, this procedure could possibly be used for children with constipation that hasn't improved despite trying all the medical treatments.

In a percutaneous endoscopic colostomy, a piece of special tubing is placed in the bowel using a narrow viewing tube called a colonoscope. This is inserted into the rectum and moved gently up to the place where the bowel is going to be connected to the abdomen. The tubing is then put into position by tying it to a piece of wire that is run from a small opening in the abdomen through to the anus. One end of the tubing is pulled out through a small opening in the abdomen and the other end gets positioned in the bowel. The surgeon checks the final position of the tubing using the colonoscope. The tubing that ends at the abdomen is then attached

to a drainage bag, which is worn outside the body. Waste from the bowel can then pass from the bowel through the tubing and out into the drainage bag. The patient has antibiotics for a few days to help stop infection after the procedure.

How well the procedure works

What the studies said

Not many studies have looked at the new procedure. One study included 15 children, 14 who had the procedure and 6 of whom were followed up afterwards. After 12 months, all 6 children were either mostly clean with occasional accidents, or had no soiling, and 2 children were able to have the tubing removed.

Another study followed what happened after the procedure in a small number of elderly people with recurrent sigmoid volvulus. Out of 5 people who still had the tubing in place, none had had any more bouts of sigmoid volvulus in the year after surgery.

What the experts said

The experts said that the results of the procedure seemed to be better in people with sigmoid volvulus than in those with incontinence or constipation.

Risks and possible problems with the procedure

What the studies said

The most common problems that affected people who had the new procedure in the studies were granulomas (where nodules of tissue form) and infection. Six out of 15 people in one study and 4 out of 6 people in another study developed granulomas after the procedure. Three out of 15 people in one study and 2 out of 6 people in another study developed an infection. Another report said that 13 out of 105 people who had the procedure developed an infection afterwards.

Other problems included:

- pain caused by an enema given before the procedure (1 person out of 15 had this pain in one study)
- leakage of bowel contents (which affected 5 out of 6 people in one study)
- changes in the skin around the tubing (which happened in 1 person out of 6 in one study).

In a group of 105 people, there were two deaths that were linked with the tubing becoming dislodged (these were both people who'd had recurrent sigmoid volvulus).

What the experts said

The experts said the possible problems included infection, damage to the bowel leading to inflammation of the lining of the abdomen (called peritonitis), and bleeding.

What has NICE decided?

For elderly people and people who are unsuitable for surgery

NICE has considered the evidence on percutaneous endoscopic colostomy as it applies to elderly people and those who are unsuitable for surgery who have recurrent sigmoid volvulus or problems with the way their bowel works. It has recommended that when doctors use this procedure for these groups, they should be sure that:

- the patient understands what is involved and agrees (consents) to the treatment, and
- the results of the procedure are monitored.

For children

NICE has also considered the evidence on percutaneous endoscopic colostomy as it applies to children. There is not much information available to support guidance for this group. NICE has decided that, if a doctor wants to offer a percutaneous endoscopic colostomy to a child, he or she should make sure that the child and/or their parents or carers understand 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 child, parent or carers only agree (consent) to the procedure after this discussion has taken place. It's particularly important that it's only offered to children who are likely to benefit from it, and this decision should be made by a team of healthcare professionals that includes a doctor who specialises in treating problems affecting the digestive system in children (a paediatric gastroenterologist) and a surgeon who specialises in surgery on the bowel (a colorectal surgeon). The procedure should be carried out in a specialist children's unit.

Other comments from NICE

Information came to light during the development of this guidance that another person had died as a result of this procedure. The person died from inflammation of the lining of the abdomen (peritonitis), which happened immediately after the tubing had been inserted.

What the decision means for you

If you are elderly or you are unsuitable for surgery

Your doctor may have offered you percutaneous endoscopic colostomy. NICE has considered this procedure because it is relatively new. NICE has decided that the procedure is safe enough and works well enough for use in the NHS. Nonetheless, you should understand the benefits and risks of percutaneous endoscopic colostomy before you agree to it. Your doctor should discuss the benefits and risks with you. In particular, he or she should discuss the risk of peritonitis.

If you are a child or a parent or carer

Your doctor may have offered you or your child percutaneous endoscopic colostomy. NICE has considered this procedure because it is relatively new. NICE has decided that there is not enough information available to be clear about the benefits of percutaneous endoscopic colostomy in children. You need to understand these uncertainties before you agree to the procedure. Your doctor should discuss the benefits and risks with you (especially the risk of peritonitis), and should explain why the procedure might be suitable for you or your child. The decision about whether to have the procedure should involve healthcare professionals with expertise in different areas. These should include a paediatric gastroenterologist and a colorectal surgeon.

If you or your child agree to the procedure, it should be carried out in a specialist children's unit.

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.

The NICE website (www.nice.org.uk) has further information about NICE, the Interventional Procedures Programme and the full guidance on percutaneous endoscopic colostomy that has been issued to the NHS. The evidence that NICE considered in developing this guidance is also available from the NICE website.

If you have access to the internet, you can find more information on colostomies on the NHS Direct website (www.nhsdirect.nhs.uk).

You can also phone NHS Direct on 0845 46 47.

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