NHS

National Institute for
Clinical Excellence

Healthcare services for bowel (colorectal) cancer

Understanding NICE guidance – information for the public

Introduction

In 1997, the Department of Health published a document called *Improving Outcomes in Colorectal Cancer*. The National Institute for Clinical Excellence (known as NICE) has now published an updated version, called *Improving Outcomes in Colorectal Cancer: Manual Update*, for the NHS in England and Wales. Some of the original recommendations have been updated, and further recommendations have been added.

Both the original document and the updated NICE version have the general name 'service guidance'. This type of guidance makes recommendations about how health services should be delivered (for example, the types of health professional that should be involved and the experience they should have).

It's important to appreciate that many service guidance recommendations require large-scale changes in the way that a section of the NHS works. Although such changes can't be made overnight, the NHS is working to put all the guidance recommendations into practice.

The key recommendations from the updated NICE version are summarised in the following sections. More information on these and the other recommendations is given in the full version of *Improving Outcomes in Colorectal Cancer: Manual Update*, which also includes a summary of the evidence that was considered when the recommendations were being prepared. The full version is available from the NICE website (www.nice.org.uk).

Although service guidance does sometimes refer to appropriate forms of investigation and treatment, it doesn't provide detailed information on these areas. Information on investigations and treatment for colorectal cancer can be obtained elsewhere. (NHS Direct Online, www.nhsdirect.nhs.uk, is a good starting point, with links to other sources of information on colorectal cancer.)

Colorectal cancer

Colorectal cancer (or bowel cancer) is a general name for one of the more common groups of cancers. These are:

- cancer of the colon, which is the longest part of the large bowel (the lower part of the digestive system, which links the small intestine to the rectum)
- cancer of the rectum (also known as the 'back passage'; the rectum is the part of the large bowel just above the anus)
- cancer of the anus.

About two-thirds of colorectal cancers are colon cancers, which are common in both men and women, and most of the rest are rectal cancers, which are more common in men. Anal cancers are very rare.

Although people of all ages can be affected by colorectal cancer, it is uncommon in people under the age of 50, but after that, the chances of having the disease increase steadily with advancing years.

Colorectal cancer can often be treated successfully, particularly if the cancer is diagnosed and treated early. Surgery to remove the tumour is the main treatment used, with radiotherapy (treatment using X-rays) or chemotherapy (treatment using anti-cancer medicines) also given to some patients.

Colorectal cancer usually develops slowly and may not always show early symptoms. It is important to try to diagnose people as early as possible. Symptoms can be very variable and similar to the symptoms of other, more minor, health problems so their significance is not always realised.

Key recommendations

People who may have colorectal cancer should be offered rapid referral for endoscopy

The Department of Health has issued guidelines for doctors to help them identify patients who should be offered urgent referral for tests such as endoscopy (see below) or to see a hospital specialist. These guidelines identify common symptoms and signs that could be caused by an early bowel cancer and should lead doctors to act quickly by offering to refer the patient for tests or to see a specialist.

NICE recommends that standard systems should be developed to improve the recognition of potential symptoms of colorectal cancer by GPs and other community-based healthcare professionals. Efficient systems should be in place to ensure that people who may have colorectal cancer are offered rapid referral by their doctor (GP or hospital doctor) to have a special procedure called an endoscopy (see the next section).

Endoscopy should be available for diagnosis

In the past, a test called a barium enema, which uses X-rays, has been most commonly used to diagnose colorectal cancer. A different test, called endoscopy, is a more accurate method for diagnosing early cancers. An endoscopy to help diagnose colorectal cancer involves putting a flexible tube with a light and a viewing lens or camera attached (an endoscope) through the anus so that the inside of the large bowel can be seen or photographed, and any abnormalities investigated. Depending on the person's symptoms, the endoscopy involves either examining just the last third of the large bowel (this is called 'flexible sigmoidoscopy') or examining the entire large bowel (this is called 'colonoscopy').

NICE recommends that all NHS cancer services should urgently look at the endoscopy services that they provide, and expand them wherever necessary.

People should be treated by a multidisciplinary team

A multidisciplinary team is one that brings together healthcare professionals with all the relevant skills, knowledge and experience related to a particular area of healthcare. A multidisciplinary team is needed because the diagnosis, treatment and care of a person with colorectal cancer can be very complex. NICE recommends that everyone with suspected or newly diagnosed colorectal cancer should be offered prompt referral to, and be cared for by, a colorectal multidisciplinary team.

Where the teams should be based

For efficient use of resources and because it's important that skills are kept up-to-date, the multidisciplinary team must treat a lot of people with colorectal cancer. NICE recommends that for this to happen, each team should serve an area that has at least 200,000 people in it. If a hospital serves a smaller number of people, or does not have the right specialists to form a colorectal cancer team, it may combine with one or more neighbouring hospitals to form the multidisciplinary team. So for some patients, the hospital nearest to where they live may not always be the one that can provide the most appropriate treatment and care.

On the other hand, a large hospital may have more than one colorectal cancer team, but these teams should all work in the same way to ensure that everyone receives the same standard of care.

Who should be in the teams

The NICE guidance says that all colorectal cancer teams should normally include, as a minimum:

- at least two surgeons who are experienced in colorectal surgery (that is, they carry out surgery aimed at curing colorectal cancer in at least 20 patients a year)
- an oncologist (cancer specialist doctor) with experience in treating people using chemotherapy and radiotherapy
- a diagnostic radiologist (a doctor who examines pictures of the body taken using X-rays and other special techniques) with experience and training in identifying colorectal cancers
- a histopathologist (a specialist who looks at samples taken from the cancer and helps describe the type of cancer and how advanced it is)
- a skilled colonoscopist (someone skilled at carrying colonoscopies, who may be a surgeon, a physician or a nurse)
- at least one clinical nurse specialist who has been trained to provide support and information for people with colorectal cancer
- a palliative care specialist (palliative care is concerned with relieving pain and discomfort, rather than treating the cancer itself)
- support staff (to organise meetings, ensure all team members attend, follow the care of each patient through their illness, and provide secretarial support).

Each multidisciplinary team should also have a team co-ordinator, who is responsible for making sure everyone in the team has the information they need at the right time and that the team's decisions are acted upon. The teams should hold weekly meetings to discuss the treatment and care of each patient for whom they are responsible.

People with colorectal cancer will sometimes need additional care, so other specialists should join the team when necessary. In particular, people who have anal cancer, or whose cancer has spread to other parts of the body, should be treated by multidisciplinary teams (see below) with additional specialist skills.

The roles of the teams

Colorectal multidisciplinary teams

Colorectal multidisciplinary teams diagnose the precise type of cancer the person has and are responsible for making decisions, in partnership with the patient, about the most appropriate treatment and care. These teams also provide most of the treatment. They are responsible for providing ongoing information, advice and support to patients and their families or carers, and for referring people to specialist teams when necessary. They are also responsible for keeping in touch with people after they have had treatment to deal with any problems and provide help and support.

It is important that the colorectal multidisciplinary team communicates with the patient's GP and other professionals who may be involved in providing care, including specialist teams.

Multidisciplinary teams with additional specialist skills

Specialist types of colorectal cancer teams provide care and treatment for people who have a less common kind of cancer or who require a particular type of care for other reasons.

Anal cancer teams. Anal cancer is rare and the treatment is different from other colorectal cancers, and so NICE recommends that people with anal cancer should be treated by a multidisciplinary team with additional expertise in managing anal cancer. As well as the usual members of a colorectal cancer multidisciplinary team, the team should include one, or preferably two, surgeons who have expertise in treating people with anal cancer. Other specialists, such as a plastic surgeon, should join the team when necessary. The team should normally be based in a centre with facilities for giving radiotherapy.

Liver resection teams. If colorectal cancer spreads to other parts of the body, it usually affects the liver first. NICE recommends that people whose colorectal cancer has only spread to the liver should be treated first by a colorectal cancer team and then be referred to a specialist cancer team called a 'liver resection team'. (Resection means surgical removal of all or part of a diseased or injured organ such as the liver.)

The team will investigate whether the spread of the disease can be successfully treated by surgery to the liver. The team that carries out this work is highly specialised and will be based in a major cancer treatment centre. It includes surgeons and other specialist doctors who are regularly involved with operations on the liver.

NICE recommends that there should be systems in place for deciding when someone should be referred to a specialist liver resection team.

Colorectal teams treating people with rectal cancer should have special training

Rectal cancers are at risk of recurring after surgery unless great care is taken to remove all of the cancer. Studies have shown that a surgical technique called 'total mesorectal excision' gives the best results. It may be combined with radiotherapy before or after the operation. The care of patients with rectal cancer should be carried out by colorectal cancer teams trained in this technique.

NICE therefore recommends that total mesorectal excision should be available to everyone for whom it is suitable, and that every multidisciplinary team that treats people with rectal cancer should be trained in all aspects of this technique. The training should include assessing the person before and after surgery, the surgical technique itself, and the use of radiotherapy.

People who need emergency treatment should be treated by a colorectal cancer team

At the moment, about a quarter of all people with bowel cancer (1 in 3 people with colon cancer and 1 in 10 people with rectal cancer) first come to hospital as emergency patients. In people with colon cancer, many of these emergencies happen suddenly because the cancer has completely blocked the large bowel. These people may be very ill by the time they reach hospital.

NICE recommends that anybody who may have colorectal cancer and who needs emergency treatment (especially those

with bowel obstruction) should be treated by a colorectal cancer team whenever possible. Although most, but not all, hospitals that treat emergency patients will have a colorectal cancer team, there may not be enough colorectal specialist surgeons in that team to provide full 24-hour cover. However, many emergency patients don't need immediate surgery, and their care can be safely taken over by the specialist team the next day. When urgent surgery is needed, or when teams do not have the necessary experience or facilities to carry out specific procedures such as emergency stenting (a special treatment to hold the bowel open and relieve symptoms), patients may have to be transferred to another hospital to receive appropriate care.

Information and support should be improved

In a recent national survey, many people with colorectal cancer said they did not feel that they had received adequate information to understand the tests they needed, the treatment available, or the possible side effects of treatment. In many hospitals, this was partly due to the lack of access to nurses, known as 'clinical nurse specialists', who have specific expertise and training and whose role is to provide information and support to people with colorectal cancer.

NICE recommends that everyone with colorectal cancer, and their carers, should be offered clear information in a format that's right for them. Information should be available on all aspects of the disease, the tests that might be offered, the treatment options and where they can find further information and support (for example, telephone helplines or local support groups).

All members of the team should be trained to communicate effectively with patients and their carers. In particular, from the time of diagnosis and throughout their disease, patients should be able to contact a clinical nurse specialist who has special training in counselling people with colorectal cancer. The clinical nurse specialist can make sure that patients receive good continuity of care and practical help in dealing with the effects of their cancer. The clinical nurse specialist should be a full member of the colorectal multidisciplinary team.

Further information

It's important to remember that your local services may be a little different from those described here – the NICE guidance sets out the way that the colorectal cancer services should develop over the coming years.

If you have any questions about your health or the health of a member of your family or a friend, speak to your GP. If you, or a friend or relative, have a colorectal cancer and you have questions about the information here, or about treatment and healthcare in general, talk to a member of the colorectal cancer team. In addition, further information on colorectal cancer (including the signs or symptoms of colorectal cancer) and support groups is available from NHS Direct (which you can access on the Internet at www.nhsdirect.nhs.uk or by telephone on 0845 46 47).

NICE has issued guidance on supportive and palliative care services for adults with cancer, which includes recommendations about issues such as communication and the types of support services people should be offered. Further information is available from the NICE website (www.nice.org.uk); copies of the information for the public are available from the NHS Response Line (telephone 0870 1555 455 and quote reference number N0476).

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Copies of this document are available from the NICE website or from the NHS Response Line (telephone 0870 1555 455 and quote reference N0557). The Guidance manual, *Guidance on Cancer Services – Improving Outcomes in Colorectal Cancer: Manual Update* (reference N0555) and a CD with all documentation including the research evidence on which the guidance is based (reference N0556) are also available.

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