

Understanding NICE guidance

Information for people who use NHS services

Infliximab and adalimumab for Crohn's disease

NICE 'technology appraisal guidance' advises on when and how drugs and other treatments should be used in the NHS.

This leaflet is about when **infliximab** or **adalimumab** should be used to treat people with severe active or fistulising Crohn's disease in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It does not cover using these drugs for mild or moderate Crohn's disease. It is written for people with Crohn's disease but it may also be useful for their families or carers or for anyone with an interest in the condition.

It does not describe Crohn's disease or the treatments in detail – a member of your healthcare team should discuss these with you. You can get more information from the organisations listed on the back page.



These may not be the only possible treatments for Crohn's disease. Your healthcare team should talk with you about whether they are suitable for you and about other treatment options.

What has NICE said?

NICE recommends infliximab and adalimumab as possible treatments for some people with Crohn's disease (see below).

Who can have infliximab or adalimumab?

Infliximab should be an option for you if:

- you are an adult with severe active Crohn's disease or active fistulising Crohn's disease, and you cannot take the standard treatments for medical reasons or the standard treatments have not worked **or**
- you are 6–17 years old and have severe active Crohn's disease, and you cannot take the standard treatments for medical reasons or the standard treatments have not worked.

Adalimumab should be an option for you if:

- you are an adult with severe active Crohn's disease, and you cannot take the standard treatments for medical reasons or the standard treatments have not worked.

If you and your specialist think infliximab or adalimumab is the right treatment for you, you should be able to have it for at least 12 months, unless it stops working well enough. After 12 months (and every 12 months thereafter, if you carry on with treatment) you should have your condition assessed again, and your specialist should discuss with you the benefits and risks of continuing treatment, or having a trial period without treatment.

If you stop treatment and your Crohn's disease gets worse, you should be able to start treatment again.

When assessing how Crohn's disease affects your quality of life, healthcare professionals should take into account any disabilities or difficulties in communicating you might have.

Why has NICE said this?

NICE looks at how well treatments work, and also at how well they work in relation to how much they cost the NHS. NICE recommended infliximab and adalimumab because they work well, and their cost is justified by the benefits they provide.

Crohn's disease

Crohn's disease is a long-term condition that usually causes inflammation (swelling) and ulcers in part of the gut called the small intestine, although any part of the digestive system can be affected. The main symptoms are abdominal pain, diarrhoea and weight loss.

A person is said to have severe active Crohn's disease if they have very poor general health and one or more of the following:

- weight loss
- fever
- severe pain in the abdomen
- usually three to four or more bouts of diarrhoea per day.

In fistulising Crohn's disease, openings known as 'fistulae' form between two parts of the body, such as between the bowel wall and the skin around the anus. People with a fistula can develop symptoms like pain, fever, tenderness, itching, and generally feeling poorly. The fistula may also drain pus or a foul-smelling discharge.

Infliximab and adalimumab

People with Crohn's disease produce too much of a substance called 'TNF alpha', which is involved in causing inflammation in the gut. Infliximab and adalimumab stop TNF alpha working in the body, reducing the inflammation and so easing the symptoms.

What does this mean for me?

When NICE recommends a treatment, the NHS must make sure it is available to those people it could help, normally within 3 months of the guidance being issued.

So, if you have severe or fistulising active Crohn's disease, and you and your specialist think that infliximab or adalimumab is the right treatment for you (see 'What has NICE said?' on page 2), you should be able to have the treatment on the NHS. Please see www.nice.org.uk/aboutguidance if you think you are eligible for the treatment but it is not available.

More information

The organisation below can provide more information and support for people with Crohn's disease. NICE is not responsible for the quality or accuracy of any information or advice provided by this organisation.

- National Association for Colitis and Crohn's Disease, 0845 130 2233
www.nacc.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts, including healthcare professionals and people representing patients and carers. They consider the evidence on the disease and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet and other versions of the guidance aimed at healthcare professionals are available at www.nice.org.uk/TA187

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2158). The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.

We encourage NHS and voluntary organisations to use text from this leaflet in their own information about Crohn's disease.