University Hospitals of Leicester
NHS Trust

Understanding clinical complete response for rectal cancer (Deferral of surgery)

Cancer Services

Information for patients

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Surgery is the gold standard treatment for rectal cancer (NICE guideline NG151)

What does clinical complete response mean?

For patients who have had **chemotherapy and radiotherapy** treatment for rectal cancer and have been followed up for at least three months, there is a 15-20% (fifteen to twenty out of 100) chance that the rectal tumour will completely disappear and cannot be seen on either a scan or flexible sigmoidoscopy (camera test). This is called a “clinical complete response”.

If this is the case for you, you will be given the option of going on to a programme of “active surveillance” (sometimes called “watch and wait”) instead of having a major operation. Active surveillance involves an intensive follow-up programme of regular scans and flexible sigmoidoscopies to examine your rectum.

In order for this programme to work, you need to attend all appointments. If you cannot do this, please let your clinical nurse specialist know.

Can I still have the operation if I choose to?

If you still feel that you would like the operation at this time, you can discuss this with your consultant and clinical nurse specialist (key worker). They will discuss with you what the operation involves and any potential risks.

What follow-up will I have on active surveillance?

Your follow-up will involve regular investigations. The table below shows how often you will need these.

	CEA	Flexi/colon	MRI	CT
3 months	√	√	√	
6 months	√	√	√	√
9 months	√	√	√	
Year 1	√	√	√	√
18 months	√	√	√	
Year 2	√	√	√	√
Year 2.5	√	√	√	
Year 3	√	√	√	√
Year 4	√	√		√
Year 5	√	√		√

Please note:

"**CEA**" is a tumour marker blood test for colorectal cancer.

Colonoscopy/flexible sigmoidoscopy involves a tube with a camera attached being passed into your back passage to visualise the previously seen area of concern.

All patients who have had treatment for rectal cancer will be offered a colonoscopy/flexible sigmoidoscopy at appropriate intervals throughout their surveillance.

What are the risks of active surveillance?

Surgery is the gold standard treatment for rectal cancer (NICE guidelines NG151). Current research suggests that two out of three (two-thirds) patients with complete clinical response of the rectal tumour after chemotherapy and radiotherapy will have no regrowth of the tumour in the rectum by three years and will not need major surgery.

However one third of patients who are thought to have a clinical complete response develop tumour regrowth during their follow-up.

Is there any evidence that this treatment is safe?

At this time, there are no guidelines recommending this treatment and it is not considered to be a standard treatment. Research studies are happening across the world in which patients are being offered the opportunity to avoid surgery to remove their rectum if they are thought to have had a complete response. All patients need to be aware that it is a new management strategy under evaluation. Centres who offer this treatment of 'watch and wait' are advised to enter their details onto the international databases so that more evidence can be collected to help with preparing guidelines in the future.

Is there a risk of the cancer spreading?

All patients with rectal cancer are at risk of spread of the cancer to other areas of the body (metastasis): Recent studies have shown that this rate is the same for those on active surveillance as those who have had an operation.

There is a risk of metastasis even if there is no tumour regrowth in the rectum. This is why **all** patients with rectal cancer have regular CT scans as part of their follow-up to try and detect areas of metastasis.

What happens if my tumour regrows ?

If you are informed that your tumour has regrown, it may still be appropriate to undergo an operation. Should this be the case, your consultant will have a detailed discussion with you about the operation. Recent studies have shown that if the tumour regrows you are very likely to be suitable for curative surgery.

What signs and symptoms should I look out for?

In between the tests outlined in the table above, here are some signs and symptoms to look out for:

- bleeding from your rectum
- change in bowel habit (for example, needing to open your bowels more often or more urgently)
- feeling like you cannot fully empty your bowels when you go to the toilet
- pain in your abdomen
- tiredness
- weight loss that is unintended

Contact details

If you have any concerns or questions please contact :

Colorectal nurse specialists (key workers):

Leicester Royal Infirmary 0116 258 5184

Leicester General Hospital 0116 258 4455

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