

This factsheet has been written for people who have anxieties about follow-up and scan results at any stage of their cancer treatment.

Patients have told us that the worry they experience before a test result is centred around emotions rather than logic. Follow-up tests are put in place over a five year period.

They can either reassure you that you are still clear of cancer or pick up any recurrence at the earliest possible opportunity so that treatment options can be considered. For some people, waiting for test results that could be life-changing can be as stressful as the time you were first diagnosed.

General follow-up guidelines

The National Institute for Health & Care Excellence guidelines state that patients with primary bowel cancer who have had treatment to cure their cancer should be offered regular follow-up tests which may include:

- at least two CT scans of the chest, abdomen and pelvis in the first three years
- regular CEA (blood) tests at least every six months in the first three years
- a follow-up colonoscopy at one year after initial treatment or sooner if you did not have one before surgery.

Your hospital team will follow local guidelines to ensure that you continue to be monitored in the most appropriate way for you. Hospital Trusts are looking to introduce differing levels of follow-up. Increasingly, suitable patients will be given the chance to opt in to 'self-managed' or 'remote' follow-up. This means that for low risk patients there will be no face-to-face appointments unless problems arise; only patients with complex problems will be required to come back to see the hospital team.

Test anxiety

We know that the biggest fear for many bowel cancer patients is that your cancer may come back or spread to other parts of your body. Many people describe how they become anxious before follow-up appointments, and that going back for clinic appointments and waiting for test results can be very stressful. Even visiting the hospital again can create anxiety for some people.

Your colorectal specialist team will help you to understand your own risk of the cancer coming back, based on your original diagnosis and the type and spread of the cancer at that time. The follow-up tests described below will allow your hospital team to monitor your progress. If there are problems identified in these tests, this will trigger review at a colorectal multi-disciplinary team meeting and further tests if necessary.

Follow-up tests

Scans

A CT scan takes a series of X rays to make a cross-sectional image of the inside of your body, including the liver, lungs and other structures. Radiation is used during the scan, which takes about eight minutes and is painless. A dye, called a contrast medium, is injected into a vein for this procedure.

You will not be given other types of scans such as MRI or PET routinely during follow-up, however these may be ordered if further images are needed in particular circumstances.

Colonoscopy

A colonoscopy is an investigation of the lining of your rectum and colon using a long thin flexible telescope fitted with a camera and lights, which is usually passed through the anus. It is an effective way of spotting problems inside the bowel lining and will be offered if you have any part of your colon left after surgery. If only your rectum is left, you will be offered a flexible sigmoidoscopy, which is a shorter scope.



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If you have a stoma, the camera will be passed through the opening. If you use a closed bag system you will need to get some open-ended ileostomy bags from your stoma nurse to manage the increased fluid from the bowel preparation.

You can't have a colonoscopy if there is a serious risk of the bowel preparation causing you harm. If you have poor kidney function, you may have to be admitted to hospital for intravenous fluid support during bowel preparation. If you are taking warfarin, you may have to change to a different blood-thinning medication for a number of days before the colonoscopy.

Tumour markers and blood tests

CEA markers

CEA (carcinoembryonic antigen) is a protein made by some types of cancer including bowel cancer. Your CEA level can be measured by a simple blood test. CEA markers can be used by your doctor to monitor the response to chemotherapy, as well as often being used in the follow-up period when treatment ends. However a CEA test cannot be used on its own as a means to diagnose bowel cancer, because not all bowel cancers produce the protein. So, some people who have bowel cancer do not show raised CEA levels at all.

Measuring CEA as part of your follow-up care becomes a useful test if your level was raised before the tumour was removed. In this case, a rising CEA level in the months and years following your operation could be an indicator of the cancer coming back. CEA can be a useful marker for detecting a new CEA-producing tumour, but a one-off raised CEA is not necessarily a sign of the cancer returning. Sometimes the CEA test is repeated to check that it wasn't just a blip or it might trigger scans in order to find out more. Understandably, any rise in your CEA level can cause a great deal of anxiety for you and everyone close to you.

What are normal CEA levels

A normal CEA level for an adult non-smoker is less than 2.5 and for a smoker less than 5. However your CEA level goes up and down over time, just like your blood sugar level, blood pressure and heart rate. So a rise of anything up to 5, 6 or 7 could still be normal.

What pattern of CEA rise triggers investigation

A CEA level rise of 4→5 does not mean that your cancer is returning. On the other hand, an upward trend of, for example, 4 →10 →20 at consecutive readings would trigger further investigation.

Other causes of a rising CEA

Several factors can cause your CEA level to rise, including smoking, an infection, inflammatory bowel disease, pancreatitis, liver cirrhosis and other cancers. Chemotherapy and radiotherapy can also cause a temporary rise in CEA levels.

Test results

In order to lessen the hospital visits patients are required to make, you may be offered a choice in how you receive your test results. This new form of 'remote monitoring' is being piloted in some hospitals for patients who have a low risk of recurrence and who would rather not have to make so many outpatient visits. This will not change the number or frequency of the tests you will be given.

If you opt for the self-management pathway, your doctor or colorectal nurse specialist will talk to you about how you would like to get test results.

It is usually best to get CT results face to face, because if the news is not good it is better to be in a place where support is immediately available. It is always helpful to bring someone with you to these meetings.

Some people may feel that they want the convenience of getting results over the telephone. If your specialist nurse is happy with this approach, this can be arranged. However results can lead to complex discussions which may be best had face-to-face.

You can also opt to get results by mail, in which case you would receive a confirmation letter if all is well. Alternatively if the tests showed a problem, you would be sent an appointment to discuss the results face-to-face.

Please bear in mind that if there is an abnormal result, your nurse cannot give you any results until they have been discussed at a multi-disciplinary team meeting, which usually takes place once a week.

New symptoms to look out for

Early recurrent disease is picked up more often by routine tests, rather than any signs and symptoms you may notice yourself. However, if you notice any new symptoms, do get in touch with your GP or colorectal specialist nurse. Most symptoms can be explained and treated easily with simple medications or other treatments.

Signs and symptoms that may need further investigation include:

- continuing pain that doesn't go away with usual painkillers
- unexplained lumps, bumps or swellings
- an unexplained change in normal bowel habit that lasts for six weeks or more – especially if you are waking up in the night with loose stools
- unexplained loss of appetite, weight loss or increasing girth
- any new bleeding from your back passage (or in urine)
- unexplained shortness of breath or cough which lasts more than three weeks
- bleeding or discharge from your wound site.

It is very normal to be more concerned about aches and pains which you would not previously have thought twice about and to think that the cancer may have come back.

Unfortunately, patients who have had cancer and treatment still get 'normal' aches and pains like the rest of the population. Do go and see your GP if you have a worry about anything unusual which is persisting.

Coping with your emotions

Waiting for scans and other test results can be a very anxious time. It's very normal to be stressed during this time and it can be very unsettling, even if you have experienced the same tests on previous occasions. You may experience 'butterflies in your tummy', a change in bowel habit, loss of appetite and other signs of anxiety. You may also feel more irritable or tired.

These symptoms can make you more anxious, especially if the physical response leads you to think this is linked with symptoms caused by your cancer coming back.

It's important to have a strategy for occasions like this, a plan of action to give you more control over your ever-changing emotions and to better fill

your time with practical ways of coping. This won't necessarily take away the anxiety completely, but allow the experience to be less traumatic. It does take some effort and self-discipline.

You may experience changing emotions where one day you want to share and talk, and the next you want to completely banish all thoughts of cancer. Being mindful of this will help you choose your coping strategies, depending on your mood. Your loved ones may need some indication of this so that they can try and support you in the best way possible.

Unfortunately, there is nothing you can change in terms of test results, where waiting can feel like an eternity, and the desire to know **now** can leave you helpless and frustrated, but you can have some control. There may be things you can do to make this time more bearable:

- Seek support from friends and family who will listen and allow you to talk!
- Talking through your concerns with the Beating Bowel Cancer nurses can help you offload with someone very used to discussing these worries.
- Let your colorectal nurse specialist or GP know if you feel your anxieties are overwhelming you. They can help, maybe with temporary medication or by offering you extra support such as talking therapies or counselling.
- For some people, having a practical plan of action can be helpful. In the event of the news being bad, what do I plan to do? How will I cope? What concerns you the most...is it the thought of another round of treatment, or your job and paying bills if you are too ill to work? Sometimes breaking these fears down into chunks and dealing with them one by one can be helpful.
- Find a support group, such as our online forum to share your thoughts.
- Beware of too much internet advice. Your health is truly unique to you; trying to find out your result through the experience of others may actually confuse you and make your anxiety worse. For some, surfing the web can be really helpful, but if it makes you anxious, you may well want to avoid it for the time being.

Distraction techniques

- Distract yourself with something that requires a lot of concentration: an intricate brain activity like detailed sewing or Sudoku.
- Meditation or mindfulness training can be very calming, especially if your anxiety is preventing you from sleeping at night. You can download a meditation tape from YouTube or borrow one from your local library. Your GP practice may know about courses available locally.
- Be active – If you are able, get out and do a physical activity. Gentle walking, yoga, dancing, anything to help release some of your body's natural endorphins, 'feel good' chemicals which can improve your mood, memory and energy.
- Have fun – Spend time with friends or family who lift your mood, tell you jokes and help to brighten your day. Do something different and inspiring or something that makes you laugh.

Getting the news

- It's helpful to write down a list of questions before the appointment so you don't forget to ask anything.
- Bring support - It can be really useful to have someone with you when you are receiving your results. They will also be able to take down notes from the discussion you have with your doctor or nurse.
- Whatever the outcome, this news will no doubt leave you feeling quite emotional. It's important to take time to absorb the news. You may not be in a fit state to work straight after an appointment like this, even if good news means you want to jump for joy.
- Before you leave the appointment, make sure that you ask your doctor or nurse how you can contact them if you have any further questions that come to mind. Check that you will be sent a written account of the discussion for your records.
- Keeping a file with all your test dates and communications from your medical team may be useful.

Extracts from www.beatingbowelcancer.org/forum

"Scanxiety! Well THAT time is here again; I'm due for my scan tomorrow morning and am soooo anxious. I know we all get like this, but the last time I was scanned I felt very little anxiety and the results were good; this time I've developed a pain in my side (I know it's probably all in my head, that's what everyone's telling me and I know it is too). I keep bursting into tears and just wanting this wretched 'thing' to go away."

"Think we all get anxious when we approach any sort of examination, you're unfortunately not alone. The small hours can be the worst. If you don't disturb the whole house by doing so, get up and have a cup of tea, read, or listen to the radio. Many folk find this sort of activity [forum] helps."

"Of course you will be very worried. We can all relate to that. A few of us are due follow-up scans and appointments soon and we're already tense. It rarely gets any easier but at least we're all in the waiting game together! We're with you. We understand. Hang on in there. You've got your dad's scan in two weeks' time but then you've got the waiting for results to follow! Just make the most of the days that lie ahead. Enjoy being together and reflecting on how well he has done since diagnosis. Take care."



If you have any questions or comments about this publication, or would like information on the evidence used to produce it, please write to us or email info@beatingbowelcancer.org.

