NHS
University Hospitals Sussex
NHS Foundation Trust

WE ARE MACMILLAN. CANCER SUPPORT

Supported bowel cancer follow up

Cancer services

Patient information

What is the supported bowel cancer follow up scheme?

The Supported Bowel Cancer Follow Up scheme enables the specialist bowel cancer team to keep a close eye on your recovery following your bowel cancer treatment. It gives you the freedom to get on with your life with the reassurance that the colorectal team is monitoring your progress and will provide a fast way back to a hospital review should you need it.

You will have regular blood tests, CT scans and colonoscopies, but will only need to attend a hospital clinic if your results show a change which warrants further investigation which you would like to discuss with your specialist face to face. 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 a review at a colorectal multi-disciplinary team meeting and further tests if necessary.

The regular tests you will need have been decided by the multi-disciplinary team.

Following your treatment for colorectal cancer, you will need to have:

CEA blood test: 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 three 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 3.4 and for a smoker, normal can be as high as eight. 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 five, six or seven could still be normal.

What pattern of CEA rise triggers investigation?

A CEA level rise of four 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, infection, inflammatory bowel disease, pancreatitis, liver cirrhosis and other cancers. Chemotherapy and radiotherapy can also cause a temporary rise in CEA levels.

CT (computerised tomography) scan

Usually three scans during your three year follow up:

A CT scan takes a series of x-rays, which build up a three dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. A dye, called a contrast medium, is injected into a vein for this procedure, it is important that you have a blood test three weeks before this scan to make sure your body can safely cope with having this dye injected.

Colonoscopy

Usually done around 12 months after completing your treatment, unless you have an ileostomy, in which case a colonoscopy can't be done until you have had your reversal operation. If you have a colostomy (on the left side of your abdomen) the scope will be passed through the stoma. Your next colonoscopy should be done at year 4 of follow up unless your surgeon decides otherwise.

As part of your surveillance the doctor may want to look inside the whole length of the large bowel, so you will have a 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.

This will be done in the hospital endoscopy department as an outpatient and takes about an hour, but you may need to be here for up to half a day and will need someone to take you home if you need sedation as part of the procedure.

How are the test results used?

Your care plan may be changed by the Multidisciplinary Team depending on the combined results of these three tests, if treatment is needed.

How does the Supported Bowel Cancer Follow Up schedule work?

When a blood test is due, please use the blood form you have been sent previously to have your blood test done. If you're due to have a CT scan or a colonoscopy, these will be arranged for you and the relevant departments will contact you to make a date.

You will also need to have a blood test in the three weeks prior to a CT scan so please contact the co-ordinator if you have not received a blood form for this test.

If your results are normal, you and your GP will receive a letter confirming this and you will be told when your next tests are due. You should receive this letter within approximately six weeks of the tests being completed but please be aware that CT scans can sometimes take longer than this to be reported. If you do not hear from us after six weeks, please contact us so we can update you with any delays.

If there are concerns about your test results, you will be telephoned by a member of the colorectal team to discuss this and the agreed plan for ongoing monitoring or any additional tests required. Your GP will also be notified. Please bear in mind that if there is an abnormal result, your team cannot give you any results until they have been discussed at a multidisciplinary team meeting, which usually takes place once a week.

Helpline

There is a special **Helpline** **01273 696955** Extension **67476** which you can telephone and leave a message if you have any concerns about your colorectal cancer or are suffering from one or more of the symptoms listed below.

If after contacting you the colorectal team feel that you need to return to hospital, you will be sent a clinic appointment.

You can also contact the Follow Up Coordinator by email:
claire.theobald1@nhs.net

Signs and symptoms to report

- A change in your bowel habit lasting more than three weeks.
- Any new bleeding from your back passage (or in urine).
- Any new abdominal/tummy pain which does not go away (especially if severe).
- A lump in your tummy.
- Unexplained weight loss and tiredness.

Obviously everyone is different and it is you who knows your body best, so we would much rather you telephoned the helpline with a concern that turned out to be nothing than have you sitting at home worrying.

The sooner you share your symptoms or concerns with us, the quicker we can help to resolve the problem.

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 medication or other treatments.

Signs and symptoms that may need further investigation include

- Continuing pain that doesn't go away with usual painkillers.
- An unexpected change in normal bowel habit that lasts for three 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 last 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.

If you experience any of these, please contact the Helpline as above or call your Clinical Nurse Specialist/Macmillan Nurse.

If your symptoms are particularly worrying, especially in the case of sudden heavy bleeding, or severe and persistent abdominal pain, you should contact your GP immediately or go straight to your nearest hospital accident and emergency department (A&E).

Coping with your emotions

Waiting for scans and other test results can be a very anxious time. You might feel more 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 your Clinical Nurse Specialist/ Macmillan Nurse or Macmillan Support Worker can help you off load with someone very used to discussing these worries.
- Let your GP or Clinical Nurse Specialist/Macmillan Nurse or Macmillan Support Worker, know if you feel your anxieties are overwhelming you. They can help you, 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 **C-Side Support Group** http://c-sidebrighton.org/ or the Mid Sussex Support Group or an 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.

Please remember:

- If you are experiencing any of the symptoms listed above, please phone the Helpline as soon as possible on the telephone number below.
- If you are asked to return for a clinic appointment and are unable to make the date and time given, please telephone the bookings hub on **0300 303 8360** to rearrange an urgent appointment.
- Telephone messages to the Helpline will not be picked up at weekends or on bank holidays. In the unlikely event of a bowel/colorectal-related emergency occurring at the weekend or on a bank holiday, you will need to contact your out of hours GP service or go straight to your nearest hospital accident and emergency department (A&E).
- Please let us know if you move house/change your address so we can ensure we send letters and test information to the correct place.

Useful contact numbers and websites

Royal Sussex County Hospital

Helpline	01273 696955 Ext. 67476
Follow up coordinator	01273 696955 Ext. 67476
Macmillan nursing team	01273 696955 Ext. 67658
Stomacare helpline	01273 696955 Ext. 64215
Stomacare	uhsussex.stomacaredepartment@nhs.net
CT department	01273 523040
MRI department	01273 523040
Mid Sussex Bowel Cancer Support Group	01273 696955 Ext. 67658

Princess Royal Hospital

Main telephone	01444 441881
CT department	01273 523040
MRI department	01273 523040

Outpatient Booking Hub

Telephone	0300 303 8360

Macmillan Cancer Support

Helpline	808 808 00 00
	https://www.macmillan.org.uk/

Bowel Cancer UK

Helpline	020 7940 1760
Bowel Cancer UK	https://www.bowelcanceruk.org.uk/
C-Side Colorectal Support Group	http://c-sidebrighton.org/

Booking a blood test

Phone	01444 441881 Ext. 68199

Brighton Blood Tests
https://app.10to8.com/book/brightonbloodtests/

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