Personalised Stratified Follow Up for Colorectal Cancer Surveillance

Your guide to surveillance and self-management

NHS
St George's University Hospitals
NHS Foundation Trust

What is **Surveillance or 'follow up' ?**

Surveillance or follow-up after bowel cancer treatment refers to the ongoing monitoring and follow-up care that patients receive after completing their cancer therapy.

This is a necessary precaution, as a small number of people can relapse. It is a way to identify problems early and act quickly enough to treat them.

It also helps manage any lasting side effects from the treatment and supports the patient's overall health and well-being.

What happens when I finish my treatment?

After you have finished your treatment, you will have a meeting with your nurse to talk about your follow-up.

During this meeting you will fill in a holistic needs assessment (HNA). This is a questionnaire that asks you about your needs and what matters to you. Your needs might be physical, practical, emotional or social.

The HNA helps your team to make a care plan. It makes sure that your needs are met and that you have all the support you need.

Your nurse will also discuss the management of any possible side affects you have following your treatment, signs and symptoms suggesting that the cancer might have returned and the investigations and tests that you will need in the future.

You will be monitored for a total of five years after finishing your cancer therapies.

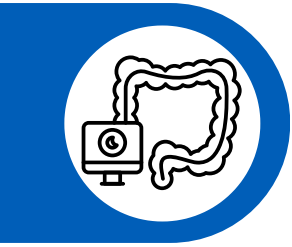
What tests will I have?

Your treating team will determine the most appropriate surveillance plan and tests for you according to the risk of recurrence. This is otherwise called **Personalised Stratified Follow Up.** Some clinicians may refer to this as a 'PSFU'.

This will include three main types of tests.

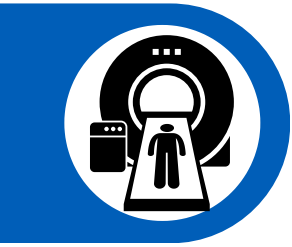
Bloods tests

Blood tests are performed every 6 months.



Colonoscopies

A colonoscopy is typically performed in year 1 and year 4. Some patients may need extra colonoscopies.



CT scans

A CT scan is typically performed in year 1, 2 and 3. Some patients may need extra CT scans.

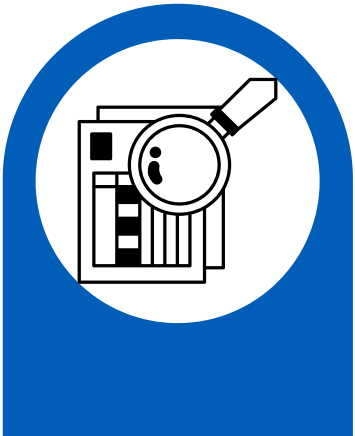
Your consultant will decide if you need more regular tests than outlined.

What do the tests look for?

Your blood tests will look at the level of **C**arcino**E**mbryonic **A**ntigen (CEA) in your blood.
CEA is a type of protein produced by some colorectal cancers and can be elevated if a cancer returns. However, not all cancers produce CEA, which is why we use colonoscopies and CT scans too.

A colonoscopy is a camera test to check your bowel.
This is done using a flexible, thin tube which has a camera inside it. This is called an endoscope.
You do not need this test if all of your large bowel has been removed.

A CT scan will check your chest, abdomen and pelvis. The scanner is like a large ring or doughnut. It is not enclosed, like some other scanners.
A CT scan takes a series of pictures of your body. It uses X-rays but gives a more detailed picture than having a plain X-ray



All of these tests mean that we will be able to identify any potential problems with your health.

We will notify you when you are due to have your tests.
You will be sent your appointment times in advance. If you are worried that your appointment has not been booked then please call 02087255349.

We will also send you the results of your tests.
If a result is abnormal, we will ask you to come to hospital for extra tests and/or a visit to discuss further management.

What happens **after 5 years?**

After five years, you should not need these tests anymore.

After your follow-up plan is complete, you will be discharged back to the care of your GP.

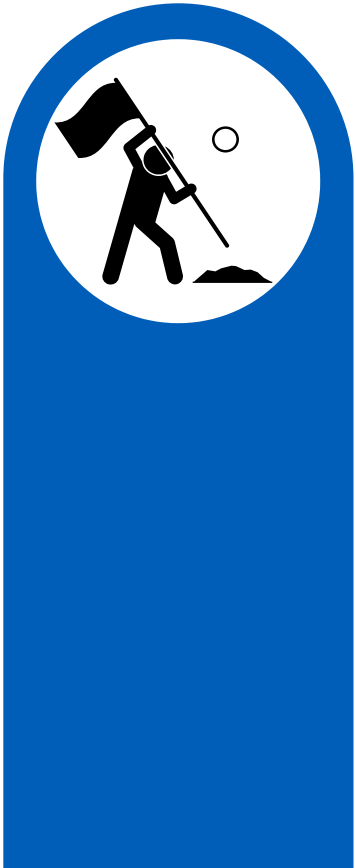
If you are eligible, you can also take part in your local NHS bowel cancer screening programme.

What is **supported self-management?**

In the past, it has been traditional for patients who have completed their treatment for bowel cancer to have regular follow-up appointments with their surgeon, clinical nurse specialist or oncologist.

Although some patients find these appointments valuable and reassuring, many find them a source of anxiety that can slow down the process of moving on after their treatment.

Supported self-management puts you in control of your care. Instead of your routine follow-up clinic appointments, you will be able to contact the clinical nurse specialists directly to arrange an appointment if you feel that you need to be seen.



If you have any symptoms or concerns, you should telephone a member of the team on 02087255349.

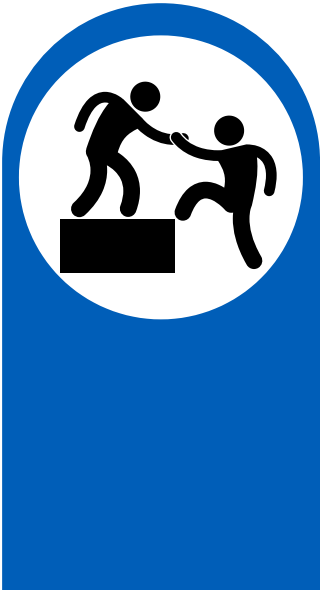
This is called patient triggered follow-up. If necessary, you will be seen urgently by the team at the earliest appointment.

Getting back to

‘Normal’

Reaching the end of your treatment can be a difficult time for many patients. Although you will feel relieved that your treatment is finally over, you may also experience a feeling of **“what now?”** and find that you miss the security of being seen at the hospital regularly.
Some patients will also find that it takes longer than expected to recover fully from their treatment.

People have different ways of living with bowel cancer. There is no right or wrong way, just what works for you.



Some people prefer not to talk, while others like to get support from talking about their experiences. Your clinical nurse specialist is there to help you with support.

Some useful

Support Groups

Bowel Cancer Support Group UK

www.bowelcancersupportgroupuk.org
An online support group with over 5,000 members

b&b Bladder & Bowel Community

www.bladderandbowel.org
08000315406

Papillon

Tackling cancer directly

A patient led support group for people with rectal cancer
www.papillonpatientsupport.com

Colostomy UK

Support for people with a stoma
www.colostomyuk.org/support
24 hour support line: 0800 328 4257/

MACMILLAN CANCER SUPPORT

www.community.macmillan.org.uk
An online community with over 80,000 members.

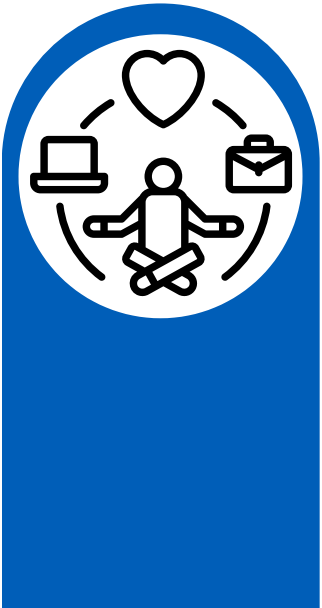
When can I return to **work**?

If you are going back to work, we recommend you meet with your employer, human resources department or occupational health staff first. It can be helpful to have someone else there (such as a work colleague or union rep) to take notes.
If you still have some side effects from the cancer treatment, discuss any reasonable changes that can be made to help you get back to work, including a phased return to work.

The Equality Act (2010) covers all types of cancer and exists to protect against unfair treatment compared to others, harassment and victimisation, and unfair dismissal.
If you think you are being treated unfairly when trying to get back to work, it is there to protect you. Disability employment advisors are based at Job Centres.

Some questions that might be helpful to ask before returning include:

- What adjustments could your employer arrange that would make work easier for you?
- Can they modify any equipment or devices that you use?
- Can you reduce your hours, work flexibly or work more at home?
- Will you need to rest at work during the day?
- Is there any counselling available if you want it?
- Are you able to park closer to your place of work if you drive? Changing where you work – for example, moving your workspace so you can access the bathroom more easily.



Telling friends and work colleagues about your cancer is the best way to overcome any uneasiness they may have about what has happened to you.

Financial concerns

A cancer diagnosis can affect your income, but you may be able to get help with NHS costs, grants and certain benefits. You can talk to several people to see if you are entitled to any additional help if financial issues are causing you to worry.

Ask your clinical nurse specialist to refer you to the Macmillan benefits clinic, Macmillan Cancer Support, Citizen's Advice Bureau or your social work department for more information.

You may be able to get help from other organisations or charities that may provide grants. You'll need to apply through a health or social care professionals, such as a district nurse or a social worker.

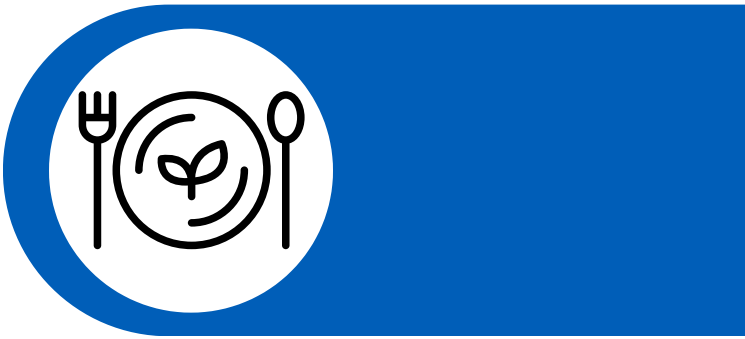
What diet should I follow?

There is no need to follow a special diet after you have been treated for bowel cancer.
Bowel function is entirely individual, especially following surgery for bowel cancer. Concerns should be covered in your consultation and self-management plan.

Your diet can be adjusted according to your personal needs. If you have a stoma, your stoma nurse will also discuss diet with you.

As a general rule, you should try to eat a good, balanced diet. Enjoying a healthy diet is especially important if you have had cancer. There are conflicting theories about diet and cancer, which can be confusing. Most experts would agree that a healthy diet is balanced and varied and provides all the necessary nutrients. If you would like specialist help, speak to your GP.

The main part of your diet should come from fresh fruit and vegetables and starchy, preferably wholegrain foods such as rice or pasta or potato. A smaller part of your diet should come from proteins such as meat, fish, nuts and seeds, dairy or alternatives.

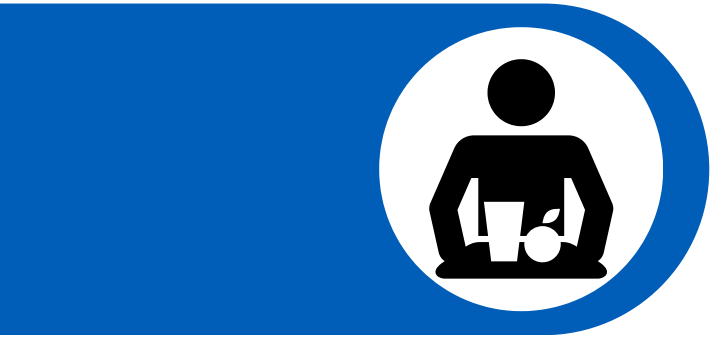


Following bowel surgery, your clinical nurse specialist will discuss your personal needs as this will vary between individuals.

You should limit foods high in fat and sugar as they are high in calories and usually cholesterol. In the long term, this diet may reduce the chances of getting heart disease and diabetes and certain types of cancer. This diet can also be used by members of your family who do not have cancer.

The main things to consider in a healthy diet include:

- eat the right amount to maintain a healthy weight
- eat plenty of fresh fruit and vegetables
- eat plenty of foods rich in fibre and starch
- avoid eating too much fatty food
- avoid sugary food and drinks
- avoid alcohol or only drink in moderation



Our diet can affect the risk of developing some cancers. A summary of the evidence regarding diet, lifestyle and cancer prevention was produced in February 2009 by the World Cancer Research Fund.

Further information is available from organisations such as the Food Standards Agency and NHS Choices.

Should I **Exercise?**

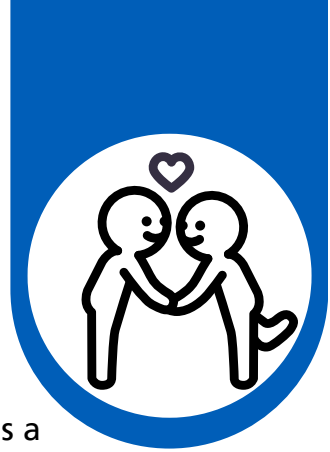
We recommend that once you have completed your treatment, you try to gradually increase your daily activity with the aim of trying to build up to at least three twenty-minute sessions of moderate activity each week.

Regular physical activity of 30 minutes at least five times a week has been shown to help prevent and manage over 20 chronic conditions – including cancer.
Walking daily and building up the distance you walk is a good starting point. You can talk to your GP or practice nurse about how best to get started and learn about local activities

Can I **drink alcohol?**

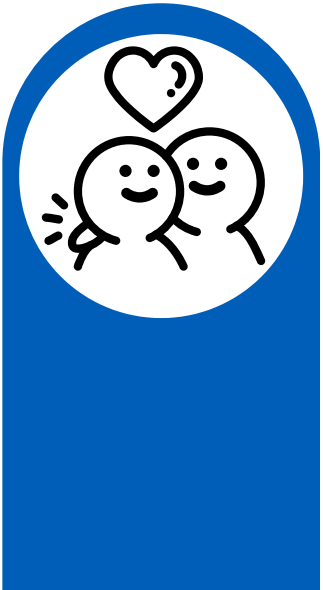
Once you have completed your treatment, there is no need to avoid alcohol entirely. We would always advise that you should not drink more than the Department of Health's recommendations.

Relationships and sexual activity



Being diagnosed and treated for bowel cancer is a complex and completely individual experience that can have far-reaching effects throughout all aspects of your life.

Relationships can be complicated during this time, both emotionally and physically. Adjusting to these changes is often difficult. It is essential that you feel able to discuss this with your clinical nurse specialist. There are several explanations for symptoms you may be experiencing. Please talk either to your clinical nurse specialist or your doctor, so we can help you cope during this challenging time and access any additional support that may be available.



The National Cancer Institute has lots of resources that your loved one may find useful in understanding how they may feel now that you have finished your treatment and how they can navigate this new chapter with you.

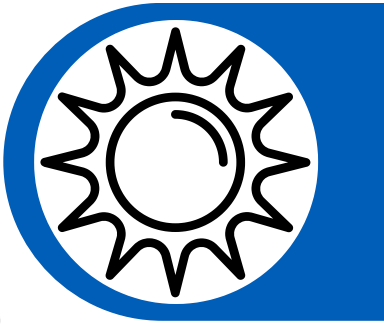
Can I travel abroad?

Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients can encounter difficulties in acquiring travel insurance if they have been treated for cancer.

The Macmillan website offers advice for the cover of patients who have had cancer. The British Insurance Brokers Association (BIBA) may also be able to help with travel insurance.

Some cancer treatments can make your skin more sensitive to the sun and you may burn more easily. This includes:

- radiotherapy
- some types of chemotherapy
- targeted therapy
- immunotherapies



It is important to protect your skin by using a suncream with both a:
high sun protection factor (SPF) of at least 30
4-star or 5-star ultraviolet A radiation (UVA) protection rating.

There are more tips on how to protect your skin after cancer treatment on the Macmillan website.

Dealing with worries

Am I cured?

You will find that most doctors do not use the term "cured", as this implies that they can give you a 100% guarantee that your bowel cancer will never return. Unfortunately, we can never make this promise to any patient. The treatment you have had to date has given you the greatest chance of being well in the long term. Your surveillance programme is designed to ensure any problems are detected early. It is essential that you contact the team if you experience any changes that cause you concern so that we can see you quickly. Later in this booklet is more information on the changes you should report.

What is the chance of my cancer returning?

The risk that your bowel cancer will come back is different for every patient; however, by having the treatment recommended by your surgeon and oncologist, you have reduced the risk of your cancer returning. Eating a healthy balanced diet and taking regular exercise can have a positive effect on your health and helps everyone to reduce their risk of getting cancer.

I am constantly anxious that my bowel cancer will return

What can I do?

It is entirely natural to feel anxious that your bowel cancer will return, and we recognise that this can make you feel very uncertain about the future and lead to difficulties in 'getting on with life'. Some people find it helpful to have some additional support in dealing with these feelings.

Please let us know if you feel you would benefit from extra help, and we will arrange that for you. Central to this approach to your follow-up is that we support your self-management; therefore, we need to know if we can help.

We leave the responsibility with you to **get in touch with us should you require support at any time**, and we trust that you feel able to contact us for help.

What sort of symptoms should I look for?

You should report any changes in your bowel pattern which continue for six weeks or more.
You should also telephone your clinical nurse specialist if you experience any bleeding or mucous discharge.
Changes in your appetite or unexplained weight loss are also essential to report.

If you have any concerns or worries, call your clinical nurse specialist for advice.

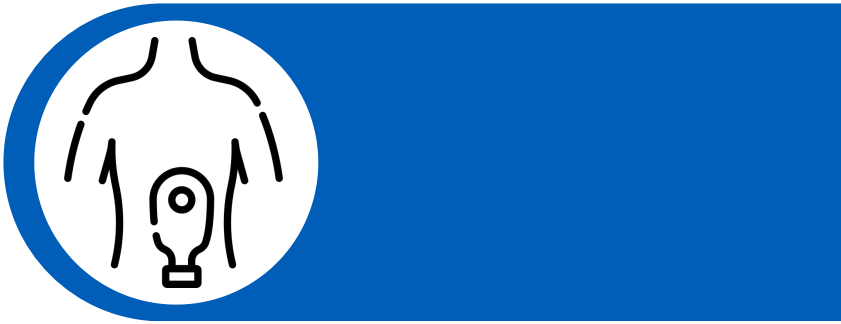
Stoma care service

If you have had a stoma formation as part of your treatment for bowel cancer, you will have met the clinical nurse specialists for the stoma care service.

The stoma care service will advise you of their follow up procedure. You can also contact them if you have any of the following problems:

- Appliance leakage
- Sore peristomal skin
- Change in bowel function
- Any problems with lifestyle issues related to stoma care management.

Stoma Care Service Telephone: 020 8725 3916



	Test due	Results
6 months	Blood Tests	
1 year	Blood Tests CT scan Colonoscopy	
1 ½ years	Blood Tests	
2 years	Blood Tests CT scan	
2 ½ years	Blood Tests	
3 years	Blood Tests CT scan	
3 ½ years	Blood Tests	
4 years	Blood Tests Colonoscopy CT	

	Test due	Results
4 ½ years	Blood tests	
5 years	Blood Tests CT	

Any other tests/results

Important

Contact details

Colorectal nursing team
Phone number: 0208 725 5349
Email: colorectalPSFU@stgeorges.nhs.uk
You can leave a message on the answering machine, which is checked every working day.
One of the colorectal nursing team will contact you within 48 hours.

Bowel Cancer UK
Telephone: 08450 719301
www.bowelcanceruk.org.uk

Bowel Cancer Advisory Service
www.bowelcanceruk.org.uk

Macmillan Cancer Support
Free information, practical and emotional support.
Telephone: 0808 808 0000 (Monday to Friday, 9am to 8pm)
www.macmillan.org.uk

Macmillan Information & Support Centre
Telephone: 020 8725 2677
Email: Cancer.Information@StGeorges.nhs.uk
You can find us:
In St George's Hospital, on the ground floor of Grosvenor Mon-Fri 9am-4.30pm

Macmillan Citizens Advice
020 7042 0332
Mon – Fri 9:30am till 5pm (excluding public holidays).
www.cawandsworth.org/macmillan/

The Patient Advice and Liaison Service
Email: pals@stgeorges.nhs.uk
020 8725 2453
If your first language is not English, PALS will be able to help and will work with the department you are attending to arrange for an interpreter to assist you.

Turn2us
UK charity helping people access money that may be available to them through welfare benefits, grants and other help. Telephone: 0808 802 2000 (Monday to Friday, 9am to 8pm) www.turn2us.org.ukNHS 111 (111
NHS Choices online www.nhs.uk

AccessAble
You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.