

Supported Self-Management and Surveillance for Colorectal Cancer

General Surgery – Colorectal Nursing Department

Introduction

This booklet aims to explain what supported self-management is and how it works. It contains all the information you need to contact the team and arrange to be seen if you are worried, plus information that we think you may find useful as you recover from your treatment.

You will have a consultation with a Colorectal Clinical Nurse Specialist or Consultant who will explain the service to you.

They will discuss your diagnosis, treatment and any possible side effects and provide advice on related health, lifestyle and wellbeing issues.

The Colorectal Clinical Nurse Specialist will also tell you about further sources of help, support and explain:

- The signs and symptoms to look out for that might indicate a return or spread of the disease
- The helpline you can contact if you have any symptoms, concerns or queries
- The arrangements for any follow-up tests, such as CEA (blood tests), CT scans, and colonoscopies, why these are important and the process for getting the results
- What patient information is available for you and your family

We will also send your GP full details of your treatment plus any monitoring tests they may need to arrange for you.

What is Supported Self-Management?

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 Colorectal Clinical Nurse Specialist directly to arrange an appointment if you feel that you need to be seen.

You can leave a message on 01902 695569 on the answer machine, which is checked every working day. One of the Colorectal Clinical Nurse Specialist or the colorectal cancer navigator will contact you within one working day.

How does supported Self management and Surveillance work?

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

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available
- If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111
- Keep the environment clean and tidy
- Let's work together to keep infections out of our hospitals and care homes.

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

Follow-up is a necessary precaution, as a small number of people can relapse. It is a way to pick up problems early and act quickly enough to be able to treat them.

We will continue to keep a close eye on you by reviewing your blood results, colonoscopies and scans every time they are performed.

If you have any symptoms or concerns, you can telephone a member of the team. That is why we call it supported self-management. If necessary, you will be seen urgently by the team at the next available opportunity.

We will continue to see you or perform a telephone consultation at regular intervals as listed in the section appointments.

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 on a regular basis. Some patients will also find that it takes longer than expected to recover fully from their treatment.

Finding support

You may have already found that people have different ways of living with bowel cancer. There is no right or wrong way, just what works for you and beyond. Some people prefer not to talk, while others like to get support from talking about their experience. Your Colorectal Clinical Nurse Specialist or Colorectal Cancer Navigator is there to help you with support.

Health and Wellbeing Events

The Royal Wolverhampton NHS Trust alongside Macmillan Support offer Health and Wellbeing events where you can get information from healthcare professionals on managing your health and wellbeing after treatment. You may also have the chance to meet other people in a similar position to you. Ask your healthcare team if there are any events in your area.

Holistic needs assessment

You will be offered a holistic needs assessment. These help to find out what practical, physical, emotional or spiritual needs you have. Your healthcare team can signpost you to other local services if you need them. Your Colorectal Clinical Nurse Specialist will discuss these assessments with you.

When can I return to work?

If you are going back to work, it will help to meet with your employer, human resources department or occupational health staff first. It can be useful to have someone else there (such as a work colleague or union representative) to take notes. If you are still having some side effects from the cancer treatment, discuss any reasonable changes that can be made to help you get back to work, including a staged return to work. The Equality Act (2010) covers all types of cancer and exists to protect against unfair treatment compared to others, harassment, victimisation, and unfair dismissal. If you think you are being treated unfairly when you are trying to get back to work, it is there to protect you. Disability employment advisors are based at Job Centres and Job Centre Plus.

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

- What adjustments could your employer arrange that would make work easier for you?
- Can you reduce your hours, work flexibly or work more from home?
- Will you need to rest at work during the day?
- Is there any counselling available if you want it?

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 have an effect on your income, but you may be able to get help with NHS costs, grants and certain benefits. There are a number of people you can talk to for information 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 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 who give grants. You need to apply through a health social care professional or General Practitioner.

Staying healthy

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. All of your concerns should be covered in your individual consultation and supported self-management plan, so 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. Following bowel surgery your Clinical Nurse Specialist will discuss your personal needs as this will vary between individuals. You may be referred to a dietitian if required.

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
- Limit red meat and avoid processed meats
- Do include lean protein like skinless chicken, fish or pulses
- Avoid sugary food and drinks, drink plenty of water
- Avoid alcohol. We would always advise that you should not drink in excess of the Department of Health's recommendations, which is no more than two to three units of alcohol per day, where a unit of alcohol equals a small glass of wine

Should I exercise?

We recommend that once you have completed your treatment, you try to gradually increase your daily activity. 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 (www.nhs.uk).

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 find out about local activities.

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. Macmillan Support and Information Centre, Macmillan website have a list of insurers specialising in the cover of patients who have had cancer and will be able to offer advice. The British Insurance Brokers Association (BIBA) may also be able to help with travel insurance.

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 very difficult during this time, both emotionally and physically. Adjusting to these changes is often difficult. It is important that you feel able to discuss this with your Clinical Nurse Specialist. There are a number of explanations for symptoms you may be experiencing. Please talk either to your Clinical Nurse Specialist or your GP so we can help you cope during this difficult time and access any additional support that may be available.

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 minimised your personal risk of having any further problems from cancer as much as possible. 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 useful to have some additional support in dealing with these feelings. Please let us know if you feel that you would benefit from some extra help and we will arrange that for you. Central to this approach to your follow-up is that your self-management is supported by us; 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 trust that you feel able to contact us for help.

What sort of symptoms should I look for?

Everyone has aches and pains, but when you have had bowel cancer you may be more aware of them and concerned that any pain or difference in your bowel habit may be related to the cancer returning.

Listed below are some of the symptoms you should report via the helpline immediately: 01902 695569:

- Any new bleeding from your back passage, or from your stoma, or in your urine
- Continuing pain that does not go away with your usual painkillers
- Any unexplained lumps, bumps or swelling around your scar or stoma
- A change in your bowel habit that lasts for six weeks or more – especially if you are waking in the night with loose stools
- Unexplained weight loss, lack of appetite, a constant feeling of nausea or increase in waist measurement
- Bleeding or discharge from your operation site
- Any physical problem that interferes with your daily life, for example fatigue, difficulty sleeping or any new problem with sexual function
- Shortness of breath or coughing that gets worse or does not go away after 3 weeks.

The Colorectal Clinical Nurse Specialist will talk through your symptoms with you and agree the best course of action. If the nurse thinks that you need to be seen or have any diagnostic tests, you will be given an appointment as soon as possible.

Getting a symptom that could indicate a recurrence or a new cancer can be frightening but it is important to remember that having one of these symptoms does not necessarily mean that your cancer has returned, as they can all be caused by many other common conditions. Please note if your symptoms are particularly worrying, especially in the case of sudden, heavy bleeding, or severe and persistent abdominal (tummy) pain, you should contact your GP immediately or go straight to your nearest A&E department.

You can contact the Colorectal Clinical Nurse Specialist Service by telephoning the supported self-management helpline if you have concerns about your bowels, any new symptoms you would like to report or if you have questions about your treatment or any other related issues.

Supported self-management telephone helpline: 01902 695569

The telephone helpline is open between 8:30pm and 4:00pm from Monday to Friday. This is a telephone answer machine service. When leaving a message, please give a brief description of your colorectal query or concern, along with your name, hospital number and telephone number and someone will call you back within 24 working hours.

Other reasons to contact the supported self-management helpline

You should also contact the helpline with any of the following:

- Questions about the side effects of your medication or treatment
- Changes to your address or telephone number – it is important that the contact details we have for you are correct
- If you have not heard about an appointment you were expecting
- If you are finding it difficult to cope and/or you would like some emotional support
- Any concerns you would like to talk through

We would rather you contact us with a concern that turns out to be nothing, than for you to be worried. We are here to support you.

What surveillance will I have?

You will have regular blood tests to check your carcinoembryonic antigen levels (CEA). CEA is a protein made by some types of cancer, including colorectal cancers. If your cancer returns it can cause the level of CEA in your blood to rise – we call this a tumour marker. A normal level of CEA does not mean the cancer has not returned, so you will have other tests too.

You will have a colonoscopy at year one and year four after your surgery. If you did not have a complete colonoscopy before your surgery, then this will be performed sooner.

You will have a CT scan at one, two and three years following surgery, or more often if your consultant decides this is necessary.

After five years of surveillance we will then discharge you from the Supported Self-Management Surveillance pathway and you will continue to be monitored by your General Practitioner.

Appointments and investigation records

If after any of the tests we feel that you need to be seen, the Colorectal Clinical Nurse Specialist will call you to arrange an appointment with the doctor. This will also be communicated to you and your GP in writing. If you have been referred to the Oncologist to discuss chemotherapy following your surgery then your surveillance with the Colorectal Clinical Nurse Specialist will commence approximately 6 months after completion of your chemotherapy.

Please note, once discharged from the hospital please see your GP if you develop any colorectal signs or symptoms.

Stoma Care Service

If you have had formation of a stoma 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 skin surrounding the stoma
- Change in bowel function
- Any problems with lifestyle issues related to stoma care management

Other useful telephone numbers :

Endoscopy: 01902 307999 Ext. 84052/84057

Radiology: 01902 307999 Ext. 86360

General Appointments: 01902 307999 Ext. 81777

Colorectal: 01902 481891.

For Senior Colorectal Clinical Nurse Specialist Contacts Number:

Please contact office on 01902 695569 (Answerphone)

Monday - Friday, between 8:00am to 5:30pm

These two charity organisations provide information including both practical and emotional support:

Bowel Cancer UK

Email: admin@bowelcanceruk.org.uk

www.bowelcanceruk.org.uk

Telephone: 020 7940 1760

Macmillan Cancer Support:

A nursing advisory service providing 24-hour answer phone and call back service:

7 days a week, 8:00am to 8:00pm

Telephone: 0808 808 0000

Email: www.macmillan.org.uk

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。