



University Hospital
Southampton
NHS Foundation Trust

Southampton colorectal unit Patient triggered follow-up

Your guide to supported self-management
and surveillance



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Important notice

If there is any change of your address or GP, please let us know by telephoning: **023 8120 6764**

Your personal details

Name:

Hospital number:

Date of diagnosis:

Pathological diagnosis:

Treatment and dates:

Surgical consultant:

Oncology consultant:

Named clinical nurse specialist:

Introducing patient triggered follow-up (PTFU)

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 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 done. If you have any symptoms or concerns you can telephone a member of the team. That is why we call it patient triggered follow-up. If necessary you will be seen urgently by the team at the earliest appointment.

This booklet aims to explain what patient triggered follow-up and 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. It also contains details about your cancer and the treatment you have had so far, as well as the investigations and tests that you will need in the future - your surveillance plan. This booklet also contains information that we think you may find useful as you recover from your treatment

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 clinical nurse specialists directly to arrange an appointment if you feel that you need to be seen.

Clinical nurse specialist contacts

Office phone number:

023 8120 6764

You can leave a message on the answer machine, which is checked every working day. One of the clinical nurse specialists will contact you within one working day.

Email:

lowerginurses@uhs.nhs.uk

Bleep:

Telephone the hospital switchboard on **023 8077 7222** and ask them to bleep your clinical nurse specialist using the following numbers: **2965/9248**.

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

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 rep) to take notes. If you're 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 and victimisation, and unfair dismissal. If you think you are being treated unfairly when you're trying to get back to work, it's 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 include:

- What adjustments could your employer arrange that would make work easier for you?
- 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?

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 or social care professional, such as a district nurse or a social worker.

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 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. 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 right nutrients needed. 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. You should limit foods that are high in fat and sugar as they are high in calories and usually cholesterol as well. In the long term, this diet may reduce the chances of getting heart disease and diabetes as well as certain types of cancer. This diet can also be used by members of your family who do not have cancer. Following bowel surgery your clinical nurse specialist will discuss your personal needs as this will vary between individuals.

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 our 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. You may reduce your cancer risk by eating a healthier, balanced diet. The information in this section is a summary of the main things to consider if you want to follow a healthier diet. Further information is available from organisations such as the Food Standards Agency and NHS Choices (www.nhs.uk).

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 find out 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 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.

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. Both the Southampton Macmillan Support and Information Centre and the 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 doctor, so we can help you cope during this difficult time and access any additional support that may be available.

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 important that you contact the team if you experience any changes that cause you concern, so we can see you quickly. See page 11 for 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 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.

Will I have any tests to check that the cancer hasn't returned?

Yes. You will be given a summary of your treatment, and so will your GP. You will also be given a surveillance plan that will include a number of tests and questionnaires about your health and wellbeing.

What surveillance will I have?

You will have regular blood tests to check your CEA levels. CEA stands for carcinoembryonic antigen. It is a marker 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 a year after your surgery. If you did not have a complete colonoscopy before your surgery then this will be performed sooner. We then repeat this every five years, unless there is a medical reason to do this more often.

You will also have a CT scan after one, two and five years, or more often if your consultant decides this is necessary.

I'm 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?

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 important to report.

If you have any concerns or worries just call your clinical nurse specialist for advice. Contact details can be found on page 5.

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. This service is provided by Solent NHS Trust and is accessible to anyone within Southampton city and parts of west Hampshire.

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
Bitterne Health Centre
Commercial Street
Southampton
SO18 6BT**

Telephone: **023 8071 8862**

Macmillan Cancer Support

Free information, practical and emotional support.

Telephone: 0808 808 0000

(Monday to Friday, 9am to 8pm)

www.macmillan.org.uk

NHS Carers Direct

Freephone 0300 123 1053

(Monday to Friday, 9am to 8pm; Saturday to Sunday, 11am to 4pm)

www.nhs.uk/carersdirect

NHS Choices

Includes all NHS online services and information, to help you make choices about your health.

www.nhs.uk

Ostomy Lifestyle

Provides support, advice and information to anyone affected by surgery on their bowel or bladder.

Helpline: 0800 7314264

www.ostomylifestyle.org

Carers Trust

Telephone: 0844 800 4361

www.carers.org

Disability Rights UK

Offer practical advice for people living with a disability or health condition. They provide access to more than 9,000 public toilets for disabled people in the UK via a Radar NKS Key which can be purchased from the Disability Rights UK online shop.

www.disabilityrightsuk.org

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.uk

Local contacts

Southampton Ostomates Support Group

Monthly peer support group

Telephone: 023 8044 6779

Email: carole.lesley@btinternet.com

Southampton Macmillan Cancer Information and Support Centre

B level, Southampton General Hospital:

Telephone: 023 8120 6037

Email: mary.weavers@uhs.nhs.uk

www.uhs.nhs.uk/macmillan

Wessex Cancer Trust

Local charity providing information, counselling, complementary therapies.

Telephone: 023 8067 2429

www.wessexcancer.org

Health Trainers

A free confidential one to one service providing support and encouragement with lifestyle changes.

Southampton: 023 8051 5222

Quitters stop smoking services

Support for people who want to stop smoking.

Hampshire: 0845 602 4663

www.quit4life.nhs.uk

Southampton: 023 8051 5221

www.southamptonquitters.nhs.uk

If you would like to make a donation to support our work please contact:

Colorectal Cancer Fund
Southampton Hospital Charity
Mailpoint 135
Southampton General Hospital
Southampton
SO16 6YD
Charity registration number: 1051543

Some of the sections in this leaflet have been adapted with permission from information by Macmillan Cancer Support.

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone 023 8120 4688 for help.

www.uhs.nhs.uk