



Salisbury **NHS**  
NHS Foundation Trust

# information

## Salisbury Colorectal Unit Patient triggered follow-up

### Your guide to supported self-management and surveillance

Salisbury NHS Foundation Trust





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## Your personal details

Name:

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Hospital No:

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Date of diagnosis:

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Initial diagnosis:

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Surgical treatment:

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Results of surgery:

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## 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.

## Attending the workshop

You will be invited to attend a workshop that is run by one of our clinical nurse specialists. This will provide you with information and advice for wellbeing in the future. We strongly recommend you attend this session.

## Clinical nurse specialist contacts

Lead Nurse Hilary Dean

Sister Gemma Denny

Sister Sara Dear

Office phone number: 01722 425194

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.

Alternatively:

If it is urgent, telephone the hospital switchboard on 01722 336262 and ask them to bleep your clinical nurse specialist using the following numbers:

Sister Gemma Denny      (Bleep) 1037

Sister Sara Dear      (Bleep) 1239





## 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 find out 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, Citizens 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.

There are conflicting theories about diet and cancer, which can be very confusing. Most experts would agree that eating a well-balanced diet rich in vegetables, fruits and other plant based foods should provide all the right nutrients needed. Supplements are not recommended for cancer prevention. Recent research shows that eating fibre rich food can help reduce risk of bowel cancer.

As your digestive system returns to normal you should gradually be able to introduce more fibre into your diet to avoid problems such as flatulence or bloating.

Fibre is only found in plant-based foods.

There are two types of fibre:

- **soluble fibre** which can be found in oats, beans, barley and citrus fruits. This has been shown to lower cholesterol levels.
- **insoluble fibre** which is found in whole wheat bread and cereals and most vegetables. It is indigestible and passes through the body without being absorbed. It is important for normal bowel function.





Fibre acts like a sponge and soaks up fluid in the stomach and bowel; therefore it is important to drink plenty.

The main part of your diet should come from plant based foods such as fruit, vegetables and starchy foods – preferably wholegrain foods such as brown rice or pasta, oats or potato and pulses such as lentils, chickpeas and beans. These foods also tend to be lower in calories and higher in fibre, which helps to fill you up and manage your weight.

A smaller part of your diet should come from protein foods such as meat, fish, eggs, Quorn, nuts and seeds. Red meat (lamb, beef, pork) can be eaten, but not every day, and avoid processed meats such as bacon, ham or salami, which are strongly linked to bowel cancer.

Milk, dairy foods or alternatives provide important sources of calcium and some vitamins, as well as protein, but opt for lower fat varieties.

Cut down on processed or manufactured foods such as crisps, chocolate or ready meals. You should limit foods that are high in fat and sugar as they are also high in calories, and linked to weight gain.

In the long term, this diet may also reduce the chances of getting heart disease and diabetes as well as certain types of cancer and can 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 from all the food groups to maintain a healthy weight





- eat plenty of fruit and vegetables – fresh, frozen, tinned or dried
- eat plenty of foods rich in fibre (both soluble and insoluble) and starch
- drink at least 8-10 glasses of water a day
- avoid eating too much fatty food
- avoid sugary drinks and limit sugary foods
- avoid alcohol or only drink in moderation.

Following bowel surgery your clinical nurse specialist will discuss your personal needs as this will vary between individuals. Dietary advice differs slightly if you have a stoma; it is sensible to avoid dried fruit, nuts, jacket potato skins, sweetcorn, mushrooms, asparagus and coconut. Beans and lentils may be good for you but the consequences can be embarrassing. Please follow the dietary advice provided by your Stoma Team.

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.

A summary of the evidence regarding diet, lifestyle and cancer prevention was produced in February 2009 by the World Cancer Research Fund. ([www.wcrf-uk.org](http://www.wcrf-uk.org)).

Further information is also available from organisations such as the Food Standards Agency and NHS Choices ([www.nhs.uk](http://www.nhs.uk)).

If you would like specialist help, speak to your GP who can refer you to a dietician.





## 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.

## Health and wellbeing programme

This is a free programme for all patients going through or having completed, treatment for cancer. It consists of educational sessions, group support and physical activity on a group or individual basis.

Contact: Che Penny, Health & Fitness Team Leader ☎ 01722 425085

## 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. The Macmillan website has 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 signs and 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 15 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 and developing practical coping strategies. 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 signs and 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 a stoma formed 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 around the stoma
- change in bowel function
- any problems with lifestyle issues related to stoma care management.





## Your Stoma Team contacts

Sister Sandra Bryan

Sister Suzie Dukes

Sister Michelle Boucher

Office phone number: 01722 429256

You can leave a message on the answer machine, which is checked every working day.

### **Alternatively:**

If it is urgent, telephone the hospital switchboard on 01722 336262 and ask them to bleep your clinical nurse specialist using the following bleep numbers: 1694 or 2045.



# Your surveillance plan

Test /months after surgery	3	6	9	12	15	18	21	24	30	36	42	48	54	60
Date of test														
CEA due	<input checked="" type="checkbox"/>													
CEA result (and date of result)														
Urea and electrolyte blood test due (needs to be done 1 week before CT scan)				<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>						<input checked="" type="checkbox"/>
CT scan usually undertaken (Sometimes these change)				<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>						<input checked="" type="checkbox"/>
Colonoscopy				<input checked="" type="checkbox"/>										
Comments														

when test is usually due, however, these may be adjusted depending upon previous results.



## Further information and useful contacts

### Age UK

 0800 169 6565 (freephone)

[www.ageuk.org.uk](http://www.ageuk.org.uk)

### Beating Bowel Cancer Advisory Service

 02089730011

[www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)

### Disabled Living Foundation

 0300 999 0004

[www.dlf.org.uk](http://www.dlf.org.uk)

### Cancer Research UK

Information, research and details of clinical trials.

 0808 800 4040

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

### Carers UK Carers Line

 0808 808 7777 (freephone, Monday to Friday, 10am to 4pm)

[www.carersuk.org](http://www.carersuk.org)

### Citizens Advice Bureau

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)



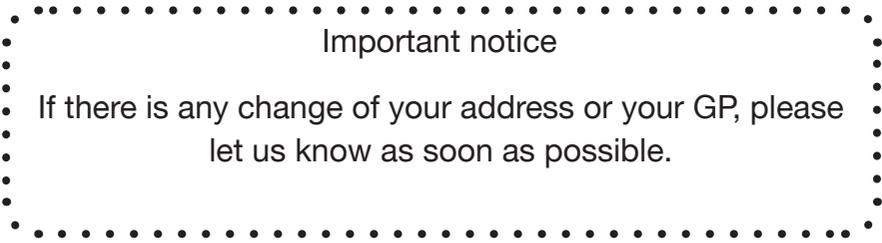


## **Wessex Cancer Trust**

Local charity providing information, counselling,  
complementary therapies.

 023 8067 2200

[www.wessexcancer.org](http://www.wessexcancer.org)



### Important notice

If there is any change of your address or your GP, please  
let us know as soon as possible.





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If you need your information in another language or medium (audio, large print, etc) please contact the Customer Care Team on 0800 374208 or email: [customer.care@salisbury.nhs.uk](mailto:customer.care@salisbury.nhs.uk)

You are entitled to a copy of any letter we write about you. Please ask if you want one when you come to the hospital.

If you are unhappy with the advice you have been given by your GP, consultant, or another healthcare professional, you may ask for a second (or further) opinion.

The evidence used in the preparation of this leaflet is available on request. Please email [patient.information@salisbury.nhs.uk](mailto:patient.information@salisbury.nhs.uk) if you would like a reference list.

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