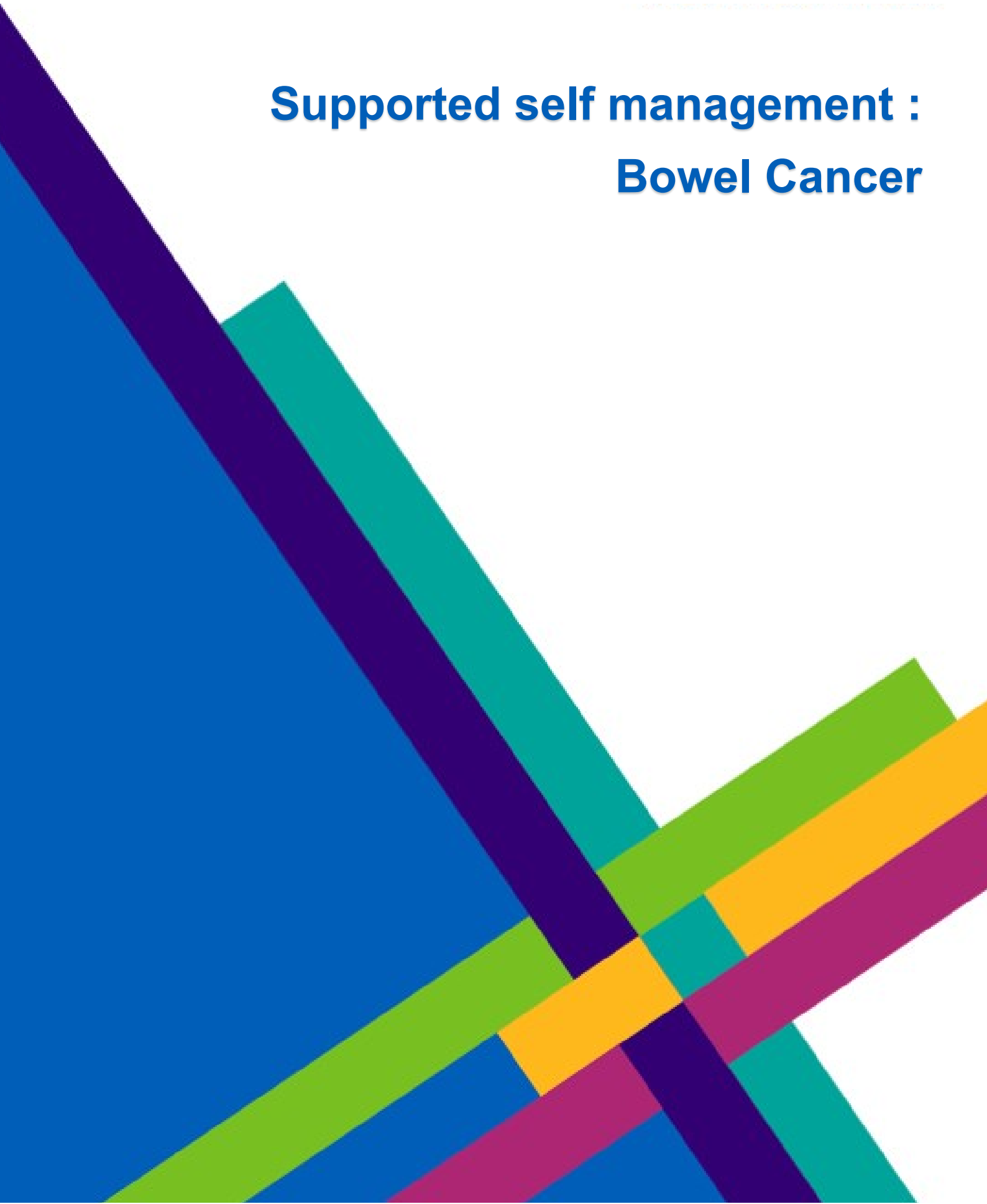




Salisbury
NHS Foundation Trust

Supported self management : Bowel Cancer



Introducing Supported Self-Management Pathway (SSMP)

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 supported self-management. If necessary you will be seen urgently by the team at the earliest appointment.

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. 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 cancer support worker on 01722 336262 ext.2417 within the colorectal team to arrange an appointment, if you feel that you need to be seen.

Moving Forward Clinic

As part of your supported self management follow up, you will be invited to attend a Moving Forward Clinic run by members of the colorectal team. This will be an educational session providing you with information and advice for your health and wellbeing in the future. We strongly recommend you attend this session.

Clinical nurse specialist contacts

Office phone number: 01722 425194

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 colorectal clinical nurse specialist using the following numbers: **1037 or 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 and cancer support worker are 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 cancer support worker or clinical nurse specialist to refer you to Macmillan Benefit Advisors 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 CNS, GP, 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/)

Further information is also available from organisations such as the Food Standards Agency and NHS Choices (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 6 week programme held for 2 hours per week 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. If you would be interested in attending please speak to your cancer support worker on 01722 336262 ext. 2417.

Alternatively Contact: Health & Fitness Centre - 01722 425085

Free Swimming Sessions

Held at the Health and Fitness Centre (Salisbury Hospital). Free weekly swimming session for patients who have had a cancer diagnosis. The pool and changing areas are closed for general use during this time.

Contact: Health & Fitness Centre - 01722 425085

Can I drink alcohol?

Once you have completed your treatment there is no need to avoid alcohol entirely. The Chief Medical Officers' guideline for both men and women states that: To keep health risks from **alcohol** to a low level it is safest not to drink more than 14 units a week on a regular basis. If you regularly drink as much as 14 units **per** week, it's best to spread your **drinking** evenly over three or more days.

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 Cancer Support 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 below 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 produced 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 four years after surgery, unless there is a medical reason to do this more often.

You will also have a CT scan after 1, 2 and 5 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 call your clinical nurse specialist for advice.

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 can be contacted on: 01722 429256 / 01722 429257

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 colorectal clinical nurse specialist using their bleep numbers: **1037 or 1239**..

Tests/months after surgery	3	6	9	12	15	18	21	24	30	36	42	48	54	60
Date of test														
CEA due	X	X	X	X	X	X	X	X	X	X	X	X	X	X
CEA result (and date of result)														
Urea and Electrolyte blood test (to be done 1-2 weeks prior to CT or Colonoscopy)				X				X				X		X
CT Scan usually undertaken (sometimes these change)				X				X						X
Colonoscopy				X								X		
Comments														

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

Further information and useful contacts

National Contacts

Macmillan Cancer Support 0808 808 0000 or visit www.macmillan.org.uk

Bowel Cancer UK 020 7940 1760 (Monday to Friday 9am - 5pm) or visit www.bowelcanceruk.org.uk

Colostomy UK 0800 328 4257 (24 hours a day) or visit www.colostomyuk.org

World Cancer Research Fund 020 7343 4200 or visit www.wcrf-uk.org

Cancer Research UK 0808 800 4040 (Monday to Friday 9am - 5pm) or visit www.cancerresearchuk.org

Age UK 0808 196 2424 (freephone) or visit www.ageuk.org.uk

Citizens Advice Bureau visit www.citizensadvice.org.uk

Local Support

Look Good Feel Better - A free confidence boosting skin care and make up workshop. For ladies - Salisbury 01722 452102. For men - Southampton - 02381 206037 www.lookgoodfeelbetter.co.uk

Jane Scarth House, Cancer Support Centre - A cancer centre in Romsey, offering complementary therapies, counselling services, information and groups. Open to adults affected by cancer and their carers and families. 01794 830374 or www.janescarthhouse.co.uk

Macmillan Benefit Advisors - Financial advice and information relating to concerns about income, costs relating to cancer. Call 01722 441393

Carers Support Wiltshire

0808 181 4118 or www.carersuk.org

Important notice:

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

