

Oncology

Colorectal Supported Self-management

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Colorectal supported self-management programme (SMP)

You have been started on a Supported Self-Managed follow-up programme. You and your clinical team believe this is the best way of checking your recovery after your cancer treatment. The Cancer Care Co-Ordinator, along with a computerised system allows us to monitor the results of your regular tests and recall you quickly to hospital if there are any concerns. It gives you the freedom to get on with your life, with the comfort that there are specialist clinicians keeping an eye on your progress.

You will continue to have any recommended CT scans, blood tests and colonoscopies, but will only be brought back in to hospital for an appointment if your results show a change which needs further investigation.

What are the benefits of supported self - management care?

- Supported self-management care puts you in control of your care. Instead of your routine follow-up clinic appointments, you will not have to make unnecessary trips to the hospital at times when you are symptom-free and getting on with your life.
- You can phone your Clinical Nurse Specialist (CNS) with any concerns or symptoms relating to your colorectal cancer - see back of the booklet for contact numbers.
- You no longer have to take time off from work or pay travelling or parking charges for outpatient appointments that you do not need.

The regular tests you will need

After your treatment for colorectal cancer you will need to have regular blood tests, CT scans and colonoscopies. Your clinical team will explain when you will need them.

When your CT scan, colonoscopy or blood test is due, you will receive a letter and a blood form asking you to book in for a blood test. The results of these tests will be recorded on the follow-up computer system and will

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be checked carefully by the relevant clinical staff.

If your results are within the range that is normal for you, you and your GP will receive a letter confirming this and you will be reminded when your next tests are due. With the self-management pathway you will not be routinely called for a follow-up appointment at the hospital if your results are normal and you don't have any symptoms.

If the results are not within a range that is normal for you, the Clinical Nurse Specialist team will be in touch with you to let you know what steps will be taken next.

What is a CEA (carcinoembryonic antigen) blood test?

This is a simple blood test to check your bowel -specific cancer markers, regularly throughout the next 5 years. CEA is a cancer marker which can sometimes help to monitor your cancer, but not all cancers show up in this way.

A blood test form will be sent to you before this test is due.

Your clinical teams want to make sure that you stay fit and well so will need to look into any results that are not normal for you, just in case there is a problem that needs to be resolved. As with all problems, the sooner they are looked into the better the chances of a successful outcome.

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. There are also a range of support groups available. Please see the telephone numbers at the back of this booklet.

What sort of symptoms should I look for?

Everyone is different and you know your body best, so we would much rather you telephone your Clinical Nurse Specialist with a concern that turned out to be nothing than have you sitting at home worrying.

You should report any changes in your bowel pattern which continue for two weeks or more. It is important that you contact the team if you experience any changes that cause you concern, so we can see you quickly.

Some symptoms might include:

- Any bleeding from your bottom (rectum) that does not go away. We are not worried about the occasional few spots on the toilet paper, but anything more than this that happens over a few days should be reported to the Clinical Nurse Specialist team (numbers at the back of this booklet)
- Any new pains that do not go away and last for longer than a week
- Losing weight unexpectedly
- Any problems with your food or intake
- Any shortness of breath or a cough

When can I go back 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 and support you.

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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 phased return if required.

- Can you reduce your hours, work flexibly or work 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 organisations you can talk to for information about additional help if financial issues are causing you to worry.

Ask your Clinical Nurse Specialist (CNS) to refer you to Macmillan Cancer Support or Citizen's Advice Bureau.

Staying healthy and how to help yourself?

What diet should I follow?

There is no need to follow a special diet after you have been treated.

Bowel function issues are common after some types of bowel cancer surgery. You should contact your Clinical Nurse Specialist (CNS) if you would like advice.

As a general rule you should try to eat a good, balanced diet, and we recommend trying to stay within a healthy weight range to reduce the risk of the cancer coming back (recurrence). Enjoying a healthy diet is especially important if you have had cancer.

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You may hear lots of different ideas about the effect of certain foods on cancer which can be confusing. Most experts would agree that a healthy, balanced diet provides all the right nutrients you need. If you would like specialist help please speak to your GP.

The main things to consider in a healthy diet include:

- The main part of your diet should come from fresh fruit, vegetables and starch, preferably wholegrain foods such as rice, pasta or potato
- A smaller part of your diet should come from proteins such as meat, fish, nuts, seeds, dairy or alternatives
- You should limit foods that are high in fat and sugar as they are high in calories and may increase your cholesterol as well
- In the long term, this diet may lower 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
- After bowel surgery your Clinical Nurse Specialist will discuss your personal needs with you

Summary:

- Eat the right amount to maintain a healthy weight
- Eat plenty of fresh fruit and vegetables
- Avoid eating too much fatty food
- Avoid sugary food and drinks
- Avoid alcohol or only drink in moderation

Physical activity

We recommend that once you have completed your treatment, you should try to slowly 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. Anyone who has had abdominal

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(stomach) surgery should be doing central core exercises to lower the risk of developing a hernia. Your Clinical Nurse Specialist will have information about these specific exercises. You can talk to your GP or practice nurse about how best to get started and find out about local activities. Contact your Cancer Information Services about support available in your area to help with increased activity- (Telephone numbers at the back of the booklet).

Can I drink alcohol?

Once you have finished your treatment you can drink alcohol. We would always advise that you should not drink more than the Department of Health's recommendations, which is no more than two units of alcohol per day. One unit of alcohol equals a 125ml glass of wine or ½ pint of standard strength beer.

Can I travel abroad?

Once you have finished your treatment, you can travel abroad. Sometimes patients have difficulty getting travel insurance if they have been treated for cancer. Talk to your Cancer Information Centre for details of travel insurance companies.

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 having. 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 they cannot give you a 100% guarantee that your bowel cancer will never return. The treatment you have had so far has given you the greatest chance of being well in the long term.

Your programme of tests and check-ups are designed to make sure we pick up any problems early.

What is the chance of my cancer returning?

The risk that your bowel cancer will come back is different for every patient.

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 by us and from your GP. This will advise on when to expect further investigations such as CT scans and Colonoscopies. These will be arranged by the hospital.

I'm constantly anxious that my bowel cancer will return - what can I do?

It is natural to feel worried that your bowel cancer will return and we recognise that this can make you feel very unclear about the future and lead to difficulties with 'getting on with life'. Some people find it useful to have some extra 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 the self-management follow-up approach is the idea that you will ask us when you need help, and we will then support you. It is

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therefore very important that you do get in touch with us if you need support.

Stoma care service

If you now have 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 talk to you about their follow up procedure. You can also contact them if you have any of the following problems:

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

Please see contact numbers at the back of the booklet

Toilet card

You may also find it helpful to get a toilet card. This is a card that you can show quickly and easily to staff in shops, restaurants and other places. It explains that you have a medical condition and need urgent access to a toilet.

Macmillan will send you a free toilet card if you request, or you can download one yourself from their website here:

<https://be.macmillan.org.uk/be/p-24952-macmillan-toilet-card.aspx>

The Bladder & Bowel Community also offer a free 'Just Can't Wait' toilet card and phone App. Visit their website for more information:

<https://www.bladderandbowel.org/help-information/just-cant-wait-card/>

Further information and useful contacts

Age UK: www.ageuk.org.uk

Advice line 0800 169 6565

Bowel Cancer UK

www.bowelcanceruk.org.uk

British Red Cross www.redcross.org.uk

Telephone: 0844 871 11 11

Disabled Living Foundation: www.dlf.org.uk

Telephone: 0300 999 0004

Cancer Research UK: www.cancerresearchuk.org

Information, research and details of clinical trials.

Helpline: 0808 800 4040

Carers UK Carers Line: www.carersuk.org

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

Macmillan Citizens Advice Bureau

www.citizensadvice.org.uk

For further information please refer to the Macmillan website

<https://www.macmillan.org.uk/>

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UHCW Contacts

Secretaries

Mr. Williams and Mr. Evans024 7696 6101
Mr. Baragwanath024 7696 6102
Mr. Bajwa and Mr. Sood.....024 7696 6099
Mr. Aslam and Miss Patel.....024 7696 6097
Mr. Wong and Mr. Leong024 7696 6103

Colorectal and Stoma Nursing Team024 7696 5825

Cancer Information Centre024 7696 6052
.....8.00am - 4.00pm
.....Monday - Friday

Gut Support Group

The Digestive Tract Cancer Support Group

Meets 1st Thursday of every month

10.00 -12.00 at Clinical Sciences building UHCW

For more information contact

Sarah Taylor024 7696 5617
Gail Goddard 024 7696 6478

SWFT Contacts

Secretaries01926 495321

Colorectal Nursing Team01926 495321 ext 4336

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Stoma Care Department01926 495321 ext 4504

8.30am - 4.30pm Monday - Friday

stomacarenursing@swft.nhs.uk

Macmillan Cancer information Centre

01926 495321 ext 8214/5871

8.00am - 4.00pm Monday - Friday

ABC (Affected by Bowel Cancer) Support Group

01926 495321 ext 4336

www.warwickabc.co.uk

The Trust has access to interpreting and translation services. If you need this Information in another language or format please contact 024 7696 7238 and we will do our best to meet your needs.

The Trust operates a smoke free policy.

To give feedback on this leaflet please email feedback@uhcw.nhs.uk

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