

Supportive Self-Management Frequently Asked Questions

Colorectal Unit
Patient Information Leaflet



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 coping following bowel cancer treatment. 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 cancer care coordinator and 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.

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.

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 cancer care coordinator or clinical nurse specialist to refer you to Macmillan Cancer Support for more information or you can contact them directly on 01253 955710

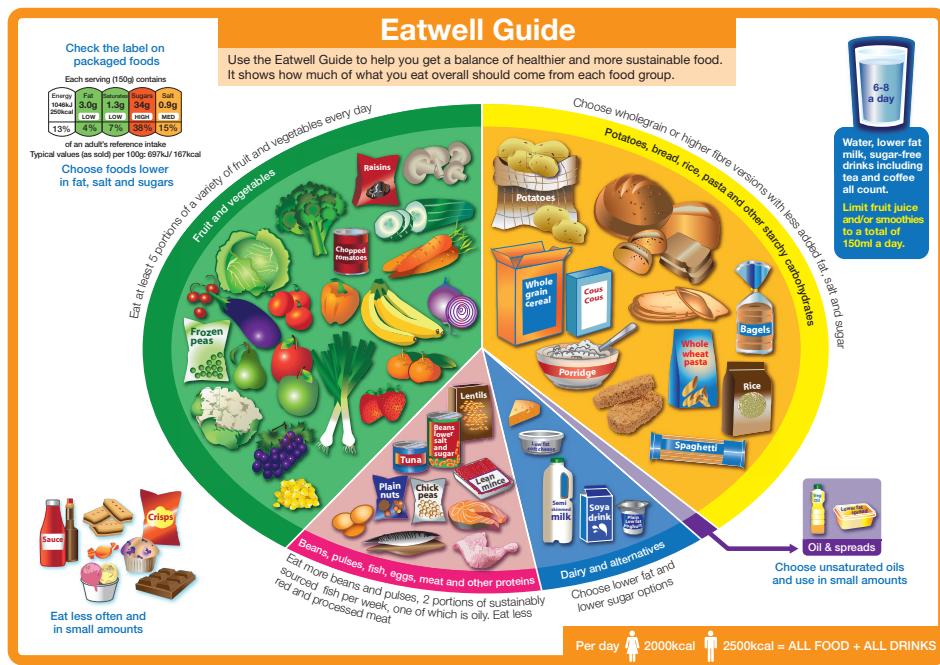
Staying healthy

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. 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. Following bowel surgery your clinical nurse specialist will discuss your personal needs as this will vary between individuals.



Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

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The main things to consider in a healthy diet include:

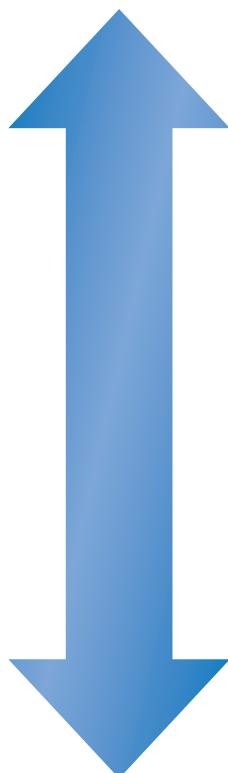
- eat the right amount to maintain a healthy weight
- eat plenty of fresh fruit and vegetables
- eat plenty of foods rich in fibre and starch
- avoid eating too much fatty food
- avoid sugary food and drinks
- avoid alcohol or only drink in moderation.

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.

Healthy Lifestyle: Benefits of Physical Activity



- Improves low mood or depression
- Improves your quality of life
- Improves bone health
- Improves heart health
- Builds muscle strength
- Helps maintain a healthy weight

- Reduces cancer-related fatigue
- Reduces stress and anxiety
- Reduces the risk of:
 - High blood pressure
 - Heart disease
 - Kidney disease
 - Diabetes
 - Stroke
 - Osteoporosis

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 Macmillan Cancer information Centre and the Macmillan website have a list of insurers specializing in the cover of patients who have had cancer and will be able to offer advice.

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 follow up 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.

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 had the treatment for your bowel cancer, 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 at some point during your five year follow up. We then repeat every five years, unless there is a medical reason to do this more often. You will also have CT scans. The timing of all the investigations will be set out on your five-year plan.

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. You will be encouraged to complete a Holistic Needs Assessment every year following your treatment. If you feel you need to complete one sooner, please contact your cancer after-care coordinator.

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 more than three weeks. 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.

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 peristomal skin
- change in bowel function
- any problems with lifestyle issues related to stoma care management.

Further information and useful contacts

Age UK

Freephone advice line 0800 169 6565
www.ageuk.org.uk

Bowel Cancer UK

Telephone: 020 7940 1760
www.bowelcanceruk.org.uk

Bowel Cancer Advisory Service

www.bowelcanceruk.org.uk

British Red Cross

Telephone: 0844 871 11 11
www.redcross.org.uk

Disabled Living Foundation

Telephone: 0300 999 0004

www.dlf.org.uk

Cancer Research UK

Information, research and details of clinical trials.

Helpline: 0808 800 4040

www.cancerresearchuk.org

Carers UK Carers Line

Freephone 0808 808 7777

(Monday to Friday, 10am to 4pm)

www.carersuk.org

Citizens Advice Bureau

www.citizensadvice.org.uk

Dial UK

Local disability information and advice.

Telephone: 0808 800 3333

www.dialuk.org.uk

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

Useful contact details

Colorectal Support Worker:

Telephone: 01253 953764

Hospital Switchboard: 01253 300000

Patient Relations Department

The Patient Relations Department offers impartial advice and deals with any concerns or complaints the Trust receives. You can contact them via tel: 01253 955588 or by email: bfwh.patientrelations@nhs.net

You can also write to us at: **Patient Relations Department, Blackpool Victoria Hospital, Whinney Heys Road, Blackpool FY3 8NR**

Further information is available on our website: www.bfwh.nhs.uk

References

Details of the references used in writing this leaflet are available on request from: **Procedural Document and Leaflet Coordinator 01253 953397 or bfwh.trustpolicyteam@nhs.net**

Options available

If you'd like a large print, audio, Braille or a translated version of this leaflet then please call: **01253 955520**



Our Four Values:

People Centred Compassion	Positive Excellence
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