

Sandwell and West Birmingham bowel cancer patient personalised follow-up

A guide to supported self-management and surveillance of bowel cancer

Cancer Services

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Your personal details and summary of your treatment

Name:

Hospital number:

Date of diagnosis:

Diagnosis:

Treatment and dates:

Surgical consultant:

Oncology consultant:

Named Clinical Nurse Specialist:

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Introducing patient personalised follow-up (PFU)

This booklet aims to explain what patient personalised follow-up (PFU) 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. This booklet also contains information that we think you may find useful as you recover from your treatment and move on to living well. It is your guide to supported self-management.

Patient follow-up after cancer treatment is a necessary precaution. It is a way to pick up problems early and act quickly enough to be able to treat them. It is especially important for the surveillance of cancer recurrence. 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 treatment.

PFU is about supporting you in self-managing your follow-up. It aims to provide you with the information and confidence needed to take more assertive action for your own health. Instead of your routine follow-up clinic appointments, you will be able to contact the clinical nurse specialists directly to discuss concerns, and if necessary they will arrange an outpatient appointment to see a member of the team as required. In addition to this you can be assured that follow-up tests which form part of your self-management plan will be ordered in accordance with national guidelines. The frequency and length of appointments will be reduced and you will benefit from less travelling to and from appointments and less waiting around to be seen.

Your Clinical Nurse Specialist will talk to you about PFU at a follow-up appointment which should happen about 6 months after treatment. At this individual consultation you will be given all the information you need to support your self-management and have the opportunity to discuss any concerns or worries you may still be experiencing. After the appointment, you will be given an End of Treatment Summary to take away with you which will be a record of the things you have discussed. Your End of Treatment Summary will also be shared with your GP so they are kept fully informed. Your End of Treatment Summary can be used as an aide memoire and is worth taking with you to any future appointments.

We will continue to keep a close eye on you by arranging and reviewing your blood results, colonoscopies and scans and informing you of the results. If you have any symptoms or concerns

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you can telephone a member of the team. That is why we call it patient personalised follow-up (PFU). If necessary you will be seen urgently by the team at the earliest appointment.

Clinical nurse specialist contacts

Office phone number: Sandwell General Hospital

0121 507 3376

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.

swbh.colorectalnurses@nhs.net

After treatment, what now?

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 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 the effects of 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 Clinical Nurse Specialist and Cancer Support Worker is there to help you with support. At Sandwell and West Birmingham Hospitals NHS Trust, we carry out an assessment of the support that you will need, this is done by having a meaningful conversation called a Holistic Needs Assessment. We often do these over the phone because it saves you having to come into the hospital and you can talk to us from the comfort of your own home. The Holistic Needs Assessment (or HNA as it is sometimes called) is an opportunity for you to chat about your worries and concerns and any physical or practical issues you may be experiencing, and for us to offer you advice and support to help resolve them. The outcomes of the HNA are summarised in a Care Plan, which is shared with you.

Cancer Champion Volunteers

We have a number of volunteers who come into the hospital and are here to help and support you. Some of them have personal experiences of cancer and others have undertaken a training course to learn about cancer and its side effects so that they are better placed to listen to your worries or concerns. Our Cancer Champion Volunteers work from the Courtyard Centre at Sandwell Hospital and can be contacted on 0121 507 3792.

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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 Team first. It can be useful to have someone else there (such as a work colleague or union rep) to take notes. If you are still having some side effects from the cancer treatment, it is important that you discuss any reasonable changes that your employer can make to help you get back to work, including a staged return to work.

The Equality Act (2010) defines all types of cancer as a disability and exists to protect against discrimination, harassment, victimisation and unfair dismissal. If you think you are being treated unfairly when you're trying to get back to work, the Act is there to protect you. Disability Employment Advisors are based at Job Centres and Job Centre Plus and are a good source of advice and support. 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?

Returning to work can be difficult, but with the right support, it can be a positive step for many in moving on after treatment. You may want to think about telling friends and work colleagues about your cancer as it is often 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 see if you are entitled to any additional help if financial issues are causing you to worry. Ask your Clinical Nurse Specialist or Cancer Support Worker to refer you to Macmillan Cancer Support, Citizen's Advice Bureau or your Social Work Department for more information.

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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. Your diet may need to be adjusted depending on your personal needs and your Clinical Nurse Specialist will discuss this with you. 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.

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.

If however you are losing weight, a healthy diet is one that includes lots of calories and we would recommend eating anything that takes your fancy.

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 (<https://www.food.gov.uk/>) and NHS Website (www.nhs.uk).

Should I exercise?

Once you have completed your treatment, some moderate form of regular physical activity is recommended. 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. They will also be able to direct you to local activities and groups. Your Council's web site is also a good place to search for local services and groups, and most leisure centres offer a wide variety of activities to help you to get active.

Can I drink alcohol?

Once you have completed your treatment there is no need to avoid alcohol entirely. We would always advise that you aim to follow the Department of Health's recommendations which you can find on their website. Further information and other advice about managing alcohol intake can be found online at drinkaware (<https://www.drinkaware.co.uk/>)

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Can I travel abroad?

Once you have completed your treatment, there is no reason why you should not be able to travel abroad. Sometimes patients can encounter difficulties in acquiring travel insurance if they have been treated for cancer. Your Clinical Nurse Specialist or your Cancer Support Worker can help you with any insurance enquiries. Macmillan Cancer Support's website also has a list of insurers specialising in the cover of patients who have had cancer and their Help Line will be able to offer advice (<https://www.macmillan.org.uk>). The British Insurance Brokers Association (BIBA) may also be able to help with travel insurance (<https://www.biba.org.uk/>).

Intimacy and sexual activity

Being diagnosed and treated for bowel cancer is an individual experience that can have far reaching effects on many aspects of life. Relationships can be difficult during this time, both emotionally and physically, and it can take time to adjust to these changes. In some instances, people prefer not to continue with a sexual relationship, however, many people still continue to enjoy intimacy. It is important that you feel able to discuss both emotional and physical relationship issues with your Clinical Nurse Specialist. They are used to supporting patients experiencing worries and can help. Please talk either to your Clinical Nurse Specialist or your doctor, so they can help you manage during this 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 self-management plan 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.

You should report any changes to your Clinical Nurse Specialist if you experience:

- changes in your bowel pattern which continue for four weeks or more.
- bleeding or mucous discharge from back passage.
- changes in your appetite
- unexplained weight loss

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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. After treatment, your Clinical Nurse Specialist will discuss the type and frequency of tests you will receive as part of your follow-up. Using tests to monitor for cancer recurrence is standardised practice and is often referred to as *surveillance*. The type and frequency of these test, as well as the length of time you will receive them after treatment (which may be 3 years or more) are tailored to you, based on current best practice clinical guidelines. The details of your 'surveillance' tests will be recorded on your End of Treatment Summary so you have written confirmation to hand. The End of Treatment Summary will also be shared with your GP so they are also aware of your follow-up plan.

What types of surveillance tests 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, these will include a colonoscopy (or colonoscopies) as well as CT scans.

I am 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 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.

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Important Contact Details

Clinical Nurse Specialist contacts

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0121 507 3376

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 SWBH NHS Trust.

The stoma care service will advise you of their follow up procedure. You can also contact them if you have any stoma issues or problems

Telephone: **0121 507 3376**

Further information and useful contacts

Age UK

Freephone advice line: 0800 678 1602
www.ageuk.org.uk

Bowel Cancer UK

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

British Red Cross

Telephone: 0344 871 11 11
www.redcross.org.uk

Disabled Living Foundation

Telephone: 0300 999 0004
www.dlf.org.uk

Cancer Research UK

Helpline: 0808 800 4040
www.cancerresearchuk.org

Carers UK Carers Line

Freephone: 0808 808 7777
www.carersuk.org

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Citizens Advice Bureau

Adviceline (England): 03444 111 444

www.citizensadvice.org.uk

Macmillan Cancer Support

Telephone: 0808 808 0000

www.macmillan.org.uk

NHS Carers Direct

Freephone 0300 123 1053

<https://www.nhs.uk/conditions/social-care-and-support-guide/>

NHS Website

www.nhs.uk

Carers Trust

Telephone: 0300 772 9600

www.carers.org

Disability Rights UK

Telephone: 0330 995 0400

www.disabilityrightsuk.org

Turn2us

Telephone: 0808 802 2000

www.turn2us.org.uk

(All websites accessed 05 August 2020)

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Local contacts

| The Courtyard Cancer Information and Support Service at Sandwell Hospital | |
|--|---|
| What can they do for you? | Your local service |
| <ul style="list-style-type: none"> • Free cancer information materials (variety of languages) • Telephone Help Line • Access to benefits advice • Access to wig services and headwear • Signposting to local support service and groups • A friendly, listening ear • Provision for learning difficulties/deaf and hard of hearing | <p>Telephone: 0121 507 3792</p> <p>Email: <i>Swbh.livingwithandbeyondcancer@nhs.net</i></p> <p>Address: The Courtyard Centre Sandwell Hospital Lyndon West Bromwich B70 4HJ</p> |
| Walsall B Friend - Bowel Cancer Support Group | |
| What can they do for you? | Your local service |
| <p>A support group based in Walsall Manor Hospital. For any queries or to express your interest in attending one of their quarterly meetings please contact them via telephone or email.</p> | <p>Telephone: 01922 656300</p> <p>Email: <i>elaine.swan@walsallhealthcare.nhs.uk</i></p> <p>Address: Colorectal Nursing Service Walsall Manor Hospital Moat Road Walsall WS2 9PS</p> |
| Dudley Whitehouse Cancer Support | |
| What can they do for you? | Your local service |
| <p>White House Cancer Support is a locally based registered charity supporting cancer patients, their family, friends, and carers in the Dudley borough and surrounding areas. Recently Diagnosed? White House Cancer Support provides a range of services for those recently diagnosed with Cancer. Transport, Craft Group, Art Therapy, Partnership, Exercise , Health and Well Being, Community Groups</p> | <p>Telephone: 01384 231232</p> <p>Address: 10 Ednam Road Dudley DY1 1JX</p> |

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Sources of information

World Cancer Research Fund & American Institute for Cancer Research (2018). Diet, nutrition, physical activity and cancer: a global perspective. Available at: <https://www.wcrf.org/sites/default/files/Summary-of-Third-Expert-Report-2018.pdf> (Accessed on: 05 August 2020).

If you would like to suggest any amendments or improvements to this leaflet please contact SWB Library Services on ext 3587 or email swbh.library@nhs.net.



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