

Colorectal Unit Self Supported Follow Up

Your guide to supported self-management and remote surveillance

This leaflet can be made available
in alternative languages / formats on request.

*如有需要，本传单可提供其他语言/版式
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Na żądanie ta ulotka może zostać udostępniona
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Personal Details

Name:

Hospital number:

Date of diagnosis:

Treatment and dates:

Surgical consultant:

Named Colorectal Nurse Specialist:

Named Stoma Care Nurse Specialist (if applicable):

Important notice

If you change your address, GP or any other personal details, please let us know by contacting the team on: **0151-290-4932**

Supported Self Management

A brief overview:

In the past, it has been traditional for patients who have completed their treatment for bowel cancer to have regular face to face follow-up appointments with their Surgeon, Clinical Nurse Specialist (CNS) 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 necessary as, in a small number of cases, bowel cancer can return. Your surveillance investigations ensure any problems that arise are picked up early. The sooner we know about a problem, the more able we are to treat a recurrence of your disease effectively.

We will continue to keep a close eye on you. You will receive notifications to attend for blood tests, scans and other surveillance investigations as usual. We will review these investigations each time they are performed and communicate the result to both you and your GP.

You will also be provided with log in details for My Medical Record – an online platform via which you can access your 'Patient Portal' to check dates of surveillance tests, view your own results and email us at a time that is convenient for you. These emails will be picked up during normal working hours by your Colorectal Support Worker and responded to as appropriate.

If you do not have access to an electronic device to view your Patient Portal, you are still able to take full advantage of remote follow-up – your Colorectal Support Worker can manage this for you and communicate everything via phone and post.

You will be asked to complete a 'Health MOT' (a health needs assessment) each time you are due to have a surveillance blood test or investigation. This allows you to communicate any physical, practical, emotional or relationship concerns to your Colorectal Support Worker who will be equipped to direct you to the most appropriate information or support service.

If you have any concerning symptoms or worries about any aspect of your cancer diagnosis, you can telephone a member of the Colorectal Support Team or email us directly on My Medical Record via the Patient Portal. If necessary, you will be seen urgently by the Colorectal Clinical Team at the earliest appointment.

Introducing Supported Self Management

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 who will arrange for you 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 as part of your surveillance plan. This booklet also contains information that we think you may find useful as you recover from your treatment.

Support

- You will have a dedicated Colorectal Support Worker who will be your first point of contact for any concerns you have regarding your cancer diagnosis. They can make you an appointment back with your clinical team if necessary.
- Your Colorectal Support Worker can be contacted via phone or email through your Patient Portal.
- You will be invited to attend a Workshop session where information will be provided by various specialists to equip you with everything you need to know to confidently self-manage your follow-up pathway and live as healthy and active a lifestyle as possible following your cancer treatment. This session is an essential part of enrolment on to the remote follow up pathway of care.
- You will be invited to a Health and Wellbeing Event which brings together a wealth of information services from a wide range of voluntary, community and faith sector organisations, which can provide advice and support to you and your family.

Self Management

- Remote follow up puts you in control of your care.
- You will be able to check the date of your surveillance tests, access your test results and contact your Colorectal Support Worker at a time that is convenient for you by using the email facility on My Medical Record via your Patient Portal.
- If you do not have access to an electronic device, you can choose who can access your Patient Portal on your behalf and choose how this information is communicated to you. You may have a relative, carer or close friend who will manage your Patient Portal together with you, or you may choose to ask your Colorectal Support Worker to help you via telephone/post.

- You can flag up concerning symptoms in a timely manner. Evidence suggests that outcomes are better when these symptoms are reported as they happen, rather than waiting until your next routine follow-up appointment.
- You can choose how much or how little you access the information and support on offer, it will all be made available to you.
- Living with and beyond your cancer diagnosis and treatment will be a personal experience, tailored by you.

Contact Information

Colorectal Nurse Specialists:

Angela Fitzgerald-Smith- Telephone: 0151-676-5252
email: angela.fitzgerald-smith@sthk.nhs.uk

Helen Carroll –Telephone: 0151-430-1269 email: helen.carrol2@sthk.nhs.uk

Gina Cave – Telephone: 0151-290-4670 email: gina.cave@sthk.nhs.uk

Desilyn Alana – email: Desilyn.alana@sthk.nhs.uk

Stoma Care Nurse Specialists:

Jean O'Reilly email: jean.oreilly@sthk.nhs.uk

Louise Smith email: louise.smith2@sthk.nhs.uk

Sandra Thomason: sandra.thomason@sthk.nhs.uk

Office Telephone: 0151-430-1221

Support Worker: email: Jacqueline.austin2@sthk.nhs.uk

Office Telephone:

You can leave a message on the answer machines of the specialist nurses. They are checked every day.

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 or beyond 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. *Ask your Colorectal Support Worker for more information on local information and 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 are 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 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. 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, to see 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, Citizen's Advice Bureau or your local social services 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.

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 also reduce the chances of getting heart disease and diabetes. This diet can also be used by members of your family who do not have cancer. Following bowel surgery your Clinical Nurse Specialist will discuss your personal dietary needs as this will vary between individuals.

The main things to consider as part of a healthy diet include:

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

Our diet can affect our risk of developing some cancers. A summary of the evidence regarding diet, lifestyle and cancer prevention is produced by the World Cancer Research Fund (www.wcrf-uk.org). 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. Further information is available from organisations such as the Food Standards Agency and NHS Choices (www.nhs.uk).

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 150 minutes of moderate activity each week in episodes of ten minutes or more at a time. Regular physical activity 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 Clinical Nurse Specialist or visit the Macmillan website (www.macmillan.org.uk) about how best to get started and find out about local activities in your area.

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.

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. Your clinical team 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 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 assess 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 colorectal 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 has not 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 follow-up investigations which your colorectal team will have discussed with you. This might be in the form of a CEA blood test. 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 also have other regular tests. These will be in the form of CT Scans and Colonoscopies. Again your colorectal team will have advised you as to how frequently these will be done and your Colorectal Support Worker will remind you each time a test is due.

I am 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 can arrange that for you.

Central to this approach to your follow up care is that your self-management is supported by us; therefore we need to know if we can help. It is essential that you get in touch with us should you require support at any time. Your Colorectal Support Worker is available as your first point of contact.

What Symptoms Should I Look Out For?

- Blood and mucus from your back passage or mixed in your motion
- Pain in your back passage or pain on opening your bowels
- Change in bowel habit
- Feeling of pressure or wanting to have your bowels open all the time
- New or worsening incontinence
- Pain in your abdomen
- Unexplained weight loss

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 peri-stomal skin
- Dietary concerns
- Change in bowel function
- Any problems with lifestyle issues related to stoma care management.

National Information

Age UK

Freephone advice line 0800 169 656
www.ageuk.org.uk

Beating Bowel Cancer

Telephone: 08450 719301
www.beatingbowelcancer.org

Bowel Cancer Advisory Service

www.bowelcanceruk.org.uk

Cancer Research UK

Information 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

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

The site includes all NHS online services and information. 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

A UK charity that helps people access money which 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

Local Information

Macmillan Information & Support Centre

Julie Parr/Lorraine Soudani
St Helens Hospital
Lower Ground Floor
Tel: 01744-647000

Macmillan national helpline/benefit line:

Tel: 0808 808 0000

Lyndale Cancer Support (Knowsley):

Tel: 0151 489 3538
www.lyndalecancersupport.co.uk

St Helens Cancer Support:

Tel: 01744 21831
sthelenscancersupportgroup.org.uk/contact-us

WIDNES and Runcorn Cancer Support Group:

Tel: 0151 423 5730
www.widnesandruncorncancersupport.org.uk

Carer Support Knowsley:

Tel: 0151 549 1412
knowsleycarers.co.uk

Carer Support St Helens:

Tel: 01744 675615
www.sthelenscarers.org.uk

Carer Support Widnes:

www.haltoncarers.co.uk

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Warrington Road,
Prescot, Merseyside, L35 5DR
Telephone: 0151 426 1600

St Helens Hospital
Marshall Cross Road,
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