

Introduction to Supported Self Management for Bowel Cancer Patients

Information for patients

Cancer Care Line Telephone Number: 01227 86 86 66

This leaflet has been written as an introduction to the East Kent Hospitals' Supported Self Management pathway for bowel cancer patients who have completed their treatment. This follow-up is not suitable for every patient. Your clinical nurse specialist or consultant will discuss this with you.

What is Supported Self Management?

Supported Self Management is a new type of follow-up. It is where routine follow-up appointments are replaced by a system where patients can call us when they have a problem; they do not have to come to hospital at times when they are feeling well and are symptom free.

We will send you blood test forms and book scans and colonoscopies for you. If your results are normal we will write to you and let you know. If there is something we would like to discuss with you based on your results, we will phone you to discuss or book you a clinic appointment to talk to you.

In the past, patients who had completed their treatment for bowel cancer had either telephone or face to face appointments with their consultant or clinical nurse specialist, to get their test results. Although some patients found these appointments useful and reassuring, many patients found coming to the hospital a source of great anxiety and not particularly helpful. There is also good evidence to show that following up patients in this way does not prevent cancer returning and does not increase life expectancy.



With Supported Self Management your care will remain the same. You will remain under the care of the hospital for five years after your treatment has stopped, and continue to have CT scans, colonoscopies, and blood tests. The difference will be that you no longer have to come into hospital for your clinic appointments for results.

Why is follow-up changing?

Many hospitals across the country, including those in Kent, have changed the way patients are followed up after bowel cancer treatment. We are moving away from a 'one size fits all' approach towards recognising that patients can manage their own health.

We know patients are more likely to pick up a new problem in between their follow-up appointments and it can be tempting to put off telling your nurse or doctor if your routine appointment is not too far away. With Supported Self Management we encourage you not to wait for your appointment, but to call the Cancer Care Line on 01227 86 86 66 if you have any questions or concerns, and speak to a member of the Bowel Cancer Nursing Team.

You will receive a telephone review appointment six months after your surgery, or if you had chemotherapy, four to six weeks after your last appointment with your oncologist. This telephone appointment will be with a clinical nurse specialist. We can arrange a clinic appointment at the hospital, if you prefer. At this appointment you will be able to talk to your clinical nurse specialist about how Stratified Self Management works, when to expect tests and results, as well as any questions or worries you have. You will still have a routine appointment with a member of the surgical team four to six weeks after your surgery, to check how your recovery is going.

What will happen at my telephone review appointment?

At this review we will discuss with you whether you are suitable for Stratified Self Management. If you are, we will explain Stratified Self Management in more detail.

We will also give you information at this appointment about health and wellbeing, including how to look out for signs and symptoms of your cancer returning and further places to find support.

Symptoms to look out for

- Bleeding from your bottom and/or blood in your poo
- A persistent and unexplained change in your bowel habit (such as how often you go for a poo)
- Unexplained weight loss
- Extreme tiredness for no obvious reason
- A pain or lump in your tummy.

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Will I still be able to access the Bowel Cancer Nursing Team if I have any concerns?

Yes. Please call the bowel cancer nurses on the Cancer Care Line 01227 86 86 66, if you have any queries or problems, especially if you have any of the symptoms listed on page 2.

If you have a stoma you will still be able to access the stoma nursing team directly for issues about your stoma.

What happens now?

If you have any questions or need any further information, please contact our Cancer Care Line.

Further help and support

- **Bowel Cancer UK**

Web: www.bowelcanceruk.org.uk

Bowel Cancer UK provides advice and support about bowel cancer including aspects of wellness after treatment, life beyond bowel cancer as well as bowel cancer treatment and side effects.

- **Macmillan Cancer Support**

Helpline: 0808 80 80 000 (7 days a week; 8am to 8pm)

Web: www.macmillan.org.uk

Macmillan Cancer Support offer emotional, physical, and financial support from the moment you are diagnosed, through your treatment, and beyond. Macmillan offer information about all types of cancer, including diagnosis, treatment, and drugs, as well as advice to help with the different ways cancer may impact your life. Visit the Macmillan web site for the following information and support.

- Online chat (7 days a week; 8am to 8pm)
- Email for advice and support (they aim to respond within two working days)
- Online community forums
- Information booklets to order or download
- Information available in video, audio, and other languages
- Where to find information and support groups in your area
- Details on fundraising events and campaigns
- Details of how you can be part of the Macmillan team.

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This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation