



Introduction to Supported Self Management for bowel cancer patients

Information for patients from the Colorectal Cancer Nurse Specialist Team

Cancer Care Line Telephone Number: 01227 868666

You have completed your bowel cancer treatment. The aim of this leaflet is to introduce you to Supported Self Management. It explains:

- what Supported Self Management is
- whether you are suitable for this type of follow-up
- what symptoms to look out for, and
- who to call if you have any concerns.

This type of follow-up is not suitable for every patient. Your clinical nurse specialist or consultant will discuss this with you. If you have any questions or concerns, please ask them.

What is Supported Self Management?

Supported Self Management is a new type of follow-up. Your routine follow-up appointments are replaced with a system where you can call us when you have a problem. You will no longer have to come to hospital for appointments when you are feeling well and 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 we need to discuss the results of these tests, we will phone you or book a clinic appointment to talk to you.

In the past, patients who had completed their bowel cancer treatment had appointments with their consultant or clinical nurse specialist, to get their test results. Some patients found these appointments useful and reassuring. However, many found coming to the hospital a source of anxiety and not very 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.
- You will continue to have CT scans, colonoscopies, and blood tests.

The difference is that you no longer have to come into hospital for your clinic appointments to get your results.

Why is follow-up changing?

Many hospitals across the country, including those in Kent, are changing the way they follow-up patients after bowel cancer treatment. We are moving away from a 'one size fits all' approach. Instead we are recognising that patients can manage their own health.

We know patients are more likely to pick up a new problem between their follow-up appointments. And, that it can be tempting to put off telling your nurse or doctor about these problems, if your routine appointment is not too far away. With Supported Self Management we encourage you not to wait for your appointment. Instead call the Cancer Care Line on 01227 868666, and speak with a member of the Bowel Cancer Nursing Team about any questions or concerns you have.

How do I know whether I am suitable for Supported Self Management?

You will receive a telephone review appointment six months after your surgery. Or if you had chemotherapy, four to six weeks after your last oncology appointment. 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:

- whether you are suitable for Supported Self Management
- and if so, how Supported Self Management works
- when to expect tests and results, and
- any questions or worries you have.

At this appointment, we will also give you information about health and wellbeing. This will include:

- how to look out for signs and symptoms of your cancer returning, and
- further places to find support.

You will still have a routine appointment with a member of the surgical team four to six weeks after your surgery. This is to check how your recovery is going.

What symptoms should I 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.

If you have any of these symptoms, please call the Cancer Care Line on 01227 868666.

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 868666, if you have any queries or problems. This is especially important, if you have any of the symptoms listed above.

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 on 01227 868666.

Further help and support

- Bowel Cancer UK (<https://www.bowelcanceruk.org.uk>)

Bowel Cancer UK provides advice and support about bowel cancer. This includes:

- aspects of wellness after treatment
- life beyond bowel cancer
- bowel cancer treatment and the side effects.

- Macmillan Cancer Support (<https://www.macmillan.org.uk>)

Helpline: 0808 8080 000 (7 days a week; 8am to 8pm)

Macmillan offers emotional, physical, and financial support from diagnosis, through your treatment and beyond. They offer information about all types of cancer. This includes 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.

Cancer Care Line Telephone Number: 01227 868666

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring 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 has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

Reference number: Web 529

First published:
April 2021

Last reviewed:
April 2024

Next review date:
August 2027

Copyright © East Kent Hospitals University NHS Foundation Trust.