

## Colorectal supported self-management information for patients

This information sheet explains the University Hospitals Birmingham NHS Foundation Trust Supported self-management approach to providing care for patients who have completed their hospital-based cancer treatment. It will explain what supported self-management is, how your care will be monitored, and how to access support if and when you need to.

### The supported self-management approach

Supported self-management is a new approach to follow-up care that is being used at many hospitals across the UK.

It replaces routine hospital-based follow-up appointments. This means that you do not need to come to hospital when you are feeling well and not experiencing any symptoms. Instead, you can contact the team at the hospital who are looking after you and arrange to see them, as and when you need to. You will continue to have all the necessary investigations such as blood tests and scans that are needed to monitor you safely.

### What are the benefits of supported self-management?

Supported self-management puts you in control of your care and allows you to take an active role in your recovery with the help from your hospital team. It aims to enable you to develop the skills and knowledge to make positive choices about your healthcare, manage the physical and emotional impact of cancer and its treatment, and make long-term positive changes to health behaviours such as staying active and eating healthily.

Whilst some patients find the pre-arranged hospital appointments useful and reassuring, many patients find them to be a source of unnecessary anxiety and distress. Most problems are identified by patients themselves in-between routine appointments and concerns or symptoms are addressed more quickly if patients report them as and when, rather than waiting for a pre-arranged appointment.

### How does supported self-management work?

After you have completed your cancer treatment your case will be discussed at the Colorectal Multidisciplinary Team meeting. You will then have an appointment with a Clinical Nurse Specialist (CNS) who will discuss supported self-management with you. You will decide together if this is the right way to manage your care. If you have specific concerns or health-related issues that make supported self-management unsuitable for you, you can continue to have traditional follow-up appointments at the hospital with your consultant or CNS.

Before starting supported self-management, you will be invited to attend a treatment review with your CNS team. During this appointment the CNS will talk to you about:

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- Your diagnosis
- Treatment side effects (short and long term)
- Signs and symptoms to be aware of and to let us know about
- Arrangements for future blood tests and scans and how you will be informed of the results
- Continued medications or potential referral to other specialities as required
- Any specific concerns identified through a holistic need assessment
- Referral to a health and wellbeing programme or event

Following your treatment review you will receive a treatment summary letter which will include details of everything discussed at the consultation. A copy of this will be sent to your GP and kept on your hospital records.

Your surveillance will continue for at least three years after your treatment and will include blood tests, CT scans and an endoscopy procedure. Appointments will be sent to you automatically, so it is very important that you inform the hospital and your GP of any changes to your contact details so that your follow-up care is not interrupted.

Investigation	Schedule
Blood test including CEA (tumour marker)	Every six months
Colonoscopy	One and four years after surgery
CT scan	Every year for three years after surgery

In between these appointments, you should contact the CNS team if you develop any of the following symptoms so that we can arrange for you to be reviewed in clinic. The contact details can be found at the end of this information leaflet.

- A new change in your bowel habit (either constipation, or diarrhoea)
- Pain or bloating in your abdomen
- Unexplained weight loss
- Bleeding when you have your bowels open
- Tiredness
- A mass or lump in your abdomen

At the end of your surveillance period, you will receive a further treatment review and treatment summary letter.

### Living well / moving forward

The treatment you have received for your cancer may mean that you continue to have physical or emotional needs. Your team will continue to support you with any concerns or help you might need.

You will be invited to attend a Health and Wellbeing Programme which is run by healthcare professionals who work at the hospital. The programme focusses on self-supported management and covers topics such as fatigue, physical activity, nutrition and emotional wellbeing.

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At your treatment review you will also be given information about services, programmes, local groups and charities that can help support you.

If you have any questions about your surveillance, symptoms, or additional support available, please contact a member of your CNS team who will be able to help you.

### Contact Details:

CNS team for Heartlands/Solihull Hospitals: **0121 424 2730**

CNS team for Good Hope Hospital: **0121 424 7429**

CNS team for Queen Elizabeth Hospital Birmingham: **0121 371 4980**

Email for Queen Elizabeth CNS team at: [colorectalnursingcns@uhb.nhs.uk](mailto:colorectalnursingcns@uhb.nhs.uk)

UHB Cancer Information and Support Service: **0121 371 3537**

**Follow us on Twitter** @uhbcolorectal

### Patrick Room – Cancer Information and Support Drop-in Centres.

QE – Cancer Centre, QE Hospital

GH – located in the Oncology Day Unit, Sheldon Unit

BHH – located in MIDRU, Heartlands Hospital

Solihull – Oncology/Haematology Day Unit, Solihull Hospital

### Further Support:

#### Local:

**Birmingham Cancer Support Centre** (Help Harry Help Others): 0121 783 5407;

[www.hhho.org.uk](http://www.hhho.org.uk)

**Sutton Cancer Support Centre:** 0300 012 0245; [www.suttoncancersupport.org](http://www.suttoncancersupport.org)

**The Holly Trust** (Bowel cancer support group): [www.hollytrust.org.uk](http://www.hollytrust.org.uk)

#### National:

##### Bowel cancer UK

Call us on 020 7940 1760. We're open Monday to Friday 9am-5pm

Email us at [admin@bowelcanceruk.org.uk](mailto:admin@bowelcanceruk.org.uk)

##### Ileostomy Association

Birmingham branch: 0121 3552745/07842 555070

Email: Mike Jameson [mike.jameson@iasupport.org](mailto:mike.jameson@iasupport.org)

[www.birmingham.iasupport.org](http://www.birmingham.iasupport.org)

##### Colostomy UK

Office Tel: 0118 939 1537- Monday- Friday 9-5

Helpline open 24 hours a day: 0800 328 4257

[hello@colostomyuk.org](mailto:hello@colostomyuk.org)

[www.colostomyuk.org](http://www.colostomyuk.org)

##### Beating Bowel Cancer

Beating Bowel cancer provide medical advice to patients through a specialist nurse advisor line on 08450 719301 or

Email [nurse@beatingbowelcancer.org](mailto:nurse@beatingbowelcancer.org)

Website: <http://www.beatingbowelcancer.org/>

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### Patient Voices

The Patient Voices Group is part of Beating Bowel Cancer and is the only UK national patient-to-patient network for people with bowel cancer.

The group has also expanded to include close relatives of bowel cancer patients. Members of the group are willing to help in a number of ways including patient to patient support, raising awareness, and fundraising.

General enquiries: 08450 719301

### Macmillan Benefits

Advisor present

Alternate Tuesdays at Good Hope Hospital Sheldon Unit

Alternate Thursdays at Heartlands Hospital

### Macmillan Cancer Line

0808 808 0000

[www.macmillan.org.uk](http://www.macmillan.org.uk)

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email [interpreting.service@uhb.nhs.uk](mailto:interpreting.service@uhb.nhs.uk).