

Your colorectal cancer follow-up after treatment

Information for patients

Follow-up is how we talk about what happens after you finish your treatment. This has been carefully planned for you and is called a personalised follow-up (PFU). This information explains your follow-up. If you have any questions, please speak to a doctor or nurse caring for you

Your colorectal team has carefully planned your follow-up care. You can contact the colorectal clinical nurse specialist (CNS) team at any time during your follow-up if you have any concerns.

Personalised follow-up

After your treatment, you might be offered personalised follow-up (PFU).

PFU is sometimes called:

- personalised stratified follow-up (PSFU)
- patient initiated follow-up (PIFU)
- open access follow-up (OAFU)
- supported self-management (SSM)

You do not need to remember all these terms. They are all ways to describe planned care after treatment for cancer. We'll explain how things will work for you.

What to expect during follow-up:

End of treatment clinic

After your treatment, we invite you to an end of treatment clinic. At this clinic, you can talk about your follow-up with your nurse.

You will fill in a holistic needs assessment (HNA). This is a questionnaire that asks you about your needs and what matters to you. Your needs might be physical, practical, emotional or social.

The HNA helps your team to make a care plan. It makes sure that your needs are met and that you have all the support you need.

We give you a treatment summary. This explains:

- the treatment that you had

- any possible side effects
- signs and symptoms suggesting that the cancer might have returned

We send a copy of the treatment summary to your GP and you can keep a copy.

Tests during follow-up

After you have finished your treatment, you need to have 3 main tests over 5 years.

- **A CEA test** is a blood test that checks your carcinoembryonic antigen (CEA) levels. CEA is a type of protein in the body. Some colorectal cancers produce CEA. Further information is available on our website: www.kch.nhs.uk/services/cancer/tests-and-investigations/blood-tests/
- **A colonoscopy** is a test to check the inside of your bowel. You do not need this test if all of your large bowel has been removed. Further information is available on our website: www.kch.nhs.uk/service/cancer/tests-and-investigations/endoscopy
- **A CT scan** creates detailed pictures of the inside of the body. Further information is available on our website: www.kch.nhs.uk/service/cancer/tests-and-investigations/ct-scan

We send you a letter whenever you are due to have a test.

Your end of treatment summary has more details about the tests and when they are due. We give you this summary at your end of treatment clinic appointment.

Some people are diagnosed with Lynch syndrome. This is an inherited condition that increases your risk of colon cancer and several other cancers. If you have Lynch syndrome, you may need more regular colonoscopies. Your CNS can talk to you about this.

Macmillan Cancer Support has information about Lynch syndrome.

Tests results

You get your test results in a letter through the post if everything is normal. If there are any concerns, your colorectal care team will phone you.

The effects of treatment, such as surgery or radiotherapy, can sometimes make it difficult for us to read the results. We might ask you to come back to the hospital to have more tests or scans. If this happens, we will phone you.

It's important to make sure we have your correct address and telephone number.

If you do not get your results 4 weeks after having your tests, please call the colorectal clinical nurse specialist (CNS) team on 020 3299 4854.

Quality of life survey

Measuring people's quality of life is about understanding:

- how cancer has affected them
- how well they are living after their diagnosis.

This includes people's emotional or social wellbeing, finances, and ongoing physical problems, such as tiredness and pain.

You will be sent a survey from NHS England by email or post 18 months after your diagnosis. Please complete the survey to tell us how cancer might have changed your quality of life.

The survey results will help us improve how we support people to live their lives as well as possible. Completing the survey can also help you to talk about the support you need with your team.

5 years after treatment

After your follow-up, we send you back to the care of your GP. If you are eligible, you can also take part in your local NHS bowel screening programme.

NHS bowel cancer screening checks to see if you could have bowel cancer. It's currently available to everyone aged 54 or over. The NHS is gradually extending the age range for the bowel screening programme.

You use a home test kit, called a faecal immunochemical test (FIT), to collect a small sample of poo. This is sent to a laboratory. They check the sample for tiny amounts of blood.

For more information, you can call the free bowel cancer screening helpline on 0800 707 60 60.

When to contact your colorectal care team

You can contact your colorectal care team on the CNS helpline at any time during your follow-up. Call 020 3299 4854, Monday to Friday, 9am to 5pm. You can contact them to arrange a call back, or an appointment to talk about any new symptoms, treatment side effects, or worries or concerns you might have.

When you call the helpline, you can leave a message asking to be called back. A nurse will call you back by the end of the next working day. If they feel that it would be best for you to come back to the hospital, you will be given a clinic appointment

Useful sources of information and support

Your colorectal care team will give you information on the support available to you. Your GP might also be able to tell you about support in your local area.

Bowel Cancer UK has information and support for everyone affected by bowel cancer. web: www.bowelcanceruk.org.uk/

Cancer Research UK has information for anyone affected by cancer. tel: 0808 800 4040, web: www.cancerresearchuk.org

Cancer Care Map helps you find cancer-related services in your local area. web: www.cancercaremap.org

Cancer Wellbeing London has information about health and wellbeing workshops, and support across London, web: www.cancerwellbeinglondon.nhs.uk

Citizens Advice Bureau gives free and confidential information and advice to help people with financial, legal and other issues, web: www.citizensadvice.org.uk

Macmillan Cancer Support has practical and emotional information and support (online or over the phone), including financial information and support with work, tel: 020 3299 5228, web: www.macmillan.org.uk

Shine Cancer Support offers support for young adults in their 20s, 30s and 40s. web: www.shinecancersupport.org

Working With Cancer helps employees, employers, the self-employed, job seekers and carers to manage cancer and work. They give coaching, training and advice. web: www.workingwithcancer.co.uk

Contact us

If you have any questions or concerns about your follow-up, please contact the Colorectal Cancer CNS team, tel: 020 3299 4854, Monday to Friday, 9am to 5pm.

King's College Hospital offers a range of cancer-related information for patients and carers, available at www.kch.nhs.uk/services/cancer/

King's Macmillan Information and Support Centre

King's Macmillan Information and Support Centre provides cancer support services. We have a drop-in information area and offer complementary therapies, psychological support and benefits advice for patients and carers.

The centre is in the Cicely Saunders Institute at King's College Hospital, Denmark Hill, tel: 020 3299 5228, email: kch-tr.macmillan1@nhs.net.

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, tel: 111, web: www.111.nhs.uk

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND
Tel: 01689 863252
Email: kch-tr.palspruh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net