

# Colorectal shared care record and action plan

Your enhanced follow-up and beyond



## Information for patients Colorectal Surgery



**PROUD TO MAKE A DIFFERENCE**

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST





## Your colorectal cancer follow-up and beyond

Your follow-up care and support will (as much as possible) be planned around your individual needs and reflected in your action plan. **The main priority will be supporting you to return to a 'normal' life after your cancer treatment.**

We work in partnership with you, your GP and other support services.

However, we will also ensure you get the correct surveillance which allows us to monitor for any signs of cancer-related problems.

We aim to give you enough information and advice to take responsibility for your own health, whilst always knowing when and how to get the help you need. There is a wide variety of help available (see resource section) and it is essential that you make the most of this varied help in order to get the best possible care.

### Hospital based follow-up

Your hospital based follow-up usually lasts for 5 years, although this may change depending on your health, circumstances and your own wishes.

Generally, your consultant team will see you within 2-6 weeks of having your operation. At this point your consultant will usually transfer you to the nurse-led colorectal follow-up service. The nurse specialists who run this service will become your key workers.

If there are any queries about your care or management whilst you are being looked after by the nurse-led service please contact the nurse specialists. The nurse specialists, if required, will try to seek the advice of your consultant or one of their consultant colleagues.

There are a number of tests that we will ask you to have during your follow-up care. These include:

## **CEA blood tests**

CEA stands for carcino-embryonic antigen which is a tumour marker blood test. Abnormal levels of CEA can sometimes be caused by bowel cancer, so it helps us to monitor for signs of cancer recurrence.

However, there are many reasons why this blood level can vary, for example smoking, infection or inflammation in the body. If you do get a higher than normal reading of CEA we will normally ask you to have this blood level checked again a month later. If it continues to rise after three readings we will often ask you to have a CT scan.

CEA is normally recorded every 3 months for the first 2 years, and 6 monthly for 3 further years.

## **CT scan**

This is a scan that allows us to look in detail at your chest, abdomen and pelvis for signs of cancer-related problems. We will usually ask you to have one of these scans 9 months, 2 years and 3 years following your operation.

## **Colonoscopy**

This is a flexible camera test of your bowel which is done by a specially trained nurse or doctor. It allows us to look at your large bowel. Its main benefit is to look for polyps which are small growths that may grow and develop over several years and become cancerous. If we find polyps, they can normally be removed during your colonoscopy.

## **MRI / PET scans**

Sometimes during your follow-up, there may be times when we would advise some further tests. This may be because you have symptoms, your CEA levels are raised or other tests have shown changes in your body. If you require these types of tests, you will be given information by your specialist hospital team.

## **Your GP follow-up care**

Your GP practice will want to contact you within 6 months of your cancer diagnosis (and at other times if needed) in order that they can talk with you about your diagnosis, treatment and any needs, issues or concerns you may have. They will help to guide you towards other sources of help if required. This is an important part of your follow-up care. It would be sensible to take this shared care record and action plan with you (if you attend an appointment with them) as your GP / practice nurse may wish to review it.

## Your follow-up clinical care plan

We do follow National Guidelines to monitor you, however, this may vary depending on your individual needs and treatment plan.

Follow-up time schedule	Follow-up action plan	Results
2-6 weeks	Consultant clinic appointment for review and results of operation	
3 months	Nurse led clinic visit. Holistic Needs Assessment review CEA blood test	
	Your GP Practice should perform a 'Cancer Care Review' within 6 months of your diagnosis	
6 months	CEA and pre-scan blood tests	
9 months	CT scan prior to clinic visit. CEA blood test and clinic with scan results	
12 months	CEA blood test	
15 months	CEA blood test	
18 months	CEA blood test	
21 months	CEA and pre-scan blood tests	
24 months	CT scan Holistic Needs Assessment review CEA blood test	
2 years 6 months	CEA blood test	

Follow-up time schedule	Follow-up action plan	Results
3 years	CEA blood test CT scan prior to clinic visit Nurse-led clinic visit If you have not had a colonoscopy since your surgery you will be due one now	
3 years 6 months	CEA blood test	
4 years	CEA blood test	
4 years 6 months	CEA blood test	
5 years	CEA blood test then stop Colonoscopy every 5 years	

Clinic visits will be individually tailored to your needs which will be agreed between yourself and your key worker.

## **Holistic needs assessment**

You will be invited to complete a holistic needs assessment at various stages of follow-up. You can also request a further holistic needs assessment at any time by contacting your key worker. The assessment is easy to do and helps to identify the needs and problems which are most important to you. We will use this information to develop a care plan to ensure these needs and problems are addressed. Your care plan will be reviewed at different stages of your care and follow-up. You will be offered a copy of your care plan.

This ensures that any outstanding issues are identified and that you can be directed to the best means of support and help. This information is also shared with your GP so that they are fully aware of what is happening and if they need to play a part.

The main priority is that you feel able to live a life beyond your cancer diagnosis with the right help and information available from the right place and at the right time for you.

## When and how to seek help – signs and symptoms to look out for

It is important to report promptly any of the signs and symptoms listed below. Whilst you are still under hospital led follow-up, we would encourage you to contact your colorectal nurse on **0114 271 4809** with any concerns or problems. Once hospital follow-up stops, it is important to see your GP as soon as possible if you experience any such problems.

These include:

- A change in your bowel habit (from your usual post-treatment pattern) that lasts more than three weeks.
- Bleeding from your back passage, particularly if the blood is mixed with the stools.
- Abdominal (tummy) pain that continues for more than three weeks and/or is at the same place in your abdomen.
- A lump in your abdomen (tummy).
- Weight loss that is not expected.
- Feeling tired or breathless.

Your health care team will be able to assess your symptoms, try some treatment if appropriate, and arrange tests and investigations as needed. Your GP will refer you urgently back to your specialist team if required.

## Contact numbers

Your GP surgery:

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Colorectal nurses

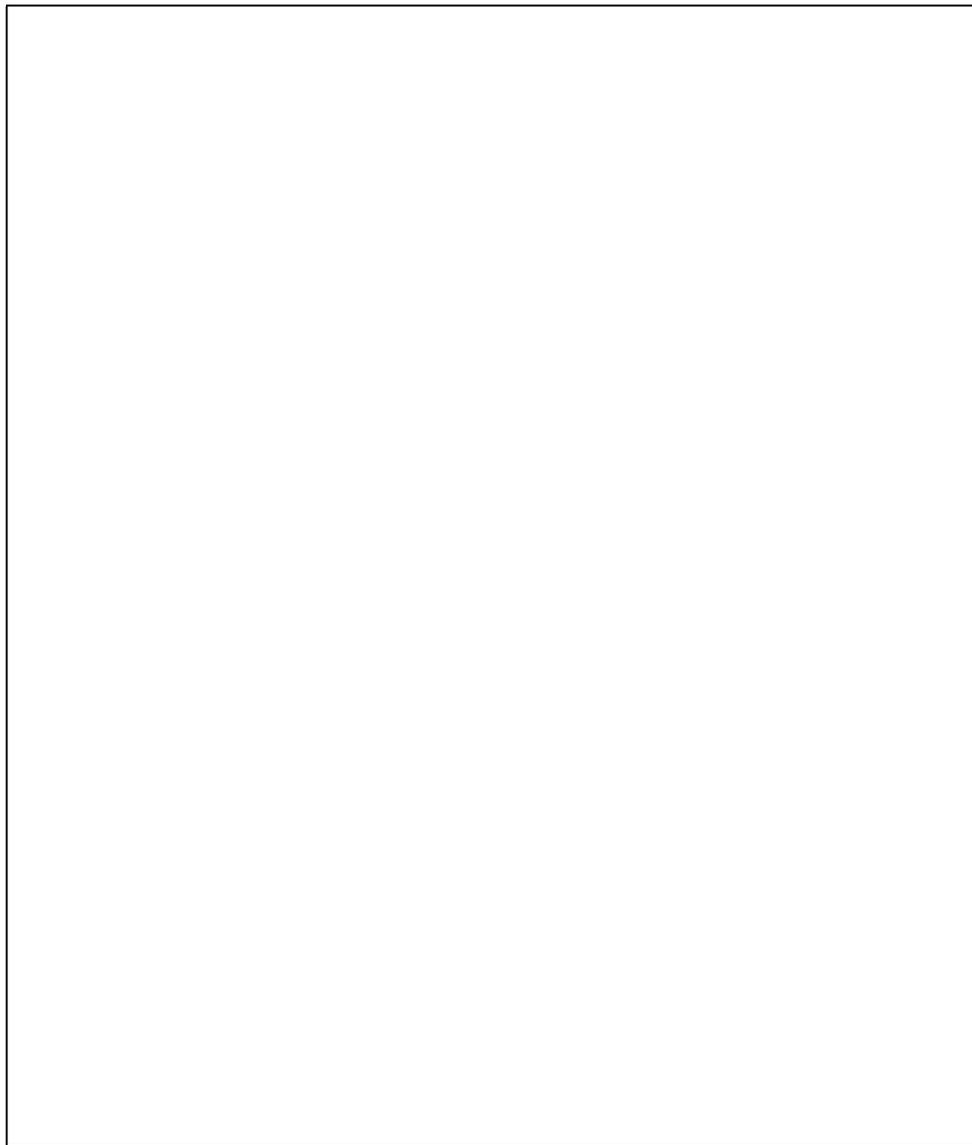
- **0114 271 4809**  
Monday to Friday, 8.00am - 5.00pm

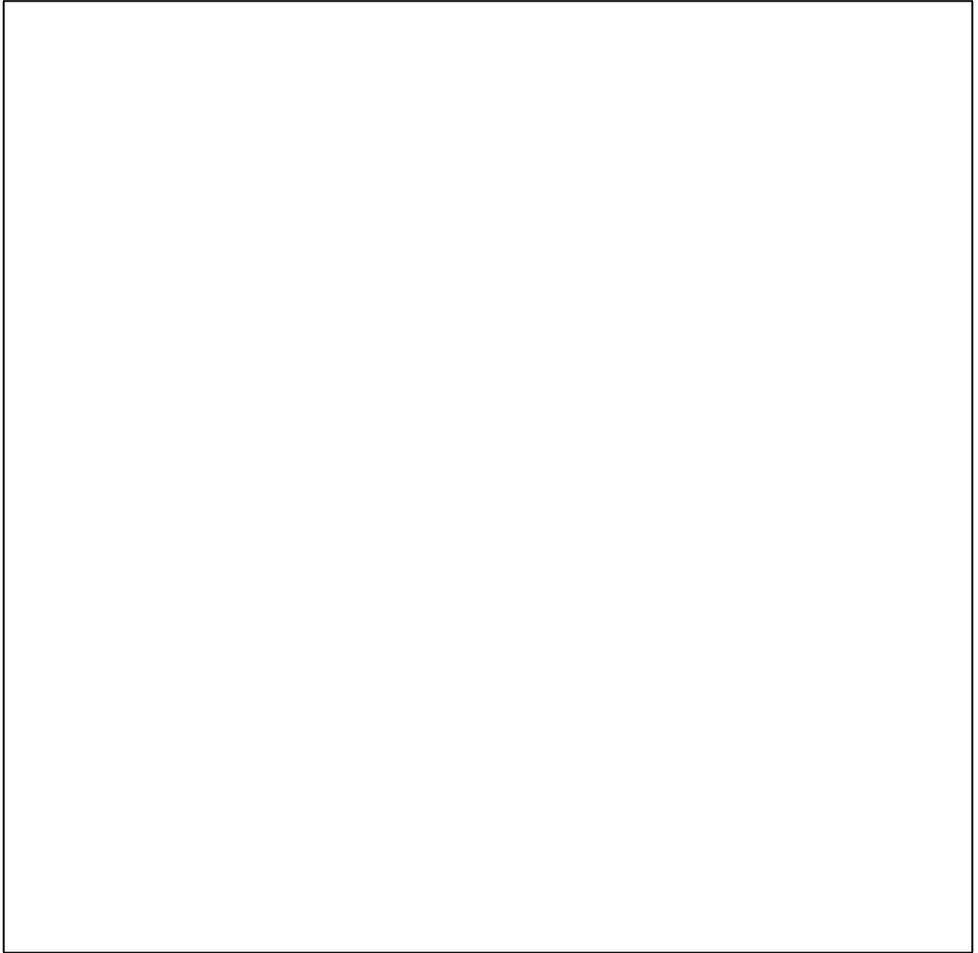
NHS 111

- **111** (non-urgent out of hours advice)

## Your space

This is an area to jot down any questions, concerns and/or feelings you may have about your follow-up and beyond.

A large, empty rectangular box with a thin black border, intended for the user to write down questions, concerns, or feelings. The box is completely blank and occupies most of the page's vertical space.



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