



Colorectal Department

Supported Self-Managed Follow-up (SSM) For patients who have completed treatment for bowel cancer

In the past it has been traditional for patients who have completed their treatment for bowel cancer to have regular follow-up appointments with their surgeon, clinical nurse specialist or oncologist. These appointments are useful and reassuring and, as your nursing team, we believe this to be a necessary precaution as it is a way to identify any problems early on and act quickly enough to be able to treat them.

Why have you been selected for SSM follow-up?

Your health and wellbeing are important to us. We believe this is the best way of keeping a close eye on your recovery following your cancer treatment and SSM puts you in control of your care. Our Remote Monitoring System (RMS) allows us to monitor the results of your regular tests and recall you quickly to hospital in the event of any concerns. Not only does this give you the freedom to get on with your life, it also provides you with the reassurance that there are specialist clinicians monitoring your progress, enabling a fast-track back to hospital should you need it.

You will continue to have any recommended blood tests, CT scans and colonoscopies, but will only be brought back to hospital for a consultant appointment if your results show a change which warrants further investigation.

SSM and the Remote Monitoring System

The RMS enables us to monitor your test results and to call you back into hospital should you need further tests or investigations. Not only does the system record and monitor your respective tests it will also a) alert the team of the results and b) alert us to when your tests are next due. The system is monitored by the clinical nurse specialists and cancer support worker.

What tests will I need?

Following your treatment for colorectal cancer you will need to have the following:

- **Blood tests:** you will have regular blood tests to check carcinoembryonic antigen (CEA) levels which is a tumour marker for colorectal cancer. These will be taken every six months for three or five years following your treatment. This will be dependent upon the stage of your disease.

- **CT scans:** you will need at least two CT scans within the first three years following treatment. This will be dependent upon the stage of your disease.
- **Colonoscopy:** you will need to have a colonoscopy one year after your surgery and then again at four years after surgery. If you did not have a complete colonoscopy prior to your surgery, this may be done sooner. The clinical team will inform you if you need to have a colonoscopy.

You may need other investigations depending on the complexity of your follow-up. Your colorectal nurse specialist or consultant will explain which tests are recommended for you. You will receive letters to remind you when your tests are due.

How does SSM follow-up work?

When your blood test is due, you will receive a letter and a bloods form requesting you to book yourself into your GP surgery or hospital for a blood test. You will also receive a letter giving you an appointment date for a CT scan or colonoscopy.

The results of these tests will automatically be recorded on the RMS system and checked carefully by the relevant clinical staff.

If your results are within the range that is normal for you, you and your GP will receive a letter confirming this and you will be told when your next tests are due.

If there are concerns about your test results, you will be telephoned to discuss this further and may be offered an appointment to attend clinic for an assessment. Your GP will also be notified.

Try not to worry if your CEA test result shows a rise. A number of factors can increase the CEA level such as smoking or if you have other medical conditions.

Your clinical team want to ensure you stay fit and well, so will investigate any abnormal results just in case there is a problem that needs to be resolved. As with all problems, the sooner they are investigated the better the chances of a successful outcome.

Getting back to normal

Reaching the end of your treatment can be a difficult time for many patients. Although you will feel relieved that your treatment is finally over, you may experience a feeling of 'what happens next' as you can miss the security of being seen at the hospital on a regular basis.

People have different ways of living with cancer and there is no right or wrong way, just what works best for you. Some people prefer not to talk about it, whilst others feel supported by talking through their experience. Your nurse specialist and support worker are there to support you in whatever way they can.

When can I go back to work?

If you are going back to work, it will help to keep in touch with your employer/HR department. You can discuss a flexible or staged return to work if that is helpful to you.

Financial concerns

If your cancer diagnosis has affected your income, you may be able to get help with NHS costs, grants or certain benefits which are usually means-tested. Your nurse specialist or support worker can refer you to the Macmillan Citizens Advice for further information.

Dealing with any worries you may have

The treatment you have had to date has given you the greatest chance of keeping well in the long term. Your surveillance programme is designed to ensure any problems are detected early. It is important to contact us if you experience any changes that cause you concern so we can act quickly.

Everyone is different and it is you who knows your body best. We would much rather you telephoned the helpline with a concern that turns out to be nothing, than have you sitting at home worrying. The sooner you share your symptoms or concerns with us, the quicker we can help to resolve the problem.

The symptoms below could indicate a return or a spread of the disease and will need further investigation:

- Any rectal bleeding which does not go away. We are not worried about the occasional few spots on the toilet paper. Anything that persists for a few days or more should be reported.
- Any new pains that do not go away and last longer than a week.
- Unexplained weight loss.

If you experience any of the above symptoms or have any concerns about your colorectal cancer, please contact us on our helpline:

01305 253144

We will aim to return your call within one working day of leaving your message. Please note that our working days are Monday to Friday 9:00am-5:00pm.

If the team feel you need to return to hospital, an outpatient's appointment will be made for you.

If your symptoms are particularly worrying, especially in the case of sudden heavy bleeding, or severe and persistent abdominal pain, you should contact your GP immediately or go straight to the hospital Emergency Department.

The benefits of being on the SSM follow-up system:

- You can telephone the helpline with any concerns or symptoms relating to your colorectal cancer and receive a call back within one working day.
- You will not need to make unnecessary trips to the hospital at times when you are symptom-free and getting on with your life.
- You no longer need to take time off work or pay travelling or parking charges for outpatient appointments that you do not need.

Further Information

We hope you have found this information useful, but if you have any questions about Supported Self-Managed follow-up (SSM) please contact us on:

Telephone: Colorectal Nurse Specialists - 01305 253144
Email: colorectalcancernurses@dchft.nhs.uk

We will be happy to answer any questions you have.

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If you have feedback regarding the accuracy of the information contained in this leaflet, or if you would like a list of references used to develop this leaflet, please email pals@dchft.nhs.uk



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