



Complex Colorectal Cancer Services

Introduction

Established in 2001, the Complex Colorectal Cancer service has been providing specialist cancer care to many patients whose needs cannot be met in general hospitals. St Mark's Hospital has a long-standing, mature service offering surgery to patients with complex and recurrent colorectal cancer.

This leaflet is an introduction to the Complex Colorectal Cancer service at St Mark's Hospital and will tell you about the key people who deliver this service and about possible treatments that may be offered. It also explains what you can expect from us now we have received your referral and the steps involved in the planning of your care. A member of the team will talk to you about everything in this leaflet, but if you have any questions, please ask.

What are complex colorectal cancers?

You have been diagnosed with a cancer within the pelvis which may be described as 'complex' or 'locally advanced'. This means that the cancer has grown outside the organ where it started, such as the rectum. Alternatively the cancer may have returned after your previous treatment, such as surgery, chemotherapy and/or radiotherapy.

Your cancer may involve the gastrointestinal system (the bowels, rectum and anus); the urinary system (the bladder and ureters) and/or the lower spine. In women, the reproductive organs may also be affected (the ovaries, womb, cervix and vagina). In men, the cancer may be close to or invading the prostate.

Who are the core team members?

The Complex Colorectal Cancer team is a multidisciplinary team led by two consultant colorectal surgeons: Mr Anthony Antoniou and Mr Ian Jenkins. Both consultant surgeons specialise in advanced pelvic cancer surgery and have pioneered new surgical techniques. Although the consultants work closely together, one will take overall responsibility for your care.

We use the term 'complex surgery' as the operation may involve removing more than just part of your bowel. As a consequence several surgeons may be involved in the operation, including:

- A consultant urologist - who is involved when there is a need to re-route the urinary system to allow removal of the bladder and/or the ureters (drainage tubes from the kidneys to the bladder) and often the formation of a urinary stoma (also called a urostomy or ileal conduit).

- A consultant orthopaedic surgeon – who may be necessary if the cancer is attached to the lower spine requiring removal of the coccyx (tail bone), or the sacrum.
- A consultant vascular surgeon - who can use specialist techniques to divert the blood flow to vital organs and your limbs, to promote wound healing after surgery. This surgeon may also be called upon to repair arteries and veins that are damaged during the surgery and thus reduce bleeding from large blood vessels in the pelvis.
- A consultant plastic surgeon - who will be involved when there is a need to fill the wound and close the skin edges (called a reconstruction). This will most commonly be achieved by using a skin flap called an IGAP (inferior gluteal artery perforator) flap across the buttocks.
- A consultant radiologist - we have three consultant radiologists who specialise in reporting and explaining to you the exact location of the cancer and the surgical approach best for you. He or she will also decide if further tests, such as CT and MRI scans are needed, at any stage in your care.
- A Macmillan colorectal nurse specialist (CNS) - to provide support and information to you and your family before, during and after your treatment with us. There are several Macmillan CNSs in the team and one will act as your main contact. The role of the Macmillan CNS includes helping you to prepare for your treatment, offering advice on managing any symptoms you experience and providing emotional support as required.

Other team members

Teamwork is an essential part of cancer care and in addition to the core team there are other important members who will also be involved in your care should you decide to have treatment here at St Mark's. These key professionals include:

- The operating team, including the consultant anaesthetist
- The nursing team, comprising of the acute pain team, stoma care nursing team, tissue viability nurse and all the ward nurses including the specialist practitioners
- The therapy teams comprising of the physiotherapy team, occupational therapy and the nutrition team.

The initial clinical consultation

Having received a referral from your doctor, we review all the relevant tests and scans, histology (tissue sample reports) and past medical history made available to us.

It may be necessary for us to request further information from your referring team and hospital.

Our first contact with you is likely to be made by the consultant colorectal surgeon's secretary who will update you with news regarding your referral and book your first appointment.

We usually hold complex colorectal cancer clinics between 11am and 2pm on Fridays. The Outpatients Department is often much quieter on this day. This allows us to have a longer consultation than usual so we can discuss your care in detail.

Preparing for the consultation

This is a combined speciality clinic and so you are likely to meet other team members alongside the consultant colorectal surgeon. We would encourage you to bring a family member or friend to this appointment as they can help you recall the content of the consultation as well as providing you with companionship and support. You may also wish to bring with you any previous written communication you have received regarding your cancer and its treatment. We are likely to ask to examine you. It can help to prepare any questions you may have, such as:

- What can surgery offer me?
- What organs might have to be removed?
- What are the risks and benefits of this surgery?
- What non-surgical options are available to me?
- What are the treatment timescales?

What happens next?

After the first consultation, a personal management plan will be developed with you. It is not always possible for the team to say at this stage, whether surgery can be offered, as further treatments, tests or consultations may be needed to decide this.

Pelvic cancer surgery is normally only offered if there is a very good chance that all the cancer can be removed. However, other cancer treatments such as chemotherapy and/or pelvic radiotherapy are likely to be considered in addition to surgery if gaining complete removal of the cancer is not certain. These treatments may be offered before surgery to reduce the size of the primary cancer and to try to reduce the chance of cancer spreading beyond the pelvis. They are often provided by a consultant oncologist (specialist cancer doctor) at a cancer centre closer to your home, although these treatments can be offered by the two consultant oncologists working in our Trust. In either situation, we would keep in close communication with your treating team and arrange to see you again once you have completed this stage of your treatment.

Deciding on treatment

As a further part of the decision-making process, we may ask you to come into hospital for one night for an examination under anaesthetic (or EUA for short), or a laparoscopy which uses key-hole techniques. This may be recommended if there is some doubt over what the imaging reports are telling us or if further tissue samples of the tumour are required.

Following the first consultation, there may be a need to consult with another specialist to help decide upon the best type of surgery to perform i.e. a meeting with a vascular, orthopaedic or urology surgeon.

If you have other health issues, a further consultation may be necessary - for example discussing your case with a cardiologist - to assess the risks involved in having such major surgery. This will either require you to attend an outpatient appointment or have a further consultation with the relevant consultants.

Further tests

You will need to undergo tests including blood tests. Once any additional tests and procedures are completed and have been reviewed, a subsequent consultation will be arranged. This is usually face-to-face but could be over the phone (particularly when long distance travel is involved), to discuss the best treatment for you.

If surgery is offered as the next treatment, you will not be expected to make a decision to accept this on the same day as the consultation. It is important that you have time to think about all the options available to you, discuss with family and/or friends and ask further questions if needed.

For some people, surgery is not the best option; it might be that the risks involved are too great at that particular time. There may be the possibility of surgery in the future if your general health improves, or it may be that the chances of fully removing the cancer are too small to warrant undertaking a major resection. If the latter is the case, we would consider other treatment options with you.

Waiting

Whatever specific treatment plan is offered, discussed and chosen with you, it is worth being aware that the planning process usually takes time as there are often many team members to consult with. Most people find the waiting hard so please bear in mind that in advanced cancer care, it is the quality of the decision-making rather than the speed that really matters. Nevertheless we recognise there is anxiety associated with the waiting, particularly if you have yet to agree upon your treatment plan and/or receive a treatment start date.

It can help to view this waiting time as your “personal preparation period” to focus on trying to enhance your health and well-being by undertaking physical activity, stopping smoking, stopping alcohol consumption and eating healthily. This is called pre-rehabilitation and can aid the recovery process. During this time it can be helpful to seek support from family and friends and plan ahead by organising your house/diaries. There is also evidence that having a healthier lifestyle can improve long-term outcomes for people who are diagnosed with a cancer.

What does complex cancer surgery involve?

It is important to know from the outset that complex cancer surgery is not an easy option and is demanding on you both mentally and physically. We have a detailed patient information booklet describing the main surgical approaches we offer. There is a separate information sheet if you require an abdomino-sacral resection or sacrectomy. Please ask the team if you would like a copy of either of these.

The consultant colorectal surgeons will inform you of the risks involved in this surgery as part of the consent process. There is a chance of major complications which includes an unplanned return to intensive therapy unit (ITU), the high dependency unit (HDU) or theatres. Other issues may be the wound taking a long time to heal or permanent changes in your mobility. As with all major surgical procedures there is also a small risk of death occurring soon after the operation.

The operation itself usually takes between 6 and 12 hours. Nearly all patients will then be transferred for one to two days to either the HDU or ITU. Our average hospital stay is 18 days but there is great variation from 9 days to many months, depending on your fitness, the extent of the surgery and the nature of any complications which might occur.

The recovery after this surgery will take approximately six months. Reassuringly, three months after advanced pelvic cancer surgery, most patients report they are recovering quite well and beginning to live a relatively independent life again. Encouragingly there is a reduction in post-operative symptoms and thus you will need minimal involvement from health care professionals. However it can take a further three months before your energy and stamina returns sufficiently for you to go out of the house for longer periods of time, to complete a task without feeling exhausted and to be able to concentrate fully on work responsibilities.

What you can expect from our service?

- Honest and detailed information about your cancer and the treatment options
- A treatment plan agreed jointly between you and your consultant
- The opportunity to discuss your treatment plan with other specialists
- Written information about your care and treatment
- Regular updates to your GP about your care and treatment
- Copies of letters written about you to other health care professionals

Further information

If you need advice about your treatment or side effects outside normal working hours, please contact your GP or NHS 111 or in life-threatening circumstances call the emergency services on 999. This will depend on the nature and urgency of your concern.

If you have a non-urgent concern related to your cancer and treatment, please contact your Macmillan Colorectal Nurse Specialist.

Macmillan Colorectal Nurse Specialist at St Mark's Hospital - 020 8869 2472
Secretary for the Complex Cancer Clinic – 020 8235 4177
Complex Cancer Patient Pathway Co-ordinator – 020 8235 4128

St Mark's Hospital, Watford Road, Harrow, Middlesex HA1 3UJ

There are several cancer charities which can offer you further information and support. They include Macmillan Cancer Support which provides practical, medical, emotional and financial information and support for patients, families and friends affected by cancer. They offer a helpline which is free and confidential: telephone: 0808 808 0000 between 9am-8pm Monday-Friday. Macmillan produce a wide range of booklets and provide information on their website describing options available for advanced colon and rectal cancer plus related topics related to cancer.

General Trust Information

Patient Advice and Liaison Service (PALS)

PALS is a confidential service for people who would like information, help or advice about the services provided by any of our hospitals. Please note that this service does not provide clinical advice so please contact the relevant department directly to discuss any concerns or queries about your upcoming test, examination or operation.

If you would like this information in an easy to read format, large print, braille, different format or language, please contact the PALS team on 020 8869 5118 or email lnwh-tr.PALS@nhs.net. We will do our best to meet your needs.