

## Complex cancer surgery for men

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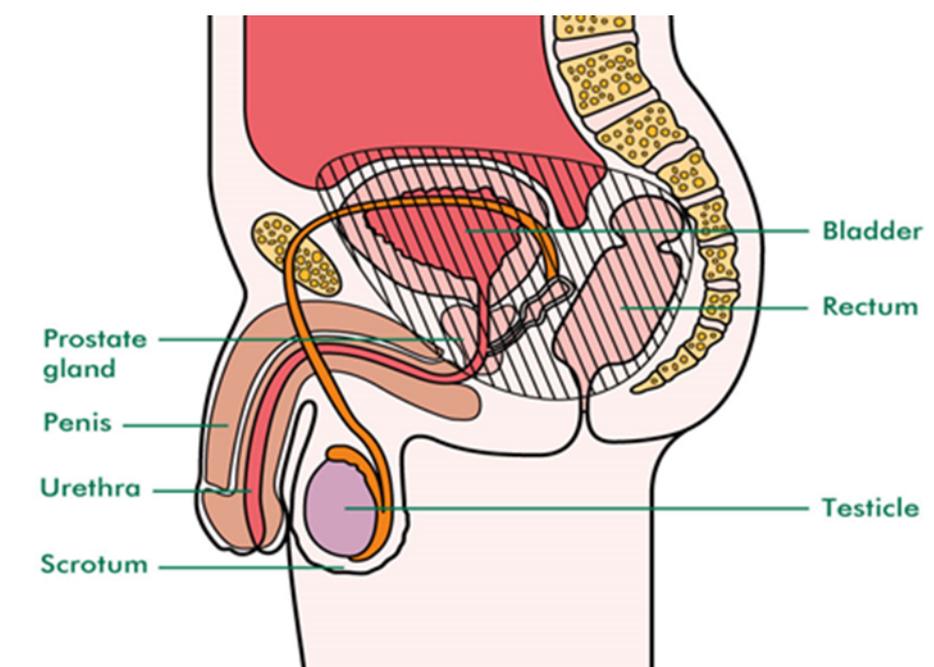
### Page Contents:

2	Introduction
	What is complex cancer surgery?
3	Stoma formation
	Removal of bone in the lower spine (sacrectomy or coccygectomy)
4	Removal of other pelvic organs
	Plastic surgery
5	What are the risks?
	What are the benefits of complex cancer surgery?
	Are there alternatives to surgery?
6	Getting ready for surgery
	What can I expect in the first days after your surgery?
7	What am I able to eat and drink?
	Wound care
8	Stoma care
	Coping with any pain
9	Coping with tiredness
	Changes in your body
	Bowel changes
10	Urinary changes
	Physical activity
	Sexual activity
11	How long will I be in hospital?
	What needs to happen before I leave hospital?
	How long will it take to recover?
12	Emotional recovery
13	What should I do if I want further information?
	General Trust information

## Introduction

You have been diagnosed with a cancer in the pelvic area (see Figure 1). Your cancer may involve the bowels (the colon, rectum and anus), the urinary system (the bladder, kidney and ureters), the prostate and/or lower spine (sacrum). Your cancer may be described as locally advanced. This means that the cancer has grown outside of the organ where it started, such as in the bowel or rectum. Alternatively the cancer may be 'recurrent' and may have returned after previous treatment, such as surgery, chemotherapy and/or radiotherapy.

A member of staff will discuss all this information with you, but if you have any further questions, please ask one of our team.



*Figure 1: Illustration showing the male pelvic organs. The shaded area indicates the organs that are removed during a total pelvic exenteration.*

## What is complex cancer surgery?

An operation to remove a locally advanced or recurrent cancer is a specialised surgical procedure as it involves removal of more than just a part of your bowel. This type of operation (surgery) will involve more than one surgeon and the operation can be at least six hours in duration.

Complex cancer surgery is only offered if there is a very good chance that all of the cancer can be removed.

Please ask your surgeon exactly what your operation will involve, as it could include the removal of:

- The rectum and lower part of colon with formation of a stoma (colostomy).
- The bladder and/or ureter(s) – if the bladder is removed there will be a stoma (urostomy). The ureters are tubes joining the kidneys to the bladder. It is

possible that one or both ureters need to be removed or repositioned during surgery.

- The seminal vesicle(s), a pair of glands behind the prostate that are involved in producing fluid that makes up semen.
- The prostate gland that is the gland around the urethra below the bladder. It produces some of the fluid found in semen and is important in a man's sex life. The sexual nerves may be affected which means that an erection may not be achieved, although sexual desire is still felt.
- A section of the spine such as the sacrum or coccyx.

Sometimes, surgery can be more successful if we start your treatment with a course of radiotherapy and/or chemotherapy. This may be given over several months followed by a period of at least six weeks rest before your surgery. The aim of chemotherapy and radiotherapy is to shrink the size of the tumour, and/or reduce the risk of it returning in the future.

## **Stoma formation**

Complex cancer surgery is likely to involve formation of a stoma, which is an opening of the bowel onto the surface of the abdomen. A colostomy and/or a urostomy are the types of stoma that are most likely to be formed.

A permanent colostomy is formed when the rectum and anal canal are removed, stitching over the anus. The colon is brought out on to the lower left side of the abdomen. Stool (bowel motion) and wind are redirected out of the body through the new opening (stoma or colostomy) on the abdomen and are collected in a stoma bag (stoma/ pouch) which is worn on the outside of your abdomen.

Occasionally in complex surgery, only a temporary stoma needs to be formed. The temporary stoma is usually an ileostomy, formed from the small bowel and will pass wind and faeces. A temporary stoma can be put back (or reversed) when the bowel has healed. This will require another operation, usually several months after the removal of the cancer.

A urostomy will be formed if the bladder has to be removed, as a new outlet for your urine. A piece of the small bowel (the ileum) is used to pass the urine out of the body from the stoma (urostomy). The stoma is called either a urostomy or ileal conduit.

## **Removal of bone in the lower spine (sacrectomy or coccygectomy)**

In cases where the cancer has become stuck to the back of the pelvic bone, it is usually necessary to remove a part of your lower spine. This area is called the sacrum and the little tailbone is called the coccyx. Removal of the sacrum is called a sacrectomy and removal of the coccyx is called a coccygectomy.

Five separate bones or vertebrae are fused together to form the triangular shape of the sacrum. If this area requires removal, the most usual procedure is a partial sacrectomy that involves removing part or most of this bone. If you have the lower part of your spine removed, you will have problems with sitting down during this healing process and there is likely to be pain for the first 3 months after surgery. You

may also have problems with walking, which you will learn to deal with over time helped with physiotherapy.

Removal of the sacrum will disturb and even damage important nerves such as the sciatic nerve. This may result in you not having the same control over certain leg muscles that you had before. If this is the case, you will be shown how to use your leg(s) when standing, transferring between seats and to control your muscles when walking. You will be supported in re-learning these important functions and receive physiotherapy in hospital to help you in this.

If there is more permanent damage to the sciatic nerves then you may be left with a dropped foot and walking will never be exactly the same as it was before the operation. You should be able to walk independently, possibly with the aid of a stick /crutches, after a short period of recovery. Some people will require additional physiotherapy after leaving hospital.

## Removal of other pelvic organs

In some cases it is necessary to remove the prostate gland. This will depend on the area within the pelvis affected by your cancer and this may result in the prostate, seminal vesicle and surrounding area being removed (radical prostatectomy). The removal of the prostate gland and seminal vesicles may mean that erections may not be possible after surgery. However, if you are able to achieve erection, your orgasm will be dry and no semen will be released.

Also removal of the prostate may result in damage to the urinary tract causing urinary incontinence or leakage. Since previous radiation therapy can also result in urinary incontinence or leakage, we often offer you the option of a urinary stoma called a urostomy or ileal conduit to improve your quality of life.

If all the main pelvic organs are removed, it is called a total pelvic exenteration. The operation will leave you with both a colostomy and a urostomy. The surgeon will remove any necessary surrounding tissues to reduce the chances of the cancer coming back.

## Plastic surgery

After complex cancer surgery you will often need plastic surgery to reconstruct your perineum (the area between the scrotum and anus). This is usually performed on the day of the main operation but if this is not possible, it will take place over the following few days.

There are a number of different ways that you may have plastic surgery and the most common is a 'flap' such as an IGAP (inferior gluteal artery perforator) flap. This involves using some of your buttocks (backside) to 'fill' the cavity left inside your pelvis that reduces the amount of space and thus fluid, that can collect within your pelvis after the operation. You will still have a buttock but there will be a triangular shaped scar on one (unilateral) or both (bilateral) of your buttocks. Occasionally a different flap will be created, depending on your body shape and the type of operation performed and this will be discussed before you agree to surgery.

## What are the risks?

As with any operation, there is a risk of complications due to anaesthesia, wound infection, or injury to adjacent organs or structures. In the case of advanced pelvic cancer surgery, there may be major complications that can occur during or following this surgery. The following complications are possible during surgery:

- Haemorrhage (bleeding) during the operation that may require a blood transfusion
- Injury to the bowel
- Injury to the urinary tract
- Failure of the kidneys

Major problems can also develop after the operation including bowel obstruction, fistula formation, narrowing of the ureters, formation of a blood clot in the lungs, retention of urine requiring permanent use of a catheter or an infection developing which may occur in the chest, urine or wound.

Around 20% (1 in 5) patients will experience a major side effect from the surgery. If a major problem does happen, you may need to have additional medication and monitoring and therefore may need to recover in a high dependency unit (HDU) or intensive therapy unit (ITU) bed until your health is more stable. There is the possibility that further surgery might be necessary. The risk of dying within 30 days of the operation is less than 2%, meaning the chances of dying during the operation are low.

Most patients will experience minor side effects from this surgery such as wound breakdown or a collection of fluid in the abdomen. These can be resolved by attention from the surgical, medical and/or nursing teams.

Please also be aware that there is a risk that you may be fully prepared for surgery but at the last assessment or even at the time of surgery, it becomes clear to the surgeon that removing the cancer is no longer possible. If this were to happen, the surgeons would not normally carry on with the large operation that was originally planned.

## What are the benefits of complex cancer surgery?

In 85% of patients that we operate on, a complete removal of the cancer is possible. This is a vitally important outcome in order to achieve local control of the cancer that will improve the overall levels of survival.

## Are there alternatives to surgery?

The alternative is usually to consider further chemotherapy and/or radiotherapy treatment. Your cancer specialist (Oncologist) can advise you of how this might help and what is involved.

## Getting ready for surgery

It is helpful to stay as active as possible in the lead up to your surgery. Getting ready for this surgery involves adopting a healthy lifestyle such as eating a nutritious diet and undertaking exercise to improve health.

Try to have a balanced diet and maintain your weight within the ideal range for your height (body mass index). If you have lost weight there are beneficial supplements that you can get from your GP, pharmacist or supermarket. It is also beneficial to increase your exercise. Building up to being able to manage a 20–30 minute walk most days can improve your stamina and help you prepare for a major operation.

It is important to stop smoking and reduce alcohol consumption for at least a month before surgery to help you to recover by reducing the risks of complications after surgery. You can get help from your GP to help you to stop smoking, if required.

You may need to see an anaesthetist, who is the doctor who will put you to sleep for your surgery. He/she will ask you about your heart and lungs, allergies and your medications. Sometimes your hospital notes are reviewed by the anaesthetist and if you are in otherwise good physical health you may not need to come to hospital for an additional review. Your blood will be matched with donated blood as you are likely to need a blood transfusion during or after the surgery. Speak to your doctor if you have any concerns about having a blood transfusion.

## What can I expect in the first days after your surgery?

You are likely to need extra monitoring for the first few days after your operation. We are able to do this best in the intensive or high dependency care unit. You will return to the ward once this special monitoring is no longer needed.

You will wake up with a tube in your throat to help you breathe until you have recovered from the anaesthetic and are able to breathe on your own. You will have several intravenous (IV) lines. One of these IV lines may be in your neck.

You will have drains in your abdomen and/or perineum to drain fluid from the pelvis. These tubes may be attached to suction devices, to take extra fluid and blood away from the incisions and help them to heal more quickly. All of these tubes, drains and equipment will make it difficult for you to move, however changing position and getting out of bed and walking is very important in the recovery process and can minimise your risk of getting a chest infection and other complications associated with lying in bed too long.

You will be seen by the physiotherapists who will help you to get up out of bed as soon as is possible. If you have a flap, this may be 1 or 2 days after your surgery, and you will be taught how to get in/out of bed from side laying to standing without sitting, in order to protect the flaps.

The nurses on the ward can help to change your position in bed and it is important that you do so every 2–3 hours. You will be asked to move your feet and legs in bed to help with circulation and maintain your strength. You will receive injections of a blood thinning medication once a day and you need to wear stockings on your lower

legs. You will be helped to get up out of bed as soon as possible. All of these things help to prevent blood clots.

Oxygen will be given until you are breathing well enough on your own. Initially whilst you may not be mobilising, you should take regular deep breaths and every 1–2 hours. This is to help minimise your risk of getting a chest infections. Holding your abdomen (tummy) when coughing is often more comfortable.

The output from any stoma (colostomy and/or urostomy) as well as the drainage from any other tubes will be checked closely. If you have any dressings on your abdomen, perineum or buttock these will be changed as often as needed.

## What am I able to eat and drink?

You may find that you do not have much of an appetite at first. If you feel sick, medicines can help, so ask your nurse. There are no rules about what you should or should not eat. Eat what you feel like and little and often is usually better than large heavy meals. Food with a low residue (low fibre) and those that are easily digested are usually best at first. You may not be able to eat much for several days and your appetite may be reduced. You will be given dietary supplements, in addition to food, to help you to recover.

If you have a stoma you may find that spicy food and a lot of salad or fruit may not be well tolerated at first. It may be a case of 'try and see' with certain foods. Try to keep up your energy levels by having a good calorie intake. Also aim to drink at least 6–8 cups of fluid per day. It is quite common to lose some weight during your recovery from this surgery and it can take months before you start to notice the weight returning.

## Wound care

All skin flaps need careful monitoring to ensure healing. Pressure such as sitting or lying on the flaps can slow down the ability of the flaps to heal so you will be asked to lie on a pressure-relieving mattress for 7 days.

After the operation it is important that you do not sit or lie on your flaps until instructed that it is safe to do so. You need to alter your position regularly for comfort and to relieve pressure to the part of the body you have been lying on. During this time, it can be difficult to get comfortable and tasks such as eating become challenging (finger food is easier than meals requiring a knife and fork).

Once the doctors say that the flaps are healthy, you can sit for 5 minutes, 4 times a day. The time that you sit on your bottom can be increased by increments of 5 minutes until 15 minutes is reached. You can then sit as long as you feel comfortable. This advice is just a guide and may change, depending upon how you are recovering. It is also advised that once you can shower, that you do so at least daily to clean the wounds. After washing, pat the wounds dry to avoid using any friction on the area. This flap(s) may need nursing care at home once you leave hospital. Sitting can be a problem for many weeks or months because of discomfort. A pressure-relieving cushion when sitting is recommended.

You will also have a scar down the middle of your buttocks where your back passage (anus) was, towards your testicles. This central wound can occasionally break down and if this happens, it will need nursing care to help it to heal. The surgeons will check the wounds at least weekly during your hospital stay and after discharge. An appointment with a plastic surgery doctor may be made to review the wounds and to give advice for your recovery.

## Stoma care

There is plenty of information and support available if you have a stoma formed. The nurses on your ward and the stoma specialist nurses will help you to learn how to care for your stoma. Most people learn quickly how to change their stoma bag/pouch, as you will need to do this at home. You will also be given specific booklets on stoma care.

Before you leave hospital we will make sure you feel able to manage your stoma, that you have enough stoma supplies and all the necessary contact telephone numbers. Please feel free to talk to your doctors or nurses about your questions or concerns. The stoma care team will give you more detailed information about having a urostomy and colostomy.

## Coping with any pain

In the initial days after your operation you will have an epidural that is a form of continual pain relief or a PCA (patient controlled analgesia), which you can use when you experience pain. After a few days, your epidural or PCA will be removed and you will be automatically given some painkiller tablets. It is important initially to take pain medication regularly. Additional pain medication can be requested around every four to 6 hours and it is better to ask for painkillers as you start to feel sore rather than waiting until the soreness is severe. Please do not suffer in silence. It is normal to feel discomfort after major surgery but it should not stop you moving around.

As the days from surgery pass, your pain should become less but if you feel your pain is worsening please tell the team looking after you. It is helpful if you can explain what pain you are experiencing is like, for instance is it dull, burning, sharp or stinging, does it come and go or is it continuous, and whether there is anything that makes it better (or worse).

At home, you will need to continue taking regular pain medication (analgesics) until the pain becomes infrequent during the day and until you can sleep comfortably through the night without the pain waking you up. Different types of painkillers may be needed to make you more comfortable. There are also ways to reduce pain that do not involve taking medication. These include the use of heat, such as hot water bottles, changing position, massage and/or relaxation that may be worth trying. A few weeks after surgery, you should be able to reduce and possibly stop taking your painkillers.

## Coping with tiredness

After surgery, you will feel a different level of tiredness, which is called fatigue. This is a whole body type of tiredness that is not relieved by sleep. It may last for only a few weeks although for some people, it may be felt for much longer, 6 months or so.

The tiredness may stop you carrying out your normal activities and can get in the way of things you enjoy or need to do.

It is important to find out if, over and above the healing and stress associated with your surgery, whether there are any other reasons why you might be feeling tired. A blood test may pick up a change in a blood level that may require further investigation or intervention such as a change in your iron count or a decrease in a hormone levels.

There is further information on fatigue on the Macmillan website at: [www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness](http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness)

## Changes in your body

After surgery, you will experience changes in your body:

- Appearance – the way you look. For example, the surgery will cause some scarring, the size of which will depend on the incisions the surgeon makes. Other changes might include weight loss/gain and skin changes.
- Function – the way your body works.
- Sensation – the way your body feels. For example, the abdomen can feel different, with areas of numbness.

These changes may be temporary or permanent, and whilst they may be very visible to you they are likely to be much less obvious to other people. Body changes can affect the way you think and feel about your body (body image), which can affect your self-confidence. You might also worry that people will treat you differently because of a change to your body.

Some people will focus on just getting through their treatment and will not think about its impact until much later and so it may be some months later that these concerns occur. It can be helpful to talk through these feelings with someone who will listen, such as a friend, your GP or the Macmillan nurse.

## Bowel changes

It can take several months for the bowel to settle after surgery and for you to develop a predictable pattern. Your bowel function is not likely to be exactly the same as it was before your operation, so your expectation of what is 'normal' for you may need to be adjusted. It takes time to adjust to having a stoma and it can be helpful to talk to other people with stomas who have been through this experience.

## Urinary changes

During surgery it may be necessary to insert stents (tubes) into the ureter. These are used to protect the ureters (the small tubes that drain urine from the kidneys to the bladder) during surgery. On occasion, an external tube might be placed into one or both kidneys, if there are problems with the passage of urine from the kidneys. These tubes are called nephrostomies and they will be inserted in theatre by the urological surgeons or in the X-Ray department by interventional radiologists.

Nephrostomy tubes drain away the urine that will collect in a small bag connected to it.

If you have not had a urinary stoma formed, you will have a urinary catheter for several days, possibly a few weeks, until any swelling in the area from the surgery has settled. Once the catheter is removed, a loss of control when passing urine is usually a temporary inconvenience after surgery, and the majority of men regain urinary control within 2 or 3 months. Some men will continue to lose small amounts of urine when sneezing, coughing or exerting themselves. Further treatment to improve urinary function may be necessary.

## Physical activity

Initially your activity will be geared towards being independent and safe when transferring in and out of the bed (with or without adaptive equipment). You might require specialist physiotherapy support to improve your lower limb strength and enhance your range of movement. The therapists will initially visit regularly after the operation to help teach you how to become more independent in relevant personal care activities.

Whilst our aim would be for you to move around independently with appropriate walking aids at the time of discharge, every patient is different. Your ability to move around independently will depend on your prior level of fitness, your length of stay in HDU/ITU, if you experience any complications that limit mobility plus and most importantly, the extent of the surgery. In general removing part of the spine bones and /or spinal nerves will cause more restrictions to your physical activity than if your operation does not include your spine.

## Sexual activity

Most patients worry about when and how to resume a sexual relationship after surgery. Cuddling and caressing may be all that you feel like doing for a while. You may want to talk with your partner about how you are feeling about the changes in your body before you decide to resume sexual relations. If everything seems to be working normally after surgery, which may be a few weeks after your operation and can be apparent with the return of your morning erection, then you can resume sexual intercourse. We do however advise that you discuss this at your hospital check-up with your doctor.

Some operations may permanently damage your erectile function and this will specifically be discussed with you before your operation. Operations such as a total pelvic exenteration will definitely cause problems with getting an erection. There are treatments available if you are experiencing any difficulties in resuming sexual intercourse.

If possible, the surgeon will preserve the nerves responsible for your erection. However you may have noticed problems before your operation and even if the surgeon thinks that the nerves were not damaged, the ability to have erections can still be affected. The ability to spare these nerves is dependent on where your cancer is.

In some patients, nerve sparing is not performed as doing so may compromise the ability to remove all the cancer cells. It is also important to understand that the likelihood of retaining sexual function after surgery depends not only on the nerves but also on your age and the pre-treatment level of erectile function. If erections do not return, a number of treatment options may be possible, such as Viagra. If erections are possible, there may be no semen with ejaculation but this will depend on the parts of your body that were removed.

## **How long will I be in hospital?**

We will usually want you to stay in hospital for about 3 weeks after the operation, but this can vary a lot between individuals. Some people go home safely, before this time. If a major complication occurs the hospital stay may be considerably longer.

## **What needs to happen before I leave hospital?**

For you to go home you need to meet a number of criteria. This ensures that you are safe to leave hospital but you may still need assistance at home such as visits from community nurses to look at your wounds. You will be asked to practise giving yourself a small injection of blood-thinning medication, which needs to be given just under the skin once a day for about 6 weeks, at home, to reduce the risk of a blood clot. You should also wear your elasticated stockings at home until you are fully mobile.

Our discharge criteria are:

- That you should be able to eat and drink sufficient quantities to prevent dehydration or low blood sugar.
- That you should be moving around, possibly with the assistance of a frame or walking stick. Some people will have a periodic physiotherapy review at home, often necessary if you have your sciatic nerve removed.
- That your pain should be controlled with oral medication.
- That you can care for your stomas.
- That your hospital tests (such as blood tests) are satisfactory.

## **How long will it take to recover?**

These operations are very big and can be difficult to cope with. It is important that you are prepared for a long period of recovery afterwards. It is unlikely that you will begin to get over the changes to your body for at least 3 months. The time taken to get back to normal activities varies a lot for different people. Do as much as you feel comfortable doing. If you need to take painkillers these may make you drowsy, so you should avoid driving or operating machinery. If lifting causes you discomfort you should avoid it. You should not drive until you feel confident that you could manage an emergency stop.

If you work, plan to take at least 3 months off sick but this will depend a little on what type of work you do. It is important for you to pay attention to your body, balancing doing as much as you feel able to with exercising and resting enough to regain your strength and confidence.

You should try to avoid excessive walking or sitting still until your wounds have healed. It would also be unwise to go swimming or undertake any vigorous exercise until the area has completely healed. Gradual increase of exercise at home for the first few months is recommended.

## Emotional recovery

Each person reacts differently to having this surgery. You may feel worried about its effect on you, your partner, or the way you live and this is to be expected. Cancer is a worrying disease and this is a complicated operation. Talking with someone close can help relieve tension. Allow yourself time to adjust physically and emotionally. It is normal to feel a little wary and anxious at first but if difficulties persist, do discuss this with your doctor.

In the first weeks at home you may have some days when you feel quite low and this is normal. Some people find that it can take some months to adjust emotionally to the surgery. When you first go home you are likely to feel tired and unwell for a while but things will get better. It is common to feel a bit low in the first weeks and to become frustrated that you cannot do everything that you would like to do. Whilst most men feel able to resume most of their normal routines and activities within six months of surgery, some report that it takes them 12 months to feel completely back to their normal selves.

## What should I do if I want further information?

If you have a problem or any questions in the first few weeks after you go home please call Frederick Salmon ward on the number below. If a problem occurs after this time, please contact your GP or community nurse for advice.

### **If you need further advice:**

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.

Frederick Salmon Ward – 020 8235 4191  
Perioperative specialist nurse practitioners – 020 8235 4000 and ask for bleep 450  
Macmillan Colorectal Nurse Specialist at St Mark's Hospital – 020 8869 2472  
Stoma care at St Mark's Hospital – 020 8235 4110  
Secretary for the Complex Cancer Clinic – 020 8235 4177

St Mark's Hospital, Watford Road, Harrow, Middlesex HA1 3UJ  
[www.stmarkshospital.nhs.uk](http://www.stmarkshospital.nhs.uk)

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## 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 call 0800 783 4372 between 10am–4pm or e-mail [lnwh-tr.PALS@nhs.net](mailto:lnwh-tr.PALS@nhs.net). 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.

**For a translation of this leaflet or for an English version in large print, audio or Braille please ask a member of staff or call 0800 783 4372.**