National Cancer
Control Programme

Patient Passport

Treatment Summary and Care Plan for patients with Colorectal Cancer

Important information

This Passport is your personal document. You should bring this with you to each hospital visit /virtual appointment so that you can update your information at that time. You can use it as a place to store your information during your treatment and as a place to refer back to for treatment details and advice when treatment ends.

Your Hospital Number

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Contents

Introduction

You have just been diagnosed with Colorectal Cancer (also known as bowel cancer, colon cancer or rectal cancer). This Passport is a guide to your treatment and follow-up care (surveillance).

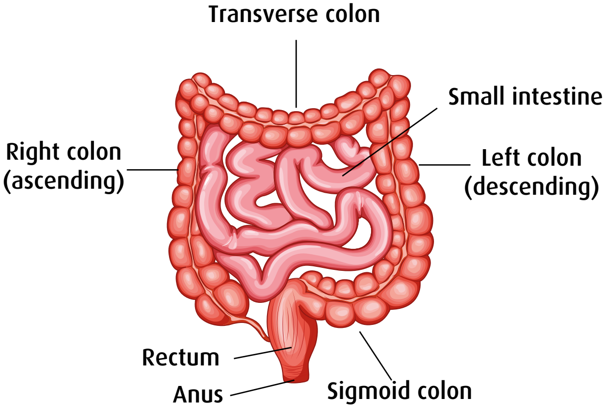
It aims to help you understand and keep a record of your treatment pathway. **Please remember to bring it to each hospital/virtual appointment.**

Just as everyone is different, everyone's treatment will be different.

This Passport outlines treatment and care for all colon and rectal cancers. **Remember not all areas of the booklet will apply to you.**

Your Consultant and Clinical Nurse Specialist (CNS) will guide you to the areas within the Passport that are relevant to you.

Diagram showing all sections of the colon and rectum.



Key contacts

Details of healthcare professionals you may meet during your treatment and follow-up:

Surgery

Hospital

Consultant Name
Tel.
Email
Clinical Nurse Specialist Name
Tel.

Radiation Oncology (radiotherapy)

Hospital

Consultant Name
Tel.
Email
Clinical Nurse Specialist Name
Tel.

Medical Oncology (chemotherapy)

Hospital

Consultant	Name
	Tel.
	Email
Clinical Nurse Specialist	Name
	Tel.
Day-Unit	Tel.
Inpatient Ward	Tel.
Out-of-hours (incl. Saturday & Sunday)	Tel.

Other healthcare professional

Stoma Care Nurse	Name
	Tel.
	Email
Social Work	Name
	Tel.
	Email

Psychology/ Psycho-Oncology

Name

Tel.

Email

GP

Name

Tel.

Email

Pharmacy

Name

Tel.

Email

Community Cancer Support Centre

Name

Tel.

Email

Dietician

Name

Tel.

Email

Other Contact

Name

Tel.

Email

Appointment Record

Appointment	
Date & Time	
Who attended	
Summary	

Appointment	
Date & Time	
Who attended	
Summary	

Appointment Record

Appointment	
Date & Time	
Who attended	
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Appointment	
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Appointment Record

Appointment	
Date & Time	
Who attended	
Summary	

Appointment	
Date & Time	
Who attended	
Summary	

Before surgery

A nurse will contact you and explain what you have to do to prepare for surgery. They will also do an anaesthetic pre-assessment. The aim of this meeting is to ensure you are as fit as you can be prior to surgery.

On the day before your surgery, you may be asked to take some medicine to help clear the contents of your bowel (depending on the specific surgery you are having). This gives you loose stools and you must drink plenty of clear fluids to replace what is lost.

Sometimes it is necessary to operate urgently on bowel tumours, without an opportunity to meet the entire team. Your doctor will decide if this is the case. If you have urgent surgery you will see all the specialists after your surgery.

Hospital specific instructions:

On the day of surgery as per hospital policy:

Routinely patients are admitted to the hospital on the morning of their surgery. You will be contacted the day before your surgery to advise you what time to come into the hospital. You will meet a doctor and a nurse, who will prepare you for theatre. They will measure you for surgical stockings which help reduce the risk of blood clots developing in your legs. You will go to a bed in the ward after your surgery.

Further instructions:

During surgery

Tubes and Drips:
A catheter (tube) will be put in your bladder to check your kidneys are working well and producing urine.

A drip will be put in your arm during your surgery to make sure you get enough fluid. This will be removed when you are sufficiently hydrated after your surgery.

If needed you may also be given oxygen via a mask and later nasal prongs (tube under your nose) for the day after surgery.

Pain Control:
It is important that your pain is controlled so that you can walk around, breathe deeply, eat, drink, feel relaxed and sleep well.

You may have an infusion in your back (epidural) which will provide a continuous supply of pain relief, by numbing the surgical area.

Alternatively you may have a patient controlled analgesia (PCA) pump. This is an intravenous infusion pump which allows you to press a button for pain relief as needed. It has a lock-out mechanism which prevents you from getting too much medicine.

Sickness:

Sometimes after surgery a person may feel sick, or potentially vomit. This is usually caused by the anaesthetic agents or drugs used in surgery. If you feel sick, be sure to tell your nurse who will get anti-sickness medicine for you.

Eating and Drinking:

On the evening after your surgery, you will start taking sips of water. From the following morning you can usually start taking some light foods and fluids, for example, tea and toast, soup, jelly and ice-cream.

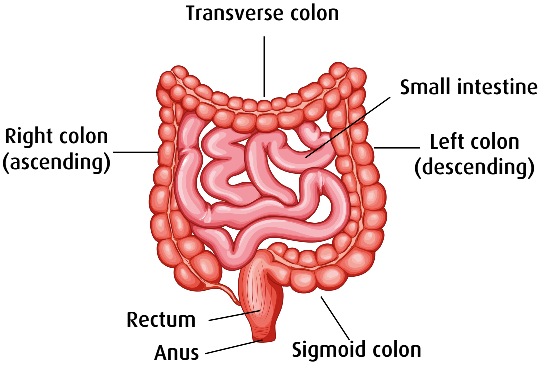
Walking:

Walking and moving around after your surgery are an important part of your recovery. You should aim to go for 4 walks on the day after your surgery and sit out for at least 6 hours. This helps to improve your circulation, reduce the risk of chest infections and reduce the risk of blood clotting. It also helps to stimulate the return of bowel function. You will be assisted to mobilise for the first few days after your surgery.

My surgery

Date of my surgery:

Details of my surgery:



For follow-up after surgery, turn to pg.26 and please see Personalised follow-up regimen on pg.58

After surgery

Going home after bowel surgery

When you are medically fit you will be discharged home. There is still a period of recovery when you get home. You may find simple tasks exhausting and it is common to feel very tired. Sometimes your energy levels can feel lower than when you were in hospital. It is well worthwhile planning in advance for your discharge. You may require someone to help with heavier jobs, for example, shopping, housekeeping etc. for a few weeks.

Don’t be surprised if your bowel habit has changed. Your bowel movements can be more frequent and looser after surgery. This is because you have had part of your large bowel or rectum removed. It is unlikely your bowel function will return completely to how it was before surgery but it should settle down in time.

Don’t be surprised if you have trouble tolerating certain foods, some foods may cause constipation and some may cause diarrhoea. You will find out what suits you or doesn’t suit you.

These are some **DO’S** and **DONT’S** for when you go home to help you recover.

Do:

- ✓ Get up and get dressed every day. This will help build up your strength and helps the return of a normal sleep pattern.
- ✓ Do some light household duties such as washing up if you feel able to do so.
- ✓ Talk to your friends and family and explain what you’re allowed (and not allowed) to do. This will help them to know how they can help you.
- ✓ Do some gentle exercise daily, maybe walking to build up your strength. Ask your treating team for advice about what exercise is best for you.
- ✓ Drink plenty of fluids, 8-10 glasses per day.
- ✓ Eat light, nutritious meals as sometimes large plates of food can be off-putting. Small frequent meals may be better for you. You may receive specific dietary information depending on your surgery.

- ✓ Eat snacks between meals if your appetite is not good.

- ✓ Take painkillers if you have pain. You may need them for a few weeks after surgery. Don't suffer in silence; if you are in pain take the painkillers you have been prescribed. This will help you recover quicker.

- ✓ **You may be referred to your local nurse to check your surgical wound. It is likely that your wound will be slightly red and uncomfortable during the first week or two. However, if your wound becomes inflamed, painful, swollen, or starts to discharge fluid, please contact your Clinical Nurse Specialist or your GP.**

- ✓ Be kind to yourself. It's common to feel quite low when you go home. This can be because of the physical effect of surgery on your body but also coping with your diagnosis of cancer.

- ✓ Support for the emotional impact of cancer is important from the time of your diagnoses. Allow yourself some space to come to terms with what has happened and talk to your family and friends. Putting on a brave face can leave you more isolated. Keep in contact with your GP who can help and advise you. Remember, your Clinical Nurse Specialist is at the end of the telephone also if you need to talk to someone.

- ✓ **Your local Community Cancer Support Centre has people available to talk to you, if you think this might help. Alternatively, the Irish Cancer Society provide support via their Cancer Nurseline (FREEPHONE 1800 200 700).**
- ✓ Resume your social activities as soon as you feel well enough. Think about joining an exercise programme. Your Clinical Nurse Specialist can advise you on what you are able for and what is available in your area.
- ✓ Resume sexual activity as you feel able, unless instructed otherwise by your doctor. If you experience any problems resuming sexual activity speak with your Clinical Nurse Specialist or your GP.

Don't:

- ✗ Don't lift heavy items such as bags of shopping for at least 10-12 weeks after your surgery. This can put pressure on the wound and cause a hernia.

- ✗ Don’t drive until you feel comfortable with quick movements such as an emergency stop. You also need to have stopped taking strong painkillers that can affect your response time. You may also need to check with your insurance company.

- ✗ Avoid heavy household duties such as vacuuming or gardening. There may be someone else who can help you.

- ✗ Don’t go swimming until your wound has fully healed, to reduce the risk of wound infection.

- ✗ Don’t be surprised if you experience a feeling that your bladder is not emptying fully. This usually improves with time. Observe the colour of your urine. If you are well hydrated you should be passing straw coloured urine. If you find that your urine is darker it may be a sign that you are dehydrated. If you feel you are not emptying your bladder fully or if you have excessive stinging when passing urine, please contact your Clinical Nurse Specialist or your GP, as you may have an infection.

In the immediate phase after your surgery, contact your Clinical Nurse Specialist if:

- You develop a high temperature **(37.5° C or above)**.
- You are unable to tolerate food or fluids.
- Your wound becomes inflamed, painful, swollen, or starts to discharge fluid.
- You have persistent diarrhoea, nausea or vomiting, which has not stopped after treatment.
- You have constipation for more than 3 days.
- You have increased abdominal pain not relieved by painkillers.
- You are feeling low and need to talk to someone.

Outside of working hours (Monday to Friday), contact your GP.

Follow-up after surgery

Return to surgical outpatients within 6 weeks of surgery to check your wound and for histology results. Your surgeon and Clinical Nurse Specialist will advise you on the need for further treatment, such as chemotherapy, or to commence a Colorectal Cancer follow-up programme.

Notes:

If you need a Stoma

Your surgery may involve a stoma which allows your bowel motion to pass through an opening on your tummy, instead of the back passage. This requires a bag to collect the bowel motion. This may be an ileostomy (opening into small bowel) or a colostomy (opening into large bowel) and may be permanent or temporary.

Where time allows, pre-op, your stoma nurse will examine your abdomen and mark in ink the best position for your stoma. Consideration is given to factors like your lifestyle and clothing style and they aim to choose a site where the skin is smooth to make placing pouches on the skin as trouble free as possible.

Having stoma surgery can be an overwhelming and emotional experience. Your Stoma Care Nurse will be there to provide you with support and help. They will teach you how to look after your stoma so you can get back to activities and a lifestyle that you enjoy.

The Stoma Care Department provides:

- Education.
- On-going support to all patients who have a stoma.
- Practical skin care advice and help.
- Dietary information.
- Prevention and treatment of dehydration.
- Care of your stoma during chemotherapy.
- Ostomy product information.
- Stoma reversal.
- Colostomy irrigation.
- Advice on sleeping.
- Psychological and sexual advice.
- Support garment fitting.
- Support group information and networking.

The Stoma Care Department has clinics that you can attend should you have any concerns or difficulties.

They will also see you routinely following your discharge home from hospital within the first 7-10 days.

Please contact the Stoma Care Department prior to your surgery follow-up visit so they can review you at the same time.

Radiotherapy

Radiotherapy uses high energy x-ray beams to stop cancer cells from dividing and growing. It is a very precise treatment so it only treats the part of the body where the cancer is (or might be). Radiotherapy uses a machine called a linear accelerator (Linac) to deliver the treatment.

Radiotherapy does not make you radioactive so it is safe to be around others during your treatment. This treatment does not hurt. Radiotherapy is usually given daily over a period of weeks, with each treatment lasting about 10-15 minutes.

Before your treatment begins you will be given a booklet in relation to your bowel cancer. This gives specific information about your radiotherapy treatment.

When is radiotherapy given?

Before surgery: radiotherapy can be given to shrink the tumour to make it easier to remove during surgery and to reduce the risk of the cancer coming back in the pelvis.

There are several ways in which radiotherapy may be given for rectal cancer:

Short-course treatment is where radiotherapy is given alone over 5 days (Monday to Friday). There are three situations where this might happen:

- 3-6 months of chemotherapy, followed by short-course treatment, followed by surgery.
- Short-course treatment, followed by 3-6 months chemotherapy, followed by surgery.
- Short-course treatment alone the week before your surgery is scheduled.

Long-course treatment is delivered over 25-28 days (Monday to Friday) usually with chemotherapy (long-course chemoradiation) at the same time. Again there are three situations where this might happen:

- 3-6 months of chemotherapy, followed by long-course chemoradiation, followed by surgery.
- Long-course treatment, followed by 3-6 months chemotherapy, followed by surgery.
- Long-course chemoradiation alone 6-8 weeks before your surgery is scheduled.

After surgery: Very occasionally, radiotherapy can be given after surgery if:

- There are cancer cells remaining after surgery.
- The cancer was difficult to remove.
- The cancer had spread beyond the wall of the rectum, into lymph nodes nearby.

When radiotherapy is given after surgery this will be long-course chemoradiation.

The length of radiotherapy treatment will depend on the type of cancer you have and will be decided on an individual basis. The most appropriate course of radiotherapy treatment for you will be discussed with you when you meet your Radiotherapy Consultant.

Planning CT scan

Radiotherapy needs to be carefully planned. Before starting treatment, you will have a planning CT (computerised tomography) scan. This CT takes pictures of the area that is going to be treated. There are no results from this scan. This scan is not used to diagnose but only to plan your treatment. It will take place in the radiotherapy centre where your treatment is going to be delivered.

You will be given advice on how to prepare for your planning CT scan and radiotherapy treatments when you go to your first visit at the radiotherapy clinic. This may involve drinking water to make sure your bladder is comfortably full for each treatment. This keeps healthy bowel away from the area being treated by radiotherapy and lessens the risk of some of the side-effects.

The planning CT scan can take up to 15 minutes. You will be required to lie still during this time. Once the scan is taken you will have 2-3 pin pricks of ink placed on your skin (usually one over each hip and the other over the lower part of your pelvis). These are permanent markings and help the radiation therapists line up the radiation beams safely and accurately each day. The radiation therapist will explain the process in detail to you on the day.

Your radiotherapy treatment will usually start 2-3 weeks after the scan is taken. You will either be given the start date on the day of your scan or phoned a few days before the treatment is due to start.

Potential side-effects of radiotherapy

Before starting your treatment, possible side-effects will be discussed with you by your radiotherapy team. You will also be given an information booklet which discusses side-effects in greater detail.

Potential side-effects of radiotherapy for rectal cancer can include:

- Change in bowel pattern causing loose stools, diarrhoea or constipation. Bowel urgency. You may also pass mucous (a clear jelly-like substance) which can sometimes be blood stained.
- Irritation inside the back passage (rectum), known as tenesmus.
- Bladder irritation such as passing urine more frequently or urgently or getting up more often at night.
- Fatigue.
- Skin irritation in the treatment area.

- Sexual problems (which may include erection issues for men and vaginal changes in women).
- Infertility – early menopause in women who have not already gone through the menopause.

You will be assessed weekly during your radiotherapy treatment and will be given specific advice on ways to manage any side-effects that you may experience. Most of the temporary side-effects last for about 10-15 days after treatment finishes.

Before you consent to radiotherapy, your radiation oncologist will discuss the likelihood of long-term and late side-effects. Not everyone has late effects. These are less common but sometimes side-effects can start months or even years after radiotherapy.

Don't be afraid to talk to one of the team if you have any questions or would like to talk about the effects of treatment on sexual health.

Radiotherapy schedule

Radiation Oncologist:

Treatment regimen:

Start date:

Approx. finish date:

Approx. date for re-imaging (and type):

Further instructions:

Follow-up after radiotherapy

Follow-up appointment

If you notice any side-effects or have any concerns within the weeks following radiotherapy treatment, please contact:

Notes

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is often given after surgery to stop the growth of any cancer cells that might remain.

Your treatment plan may or may not include chemotherapy. Chemotherapy can be given:

- before surgery,
- after surgery, or
- given without the need for surgery.

For rectal cancer, chemotherapy is often used with radiotherapy before surgery to shrink down the tumour.

Your Medical Oncology Consultant will decide on the most appropriate treatment regimen for you.

Before chemotherapy

After your first consultation with your Medical Oncology Consultant, you will meet your Clinical Nurse Specialist. They will guide you through your treatment regimen and be your contact for support and advice as you go through your treatment. Specific written information will be given to you on each individual drug.

After this initial meeting, you will be given the details for your chemotherapy education and pre-assessment. Any specific side-effects related to your treatment and the method of chemotherapy administration will be discussed with you by your oncology Clinical Nurse Specialist.

You may need to have a long-term device inserted to facilitate your chemotherapy treatment.

A dental check may be required before starting treatment.

It is also important to have a thermometer so you can check your temperature after your chemotherapy.

Potential side-effects of chemotherapy

- A lowered immune system
- Diarrhoea
- Peripheral Neuropathy
- A sore mouth (mucositis)
- Throat spasm
- Fatigue
- Nausea/vomiting
- Reduced fertility
- Hair thinning

Please note that this list is not exhaustive.

Some of these side-effects are explained in more detail in the following pages.

Contact your oncology team on the numbers provided if you feel unwell or attend your local A&E, for review.

Lowered immune system and high temperature

During treatment, some people may experience a lowered immune system. White blood cells fight infection. If you do not have enough white blood cells in your body (termed neutropenia), you will not be able to fight infection as you would normally. Infection is a serious complication of chemotherapy which can be identified by checking your temperature and needs to be treated promptly.

You don't have to check your temperature daily, unless you are feeling unwell.

Please follow the instructions below:

If your temperature is ABOVE 37.5°C or BELOW 36°C, call the number given to you by your hospital, even if it is the middle of the night. You will be asked to attend A&E, or if it can be facilitated, you may be asked to attend the oncology day-unit for review and a blood test to check if your immune system is reduced.

If you have no temperature, but feel generally unwell (such as a sore throat, cough, or diarrhoea) contact your oncology day-unit for advice.

Do not take Paracetamol or any products containing Paracetamol unless advised to do so by your oncology team.

For further information, please see "**3 steps to prevent infection during your chemotherapy cancer treatment**" available at:
https://tinyurl.com/infection-advice

Diarrhoea

Diarrhoea may be a side effect of your chemotherapy. If you experience diarrhoea, **please contact your oncology team who will advise you.**

It is also important to increase your fluid intake.

If you are on immunotherapy, please contact the oncology department with any symptoms of diarrhoea or abdominal pain.
DO NOT self-medicate.

Mouth Care

Make sure you practise good oral hygiene at all times to help avoid infections.

- ✓ Use a soft toothbrush, fluoride toothpaste and wash your teeth after each meal.
- ✓ Remove dentures before doing mouth care. Rinse your mouth regularly with a salt and water mouthwash, to help keep your mouth clean and ease discomfort. Mix 1 teaspoon of salt with 500mls of **cooled** boiled water. Stir and leave to settle before rinsing your mouth with the mixture.
- ✓ Ask your oncologist or Clinical Nurse Specialist if you need to have a dental check before you start treatment.
- ✓ **Contact your oncology unit if you have mouth ulcers or sores during your treatment. Use the numbers provided.**
- ✗ Avoid using mouthwashes with alcohol.
- ✗ Avoid foods or liquids that can irritate your mouth For example, spicy or salty foods, citrus fruit.

Throat Spasm

This is a tingling of the back of the throat/choking sensation/spasm or the feeling of your breath being taken away, for example, when you take a cold drink or if it's a cold windy day.

✓ Practise deep breathing.

✓ Drink room temperature or warm drinks only, for this period of time or longer if the tingling persists.

✓ Wear a scarf to cover your nose and mouth on a cold day and remember to bring the scarf with you on your day of chemotherapy.

✗ Don't drink anything cold for at least 48 hours after each chemotherapy treatment.

Most importantly, don't panic.

Peripheral Neuropathy (PN)

Peripheral Neuropathy (PN) is damage to your peripheral nerves. The damage is mainly in the nerves to the hands and feet.

If you are on Oxaliplatin chemotherapy you may experience a tingling of the fingers or toes. This can come in two forms:

Acute

From the start of treatment to a few days after each dose of Oxaliplatin you may experience tingling of the fingers or toes when you touch anything cold.

- When you need to take anything out of the fridge, try to reduce your exposure to the cold. You could wear gloves to protect yourself.
- Don't wash your hands in cold water; allow the tap to run and the water to heat up before putting your hands underneath it.

Chronic

The further into treatment that you go, you may start to experience a tingling of the fingers or toes even without touching anything cold.

- **It is very important that you report this to your oncologist at your next hospital visit,** that is, how long it's lasting and if it's travelling up your fingers or into your feet, **as this can become progressively worse 3-6 months after your treatment**.
- The dose of your treatment may need to be adjusted, to prevent this from becoming a long term problem.

Sex and Fertility

For some, chemotherapy may have no impact on their sex life. However, for others, fatigue and anxiety may have a big impact. Changes are usually temporary and settle once chemotherapy finishes.

Barrier contraception in the form of condoms should be used, even if you or your partner are on the contraceptive pill. This is to ensure that you don't expose your partner to any chemicals from the chemotherapy that may be in your bodily fluids.

It is very important **not** to conceive a child while on chemotherapy. Seek advice from your oncology team if you think you might be pregnant or if you are considering getting pregnant after your treatment ends.

Fertility

Fertility may or may not be affected by chemotherapy, however there is an opportunity for fertility treatment for both men and women.

For **men** there is the option of freezing your sperm before treatment begins. Speak with your oncology team if this is something that you wish to consider.

For **women** undergoing chemotherapy, your periods may become irregular or stop during treatment. You may experience menopausal symptoms, for example, hot flushes. The nearer you are to menopause, the more likely chemotherapy is going to stop your periods permanently. There is the option of freezing your eggs before treatment begins. Talk to your oncology team before you start treatment to explore what options may be available to you.

Chemotherapy treatment plan

Oncologist:

Port ☐ PICC ☐

Regimen/Medication:

Start date:

No. of planned treatments:

Your oncology team will advise you on the medication to be taken prior to treatment.

After chemotherapy

Follow-up after chemotherapy

- You will have a CT scan to ensure there is no evidence of cancer.
- Contact your oncology team if any issues or side-effects arise within 2 weeks of completing chemotherapy.
- Go to your first clinic follow-up appointment, which will be in the outpatients department.
- If you received chemotherapy for rectal cancer before surgery, you will be referred straight back to the Surgical team, who will co-ordinate your care.

If you have a long-term device in place, please ensure you talk to your Clinical Nurse Specialist about future care.

Late and long-term side-effects and bowel function

Most people have side-effects during and after treatment for colorectal cancer. Sometimes certain side-effects may be permanent. These are long-term side-effects. Some people may develop side-effects months or even years after treatment. These are called late-effects.

Possible late and long-term side-effects have been mentioned throughout this patient passport.

Not everyone gets late or long-term side-effects but if you do it is important to discuss these with your treating team.

Bowel function

Your bowel function may never return to what it was before you had treatment for colorectal cancer. This may be as a result of radiotherapy, chemotherapy or surgery.

If you have had bowel surgery with or without a temporary stoma, this has changed the structure of your bowel. After surgery or stoma reversal, this change in your bowel structure can change how it works.

You may experience:

- Constipation
- Diarrhoea
- Leakage or incontinence
- Frequency
- Urgency
- Clustering of motions
- Incomplete evacuation

For most people, if you experience any or all of these symptoms, they are usually temporary and will improve in the weeks following your surgery or stoma reversal to a level that is manageable and does not affect your daily life.

A diary of your bowel function may be helpful when discussing your symptoms with your treating team.

There are things you can do to help manage your bowel function and your treating team will advise and assist you with this.

Supplementary information may also be provided.

Notes

End-of-Treatment follow-up (surveillance)

After treatment, you want to give yourself the best chance of remaining cancer-free. The reason for doing follow-up tests is to detect any new cancer or to detect any spread of cancer early. For some people, regular tests may cause worry, but they reassure others. It also gives you the chance to discuss any concerns you may have in relation to your bowel cancer or any other problems you may be experiencing, for example, bowel function or any new symptoms you may experience.

- **You are responsible for your own surveillance**, with the support of the medical and nursing team.
- All follow-up tests are booked at your outpatients visits.
- If you do not attend your outpatient appointment, your follow-up may be delayed or incomplete.

Please ensure you have an outpatient appointment after your scan or colonoscopy is complete. You may need to ring your consultant's secretary to book an appointment to get your results.

REMEMBER:

My surveillance, my responsibility.
Please bring your patient passport
to every clinic visit/virtual appointment.

You will be followed up for 5 years after your diagnosis of colorectal cancer by your treating team.

Throughout your 5-year follow-up period you can contact your Clinical Nurse Specialist **at any time**, if you or your family are concerned about your health in the aftermath of your colorectal cancer treatment.

After 5 years you will be discharged back to your GP.

There may be variations to this timeline, as advised by your treating team.

If you develop the symptoms listed below and they last for more than **one month** you should contact your Clinical Nurse Specialist or your GP.

- Change in bowel habit
- Unexplained loss of appetite
- Unexplained weight loss
- Discomfort in your abdomen or back passage

If you have any worrying symptoms your Clinical Nurse Specialist will arrange an early outpatient appointment for you.

Personalised follow-up regimen (tick as appropriate)

YEAR 1

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
Carcinoembryonic antigen (CEA) test	☐		
Colonoscopy	☐		
Other	☐		
Notes:			

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
CEA test	☐		
Colonoscopy	☐		
Other	☐		
Notes:			

YEAR 1

_____MONTHS AFTER TREATMENT

Examination	**Month Due**	**Results**
CT scan ☐		
Carcinoembryonic antigen (CEA) test ☐		
Colonoscopy ☐		
Other ☐		
Notes:		

_____MONTHS AFTER TREATMENT

Examination	**Month Due**	**Results**
CT scan ☐		
CEA test ☐		
Colonoscopy ☐		
Other ☐		
Notes:		

YEAR 2

_____MONTHS AFTER TREATMENT

Examination	Month Due	Results
CT scan ☐		
Carcinoembryonic antigen (CEA) test ☐		
Colonoscopy ☐		
Other ☐		
Notes:		

_____MONTHS AFTER TREATMENT

Examination	Month Due	Results
CT scan ☐		
CEA test ☐		
Colonoscopy ☐		
Other ☐		
Notes:		

YEAR 2

_____MONTHS AFTER TREATMENT

Examination	**Month Due**	**Results**
CT scan ☐		
Carcinoembryonic antigen (CEA) test ☐		
Colonoscopy ☐		
Other ☐		

Notes:

_____MONTHS AFTER TREATMENT

Examination	**Month Due**	**Results**
CT scan ☐		
CEA test ☐		
Colonoscopy ☐		
Other ☐		

Notes:

YEAR 3

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
Carcinoembryonic antigen (CEA) test	☐		
Colonoscopy	☐		
Other	☐		

Notes:

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
CEA test	☐		
Colonoscopy	☐		
Other	☐		

Notes:

YEAR 4

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
Carcinoembryonic antigen (CEA) test	☐		
Colonoscopy	☐		
Other	☐		
Notes:			

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
CEA test	☐		
Colonoscopy	☐		
Other	☐		
Notes:			

YEAR 5

_____MONTHS AFTER TREATMENT

Examination		Month Due	Results
CT scan	☐		
Carcinoembryonic antigen (CEA) test	☐		
Colonoscopy	☐		
Other	☐		
Notes:			

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Other	☐		
Notes:			

REMEMBER:

My surveillance, my responsibility.
If you do not receive a date for one of your tests, contact your Clinical Nurse Specialist.

End-of-Treatment workshop

A patient education workshop has been jointly created by the National Cancer Control Programme (NCCP) and the Irish Cancer Society (ICS), to bridge the gap in services between the end of active treatment and potentially, suitable longer term support.

The Life and Cancer – Enhancing Survivorship (LACES) workshop is for adult patients who have finished their active cancer treatment and are beginning their long-term follow up. This includes patients who are post-surgery, radiation therapy, or the acute phase of their chemotherapy treatment. The workshop allows patients to access appropriate information and signposting to improve their quality of life after cancer. The focus is on health and well-being, enhancing the use of community supports and survivorship programmes.

For more information on LACES, please contact the Daffodil Centre in your hospital or **daffodilcentreinfo@irishcancer.ie**

Psycho-Oncology

Cancer has a significant psychological impact on patients and families. This can occur at any time from the time of diagnosis onwards.

In addition to the physical side-effects that you might experience, a significant proportion of cancer patients also endure psychosocial consequences as a result of their cancer and its treatment, such as distress, fear of recurrence, fatigue, anger, sadness and financial worries. With the correct information, assessment, treatment and support, these side-effects can be managed and alleviated.

If you feel you could benefit from speaking to someone who might be able to help you, please make contact with your local Cancer Support Centre.

Your CNS will also be able to provide information for support services in your area - offering psychological support; programmes which will support you in relation to self-management (e.g Cancer Thriving & Surviving); and group support.

Cancer Thriving and Surviving

CTS is an evidence-based Self Management Programme which has been positively evaluated with over 20 years of research. The programme is peer and professionally led and each course runs over 6 weeks for two and a half hours each week, either online or face-to-face.

The emphasis is on patient empowerment. The programme offers a sense of confidence and a chance to learn self-management skills when moving on from your cancer treatment. You will learn techniques to deal with problems such as:

- Getting better sleep
- Nutrition
- Managing frustration, fatigue or pain
- Setting priorities
- Making decisions about treatment
- Relationships
- Communicating effectively with family, friends and health professionals
- Regaining and maintaining physical flexibility and endurance

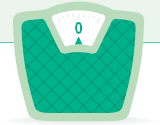
If you feel you could benefit from this you can self refer yourself to the programme. For more information please contact your local cancer support centre.

Cancer Survivorship & a healthy lifestyle

Leading a healthy lifestyle helps recovery from colorectal cancer and improves your general wellbeing. You can improve your general health and reduce the risk of developing further health issues by using the following advice:

BODY WEIGHT

Take action to be a healthy body weight throughout life, from childhood to adulthood.



SMOKING

Do not smoke. Do not use any form of tobacco.

Make your home and car smoke free. Support smoke-free policies in your workplace.

For support to quit smoking go to www.quit.ie or call 1800 201 203.

UV EXPOSURE

Protect your skin from ultraviolet radiation from the sun and artificial sources.

Follow the Healthy Ireland SunSmart 5'Ss from April to September

- **S**lip on clothing that covers your skin such as, long sleeves, collared t-shirts;
- **S**lop on sunscreen on exposed areas, using factor 30+ for adults and 50+ for children;
- **S**lap on a wide-brimmed hat;
- **S**eek shade – especially if outdoors between 11am and 3pm – and always use a sunshade on a child's buggy;
- **S**lide on sunglasses to protect your eyes.

Do not deliberately try to get a suntan. Remember tanned skin is damaged skin. Avoid getting a sunburn.

Never use a sunbed.

Cancer Survivorship & a healthy lifestyle

PHYSICAL ACTIVITY

Be physically active in everyday life as much as possible. Move more and sit less.

HEALTHY EATING

Enjoy food, have a healthy varied diet:

- Eat plenty of wholegrains fruit and vegetables.
- Limit high-calorie foods such as "fast foods", sugary drinks and foods high in sugar or fat.
- Avoid processed meat.
- If you eat red meat such as beef, pork and lamb, limit consumption to a moderate amount, (no more than about three portions per week).

ALCOHOL

For cancer prevention, it's best not to drink alcohol. If you must drink alcohol stay below the recommended low risk guidelines. Be aware there is no safe limit of alcohol for cancer prevention.

Alcohol aids the movement of cancer-causing substances from cigarettes through the body, especially to the mouth, head and neck.

SCREENING

Take part in organised cancer screening programmes for:

- Bowel cancer (men and women)
- Breast cancer (women)
- Cervical cancer (women)

For more information go to www.screeningservice.ie

All graphics have been provided by the Irish Cancer Prevention Network.

Irish Cancer Prevention Network

Marie Keating Foundation
breakthrough CANCER RESEARCH
nccp National Cancer Control Programme
Irish Cancer Society
Irish Skin Foundation

The following websites are a useful resource:
www.getirelandactive.ie
www.sielbleu.ie
www.safefood.ie
www.irishskin.ie
www.gov.ie/en/campaigns/healthy-ireland/
www.bowelcanceruk.org.uk
www.macmillan.org.uk
There are some excellent physical activity programmes available throughout the country. Speak with your CNS or GP to find out more information.

Financial advice

For some, there may have been a significant financial cost related to your treatment. If you need to get information on supports in relation to rent/mortgage allowances, family income support or if your income has decreased, the citizens advice offices /social welfare offices or social workers can all help in reviewing your entitlements (incl. medical card).
www.citizensinformation.ie

Returning to work

A Returning to Work – information booklet is available on the Marie Keating Foundation website
www.mariekeating.ie/back-to-work-after-cancer

Irish Cancer Society

National Cancer Helpline: 1800 200 700
Email: cancernurseline@irishcancer.ie
Website: **www.cancer.ie**

Questions to ask your healthcare team

Write down any questions you have so that you remember to ask your healthcare team the next time you see them.

Glossary

Acute

Occurring suddenly or sharply over a short period of time.

CEA test (carcinoembryonic antigen)

This is a type of blood test most commonly used to monitor patients with bowel cancer.

Chronic

A chronic condition is one that lasts 3 months or more.

CNS (Clinical Nurse Specialist)

Nurses who provide supportive care to patients and their families. They coordinate the patients care and provide education on surgery and the side effects of treatment, and how to manage them, if they occur.

Colonoscopy

A colonoscopy is a way of examining the lining of the bowel from the inside.

CT scan

CT scan stands for computerised tomography scan. The scan uses x-rays and a computer to create detailed images of the inside of your body.

Fertility

The ability to conceive.

Immunotherapy

A treatment that uses the immune system to find and attack cancer cells.

Late effects

Side-effects that do not affect you during treatment but begin months or even years after your treatment ends.

Long-term device

See PICC and Port below.

Long-term side-effects

Side-effects that begin during or shortly after treatment and do not go away within 6 months – they can become permanent.

Oncologist

A doctor specialising in treating cancer.

Outpatient

Attending hospital for an appointment, test or treatment and going home afterwards.

PICC

Peripherally inserted central catheter (tube) - A thin tube inserted into a vein in your arm that is guided all the way to a vein near your heart, called the vena cava. PICC lines are left in place for weeks or months and can be used to take blood samples and give drugs and fluids.

Port

A port is a catheter (tube) with a small reservoir (port) attached to it. It can be used to give chemotherapy or medicine into your vein, or to take blood.

Psychosocial

Cancer can affect a patient's thoughts, feelings, moods, beliefs, ways of coping, and relationships with family, friends, and co-workers. There are different types of psychosocial support that can help cancer patients.

Radiation therapist

Radiation therapists are highly skilled specialists trained to plan and deliver your radiotherapy treatment.

Stoma

Stoma is a term commonly used to describe an opening, that is, a colostomy, an ileostomy, a urostomy and a tracheostomy.

Symptom

In medical terms a symptom is a sign that there is something wrong with a particular area of the body.

Acknowledgements

The original version of the colorectal Patient Passport was developed by the colorectal team of Beaumont Hospital. We are grateful to them and our Nursing colleagues in the participating hospitals for sharing their knowledge and expertise to ensure that the information now includes medical oncology and radiation therapy aspects of care.

We also wish to thank our patient representative for his commitment to the project.

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