

Adapting to metastatic Colorectal Cancer (mCRC)

A guide for people living with metastatic Colorectal Cancer and their caregivers

INTRODUCTION

Welcome to Adapting to metastatic Colorectal Cancer,

part of the Support Harmonized Advances for better Patient Experiences (SHAPE) program.

This guide aims to help people living with metastatic Colorectal Cancer (mCRC). It has been developed for you with input from people living with cancer, patient advocates, and cancer experts.

HOW CAN THIS GUIDE HELP YOU?

When you are diagnosed with metastatic Colorectal Cancer, you start a new part of your life. You are unlikely to have experienced anything like this before, and may feel there is a lot of information to take in.

This guide can give you a clearer idea of what to expect along the way. It's designed to support you, your family, and caregivers as you experience the different steps of mCRC.

You can use this guide to help you better understand the information you receive from your health care team. This guide also provides advice on questions you may ask yourself, loved ones and your health care team, which can help you feel more at ease.

As you move forward, this guide will support you to adapt to life with mCRC.

DEVELOPED WITH SPECIAL INPUT FROM:





Laura Monje-Garcia Nurse Practitioner. United Kingdom

Thomas Gruenberger GI surgeon, Austria

anie Airey © Getty Images

"We've worked together, [with] patients, carers and oncologists, with the mission to really make things different, [and] help the patient to make the decisions that they want to make."

Barbara Moss, Digestive Cancers Europe

"The SHAPE program is based on our multi-professional experience by nurses, doctors, pharmacists and patients to find a good support for GI patients and to support them with tools for their daily needs."

Klaus Meier, Oncology Pharmacist



Klaus Meier Oncology Pharmacist, Germany



Jenni Tamminen-Sirkiä Patient advocate, board member of DiCE and executive director of Colores. Finland

THE ADAPT PATHWAY

Every person living with mCRC is unique. Your experiences and those of your family will be individual to you. However, there are key steps that are important for everyone.

The ADAPT pathway brings together information that can help you understand how your life will change after your diagnosis. It can also point you in the direction of resources that provide more detailed information.

Key steps following diagnosis are shown. However, your pathway may not run in this order. Whether you are reading this just after being diagnosed, during treatment or afterwards, you can use the ADAPT pathway to take you to the information that is most important to you right now, and return to earlier sections or jump to later ones whenever you need.



Awareness

Helping you to understand your diagnosis and find more information online

Discussions with loved ones and your health care team

Dialogue

How to talk about your diagnosis, includina:

- Sharing the news with family. friends, and peers
- Preparing for conversations with health care professionals (including shared decision-making)

Access

Information to help and support you before, during and after treatment. includina:

Getting the most from health care teams and treatment

Treatment

Clinical trials information



Psychological and physical well-being

Looking after your psychological and physical well-being, including:

- Emotional health
- Nutritional health
- Physical health

This will be the beginning of your mCRC pathway where you receive a diagnosis and find out more about what this means for you.

Dialogue is important throughout the whole pathway and may be relevant whenever you need to speak to your family, loved ones or health care team about your cancer and how you feel.

Treatment will usually happen for a period of time and then stop, but you may need to have treatment several times to help you feel better. Living well is important at all times during your pathway, especially during and after treatment.



Take care

Taking care of different aspects of everyday life and planning for the future. includina:

- Relationships •
- Work-life balance
- Finances
- Palliative care .

You can choose to plan whenever you wish. You might prefer to think about the future early or after your treatment.



This chapter focuses on what Colorectal Cancer and mCRC is, the symptoms, tests for diagnosis, introducing the health care team and guidance on how to find trustworthy information.

WHAT ARE THE COLON AND RECTUM?

The colon and rectum are parts of the large intestine (or large bowel), which makes up a section of the digestive system, responsible for breaking down and absorbing food, along with the small intestine.¹ The rectum is sometimes called the back passage.

WHAT IS COLORECTAL CANCER?

Colorectal Cancer is a type of gastrointestinal (GI) cancer that can also be called bowel cancer. colon cancer or rectal cancer. which all refer to any cancer that grows in the large intestine. Most Colorectal Cancers start as abnormal growths, called polyps.¹

WHAT ARE THE SYMPTOMS?

Every Colorectal Cancer patient is different. You may have few or several symptoms, such as:2











A change in your normal bowel habit - such as needing to pass stools more often, or feeling like you haven't emptied your bowels properly

Bleeding from your bottom

Blood in your stool, which may look red or black

Losing weight without a reason

A pain in your tummy



Feeling more tired than usual

HOW IS COLORECTAL CANCER DIAGNOSED?

After you have noticed any symptoms and spoke to your health care team, they may do tests to see if you have Colorectal Cancer. These tests include:3

TYPE OF TEST	WHAT HAPPENS DURING
Examination of the rectum (back passage)	Your doctor touches and feels the inne
Testing for blood in your stool	A test that looks for blood (that you ma
Colonoscopy	A thin, flexible tube with a camera at the see live videos and take pictures of the
Flexible sigmoidoscopy	Similar to a colonoscopy, but only look
Colon capsule endoscopy	You swallow a capsule (of a size of a l takes pictures of your bowel as it trave
Computed tomography (CT) colonography	A scan that uses X-rays and a compute

G THE TEST?

ner part of your rectum using their finger

ay not notice) in a sample of your stool

the end, that your doctor introduces into your rectum (back passage) to he inner part of your whole bowel

ks at the lower part of your bowel

large vitamin pill) that contains a small disposable camera which els throuah it

ter to check your colon and rectum

WHAT HAPPENS AFTER A DIAGNOSIS?

Once Colorectal Cancer has been diagnosed, the cancer is staged. Staging is a way of describing where the cancer is in your body, if or where it has spread to, and whether it is affecting other parts of the body.³

Knowing the stage of cancer helps to decide on the best treatment for it,³ and in some cases, whether a clinical trial may be a treatment option.

To stage your cancer, your doctor may order some more imaging tests (CT scan, PET-CT scan, MRI scan and/or ultrasound).³



WHAT ELSE MIGHT HAPPEN AFTER DIAGNOSIS?

After diagnosis, your doctor may order blood tests to look for tumour markers – substances that can help give the doctor a better idea of which treatment/s may be right for you.⁴

WHAT ARE THE STAGES OF COLORECTAL CANCER?⁵

STAGE 1/I

The cancer has grown through the inner lining of the bowel. It has not spread to lymph nodes (they help the body fight infections as part of the immune system) or other body parts further away.

STAGE 2/II

It has spread into the outer wall of the bowel or into parts of the body next to the bowel. It has not spread to the lymph nodes or body parts further away.

STAGE 3/III

It has spread to nearby lymph nodes but hasn't spread to body parts further away.

STAGE 4/IV

It has spread to body parts further away, such as the liver or lungs. It's also called **metastatic Colorectal Cancer (mCRC) or advanced Colorectal Cancer**

WHAT ARE THE SYMPTOMS OF mCRC?

These will vary for each person, and you may get different symptoms at different periods of time or depending on where in your body it has spread to. Symptoms can include:⁶

- Feeling tired or generally unwell
- Low energy levels
- Having less appetite
- Feeling sick
- A cough that doesn't go away
- Breathlessness
- Aches and pains in bones
- Weight loss
- Loose bowel movements (diarrhea) or constipation
- Yellowing of the skin and eyes (jaundice)

These include only the most common mCRC symptoms. If you have any other symptoms that concern you, reach out to your health care team as soon as possible, and they can support you.

AWARENESS



Chomas Barwick C Getty Images

QUESTIONS TO ASK YOUR HEALTH CARE TEAM AFTER DIAGNOSIS

There may be lots of information to take in when you are diagnosed with mCRC. The following questions may help you better understand what this diagnosis means to you and your family:

Where has my cancer spread to?

What is the stage of my cancer, and what does that mean in my case?

What other tests do I need before we discuss treatment options?

Do I need to see any other kinds of specialists/HCPs?

Could you share your experience in treating this type of cancer?

How will this cancer affect my quality of life?

HOW LONG WILL I LIVE AFTER A mCRC DIAGNOSIS?

Outlook, or prognosis, will vary for each person with mCRC. Your doctor will be able to give you an approximate idea of what to expect.

Treatment options are rapidly evolving, leading to improved outcomes.¹ You may also not wish to know your outlook; instead, you may want only your loved ones to know.

If you want to understand more about your outlook, you may want to ask your health care team:

What are the best things I can do to stay as healthy as possible?

What should I watch for to know whether I am likely to live longer or shorter than expected?

Diagnosis can be confusing, and it is normal that you want to find more information online. You should try not to rely only on information found online, as this is not always correct and can be confusing and frustrating. If you want to do your own research into Colorectal Cancer or mCRC, the <u>SHAPE MyWeb brochure</u> can help you find trustworthy information.

COULD I PASS MY CANCER ON TO MY CHILDREN, OR COULD MY SIBLINGS ALSO BE AT RISK OF GETTING THIS?

Although Colorectal Cancer does not spread like the common cold, it can sometimes be passed down from your parents to you or your siblings, or you could pass it on to your children through genes that you share with your relatives, just like other types of cancer.⁷

If you are offered a genetic test, it may be because you have been diagnosed with cancer at an early age (under 40 years of age), you have closely related family members that have also been diagnosed with Colorectal Cancer, or you have more than one type of cancer.⁸

You may wish to consider genetic testing even if you do not know of any relatives who have cancer. It may not be suitable for everyone so please discuss with your health care team.

Having this knowledge means your family can be especially aware of any Colorectal Cancer symptoms and have tests during their lives to see if they are developing Colorectal Cancer, called screening tests.⁷

If you want to check if your Colorectal Cancer could be passed on through genes, ask your health care team:

AWARENESS



Do you think my cancer could be passed down to my children?

- Could my siblings also be at risk of this cancer?
- How can you rule out that I can't pass my cancer to my children?
- Should I have a test to check if my cancer can be passed down to my children?



MEET YOUR HEALTH CARE TEAM: THE PROFESSIONALS WHO WILL SUPPORT AND GUIDE YOU			TEAM	THEIR ROLE	TEAM	THEIR ROLE	
Although, at times, you may feel on your own, you'll have the support of a team of highly specialized and expert doctors, nurses and other health care staff. Which experts are included will depend on where your mCRC has spread to and what type of treatments you		• •	MEMBER Occupational therapist	A HCP who has expertise in helping	MEMBER Psychiatrist	A doctor who specializes in diagnosing	
have. This team is sometimes called a multi-disciplinary team (MDT). Their goal is to decide on the best treatment for you and to support you with your input if you wish. The table below includes some professionals who may make up your MDT:			if you wish. The table below includes some		you regain independence after treatment.		and treating mental illness using a variety of treatments, including medications and talking therapy.
TEAM MEMBER	THEIR ROLE	TEAM MEMBER	THEIR ROLE	Pathologist	A doctor or a clinical scientist who will interpret the changes in your tumor before, during, and after your treatment.	Radiologist	A doctor who uses X-rays and other screening machines to locate and measure cancer and guide treatments.
Anesthetist	A medical specialist who administers anesthesia, especially on patients who need to undergo surgery.	Counsellor	A professional who uses non-medical techniques to support your emotional needs.	Pharmacist	An expert who provides ongoing	Radiotherapist	An expert who specializes in using high-
Case manager	Your first point of contact who knows your case well.	Dietitian and nutritionist	Experts who focus on supporting you to eat and drink well and maintain a healthy weight.		support with medication therapy management and advice on additional supportive medicines.		energy rays to treat cancer.
Clinical oncologist	A doctor who specializes in treating cancer patients.	Gastroenterologist	A doctor who specializes in investigating, diagnosing, and treating diseases of the stomach, intestines, and pancreas etc.	Physiotherapist	A Healthcare Professional (HCP) that helps you regain strength and mobility after treatment, particularly surgery.	Surgeon	A doctor that performs surgery – typically GI, or further specialist surgeons if the cancer has spread to other areas.
Clinical psychologist	An expert who specializes in supporting you emotionally. Other experts with a similar role are psycho-oncologists who focus on the cancer experience for patients and their loved ones.	Gastrointestinal cancer clinical nurse specialist	A nurse who specializes in caring for GI cancer patients. They may also be your case manager.		You and your family are an important treatments and the risks and benefits, As much as you are willing and able, y that works for you.	you know your own boo	ly and what you want from your life.

AWARENESS





This chapter aims to support difficult discussions with your loved ones and improve communication with your health care team to help shared decision-making.

At times, you may need to have difficult conversations with your loved ones. Remember that these discussions should be on your terms. You only need to have them when you're ready and feel prepared. Although difficult, letting people who you trust know about things like your diagnosis and treatment decisions can help you feel better supported.

SHARING WITH OTHERS: WHY TALKING CAN HELP

As well as getting more support, talking about your cancer can help you to:⁹

- Understand your feelings and be reassured that they are normal
- Feel more in control
- Make important decisions
- Feel less anxious

BEFORE THE CONVERSATION, TRY TO:9

- Think who you would be comfortable speaking with
- Take paper and a pen with you so you can write down any questions
- Consider how much you would like to talk about your diagnosis. Remember, it's fine to revisit the conversation later.

To find out more and see more examples of conversation starters, see the <u>MyJourney</u> patient brochure.

Bring a support person to healthcare appointments:

Having a trusted friend or family member accompany you to appointments can provide emotional support and help you remember the information shared during the visit.



I HAD A GENETIC TEST AND HAVE BEEN INFORMED THAT I HAVE A GENETIC CONDITION. HOW CAN I TELL MY CHILDREN AND / OR SIBLINGS THAT THEY MAY BE AT RISK OF COLORECTAL CANCER?

It may be difficult for you to share this information with your children or siblings, but you should know that this is not your fault, and you are not to blame. By sharing this information, you are helping them to keep an eye out for symptoms and to have screening tests when they get to a certain age.

How you have this discussion will depend upon the age of the person you're telling it to, but it is important to remember that this doesn't mean they will get Colorectal Cancer, just that they may be at a higher risk of getting it.

The HCP that offered the genetic test will be able to help you share this information with family members. They often provide letters and leaflets to help patients share their diagnosis and provide the relevant information to GPs so that they can support with the referral and give more information on what to do next.

If your children are young, it may be worth waiting until they are older, or asking a relative or friend to do it at the right time. You may want to try these conversation starters below:

"I've had my genetic test results back, and there is a chance that you may also get Colorectal Cancer at some point in your life"

"It's important to know that this doesn't mean you will get Colorectal Cancer, but you should be aware of the signs and symptoms just in case"

"If you spot any of the signs and symptoms of c]\ Colorectal Cancer, you should speak to your GP straight away"

CONVERSATIONS WITH YOUR HEALTH CARE TEAM

Although your health care team will be made up of experts in your cancer, you still have a say in your treatment, if you wish.

SHARED DECISION-MAKING

Is the conversation that happens between a patient and their health care team to make health decisions together, taking into account:^{10,11}

- Your preferences, personal experiences, goals, and values
- Your health care team's knowledge of available treatments, and the potential risks and benefits of those treatments – there can be more than one option

You are free to participate in the shared decision-making process if you want to. Some people may decide that they do not want to take such an active role in decision-making. Whatever you choose, positive and open communication with your health care team may help you reach decisions that are right for you.

For more information on shared decision-making and how to make the most of your medical appointments, visit the <u>MyDialogue patient brochure</u>.

DIALOGUE

Tom Werner © Getty Images

Talking Bowel Movements

Bowel movements and talking about going to the toilet are very private matters for many people. But the staff at the hospital or clinic are used to talking about these things and so you shouldn't feel embarrassed.

Share all your symptoms and their severity, even if you think they're not relevant.

SDI Productions © Getty Images

GETTING A SECOND OPINION

Your diagnosis and treatment plan will involve your experienced health care team. However, you may want a second opinion.

While some health care professionals may encourage you to look for a second opinion, it is not always necessary or possible, so think carefully before asking for one.

ADVANTAGES

DISADVANTAGES

 Reassurance that different doctors agree on your diagnosis and treatment

-``Q`

Access to different
 treatment options

- Delays to starting your treatment
- Receiving conflicting information
- Having to travel to different (sometimes foreign) hospitals

DIALOGUE



If you decide you would like a second opinion, the following questions for your health care team may help:

If you had mCRC, is there another doctor you'd want to talk to about your options? Will you refer me to them?

I'd like to see another doctor to get a second opinion about my mCRC diagnosis. Who would you recommend?



This chapter focuses on treatment options and what these may mean for you.

Starting treatment for your mCRC is an important moment. Receiving care for your symptoms can be relieving, but it can also be scary.

Every mCRC patient is different. This means that some treatments will be suitable, whereas others will not. The best treatment or combinations of treatment for you will depend on:¹

The characteristics of your tumor(s)

Size, number and location of tumors

How you have responded to previous cancer treatments

Your general health and level of fitness

HOW IS TREATMENT DECIDED?

As part of your diagnosis, you will likely have had numerous tests to describe the cancer, known as '**staging**'.

Your health care team may also perform other tests to better understand your cancer and how it may react to different treatments. Tests could include genetic testing, somatic testing, or tumor marker testing.^{12,13}

WHAT ARE MY TREATMENT OPTIONS?

The general aims of your treatment are to increase survival, improve symptoms, stop the tumor from growing or spreading further and maintain quality of life.¹⁴

You may be eligible for surgery for mCRC to remove the initial tumor and possibly other tumors that have spread elsewhere in the body. In some specific cases, the outcome of surgery is that you become cancer-free.^{1,14}

If needed, you may receive as single treatment or in combination: $^{\!\!\!1,14}$

- Chemotherapy (a treatment that kills fast growing cells, including cancer cells)
- Targeted therapy (a type of treatment that targets specific sites in cancer cells that help them grow, divide and spread)
- Immunotherapy (a type of treatment that helps your immune system attack cancer)

- You may have a **biopsy** (a sample taken from your tumors) to see what targeted therapy or immunotherapy will work on your cancer
- Radiotherapy (radiations beams that kill the cancer cells)

In some cases, your health care team may decide you cannot have surgery because of the location of the cancer in your body. Instead, you may have chemotherapy, targeted therapy, immunotherapy, radiotherapy or different combinations of these treatments.^{1,14} If this treatment works, your health care team may then decide that you can have surgery.^{1,14}

Although everyone's treatment experience will be different, the following questions may help you better understand what to expect, and if you wish, help you decide what treatment is best for you:

What treatment would you recommend?

Are there any other ways to treat my mCRC?

How long will I need treatment for?

How effective is this treatment?

WHAT IF I CHOOSE NOT TO HAVE TREATMENT?

You may decide not to have treatment for your cancer.

Bearing this preference in mind, your health care team will offer you a treatment that keeps you comfortable and reduces the burden of symptoms. This is called palliative care.¹⁵

Your health care team will discuss what not having treatment could mean. It can sometimes be very hard for your family and friends to accept that treatment should stop, which your healthcare team will help you manage.



HOW WILL MY SYMPTOMS BE MANAGED?

Your health care team will offer support and treatment to help you feel more comfortable. This will include pain relief, and treatment to help with sickness and nausea, if you need it. There are treatments available that can address specific symptoms, such as a blockage in the intestine, including:¹

TREATMENT	DESCRIPTION
Stents	A stent is inserted through your rectum, which expands and keeps the bowel open so stool can pass through again. It relieves symptoms and gives your surgeon time to plan surgery to remove the blocked part of the bowel.
Stoma	A stoma is a permanent or temporary opening that is made through the tummy (abdominal) wall, ensuring stool doesn't pass out of the rectum and anus in the usual way. Instead, it passes out of the stoma, into a disposable bag that is worn over the stoma.

ACCESS

WHAT ARE THE RISKS OF TREATMENT?

Surgery for mCRC can be a major operation, and chemotherapy and other treatments have side effects.¹ However, your health care team will make sure that the possible benefits of your treatment are higher than the potential risks. You may wish to ask your health care team:

What will happen if I don't have this treatment?

What side effects will I experience that could affect my everyday life?

(For surgery) What are my chances of surviving the surgery?

WHAT IS A CLINICAL TRIAL?

A clinical trial is a study that compares treatments that are currently used with new treatments that aren't currently used to find more effective and/or safer treatments.¹ Your health care team may recommend them to you if they believe that the new treatment has a chance of treating you better than currently used treatments.¹⁶

However, there are both benefits and risks of joining a clinical trial:¹⁶

BENEFITS:	POSSIBLE RISKS:
Receiving a treatment that is more effective than the current standard treatment	Receiving a treatment that is less effective, than the standard treatment
Free treatment and care	Having unexpected side effects or side effects that are worse than the standard treatment
Close monitoring by HCPs and more opportunities for questions	Needing extra tests, which could be uncomfortable or time consuming
Contributing to important research that can help other cancer patients in the future	Not being allowed other treatments after the trial, even if the treatment did not work for you
	Travelling to different hospitals, or even different countries, to take part in the trial.

HOW DO I GET INVOLVED IN A CLINICAL TRIAL?

Your health care team may already know about clinical trials that might be right for you and discuss these with you. Or, you or your loved ones may find clinical trials yourselves. You can find clinical trials online on trustworthy websites, such as <u>https://clinicaltrials.gov/</u>.

The only way to join most trials is if your health care team thinks it is right for you, and you agree. You may wish to ask the following questions to help with your decision:

Am I eligible for a clinical trial?

What kind of clinical trials are available for my cancer currently?

To what extent will my doctor be involved if I choose to participate in a clinical trial?

What treatments will I be allowed/not allowed after a clinical trial?

How time consuming will it be?

ACCESS

Treatments for mCRC regularly change and there are many treatments and combinations of treatments currently being researched, which differ per country.¹ You can stay updated about them by visiting the European Society of Medical Oncology (ESMO) Cancer Guides for Patients (<u>https://www.esmo.org/forpatients/patient-guides</u>).

UNDERSTANDING CARE BEFORE, DURING AND AFTER TREATMENT

HOW CAN I PREPARE BEFORE THE **TREATMENT BEGINS?**

Your health care team may mention something called 'prehabilitation'. This helps you to prepare for treatment, cope with any challenges and potentially improve your recovery after treatment.¹⁷ Some things that may help you prepare are:¹⁷



Eating a wide range of foods in the right proportions, a varied diet.



Being physically active; even just making small changes to your routine, like walking around your garden can help.



Looking after your mental well-being.

What you can do to help prepare for treatment will be individual to you and your treatment. Speak to your health care team about what you can do using guestions like:

Is there anything I should stop or avoid doing before treatment?

Is there anything I can do to help myself before treatment?

If you are having certain types of bowel surgery, or you are having tests like a colonoscopy, you may need to follow a special diet or take some medicine, called laxatives.¹⁸ This is to empty your bowels before your surgery.¹⁸ For example, you may need to take a laxative for a few days before the operation.¹⁸ You will also be asked to not eat or drink for a few hours before the operation.¹⁸ Your health care team will advise you about this.

WHAT CAN I EXPECT DURING TREATMENT?

The following table gives a simplified description of what you can expect when you have each type of treatment:^{1,19-21}

TREATMENT TYPE:	WHAT TO EXPECT:
Surgery	 Your health care team will give you a or parts of it You may receive a temporary or per
Chemotherapy, targeted therapy or immunotherapy	 You will be given a medicine as a pil This will happen in hospital/health c care team (at least the first time you
Radiotherapy	 You will lie down on a bed while a ra Members of your health care team v If your mCRC has spread to your live with very small balls of radioactive r few weeks



a general anesthetic (to put you to sleep) and remove the tumors

rmanent stoma

pill, by injection or through a drip clinic or potentially at home, and you will be monitored by your health ou receive the treatment)

radiotherapy machine targets your cancer with high energy waves will watch you during the process ver, you may be given internal radiotherapy, where you are injected

metal, which deliver the energy waves and leave your body after a

WHAT TO EXPECT AFTER TREATMENT?

Different treatments may impact your health in different ways. By understanding the treatments, you may be able to cope with them better.

AFTER SURGERY

- When you wake up after a surgery, you will have some pain and need medicine for a few days. For the first couple of days, you may not be able to eat or drink much to help the colon recover. ²²
- Sometimes the bowel takes longer than normal to "wake up" and start working again. In this case, your doctor may want to delay eating solid food or even liquids, especially if you are having nausea and/or vomiting.²²

AFTER CHEMOTHERAPY

- Chemotherapy weakens your body's immune system.^{19,23}
 - After your chemotherapy session, it's advised that you avoid people with colds or other infections.²³
- Your health care team may suggest that you drink lots of fluids for 48 hours after chemotherapy²³
 - This helps move the medicines through your body.²³

AFTER RADIOTHERAPY

Usually you will feel ok straight after radiotherapy, but you may begin to feel tired or have side effects in the days or weeks after the session^{21,24}

TARGETED THERAPY OR IMMUNOTHERAPY

Depending on the type of targeted therapy/immunotherapy,
 you could begin to feel unwell in the days, weeks or even
 months after treatment^{25,26}

WHAT SIDE EFFECTS CAN I EXPECT FROM MY TREATMENT?

Side effects of mCRC treatment are common, and will depend upon many different things, like the type of treatment, where the cancer has spread to and how your body works. Your health care team will notify you of any expected side effects of treatment and help you to manage them. Depending on the treatment received, Possible side effects may include:^{1,19,22-28}

TREATMENT:	POSSIBLE SIDE EFFECTS*:		
Surgery	 Your health care team will give you a general anesthetic (to put you to sleep) and remove the tumors or parts of it 	You may receive a temporary or permanent stoma	
Chemotherapy	 Fatigue Diarrhea Feeling and being sick Losing your hair Blood clots 	 Loss of appetite, taste changes or a sore mouth Increased risk of infection Tingling or numbness in fingers and toes Redness, swelling and pain on the palms of your hands or soles of your feet; blisters may appear 	
Radiotherapy	 Fatigue Mild skin reactions Upset stomach or loose bowel movements 	 Bloody stools from bleeding through the rectum or blockage of the bowel 	
Targeted therapy	 A rash to the face and upper body, or other skin reactions 		
Immunotherapy	 Fatigue Diarrhea Rash or itching Nausea or vomiting 	 Fever Muscle, bone, joint or abdominal pain Cough or shortness of breath Decreased appetite 	

It is likely that you will get some of the side effects listed above, but you are very unlikely to have them all. Most are temporary and can be managed by medicine or lifestyle changes.¹ Speak to your health care team as soon as you notice any side effects so they can support you.



*not an exhaustive list

HOW CAN I GET THE MOST OUT OF TREATMENT THROUGH DISCUSSIONS WITH MY HEALTH CARE TEAM?

Staying connected with your health care team during your treatment may help you benefit the most from your care.

You may wish to use the questions for yourself below to understand if you're happy with how your treatment is going:

BETWEEN APPOINTMENTS:

How well do you feel your last appointment went?

How well is your care plan working for you - given your own preferences, experiences, goals, and values?

What would you like to discuss during your next appointment?

AFTER MY APPOINTMENTS:

Did I ask everything I wanted to?

Is there anything I don't understand?

Are there any medical terms I don't understand?

If there are any medical terms you don't understand, the glossary of terms at the end of this guide is a good starting point.

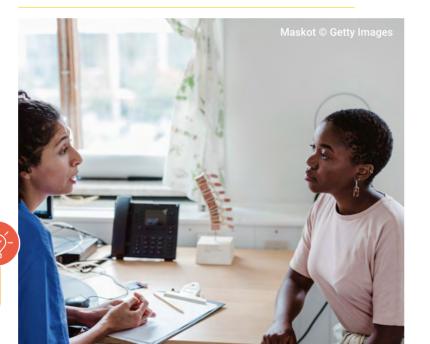
MY TREATMENT AND CARE PLAN SO FAR:

Do I understand my treatment and care plan?

Does the plan match with my personal goals and preferences?

Is my treatment working for me and do I want to continue it?

Am I experiencing any side effects, and do I know how to manage these?



WHAT IF MY TREATMENT DOESN'T WORK?

Sometimes, your treatment may not work as planned. In these cases, you and your health care team will decide whether you should try a different treatment. This is sometimes known as 'second-line' (or 'third-line' if second-line does not work) treatment and can include any of the treatments mentioned earlier in this chapter. It may also be at this point that you or your health care team consider a clinical trial.

Potentially, your health care team may believe that continuing treatment will not be beneficial for you. You can also be a part of this decision, as you know how you feel and whether this fits with your goals. You may also wish to get a second opinion from a different HCP

If you do decide that you no longer want treatment, you will then begin palliative care to manage your symptoms and ensure you are comfortable.

If I become cancer free during treatment, could my cancer come back?

ACCES

AFTER TREATMENT – WHAT HAPPENS NEXT?

When you finish treatment, it can be an emotional time. While you may feel glad or relieved, it can feel strange to have fewer hospital appointments and check-ins with your health care team.

Depending on how your treatment went, you will continue to be in contact with your health care team who will provide support to help you manage any side effects. You may also continue to have tests to monitor your cancer and see if more treatment is needed. Remember, there is no right or wrong way to feel. It can take some time to get used to your new-normal.



PSYCHOLOGICAL WELL-BEING

This chapter focuses on the importance of emotional health and understanding the different feelings you may experience. It includes practical tips to help manage different emotions and advice on seeking additional help from a professional, such as a psychologist or psychiatrist.

LOOKING AFTER YOUR EMOTIONAL HEALTH

You may feel many different emotions during your cancer journey: as you receive a diagnosis, learn to live with cancer and its symptoms, receive different treatments and experience side effects, and as the cancer potentially becomes more advanced.²⁹

It is important to remember that these feelings are normal, understandable, and many people feel the same way.

Your immediate response to diagnosis - or learning your cancer has advanced - may be shock, fear, guilt, or uncertainty about the future.³⁰ Some days, you might feel positive and ready to face your cancer head-on, but in other moments, you may not know what to do next.



DO WHAT YOU CAN TO HELP YOURSELF

Ask: How do I feel today? Then ask: What might I be able to do about this today? Practical things you could do to positively impact how you are feeling, could include:

TIP:	SUGGESTED ACTIVITIES:			
Staying connected to the people you enjoy spending time with and the things you enjoy doing	 Communicate with your loved ones Take part in group classes or activities Prioritize the things you enjoy doing, such as a hobby 			
Being kind to your body	 Eat what you can, when you can Focus on getting good quality sleep Keep moving your body 			
Lowering your stress levels	 Practice positive self-talk and mindfulness exercises Keep a journal and write down how you are feeling or any questions to ask your health care team 			

The <u>MyMood patient brochure</u> includes a diary you can use to write down your thoughts and feelings, as well as mindfulness exercises to try.

ASK OTHER PEOPLE FOR HELP

Talk to your family, friends, and other patients. Talk to a HCP.

Tell them how you feel and ask for the help you really need.

Ask: Do I need to speak to a mental health professional?

If negative feelings are significantly impacting your daily life, speaking to a mental health professional could help you to cope better.

WHAT CAN I EXPECT IF I SEE A PSYCHOLOGIST OR PSYCHIATRIST?

You can expect the person to listen to your experiences and help you understand more about how you are thinking and feeling and how you might be able to overcome these thoughts and feelings.³¹

Most mental health professionals will see patients once a week for about 45-50 minutes. Some types of therapy will last for a few sessions, while other types may continue for months or longer.³¹



\ }_)___

Join Support Groups

Consider joining a support group for people living with mCRC. Sharing your experiences and hearing about how other patients cope can be very useful.

PSYCHOLOGICAL WELL-BEING

Klaus Vedfelt © Getty Images



PHYSICAL WELL-BEING- NUTRITIONAL HEALTH

This chapter focuses on the importance of diet and nutrition with guidance on how to adapt your diet for the different challenges you may face.

It's important that you maintain a healthy and balanced diet, making sure you have an adequate intake of nutrients and calories to help keep you strong throughout your treatment and recovery.³² This can be a real challenge especially when dealing with cancer and treatment.³²

Cancer symptoms or side effects of treatment may affect your appetite, and you may not enjoy eating the way you did before.³² Your weight or bowel movements may change. These effects are common, and there are ways you can overcome these, with the right support.³²

DOES MY DIET AFFECT MY CANCER JOURNEY?

With the right guidance and support, changes to your diet and nutrition could impact:³²



How your cancer develops

Your response to treatment or surgery

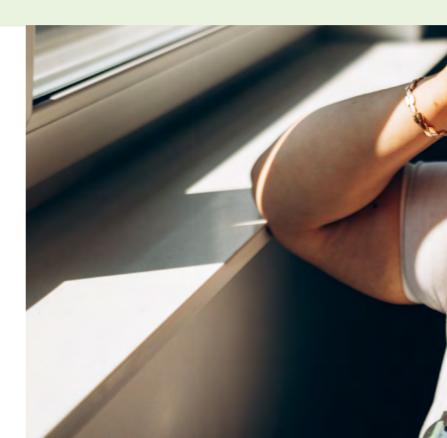


The symptoms you experience



Your quality of life and well-being

Thinking about your nutrition could help you ensure you are eating the food your body needs.



Liliya Krueger © Getty Images

TOP TIPS FOR EATING WELL WITH mCRC

Below are some of the common nutritional challenges you may experience, along with some top tips to help you manage. Always ensure you speak with your health care team before making changes to your diet.^{32,33}

ISSUE:	TIP:
Preparing for chemotherapy and radiotherapy	 Eat a light meal 2-3 hours before travelling for treatment to allow the stomach to settle Avoid fatty, greasy or spicy foods
Preparing for surgery	 High-protein foods can help you feel stronger and support your recovery, including chicken, eggs, or fish Energy-rich wholegrains like pasta, bread, and rice are also recommended
Stoma	 You may need to initially eat a low-fiber diet after a stoma procedure Try foods including low fiber carbohydrates (white rice, pasta, noodles, cereals) and peeled or cooked fruit and vegetables (avoid seeks and pith) These foods may be easier for your body to digest and may reduce discomfort from symptoms like bloating or gas
Feeding tube	 You will receive food in that contains the essential nutrients for your body If you can swallow, you might also be able to eat and drink soft foods
Low appetite	 Instead of eating three large meals per day (breakfast, lunch and dinner), you may want to have five or six meals smaller meals per day introducing three snacks (one for the morning, afternoon and evening)

ISSUE:	TIP:
Swallowing difficulties	 Try soft foods like scrambled eggs, Ensure you chew everything really v Mixing or blending foods into soups
Feeling or being sick	 Peppermint and ginger tea can help Avoiding fatty or strong-smelling for
Taste changes	Try experimenting with highly flavou or lemon juice
Diarrhea	Foods like plain chicken and well-co
Constipation	 Eat high fiber foods such as brown Try to remain well hydrated

8

For more information and guidance on adapting your diet and eating well with mCRC, see the MyFood patient brochure and MyFood mCRC video.

PHYSICAL WELL-BEING



- s, mashed potato, slow-cooked meat and vegetables **well** before swallowing ps or smoothies may also help
- Ip provide relief if you feel sick oods can also help

oured foods in your meals, like spices, marinades, vinegar, pickles

cooked vegetables may be easier to tolerate

n bread, wholegrains, fruit and vegetables



PHYSICAL WELL-BEING – PHYSICAL HEALTH

This chapter focuses on the importance of physical activity and exercise with guidance on how you can introduce movement into your everyday life.

Treatment for mCRC can make you tired and inactive; sometimes for long periods after treatment finishes. It is common to experience fatigue from your cancer or your treatment; 9 out of 10 people living with cancer are affected by this.³⁴ Pain is also common.³⁴

However, there is good evidence that people with GI cancers who do some physical exercise have a better quality of life, fewer and less severe side effects, and even a prolonged life.^{35,36}

BEFORE YOU START TO CONSIDER PHYSICAL EXERCISE, REMEMBER THE 4 PS:



PATIENCE

Be patient. Everyone is different. Remember, it will take time! Start slowly and invest in rest.



PROGRESSION

Build it up. When you feel you can, try new things. Always listen to your own body and make changes if needed.

PERSEVERANCE

Keep going. Even the smallest amount of movement can be beneficial.

HOW CAN PHYSICAL ACTIVITY HELP ME?



POSITIVE EMOTIONS

Physical activity may have a positive effect on your mood, helping with difficulties like depression or anxiety. It can also help you feel more confident and increase your independence.^{35,37,38}



HEART AND MUSCLE FITNESS

Movement can help preserve and improve your heart and muscle fitness before, during and after treatment.^{36,37,39–47}



BONE HEALTH

Resistance training (strengthening activities) can have a positive effect on your bone health.⁵³



POSITIVITY

Focus on the positives. Record what you have achieved: even if you planned a 30-minute walk and you only took one step... that's a step in the right direction.





OVERALL WELL-BEING

Physical movement can improve your overall quality of life, which includes your physical, mental, and social well-being.^{35,37}



REDUCES SIDE EFFECTS

Physical activity may reduce some side effects of cancer treatment, such as tiredness and joint pain.^{36,37,40,48-52}



SURVIVAL

Evidence shows that increased physical activity can prolong life in people with mCRC.⁵⁴

You should always check with your doctor or nurse before starting any exercise plan, particularly if you have had an operation. For example, you may need to modify your activity if you have very low iron levels, a low ability to fight infection, and/or loss of sensation in your hands and feet.55

In general, try to find a type of exercise you enjoy and take it easy.

Gentle exercise when you feel able to is recommended. If you don't want to exercise alone, you could even ask your loved ones to join you.⁵⁶⁻⁵⁸

Examples of gentle exercise to try:56-58



A short walk



Get out in the garden or go to the local park



Light housework or grocery shopping

Your health care team may also be able to refer you to a physiotherapist who can help to tailor an exercise plan based on your cancer and overall health and wellness.58

On the next page, an exercise routine has been outlined for you to try. This has been developed by a cancer and rehabilitation specialist, to help meet your needs.

For more routines and an exercise planner to record your movement day-by-day and week-by-week, the MyMove patient brochure has been developed specifically for metastatic Colorectal Cancer patients.



SIMPLE SOUAT

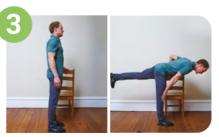
- 2.
- 3. Return by lowering arms and standing tall.

OPEN ARM STEP

Ø

- 1. Stand tall. Feet hip width apart. Palms together, in front of you at shoulder height.
- In one movement, step back on one leg and arch arms back.
- 3. Return by stepping forward and returning arms to the start position. Immediately repeat on the other side, so you are alternating legs.

Progression: Bend knees until back knee is just above floor.



LEG SLIDE

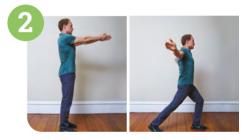
- leg backward.

line from head to toe.

PHYSICAL WELL-BEING



1. Stand tall. Feet shoulder width apart. Relax arms and shoulders. In one movement, raise both arms to shoulder height while squatting down.



1. Hold onto a chair. Stand tall. Feet hip width apart.

2. In one movement, slide hand down on the outside of leg while bringing the opposite

3. Return by sliding the hand up leg to stand tall. Perform all your exercises on one side, then repeat with the same number on the other side.

Progression: Bring the leg backwards and the torso forwards until the body is in a straight



TOUCH ACROSS

- 1. Stand tall. Feet shoulder width apart. One arm raised to one side. Look at your hand.
- 2. Keeping the raised arm straight, rotate spine and bend at the waist to touch the opposite knee. Keep looking at your hand.
- 3. Return by lifting your arm back to the starting position. Keep looking at your hand. Perfrom all your exercises on one side, then repeat with the same number on the other side.

FRONT STEP AND TURN

- 1. Stand tall. Feet hip width apart. Palms together, in front of you at shoulder height. Look at your hands.
- 2. Step forward, then twist spine to rotate arms toward and over the front leg. Keep looking at your hands.
- 3. Return arms to the center of the body and step back to the starting position. Keep looking at your hands immediately repeat on the other side, so you are alternating direction.





WALL PRESS

- 2.
- 3.

LEG BALANCE

- 1. Stand tall. Hold onto a chair. Feet hip width apart. Balance on the leg nearest the chair.
- 2. Hinge at the knee to extend your leg in front of you. Perform all your exercises on one side, then repeat with the same number on the other side.

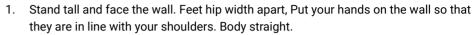
Progression: Don't hold onto the chair.

STANDING TWIST

- Stand tall. Feet hip width apart. Palms together, in front of you at shoulder height. Look at your hands.
- 2. Rotate through your spine and let your head fllow your hands.
- 3. Continue a smooth rotation to opposite side. Keep looking at your hands.

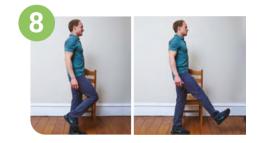
REST UP FOR ONE MINUTE. IF YOU FEEL ABLE. TRY TO COMPLETE THE ROUTINE AGAIN.

PHYSICAL WELL-BEING



Bend elbows in a push-up motion to move your body towards the wall.

Extend arms to return to the starting position.



TA

TAKE CARE

This chapter aims to provide 'beyond treatment' guidance and support for different aspects of everyday life including socializing, sex, work and finances. At the end of the chapter, there is also information on palliative care.

MANAGING RELATIONSHIPS WITH mCRC

During mCRC treatment and afterwards, you may have to change the way you live your life. But, in time, you should try to do some of the things that you enjoyed before.

An mCRC diagnosis, going through treatment and dealing with the long-term effects is stressful for you and your loved ones. You may have to stop some of the things you regularly did with family and friends for a time. Moving forward, adaptations to the things you once did can make them easier and allow you to slowly bring them back into your life.

HOW CAN I STAY SOCIAL WITH mCRC?

Most people say that remaining connected with others can help if you have mCRC or are undergoing treatment.

If meeting friends or family at a café or restaurant, you may want to check the menu in advance to make sure there is something you feel like eating or call ahead to book a table near to a toilet.



may need to make long-term adaptations to your sex life.¹⁶ Whatever your situation, be reassured you can continue intimate relations, even if you have to make some changes. Try not to be ashamed or embarrassed – communication is key.¹⁶

BODY IMAGE CONCERNS AFTER

Having a stoma can impact your body image. You

may worry about smells, leakage, and how people

a stoma care nurse specialist can help manage

will react to your stoma.⁵⁹ If you need extra support,

mCRC and treatment can put your sex life on hold for a time.

emotional or mental challenges that make you feel

Many changes are temporary, however, in some cases, you

You simply may not feel like having sex due to:16,60

embarrassed or uninterested in sex.

physical changes to your body that make sex

STOMA SURGERY

any worries.

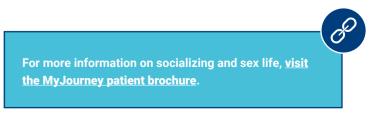
SEX LIFE WITH mCRC

uncomfortable or painful

WHAT SHOULD I DO IF I'M HAVING PROBLEMS WITH MY SEX LIFE?

If you have a partner, being open and talking about your problems can help. Showing intimacy, such as hand holding and cuddling, can help you to feel close to your partner.¹⁶

If you are single, consider speaking to a close friend or seek professional help from your health care team or a psychosexual councillor.¹⁶



WORKING WITH mCRC

mCRC or undergoing treatment can impact your work life. How much will depend on a variety of things such as the type of job you have, how you feel, both physically and emotionally, your treatment and side effects, and your financial situation; including that of those who support you.¹⁶



MAKING A DECISION ON WORK BEFORE AND DURING TREATMENT

The physical and emotional impact of treatment will be unclear. While surgery could require long periods of rehabilitation, you might still want to work if you have a different treatment. Speak to your health care team to get a better idea of how your treatment may impact work and consider relaying this information to your employer.¹⁶



Depending on your age and financial situation, working less or not at all may be an option. Often, people see this as an opportunity to retire. You could also choose to switch to part-time working and spend more time doing the things you enjoy.¹⁶



TAKE CARE



ROLE OF PATIENT ORGANIZATIONS AND PEER SUPPORT

Colorectal or general cancer patient organizations are readily available to support you and your family and friends. They often employ people or have volunteers with cancer experience and will be trained to talk to you.¹⁶

WHAT IS PEER SUPPORT?

Peer support means using first-hand experiences to help others.⁶¹ This typically means meeting other mCRC cancer patients and their loved ones to listen, share experiences, and provide useful advice.



For further information on working, managing finances, and the role of patient organizations and peer support, refer to the <u>MyJourney patient brochure</u>.

CARING FOR SOMEONE WITH mCRC?

If you are a partner, family member, or friend of a person with mCRC, there are a lot of things to consider, including the many different ways you can help. Becoming a person's caregiver can be rewarding, but it is a significant responsibility, and you will need support along the way.

WHAT DOES BEING AN mCRC PATIENT CAREGIVER MEAN?

A caregiver is someone who provides voluntary help to a person with mCRC who would be unable to manage without them.⁶²

If you decide to become a person's caregiver, you should make yourself known to the health care team as soon as possible. This means you can contact them more easily if you or the person with mCRC have any concerns.⁶²

HOW CAN I HELP?

Things you could do to help include but are not limited to:63

- attending hospital appointments to take notes and help them digest the information
- · helping the patient to take their medication correctly
- managing the patient's self-care needs, ensuring they use the facilities safely and protecting their dignity
- listening and talking to the patient about their concerns and helping them with decision-making
- assisting with financial and insurance issues.



HOW WILL MY RELATIONSHIP CHANGE WHEN I BECOME A CAREGIVER?

Having different feelings toward the person you care for is a normal part of the process. To help keep your relationship healthy:^{63,64}

- Take time to become familiar with your role. It can feel strange if the caring relationship has reversed, such as looking after a parent or grandparent.
- Be open and honest with each other. You cannot understand one another without talking about any issues.
- Let the person know they are the one in control. Try not to take away their role as the key decision-maker for as long as possible.
- Use humor where and when appropriate. This can help you both to stay positive and maintain your relationship.
- Know the boundaries of the care you give. If the person can do something safely and independently, let them do it.

TAKE CARE



HOW CAN I SUPPORT MYSELF AS A CAREGIVER?

When you are a caregiver, its important for you to look after yourself. Staying well means you can provide better care, try to: $^{65-66}$

- Take breaks from care and continue to do the things you enjoy.
- Eat well. Try to eat healthily, but also foods you like.
- Stay active. Although you will be tired, exercising can help you feel stronger.
- Get enough sleep. Night times can be especially difficult, and you may need help from others or social care if you are providing care during the night.
- Talk about how you feel. Try not to hold back your emotions – talk to family members, friends or professionals.

PALLIATIVE CARE WHAT IS PALLIATIVE CARE?

At some point in your mCRC journey, you may receive palliative care. This can happen if: $^{\rm 67}$

- symptoms or side effects related to your mCRC and treatment make it challenging for you to continue your therapy
- your cancer is incurable, meaning that it will not go away with treatment.

Palliative care is treatment that helps to reduce the impact of symptoms and improve or maintain your quality of life.⁶⁷

WHY AM I RECEIVING PALLIATIVE CARE SO SOON?

Palliative care is often mistaken with end-of-life care. Palliative care can begin at any stage during your treatment to support care, enhance quality of life, and enable you to continue your cancer treatment.^{16,67} Palliative care can be given for months or years depending on your individual circumstances.¹⁶



Understandably, this can be a very difficult for you and you loved ones. <u>The MyMood</u> and <u>MyDialogue brochures</u> may help to support your emotional health and during difficult discussions at this time.

WHAT DOES PALLIATIVE CARE INCLUDE?

As well as pain relief, anti-sickness medication, and nutritional support palliative care includes other treatments to reduce symptoms. Palliative treatments may include:^{67,68}



Palliative care also aims to fulfil your holistic needs, including psychological, social, and spiritual support.⁶⁷

You might have some side effects from palliative cancer treatments. However, the aim is to make you feel better, so your health care team will choose treatments that have as few side effects as possible.⁶⁸

TAKE CARE



WHEN SHOULD I START THINKING ABOUT PALLIATIVE CARE?

Discussions about death can be challenging. They can be perceived as negative or giving up. However, there are benefits to having palliative care discussions when you are well and able, rather than unwell, such as improved symptom control, reduced distress, and care that matches your preferences.⁶⁹

Living with mCRC can be a distressing time for you and your family, but it is important not to lose hope. Finding joy in small, everyday activities can help you to feel better about your condition. This could include making time to visit family and friends, or organising activities you enjoy. Sharing your hopes with your loved ones can also help them to make sure they are fulfilled, so you can continue living as well as possible.

If you have questions about end of life care, the SHAPE Managing End of Life Care guide can help to provide more information.



"I suspected that I had cancer because I had all the symptoms, but I was misdiagnosed for six years. Even so, it was a shock. We had so many questions to ask but got very few answers at first. It was so difficult to wait for test results. My husband and I would write down our questions together in preparation for the doctor's appointment. There were so many things to think about and get in order: applying for an early retirement, updating our will, reviewing our finances.

Cancer affects the whole family and although our sons were young adults, they shared my husband's feeling of imminent loss. Living each day, our happiest moments were when we kept life as normal as possible. Mealtimes were important, though my appetite varied a lot. We went away between treatments, enjoying each morning and resting in the afternoon. This always gave us something to look forward to and we have fond memories of these times. Above all, I really feel that what helped me the most was that I was happy and appreciated the love and care around me."

Barbara Moss, Digestive Cancers Europe

TAKE CARE



TERM:	DEFINITION	Prognosis:	an estimate of how a disease will progress
Biopsy:	a medical procedure where a small sample of tumor is taken and examined under a microscope	Radiotherapy:	a cancer treatment that uses X-rays or sim
Chemotherapy:	a drug treatment used to treat cancer by killing cells, or stopping them from growing and multiplying	Second-line treatment:	the second treatment recommended for a
Computerized tomography (CT) scan:	an imaging test that uses a series of X-rays to create images of the inside of your body, showing a tumor's shape, size, and location		treatment has failed, stopped working, or l
End-of-life care:	a type of care given to people in the final days, weeks, or months of life.	Side effects:	symptoms experienced following treatment
Genetic Testing	looks for certain changes, or mutations, in your cells. Genetic information includes genes, chromosomes, and DNA. This information can impact your health.	Somatic Testing	a type of genetic testing that looks for spe somatic cells).
Immunotherapy:	a type of treatment that helps the immune system to fight cancer.	Stent:	a small tube which opens the blockage.
Magnetic resonance imaging (MRI) scan:	an imaging test that uses strong magnetic fields to show a tumor's shape, size, and location.	Targeted therapy:	a type of treatment that targets the chang
Metastatic:	when cancer cells break away from the original tumor, spread to other organs or parts of the body and form a new tumor.	Tumor marker analysis:	a test that looks for biological signs in the therapies will work on their cancer.
Palliative care:	care that aims to improve quality of life, reducing the burden of symptoms, and is typically given when a metastatic GI cancer is incurable, but it can add value at any stage of the treatment journey as needed.	Tumor marker testing:	looks for certain substances in your body to the cancer.
Positron emission tomography- computerised tomography (PET-CT) scan	combines a CT scan with a PET scan, which uses a special type of medicine that shows up areas where cancer cells are	Ultrasound:	a test that uses high-frequency sound way
Prehabilitation:	preparation for cancer treatment.		



ess.

similar types of radiation to kill cancer cells.

or an illness, such as metastatic gastric cancer, when the first-line or has side effects that are not tolerated.

nent.

specific changes in the cells that are causing cancer (also known as

nges in cancer cells that help them grow, divide, and spread.

the blood, urine, or tissues of people with cancer to see if certain

dy that are made by cancer cells, or by other cells in response

waves to create an image of part of the inside of the body.

FURTHER INFORMATION AND SUPPORT

If you would like to find further information on mCRC, here are some recommended patient organizations you can visit:

O BIGESTIVE CANCERS

DIGESTIVE CANCERS EUROPE

Patient resources, awareness, and education https://digestivecancers.eu/



BOWEL CANCER UK

Patient resources, awareness, and education https://www.bowelcanceruk.org.uk/



REFERENCES

- ESMO. Colorectal Cancer: A Guide for Patients. 2016. Available at: <u>https://</u> www.esmo.org/for-patients/patient-guides/colorectal-cancer [Last accessed February 2024]
- NHS. Symptoms of bowel cancer. 2023. Available at: <u>https://www.nhs.uk/</u> conditions/bowel-cancer/symptoms/ [Last accessed February 2024]
- Cancer Research UK. Tests for bowel cancer. 2021. Available at: <u>https://www.cancerresearchuk.org/about-cancer/bowel-cancer/getting-diagnosed/tests</u> [Last accessed February 2024]
- American Cancer Society. Tests to Diagnose and Stage Colorectal Cancer. 2023. Available at: https://www.cancer.org/cancer/types/colon-rectal-cancer/ detection-diagnosis-staging/how-diagnosed.html#:~:text=The%20most%20 common%20tumor%20marker.screen%20for%20or%20diagnose%20cancer. [Last accessed February 2024]
- Cancer Research UK. Number stages of bowel cancer. 2022. Available at: https://www.cancerresearchuk.org/about-cancer/bowel-cancer/stages-typesand-grades/number-stages [Last accessed February 2024]
- Cancer Research UK. Symptoms of advanced bowel cancer. 2022. Available at: https://www.cancerresearchuk.org/about-cancer/bowel-cancer/advanced/ symptoms-advanced-cancer [Last accessed February 2024]
- Cancer Research UK. Risks and causes of bowel cancer. 2021. Available at: https://www.cancerresearchuk.org/about-cancer/bowel-cancer/risks-causes [Last accessed February 2024]
- NHS London North West University Healthcare NHS Trust. Inherited bowel cancer gene panel test. 2023. [Last accessed February 2024]
- Macmillan Cancer Support. Talking about your cancer diagnosis. 2019. Available at: https://www.macmillan.org.uk/cancer-information-and-support/ diagnosis/talking-about-cancer/talking-about-cancer#:~:text=You%20may%20 feel%20less%20pressure.on%200808%20808%2000%2000 [Last accessed February 2024]
- SHAPE. Getting more from your conversations with health care professionals

 for people with metastatic colorectal cancer. 2019. Available at: https://digestivecancers.eu/publication/my-dialogue-getting-more-from-your-conversations-with-health-care-professionals-for-people-with-metastatic-colorectal-cancer/ [Last accessed February 2024]
- The King's Fund. Making Shared Decision-Making a Reality. 2011. Available at: https://www.kingsfund.org.uk/sites/default/files/Making-shared-decisionmaking-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf [Last accessed February 2024]
- 12. Seattle Children's Hospital. PE2960 Somatic and Germline Cancer Testing. Available at: <u>https://www.seattlechildrens.org/globalassets/documents/for-</u>

patients-and-families/pfe/pe2960.pdf [Last accessed February 2024]

- Oncolink. Tumor Markers for Colorectal Cancer. Available at: <u>https://www.oncolink.org/cancers/gastrointestinal/color-cancer/treatments/tumor-markers-for-colorectal-cancer</u> [Last accessed February 2024]
- Cervantes A et al. Metastatic colorectal cancer: ESMO Clinical Practice Guideline for diagnosis, treatment and follow-up. Ann Oncol. 2023 Jan;34(1):10-32. doi: 10.1016/j.annonc.2022.10.003. [Last accessed February 2024]
- Cancer Research UK. Palliative Treatment. 2021. Available at: <u>https://www.cancerresearchuk.org/about-cancer/treatment/palliative</u> [Last accessed February 2024]
- SHAPE. MyJourney. 2022. Available at: <u>https://digestivecancers.eu/</u> wp-content/uploads/2022/08/ALL_Cancers_PATIENT_MyJourney-patientbrochure.pdf [Last accessed February 2024]
- Cancer Research UK. What is prehabilitation? 2021. Available at: <u>https:// www.cancerresearchuk.org/about-cancer/treatment/prehabilitation/what-isprehabilitation [Last accessed February 2024]</u>
- Macmillan Cancer Support. Preparing for bowel cancer surgery. 2020. Available at: https://www.macmillan.org.uk/cancer-information-and-support/bowelcancer/preparing-for-bowel-cancer-surgery [Last accessed February 2024]
- Cancer Research UK. Chemotherapy for advanced bowel cancer. 2022. Available at: <u>https://www.cancerresearchuk.org/about-cancer/bowel-cancer/advanced/treatment/chemotherapy-treatment</u> [Last accessed February 2024]
- Cancer Research UK. Targeted and immunotherapy drugs for advanced bowel cancer. 2023. <u>https://www.cancerresearchuk.org/about-cancer/bowel-cancer/ advanced/treatment/targeted-cancer-drugs-treatment</u> [Last accessed February 2024]
- Cancer Research UK. Having radiotherapy for advanced bowel cancer. 2022. Available at: <u>https://www.cancerresearchuk.org/about-cancer/bowel-cancer/advanced/treatment/radiotherapy/having-radiotherapy</u> [Last accessed February 2024]
- American Cancer Society. Surgery for Colon Cancer. 2020. Available at: https://www.cancer.org/cancer/types/colon-rectal-cancer/treating/colon-surgery.html [Last accessed February 2024]
- Cancer.net. What to Expect When Having Chemotherapy. 2021. Available at: <u>https://www.cancer.net/navigating-cancer-care/how-cancer-treated/ chemotherapy/what-expect-when-having-chemotherapy</u> [Last accessed February 2024]
- Cancer Research UK. Side effects of radiotherapy for advanced bowel cancer. 2022. <u>https://www.cancerresearchuk.org/about-cancer/bowel-cancer/advanced/treatment/radiotherapy/side-effects</u> [Last accessed February 2024]

- American Cancer Society. Targeted Therapy Side Effects. 2020. Available at: https://www.cancer.org/cancer/managing-cancer/treatment-types/targetedtherapy/side-effects.html [Last accessed February 2024]
- Cancer Council. Understanding Immunotherapy. Available at: https://www. cancer.org.au/assets/pdf/understanding-immunotherapy-fact-sheet [Last accessed February 2024]
- American Cancer Society. If You Have Colon or Rectal Cancer. 2020. Available at: https://www.cancer.org/cancer/types/colon-rectal-cancer/if-you-have-colonrectal-cancer.html#:~:text=ln%20most%20cases%2C%20colon%20and,it%20 from%20turning%20into%20cancer [Last accessed February 2024]
- Cancer.net. Hand-Foot Syndrome or Palmar-Plantar Erythrodysesthesia. Available at: <u>https://www.cancer.net/coping-with-cancer/physical-emotional-and-social-effects-cancer/managing-physical-side-effects/hand-foot-syndrome-or-palmar-plantar-erythrodysesthesia</u> [Last accessed February 2024]
- National Institutes of Health. Feelings and Cancer. 2023. Available at: <u>https://</u> www.cancer.gov/about-cancer/coping/feelings [Last accessed February 2024]
- Macmillan Cancer Support. Cancer and your emotions. 2019. Available at: <u>https://www.macmillan.org.uk/cancer-information-and-support/treatment/</u> <u>coping-with-treatment/cancer-and-your-emotions</u> [Last accessed NFebruary 2024]
- 31. Cancer Research UK. What is counselling? 2022 Available at: <u>https://www.cancerresearchuk.org/about-cancer/coping/mental-health-cancer/counselling/what-is-counselling</u> [Last accessed February 2024]
- 32. SHAPE. MyFood. 2022. Available at: https://digestivecancers.eu/publication/ eating-well-with-gastrointestinal-cancer/ [Last accessed February 2024]
- Bowel Cancer UK. Eating well A guide to diet and bowel cancer. 2023. Available at: <u>https://bowelcancerorguk.s3.amazonaws.com/Publications/EatingWell_ BowelCancerUK.pdf</u> [Last accessed February 2024]
- Macmillan. Tiredness (fatigue). 2018. Available at: <u>https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/tiredness</u> [Last accessed February 2024]
- Mishra SI, Scherer RW, Geigle PM, et al. Exercise interventions on healthrelated quality of life for cancer survivors. Cochrane Database Syst Rev. 2012;8:CD007566. [Last accessed February 2024]
- Dittus KL, Gramling RE, Ades PA. Exercise interventions for individuals with advanced cancer: A systematic review. Prev Med. 2017;104:124-132. [Last accessed February 2024]
- Fong DY, Ho JW, Hui BP, et al. Physical activity for cancer survivors: metaanalysis of randomised controlled trials. BMJ 2012;344:e70. [Last accessed February 2024]

- Craft LL, Vaniterson EH, Helenowski IB, et al. Exercise effects on depressive symptoms in cancer survivors: a systematic review and metaanalysis. Cancer Epidemiol Biomarkers Prev. 2012;21(1):3-19. [Last accessed February 2024]
- Cavalheri V, Granger C. Preoperative exercise training for patients with nonsmall cell lung cancer. Cochrane Database Syst Rev. 2017;6:CD012020. [Last accessed February 2024]
- Furmaniak AC, Menig M, Markes MH. Exercise for women receiving adjuvant therapy for breast cancer. Cochrane Database Syst Rev. 2016;9:CD005001. [Last accessed February 2024]
- Baumann FT, Zopf EM, Bloch W. Clinical exercise interventions in prostate cancer patients – a systematic review of randomized controlled trials. Support Care Cancer. 2012;20(2):221-233. [Last accessed February 2024]
- van Haren IE, Timmerman H, Potting CM, et al. Physical exercise for patients undergoing hematopoietic stem cell transplantation: systematic review and meta-analyses of randomized controlled trials. Phys Ther. 2013;93(4):514-528. [Last accessed November February 2024]
- Van Moll CC, Schep G, Vreugdenhil A, Savelberg HH, Husson O. The effect of training during treatment with chemotherapy on muscle strength and endurance capacity: a systematic review. Acta Oncol. 2016;55(5):539-546. [Last accessed November February 2024]
- Stene GB, Helbostad JL, Balstad TR, Riphagen II,Kaasa S, Oldervoll LM. Effect of physical exercise on muscle mass and strength in cancer patients during treatment: a systematic review. Crit Rev Oncol Hematol. 2013;88(3):573-593. [Last accessed February 2024]
- Gardner JR, Livingston PM, Fraser SF. Effects of exercise on treatment-related adverse effects for patients with prostate cancer receiving androgen deprivation therapy: a systematic review. J Clin Oncol. 2014;32(4):335-346. [Last accessed February 2024]
- Cavalheri V, Tahirah F, Nonoyama M, Jenkins S, Hill K. Exercise training undertaken by people within 12 months of lung resection for non-small cell lung cancer. Cochrane Database Syst Rev. 2013;7:CD009955. [Last accessed February 2024]
- Quist M, Adamsen L, Rørth M, Laursen JH, Christensen KB, Langer SW. The impact of a multidimensional exercise intervention on physical and functional capacity, anxiety, and depression in patients with advanced stage lung cancer undergoing chemotherapy. Integr Cancer Ther. 2015;14(4):341-349. [Last accessed February 2024]
- Adams SC, Segal RJ, McKenzie DC, et al. Impact of resistance and aerobic exercise on sarcopenia and dynapenia in breast cancer patients receiving adjuvant chemotherapy: a multicenter randomized controlled trial. Breast

Cancer Res Treat. 2016;158(3):497-507. [Last accessed February 2024]

- Cramp F, Byron-Daniel J. Exercise for the management of cancer-related fatigue in adults. Cochrane Database Syst Rev. 2012;11:CD006145.
- Capozzi LC, Nishimura KC, McNeely ML, Lau H, Culos-Reed SN. The impact of physical activity on health-related fitness and quality of life for patients with head and neck cancer: a systematic review. Br J Sports Med. 2016;50(6):325-338.
 Macmillan Cancer Support. Looking after someone with cancer. 2019. Available at: <a href="https://www.macmillan.org.uk/cancer-information-and-support/su
- Irwin ML, Cartmel B, Gross CP, et al. Randomized exercise trial of aromatase inhibitor-induced arthralgia in breast cancer survivors. J Clin Oncol. 2015;33(10):1104-1111.
- Jensen W, Baumann FT, Stein A, et al. Exercise training in patients with advanced gastrointestinal cancer undergoing palliative chemotherapy: a pilot study. Support Care Cancer. 2014;22(7):1797-806.
- Rief H, Petersen LC, Omlor G, et al. The effect of resistance training during radiotherapy on spinal bone metastases in cancer patients: a randomized trial. Radiother Oncol. 2014;112(1):133-139.
- Guercio BJ, Venook AP, Niedzwiecki D, et al. Association of physical activity with survival and progression in metastatic colorectal cancer: results from CALGB 80405 (Alliance). ASCO Gastrointestinal Cancer Symposium 2017. J Clin Oncol. 2017;35(suppl 48):abstract 659.
- Rock C, Doyle C, Demark-Wahnefried W, et al. Nutrition and physical activity guidelines for cancer survivors. CA Cancer J Clin. 2012;62(4):243-274.
- SHAPE. MyMove. 2019. Available at: <u>https://digestivecancers.eu/publication/a-practical-guide-to-moving-more-for-people-with-metastatic-colorectal-cancer/</u> [Last accessed February 2024]
- Bowel Cancer UK. Physical activity. 2019. Available at: <u>https://www. bowelcanceruk.org.uk/about-bowel-cancer/living-with-and-beyond-bowelcancer/physical-wellbeing/physical-activity/#:~:text=Build%20up%20to%20 at%20least,like%20running%2C%20cycling%20or%20swimming. [Last accessed February 2024]
 </u>
- Cancer Council. Exercise for People Living with Cancer. 2019. Available at: https://www.cancer.org.au/assets/pdf/exercise-for-people-living-with-cancer [Last accessed February 2024]
- 59. Cancer Research UK. Coping with a stoma. 2022. Available at: <u>https://www.cancerresearchuk.org/about-cancer/bowel-cancer/living-with/having-stoma</u> [Last accessed February 2024]
- 60. Macmillan Cancer Support. Sex and cancer. 2019. Available at: <u>https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/sex-and-cancer</u> [Last accessed February 2024]

- Mind. Peer support. 2019. Available at: <u>https://www.mind.org.uk/information-support/drugs-and-treatments/peer-support/about-peer-support/</u> [Last accessed February 2024]
- Cancer Research UK. How to support someone with cancer. 2021. Available at: <u>https://www.cancerresearchuk.org/about-cancer/coping/family-friendscaregivers/how-support-someone-with-cancer [Last accessed February 2024]</u>
- Macmillan Cancer Support. Your relationships as a carer. 2019. Available at: https://www.macmillan.org.uk/cancer-information-and-support/supportingsomeone/emotional-support-for-carers/your-relationships-as-a-carer [Last accessed February 2024]
- Macmillan Cancer Support. Looking after yourself as a carer. 2019. Available at: https://www.macmillan.org.uk/cancer-information-and-support/supportingsomeone/emotional-support-for-carers/looking-after-yourself-as-a-carer [Last accessed February 2024]
- Cancer Research UK. Taking care of yourself. 2021. Available at: <u>https://www.cancerresearchuk.org/about-cancer/coping/family-friends-caregivers/taking-care-of-yourself#:~:text=Eat%20well%20%E2%80%93%20try%20to%20eat,if%20it%20is%20a%20problem.</u> [Last accessed February 2024]
- 67. Bowel Cancer UK. Palliative care. 2016. Available at: <u>https://www.</u> bowelcanceruk.org.uk/about-bowel-cancer/advanced-bowel-cancer/treatingadvanced-bowel-cancer/palliative-care/ [Last accessed February 2024]
- Cancer Research UK. Palliative Treatment. 2021. Available at: <u>https://www.cancerresearchuk.org/about-cancer/treatment/palliative</u> [Last accessed February 2024]
- Howie L and Peppercorn J. Early palliative care in cancer treatment: Rationale, evidence and clinical implications. Ther Adv Med Oncol. 2013;5:318-323. Available at: <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3799294/</u>. [Last accessed February 2024]

This guide is part of the Support Harmonized Advances for better Patient Experience (SHAPE) initiative that is supported by an unrestricted grant from Servier.

Pictogram credits: iStock/Getty Images Plus & Getty Images DigitalVision Vectors





