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**Guiding you through  
the different stages of  
living with metastatic  
gastrointestinal cancer**

MyJourney Program



# Contents list

Welcome to MyJourney	1	Beyond treatment:	
.....		Living well with GI cancer	22
Glossary of terms	2	– Eating with GI cancer	24
.....		– Exercising with GI cancer	26
What your metastatic GI cancer journey may look like	4	– Socializing with GI cancer	29
.....		– Sex life with GI cancer	30
What does a metastatic GI cancer diagnosis mean?	6	– Working with GI cancer	32
– Thoughts and feelings at diagnosis	8	– Managing finances with GI cancer	34
– Explaining your diagnosis to loved ones	10	.....	
.....		Family, friends, and carers:	
Treatment	14	My role as a GI cancer caregiver	36
– Before treatment	14	– My relationship as a caregiver	38
– Treatment and side effects	15	– Support for caregivers	40
.....		– Role of patient organizations and peer support	42
The health care professionals who will support you along the way	16	.....	
.....		Palliative care	46
Getting the most out of your health care team and treatment	18	.....	
– Getting a second opinion	19	Key contacts in your multidisciplinary team	48
– Clinical trials	20	.....	
.....		Resources	49
		.....	
		References	50
		.....	

# Welcome to MyJourney

**MyJourney is part of the Support Harmonized Advances for better Patient Experiences (SHAPE) program: an international, multi-stakeholder initiative that aims to transform the lives of patients with metastatic gastrointestinal (GI) cancer.**

When you receive a metastatic GI cancer diagnosis (including colorectal, gastric and pancreatic cancer), you are at the beginning of a new period of your life. You are unlikely to have experienced anything similar to this before, and your everyday life will change significantly.

You may be unsure of what your diagnosis means, what your treatment will look like or which health care professionals (HCPs) you will meet along your journey. Beyond treatment, worrying about how your life and that of your loved ones will change, from work to socializing and relationships, is normal. Ultimately, the course of your cancer and the impact on your survival may be your main concern.

Whatever your worries or fears, let's look forward together to see how you can begin your new life.

While everyone's experience of metastatic GI cancer is unique, the

changes caused by metastatic cancer will progress in a generally similar way with key stages that could be relevant to you, including:

- diagnosis, staging, and treatment decision-making
- treatment and review
- monitoring and remaining well or recurrence / progression
- for some, the need for further treatment or decisions about the future.

Each step will result in different experiences and trigger a range of emotions. The MyJourney brochure is designed to help guide and support you, your family, friends, and caregivers along the way, providing a clearer picture of what the future might hold for you.

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# Glossary of terms

The following glossary contains explanations of medical terms used in this brochure.

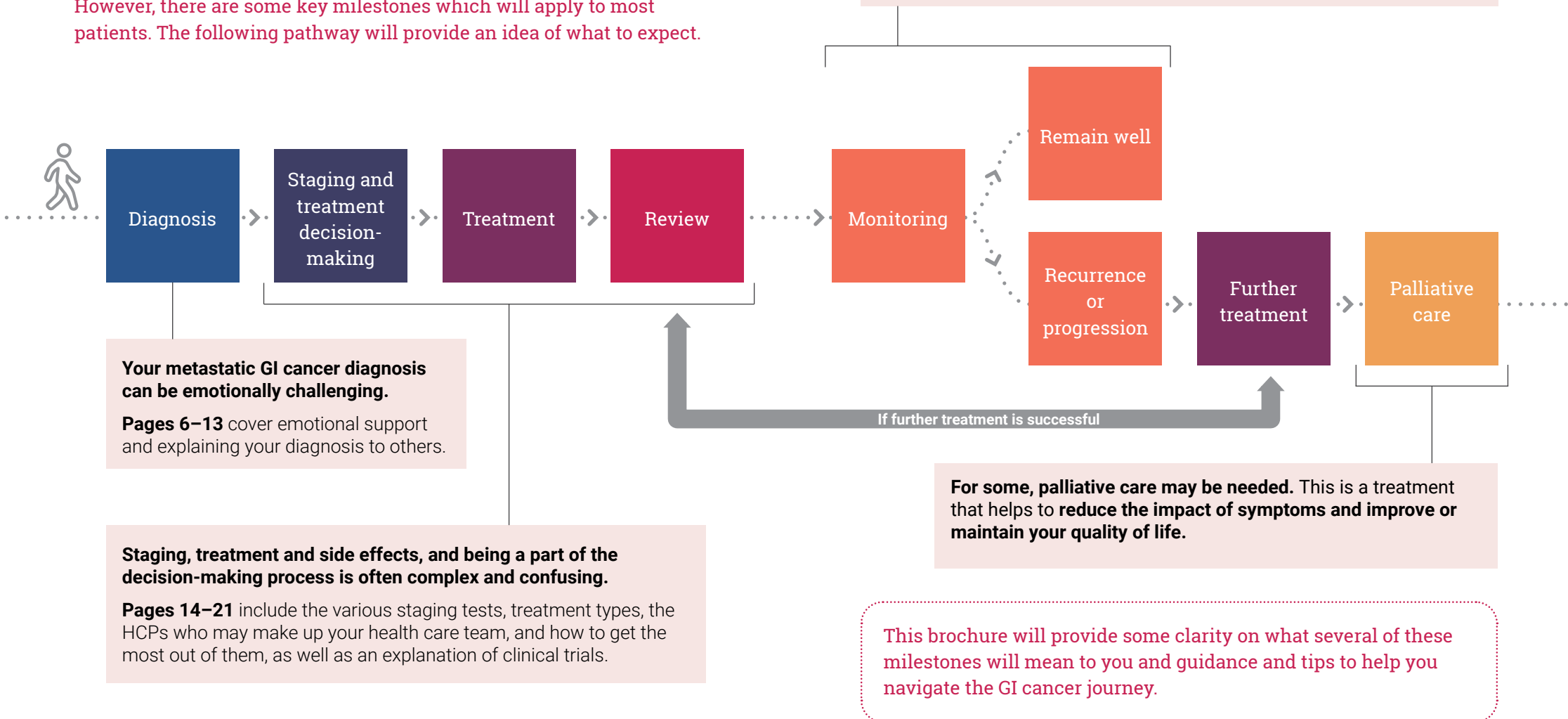
<b>Biopsy:</b>	a medical procedure where a small sample of tumor is taken and examined under a microscope
<b>Chemotherapy:</b>	a drug treatment used to treat cancer by killing cells, or stopping them from growing and multiplying
<b>Computerized tomography (CT) scan:</b>	an imaging test that uses a series of X-rays to create images of the inside of your body, showing a tumor's shape, size, and location
<b>End-of-life care:</b>	a type of care given to people in the final days, weeks, or months of life
<b>First-line treatment:</b>	the first treatment recommended for an illness such as metastatic GI cancer
<b>Gastrointestinal (GI) cancer:</b>	relating to cancers of the digestive system, including the stomach, pancreas, intestines, colon, and rectum
<b>Immunotherapy:</b>	a type of treatment that helps the immune system to fight cancer
<b>Magnetic resonance imaging (MRI) scan:</b>	an imaging test that uses strong magnetic fields to show a tumor's shape, size, and location
<b>Metastatic:</b>	when cancer cells break away from the original tumor, spread to other organs or parts of the body and form a new tumor
<b>Palliative care:</b>	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

<b>Positron emission tomography (PET) scan:</b>	an imaging test that helps reveal the location and size of a tumor
<b>Radiotherapy:</b>	a cancer treatment that uses X-rays or similar types of radiation to kill cancer cells
<b>Second-line treatment:</b>	the second treatment recommended for an illness, such as metastatic GI cancer, when the first-line treatment has failed, stopped working, or has side effects that are not tolerated
<b>Stoma surgery:</b>	a type of surgery that diverts the bowels through an opening in the tummy
<b>Targeted therapy:</b>	a type of treatment that targets the changes in cancer cells that help them grow, divide, and spread
<b>Tumor marker analysis:</b>	a test that looks for biological signs in the blood, urine, or tissues of people with cancer to see if certain therapies will work on their cancer



# What your metastatic GI cancer journey may look like

Every metastatic GI cancer patient is unique, which makes it challenging to provide a clear roadmap of what the future will hold. However, there are some key milestones which will apply to most patients. The following pathway will provide an idea of what to expect.







# What does a metastatic GI cancer diagnosis mean?

Metastatic GI cancer is cancer that has spread from the GI tract (the passage from mouth to anus) to other parts of the body. It is also sometimes called advanced, stage 4/IV or secondary GI cancer. This brochure will specifically focus on three types of metastatic GI cancer.



## Metastatic colorectal cancer (mCRC)

mCRC is a cancer that originally developed in the large intestine, and the tumor has spread to other parts of the body.<sup>1</sup> Colorectal cancer is the third most commonly diagnosed cancer globally, responsible for approximately 10% of all cancer cases.<sup>2</sup>



## Metastatic gastric cancer (mGC)

mGC is a cancer that originally developed in the stomach, and the tumor has spread to other parts of the body.<sup>3</sup> Globally, gastric cancer is the fifth most frequently diagnosed cancer.<sup>2</sup>



## Metastatic pancreatic cancer (mPaC)

mPaC is a cancer that originally developed in the pancreas, and the tumor has spread to other parts of the body.<sup>4</sup> Pancreatic cancer is the fourteenth most frequently diagnosed cancer worldwide.<sup>2</sup>

For more specific information on your metastatic GI cancer, including symptoms, please refer to the relevant condition-specific leaflet.

[\[insert download links here\]](#)





## The journey begins: Thoughts and feelings at diagnosis

When you receive a cancer diagnosis, you and your loved ones will have many different feelings, thoughts, and questions. You may have been feeling unwell for some time and have had several clinic visits and tests, or this news may be a complete shock to you.

It is normal for you to feel anger, guilt, sadness, and uncertainty. A diagnosis of metastatic cancer can intensify these feelings further and make you feel like your life is out of control.

**Everyone will react to the news of their diagnosis differently.** At points, you will feel anxious or stressed. These can result in physical symptoms, like tiredness, shortness of breath, or lack of sleep.<sup>5</sup> **You should try not to rely only on information found online, as this is not always correct and can be confusing and frustrating.**

Your health care team can help you in many different ways if you are struggling to cope. There are also some key things that you can do to help you feel better about the situation.<sup>5,6</sup>



**Look after yourself.**  
Unhealthy behaviors, like heavy drinking or drug use, will make you feel worse.



**Find time to do the things you enjoy.**



**Practice mindfulness**  
to help you relax.



**Eat healthily, do some exercise and get a good amount of sleep.**

However you may feel, give yourself time to think over your diagnosis. You can do this on your own or with the support of your family and friends. If you find it difficult to speak to your family, there are specialists such as psychologists and psycho-oncologists that can help. Whoever you choose, try to find someone to talk to about how you feel.

**For more information and support on how to look after your emotional health, please see the SHAPE MyMood brochure**

[https://www.digestivecancers.eu/wp-content/uploads/2020/07/MyMood\\_Patient.pdf](https://www.digestivecancers.eu/wp-content/uploads/2020/07/MyMood_Patient.pdf)



## Diagnosis checklist

The following list contains some common considerations and priorities for people who have been newly diagnosed with metastatic GI cancer. Although not all of these will be relevant or appropriate for you, some may help you to organize yourself in the days and weeks after your diagnosis:

Have you considered what help you will need at home?



Have you informed your employer of your diagnosis?



Have you informed your health insurance provider?



Have you considered child support?



Have you written your will?





## Taking the first step: Explaining your diagnosis to loved ones

Once you've had time to personally reflect, the next step is to consider if and how you will share this news with those close to you. Although difficult, letting people who you trust know about your diagnosis can help you feel better supported.

### Sharing your problems: Why talking about your diagnosis can help

As well as getting more support, talking about your cancer can help you to:<sup>7</sup>

- understand your feelings and be reassured that they are normal
- feel more in control
- make important decisions
- feel less anxious.



### Before the conversation, try:<sup>7</sup>



**thinking who you would be comfortable speaking with**



**taking a paper and pen with you so you can write down any questions**



**considering how much you would like to talk about your diagnosis. It's fine to revisit the conversation later.**

### During the conversation, try:<sup>8</sup>

**beginning the discussion steadily 'I have something to say, which is not going to be easy...'**

**clarifying what they already know about cancer**

**giving the information in small sections and regularly check if they understand.**

### Speaking to young children and grandchildren

How much children will understand will depend on their age. It can help them if you explain it is not their fault, and they cannot catch cancer from you. Being honest and including them in what's happening is usually the best approach.



If talking to family or friends is not an option, there are many other people you can contact, whether in person, talking over the phone, or chatting online.

**You could speak to:**

- **cancer charities and patient organizations**, both general and GI cancer specific. Family and friends can also receive support from these groups. Pages 30 & 31 provide more on this.
- **other patients, called 'peer support'** (see pages 30 & 31 for more details).
- **your health care team, family doctor, oncology nurse, or a community nurse service** who answer many of your questions, even those not directly related to your treatment. Other specialists, such as psychologists and psycho-oncologists, could also be available to you.
- a **religious leader** for spiritual support.



## Not ready to talk yet?



Feeling like you don't want to talk about your diagnosis is normal too. It's important that you give yourself some time to absorb and reflect on this news. You may just want to carry on your life as normal.

If you don't feel ready to talk, you could think of ways to talk to people if they ask you about your cancer:

*"Thanks for asking. I'm not ready to talk about it right now, but I will reach out to you when I am."*

However, at some point, it's advised that you speak to someone about your GI cancer diagnosis, as this can help you make decisions on your treatment and improve your relationships with family and friends.<sup>7</sup>





## Reaching an important milestone: Treatment

Starting treatment for your metastatic GI cancer is an important moment. Receiving care for your symptoms can be relieving, but it can also be a scary prospect.

Every GI cancer patient is different. This means that some treatments will be suitable, whereas others are not. The best treatment or combinations of treatment for you will depend on a variety of things, including:

- the type of metastatic GI cancer you have
- the size, quantity, and location of tumors
- if your cancer has certain characteristics
- how you have responded to any previous cancer treatments.

### Before treatment

As part of your diagnosis, you will likely have numerous tests to understand the location, size, and what treatment might be best for the cancer, known as 'staging'. These tests can include computerized tomography (CT), magnetic resonance imaging (MRI), and positron emission tomography (PET) scans.<sup>9</sup> You may also require a biopsy to confirm the cancer and where it originally came from.

As well as confirming the size and location of the tumors, these tests will show your health care team which treatments will work best on your cancer.

Your doctor may have also taken a sample of your cancer cells or your blood to determine the molecular profile of your cancer. This is known as **tumor marker analysis**.

If your GI cancer contains certain 'markers', also known as mutations, some newer treatment options called targeted therapies could be available to you. These drugs target specific processes involved in the growth of cancer cells with the aim of shrinking or stopping the growth of tumors.

## Treatment

The following flow chart shows the general treatment process for metastatic GI cancer, although it will be highly individual to each patient.<sup>10–12</sup>

### First-line 'systemic' treatment

- chemotherapy, radiotherapy, targeted therapy, or immunotherapy
- combination of any of the above.

### Second-line treatment

Depending upon the response to first-line treatment, this can include:

- surgery to remove part, or all of the tumors
- further chemotherapy
- further radiotherapy
- further targeted therapy.

### Deviations from this could include:

- emergency surgery if the tumors obstruct other parts of the body
- radiotherapy for metastatic rectal cancer.

Treatment for metastatic GI cancer regularly evolves and there are many different treatments and combinations of treatments currently being researched. For the latest information on treatment visit the ESMO Cancer Guides for Patients (<https://www.esmo.org/for-patients/patient-guides>).

### Side effects

Side effects of metastatic GI cancer treatment are common, and their type and severity will depend upon many factors such as the type of treatment, the type of cancer, and the individual.

Your health care team will notify you of any expected side effects of treatment and help you to manage them.

To learn more about the different metastatic GI cancer treatments and their side effects, please refer to the relevant condition-specific leaflet: [\[insert download links here\]](#)



# Meet the team: The health care professionals who will support you along the way

You are not alone on this journey. In fact, you will be partnered with a variety of highly specialized and expert HCPs. These will differ depending on the type of GI cancer you have, where your cancer has spread to, and the type of treatments you have.



Your team of HCPs will work together to discuss your treatment and care. This is often called a multidisciplinary team and will typically include:

Clinical oncologist	A doctor who specializes in treating cancer patients
Surgeon	A doctor who specializes in performing surgery – typically GI or further specialist surgeons if the cancer has spread to other areas
GI cancer clinical nurse specialist (case manager)	A nurse who specializes in caring for GI cancer patients. This HCP will likely be your first point of contact and know your case well
Radiologist	A doctor who specializes in using X-rays and other screening machines to locate and measure cancer and guide treatments
Radiotherapist	An HCP who specializes in using high-energy rays to treat cancer
Gastroenterologist	A doctor who specializes in investigating, diagnosing, and treating diseases of the stomach, intestines, and pancreas etc.
Pathologist	A doctor or clinical scientist who will interpret the changes in your tumor before, during, and after your treatment
Dietitian and nutritionist	HCPs who specialize in supporting you to eat and drink well and maintain a healthy weight
Clinical psychologist	An HCP who specializes in supporting you emotionally
Psycho-oncologist	An HCP with a similar role to a clinical psychologist but with a focus on the cancer experience for patients and their loved ones
Physiotherapist	An HCP who specializes in helping you to regain strength and mobility after treatment, particularly surgery
Occupational therapist	An HCP who specializes in helping you regain independence after treatment
Counsellor	A professional who uses non-medical techniques to support your emotional needs

An address book can be found at the back of this brochure, which you may wish to fill out with your key health care contact details



## Getting the most out of your health care team and treatment

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

**Shared decision-making** is the conversation between patient and HCPs to make health decisions together. This considers both the preferences and goals of the patient as well as the expertise and knowledge of the HCPs.<sup>13</sup>

**For example**, you may wish to maximize your time with family and friends. Bearing your preference in mind, your health care team will try to offer you a treatment that allows that while also keeping you comfortable and reducing the burden of symptoms.

**You are free to participate in shared decision-making as much as you want. You can also decide to leave choices to your HCPs.** Whatever you choose, there are ways you can prepare for your appointments as time with HCPs is a valuable opportunity to ask questions.

For more information on shared decision-making and getting the most out of your consultations, see the SHAPE MyDialogue brochure.

### Getting a second opinion

**Your treatment plan will be decided by an experienced group of HCPs. However, you may want a second opinion from another HCP. While some HCPs may encourage you to look for a second opinion, it is not always necessary or possible, so think carefully before asking about a second opinion using the information below.**

#### Getting a second opinion can:

- confirm your diagnosis or treatment you've been offered
- enable you to take part in a clinical trial if you are eligible
- help find a doctor that best suits you.

#### The advantages of getting a second opinion are:

- reassurance that different doctors agree on your diagnosis and treatment
- access to different treatment options.

#### The disadvantages of getting a second opinion are:

- delays to starting your treatment
- receiving conflicting information
- having to travel to different (sometimes foreign) hospitals.







## Clinical trials: What are they and how you can be involved

### A clinical trial is:

a study which compares currently used treatments with experimental treatments to find more effective and safer treatments.

### Your doctor is recommending a clinical trial because:

they may believe that the experimental treatment has a chance of improving your outcomes better than currently available therapies.

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

#### The possible benefits of joining a clinical trial are:

- receiving a treatment that is more effective than the current standard treatment
- free treatment and care
- close monitoring by HCPs and more opportunities for questions
- contributing to important research that can help other cancer patients in the future.

#### The possible risks of joining a clinical trial are:

- receiving a treatment that is no better, or less effective, than the standard treatment
- having unexpected side effects or side effects that are worse than the standard treatment
- needing extra tests, which could be uncomfortable or time consuming
- exclusion from other treatments after the trial even if the trial treatment did not work for you
- travelling to different hospitals, or even different countries, to take part in the trial.



Speak to your health care team if you are interested in taking part in a clinical trial



## Beyond treatment: Living well with GI cancer

When your treatment finishes, this is the beginning of a new stage; a time to try and do the things you enjoy, see friends and family, or just relax after the stresses of treatment. However you feel, this is now your time to take part in whatever activities you choose.

It is important that following your GI cancer treatment you look after yourself as well. There is evidence to show that people with cancer who eat healthily and exercise have better outcomes and quality of life.<sup>14–16</sup>

Treatment is physically and emotionally draining with sometimes long recovery times. Additionally, you might have concerns about your cancer and the side effects of treatment and how these could impact your future.

The following pages give advice on:



**eating well  
and exercising**



**continuing to  
socialize with your  
family and friends**



**maintaining  
your sex life**



**choosing how much to  
work, or if you would like  
to take a break or retire**



**managing  
your finances.**

**“** My own journey started with the diagnosis of esophageal cancer, but after treatment I felt that the journey was going to be a lifelong one with many hurdles along the way. I was relieved when the treatment was over, but it was terrifying for me as a patient (and for my wife as well) to think what the future would be living with cancer.

My biggest worry was knowing where to look for the right information from the right people who understood and knew what was in front of me, especially what changes in life I needed to make after surgery to live as well as I could. First was a new routine of eating little and often to make sure I was eating healthily, and to exercise by taking a walk each day. **”**

**Dave Chuter**, Patient

**“** When my treatment finished, I felt so relieved. It was like a huge weight fell off my shoulders and I felt gratitude and happiness. I finally could take deep breaths and feel alive – the sun started to shine again! I couldn't believe it was behind me.

But I knew I had to make changes to my daily routine to help improve my quality of life and stay healthy. I changed my diet to a healthier one, I started going on walks everyday – no matter the weather. I've also become very organized and started taking my medical files (in electronic format) on every trip – just in case! I've created my yearly routine with medical 'check points' so I know everything is okay. And I've also started therapy, which has helped take care of my mental health in the best way possible. **”**

**Pat Rzakowska**, Patient





## Eating with GI cancer

### Importance of eating well with metastatic GI cancer

Metastatic GI cancer and treatment for it can impact your diet in multiple ways, but it is important that you try and eat well, and there are ways you can overcome some of these challenges.

You are likely to have cancer symptoms that will make it difficult to eat, such as problems with swallowing or side effects of treatment that affect your appetite or weight. In fact, as many as 8 in 10 people with cancer will struggle to get the right nutrients or take in enough calories.<sup>17,18</sup>

While diet alone will not cure your cancer or prevent it from returning, eating a healthy and balanced diet and maintaining your body weight can help you to stay strong, reduce your risk of infection, cope better with side effects of treatment, and recover from therapy.<sup>14</sup>

### What should I be eating as a balanced diet?

A balanced diet is high in healthy proteins (such as fresh chicken, lentils or fish), fruits and vegetables, and wholegrains (like brown pasta or rice).<sup>19</sup>

### How can treatment affect my diet?

Different treatments may affect your diet in different ways. For example:

- **chemotherapy, radiotherapy, or targeted therapies** can make your mouth and throat sore, cause nausea, or change your sense of taste or smell<sup>20</sup>
- **surgery** can make it harder for you to digest certain foods<sup>14</sup>
  - eating smaller meals more often can help with this.

### Who should I speak to if I have diet concerns?

Your health care team will provide you with specialized nutritional advice that is appropriate for your treatment plan. Speak to a dietitian if you have any specific issues or questions.



For more information on diet and nutrition with GI cancer, as well as tips and tricks and GI cancer-friendly recipes, please see the SHAPE MyFood brochure.



## Exercising with GI cancer

### Keeping active with GI cancer

Treatment for GI cancer 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.<sup>21</sup> Pain is also common.

However, there is good evidence that people with GI cancer who do some physical exercise have a better quality of life, fewer and less severe side effects, and even a prolonged life.<sup>15,16</sup>

#### How can I get active again?

You should start easy and slowly build up your activity. Walking is a good start to keeping active during or after treatment; around the room, house, or garden until you get your strength back. Try to avoid sitting or lying down for long periods of time.<sup>22</sup>

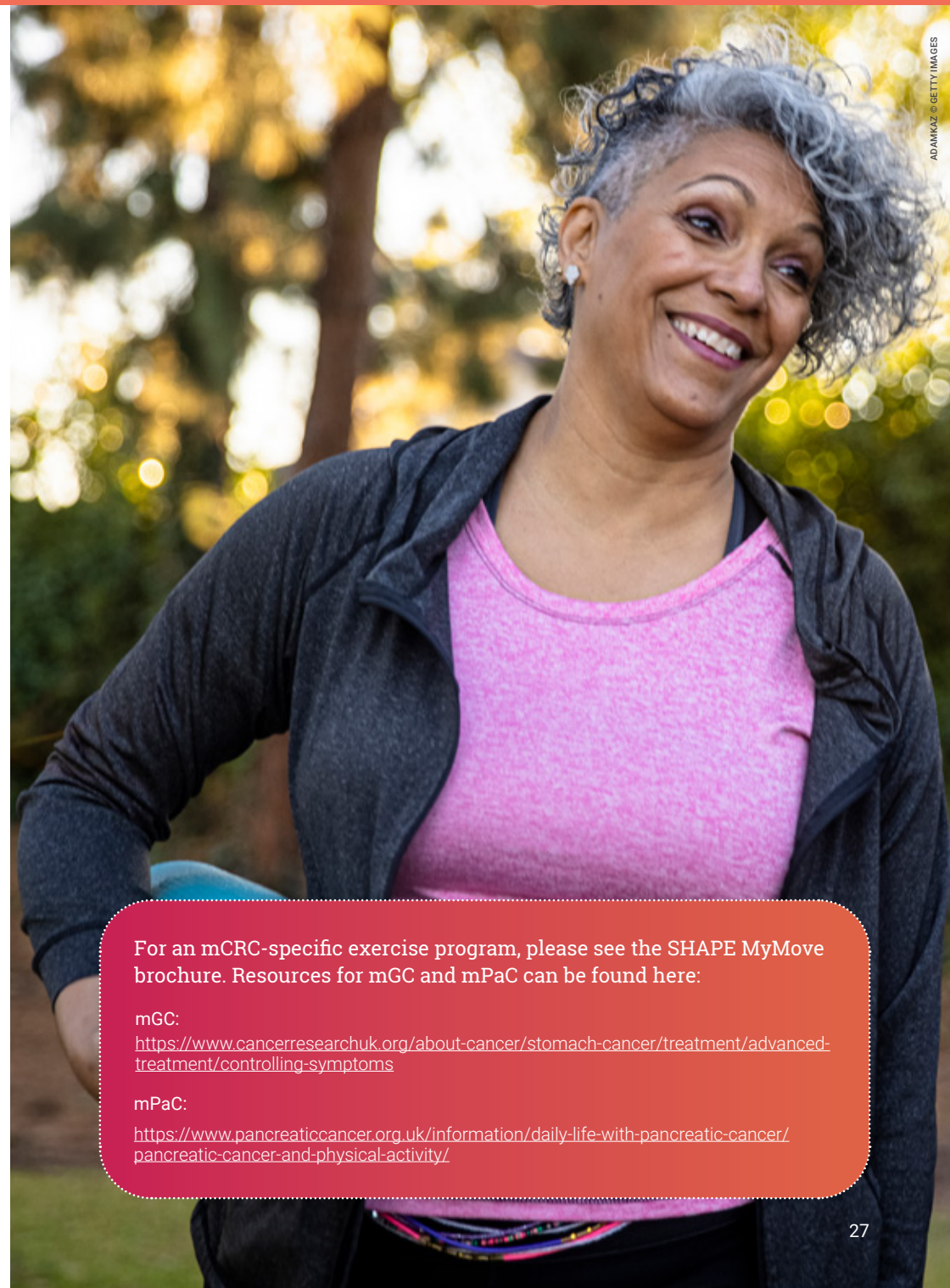
#### What changes will I need to make to my exercise routine?

Speak to your health care team before undertaking any rigorous exercise. For example, if you've had surgery, you may be at risk of causing a hernia if you lift anything too heavy before you are fully healed.<sup>23</sup> Overexercising can make you feel tired for longer, so try not to overpush yourself until you've built up your fitness and strength, gradually increasing your work rate over time.

#### What kind of exercise should I be doing, and for how long?

Again, speak to your health care team before starting any new exercise. There is no one type of exercise that is best for everyone. Try a mixture of aerobic (walking, jogging, or swimming), strength exercises (using no or small weights), and flexibility and balance exercises (yoga, tai chi).<sup>23</sup> Select exercises you enjoy.

A good goal is to try and do at least 2½ hours of physical activity per week.<sup>23</sup> You can split this up into short sessions if it helps.



For an mCRC-specific exercise program, please see the SHAPE MyMove brochure. Resources for mGC and mPaC can be found here:

mGC:

<https://www.cancerresearchuk.org/about-cancer/stomach-cancer/treatment/advanced-treatment/controlling-symptoms>

mPaC:

<https://www.pancreaticcancer.org.uk/information/daily-life-with-pancreatic-cancer/pancreatic-cancer-and-physical-activity/>





## Socializing with GI cancer

Most people say that remaining connected with others can help if you have metastatic GI cancer or are undergoing treatment. A study found that metastatic GI cancer patients and their loved ones who received emotional support from others were less lonely with possible mental health benefits.<sup>24</sup>

There are several ways to help you plan and prepare ahead of social events.

### TOP TIPS for socializing

#### TOP TIPS

- ✓ Check the venue's facilities beforehand so you feel prepared.
- ✓ Try to only do as much as you feel like doing and go where you feel comfortable.
- ✓ If you go out for dinner, it's OK to just order a starter or ask for a smaller portion (have a look at the menu beforehand).
- ✓ Try not to eat too late in the evening.
- ✓ Take all the medication you need with you.
- ✓ Check with your health care team before drinking alcohol (this can sometimes interfere with your treatment. If you can drink, try to only drink a little).
- ✓ Consider avoiding people whom you know are ill – certain treatments can increase your risk of infection.
- ✓ Do not force yourself to socialize if you are feeling tired or unwell.
- ✓ If you feel tired, consider using virtual platforms like Zoom to continue socializing from the comfort of your own home.



## Sex life with GI cancer

Metastatic GI cancer and treatment can put your sex life on hold for a time. You simply may not feel like having sex. This can be caused by:<sup>25</sup>

- physical changes to your body that make sex uncomfortable or painful
- emotional or mental challenges that make you feel embarrassed or uninterested in sex.

Many changes are temporary, however, in some cases, you may need to make long-term adaptations to your sex life. 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.

### How can GI cancer and treatment affect your sex life?

There are many ways GI cancer and treatment can affect your sex life, such as:<sup>26</sup>

- surgery, chemotherapy, and radiotherapy causing erectile dysfunction in men and vaginal dryness / tightening in women
- rectal surgery and radiotherapy damaging nerve endings in the anus making vaginal and anal sex painful or not possible
- loss of your libido
- hair loss, scars, stomas, or other side effects making you feel self conscious.

### 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, even in non-sexual ways such as hand holding and cuddling, can help you to feel close to your partner.

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



### Tips for a healthy sex life

TOP  
TIPS

Don't be embarrassed about speaking to your health care team or GP. They are experienced in having these kind of conversations.

Try to avoid thinking you'll hurt each other when being intimate. Talking and gently experimenting can help you to understand your boundaries.

Lubricant can help with vaginal tightening or dryness. There is readily available medication to help with erectile dysfunction.



## Working with GI cancer

Metastatic GI cancer 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, the type of metastatic GI cancer 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.

### 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.

#### After treatment

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.

If you need time after treatment to fully recover, sick pay may be available to you.

**However you feel, speaking to your partner, family, and friends can help you decide what is best for you.**



### Points to think about when making a decision

**If you can financially afford it, don't feel pressured to return to work until you feel ready, or retire early if you want to.**

**If you feel that work keeps you active and gives you purpose, carry on, but it's also fine not to work if you physically or emotionally can't manage it.**

#### If you go back to work:

You should speak to your employer about how you can be supported, such as:<sup>27</sup>

- better access to toilet facilities
- flexible working hours
- working from home (depending on the type of work you do)
- extra breaks
- to use sick leave for hospital appointments.

#### Support for those who must continue to work

Stopping work is not always an option. If so, there are some things you can do to help you carry on working while also having the time to rest and relax.

**Ask family or friends to help with household chores, shopping, or childcare.**

**Speak to your employer to see if there is any way they can support you.**

**Reach out to a patient support organization for guidance or help.**





## Managing finances with GI cancer

A GI cancer diagnosis can have a financial impact with a knock-on emotional effect. Not being able to work as much as you did previously or having to spend more money elsewhere can make you anxious and is linked to negative health outcomes.<sup>28</sup> However, there are ways to stay in better control of your money.

### What financial support is available to me?

**Benefits or government grants are sometimes available, particularly if you are unable to work and have extra costs at home.**

- Applying for benefits can be challenging and a lengthy process – there are several financial services that can help you.
- Charities and patient organizations can support you in certain ways, eg, transport assistance to hospitals.

**You or your family may have savings, investments, or a pension which you can take early.**

- It can be difficult to decide to use this money, but you should consider the comfort of worrying less about money during and after your treatment.

#### TOP TIP

Don't be afraid to accept financial help if it is offered and you need it.

### How can I manage my spending?

There are some simple ways of staying in control of your money.

Your **income** is the amount of money you have coming in. Your **spending** is the amount of money going out. You can split your spending into two groups.

- 1. Essential spending** – this includes things like rent or mortgage payments, energy bills, and food costs.
- 2. Non-essential spending** – including eating out, holidays, and movie streaming services.

Decreasing your non-essential spending and finding ways to reduce essential spending – like changing energy supplier or using a less expensive supermarket – can save you money.





## Family, friends and carers: My role as a GI cancer caregiver

If you are a partner, family member, or friend of a person with metastatic GI cancer, 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 a GI cancer patient caregiver mean?

A caregiver is someone who provides voluntary help to a person with GI cancer who would be unable to manage without them.<sup>29</sup>

You may not immediately see yourself as a caregiver. Your own life and routine will change suddenly because of your loved one's diagnosis, and you might not have had time to reflect on the situation. Once you recognize you are a caregiver, it can become easier for you to provide care and get further support.<sup>29</sup>

### How can I help as a caregiver?

There are many things you can do as a caregiver. This can include, but is not limited to:<sup>30</sup>

- attending hospital appointments with the patient 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.

*“I became a caregiver very suddenly when my wife was diagnosed with stage IV colon cancer. This was a complete new role for me. My life changed to take on new responsibilities. Barbara's care was most important and of course, I wanted to do everything correctly. It took time to liaise with the family, the doctors, my work, and get used to a completely new routine for which I had no training.*

*It was very difficult to see someone I love going through so much intensive treatment and become dependent on me. Barbara and I always communicated well and this helped so much. I was not afraid to ask for advice.*

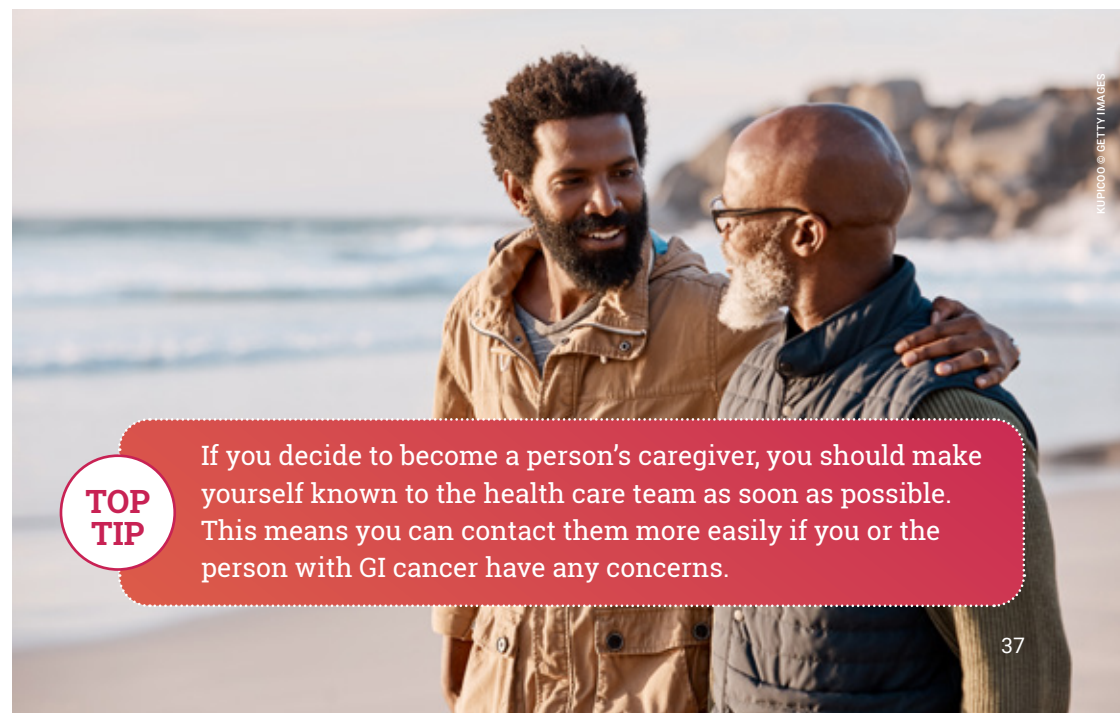
*I asked so many questions about options and treatments available. Together, we made decisions and took risks regarding life and death. Miraculously, the treatment worked and I was aware of the emotional support needed during recovery. There were tests, checkups, and tense times awaiting results.*

*No-one's life is the same after a cancer journey.”*

**Mark Moss**, Caregiver

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 GI cancer have any concerns.

**TOP  
TIP**







## My relationship as a caregiver

Relationships change when you become a caregiver. Having different feelings toward the person you care for is a normal part of the process, and there are some top tips that may help keep your relationship healthy.<sup>30,31</sup>

**Take time to become familiar with your caregiver 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 with GI cancer 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.





## Support for caregivers

As a caregiver, it is easy to focus too much on the person you are caring for and neglect your own health; they are ill so you push yourself to support them. However, this can result in burnout or becoming ill yourself – staying well means you provide better care. There are several things you can do to look after yourself.<sup>32,33</sup>

**Take breaks from care and continue to do the things you enjoy.**

Providing care can feel like a full-time job, so you will need relaxation time.

**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.







## Role of patient organizations and peer support

There are many people out there who have or have had metastatic GI cancer, or cared for someone with metastatic GI cancer, and have a first-hand understanding of what you are going through.

GI cancer 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.

### What do patient organizations do?

**They cannot give you medical advice; this is the sole responsibility of your health care team, but they can:**<sup>34</sup>

- support you through advice, education and sometimes hands-on care
- participate in and fund research, as well advocate on behalf of patients and caregivers
- offer group and one-to-one buddy support for patients and caregivers, sometimes known as peer support.

### What is peer support?

**Peer support means using first-hand experiences to help others.**<sup>35</sup> This typically means meeting other GI cancer patients and their loved ones to listen, share experiences, and provide useful advice.







### Peer support groups can be:

- face-to-face meetings individually or in groups in a private or public setting
- virtual, through teleconference platforms like Zoom
- phone calls
- online, through social media forums.

They may be moderated by HCPs, such as nurses, but it can also just be patients and caregivers, past and present.

Speak to your health care team first if you are given any lifestyle advice, particularly around your medication.

### Peer support groups can help you by:

- making you feel more positive about your cancer, treatment, and life
- allowing you to talk about things you struggle to tell your health care team
- providing a platform to share advice and tips on how to live well and cope with side effects of your cancer and treatment.

There is some evidence to show that peer support may improve survivorship in cancer patients.<sup>36</sup> Peer support has also been shown to improve taking treatments as prescribed by your health care team.<sup>37</sup>





This section of the brochure may not be relevant to you. Your health care team will inform you if palliative care is a part of your journey.

## Palliative care

Talking about the end of the journey is hard and sad. You may have had this thought for some time, or you may have chosen to push it out of your mind. The better we prepare for death, the easier it is for our friends and family that we leave behind.

### What is palliative care?

At some point in your metastatic GI cancer journey, you may **receive palliative care**. This can happen if:

- symptoms or side effects related to your metastatic GI cancer 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.

### Why am I receiving palliative 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. Palliative care can be given for months or years depending on the type of metastatic GI cancer you have.

#### What is end-of-life care?

End-of-life care is care provided in the last months or weeks of your life.

### What does palliative care include?

As well as pain relief and anti-sickness medication, palliative care includes other treatments to reduce symptoms, such as chemotherapy or radiotherapy. Palliative care also aims to fulfill your holistic needs, including psychological, social, and spiritual support.

Being told your cancer is incurable can be emotionally difficult. Making plans for your future care and your wishes after death may make it easier for you and your family and friends later.

### Talking about palliative care earlier

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.<sup>38</sup>

### Planning ahead

Planning ahead can be beneficial for some people with metastatic GI cancer. Although the future may be unclear, you can become too ill to make decisions about your care or finances. It could be helpful to at least begin the conversation around things like wills, finances, and power of attorney with your family and loved ones.

### While you feel well

You may want to speak to your health care team or reach out to patient support organizations who can provide guidance and resources to help you and your family plan for what comes next.

# Key contacts in your multidisciplinary team

You may wish to complete the below boxes so that you have a record and contact details of your key HCPs

Name	
Position	
Tel	
Email	

Name	
Position	
Tel	
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Name	
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Name	
Position	
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# Resources

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#### **Index of SHAPE brochures**

1. MyMove – moving more with mCRC
2. MyMood – managing your emotional health with mCRC
3. MyDialogue – getting more from your conversations with health care professionals
4. MyFood – managing your nutrition with GI cancers
5. **MyJourney – guiding you through the different stages of living with metastatic gastrointestinal cancer**

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