

Adapting to metastatic Gastric Cancer (mGC)

A guide for people living with mGC and their caregivers

# **INTRODUCTION**

#### Welcome to Adapting to Metastatic Gastric Cancer,

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

This guide aims to help people living with metastatic Gastric Cancer (mGC). 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 Gastric Cancer, you are at the start of 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.

The aim of this guide is to give you a clearer idea of what to expect along the way. It has been designed to support you, your family and caregivers as you experience the different steps of mGC.

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

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

# **DEVELOPED WITH SPECIAL INPUT FROM:**







**Thomas Gruenberger** GI surgeon, Austria



Laura Monje-Garcia Nurse Practitioner. United Kingdom

This guide is designed to support patients, their caregivers and family members from diagnosis and throughout the treatment pathway and beyond. This is so important as often patients do not have access to all the information they need, and this guide means that they have it for every stage of their pathway.

Dave Chuter, Patient Advocate, UK

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



lga Rawicka Patient Advocate. Poland

# THE ADAPT PATHWAY

of your family will be individual to you.

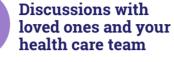
The ADAPT pathway below brings together information that can help you to understand how your life will change after your diagnosis. It can also point you in the direction of resources that provide information in more detail.

Key steps following diagnosis are shown here. However, your pathway may not run in this order. Whatever stage you are at, you can use the ADAPT pathway to take you to the information that is most important to you right now, return to earlier sections or jump to later ones whenever you need.



# Awareness

Helping you to understand your diagnosis and find more information online.



Dialogue

includina:

How to talk about your diagnosis

friends, and peers

Sharing the news with family.

shared decision-making)

Preparing for conversations with

health care professionals (including

# 1+

Information on before, during and after treatment, including:

Treatment

- Getting the most from health care teams and treatment
- •



# **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 mGC 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.

Access

Clinical trials information



# **Future Planning**

# 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 Gastric Cancer and mGC is, the symptoms, tests for diagnosis, introducing the health care team and guidance on how to find trustworthy information.

### WHAT IS THE STOMACH?

The **stomach** is part of the digestive system.<sup>1</sup> It's in the upper left side of the tummy (abdomen).<sup>1</sup> When food is swallowed, it travels down the food pipe (known as the oesophagus) into the stomach. The stomach then stores the food and breaks it down (digests it) so our body can absorb it.<sup>1</sup>

### WHAT IS GASTRIC CANCER?

Gastric Cancer is a type of gastrointestinal (GI) cancer that forms inside the stomach or on the stomach wall and is sometimes called stomach cancer.<sup>2</sup> In most cases, Gastric Cancer begins in the cells in the inside lining of the stomach, which is known as adenocarcinoma of the stomach.<sup>2</sup>

#### WHAT ARE THE SYMPTOMS?

Every Gastric Cancer patient is different. You may have few or several symptoms. The most common symptoms include:<sup>3</sup>



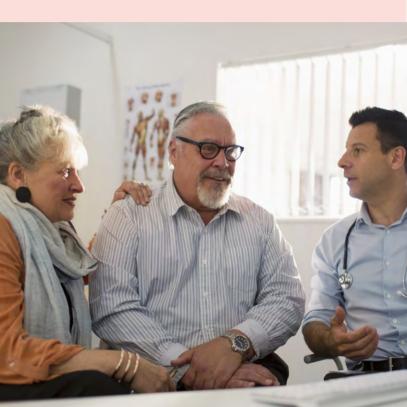
small amounts

# HOW IS GASTRIC CANCER DIAGNOSED?

After you have noticed any symptoms and spoke to your health care team, they may do tests to see if you have Gastric Cancer.

The most common test is:4

TYPE OF TEST	WHAT HAPPENS DURING THE TEST?
Gastroscopy	A thin, flexible tube with a camera at the end is passed down the food pipe to examine the stomach.
	If something looks like cancer in your stomach, your doctor may pass special tools down the tube to take a sample for testing (called a biopsy).



Caia Image © Getty Images

### WHAT HAPPENS AFTER A DIAGNOSIS?

Once Gastric 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.<sup>4</sup>

Knowing the stage of cancer helps to decide on the best treatment for it, 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).<sup>4</sup>



#### 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.<sup>4,5</sup>

# WHAT ARE THE STAGES OF GASTRIC CANCER?<sup>5</sup>

# STAGE 1/I

The cancer has grown on the lining of the stomach.

## STAGE 2/II

It has grown through the lining of the stomach and into the thick inner muscles of the stomach.

## STAGE 3/III

It has grown into or through the layers of your stomach and may have also spread to nearby lymph nodes (they help the body fight infections as part of the immune system), but it has not spread to other organs.

# **STAGE 4/IV**

The cancer has grown into nearby tissues and organs or has spread across your body. It's also called metastatic Gastric Cancer (mGC), advanced Gastric Cancer or secondary Gastric Cancer.

### WHERE DOES mGC SPREAD TO?

mGC typically spreads to the liver, lungs, lymph nodes (help to fight infection), and the tissue lining of the abdominal cavity (where your organs are contained).<sup>6</sup>

# WHAT ARE THE SYMPTOMS OF mGC?

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.<sup>6</sup> Symptoms can include:<sup>7</sup>

- Feeling tired or generally unwell
- Unexplained weight loss
- Black stools, which contain blood
- Feeling and being sick
- Stomach pain
- Difficulty swallowing
- Breathlessness

The above list includes only the most common mGC 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 Gerty Images

### QUESTIONS TO ASK YOUR HEALTH CARE TEAM AFTER DIAGNOSIS

There may be lots of information to take in when you are diagnosed with mGC. 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?

Don't worry if you feel something has already been covered by your health care team and you need to ask a question again. You might want to bring someone with you to your appointments for support and to help you remember key points or record the appointment on your phone (remember to ask permission from your health care team to record).

# HOW LONG WILL I LIVE AFTER A mGC DIAGNOSIS?

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

You may also not wish to know your outlook; instead, you may want only your loved ones to know or how your symptoms may change over time.

If you want to understand more, 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 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?

Most cases of Gastric Cancer are random, meaning they don't run in families. Only about 3% of people with Gastric Cancer have a family history of it.<sup>5</sup>

However, if one or both of your parents has/had Gastric Cancer, you may want to consider speaking to your health care team. They may refer you to have specific genetic tests which will find out if you could pass your cancer on to your children, or if your siblings could also be at risk.<sup>5</sup>

Having this knowledge means your children or siblings can be especially aware of any symptoms and have tests during their lives to see if they are developing Gastric Cancer, called screening tests.<sup>5</sup> Having regular screening tests may also result in an earlier diagnosis, which can lead to better outcomes.

# AWARENESS



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

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?



This team is sometimes called a multi-disciplinary team (MDT), and their goal is to decide on the best treatment for you and support you.				Pathologist	A doctor or a clinical scientist who w interpret the changes in your tumor before, during, and after your treatme
TEAM MEMBER	THEIR ROLE	TEAM MEMBER	THEIR ROLE	Pharmacist	An expert who provides ongoing support with medication therapy
Anesthetist	A medical specialist who administers anesthesia, especially on patients who need to undergo surgery.	Dietitian and nutritionist	Experts who focus on supporting you to eat and drink well and maintain a healthy weight.	Physiotherapist	management and advice on addition supportive medicines. A health care professional (HCP) tha
Case manager	Your first point of contact who knows your case well.	Gastroenterologist	A doctor who specializes in investigating, diagnosing, and treating diseases of the stomach, intestines, and pancreas etc.		helps you regain strength and mobili after treatment, particularly surgery.
Clinical oncologist	A doctor who specializes in treating cancer patients.	Gastrointestinal (GI) cancer clinical nurse specialist	A nurse who specializes in caring for GI cancer patients. They may also be your case manager.	Psychiatrist	A doctor who specializes in diagnosi and treating mental illness using a variety of treatments, including medications and talking therapy.
Clinical psychologist	An expert who specializes in supporting you emotionally, using non-medical techniques including talk therapy. Other experts with a similar role are psycho-oncologists who focus on the cancer experience for patients and their loved ones.	Occupational therapist	An HCP who has expertise in helping you regain independence after treatment.		You and your family are an impor treatments and the risks and bene As much as you are willing and at care team to decide on care that y

#### MEET YOUR HEALTH CARE TEAM: THE PROFESSIONALS WHO WILL SUPPORT AND GUIDE YOU

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. These will differ depending on where your mGC has spread to and what type of treatments you have.

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THEIR ROLE

TEAM

**MEMBER** 

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# AWARENESS



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#### Radiotherapist

Surgeon

# THEIR ROLE

A doctor who uses X-rays and other screening machines to locate and measure cancer and guide treatments.

An expert who specializes in using highenergy rays to treat cancer.

A doctor that performs surgery – typically GI, or further specialists if the cancer has spread to other areas.

tant part of this team. While your health care team know about efits, you know your own body and what you want from your life. ble, you and your family can discuss and work with your health works for you.



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 those who you trust know about things like your diagnosis and treatment decisions can help you to feel better supported.

# SHARING WITH OTHERS: WHY TALKING CAN HELP

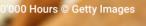
As well as getting more support, talking about your cancer can help you to:  $\ensuremath{^8}$ 

- 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>8</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.

For more information and guidance on having these conversations, see pages 10-13 of the <u>MyJourney</u> <u>patient brochure</u>.



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 GASTRIC 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 signs and 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 Gastric 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 Gastric Cancer at some point in your life"

"This doesn't mean you will get Gastric Cancer, but you should be aware of the signs and symptoms just in case"

"If you spot any of the signs and symptoms of Gastric 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 Gastric 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:<sup>9,10</sup>

- 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 will 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>. This brochure was developed to support people living with metastatic Colorectal Cancer (mCRC) and their caregivers, however, the guidance included is also suitable for other GI cancers, including mGC.

# DIALOGUE

#### **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 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:

#### **ADVANTAGES** DISADVANTAGES Reassurance that Delays to starting your different doctors treatment agree on your Receiving conflicting diagnosis and information treatment Having to travel to different (sometimes Access to different treatment options foreign) hospitals

#### Talking trapped wind and bowel movements:

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It is normal for people to feel uncomfortable talking about their bowel movements, especially the colour or shape of their stools. However, if you notice a change in your stools, it's important to share this information with your healthcare professional. Don't feel embarrassed as they are used to talking about these things.

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



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

If you had mGC, 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. Who would you recommend?



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

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

Every mGC 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:5



The size, quantity and location of tumor(s)

If your cancer has certain characteristics



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'.5

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.<sup>11,12</sup>

#### 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 maintaining guality of life.<sup>13</sup>

#### **CHEMOTHERAPY**<sup>5</sup>

This is the standard treatment for mGC. There are different types of chemotherapy that can be used for mGC, but not all of them will be suitable for all patients.

Your doctor will choose the kind of chemotherapy to give you based on your general health and tumor test results.

# **TARGETED THERAPY AND IMMUNOTHERAPY<sup>5</sup>**

Depending upon the results of your biopsy during staging you may also receive (alongside chemotherapy) targeted therapy (a type of treatment that targets specific areas in cancer cells that help them grow, divide and spread) or Immunotherapy (a type of treatment that helps your immune system to attack cancer).

The biopsy result will show your health care team what type of targeted therapy or immunotherapy will work on your cancer. Allthough 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 mGC?

How long will I need treatment for?

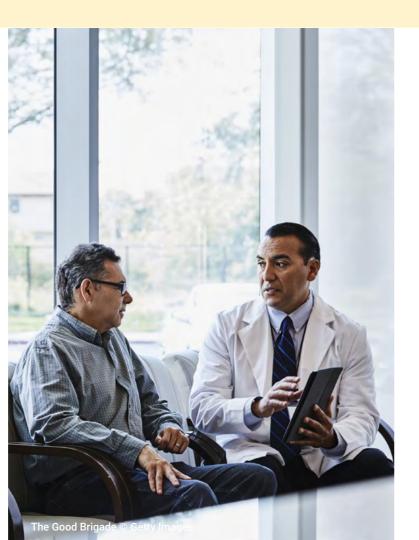
How effective is this treatment?

# WHAT IF I CHOOSE NOT TO HAVE TREATMENT?

You may decide not to have treatment for your cancer. This may be because you want to spend as much time as possible with your family and friends without spending lots of time in hospital or having side effects of treatment.

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.

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 treatment options and care available that can address specific symptoms.<sup>5</sup>

SYMPTOM	TREATMENT
Problems with eating	Surgery for stomach cancer before it reaches the metastatic stage may cause <b>problems with eating</b> . A dietician can provide advice on eating well. You may need a <b>feeding tube</b> , which will go through your skin and directly into your stomach or intestine via a stoma (an opening into the body).
Blockages	You may need surgery to <b>remove</b> <b>blockages</b> in the stomach. This may include having a stent (a small metal or plastic tube) inserted to relieve the blockage.
	In some cases, you may have part of or your entire stomach removed to reduce symptoms (known as a <b>gastrectomy</b> ).
Trouble swallowing	You may have <b>radiotherapy</b> to shrink tumours that interfere with swallowing.

# ACCESS

# WHAT ARE THE RISKS OF TREATMENT?

Chemotherapy and other treatments for mGC can have side effects, and surgery to reduce symptoms can be a major operation. 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 are the side effects of this treatment?

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 potential new treatments that aren't currently used to find more effective and/or safer treatments. 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.<sup>5</sup>

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

POSSIBLE 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?

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

ACCES

# **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.<sup>14</sup> Some things that may help you prepare:<sup>14</sup>



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 questions like:

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

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



#### 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:<sup>5,15</sup>

TREATMENT TYPE:	WHAT TO EXPECT:
Chemotherapy, targeted therapy or immunotherapy	<ul> <li>You will be given a medicine as a pil</li> <li>This will happen in hospital/health c care team (at least the first time you</li> </ul>
Surgery (to have a stent)	<ul> <li>You have an injection to make you f</li> <li>The doctor passes a thin, flexible tu</li> <li>This tube is then used to place the s</li> </ul>
Surgery (to have your stomach removed)	<ul> <li>You have an injection, called a gene</li> <li>The surgeon will remove part or all or</li> </ul>
Radiotherapy	<ul> <li>You will lie down on a bed while a ra</li> <li>Members of your health care team value</li> </ul>



- pill, by injection or through a drip
- clinic or potentially at home, and you will be monitored by your health ou receive the treatment)
- feel relaxed and sleepy.
- tube with a camera at the end (called an endoscope) into your mouth e stent to keep the section of your insides open and allow food to pass
- neral anaesthetic, which puts you to sleep I of your stomach while you are asleep
- radiotherapy machine targets your cancer with high energy waves will watch you during the process

# 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 CHEMOTHERAPY<sup>16</sup>**

- Chemotherapy weakens your body's immune system.
  - This means after your chemotherapy session, try to avoid people with colds or other infections.
- Your health care team may suggest that you drink lots of fluids for 48 hours after chemotherapy.
  - · This helps move the medicines through your body.

#### After targeted therapy or immunotherapy<sup>17,18</sup>

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

#### After radiotherapy<sup>19</sup>

 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

#### After surgery<sup>5</sup>

- When you wake up after a surgery, you will have some pain and need medicine
  - · You may not be able to eat or drink much
  - You may need to remain in hospital for several days

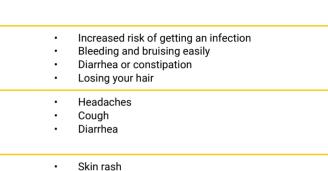
#### What side effects can I expect from my treatment?

Side effects of mGC 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 can include:



TREATMENT:	POSSIBLE SIDE EFFECTS:*5,15-18
Chemotherapy	<ul> <li>Feeling sick</li> <li>Loss of appetite</li> <li>Losing weight</li> <li>Feeling very tired</li> </ul>
Targeted therapy	<ul> <li>Tiredness and weakness</li> <li>Fever and chills</li> <li>Nausea and vomiting</li> <li>High blood pressure</li> </ul>
Immunotherapy	<ul> <li>Feeling tired or weak</li> <li>Fever</li> <li>Cough</li> <li>Feeling sick</li> <li>Itching</li> </ul>
Surgery	<ul> <li>Pain and tenderness in the area of the ope</li> <li>Constipation or diarrhea</li> <li>If you have a stoma fitted, you may have in</li> </ul>
Radiotherapy	<ul> <li>Fatigue</li> <li>Mild skin reactions</li> <li>Feeling and being sick</li> </ul>

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.<sup>16,17,19</sup> Speak to your health care team as soon as you notice any side effects so they can support you.



ACCESS

- Loss of appetite
- Muscle or joint pain
- · Shortness of breath
- Constipation or diarrhea

peration

irritation around the stoma

- Diarrhea
- Low blood cell count (known as anemia)

\*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.

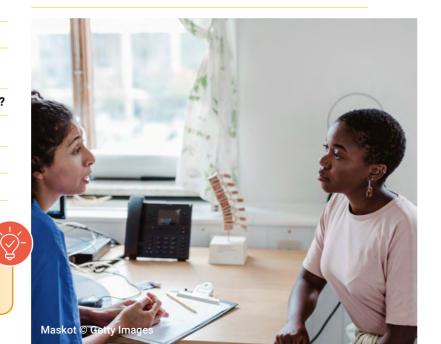
#### MY TREATMENT AND CARE PLAN SO FAR:

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. ACCESS

# 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.

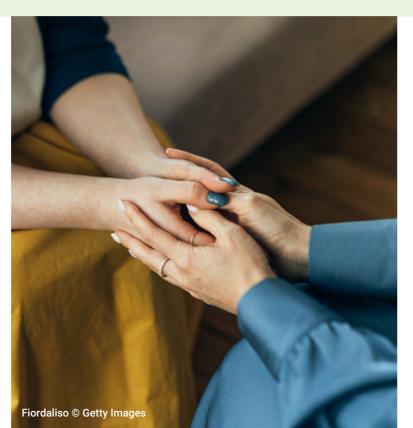
### LOOKING AFTER YOUR EMOTIONAL HEALTH

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.<sup>20</sup>

It is important to remember that these feelings are normal, understandable, and many people feel the same way.<sup>21</sup>

Your immediate response to diagnosis - or learning your cancer has advanced - may be feeling numb, shock, fear, guilt, or uncertainty about the future.<sup>22</sup> 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.

Everyone's cancer journey is different - each person will react differently to the difficult news of a cancer diagnosis, challenges of treatment, life after treatment and thinking of the future. There are no right or wrong reactions or emotions.



## 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:		
<b>Staying connected</b> to the people you enjoy spending time with and the things you enjoy doing	<ul> <li>Communicate with your loved ones</li> <li>Take part in group classes or activities</li> <li>Prioritize the things you enjoy doing, such as a hobby</li> </ul>		
Being kind to your body	<ul> <li>Eat what you can, when you can</li> <li>Focus on getting good quality sleep</li> <li>Keep moving your body</li> </ul>		
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. This brochure was developed to support people living with metastatic Colorectal Cancer and their caregivers; however, the diary and mindfulness exercises are also suitable for other GI cancers, including mGC.

#### **ASK OTHER PEOPLE FOR HELP**

Talk to your family, friends, and other patients. Talk to a health care professional.

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?

This can depend on the type of mental health professional you see and your own experiences.

You can expect the person to listen to your experiences and help you understand more about how you are thinking and feeling and might be able to overcome these thoughts and feelings.<sup>23</sup>

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.<sup>23</sup>

# Body image and mGC

Stomach cancer, including metastatic Gastric Cancer, and its treatments are likely to cause physical changes in your body such as weight and hair loss. These might affect the way you feel about yourself and the way you relate to other people. Your dietitian can help you maintain your weight and your nurse can help you look at ways to cope with hair loss.<sup>20</sup>

Joining a mGC support group may also help you to deal with these new feelings. Sharing your experiences with other patients can be very comforting in knowing that you are not alone.



# **PSYCHOLOGICAL WELL-BEING**

Klaus Vedfelt © Getty Images



# **PHYSICAL WELL-BEING - NUTRITION**

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.

When you are faced with an mGC diagnosis, it is 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.<sup>24</sup> This can be a real challenge, especially when dealing with cancer and treatment.<sup>24</sup>

Cancer symptoms or side effects of treatment may affect your appetite, and you may not enjoy eating the way you did before.<sup>24</sup> Your weight or bowel movements may change. These effects are common, but there are ways to reduce them, with the right support.<sup>24</sup>

### DOES MY DIET AFFECT MY CANCER JOURNEY?

Diet and nutrition are especially important considerations for people with mGC. With the right guidance and support, changes to your diet and nutrition could impact:<sup>24</sup>



How your cancer develops

Your response to treatment or surgery

The symptoms you experience



Your quality of life and well-being

# HOW WILL CANCER AFFECT THE WAY I EAT?

Since everyone's cancer journey is different, the foods you can or want to eat may be affected. It is possible to make adjustments to your diet that help you continue to eat well while you undergo treatments or procedures, or if you experience certain symptoms.

You can speak to your health care team for advice about your diet. Your dietary needs should be regularly reviewed by your health care team and rebalanced as needed.

Your diet may change in a number of ways:24

- You may need to change your diet because of symptoms, which depend on the where your mGC has spread to
- You may be preparing your body for treatment

- **Treatments** like chemotherapy or radiotherapy may change the way food tastes to you and affect your appetite.
- Always speak to your health care team before you decide to take additional medicines, vitamins, supplements, or probiotics yourself, as these can affect your treatment



#### Eat little and often

If you've had surgery to remove all or part of your stomach, you'll only be able to eat small amounts of food until your body adjusts. You may have to eat little and often, and make changes to the types of food you eat. Your care team will be able to advise you about what and when you should eat.

# ARE THERE ANY EATING-RELATED PROBLEMS SPECIFIC TO GASTRIC CANCER, AND HOW CAN I BETTER COPE WITH THEM?

#### **DUMPING SYNDROME?**<sup>25</sup>

Dumping syndrome is a group of symptoms that can sometimes happen if you've had surgery for Gastric Cancer. Food you've eaten may move too fast into the small bowel, which means a large amount of water is pulled from the rest of your body to help break down the food. This can cause a sudden drop in blood pressure and may make you faint and feel dizzy.

#### Other symptoms of dumping syndrome include:

- Feeling sick
- Diarrhea
- Tummy cramps
- Bloating
- Flushing
- A strange-feeling heartbeat (palpitations).

# HOW CAN I REDUCE THE SYMPTOMS OF DUMPING SYNDROME?<sup>25</sup>

- · Eat slowly, and rest after you eat
- Lots of sugary foods can make dumping syndrome worse, so try to cut sugar down and replace with foods higher in fat instead
- Add more fibre to your diet
- Eat smaller meals more regularly
- Avoid soup and very liquid foods

You may also experience other symptoms and changes due to your Gastric Cancer diagnosis. It is important that you speak with your healthcare team before making changes to your diet if you experience any of the following:

SYMPTOM:	TIPS FOR MANAGING YOUR SYMPTOM
Diarrhea	<ul> <li>If you've had Gastric Cancer surgery, food diarrhea. Surgery and treatments such as diarrhea.</li> <li>Your healthcare team may advise you to ta diarrhea. Foods like plain chicken and well</li> </ul>
Steatorrhea	<ul> <li>This happens when your stools float, look correctly.</li> <li>Your healthcare team may prescribe table</li> </ul>
Feeling and being sick in the morning	<ul> <li>If you have had part of your stomach remo severe, please speak to your health care to surgery.</li> </ul>
Feeling bloated	<ul> <li>You may regularly have wind and bloating</li> <li>Peppermint tea or adding a few drops of p pain.</li> <li>Remember to take small, slow sips.</li> </ul>
Indigestion	<ul> <li>mGC and surgery can cause indigestion</li> <li>Certain foods, like fizzy drinks, alcohol, sp</li> <li>Try to find a balance between treating you with symptoms.</li> </ul>
Weight loss	<ul> <li>The side effects of mGC and the treatment</li> <li>Weight loss is typically caused by loss of a needs from the food you are eating.</li> <li>Talking to a dietitian can help create a food</li> </ul>



For more information and guidance on adapting your diet and eating well with mGC, see the <u>MyFood patient brochure</u> and <u>MyFood mGC video</u>.

# **PHYSICAL WELL-BEING**



#### **MS:**<sup>25</sup>

d may move quicker through your digestive system which can cause s chemotherapy, targeted therapy and radiotherapy can also cause

take anti-diarrhea medicine early in the morning to help to reduce ell-cooked vegetables may be easier to tolerate.

k pale or have a bad smell. This is caused by your body not digesting fat

lets, which help you to better digest fat.

noved, you may feel or be sick in the morning. If your symptoms are team as they may be able to recommend additional treatments and/or

g pain after stomach surgery.

peppermint oil to some hot water can help to relieve trapped wind and

picy food, caffeine and chocolate may trigger this purself with foods you enjoy and taking a break from them to help cope

ent can make it difficult to stay at a healthy weight. f appetite or by your body not being able to absorb all the nutrients it

Talking to a dietitian can help create a food plan that works for you.



# **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 mGC 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>26</sup> Pain is also common.<sup>3</sup>

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.<sup>27,28</sup>

# **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.

# B

# 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.



# 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.<sup>27,29,30</sup>



### **OVERALL WELL-BEING**

Physical movement can improve your overall quality of life, which includes your physical, mental, and social well-being.<sup>27-29</sup>



### HEART AND MUSCLE FITNESS

Movement can help preserve and improve your heart and muscle fitness before, during and after treatment.<sup>28,29,31-39</sup>



# **REDUCES SIDE EFFECTS**

Physical activity may reduce some side effects of cancer treatment, such as tiredness and joint pain.<sup>28,29,32-34,40-44</sup>



## **BONE HEALTH**

Resistance training (strengthening activities) can have a positive effect on your bone health.<sup>45</sup>



# SURVIVAL

Evidence shows that increased physical activity after diagnosis can prolong life in people with Gastric Cancer.<sup>44</sup>



# SURGERY PREPARATION AND RECOVERY

Regular physical activity (approx. 30-mins per day) at least one-month before surgery can help improve your physical fitness, which helps to minimize potential complications following surgery and during the recovery process.<sup>46,47</sup>

# HOW CAN I PREPARE PHYSICALLY FOR SURGERY?

# **BEFORE SURGERY?**

Regular exercise before surgery, which is part of 'prehabilitation', can get your body in the best possible shape for the operation.<sup>47</sup> Your health care team will give you guidance on an exercise program, but in general, being active for 30-60 minutes, 5 times a week is a good target to aim for.<sup>47</sup>

It's important to remember that there is no one size fits all approach - there are many different types of exercise you can do to help prepare you for surgery. The FITT method can help you set your own fitness goals at this time:



#### Frequency

how often are you doing physical activity? Try to aim for 30 minutes daily

#### Intensity



how hard is the activity? Moderate intensity is recommended (i.e., brisk walk, heavy chores, badminton, etc.)



#### Time

how long? 30 minutes is recommended, although this can be broken into chunks

# Туре

a balance of some aerobic activity (walking, biking, swimming) and some resistance training (using resistance bands or dumbbells) could be included

# **AFTER SURGERY?**<sup>48</sup>

Recovery following surgery can be a slow process and you will work closely with your health care team to build up your physical fitness. Suggested activities include:

- Sitting up and breathing deeply while your bed is in an upright position, practice 10 big breaths in/out. Try to do this at least a few times every hour.
- 2. Leg movement while in bed with your legs straight, practice wiggling your toes, flexing and pointing your feet, rotating both ankles right and left.
- 3. Sitting in a chair get out of bed and sit upright in a chair.
- 4. Walking you should walk up and down a hallway as much as possible. Your nurse will help you at the beginning.

# WHAT TYPES OF EXERCISE COULD I DO?

Before starting any exercise plan, speak to your health care team as they can advise on the best activities for you and can confirm if there are any safety issues to keep in mind.<sup>49</sup>

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

Gentle exercise when you feel able to is recommended.49

Examples of gentle exercise to try include:49



Going for a short walk or walking up and down a few steps



Light housework or gardening



Trying yoga or stretching



# **PHYSICAL WELL-BEING**

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.<sup>47</sup>

The MyMove patient brochure includes an exercise planner to record your movement, day-by-day, week-by-week. This brochure was developed to support people living with mCRC and their caregivers, however, the exercise planner is also suitable for other GI cancers, including mGC.

#### TOP TIPS

- Consistency creates change: Try your best to do 2+ sessions per week.
- Move in the morning: You'll feel the benefits for the whole day.
- Walking does wonders: Be as active as possible during your days.

#### **mGC EXERCISE ROUTINE**

To help you move more, there is an exercise routine on the next page. This has been developed by Mark Wild, a cancer rehabilitation expert. This routine aims to help improve your quality of life by creating change with kindness, and bringing big benefits to your muscles, movement, and mind.

Before attempting the routine, speak to your health care team and refer to the information below.

### HOW TO DO THE ROUTINE?

- **Rounds:** Do the exercises back to back try to keep a nice rhythm throughout.
- **Repetitions:** Try starting on 6 or 8 repetitions per exercise.
- **Rest:** For 30-60s at the end of the round.
- Repeat: When you feel capable repeat the round once or twice more.
- If you would like to raise the intensity, you can add more repetitions per exercise (e.g., 10 / 12 / 14).

#### HOW TO TAILOR YOUR SESSION:

Choose a 'mode' that suits how you feel:

- Control mode: Perform the exercises nice and slowly keep your breathing soft and stable.
- Challenge mode: Perform the exercises quicker maintain a slight level of breathlessness.



#### GOLDEN RULE: Listen to your body.

Listening to your body installs awareness; ensuring safety and elevating effectiveness.

Do what you're capable of: Start sessions slowly and do what you can. When you feel able to do more - do more!

Acknowledge how you feel during and after a session: This brings an understanding as to what's best for your body.







#### SOUAT HIP HALO

- 2
- 3

Progression: Squat lower.

Restricted range of movement? Bring arms back as far as you feel comfortable.

## SINGLE LEG SLIDE (CHAIR)

- 2. the front of supporting leg.
- 3. all repetitions - Then switch sides.

Progression: Try without a chair.

## **WOODCHOP**

- 2.
- 3 Then switch sides.

Progression: Bend knees more. Restricted range of movement? Bring arms across to touch opposite thigh/knee.

# **PHYSICAL WELL-BEING**



Stand tall - Feet shoulder width - Arms to front - Hands in fists pushed together.

In one movement – Bend knees and arch arms behind hips to tap fists together.

Return by arching arms forward whilst coming upright

Stand tall side on to a chair - Feet hip width - One hand on chair.

In one movement-Lift the leg closest to the chair backwards whilst sliding your hand down

Return by sliding the hand up your leg whilst bringing lifted leg down to the floor - Repeat

Restricted range of movement? Slide hand as far as you feel comfortable.

Stand tall - Feet outside shoulder width - Hands together at shoulder height.

In one movement – Bend the knees and bring arms across your body – Head follows hands.

Return by bringing arms back across your body to stand upright - Repeat all repetitions -



# LUNGE BACK LOOP UP

- 1. Stand tall Feet hip width Hands to side of hips.
- 2. In one movement Lunge one leg backward whilst lifting arms forward to loop them up.
- 3. Return by stepping forward and bringing arms down Switch legs so you're alternating. Progression: Lunge lower so the back knee is just above floor.

Restricted range of movement? Lift arms up as far as you feel comfortable.



# SIDE STEP SOUAT

- Stand tall Feet hip width Hands bunched together in centre of body.
- 3. Return by stepping in to upright Switch legs so you're alternating. Progression: Squat lower.



# TIP TOE PUNCH UP

- 1. Stand tall Feet hip width Slight bend at knees Hands in fists on shoulders.
- 2. In one movement Pop up to your tip toes and punch arms overhead.
- 3. Return by bringing arms down and bending knees slightly.
- Progression: Bend knees more to do a full squat.



### SIDE LEG LIFTS



# FRONT LUNGE ELBOW OPEN

- 1. Stand tall Feet shoulder width Finger tips on shoulders Elbows forward and up.
- 2. In one movement Lunge forward and open your elbows to bring shoulders back.
- 3. Return by stepping back whilst bringing elbows in Switch legs so you're alternating.
- Progression: Lunge lower so back knee is just above floor.

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

# **PHYSICAL WELL-BEING**



- 2. Keeping one leg in place Step sideways and bend both knees to squat
  - down Move body so your weight is even in both legs as you squat.

- Stand tall Feet shoulder width Arms horizontal at shoulder height.
- 2. Keeping both legs long Lift one leg out to the side.
- 3. Return by lowering leg Switch legs so you're alternating.
- Progression: Lift leg as high as possible.



# **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.

During mGC treatment and in the time 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.

# MANAGING RELATIONSHIPS WITH mGC

An mGC diagnosis, going through treatment and dealing with the long-term side 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.



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.



# SEX LIFE WITH mGC

mGC and treatment can put your sex life on hold for a time. You simply may not feel like having sex due to:  $^{\rm 50}$ 

- 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.<sup>51</sup> 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.<sup>51</sup>

### 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 through hand holding and cuddling, can help you to feel close to your partner.<sup>51</sup>

If you are single, consider speaking to a close friend or seek professional help from your health care team or a psychosexual councillor.<sup>51</sup>



For more information on socializing and sex life, <u>visit</u> the MyJourney patient brochure.

#### **WORKING WITH mGC**

How much your mGC impacts your life will depend on 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.

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.<sup>51</sup>

#### 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.<sup>51</sup>



# **TAKE CARE**



# ROLE OF PATIENT ORGANIZATIONS AND PEER SUPPORT?

Gastric 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.<sup>52</sup>

# WHAT IS PEER SUPPORT?

**Peer support means using first-hand experiences to help others.**<sup>52</sup> This typically means meeting other mGC patients and their loved ones to listen, share experiences, and provide useful advice. Patient support groups will often offer peer support.



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

## **CARING FOR SOMEONE WITH mGC?**

If you are a partner, family member, or friend of a person with mGC, 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 mGC PATIENT CAREGIVER MEAN?

A caregiver is someone who provides voluntary help to a person with mGC who would be unable to manage without them.  $^{\rm 53}$ 

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 mGC have any concerns.<sup>53</sup>

# HOW CAN I HELP?

Things you could do to help include but are not limited to:54

- 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?

**Relationships change when you 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:<sup>54-55</sup>

- 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:  $^{56-57}$ 

- 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 mGC journey, you may receive palliative care.  $^{\rm 51}$  This can happen if:  $^{\rm 51}$ 

- symptoms or side effects related to your mGC 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.<sup>51</sup>

#### 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.<sup>51</sup> Palliative care can be given for months or years depending on your individual circumstances.<sup>51</sup>

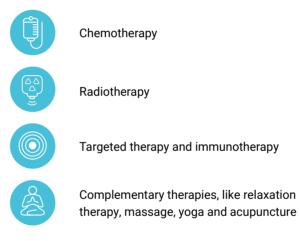


Understandably, this can be a very difficult for you and you loved ones. <u>The MyMood and MyDialogue brochures</u> may help to support your emotional health and during difficult discussions at this time.

Justin Paget © Getty Images

# 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:<sup>5,58</sup>



Palliative care also aims to fulfil your holistic needs, including psychological, social, and spiritual support.<sup>51</sup>

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.<sup>51</sup>

# **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.<sup>59</sup>

Living with mGC can be a distressing time for you and your family, but it is important to not lose hope. Finding the joy in small, everyday activities can help you to feel better about your situation. This could include making time to visit family and friends, or organizing 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 provide some answers for people living with metastatic GI cancer and their caregivers.



"mGC patients and their loved ones can often experience shock and disbelief at diagnosis, and patients may react differently than their loved ones as they can worry more about the sudden change in family life. It is hard for patients to take everything in at diagnosis so, if possible, it is better that a loved one can be there as well, to help ask questions to the health care team and to take in what is explained. Barriers to talking to the health care team is often just not knowing what to ask... Is it silly question? Am I wasting their time, or do they have the time? Talking to your family can be hard as well. Feeling hopeful is so important for patients and loved ones, many of our support group members do something they enjoy, a walk in the countryside, gardening, photography or start a new hobby, it is doing something that helps take away their thoughts even for just a little while."

Dave Chuter, Patient Advocate, UK

# **TAKE CARE**



# **GLOSSARY OF TERMS**

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TERM:	DEFINITION		Prehabilitation:	preparation for cancer treatment.
Biopsy:	a medical procedure where a small sample of tumor is taken and examined under a microscope		Prognosis:	an estimate of how a disease will progres
Chemotherapy:	a drug treatment used to treat cancer by killing cells, or stopping them from growing and multiplying		Radiotherapy:	a cancer treatment that uses X-rays or sin
End-of-life care:	a type of care given to people in the final days, weeks, or months of life.	Second-line treatment:		the second treatment recommended for a
Gastrectomy:	A surgery where you may have part of or your entire stomach removed to reduce symptoms.			treatment has failed, stopped working, or
Genetic Testing	looks for certain changes, or mutations, in your cells. Genetic information includes genes, chromosomes, and		Side effects:	symptoms experienced following treatme
	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.			somatic cens).
Magnetic resonance imaging	an imaging test that uses strong magnetic fields to show a tumor's shape, size, and location.		Stent:	a small tube which opens the blockage.
(MRI) scan:			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
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:	to the cancer. a test that uses high-frequency sound way
317. 7				



ress.

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.

ment.

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

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

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

ody 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 mGC, here are some recommended patient organizations you can visit:

DIGESTIVE CANCERS EUROPE DIG

DIGESTIVE CANCERS EUROPE Patient resources, awareness, and education

https://digestivecancers.eu/



GASTRIC CANCER FOUNDATION Patient resources, research, and nutrition https://gastriccancer.org/



DEBBIE'S DREAM FOUNDATION Awareness raising and mentor program for patients and caregivers https://debbiesdream.org/



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