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A companion guide for health care professionals

to help lead patients through
the stages of metastatic
gastrointestinal cancer

MyJourney Program



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Welcome to the MyJourney companion brochure

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.

Patients recently diagnosed with metastatic GI cancer (colorectal [mCRC], gastric [mGC], pancreatic [mPaC]) are about to undergo a journey that is likely completely unknown to them. They may feel unprepared for how their everyday life will change – from what treatment will look like and which health care professionals (HCPs) will be involved in their disease management, outcomes, survival, and wider lifestyle changes.

Providing clear information on cancer and treatment can improve patients' quality of life (QoL) and reduce their anxiety and depression.¹ It is also important that HCPs are correctly supported to provide holistic management for their patients. A strong patient-HCP relationship, utilizing your expertise and considering the patient and their loved one's preferences can help to guide them along this journey.

This companion brochure aims to support you in providing holistic support to your metastatic GI cancer patients and supplement communication of the information found in the **MyJourney** patient brochure, which you may wish to give to your patients.

This brochure provides:

- guidance on having treatment discussions with patients and their caregivers
- practical advice and resources for non-treatment-related questions
- advice on palliative care discussions.

Developed with special input from:

- **Dave Chuter**, patient advocate, United Kingdom
- **Thomas Gruenberger**, GI surgeon, Austria
- **Patrycja Rzadkowska**, patient advocate, Poland
- **Maja Juznic Sotlar**, patient advocate, Slovenia
- **Claire Taylor**, oncology nurse, United Kingdom

Introduction to MyJourney from Claire Taylor and Thomas Gruenberger

“A metastatic GI cancer diagnosis can change everything for a patient. They may never have experienced anything similar in their lives. In fact, their everyday lives will likely change significantly in many ways. The MyJourney patient brochure offers a picture of what the future might hold beyond diagnosis and supports people through each aspect of the journey to come – including staging, treatment, living with cancer and, potentially, palliative care.

This brochure is designed to support you, as the HCP, to discuss treatment options with your patients and provides practical advice and resources for non-treatment-related questions, including advice on talking about end of life. I hope you find it helpful.”

Claire Taylor, MBE, RGN, PhD,
Macmillan Nurse Consultant in Colorectal Cancer,
London North West University Healthcare NHS Trust.

“We know that a strong HCP–patient relationship is very important in guiding our patients along their cancer journey. It is important that you as the HCP are also supported to provide your expertise and holistically manage your patients' care.

This brochure aims to support you in doing that, supplementing the MyJourney patient brochure, which you may wish to give to your patients.”

Professor Thomas Gruenberger, MD
Professor and Chairman,
Department of Surgery,
Hepato-Pancreato-Biliary Center,
Health Network Vienna.



Why should you give the MyJourney patient brochure to your patients?

Having the correct information and support at the right time is key for cancer patients and their caregivers.

An international survey of cancer patients highlighted a lack of information and psychological support in their care, and only half reported that they were sufficiently involved in shared-decision making.² Moreover, a Digestive Cancers Europe (DiCE) study of mCRC patients emphasized a need for better guidance on treatment, side effects, and emotional well-being.³

Holistic aspects of life with cancer are often what matter most to patients and are reflected in how they view their treatment journey. A study of cancer patients (various tumor types) treated with an integrated cancer care model that targeted holistic needs found that:



Those who live long term with cancer have a chronic condition, and this can negatively impact different aspects of QoL – including physical, psychological, social, and financial.^{5,6} There is a clear need to support these areas in routine metastatic GI cancer care.



The MyJourney patient brochure is designed to inform and support patients with metastatic GI cancer and their families and caregivers on topics related to the whole patient journey, helping them to:

- understand the available treatment options and main HCPs involved in the patient journey
- highlight the importance of getting a second opinion
- understand their diagnosis and explain it with their friends and family
- live well with GI cancer with support for eating and exercise, socializing, sex life, working, and managing finances
- understand the role of caregivers and patient support organizations
- understand the role of palliative and end-of-life care when appropriate.

A separate GI cancer-type summary is available for mCRC, mGC and mPaC, which includes specific clinical information for your patients.

Discussing diagnosis and treatment options with patients and loved ones

At diagnosis

A metastatic GI cancer diagnosis can be shocking and frightening for patients and their loved ones, so it is important that they are not overwhelmed with information that they may struggle to absorb.

Metastatic GI cancer patients often have many questions when they are diagnosed. This is a difficult and confusing time for them, and they should receive clear information from the outset.

The most common question asked by metastatic GI cancer patients at diagnosis is:

“How long have I got?”

This may be difficult to predict soon after diagnosis and will depend upon a variety of factors, such as the type of metastatic GI cancer and the patient’s age at diagnosis. The following data may help you to give your patients an approximate idea of the average prognosis.



COLORECTAL	
Median survival for advanced disease with treatment (months)	≈30 ⁷
1-year survival rate (%)	≈80 ⁷
5-year survival rate (%)	≈20 ⁷
GASTRIC	
Median survival for advanced disease with treatment (months)	≈10 ⁸
1-year survival rate (%)	≈40 ⁸
PANCREATIC	
Median survival for advanced disease with treatment (months)	≈8 ⁹
1-year survival rate (%)	≈30 ⁹

Based on your experience and the available data, consider balancing your response on potential survivorship to be realistic but also to reassure the patient and their loved one with the treatment options available.



Discussing treatment:

The treatment landscape of metastatic GI cancer is constantly changing. Up-to-date local guidelines and ESMO, ESSO, and ASCO (<https://www.esmo.org/guidelines>) / (<https://www.essoweb.org/guidelines/>) / (<https://www.asco.org/research-guidelines/quality-guidelines/guidelines>) will contain the most recent treatment guidance.

The following flowchart provides a simplified and generalized treatment algorithm (adapted from ESMO) for your metastatic GI cancer patients. This only serves as a reference, and should be clarified against the latest guidelines.

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:

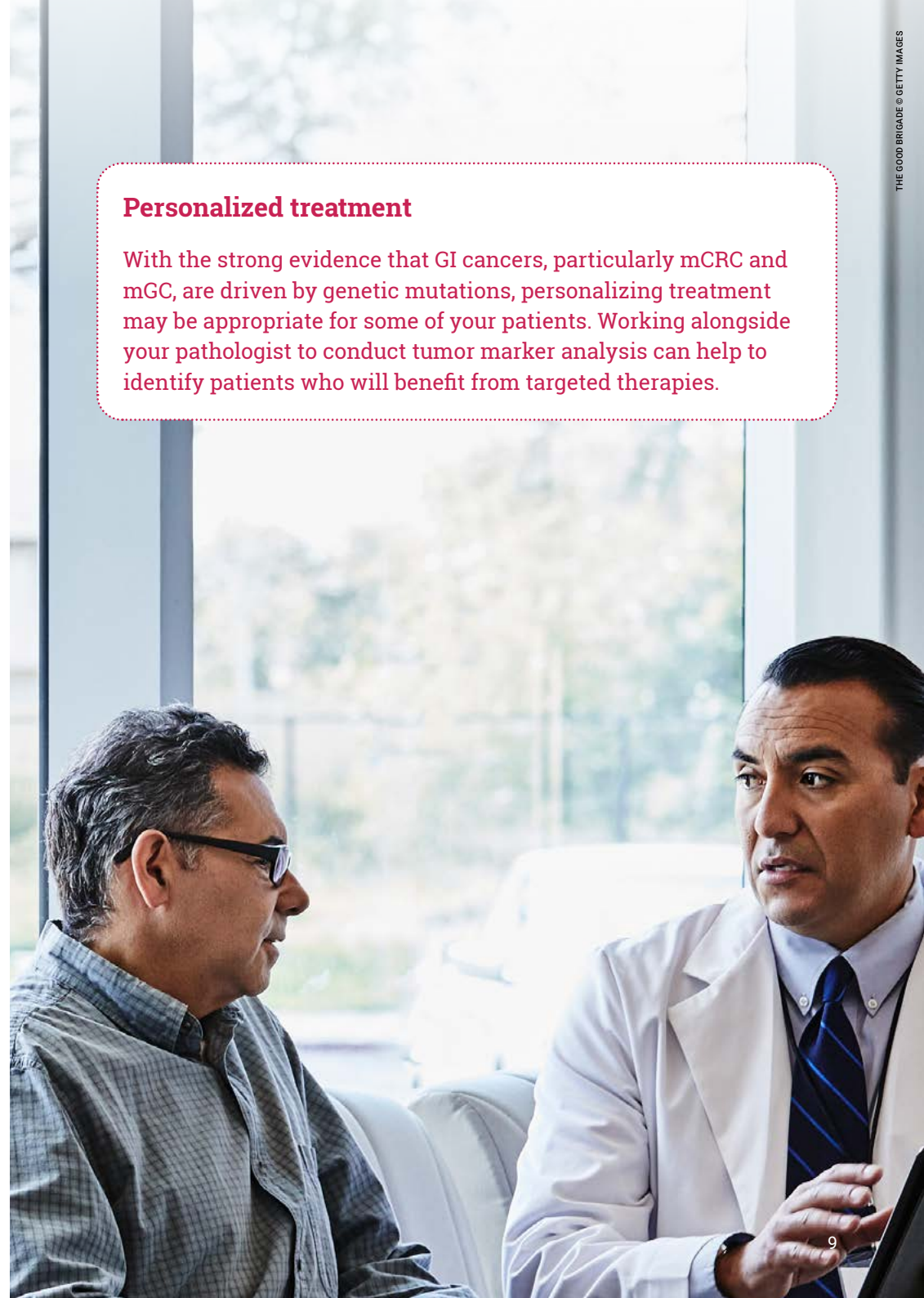
- surgery to remove part, or all of the tumors if now resectable
- further chemotherapy
- further radiotherapy
- further targeted therapy or immunotherapy.

Deviations from this could include:

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

Personalized treatment

With the strong evidence that GI cancers, particularly mCRC and mGC, are driven by genetic mutations, personalizing treatment may be appropriate for some of your patients. Working alongside your pathologist to conduct tumor marker analysis can help to identify patients who will benefit from targeted therapies.



Discussing diagnosis and treatment options with patients and loved ones

Shared decision-making: Working with your patients to reach decisions that are right for them

The relationship between HCPs and patients and their loved ones should be viewed as a partnership. Shared decision-making supports patients to make choices on their treatment and care that work best for them. It is a collaborative process where the HCP assists a patient to make their own judgments. There is some suggestive evidence that shared decision-making can improve QoL outcomes for cancer patients.¹⁰

Aspects of shared decision-making you should consider

Consider the patient's mindset within the available treatments

The patient may have their own treatment goals (eg, they may wish to have a better QoL rather than pursuing aggressive treatment that offers longer survival). You should listen to their perspective and try to incorporate this into appropriate treatments that are available.

Make the patient feel comfortable in sharing their own thoughts

Talk about treatment and care as a partnership, rather than a one-way channel. You should allow the patient to understand that they can be as active or passive in the decision-making process as they wish.



For more information about using shared-decision making in your consultations, please see the MyDialogue patient and HCP brochures.

Importance of a second opinion

Patients may or may not have the right to a second medical opinion in your country, or there could be specific rules on which patients can have a second opinion. However, you may still want to consider offering this as an option to your patients.

You should try to:

✓ not take offense if a patient asks for a second opinion

Patients and their loved ones do not always seek a second opinion to find a different clinician. They may have other reasons such as joining a clinical trial that your site does not offer. Where possible, try to help them find and contact another specialist

✓ manage patients' expectations

It may help to make patients and their loved ones aware that a second opinion:

- does not necessarily mean they will have a more effective treatment or be treated at a different hospital
- may delay when treatment starts.

However, a second opinion may help the patient and their loved ones feel better knowing that two experts have agreed on a diagnosis/treatment plan or that different treatment options are available to them.

Clinical trials

During treatment discussions, it may be appropriate to mention clinical trials. Informed patients and their loved ones may also arrive with a selection of clinical trials that they wish to join. Try to manage their expectations and explain the positives and negatives of a clinical trial in a balanced and fair manner. Important points to mention are:

- you may or may not receive a more effective treatment than standard of care
- you may be excluded from receiving other proven treatments afterwards
- you may have to travel, sometimes to other countries, which can delay treatment initiation.

It may help to explain that while clinical trials can benefit the patient, they also aim to improve research and treatment for future patients. Providing the patient and their loved one with the correct resources and information to consult in their own time can help this process.



The importance of holistic management

There may only be a short amount of time during your appointments to discuss non-treatment-related questions. However, addressing non-treatment-related factors can have a positive impact on your patients.

Between 25% and 60% of cancer patients report distress during their consultations.¹¹ Levels of depression and anxiety are higher for those with a worse prognosis, such as mPaC patients.¹² Much of this distress comes from financial worries and symptom-related depression and anxiety.^{13,14} Research suggests that patients who experience high levels of untreated distress are less adherent to treatment, more likely to be dissatisfied with their care, and have poorer rates of QoL and survival.¹⁵⁻¹⁸

These data suggest that assessing the holistic needs of your patients at regular points on their treatment journey may help to identify areas of distress and allow you to take action to reduce them.



What is a holistic needs assessment?

Some patients may find it difficult to voice some or all of their non-treatment-related concerns without encouragement. A holistic needs assessment prompts patients to score their physical needs/symptoms, social, psychological, and spiritual needs in a structured way.¹⁹

A holistic needs assessment will typically comprise:²⁰



How can a holistic needs assessment help my practice?²⁰

- Help to focus the conversation on the areas that matter most to patients
- Help to personalize care and support
- Inform the wider multidisciplinary team (MDT) of holistic needs
- Help patients to feel more understood and identify potential issues earlier

Assessing your patients' needs

What tools can support the assessment of my patient's holistic needs?

Tools specific for cancer type

[Functional Assessment of Cancer Therapy \(FACT\) – Colorectal](#) is a freely available and validated measure that can be self-administered or done via interview and focuses on physical, social, emotional, and functional well-being, as well as a selection of colorectal cancer-specific questions.²¹

There is also a [FACT – Gastric](#) and [FACT - Hepatobiliary Cancer Symptom Index \(covering pancreatic cancer\)](#) which are free and follow a similar process to FACT – Colorectal.^{22, 23}

General tools

[The Distress Thermometer](#) is a patient self-reported questionnaire that scores total distress and highlights specific physical, practical, family, emotional, and spiritual issues faced.¹¹ It is free, widely translated, and adequately reliable.¹¹

[The PEPSI-COLA](#) (Physical, Emotional, Personal, Social support, Information, Control, Out of hours, Living with your illness, After care) aide memoire is a free HCP-led checklist that can help remind you of the non-treatment-related factors that can affect your patients' lives.²⁴

These tools can help you to identify areas of concern in patients' lives and guide a referral to specialist support if needed.

The value of peer support

There are patient organizations, charities, and support groups available to supplement the holistic care you provide for your patients.

These types of psychosocial interventions, such as supportive group therapy, have been found to improve chemotherapy adherence.²⁵ You may even like to join a patient organization or attend a local peer support group yourself to help inform your practice.

Patients and their loved ones are often unaware that these types of groups and meetings exist, so you may wish to make them aware, highlight the benefits of joining, and provide national and local contact details.

Peer support can come in many different formats, such as:



online forums
and social media
platforms



face-to-face
individual or
group meetings



virtual meetings,
through software like
Zoom or Teams



phone calls.

You may also want to remind patients and their loved ones that patient organizations and peer support groups cannot give medical advice.

Any advice given through peer support, especially relating to treatment, should be clarified with you or the wider health care team.

Areas that may be of concern to your metastatic GI cancer patients

The following concerns may be faced by your patients at some point during their metastatic GI cancer journey¹⁹

Adapted from the MacMillan Concerns Checklist



Physical concerns

Changes in bladder/bowel habits, stoma, fatigue, pain or discomfort, weight changes, swallowing, indigestion, dumping syndrome, sore or dry mouth/ulcers, movement issues, skin issues, wound care, appearance, sleep problems, and sex or intimacy issues.



Emotional concerns

Uncertainty, loss of interest in hobbies, loss of emotion, thinking about the future, regret, anger, frustration, hopelessness, loneliness, sadness/depression, guilt, anxiety, and independence.



Spiritual concerns

Faith or spirituality, meaning or purpose of life, being at odds with own culture and beliefs or values.



Practical concerns

Working, education, caring for others, finances, housing, travel, housework, cooking, shopping, smoking cessation, alcohol and drug problems, and issues with medication.



Social concerns

Partners, children, caregivers/loved ones, friends, and people they provide care for.



Information or support needs

Exercise, diet, complementary therapies, planning for future priorities, legacy planning, holistic well-being, peer support (patients and loved ones), and symptom management.

Managing holistic conversations with cancer patients: Answering your patients' questions and concerns

Some patients and their loved ones will come to consultations with questions about how their GI cancer will impact their lives. The following list is a selection of common queries with suggested guidance on how to respond.

Can I live well with GI cancer?

Advise that although GI cancer and treatment can be physically and emotionally draining, with support, many people can continue to live well. Caveats are those with mPaC and some mGC patients as these typically have a much shorter length of survival.^{8,9}

Example response: "Living with metastatic GI cancer is not easy; there will be many hard moments, and you may have to stop certain activities. However, as your health care team, we can help and support you to continue or return to some of things you enjoy as comfortably as possible."

How will my diet be affected?

Nutritional deficiency affects as many as 50% of cancer patients.²⁶ This issue is often intensified by GI surgery and chemotherapy side effects. Advise that eating well can help maintain strength, reduce the risk of infection, cope better with side effects/treatment, and recovery from therapy.²⁷ You may also want to highlight specific issues, such as the importance of fiber for mCRC patients, dumping syndrome in mGC, and the possible need for pancreatic enzyme replacement therapy in mPaC.²⁸⁻³¹ **The MyFood patient brochure is a useful resource to help discuss specific issues with diet and nutrition and provide support.**

Example response: "It is likely that your cancer or treatment will affect your diet and cause weight loss. However, with adaptations to how you eat, we can reduce this and make you feel a bit better. Please let me or the wider health care team know if you notice any weight loss or have problems with eating. We can help you to keep eating well."

Should I continue to exercise?

Highlight the strong evidence that people with GI cancer who do some physical exercise have a better QoL, fewer and less severe side effects, and even prolonged life.^{32,33} **The MyMove patient brochure contains an mCRC exercise program developed by a cancer rehabilitation specialist that may be useful for your patients.**

Example response: "I would highly recommend doing some very light and easy exercise when you can, but only as much as you feel like doing, and it is fine to have days off. Even just walking around the house or garden may help."

Can I still socialize with GI cancer?

Advise your patients to stay in contact with loved ones to avoid social isolation. Evidence shows that GI cancer patients and their loved ones who received emotional support from others were less lonely, with possible emotional benefits.³⁴ **The MyMood patient brochure may offer some guidance for your mCRC patients (although parts of it can be applied to other GI cancers) on looking after their emotional health.**

Example response: "Although you may feel tired or unwell, socializing with others may actually make you feel better. Try calling a friend or family member for a chat when you feel up to it."

How will my sex life be affected?

You should be transparent from the start on how your patients' sex lives may be affected. GI cancer and treatment can cause issues with libido, body image, erections, ejaculation, and vaginal tightening and dryness. There can also be nerve damage following rectal surgery that may affect anal sex and cause problems with erection and ejaculation in some men.³⁵

You should recommend your patients be open about sex life issues either with their partner or yourself and the wider health care team. You could also refer them to a sexual therapist or other specialist if they are struggling to talk about this issue.

Example response: "Your cancer and treatment may affect your sex life in a number of ways. As your health care team, we are trained and available for you to talk about any issues you may have. We can also refer you to a sex specialist if you would like."

Will I still be able to work?

You should let your patients know that while working full time during and after treatment can be challenging, some work does help people to remain physically and mentally active. This will depend upon the cancer and treatment type.

Example response: "While you may now want to take time away from work, indefinitely or permanently, employment can help to keep you physically and mentally active. We can talk about this further based on how I think your cancer will affect you on an everyday basis moving forward."

Will my finances be impacted?

It is likely that your patients' and their loved ones' finances will be impacted in some way depending upon current circumstances. You could provide them details of patient organizations who can assist them.

Example response: "Having cancer can increase your outgoings. Have you thought about budgeting? I can give you the details of someone who can help you to do this?"

Who should I speak to about the daily changes caused by my GI cancer and treatment?

Make it clear that they can discuss these issues with you and other members of the MDT. This is also a good opportunity to signpost to patient organizations and peer support networks for their holistic benefit.

Example response: "We work as an experienced team comprised of many different specialties. If I can't answer your question now, I can find an answer for you or point you in the right direction. If you would feel more comfortable speaking to an organization for patients, or other people who have had or have cancer, I can put you in touch with them too."

Palliative and end-of-life care

Palliative care conversations can be challenging for both patients and HCPs. Some metastatic GI cancer patients will want to discuss these frankly; others will not.

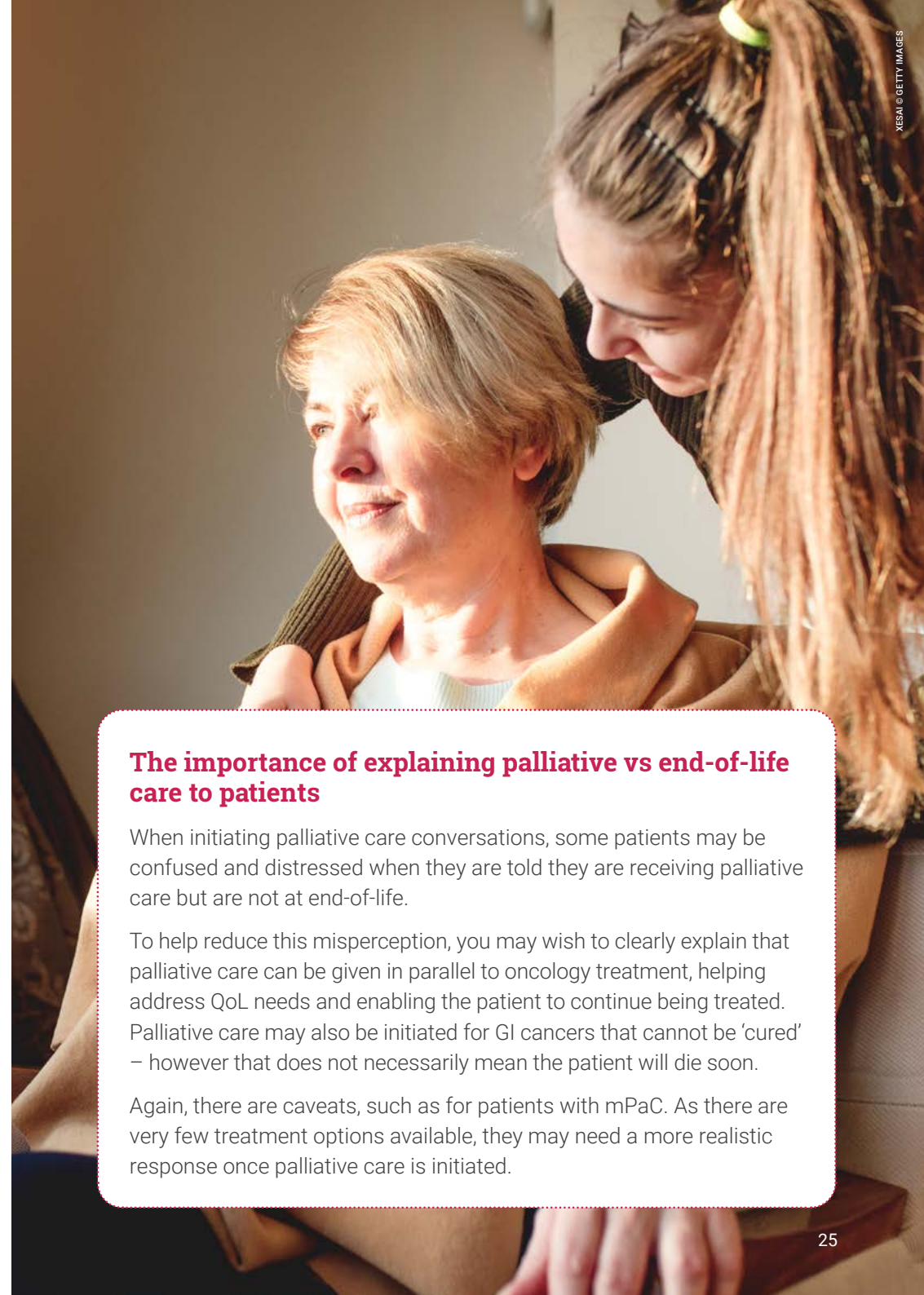
You, as the clinician, are often expected to initiate the palliative care dialogue. There are some ways that you can improve your palliative care discussions.

Balancing the need for the conversations against taking away patients' hope

Death is a difficult topic for some patients and their loved ones – they may see it as giving up. On the other hand, it may be beneficial for palliative care discussions to happen when a patient is well and able rather than when they are very unwell and distressed. There is evidence to suggest that early initiation of palliative care can lead to improved symptom control, reduced distress, and care delivery that matches the preference of the patient.³⁶

The timing of palliative care discussions should be based individually on the patient and their loved one, considering their emotional state, available treatment options, and prognosis. For example, it may be more appropriate to initiate palliative care discussions with mPaC and mGC patients earlier as they have a much lower median survival rate than those with mCRC.^{8,9}

You can find European palliative care guidelines and resources here:
<https://www.eapcnet.eu/publications/national-guidelines/>



The importance of explaining palliative vs end-of-life care to patients

When initiating palliative care conversations, some patients may be confused and distressed when they are told they are receiving palliative care but are not at end-of-life.

To help reduce this misperception, you may wish to clearly explain that palliative care can be given in parallel to oncology treatment, helping address QoL needs and enabling the patient to continue being treated. Palliative care may also be initiated for GI cancers that cannot be 'cured' – however that does not necessarily mean the patient will die soon.

Again, there are caveats, such as for patients with mPaC. As there are very few treatment options available, they may need a more realistic response once palliative care is initiated.

Initiating palliative and end-of-life discussions – A four-step process³⁷

Adapted from A Physician's Guide to Talking About End-of-Life Care

1. Initiating dialogue

Patients and their loved ones will speak more openly and put trust in the HCP when they feel compassion and empathy. In doing so, death becomes less of a challenging subject. You may wish to:

- **create a supportive relationship with the patient and their loved ones**

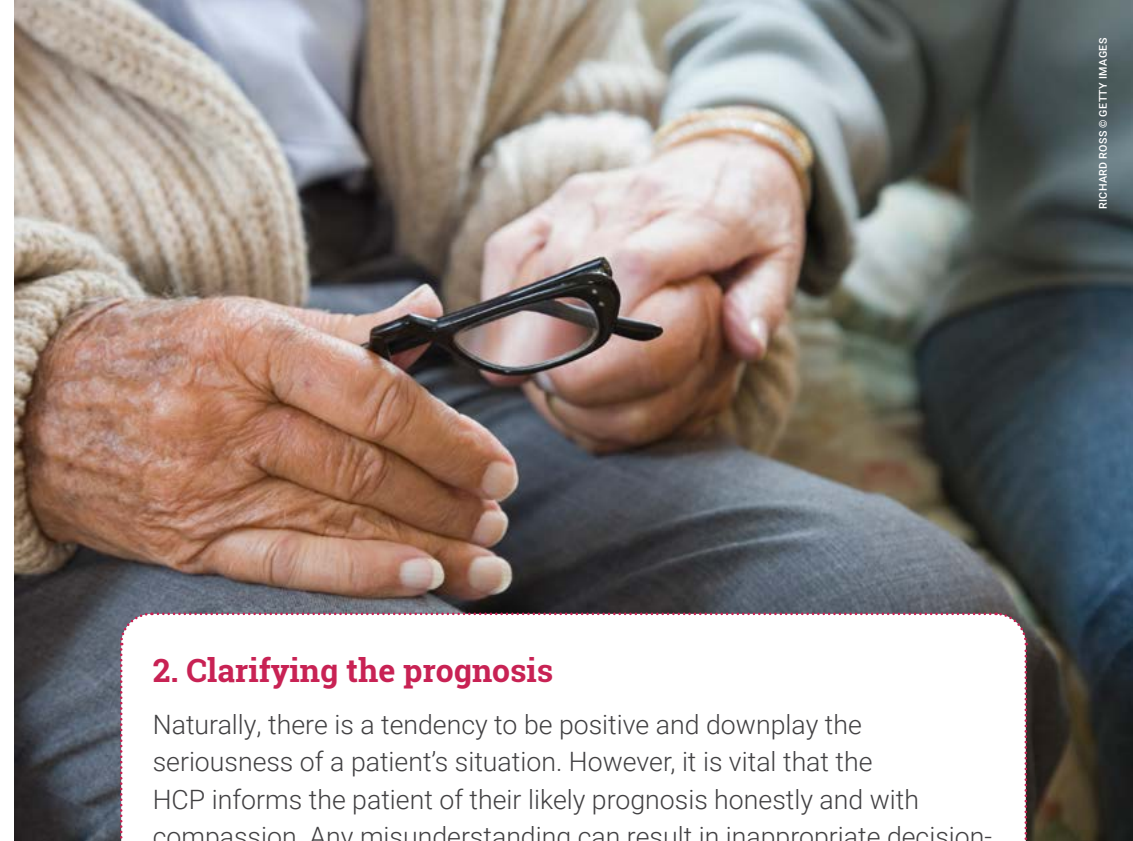
"I know this is a very challenging and frightening time for you and your family, but as bad as it is, we will deal with it together."

- **appoint a surrogate decision-maker**

"If you became too ill to speak for yourself, who would you want to make decisions about your care?"

- **explore the patient's thoughts on palliative and end-of-life care to begin to understand preferences**

"We cannot predict exactly what medical treatment you may need, but it's important for me to know what you would like to receive. How do you imagine spending your last months, weeks, and days?"



2. Clarifying the prognosis

Naturally, there is a tendency to be positive and downplay the seriousness of a patient's situation. However, it is vital that the HCP informs the patient of their likely prognosis honestly and with compassion. Any misunderstanding can result in inappropriate decision-making from the patient and their loved ones, so you should:

- **be direct, but show empathy**

"Treatments that may have worked for you are no longer helping. I know that you want to be better, but that is not realistic."

- **tell the truth but maintain regard for the situation**

"Most people with your illness may continue to do well for 2-3 years. However, that is the average patient, and I cannot tell you exactly how you will do. I hope you will do much better than the average, but there is also a chance you will do much worse."

- **use simple language and check understanding.**

"I want to be sure I've clearly explained your situation. Could you tell me your understanding of what is ahead for you?"

3. Identifying the patient's goals

Once the prognosis is clear, the HCP's role is to allow open discussions around preferences for medical care and remaining life goals.

"As your health care team, we want to make sure we're always doing things that might help you and nothing that won't help you or you don't want. I need to know what things are most important to you. How do you want to spend your remaining time?"

- **most patients will have similar aims, such as:**

- maximizing time with loved ones
- avoiding unnecessary use of health care
- minimizing pain
- maintaining functionality.

This is also an opportunity to revisit earlier advanced care discussions to see whether the patient's desires need to be altered.

"A few months ago we spoke about your care preferences if you became very ill. We are now facing that scenario right now, and I want to check to see if your thoughts are the same or they have changed?"

4. Developing a care plan

Patients and loved ones will look to HCPs for guidance around care, and this should be based on your expertise and their preference. Patients and loved ones should be clear on resuscitation to forgo unnecessary and invasive treatment. You should:

- **make recommendations on appropriate treatment but consider the patient's decisions**

"We can organize your chemo on an outpatient basis and arrange visiting nurses to see you at home when needed to maximize the time you spend with your grandchildren."

- **clarify resuscitation orders, if necessary**

"I will ensure you're comfortable at all times, and ultimately, you are able to die comfortably. We will not plan to use any form of resuscitation. Does that correctly fit into your preferences?"

- **initiate timely and appropriate palliative care to reduce pain and provide maximal comfort**

"Continuing aggressive treatments now will not help you and may actually be painful. However, we can now make you comfortable, so you don't feel any more pain."

Be aware that a patient may accept an outcome, but a loved one may not (or vice versa). It may help to give all stakeholders the time to discuss amongst themselves without rushing them to a decision.

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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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