



**Getting more from
your conversations
with health care
professionals –**
for people with metastatic
colorectal cancer

MyDialogue Program

Welcome to MyDialogue

MyDialogue is part of the Support Harmonized Advances for better Patient Experiences (SHAPE) program, which provides lifestyle support to people with metastatic colorectal cancer (mCRC). This brochure has been developed with input from people with cancer, patient advocates, and cancer experts.

Sometimes, conversations with health care professionals about your cancer can be confusing and overwhelming. There is often a lot of information to take in. There may be parts of your condition you just don't want to talk about. It can be difficult to think about the future or have conversations about your treatment plan.

MyDialogue is about making these conversations easier and sharing in the decisions that will impact your life and health.

Your health care professional knows about the treatments they can offer you and the risks and benefits. You know about your body. You bring your own personal experiences,

values, and goals. You know what you want from your life. As much as you are willing and able, you can share treatment decisions – working with your doctor or nurse.¹⁻⁴

The MyDialogue brochure aims to help you communicate with health care professionals, so that – as far as possible and as much as you desire – decisions about your care can be made with you in mind.

Developed with special input from:

- *Alberto Sobrero, oncologist, Italy*
- *Claire Taylor, oncology nurse, UK*
- *Barbara Moss, mCRC survivor and patient advocate – Digestive Cancers Europe*
- *Mark Moss, patient representative, carer – Digestive Cancers Europe*
- *Maja Juznic Sotlar, patient advocate – Digestive Cancers Europe*



Contents of the MyDialogue brochure

Shared decision-making: Working with your health care professional to reach decisions that are right for you

- What is shared decision making?
- How can I be involved in shared decision making with my health care professional?

Preparing for conversations with health care professionals

- How can I get the most out of my conversations with health care professionals?
- How do I prepare for my medical appointment?
- What are my personal experiences, my goals, and my values?

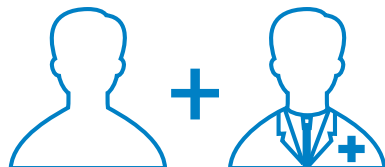
Evaluating your treatment plan between appointments

- Did I ask everything that I wanted to at my last appointment?
- Is my treatment plan working for me?
- What happens next?

Glossary of terms

**TOP
TIP**

No question is a stupid question when it comes to cancer – you can ask anything that you want!



Shared decision-making: Working with your health care professional to reach decisions that are right for you

Shared decision-making is the conversation that happens between a patient and a health care professional to make health decisions together, taking into account:⁵

- Your preferences, your personal experiences, your goals, and your values
- Your health care professional's knowledge of available treatments, and the potential risks and benefits of those treatments – there is always more than one option.

When you attend a medical appointment, you may want to have a meaningful discussion that takes full advantage of your health care professional's expertise and knowledge, while also being able to talk about your own questions or concerns.⁶

As a patient, 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 professional will help you reach decisions that are right for you.



**TOP
TIP**

You might want to bring someone with you to appointments for support

Patient
Expert in your own life

I know my own
body and my personal
needs and goals, and I want to
understand how the different
options could affect me





Health care professional
Expert in health care

I know the
treatment options I can
propose – and want to
help you understand the
risks and benefits
of each







Share: You and your health care professional share expertise. You share what is important to you – your experiences, your goals, and your values – and your health care professional helps you explore treatment options and the potential risks and benefits of each.

► **Example questions**

-  What are the available treatment options?
-  What are the risks and benefits / advantages and disadvantages of each option?
-  What do I want from my treatment plan?
-  What do I care about the most?

Discuss: You both discuss your potential treatment and care based on the available evidence and your personal values and choices.

► **Example questions**

-  How will these different options impact my life?
-  What do these options mean for me personally?
-  What risks am I willing to take?
-  What could the side effects be?

Agree: You make a decision together on the most suitable treatment and care plan for you.

Preparing for meaningful conversations with health care professionals

Preparing for medical appointments can make it easier for you to have a meaningful conversation about your treatment options and personal experiences. This is especially true if you often feel overwhelmed or confused.

You might want to start by thinking about your personal questions and concerns. These may be directly related to your treatment plan or may be about the impact of your mCRC diagnosis on your life.

My diagnosis:

- What does the diagnosis of mCRC mean for me?
- What are my chances?
- What will happen next?
- Can I have any information to take away with me?
- Can I ask for a second opinion?

My commitments:

- Can I continue to work if I wish to?
- Will my diagnosis and care have an impact on my family?
- Will my diagnosis and care have an impact on my hobbies?

My support system:

- Will you be my main point of contact?
- Who else could answer my questions?
- Can I have access to any other support?
- Is counseling available for me and my family?

Changes:

- Will my appearance change?
- Will my appetite change?
- Will I experience any other changes?

Each person is different and your experience is unique – these are suggestions, not an exhaustive list.

**TOP
TIP**

You might want to record your appointments to revisit at a later time. Ask your doctor if this is possible.



Use this space to write down your own top-priority questions and concerns...

**TOP
TIP**

Keep a dedicated notebook to write down questions when they come to mind – and take it with you to appointments!



Evaluating how your care plan is working for you

Between appointments, you may wish to take time to:

- Think about how your last appointment went
- Evaluate how well your care plan is working for you – given your own preferences, goals, and values
- Look ahead and plan for your next appointment.

After my appointment:

- Did I ask everything I wanted to?
- Is there anything I don't understand?
- Are there any medical terms I want to look up? (see the glossary of terms at the end of this brochure as a starting point).

My care plan so far:

- Do I understand my 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?

My next appointment:

- When and where is my next appointment?
- Is there anything I can do to prepare for my next appointment (eg, tracking symptoms and treatment side effects)?
- Do I want to ask anything else at my next appointment?



Each person is different and your experience is unique – these are suggestions, not an exhaustive list.

**TOP
TIP**

It is a good idea to ask your health care professional for a summary of your session



Use this space to write down any other questions or concerns that come to mind...

**TOP
TIP**

You can always ask for a second opinion if you feel this is necessary



Glossary of terms

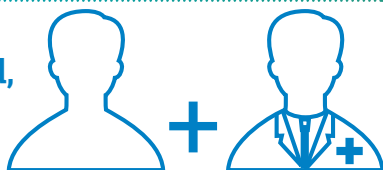
This glossary is designed to help you understand some of the terms related to mCRC that are used most often.

It is not a comprehensive list, other terms may be used by health care professionals.

- **Abdomen** – the part of the body that contains the stomach, bowels, and other organs, sometimes called the ‘belly’
- **Adjuvant** – a substance that helps or improves the effect of a given treatment (for example, chemotherapy may be given as an adjuvant to surgery)
- **Biopsy** – a procedure to remove a piece of tissue or a sample of cells from the body for examination. The examination allows your doctor to check whether disease is present
- **Blood test** – a procedure where a sample of blood is tested. It is usually done to help diagnose or find out more about a disease
- **Chemotherapy** – a type of treatment used to stop the growth of cancer cells, either by killing the cells or stopping them dividing
- **Colon** – a long, tube-like organ in the body - the part of the digestive system where water is removed from digested food
- **Colonoscopy** – a procedure in which a doctor puts a tube-like device into the body to look inside the colon
- **Colostomy** – a surgical operation in which the colon is connected to an opening in the abdomen. This allows stool to leave the body
- **Endoscopy** – a procedure in which a doctor puts a tube-like instrument into the body to look inside
- **First-line, second-line** – the first-line treatment is the standard, preferred or first given for a disease; your doctor may then suggest a second-line treatment, or a third, if the first is not effective
- **Genetic testing** – a kind of test that provides information about a person's genes – can be used in the diagnosis of some types of cancer
- **Ileostomy** – a surgical operation in which the part of the intestine, called the ileum, is connected to an opening in the abdomen. This allows stool to leave the body
- **Ileus** – a condition where there is a lack of movement in the digestive system
- **Metastatic cancer** – a cancer that has spread from the primary location to other parts of the body
- **Palliative care** – care given to improve the quality of life of patients and families faced with a life-threatening illness
- **Peritoneum** – a lining that covers the wall of the abdomen and the abdominal organs
- **Polyp in the colon** – small growth on the lining of the colon or rectum – most are non-cancerous, but some types of polyp can become cancerous. This is why it is important to have them removed

TOP TIP

If your doctor or nurse says a word you do not understand, ask them to explain it in simple terms



- **Radiotherapy** – a type of treatment that uses high-energy rays to kill cancer cells and stop them from growing and dividing
- **Rectum** – the last part of the digestive system that ends at the anus
- **Hemicolectomy** – a surgical operation to remove part of the colon
- **Shared decision-making** – The conversation that happens between a patient and their health care professional to reach a health care choice together
- **Stoma** – an opening on the surface of the abdomen which has been surgically created to divert the flow of waste. This is the outcome of a colostomy or ileostomy
- **Terminal care** – care given to a person when they are critically ill

For more information and support, you can contact your local association:

Bosnia and Herzegovina	UORDC
Cyprus	The Cyprus Association of Cancer Patients and Friends (PASYKAF)
Czech Republic	Onkomajak
Finland	Colores - The Finnish Colorectal Cancer Association
Greece	AgaliaZO
Italy	EuropaColon Italia Onlus
Italy	Vivere senza Stomaco si può
Lithuania	Lithuanian Cancer Patient Coalition (POLA)
Malta	Malta Colorectal Cancer Awareness Group - MCRCAG
Poland	Fundacja EuropaColon Polska/EuropaColon Poland
Romania	Community Health Association
Russia	Russian Association of Oncology Patients "ZDRAVSTVUY!"
Serbia	CRC Patient Association
Slovenia	EuropaColon Slovenia
Turkey	Dance with Cancer
UK	Bowel Cancer UK
Macedonia	Borka
Netherlands	Colon Cancer Workgroup
Portugal	EuropaColon Portugal
Hungary	Recovering Together Associaiton
Spain	EuropaColon España
Slovakia	Nie Rakovine
Belgium	FAPA
Belarus	The Center for Support of Oncological Patients "In the Name of Life"
France	Mon réseau Cancer Colorectal
Spain	Asociación contra el cáncer gástrico y gastrectomizados

The SHAPE Steering Committee:

- **Chair:** Professor Alberto Sobrero, oncologist, Italy
- Alexander Stein, oncologist, Germany
- Zorana Maravic, patient advocacy leader, Serbia
- Sarah Dauchy, psycho-oncologist, France
- Claire Taylor, oncology nurse, UK
- Klaus Meier, oncology hospital pharmacist, Germany

The MyDialogue Program is part of the Support Harmonized Advances for better Patient Experiences (SHAPE) initiative which is an unbranded patient program funded by Servier.

Thanks go to our partner in patient perspectives and insight - Digestive Cancers Europe (DiCE) - and its members for their collaboration.

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 (planned)
5. MyJourney – negotiating the GI cancers journey (planned)

References

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6. The SHARE Approach—Essential Steps of Shared Decision-making: Quick Reference Guide. Available at: <https://www.ahrq.gov/health-literacy/curriculum-tools/shareddecisionmaking/tools/tool-1/index.html> (last accessed October 2019).