



A companion guide for health care professionals

to encourage more productive
communication with metastatic
colorectal cancer patients

MyDialogue Program

Welcome to the MyDialogue companion brochure

MyDialogue 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 colorectal cancer (mCRC). The SHAPE program is funded by Servier.

As you know, a cancer diagnosis is almost always a shock for patients. They may feel confused and alone. Medical terminology may be incomprehensible or overwhelming. There may be elements of the diagnosis or treatment plan that some patients don't understand or simply don't want to talk about. Some patients will want to hear a lot of information; others will not want much at all.

Clear and simple communication is vital so that decisions about care and treatment can be shared with patients, as much as they are willing and able to be involved.

The MyDialogue patient brochure is designed to help patients get the most from their discussions

with health care professionals. It reminds patients about the importance of sharing decisions with their health care professional to make choices that are right for them and that they feel comfortable with; it helps them to prepare before appointments and evaluate what was discussed and how they feel about their ongoing treatment plan after appointments.

This MyDialogue companion brochure reiterates the importance of shared decision-making and effective communication with our patients to help support best outcomes.



Developed with special input from:

- **Professor Alberto Sobrero**, oncologist, Italy
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“ At the heart of shared decision-making is recognizing that health care professionals and patients bring different, but equally important, forms of expertise to the decision-making process. Positive, open communication with our patients is critical to identify each person's own preferences and values – and help them to gain a clear understanding of their diagnosis and treatment options – to ultimately reach decisions that work for their personal circumstances. ”

Professor Alberto Sobrero,
San Martino Hospital, Genoa, Italy

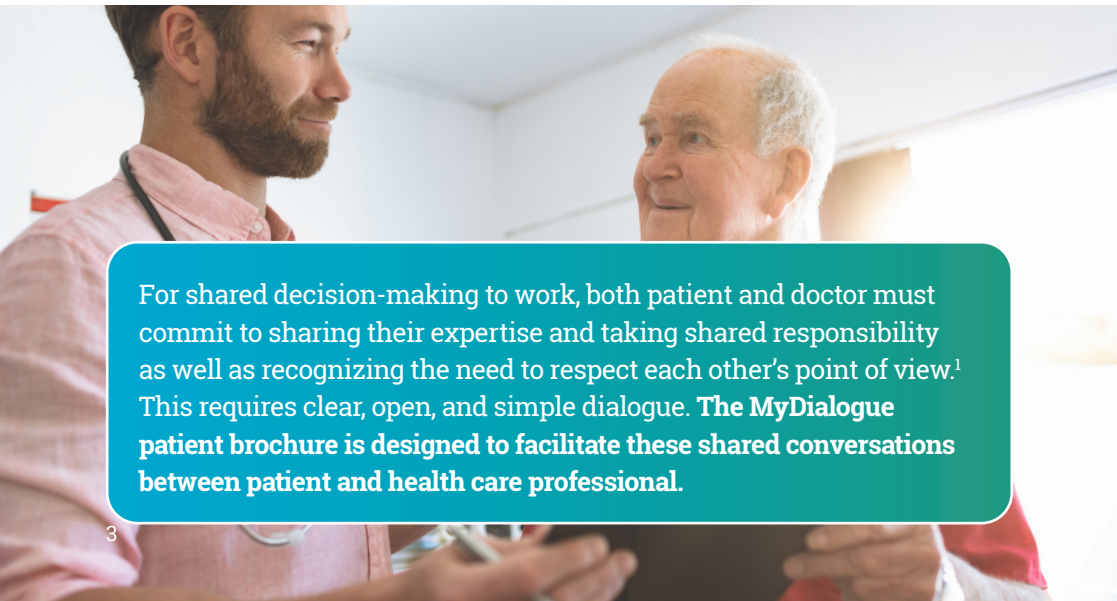
Shared decision-making: Working with patients to reach decisions that are right for them

Getting to know your patient:¹

When working with patients, try to ask questions which get them thinking about what matters to them. It's good to acknowledge the important role they play when making decisions about their treatment. This will help lead to better decisions and also tailor support more appropriately to that individual.

Practising good evidence-based medicine means integrating the following into decision-making:²

- **Best available evidence** – clinically relevant research, including patient-focused studies exploring specific therapeutic regimens, prognostic markers, and diagnostic tests.
- **Individual clinical expertise** – not only encompasses effective and efficient diagnosis, but also thoughtful identification and use of patients' individual rights, preferences, and values.¹



For shared decision-making to work, both patient and doctor must commit to sharing their expertise and taking shared responsibility as well as recognizing the need to respect each other's point of view.¹ This requires clear, open, and simple dialogue. **The MyDialogue patient brochure is designed to facilitate these shared conversations between patient and health care professional.**

| Health care professional expertise | Patient expertise |
|------------------------------------|--|
| Diagnosis | Personal experience of illness / treatment to date |
| Etiology | Personal circumstances |
| Prognosis | Attitude to risk |
| Treatment options | Values and goals |
| Possible outcomes | Treatment preferences |

*Table based on: The King's Fund. Making Shared Decision-Making a Reality.



Health care professional
Expert in health care



Patient
Expert in their own life



MyDialogue patient brochure: An overview

Shared decision-making

Reminds patients that they can play a role in the decision-making process – to the extent that they are willing and able.

As health care professionals, we should explore each of the care options with the patient, discussing the risks and benefits – simplifying or tailoring our recommendations as needed to the person in question – and we should work to understand each individual's own preferences, goals, and values.

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:

- 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.*

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.

Diagram: A flowchart showing the process of shared decision-making. It starts with 'Patient: Expert in your own life' and 'Health care professional: Expert in health care'. These lead to '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.' This leads to 'Discuss: You both discuss your potential treatment and care based on the available evidence and your personal values and choices.' This leads to 'Agree: You make a decision together on the most suitable treatment and care plan for you.'

Example questions:

- Share:**
 - What are the 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:**
 - 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?

Preparing for meaningful conversations

Encourages patients to consider their own personal questions and concerns before attending medical appointments – whether these are related specifically to their treatment plan, or more generally, about the impact their diagnosis may have on their life.

As the health care professional, we should listen to and answer all of the patients' questions and concerns, ensuring we understand their priorities.

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 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 change?

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?

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...

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

Checking in before the next appointment

Encourages patients to use the time between appointments wisely – to think about how their last appointment went; evaluate how well their treatment plan is working for them; and to look ahead to their next appointment.

As the health care professional, we should encourage the patient to reflect upon their previous appointment and prepare for the next, considering any shifting personal goals.

Evaluating how your care plan is working for you

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...

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)
- Do I want to ask anything else at my next appointment?

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 them?

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

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

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

References:

1. Kebede S. Ask patients "What matters to you?" rather than "What's the matter?" *BMJ*. 2016; 354 :i4045.
2. Sackett D, Rosenberg W, Muir Grey J, et al. Evidence based medicine: what it is and what it isn't. *BMJ*. 1996; 312:71.
3. The King's Fund. Making Shared Decision-Making a Reality. Available at: https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf (last accessed September 2019).