Looking after your emotional health

for people with metastatic colorectal cancer

MyMood Program

mCRC SHAPE

Welcome to MyMood

MyMood is part of the **S**upport **H**armonized **A**dvances for better **P**atient **E**xperiences (SHAPE) program, which provides lifestyle support to people with metastatic colorectal cancer (mCRC). This brochure has been developed with input from people with cancer, as well as experts in emotional health and cancer.

Living with cancer is often a long journey – and can affect your emotional health, just as it affects your physical 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.[1]

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

Your immediate response to diagnosis – or learning your cancer has advanced – may be shock, fear, guilt, or uncertainty about the future.[2] 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. In fact, you may experience a whole range of emotions and variations in your mood within the same day or week. Some people may experience more severe difficulties like depression and anxiety.[3]

This brochure will help you understand the different feelings you may experience with practical tips to help you manage these emotions day-to-day and advice in case you need to seek help from a professional, such as a psychologist or psychiatrist.

Developed with special input from:

- *Sarah Dauchy, psycho-oncologist, (psychiatrist with oncology specialism), France*
- *Claire Taylor, oncology nurse, UK*
- *Zorana Maravic, patient advocacy leader, Serbia*
- *Carlos Hué, patient representative, Spain*

Looking after your emotional health as you live with a cancer diagnosis

Everyone's cancer journey is different – each person will react differently to the difficult news of a cancer diagnosis. There is no right or wrong reaction.

While emotional reactions are natural, they should not impact your daily life in a significant or lasting way. It is important to regularly check in with how you are feeling. There are things you can do that could positively impact your emotional health and quality of life. Or, you may need extra help from a professional to manage your emotions – remember that it is OK to ask for what you need.

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?

Try some of the techniques and tools on the following pages of this brochure.

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?

Ask: how do I feel today?

It can be helpful to check in with how you are feeling each day. This can help you to speak to others about your emotions. Sometimes you might find it difficult to identify your emotions, or to accept how you are feeling. That is OK!

Relieved Prepared Anxious

Happy Peaceful Confused Scared

Determined Lonely

Positive Depressed

Lost

Suicidal*

Unsure

Despairing

Tired

Sad Overwhelmed

Irritable Angry

TOP TIP If you feel better emotionally, you will find it easier to live with your cancer diagnosis and treatment, so don't be afraid to ask for help.

*If you are having suicidal thoughts, find someone to talk to as a first step. If not a member of your family or a friend, then call on the help of a local support group or charity. A health care professional, such as a psychologist or psychiatrist, will be able to provide appropriate treatment and care.

Ask: what impact are these feelings having on my life?

How do I know if it's something more serious?

It's normal to feel any one or more of these feelings from day-to-day. But, it is important to know the difference between a few 'down days' and signs of something more serious, like depression.

Depression can range from mild, which may have some impact on your life, to severe, which can make it very difficult to get through each day.[4]

If you experience negative feelings, such as sadness, loss of pleasure and irritability, or insomnia, and these are excessive, interfere with daily life, and continue for more than a couple of weeks, then you may be experiencing some form of depression.[5]

You should share these feelings with your health care professional. They will be able to signpost you to the appropriate person who can help you.

Am I still able to appreciate my daily life?

Have I been experiencing these emotions for more than a few days or weeks?

Do I need to ask for help?

Patient and carer testimonials

“Barbara, my wife, was diagnosed with Stage IV colon cancer and given a prognosis of 3 months. It came as a complete shock and was difficult to comprehend as treatment could only be palliative. After a few days, Barbara became extremely calm. She was able to organise her thoughts, thinking about work, finances, our children and leaving so suddenly. She wrote down her goodbyes and expressed her innermost emotions. With such little time left, she didn't want anything left undone.

I was not so composed. I had to inform family and work colleagues of this terrible news. My feelings of losing her so suddenly were overwhelming and difficult to manage, but I had to find the inner strength to cope.

After one week, more tests were carried out and this helped me to feel better. Having a treatment plan gave us a feeling of hope. We were able to start arranging our affairs together. She remained very collected, which helped tremendously.

When treatment began, she needed a lot of support with side effects. I felt very helpless watching her go through such discomfort. The help that I could provide felt minor compared to her condition. The hospital staff were very helpful, advising what precautions to take.

Barbara went to the local hospice for support, which was very helpful. The staff were experienced in handling our emotions. We knew that we would never feel the same after her diagnosis. By working together, accessing the right support and through good communication, we were able to do our best.”

Mark Moss, Carer

Despite it being devastating at the time of diagnosis and being told she may have only a few months to live, Barbara has now been in remission for over 12 years. Barbara and Mark became involved in making choices during the cancer journey. They are now both active patient advocates for several cancer groups, where Mark aims to highlight the important role that the carer plays in supporting patients.

I was 53 years old and an extremely healthy man; a non-smoker, I didn't drink alcohol, and I played sports. So, my diagnosis was absolutely unexpected. I had been suffering with frequent diarrhoea, but not with serious symptoms. The news was delivered by an oncologist, who told me I had a tumour and needed to have urgent surgery.

My first reaction was to become paralyzed – I suddenly stopped thinking. My first thought was that I would die in 3 months' time. This was my first experience of cancer and I had heard about the seriousness of the disease. But as I was a psychologist specialising in emotional intelligence (and at that time giving lectures about resilience) – I decided that if there were survivors, I would be one of them.

Before I had surgery, I decided to remain optimistic. So, I carried on with my daily routine, in order to continue life as usual.

I spent three weeks at hospital having the surgery and recovering. My attitude was always positive. I remember when my friends came to visit – we laughed about how strange it is to have a colonoscopy, because they need to access your backside and this can feel like a loss of dignity.

As time went on, I received lots of love from my family and my friends, which was a great source of comfort from my hospital bed. In my lectures, I explain that if you are alive you don't need anything else to feel well.

I am a psychologist and also received enough emotional support from my environment, so I didn't need to find extra support. Nevertheless, I recognize that professional support may be required depending on each person's psychological situation.

Carlos Hué, Patient

Carlos is currently doing well and is still working as a practicing psychologist with a focus on improving people's emotional well-being. He has been in remission for 17 years since his diagnosis.

Ask for help

Know that it is OK to share how you feel and ask for what you need.

It is important that you do not try to do everything alone. Work out what kind of help you need, and clearly share this with your family, carers, and friends.

We are all different: some people want to talk about their cancer, others don't; some like to receive visits; others don't... and so on! It is OK to let your friends and family know what you expect – so they know how to help you.

People may not ask you, so let them know what kind of help you need. You may just need someone to talk to, or you may need more practical help, i.e. with the school-run, food shopping, travel to appointments, and so on. Asking for the help you need may reduce your 'mental load'.

Beyond your family, carers, and friends, patient groups are another great place to seek support and guidance – and to connect with other people who are living with mCRC. People who belong to patient groups have shared experiences and concerns so are well-placed to provide emotional and moral support for one another.

Talking is really important and can help in the fight against cancer.

TOP TIP

If your loved one was in a similar situation you would probably want to support them. Let them help you, and help them to give you the support you need by clearly asking for what you expect.

Ask: is there anything I can do to help myself?

There are lots of practical things you can do that could positively impact how you feel day-to-day.

You could focus on trying to:

- Stay connected – to people you enjoy spending time with and things you enjoy doing
- Be kind to your body – as much as you are able
- Find ways to manage and lower your stress levels.

TOP TIP

Try to protect what is important to you – things that were sources of pleasure before your diagnosis. If it is hard to still find pleasure in these things, such as meeting your loved ones, talk with a health care professional. This could be the beginning of depression.

Stay connected to other people and to what you enjoy

Communicate with people

- Try to spend time with your friends and family.
  You may also want to connect with other people with cancer. For example, you could get in touch with a local patient group:

  www.digestivecancers.eu/members/#section-full-member

- Group classes and activities are another great way to connect with people – you could get creative at a craft class or try out an exercise class that gets your body moving.

Do things you enjoy each day

Think about the things you enjoy doing most and, as much as possible, make sure those things are a part of your daily life. This might include:

- getting out for a walk
- grabbing a coffee with a friend
- making your favorite meal
- doing your favorite hobby.

Spend your energy well

Try to prioritize things that are most important to you, so you spend your energy well. Try not to worry about the less important things. This might include:

- letting the laundry wait
- asking someone to help you cook the evening meal.

Be kind to your body

Eat what you can, when you can

Sometimes people with colorectal cancer may find it difficult to eat enough or to eat a balanced diet. Don't be too hard on yourself if you are struggling with this. Try and eat small portions of things you enjoy and speak to your doctor or nutritionist for advice.

Take a look at the SHAPE 'MyFood' brochure for more ideas.

Keep moving your body

Being active can have a positive effect on your emotional health and could help you feel more confident and independent.[7-9]

- Some days you may want to walk, swim or get into the garden.
- Other days, you may want to focus your energy on tasks around the house.

Take a look at the SHAPE 'MyMove' brochure for more ideas.

Focus on getting good quality sleep

The physical and emotional distress that comes with cancer can make it difficult to sleep.

- Try to respect your own sleep-wake pattern.
- Do not hesitate to have a nap during the day if you need to.
- Try to 'wind down' as you prepare for sleep: you could have a warm bath, read a book, or write down your thoughts.
- Clear your mind of distractions and avoid looking at screens before you go to bed.[10]

Lower your stress levels

Positive self-talk

Challenging negative thoughts, and trying to replace them with honest, encouraging thoughts about yourself can be a useful tool to improve your mood.

Ask yourself: "Is this thought true?" You might try writing down thoughts that are more positive and encouraging.

You could use the MyMood diary at the back of this brochure.

Practice mindfulness exercises

Mindfulness exercises can help us to better understand ourselves and find enjoyment in our lives, taking notice of your thoughts and feelings and the world around you.[11,12]

Examples of mindfulness exercises you could try are provided over the page.

Write it down

It might be useful to write down your thoughts and feelings – you could keep a journal to write in before you try to go to sleep. This could help you understand your emotions more clearly. You may also want to write down questions to ask your health care professional or information about your treatment or disease.

You could try using the MyMood diary at the back of this brochure as a starting point.

Mindfulness is a type of meditation where you focus on being aware of what you are feeling or sensing in any given moment. Mindfulness is all about being fully present – it is about being aware of where you are and what you are doing.[11,12]

Mindfulness exercises

There are many simple ways you can practice mindfulness as a part of your daily life:[11,12]

- **Be kind to yourself** – try to have an awareness of any negative thoughts you are having. You could start by treating yourself like you would a close friend! Ask: "Would I say this negative thing to my friend?"

- **Pay attention to the world around you** – the world we live in is busy, so it can be difficult to slow down. Try to notice and take pleasure in the little things in life eg. observing nature around you such as a change in seasons/ nice weather, reading a good book or listening to your favorite music.

- **Focus on what was good today** – it might be helpful to write down three positive things from your day that you are grateful for.

- **Try some breathing exercises** – sit down, close your eyes, take a deep breath, and focus on your breath moving in and out of your body.

- **Try a body scan meditation** – Lie on your back, or sit on a chair with your eyes closed. Focus your attention on each part of your body in turn, starting from your toes and working your way all the way up to your head – try to pay attention to how you feel as you focus on each body part.

What if I need additional support?

If you have negative feelings that significantly impact your daily life, you should share these feelings with your health care professional. They will be able to direct you to the appropriate place for additional support.

Many people who experience problems in their lives seek counseling or other forms of therapy, including both individual and group therapies. These kinds of support can help people to manage certain experiences, thoughts, and feelings.

People may want to discuss a difficult life event, to learn new ways to manage problems in a relationship or at work or may need support for depression or anxiety.[13] People living with cancer may need support for the same reasons, as well as for issues related to their cancer.[14]

Do I need to speak to a psychologist or psychiatrist?

A **psychologist** is a health care professional who helps people learn to cope more effectively with life issues or psychological suffering. Most commonly they use talking therapies. Psychologists help a wide variety of people with many different problems.[15]

A **psychiatrist** is a trained medical doctor who specializes in helping people with emotional disorders and mental health problems. They use a variety of treatments, including medications and talking therapy, depending on the person's needs.[16]

Where and how can I find this kind of specialist?

Ask your physician about local psycho-oncology units, and seek support from patient organizations.

What can I expect if I see a psychologist or psychiatrist?

That depends on the type of counseling you receive and the person you see (i.e. a psychologist or a psychiatrist). And, of course, it depends on your own personal experiences.

You can expect the person to listen to your experiences and help you understand more about how you are thinking and feeling and how you might be able to overcome these thoughts and feelings.[17]

Most professionals who specialize in helping with emotional health will see patients once a week for about 45-50 minutes. Some types of therapy or counseling will last for a few sessions, while other types may continue for months or longer.[17]

The MyMood weekly diary

MONDAY

TUESDAY

THURSDAY

FRIDAY

Use this diary each day to write down your thoughts and feelings.

Ask yourself:

At the beginning of the day

- How do I feel today?
- Is there anything I can do to help me feel better?
- Are there any goals I could set for myself today?
- Is there anyone I can talk to about how I feel?

At the end of the day

- What have been the most pleasant moments of the day?
- Can I turn any negative thoughts into honest, encouraging thoughts?

WEDNESDAY

SATURDAY

SUNDAY

Notes

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For more information, you might want to use some of the links below:

SCAN ME

Digestive Cancers Europe:

Digestive Cancers Europe's, 'For Patients' page provides resources including patient testimonials, information on patient rights, and a dedicated carers guide. To learn more, please visit the following link: https://www.digestivecancers.eu/patient-voices/

SCAN ME

Depression:

https://www.cancer.gov/about-cancer/coping/feelings/depression-pdq#_AboutThis_1

SCAN ME

Anxiety and distress:

https://www.cancer.gov/about-cancer/coping/feelings/anxiety-distress-pdq

SCAN ME

Cancer-related PTSD:

https://www.cancer.gov/about-cancer/coping/survivorship/new-normal/ptsd-pdq

The SHAPE Steering Committee:

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

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

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