

Questions to Ask Your Healthcare Provider

FOR COLORECTAL CANCER PATIENTS IN REMISSION

Table of contents

Tips for Your Next Appointment

Questions for Patients in Remission

Glossary

Tips for Your Next Appointment

To prepare for your next medical appointment(s) and to ensure that it runs smoothly, please consider the following:

- Make a list of your **medical history** (including allergies, medical conditions, previous illnesses and/or surgeries, and relevant family history).
- Make a list of **all the medications** you take.
- Collect and bring all your relevant medical reports.
- Bring a notebook with you to take notes.
- Consider bringing a friend or family member to your appointment.
- Consider the opportunity to ask for an **interpreter** if the appointment is held in a language different from your native one (if needed).

It may be helpful to prepare important questions and aspects that you would like to have clarified during your appointment. Use the following Q&A to prepare your list of questions and identify your concerns. The Q&A is organized around the most important steps of the patient pathway and you can therefore review those that are most relevant to you.

Some questions you may have might be addressed automatically in your appointments, however, be sure to bring any unanswered questions to your next appointment. If you think that some of the following questions were not answered or were not clear, don't hesitate to ask your healthcare team for clarifications.



Understanding Monitoring and Long-Term Care

Follow-up care in the first five years after your treatment is important as this is when the risk of recurrence is highest. Your doctor will continue to monitor your condition, manage any side effects, and monitor your overall health. While in remission, remain vigilant of any changes in your health and report them to your doctor. You will have regular blood and imaging tests done as part of regular follow-up care. These testing recommendations depend on several factors, including the type and stage of cancer at diagnosis and the types of treatment given. Your doctor may order a CEA (carcinoembryonic antigen) test for you as part of your blood work.

Possible Questions to Ask About Your Follow-Up and Long-Term Care

What Kind of Tests Will I Need?

- What types of tests will I undergo when I'm in remission?
- When will I receive the results?
- Will I have to pay for these tests? Is there any financial support for these tests?

What Signs, Symptoms and Late Side Effects Do I Need to Look Out For?

- I'm worried about my colorectal cancer recurring or worsening, what signs or symptoms should I look out for?
- What long-term or late side effects should I look out for based on the treatment I received?

How Can I Reduce My Risks?

- Is there anything I can do to reduce my risk of recurrence?
- How often should I see my doctor to monitor my condition after my treatment has been completed?
- Can diet help me reduce my risks and what type of diet should I follow?
- Is it good to exercise and what kind of physical activity is good for me?

Where Can I Get Support?

- Where can I find additional information on survivorship care plans or survivorship clinics in my area?
- Are there any patient organizations with support groups for persons in remission?
- Where can I find additional information or patient organizations to support me?
- Are there any support groups available in my area where I can speak to other patients like me?



Glossary

You can find here below a short glossary of terms¹ to help you navigate this resource:

- **Cancer stage:** The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.
- CEA (carcinoembryonic antigen): A protein marker in the blood that may be present with some cancers and other diseases; may be used in some cases of colorectal cancer to monitor response to treatment or disease recurrence.
- **Diagnosis:** The process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis.
- Diagnostic test: A type of test used to help diagnose a disease or condition.
- **Relapsed disease:** The return of a disease or the signs and symptoms of a disease after a period of improvement.
- Remission: A decrease in or disappearance of signs and symptoms of cancer.

¹ This glossary has been built based on the definitions reported in the following documents: Lungevity Glossary: <u>https://www.lungevity.org/for-patients-caregivers/helpful-tools/glossary#g</u>; National Human Genome Research Institute Glossary: <u>https://www.genome.gov/genetics-glossary/g#glossary</u>; National Cancer Institute Dictionary of Cancer Terms: <u>https://www.cancer.gov/</u> <u>publications/dictionaries/cancer-terms/expand/D</u>; Colorectal Cancer Alliance Glossary: <u>https://www.ccalliance.org/colorectal-cancer-information/glossary-of-terms</u>



Acknowledgements



This resource is the result of the co-creation efforts of the <u>From Testing to Targeted</u> <u>Treatments (FT3) Education & Awareness Working Group</u>. FT3 is a global, multi-stakeholder collaborative program with the shared goal to make precision medicine an accessible reality for all patients who could benefit from it.

This resource was co-created by building on existing good practice resources². The content is formulated in the form of an adaptable Q&A builder that incorporates precision medicine elements to support patients in asking the right questions at the right time. The resource is available to any precision medicine champions who wish to adapt it to a specific condition and/or local context. If you wish to receive an editable version of this tool to develop a resource for a given geography and/or condition, please contact silvia@thesynergist.org.

We thank the FT3 Education & Awareness Working Group contributors for their hard work in delivering this resource and acknowledge the organizations referenced below for their good practices to draw from.

² Personalized Medicine Coalition (PMC) <u>More than a Number: Better health begins with you</u>; Decibio, <u>Precision Medicine</u> <u>Landscape Map</u>;MacMillan Cancer Support, <u>Ask about your cancer treatment</u>; Cancer101, <u>Questions to Ask My Health Care</u> <u>Team</u>; Cancer Support Community, <u>Cancer Diagnosis? What You Need to Know</u>; MacMillan Cancer Support, <u>Questions to ask your</u> <u>healthcare team</u>; American Cancer Society, <u>After diagnosis: a guide for patients and families</u>; American Cancer Society, <u>Questions</u> <u>to Ask Your Doctor When You Have Cancer</u>; Cancer.net, <u>Mobile application</u>



5