

# Questions to Ask Your Healthcare Provider

FOR NEWLY DIAGNOSED COLORECTAL CANCER PATIENTS



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## 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 Your Disease

Understanding better what disease you have and how it may affect you - your body, mind and lifestyle - is a good idea as it makes you better equipped to deal with the possible journey you have ahead. Below a list of suggested questions to help you understand your newly diagnosed colorectal cancer.

## Possible Questions for Your Healthcare Provider to Help you Understand Your Disease

- Where can I find information to learn more about my colorectal cancer diagnosis?
- Would you recommend getting a second opinion, do you have a colleague you can recommend?
- Are there patient organizations or other patients like me that I can speak to?
- Might I need to pay for my tests and/or treatment? If so, are there financial assistance programs or resources you can recommend?

## Understanding Diagnostic Procedures

Your doctor may order various diagnostic tests to help understand and diagnose your condition. These may include a biopsy, scans and/or blood tests.

Please review below some important questions that you can ask your doctor to acquire a better understanding of diagnostic and testing options. Biomarker testing may not be considered standard of care everywhere, so we recommend requesting from your doctor that biomarker testing be done before your treatment is initiated.

A biomarker test is particularly important if you are diagnosed with stage III or stage IV colorectal cancer, as targeted therapy and/or immunotherapy may be beneficial for you.

## Possible Questions to Help You Understand Diagnostic Procedures/Tests

### What Types of Tests Are There?

- What is the difference between genetic and biomarker (mutation, genomic, or molecular testing)?
- What is the difference between tissue biopsy and liquid biopsy for biomarker testing?
- Which biomarkers are important for colorectal cancer?
- What types of treatments might biomarker testing identify?
- What will the tests involve?

## Which Tests Are for Me?

- Which testing method is most appropriate for me and why?
- What diagnostic tests do you recommend for colorectal cancer and why?
- What types of tests should I request from my doctor and how will they determine my course of treatment?
- Do you recommend biomarker (mutation, genomic, or molecular) testing?
- Will I be tested for specific biomarkers like MSI/dMMR, RAS, NTRK and BRAF that have targeted treatments for colorectal cancer available in my country/region?

## Test Timing

- When and where will I have my testing done?
- Will all testing be completed immediately, or will some be done at a later time?
- What is the turnaround time for getting results returned (how long will it take to get the results)?
- Do I need to wait to get all of the test results back before starting treatment?
- How much time/energy will the tests take of me?

## What About the Test Results?

- What can the test results tell me about my condition?
- How will I be given my results? Who can help me understand the test results? Can I have a copy of my test results?
- Will I receive the full results of the test even if it includes results of something not being looked for originally?

## Do I Have Access to These Tests?

- Are the tests available to me in my country?
- Where can I access liquid biopsy testing?

## How Much Will the Tests Cost?

- Might I need to pay for my tests? If so, are there financial assistance programs or resources you can recommend?

## Is There a Hereditary Factor to My Cancer?

- Is there a genetic (hereditary) explanation for my cancer?
- Do you recommend genetic testing for my family members?
- What screening methods for prevention and/or early detection are recommended for my family members?
- What does it mean if I am diagnosed with Lynch Syndrome (HNPCC)?
- What does it mean if I am diagnosed with Familial Adenomatous Polyposis (FAP)?
- What does it mean if I am diagnosed with Attenuated Familial Adenomatous Polyposis (AFAP)?

## Understanding Treatment Options

Treatment options depend on the stage of your colorectal cancer and your tumor profile.

- Standard care for colon cancer involves surgical interventions, chemotherapy, targeted therapy, and immunotherapy, all of which depend on your tumor profile.
- Standard care for rectal cancer involves surgical interventions, chemotherapy, targeted therapy, immunotherapy, as well as radiation, all of which depend on your tumor profile.

## Possible Questions to Help You Understand Your Treatment Options

### Which Treatment Options Do I Have?

- Which treatment or combination of treatments would you recommend for me and why?
- Is immunotherapy a viable option for me?
- Is targeted therapy a viable option for me?
- Will the treatment interact with other medications that I am taking for my condition? How can I manage this? How will I receive my treatment and how often? Over what period of time will I receive my treatment?
- Is there time to consider alternative treatment options?
- Are there any clinical trials that could be applicable to me and how do I access them?

### What About Targeted Therapy?

- What is the goal of targeted therapy?
- How effective are targeted treatments compared to the standard chemotherapy treatment for colorectal cancer?
- What are the potential side effects of the targeted treatments? How might they affect my quality of life? And what can I do to manage them?
- How are the side effects of targeted therapy different from other colorectal cancer treatments?
- Can targeted therapy be taken in combination with chemotherapy for colorectal cancer?
- What are the different targeted therapy options?
- How do I know my eligibility for targeted therapy?
- If I am eligible for targeted therapy, will I be taking other colorectal cancer treatments with it as well?
- Will I be immunocompromised with the targeted therapy? How can I best take care of myself while undergoing treatment?

### What About Support for My Quality of Life Before, During and After Treatment?

- Is there any psychological/social/emotional support or tools available during my treatment to support me and/or my family members?

- Is there any nutritional support available during my treatment?
- Can I do physical activity? Which type? Should I get a physiotherapist to help me with this?
- Might I need to pay for my treatment? If so, are there financial assistance programs or resources you can recommend?

#### Where Can I Get Support?

- Where can I find additional information about my treatment options?
- Are there any patient organizations with support groups?
- 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?

## Understanding Diagnostic Procedures

If you are diagnosed with stage IV metastatic colorectal cancer, you should be tested for at least the following predictive biomarkers: RAS, BRAF, MSI/dMMR, NTRK, and possibly HER2.

# Glossary

You can find here below a short glossary of terms<sup>1</sup> to help you navigate this resource:

- **Attenuated Familial Adenomatous Polyposis:** A rare, inherited disorder in which multiple polyps (abnormal growths) form on the inner walls of the colon and rectum. People with attenuated familial adenomatous polyposis usually develop fewer than 100 polyps. Benign (not cancer) tumors may also occur in the stomach, small intestine, bone, skin, and soft tissue.  

People with attenuated familial adenomatous polyposis have a very high risk of developing colorectal cancer and may also be at risk of developing cancers of the stomach, small intestine, liver, and breast. Attenuated familial adenomatous polyposis is caused by mutations (changes) in the APC gene that are inherited in an autosomal dominant manner. It is a type of hereditary cancer syndrome. Also called AFAP.
- **Biomarker:** A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker can be a change in DNA (mutation), RNA, or protein. A biomarker may be used to 1) detect a disease, 2) decide on a course of treatment, or 3) determine how well the body responds to a treatment of a disease or condition. Sometimes, a biomarker may perform more than one of these functions.
- **Biomarker testing (mutation, genomic, or molecular testing):** Testing for any unique changes to the DNA or other biomarkers found in a person's cancer. The information is used to identify and create targeted therapies that are designed to work for a specific cancer tumor profile.
- **Biopsy:** The removal of cells or tissues for examination by a pathologist. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue.
- **BRAF:** A gene that makes a protein that is involved in sending signals in cells and in cell growth. Mutated (changed) forms of the BRAF gene and protein have been found in many types of cancer. These changes can increase the growth and spread of cancer cells.
- **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.
- **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.
- **Familial Adenomatous Polyposis:** A syndrome in which a gene mutation that influences the development of colon, rectal, and other cancers is inherited. People with FAP usually have hundreds, and sometimes thousands of pre-cancerous polyps, or growths developing at a very early age. FAP is defined as the presence of more than 100 benign (adenomatous) polyps in the colon at one examination and confirmed through genetic testing.

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

- **Genetic testing:** Genetic testing is the use of a laboratory test to look for genetic variations associated with a disease. The results of a genetic test can be used to confirm or rule out a suspected genetic disease or to determine the likelihood of a person passing on a mutation to their offspring.
- **HER2:** A protein involved in normal cell growth. HER2 may be made in larger than normal amounts by some types of cancer cells. This may cause cancer cells to grow more quickly and spread to other parts of the body. Checking the amount of HER2 on some types of cancer cells may help plan treatment.
- **Hereditary cancers:** A type of inherited disorder in which there is a higher-than-normal risk of certain types of cancer. Hereditary cancers are caused by inherited genetic variants and may be associated with several clinical manifestations.
- **Immunotherapy:** A type of therapy that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases. Some types of immunotherapy only target certain cells of the immune system. Others affect the immune system in a general way.
- **Lynch Syndrome:** an inherited condition that greatly increases a person's risk for developing colorectal cancer. People with this condition tend to develop cancer at a young age without first having many polyps. Colon and rectal cancer occur frequently in HNPCC families.
- **MSI/dMMR:** A change that occurs in certain cells (such as cancer cells) in which the number of repeated DNA bases in a microsatellite (a short, repeated sequence of DNA) is different from what it was when the microsatellite was inherited. MSI may be caused by mistakes that don't get corrected when DNA is copied in a cell. Knowing whether a cancer has MSI may help plan the best treatment. Also called microsatellite instability.
- **NTRK:** A mutation (change) that occurs when a piece of the chromosome containing a gene called NTRK breaks off and joins with a gene on another chromosome. NTRK gene fusions lead to abnormal proteins called TRK fusion proteins, which may cause cancer cells to grow. Also called neurotrophic tyrosine receptor kinase gene fusion.
- **RAS:** A family of genes that make proteins involved in cell signaling pathways that control cell growth and cell death. Mutated (changed) forms of the RAS gene may be found in some types of cancer. These changes may cause cancer cells to grow and spread in the body. Members of the RAS gene family include KRAS, HRAS, and NRAS.
- **Refractory disease:** A disease or condition that does not respond to treatment.
- **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.
- **Targeted Therapy:** A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells. Some targeted therapies block the action of certain enzymes, proteins, or other molecules involved in the growth and spread of cancer cells. Other types of targeted therapies help the immune system kill cancer cells or deliver toxic substances directly to cancer cells and kill them. Targeted therapy may have fewer side effects than other types of cancer treatment. Most targeted therapies are either small molecule drugs or monoclonal antibodies.



# Acknowledgements



This resource is the result of the co-creation efforts of the [From Testing to Targeted Treatments \(FT3\) Education & Awareness Working Group](#). 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 resources<sup>2</sup>. 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](mailto:silvia@thesynergist.org).

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