

# QUESTIONS TO ASK YOUR HEALTHCARE PROVIDER

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# Tips for your next appointment

To prepare for your next medical appointment 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 option 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, ask for clarifications.

## NEWLY DIAGNOSED patients

### Understand your disease

If you are newly diagnosed with colorectal cancer, these are important questions to have in mind ahead of your next appointment(s).



#### Questions you could ask:

- Where can I find information to learn more about my colorectal cancer diagnosis?
- In Canada, are there patient organizations or support groups with other patients like me that I can speak to?
- Will I be able to take a leave of absence and be covered by the Canadian Assistance Programs ([cancerandwork.ca](http://cancerandwork.ca))?
- Are my diagnostic tests (including biomarker testing) covered by my provincial or territorial public program?
- Will my private insurance or pharmaceutical support program (PSP) cover my expenses for a specific drug?
- Are there other financial assistance programs or resources that you can recommend?

# Understanding diagnostic procedures

Your doctor may order various diagnostic tests to 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. In some provinces in Canada, biomarker testing may not be considered standard of care, 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 3 or stage 4 colorectal cancer, as targeted therapy and/or immunotherapy may be beneficial for you.

## Questions you could ask:

### DIAGNOSTIC TESTING:

- What diagnostic tests do you recommend for colorectal cancer and why? What can the test results tell me about my condition?
- What types of tests should I request from my doctor and how will they determine my course of treatment?
- What will the tests involve? Are they available to me? How much time/energy will it take of me?
- When and where will I have my testing done?
- Will all testing be completed immediately, or will some be done at a later time?

### GENOMIC AND GENETIC TESTING:

- Do you recommend biomarker (mutation, genomic, or molecular) testing?
- 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?
- Which testing method is most appropriate for me and why?
- Where can I access liquid biopsy testing?
- What types of treatments might biomarker testing identify?
- Will I be tested for specific biomarkers like MSI/dMMR, RAS, NTRK and BRAF that have targeted treatments for colorectal cancer in Canada?
- What is the turnaround time to receiving results back (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 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?
- Is testing available in my institution or do I have to go to a private laboratory? Would I be responsible for the cost?
- Are my diagnostic tests (including biomarker testing) covered by my provincial or territorial public program? Are there financial assistance programs or resources you can recommend?
- 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 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 and immunotherapy, as well as radiation, all of which depend on your tumor profile.

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.



### Questions you could ask:

- 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 whether I am eligible for targeted therapy?
  - If I am eligible for targeted therapy, will I be getting other colorectal cancer treatments with it as well?
- Which treatment or combination of treatments would you recommend for me and why?
- Is immunotherapy a viable option for me?
- What clinical trials are applicable to me and how do I access them?
- Is there time to consider alternate treatment options?
- Will I be immunocompromised with targeted therapy? How can I best take care of myself while undergoing treatment?
- Will the treatment interact with my 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 any psychological/social/emotional support or tools available during my treatment to support me and/or my family members?
- Will my targeted therapy be covered by my provincial or territorial public program? Are there financial assistance programs or resources you can recommend?

# Patients on TREATMENT

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## Understanding disease and treatment monitoring

You will continue to be monitored once you have started your treatment. Over time your doctor will monitor how your illness is responding to the treatment. Your monitoring plan will depend on the stage of your cancer at diagnosis and the treatment plan chosen for you. For all treatment plans, you will have regular monitoring to evaluate the cancer's response to the treatment. You will also be monitored for any side effects and a management plan will be tailored to your needs. Your doctor may order a CEA (carcinoembryonic antigen) test for you to monitor your reaction to the cancer treatment. The questions below can support your upcoming conversation with your doctor.

### Questions you could ask:

- How will we know if my treatment is working? Will I need to have any further tests?
- What can I do to manage my treatment side effects?
- What happens if I experience severe side effects, will I need to stop my treatment?

# Patients with RELAPSED/REFRACTORY DISEASE

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## Understanding additional testing and/or treatment options

Regular monitoring will inform whether your colorectal cancer is responsive to the treatment. When a treatment is not effective for you, you may need to explore other treatment options with your doctor. You may also have additional testing to inform additional treatment decisions.

If there are few treatment options available for your condition, you can speak to your doctor about the possibility of taking part in a clinical trial.

### Questions you could ask:

- Do I need to change my treatment plan or start a new treatment if the cancer recurs or if the current treatment does not work?
- Is there a need for another biopsy to be performed?
- Do you recommend biomarker (mutation, genomic, or molecular) testing at this stage?
  - If so, what types of biomarker testing should I undergo?
  - If so, what types of treatments might biomarker testing identify?
- Are there any additional types of tests available that might open up other treatment options?
- Can you explain the benefits and risks of the treatment/s proposed?
- Are there any additional research options or clinical trials we could explore? Can you refer me?

# Patients in REMISSION

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## Understanding monitoring and long-term care

Follow-up care in the first 5 years after your treatment is important as this is when the risk of recurrence is the 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 tests and imaging tests done as part of your 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.

### Questions you could ask:

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

# Glossary

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

- **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.
- **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.
- **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.
- **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.
- **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.
- **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.

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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>

# 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](#)