Hope in Action: A Patient's Guide to Cancer Immunotherapy

for Colorectal Cancer

CRI Cancer Research Institute™

From a Patient's Perspective

Tom Vibert
Colon Cancer Survivor, Stage IV

My name is Tom Vibert, and I'm a stage 4 colon cancer survivor with Lynch syndrome. When I was diagnosed in 2012, I was active, healthy, and spending as much time as I could on my bike. Cancer divided my life into before and after. I started with chemotherapy, but when it stopped working, I was running out of options.

Before my first round of chemo, my doctor had suggested I get genetic testing. I didn't fully understand why at the time, but I trusted them. My test results made me eligible for a new immunotherapy clinical trial studying nivolumab (Opdivo®). I later learned my tumor was "MSI-high," meaning it had many mutations that could make it more responsive to immunotherapy.

That trial was the game changer. After just one dose, my tumor shrank more than it had in two years of chemotherapy. For the first time in a long time, I wasn't in pain. Eventually, I went into remission. Immunotherapy didn't just treat my cancer — it gave me time.

I also understood that my opportunity existed because other patients had stepped forward before me. Research and clinical trials matter. Knowing your biomarkers matters. Treatments today are increasingly targeted, and unless you know what's inside your tumor, you may not know what options are available.

Cycling has always been part of who I am, so I returned to the bike — not just for myself, but to raise awareness and support cancer research. My message to other patients is simple: ask questions. Seek second opinions. Know your biomarkers. And don't be afraid to advocate for yourself. Progress is happening because patients, doctors, and scientists are working together — and I'm here today because of that partnership.

Starting with What You Need to Know

Hearing the words *"You have colorectal cancer"* can feel overwhelming. You may feel scared, confused, or uncertain about what comes next. These feelings are not unexpected — and you are not alone. You don't have to become an expert overnight.

This guide from the Cancer Research Institute (CRI) is designed to help you understand a treatment option called immunotherapy, how it may fit into your colorectal cancer treatment plan, and what questions you may want to ask your health care team along the way.

Getting a Diagnosis:
What is Colorectal Cancer?

What is colorectal cancer?

Colorectal cancer includes colon cancer and rectal cancer. Most colorectal cancers start in the inner lining of the colon or rectum and may begin as growths called adenomatous polyps, which can slowly develop into cancer over time. Screening can often catch and remove polyps before cancer develops.

What's the difference between colon cancer and rectal cancer?

Colon and rectal cancers are closely related, but treatments can differ. That's because the rectum sits in a tighter space in the pelvis and is often treated differently with surgery and radiation. Your health care team may describe your cancer by both stage and location (colon vs. rectum), as each can influence treatment decisions.

Making a Decision:
Understanding Immunotherapy

What is immunotherapy?

Immunotherapy is a type of cancer treatment that helps your immune system recognize and attack cancer cells. In colorectal cancer, immunotherapy most often refers to immune checkpoint inhibitors (ICIs), a type of treatment that "releases the brakes" on immune cells so they can respond more strongly to cancer.

Does immunotherapy work for everyone with colorectal cancer?

Not currently. Immunotherapy is most effective when colorectal tumors have specific features called MSI-H or dMMR (microsatellite instability-high or mismatch repair deficiency). These features help predict whether immunotherapy is likely to work.

MSI-H/dMMR tumors are found in about 5–15% of colorectal cancers and are more common in earlier-stage disease than in metastatic disease.

What are MSI-H and dMMR, and why do they matter?

MSI-H and dMMR are closely related results from tumor testing that show how well colorectal cancer cells can repair DNA errors. When your DNA repair system isn't working, tumors accumulate many genetic changes, which can make them more visible to the immune system. Because of this, MSI-H/dMMR tumors are more likely to respond to immunotherapy.

How do I get MSI/MMR testing?

Ask your health care team whether your tumor has been tested for MSI and MMR status and what the results were. Testing — sometimes called universal tumor screening — is usually done on tumor tissue from a biopsy or surgery. Pathology reports may list mismatch repair genes such as *MLH1, MSH2, MSH6,* and *PMS2* and whether they have any mutations.

Should I be tested for Lynch syndrome or other inherited conditions?

If your tumor is MSI-H or dMMR, your health care team may recommend additional testing to determine whether this is related to Lynch syndrome. Lynch syndrome is a hereditary condition caused by a germline mutation in a mismatch repair gene or *EPCAM*. A blood or saliva test can confirm whether a germline mutation is present, which may affect your care and help family members decide about testing and earlier screening.

When is immunotherapy most likely to be recommended?

Your health care team considers many factors, including cancer stage, overall health, and tumor biomarkers before recommending a cancer treatment. In general:

Metastatic or unresectable MSI-H/dMMR colorectal cancer	Some early-stage MSI-H/dMMR rectal cancers	Tumors that do not have MSI-H or dMMR features
Immunotherapy is the standard of care and likely to be used early in treatment.	Immunotherapy might be given before surgery in select situations.	Immunotherapy has not been shown to have consistent results but is being studied through clinical trials or specific combinations.

Which immunotherapy drugs are used for colorectal cancer today?

The most common immunotherapies used for patients with colorectal cancers are immune checkpoint inhibitors (ICIs), including:

Pembrolizumab (Keytruda®)	Nivolumab (Opdivo®)	Nivolumab + Ipilimumab (Yervoy®)	Dostarlimab (Jemperli®)
Approved as a first-line treatment for patients with unresectable or metastatic MSI-H/dMMR colorectal cancer	Used alone or in combination for certain patients with MSI-H/dMMR colorectal cancers	Used in combination for certain patients with MSI-H/dMMR colorectal cancers	May be an option for some patients with dMMR tumors, depending on prior treatments and disease setting

If my tumor is not MSI-H or dMMR, do I have any immunotherapy options?

If your tumor does not have MSI-H or dMMR features — sometimes called MSS/pMMR (microsatellite stable/proficient mismatch repair) — immunotherapy is not a standard treatment at this time. However, several immune-based or targeted monoclonal antibodies are commonly used for treatment and are also being studied in combination with immunotherapy in clinical trials, including:

Bevacizumab (Avastin®)	Cetuximab (Erbitux®)	Panitumumab (Vectibix®)	Ramucirumab (Cyramza®)
Often used with chemotherapy in patients with advanced colorectal cancer	Approved for certain patients with advanced colorectal cancer whose tumors do not have specific *RAS* gene mutations and recommended preferentially for left-sided tumors without *RAS* or *BRAF* gene mutations	Used in select patients with advanced colorectal cancer	May be used with chemotherapy in patients with some advanced cases

How do I find clinical trials that may be right for me?

Clinical trials are carefully monitored research studies that test the safety and effectiveness of new treatments. They may offer access to promising therapies not yet approved by U.S. FDA. You can ask your doctor about trials at your treatment center or use CRI's Clinical Trial Finder to explore options that you may be eligible for.

Starting Treatment: What to Expect

How is immunotherapy given?

ICIs are most commonly given through an IV (intravenous) infusion in an outpatient clinic, hospital, or cancer center. For colorectal cancer, treatment is often scheduled every two to six weeks, depending on the treatment and plan, and appointments may last from about 30 minutes to a few hours.

Some patients receive immunotherapy alone, while others receive it in combination with chemotherapy, radiation, or other treatments — particularly in clinical trials or specific rectal cancer approaches. Your health care team will explain how often you'll receive treatment, how long each visit will take, and what to expect on infusion days.

What side effects should I expect?

Many people tolerate immunotherapy well, but side effects can happen because the immune system becomes more active. Common side effects include fatigue, skin changes (such as a rash or itching), and diarrhea.

Rarely, ICIs can cause immune-related side effects, where the immune system inflames healthy organs like the colon, liver, lungs, or hormone glands. Because gastrointestinal symptoms are already common in colorectal cancer, it's especially important to report new or worsening diarrhea, abdominal pain, blood in the stool, or fever as soon as possible.

How will I know if immunotherapy treatment is working?

Your health care team will monitor your response through regular follow-up visits, which may include imaging scans (such as CT or MRI), blood tests, and sometimes scopes or biopsies — particularly for patients with certain rectal cancer treatment approaches.

Your doctor will look at scan results alongside lab findings and ask how you're feeling overall to determine whether treatment is helping. They'll also explain what "response" means in your specific situation and how often you'll be monitored.

Looking and Living Forward:
After Treatment and Ongoing Support

What ongoing care will I need?

After treatment, you'll continue to have regular checkups to monitor for recurrence and manage any long-term side effects. Follow-up care may include physical exams, blood tests, imaging scans, and conversations about how you're feeling physically and emotionally.

What if immunotherapy doesn't work or my colorectal cancer comes back?

Not everyone responds to immunotherapy, and it's understandable to feel discouraged if the results aren't what you hoped for. If treatment isn't effective or the cancer returns, your doctor may recommend a different therapy, a combination approach, or a clinical trial.

Where can I find support from others with colorectal cancer?

Connecting with others who have had colorectal cancer can help you feel less alone and more supported. You can explore personal stories from patients and survivors treated with immunotherapy on CRI's website. Organizations such as Fight Colorectal Cancer and the Colorectal Cancer Alliance also offer support communities, helplines, and peer-to-peer programs specifically for patients and caregivers affected by colorectal cancer.

What Comes Next

Colorectal cancer treatment has changed significantly in recent years, and immunotherapy has become a cornerstone for many people whose tumors are MSI-H/dMMR.

No matter where you are in your journey — newly diagnosed, in treatment, or considering next steps — your questions matter. Keep asking. Bring support when you can. And let your health care team know how you're feeling, both physically and emotionally.

Acknowledgements

We extend our sincere gratitude to the CRI ImmunoAdvocates, a group of patients treated with immunotherapy, who generously shared their experiences, insights, and time to help shape this guide. By telling your stories and offering your perspectives, you've helped ensure that people newly diagnosed with cancer feel seen, supported, and empowered as they begin their immunotherapy journey.

Appendix

10 Questions to Ask Your Doctor About Colorectal Cancer and Immunotherapy

Being diagnosed with colorectal cancer may feel overwhelming, and understanding your treatment options can make a big difference. Asking the right questions can help you take an active role in your care, make informed decisions, and feel more confident as you move forward.

Here are 10 key questions you can use in your conversations with your doctor:

1. What is my exact diagnosis and stage, and is it colon or rectal cancer?
2. Have we tested my tumor for MSI/MMR? What were the results?
3. Do I need additional biomarker testing (like the *RAS/BRAF* genes) to guide treatment or trials?
4. Is immunotherapy a recommended option for me right now?
5. If immunotherapy is an option, which treatment(s) and what schedule?
6. What side effects should I watch for, and when should I call you?
7. How will we monitor response, and how often will I have scans or labs?
8. Are there clinical trials I should consider now or later?
9. What are the costs of treatment(s), and is it covered by my insurance?
10. What supportive resources — emotional, mental, or financial — are available for me and my family?

Glossary

Biomarkers

Biomarkers are proteins or genes that provide a more detailed understanding of a tumor, its prognosis, and the potential response to treatment.

Biopsy

A biopsy is a procedure in which a doctor removes a small sample of tissue. This sample is then examined under a microscope so that cellular abnormalities can be observed.

Chemotherapy

Chemotherapy, often called "chemo", is a cancer treatment with drugs that kills fast-dividing cells. Chemotherapy can be used alone or in combination with other treatment types.

Clinical trials

Clinical trials are an important part of medical research that form the basis for the approval of all new treatments. The primary goals of clinical trials are to figure out whether a treatment works and if it is safe.

Genetic mutations

Genetic mutations are changes in your DNA sequence. Some genetic mutations are associated with some types of cancer, and some genetic mutations may indicate a better chance of response to a specific immunotherapy treatment.

Immune checkpoint inhibitors (ICIs)

Immune checkpoint inhibitors are a type of immunotherapy used to "release the brakes" on the immune system, allowing your body to respond more aggressively to cancer.

Immune system

The immune system is a highly evolved network of organs, cells, and molecules that helps defend your body against threats such as bacteria, viruses, and cancer.

Immune-related side effects (irAEs)

Immune-related side effects are reactions that happen when the immune system becomes overactive and starts affecting healthy parts of the body. These side effects can impact organs like the skin, liver, lungs, or intestines and often need prompt treatment.

Immunotherapy

Immunotherapy is a form of cancer treatment that uses the power of your body's own immune system to prevent, control, and eliminate cancer. Immunotherapy can be used for many types of cancer, alone or in combination with other treatment types.

Monoclonal antibodies

Monoclonal antibodies are a special type of protein designed to target antigens, or markers, located on the surface of cancer cells. Antibodies identify antigens and recruit immune cells to attack.

Radiation

Radiation, or radiation therapy, uses high-energy particles or waves to destroy or damage cancer cells. It is one of the most common treatments for cancer and can be used alone or in combination with other treatment types.

Staging

Staging is used to determine the extent (or "stage") of cancer. It is based on whether a tumor is local to its area of origin or has spread to the lymph nodes or other parts of your body as well as how deeply it has invaded surrounding tissues.

Tumor

A tumor is an abnormal lump or mass of tissue. Tumors can be benign (non-cancerous) or malignant (cancerous).

Disclaimer

This information is intended for educational purposes only and is not a substitute for professional medical advice, diagnosis, or treatment. Always talk with your health care team about questions or decisions related to your care.

About CRI

The Cancer Research Institute (CRI) is a nonprofit organization dedicated to advancing the field of cancer immunotherapy through rigorous scientific research and global collaboration. Since 1953, CRI has been instrumental in uncovering the fundamental biology of the immune system and its application to cancer treatment, laying the groundwork for breakthroughs such as checkpoint blockade, cancer vaccines, and engineered cell therapies.

CRI's mission is to create a world immune to cancer by driving scientific discovery, accelerating collaboration, and turning breakthroughs into life-saving treatments. Our work bridges the gap between discovery and patient impact, ensuring that scientific innovation translates into real-world treatments.

To date, CRI has committed over $560 million to research impacting more than 30 cancer types. Our funding strategy is built on the framework of People × Biology × Data: supporting world-class scientists, deepening understanding of tumor–immune system interactions, and harnessing data to guide discovery and translation. By uniting these elements, CRI catalyzes innovation through our global research ecosystem to drive the next generation of discoveries forward.

Cancer Research Institute
29 Broadway, Floor 4
New York, NY 10006-3111
800-992-2623 | 212-688-7515

info@cancerresearch.org

Learn more at **cancerresearch.org**