



# PATIENT RESOURCES

## LONG-TERM CARE AND SURVIVORSHIP



### WHAT IS CANCER SURVIVORSHIP?

You will find several definitions or descriptions for the term 'cancer survivor.' The most common definition is a person who is in complete remission—meaning no signs or symptoms of cancer following the end of treatment. The National Cancer Institute, however, describes everyone diagnosed with cancer as a survivor "through the balance of his or her life." This definition includes the survivor's family, friends, and caregivers as well.

Cancer survivorship, which begins at diagnosis, can be categorized into the following stages:

- ✔ From diagnosis to the end of initial treatment
- ✔ The transition from treatment to extended survival
- ✔ Long-term survival

Survivorship can be one the most complicated and challenging aspects of having/living with cancer, because it is unique to every patient and involves emotional, mental, psychosocial, and physical factors. Survivors may feel a whirlwind of emotions including guilt and unease when their frequent health visits become infrequent as their treatment nears end. Every survivor may have a unique way of coming to terms with their survivorship, but it may be helpful to consult resources that could guide you through your journey. These resources can help set expectations and prepare you to face the long-term impact of your diagnosis and treatment:

- ✔ [Colorectal Cancer: Survivorship](#)
- ✔ [American Cancer Society Colorectal Cancer Survivorship Care Guidelines](#)
- ✔ [Living as a Colorectal Cancer Survivor](#)
- ✔ [Colon Cancer Survivorship](#)
- ✔ [Survivor Stories](#)

### RECURRENCE

[Recurrence](#) may be local or distant.

*Local Recurrence:* When the cancer returns at the original site, it is classified as local recurrence and may be characterized by:

#### **Changes in bowel habits**

- ✔ Less frequent bowel movements
- ✔ Narrow stools
- ✔ Hard stools

#### **Obstruction**

- ✔ Abdominal bleeding
- ✔ No bowel movements
- ✔ Abdominal pain
- ✔ Vomiting
- ✔ Increase in size of the abdomen

A colonoscopy may be needed to detect any recurrence that is inside the colon. However, if the recurrence is outside the wall of the colon, it will not be visible by colonoscopy but may need a CT scan or tumor marker test (CEA levels). Local recurrence is usually treated with another surgery. Colon cancers are usually easier to remove, but complications may arise with local recurrence of rectal cancer, especially if adjacent organs are involved. [Radiation therapy](#) may be recommended, and the surgeon may need to remove other organs.

*Distance Recurrence:* Liver and lungs are the most common sites of distant CRC recurrence. They usually lack specific symptoms and may be diagnosed after a follow-up CT scan or abnormal levels of CEA protein. Chemotherapy would be the most likely line of treatment for distant recurrence.

## FOLLOW-UP CARE

Follow-up care will depend on your specific treatment. It is important that you understand these guidelines and that you follow through with them as they are vital to maintaining your quality of life and for ensuring your best health.

Cancer patients often require long-term monitoring for adequate management of treatment-related side effects, [late-effects](#) that may emerge, and recurrence, meaning the cancer comes back, often within the first five years of treatment. You should speak to your doctor about what a follow-up care plan will look like for you.

## Recommendations for Stage II/III CRC

### **Regular physical exams every three to six months**

#### **Clinical exams to monitor recurrence:**

- ✔ Tumor marker testing: CEA protein levels may be monitored every three to six months for five years.
- ✔ Computed Tomography or CT scan: These are 3D x-rays of the inside of your body, usually abdomen and chest, recommended annually for three years. Your doctor may recommend a CT scan every six to 12 months if you are at a high risk of recurrence. For those who had rectal cancer, a pelvic CT scan may be recommended.
- ✔ Colonoscopy: This test allows the doctor to view the rectum and colon with a flexible tube called a colonoscope. It may be performed after a year of surgery but is typically recommended once in five years.
- ✔ Rectosigmoidoscopy: Similar to a colonoscope, a flexible tube is inserted into a patient's rectum to check the area for polyps or cancer. For those who were not treated with radiation therapy following rectal cancer, a rectosigmoidoscopy is recommended every six months.

Follow-up care varies for patients who have had surgery for metastatic colorectal cancer (CRC) or those who have inherited CRC. Since there is no clarity around follow-up testing for those who had stage I CRC, it's best to speak with your care provider.

Specific information on yearly treatment plans [can be found here](#).

Here are some additional resources for follow-up care:

- ✔ [Do Frequent Follow-Up Tests Benefit Colorectal Cancer Survivors?](#)
- ✔ [Recommendations for follow-up of colorectal cancer survivors](#)
- ✔ [Colorectal cancer NICE guideline](#)

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