



# Treatment & Survivorship Care Plan

for Gastrointestinal Cancers



The GI Cancers Alliance was formed in 2015 to create a stronger, more unified voice for all those affected by GI cancers. We are a voluntary collaboration of advocacy organizations, healthcare professionals, and corporate and industry partners working in partnership to raise awareness, provide education and advocate for the prevention, treatment and cure of gastrointestinal cancers.

In the fall of 2016 the GI Cancers Alliance created a nationwide survey to identify the Unmet Needs of GI Cancer patients. Based on the survey feedback, we learned that **92 percent of patients nationwide did not have a Treatment or Survivorship Care Plan**. Understanding the importance of having a Care Plan or ‘road map’ to guide patients through their cancer journey, the GI Cancers Alliance created the first GI Cancer-specific Treatment & Survivorship Care Plan to help address this unmet need in our GI cancer community.

A Treatment & Survivorship Care Plan is a complete record and documentation of a patient’s cancer journey—from diagnosis into long-term survivorship. Just as we are all different and unique as individuals, no two Care Plans will be the same. Our goal is to help facilitate a dialogue between patients and their healthcare team as Care Plans are completed together. We encourage patients to bring their Care Plans with them to appointments, update as needed, and keep healthcare records together as part of the Care Plan. It is our hope that the GI Cancers Alliance Treatment & Survivorship Care Plan will help empower our GI cancer patient community and provide the information needed to help make informed healthcare decisions ultimately leading to better patient outcomes.

For additional information and resources, please visit [www.GICancersAlliance.org](http://www.GICancersAlliance.org).

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Bristol-Myers Squibb



**We are the GI Cancers Alliance.**

**A stronger, more unified voice to fight gastrointestinal cancers**

*The GI Cancers Alliance Survivorship Care Plan is made possible by the generous support of Taiho Oncology, Lilly Oncology, Bristol-Myers Squibb, BTG International*

## General Information

Patient Name

Address

Phone

Date of Birth

Age at Diagnosis

Primary Caregiver

Secondary Caregiver

## Healthcare Providers

## Contact Info

Oncologist

Surgeon

Radiation Oncologist

Primary Care

Nurse/RN, NP

Genetic Counselor

Social Worker

Nutritionist

Oncology Center

Hospital Network

2nd Opinion – Date/Healthcare Professional

**Important Note:** Ask for copies of test results, physician notes, treatment names/dates and any side effects, scan results, pathology reports, blood work, etc. Keep these copies with your Treatment & Survivorship Care Plan so you have all your healthcare information together.

**Diagnosis**

Date of Diagnosis			
Cancer Type/Location			Stage
<b>TNM:</b>	Tumor Size	Lymph Node	Metastasis
Familial History			
Genetic Testing	Type	Results	
Pre-Op Testing/Biopsy			
CBC/Markers (pre-treatment)			

**Treatment Plan**

Treatment Goal		
<b>Surgery:</b>	Date	Procedure/Location
Pathology Findings		
<b>Radiation:</b>	Date	# of Treatments Planned
Systemic Therapy: (Chemotherapy, Hormonal Therapy, Immunotherapy)		

## Treatment Plan *continued*

Pre-Surgery Care or Therapy Needed

Yes

No

Treatment Name/Agents Used

# of Treatments Planned

Adjuvant Care or Therapy Needed

Yes

No

Adjuvant Therapy Treatment Name/Agents Used

# of Treatments Planned

2nd Line Therapy Needed

Yes

No

Treatment Name/Agents Used

# of Treatments Planned

Additional Treatment Options:

CBC/Markers (During Treatment)

Clinical Trial Information

## Treatment Related Physical Side Effects

- Fatigue
- Infections/Fever
- Low White Blood Cell Count (Neutropenia)
- Low Red Blood Cell Count (Anemia)
- Allergic Reactions
- Diarrhea or Constipation
- Mouth Sores
- Numbness/Tingling in Hands/Feet
- Skin Changes
- Trouble Thinking/ Concentrating
- Urinary Symptoms
- Trouble Breathing
- Nausea/Vomiting
- Muscle/Bone Soreness
- Pain (Location, Degree)
- Hair Loss
- Heart Damage
- Ostomy Concerns
- Feeding Tube Concerns
- Sleep Disorders

**83% of our nationwide survey respondents indicated that they were not adjusting well to a 'new normal' since their cancer diagnosis.**

Visit [GICancersAlliance.org](https://www.GICancersAlliance.org) to learn more.

## Emotional/Psycho-Social Side Effects or Concerns

- Depression
- Anxiety
- Fear
- Sexual Health/Concerns
- Fertility Preservation/Issues
- Family Concerns (Parenting, Relationships, etc.)
- Smoking Cessation
- Substance Abuse
- Guilt – Survivor's Guilt
- Adjusting To a 'New Normal'

**58% of our nationwide survey respondents indicated that they didn't have adequate emotional support.**

Resources & Support services are available at [GICancersAlliance.org](https://www.GICancersAlliance.org)

## Financial/Insurance/Workplace Concerns

- Employment
- Financial
- Health Insurance
- Life Insurance
- Disability Insurance

## Post-Treatment Follow-Up Care Plan

Goal of Follow-Up Care

CBC/Markers (Post-Treatment)

Additional Treatment Options:

## Schedule of Follow-up Surveillance

Test or Procedure	Frequency	Test Date

Results (Scans CD, written reports, CBC reports, etc.)

## Schedule of Follow-Up MD Visits

Physician Name/Address	Frequency	Test Date

Questions to Ask Physician (including new symptoms or concerns, persistent side effects, possible late or long-term side effects, etc.):

## Resources and Support Services

Please visit the GI Cancers Alliance Resource Library for comprehensive listings to support services, patient and caregiver resources, educational videos, financial assistance programs, insurance and disability information, clinical trials and GI Cancers Alliance member organizations.

[www.GICancersAlliance.org](http://www.GICancersAlliance.org)

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A stronger, more unified voice to fight gastrointestinal cancers



## Glossary of GI Cancer and Treatment Terms

**Adjuvant Therapy:** Treatment given in addition to primary treatment or surgery to maximize effectiveness. Adjuvant therapy may include chemotherapy or radiation.

**Alopecia:** Hair loss.

**Anemia:** Low levels of iron in the blood, which can lead to fatigue and weakness.

**Benign:** A tumor or cells that are not cancerous.

**Bile:** The liver makes bile, which is a yellow-brown liquid made from lecithin, bile salts, cholesterol and bilirubin.

**Biological therapy:** A treatment that works with your body's immune system to help it fight cancer cells or to control side effects from other cancer treatments.

**Biopsy:** A biopsy is a minor surgery to remove cells, body fluid or small pieces of body tissue. The removed cells or tissues are usually examined by a pathologist. Types of biopsies include: incisional biopsies, in which only a sample of tissue is removed; excisional biopsy, in which an entire lump or suspicious area is removed; and needle biopsies, in which a sample of tissue or fluid is removed with a needle.

**Bone marrow:** The soft, sponge-like tissue in the center of most bones. Bone marrow makes all kinds of blood cells: white blood cells, red blood cells, and platelets (clotting cells).

**Cancer:** A disease in which cells grow out of control. Cancer cells can invade nearby tissue and spread to other parts of the body.

**Cancer registry:** Information collected about cancer patients and treatments from doctors and hospitals to help understand and track cancer across the country.

**Cancer survivor:** A person who has been diagnosed with cancer, from the time of diagnosis until the end of life.

**Carcinogen:** A substance or agent that causes cancer.

**Carcinoma:** A cancer that starts in the skin or the tissues that line internal organs.

**Caregiver:** A person who provides support and help to a cancer survivor—such as a family member, neighbor or friend. (See also Formal Caregivers.)

**Caregiver assessment:** A tool that identifies the needs, resources and strengths to help care for caregivers and cancer patients from the point of view of the caregiver. Doctors can recommend community resources, professional services and agencies that may help.

**CAT scan:** See CT Scan.

**CBC – Complete blood count:** Also called complete blood cell count, full blood count or full blood exam. A blood panel that gives information about the cells in a patient's blood, including cell count and concentrations of proteins and minerals. Also included in a CBC are the measure of white blood cells (WBC) that help protect against infection.

**Cell:** The basic unit that makes up the human body. Cells contain genetic information.

**Chemotherapy:** A drug or combination of drugs used to shrink or kill cancer cells. The drugs can be pills you take (oral) or medicines given in your veins, or sometimes both.

## Glossary of GI Cancer and Treatment Terms *continued*

**Chronic disease:** A disease that a person has for a long period of time. Cancer can be a chronic disease.

**Cirrhosis:** A scarring of the liver caused by inflammation (swelling).

**Clinical trials:** Studies that research drugs, medical plans, treatments or devices to see if they are safe and effective for people who have cancer or other illnesses. Clinical trials can also study whether interventions that change health behaviors, such as diet, are effective.

**Colonoscope:** A long, thin, flexible tube with a camera and light on the end that is used to examine the large intestine/colon.

**Colonoscopy:** Procedure that allows the doctor to see inside the large intestine.

**Colostomy:** A surgical procedure where a piece of the large intestine (colon) is diverted to an artificial opening in the abdominal wall to bypass a damaged or diseased part of the colon.

**Complementary and alternative medicine:** Medicines and health practices that are not standard cancer treatments, such as meditation, yoga, and supplements like vitamins and herbs.

**Constipation:** Hard stool or difficulty passing stool.

**Coordinated care:** A plan to organize patient care activities among doctors, social workers, caregivers and family to manage a patient's treatment and follow-up care and make sure they receive the services they need.

**CT scan:** Computerized tomography scan or computerized axial tomography (CAT) scan—a series of pictures created by a computer linked to an x-ray machine. The scan gives detailed images of internal organs in the body.

**Diagnosis:** Identification of a disease from symptoms, signs and testing.

**Diarrhea:** Loose stool or passing stool very rapidly.

**DNA:** The chemicals that make up the genes in cells. Some cancers can be carried and passed along by families through their DNA.

**Duct:** A tube that carries fluid (such as a bile duct).

**Duodenum:** First portion of the small intestine that links the stomach to the small intestine.

**Emotional Distress:** Feelings of depression, fear, and anxiety that can happen after being diagnosed with cancer.

**Endoscope:** A long, thin flexible scope with a small camera on the end that is used to look inside the mouth, esophagus, stomach and duodenum.

**Endoscopy:** Procedure to examine the upper digestive system using an endoscope.

**EUS (Endoscopic Ultrasound):** Procedure using the endoscope to view the throat, stomach, and small intestine. The ultrasound attachment used with the scope produces sound waves to view the pancreas and bile ducts. An EUS is used to view the upper or lower GI tract.

## Glossary of GI Cancer and Treatment Terms *continued*

**False positive:** A test result that indicates that a person may have cancer when he or she does not.

**Family health history:** A record of current and past medical conditions of all family members to help understand a person's risk of cancer. Knowing a person's family history can help show a pattern of certain diseases that may be inherited.

**Fertility preservation:** Certain cancer treatments, such as radiation therapy or chemotherapy, may cause infertility. Fertility preservation is a way of helping a person keep his or her ability to have children, before he or she begins cancer treatment. Examples of fertility preservation procedures include banking a man's sperm, freezing a woman's egg, in vitro fertilization with embryo freezing and certain types of surgery.

**Fistula:** An abnormal connection between two or more body parts that are not commonly joined together. Fistulas can form from surgery, infection or inflammation.

**Follow-up care:** Getting routine checkups and other cancer screenings after cancer treatment ends. Follow-up care can help find new or returning cancers early and look for side effects of cancer treatment.

**Formal caregivers:** People who are trained and paid to provide care, such as nurses, therapists, social workers, and home health aides. Formal caregivers may work for home care agencies, community or social service agencies, or for-profit providers.

**Gastroenterologist:** A medical doctor specializing in diseases of the gastrointestinal tract.

**Gastrointestinal tract:** Also known as the GI tract or digestive system. Organs that process

food for energy, absorb nutrients and process waste.

**Gastrostomy:** A surgical opening made into the stomach from the abdominal wall to insert a tube for feeding or drainage.

**Genes:** The instructions that tell cells how to behave and what type of cells to become. Genes are responsible for traits passed along in families, like eye color, height and even cancer risk.

**Genetics:** The study of genes and how they affect the human body.

**GI Cancers – Gastrointestinal cancers:** Cancers that affect the digestive system, including cancer of the: esophagus; gallbladder; liver; biliary system; pancreas; appendix; gastrointestinal carcinoid tumor; stomach; small intestine; large intestine/ colon; rectum; and anus. GI cancers are the most common and deadliest types of cancer in the United States.

**Hormonal therapy:** A treatment that blocks cancer cells from getting the hormones they need to grow.

**Ileostomy:** A surgical opening in the abdominal wall where the ileum (the lowest section of the small intestine) is brought through the opening to form a stoma to evacuate feces.

**Imaging test:** Different tests that create images of parts of the body, such as X-rays, magnetic resonance imaging (MRI), computed tomography (CT) and positron emission tomography (PET).

**Immune system:** The body's natural defense system against getting an infection and disease. White blood cells are the main part of your immune system that fight infections.

## Glossary of GI Cancer and Treatment Terms *continued*

**Immunotherapy:** Also called biologic therapy. Therapies that use the patient's immune system to combat cancer. Treatment is designed to target the biology of the cancer cell and boost the body's natural defenses to combat cancer.

**Infection:** When germs enter a person's body and multiply, causing disease. The germs may be bacteria, viruses, yeast or fungi. When the body's natural defense system is strong, it can often fight the germs and prevent infection. Some cancer treatments can weaken the natural defense system.

**Inflammation:** Redness, swelling or pain in tissue.

**Jaundice:** When skin and/or the whites of the eye turn yellow.

**Late effect:** A health problem that occurs months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, psychosocial problems, and second cancers.

**Long-term side effect:** A problem that is caused by a disease or treatment of a disease and may continue for months or years after treatment, such as: gastrointestinal tract problems; pain, numbness, tingling, loss of feeling, heat or cold sensitivity in the hands or feet, fatigue.

**Malignant:** A tumor or cells that are cancerous.

**Metastasis:** The spread of cancer from one part of the body to another, through the lymph system or bloodstream. A tumor formed by cells that have spread is called a "metastatic tumor" or a "metastasis." The metastatic tumor contains cells that are like those in the original (primary) tumor.

**MRI – Magnetic Resonance Imaging:** Imaging technique using a magnet that is linked to a computer to create detailed pictures of organs or soft tissues in the body.

**Mutation:** A change in the DNA of a cell. Most mutations do not cause cancer, though some are linked to higher risk for cancer.

**NED – No evidence of Disease:** No signs of any cancer in the body. Also called complete remission.

**Neutropenia:** When the body has very low levels of certain white blood cells called neutrophils (infection-fighting white blood cells). It is a common side effect of chemotherapy treatment.

**Oncologist:** A medical doctor specializing in treating and managing patients diagnosed with cancer.

**Oncology:** Healthcare that focuses on the diagnosis and treatment of cancer.

**Ostomy:** An artificial opening created during surgery in an organ of the body, such as a colostomy, ileostomy, gastrostomy or stoma.

**Patient navigator:** A person who guides a cancer patient through tests, treatment, follow-up care, insurance and financial concerns.

**PET scan – Positron emission tomography:** An imaging test that checks for disease in the body by using radioactive tracers/glucose in a special dye. The dye is injected into a vein and absorbed by organs and tissues and can help detect cancer in the body.

**Polyp:** Flat or mushroom-type growths.

**Primary cancer:** The original cancer that develops in one place in the body.

## Glossary of GI Cancer and Treatment Terms *continued*

**Psychologist:** An expert or specialist in psychology (the study of the mind and behavior).

**Psychosocial factors:** A person's thoughts, emotions, behaviors, spirituality and social interactions.

**Quality of life:** A cancer survivor's overall enjoyment of life, including his or her sense of well-being and the physical, mental, emotional and social ability to do the things he or she wants to do.

**Radiation therapy:** Using high-energy rays (similar to X-rays) to kill cancer cells.

**Radiologist:** Doctors who specialize in diagnosing and treating diseases and injuries using medical imaging techniques, such as X-rays, computed tomography (CT), magnetic resonance imaging (MRI), nuclear medicine, positron emission tomography (PET) and ultrasound.

**Recurrence:** When a cancer comes back after treatment or after remission.

**Remission:** When the cancer has gotten smaller, is gone, or is under control. Partial remission means that the cancer is still there, but the tumor is smaller or there is less cancer throughout the body.

**Risk factor:** Something that is linked with a person's chance of getting a disease. These can include behaviors such as smoking or lack of exercise.

**Sarcoma:** A cancer that develops in connective tissue like muscle or fat.

**Screening:** Checking for cancer before symptoms appear. Screening may find diseases at an early stage, when there may be a better chance of treatment.

**Second opinion:** When a patient gets an opinion from more than one doctor or specialist.

**Secondary cancer:** A cancer that has spread to another part of the body from the area where it started. See Metastasis.

**Side effects:** Reactions or effects from medication or therapy.

**Social worker:** Social workers help individuals, families, and caregivers with numerous items, including emotional support, financial or health insurance questions, relationship concerns.

**Stage:** A way to describe cancer, usually based on the size of the tumor, whether lymph nodes contain cancer, and whether it has spread to other organs or tissues in the body.

**Stem cell transplant:** Stem cell transplants may be done after chemotherapy or radiation therapy. Stem cells are cells that live in the bone marrow and make new blood cells. Stem cell transplants take stem cells from the blood of a donor and put them into a cancer patient after treatment.

**Support network:** A group of people who help a cancer survivor like caregivers, friends, family members, doctors, and therapists.

**Surgeon:** A doctor who performs surgeries.

**Surgery:** Medical treatment to remove damaged or diseased parts of the body, such as the removal of tissue with cancer cells.

**Surveillance (medical):** Surveillance can be used to monitor a person's health by doing certain tests on a regular schedule. It may be done for individuals who are at increased risk of cancer, patients in early stages of cancer, or survivors who are in remission.

## Glossary of GI Cancer and Treatment Terms *continued*

**Survivor:** See Cancer Survivor.

**Survivorship care plan:** A complete record of a cancer patient's cancer history, treatments given, the need for future checkups and cancer tests, possible long-term effects of the treatment and ideas for staying healthy. The plan needs to identify the healthcare providers that were responsible for care.

**Symptom:** A sign of illness in the body. There are some symptoms that are associated with different types of cancer.

**Tumor:** A tumor is an abnormal growth of body tissue. Tumors can be cancerous (malignant) or noncancerous (benign). Cancerous tumors can have uncontrolled growth and may spread to other parts of the body. Noncancerous tumors do not grow or spread.

Additional Glossary Terms:

Notes:



**Receiving a GI cancer diagnosis is a journey. Here is what people living with GI cancer have to say.**

"Give yourself time to balance your emotions, understanding your diagnosis and options to treatment. There may be bumps in the road. Stay the course. Cancer is what I have—I do not let it define me."

"I don't seem to fit in with my friends and co-workers anymore—I am having trouble figuring out what 'normal' is since my diagnosis."

"This is a mental and emotional battle just as much as it is physical. Try not to let the disease define your entire life."

"Get a second medical opinion. Get educated on your type of cancer."

"Your journey is your own. Just because someone else experienced something, doesn't mean you will experience the same."

"I am anxious and scared all the time. I don't feel like I have any control of my life, and I need to figure out a way to balance my emotions."

"[Develop] a road map to help [you] determine next steps now that treatment is over."



**g i c a n c e r s**  
ALLIANCE

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