



Patient Advocacy & Navigation Guide

For Colon Cancer Patients, Survivors & Caregivers

Patient Navigation: Parts 1-7

Understanding • Diagnosis • Treatment • Insurance • Support • Follow-Up • Advocacy

Understanding Colon Cancer

What is Colon Cancer?

Colon cancer develops in the large intestine (colon), often beginning as small, noncancerous clumps of cells called polyps that can become cancerous over time. Early detection through screening is key to successful treatment.

Main Types

- Adenocarcinoma (most common)
- Carcinoid tumors
- Gastrointestinal stromal tumors (GISTs)
- Lymphoma

Risk Factors

- Age (increased risk over 45)
- High-fat, low-fiber diet
- Family history and genetics
- Sedentary lifestyle
- Inflammatory bowel disease
- Smoking and heavy alcohol use

Common Symptoms

- Changes in bowel habits
- Blood in stool
- Persistent abdominal pain or cramping
- Unexplained weight loss
- Fatigue and weakness

Awareness

Regular check-ups and colonoscopies are essential, especially for individuals over 45. Early detection significantly improves treatment outcomes and survival rates.

Resources

- The Cancer Compass Beyond The Diagnosis – www.tccbtd.org
- National Cancer Institute – www.cancer.gov
- American Cancer Society – www.cancer.org

Colon Cancer Diagnosis

Receiving a Diagnosis

A colon cancer diagnosis can be overwhelming emotionally and practically. Understanding your diagnosis is the first step toward taking control of your care journey. Ask your medical team to explain your results clearly and don't hesitate to request additional time or information.

Staging & Grading

- Stage I – Cancer is in the inner lining
- Stage II – Cancer has grown through the colon wall
- Stage III – Cancer has spread to lymph nodes
- Stage IV – Cancer has spread to distant organs

Tumor grading indicates how abnormal cells look and how quickly they may grow.

Diagnostic Tests

- Colonoscopy
- CT scan (computed tomography)
- Biopsy and pathology report
- Blood tests (CEA marker)
- MRI or PET scan if needed

Patient Checklist

- Get copies of all test results
- Write down questions before appointments
- Bring a trusted person to appointments
- Request a written summary of your diagnosis
- Ask about next steps and timeline

Download the full patient checklist at:
www.tccbtd.org/resource-center

Tip: Understanding your diagnosis empowers you to make informed decisions. Don't rush — take the time you need to process and ask questions.

Treatment Planning

Treatment Options

- Surgery (removal of tumor and surrounding tissue)
- Chemotherapy (systemic drug treatment)
- Radiation therapy (targeted energy treatment)
- Immunotherapy
- Clinical trials (access to new treatments)

Your treatment plan will depend on the stage, location, and characteristics of your cancer.

Decision Making

- Make a pros and cons list for each option
- Discuss quality of life considerations
- Ask about short-term and long-term side effects
- Consider seeking a second opinion
- Take time to process before deciding

Your Care Team

Build a multidisciplinary team:

- Surgical oncologist
- Medical oncologist
- Radiation oncologist
- Gastroenterologist
- Registered dietitian
- Nurse navigator
- Social worker
- Mental health professional

Resources: NIH (www.nih.gov) • NCI (www.cancer.gov) • ClinicalTrials.gov • CenterWatch (www.centerwatch.com) • CISCRP (www.cisrp.org)

Navigating Coverage

Types of Insurance

Private Insurance

Employer-sponsored or individually purchased plans. Coverage varies by plan — review your policy for cancer treatment benefits, in-network providers, and prior authorization requirements.

Medicare

Federal program for adults 65+ or those with qualifying disabilities. Covers hospital stays, doctor visits, and many cancer treatments.

www.medicare.gov

Medicaid

State and federal program for low-income individuals. Coverage varies by state but typically includes cancer screening and treatment.

www.medicaid.gov

Understanding Costs

- Co-pays: Fixed amount you pay per visit or service
- Deductibles: Amount you pay before insurance kicks in
- Out-of-pocket maximum: Most you'll pay in a year
- Coinsurance: Percentage you pay after deductible

Keep detailed records of all medical bills and insurance communications.

Financial Assistance

- Hospital financial aid programs
- Nonprofit patient assistance organizations
- Government assistance programs
- Pharmaceutical company patient programs
- Cancer-specific grants and foundations

Speak with a hospital social worker or financial counselor early in your treatment.

Support Systems & Symptom Management

Mental Health & Emotional Well-Being

- Individual therapy or counseling
- Cancer support groups (in-person and online)
- Cognitive Behavioral Therapy (CBT)
- Mindfulness and meditation practices
- Journaling and creative outlets
- Family involvement in appointments
- Peer support and mentorship programs

Family & Caregiver Support

Encourage family members to participate in medical appointments. Open communication helps everyone understand the treatment plan and provides emotional support throughout the journey.

Symptom Management

- Communicate openly with your healthcare team about all symptoms
- Deep breathing and relaxation techniques
- Yoga and gentle stretching
- Balanced nutrition and proper hydration
- Consult a registered nutritionist
- Maintain light physical activity as tolerated
- Track symptoms in a daily journal

Nutrition Tips

- Eat small, frequent meals
- Stay hydrated throughout the day
- Focus on high-protein foods for healing
- Avoid processed and high-fat foods
- Work with a dietitian for a personalized plan

Follow-Up Care & Advocating for Yourself

Part 6: Follow-Up Care

Post-treatment monitoring is essential to detect any recurrence early. Work with your care team to establish a regular follow-up schedule.

Typical Follow-Up Procedures

- Regular physical examinations
- Blood tests (CEA and other markers)
- CT scans and imaging
- Colonoscopies at recommended intervals
- Monitoring for late side effects

Survivorship Care Plan

- Create a personalized survivorship care plan
- Maintain a balanced diet and regular exercise
- Continue counseling or therapy as needed
- Stay connected with your support network
- Report any new symptoms promptly

Part 7: Advocating for Yourself Your Patient Rights

- Right to privacy (HIPAA protections)
- Right to informed consent
- Right to seek a second opinion
- Right to access your medical records
- Right to refuse treatment

Getting Involved

- Attend communication workshops
- Join patient advocacy groups
- Participate in community awareness events
- Support cancer research fundraising
- Share your story to help others
- Connect with organizations like TCCBTD