



Patient Advocacy & Navigation Guide For Colon Cancer Patients, Survivors & Caregivers.

Patient Navigation: Part 1

Understanding Colon Cancer

Colon cancer is a type of cancer that starts in the large intestine, known as the colon. It usually begins as a small growth called a polyp, which can develop into cancer over time.

The main types of colon cancer include adenocarcinoma, carcinoid tumors, gastrointestinal stromal tumors (GISTs), and lymphoma. While the exact causes are not fully understood, some possible risk factors are age, diet, lifestyle choices, genetic factors, and existing conditions like inflammatory bowel disease.

Common symptoms to watch for include changes in bowel habits, blood in the stool, belly pain, unexpected weight loss, and feeling very tired. People over 50, those with a family history of colon cancer, a personal history of polyps or inflammatory bowel

disease, a lack of physical activity, a diet high in red or processed meats, smokers, and those who consume alcohol are at higher risk.

Awareness

Regular check-ups, such as colonoscopies, are crucial for early detection, especially for those over 45 or with other risk factors. Catching cancer early can significantly improve treatment outcomes.

Resources

- The Cancer Compass Beyond The Diagnosis: Offers essential resources, support, research updates, and health information regarding colon cancer.
- National Cancer Institute: Provides comprehensive information on cancer treatment, prevention, and research.
- American Cancer Society: Offers resources, assistance, research updates, and guidelines for cancer care.

Patient Navigation: Part 2

Colon Cancer Diagnosis

Receiving a colon cancer diagnosis can lead patients on differing paths. It's vital for patients to navigate their journey through cancer care, which includes understanding their diagnosis, treatment options, recovery, and life post-cancer.

Interpreting Results

Understanding your medical results is important. We recommend having a healthcare professional or caregiver explain medical terms, such as tumor stages (I-IV) and grading (how abnormal the cells look).

Resources

We suggest using our patient checklist, available on our website, to help prepare questions for doctor visits.

Website: www.tccbtd.org/resource-center

Awareness

Consider tests like colonoscopies, CT scans, and biopsies, which are crucial for confirming a diagnosis and determining the stage of colon cancer. Regular screenings are essential for early detection, especially for those over 45 or with risk factors.

Patient Navigation: Part 3

Treatment Planning

Patients should discuss treatment options with their doctor, including surgery (removing the tumor), chemotherapy (drugs to kill cancer cells), radiation therapy (using radiation to target cancer), and clinical trials (experimental treatments). Having a team of specialists, such as surgeons, oncologists, nurse navigators, and dietitians, can help coordinate care effectively.

Decision Making

We recommend making a list of pros and cons to compare your treatment options. Research treatment centers and specialists to assess their credentials, reviews, and rankings.

Resources

- National Institutes of Health: www.nih.gov
- Center for Information and Study on Clinical Research: www.ciscrp.org
- National Cancer Institute: www.cancer.gov
- ClinicalTrials.gov: www.clinicaltrials.gov
- CenterWatch: www.centerwatch.com

Patient Navigation: Part 4

Navigating Coverage

There are three types of insurance: Private Insurance, Medicare, and Medicaid. Private insurance may be provided by employers or purchased, covering various services, but coverage depends on the specific plan.

Medicare is a federal program for those aged 65 and older or younger people with disabilities. It includes Part A (hospital insurance) and Part B (medical insurance), covering hospital stays and some outpatient treatments. Part D covers prescription medications. Medicaid is a program for low-income individuals and families, offering coverage that generally includes comprehensive cancer treatment. Check state-specific programs for details on how colon cancer treatments are covered.

Co-pays & Out-of-Pocket Expenses

Co-pays are fixed amounts for services like doctor visits, while out-of-pocket expenses include co-pays and deductibles. Knowing your insurance plan can help forecast treatment costs.

Resources

- Many hospitals offer financial aid programs based on income.
- Nonprofit organizations provide support for cancer patients.
- Government assistance like Medicare and Medicaid is available if eligibility requirements are met.

Websites: Medicare: www.medicare.gov | Medicaid: www.medicaid.gov

Patient Navigation: Part 5

Support Systems

Taking care of mental health is crucial during cancer treatment. Therapy and support groups can help patients manage emotional challenges. Techniques like cognitive behavioral therapy (CBT) can alleviate anxiety and depression.

Common coping strategies include mindfulness, journaling, and gratitude practice. We encourage patients to express their feelings through creative outlets like art or writing. Involving family and friends is vital for emotional support, and we suggest loved ones accompany patients to appointments and participate in discussions about treatment.

Support groups, both in person and online, can create a community. Connecting with others who share similar experiences can provide valuable encouragement and insights.

Symptom Management

Treatment may bring physical and emotional side effects. It's important to communicate openly with healthcare teams about any symptoms, as treatment plans may need adjustments.

We recommend relaxation techniques like deep breathing, yoga, or gentle stretches to promote well-being. Proper nutrition is also essential. Eating balanced meals, staying hydrated, and possibly consulting a nutritionist about cancer care can be beneficial. Regular physical activity, even short walks, can boost mood and energy levels.

Patient Navigation: Part 6

Follow-Up Care

Monitoring after treatment is vital for catching any potential recurrence of colon cancer early. Regular follow-up appointments allow healthcare teams to check health, perform necessary tests, and adjust care plans. These visits may include physical exams, blood tests, and imaging studies. Staying proactive helps address any issues promptly.

Creating a personalized survivorship care plan can help patients move from treatment to survivorship by outlining future screenings, preventive care, health goals, and lifestyle changes. A balanced diet rich in fruits, vegetables, whole grains, and lean proteins is important. Consulting a nutritionist specializing in cancer recovery can provide personalized dietary guidance, while regular physical activities like walking or swimming can enhance physical strength and emotional well-being. Joining counseling or support groups for cancer survivors offers a safe space for sharing feelings and experiences.

Patient Navigation: Part 7

Advocating for Yourself

As patients, you have rights, including privacy, informed consent, and seeking a second opinion. Your medical records are confidential under laws like HIPAA in the U.S.

Patients must understand their diagnosis, treatment options, and potential risks and benefits before agreeing to any procedures. This helps them make informed healthcare decisions. Seeking a second opinion can ensure confidence in your diagnosis and treatment plan.

Workshops

We recommend attending workshops that teach effective communication. These workshops can help you express concerns, ask questions, and understand medical terms better. The Cancer Compass Beyond The Diagnosis provides a list of questions for patient use during doctor visits.

Engage

Joining advocacy groups and peer networks is encouraged. Connecting with local support groups or online forums allows patients and caregivers to share experiences and advocate for cancer research. Participating in community events, like runs or walks supporting colon cancer research, and making financial contributions can help raise awareness and support efforts in the fight against cancer.