EARLY AGE ONSET COLORECTAL CANCER
Information Booklet
We at CCRAN want to welcome you to our patient-focused resource and advocacy network for young adult colorectal cancer.

It can be daunting to receive a new diagnosis of early age onset colorectal cancer. This information booklet has been developed to help you better understand your diagnosis of early age onset colorectal cancer and to help you find resources to aid you on your journey.

By knowing more about your disease and the treatment options available to you, we hope to help you find reassurance that your colorectal cancer is highly treatable. New innovations in care for colorectal cancer and in clinical trials means there is more hope than ever for great treatments and better outcomes.

There is always hope!
Increasing numbers of Canadians are being diagnosed with colorectal cancer at significantly earlier ages than in the past, and the trend is increasing. While the incidence of colorectal cancer is decreasing among older Canadians, it is rising rapidly in people in their 20s, 30s, and 40s.

To make matters worse, when younger patients are diagnosed, they are generally found to have far more advanced disease, which may be more difficult to treat and may result in poor health outcomes. Younger colorectal cancer patients report that the effects of the disease on their lives are profound and differ in many ways from the experiences of their older counterpart patients.

One reason why the disease is diagnosed at a later stage is that colorectal cancer is viewed as a disease of the elderly population. Younger Canadians and their family physicians often do not suspect that symptoms, such as altered bowel patterns, rectal bleeding, or unexplained anemia, could be due to a malignant tumour. Additionally, many are unaware of the importance of family history of colorectal cancer as a risk factor.

Another aspect of the disease in younger adults is that colorectal tumours in this population tend to show different characteristics than those that develop later in life. These tumours are generally more difficult to treat because they are often more aggressive in nature, are localized in higher-risk areas of the gastrointestinal tract, and show different mutational profiles. One consequence is that traditional methods of screening and treatment may not be as effective in younger people.
What is being done?

Addressing two critical areas can save lives: raising awareness that colorectal cancer can and does occur in younger people, and early detection through screening programs.

1. Comprehensive research programs have been initiated in Canada and elsewhere to identify the distinguishing characteristics of colorectal tumours in younger people. The aim is to develop clinical tools that can be used to tailor population-based colorectal screening programs and treatment protocols.

2. CCRAN would like to influence practice change amongst primary care physicians to support early diagnosis of EAOCRC.

3. CCRAN is playing a key role in raising awareness among Canadians in general, and family doctors in particular, that colorectal cancer is not just an older person’s disease – it can and does occur in much younger people. Recognition by the general public of the possibility and symptoms of colorectal cancer and a raised index of clinical suspicion among primary care physicians can save lives.
What is different about early age onset colorectal cancer?

People under the age of 50 can and do develop colorectal cancer. Although this age group represents approximately 10% of colorectal cancer cases, the incidence in younger people is rising rapidly worldwide and especially in developed countries like Canada.

Younger patients are often diagnosed outside of organized colorectal cancer screening programs. These are limited to persons at average risk aged 50 to 74, although they can include younger persons at high risk, such as those with a strong family history of the disease. Because a diagnosis of colorectal cancer is unexpected in a younger person, symptoms often are not reported to physicians or are attributed by doctors to more benign conditions.
As a result, younger patients tend to be diagnosed at later stages of disease. Also, their tumours are often more aggressive in nature. Treatments typically require the use of surgeries, radiation therapies, and chemotherapies, all of which can be quite invasive in order to help destroy the cancer. This can in turn incapacitate patients and lead to long term side effects from the treatments. Recurrence may also occur after treatments have been employed and cause significant emotional stress and anxiety. More potential life years are lost in this group as a result of their young age and poor outcomes.

Potential long-term implications from treatment may affect future fertility and impair the patient’s ability to achieve their life goals. A diagnosis of colorectal cancer at a young age and its treatment impacts can affect a person’s emotional and physical well-being and quality of life. The disease and the arduous treatment journey often cause social and economic disruptions within families, communities, and workplaces. But the proper management of the disease and social support network can improve a patient’s journey and allow them to move forward with competence and confidence.
Topography: Primary Tumour Sidedness

The sidedness of colorectal tumours accounts for some of the differences seen in the molecular profile described earlier. Right-sided colon cancers have a higher frequency of BRAF mutations, microsatellite instability, and CpG island promoter methylation when compared with left-sided colon cancers. Rectal cancers have similar molecular profiles to left-sided colon cancers, although some studies suggest rectal cancers have distinct features, such as KRAS and SMAD4 mutation.

Tumour sidedness also has implications for treatment, as it predicts response to anti-EGFR (epidermal growth factor receptor) therapies. Emerging evidence suggests, for example, that only patients with left-sided colon cancers benefit from cetuximab or panitumumab as first-line therapy for metastatic disease.
The majority (65-80%, depending on race/ethnicity) were in good or excellent health before diagnosis.

75% were employed full time.

66% took a leave of absence from work/school because of their diagnosis.

According to this 2019 Survey conducted by the Colorectal Cancer Alliance:

The following characteristics generally defined this younger group:

- The majority (65-80%, depending on race/ethnicity) were in good or excellent health before diagnosis.
- 75% were employed full time.
- 66% took a leave of absence from work/school because of their diagnosis.

There was a gap in awareness of personal risk factors for developing colorectal cancer:

- Nearly 28% indicated they have a family history of colorectal cancer.
- 52% were aware that their family history increased their risk for colorectal cancer.
- 49% had no knowledge of signs and symptoms of colorectal cancer before their diagnosis.
- Respondents who are aware of their family history of colorectal cancer were diagnosed at earlier stages than those who did not know or did not have a family history.
The journey from symptoms to diagnosis was long and complex:

Patients experienced multiple symptoms (three or more), with blood in the stool being the most common. Younger patients made multiple physician visits prior to their diagnosis.

- 75% saw at least two different doctors.
- 63% waited at least 3 months after experiencing symptoms before visiting a doctor.
- 45% waited at least 3 months to be diagnosed.
Initially, many patients (54%) were misdiagnosed:

The most common mistakenly diagnosed conditions were:

- Hemorrhoids
- Anemia
- Irritable Bowel Syndrome (IBS)
- Mental health issues

About half of respondents felt that doctors dismissed signs and symptoms of colorectal cancer because of their age.

More women than men reported that their symptoms were dismissed.
Colorectal cancer had important impacts on other aspects of patients’ lives:

- Fatigue affected participation in social activities and everyday activities in approximately 40% of respondents.
- Financial health was an important factor in terms of insurance coverage and income.

Please see the Virtual Symposium page for more information: https://ccran.org/videos/EAOCC_Symposium/