Colon Cancer Screening for People with Down Syndrome

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Is colon cancer screening recommended for people with Down syndrome?

Please note that this handout discusses screening colonoscopies (i.e. colonoscopies performed to identify pre-symptomatic or unrecognized symptomatic colon cancer). If there is an abnormality or symptom, we refer patients for colonoscopies when appropriate. This information is for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.

There are no official guidelines for colon cancer screening that are different for people with Down syndrome compared to those without Down syndrome. However, there are a few things to consider:

1. The incidence of colon cancer is lower in people with Down syndrome. Solid tumors (including colon cancer) are less common in people with Down syndrome1 (see references below for additional information).
2. Our experience is that most people with Down syndrome require significant sedation and many even require general anesthesia to complete a colonoscopy. People with Down syndrome have a greater risk of complications from anesthesia (see references below for additional information).

There have been several studies that have found that colon cancer is less common in people with Down syndrome. In one of these, Hasle et al. (2016) concluded: “The risk of all major groups of solid tumors was decreased, except testicular cancer. Altered screening strategies should be considered for persons with Down syndrome.” Therefore, we discuss these points with our patients and their families and generally do not recommend screening colonoscopies for our patients (the risk is higher and the benefit lower). However, there may be factors such as family history of colon cancer, previous medical history, or other risk factors that might move the decision in the direction of screening.

Here are some additional questions we have been asked:

Why don’t we recommend testing the stool for blood or some of the other tests?

1 Despite most cancer being less common in people with DS, it should be noted that there are some cancers that are more common, including leukemia (especially in children and adolescents), cancer of the testicle, cancer of the ovary, and possibly lymphoma.
The reason is that if the test is abnormal, then a colonoscopy is generally recommended. The same issues that we just addressed would then be present.

**People with Down syndrome are living longer. Will we see a higher incidence of colon cancer that will justify colonoscopy screening?**

That is a good question for which we don’t know the answer. While the risk for colon cancer increases with age in people without Down syndrome, this has not been studied specifically in people with Down syndrome. At this time, the information that we have is that solid tumors, including colon cancer, are less common in people with Down syndrome. Unfortunately, the life expectancy of people with Down syndrome seems to be plateauing at about 60 years of age. Alzheimer’s disease is a major contributor to the plateau. We will need to continue to monitor the situation into the future to see if there will be greater benefit from colon cancer screening if life expectancy changes as treatments for other conditions improve.

**If we choose to get screening, what are the recommendations?**

We discuss the recommendations of the United States Preventive Services Task Force with our patients and their families. Additional information can be found at:


**References**


**Additional References on Lower Risk of Cancer**


References on Higher Incidence of Complications from Anesthesia
