

Attenuated Familial Adenomatous Polyposis

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Overview

What is attenuated familial adenomatous polyposis?

Attenuated familial adenomatous polyposis (AFAP) is a subtype of a condition known as [familial adenomatous polyposis](#) [2] (called FAP or classic FAP). People with FAP or AFAP will have an increased number of adenomatous colon polyps during their lifetime and an increased risk of developing [colorectal cancer](#) [3]. An adenomatous polyp is a lump filled with the cells that make mucous and line the inside of a person's colon. Normally these cells are in flat sheets, but in FAP and AFAP they build up into polyps inside the intestinal tract. In AFAP, the total number of colon polyps is less than 100, with 30 being average. In FAP, there are many more polyps.

Polyps in people with AFAP tend to develop later in life than in individuals with classic FAP, although polyps may develop as early as the late teens. [Colorectal cancer](#) [3] can develop later in people with AFAP as well, with the average age at diagnosis being around 50. Polyps and cancer of the [stomach](#) [4] and [small intestines](#) [5] are also seen in families with AFAP.

AFAP is still being defined by doctors. It has not been determined if families with AFAP have the same risk for other types of cancer, in addition to colon cancer, as families with classic FAP. Risks for some of the other, noncancerous features associated with classic FAP have not been determined. For instance, people with AFAP appear to have a lesser chance of developing desmoid tumors (noncancerous fibrous tumors that can grow anywhere in the body) or congenital hypertrophy of the retinal pigment epithelium (CHRPE, which is an eye condition), than people diagnosed with FAP. Find out more about [classic FAP](#) [2].

What causes AFAP?

AFAP is a genetic condition. This means that the cancer risk can be passed from generation to generation in a family, but usually not all children of a person with AFAP will be affected. The gene associated with AFAP is *APC*; *APC* stands for adenomatous polyposis coli. A mutation (alteration) in the *APC* gene gives a person an increased lifetime risk of developing multiple adenomatous colon polyps, [colorectal cancer](#) [3], and other cancers of the digestive tract. People who are diagnosed with AFAP, and their family members, should talk with a [genetics counselor](#) [6] or medical genetics specialist (a health professional with specialized training in medical genetics).

How is AFAP inherited?

Normally, every cell has two copies of each gene: one inherited from the mother and one inherited from the father. AFAP follows an autosomal dominant inheritance pattern, in which a mutation happens in only one copy of the gene. This means that a parent with a gene mutation may pass along a copy of their normal gene or a copy of the gene with the mutation. Therefore, a child who has a parent with a mutation has a 50% chance of inheriting that mutation. A brother, sister, or parent of a person who has a mutation also has a 50% chance of having the same mutation.

How common is AFAP?

AFAP is uncommon and possibly under-diagnosed. Most colorectal cancer and colon polyps are sporadic (occurs by chance), not related to AFAP, classic FAP, or other [inherited syndromes](#) [7]. The number of colorectal cancer cases and the number of people with multiple adenomatous colon polyps that are related to AFAP are unknown.

How is AFAP diagnosed?

AFAP is suspected when a person has a history of more than 20, but less than 100, adenomatous colon polyps. People suspected of having AFAP

can have a blood test to look for a mutation in the *APC* gene. If an *APC* gene mutation is found, a diagnosis of AFAP is confirmed. Other family members may be diagnosed with AFAP if they are tested and have the same gene mutation.

What are the estimated cancer risks associated with AFAP?

The cancer risks for AFAP are considered to be similar to the risks associated with classic FAP, but the overall cancer risks may be lower. As more information is learned about AFAP, more specific cancer risks may emerge.

- [Colorectal cancer](#) [3] considered to be high, but less than 100% (if not treated)

Estimated digestive tract cancer risks for classic FAP. (It is unknown if risks are the same in AFAP but screening is suggested due to the similarities in both syndromes.)

- [Small bowel cancer](#) [5] (intestines) 4% to 12%
- [Pancreatic cancer](#) [8] 2%
- [Stomach cancer](#) [4] 0.5%

What are the screening options for AFAP?

It is important to discuss with your doctor the following screening options, as each individual is different:

- [Colonoscopy](#) [9] every two to three years, beginning at age 18
- Colectomy (the surgical removal of the entire colon). This may be considered if polyps cannot be managed with regular colonoscopies because there are too many or if a patient cannot have colonoscopies on the recommended schedule above.

There is an increased risk of polyps of the upper digestive tract in AFAP, and regular screening should be considered similar to classic FAP. The suggested screening for classic FAP is below.

- [Upper endoscopy](#) [10] (EGD) every one to three years, beginning at age 25 or after polyps are detected
- X-ray or [computed tomography](#) [11] (CT or CAT) scan of the small bowel if adenomas are found on the EGD or before a colectomy; repeat every one to three years depending on symptoms

It is unknown whether screening of the thyroid or screening for [hepatoblastoma](#) [12] (a type of liver cancer) in young children is appropriate for families with AFAP as it is with classic FAP; see [additional suggested screening for families with classic FAP](#) [13].

Screening options may change over time as new technologies are developed and more is learned about AFAP and classic FAP. It is important to talk with your doctor about appropriate screening tests.

Learn more about [what to expect when having common tests, procedures, and scans](#) [14].

Questions to ask the doctor

If you are concerned about your risk of [colorectal cancer](#) [3], talk with your doctor. Consider asking the following questions of your doctor:

- What is my risk of developing colorectal cancer?
- How many colon polyps have I had in total?
- What type of colon polyps have I had? (The two most common kinds are hyperplastic and adenomatous.)
- What can I do to reduce my risk of cancer?
- What are my options for cancer screening?

If you are concerned about your family history and think your family may have AFAP, consider asking the following questions:

- Does my family history increase my risk of colorectal cancer?
- Should I meet with a genetic counselor?
- Should I consider [genetic testing](#) [15]?

Additional resources

[Guide to Colorectal Cancer](#) [3]

[The Genetics of Colorectal Cancer](#) [16]

[What to Expect When You Meet With a Genetic Counselor](#) [6]

Colon Cancer Alliance [17]

www.ccalliance.org [17]

Colorectal Cancer Coalition (C3)

www.fightcolorectalcancer.org [18]

National Cancer Institute

www.cancer.gov [19]

American Cancer Society

www.cancer.org [20]

CancerCare

www.cancercare.org [21]

To find a genetic counselor in your area, ask your doctor or visit the following websites:

National Society of Genetic Counselors

www.nsgc.org [22]

National Cancer Institute: Cancer Genetics Services Directory

www.cancer.gov/cancertopics/genetics/directory [23]

Links:

- [1] <http://www.cancer.net/about-us>
- [2] <http://www.cancer.net/node/18852>
- [3] <http://www.cancer.net/node/18701>
- [4] <http://www.cancer.net/node/19645>
- [5] <http://www.cancer.net/node/19632>
- [6] <http://www.cancer.net/node/24907>
- [7] <http://www.cancer.net/node/24905>
- [8] <http://www.cancer.net/node/19495>
- [9] <http://www.cancer.net/node/24481>
- [10] <http://www.cancer.net/node/24731>
- [11] <http://www.cancer.net/node/24486>
- [12] <http://www.cancer.net/node/19134>
- [13] <http://www.cancer.net/node/18503>
- [14] <http://www.cancer.net/node/24959>
- [15] <http://www.cancer.net/node/24895>
- [16] <http://www.cancer.net/node/24898>
- [17] <http://www.ccalliance.org/>
- [18] <http://www.fightcolorectalcancer.org>
- [19] <http://www.cancer.gov>
- [20] <http://www.cancer.org>
- [21] <http://www.cancercare.org>
- [22] <http://www.nsgc.org/>
- [23] <http://www.cancer.gov/cancertopics/genetics/directory>