What doctors want patients to know about Crohn's disease

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AT A GLANCE: Crohn's disease is a condition that can affect any part of the digestive system. While it affects people throughout their lives in different ways, more treatment options are now available. Physicians are also finding promising lifestyle adjustments to help with the disease. Here are five things you will learn about Crohn’s disease from Sowmya Palam, MD, a gastroenterologist with Confluence Health, in this article:

- Symptoms of Crohn’s disease often include diarrhea, abdominal pain, fatigue and weight loss.
- Crohn’s disease can lead to complications inside the intestines, and in other parts of the body.
- The condition usually requires lifelong management and treatment.
- While there is no cure, modern therapies can help control inflammation and improve quality of life while living with the disease.
- Patients need to be in regular contact with a gastroenterologist to best manage their Crohn’s disease.

Crohn's disease affects millions of people worldwide. While it most commonly affects the small intestine and colon, manifestations can develop anywhere along the gastrointestinal tract—from the mouth to the area around the anus.

Symptoms of Crohn’s disease can vary significantly from person to person. While some people will experience mild symptoms for several years, others may develop serious complications that require surgery. The disease is chronic and progressive, making early diagnosis and ongoing management highly important for livable outcomes.

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Although there is currently no cure for Crohn’s disease, treatment options have expanded with strong potential in recent years. Newer therapies can help patients control inflammation, lessen complications and improve their overall quality of life.

The AMA’s?What Doctors Want Patients to Know™ series gives physicians a platform to share what they want patients to understand about today’s healthcare headlines.

In this installment, Sowmya Palam, MD, a gastroenterologist with Confluence Health, took the time to discuss what patients should know about Crohn’s disease symptoms, risk factors, treatment and long-term management.

Confluence Health is part of the AMA Health System Member Program, which provides enterprise solutions to equip leadership, physicians and care teams with resources to help drive the future of medicine.

Crohn's disease can affect the entire digestive tract

“Crohn’s disease is a chronic inflammatory disorder that can lead to inflammation in any part of the gastrointestinal tract from mouth to perianal region,” Dr. Palam said, “although it commonly involves the small bowel and colon.”

“The age of onset is most commonly between 15 and 30 years,” she said, “although it can present at any age with a second peak noted to be between 50 and 80 years.”

There are several ways physicians classify Crohn's disease

“Crohn’s disease is classified based on location, behavior and age at diagnosis,” Dr. Palam explained. “It can be isolated to the small bowel, colon or less commonly, upper gastrointestinal tract, or can involve multiple of these locations.”

“Inflammation in Crohn’s disease can involve deeper layers of the intestines, unlike its cousin ulcerative colitis, which is limited to the innermost lining of the colon,” she said. “Most patients have mainly inflammation without development of strictures, fistulas or

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abscess, but some patients can develop these complications especially if inflammation is not controlled with treatment."

Crohn's disease can reach other parts of the body

Crohn's disease is often thought of as a digestive condition, but its effects can extend throughout the body.

"Patients with Crohn's disease can also have extra-intestinal manifestations involving the joints, skin, eyes, liver and bile ducts," Dr. Palam said. "They can also be at increased risk of developing blood clots and decreased bone density with active disease."

Crohn's disease is relatively uncommon

"Crohn's disease affects approximately 0.3% to 0.7% of the population in high-income countries, with the highest prevalence rates reported in North America and Europe," Dr. Palam said.

Research estimates that up to 1 million people in the U.S. are currently living with Crohn's disease. https://www.ama-assn.org/public-health/prevention-wellness/what-doctors-want-patients-know-about-inflammatory-bowel-disease About 1 in 400 adults in the U.S. has Crohn's disease, with higher rates in people who are white and a growing presence across all racial groups.

Symptoms of Crohn's disease include diarrhea, abdominal pain, and fatigue

"The most common symptom is chronic diarrhea, but some patients may not have this symptom," Dr. Palam said. "Other common symptoms include abdominal pain, blood in stools and weight loss."

Additionally, "fatigue is a very prevalent symptom and can arise from factors such as anemia and vitamin and mineral deficiencies, which can be seen in this condition due to

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poor absorption of nutrients," she explained.

For children and adolescents, there may be additional challenges, according to Dr. Palam. "In younger patients, there can be signs of growth failure as well."

The exact cause of Crohn's disease is unknown

"It is unclear what exactly causes Crohn's disease," Dr. Palam said. "However, it is thought to result from a complex interaction between genetic susceptibility, environmental exposures and the intestinal microbiome."

Family history also plays a role, but it does not explain every case.

"If you have a first-degree relative with Crohn's disease, you are 20 times more likely to be diagnosed with the condition," she said. "However, only 15% of patients with inflammatory bowel disease, such as Crohn's disease, have a first-degree relative with the disease."

"Factors that have been linked to increased risk are cigarette smoking, antibiotic exposure—especially in childhood—high intake of ultraprocessed foods, urban living, vitamin D deficiency, environmental pollutants, cesarean delivery, tonsillectomy and appendectomy," she said.

Crohn's disease can also increase risks of certain cancers and nutritional problems.

"Complications can include malignancies such as small bowel cancer or colon cancer, as well as malnutrition, anemia, dehydration and vitamin deficiencies," Dr. Palam said.

Diagnosis of Crohn's disease requires multiple tests

"Crohn's disease is diagnosed based on a combination of imaging findings, endoscopic findings and tissue biopsies," Dr. Palam said, explaining that physicians may use several different procedures.

"Endoscopic evaluations may include colonoscopy, upper endoscopy and capsule endoscopy," she said. Also, "blood work can help assess severity and complications but is

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not sufficient for diagnosis of the disease.”

Most patients with Crohn’s disease require long-term treatment

“Crohn’s disease generally requires treatment with medications such as biologics,” Dr. Palam said. “Treatment typically consists of two phases: induction therapy to help quickly achieve control of inflammation and symptoms, followed by maintenance therapy to keep it under control and prevent flares or complications such as strictures, fistulas or abscesses.”

Patients may eventually require surgery, though this has declined significantly with new treatments available.

“Surgical management can be required for emergent or non-emergent conditions,” she said, noting that emergencies can include “acute bowel obstruction, intestinal perforation and pelvic infection.”

Other reasons for surgery include “medically refractory disease, strictures causing obstruction, fistulas or abscesses, intractable hemorrhage and dysplasia or cancer,” Dr. Palam said.

Diet can help Crohn’s disease, but careful monitoring is still required

Many patients ask whether dietary changes can replace medications for Crohn’s disease.

“A primary dietary-based treatment approach is generally limited to patients with mild or limited disease involvement and with low risks of disease progression,” Dr. Palam said.

Even then, careful monitoring is essential.

“Routine monitoring of symptoms, blood work and diagnostic assessments are needed to identify any disease progression in such patients,” she said.

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Unfortunately, “there is no cure for Crohn’s disease,” Dr. Palam said. “It is a chronic, lifelong inflammatory condition that cannot be eliminated with current medical or surgical treatments.”

Many patients can still live well with Crohn's disease

“The disease course can vary quite a bit,” Dr. Palam said. “Crohn’s disease is a chronic, progressive condition in most patients with a relapsing-remitting course, with periods of flare-ups followed by periods of partial or complete recovery.”

But not every patient experiences progressive disease.

“About 20% to 30% will have a nonprogressive or indolent course, meaning slow or minimal progression and mostly asymptomatic for extended periods of time,” she said. “Most patients require active management and treatment to control inflammation, and modern treatments have improved long-term outcomes.”

Pregnancy requires careful planning

“Pregnant patients with Crohn’s disease have an increased risk of preterm birth, low birth weight, fetal growth restriction, hypertensive disease of pregnancy and cesarean birth in the setting of active disease,” Dr. Palam said.

The best approach is to control the disease before pregnancy.

“Achieving clinical remission before getting pregnant and maintaining it helps improve outcomes,” she said, emphasizing the importance of discussing medications before conception.

“It is important to continue biologic therapies throughout pregnancy and the postpartum period,” Dr. Palam said. “However, there are a few medications that do need to be stopped at least six months before trying to get pregnant. It is very important to consult with your gastroenterologist if you are trying to get pregnant.”

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Crohn's disease cannot be prevented, but healthy habits may help

“Currently, there is no proven way of preventing Crohn’s disease,” Dr. Palam said. “However, research suggests that adherence to modifiable lifestyle factors could potentially prevent about 40% to 60% of cases.”

“Factors that may decrease risk include breastfeeding during childhood, physical activity, a Mediterranean diet, a high-fiber diet, exposure to green space in early life, proximity to pets or farm animals and high vitamin D levels,” she said.

Still, there are limitations to what researchers know.

“Most of this evidence comes from observational studies rather than interventional trials, and therefore we cannot definitively say that these factors can reduce incidence in high-risk populations,” Dr. Palam said.

Know when to contact your doctor about Crohn’s disease

“If you develop diarrhea that does not improve after four weeks and persists along with symptoms of abdominal pain, blood or mucus in stools, weight loss or fatigue,” Dr. Palam said, “these are all indications to be evaluated by your doctor as soon as possible for possible Crohn’s disease.”

Long-term follow-up is essential for Crohn’s disease

“The most important points to emphasize about Crohn’s disease include its chronic progressive nature requiring lifelong management, the importance of early aggressive treatment to prevent complications, the need for objective monitoring through a gastroenterologist beyond symptoms and the risks of stopping therapy even when feeling well,” Dr. Palam said, stressing that treatment decisions should never be made alone.

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Any “decision to stop or de-escalate treatment should only be made in partnership with gastroenterologist after careful consideration of depth of remission, disease markers and individual risk factors,” she said. “It is also very important to maintain long-term follow-up with a gastroenterologist to guide long-term management and help improve outcomes with Crohn’s disease.”

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