PXE Guide

Gastrointestinal Bleeding

What is PXE?

Pseudoxanthoma elasticum (PXE) is an inherited condition that causes abnormal mineralization in some elastic tissues of the body. PXE most often affects the skin, eyes, and mid-sized arteries. Less commonly, it can involve the gastrointestinal system.

PXE and the gastrointestinal system

Most people with PXE do not have gastrointestinal disease as a result of PXE. However, PXE has long been associated with upper gastrointestinal bleeding, particularly from the stomach. This bleeding is uncommon, but when it occurs it can be sudden, severe, and life-threatening.

GI bleeding in PXE can be difficult to localize. Gastroscopy may show diffuse punctate bleeding or erosions rather than a single obvious bleeding point. The exact mechanism is not fully understood. One proposed explanation is that superficial injury to the stomach lining, such as erosive gastritis, can become more serious because affected blood vessels do not constrict normally.

Get urgent medical care immediately for:

- Vomiting blood or material that looks like coffee grounds.
- Black, tarry stools.
- Large amounts of red blood in stool or rectal bleeding that does not stop.
- Dizziness, fainting, weakness, rapid heartbeat, chest pain, or shortness of breath with possible bleeding.
- New or worsening abdominal pain with signs of bleeding or anemia.

Gastrointestinal bleeding

GI bleeding has many causes. People with PXE can have the same common GI problems as anyone else, including reflux esophagitis, gastritis, peptic ulcers, colon polyps,

inflammatory bowel disease, colitis, Crohn's disease, diverticular bleeding, hemorrhoids, tumors, and medication-related bleeding. Not every GI symptom in a person with PXE is caused by PXE. Do not allow medical professionals to blame PXE and fail to perform the appropriate testing. Make sure they find the cause.

Bleeding can be silent. Slow blood loss may not be visible but can lead to iron deficiency or anemia. Bleeding can also be obvious. Lower GI bleeding often appears as bright red blood in stool. Upper GI bleeding can present as black, tarry stool (melena) or as vomiting blood.

Upper GI bleeding, sometimes massive, is the GI complication most clearly associated with PXE. It is uncommon but clinically important because it can be dramatic and difficult to control. Management may include endoscopy, blood transfusion, medications to suppress stomach acid, interventional radiology procedures such as embolization, or surgery in severe cases.

Aspirin, NSAIDs, anticoagulants, and bleeding risk

Aspirin and nonsteroidal anti-inflammatory drugs (NSAIDs), including ibuprofen, naproxen, and similar medications, can irritate the stomach lining and increase the risk of GI bleeding. In PXE, these medications should be avoided when possible unless a clinician determines that the benefit outweighs the risk. If you are at risk for a stroke or heart attack, your specialist might determine that these life-threatening and disability-causing risks are more critical than worrying about a slim chance of a gastrointestinal bleed.

This is especially important for people with a previous GI bleed, anemia, stomach ulcers, use of blood thinners, use of antiplatelet medications, or frequent need for pain medication. People who have been prescribed aspirin, anticoagulants, or antiplatelet drugs for stroke prevention, heart disease, stents, atrial fibrillation, or another serious reason should not stop them on their own. The prescribing clinician should weigh the vascular benefit against the bleeding risk.

COX-2 inhibitors, such as celecoxib, may have less effect on platelets and may cause less upper-GI injury than some traditional NSAIDs, but they are not risk-free and can have cardiovascular risks. They should be used only after discussion with the treating clinician.

For pain or arthritis, options that do not increase GI bleeding risk may be available, depending on the condition being treated. A primary care clinician, rheumatologist, pain specialist, or other appropriate clinician should help choose the safest option.

Intestinal angina

Intestinal angina is abdominal pain caused by reduced blood flow to the intestines, usually from narrowing of arteries supplying the gut. It is rare but has been described in PXE. Symptoms can include cramping abdominal pain after eating, fear of eating because of

pain, nausea, diarrhea, or unexplained weight loss. Diagnosis and treatment usually require coordination among a gastroenterologist, vascular specialist, interventional radiologist, and surgeon.

Colonoscopy and colorectal cancer screening

PXE itself is not known to make colonoscopy more dangerous than it is for people without PXE. People with PXE should follow ordinary colorectal cancer screening guidance and should also have colonoscopy or other evaluation when symptoms such as bleeding, anemia, unexplained weight loss, or a change in bowel habits warrant it.

In the United States, average-risk adults are generally advised to begin colorectal cancer screening at age 45 and continue through age 75. Screening decisions from age 76 to 85 are individualized based on health, prior screening history, and preferences. People at increased risk because of family history, prior polyps, inflammatory bowel disease, or other factors may need earlier or more frequent screening.

Before colonoscopy or endoscopy, tell the gastroenterologist that you have PXE, and give a history of any GI bleeding, anemia, vascular disease, aspirin or NSAID use, blood thinners, antiplatelet medication, or prior reactions to anesthesia.

What to tell your clinician

Because many clinicians have not seen PXE, people with PXE should tell each treating clinician that PXE can be associated with upper GI bleeding and vascular disease. This is particularly important in emergency departments, before endoscopy or surgery, and when medications that increase bleeding risk are being considered.

- History of any black stools, vomiting blood, anemia, transfusion, hospitalization, or endoscopy.
- Use of aspirin, ibuprofen, naproxen, anticoagulants, antiplatelet drugs, steroids, or SSRI antidepressants.
- History of ulcers, reflux, gastritis, liver disease, kidney disease, inflammatory bowel disease, or colon polyps.
- Any abdominal pain after meals, weight loss, or symptoms suggesting reduced intestinal blood flow.

What can people with PXE do?

- Avoid aspirin and NSAIDs when possible unless a clinician has specifically recommended them after weighing risks and benefits.
- Do not stop prescribed aspirin, anticoagulants, or antiplatelet medications without medical advice.

- Seek urgent care for vomiting blood, black tarry stool, severe rectal bleeding, fainting, marked weakness, or symptoms of anemia.
- Tell emergency clinicians and gastroenterologists that PXE can be associated with upper GI bleeding.
- Follow standard colorectal cancer screening guidance and report unexplained anemia or bleeding promptly.
- Ask whether stomach-protective medication is appropriate if a medication that increases GI bleeding risk is necessary.

What remains uncertain

The frequency of GI bleeding in PXE is not precisely known. Older reports and reviews often cite a minority of affected individuals, but estimates vary depending on how patients are identified, how bleeding is defined, and whether data come from case reports, clinics, or participant-reported surveys. The mechanism of bleeding also remains incompletely understood. There is not enough evidence to say that people with PXE develop ordinary ulcers more often than the general population. The more defensible statement is that PXE can make some bleeding events more clinically significant when they occur.

More systematic data are needed on age at first bleed, recurrence, medications, endoscopic findings, anemia, transfusion, hospitalization, interventions, and long-term outcomes. These are priorities for PXE International's continuing natural history work.

Bottom line

GI bleeding is not one of the most common PXE problems, but it is one of the complications that matters most because it can be sudden and severe. People with PXE should avoid unnecessary aspirin and NSAID exposure, make sure clinicians know about PXE before procedures or when prescribing medications, and seek urgent care for signs of GI bleeding.

Sources and further reading

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