CONDITION

Protein-losing enteropathy

Protein-losing enteropathy is excessive loss of blood proteins through the digestive tract.

WHAT IT IS
Excessive loss of blood proteins through the digestive tract

BODY SYSTEM
Digestive system, sometimes heart and lymph vessels

MAIN SYMPTOMS
Leg swelling, diarrhea, abdominal swelling, fatigue

WHAT CAUSES IT
Digestive disease, blocked lymph flow, or heart disease

HOW IT IS DIAGNOSED
Stool alpha-1 antitrypsin clearance and cause-specific tests

MAIN TREATMENT
Treating the cause, nutrition support, and swelling control

CAN IT BE CURED?
Sometimes - treating the cause stops protein loss

IS IT AN EMERGENCY?
Sometimes - breathing trouble or severe dehydration

LONG-TERM OUTLOOK
Often improves when the underlying cause is controlled

Overview

Protein-losing enteropathy, or protein-losing gastroenteropathy, is a condition in which too much protein leaks from the blood into the digestive tract. It is not one specific disease. It is a result of another problem affecting the stomach, intestines, lymph vessels, or circulation.

Albumin is one of the main proteins lost. It helps keep fluid inside blood vessels. When albumin becomes very low, fluid can collect under the skin, in the abdomen, or around the lungs.

Other proteins may also be lost. These include antibodies that help fight infection and proteins that carry hormones, vitamins, and medicines through the blood.

Protein-losing enteropathy matters because the protein loss can affect nutrition, fluid balance, and immune function. Treatment focuses on finding and managing the underlying cause rather than only replacing the lost protein.

Symptoms

Symptoms differ according to how much protein is being lost and what is causing the condition. Some people have digestive symptoms, while others mainly notice swelling.

Common symptoms include:

Fluid may also collect around the lungs. This is called a pleural effusion and can cause breathlessness or chest discomfort.

Not everyone with protein-losing enteropathy has diarrhea. This is especially true when the protein loss is related to abnormal lymph flow or heart circulation.

Loss of antibodies and certain white blood cells can make infections more likely in some forms of the condition. Vitamin and mineral deficiencies may cause muscle cramps, numbness, bone problems, anemia, or other symptoms.

- Swelling of the feet, ankles, legs, face, or hands
- Abdominal swelling from fluid, called ascites
- Diarrhea, which may be persistent or come and go
- Abdominal pain, nausea, or poor appetite
- Tiredness, weakness, or reduced ability to exercise
- Unplanned weight loss or poor growth in children

Causes and risk factors

Protein-losing enteropathy develops through several different pathways. The lining of the digestive tract may be damaged or unusually permeable, meaning proteins can pass through it too easily. Pressure may also build up in lymph vessels, causing protein-rich lymph fluid to leak into the intestine.

Conditions that can damage or inflame the digestive lining include inflammatory bowel disease, severe infections, celiac disease, stomach or intestinal ulcers, and some immune-related disorders. Certain cancers involving the digestive tract can occasionally cause it.

Ménétrier disease, a rare condition that enlarges the folds of the stomach lining, can cause substantial protein loss. Eosinophilic digestive diseases, in which a type of white blood cell builds up in the digestive tract, are another possible cause.

Lymph-related causes include primary intestinal lymphangiectasia. In this condition, lymph

vessels in the intestinal wall are widened and leak fluid. It may begin in childhood, although it can also be found in adults. Lymph flow can also be blocked by scarring, tumors, or other structural problems.

Heart and circulation problems may raise pressure in the veins and lymph vessels. Examples include severe right-sided heart failure and constrictive pericarditis, in which the sac around the heart becomes thick and stiff. Protein-losing enteropathy is also a recognised complication in some people who have had a Fontan operation for congenital heart disease.

Risk is therefore linked to the underlying condition. Protein-losing enteropathy itself is not contagious.

Diagnosis

Low blood protein may suggest protein-losing enteropathy, but it does not confirm it. Albumin can also be low because of liver disease, protein loss through the kidneys, severe inflammation, poor nutrition, or major burns. These possibilities usually need to be assessed.

Blood tests commonly measure albumin, total protein, blood cell counts, liver and kidney function, electrolytes, and markers of inflammation. Urine testing can check whether protein is being lost through the kidneys.

The main test used to confirm excessive protein loss through the digestive tract is stool alpha-1 antitrypsin clearance. Alpha-1 antitrypsin is a blood protein that usually remains intact as it passes through the intestines. The test compares its level in a timed stool collection with its level in the blood.

Once protein loss is confirmed, further testing looks for the cause. This may include:

The exact assessment is guided by symptoms, medical history, previous surgery, and initial test results.

- Upper endoscopy or colonoscopy to examine the digestive lining
- Small tissue samples, called biopsies, taken during endoscopy
- Imaging of the abdomen, lymph vessels, or heart
- An echocardiogram, which is an ultrasound scan of the heart
- Tests for celiac disease, inflammation, infection, or immune disorders
- Nuclear medicine imaging to locate where protein is leaking

Treatment and management

Treatment aims to reduce protein loss by controlling the underlying condition. There is no single treatment that works for every cause.

For inflammatory or immune-related digestive disease, treatment may involve medicines that reduce inflammation or alter immune activity. An infection may need specific antimicrobial treatment. Celiac disease is managed with a strict gluten-free diet after the diagnosis has been confirmed.

Heart-related protein loss may improve when circulation and heart pressures are treated. People who have had Fontan surgery usually need care from a congenital heart disease team because management can be complex.

Nutrition support is often important. A dietitian may recommend more protein to replace ongoing losses. The amount and type of protein should take account of kidney function, appetite, and the underlying condition.

For intestinal lymphangiectasia, reducing long-chain dietary fats may lower pressure in the lymph vessels. Medium-chain triglycerides, a type of fat absorbed more directly into the bloodstream, may sometimes be used. This approach is not needed for every cause and should be planned with a clinical dietitian.

Other management may include:

Albumin infusions do not correct the source of the protein leak. Their benefit may be brief if protein loss continues.

Regular blood tests help track albumin, nutrition, kidney function, and treatment effects. Monitoring may also include weight, swelling, bowel symptoms, and the underlying heart or digestive condition.

- Replacing vitamins, minerals, or other nutrients shown to be low
- Limiting salt when fluid retention is a problem
- Medicines that help the body remove extra fluid
- Temporary albumin infusions in selected cases with severe symptoms
- Procedures or surgery for a treatable blockage or structural problem

Complications

Persistently low albumin can cause widespread swelling. Fluid may collect in the abdomen or around the lungs, affecting comfort, movement, and breathing.

Poor absorption and ongoing loss of nutrients can lead to weight loss, muscle loss, anemia, and vitamin deficiencies. Children may have delayed growth or puberty.

Some lymph-related forms cause loss of lymphocytes, a type of white blood cell, and immunoglobulins, which are antibodies. This can weaken part of the immune response and increase the risk of infection.

Fluid-removing medicines, diarrhea, and reduced food intake can contribute to dehydration, low blood pressure, or changes in body salts. These risks are one reason treatment and blood testing need to be monitored.

Complications also depend on the underlying cause. For example, heart disease, inflammatory bowel disease, or a lymphatic disorder may require long-term management even after protein levels improve.

Prevention

Protein-losing enteropathy cannot always be prevented. This is especially true when it results from an inherited lymph vessel disorder, congenital heart disease, or an unavoidable structural problem.

Managing a known digestive or heart condition may reduce the chance of severe or recurring protein loss. This means following the agreed treatment plan and attending routine monitoring, even when symptoms are stable.

If you have previously had protein-losing enteropathy, report a return of swelling, diarrhea, unexplained weight change, or reduced exercise tolerance. Early testing may identify a recurrence before protein levels become very low.

There is no general diet or supplement proven to prevent every form of the condition. Restrictive diets should not be started without a clear reason because they can make nutritional problems worse.

Living with it and what to expect

The course of protein-losing enteropathy is shaped mainly by its cause. When a temporary infection or treatable digestive disorder is responsible, protein levels may recover after that problem is controlled. Recovery can take time because the body must replace lost protein and rebuild nutritional stores.

Some causes are long term. Intestinal lymphangiectasia, inflammatory disease, or

heart-related circulation problems may lead to periods of improvement and recurrence. In these cases, treatment aims to limit protein loss, control swelling, and maintain nutrition.

You may need repeated blood tests and occasional stool testing. Keeping a record of weight, swelling, bowel symptoms, appetite, and exercise tolerance can help identify meaningful changes. Day-to-day weight changes may reflect fluid rather than body fat.

Food choices may become part of long-term management, but the right plan is specific to the cause. A dietitian can help make the diet practical and nutritionally complete. Children and teenagers may need growth monitoring.

Many people can continue work, school, exercise, and family activities, although symptoms such as diarrhea, fatigue, or swelling may require adjustments during flare-ups. The outlook is less favourable when the underlying heart, intestinal, or lymphatic disorder cannot be controlled. Regular follow-up focuses on detecting changes early and reducing complications.

When to get medical help

Arrange a routine medical appointment if you develop persistent leg or facial swelling, ongoing diarrhea, unexplained weight loss, increasing abdominal size, or unusual fatigue. These symptoms have many possible causes and need assessment rather than self-diagnosis.

If you already have protein-losing enteropathy, contact your care team promptly if swelling is increasing, your weight changes quickly, diarrhea becomes more frequent, or you are eating and drinking less than usual. Reduced urination, repeated infections, or new shortness of breath also need prompt advice.

Seek urgent or emergency care for:

These symptoms are not typical of stable protein-losing enteropathy and may indicate a serious complication or another urgent condition.

- Severe or rapidly worsening difficulty breathing
- Fainting, confusion, or extreme weakness
- Signs of severe dehydration, such as very little urine or inability to keep fluids down
- Vomiting blood, black stools, or heavy rectal bleeding
- Severe chest pain or a sudden major decline in your condition

Common questions

Is protein-losing enteropathy a type of cancer?

No. It is a condition caused by excessive protein loss into the digestive tract. Cancer is only one of several uncommon possible causes. Digestive inflammation, abnormal lymph vessels, and heart circulation problems are more typical categories of cause.

Does low albumin mean I have protein-losing enteropathy?

Not by itself. Low albumin can result from liver disease, kidney protein loss, inflammation, poor nutrition, or other illnesses. Stool alpha-1 antitrypsin clearance and additional tests help determine whether protein is being lost through the digestive tract.

Can protein-losing enteropathy be cured?

Sometimes. It may resolve when a treatable cause is removed or controlled. Long-term heart, lymphatic, or inflammatory conditions may require continuing management, and protein loss can return.

Can I have protein-losing enteropathy without diarrhea?

Yes. Some people mainly have swelling, abdominal fluid, fatigue, or breathlessness. Diarrhea may be absent, particularly when abnormal lymph flow or heart circulation is involved.

What should I eat if I have protein-losing enteropathy?

Nutrition plans are based on the cause. Extra protein is often considered, while a low-fat diet with medium-chain triglycerides may be used for some lymphatic disorders. These changes should be planned with a dietitian because an unnecessary restrictive diet may worsen malnutrition.

Is protein-losing enteropathy contagious?

No. The condition itself cannot spread between people. An infection can occasionally trigger protein loss, but most underlying causes are inflammatory, structural, lymphatic, or related to circulation.

Sources

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