

## **Acute Intermittent Porphyria: Symptoms, Triggers, and Other Factors**

### **Common symptoms of acute intermittent porphyria (AIP)**

AIP can cause many different symptoms that tend to come and go. When someone with AIP has these symptoms, the episode is called an AIP attack. These symptoms may vary from one attack to the next; they may also vary over time or during the course of an AIP attack.

#### Severe abdominal pain

- Severe abdominal pain is the most common symptom of AIP. More than 85% of people have abdominal pain during AIP attacks.
- The pain often lasts for hours or days.
- The pain tends to begin slowly and become worse.
- The pain tends to be all over and not in one small area.
- The pain may start in the chest or back and move to the abdomen.
- Pain medicines such as Advil® (ibuprofen) or Tylenol® (acetaminophen) usually don't help much. This is because the pain is caused by nerves.

#### Nausea or vomiting

- Nausea or vomiting is common during AIP attacks.
- People with AIP often have nausea or vomiting along with abdominal pain.

#### Constipation

- Constipation is common during AIP attacks.
- Loss of bladder control may go along with constipation.

#### Dark or reddish urine

- Urine that turns reddish or dark over time when exposed to light and air is common during AIP attacks.
- The change in urine color is due to certain chemicals in the urine during AIP attacks.

#### Muscle weakness

- Muscle weakness is common during AIP attacks.
- Muscle weakness usually begins in the arms and often in the shoulders.

## **Common symptoms of AIP (cont.)**

### Pain in the arms, legs, back, chest, neck, or head

- Abdominal pain is the most common symptom of AIP. But pain in other areas is also common.
- Pain may start in the chest or back and move to the abdomen.
- Pain medicines such as Advil® (ibuprofen) or Tylenol® (acetaminophen) usually don't help much. This is because the pain is caused by nerves.

### Fast heartbeat

- Fast heartbeat is common during AIP attacks.

### High blood pressure

- High blood pressure is common during AIP attacks.

### Emotional changes

- People with AIP often experience emotional changes.
- Certain emotional changes may mean that an attack is coming on. These changes include:
  - Feeling anxious or restless
  - Having a hard time sleeping
- Over time, more severe emotional changes may develop, such as:
  - Feeling upset or confused
  - Seeing or hearing things that aren't there
  - Feeling sad or depressed

## **Frequency of symptoms**

- AIP attacks are “acute” and “intermittent,” meaning they are sudden and intense and they tend to come and go.

## **Gender and AIP**

- AIP attacks are 4 to 5 times more common in women than in men.
- AIP attacks are more common during child-bearing years, often in women in their thirties.

## **Possible triggers for AIP symptoms**

If you have AIP, certain things may upset your body's chemical balance enough to cause symptoms. One or a combination of triggers can lead to an AIP attack.

### Monthly cycle/hormone changes

- AIP attacks are more common during the two weeks before a period starts.
- Hormones fluctuate the most during these two weeks.

### Changes in diet or eating habits

- Dietary changes, such as going on a diet or fasting, are common triggers of AIP attacks.

### Medicines

- Taking certain kinds of medicines, including estrogens (oral contraceptives), barbiturates (sometimes used to aid sleep or treat epilepsy), steroids (body hormone-like drugs), and some antibiotics, can trigger AIP attacks.
- Starting a new medicine may trigger an AIP attack.

### Substance use

- Drinking alcohol, smoking cigarettes, or using illegal drugs such as amphetamines or cocaine may trigger AIP attacks.

### Sickness or infections

- Stress on the body caused by infections, illness, or surgery may trigger AIP attacks.

## **Family history of AIP**

- AIP is caused by a partial lack of activity from an enzyme that the body needs. AIP is inherited—people with the enzyme deficiency are born with it.
- You can inherit the enzyme deficiency from one parent. If you do, you can have AIP. But most people with the enzyme deficiency never experience symptoms.

Untreated AIP attacks can cause serious, long-term health problems. If you think you may have AIP, work closely with your doctor to get a correct diagnosis and treatment that is right for you.

## References

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Recordati Rare Diseases, Inc.

Bridgewater, NJ 08807

Date of last revision: October 21, 2024

NP-AIP-US-0061v2