

Sharing Your Story About Living with Acute Intermittent Porphyria (AIP)

Acute intermittent porphyria (AIP) is a serious disease. It's important to tell others, especially women who are related to you, about AIP. This form is designed to help you tell the story of how you live with AIP. The prompts will help you share your experiences. If you prefer to write your story without using the prompts, you can use the "My own words" box at the end of the form.

1. Over time, my AIP symptoms have changed in these ways:

2. These symptoms affect me the most:

Severe abdominal pain

Nausea or vomiting

Constipation

Muscle weakness

Pain in my legs, arms, back, chest, neck, or head

Fast heartbeat

High blood pressure

Emotional changes, such as feeling anxious, confused, or depressed

3. Certain things seem to trigger my symptoms, including:

Monthly hormone changes

Use of certain medications

Dieting

Infections or illness, such as the flu

4. Here are a few other things I'd like my family to know about AIP and what it feels like during an AIP attack:

5. If any of my family members have symptoms that might be caused by AIP, I would advise them to:

6. Here are some things I do to help manage my AIP:

7. The things I've struggled with most about living with AIP are:

8. I feel good about accomplishing many things while living with AIP, including:

9. Here are some tips or strategies I've discovered along the way that may help other people live with AIP:

My own words:

A large, empty rectangular box with a thin black border, intended for the user to write their own words. The box occupies most of the page's vertical space.