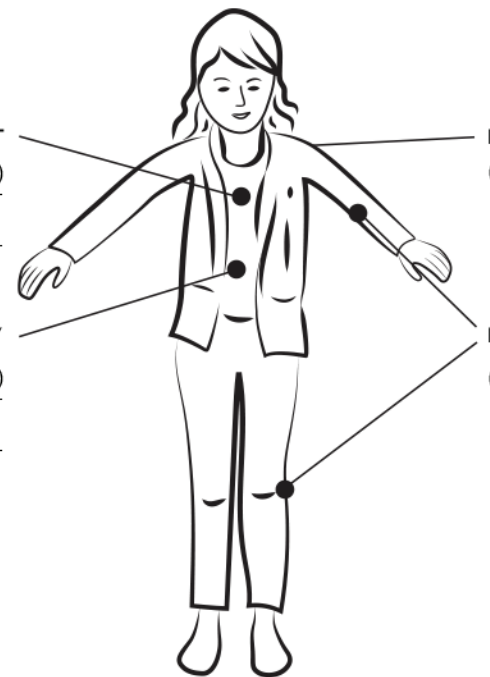


Use this discussion guide to help keep track of your signs and symptoms, and be sure to select all options that apply to your experience. During your next health visit, present this guide to your doctor to discuss if you should be tested for AHP.

## 1. Have you had severe, unexplained pain for more than one day in these areas?

Circle where you have experienced this pain and describe any details using the lines below.<sup>1</sup>



**CHEST**  
(Describe)

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**BACK**  
(Describe)

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**BELLY**  
(Describe)

---



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**LIMBS**  
(Describe)

---



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## 2. Have you experienced any of these signs and symptoms? Check all that apply<sup>1-5</sup>:

- |  |   |   |  |
|--|---|---|--|
| <input type="checkbox"/> Limb weakness or pain | <input type="checkbox"/> Confusion                | <input type="checkbox"/> Abdominal pain                           | <input type="checkbox"/> Dark or reddish urine |
| <input type="checkbox"/> Numbness              | <input type="checkbox"/> Anxiety                  | <input type="checkbox"/> Pain in back or chest                    | <input type="checkbox"/> Low blood sodium      |
| <input type="checkbox"/> Fatigue               | <input type="checkbox"/> Seizures                 | <input type="checkbox"/> Nausea and vomiting                      |  |
| <input type="checkbox"/> Tiredness             | <input type="checkbox"/> Insomnia                 | <input type="checkbox"/> Lesions or blisters on sun-exposed skin* |  |
| <input type="checkbox"/> Paralysis             | <input type="checkbox"/> Hallucinations           | <input type="checkbox"/> Rapid heart rate                         |  |
| <input type="checkbox"/> Respiratory paralysis | <input type="checkbox"/> Depression               | <input type="checkbox"/> High blood pressure                      |  |
| <input type="checkbox"/> Sensory loss          | <input type="checkbox"/> Constipation or diarrhea |   |  |

\*Hereditary coproporphyrria and variegate porphyria.

How long have you been experiencing these symptoms?

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Have your symptoms ever required you to go to the hospital?

- Yes     No

Please write down any additional information you feel may be important to tell your doctor:

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### 3. Have you had any of the following diagnoses or surgeries? Check all that apply:



#### Gastrointestinal disorders<sup>5-7</sup>

- Irritable bowel syndrome (IBS)
- Acute gastroenteritis with vomiting
- Hepatitis



#### Neurological/neuropsychiatric disorders<sup>5,6</sup>

- Fibromyalgia
- Guillain-Barré syndrome
- Psychosis



#### Gynecological disorders<sup>6</sup>

- Endometriosis



#### Abdominal conditions requiring surgery<sup>5</sup>

- Appendicitis (inflammation of the appendix)
- Cholecystitis (inflammation of the gallbladder)
- Peritonitis (inflammation within the abdomen)
- Intestinal occlusion (intestinal blockage)

After surgery, do you still have the same severe, unexplained pain?  Yes  No  Not applicable

### 4. Have symptoms started within recent days after exposure to any of the following?

Check all that apply<sup>1</sup>:



SOME MEDICATIONS



HORMONE CHANGES including levels of estrogen and progesterone. These hormones fluctuate the most during the 2 weeks before a woman's menstrual cycle begins.



DRINKING ALCOHOL



SMOKING



STRESS CAUSED BY:  
-Infections  
-Surgery  
-Physical exhaustion  
-Emotional exhaustion



FASTING or extreme dieting

### 5. Have your symptoms disrupted parts of your life? Check all that apply<sup>8,9</sup>:

- Sleep
- Work
- Eating
- Socializing/Planning
- Memory/Clear thinking
- Completing tasks
- Maintaining energy
- Other: \_\_\_\_\_

How disruptive?  1 Less  5  10 More

How frequently?  Daily  Weekly  Monthly  Yearly

### 6. Has anyone in your family been previously diagnosed with a type of AHP?

- Acute intermittent porphyria (AIP)
- ALAD-deficiency porphyria (ADP)
- Variegate porphyria (VP)
- No
- Hereditary coproporphyria (HCP)
- Unsure

Please write down any additional information you feel may be important to tell your doctor:

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AHP refers to a family of rare genetic diseases characterized by potentially life-threatening attacks and, for some people, chronic debilitating symptoms that negatively impact daily functioning and quality of life.<sup>1,8</sup> The two most common techniques a doctor uses to help determine if a person has AHP are a **urine test** and a **genetic test**. A diagnosis of AHP is based on clinical judgement:<sup>3,11</sup>

## Urine Test



- A urine test for PBG (porphobilinogen), ALA (delta-aminolevulinic acid), and porphyrin levels can help inform a diagnosis of AHP\*
- It is recommended to have a urine test during or shortly after an attack
- Porphyrin analyses may help identify the specific type of AHP, but are not used alone to diagnose AHP

## Genetic Test



- A genetic test using a blood or saliva sample may help to confirm a diagnosis or determine the specific type of AHP
- It can help rule out AHP if there is not a genetic mutation
- A genetic test can be useful for family members of people with AHP who want to know if they carry the genetic mutation. Not everyone with a genetic mutation suggesting AHP will have symptoms<sup>5</sup>

\*PBG and ALA are substances that are produced when the liver makes heme. Increased levels of PBG and ALA can become toxic and have been associated with the symptoms and attacks of AHP.<sup>2,10</sup>

## One genetic testing option:

Doctors can request no-charge genetic testing through the AInylam Act<sup>®</sup> program for patients meeting certain criteria. While the program is sponsored by AInylam Pharmaceuticals, all services are performed by independent third parties.

For more information and program rules, download a brochure at [AInylamActAHP.com](https://AInylamActAHP.com).



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