

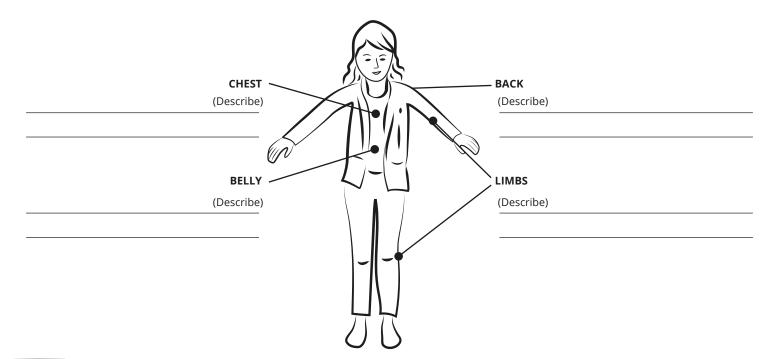


The Acute Hepatic Porphyria (AHP) Discussion Guide Start the conversation with your doctor

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.



2. Have you experien	ced any of these signs	and symptoms? Check all t	hat apply:				
☐ Limb weakness or pain	☐ Confusion	☐ Unexplained abdominal pain	☐ Dark or reddish urine				
□Numbness	□Anxiety	☐ Pain in back or chest	□ Low blood sodium				
□ Fatigue	□Seizures	☐ Nausea and vomiting					
□Tiredness	□Insomnia	☐ Lesions or blisters on					
□ Paralysis	☐ Hallucinations	sun-exposed skin*					
□ Respiratory paralysis	□ Depression	□ Rapid heart rate	*Hereditary coproporphyria and variegate porphyria only.				
☐ Sensory loss	☐ Constipation or diarrhoea	☐ High blood pressure					
How long have you been ex	periencing these symptoms?	Have your symptoms ever required you to go to the hospital? ☐ Yes ☐ No					
Please write down any addition	al information you feel may be im	nportant 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 □ Irritable bowel syndrom (IBS) □ Acute gastroenteritis with vomiting □ Hepatitis □ Crohn's disease		Neurological/nedisorders Fibromyalgia Guillain-Barr Psychosis Gynecological d Endometrios	é syndrome isorders		requir □ App □ Cho □ Peri	leocystiti tonitis (int		the gallbladde
After	r surgery, do you still have th	ne same sev	ere, unexplained	I pain? □ Yes	ı	□No	□Not	applicable	
	ve symptoms startook all that apply:	ed withi	n two days	after exposu	re to	any	of the	followin	g?
				\$,				
	SOME		DRINKING ALCOHOL	☐ SMOKING		STRESS USED BY		☐ FASTING	
p i c	Talk to your Including level of oestrogen a progesterone. T hormones fluct the most during uitable to you. Talk to your Including level of oestrogen a progesterone. T hormones fluct the most during weeks before a with menstrual cycle by the most during	els and These ruate the 2 oman's	ALCOHOL		- Infe - Sur - Phy	ections	ustion	or extreme dieting	
5. Hav	ve your symptoms	disrupte	ed parts of	your life? Check	all tha	t apply:			
□Sle	eep □Work □Eating	□ Social	izing/Planning	How disrupting	?				
□М	emory/clear thinking 🔲 🕻	Completing	tasks		1			5	10
□М	aintaining energy □Other:			How frequently	? 🗆 Da	aily 🗆] Weekly	□Monthly	□Yearly
	s anyone in your fa								
ΠA	cute intermittent porphyria	(AIP) □V	ariegate porphy	ria (VP) □ Heredi	tary co	propor	phyria (H	ICP)	
□Al	LAD-deficiency porphyria (A	DP) 🗆 N	lo □Unsure						
Please v	vrite down any additional inf	ormation y	ou feel may be ir	nportant to tell your	docto	:			



How AHP is diagnosed

Acute hepatic porphyria (AHP) refers to a family of rare genetic diseases characterised by potentially life-threatening attacks and, for some people, chronic debilitating symptoms that negatively impact daily functioning and quality of life. The two most common techniques a doctor uses to determine if a person has AHP are a **spot urine test** and a **genetic test**:



Spot Urine Test

- AHP can be diagnosed with a spot urine test of PBG (porphobilinogen), ALA (aminolevulinic acid), and porphyrin levels*
- A 24-hour urine collection is not recommended and may result in considerable delay in confirming the diagnosis
- 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 rule out AHP if there is not a genetic mutation
- AHP is a genetic inherited disease, so family members of someone who has AHP may also
 have inherited the altered gene responsible for the disorder. While most people with an altered gene may never have symptoms, they are however at risk of having an attack, or at risk
 of complications associated with elevated levels of ALA and PBG. Knowledge of genetic risk of
 AHP may enable people to make informed decisions regarding lifestyle and medications with
 the intent to prevent attacks and complications of the disease. Therefore, family members of
 someone who has AHP may want to talk with their doctor about genetic testing for AHP.

This information is intended for disease awareness purposes only. Nothing on the site constitutes individual medical advice. Individuals are advised to consult their physician or other appropriate HCP.

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^{*}PBG and ALA are substances that are produced when the liver makes haem. Increased levels of PBG and ALA can become toxic and have been associated with the symptoms and attacks of AHP.