

# Weight loss in the acute porphyrias

## Factsheet

This factsheet outlines the most recent guidance from the **International Porphyria Network (IPNET)** on the safety of weight loss interventions in the acute porphyrias.

IPNET is an international network of experts working together to improve healthcare services for porphyria patients. The recommendations are available at:

[https://doi.org/10.1016/S2352-3026\(26\)00044-X](https://doi.org/10.1016/S2352-3026(26)00044-X) or contact us for a PDF version.

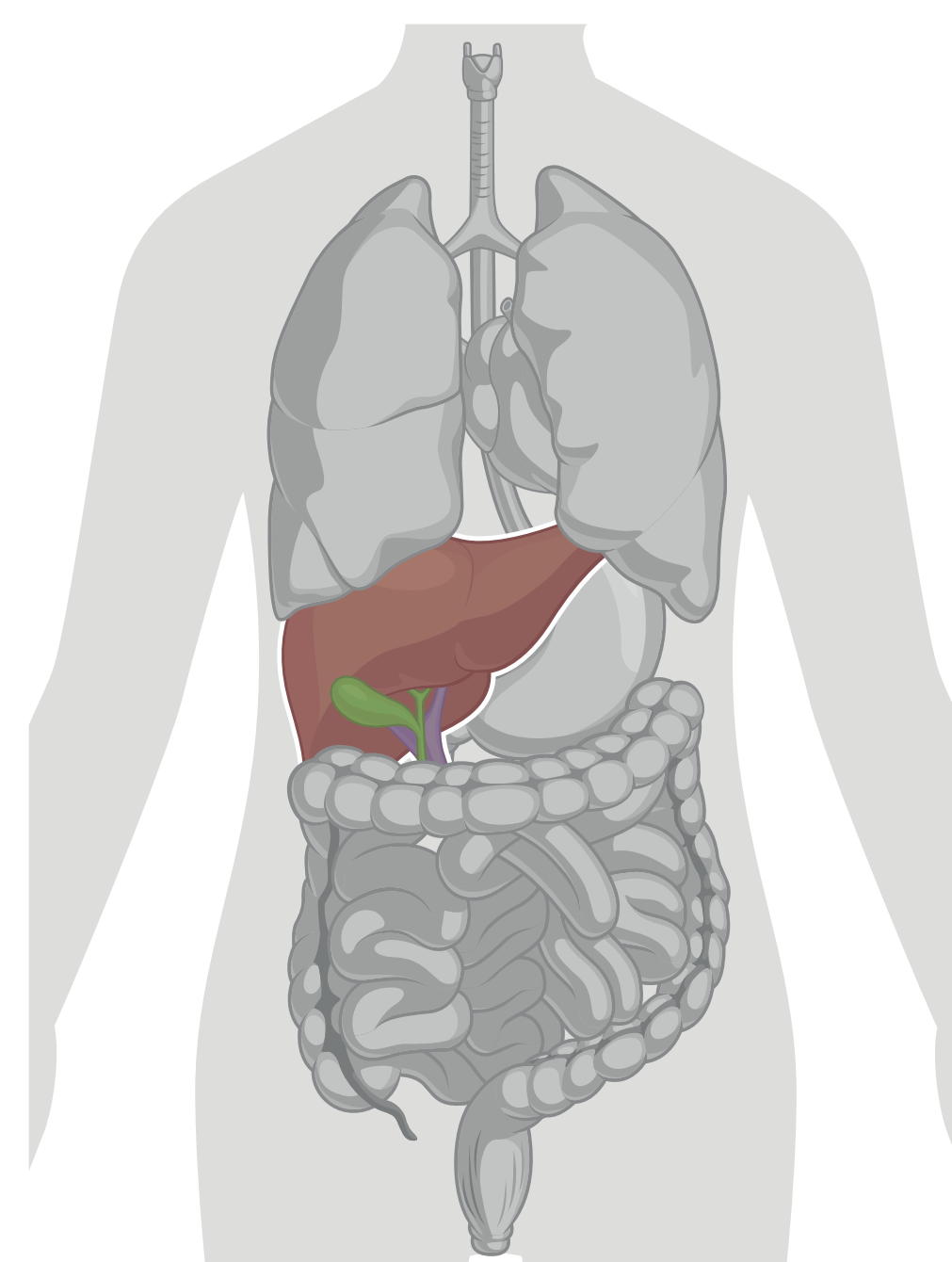
**Keeping on top of your general health and wellbeing is important for all, but it can be extra difficult when you have a long-term medical condition.**

If you have an acute porphyria, planned weight loss **can** still be an important part of managing general health, alongside other lifestyle choices. However, the timing and method of weight loss must be **carefully managed** to minimise the risk of triggering acute attacks. This risk is considered highest in patients with the most **active acute porphyria**.

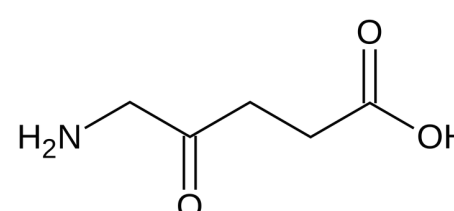
Weight loss that occurs too quickly puts you at **increased risk** of an acute attack, as it can trigger the liver to produce high quantities of **ALA** and **PBG**\* that can set off a painful attack.

Diets that involve **severely limiting carbohydrate** (starchy or sweet foods and drinks) can also make you **more likely** to have an attack.

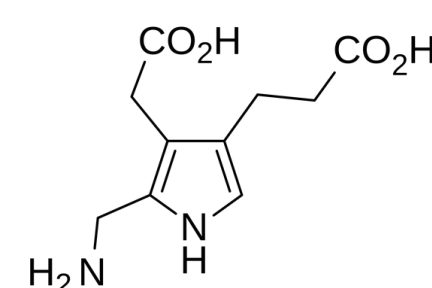
The risks versus benefits of any weight loss plan should be discussed with your porphyria specialist before it is put into action, to minimise the risk of acute attacks.



Structural diagram of aminolevulinic acid (ALA)



Chemical structure of porphobilinogen (PBG)



\*ALA and PBG are natural chemicals made in the body when it produces haem, an important part of blood. In some types of porphyria, these can build up and cause symptoms.

Visit [porphyria.org.uk/get-support](http://porphyria.org.uk/get-support) to browse our practical resources for living well with porphyria, including advice on:

- drug safety
- skin safety
- diet and sleep
- getting insurance
- contraception and pregnancy
- getting help with health costs



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## Recommendations

### Active acute porphyria

If you have had an attack **in the last 2 years** then planned weight loss through **dieting, prescribed weight loss medications, or bariatric surgery** should be **avoided** as this may trigger attacks and make your porphyria worse.

However, most people with active acute porphyria can still make **safe dietary changes** to help with weight management **following discussion with their porphyria specialist** or medical team.

### High excreters

If you have **high levels of ALA and PBG** in your urine (whether you have porphyria symptoms or not), **bariatric surgery should be avoided** as it may trigger attacks and cannot be reversed.

**Reversible** ways of losing weight, such as **dieting or prescribed weight loss medications**, are safer but should be **discussed with your porphyria team** before going ahead.

### Latent and asymptomatic porphyria

If you know you have a gene variant causing porphyria but you have had **no symptoms or attacks in the last 2 years**, and your urine ALA and PBG are **not raised**, then **dieting, prescribed weight loss medications, or bariatric surgery** should all be **possible**, although you should **discuss with your doctor first**.

**Anyone** with acute porphyria who is thinking about bariatric surgery or who wants to lose a lot of weight should be **referred to a porphyria specialist** beforehand.

	Diet	Prescribed weight loss medications	Bariatric surgery	
Active porphyria				* Some dietary changes can be made in consultation with a porphyria specialist.
High excreter				** Anyone with acute porphyria who wants to lose a lot of weight or wants bariatric surgery should be referred to a porphyria specialist beforehand. Rapid weight loss or diets that involve severely limiting carbohydrate can also make you more likely to have an attack.
Latent and asymptomatic porphyria				

 You should be safe to explore this option for weight loss

 Seek advice before undertaking weight loss

 It is recommended that you do not use this form of weight loss