



Acute Hepatic Porphyrias — AIP, HCP, VP, ALAD Porphyria (ADP)

During an acute attack (ER / inpatient)

- **Give carbohydrate.** Glucose suppresses the hepatic heme pathway and lowers porphyrin-precursor overproduction. Target about **300 g/day** of dextrose or other metabolizable carbohydrate.
- **Use IV glucose** when the patient can't take carbohydrate by mouth. The GI tract usually doesn't work properly during an attack (nausea, vomiting).
- **Hemin (Panhematin®) or heme arginate** has a similar but much more potent effect, with faster improvement. It is increasingly preferred as initial therapy over glucose alone.
- **Severe or prolonged attack:** TPN through a central line can meet full energy needs, with vitamins, minerals, amino acids and fat.
- **Recovery:** bring back oral feeding gradually as GI function returns, then prescribe a **high-carbohydrate regimen**.
- **Look at diet even when a drug or hormone seems to be the cause.** Triggers add up (see below).
- Some physicians write **standing ER orders for glucose** for known patients to prevent hospitalization.

Tell the patient: everyday eating

- **Don't skip meals or fast for long.** Eat at least **3 regular meals** a day. Normal overnight gaps are fine; fasting **>24 hours** is risky.
- **Always include carbohydrate**, about **55–60%** of calories. Eating extra beyond that does not prevent attacks.
- **No low-carb or crash diets** (e.g., Atkins). These have caused attacks, including in people who had never had symptoms.
- **Fat <30%** of calories. Protein at the RDA; avoid excess protein.
- Fiber about **40 g/day**, not above **50 g** (less with upper-GI problems).
- Limit charcoal-broiled meat and large amounts of cabbage and Brussels sprouts. These can induce hepatic ALAS1.

Tell the patient: what to avoid

- **Alcohol:** best avoided. It is the only food or drink with clear evidence of triggering attacks. If any, no more than **1 drink/day (women) or 2 (men)**.
- **Herbal remedies:** not recommended. They are unregulated and may contain ALAS1-inducing chemicals or heavy metals.
- **Supplements:** not routinely needed with a balanced diet. Avoid excess vitamins A, D and E. **No iron** unless deficiency is documented.

Before surgery or a procedure

- NPO periods need a **plan for supplying adequate calories** (e.g., IV dextrose).

Weight loss: slow and supervised

- Rapid, very-low-calorie dieting has caused **severe attacks**.
- Restrict only **500–1,000 kcal/day** below maintenance (or **≤10%**). Use a balanced, complete diet and aim for gradual loss.
- Do it under a physician's supervision, ideally with a dietitian. The patient should tell any weight-loss program they have porphyria.

Triggers add up

- Dieting/fasting, harmful drugs (e.g., barbiturates, sulfonamides), alcohol and **progesterone** act **together**.
- Women are more vulnerable to a dietary lapse in the **luteal phase** (second half of the cycle).
- Poor intake makes a drug or alcohol more likely to provoke an attack.

Screen eating behavior

- Weight loss and recurrent vomiting from porphyria can look like anorexia or bulimia.
- Even mild disordered eating can have big effects in these patients. Ask about eating attitudes and habits, not just intake.

Recommended vaccinations

- Annual influenza vaccine; pneumococcal (Pneumovax)
- Tdap/Td with boosters every 10 years
- Hepatitis A/B; shingles vaccine if they have had chickenpox

Cutaneous / Non-Acute Porphyrias

Porphyria Cutanea Tarda (PCT)

- **Avoid all alcohol.**
- **No iron supplements or medicinal iron.**
- Strict dietary iron restriction is usually unnecessary. Advise limiting liver and red meat until remission.
- Carbohydrate and calorie intake are **not** major drivers of PCT.

Phlebotomy	1 unit every 1–2 weeks until iron-reduced
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Target ferritin	50–100 ng/mL
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Expected course	Usually 8–12 units total; each unit lowers ferritin by about 30 ng/mL
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Erythropoietic Protoporphyria (EPP)

- Protoporphyrin comes mainly from bone marrow. Marrow is **not** sensitive to carbohydrate or calories, but **is** sensitive to iron deficiency.
- Make sure iron intake is adequate. Give iron supplements **only if labs show low stores**, cautiously and with monitoring.
- If there is significant liver involvement or liver damage, follow the **acute-porphyria diet** guidance.
- A few reports suggest glucose may improve symptoms.

Congenital Erythropoietic Porphyria (CEP)

- Diet plays no specific role. Excess porphyrins come from bone marrow.
- Prevent nutritional deficiencies that could worsen anemia.

All Porphyrias

- A balanced diet that provides all essential nutrients.
- No herbal remedies; no routine high-dose supplements.
- Needs vary by patient. Refer to a dietitian for an individual plan (e.g., Harris-Benedict energy estimate).

At a glance

Acute attack	Carbohydrate ~300 g/day (IV if not tolerating oral); hemin is more potent and increasingly first-line; TPN if prolonged
Acute: daily diet	≥3 meals; no fasting >24 h; carbs 55–60%; fat <30%; no low-carb or crash diets; avoid alcohol
Acute: weight loss	Deficit of 500–1,000 kcal/day (≤10%), gradual, physician-supervised
PCT	No alcohol, no iron supplements; phlebotomy to ferritin 50–100 ng/mL
EPP	Ensure adequate iron; supplement only for proven deficiency
CEP	No specific diet; prevent deficiencies

Porphyria expert help

American Porphyria Foundation

Phone

1-866-APF-3635

Email

general@porphyriafoundation.org

Full information

PorphyriaFoundation.org/for-patients/diet-and-nutrition

Summarized from the APF Diet & Nutrition section (10 subsections). This is educational material for healthcare providers, not medical advice. Individual nutritional needs vary with the type and severity of disease, so treatment decisions rest with the treating physician. Drug safety: see the APF drug database.

Medically reviewed by the American Porphyria Foundation Scientific Advisory Board. This information is for educational purposes and does not replace advice from your healthcare provider. **Last reviewed:** October 2026

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