

ACETAZOLAMIDE

For patients with Idiopathic Intracranial Hypertension (IIH)

Acetazolamide tablets can be used to help control symptoms in Idiopathic Intracranial Hypertension (IIH) and other conditions (such as glaucoma). However, as with all drugs, some people will have side-effects. This leaflet sets out what you need to know if your doctor has prescribed you Acetazolamide.

What is Acetazolamide?

Acetazolamide is a medication from the family of carbonic anhydrase inhibitors. It is also called Diamox. It is most commonly used in glaucoma, epilepsy, acute mountain sickness, and IIH.

Why is it used in IIH?

Acetazolamide is used in IIH as it can decrease the production of the fluid in the brain (the cerebrospinal fluid -CSF).

The IIH Treatment Trial ("IIHTT"), a large study in USA, found some improvements in the patient's vision (on the visual field). The patients using Diamox were also on a low-sodium weight-reduction diet. The study looked at those with mild visual loss. They showed an improvement in their quality of life.

In 2015, the Cochrane review group compared treatments in IIH. They said that Acetazolamide only showed small benefit in some visual tests. They thought more research would be helpful, as they could not decide whether they should recommend or reject Acetazolamide use for IIH. Because of this, not every doctor in the UK prescribes Acetazolamide for IIH.

What does your doctor need to know about you?

It is helpful for your doctor to know if you have any of the following problems:

- Kidney problems
- Low potassium (Hypokalaemia)
- Low sodium (Hyponatraemia)
- History of sulphonamide hypersensitivity (e.g., Sulfamethoxazole/ Trimethoprim)

They may not prescribe you Acetazolamide, as it might make you unwell.

Doctors will also take care in prescribing Acetazolamide if you have.

- Diabetes mellitus
- Chest problems (such as impaired alveolar ventilation or pulmonary obstruction)
- Kidney (Renal) stones
- Used the tablet over a long period of time.

As Acetazolamide is processed in the kidneys, those with kidney problems may either not use the drug or use low doses. Any person having dialysis may need to have supplement doses.

Are you taking any other medications?

If you take other medications, you will need to inform your doctor before you take Acetazolamide:

- High-dose Aspirin increases the risk of severe toxic reaction.
- Causes problems with Lithium.
- Increases risk of overheating and dehydration if taken with Zonisamide
- Makes Methotrexate not work as well.
- Makes Methenamine not work as well.

What are the possible Side Effects?

A number of side effects are associated with Acetazolamide. They are often the reason patients stop using it. The slow- release preparation of Acetazolamide is used to reduce the severity of side effects, but it may not always be available in the UK.

How can I reduce the side-effects?

Some people can only tolerate low doses of this medication. Some find increasing the dose gradually helps reduce side-effects. It is often reported that holding the medicine at a particular dose for a short period of time (such as a few weeks) reduces the side-effects. Unproven remedies that some find helpful include taking Acetazolamide with meals, taking Sodium Bicarbonate or eating potassium rich foods (some yoghurts, sweet potato, squash, potatoes, spinach, avocado, dried apricots, pomegranate, coconut water etc.).

Common side effects = paraesthesia (tingling) 41%, nausea 26%, fatigue 14%, headache 13%, taste disturbance 13%, vomiting 12%, diarrhoea 12%, dizziness, ataxia (lack of voluntary co-ordination), depression, excitement, flushing, irritability, loss of appetite, increased frequency of urination, reduced sex drive (libido), thirst.

Uncommon = tinnitus (ringing in ears) 11%, rash 7%, bone marrow suppression, confusion, drowsiness, electrolyte disturbance, fever, glycosuria (glucose in urine), haematuria (blood in urine), melena (black, tar-like stool), metabolic disturbance, kidney stones, kidney failure.

Dangerous and Rare = Stevens-Johnson syndrome, toxic epidermal necrolysis, fulminant hepatic necrosis, agranulocytosis, aplastic anaemia, blood dyscrasia.

Information for Patients

How do I take it?

There is no right dose for patients with IIH. The most commonly used starting dose is 250-500mg twice daily and there is the possibility to bring the dose up slowly. The dose can be split up to four times a day.

The recommended maximum dose varies from 2-4g/daily although the majority of patients in the UK may use less than this.

One study showed 48% of their patients stopped the drug at a daily dose of 1.5g due to side effects. (For patients with other conditions such as glaucoma and epilepsy, the recommended dose is lower at 0.25-1g daily.)

Do I need Long-term Monitoring?

For all patients on long-term use of Acetazolamide, monitoring of blood is suggested by the manufacturers but there is no general consensus on the timing of monitoring.

Can I take Acetazolamide if I am Pregnant?

Manufacturers do not recommend the use of Acetazolamide in pregnancy, especially at the start of the pregnancy (first trimester). If you wish to have children and are on Acetazolamide, then speak to your doctor. It is likely you will be told to stop taking it in the United Kingdom. This reduces the potential risk of birth defects to your unborn baby.

There has been a case study of 50 patients taking Acetazolamide which reported no adverse effects on either the mother or baby. This evidence is not enough to confirm safety. But it indicates that Acetazolamide can occasionally be considered after the first trimester following discussion between you and your doctor.

Can I take Acetazolamide if I am breastfeeding?

Advice is that Acetazolamide is safe for breastfeeding. Only a tiny amount of the drug is transferred to the baby. The child ingests only 0.06% of the dose given to the mother. The risk of harm to the child is very small.

Your doctor has recommended you take your acetazolamide in these divided doses in the table:

Time / Dosage				

Get more medication from your GP.

Information for Patients

Write notes or questions for your appointment here:

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Where can I get more information?

IIH UK website: www.iih.org.uk

Acetazolamide package leaflet: information for the user:

www.medicines.org.uk/emc/files/pil.2785.pdf

NHS Choice: www.nhs.uk/conditions/medicines-information/

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A team of people contributed to this booklet. It was written by H. Lyons; Z. Zimdahl (RGN) critically reviewed S. Mollan.

It was assessed in the draft stage by the ophthalmology nursing team at University Hospitals Birmingham (UHB). It was reviewed by a group of patients who have IIH, and also assessed by friends and family that attended the Joint IIH clinic at UHB. S Mollan is responsible for the final version. The views expressed in this booklet are of the authors and not their employers or other organisations.

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