
Management of cystinosis

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Cysteamine treatment

There is currently no complete cure for cystinosis. The aim of specific treatment is to reduce the amount of cystine within the cells. Cysteamine is a cystine-depleting drug which significantly reduces the level of cystine within the lysosomes.

Cysteamine is most effective when taken four times a day at six hourly intervals. This medication is a life-long treatment and must be taken every day.

Benefits of cysteamine therapy

- Cysteamine treatment has significantly changed the course of the disease
- The progression of renal failure in children treated with cysteamine sufficiently early was delayed from the age of ten to the mid 30s
- Cysteamine treatment also reduces the damage to other organs, in particular the muscles and nervous system
- To achieve the maximum efficacy of cysteamine it is important to start treatment early, to have regular monitoring, adequate dosing, and good compliance

Side effects

It is important to remember that everybody is different and not all patients will have side effects. Unfortunately cysteamine has some potentially unpleasant side effects. These include:

- Vomiting
- Nausea
- Diarrhoea
- Lethargy

- Skin and breath odour

Cysteamine may cause drowsiness. When you start therapy or have a dose increased you should not engage in potentially hazardous activities (e.g. driving) until you are aware of the effects.

If you are experiencing any side effects or would like further information about side effects please discuss this with a healthcare professional.

Taking cysteamine

Due to the unpleasant side effects it is understandable that taking cysteamine can sometimes be difficult.

It is important that you discuss any concerns you have about your medication with a healthcare professional.

Do not be scared to talk to your hospital team if you are not managing to take your cysteamine as there are often ways to remedy unpleasant side effects.

Further information

Cysteamine is made by Orphan-Europe and has the brand name Cystagon. For further product information, speak to your nephrologist or contact Orphan-Europe via:

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