

Treating swelling caused by hereditary angioedema (HAE) with oral steroid (danazol)

Department of Immunology

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Information for Patients

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What is hereditary angioedema (HAE)?

Angioedema is swelling underneath the skin. HAE is a rare genetic disease affecting between 1 in 20,000 and 1 in 50,000 people. There is a 50% chance an affected parent will pass the gene onto their children. The gene that is affected controls the production of a blood protein, which controls swelling in the body. There is no specific trigger for an attack. Hereditary angioedema cannot be cured, but medicines can help prevent and treat the swelling.

Symptoms of HAE include:

- sudden onset of swelling to different parts of the body such as limbs, face, intestinal tract, and airway
- repeated and unexplained tummy (abdominal) pain

Taking anti-histamine medicine does not help symptoms.

You must call 999 if you have any of the following symptoms:

- sudden or worsening breathing problems
- feeling faint or dizzy
- You pass out or collapse

Patients with HAE are seen in hospital every 6 to 8 months.

What is danazol?

Danazol is a steroid tablet. Danazol works by

- decreasing certain hormones in the body and

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- increasing the blood plasma levels of the proteins needed to prevent an HAE attack.

Danazol can cause unwanted side effects, especially in females. It is important to keep the dose of danazol as low as possible. Side effects should be reported to the immunology team as they are usually reversible if medication is stopped promptly.

You can only get prescriptions for danazol from a hospital pharmacy. Please contact the Immunology department to order your next prescription 2 weeks **before** you run out of medication.

Recommended dose is usually 1 to 2 tablets once a day for prolonged periods.

Common side effects

Please tell the immunologist if you have any of the following side effects:

- Danazol can increase growth of hair particularly on your body or face, voice changes, hair loss similar to male baldness.
- Some people develop acne, skin rash and muscle cramps,
- Some people find danazol increases their appetite and they can put on weight. Please make sure you eat well and exercise regularly to maintain a healthy weight.
- Females taking danazol may have irregular menstrual periods, vaginal dryness and irritation also reduction to breast size.
- Some people have mood changes, changes in desire for sex and hot flushes.
- Some people have sensitivity to light while taking danazol.

Less common side effects

The following side effects are rare. Should you have any of the following please tell the immunologist:

- diabetes
- high blood pressure or fast heart rate. We recommend you have your blood pressure checked regularly
- blood clots such as the ones that can develop in your legs (deep vein thrombosis) or lung (pulmonary embolism)

Further information

- Patients on danazol should have blood tests taken every 3 to 6 months via their GP surgery and a yearly liver ultrasound scan. This will be arranged by the hospital .
- Do not take danazol if you have a history of blood clots.
- Danazol should not be taken with medication for high cholesterol such as simvastatin.



- Do not use danazol if you are pregnant. It could harm the unborn baby or cause birth defects. If you are thinking of becoming pregnant please let your doctor know so that we can talk about other treatments to manage your condition.
- Danazol can pass into breast milk. You should not breastfeed while you are using danazol.
- Danazol is not approved for use by anyone younger than 18 years old.

Contact details

Department of Immunology: 0116 258 6702 0116 258 6711 Monday to Friday 8am to 4pm

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