Desmopressin (DDAVP) for people with inherited bleeding disorders

Information for patients, relatives and carers

Introduction

This leaflet explains what Desmospression (DDAVP) treatment is and how it works. If you have any questions about the information below please speak to your haemophilia nurse or doctor.

What is Desmopression (DDAVP)?

DDAVP is a synthetic drug that increases the clotting factors in your blood (factor VIII and von Willebrand factor) and also improves platelet function.

DDAVP increases the amount of factor VIII and von Willebrand factor circulating in your blood by around three to five times your normal level. This effect lasts for 12 to 24 hours. The increase is usually enough to control minor bleeding and to avoid bleeding from minor operations, including dentistry.

If necessary, the dose may be repeated after 8 -12 hours. After three doses, the response may be less effective as the body has not had the chance to build its stores back up.

Who can have DDAVP treatment?

- Most people with mild haemophilia A factor VIII (8) deficiency
- Most people with von Willebrand's disease type 1
- Some people with moderate haemophilia A
- Some people with von Willebrand's disease type 2
- People with platelet function defects

How is DDAVP given?

The dose you need will be calculated according to your body weight. There are three ways of having DDAVP treatment:

- subcutaneously (an injection under the skin, usually given in the upper arm, like a vaccination)
- intravenously (via a drip into a vein). The DDAVP is added to a small bag of sodium chloride (salt solution) to dilute it. This drip is then infused into a vein through a 'butterfly' needle over 20-30 minutes
- nasal spray. This has been used mainly for problems such as heavy periods

Before DDAVP can be used we need to measure your response to it. This will involve having several blood tests before and after you have DDAVP.

Side effects

DDAVP can cause skin flushing (your skin will turn pink). If it is being given via drip, we will slow down the infusion.

Some people develop a headache or feel their heart rate increase.

Fluid intake

DDAVP is similar to a normal hormone in the body. It can cause fluid to be retained by the body so adults should not drink more than one litre of fluid in the 24 hours after having DDAVP.

Are there any alternative treatments to DDAVP?

DDAVP is the main treatment offered. If it is unsuccessful, the doctor will discuss the possibility of having clotting factor infusions with you.

When to contact the haemophilia centre

If you pass very little urine in the 24 hours after your DDAVP treatment or you have a headache which is getting worse, please contact us:

Haemophilia centre Second floor, Garry Weston Centre Hammersmith Hospital Du Cane Road London W12 0HS

Telephone: 020 3313 4345 (09.00 – 17.00, Monday to Friday)

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (PALS) on 020 3313 0088 (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or 020 3312 7777 (St Mary's and Western Eye hospitals). You can also email PALS at **imperial.pals@nhs.net.** The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY

Email: ICHC-tr.Complaints@nhs.net Telephone: 020 3312 1337 / 1349

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:

imperial.patient.information@nhs.net

Wi-fi

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK_FREE or WiFiSPARK_PREMIUM

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