



DDAVP (Octim or Desmopressin)

Information for patients and parents from the Haemophilia Centre

What is DDAVP and what is it used for?

DDAVP is a medicine given to help your blood to clot. It is usually given because of bleeding, either following an injury or before a procedure such as an operation or dental treatment.

It is made in a laboratory, so does not come from blood donors. It works by copying a hormone that our body makes naturally.

It causes a temporary rise of clotting factor in your blood stream and has been widely used in Haemophilia Centres for many years. It helps your body release its own stores of von Willebrand Factor and Factor VIII kept in reserve for when it is needed. Von Willebrand Factor is a protein that helps your blood to clot.

DDAVP can also be used if your platelets are not sticky enough (platelet dysfunction disorders) or, in some cases, if you have an unexplained bleeding tendency.

Does DDAVP have any side effects?

As with all medicines, DDAVP can have side effects. The most common of which include:

- a red or flushed face (this is only temporary)
- headaches
- · dizziness
- mild stomach pain
- nausea (sickness)
- allergic reactions (rare), and
- · fits (very rare).

DDAVP makes your body retain (keep hold of) fluid and as a result your body will make less urine. Because of this it is important to limit the amount of fluid you drink for 24 hours after you have had your treatment. We

usually advise no more than 1 to 1.5 litres during the 24 hour period.

Are there any times I should not have DDAVP?

In general you should not have DDAVP if you:

- · are over the age of 65
- · have problems with your heart
- · have high blood pressure, or
- have had problems in the past with DDAVP.

How is DDAVP given?

- DDAVP is usually given as a single injection just under your skin. We normally monitor your blood pressure for one hour after your injection.
- In some cases it can be given at home; please discuss this with your consultant or specialist nurse.
- It can also be given as a nasal spray or directly into a vein through a cannula (a small needle in your arm). This method is usually given slowly over about 30 minutes.

What is a DDAVP trial and why do I need one?

It is sometimes useful to check how well DDAVP is working for you. This is done by checking the clotting factors before and after we have given you DDAVP. This is called a DDAVP trial.

What will happen during the trial?

You will be asked to come to the Haemophilia Centre. We will check your blood pressure, weight, and whether there are any reasons you should not have DDAVP. We will then take some blood to check your clotting factor before we give you DDAVP.

DDAVP will then be given as an injection just under your skin. We will monitor your blood pressure during the next hour and then take another blood test to check the clotting factors. We may ask you to have a further blood test three hours after this (four hours after your treatment). This would have been discussed with you at the time of making your appointment.

What if there are any concerns following treatment?

If you have any side effects that you are concerned about, please contact the Haemophilia Centre for advice. Staff are available in the Centre from 8:30am to 5pm, Monday to Friday (excluding bank holidays).

If there are problems outside these hours the on-call consultant is available on 01227 783190. Please make sure you ask for the doctor looking after haemophilia.

What if I have been given treatment to take home?

You may have been given DDAVP either to keep at home, take on holiday with you, or to take to hospital for a planned procedure. It is important that any DDAVP is stored correctly. Please keep it in the fridge.

You may also be taught how to give yourself the treatment, either to help with heavy periods or to treat a bleed early whilst at home. If this is the case you will be given additional information and training. Please ask a member of staff if this is something you would like more information about.

If you are travelling abroad you will need to take a Travel Letter with you explaining why you are carrying DDAVP. Please ask a member of staff if this is something you need.

If you are taking DDAVP on holiday, it can be kept out of the fridge for up to 30 days at temperatures up to 30°C.

It can also be kept at temperatures of up to 39.5°C for a period up to 24 hours or at 1 to 2°C for any period of time.

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- · If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (https://www.ekhuft.nhs.uk/ais).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (https://pp.ekhuft.nhs.uk/login).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekhtr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (https://www.ekhuft.nhs.uk/patient-information).

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