

Desmopressin intranasal spray

Information for parents and carers.

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What is desmopressin?

Desmopressin is a man-made hormone that produces a temporary rise in the amount of clotting factor in the bloodstream. It does this by helping the body to release its stores of von Willebrand factor and factor VIII (see below). It can also help to correct mild platelet function disorders.

What are von Willebrand factor and factor VIII?

These proteins act as our body's natural 'glue'. They help to make platelets stick to any areas of blood vessels that are damaged because of a cut or injury, which helps the blood to clot. If there is not enough of either of these factors, the platelets don't stick properly. This means bleeding will continue for longer.

Why has your child been prescribed desmopressin (Octim®) intranasal spray?

Your child may have been diagnosed with a mild bleeding disorder such as haemophilia, von Willebrand disease, or a platelet function defect, and they are experiencing abnormal bleeding. The desmopressin will help to manage this, by helping your child's blood to clot. Your child's Haemophilia Centre doctor will let you know when your child should use their spray.

Taking an unlicensed medicine

Desmopressin is an unlicensed medicine. If you would like a copy of our leaflet, **Unlicensed medicines – a guide for patients**, please ask your doctor, nurse or pharmacist, or you can call the pharmacy medicines helpline (details at the end of this leaflet).

What are the benefits of using desmopressin intranasal spray?

- It is a convenient treatment your child can use at home rather than having to attend the haemophilia centre.
- Treatment can be started as soon your child has a bleed.
- The spray is easy to use and does not involve the use of needles.
- Predictable bleeding such as heavy periods can be treated in advance, to prevent symptoms.
- Your child may require less frequent visits to the hospital.

What are the drawbacks of using desmopressin intranasal spray?

- The rise in von Willebrand factor and factor VIII levels following use of the spray may not be as high as when desmopressin is given by injection.
- Your child's response to this treatment may vary according to how well it has been absorbed into the body
- If you do not find this treatment effective for your child, you must tell your doctor or nurse at the Haemophilia Centre. Your child may require a blood test to check that their levels of von Willebrand or factor VIII are high enough.

Is desmopressin a suitable treatment for your child?

Some medicines are not suitable for people with certain conditions, and sometimes a medicine may only be used if extra care is taken. Before your child starts any treatment with desmopressin, you must let your doctor or pharmacist know if your child:

- has heart problems or blood vessel disease
- has problems with the way their kidneys work
- has high blood pressure, asthma, epilepsy or migraines
- has cystic fibrosis
- has ever had an allergic reaction to a medicine.

Can your child use desmopressin spray if they are taking other medicines?

Desmopressin may interact with some medicines, for example, diuretics (water tablets). It is therefore important that you tell your doctor about all of the medicines that your child is currently taking, including those prescribed by their GP and any that you buy yourself over the counter (including alternative medicines, such as herbal remedies).

Are there any side effects?

Like all medicines, desmopressin can cause side effects, although not everybody will get them. The most common side effects include facial flushing and facial warmth. Less common side effects include:

- headache
- stomach pain
- nausea (feeling sick)
- congested or runny nose.

Desmopressin may also be associated with some more serious side effects. If your child experiences **any** of the following, you seek **immediate medical attention**:

- **Fluid retention** – Early symptoms include swelling of the face, hands or feet; bad or prolonged headaches; drowsiness (feeling sleepy); unexplained weight gain; feeling sick (nausea) and being sick (vomiting).
If your child has any of these symptoms, contact your doctor straight away. Do not give desmopressin again until advised to do so by your doctor.
- **Seizure (fitting)** – If your child has a seizure (this is very uncommon) you should **take them to hospital straight away or call for an ambulance**. This could be a symptom of serious fluid retention. Tell the doctor that your child has been taking desmopressin (if possible take the medicine with you to show them).
- **Allergic reaction** – If your child has any signs of an allergic reaction, such as a blotchy red rash or swelling to the lips, face or tongue, you should **contact your doctor straight away or call for an ambulance**.

If you would like further information on possible side effects, please see the manufacturer's leaflet that comes with the medicine. If you have any questions or concerns please speak to your doctor or staff at the Haemophilia Centre, or call the Evelina London Medicines Helpline (details at the end of this leaflet).

When should you treat your child at home?

Desmopressin intranasal spray may be used at home for minor bleeding episodes such as nosebleeds, mouth bleeding, minor injuries or heavy periods.

A more severe bleed, for example joint or muscle bleeds, should always be assessed at the Haemophilia Centre. The common symptoms are swelling, redness, pain, and the site being warm to the touch. A dose of intranasal desmopressin before your child attends the hospital may mean the bleed is less serious once your child reaches the Centre. However, you should contact the haemophilia centre before giving your child this dose.

Treatment for heavy periods

Often tranexamic acid can be used on its own to lessen the symptoms of heavy periods. If not, tranexamic acid and desmopressin intranasal spray together may be used to control the symptoms. For more information about tranexamic acid, see our leaflet **Tranexamic acid: Information for parents and carers**.

The treatment centre will monitor your child when using this medicine at home. You are advised to contact the centre prior to treating your child with desmopressin at home.

You should contact the Haemophilia Centre if:

- you are not sure whether your child's symptoms are caused by a bleed**
- the bleed does not improve within 24 hours**
- you have any other concerns about your child's bleed.**

What dose should your child take?

Your Haemophilia Centre will advise you on the correct dose of both tranexamic acid and desmopressin, and how often your child should take them.

Do not exceed the recommended dose under any circumstances as this may lead to fluid retention and severe side effects.

If your child requires treatment, you will be advised on the correct dose.

How does your child use the desmopressin intranasal spray?

Please follow the instructions below when using the spray. More information on how to use the spray is available in the manufacturer's leaflet that comes with the medicine.

1. Your child should clear their nose.
2. Mix the contents by shaking the bottle gently.
3. Remove the cap and put to one side (this will need to be replaced after use).
4. Prime your child's spray (this only needs to be done when the spray is first used). To do this, hold the bottle upright with your thumb under the bottle and your forefinger and middle finger on the pump. Firmly press down the pump until a fine spray can be seen coming out of the top. The spray is then ready for use.
5. Tilt your child's head back a little.

6. Insert the pump into one nostril and press the pump firmly, once only, and remove. **Your child must hold their breath for 30 to 60 seconds.**
7. If the doctor has advised to use two puffs, then repeat steps 5 and 6 in the other nostril.
8. Keep your child's head tilted back slightly.
9. Your child must breathe in gently through their nose.
10. Dab the end of your child's nose to catch any drips.
They should not blow their nose.
11. Once your child feels the fine spray has been absorbed (ie their nose is not runny) they should resume their normal position.
12. Clean the pump with a tissue and warm water, and replace the cap after use.
13. A form will be provided for you to record all your child's treatment doses.

Restricting your child's fluid intake

To help prevent water retention, you need to limit the amount of fluid your child takes for 24 hours after they have taken a dose of desmopressin.

Your child should drink only as much as they need to satisfy thirst. Your Haemophilia Centre will advise you on the amount spread over 24 hours. This includes tea, coffee, soft drinks and water. You will be advised about how much fluid your child can drink.

How should I store desmopressin intranasal spray?

Your child's bottle of desmopressin should be stored at room temperature (below 25°C). It should not be frozen and should be protected from sunlight and stored in the outer carton when not in use.

You should not use the nasal spray after its expiry date.

How do I get a repeat prescription?

You will need to contact your Haemophilia Centre if you need a further supply. This is because we need to monitor how often your child uses their desmopressin. Your child's Haemophilia Centre doctor will prescribe more if it is necessary to do so.

Contact us

Haemophilia Centre for **adults**, St Thomas' Hospital Reception, **t:** 020 7188 2807/2781
Nurses, **t:** 020 7188 2790

Haemophilia Centre for **children**, Evelina London Children's Hospital
Secretary, **t:** 020 7188 7545
Nurses, **t:** 020 7188 4704

Out of hours and emergencies

Please call the hospital switchboard, **t:** 020 7188 7188, and ask for 'haematology doctor on-call for haemophilia'.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Notes

Useful sources of information

The Haemophilia Society

UK charity for everyone anyone by a bleeding disorder.

t: 020 7939 0780(helpline)

e: info@haemophilia.org.uk

w: www.haemophillia.org.uk

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday

e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagessupport@gstt.nhs.uk

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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