

■ What is desmopressin?

It is a drug that helps your body make blood clots.

It does this by helping you release:

- factor VIII, and
- von Willebrand factor

from places where they are stored in your body.

When you take desmopressin:

- you will be able to form better blood clots;
- you will not bleed as long;
- you will have higher levels of factor VIII and von Willebrand factor in your body.

■ Who can take desmopressin?

You can take desmopressin if you have:

- mild hemophilia A;
- von Willebrand disease;
- a platelet function disorder.

■ Why will I get desmopressin?

- To **prevent** bleeding. For example, you may take it before going to the dentist or before a minor operation. Desmopressin is given 30 to 60 minutes before the time you are expected to bleed.
- To **control** bleeding. When you take it for this reason, you may need to take it more than once over the course of 24-48 hours. You should only take it once during the first 24 hours. This is so your body can build up a new supply of clotting factors.

■ How will I know if desmopressin is right for me?

You will have blood tests BEFORE and AFTER the first time you get desmopressin. The tests will tell you if the drug works for you. The test is called a desmopressin trial.

Before you take desmopressin, you should tell your doctor or nurse:

- if you have high blood pressure, AND
- the names of all other drugs you are taking.

You must do this because:

- Desmopressin can make your body hold onto fluids. This can raise your blood pressure.

■ How will I take desmopressin?

There are 3 ways to take the drug:

By vein. A doctor or nurse will set you up with a needle that goes into a vein. Getting the drug this way takes about 30 minutes.

Under the skin. The drug will go into your arm [or thigh with a needle that pricks your skin. The needle does not go into a vein. Some people let a doctor or nurse help them with this. Others learn how to do it on their own.

In the nose. You spray the drug into your nose.

No matter how you take desmopressin, it's very important to make sure you are trained by a healthcare professional to ensure the correct techniques and dosage.

■ How fast does it work?

Desmopressin has the most effect about 1 hour after you take it.

After 1 hour, the clotting levels begin to fall off.

For most people, desmopressin keeps working for 8-12 hours.

A repeat dose may be given at the discretion of your hematologist.

■ What are the side effects?

- The most common side effect is having a red (or flushed) face which is temporary.
- Sometimes, people get a headache, feel dizzy, or have mild stomach pain.
- A change in your blood pressure and pulse can occur.
- The drug makes the body hold onto fluids, and you may not pass urine as often. For this reason, you must reduce your fluid intake after receiving this drug.

Adults: limit fluids to six 8 oz glasses for 24 hours.

Children: unless your child indicates he/she is thirsty, do not offer fluids for the first 24 hours, following desmopressin. Seek further advice from your doctor or nurse.

- If you have a very bad headache OR you have not been able to pass urine for 24 hours after taking desmopressin you should call your treatment centre or go to the ER for help.

■ How should I store desmopressin?

Keep it in the fridge but do NOT freeze it.

If you plan to travel with desmopressin, please call or visit your treatment centre for more details. It must be kept cool when you travel but you should NOT let it freeze.

■ How long can I keep desmopressin?

To find out, check the expiry date on the label. Do not use desmopressin after the expiry date has passed and never use after 7 days at room temperature.

■ The Canadian Hemophilia Society

The Canadian Hemophilia Society (CHS) strives to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure.

The CHS consults qualified medical professionals before distributing any medical information. However, the CHS does not practice medicine and in no circumstances recommends particular treatment for specific individuals. Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company. In all cases, it is strongly recommended that individuals consult a hemophilia-treating physician before pursuing any course of treatment.

For further information, please contact:

Canadian Hemophilia Society
625 President Kennedy Avenue, Suite 505
Montreal, Quebec
H3A 1K2

Telephone: 514-848-0503
Toll-free: 1-800-668-2686
Fax: 514-848-9661
E-mail: chs@hemophilia.ca
Web site: www.hemophilia.ca

■ For more information

Get in touch with your treatment centre if you have questions about desmopressin. You can also ask questions about your bleeding disorder.

TREATMENT CENTRE:

DOCTOR'S PHONE NUMBER(S):

NURSE'S PHONE NUMBER(S):

■ Acknowledgements

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Kay Decker, RN, nurse coordinator
Hemophilia Program
Hamilton Health Sciences Corporation
Hamilton, ON

Kam McIntosh, RN, nurse coordinator
Hemophilia Program of BC (Adult Division)
St Paul's Hospital
Vancouver, BC

Sherry Purcell, RN, nurse coordinator
South Eastern Ontario Regional
Inherited Bleeding Disorders Program
Kingston General Hospital
Kingston, ON

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CANHC group

Dr. Paula James, co-director
South Eastern Ontario Regional
Inherited Bleeding Disorders Program
Kingston General Hospital
Kingston, ON

Dr. Manuel Carcao, co-director
Comprehensive Care Hemophilia Program
Hospital for Sick Children
Toronto, ON

Dr. Georges-Étienne Rivard, medical director
CHU Sainte-Justine
Montreal, QC

Dr. Anne Brusby, MRCP (UK) FRCPC
Medical Director, Ferring Inc.
North York, ON

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A Guide for Patients and their Caregivers

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