



Other medicines we can prescribe to help mouth, nose, or menstrual bleeding are **Amicar[®]** or **Cyclokapron[®]**. **These medicines do not make you stop bleeding, but when you do form a clot, they will help keep that clot from breaking down.** They come as a pill or a liquid that you will **swallow**. You have to take these medicines exactly as the doctor or nurse tells you.

There are a few medicines that you should **not** take without asking your doctor or nurse first.

These medicines can make anyone who takes them bleed more than usual. You don't need that! So before taking any **aspirin** or **Advil[®]** or **Motrin[®]**, ask. And, ask your doctor or nurse if there are other medicines that they don't want you to take.

You can take Tylenol for a fever or for pain.



Any questions?



Ask the nurse. Your nurse is a special nurse that just takes care of people with bleeding disorders and is there to help you answer your questions.

You also have a special doctor, other people who are a 'TEAM',



social worker, physical therapist and

working together to help you.

Isn't it great to have your own team?

Your Diagnosis:

Your doctor's name(s):

Your nurse's name(s):

Telephone number(s):

Emergency number(s):

Your treatment center name:

Other team members:

Telephone number(s):

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Von Willebrand Fact(or) Sheet

FOR ADULTS

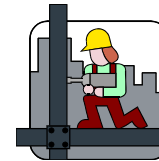
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This fact sheet was created to help you understand von Willebrand disease (vWD), a bleeding disorder.

veins are lungs. cells (where platelets (one of the parts of the blood that help you to stop



Blood does a lot of different things as it goes around inside your veins. The like a pipeline carrying your blood cells filled with oxygen to your heart and Blood is also made up of **many** different cells, like red blood cells, like red blood cells (these fight infection), and iron is stored), white blood cells (these fight infection), and platelets (one of the parts of the blood that help you to stop bleeding). Sorry, there are no **blue** blood cells!



Blood is **also** made up of '**factors**' that all work together to help you stop bleeding. Some factors have a number name, like Factor 8 or Factor 9. If a person is missing one of these factors, they have the blood disorder called hemophilia.

You are missing, have non-functioning or have only a small amount of a factor called **von Willebrand factor**. A doctor named Eric von Willebrand discovered this factor, so they named it after him. It's kind of a hard name to remember. You might think it would have been easier to remember a number like 8 or 9. Sorry, you need to remember the name- **von Willebrand**. It is a bleeding disorder.

There are 3 sub-categories or 'Types': Type 1 patients have decreased amounts of vWD factor, Type 2 have non-functioning & may have decreased amounts of vWD factor (sub-groups are a, b, n, or m) and Type 3 are missing vWD factor altogether. You need to know what Type of vWD you have.

How did we know you have von Willebrand disease?

Your doctor tested your blood to see how much von Willebrand factor you have. Sometimes people have to be tested a couple of times because the von Willebrand factor levels in your blood can **briefly** (for a day or two) go higher from things like exercise, surgery, certain medicines, illness, or if you are upset or stressed -like when someone is sticking you with a needle!

How do you get von Willebrand disease?

You **inherited** the gene from your family (like eye or hair color). **OR** there could also be a chance of a genetic mutation occurring. **You will always have von Willebrand disease, it does not go away and it can be passed on, in your genes, to your children (there's a 50/50 chance with each child).** Both males and females can have von Willebrand's.



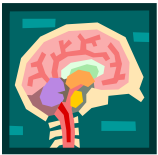
So, what does it mean to be missing, have non-functioning or decreased von Willebrand factor?

It means that you have everything else to help you stop bleeding, you have all the other factors (there are twelve) that work together to make a clot or scab. You are just missing or have small amounts of one of the factors. But, people need all of the factors to stop bleeding right away. For people with vWD:

They do not bleed **more** than other people; instead, they bleed

LONGER

We call it **oozing**, because it happens slowly. You can **ooze on the outside**, where you see the blood (like a nosebleed). You can **ooze just under the skin** (like in a bruise). Or, you can **ooze deep inside your body** (internally). If someone is bleeding internally, the person will have pain and they may (or may not) see swelling. This is the most serious type of bleeding, especially if it happens inside the head (lots of damage can be done in there), joints or muscles.



What does this mean for you?

It just means that you will get **bigger bruises** than other people who don't have von Willebrand disease. You may get **nosebleeds** that take a long time to stop, or when you go to the dentist your **gums may ooze blood** for a long time. For women, they may experience very heavy bleeding with their periods. If you have to have surgery or if you were hurt, doctors would need to know that you have von Willebrand's so bleeding could be taken care of with medicine. All of your doctors, the dentist, etc. need to know that you have von Willebrand disease so they can care for you properly.

There are medic alert bracelets, ankle bracelets, chains, etc. you can wear to let medical personnel know you have von Willebrand's if you are in an accident or unconscious.

Can I play sports?

Really you **can do almost anything** ...play basketball, baseball, soccer, and track. You **can** be on a ski team, swim team and you **can** do gymnastics. It doesn't mean you might not accidentally get hurt. You should **always wear protective gear**, like helmets (essential in any sport that puts you on wheels) and pads to try and prevent injuries. And you should know to seek medical care if you get hurt.



We want you to play in non-contact sports and be normal.

We can take care of accidents that may happen.

You should **NOT** play contact sports, like tackle football, hockey and boxing, though. That's because someone is out to hurt you in those sports. If you get badly hurt, we know you will have more bleeding than the person who doesn't have a bleeding disorder. That is too big of a risk to take.



What would we do for bleeding?

That depends on a couple of things, like what type of von Willebrand disease you have. The front page describes the three 'types': Type 1, Type 2 (a, b, m or n) and Type 3.



For a lot of problems, you can just clean the cut and **put pressure on the bleeding** with a band-aid or clean cloth.

You can also **put ice on an injury**, not use or **rest the injured area** and also raise or **elevate the injury**. These simple things will often stop the bleeding.



Remember **RICE**

Rest


Ice

Compression

Elevation

What medicines are used to stop bleeding?

For some types of von Willebrand disease, levels of the vWD factor will go higher if the person gets a medicine called **DDAVP**. For other types, the actual von Willebrand factor is given in a vein (IV). When von Willebrand levels are higher, the bleeding should stop.

DDAVP treatment is usually given as a spray in the nose with a special medicine called **Stimate®**. This medicine helps boost the amount of von Willebrand factor, so that you can  clot. It only lasts for 1-2 days, it is usually given every 48 hrs.

Stimate® is kept in the refrigerator and you can have it at your house to give your - self when you are bleeding (per your doctors orders). Only the nasal spray form of DDAVP named **Stimate®** will stop the bleeding. It starts to work in about 1 hr.

Ask your nurse about side effects.

DDAVP can also be given by injection in an arm or leg. Or it can be given IV at the hospital. It may be given by injection or IV for testing purposes.



A special **factor product**, given IV, that actually **has von Willebrand factor (and factor 8)** in it can also be used to stop bleeding. This is given at the hospital or, if you have been taught to start an IV, at home. Your doctor or nurse will tell you when to give this factor. **This is what is given if you are really bleeding a lot or if the Stimate® spray doesn't work for you.** This factor product can make your von Willebrand levels go up or be normal. A dose only lasts for awhile, though (12-24 hours, sometimes longer). It comes as a powder in a little bottle. You mix the powder with the special water that also comes in a little bottle. Then you draw up the medicine in a syringe and using an IV needle, give it into a vein over just a few minutes. It starts to work in about 15 minutes. You can learn to give this factor to yourself per your doctor's directions.

