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 your child will swallow. You have to give these medicines exactly as the doctor or nurse tells you.

There are a few medicines that your child 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 giving 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 give.

You can give Tylenol for a fever or for pain.

Any questions?

Ask the nurse. Your child's nurse is a special nurse that just takes care of people with bleeding disorders and is there to help you and your child understand von Willebrand's. 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 Child’s 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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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 you 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 your child?**

It just means that they will get bigger bruises than other people who don’t have von Willebrand disease. They may get nosebleeds that take a long time to stop, or when they go to the dentist their gums may ooze blood for a long time. For girls, they may experience very heavy bleeding with their periods.

If your child has to have surgery or if they were hurt, doctors would need to know that they have von Willebrand’s so bleeding could be taken care of with medicine. All of your child’s doctors, the dentist, plus teachers need to know that your child has a bleeding disorder.

There are cool medic alert bracelets, ankle bracelets, chains, etc. you can buy for your child to wear to let medical personnel know they have von Willebrand’s.

**Can my child play sports?**

Really he or she can do almost anything ... play basketball, baseball, soccer, and track. They can be on a ski team, swim team and they can do gymnastics. It doesn’t mean they might not accidentally get hurt. They should always wear protective gear, like helmets (essential in any sport that puts the child on wheels) and pads to try and prevent injuries. And they should know to tell you or an adult if they get hurt.

We want your child to play in non-contact sports and be normal. We can take care of accidents that may happen.

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

**What would we do for bleeding?**

That depends on a couple of things, like what type of von Willebrand disease the person has. 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.

**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 have a 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 child when they 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 your child is really bleeding a lot or if the Stimate® spray doesn’t work for your child, this factor product can make 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. If old enough, your child can learn to give this factor to themselves.