

von Willebrand Disease

Piecing together the VWD puzzle



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders



The National Hemophilia Foundation (NHF) would like to thank the members of the working group that independently developed this brochure: Jeanette Cesta, National Bleeding Disorder Educator; Jessica Graham; James Hammel, MD, MA, MSc, FAPA; Debbie L. Nelson and Katherine Rosenblatt, LMSW.

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Just diagnosed with VWD?

Now what?

A diagnosis of von Willebrand disease, or VWD, can be scary, but it can also feel like all the pieces of a puzzle are finally in place. Your new diagnosis means that now you can get the care you need to control your symptoms, like bleeding or bruising. VWD is a genetic disorder caused by a missing or defective clotting protein in the blood called von Willebrand factor (VWF). VWF is important because it carries and protects another clotting factor in the blood – factor VIII. Without VWF, factor VIII becomes rapidly destroyed in the bloodstream/circulation, resulting in low factor VIII levels. It also helps platelets stick to the blood vessel walls at an injury site. The amount of VWF circulating varies over time and with different stress levels or activities, which complicates diagnosis and management.



There are several different types of VWD: 1, 2 (with 4 subtypes: 2A, 2B, 2M, 2N) and 3.

Many new patients are unsure of their type, so ask your doctor to explain your type, its severity and proper treatment.

What should I expect and anticipate? (Your VWD Survival Guide)

You'll find support and the encouragement to live a happy, healthy life with VWD. Learn all you can about VWD, then educate others. Telling close friends and your family about your VWD (this is referred to as "disclosure") and be prepared for emergencies. Get connected to the National Hemophilia Foundation's bleeding disorders community, where you'll find support and encouragement.

Sometimes having VWD can seem overwhelming. Just take a deep breath and reach out for help when you need it. There are many resources and helpful people in your own community. Take things one step at a time, beginning with this VWD checklist:





VWD Checklist:



1. Annual or Biannual VWD Visit – individuals with VWD should schedule routine follow-up visits with a medical provider who can help you manage your symptoms. You may be referred to a hemophilia treatment center (HTC), a specialized healthcare center staffed by a team of doctors, nurses and other health professionals experienced in treating people with VWD, or you may see an independent hematologist. During the visit, treatment options may be discussed, as well as tests to make sure your treatment works to manage your symptoms. HTC staff can answer questions about insurance coverage, educate school staff and help you adjust to life with VWD. Visit your hematologist regularly, even if nothing has changed. That way you will be aware of any new tests, treatments or information that could help. Regular visits strengthen your relationship with your medical team and keep them updated on any changes in your life that may affect your treatment.



2. Schedule Routine Healthcare Appointments –

Keep up with routine healthcare appointments and screenings, and attend to other medical issues promptly. Don't let that cavity (a typically minor bleeding issue) turn into a root canal or extraction (typically a greater bleeding issue).

- a. Primary Care Physician/Pediatrician: All of your physicians should be aware of your VWD diagnosis. VWD needs to be addressed before any procedures can be done, because some medications should not be given to patients with VWD. If surgery is being considered, communication with your VWD provider is critical to ensure that a plan is in place to address any bleeding complications. In fact, many surgeons will not schedule surgery without clearance from your doctor.
- b. Dentist/Oral Surgeon: Without pretreatment, some dental care procedures, such as deep cleanings, can cause a mouth bleed. Further, your VWD diagnosis must be considered before tooth extractions or gum procedures can be performed. Give your dentist your VWD provider's contact information so that they may coordinate the procedures.



3. Be Prepared for Emergencies –

Keep a supply of your medications, have current and after hours contact information for your medical team or local ER readily available and maintain a support team of family members/friends who can help in an emergency. Have a plan in place and share it with caregivers so that when a medical situation occurs, everyone knows what to do.



4. Wear Medical Alert Identification – A medical alert

identification bracelet, necklace or dog tag, notifies emergency workers that the wearer has a medical condition and who to contact for details. It has room to inscribe specifics such as diagnosis and allergies, and has a number to call for further information. Some products even have the information stored electronically in the medical alert identification.



5. Request a Travel Letter – It is important to request

a travel letter (sometimes called an introduction letter) from your VWD provider. The letter includes information such as your diagnosis (VWD and type), treatment plan for both minor and major bleeds, a list of your allergies and contact information for your hematologist. It is helpful in emergency rooms, when traveling and at school.



6. Stay Physically Active – Physical activity is important for overall health and for your VWD as well. Talk to your VWD provider about which activities are safe for you, and what protective gear or treatment you need beforehand. If you or your child is active in sports, tell the coach about your VWD diagnosis, symptoms and treatment, and that your medical alert identification can safely be worn during practices and games.



7. Communicate with School/Childcare/After-school programs – The school or child care provider should be informed of your child’s diagnosis. The best way to communicate with your child’s school is through a 504 plan. 504 plans help guarantee that every child has access to equal education regardless of a medical issue. Ask your child’s school about setting up a 504 plan, which often includes a meeting with key school personnel (e.g., teachers, school nurse, coaches, bus driver). During the meeting you can educate the staff about your child’s VWD, discuss any possible issues regarding school activities, prepare an emergency plan, and request accommodations you and your medical team feel are needed. These might include:

- a. Immediate access to the school nurse and bathroom when needed.
- b. Medication storage/administration at school.
- c. Permission to carry and use a cell phone for a medical issue.
- d. Accommodations when traveling on field trips (medication, travel letter, etc.)

If your child’s school doesn’t use 504 plans, you can still ask for a meeting to discuss any accommodations your child may need at school.



8. Disclosure in the Workplace/College –

Talk with your HTC social worker about your rights and how to inform your workplace or college.

Visit: www.stepsforliving.hemophilia.org for more information.



9. Connect with Your Bleeding Disorders

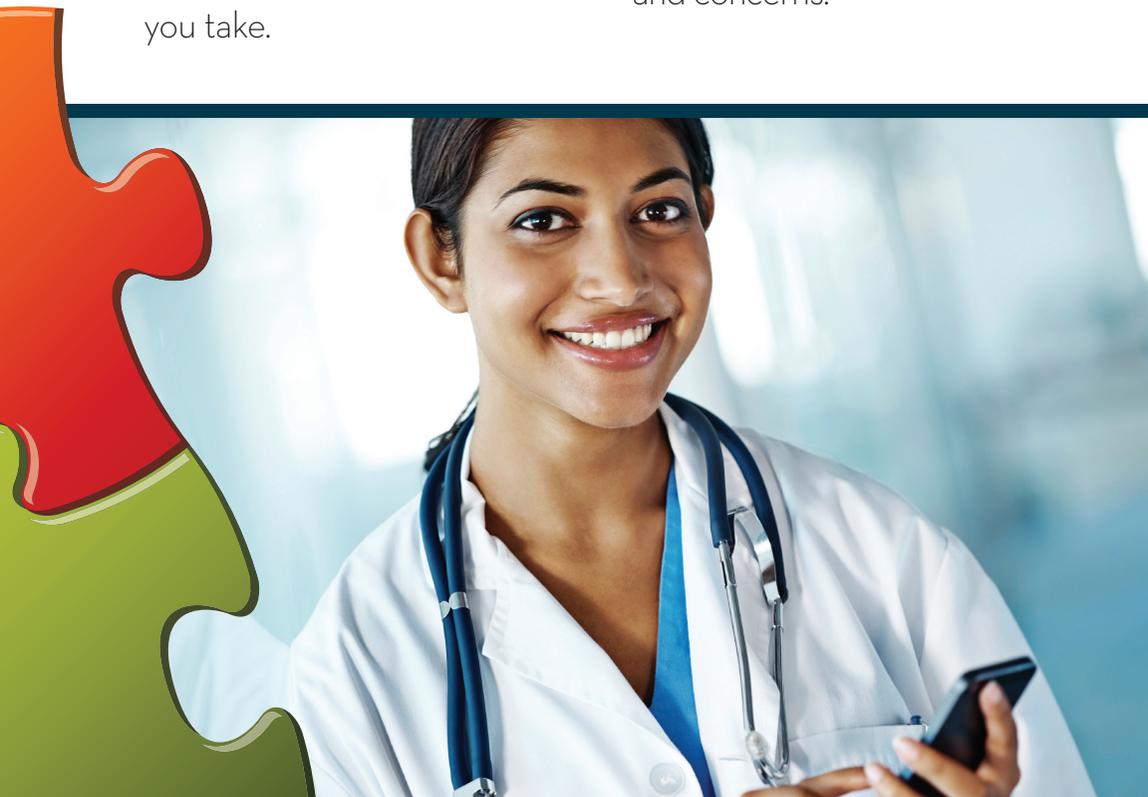
Community – Getting involved with your bleeding

disorders community has many benefits. It will help you stay updated with the latest information on VWD, provide you with access to resources (educational materials, webinars, scholarships, etc.) and help you meet others who have a bleeding disorder through social and educational events. The best way to start is to contact your local chapter or HTC (see back of brochure).

What information do I need to share with my Hematologist/HTC?

When visiting your hematologist or HTC staff, come prepared with the following information:

- Your family history of a bleeding disorder. Document if your mother, father, siblings or children have or had bleeding problems.
- Prepare a list of the over-the-counter, prescription and herbal medications you take.
- Jot down your bleeding and bruising symptoms. If possible, make a list of recent bleeding or bruising episodes.
- The results of recent lab work.
- A list of your questions and concerns.



Know the symptoms, treat them and enjoy life

For Anyone: Frequent and prolonged nosebleeds, easy bruising and heavy bleeding after surgery or dental work are symptoms anyone with VWD may face. In more severe cases, bleeding into soft tissues and joints may occur. The treatment for VWD depends on the type and severity of the bleeding disorder, so talk to your hematologist/HTC to come up with the best treatment plan for you. Treatments are given by injection, nasal spray or pills.

For Women and Girls: Heavy menstrual bleeding is often a primary symptom for adolescent girls and women, but can be controlled with proper treatment. Women and girls can often participate in sports and other physical activities. They can progress safely through pregnancy, childbirth and menopause—all by staying engaged with their hematologist/HTC.

For Men and Boys: VWD is sometimes diagnosed at a later age in boys and men, even though it is equally common in men and women. The most common symptom in boys is frequent and prolonged nosebleeds. It is sometimes caught “by chance” by medical providers if there isn’t a clear family history, or if it isn’t recognized by care providers due to the challenges with diagnosis. VWD can cause significant problems among boys and men if not diagnosed and treated. Boys and men with VWD can often participate in many sports, and should stay engaged with their hematologist/HTC.



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For More Information and Support

For information about NHF and to find a local chapter:

www.hemophilia.org

For information on living with a bleeding disorder
through all life stages:

www.stepsforliving.hemophilia.org

Any other questions?

Call or email HANDI, NHF's information resource center:

800.424.2634 or **handi@hemophilia.org**

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. Its programs and initiatives are made possible through the generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

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