

WHAT WOMEN AND GIRLS SHOULD KNOW ABOUT GETTING TESTED FOR BLEEDING SYMPTOMS

Your guide to lab tests, screening tools and health exams



NATIONAL
BLEEDING DISORDERS
FOUNDATION

About This Booklet

IF YOU ARE in the process of trying to find out how to explain your bleeding symptoms, your healthcare provider may ask you some questions or run some lab tests to better understand what is going on. If this process feels confusing or overwhelming, you are not alone. This booklet explains common health tools, called “assessments,” that are used to help understand a person’s current and future state of health. It also gives information on a variety of lab tests that healthcare providers may run to assess for a possible **bleeding disorder** when a woman or girl is having bleeding symptoms. This booklet also shares things to consider before having the tests.



Not sure what some of the terms mean? Words in **red** are explained in more detail in the Glossary at the back.



Assessment Tools

This section describes the questionnaires or tools your healthcare provider may use before deciding to order blood tests and lab tests. All of the abbreviations and medical terms can feel overwhelming. This section explains why these assessments are important and what information they provide about you. The information in this section can help you take charge of your own health care.

Tool	What It Is	Things To Consider
GENERAL ASSESSMENTS		
Health History	Your healthcare provider will ask general questions about your health and possibly your family members' health too. Your healthcare provider might also ask you about specific bleeding symptoms, such as heavy menstrual periods, nosebleeds, bruising, and/or bleeding after dental or medical procedures.	Be prepared. Think through all of your bleeding symptoms before your healthcare appointment, and ask your family if any of them have had bleeding symptoms too. Write down all of this information in a health diary , so you don't forget anything.
Physical Exam	Your healthcare provider will look at you for physical signs of a bleeding disorder (such as bruising), test how well your joints move, and check your joints for tenderness. A physical exam is usually a full body exam.	Write down a list of concerns about your bleeding and questions you would like to talk about with your healthcare provider, and bring it to your appointment. All of your questions are important. The healthcare provider may also ask you questions that may feel personal or embarrassing, such as details about your periods. These questions provide information about your health and can help identify the cause of your symptoms.
BLEEDING ASSESSMENTS		
Menorrhagia Impact Questionnaire (MIQ)	This survey asks you about the ways in which bleeding symptoms related to your periods have affected your quality of life and day-to-day activities.	This tool helps your healthcare provider determine the impact that your bleeding symptoms have on your life. Being open about what you are experiencing can help your doctor recognize the problem and get you the help you need.
Bleeding Assessment Tools (BATs)	A questionnaire developed for children to help find out if bleeding symptoms indicate the possibility of a bleeding disorder.	This questionnaire is often one of the first tools a healthcare provider will use to collect information on bleeding.

Tool	What It Is	Things To Consider
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BLEEDING ASSESSMENTS, CON'T.

International Society on Thrombosis & Hemostasis (ISTH) Bleeding Assessment Tool	<p>This is a specific bleeding assessment tool, designed by ISTH, that is used by healthcare providers to help identify children and adults with mild bleeding disorders.</p>	<p>People who are seeing a healthcare provider for the first time to find out if they may have a bleeding disorder are often asked to complete this questionnaire.</p>
Condensed Molecular and Clinical Markers for the Diagnosis and Management of Type 1 (MCMDM-1) VWD Bleeding Questionnaire	<p>This questionnaire measures bleeding symptoms and the severity of bleeding.</p>	<p>This tool is used to help diagnose or rule out von Willebrand disease (VWD).</p>
Pictorial Bleeding Assessment Chart (PBAC)	<p>The PBAC is a visual tool that women or girls may be asked to complete during 1 or 2 of their periods to find out if they have heavy menstrual bleeding (HMB).</p>	<p>Before your healthcare appointment, it may be helpful to track 1 or 2 of your menstrual cycles and bring that information with you. You can do this with a free downloadable menstrual chart and scoring system PBAC as well as other information on how to prepare for a doctor visit at betteryouknow.org/women/at-risk/how-to-prepare. Remember to discuss the absorbency of the tampon or pad you are using and whether you use both pads and tampons together.</p>

PEDIATRIC ASSESSMENTS

Pediatric Quality of Life Inventory	<p>A survey for children and teens to measure their overall health-related quality of life.</p>	<p>The tool is available for children and teens to report their own symptoms or for a parent or guardian to fill out for their child or teen if needed.</p>
Pediatric Bleeding Questionnaire (PBQ)	<p>A questionnaire developed for children to help find out if bleeding symptoms indicate the possibility of a bleeding disorder.</p>	<p>This questionnaire is often one of the first tools a healthcare provider will use to collect information on bleeding.</p>

THE BOTTOM LINE ON ASSESSMENT TOOLS

There are many different tools and many ask similar questions. Whichever one is used, your healthcare provider will probably be asking you many questions about various ways you bleed, both now and in the past. Coming to your visit prepared and ready to discuss ALL of your symptoms in detail will help you get a more accurate diagnosis and receive better care.

Lab Tests

Based on the results of the assessment tool(s) discussed in the previous section, your healthcare provider may order some lab tests that require a blood sample. It may be necessary to repeat lab tests several times.

Lab Test	What It Is	Things To Consider
INITIAL TESTING		
Complete Blood Count (CBC)	The CBC measures the red blood cell count, white blood cell count, hemoglobin, hematocrit , and platelet count. Any increases or decreases in cell counts can be a sign that a medical condition exists that needs to be looked into further.	A CBC may be requested when someone has signs and symptoms related to disorders that affect blood cells. The test may be ordered if someone is frequently tired or has an infection, swelling, bruising, or bleeding to help determine the cause and/or the severity of the disorder. A low red blood cell count may be due to anemia or possibly heavy menstrual bleeding and may mean that further testing for iron levels is needed.
Thyroid Stimulating Hormone (TSH)/Total Thyroxine (T4)	The TSH level is used to measure how well the thyroid gland is working. TSH directs the thyroid gland to make T4, or thyroid hormone, which helps to control your body's metabolism .	A thyroid gland that does not work the way it's supposed to can cause frequent and irregular menstrual periods. To prepare for the test, be sure to tell your healthcare provider if you take medicines that thin your blood (such as aspirin and warfarin). Rarely, an underactive thyroid gland can cause a bleeding disorder.



Lab Test	What It Is	Things To Consider
INITIAL TESTING, CON'T.		
Prothrombin Time (PT) & Partial Thromboplastin Time (PTT)	<p>The PT and PTT tests both measure the length of time it takes blood to clot by looking at different parts of the blood.</p> <p>These tests help check the levels of various blood clotting factors (I [1], VII [7], VIII [8], IX [9], and XI [11]).</p>	<p>Typically, results outside the range of 10 to 14 seconds would indicate that further testing is needed. However, interpretation of these values can vary by lab and other factors.</p> <p>A longer than normal PT may indicate low amounts of clotting factor I (1), clotting factor VII (7), or fibrinogen. Blood thinning medicines (such as warfarin) can also cause a longer PT. Having a longer than normal PTT and normal PT may indicate low amounts of clotting factor VIII (8), IX (9), or XI (11).</p> <p>By looking at the results of the PT and PTT together, a healthcare provider can get clues as to what bleeding or clotting disorder a patient may have. Healthcare providers cannot use these tests alone to make a diagnosis, but usually the test results provide information on whether further tests are necessary.</p>
Activated Partial Thromboplastin Test (aPTT)	<p>The aPTT measures how long it takes blood to clot in a tube after adding certain substances needed for this to happen in the body. The test is also used to find out if irregular bleeding and bruising are due to low levels of blood clotting factors.</p>	<p>Typically, values for the aPTT that are longer than 40 seconds could indicate low levels of blood clotting factors and prompt additional lab tests. The aPTT can vary based on your age, health, and other considerations. Be sure to discuss with your healthcare provider what is considered a normal range for you.</p> <p>The aPTT can also be used to track a person's response to heparin therapy that is being used to prevent or to treat clots.</p>

Lab Test	What It Is	Things To Consider
Thrombin time (TT)	A TT test monitors how long it takes plasma (the liquid part of the blood), specifically fibrinogen in plasma, to form a clot. The result of the test might indicate that there is a low level of fibrinogen or that the fibrinogen is not working properly. This test can be used with reptilase time to determine if there is low fibrinogen, which can be the cause of other blood disorders.	Many things can affect your TT test results, such as the lab procedure, your overall health, and medicines, such as heparin and warfarin, so it is important to talk with your healthcare provider. Tell your healthcare provider if you have pre-existing health conditions and if you take prescription or over-the-counter medicines, especially those that might affect the ability of your blood to clot.
Fibrinogen Activity	A fibrinogen activity test is done to find out how well fibrinogen helps blood to clot.	<p>A fibrinogen test may be requested by your healthcare provider based on the results of your PT and PTT.</p> <p>The normal range for the test can vary among different labs, due to different measurements or samples. To interpret the results correctly, your healthcare provider will look at your fibrinogen activity along with the results of other blood clotting tests.</p> <p>If the fibrinogen activity is low, a follow-up test called the fibrinogen antigen test may be ordered, which can indicate that you aren't making enough fibrinogen or that the fibrinogen you make doesn't work properly.</p>

VON WILLEBRAND DISEASE (VWD) TESTS

Von Willebrand Factor (VWF) Antigen Test	The VWF antigen test measures the amount of VWF protein in the blood. However, it does not determine whether the VWF protein works properly to clot blood. People, who are diagnosed with VWD, usually have less than half of the normal amount of VWF protein in their blood.	<p>Sometimes tests need to be repeated because the levels of VWF protein can change based on the following:</p> <ul style="list-style-type: none"> a. Stress and recent exercise. Often, the stress of having lab tests done can affect the result. b. Pregnancy, certain types of birth control pills, or breastfeeding. c. An overactive thyroid gland. d. Recent surgery or a blood transfusion. e. Blood type. Individuals with blood type O are more likely to have reduced VWF. f. Menstrual cycle. g. Age.
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Lab Test	What It Is	Things To Consider
VON WILLEBRAND DISEASE (VWD) TESTS, CON'T.		
Von Willebrand Factor (VWF) Activity (Ristocetin CoFactor Test)	A VWF activity test determines whether the VWF protein is working properly to clot blood.	Blood with enough working VWF clots normally when ristocetin is present. Blood that doesn't have enough VWF or has VWF that doesn't work properly won't clot the way it should, which can be a sign of VWD. People who are diagnosed with VWD usually have a low percentage of VWF reported in their test results.
FACTOR DEFICIENCY TESTING		
Factor VIII (8) Testing	This blood test, which is also called an assay, measures the clotting ability of factor VIII (8), one of the proteins that help blood to clot.	<p>Factor VIII (8) deficiency (a lack or decrease of clotting factor VIII (8)) is also known as hemophilia A. Factor tests are often ordered when the results of a PTT show that it takes longer than normal for blood to clot. A factor VIII (8) test shows the level of factor VIII in the blood and can determine disease severity. A lot of conditions can impact your factor levels. You could have high factor level and still have high bleeding symptoms and vice versa. Levels of 50% and above do not typically lead to bleeding symptoms. Those with factor VIII (8) levels below 30% generally have mild hemophilia symptoms.</p> <p>This test is one part of the diagnostic picture for having a bleeding disorder. Make sure to ask about other tests that are done for you and how they fit together.</p>



Lab Test	What It Is	Things To Consider
Factor IX (9) Testing	This blood test, which is also called an assay, measures the clotting ability of factor IX (9), one of the proteins that help blood to clot.	<p>Factor IX deficiency (a lack or decrease of clotting factor IX (9)), is also known as hemophilia B. With factor IX (9) deficiency, a PTT would show that it takes longer than normal for a person's blood to clot. A factor IX (9) test shows the level of factor IX (9) in the blood and can determine disease severity.</p> <p>A lot of conditions can impact your factor levels. You could have high factor level and still have high bleeding symptoms and vice versa. Levels of 50% and above do not typically lead to bleeding symptoms. Those with factor IX (9) levels below 30% generally have mild hemophilia symptoms.</p> <p>This test is one part of the diagnostic picture for having a bleeding disorder. Make sure to ask about other tests that are done for you and how they fit together.</p>
Factor XI (11) Testing	This test, which is also called an assay, measures the amount of factor XI (11) protein in blood.	<p>Factor XI (11) deficiency (either reduced levels of factor XI (11) or factor XI (11) that does not work properly) is sometimes known as hemophilia C. Factor tests are often ordered when results of a PTT show that it takes longer than normal for a person's blood to clot. A lot of conditions can impact your factor levels. You could have high level and still have high bleeding symptoms and vice versa. Levels of 60% and above do not typically lead to bleeding symptoms. However, the results vary based on the lab, so discuss your results and any symptoms you may have with your healthcare provider.</p>

Lab Test	What It Is	Things To Consider
PLATELET LAB TESTING		
Platelet Function Testing: PFA-100 Closure time	The PFA-100 (Platelet Function Analyzer-100) is a testing device used by hospitals to measure closure time (CT). CT is the time it takes a blood clot to form inside a glass tube and prevent blood flow. If the CT is normal, it is unlikely that the person has a problem with his or her platelets working properly.	When a person's platelets don't work normally, this could signal a potential bleeding disorder. A longer than normal CT means the platelets are not working as well as they should. Abnormal test results can be caused by a low number of platelets (platelet count), platelets or proteins not working properly, or the presence of medicines that prevent blood clots, such as aspirin. This test can be used to screen for VWD and some platelet function disorders.
Platelet Transmission Electron Microscopy (PTEM)	This test is used to figure out if there are problems with the size, shape, or contents of the platelets in the blood.	PTEM is used to test for a variety of platelet disorders, including delta platelet storage pool deficiency .
Platelet Aggregometry	Platelet aggregometry uses 4 to 8 different tests. The tests measure how platelets clump together over several minutes. The tests are reviewed and interpreted together to see if the platelets are not working properly.	Platelet aggregometry is the best test to find out if a person's platelets are working properly. This test can be used to identify many platelet function disorders.
Flow Cytometry	This test uses lasers to see the proteins that are on the outside of the platelet and how they change under different conditions. The test can find problems with how the platelets are working.	This test can assist in confirming a diagnosis of Bernard-Soulier syndrome and Glanzmann thrombasthenia . It may only be available in a few university hospitals and laboratories because specialized equipment and training are needed.

THE BOTTOM LINE ON ASSESSMENT TOOLS

Many different tests may be needed to reach a diagnosis. Ask your healthcare provider the reason for each test and to explain the results. Be patient. This can be a long process for many women, and the results may not be clear the first time. In the meantime, talk to your healthcare provider about how to manage any symptoms you may have while you wait for your test results.

Glossary

Antigen: a substance (such as bacteria, viruses, chemicals, etc.) that causes the immune system to develop proteins called antibodies that fight against it. A normal immune system, in an effort to keep a person healthy, tries to fight off substances it doesn't recognize.

Anemia: a medical condition in which the amount of red blood cells or hemoglobin in the blood drops below normal. It is a fairly common condition that can be acute (sudden) or chronic (long-lasting) and the severity can be mild, moderate or severe. Iron-deficiency anemia is a type of anemia in which there are too few healthy red blood cells due to too little iron in the body. It can be caused by a woman's menstrual period if she experiences heavy menstrual bleeding. Symptoms of anemia can include fatigue, dizziness, loss of energy, shortness of breath, and difficulty concentrating.

Bernard-Soulier syndrome: a platelet function disorder caused by a missing or non-working protein on the outside of platelets.

Bleeding disorder: a general term for a wide range of medical problems that lead to poor blood clotting and continuous bleeding. Healthcare providers call these conditions by many different terms, including coagulopathy, abnormal bleeding, and clotting disorders. While hemophilia is the best-known bleeding disorder, many types exist, and most are inherited. More information can be found here: www.betteryouknow.org/women/at-risk/what-to-know

Clotting factors: proteins made by the body that are needed for blood to clot normally. They are numbered I, II, V, VII, VIII, IX, X, XI, and XIII (in other words, 1, 2, 5, 7, 8, 9, 10, 11 and 13): A problem with or lack of one of these clotting factors can cause problems with blood clotting.

Delta platelet storage pool deficiency: a platelet disorder where there are not enough granules (essentially tiny "bags" inside platelets that store proteins and other chemicals that help platelets work properly) or the platelets are unable to empty the contents of the granules into the bloodstream.

Fibrinogen: a protein found in the liquid part of blood, called plasma, which helps blood clots to form. It is also known as factor I (I).

Glanzmann thrombasthenia: a platelet function disorder caused by missing proteins or too few proteins on the outside of platelets.

Heavy menstrual bleeding (HMB): menstrual periods with abnormally heavy bleeding that can limit daily activities. If left untreated, HMB can place women and girls at an increased risk for health problems.

Hematocrit: a measure of the amount of red blood cells in the body. It is often used to check for anemia or to screen for a number of other conditions that can affect the part of the blood made up of red blood cells. Hematocrit can also be denoted as Hct.

Hemophilia A: a genetic disorder caused by missing or non-working factor VIII (8), a protein needed for blood to clot.

Hemophilia B: a genetic disorder caused by missing or non-working factor IX (9), a protein needed for blood to clot. Hemophilia B is also known as factor IX (9) deficiency or Christmas disease.

Hemophilia C: a genetic disorder caused by missing or non-working Factor XI (11), a protein needed for blood to clot.

Glossary

Hemoglobin: a protein in the blood that carries oxygen throughout the body. A low hemoglobin level is generally defined as less than 12 grams per deciliter (120 grams per liter) for women.

Hemoglobin can also be denoted as Hb or Hgb.

Heparin: a blood thinning medicine that is used to prevent blood clots from forming.

Menorrhagia: menstrual periods with abnormally heavy bleeding that can limit daily activities, also referred to as heavy menstrual bleeding (HMB).

Metabolism: the chemical reactions in the body's cells that change the food we eat into energy needed to engage in our everyday lives.

Overactive thyroid gland: a condition where the thyroid gland makes too much thyroid hormone, which speeds up metabolism. This is also known as hyperthyroidism.

Plasma: the liquid part of the blood. Plasma makes up about half of the amount of blood.

Platelet count: a measure of the number of platelets in the blood. The number of platelets in blood can be affected by many diseases. Platelets can be counted to monitor or diagnose diseases, or to look for the cause of too much bleeding or clotting. Platelet count can also be denoted as Plt.

Red blood cell count: a test that shows how many red blood cells are in the blood. Red blood cells contain hemoglobin, which carries oxygen to the body's tissues. Red blood cell count can also be denoted as RBC.

Reptilase time: a test that measures the time it takes for a clot to form after reptilase (a protein molecule that speeds up reactions in the body) has been added to plasma. This test is performed when there is a longer than normal clotting time because of a TT test (see lab test tables).

Ristocetin: an antibiotic that causes VWF and platelets to stick together. It is added in the VWF ristocetin cofactor test.

Thyroid gland: a gland in the neck that makes and stores hormones that help control the heart rate, blood pressure, body temperature, growth and metabolism rate.

Underactive thyroid gland: a condition where the thyroid gland doesn't make enough thyroid hormone, which slows down metabolism. This is also known as hypothyroidism.

Von Willebrand disease (VWD): a disorder that is caused by a lack of or problem with the von Willebrand factor (VWF) in the blood. People with VWD either don't have enough VWF or it doesn't work properly. VWD is the most common bleeding disorder and it affects both men and women equally. There are several different types of VWD: type 1, type 2, and type 3, and even some subtypes.

Von Willebrand factor (VWF): a clotting protein that helps platelets stick together to stop bleeding; factor VIII (8) is attached to VWF.

White blood cell count: a test that measures the number of white blood cells (also called leukocytes) in the blood. These cells are the front line of defense in our body's fight against germs and infection. White blood cell count can also be denoted as WBC.





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The National Bleeding Disorders Foundation (NBDF) would like to express its appreciation for the entire Better You Know working group for their insights and review, especially Robert F. Sidonio, Jr, MD, MSc, and Chris Guelcher, Hemostasis RN-BC, MS, PPCNP-BC, as well as Charletta A. Ayers, MD, MPH, and Gloria A. Bachmann, MD, MMS. The information contained in this publication is general information only. NBDF does not give medical advice or engage in the practice of medicine. NBDF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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