

Managing Your Bleeding Disorder – Before, During, and After Pregnancy

Learn what steps to take now to plan for a healthy and successful pregnancy.

Congratulations! Thinking about starting a family can be an exciting journey. It also can make you concerned. That's because there are a number of extra risks associated with having a bleeding disorder during pregnancy for both you and your child. But by taking some time now to become informed and take the steps to plan for a healthy pregnancy, you can save yourself worry and reduce your risks.

To help you along, we offer information on preparing your body for pregnancy, labor and delivery, and more.

Preparing Your Body for Pregnancy

Before you become pregnant (Preconception Care) –

Ideally, planning for pregnancy starts before conception. It is a good idea to have a preconception care checkup to ensure of your own health status before you get pregnant. The goal of this checkup is to help increase your chances of having a healthy pregnancy and a healthy baby.

During this visit, your provider will ask about your medical and family history, your diet and lifestyle, medications you take, and any other past pregnancies.

Your provider will also encourage you to maintain good general health. The best way to ensure good health is to follow some simple guidelines. These include:

- ✚ Eat a balanced and healthy diet that includes fresh fruits and vegetables, especially dark leafy greens
- ✚ Get plenty of rest
- ✚ Participate in regular physical activity
- ✚ Manage stress
- ✚ Adopt a smoke-free, drug-free lifestyle and keep alcohol use to a minimum
- ✚ Avoid taking certain medications

Your provider may also recommend that if you have not already been vaccinated you should be immunized against hepatitis A and hepatitis B. This is in case you might need a transfusion during delivery.

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Bleeding Disorders and Pregnancy: What to Expect

What to expect before pregnancy

If you, the father of your baby, or any close family member have a history of an inherited bleeding disorder, you may have a higher chance of having a baby with the same challenges. Therefore, your provider may recommend that you consider speaking to a genetic counselor regarding the inheritance of a condition. This helps you to discuss the options for diagnosis of a bleeding disorder before birth (or even before you become pregnant), as well as discuss the other aspects of pregnancy management.

What to expect during pregnancy

Your care will be carefully managed in conjunction with other specialists including a hematologist. During your pregnancy your clotting factor levels will be checked. If your clotting factor levels are low before an invasive test or before delivery, you may need preventative treatment with clotting factors. Sometimes a medication called Desmopressin is given for this purpose. Additionally, women with von Willebrand disease (VWD) have a greater risk of bleeding during pregnancy, therefore, it is important to notify your doctor of any signs of bleeding while being pregnant. During this time you also will be referred to see an anesthesiologist to discuss your options for pain relief during labor, including an epidural.

What to expect during labor and delivery

Many measures will be taken to reduce the risk of bleeding to you and your baby. If your baby is at risk of bleeding, there are certain procedures that are generally **avoided** during labor and delivery. These procedures include an internal fetal heart rate monitor and delivery by vacuum extraction or forceps. If your baby is at risk of severe bleeding, your doctor will likely recommend delivery by cesarean and in a specialized center.

What to expect after delivery

If your clotting factors are low around the time of delivery, you may need treatment with clotting factors for a few days following delivery to reduce your risk of bleeding. A cord blood sample will be taken from the umbilical cord after delivery to check if the baby is affected or not. It may be recommended that your baby receive Vitamin K by mouth rather than injection. And, if you are planning on having your baby boy circumcised, this should be delayed until the clotting status of your baby is known. Last, some babies may need a special scan of their brain to ensure that there is no bleeding inside of the baby's head after delivery.

Pregnancy Planning Checklist

Use this list to help you plan a successful pregnancy

What you need to do BEFORE you become pregnant:

The best preparation starts with getting the right advice and assistance before you become pregnant. The treatment that your providers recommend will depend on your bleeding disorder, your overall health and your pregnancy.

First, seek out specialized, integrated and comprehensive care. Consult with a hematologist and a maternal-fetal medicine physician or an OB/GYN who specialize in high-risk pregnancies to create a pregnancy management plan. When you do, be sure to:

- Find out more about any potential risks you may have of bleeding and/or clotting during and after delivery.
- Find out about any potential risks of bleeding complications to the fetus during birth, and what types of monitoring techniques and deliveries should be used to avoid bleeding.
- Meet and consult with a genetic counselor to find out more about the inheritance of your disorder and what prenatal diagnostic options are available. (*See more information on the next page.*)
- Ask about your options for pain management during labor.
- Find out when and if a caesarean section (also called a C-section) is advised during delivery. If it is, you may require treatment to raise factor levels prior to your procedure.
- Learn more about whether it will be necessary for you to receive treatment to prevent postpartum hemorrhage after delivery and what that treatment will be.
- Seek out additional counseling during your pregnancy to receive information on lifestyle advice related to your disorder beyond your pregnancy and additional information that may help you and your child.
- Other notes:

Management of Pregnancy and Childbirth

Creating a Birth Plan

A birth plan is a document that lets your medical team know your preferences for things such as how to manage labor pain. Keep in mind that you can't control every aspect of labor and delivery, and you'll need to stay flexible in case something comes up that requires your birth team to depart from your plan. However, a printed document gives you a place to make your wishes clear. It can also help you make sure that all procedures and medications are clearly explained to you before being given to you and/or your baby. Most hospitals provide a birth plan worksheet or brochure to explain their policies and to let you know what your options might be. That information can help you and your provider discuss your labor and delivery preferences and options. Some items to consider when creating your birth plan are:

During Labor:

- How will the fetus be monitored?
- What type of pain medication is safe for my baby and me?
- Will I be able to have an epidural?
- In what circumstances will I need to have a cesarean delivery?
- Other:*

After Delivery:

- How will the umbilical cord be handled?
- Should I bank my baby's cord blood?
- If my baby is a boy, circumcision should be delayed until status is known.

During Labor

The management of childbirth will depend on your needs and your potentially affected infant at the time of delivery. If you or your baby are at risk for severe bleeding, it is recommended that you seek prenatal care and delivery in a state-of-the-art facility where, in addition to specialists in high-risk obstetrics, there is a hematologist with expertise in hemostasis.

Many hospitals as well as hemostasis and thrombosis treatment centers (HTCs) offer specialized care for pregnancies involving bleeding disorders, and have the resources required in order to address serious bleeding problems if needed (i.e., laboratory, blood bank, transfusion services and pharmacy). To find an HTC near you, visit: www.fwgbd.org/clinics

A Word About Pain Relief During Labor

An epidural anesthetic provides pain relief during labor. Since bleeding can occur in the epidural space, anesthesiologists usually refrain from giving a patient with a bleeding disorder an epidural or spinal anesthetic unless her factor levels are continuously higher than 50 percent of normal. If you need pain relief while in labor and do not have levels that are continuously higher than 50 percent of normal, narcotic pain relievers can be used instead. If you require a cesarean delivery, a general anesthetic can also be used instead of a spinal.

After Delivery

Abnormal Bleeding After Delivery

Excessive bleeding from the uterus, or postpartum hemorrhage, is a concern for many women who have a bleeding disorder. It can occur soon after delivery but may occur as late as 1 month afterward. Women with bleeding disorders are particularly vulnerable to **delayed postpartum hemorrhage**, the type that occurs more than 24 hours after childbirth.

Blood loss is considered to be abnormal or excessive if one of the following occurs within 24 hours of delivery:

- 🔥 More than 2 pints of blood are lost
- 🔥 You experience symptoms along with the blood loss of low blood pressure, rapid heart rate, dizziness, light-headedness, fatigue and weakness

The most common cause of excessive bleeding at delivery is when the uterus does not contract adequately. However, excessive bleeding can also result from incisions or tears.

Prevention

One of the most important things you can do to decrease the risks of postpartum hemorrhage is to make sure that a knowledgeable physician or hematologist is caring for you. Before going into labor, your physician should take steps to prevent or to prepare for excessive bleeding after delivery by ensuring that your factor levels are sufficient. After delivery, your team will monitor you closely to make sure that the uterus has contracted and to assess bleeding.

Treatment

If excessive bleeding occurs, your provider will perform measures to address the problem. If the bleeding continues, additional medications, blood products and even surgery may be required.

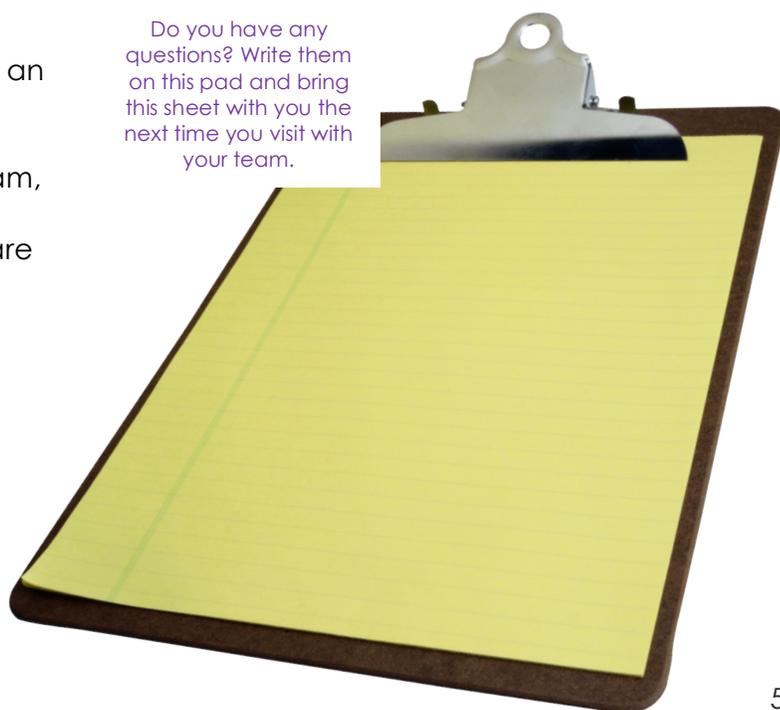
You and Your Healthcare Team: A Healthy Partnership

To ensure that you have a successful pregnancy, it is especially important to take an active role in your healthcare. That means providing as much information as you can about your condition to your healthcare team, as well as making sure you understand all treatment decisions and procedures. Here are some tips to help you ensure good, clear communication between you and your healthcare team:

Be prepared
Bring a support person
Ask questions
Inquire about procedures
Ask about treatments

Speak up
Ask

Do you have any questions? Write them on this pad and bring this sheet with you the next time you visit with your team.



Resources

Hemophilia of Georgia

www.hog.org

The Hemophilia of Georgia has a library of resources covering a wide range of topics related to bleeding disorders as well as topics such as child development and coping with a chronic illness.

Hemophilia Federation of America (HFA)

www.hemophiliafed.org

National Hemophilia Foundation (NHF)

www.hemophilia.org

Centers for Disease Control (CDC)

<https://www.cdc.gov/features/bleedingdisorder/index.html>

Foundation for Women and Girls with Blood Disorders (FWGBD)

www.fwgbd.org

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