

The Basics of Bleeding Disorders for School Nurses

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Outline



- Bleeding Disorder Basics
- Hemophilia
- von Willebrand disease
- Women and Girls Bleed Too
- Hemophilia Treatment Center at LVHN
- Care Coordination with Schools
- Possible Issues at Schools
- Kids, Sports, and Exercise
- Resources for Schools
- Questions

Bleeding Disorders Quiz



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Bleeding Disorders Quiz



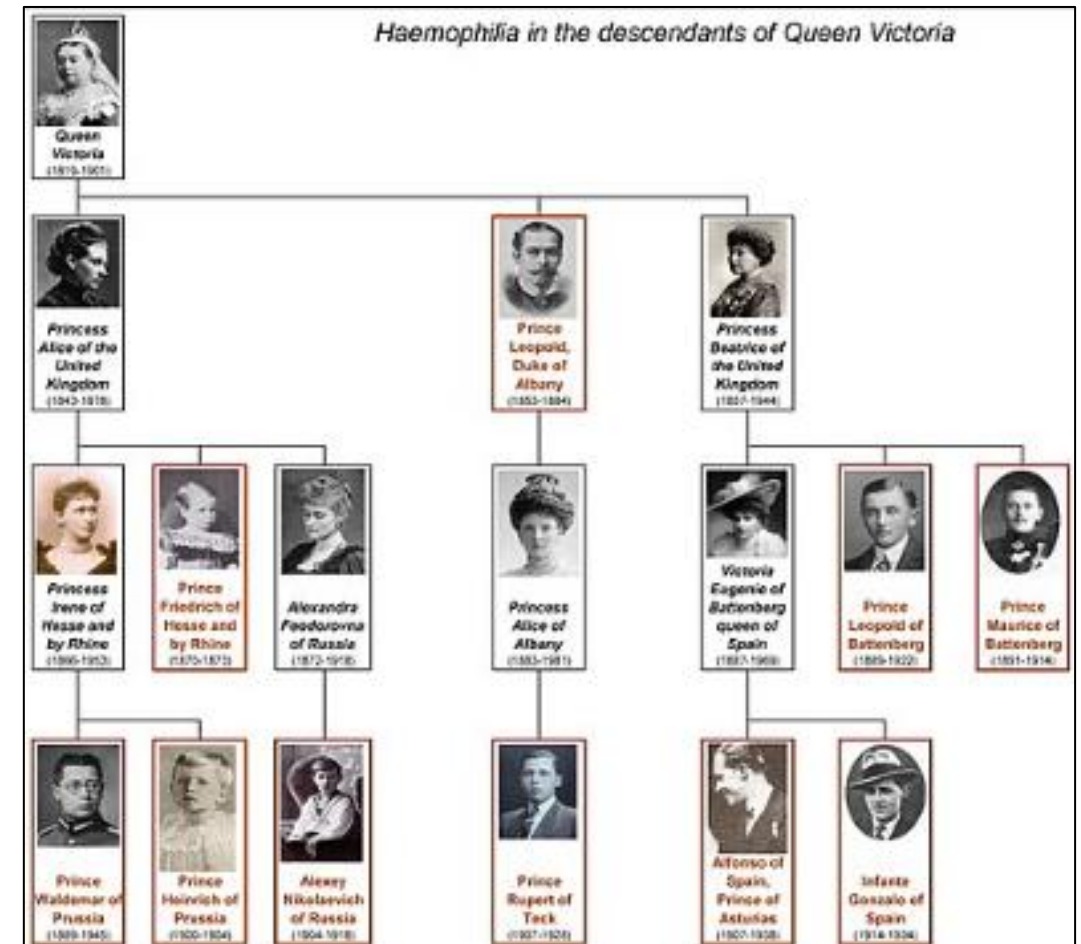
True or False...

Only women can have von Willebrand disease (VWD).

Basics of Bleeding Disorders

History of Bleeding Disorders Prior to the 20th Century

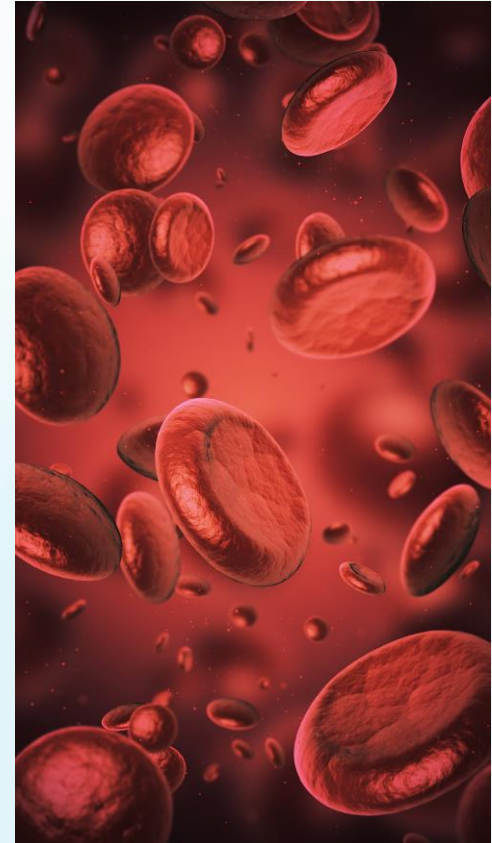
- **1000** - first description of an inherited bleeding disorder - referenced in the Talmud, an ancient body of Jewish law compiled in the 2nd century AD
- **1639** - first European with a bleeding disorder arrives in the American colonies
- **1791** - first American with hemophilia dies at age 19 from a minor cut on his foot
- **1803** - Hemophilia is named
- **1837-1901** - Queen Victoria ruled the United Kingdom. She is the originator of hemophilia in the European royal families.



https://en.wikipedia.org/wiki/Haemophilia_in_European_royalty

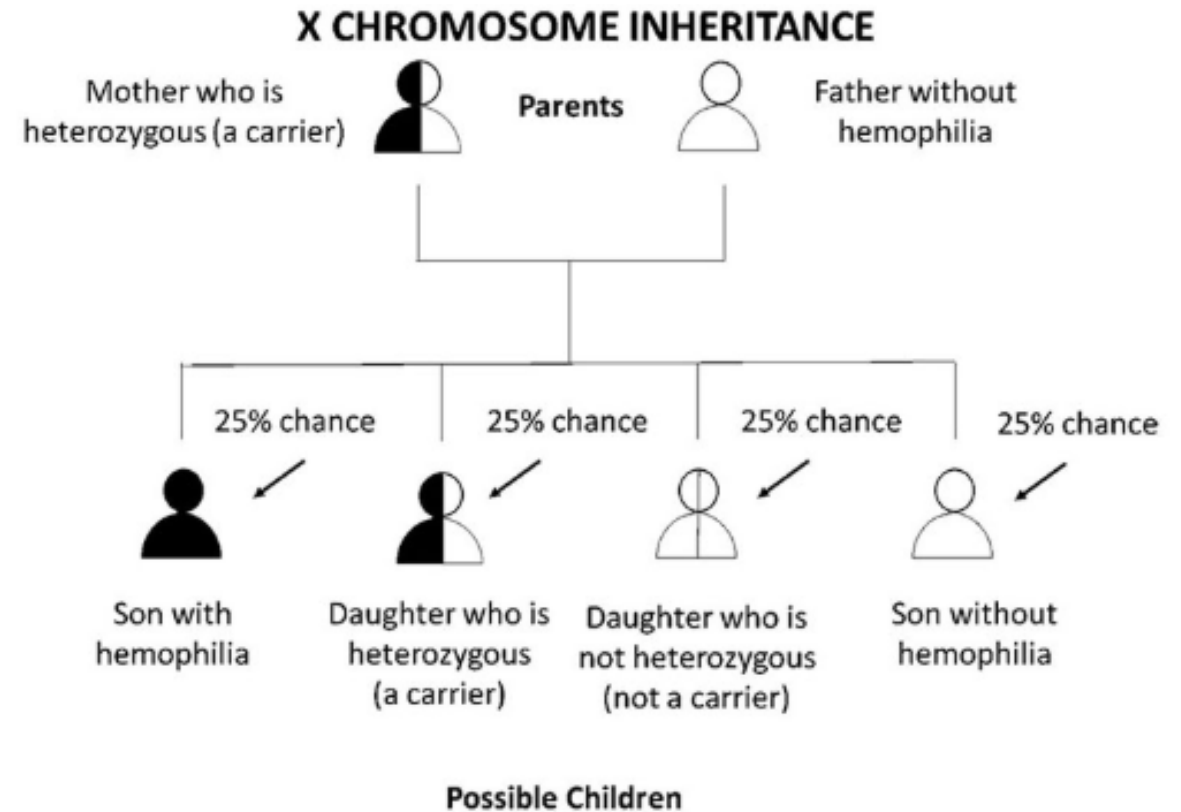
Bleeding Disorder Basics

- Inability to form a proper blood clot
- Levels can be mild, moderate, or severe
- Body produces 13 clotting factors - any can be defective or deficient
- Causes
 - *Inherited*
 - *Acquired*
 - *Conditions - anemia, cirrhosis of the liver, HIV, leukemia, and vitamin K deficiency*
 - *Medications - aspirin, heparin, and warfarin*



Hemophilia

- Types
 - Hemophilia A (missing or low factor VIII)
 - Hemophilia B (missing or low factor IX)
 - Hemophilia C (missing or low factor XI)
 - Ultra rare (missing or low factor I, II, V, VII, X, XI, XIII)
- Severity levels - mild, moderate, severe
- Hemophilia A and B more common in men than in women
- Affects all races and ethnic groups
- Risk of developing acquired hemophilia is higher during and after pregnancy
- Genetics: sex-linked X-chromosome



<https://www.cdc.gov/hemophilia/testing/how-hemophilia-is-inherited.html>

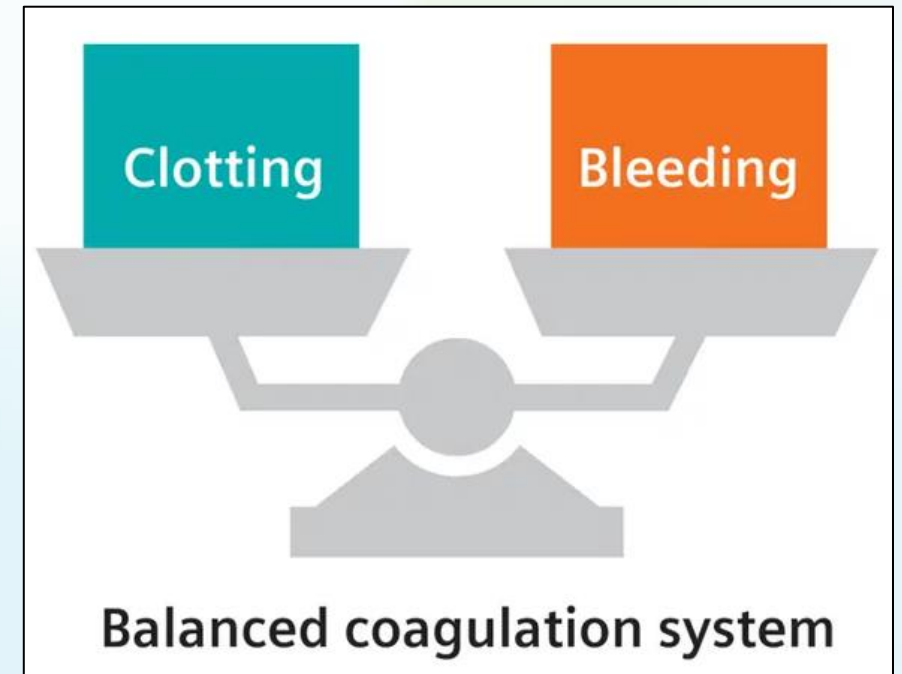
Hemophilia – Signs and Symptoms

- Bleeding into the joints
- Bleeding into the skin or muscle and soft-tissue causing a hematoma
- Bleeding of the mouth and gums and bleeding that is hard to stop after losing a tooth
- Bleeding after circumcision
- Bleeding after having shots
- Bleeding in the head of an infant after a difficult delivery
- Blood in the urine or stool
- Frequent and hard-to-stop nosebleeds



Hemophilia Treatments

- Clotting factor products - intravenous infusions
 - *Prophylactic*
 - *Episodic*
- *Hemlibra* - prophylaxis (subcutaneous injection)
- *DDAVP* (nasal spray or intravenous)
- *Amicar* (aminocaproic acid) (injection or by mouth)
- *Lysteda* (tranexamic acid) (by mouth)
- *Roctavian, Hemgenix*- gene therapy



von Willebrand Disease

- Most common bleeding disorder
- Low or missing activity of von Willebrand factor
- 3 Main Types: Type 1, Type 2 and Type 3
 - Additional: Acquired VWD
- Men and women are affected equally
- Affects approximately 1 in every 100 people



National Heart, Lung, and Blood Institute. December 2007.
www.nhlbi.nih.gov/health/bleeding-disorders

von Willebrand Disease

CDC estimates it takes a woman an average of **16 years** from onset of symptoms to be diagnosed with VWD, and men may be longer or go undiagnosed.

Most common bleeding symptoms:

- *Women - heavy menstrual bleeding (93%)*
- *Men - nosebleeds (53%)*



<https://www.cdc.gov/von-willebrand/data/index.html>

von Willebrand Disease (VWD)

Signs and symptoms

- Frequent or hard-to-stop nosebleeds
- Easy bruising
- Heavy menstrual bleeding
- Longer than normal bleeding after injury, surgery, childbirth, or dental work

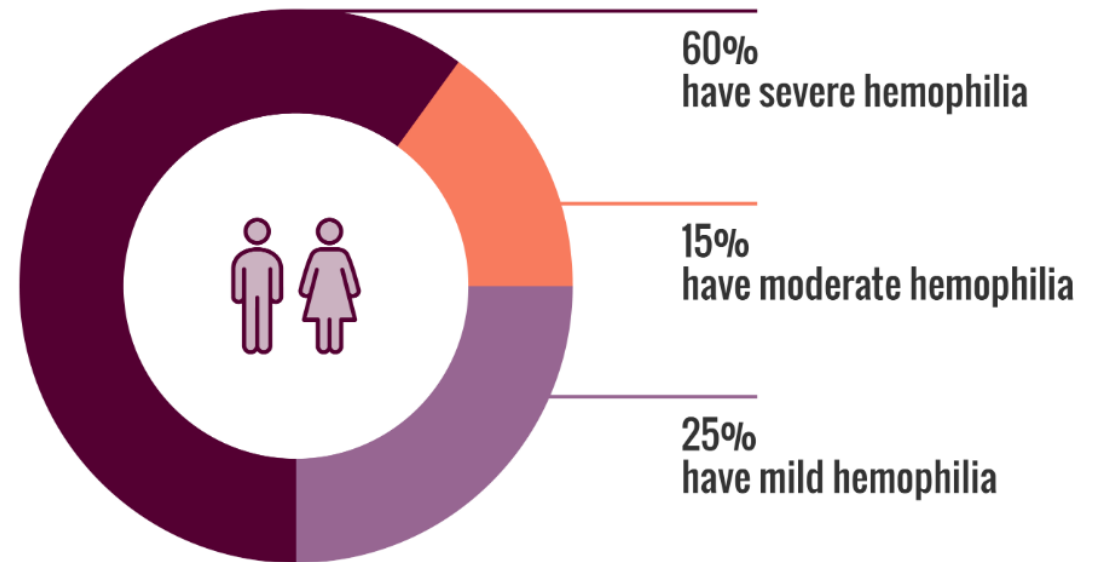
Treatment

- DDAVP (injection) or DDAVP (nasal spray)
- Factor replacement therapy
- Antifibrinolytic drugs (Aminocaproic acid, Tranexamic acid)
- Birth control

Epidemiology of Bleeding Disorders

- Hemophilia
 - *Approximately 5 out of 100,000 people*
 - *CDC estimates there are at least 33,000 males with some form of hemophilia*
- Von Willebrand's Disease
 - *1% of the population*
 - *Approximately 3.4 million patients*

There are between 30,000 - 33,000 people living with hemophilia in the US.



<https://www.bleeding.org/bleeding-disorders-a-z/overview/fast-facts>

L Women and Girls

Women and Girls Bleed Too



CDC

IF YOU HAVE HEAVY PERIODS, YOU ARE NOT ALONE.

1 in 5

WOMEN HAVE HEAVY PERIODS.


Heavy periods can be caused by many medical conditions, including having a **bleeding disorder**.

CDC

<https://www.cdc.gov/female-blood-disorders/about/information-for-adolescents.html>

Underserved and Overlooked

2025 UK Study: How our health systems are failing women and girls with a bleeding disorder



The infographic features four portraits of women and girls, each with a quote or statistic. The background is split into orange and dark purple sections. The Haemophilia Society logo is in the bottom left.

Top Left: Portrait of a woman with blonde hair. Quote: 'It would be nice to be taken **seriously**'

Top Right: Portrait of a woman with red hair and glasses. Quote: 'On average, women are diagnosed with a bleeding disorder **16 years later** than men'

Bottom Left: Portrait of a young girl with dark hair. Quote: 'It's estimated there could be up to **50,000** women and girls in the UK with an undiagnosed bleeding disorder'

Bottom Right: Portrait of an older woman with glasses. Quote: 'Women with a bleeding disorder are treated different to men - **they're ignored**'

Bottom Left: The Haemophilia Society logo.

Difficulties with Women and Girls

- Long delays in diagnosis
- Being rebuffed in their diagnosis journey can put women off seeking a diagnosis
- Use of hormonal treatments for heavy menstrual bleeding or for contraception can lead to further delays in diagnosis
- Many women and girls normalize their symptoms
- If a bleeding disorder is not caught by a provider
 - *Serious bleeds can be life-threatening (post-surgery or post-partum)*
 - *Iron deficiency anemia*
 - *Lower bone density may lead to greater risk of fractures*



Patient Stories from UK Study

Jenny

- Diagnosed at birth with VWD
- Struggled mentally and physically with her condition
- Elementary school - classmate announced in the lunch hall, “my mummy says her parents are beating her up”
- Avoided sports she enjoyed as a child

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Val

- Diagnosed with VWD at age 57 despite showing symptoms of a bleeding disorder for more than 40 years
- Heavy periods at onset (age 10)
- Bleeding and frequent bruising
- As an adult - coworkers feared she was experiencing domestic abuse
- Hysterectomy at age 37 (nearly bled out and went into shock - no one looked at why)
- After diagnosis, her 35-yr old son, grandson, sister, and niece were diagnosed

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Catherine

- Estimates more than 100 hospital visits before being diagnosed with Hemophilia B at 12 years old
- Family history of the condition
- Frequent nosebleeds and bruising
- School reported her symptoms to a general practitioner and referred her to a specialist

Hemophilia Treatment Center

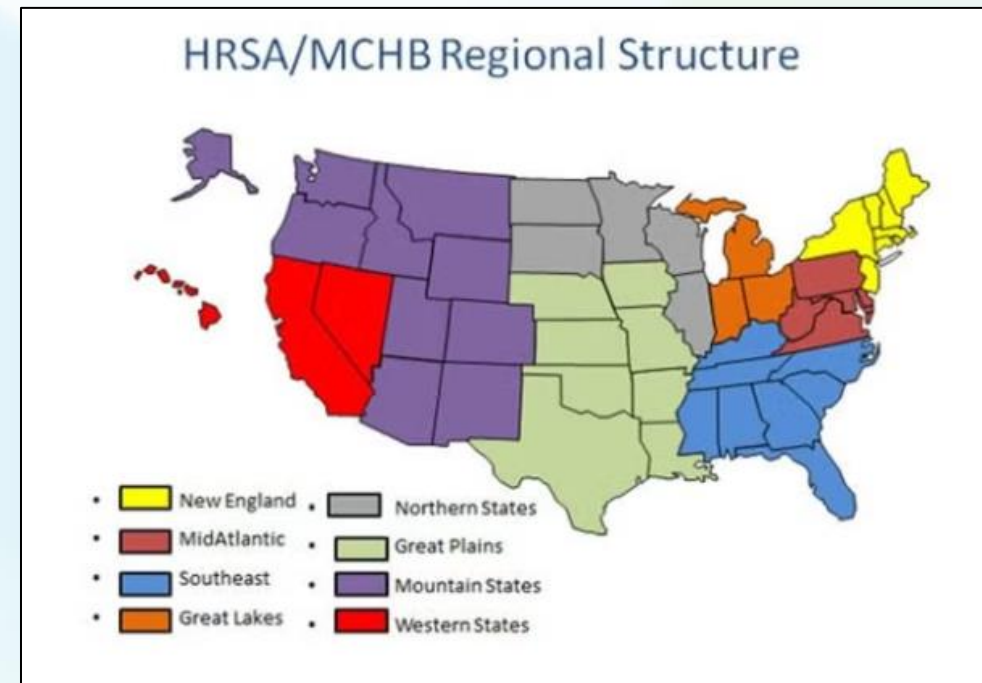
Lehigh Valley Hemophilia Treatment Center (HTC)



- State and federally funded
- 1 of 7 HTCs in Pennsylvania
- Multidisciplinary care team
 - *Hematologists*
 - *Genetic counselor*
 - *Physical therapist*
 - *Social worker*
 - *Nurses*
 - *Dietitian*
 - *Outreach specialist*

National Network of HTC's

- More than 140 Hemophilia Treatment Centers in the United States
- Supported and funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC)
- Mid-Atlantic Region III - 16 hospitals
 - *Pennsylvania*
 - *Delaware*
 - *Maryland*
 - *Virginia*
 - *West Virginia*
 - *District of Columbia*



Adult Clinic – LVH Muhlenberg



Pediatric Clinic – LVH Cedar Crest



Bleeding Disorders and Schools

Reasonable Accommodations



- An extra set of books at home or school to avoid having to carry heavy bags
- Extra time to complete assignments when absent due to hospital stays or health care provider visits
- Modified physical education

Possible Issues at Schools

- Absences
 - *May be prolonged depending on episode*
 - *Missed work*
 - *Time and rest to recover*
- Activity restrictions
 - *Informed choices about sports*
 - *Accommodations for PE as needed*
- Pain
 - *Acute*
 - *Chronic, at times*





Kids, Sports, and Exercise

Category I

Can participate safely

- Swimming
- Golf
- Walking

Category II

Benefits outweigh risk

- Tennis
- Cross county running
- Diving

Category III

Risks outweigh benefits

- Wrestling
- Football
- Field/Ice hockey

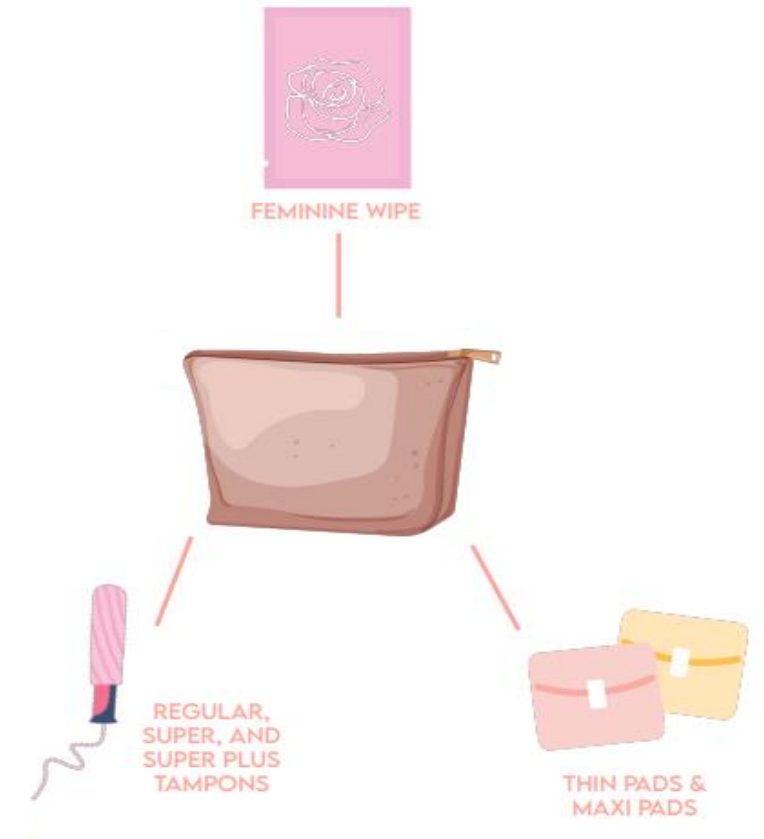
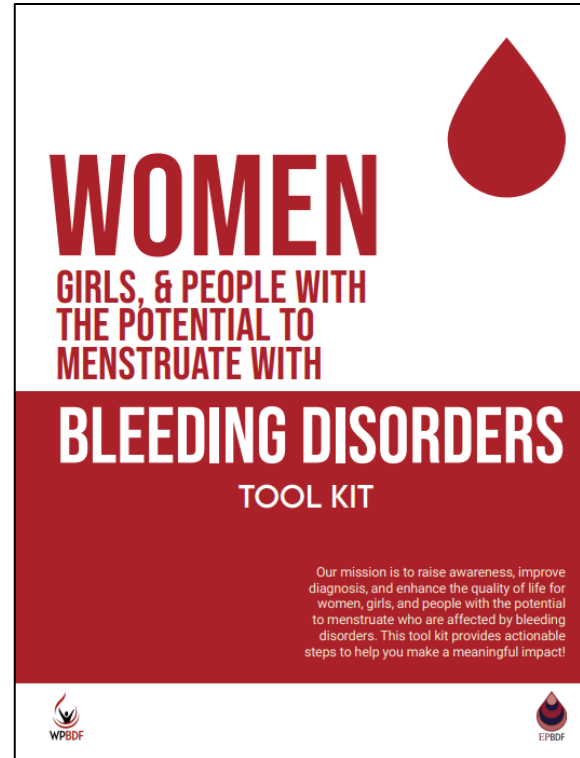
Care Coordination with Schools

- Provide a diagnosis and treatment letter
 - *Medication recommendations*
- Provide support documentation for a 504 plan
- Provide support to school nurse for questions
- Provide education to school staff
- If requested by family and school, we can provide education to teachers and students



Resources for Schools

- WGPPM (*Women and Girls and People with the Potential to Menstruate*) Bleeding Disorders Took Kit
- Period Packs



Resources for Schools

- Playing It Safe (sports and exercise)

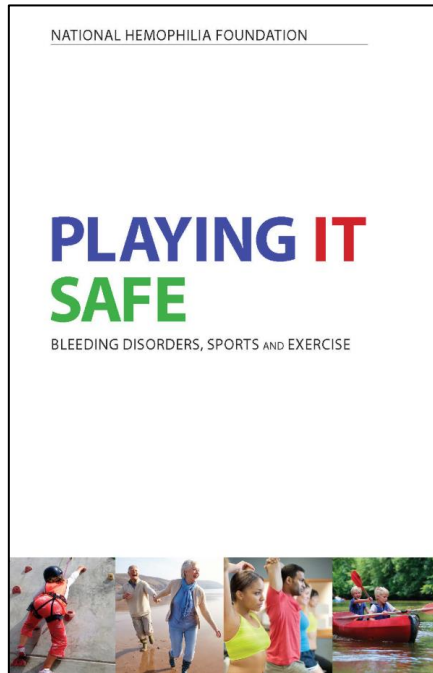


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Resources for Schools

- Nosebleed Kits
- Information FAQ



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Questions?

*Lehigh Valley Hospital - Muhlenberg
Hemophilia Treatment Center
484-884-2080, option 1*



part of  Jefferson Health

PEDIATRIC SICKLE CELL AND ONCOLOGY

L

WHAT A SCHOOL NURSE NEEDS TO KNOW

SICKLE CELL DISEASE



- When a child has sickle cell disease, their red blood cells change from the usual soft, round shape to a hard and twisted sickle-like shape. Sickled red blood cells stick together blocking the flow of blood and oxygen causing pain and other serious complications

RED BLOOD CELLS



Normal
Red Blood Cell



Sickled
Red Blood Cell

alamy

Image ID: 17144
www.alamy.com

Chronic Anemia

Chronic anemia is a fact of life in children with sickle cell disease; most adjust well and are without symptoms. However, chronic anemia may contribute to the following complications:

- Jaundice (yellowing of eyes and skin)
- Reduced stamina and endurance
- Delay in skeletal maturation
- Delayed onset of puberty

CARE IN THE SCHOOL SETTING

Be aware of the need to rest. For many children, admitting to fatigue and taking a break from sports and gym activities can be embarrassing and draw unwanted attention. While participation should be encouraged, make it easy (and as inconspicuous as possible) for the child with sickle cell disease to take regular breaks.

- Encourage the child to participate up to his level of tolerance
- Allow recovery time after vigorous physical activity
- If active participation is not realistic, give the child a duty related to the activity, such as scorekeeper

PAIN

Pain is the most common complication of sickle cell disease. It occurs when sickled cells block the flow of blood and oxygen

SIGNS AND SYMPTOMS OF PAIN

- Chest pain
- Difficulty breathing
- Fever 101 or higher
- Priapism (prolonged, painful erection)
- Nausea, vomiting
- Severe abdominal pain
- Bone pain and swelling

CARE IN THE SCHOOL SETTING

Pay attention to temperature control. Simply becoming overheated or too cold could trigger a pain episode. The child should not sit in drafts or directly in front of fans or air conditioners.

Remind the child to wear a jacket outside during cold weather or to take off a layer of clothing if it is hot

TREATMENT FOR MILD TO MODERATE PAIN

- Fluids - water, fruit juice, popsicles, clear broth, jell-o
- If pain is mild, the child should be allowed to rest and return to the classroom when pain subsides
- Analgesics as directed by the physician
- Relaxation exercises to help relieve pain (if the child is familiar with these techniques)
- Moist heat applications
- **Never apply cold packs as these could increase vessel constriction**
- If a child has a fever, phone parents immediately

HYDRATION

Allow extra water and bathroom breaks. In busy classrooms, it is not uncommon to limit water and bathroom breaks. For children with sickle cell disease, however, these rules need to be relaxed a little. The simple act of staying well hydrated can help prevent pain episodes and avoid organ damage. Children with sickle cell disease also need to take bathroom breaks more frequently, not only because of increased water intake but because their kidneys produce more urine, even when they're dehydrated

HYDRATION

- The child should be allowed to use the bathroom frequently
- A special bathroom pass should be provided, if possible
- The child should have access to unlimited fluids throughout the day
- The child should be allowed to have a water bottle or juice box in their backpack

**Phone the parent
immediately if the child
has a temperature
greater than 101**

ILLNESS

A child with sickle cell anemia will get colds, sore throats and ear infections just like other children. However, some infections can represent a life-threatening complication in these children

Fever 101 degrees or greater is
the most common symptom of
infection

Lethargy (unexplained tiredness)

CARE IN THE SCHOOL SETTING

Do not give medication for fever before checking the temperature with a thermometer

Fever in a person with sickle cell disease of 101 degrees or higher is a medical emergency

The child's family and physician should be contacted immediately

The child should be seen in a hospital (emergency room) as soon as possible

LEARNING PROBLEMS

Learning problems can affect how well children do at school and in their social lives. Children with sickle cell disease are more prone to silent brain infarctions that can result in cognitive deficits. If a teacher notices a change in a child's school performance, parents should be informed.

ACCOMODATIONS

All sickle cell patients should have education accommodations in place. Contact the social worker at the sickle cell treatment center to have and IEP or 504 plan put into place for each student.

PEDIATRIC ONCOLOGY

IN THE UNITED STATES

- About 46 children and adolescents are diagnosed with cancer every weekday
- On average, 1 in every 4 elementary schools has a child with cancer
- The average high school has two students who are a current or former cancer patients
- There are currently more than 270,000 childhood cancer survivors in the United States
- One out of every 250 young adults (<20yo) is a cancer survivor

TYPES OF CANCER

- Leukemia is the most common childhood cancer
- Brain tumors are second most common
- Lymphomas are the third most common
- Then solid tumors outside the CNS
- Neuroblastoma - neural crest derived
- Wilms - renal tumors and syndromes
- Bone tumors
- Rhabdomyosarcoma - soft tissue sarcomas

WHAT IS CHILDHOOD CANCER

Among the 12 major types, Leukemias (cancer in the blood) and brain tumors account for more than half of all cases.

- The median age at diagnosis is six years old.
- Some forms of pediatric cancer have a 5 year survival rate of more than 90%, while others have a 5 year survival rate of less than 2%

EFFECTS OF CHILDHOOD CANCER

- Many adult cancer patients endure no more than a year of treatment.
 - On the other hand, the average length of treatment for children, from initial diagnosis to cure or remission, is three years.
- If the child experiences a relapse, the treatment time could possibly be extended over many years with a potentially lowered prognosis.

IMMUNOCOMPROMISED

During and after chemotherapy, children will have lower resistance to normal childhood illnesses than other children. This is called being immunocompromised

ILLNESS

Inform the child's parent if any child in their class develops a communicable illness so they and the child's doctors can decide how to best handle the situation

VARICELLA

- Most of our children lose immunity to chicken pox due to chemotherapy/ steroids
- Chicken pox in an immunodeficient patient can be bad
- Exposure to varicella is defined as close contact for 30 minutes or more
 - This means the child with varicella would need to be in the same classroom as the oncology child
 - Brief exposure in the hallways or cafeteria is not considered a significant risk
- If exposure is confirmed, the child's parents need to be notified immediately
 - There is a 72-hour window of opportunity to give immunoglobins to the exposed child to avoid infection

RETURNING TO SCHOOL

While receiving treatment, children may return to the classroom. The following is a list of some, but not all, of the possible side effects that the student may experience

SIDE EFFECTS

- Susceptibility to infection (immunocompromised)
- Nausea or vomiting
- Hair loss
- Weight loss or weight gain (either lack of appetite or increased appetite)
- Mouth sores
- Sensitivity to the sun
- Forgetfulness
- Sleepiness
- Poor concentration or changes in cognition
- Irritability
- Hyperactivity
- Inappropriate reactions
- Regressive behaviors both socially and academically
- Acting out or Controlling behaviors
- Other physical symptoms (stomach aches, headaches, body aches, frequent urination)

FATIGUE

A child with cancer can struggle with fatigue due to the treatment. The child should be allowed to participate in activities as tolerated. They should also be offered time to rest as needed.

FEVER

- Fever criteria is a temperature of 100.4 which occurs 3 times in 24 hours, or a temperature of 101.3 or higher one time
- If fever criteria is reached, it is considered a **medical emergency** and the child needs to be seen by MD within an hour
- The child's parents would need to be notified immediately and steps should be taken to get the child to our center
- No Tylenol or Motrin should ever be given without physician approval
 - We do not want to mask a fever, which may be the only sign of infection

HANDWASHING

We strongly encourage good hand washing habits both in the classroom and out

If no sink is available in the classroom, we recommend that waterless antibacterial soap be available in the classrooms

All children should be encouraged to wash their hands after they sneeze, cough, come in from playground or cafeteria

A SUCCESSFUL SCHOOL RE-ENTRY

These children WANT to come back to school- they want to feel
NORMAL

- Need socialization
- Need to know life is moving forward
- Need to be able to fulfill their potential

They will have missed many days of school for hospitalizations for chemo/ infections, treatment side effects, weak immunity

Resuming school sends a message of hope for the future

- Can be one of the most positive milestones in a child's cancer journey

WHAT ARE CHALLENGES

“Vulnerable Child Syndrome”

- Protected
- Feelings of isolation from peers

Medication

- Multiple chemo agents have neurologic side effects that affect the way children learn
- Intrathecal methotrexate, radiation
 - Mild: More difficult time with reading comprehension, math processing
 - Severe: Loss of IQ points
- Steroids can make children moody, depressed, agitated
- Chemotherapy can make them achy, fidgety
- May have vision or hearing problems, handwriting difficulty

Low blood counts

- Anemia makes you tired, gives you headaches, poor attention

PTSD

A SUCCESSFUL SCHOOL RE-ENTRY

Concerns for the patient

- Hair-loss
- Falling behind in work
- Ongoing absences
- Less participation in sports

To help ease school re-entry for the patient

- May need to start with 2 hours or half day
- Recognize fears
- Support to wear hats
- Allow for adjustments in the classroom
 - Rest when needed
 - Snacks and water available
- Pain and nausea medications available

A SUCCESSFUL SCHOOL ENTRY

- Gaining acceptance and support of peers is critical
- To help ease school re-entry for classmates
 - Reassure classmates when absences occur
 - Expect Normal reactions
 - Fear of disease, fear of friend's death
 - Leads to confusion
 - Leads to avoidance
 - Leads to anger
 - Leads to bullying
 - Leads to isolation

ACCOMODATIONS

- Accommodations for cognitive problems
 - Multi-sensory instruction methods
 - Aural vs written instruction/ books
 - Oral vs written tests
- Accommodations for organization and study skills
 - Instruction in study skills
 - Provide homework diary
 - Check in regularly with child and family

ACCOMMODATIONS

All pediatric cancer patients should have education accommodations in place. Contact the social worker at the pediatric cancer center to have an IEP or 504 plan put into place for each student.



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