

LIVING WITH HEMOPHILIA:

PRACTICAL TOOLS TO HELP MANAGE LIFE IN TODAY'S BUSY WORLD

Talking Points for the School Visit

Parents that are knowledgeable about their child's hemophilia can easily educate school staff at the beginning of each school year. If the child experiences a major health problem requiring extended absences, changes schools or the school requests a more formal presentation, contact your HTC nurse to arrange a visit.

The school nurse may be assigned to other schools. Arrange your visit on the day that the nurse is at your child's school. Also, the principal, school secretary, teachers, coach and bus driver should be present.

Speak with authority!

Remember, you know a lot more about hemophilia than your audience; even if they are educators. The following "talking points" are for your review before your presentation. Devise your own outline and remember to tell positive personal stories to spice up your presentation.

Introduction/Background

- Start by telling a bit about your son's hemophilia experience. Reinforce that all bleeding episodes are treatable.
- Give the school a detailed contact list and assure them that you will respond if called by the school.
 - Assure the school that you expect them to call frequently at first until they feel comfortable with your child's hemophilia.
 - Give them a copy of *NHF's The Child With A Bleeding Disorder: First Aid for School Personnel Brochure* with the *Important Phone Numbers* section filled out.
- Define hemophilia: a congenital bleeding disorder. The child is born missing one of the necessary clotting proteins. Your son's hemophilia is factor _____ and his severity is _____, meaning his bleeding pattern is _____ (frequent, moderate or infrequent).
- Hemophilia is rare.
 - One in 7,500 boys has hemophilia.
 - Note: The school may never have had another child with hemophilia. It is understandable that they may not have much information about hemophilia. (This statement relieves the educators). Hemophilia affects all races and nationalities.
 - It is inherited. The mother is the carrier and the gene is on the sex chromosome which is why boys, primarily, are affected. Don't get bogged down by drawing out the inheritance tree.

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Introduction/Background (con't)

- Bleeding is mostly internal: in the soft tissues, muscles or joints.
- Bleeding is of a slow, oozing nature.
 - Important to explain the school always has time to contact you and you will arrange treatment. It is important, however, to notify you once bleeding is recognized.
 - The school should not wait until the end of the day to call you.
- Your son understands his hemophilia (depending on age and grade) and knows to tell the teacher if he is experiencing bleeding (or not).
- Explain the treatment:
 - It is replacement of the missing clotting protein.
 - Treatment through intravenous infusions of commercially prepared factor concentrate (at home or the ER).
 - You may want to talk about recombinant products – not made from blood which assures no infection transmission.
- Your child calls his factor concentrate “_____”. This is important for the teacher to know as he may talk about receiving therapy.
- If your child self-infuses, speak to the school about his keeping factor concentrate in the school infirmary.
 - Talk with the school nurse about assisting/observing your son with his infusions.
 - Your HTC can provide a letter about his competence, dosage and provide infusion records.
 - Self-infusing will allow your child to return to class sooner.
- If you wish to infuse your child at the school, speak to the school nurse about storing factor and infusion equipment at school.
 - Note: If you can infuse at school your child can return to his classroom sooner.
- You will send a note if he received an infusion at home or in the ER the evening before so the teacher will know that he needs to avoid PE or running (you will specify in the note).

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What to do if there is a Bleed.

Important: Ask about the school policy for dealing with blood spills. They should discuss use of gloves, cleaning solutions and disposal.

The school should call you if they suspect soft tissue, muscles or joint bleeding so you can arrange treatment. Until you arrive they should use, R.I.C.E (refer to handout).

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|-----------------|--|
| - R-rest | Keep him quiet |
| - I-ice | Apply an ice pack to the bleeding area |
| - C-compression | If possible, wrap the area with an ace bandage |
| - E-elevation | Prop the limb up on a pillow |

- It is not necessary for the teacher or school nurse to check your child daily for bleeding signs or symptoms. However, they should be on the look-out for:
 - Limping
 - Guarding
 - Holding a limb to the body
 - Change in behavior
- Joint bleeds may be your child's most frequent type of bleed. The teacher should watch for swelling, warmth, redness, and tenderness at the joint.
 - She/he should put hands on both elbows, for instance, to measure warmth and swelling. It will be easier if this comparison is done.
 - Muscle or soft tissue bleeds can be seen with swelling, warmth, redness and tenderness over the area.
 - Bleeding from a cut or scrape can be controlled by direct pressure and band-aid application.
- Mouth bleeding is uncommon but may be seen if a loose tooth is knocked out or if he bites his lip or tongue.
 - Apply a popsicle to the mouth. (apply pressure. bite on a wet tea bag.)
- Nosebleeds are uncommon.
- Hold the head midline or down (not tilted back).
- Hold pressure on the side of bleeding for 20 minutes.
- The most concerning injury is head trauma!
 - Describe the type of trauma that may cause brain bleeding---a blow to the head, falling onto a hard surface head-first, etc.
 - There may be no raised lump even after significant head trauma. The "head" includes anything from the neck up. Any neck swelling should be reported.
- You must be notified immediately for head injury. You will arrange transport and treatment.
 - Signs of increased intracranial pressure are: headache, nausea or vomiting, drowsiness, confusion, visual changes, loss of consciousness.

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- Another concern is abdominal trauma. Describe the type of trauma that may cause abdominal bleeding---falling over bicycle handlebars, being punched in the stomach, etc.
 - You must be notified immediately for abdominal injury. You will arrange transport and treatment.
- It is less threatening to the school personnel if you describe bleeding episodes in this order rather than begin by discussing head bleeding, which is less common than joint or soft tissue bleeding.
- Remind that there are no special medicines or diet that your child needs to follow. Talk about his inability to use aspirin and why---it prolongs the bleeding time in all of us.
 - If your child may need to take pain medication mid-day in order to stay in class all day, arrange with the school for a supply of Tylenol for him with clear directions. The same for Amicar if he is using this after oral bleeding.
- Bruising is common but does not require a treatment.

Fitness in School Setting

- Talk about the importance of exercise. The stronger his muscles, the better joint support and less bleeding.
- Discuss safe play activities and sports.
- Talk about using safety equipment—helmets, padding, high-topped shoes---so your son may participate fully.
- Discuss potential sports that are too dangerous for your child such as tackle football, wrestling, boxing because of possible head injury.
- Encourage the PE teacher and coach to allow your child to play and become competent in as many sports and activities as possible.
- Remind them that boys socialize through sports and play.

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Additional Important Talking Points:

- If your child is on prophylaxis, explain this briefly and state that this allows him to exercise and play more fully.
- While recovering from a bleeding episodes, your child may need to be excused from PE for a time. You will send a note about this.
- Your child may attend school on crutches, in a sling or splint for a brief period.
 - Accommodations should be made to assist him in carrying books, lunch trays and use of an elevator (if available), assistance boarding the school bus and time to safely change classes.
- If school is missed due to a recovery period, arrange to get his assignments and help him make up missed school work.
- Realize that the child may feel “different” being the only one in school with hemophilia. Help him develop a brief explanation of hemophilia for his friends and teachers.
- Talk with his teachers about allowing the child to disclose about his hemophilia only to those he wishes. There should be no general announcement to the class by the teacher.
- The teacher should not say hemophilia is the reason he should not be hit. Hitting is not acceptable for all.
- Ask the teacher to report teasing to you so you can help your son deal with it.
- If the child wishes, ask the school to help him develop a science project, for instance, that can help him explain his hemophilia to the class.
- Preferential treatment by the teacher to your child because of his hemophilia may be harmful to normal social development.
- Remind the school staff that it is important that your child receive a complete education as some manual labor jobs will be off limits to him. Career planning is an important part of his educational process.

Note: This long list does not need to be fully discussed with the school staff. It is given to you to stimulate the discussion about hemophilia. Remember to avoid using medical terminology. Sprinkle your talk with anecdotes about how you handle situations at home. This may help your school to become comfortable with hemophilia.

Best wishes for your school visit!