STUDENTS WITH BLEEDING DISORDERS

This guide is meant as a starting point for discussions about how to best address the unique healthcare needs of students who have a bleeding disorder. It is important that YOUR hemophilia treatment center (HTC) be involved in these conversations from the start so that – together – you, the HTC team, and the school staff can appropriately address your child’s individual needs.

Step 1: Nursing Assessment

Should include but not be limited to:

1. **Identifying Information / Contact Information**
   - Name of parent/guardian, address, phone, and emergency contacts
   - Name and phone number of primary care provider
   - Name and phone number of hemophilia care provider

2. **Personal Health History / Hemophilia History**
   - Family history of hemophilia
   - Initial diagnosis, progress of disease
   - Concurrent medical conditions
   - History of hemophilia emergencies, hospitalizations, ER visits
   - Number of days of school missed in the past year
   - Limitation of activities
   - Physical Education restrictions
   - Recess activities restrictions
   - Student awareness of symptoms of excessive bleeding
   - Complications (target joints, inhibitors, etc.)
   - Other medications in addition to factor
   - Need and regimen for prophylactic factor
3. **School Hemophilia Management**
   - **Factor Concentrate**
     - Brand name
     - Dose, frequency, indications
     - Method of administration
     - Storage of factor at school
   - Administration of factor at school
     - How dose is administered (i.e., port or other device, peripheral infusions, etc.)
     - When factor will be administered at school
     - Self-administered by student – amount of supervision required
     - Administered by school nurse (Is it an option? Not all school systems will do this)
     - Administered by parent or visiting nurse
     - Ancillary supplies needed
   - Equipment used (i.e., crutches, wheelchair, etc.)
   - Student’s level of understanding and independence
   - Access to the school nurse’s office (i.e., case-by-case basis, permanent pass for the year)
   - Student’s medical alert identification such as bracelets, necklaces, shoe tags, etc.

4. **Educational Information / Considerations**
   - School performance, grade level
   - Need for 504 plan or IEP (see separate handout with more information on 504s and IEPs)
   - Participation in special programs (i.e., field trips, school-sponsored activities, evening high school, alternative education program, work study, vocational programs, etc.)
   - Transportation issues (in general, a student with hemophilia should not require special transportation, but each student’s needs should be evaluated individually)
   - Availability and location of emergency supplies

5. **Psycho-Social Considerations**
   - Family status, support available
   - Family stresses and student’s concerns
   - Student’s and family’s understanding of the condition and ability to cope
   - Developmental issues
   - Disability awareness and/or bleeding disorder education to be provided to peers
   - Involvement in community support groups
   - Issues related to access to health care and hemophilia supplies, health insurance needs, any additional resources
   - Cultural issues
   - Adherence with hemophilia management plan
Step 2: Individual Healthcare Plan (IHP or IHCP)

- A formal written agreement developed through a collaboration by the school staff, the student’s family, and the student’s health care provider(s)
- Identifies your child’s health needs, and creates solutions to potential health problems that can occur in a school environment
- Provides a safe environment that helps your child learn and makes goals for your child’s healthcare
- The plan should address both routine and emergency care
- The plan should document what steps to take if the nurse is not available as well as what interventions the nurse will provide
- The plan should outline any classroom accommodations that may be needed, as well as guidelines regarding participation in PE, recess, field trips, etc.
- The plan should include information related to training school staff and educational planning

"Hallmarks" of a Good Individual Health Plan
Contains information, guidelines & standards that promote a student’s health & educational goals.
Avoids unnecessary risk, restriction, stigma, illness & absence.

Step 3: Emergency Care Plan
(Some schools may include the Emergency Care Plan as part of the Individual Healthcare Plan)

- Types of injuries – when to call parents, when to call the HTC, when to call 911
  - Explain the difference between joint bleeds, muscle bleeds, soft tissue bleeds, mucous membrane bleeding
  - Emphasize areas that require immediate attention: head trauma, blow to neck or abdomen, eye injury
  - Educate on the signs and symptoms of a head bleed, which in rare cases can happen without known trauma or external manifestations
- Treatment of bleeds
  - Explain the difference between early onset symptoms and late onset symptoms
  - Emphasize the importance of early treatment
  - Obtain orders from the student’s health care provider on appropriate Medication Authorization Form – parents should be responsible for providing the completed forms to the school
  - Identify a clearly marked location/storage of medication and equipment
- The school should provide the following:
  - Sharps container and gloves
  - Locked storage for medication and equipment including refrigerator for the factor if requested
- The parent/guardian will provide when needed:
  - Medications and all supplies for intravenous infusion
  - Student’s medical alert identification such as bracelets, necklaces, shoe tags, etc.
  - Protective gear such as helmets, knees and elbow pads
Step 4: Misc.

- Field Trips / School Sponsored Activities
  - All students have the right to participate – participation cannot be denied because of the need for medication/treatment or requirement of additional assistance
  - If a field trip is planned, the teacher should give two weeks-notice to the school nurse so that a plan can be put into place for the student. The plan should always include factor and emergency supplies
  - In some cases, a nurse or parent may be needed to accompany a student
  - Prior to the field trip, the school nurse should provide to the teacher/staff member in charge copies of the student’s care plan

- Staff Training - training of appropriate staff should include:
  - Definition of Hemophilia
  - Confidentiality
  - Symptoms to report to the school nurse
  - Field trip and school sponsored activity accommodations
  - Physical activity or PE restrictions
  - Staff roles in the implementation of the Emergency Protocol Plan
  - Student’s functional limitations
  - Available resources

- Evaluation
  It’s an ongoing process and should include the following:
  - Orders reviewed with family and health care provider annually and as necessary
  - Documentation of medications and treatments given
  - Communication with the health care provider and family
  - Need for staff training
  - Effectiveness of the plan to meet the student’s health and educational needs at a minimum of every two to three months
  - Assessment and documentation of student’s response to the management plan at a minimum of every six months.


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