



The Student With A Bleeding Disorder

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Historically, school absences have been an issue for students with severe hemophilia. Frequent absences can result in reduced educational opportunities now and in the future which may impact graduation and employment opportunities and produce lower self esteem. (1) The causes of absenteeism for students with hemophilia are multifocal. While poorly treated joint bleeding is a main cause of absenteeism, (13) other factors such as pain, logistics, and lack of knowledge regarding resources, as well as parental fear of injury and social isolation, contribute to this problem. With advances in treatment and federal laws mandating services for all persons from birth to age 21 who have a disability and/or chronic illness, all children with bleeding disorders should have access to education. (6,7,8,11) Both parents and healthcare providers must advocate to develop and implement specific programs at school to meet the individual needs of these children and to clear up misconceptions about bleeding disorders for school personnel. This chapter focuses on the role of the bleeding disorders nurse in helping parents, the student with a bleeding disorder, and school personnel to work together to provide a productive school experience.

PREPARING FOR SCHOOL

In the United States, the average school-age child spends 28% of the day in school. (8) Of these children, 12.8% have a special healthcare need, which translates to an estimated 9.3 million children nationally. (15) When a child with a bleeding disorder starts school for the first time or changes schools, the treatment center nurse plays a critical role in helping school personnel, as well as other students and parents, become educated about the child's disease, how it could impact the child's school life, what precautions should be taken, and what systems should be in place to deal with a medical emergency. (12) In addition, the bleeding disorders nurse should explain that the vast majority of children with bleeding disorders do not suffer from any developmental disabilities as a result of their condition and that school provides an arena for achieving success, socialization, and identification of one's role as an important member of society, regardless of whether that person has a bleeding disorder. (1-3)

It would be optimal if, before the child goes to school, a meeting with school officials including the school nurse, the hemophilia treatment center (HTC) nurse, and the parents could take place. Ideally, this meeting should take place prior to the start of the school year but no later than the end of the first month of school. Often, however, telephone communication must suffice when face-to-face contact cannot occur. The goal of this meeting should be to provide information to the parents about school policies, to educate school staff about bleeding disorders, and to create a working relationship among all parties. Parents will feel more comfortable sending their child to school knowing that there is a support system in place. School personnel can allay their own

fears and better foster the child's education if they know what to expect and how to deal with potential problems that may arise.

Before meeting with school personnel, the HTC nurse may want to inquire about the services the school provides. For example, does the school have a full- or part-time nurse? If the nurse is not at the school on a full-time basis, who handles medical emergencies when the nurse is not available? Who has been assigned the task of calling the parent and/or initiating a call to 911? Does the school have a medication refrigerator or storage cabinet for storing factor for infusion by parents or the child in the event of a minor bleed? Can the child or parent infuse at the school? Is there someone who can supervise a child infusing without a parent being present? This information can be obtained from discussions with parents and school staff.

It is recommended that the HTC nurse discuss parents' concerns, preferences for making up schoolwork, emergency contacts, etc., with the parents prior to discussing the plans with the school. This dialogue will ensure that the nurse and the parents agree on the student's plan of care, which will make the meeting with the school personnel flow smoothly. When discussion of the student's abilities and limitations is necessary, emphasis must be placed on what the student can do rather than what he/she cannot do. While parents are often anxious about their child going to school and entrusting their child's safety to others, school personnel can be more anxious than the parents, since they may never have had a child with a bleeding disorder in the school. In the event the parent cannot attend the meeting, the nurse can answer questions about the disease in general without a release, but he/she should seek the parents' consent so that the discussion can be tailored to the individual student's needs.

It is important for HTC staff to dispel myths and to provide accurate information about bleeding disorders. For example, educators often need reassurance that children with bleeding disorders (1) do not bleed to death from cuts or scratches, (2) rarely experience external bleeding (and usually only after trauma) and (3) typically bleed into joints and muscles, bleeds that are not life threatening. However, the potential for life-threatening bleeding episodes should be defined. Educators need to be informed of the child's use of medication. (7) They also need to have knowledge of over-the-counter medications to avoid in children with bleeding disorders. Some over-the-counter medications, such as non-steroidal anti-inflammatory drugs (NSAIDs) or aspirin-containing products, prevent the platelets from sticking together to form the initial clot after a bleed and should not be given to a child with a bleeding disorder. (7)

Contact with the school may take the form of written, telephone, or face-to-face contact with teachers, support staff, administrators, and nurses at the child's school. Due to right-to-privacy issues, the HTC nurse must obtain a signed written release at the start of the school year prior to providing information to school personnel about a child with a bleeding disorder.

For more information on planning for and conducting meetings with parents and school staff, consult *The Student with Hemophilia—Teaching Strategies and Hemophilia and School: Developing an Individualized Healthcare Plan (IHP)*, developed by the Nurses' Working Group of the National Hemophilia Foundation (NHF).

THE PARENTS

Parents or legal guardians need to communicate with school personnel and the HTC about integrating their child into the school environment. Parents need to investigate what services the school district provides, methods of obtaining services, and the significance of individualized educational plans (IEPs). (3, 4) Parents should also inquire about accommodations for students with crutches or wheelchairs or when an extremity should need to be elevated in the classroom.

The bleeding disorders nurse and other members of the HTC team should establish a dialog with families regarding their child's performance in school during clinic visits and through telephone contacts. Parents are the bridge between the child and his school. They are ultimately responsible for encouraging their child to keep his commitments in the classroom and for keeping teachers abreast of any health changes that affect their child's ability to perform in the classroom. (3) Notifying the school of resolving bleeds may alleviate a teacher's/school nurse's concern when a child is not completing classwork or is reluctant to participate in other classroom activities. In the rare situation where a teacher suspects that a child may be using his bleeding disorder as an excuse not to complete work or participate in other classroom activities, the child's parents should be called and the teacher's/school nurse's observations discussed in a non-threatening manner. It is important to remember that children will be children and that manipulation is a coping mechanism which may sometimes be used in school. Discussion with parents will allow the teacher to express concerns while allowing the parents to sort out the behavior and determine if a bleed needs to be treated or if there are other circumstances causing the behavior.

Schools should also be informed if a student has a central line, such as a port or broviac, in place. Any restrictions or special precautions for these children should be discussed with the school nurse, physical education teacher, and other pertinent school personnel. Parents may also wish to inform the school if their child is on prophylaxis or has an inhibitor, along with a brief explanation of what that means.

It is best to be up front about the potential of missing class due to bleeds and comprehensive clinic appointments. Teachers may be able to offer assignments ahead of time so that they can be turned on the next day that the child attends school.

THE STUDENT

School helps children master each developmental stage. Children with bleeding disorders need to be involved in an age-appropriate manner in those decisions that impact their ability to attend school and participate in school activities. The child needs to be instructed and encouraged to seek help from school personnel when he or she starts to develop symptoms of a bleed. The HTC nurse plays a critical role in helping children understand their condition as well as correcting knowledge deficits and misconceptions about bleeding disorders. A child who understands the necessity of treatment of bleeds will seek treatment for bleeding episodes more quickly. Students must also understand their responsibility to teachers to complete assignments and be honest when bleeds prevent them from doing so in a timely manner. Parents, teachers and students must communicate and work together to ensure that assignments are completed in as timely a manner as possible.

SCHOOL STAFF

The school should provide reasonable protection for all students. If students are injured, the initial treatment and use of universal precautions for a child with a bleeding disorder is the same as for all students who injure themselves at school. The teachers need to be aware of normal safety measures, bleeding symptoms, and whom and when to call in case of a problem. School personnel should understand that it is not their responsibility to “diagnose” a bleed but rather to call the designated emergency contact when the child complains of pain or is not acting “right,” or if a possible injury has occurred. It is imperative that schools respect all students’ privacy and not single them out regarding their diagnosis or any apparatus they may need in school.

Additionally, for the child with a bleeding disorder, school personnel must understand the social, physical, academic, and emotional ramifications of a bleeding disorder. (1, 5, 6)

Educators must also have a plan for managing various types of injuries. Teachers who are made aware of the circumstances that put these children at risk for a bleed can make creative and appropriate adjustments in activities on behalf of the student. (8) It is also vital to help teachers understand that they should believe the student with a bleeding disorder when he or she reports any symptoms of a bleed and follow through with appropriate treatment or a telephone call to the emergency contact.

The school nurse must recognize signs of a bleeding episode, such as a child who holds an affected area or limb and demonstrates signs of discomfort or pain, warmth and/or swelling, and decreased range of motion accompanied by pain.

Initial treatment for an open wound requires standard first aid care such as cleaning the area and applying pressure and a dressing following universal precautions. For a closed bleed such as a joint bleed or traumatic injury, ice should be applied to the affected area to decrease pain, swelling, and hemorrhage. In either scenario, school personnel should immediately contact the child’s parents and/or the hemophilia treatment center. In the case of a severe blow to the head, neck, chest, or abdomen, 911 emergency services should be contacted if there is any question about the severity of the injury.

AREAS OF EDUCATION AFFECTING CHILDREN WITH BLEEDING DISORDERS

Three areas of education may need to be addressed: (1) academics, (2) physical education, and (3) extracurricular activities such as field trips, all of which may require ongoing attention.

Academics: Multiple studies have shown that children with a bleeding disorder are not cognitively impaired by their disorder but may demonstrate discrepancies between their intellectual potential and academic achievement. Such children continue to have unmet educational needs. These needs may be due to absenteeism or to continued pain associated with bleeding episodes despite having received factor replacement therapy at home, both of which have an effect on academic and social adaptation of these children. (9, 12, 13)

Four federal laws have had a direct impact on options available to children with bleeding disorders and their families: Public Law 101-476, Education for Individuals with Disabilities

Education Act (IDEA) 15; Section 504 of Public Law 93-112 16, The Rehabilitation Act of 1973, and Public Law 101-336, The Americans with Disabilities Act. Briefly, PL 101-476, which in 1991 reauthorized PL 94-142, Education for All Handicapped Children Act of 1975, requires that children be educated in the least restrictive environment. (6,7,10,11) It also provides that parents of children who have disabilities such as hemophilia are entitled to one of the following: an Individual Education Plan (IEP) for children aged 3 through 21 years, or an Individual Family Service Plan (IFSP). These plans outline those services necessary for each child to receive the most from their educational experience. They are good for one year and provide due process provisions for redress of grievances through the state educational system or civil courts. Under these plans, schools must provide services for identified needs, which include administration of medications (currently believed not to include factor replacement), speech therapy, occupational therapy, physical therapy, and vocational training. Services provided as part of an IEP may not unreasonably preclude the student from interactions with other children who do not have a disability.

In addition to services under PL 94-142, children with bleeding disorders, whether or not they qualify for an IEP, may qualify for services under Section 504 of PL 93-112. Section 504 prohibits discrimination based on disability in federal and federally assisted programs. Under Section 504 modifications, children with chronic diseases and disabling conditions are entitled to appropriate modifications to accommodate their special needs in their educational program. This mandate for supplemental services is independent of whether a child is receiving education in regular or special educational classes. These services may include counseling, psychological testing and evaluation, physical and occupational therapy, and medical services. The level of services provided by a 504 modification plan can vary from school system to school system.

The American with Disabilities Act of 1990 (ADA), PL 101-336, guarantees all persons with a disability the right to equal opportunity in employment, public accommodation, transportation, telecommunication, and other (local) governmental services. This law is particularly helpful in transitioning older students into the adult work environment. (1, 7)

The newest federal law, PL 108-446, became law on July 31, 2005. New provisions clarify that the transition process for a student with a disability now begins at age 16. It also provides that whether a child is transferring schools in the same state or between states, the child's previous IEP will be valid. This provision helps parents of transferring students know what they can expect from their new schools. (10, 11)

In the event of illness, injury or surgery, the school system may offer services to help the child keep up with schoolwork while in the hospital or at home. Some jurisdictions have in-home tutoring programs that provide teachers to homebound students while they are recuperating from an illness or surgery. To learn about the enrollment process, parents should contact the school or the local Board of Education. The HTC nurse and parents need to be aware of these services and initiate a request for such services when coordinating an inpatient hospital admission. By enrolling children in these programs at the start of the school year, students should not have to fall behind in schoolwork due to unexpected illnesses, injuries or planned surgeries that prevent them from attending school.

Physical Education: Physical education and athletics are a major part of the school experience. (16) Participating in a regular exercise program and sports develops an awareness of one's body and its limitations, enhances relationships with peers, and promotes self-esteem. (17, 18) Adult supervisors of physical activities need to be aware of medical information relevant to a child's ability to participate in physical activities.

A child's ability to participate may change due to bleeds, development of target joints or an inhibitor, or recent surgical procedures. Schools should be notified of the event, resulting restrictions, and anticipated duration of the limitations. The HTC nurse is often the liaison between the school and the family to discuss the plan and any temporary or permanent modifications for PE. When children cannot fully participate in physical education classes, HTC nurses should encourage schools to involve the child in some other form of participation such as team captain, coach, scorekeeper, equipment manager, or other participant in the activity.

Contrary to many prior beliefs about hemophilia and bleeding disorders, regular safe exercise is important to maintain healthy joints and prevent joint bleeds by strengthening surrounding muscles and maintaining a healthy weight. (19) Additionally, participation in sports promotes positive self-esteem through recognition from team members and coaches as well as allowing children with hemophilia the opportunity to socialize with their classmates and peers.

Before any decisions are made regarding sports, children with hemophilia need to be evaluated by a physician with the appropriate knowledge and experience to assess the safety of a given sport for the child. The physician considers the severity of the hemophilia, age of the child, previous bleeding history, the nature of the sport, and the types of injuries associated with play. Other factors impacting the decision to recommend or discourage an activity include the child's emotional maturity, judgment, and physical maturity.

Generally, there are two types of injuries sustained by individuals who participate in sports: overuse injuries and acute injuries such as contusions, sprains and strains. (20) Overuse injuries occur when repeated micro-trauma causes chronic inflammation of a joint or muscle. Acute injuries result from direct impact or micro-trauma due to contact with another person or an inanimate object such as a baseball or from blows to the body when one falls and hits the playing surface. (21) These injuries can be more severe in a student with hemophilia. It is important to remind school staff not to dismiss an injury as a simple injury or bleed when it could also involve a more serious injury such as a fracture or ligament tear. Parents should be notified of such an injury and the circumstances so they can seek medical intervention if needed.

The physician, the parents and the child must weigh the advantages and risks associated with participation in an individual sport. (22) The American Academy of Pediatrics has devised a list of sports and categorized them according to likelihood for contact or collision (Table 1). (22) The differences between contact (e.g., football and lacrosse) and collision sports (e.g., soccer and basketball) pertain to the intent and force with which an athlete in the sport hits or collides with another athlete or an inanimate object. Sports in which participants have limited contact with other players and objects can be as dangerous as sports in which collisions occur on a regular basis. While serious injuries can occur from non-contact sports such as weight lifting, these

injuries often relate to overuse rather than to collision or contact with persons or inanimate objects.

The nature of the bleeding disorder and the degree of injury affect the recovery process and the speed at which one can return to a sport. Safety devices such as helmets for bicycling help reduce the incidence of injury. Sport activity forms signed by the physician and parents can help identify appropriate sports activities, level of competition, and protective equipment required for play. This comprehensive plan should include a physical conditioning program such as warm-up and cool-down exercises. Recommendations should be reassessed regularly and may change as the child with a bleeding disorder grows older and play gets rougher. (20)

TABLE 1 Classification of Sports According to Amount of Contact (22)

Contact	Limited Contact	Non-contact
Basketball	Adventure racing ^a	Badminton
Boxing ^b	Baseball	Bodybuilding ^c
Cheerleading	Bicycling	Bowling
Diving	Canoeing or kayaking (white water)	Canoeing or kayaking (flat water)
Extreme sports ^d	Fencing	Crew or rowing
Field hockey	Field events	Curling
Football, tackle	High jump	Dance
Gymnastics	Pole vault	Field events
Ice hockey ^e	Floor hockey	Discus
Lacrosse	Football, flag or touch	Javelin
Martial arts ^f	Handball	Shot-put
Rodeo	Horseback riding	Golf
Rugby	Martial arts ^f	Orienteering
Skiing, downhill	Racquetball	Power lifting ^c
Ski jumping	Skating	Race walking
Snowboarding	Ice	Riflery
Soccer	In-line	Rope jumping
Team handball	Roller	Running
Ultimate Frisbee	Skiing	Sailing
Water polo	Cross-country	Scuba diving
Wrestling	Water	Swimming
	Skateboarding	Table tennis
	Softball	Tennis
	Squash	Track
	Volleyball	
	Weight lifting	
	Windsurfing or surfing	

a. Adventure racing has been added since the previous statement was published and is defined as a combination of 2 or more disciplines, including orienteering and navigation, cross-country running, mountain biking, paddling, and climbing and rope skills. (1)

b. The American Academy of Pediatrics opposes participation in boxing for children, adolescents, and young adults. (2)

c. The American Academy of Pediatrics recommends limiting bodybuilding and power lifting until the adolescent achieves sexual maturity rating (Tanner stage V). (5)

d. Extreme sports have been added since the previous statement was published.

e. The American Academy of Pediatrics recommends limiting the amount of body checking for hockey players 15 years and younger to reduce injuries.

f. Martial arts can be sub-classified as judo, jujitsu, karate, kung fu, and tae kwon do; some forms are contact sports and others are limited-contact sports.

g. Orienteering is a contest in which competitors use a map and a compass to find their way.

Extracurricular activities: The nurse coordinator and the parents may need to address activities such as school transportation, class field trips, and before- and after-school care. For example, what type of transportation will be used to take the child to and from school? Parents often have concerns about school bus safety and what information they need to give the school bus company. On field trips, decisions need to be made about transporting factor and supplies in the event of an emergency. Some parents circumvent these problems by giving prophylaxis on the day of the event, transporting their child to school, and volunteering as chaperones on class trips. Parents need to be aware that before- and after-school programs may not be run by the school but by an outside contractor who will also need to be educated on issues related to hemophilia.

CONCLUSION

To prevent or allay potential obstacles to learning and to provide a positive learning experience for a child with hemophilia, planning and education are essential. Obstacles may include the student's own fear, parental anxiety, and educators who lack knowledge and understanding about hemophilia. The hemophilia nurse coordinator plays a pivotal role in helping students with bleeding disorders adjust to the school environment, decreasing parental fears, and educating school personnel on the implications of hemophilia and the need to provide a safe educational experience for the child.

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