Child Development with a Bleeding Disorder and Transition

Maribel J. Johnson, RN, MA
Jocelyn Bessette Gorlin RN, MSN, CPNP

A chronic bleeding disorder, such as hemophilia, von Willebrand disease, other factor deficiencies, or platelet abnormalities, can influence a child's development. The family's level of understanding of normal child development and their interventions with the child at each age can either enhance or hinder the child's development. In addition, it is important for families to understand from a cognitive standpoint how a child comprehends his bleeding disorder. A child's proper understanding of the bleeding disorder can potentially influence his ability to identify the need for treatment, administer treatment and ultimately affect his future.

This chapter describes the progression of developmental skills from birth through adolescence. The first section is divided into five major parts, based on the five phases of development: infant, toddler, preschool child, school-age child, and the adolescent. In each age group, various parameters are discussed. Personality and cognitive development as well as motor, social, and language development are summarized. Additionally, special considerations for the child with a bleeding disorder are included in each age group. New in this edition are two additional sections: Teaching Children about Bleeding Disorders and Transition Issues.

There are two concepts to review before beginning this chapter. First, the developmental process is unique for every individual, and although the sequence of developmental events is similar from child to child, the "normal age" for the appearance of a particular skill can vary widely. Second, children with bleeding disorders and their families theoretically progress through the same developmental phases as those with normal clotting parameters, although the rate may be altered.

We hope that providing this information will help you to promote optimal understanding and development of the child with hemophilia or another bleeding disorder. In this way, children can reach their potential as they progress from birth to adolescence to become generative members of their family and society.

[Authors' note: When referring to the child we will refer to the child in the male gender (he/him/his), although we may actually be referring to both male and females. Likewise, "the parent" can refer to one or both parents and/or caregivers.]

INFANT: THE FIRST YEAR

PERSONALITY DEVELOPMENT

The psychoanalyst, Erik Erikson, lists eight overlapping stages of personality development that begin at birth and continue through old age. During the first two years of life, the development of trust is vital. If the child feels accepted and wanted and is fed, comforted and kept warm and

dry, he will develop a basic trust in the parents and the environment. Gradually, the child learns that even when the parents are out of sight, they continue to exist and can be trusted to return.

COGNITIVE DEVELOPMENT

Jean Piaget, philosopher and psychologist, stated that children of different ages have different qualities of thinking and, therefore, uniquely different ways of solving problems. Until the age of two, a baby is not able to plan or intend for events to happen, and only that which can be seen, heard, or touched is real. The baby learns most if he has a stimulating environment and responsive caretakers. Starting from the age of three or four months until the child learns to crawl, the use of an infant seat and baby carrier will help broaden the infant's world. Infant seats can be moved from room to room so that the infant can watch the mother or other family members. Infant carriers and colorful mobiles also expose infants to new and stimulating things.

By six months, the child recognizes that he is separate from the primary caretaker, and the 12-month-old realizes that his mother and his bottle exist even when they are out of sight. Playing peek-a-boo is fun and helps the child develop this concept.

MOTOR, SOCIAL, AND LANGUAGE DEVELOPMENT

THE NEWBORN

At birth, the newborn has very little motor control and is dependent on the parents for almost everything. The newborn infant responds to human touch, follows moving objects with the eyes, and makes cooing and squealing sounds as well as crying sounds.

ONE MONTH TO FOUR MONTHS

The baby gradually gains control of the head and then the upper extremities. By age four months, head control is good, and the baby may roll from side to side and begin reaching for objects. Objects can be suspended above the baby in such a way that they can be grasped without being batted out of reach. At around three or four months, the baby also begins cooing and chuckling in response to attention and starts experimenting with sounds.

FIVE MONTHS TO EIGHT MONTHS

The infant continues to gain more and more control of the trunk, arms, and then legs. By age six months, the baby can usually sit with minimal support and transfer objects from hand to hand and from hand to mouth. The baby uses these new skills to explore his own body as well as objects within reach. Parents should provide the baby with objects of various sizes, shapes, colors, and textures. When the baby begins to crawl, there should be at least one room of the house where the parents feel comfortable letting the child crawl and explore.

During this time, the infant's repertoire of sounds increases, and the eight-month-old will often repeat monosyllabic utterances. The infant also seems to understand a few words such as "bottle" and "mommy." He becomes more social with family members, but may go through a period of "stranger anxiety," withdrawing or even showing fear when unfamiliar people approach.

NINE TO 12 MONTHS

At this age, the child usually learns to pull to a standing position and starts walking around by hanging onto furniture. Control of the lower extremities is not complete, and the child often falls, causing bumps and cuts. In addition, several teeth erupt by the first birthday, and cuts inside the mouth from falls are not uncommon. The child also learns to pick up small objects with thumb and forefinger, hand objects to someone else, eat finger foods, drink from a cup with assistance, and hold a spoon. Parents should encourage their child to practice self-feeding as soon as he seems ready, even if it creates a mess.
At one year, the child gives affection, pays attention to his own name, responds to "no," and copies the simple actions of others. The child also imitates sounds, may say two or three words, and usually understands a simple direction (e.g., if someone says, "Come," the child will raise his arms). During the entire first year, social development is very dependent on the amount and kind of attention the infant receives from the primary caretakers, and language development will be encouraged if parents talk to their baby and respond to sounds the baby makes.

SPECIAL CONSIDERATIONS FOR THE CHILD WITH A BLEEDING DISORDER

Many parents are afraid to handle their infant because of the child's fragile appearance. If the diagnosis of a bleeding disorder is made at birth, parents may be even more hesitant to handle their infant. However, holding, rocking, hugging and patting the baby will not cause harm, and touch and physical contact are both a major means of communication with the infant and an important way to make the child feel loved and wanted. In fact, one of the best toys parents can give their child at this age is their smiling face for him to see and touch.

Touch is also very effective for calming the baby during and after venipunctures or other medical procedures. If treatment is necessary and the child comes to the clinic, encourage parents to stay with their child if the child needs to receive an infusion or any treatment. When interviewed as adults, several young men with hemophilia have anecdotally mentioned that they recall gaining great comfort as a child when their parent stayed with them and talked to them while they received an infusion.

Infants under one year with hemophilia seldom have bleeding episodes, but they may have more bruises than other infants. Bruises are often not serious and usually do not require treatment unless they are accompanied by pain. However, sometimes the bruises are large, lumpy and colorful. Unfortunately this may result in medical staff or neighbors erroneously reporting the family for child abuse. The medical team should discuss this possibility with parents..

Once the child starts crawling and walking, the number of bleeding episodes may increase. Joint bleeding is infrequent at this age, but mouth bleeds and head bumps are common. Chewing on hard and/or sharp objects may cause gum bleeding. Falls are part of learning to walk. Falling onto the face may tear the frenulum or cause a tooth to injure the tongue or lip. Falls often result in head bumps as well. In spite of the increased bleeding, crawling and walking are important for normal motor and cognitive development. Strong muscles protect joints and help prevent joint bleeding as the child gets older and becomes more active.

Parents naturally want to keep their child from getting hurt, but if their protective actions become excessive, they can hamper the child's development. A home visit by a nurse or social worker is a very effective way to help parents "baby proof" their home. Parents may be tempted to keep their child in a playpen to prevent injuries. However, most children become bored after 10 minutes in a playpen, so its use should be limited. Putting gates on stairwells; removing furniture, toys or baby seats that tip over easily; and padding table corners or fireplace hearths will make it easier for parents to allow the child to explore. Small padding can also be sewn onto pants at the knee, and small knee pads can be purchased for use while the baby crawls. Parents should also understand that it is not possible to prevent all bleeds, and it is best for their child if they take routine safety measures while allowing him the freedom to explore. If parents can be assured of receiving prompt, appropriate treatment for their child when there is a bleeding episode, their feelings of anxiety and over-protectiveness will usually decrease.

Hospitalization is uncommon during this first year unless the child sustains a major injury, requires surgery, or develops an inhibitor. If hospitalization does become necessary, one of the parents should be encouraged to stay with the child. Even babies under three months will show distress on separation from the primary caretaker, and by six months, separation may even produce signs of mourning in the infant.

In summary, a bleeding disorder does not usually have a direct effect on the child's development during the first year. However, if parents react to the diagnosis of hemophilia with extreme, overprotective behavior, the child’s normal development may be delayed. Staff should acknowledge the parents' real concerns and provide support and suggestions for keeping those concerns within reasonable parameters. They can review appropriate safety measures and help parents "baby proof" their house, explain the possible effects of overprotection on development, help the parents examine their degree of protectiveness, and make sure that the parents can get prompt treatment for their child when needed.

THE TODDLER: AGES 1-3 YEARS OLD

PERSONALITY DEVELOPMENT

As the child enters the toddler stage, the child develops trust in himself as well as in the parents. Parents must help the growing child learn how to gain physical control of bodily functions, such as bowels and bladder, as well as emotional control, such as managing outbursts. In this way,

the parents help their children learn to trust themselves and their ability to exercise control over their own actions.

At the same time, toddlers begin developing a sense of autonomy. They learn to make choices and accept their consequences. This is a trying time for parents because the child frequently opposes their will and constantly tests the limits while striving to become more independent. It is important for parents to maintain firm, reassuring control. A healthy sense of autonomy will develop if parents allow their child to make choices but set firm, clear limits that prevent the child from making inappropriate or harmful choices, for example, "It's time to go to bed now. Do you want to take your teddy bear or your lion to bed?"

COGNITIVE DEVELOPMENT

By age two, the child has mental pictures of objects that are not present (this is called object permanence). The two-year-old will respond to simple words or commands, but commands will probably need to be repeated. For example, the child may stop pulling the cat's tail when told to, but the next time the cat is within reach, the child will probably attempt to pull its tail again.

The three-year-old begins using words as well as pictures as tools of thought. This ability allows the child to begin internalizing rules and complying with cultural demands. However, the child's reasoning ability and memory are very limited, so it is important to decide on a few important rules and enforce them consistently. It is also important to realize that the three-year-old learns through observing and imitating adults.

MOTOR, SOCIAL, AND LANGUAGE DEVELOPMENT

By age 15 months, the toddler is usually able to walk alone and up stairs but not down and can feed himself some foods. The child can recognize himself in a mirror or picture, respond to words or commands, and can usually say several words. By 18 months, the toddler starts to run and can climb onto a low chair. He becomes aware of other children, watches what they are doing, and often copies their activity.

The two-year-old is very active. The child runs easily, walks up and down stairs with help, may climb on furniture and counters, and can throw and kick a ball, jump in place, open doors, turn pages, manipulate some tools and scribble spontaneously. These activities are important for motor development. They also increase the child's ability to explore the environment and experiment with the ability to do things. Exploration and experimentation are important for cognitive, personality, and social development as well as physical development. Social interaction with peers is still very limited at this stage, and sharing is almost impossible. The two-year-old may push or hit to get a toy, but there is usually no intent to hurt because he has no concept of hurting.

By age two-and-one-half years, the child's vocabulary contains over 400 words. Parents can help the child increase his vocabulary by naming household articles and telling their functions, naming animals, and using picture books.

The three-year-old can learn to ride a big wheel or tricycle, paint, snip with scissors, and wash and dry his hands with assistance. The child knows his own gender and begins to interact with other children. He will share toys and take turns with assistance. Opportunities to observe and interact with peers are beneficial to the child's social development during this stage.

The three-year-old child usually uses short sentences and asks "what" and "where" questions. Parents can help language development by reading simple stories to their child. They should use short sentences but avoid baby talk.

SPECIAL CONSIDERATIONS FOR THE TODDLER WITH A BLEEDING DISORDER

The child's increased but unsteady mobility, coupled with a lack of awareness of consequences, make him prone to accidents. Mouth bleeds, soft tissue bleeds, and head trauma are common for this age group. Parents will naturally worry about their child getting hurt, and overprotective behavior is so common that it is appropriate for the nurse to address it when the child is beginning to walk. The nurse should reinforce the idea that it is simply not possible to prevent all bleeding episodes.

A frank recognition of the risks of trauma to the toddler should be coupled with a discussion of the long-term emotional risks of limiting exploration. Remember that autonomy is the goal at this age. Constantly reminding toddlers to be careful may make them fearful and interfere with their developing sense of autonomy. Parents should make the house and yard safe and discreetly supervise exploring. A home visit by a nurse or a social worker is probably the best way to help parents decide on appropriate safety measures. The same safety measures recommended for any other toddler without a bleeding disorder are usually sufficient. Additional measures often lean in the direction of being too protective, although some healthcare centers recommend helmets and pads for toddlers during this period of time. Parents should understand that such equipment may not prevent bleeds, but they will reduce the small hematomas and bruises so common to toddlers while still allowing them to explore their world.

If parents are confident that bleeding episodes will be treated quickly and efficiently, they can be more relaxed in general. . Venipuncture is usually stressful for the parents as well as for the child. To minimize the family's anxiety, a physician, nurse or social worker they know and trust should meet the parents in the clinic or emergency room if possible. A skilled phlebotomist should perform the venipuncture. The use of topical anesthetic cream may be helpful. Parents should begin to build a "toolbox" of methods to distract and comfort the child during infusions. If Child Life Specialists are available in the clinic, they can assist in helping to prepare and/or distract the child while he gets an infusion.

Home infusions of factor by the parent often begin at this age. Prophylaxis treatment may be recommended. Prophylactic infusions have been found to potentially decrease the frequency of bleeding episodes, pain and disability and may decrease the parents' anxiety as well.

Hospitalization is often not necessary during this stage unless the toddler sustains a major injury, requires surgery, or develops an inhibitor. If the toddler must be hospitalized, ideally one of the parents can share a room with the child and participate in his care. The toddler's attachment to the primary caretaker is very strong, and his capacity for verbal expression is still limited, so children of this age have a greater amount of regression due to separation than any other age group. If a parent cannot room with the child, frequent visits and leaving personal articles and familiar toys will help. Parents should indicate when they will return in relation to the child's activities, since children in this age group do not understand time. It is also important that the surroundings and any procedures be explained. Visual aids for the child are essential for explaining new procedures.

Comforting the child requires the parents to come to terms with their own feelings such as when hearing their child cry and when seeing needles, for example. Parents may need to express these feelings to the staff. Involving the social worker may help in providing support around these and other issues.

Positive attention and praise are necessary for normal growth and development. Parents of a child with a bleeding disorder may be distracted from the child's normal emotional needs by frequent acute medical problems. Parents should try to spend time doing enjoyable things with their child regularly. Talking with parents about leisure-time activities will help illuminate the importance of the non-medical aspects of their relationship with their toddler.

Discussion groups are often helpful for parents of toddlers. Common topics are: safety precautions versus overprotection, suitable toys, common worries and concerns, daycare issues, and child management problems. Some parents are more comfortable receiving suggestions from other parents than from the HTC staff. Advice is often particularly welcome from parents whose experiences are relevant to the problem being discussed.

THE PRESCHOOL CHILD: AGES 4-6

PERSONALITY DEVELOPMENT

The stage of initiative and imagination becomes predominant around age four, after the child has developed a concept of himself as a person separate from the parents and the environment. The preschool child explores the world through the senses, through thinking, and through imagining what he or she can do.

The child begins planning, undertaking and attacking a task for the sake of being active and to test his or her abilities. Children enjoy helping parents with whatever the parents are doing and are capable of taking on small responsibilities such as helping set the table, picking up toys, etc.

It is often easier and faster for parents to do everything themselves, but allowing children the opportunity to "help" with certain tasks is important for their development.

COGNITIVE DEVELOPMENT

The four-year-old knows his first and last name and can recognize and match six colors. At four, the child starts developing a conscience and is capable of internalizing some rules. However, rules and limits should still be kept simple and small in number.

The five-year-old names four to six colors and matches pictures of familiar objects. He or she can draw, name, and describe a picture and count to five. The six-year-old can retell a story from a picture book with reasonable accuracy and name some letters and numerals. He or she begins to accurately use words that refer to time concepts like "tomorrow" and "yesterday." The six-year-old can usually communicate well with family, friends, or strangers. He can give and receive information easily.

MOTOR, SOCIAL, AND LANGUAGE DEVELOPMENT

The four-year-old can put most clothes on, go to the bathroom, and wash and dry his hands without help. At four, the child can handle eating utensils well and carry liquid without spilling. Most four-year-olds can safely use a slide without assistance, throw a ball overhand, and catch a ball that is bounced to them. They can manipulate clay and drive large wooden nails and pegs.

The four-year-old joins in play with other children and with encouragement can share toys and take turns. He plays cooperatively with special friends, but there is frequently a lot of tattling, disputing and quarreling in larger playgroups. Dramatic play may begin at this age. The four-year-old is very concerned about his body, and exploration, including masturbation, is common.

By age four, most children have a vocabulary of approximately 1,800 words and talk in sentences of three or more words. Strangers can usually understand their speech.

The five-year-old can usually lace shoes and may tie bows loosely. He can cut some foods with a knife, hop on one foot, skip, walk heel-to-toe, and turn somersaults. Many five-year-olds can color within the lines, cut on lines, and copy designs, letters and numbers. The five-year-old can interact in large groups but plays best in a group of three. The dramatic play of the five-year-old comes closer to reality and often involves real-life situations (playing house, going to the doctor, etc.). The five-year-old may demonstrate protective feelings toward younger children.

The average five-year-old has a vocabulary of approximately 3,500 words. He can begin to understand a logical sequence of events such as, “First we’ll go to the store, and then we can make the cake.”

The six-year-old can usually dress him completely and brush his teeth with little assistance. The child can learn to cross streets safely and can walk a balance beam, jump rope, and skate. Most

six-year-olds can also learn to ride a bicycle. Children of this age can cut out simple shapes, copy their first name, and paste and glue.

A six-year-old is able to play competitive games and simple board games. He can engage in play involving group decisions and role assignments. The six-year-old realizes gender is constant and understands the relationship between differences and sexual identity.

SPECIAL CONSIDERATIONS FOR THE PRESCHOOL CHILD WITH A BLEEDING DISORDER

The preschool child is more coordinated than the toddler and will generally have fewer mouth injuries and head bumps. However, the preschooler is also bigger, heavier, more active and interactive, and therefore may start having more joint and muscle bleeds related to running, jumping and climbing. Since physical abilities progress faster than judgment of what is safe and not safe, parents must still take safety precautions without being overcautious or overprotective.

Parents are often afraid that their son will get hurt playing with other children. However, such play will enhance development and should be encouraged. To the degree possible, children should be allowed to settle their own quarrels. If parents feel they must intervene, they should strive to be impartial. Preferential treatment should not be given to either the younger child or the child with a bleeding disorder.

Separation is not as difficult for the preschool child as it is for the toddler, but if hospitalization is necessary for a child of three or four, staying in the child's room is still preferable. If the primary caretaker cannot stay with the child, a regular visiting pattern will help the child feel confident that his parents will return.

If the older preschool child of five or six is hospitalized, he should be encouraged to participate in his own care. If possible, it is nice to have the parent stay with the child if he is hospitalized. If this is not possible, frequent, regular visits from parents should be encouraged. Treatment procedures may be viewed as serious threats to preschoolers who have concerns about their body and its intactness. Visual aids and explanation should be used to prepare the child for these procedures. The child also needs to be reassured that no one is to blame for the hospitalizations or bleeding episodes.

THE SCHOOL-AGE CHILD: AGES 6-12

PERSONALITY DEVELOPMENT

The stage of industry, also known as the stage of duty and accomplishment, begins during the preschool years but does not become predominant until the school years. During this stage, the child learns to win recognition by producing. The school-age child learns how to do a variety of things and do them well. Whereas in the preschool years jobs may get started, the school-age child learns how to complete them. The child is able to help with household tasks and run errands. He likes to do things to please his parents.

Successful development of intellectual, motor and social skills all contribute to the child's feelings of adequacy and self-esteem. However, if the child is not able to win a certain amount of recognition from parents, peers and teachers, feelings of inadequacy and inferiority may develop.

COGNITIVE AND LANGUAGE DEVELOPMENT

The school-age child articulates more clearly and uses longer, more complicated sentences. He can store information in the form of words and pictures. It is still hard for the school-age child to learn about things without personally experiencing them, but children do eventually develop the ability to take the place of another person at this age or understand what it is like to be in another's shoes.

PHYSICAL DEVELOPMENT

The child's rate of growth is slower during the school years, but coordination and dexterity continually improve. Much of the child's playtime is spent in motor activities. This constant activity is important for normal development and results in increased speed, agility, reaction time, and strength.

SOCIAL DEVELOPMENT

The six- and seven-year-old spends very little time in individual play and considerable time in play with a constant friend. Group play is also common but is usually unorganized. For the eight- and nine-year-old, group play becomes more organized, and interest in competition increases. Playing on a sports team can be important for a child of this age. He also becomes more critical of self and seeks peer approval.

The 10- and 11-year-old becomes more self-conscious, sensitive, self-critical, and socially insecure. Children of this age want to please and have difficulty accepting criticism.

SPECIAL CONSIDERATIONS FOR THE SCHOOL-AGE CHILD WITH A BLEEDING DISORDER

Physical activities are especially important for this age group. These activities help develop strong muscles that protect joints, and the acquisition of specific motor skills enhances the child's feelings of adequacy. Of course, the increased chance of bleeding due to certain physical activities has to be considered, but in general children with bleeding disorders should be treated like other children.

The child should be enrolled in the regular school physical education program. Ideally, a member of the HTC staff should meet with parents and school personnel to discuss the specific program so that they can decide if certain activities should be either adapted or avoided entirely.

The frequency of joint bleeding may increase as the child becomes more active. If the child has severe hemophilia and has not already started a prophylactic infusion program, it should be seriously considered at the time of school entry. Prophylactic infusions decrease the number of bleeding episodes and therefore decrease both chronic joint disease and school absences. Regular school attendance should be encouraged even if the child occasionally needs to use crutches.

In the past, children with a bleeding disorder were encouraged to avoid all contact sports and had limited options for sports activities. Now with the advent of prophylaxis, more and more activities are possible. It is important for HTC staff to develop parameters for what sports activities they recommend and discuss this with families. Typically, clinics will limit some sports such as boxing, wrestling, and tackle football. They will usually encourage children to participate in life sports that they can use for the rest of their lives.

It is of note that in Middle School, sports become more competitive in general, and sports accidents occur more frequently. Though some children want to participate in contact sports earlier on, it is often difficult at this age to have to suddenly limit participation. It is for this reason that life sports are often recommended from an early age. These may include but are not limited to golfing, swimming, biking, hiking, running, cross-country skiing, dancing and bowling. These are life-long activities which promote health and inspire confidence.

The school-age child is often interested in learning to perform his own venipunctures. This interest in self-care should be encouraged, and the child should take more and more responsibility for his care. With supervision, the school-age child can assemble the necessary materials, mix the clotting factor, help keep the bleeding log at home, and start learning venipuncture technique.

If the school-age child must be hospitalized, one nurse should be assigned to his or her care for as much of the time as possible. Schedules, routines, and rules should be consistent. Peer and sibling visits as well as regular visits from parents should be encouraged. Self-care and participation in treatment planning should also be encouraged. Visual aids and explanation are still important for teaching the child about procedures.

ADOLESCENCE: AGES 12-21

Bridging childhood and adulthood, adolescence is a time of dramatic physical, psychological, intellectual, and social changes. As a result, associated developmental tasks may seem overwhelming to the adolescent. The adolescent's behavioral responses to these rapid changes and the approaching responsibilities of adulthood are often difficult for the family to handle. A better understanding of the physical and emotional changes taking place will help parents provide effective support and guidance to the adolescent with a bleeding disorder.

PERSONALITY DEVELOPMENT

The adolescent continues to work on developing a sense of industry. The teen has to develop and perfect many intellectual and social skills and assume new responsibilities. This is also the time of identity development. The teen must start to separate from dependency and identification with parents while determining who he is as an individual and how he fits into the world.

In an attempt to establish identity, the adolescent may over-identify with the peer group. The early adolescent is acutely aware of his changing body as well as the awkwardness that accompanies these changes. The teen has to establish a new identity in accordance with the cognitive, physical, and social changes that have occurred. Any differences seen between him and friends must also be dealt with and incorporated into the teen's body image.

COGNITIVE DEVELOPMENT

Adolescence is a period of transition from concrete to more abstract thought processes. As the adolescent matures, he becomes more capable of logical thought and abstract reasoning. The teen develops increased flexibility in his thinking and can consider not only what is but also what could be. He is also increasingly able to imagine that which he actually cannot see.

Adolescents become capable of self-evaluation and can see themselves as others do. They become more introspective, and moods often swing between over-evaluation of oneself and self-doubt and self-castigation.

The adolescent begins to solve problems that require consideration of two or more variables at the same time. However, it is important to realize that the capability to think logically does not mean the adolescent will necessarily do so. The teenager has not had enough life experiences to know all the alternatives available, and emotions and hormones may also play a role in hampering logical thinking.

PHYSICAL DEVELOPMENT

Adolescents experience more physical changes than at any other life stage following birth. The transformation of a child's body to that of an adult can occur in as few as two or three years, although the process of puberty may take six or seven years to complete. In boys, puberty can begin as early as age nine or as late as age 13. Once it begins, the rate of growth accelerates, and body proportions start changing. Pubic, axillary and facial hair begin to appear, and external genitalia enlarge. Approximately 50% of boys have some temporary breast tissue enlargement that may occasionally be mistaken for bleeding. Muscle mass and strength also increase. However, since not all parts of the body grow at the same rate, growth may lead to a lanky, gawky appearance. Growth spurts may also decrease muscle mass around joints and increase joint bleeding during this time.

Between the ages of 15 and 17, the dramatic growth spurt usually ends, the awkwardness gradually disappears, and the gawky appearance dissipates. Sexual maturation is usually

complete by the end of this period. Slow growth may continue, but most males complete their growth between ages 18 and 21.

For girls, puberty begins approximately two years before boys. The first sign of puberty, which can occur as early as age eight-and-one-half, is the appearance of a small nubbin of breast tissue (breast bud) followed by the appearance of some pubic hair. The growth spurt begins about the same time. Most girls have completed their growth by age 14. Menarche usually occurs between ages 10 and 16. For most girls, menarche occurs well after the growth spurt has started, pubic hair is evident, and additional breast development has occurred. Girls with a severe bleeding disorder may have significant bleeding with their menses. They and their parents need to be prepared for this possibility.

SOCIAL DEVELOPMENT

The early adolescent (ages 12 to 15) begins to separate from the home environment and concentrate on relationships with peers. The early adolescent compares his appearance, dress and other attributes with peers of the same sex, and the peer group increasingly influences the adolescent's behavior.

The middle adolescent (ages 15 to 17) follows peer group behavior standards. The peer group also plays the major role in gratifying the adolescent's needs. Identification with the peer group is an important mechanism for decreasing dependence on parents and establishing a separate identity. The middle adolescent also usually becomes interested in members of the opposite sex and explores his ability to attract them.

By late adolescence (ages 17 to 21), emancipation from parents is nearly secured, body image and sex role are essentially stable, and attention shifts to goals related to the youth's future. Relationships become less self-centered and include more giving and sharing.

SPECIAL CONSIDERATIONS FOR THE ADOLESCENT WITH A BLEEDING DISORDER

A lifelong bleeding disorder creates a unique set of issues for the adolescent. The severity of the problems depends on the amount of physical disability, the impact it has on peer relationships, the degree to which the youth has already integrated the bleeding disorder into his lifestyle, and how the family has dealt with the disorder. The early adolescent is mainly concerned with self-image and how the bleeding disorder affects physical appearance, function and mobility. The middle adolescent often worries about any visible physical disability that affects his ability to attract others of the opposite sex. Enforced dependency due to medical treatment and/or hospitalization is almost intolerable to the middle adolescent because he is striving for independence. The late adolescent is mainly concerned with the impact the bleeding disorder may have on dating relationships, education plans, and a future career.

The adolescent’s desire for perfection makes any imperfection seem intolerable, and he may tend to exaggerate any apparent personal flaws. Revising body image to incorporate a deviation is

likely to be a painful process. This not only makes it difficult for the teen to incorporate his bleeding diagnosis into his self-concept but also may result in denial and delayed treatment.

Mobility and physical activities are central to most adolescents' everyday lifestyle, self-expression and social contacts. The adolescent may engage in activities that he knows can cause bleeding just because everyone else is doing them. However, lecturing the teen will not usually help. Encouraging the adolescent to express feelings and thoughts associated with actions (such as delaying treatment or engaging in high-risk activities) may help the teen think logically about what he is doing and why.

Peers of both sexes play an even more important part in the adolescent's life than they did during childhood. Friendships and love relationships enhance the adolescent's self-concept. If hospitalization, medical treatment, or feelings of inferiority limit the adolescent's social experiences, they not only interfere with identity development but also limit the development of social skills that are important for assuming an adult role. The girl with menorrhagia may be reluctant to take part in physical education classes or even attend school or social events during her period. It is unlikely that she will mention this concern unless parents or the HTC staff asks specifically about how she manages her periods at school and at home.

The adolescent's negative reactions to being different may take time to resolve. Although social experiences are a necessary part of this process, some social experiences may be negative rather than helpful. Parents can help their teenager weather the distresses of peer critique in several ways. These include assisting in 1) identifying personal characteristics and abilities that enhance self-esteem, 2) understanding possible reasons for negative reactions and putting them in perspective, and 3) viewing the bleeding disorder and/or orthopedic problems as only one aspect of body image. Someone outside the family may be more suited for this role because the adolescent may view family members as biased and therefore not credible and that they are just saying things to make him feel better.

Good communication among the adolescent, his parents, and the HTC staff is critical. The adolescent often needs help expressing feelings of inadequacy, recognizing academic successes and talents that can provide avenues for pride in accomplishment, and exploring occupational roles. Parental examples can also influence how the adolescent with a bleeding disorder learns to react to temporary or permanent physical limitations and other disappointments. In addition, counseling may be helpful for the adolescent and/or family. Referrals to the HTC Social Worker or other psychosocial professional should be made if either the adolescent or the parent feels a need for this service.

TRANSITION GUIDELINES:

Transition is the act of passing from one developmental state to the next. In child development, transition begins at birth and flows from one age to the next. The ultimate goal is for the child to become an independent adult who is a productive member of society.

The National Hemophilia Foundation Medical and Scientific Advisory Council noted that children with bleeding disorders have unique challenges in achieving these developmental milestones. Healthcare providers also face challenges as they care for pediatric patients that become adult patients, often necessitating a transfer to an adult care facility. Because of this, a task force developed transition guidelines to assist healthcare providers with these transitions. These can be found at www.hemophilia.org> Researchers and Healthcare Providers>Medical and Scientific Advisory Council>View MASAC Recommendations> Document #147.

The recommendations are age-specific. They include the entire life span with ages grouped into five major categories: 0-4 years old, 5-8 years old, 9-12 years old, 13-15 years old, and 16-18 years old. Transitions are a team effort between healthcare providers, patient and staff. Transition categories in each age group include topics such as: social support, health and lifestyle, educational/vocational/financial planning, sexual health, self advocacy and self esteem, and independent healthcare behaviors.

The goal is to assist the patient and his family throughout life to attain appropriate developmental milestones for each age and to provide health care that is uninterrupted, coordinated, and developmentally appropriate as he transfers to an adult system. The summary is very thorough. The intent is that they be adapted for use in individual HTC clinics.

RECOMMENDED READING FOR PARENTS:

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Piaget J, Inhelder B. (2000). *The Psychology of the Child*. New York: Basic Books.