



The Child With A Bleeding Disorder: Guidelines For Finding Childcare



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

The Child with a Bleeding Disorder: Guidelines for Finding Childcare

National Hemophilia Foundation Mission

The National Hemophilia Foundation is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research.

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The Child with a Bleeding Disorder: Guidelines for Finding Childcare

Parents of a young child with a bleeding disorder, like parents of any young child, often feel uneasy about leaving him/her in another person's care. When a child has a special health condition, there is usually more worry about choosing the "right" provider. This pamphlet contains guidelines and general information about childcare options. When considering childcare, it is important to know the kinds of care available in your community. You will want to consider whether to have someone come to your home (eg, a nanny, relative, or au pair) or choose a childcare setting close to home or close to work. Needless to say, how much the family can afford for childcare influences, or even controls, choice. When you are ready to look for care—whether an in-home babysitter, a family daycare home or a center-based program—talk with relatives, friends, neighbors and co-workers. They are likely to know about resources in the community. They may even have recommendations for specific providers. Remember, your hemophilia treatment center (HTC) and local NHF chapter can link you to other families who have young children with bleeding disorders, and they may have helpful advice.

When leaving your child with a babysitter or caregiver, always leave the telephone and/or cell phone numbers where you and your child's doctor can be reached. Also leave the phone number of your HTC. Check to be sure that your work phone, pager and cell phone numbers, as well as instructions on how to reach you, are clearly posted. Remember that these and other emergency numbers, such as fire and police, should be posted in large print near *all* telephones. In your home, it is also advisable to post your house address next to your phone(s).

Under stress, a babysitter in your home may forget where he or she is. During an emergency, the sitter may automatically give *his* or *her* address, rather than yours. Consider having a trial run of how the caregiver would contact you in case of an emergency.



IN-HOME CARE

Care shared by parents

In some two-parent working families, the adults have flexible work schedules that allow them to take turns being at home with their child. This arrangement may save money, offer the child individual attention and give the parents opportunities to watch their child's development firsthand. Also, children cared for at home may be less likely to be exposed to illnesses than those in group-care settings. On the other hand, the child in the fulltime care of his or her parents at home may have fewer opportunities to play and share with peers. In families where the parents are separated or divorced, it is especially important to work together cooperatively to create an acceptable childcare arrangement that keeps as consistent a schedule as possible for the child.

In-home care by someone other than the parent

Neighbors, friends and relatives are often the best resources for finding in-home caregivers. An obvious, yet overlooked, resource for temporary or part-time babysitters is the local hemophilia chapter. Many chapters sponsor youth programs and know of teens or young adults in the community who have an interest in caring for young children with hemophilia. High schools, colleges, nursing schools, hospital clinics, churches, synagogues, senior citizen's groups and childcare licensing agencies may be other sources of recommendations. Still, other possible resources are the Red Cross, YWCA or Girl Scout babysitter-training programs. If your child is eligible for special services, the HTC social worker will be



able to refer you to agencies that serve children with special needs. If you decide to advertise for an in-home caregiver, always remember to contact previous employers for references.

Cooperative childcare

Cooperative childcare usually refers to programs in which organized groups of parents exchange childcare services with each other. These informal groups typically do not pay for each other's services. The National Association of Child Care Resource and Referral Agencies (NACCRRA) or your local Yellow Pages are resources for finding childcare resource and referral agencies. These agencies can provide information about cooperative childcare exchange programs.

OUT OF HOME CHILDCARE

There are several different types of childcare programs. These include:

- Licensed childcare homes (eg, family daycare homes) are homes that may be licensed to care for a limited number of children of varying ages.
- License-exempt childcare (eg, a family home where a parent is allowed to care for one or two unrelated children *in addition* to his or her own; also, governmental, university, church, synagogue, public school and hospital-based programs)
- Center-based childcare (eg, group care where there is trained and paid staff)

To find out about programs where you live, call Child Care Aware, a program of NACCRRA, at 800-424-2246. Child Care Aware also has a web site (www.childcareaware.org). This agency can direct you to resources for information about specific programs in your area. If you live near a major university, inquire about college-affiliated center-based programs. Your community's park district or public libraries may also be resources. Finally, check for local listings in the Yellow Pages under "Babysitters," "Day Nurseries" or "Child Care." Cities and/or state agencies typically license childcare centers. To check on the licensing of these facilities, call your Department of Children and Family Services, Department of Public Welfare, Department of Public Health or your school district office.

Center-based childcare

Center-based care, including preschools, may be organized by school districts, public or private agencies, religious groups, agencies serving handicapped children or child development centers. Usually these centers serve children of working parents and are often open from very early in the morning to early evening. There are licensing requirements for the number (ratio) of staff to children. The required ratio depends upon the age of the children, the size of the facility and the nature of the program. In general, the recommendations are as follows:

- **Under 2 years:** 1 staff person per 3 children.
- **2-3 years old:** 1 staff person per 8 to 10 children, with a teacher's aide.
- **3-4 years old:** 1 staff person per 10 to 16 children, with a teacher's aide.
- **5-6 years old:** 1 staff person per 20 children, with a teacher's aide.

How to choose a daycare center

The program goals and policies at daycare centers vary. Whenever possible, meet with the daycare staff to discuss details of the center's program and daily schedule to learn whether the facilities and program meet your family's needs. Feel free to ask any and all questions including those listed in the next section of this pamphlet. Remember, your child is a *person* who has a bleeding disorder. When choosing a center, keep in mind his or her habits, personality, needs, likes and dislikes; these needs are similar to those of his or her peers who do not have a bleeding disorder. Gather as much information as possible about a childcare center before choosing a program. A guide to help you compare programs is included in this brochure. Take it with you when you visit the centers you are considering. A personal visit to the facility and discussion with the staff are always essential. When visiting each center, try to answer the following questions:

1. Does this center have a good reputation in the community?
2. How does it feel to be in the center? Does it feel tense, cheerful, relaxed, etc.? Will I be able to leave for work feeling comfortable about leaving my child in the care of this staff?
3. Is the license of the facility posted where it is easy to see? Is it up to date?
4. Is there enough staff for the number and ages of the children?

- 5.** What are the qualifications of the staff members? Do their interactions with the children show they are experienced? Do they appear to enjoy what they are doing with the children?
- 6.** Is at least one staff person currently certified in first aid, CPR and the Heimlich maneuver?
- 7.** Does the staff relate to the children with patience and warmth?
- 8.** Does the staff react to the children with interest and respect for the cultural and ethnic differences of the children in their care? Does the staff reflect the cultural diversity of the children?
- 9.** Are the children occupied with activities? Are they playing together? Sharing? Fighting? Looking lost or bored?
- 10.** Will the center take the time to listen to my special concerns? Is the center open with me about my child's progress?
- 11.** Is there a written agreement that clearly spells out the fee arrangements? The calendar? Sick-child policies?
- 12.** Will the center allow me to make drop-in visits?
- 13.** Is play equipment well-designed, safe, creative, clean and age appropriate? Is there enough staff to supervise my child on the equipment?
- 14.** Are there programs for language and social development as well as for the development of physical small and large motor skills?
- 15.** What plans are in place in the event that there is an emergency, such as an earthquake, power outage, fire, etc.?
- 16.** Are the meals and/or snacks nutritious?



Following are additional questions to consider when choosing a program for a child with a bleeding disorder:

1. Do staff members have experience or educational background in dealing with children with a chronic medical condition?
2. Are staff members motivated to learn more about my child's medical condition? Are they motivated to meet and learn from me and from my child's healthcare providers?
3. Is there a plan in place for my child if there is a medical emergency?
4. Is the center willing to keep factor concentrate in their refrigerator for use in an emergency?
5. Will the center let me give my child a factor treatment at the center?

In a childcare facility, it is likely the caregivers will, at first, feel nervous about their responsibility for your child. Provide as much information about your child's bleeding disorder as you believe is necessary for his or her safety. Be open to answering questions, even those that are asked over and over. Remember that most people know little or nothing about bleeding disorders. Your childcare provider may believe many of the familiar myths about hemophilia. This is your chance to set the record straight! There are many available resources. Some HTC's make daycare center visits to educate the staff about hemophilia and other bleeding disorders. There are also publications available from HANDI, the information service of NHF (800-42-HANDI).



The following are suggestions to help ensure your child's safety and well being while in the care of others:

- Be sure your child's emergency information is always up to date.
- If your child uses a Medic Alert emblem, make sure the information is up to date.
- Maintain open and regular communication with staff members.
- Educate staff about the kinds of bumps and injuries you want to hear about – and how quickly. For example, when they should call you immediately and when they can tell you at pick-up time.
- Reassure the daycare providers that you will inform them of injuries that require temporary activity restrictions.

To avoid unnecessary suspicion, be sure the center staff knows that nasty-looking bruises can be typical for children with hemophilia, especially severe hemophilia and von Willebrand disease. Call NHF for the brochure that specifically deals with issues related to hemophilia and suspected child abuse, "Inherited Bleeding Disorders and Child Abuse Investigations."

Arrange for you and your child to spend time with the provider the day or two before you leave the child in the person's care. Be sure to allow enough time—at least one-half hour—on the day you meet with the new person for the first time. This enables you, your child and the caregiver to begin to build a relationship. It also allows you time to describe your child's habits and needs. Remind the caregiver about routine, common sense practices, e.g. careful hand washing after changing a diaper and when cleaning coughed up or vomited material, close supervision of a child in the bathtub, etc.

Be sure the caregiver understands your permission is required before any medicines may be given. There are no exceptions.

Summary

Finding suitable and affordable childcare is a challenge for most families. The task is complicated when a child has special healthcare needs. To make informed decisions, parents first must consider their child's and their family's needs and then set about finding an acceptable program. This pamphlet provides basic information to help parents focus their search. More information on this topic is available. The following is a list of written and other resources.

Suggested reading

Child Care Aware. *Give Your Child Something That Will Last a Lifetime*. Washington, DC: National Association for the Education of the Young Child, #770, 1993.

Child Care Choices: A Family's Guide. Chicago: Day Care Action Council of Illinois and Child Care Initiatives of Jane Addams Hull House Association, 1999.

Howes, C. Can the Age of Entry into Childcare and the Quality of Child Care Predict Adjustment in Kindergarten? *Developmental Psychology* 1990; 26: 292-303.

Inherited Bleeding Disorders and Child Abuse Investigations. New York: National Hemophilia Foundation, 1998.

Rogers, F. *When You Have a Child in Day Care*. Pittsburgh: Family Communications, Inc., 1996.

What Are the Benefits of High Quality Early Childhood Programs? Washington, DC: National Association for the Education of the Young Child, #540, 1990.

Other resources

National Association of Child Care Resource and Referral Agencies (NACCRRA), 800-424-2246, or its Web site at www.naccrra.org.

WORK SHEET



| | PROVIDER 1 | PROVIDER 2 | PROVIDER 3 |
|--|------------|------------|------------|
| Name, address, phone | | | |
| Type of program (family daycare, center-based, license exempt) | | | |
| Experience and qualifications | | | |
| Driving time/distance from home | | | |
| Driving time/distance from work | | | |
| Contents of written agreement/contract regarding daily hours/fees, etc. | | | |
| Cultural diversity of staff and children | | | |

WORK SHEET



| | PROVIDER 1 | PROVIDER 2 | PROVIDER 3 |
|--|------------|------------|------------|
| Drop-in visit policy | | | |
| Quality and age-appropriateness of play equipment, both indoor and outdoor | | | |
| Experience with children with special healthcare needs | | | |
| Willingness to learn about my child's special healthcare needs | | | |
| How many of the staff members are trained in CPR, first aid and the Heimlich maneuver? | | | |
| Quality and appropriateness of meals and/or snacks | | | |
| Ways the program meets my child's and my needs— "What I liked." | | | |
| Shortcomings of the program— "What I didn't like." | | | |



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