TIPS FOR FINDING Childcare

A Guide for parents of children with bleeding disorders
CANADIAN HEMOPHILIA SOCIETY

The Canadian Hemophilia Society strives to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure.

The CHS consults qualified medical professionals before distributing any medical information. However, the CHS does not practice medicine and in no circumstances recommends particular treatment for specific individuals. Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company. In all cases, it is strongly recommended that individuals consult a hemophilia-treating physician before pursuing any course of treatment.

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Starting childcare is a major step for families living with a bleeding disorder. For both parents and children, the transition is an important part of learning how to live with a bleeding disorder. However, making decisions about childcare and finding the right caregiver can be a challenging process. It is important to take the time to research your childcare options and find a reliable caregiver who will provide a safe and nurturing environment.

It is understandable for parents of children with bleeding disorders to feel anxious about starting childcare.

Keep in mind that:

- Whether through childcare or school, at some time or another your child will be under someone else’s supervision and care — it is important for both you and your child to gain confidence in alternative care arrangements.

- Interaction with new people and environments is important to your child’s development. Good childcare helps nurture a child’s sense of discovery, autonomy, happiness and well-being.

- The key to having good childcare is to make sure that the caregiver has the basic information, skills and qualities necessary to provide good care for your child.

- It is also important for the caregiver to know that you will provide guidance and support throughout the time your child is under their care.
This booklet provides information to help parents of children with bleeding disorders assess their childcare needs and suitable options, with steps for finding the right caregiver. These guidelines are meant as practical considerations for choosing a caregiver. Keep in mind that, depending on the daycare situation in your area, it might not be possible to meet all of the criteria and parents may need to set priorities when making their decision. The booklet also outlines basic medical, health and safety information that caregivers need to know. Additional resources on childcare and bleeding disorders are listed at the back.

“During those five marvellous years that he attended my daycare, I offered him a safe environment adapted to his needs. I wanted him to feel just like the others and it was the group who adapted to him.”

- Childcare worker in a private home
Childcare refers to the temporary care and supervision of a child by someone other than a parent. The majority of Canadian parents today rely on some form of childcare, whether part-time or full-time. There are many childcare options:

- Informal childcare provided by a relative, friend, neighbour or babysitter in your home or at the caregiver’s home.
- Childcare by a caregiver trained in early child development, in or outside your home.
- Regulated childcare provided in licensed home-based childcare settings.
- Regulated/licensed childcare at a daycare, nursery or preschool centre, or before/after-school program.

Another family affected by a bleeding disorder may be able to recommend a suitable caregiver or childcare services. Your hemophilia treatment centre (HTC) nurse coordinator and local chapter of the Canadian Hemophilia Society can put you in touch with other families. Other possible resources include recommendations from relatives, friends, neighbours and co-workers.
Regulated childcare services

Each province and territory has its own regulated childcare services and licensing and/or monitoring standards. Standards vary among jurisdictions but generally include maximum child-to-adult ratios, minimum training and educational requirements for staff, and minimum standards for facilities and equipment. The availability and costs of regulated childcare also vary in different jurisdictions. Consult your provincial or territorial childcare services department to learn about the licensed options in your area.

Childcare support and funding resources

Many jurisdictions provide a range of resources for special needs at no extra cost to parents and/or childcare providers. This may include onsite caregiver education by an HTC nurse coordinator, free safety assessment of childcare settings, and financial subsidies for childproofing and safety modifications. Your HTC team and/or a community social worker can point you in the right direction to find out what’s available where you live.

“My daycare bought things like mats he could jump on, an extra helmet to keep at the daycare, cushions to put at the end of the slides to protect his little bottom, and so on. They also used this money to buy a wonderful first aid kit that we put to good use!”

- Mother of a young child with hemophilia
Finding the right childcare

Childcare needs and priorities will vary from family to family and over time. Here are some steps to help you determine the best childcare arrangements for your family.

- **Assess your family’s childcare needs and circumstances.** Does your family need full-time or part-time childcare? Will an individual or group environment work best for your child? Appropriate childcare will vary depending on your child’s age.

- **Determine your family’s childcare priorities.** Important factors may include:
  - Caregiver training and experience in early childhood development
  - Caregiver training for children with chronic medical conditions
  - Caregiver training in first aid and cardiopulmonary resuscitation (CPR)
  - Low caregiver/child ratio
  - Regulated/licensed childcare
  - Referral or recommendations
  - Health practices and safety policies
  - Adherence to universal precautions to prevent the spread of infections
  - Childcare costs
  - Access to childcare support and financial assistance
  - Accessibility (location and distance from your home or workplace)
  - Proximity of childcare setting to hospital or emergency medical services
  - Transportation arrangements for medical care (caregivers generally do not provide transportation so it is important to have an emergency plan for situations that may require medical attention)
  - Hours of care (full-time, part-time, drop-in, without notice, outside normal business hours, during holidays, etc.)
Identify the childcare services that meet your family's needs. Make a list of possible caregivers in your area who meet your childcare criteria.

Contact potential caregivers about their services, qualifications and availability. Contact each potential caregiver by telephone or e-mail. Ask about their services and whether they have experience providing care for a child with a bleeding disorder or another medical condition. Then select which ones could be suitable caregivers for your child.

Meet with each caregiver in person. This is a good time for you and your child to get a sense of a caregiver and whether there is a good rapport. Ask questions such as:

- Are you willing to learn about my child's special healthcare needs?
- Would you be willing to make safety and childproofing modifications to meet my child's needs?
- What is your approach to childcare?
- What is the quality and age appropriateness of play equipment, both indoor and outdoor?
- What art, music, educational and outdoor activities do you offer?

Make sure the childcare environment is clean and safe. Check whether childcare daycares and other childcare facilities are licensed or regulated, and whether universal infection control precautions are followed.
Identify the overall strengths and shortcomings of each caregiver. The ideal choice will vary according to your child's age, skills, interests and personality traits. In addition to the caregiver's qualifications, it is important that you have a strong feeling of trust and confidence in the individual.

Involve your child in the childcare decision. Introduce your child to the caregiver and make sure there is a good rapport. Keep in mind that it will take a bit of time for everyone to become confident with a new childcare arrangement.

Choose the caregiver that best meets your child's needs. The caregiver's childcare approach and rapport with your child should be key factors in your decision. The caregiver must be trained, or receive training, in how to recognize and treat common bleeds and bruises and respond to emergency medical situations.

Always check references. Ask each reference about the caregiver's strengths and weaknesses, and why and how strongly they would recommend the caregiver. References should include parents who have used the childcare services.

“In the beginning, I felt a bit insecure. Each day, I would copy his bruises onto a little figure drawing and when I changed his diapers, I’d check to make sure everything was normal.”

- Daycare worker in a private home
To provide good care, caregivers need to be well-informed about the child’s bleeding disorder. It is important to give clear guidelines about what a caregiver can and cannot do to manage your child’s bleeding disorder and potential health issues. Parents should provide caregivers with basic information about the bleeding disorder, important health and safety precautions, symptoms of bleeding and first aid, and handling medical emergencies.

“When I learned that I was going to have a boy with hemophilia in my group, my level of stress rose a bit. But when the parents came to talk to us they presented hemophilia the way they experience it on a daily basis, and I felt very reassured.”

- Daycare worker in a preschool centre

Information about the bleeding disorder

As parents, your role is to educate your child’s caregivers about the bleeding disorder and its management. Your child’s needs will change over time. Giving caregivers reliable information about the bleeding disorder and the appropriate health and safety precautions at different stages of your child’s development is the best way to prevent misunderstanding and anxiety. Speak to your HTC care team or contact the Canadian Hemophilia Society for guidance and assistance on caregiver education.

Basic points about inherited bleeding disorders include:

- An inherited bleeding disorder is genetic — it is not contagious.

- Children with bleeding disorders do not bleed faster, they bleed longer.
Bleeding may differ from one child to another, depending on the level of the disorder's severity (mild, moderate or severe) and nature of the bleed.

A small cut or scrape is not life-threatening.

First aid is the same as for any other children. Rest, ice, compression and/or elevation may be appropriate for some injuries.

Bleeding from severe injuries may require treatment such as an infusion of clotting factor concentrate, which is given by the parent/guardian or the HTC nurse coordinator.

Bleeding is sometimes internal and may be difficult to recognize. If there is any uncertainty about the severity of an injury, the caregiver should call the parents immediately so that they can decide the appropriate action to take (infusion, emergency care, etc.).

Educational resources that may be useful for caregivers are available from the Canadian Hemophilia Society and through its Web site at www.hemophilia.ca.

Safety precautions and childproofing

The appropriate safety precautions will vary depending on your child's specific bleeding disorder, age, physical agility and activity level. Consult your pediatrician or a member of your HTC care team regularly about the precautions you should be taking to protect your child at home and in other childcare settings. Be sure to discuss when a specific precaution is appropriate, as well as when it is no longer necessary. These precautions may include:

Crib padding: Padding is sometimes used in the crib in the early months when a baby is gaining basic motor skills (lifting head, rolling over, crawling). Crib padding (also called bumper pads) helps prevent bruising and injury from banging of the baby's head or other parts of the body against the bed frame and railings. Padding must be fit properly and securely around the entire crib. Talk to your care team about whether crib padding is advised for your baby and when it should be removed.
**Helmets:** A helmet can provide valuable padding and protection during your child’s early years of physical development and exploration. Talk to your care team about whether and when your child should use a helmet.

**Padded clothing:** Some parents sew elbow and knee pads or other padding into clothing or buy padded clothes for young children. Factors for consideration include your child’s activity level, degree and frequency of bruising and treatment needs.

**Padded furniture/corner walls:** The hard corners and sharp edges of furniture and walls can be cushioned with bumper pads. Breakable and hazardous items should be kept out of children’s reach.

**Padded carpeting/flooring:** Watch for hard surfaces such as concrete floors and slippery surfaces such as loose rugs. Padded, slip-proof carpeting or mats are useful for absorbing the impact of falls.

**Child safety gates:** Use child safety gates (also called child security gates) to prevent access to off-limit areas, especially stairways, fireplaces and potentially hazardous areas of the kitchen.

**Safety latches:** Put safety latches on cupboards and drawers within your child’s reach. All sharp objects (knives, scissors, tools etc.), medicines, cleaning and hazardous products should be kept well out of children’s reach.

“For his safety, he wore a little padded helmet that added to his charm! He never demanded more time or energy than the others, just a bit more vigilance.”

- Childcare worker in a licensed daycare centre
The ideal childcare setting is safe without being over-protective. Finding the right balance can sometimes be a challenge. Keep in mind that some bumps and falls cannot be avoided on your child’s journey towards independence. A child learns how to judge potential danger by exploration, and sometimes trial and error. As your child grows, some precautions will no longer be necessary — but new ones will arise. Consult your HTC care team whenever you need guidance. Continual communication with the care team and your child’s caregiver is essential.

Age-appropriate toys/play equipment: Toys must be clean, safe and free of sharp corners and edges.

Age-appropriate sports and physical activities: Some sports and physical activities are not advised for children with bleeding disorders. Sometimes your child may require extra protection such as a helmet or padding. It is important to talk to your care team as well as the caregiver about which activities are appropriate or prohibited throughout your child’s developmental stages.

First-aid kit and ice packs: A well-stocked first-aid kit, kept within easy reach, is a necessity in every childcare setting. Ice packs are sometimes used to treat bruises or swelling and should be kept on hand — however, it is important for both parents and caregivers to learn when ice treatment is appropriate or not and how to ice an injury.
Communication

It is important to have an ongoing, two-way communication system with the caregiver. Having a notebook or event diary is a very useful way to exchange information about your child’s health. You can make notes to the caregiver about particular health issues or needs, and the caregiver can record significant activities or events that occur during childcare. A notebook or event diary is an effective way to establish open and continual dialogue with the caregiver.

Medical guidelines and instructions

It is important to give clear guidelines about what the caregiver can and cannot do to manage your child’s bleeding disorder and health issues. Always make sure your child’s caregiver knows how to reach you and/or emergency medical services if needed.

Important points to discuss with the caregiver include:

- Do not give any medications, except with specific permission and instructions. Never give ASPIRIN (ASA or acetylsalicylic acid products) or non-steroidal anti-inflammatory drugs such as IBUPROFEN because they interfere with clotting.

- Watch for symptoms of injury and/or bleeding.

- Some bleeding episodes may be internal, and difficult to recognize. Look out for symptoms such as limping, diminished mobility or activity, unusual lethargy and signs or complaints of pain or a heated, tingly sensation.
Know what kind of treatment to apply depending on the severity of the injury. Treatment for bleeding episodes may consist of basic first aid and RICE (Rest, Ice, Compression and Elevation) for minor injuries, or an infusion of clotting factor concentrate for more significant injuries.

Do not hesitate to get help for any serious injury or bleed. Contact parents and/or the hospital immediately to determine what medical attention is needed.

Call emergency medical services (9-1-1) for severe or possibly life-threatening injuries, including trauma to the head, neck or abdomen.

The CHS booklet and video Hemophilia – What School Personnel Should Know are useful guides for caregivers on first aid for children with bleeding disorders and how to respond to different bleeding situations. See also the CHS booklet Navigating the ER for information on being prepared for medical situations and getting emergency care.

Written information

Written information to give your child’s caregiver should be kept up-to-date. Key information includes:

- You and your child’s full names, home address and telephone number.
- The telephone number and address where you can be reached.
- A list of telephone numbers and addresses for important contacts such as:
  - Pediatrician and/or hematologist
  - Hemophilia treatment centre
  - Hospital/Emergency Room
  - Relative or friend as alternate contact for emergencies
- A document from your child’s physician containing medical information such as:
  - Hematologist’s name and telephone number
  - Hospital address and telephone number
  - Type and severity of bleeding disorder
  - Factor level and therapy used
  - Any medical conditions (allergies, inhibitors, etc.)
Emergency preparedness

It is helpful to keep a bag packed and ready to go in case a medical situation arises. This saves time should your child needs to go to the doctor’s office or hospital for medical attention or treatment. Keep your child’s medical information and items such as medications, a change of clothes and diapers in the bag. Books, a special toy and some snacks can help pass the time while waiting for medical care or results.

The CHS poster How to recognize and treat bleeds and bruises contains guidelines for caregivers and a place for parents to put contact information. Contact your hemophilia treatment centre or the CHS for the poster.
Making the childcare transition

It will take time and practice for you, your child and a new caregiver to grow confident with a new childcare arrangement. Here are a number of ways to help the transition.

- **Tell your child what to expect.** Explain that you will be apart for a period of time and describe the fun activities to be enjoyed with the caregiver. Reassure your child that you will be back.

- **If allowed by the caregiver, bring along a special toy, blanket, etc.** A favourite item can give your child a sense of familiarity and security in the new arrangement.

- **Introduce the childcare gradually.** Start with a short visit together, then ease into short periods of time apart. Gradually build up to the childcare arrangement.

- **Allow time for your child to adjust.** The child/caregiver relationship will require some nurturing and fine-tuning at the beginning.

If your child is not happy and thriving in childcare after about a month, reassess the arrangement. If it's not a good fit, find a more suitable arrangement as soon as possible. It is essential to make sure that your child has a positive and nurturing childcare experience.

“I’m no longer afraid of hemophilia, and I wouldn’t hesitate to live this same experience again.”

– Daycare worker in a private home
A final reminder

Always talk to your pediatrician or a member of the HTC care team when you are uncertain what to do. Call even just to make sure you are doing the right thing. The care team can give you medical information and much-needed support. Finally, the Canadian Hemophilia Society and your local chapter are here to provide resources and support for your family’s continual learning about living with a bleeding disorder.

For further information or to get in touch with a hemophilia treatment centre or your CHS chapter, please contact:

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Additional resources

A wide range of publications and resources on inherited bleeding disorders is available on the CHS Web site at www.hemophilia.ca.

The Hospital for Sick Children in Toronto offers a comprehensive online resource at www.aboutkidshealth.ca. The Web site includes sections on childproofing your home, finding a caregiver or daycare centre and helping children adjust to childcare.
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