

LIVING WITH HEMOPHILIA:

PRACTICAL TOOLS TO HELP MANAGE LIFE IN TODAY'S BUSY WORLD

Communication Resource

What is a Bleeding Disorder?

- A bleeding disorder is a flaw in the body's blood clotting system.
- Hemophilia is the most known disorder and there are two kinds: Hemophilia A (factor VIII) and Hemophilia B (factor IX).
- If the child has Severe Hemophilia, it means he is completely missing the protein Factor VIII in his body.
- If the child has moderate or mild, it means there is some factor circulating in the body.
- The factors work like dominoes in conjunction with one another, when one is missing, the process stops and cannot continue.
- The most common symptom of hemophilia is bleeding into the joints and muscles
- When a person with Hemophilia is injured, he does not bleed faster, he just bleeds longer.
- Small cuts and surface bruises are usually not a problem (use first aid procedures to clean and bandage it).
- Deeper injuries may result in bleeding episodes that may cause serious problems and lead to permanent disability unless treated promptly.

What Should a Child with Hemophilia Avoid Doing to Prevent Injury?

- Allow the child to be who they Are!
- The child is a child first, then he is a child who has Hemophilia.
- Enforce all the regular safety rules as you do with others.
- Do not keep the child from doing everything everyone else is doing unless there is a note from his parents explaining the situation or unless the child himself is complaining about soreness or pain (then contact his parents right away).

If the Child Hurts Himself...

...or says he is having a bleed, complains of tingling, pain or stiffness.

...or appears to have a part of the body that is swollen and/or warm to the touch.

...or if he favors an arm or a leg and limps.

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If a child hurts himself you should:

- Contact his parents for instruction
- Keep him still to avoid further injury
- Apply an ice pack and elevate the affected body part

If the child has external bleeding from a cut or a scrape you should:

- Clean the cut or scrape with antiseptic soap
- Apply firm pressure and elevate the body part until bleeding stops
- Apply a sterile dressing and an ice pack to the area over the dressing
- Call the parents or the HTC if bleeding does not stop within a few minutes

Important information:

- Make sure you have all telephone numbers of the parents and the hemophilia treatment center and...

WHEN IN DOUBT CALL THE PARENTS!!!!

Important contact information:

Name: _____ Number: _____

Name: _____ Number: _____

Name: _____ Number: _____

Name: _____ Number: _____

Dates/Notes about injuries, infusions: _____
