

# LIVING WITH HEMOPHILIA:

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

## Communication Resource

### What is a Bleeding Disorder?

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- 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?

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- 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...

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...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: \_\_\_\_\_

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