Preparing for Emergencies as a Young Adult With Hemophilia

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During the journey to adulthood, you may find yourself with new obligations, and may learn new lessons about being on your own; this is all part of being independent. It can be difficult handling new responsibilities and uncertainties while living with a chronic condition. Being prepared for an emergency is part of transitioning to life as a young adult with hemophilia.

Recognizing Emergency Situations

Though there may be no visible signs or symptoms, bleeding issues such as joint hemorrhages, head injuries, muscle bleeds, and trauma can be life-threatening. Emergency bleeding events require recognition and immediate intervention with factor replacement product.[1] **The following situations typically require factor replacement therapy:**

- Suspected bleeding in the brain, which is life-threatening and requires immediate emergency care[2]
- Suspected bleeding into a joint or muscle[1]
- Significant injury to the head, neck, mouth, or eyes, or evidence of bleeding in those areas[1]
- New or unusual headaches particularly following trauma[1]
- Severe pain or swelling at any location[1]
- Open wounds requiring surgical closure, wound adhesive, or bandages[1]
- History of an accident or trauma that might result in internal bleeding[1]
- Invasive procedure or surgery[1]
- Heavy or persistent bleeding from any site[1]
- Gastrointestinal bleeding[1]
- Heavy menstrual bleeding leading to moderate to severe anemia/volume instability

Recognizing Emergency Situations (continued)

- Acute fractures, dislocations, and sprains[1]
- Limited motion, pain, or swelling of any area[2]

Preparing for Emergency Care

It's important to think ahead regarding the need for factor before an emergency happens. This is an important aspect of hemophilia self-care.

Take factor with you[3]: Factor replacement therapy is used for patients with hemophilia for acute bleeding episodes or presumed acute bleeding episodes.[4,5]

Keep an emergency dose of clotting factor concentrate in your home[1]: Clotting factor concentrates might not be available at some hospitals. If you do not have factor with you, and are advised by your hemophilia treatment center to go to the hospital, the emergency department (ED) personnel may have to identify another hospital to best deal with the emergency, which could delay treatment.

Take factor with you when you travel and/or if you go to the ED[1,3]: ED personnel may ask if you have your factor with you, and they may ask you to infuse the dose yourself.

Personal Empowerment

The transition from living with your parents to being on your own can be both exhilarating and overwhelming. The education and advice you receive may help prepare you to handle both everyday events as well as emergencies that may occur. Important components of leading an active lifestyle with hemophilia include prompt treatment of bleeds, staying in contact with your HTC and adopting healthy habits.

References: 1. National Hemophilia Foundation (NHF). MASAC document #257. Guidelines for emergency department management of individuals with hemophilia and other bleeding disorders. New York, NY: National Hemophilia Foundation (NHF); 2019. https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASAC-Recommendations/Guidelines-for-Emergency-Department-Management-of-Individuals-with-Hemophilia-and-Other-Bleeding-Disorders. Accessed May 10, 2020. **2.** National Institutes of Health (NIH). National Heart, Lung, and Blood Institute (NHLBI). Living with hemophilia. NHLBI.NIH.gov Web site. https://www.nhlbi.nih.gov/health-topics/bleeding-disorders. Updated September 11, 2019. Accessed May 10, 2020. **3.** Morris C. The Emergency Room: Prepare to Succeed. A Guide to the ER for Persons with Bleeding Disorders. Montreal, Quebec: Canadian Hemophilia Society (CHS); 2018. http://www.hemophilia.ca/files/er2.pdf. Accessed May 10, 2020. **4.** National Hemophilia Foundation (NHF). Hemophilia B. Hemophilia.org Web site. https://www.hemophilia.org/Bleeding-Disorders/Types-of-Bleeding-Disorders/Hemophilia-B. 2020. Accessed May 10, 2020. **5.** Moake JL. Coagulation Disorders: Hemophilia. Kenilworth, NJ: Merck & Co., Inc.; 2020. https://www.merckmanuals.com/professional/hematology-and-oncology/coagulation-disorders/hemophilia. Accessed May 10, 2020.

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