

18 Steps to 18

Self-Management Milestones for Transitioning to Adult Care

- 1. General Health:** I will visit my primary care physician on a regular basis for my general healthcare and I will notify all medical providers involved in my care about my bleeding disorder.
- 2. General Health:** I will develop a lifestyle plan that includes regular exercise and a healthy diet.
- 3. General Health:** I will be able to list the medications I take by mouth including the dose, schedule, and reason prescribed.
- 4. Contact Information:** I will carry the telephone numbers for my hemophilia treatment center, primary care physician, pharmacy provider, and other important medical care providers.
- 5. Hemophilia Treatment Center (HTC):** I will see my HTC provider as recommended, including attending comprehensive clinic, calling the center with changes in address, phone and insurance, and calling in advance if I am unable to keep a scheduled appointment.
- 6. Emergency Treatment:** I will have a plan for emergencies that includes contacting my HTC regarding travel plans and knowing the location of the local emergency room and HTC closest to my travel destination.
- 7. Emergency Treatment:** I will wear a medic alert bracelet/necklace so that emergency responders will be aware of my bleeding disorder in the event that I am unable to tell them.
- 8. Bleeding Disorder:** I will be aware of my diagnosis, the name of my treatment product, and the dose needed to treat bleeding episodes.
- 9. Bleeding Disorder:** I will know how my bleeding disorder is inherited. I will understand why it is recommended that “at risk” people contact the HTC for evaluation.
- 10. Treatment:** I will take responsibility for calling my pharmacy provider for medication/clotting factor concentrate refills to prevent running out.
- 11. Treatment:** I will have a safe, secure location to store my clotting factor concentrate and supplies. I will dispose of all bio-hazardous waste such as needles as recommended by my HTC.
- 12. Treatment:** I will understand and recognize the signs/symptoms of a bleeding episode and know how to calculate the clotting factor concentrate/Stimate dosage and the schedule needed to treat each bleeding episode.
- 13. Treatment:** I will be able to self-infuse or know where to go for infusion if needed. I will keep track of all infusions in a treatment log.
- 14. Treatment:** I understand that prompt treatment is very important for bleeding episodes and I will treat within 3 hours of recognition of a bleeding episode or injury. In addition to infusion, I will treat injuries and bleeding episodes with other therapies such as R.I.C.E.
- 15. Procedures:** I will contact the HTC at least 2 weeks prior to a scheduled procedure, such as a surgery or a dental intervention, to ensure an appropriate plan is made to prevent bleeding.
- 16. Education:** I will be aware of local and national patient advocacy organizations (such as Hemophilia of Indiana, Inc., and The National Hemophilia Foundation) and how to access the information and services they provide.
- 17. Prevention:** I will take precautions prior to engaging in activities that may cause a bleeding episode. These precautions could include the use of protective equipment like a bicycle helmet, or infusion prior to participation in certain activities. If I am on a sports team, I will notify my coach of my bleeding disorder.
- 18. Insurance:** I will contact the HTC social worker to discuss insurance options prior to selecting a new policy or losing coverage.

