



**RECOMMENDATIONS ON REDUCING BARRIERS TO SUBSTANCE
USE DISORDER (SUD) TREATMENT FACILITIES AND PROGRAMS
FOR PERSONS WITH BLEEDING DISORDERS (PWBD)**

The following recommendation was approved by the Medical and Scientific Advisory Council (MASAC) on August 19, 2023, and endorsed by the NBDF Board of Directors on August 20, 2023.

- I. Preamble
 - a. MASAC is aware of multiple reports of PwBD being denied access to residential SUD treatment facilities, despite being appropriate for admission.
 - b. Every person, assuming they are medically stable and otherwise appropriate for admission, should have equal access to residential/inpatient SUD treatment facilities, regardless of their inherited bleeding disorder diagnosis, the treatments/medications they use, or state in which they live.
 - c. The role of a comprehensive hemophilia treatment center (HTC) is to provide holistic, individualized patient care, and to support and advocate for PwBD throughout their lifespan. This includes ensuring that the BD and associated treatments are not barriers to a person's SUD care and that the PwBD can continue to receive the standard of care for their BD while residing in a SUD treatment facility.

- II. Background on bleeding disorders (BD)
 - a. Inheritable BD are lifelong, genetic conditions with no known cure.
 - b. Provided a PwBD is stable (see section III for definition of stability from a BD perspective) and can maintain their established treatment protocol, having an inheritable bleeding disorder should not preclude a person from receiving SUD treatment in a residential/inpatient setting.
 - c. PwBD who are stable and well-maintained on their medication typically live in the community and do not require any direct medical supervision related to this condition. They typically lead full, active, and independent lives.
 - d. There are no restrictions for activities except participation in contact or collision sports/activities that could result in significant physical injury.

 - e. PwBD managed through prophylaxis

- i. One subset of PwBD (e.g., some individuals with hemophilia A or B, severe von Willebrand disease, and other rare BD) use BD medication prophylactically to prevent bleeding.
 - ii. Depending on the type of medication utilized, they are administered either as an intravenous push or as a subcutaneous injection. Typically, intravenous infusions take approximately 5-10 minutes. Medications delivered subcutaneously can be administered in under one minute.
 - iii. For this subset of PwBD, prophylactic treatment is required to ensure stability from a BD perspective.
 - iv. PwBD managed through prophylaxis may also require BD medication to treat bleeds in the event of trauma or injury.
 - f. PwBD managed episodically
 - i. Another subset of PwBD (e.g., individuals with moderate or mild hemophilia A or B, or mild or moderate von Willebrand disease, other BD), do not require regular BD medication to maintain stability from a BD perspective and typically only treat in response to trauma or in advance of an invasive medical procedure.
 - ii. The BD treatment team should be contacted upon admission to advise the facility regarding the PwBD's individualized care plan while at the facility.

III. Medical stability from a BD perspective

- a. BD stability from on-going / management perspective
 - i. BD stability is determined by the BD treatment team.
 - ii. For PwBD, BD stability is defined as adherence to an established treatment regimen and/or minimal to no spontaneous bleeding.
- b. BD stability from an acute perspective
 - i. A PwBD with a major, active bleed is not stable. Major, active bleeds (e.g., deep soft tissue bleeds, gastrointestinal bleeding, intracranial hemorrhage) require treatment in an inpatient medical setting and are not appropriate for admission to a residential / inpatient SUD facility.
 - ii. PwBD with minor bleeds who have been cleared by their BD treatment team to manage their BD in the outpatient / community setting, are stable and eligible, from a BD perspective, for admission to an inpatient / residential SUD treatment facility.
- c. Importance of maintaining established treatment protocol for BD stability
 - i. MASAC is aware of situations where PwBD have been asked to discontinue their prophylactic treatment as a prerequisite to admission to treatment facilities.

- ii. Asking a PwBD to discontinue their BD treatment in order to secure SUD treatment would be a gross violation of the standard of care.
 - iii. Maintaining the PwBD's established treatment protocol is essential to ensuring BD stability and significantly reduces the likelihood that SUD treatment will be interrupted by bleeding events.
- IV. Distinguishing medical complexity from a stable, rare, genetic medical condition
 - a. BD are rare, genetic, chronic conditions that are unfamiliar to many providers which may lead them to assume that the daily management of the condition is complex. However, if a PwBD is stable (as defined above) and has an established treatment protocol (individualized treatment plan) from a hematologist, the daily, on-going management of the condition is straightforward and not complex.
 - b. Stable PwBD typically manage their condition in accordance with the established treatment protocol in the community. They do not require hospitalization, frequent medical visits, remote monitoring, or medical supervision.
 - c. It is important to recognize that over the course of their disease or disability, a subset of PwBD will be unstable from a bleeding perspective or will require treatment protocols that are sufficiently complex as to require management in a hospital setting.
 - d. PwBD who are not medically stable are not appropriate for admission to an inpatient or residential SUD facility that does not have the expertise and resources of an inpatient medical facility.
 - e. If the PwBD experiences a medical event unrelated to their BD during a stay at an inpatient / residential treatment facility, the facility should treat the PwBD in accordance with the usual standard of care.
- V. Accommodations that will facilitate the PwBD's medical stability from a BD perspective and enable the PwBD to complete the required SUD treatment.
 - a. Prior to admission, the PwBD's care team should create and share with the SUD facility an individualized treatment plan for the PwBD that includes an emergency action plan. The emergency action plan should include emergency contact information for the BD care team.
 - b. PwBD managed through prophylaxis will also require:
 - i. Access to prescribed BD medication,
 - ii. Secure, climate-controlled storage for BD medication and supplies,
 - iii. Time during the day to receive BD medication,

- iv. Permission to administer (self-infuse or inject) the BD medication or a provider to administer the BD medication (staff or external),
 - v. Private space in which to administer the BD medication (e.g., a medication room or a private office)
 - c. PwBD managed episodically may also require:
 - i. Some of the accommodations described above (for the PwBD managed through prophylaxis) in the event of an injury or other bleeding event.
- VI. Self-infusion / injection for PwBD
 - a. Some PwBD may have the ability to self-infuse / inject their BD medication while other PwBD will require the assistance of a provider to administer the infusion / injection.
 - b. The determination of whether the PwBD is able to independently self-infuse / inject their medication should be made by the BD treatment team in cooperation with the PwBD.
 - c. If the BD treatment team, the PwBD and the facility agree that the PwBD will receive their BD medication through self-infusion / injection, the facility will need to provide the following accommodations in addition to those described above:
 - i. Presence of a staff member to ensure that only the BD medication is infused / injected, thereby protecting the integrity of the SUD recovery process.
- VII. Additional recommendations for providers of PwBD
 - a. Local hemophilia organizations along with HTC and other providers who care for PwBD should be encouraged to establish relationships with their preferred residential/inpatient SUD treatment facilities prior to need.
 - b. BD treatment teams should support PwBD in getting access to SUD facilities by educating facilities about BD and collaborating with SUD facility staff about the best way to ensure that the PwBD is able to maintain their established BD treatment protocol while receiving treatment at the facility.

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