



Supporting Independence for Hemophilia Patients and Caregivers

US Bioservices Specialty Pharmacy



Independence is an important part of life, but for hemophilia patients and their caregivers, additional steps may need to be taken to obtain—and maintain—a sense of normalcy. Hemophilia is primarily a genetic condition where patients are born with a deficiency of a specific clotting factor protein in their blood. Although diagnosis can range from mild to severe, all hemophilia patients require factor replacement therapy to maintain their condition. Parents, caregivers, and eventually patients take responsibility for administering infusions to maximize speed to therapy for a bleeding episode.

Fortunately, treatment improvements have made it possible for a child diagnosed with hemophilia to live a normal lifespan, and patients don't have to look farther than their specialty pharmacy for disease-specific resources and support.

Jannifer Stovall, US Bioservices' National Director of Nursing, shares some ways our pharmacy's specialty infusion nurses help patients and their caregivers develop greater autonomy by administering infusions independently.



Treating the whole patient

According to Stovall, greater patient independence starts with holistic patient support. Because most hemophilia patients are diagnosed at birth, parents typically play an integral role in administering infusions for their children, but home infusion doesn't automatically make things easier for families. Because parents are fearful of accidents or bleeding episodes, they are often anxious about leaving their young children with individuals who don't know how to administer therapy. This additional stress can often affect their willingness to spend time away from their children or carry out normal day-to-day activities. Stovall states, "Without an additional support system, parents of factor patients are often limited in their ability to sustain a normal quality of life for their families."

US Bioservices specialty infusion nurses encourage patients and their families to manage the condition rather than letting it manage them. Our nurses consider the entire family's needs when providing support. According to Stovall, "We focus on the family because the family affects the patient and the patient affects the family." Our nurses recommend that parents identify several additional caregivers who can be trained to administer therapy. This increased patient support system creates greater peace of mind and more flexibility for parents while ensuring patients receive better overall care. In addition, our nurses encourage patients and families connect with their local chapter of the National Hemophilia Foundation or other hemophilia-focused patient advocacy groups for additional community support and resources.



Individualizing training and support

Our specialty infusion nurses provide extensive training for patients, their families, and other individuals who may need to provide patient care. Stovall states, “We understand that infusing is not easy, so we provide as much training as needed to ensure our patients and their caregivers are comfortable with the process.” The amount of time needed to learn proper infusion techniques varies from person to person, so our nurses give the patient or caregiver the flexibility to determine when they’re ready to administer independently. This individualized approach alleviates stress and increases confidence. Our nurses “bring life-like teaching models and resources with us to help patients and their families practice administering infusion on an apparatus before attempting it on the patient,” said Stovall. These tools allow caregivers and patients to practice infusions in a non-intimidating way.



Additionally, US Bioservices offers 24/7 access to our clinicians and infusion nurses who are available to answer dosing questions and provide infusion-related support.

Because young patients may spend significant time at school, training opportunities can extend beyond the home. Our infusion nurses can work with the school nurse as well as teachers to ensure they have the knowledge and training to provide care in the event of an accident or bleed. All of these training resources foster greater confidence with the infusion process, which ultimately improves quality of life for the entire family.

Utilizing innovative technology

Even patients and caregivers who are confidently administering infusions in the home still face additional challenges maintaining a sense of normalcy. Factor replacement therapy requires precise temperature control, and as Stovall points out, “it isn’t uncommon for factor vials to take over the lion’s share of the family refrigerator, especially if there are multiple hemophilia patients in the home.” US Bioservices is part of AmerisourceBergen, a global healthcare solutions company, which allows our pharmacy to offer innovative patient solutions. ASD Healthcare®, also an AmerisourceBergen company, offers the myCubixx® medication management and storage solution that safely stores critical, temperature-sensitive medications like factor inside homes.

US Bioservices is now beginning to offer this technology to patients, and Stovall is excited about the possibilities the compact unit will provide. “[The myCubixx® system] helps patients manage factor inventory and keeps them in constant contact with our pharmacy. Because the unit is small, it can be stored in a bedroom where patients can easily and discretely access the medication when it’s time for an infusion,” said Stovall. Our specialty infusion nurses are currently working to introduce our hemophilia patients to the myCubixx® technology with the hope that it can promote greater independence and improve patients’ ability to manage their condition effectively.



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