

Infusion Logs

As the mother of a fifteen-year-old son with hemophilia, I'm no stranger to keeping an infusion log. I have received lots of positive feedback over the years from our hematologist and staff regarding the ease of which they can locate information during our yearly visits. As a registered nurse, I know the importance of documentation and organization. It is my hope that I can share some of my experience and it will give you ideas to make your record keeping both easier and beneficial to you and your provider.

Document! Whether you infuse Factor on a schedule or an as-needed basis, it's important to document when and why treatments are given. Keeping track of infusions can seem like the least important part of the infusion process, but it's actually a valuable tool in tracking and sharing information with your local treatment center. The following information is intended to help you with record keeping, whether this is your first or one of many infusions.

Why do I need to document every infusion?

There are many reasons. Unfortunately, we all know how expensive Factor is and so do insurance companies. Most everyone infuses at home these days. As a result, local treatment centers and insurance companies lose track of the doses and frequency given. When dispensing thousands of dollars every month in Factor, they need to know if it is necessary and that it is being used appropriately. This is where the infusion log comes in.

Not only is it important to know when and how much Factor is being given, it's also important to know **why**. **Keeping an accurate record of infusions can provide valuable information related to trends that may be developing.**

For example, you may notice that you tend to have an increase in the number of bleeds in the winter when you're skiing. As a result, you and your provider might want to discuss prophylaxis during those months. Maybe this is the fourth time your child had a bleed in his right ankle this year. **Multiple bleeds could indicate a target joint is developing.**

Or maybe you didn't realize most bleeds used to resolve in one or two doses and are now taking three or four doses.....*Could an inhibitor be developing?* As you can see, changes can be subtle. **An infusion log can help detect changes, so early intervention can be implemented.**

Once you've found a method of tracking your infusions, the next step is to determine what information to include. You can keep as much information as you need, but the basics to include are:

- Date and Time
- Dose
- Lot Numbers
- Reason for Infusion (Prophylaxis vs. bleed)
- Location of bleed (if any)

Keeping an Infusion Log

This does not have to be a daunting task that takes up all of your time! There are many ways to document your infusions, and no one is better than the other. It just depends on what works best for you. You can keep anything from a computer file to something as basic as writing it down on notebook paper. BioRx provides a booklet in which you can write your infusion information. Many Factor companies offer online services to help you with your record keeping. The possibilities are endless.

When we infuse our son, we tear the lids off the Factor box. This gives the lot number and units and we just write the date and time. If there was a bleed at the time, we write that too. We keep the lids in a safe place until we are ready to enter them into the computer.

It's a good idea to highlight in some way the infusions that were due to a bleeding episode, so they can be easily identified during your office visits. I record infusions on the computer and use bold print to show the bleeding episodes.

It's also a great idea to get your child started in this record keeping process as soon as possible. Creating this lifelong habit early on will give them tools for successful infusing later in life where they too can identify problems early on.

It's really that simple! Just remember, if you're keeping track, there's really no wrong way to do it. **Be creative and find what works best for you!**

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