WHY KEEP AN INFUSION LOG?

It's Monday morning and you're running late for work. You started treating a bleed yesterday and are supposed to treat again this morning, so you hurriedly perform the infusion and rush out the door. Did you record the treatment in your infusion log? Not this morning…you are already running late. Will you remember to record it this evening when you get home?

Life is always a rush and there are no guarantees that time will be available at any certain time of the day, so it is important to make recording treatments in your infusion log a part of your normal infusion routine. At first, keeping your log will be a matter of discipline and commitment, but as time continues it will become second nature.

So, why keep an infusion log in the first place? Will you keep it because your treatment center, pharmacy, or insurance company requires it or will you keep it for yourself? Think about it. Just as daily entries into a diary tell stories about a persons life, your infusion log tells a story about your hemophilia. This story, when shared with your healthcare team, provides opportunities for better care, ultimately resulting in a better quality of life for yourself.

There is a lot of valuable information that can be obtained from a properly kept infusion log, such as when and how much factor was infused, the purpose of the infusion, the site of the infusion, and the outcome. Why is this important? Consider the following stories, keeping in mind that while your story is likely to be different, your results could be just as beneficial.

Story 1:

A teenager with Severe Hemophilia A, who is a competitive swimmer on his high school team, has been treating bleeds on demand. When he goes to the HTC for his annual appointment, he takes along his infusion log which shows an average number of 15 infusions, at 50 units/kg each, per month. After a discussion about the findings, the patient and physician agree to try a prophylaxis regimen involving three infusions, at 30 units/kg each, per week. The patient continues to keep records of all infusions in his infusion log and returns to the HTC for a check up after 6 months. The infusion log reveals that the 12 monthly prophylactic infusions were sufficient to prevent most bleeds. The patient only had to treat 2 additional bleeds in the six month time frame.

By examining the patient's infusion log, the physician was able to recommend a dosing regimen that decreased overall factor usage (by an average of 3 doses per month and 20 units/kg for each prophylactic dose) and prevented further joint damage. This patient also reported less pain with the prophylactic dosing regimen due to decreased frequency of bleeds.

Story 2:

A 33 year old patient is prescribed a high-volume factor medication, requiring lengthy infusion times. As requested by his HTC, the patient keeps records of all bleeds and treatments in his infusion log. When he turns in his infusion log records, his physician notices that the patient has not infused the full amount of medication prescribed for each treatment. In addition, the patient had to perform excessive numbers of infusions (4-5) to treat each bleed. When questioned as to why this occurred, the patient admitted that he often doesn't have the time to infuse the entire dose, so he had only been infusing a little more than half the prescribed dose per infusion. This caused him to have to treat each bleed multiple times. Based on the information provided, the physician decided that it may be beneficial for the patient to try a different medication that would allow him much shorter infusion times. The patient voiced concern that he would have to use this new medication much more frequently, however he agreed to try it.

He returned to the HTC after 3 months for evaluation of his new therapy. At this visit, the patient's infusion log showed that he had infused each dose appropriately and thus each bleed was able to be treated with 2-3 doses of factor and his reported pain levels were lower than previously reported.

These are just two examples of how documentation can help promote better outcomes. Keep infusion logs handy, with your supplies or medication. Make time in your routine to fill them out. Chances are you'll be glad you did. By reading your story, you and your healthcare team are more likely to make better decisions about your care.