

Sites of Care

Josh Harrison was at his computer, playing World of Warcraft,* when he messaged the person he was playing with that he had to get up and go for a minute.

“Where are you going?” asked the other player.

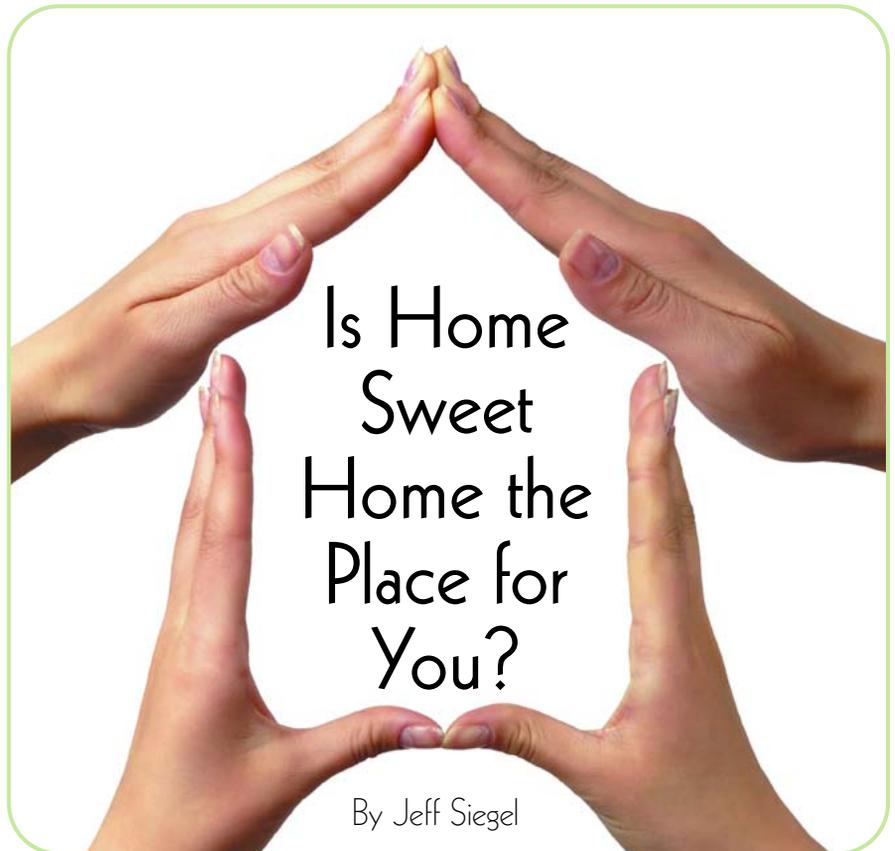
“Oh, I have to go do something for my infusion,” said Josh, a 17-year-old in suburban Seattle who has X-linked agammaglobulinemia, a primary immune deficiency. And with that, he turned away from the computer and did what needed to be done, returning to the game a few minutes later.

And it’s just part of a day in the life of someone who receives their immune globulin (IG) infusions at home. Many in the IG universe are hospital outpatients or visitors to infusion suites or doctor’s offices. But a growing number are doing it at home—whether it’s more convenient, whether they don’t feel comfortable in a clinical setting, or whether they just think it’s best for them. By one estimate, as many as 1 million people across the United States may be receiving infusions at home.

“It’s not really that big a deal anymore,” says Josh, who has been getting infusions for most of his life. “I can use the computer, I can watch TV or whatever. The nurse takes the vitals, and then I can take the IV out. I’m really not squeamish about it.”

Yet, having said that, doctors, homecare experts, and even patients acknowledge that home infusions are not for everyone. The option may be growing in popularity, thanks to improved technology, physicians more willing to recommend it, and an emphasis from the insurance industry to shift patients out of hospitals and doctor’s offices, if possible.

“But there are people who shouldn’t do it,” says Jordan Orange, MD, who teaches at the University of Pennsylvania’s Medical School and is on staff at Children’s Hospital in Philadelphia in the division of immunology. “They might be more subject to adverse events and could need direct and expert supervision. But the majority who



receive infusions without any difficulty, those people are afforded a choice with homecare.”

Infusing at Home

An infusion is pretty much the same wherever it’s done, whether it’s the equipment, the drugs or the procedure. After all, an IV is an IV, regardless of the setting.

What’s different—and this is a crucial difference—is that, at home, the patient is in charge of the procedure. That means lining up the equipment, ordering supplies, and, in some cases, actually performing the infusion.

“Now, for us, things have gone smoothly,” says Catherine Beal of suburban Cleveland, who does all of that for her 7-year-old son, Jacob, a primary immune deficient patient who receives his infusions subcutaneously. “But we’re not the first family our immunologist switched to home, so things were in place for us. We knew what to expect.”

Typically, people who want to do home infusions must understand:

- **The role of their specialty pharmacy or homecare service.** These companies—some local, some ➤



regional, and some national—provide the equipment, drugs and supplies as well as the nurse who does the infusion, monitors the patient's vital signs, and is in the home if there is an emergency. Beal says that next to a supportive doctor, a first-rate specialty pharmacy is a must for home infusions. One note about equipment: It's much smaller and takes up less space than ever before. The Harrisons keep everything they need in a large Tupperware-style container that slides under a bed.

- **What their insurance will and won't cover, plus the various network and out-of-network benefits and limitations.** Generally, though it's not a hard and fast rule, insurance companies don't mind seeing infusions done at home (part of their philosophy that the more healthcare provided outside of a hospital, the less it's going to cost). But each insurer is different, and anyone interested in home infusions needs to understand their coverage thoroughly.
- **How it's done.** Who will infuse the drug? Who will take out the needle? Where in the house will it be done? When will it be done? What equipment is needed? Where will it be stored? What happens if there's a power failure during the infusion, and the pump stops working? If something goes wrong, where is the phone? Who is supposed to call 911? Some of these questions can be answered by the physician or specialty pharmacy. Some can best be answered by talking to parents and patients who already do home infusions.

"What we're seeing is the market continue to grow for this," says Katherine Werner, vice president, professional affairs, for the National Home Infusion Association in

Alexandria, Va. She estimates that there are 4,000 homecare providers in the United States, with an average of 250 patients each (and that number is probably conservatively low).

"And there is still a lot of growth possible for this market," says Werner. "As you see more biotech products come out that require infusions, you're going to see more acceptance of home infusions. We've come from where we've had a hard time convincing physicians and payers to pretty much that it's acceptable and safe."

Making the Choice

Who is a candidate for home infusion? That requires agreement between the physician and the patient, and the patient's parents, if necessary. It's not for everyone. The first question to answer, say doctors, experts and patients, is whether the patient wants to do it. If not, none of the other advantages—convenience and flexibility foremost among them—matters. Some people, says Dr. Orange, prefer doing it in a hospital or infusion suite—whether for the social experience or because they feel safer there than having the infusion at home. "It's a quality of life issue," he says, "and there are personal reasons for what people do."

One key resource for evaluating the option of homecare, says Orange, is the IVIG toolkit, available at the American Academy of Allergy, Asthma & Immunology website at aaaai.org/members/resources/initiatives/ivig.stm. In addition, he recommends that anyone interested in home infusion check out the AAAAI site-of-care guidelines for administration of IVIG, which are part of the toolkit.

The second consideration is the patient's health.



Typically, says Werner, home infusion is used only by people with chronic diseases like primary immune deficiencies or other immune system-related illnesses. Someone who needs infusions only for a relatively short period isn't a good candidate, since the effort to set up the home infusion system is greater than the benefit they'll get from it.

Additionally, the patient should be able to handle the overall infusion process well. This means not only that they don't have any serious adverse reactions from it, but that they're comfortable with it, understand it and know what's required to do it.

"I think the age of the child is important," says Carol Harrison, Josh's mother. "A teenager is going to have less trouble at home than a toddler. It's about temperament. Some kids just don't do well with that sort of thing."

Seven-year-old Jacob Beal is so comfortable, in fact, that he does his subcutaneous infusion while he is sitting in class. His mother puts the needle in before he leaves, and the pump, about the size of a large billfold, is in a fanny pack around his waist. When the infusion is complete, Jacob removes the needle. Plus, his mother says with a laugh, when someone asks Jacob what he's doing, her son can describe the process accurately and precisely. "We've worked hard to help Jacob understand exactly what's going on," she says.

Even then, there are caveats. The school administrators know what Jacob is doing, and Catherine works in the same building. Whenever doing a home infusion (and especially if there isn't a nurse handling the infusion), make sure someone else knows what's going on, when the infusion is taking place, and how long it should take. Older kids who do it themselves have a tendency to not

want to tell anyone what's going on, which can lead to problems if something goes wrong. Anyone who does it themselves must realize they aren't soloing.

Which is the case in point. If someone doesn't want to go to that much trouble, then they shouldn't do an infusion at home. Says Catherine Beal, whose son has had home infusions for three years: "A lot of it is because of our schedule. I'm a working mom, and now that Jacob is older, he needs to be in school."

Scheduling, says Carol, also has a lot to do with why Josh does his infusions at home. Interestingly, when he started infusions in the late 1990s in the San Francisco Bay area, it was less expensive to do it at home than as an outpatient. It really has never been a problem for her son. "Overall, it really went very well," she says. "He was quite a good patient. By the time he was 3, he had learned it was in his best interest to cooperate."

Which is something Josh still understands. Or else he wouldn't be able to do it as well as he does. Save for drinking extra fluids to prepare for the IV, his home infusion doesn't seem to be that much of an inconvenience, he says.

And his mother agrees. "People are really interested in it," Carol says. "The ones we've talked to say it's a positive thing. And trust me—the stress level goes way down when you're doing it at home. It beats driving all that way and then sitting in the office. The benefits outweigh the small problems."

And besides, Josh gets to play World of Warcraft while infusing. ■

* World of Warcraft is a registered trademark of Blizzard Entertainment Inc.