

Distraction Techniques



Though these may not be helpful for Hemlibra injections, using **Buzzy Bee** or **Buzzy Lady Bug** ice pack with vibration may help if giving an infusion. According to a study published in Acta Biomedica, Buzzy has been found to lessen the perception of pain for kids. It particularly works well for kids aged 7-10.

Jody Thomas, PhD, states, "Most people don't realize that pain is actually 'in our head.' When our body feels a possible threat, it sends a warning signal along our nerves to the brain. But there are ways to stop the signal from reaching our brain. One way is to use

vibration on the skin to create a traffic jam in the nervous system. When we place a vibration tool on the arm (or leg for younger kids) just above the injection site, it stops the signal, changes the sensation, and prevents the pain."

While not for everyone, some kids (and adults) have found this helpful.*

iPad/Cartoons/Video Games. If your child has a favorite show or cartoon, sit down to watch the show while they're being treated. Paw Patrol, Bluey or any other type of show that mesmerizes your kid are good options. If you've ever tried to get your child's attention during one of these shows, you understand.



Blowing Bubbles. Not only do the bubbles distract younger kids, but the deep breathing they need to "blow" is an extra benefit. Breathing deeply into the diaphragm helps the body release tension.

Older kids can practice breathing techniques and imagine that they're on a beach or a special place they enjoy.



Just as teens respond to talking during treatment, toddlers respond to **flashing lights, light wands, or interactive toys.** They may also want to hold a special stuffed animal or blanket while getting their treatment.

Give **singing or counting** a shot. (No pun intended.) If you can, get the whole family involved! At the Toledo HTC, the staff sings together on occasion to help younger kids during their treatment. One nurse not only sang funny kids' songs, but also did impressions of animals to humor the kids and distract them from the infusion.



Try the **Magic Glove Technique** for factor infusions. This works well for Heather Hutzl, MD. Lull your child into a relaxed state and tell him that he's putting on a magic glove. Rub each finger and the hand as if you're putting on the magic glove. You might even put on EMLA cream on the site while you're doing this. Using their imagination that the magic glove will help them get through the infusion may relieve anxiety.

Continued on back page

According to Kristen Peace, RN, "**Jolly Rancher sour/sweet suckers** work great to trick the brain to lessen pain. For younger kids, give them a sucker right before the infusion. Let them know it's a "Magic Sucker" that helps to make the poke easier or help them not to even feel it! Let older kids know the sour part of the sucker 'tricks your brain' so you don't feel it!" Kristen says she has had excellent responses to this nifty trick and it's the one they use most often.



Oddly, according to one study sour tasting candy promotes riskier behavior.* This doesn't mean that your child will act irrationally, it only seems to help them overcome risky situations.

Resources
Taking Fear and Pain Out of Needles—for Your Child and You
healthychildren.org/English/safety-prevention/immunizations/Pages/Managing-Your-Childs-Pain-While-Getting-a-Shot.aspx

* Vi, C. & Obrist, M. (2018) Sour promotes risk-taking: An investigation into the effect of taste on risk-taking behaviour in humans. *Sci Rep*, 8(1), 1-8. doi.org/10.1038/s41598-018-26164-3

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A Message from Cascade's Colleen Joiner, Social Worker



Colleen Joiner, LMSW, CCM
Clinical Care, Education & Outreach Manager

Dear Readers,

According to Heather Hutzl, PhD, from Children's Hospital of Orange County, "One in ten children nationwide are so afraid of needles that it is debilitating." Many parents in the bleeding disorders community have been through the "right of passage" of helping their child through treatment and the challenges it can sometimes present.

Although we know that most kids outgrow their fears, some continue to have challenges. Kids who have mild or moderate bleeding disorders, for example, infuse less frequently and it may take them longer to adjust. Heck, even some adults dislike needles or fear infusions and injections!

Your goals are to help your child learn ways to cope with the psychological anticipation of a needle stick and to minimize the perception of physical pain. Fear of treatment can vary from child to child, but remember, it usually gets easier. Hopefully, some of the suggestions in this issue of the newsletter help along the way.

Cascade Hemophilia Consortium Mission

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research.

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Helpful Tips for Treatment Success



Jennifer Luitje, BSN, RN
Bronson Methodist Hospital HTC

"If you're able to have another person help with infusions, divide the job. Have one person responsible for distraction, while another does the poke. And keep in mind that kids go through healthy developmental stages that may challenge the power dynamic of your relationship. Your child may have been fine with infusions at age four but have difficulty in later years. This is normal. Please call your treatment center for advice or infusion assistance if needed."



Kristen Peace, BS, RN
Toledo ProMedica HTC.

"Kids who have been infusing their whole lives tend to adjust to treatments as they get older. Although some kids will regress once the port is removed and they begin to infuse or inject their product, most kids outgrow their fear over time. In my experience, two-year-olds are the most challenging as they have an extremely tough time staying still and don't react well to being held down. Luckily, they tend to outgrow that stage."

Setting the Stage

Being prepared for your child's treatment helps set the stage for a better experience. According to Kristen Peace, RN, "It's always helpful to set up the supplies prior to the infusion so that you can foster a routine and casual process. The most important thing to remember is to keep the environment calm and make treatment a part of the normal routine."

Regardless of whether you're infusing a factor product or injecting Hemlibra, cultivating a soothing environment often helps with anxiety. Experiment with playing soft music or, if your child likes to be held, give them some "love" during treatment.

If your child is infusing a factor product, be sure they are well hydrated to increase the volume of his or her veins, particularly if vein access is a concern. To help, a warm shower or bath right before treatment can also increase the ease of an infusion. Or you can place a heated pad on the injection site to help dilate the vein if that is an easier solution.

Some parents find EMLA cream helpful if applied to the area a half hour before the injection or infusion. It may numb the skin and lessen the perception of pain. However, EMLA cream may constrict the veins, so if vein access is an issue ask your doctor if this is right for you and your child.

Jennifer Luitje, RN, offers another helpful tip. "Many parents place their toddlers in a highchair near a TV for infusions. This can help your child get used to infusing while sitting up. You're also physically at the same level. Standing over them as they are laying down tends to increase anxiety."



Help Your Child Feel More in Control by Encouraging Participation

Give your child some level of control by allowing them to be an active participant in the treatment process. This tends to help children feel more in charge and less vulnerable. Jennifer Luitje states, "It's important to set yourself up for success. You want to avoid questions that can result in a 'no' response. For example, don't ask if 'they are ready for their shot?' which may promote a power struggle."



Questions such as, "Do you want to sit at the kitchen table or on the bed?" or "Which arm would you like to get your poke today?" or "Would you like your poke before or after breakfast today?" gives your child control. Offering your child reasonable choices not only promotes participation but helps them feel more agreeable to the process.

If age-appropriate, allow your child to hold or set up the supplies, press the plunger of the syringe, or tape down the butterfly needle. This not only helps build your child's confidence and lower anxiety, but it also starts the early learning process to eventually infuse themselves one day.

Siblings can also get involved in setting up the supplies. Allowing them a chance to participate helps some siblings feel included according to many parents.

Outside of treatment time, parents of young kids have offered their child to "infuse" a teddy bear or even watch older kids infuse if they can. And if your child is old enough to go to camp, it can be an incredible way to help them see other kids infuse or inject themselves. At camp, kids as young as 7-8 years old learn to complete their own infusions for the first time.

Use of Words

According to one study published in Brain Behavior in 2019, researchers found that pain-related and negative words made the intensity of pain worse than neutral language.

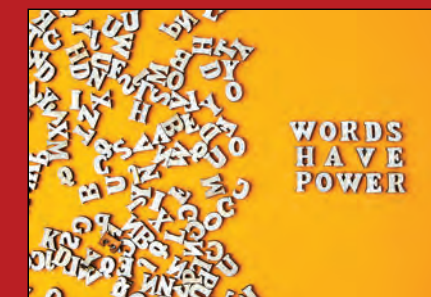
Words (and their meanings) can illicit strong feelings even if we're not conscious of their effect. Try to choose your words wisely. Instead of the word pain, use something similar such as discomfort. Instead of needle or shot, try using the word "poke." Some words activate the flight or fight response, and these words aren't as emotionally charged.

Allow your child to express their fears if they have them. Talk openly and let them know it's okay to not like needle pokes. Fibbing by saying it won't hurt at all can cause mistrust. Instead, remind them that they were brave before and assure them they can manage this too.

Many child life specialists suggest asking your child to describe their experience rather than telling them how it feels. Instead of saying "This might sting," say "Tell me how it feels." Or instead of "Be a big boy," say "When I count to three, blow the feeling away from your body." Instead of "Don't cry," say "that was hard, but you did it!" Encouraging words before and rewarding words afterward can go a long way.

Resources

Needle Know-How Hemaware by Heather Boerner, May 29, 2020. hemaware.org/life/needle-know-how
Can Words Change the Brain? Psych Central: psychcentral.com/blog/words-can-change-your-brain



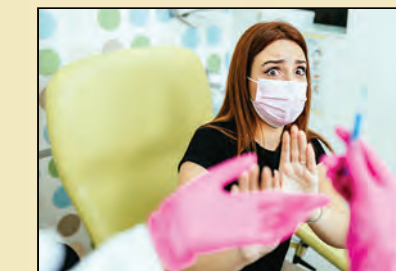
Rewards (Not Bribes)

Some parents like to place stickers or stars on a board for each infusion. When your child gets through the week, you can offer something special to do together. Though try to avoid making it sound like a bribe. "Bribes are finicky," says Jennifer Luitje, RN. "Your child may not want what you are offering on a particular day. And the nature of a bribe is that it needs to be increased each time." One alternative is to casually say, "After you get your medicine, we'll go to the park and play." Even giving a hug or verbal praise afterward can also be a reward. Of course, the big reward for parents is that their child gets their life-saving treatment.



Recognize Your Own Emotions

It's completely human for parents to have their own feelings about infusions. Whether it's your own fear of needles, frustration when having difficulty finding a vein, or guilt at having to infuse your child, please remember that you're not the only parent to experience these feelings.



One new mom in the community admitted her fear of needles. On one occasion, she was once asked to step outside while her 7-year-old child was being infused. She was initially puzzled, and even slightly offended, but the physician kindly explained to her that her own fear of needles was affecting her child. This was her "a-ha" moment. Her son, sensing mom's clear discomfort, became upset at each infusion. Once out of the room, her son was treated with little issue. After recognizing this, mom was happy to work on her own responses for future treatment.

As one wise mother once said, "I try to be like a duck around my kids. Above the water I'm very calm but I try to not let my child see my feet kicking below the surface."

If your child struggles with treatment, please remember that you can speak with your HTC Nurse or Social Worker about ways to ease their fears. Also, many hospitals have child life specialists available to lend a helping hand.

