



Complex Child E-Magazine

www.ComplexChild.com

Living with a Nurse in the Home: Suggestions, Stories, and Solutions

by Varsha Daryanani

The thought of having a complete stranger take care of your child is never easy. When you add in the complexities of a child with special needs, that thought becomes downright nerve-racking. Logically speaking, knowing that the caregiver is a registered nurse, licensed vocational nurse or certified nurse assistant should put your mind at ease. Who better to take care of your child than a trained professional? But as a parent, we are naturally inclined to feel that we are the best caregivers for our children. If we leave them with a nurse, we can't help but wonder if the nurse will give the medicines in the right order or start the feeds on time. Giving up a little control of our children's daily activities is never easy. In the long run, however, it will benefit your child because it will give you a chance to recharge and refresh from the challenges of raising a child with special needs.

Dealing with nurses is not new to us. When our children are hospitalized, we entrust these professionals to take care of our children, even though many of us never leave the bedside. That being said, having a nursing professional in your home is a whole different ball game. All of the sudden, you've got another individual in your home and in your space. How do you cope? Here are some tips:

- 1) **Tell the nursing agency exactly what qualities you are looking for in a nurse.** Ask how long the nurse has been working for the agency. Ask if the nurse specializes in pediatric care. Also ask if they can give you any referrals. Perhaps you could speak to some other families that have used that nurse. Remember, all nurses are different and some will mesh better in your home than others.
- 2) **Teach the nurse *exactly* how you like things done.** Yes, the nurses are trained, but everyone has his or her own style. If the nurse does things just like you do, then your child will feel at ease. Encourage the nurse to ask questions if anything is not clear.
- 3) **Set parameters.** Let the nurse know where she is allowed to go in the house. If there is any particular area that is off limits, tell her. Also, let her know if she can use your kitchen. If you don't allow certain foods into your house (e.g. because you are vegetarian), then let the nurse know. Bottom line is that the nurse is the "guest" in your house and should abide by your rules.

- 4) **Provide feedback!** I asked my nurses what they wish parents would or would not do. All of them said, “Give us feedback!” If the nurse is doing something that bothers you speak up immediately! You can’t expect him to read your mind.
- 5) **Learn to let go – just a little.** I remember the first time I had a night nurse. I heard my daughter wake up in the middle of the night and I had such a strong urge to go check on her, but I forced myself to stay put. The nurse was with her and I had to let her do her job. Plus, I knew that if anything was terribly wrong, the nurse would come get me. It will take time to let go, but as you get to know the nurse, it will get easier.

Fortunately, I’ve been blessed with great day nurses and a fantastic night nurse...but it took me some time to find them and train them. In the interim, I’ve had my fair share of bad experiences. A couple of nurses we had felt inclined to just sit in the rocking chair and watch TV while my daughter sat in her swing or bouncy chair. Not acceptable! Just because my daughter is not mobile doesn’t mean that you can leave her in a corner. She needs to be stimulated and entertained just like any other child. And just a couple of weeks ago, I saw another nurse put hand sanitizer on my daughter’s body like it was lotion! The nurse didn’t speak much English so I don’t know if there was a language barrier, but I just about passed out when I saw that. Needless to say, that nurse won’t be coming back to our home.

Despite these experiences, I must admit that having nursing help in the home has been a huge blessing. I don’t feel as overwhelmed anymore and I think that has actually made me a better mother. I finally have time to go to the gym, run my errands in peace and even get some down time. I am so confident in my nurses that I have even planned a weekend trip away in April. It will be my first time away from my daughter and I will probably be a nervous wreck, but I know she will be in good hands and I will finally get my much-needed break.

Varsha Daryanani is a full-time mom to Alisha, a 2-1/2-year-old diagnosed with Wolf-Hirschhorn Syndrome and Cerebral Palsy. Prior to becoming a mom, Varsha was a Commercial Real Estate attorney for a mid-size California law firm.