Strangers in your HOME

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How families can create a successful home health experience

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To Evelyn Pearl and everyone
who needs and deserves excellent home health care.

Contents

Introduction

I am aware that first responders, paramedics, nurses, doctors, and other health care specialists save lives every day through their intelligence, skill, and tireless efforts.

I recognize that most of the time medical professionals know what they're doing and typically care about patient outcomes.

That said, I don't trust medical professionals. I am skeptical of their decisions. I don't assume that they actually know what is best for my daughter Evelyn or that they even value her recovery, comfort, or life.

I'm not saying that I have never trusted a medical professional. I'm saying that "trust" comes with time and research. In other words, simply the title "medical professional" does not automatically invoke trust for me. I invest energy in observing, listening, and learning. Then, with caution, I choose to consent or object to their opinion.

Because, like many medical professionals, I, too, am intelligent, capable, and tireless.

And, unlike health care professionals, I truly love Evelyn, my beautiful daughter.

We found ourselves thrust into the unfamiliar world of brain injuries, first responders, medical care, and home health care when our ten-year-old daughter Evelyn was struck by lightning while playing in the yard about seventy-five feet from our back door on a Sunday evening in August of 2015.

Nothing had prepared us for the experiences that followed. We've learned so much in the years since the accident. We've also met many other wonderful families who, like us, have found themselves thrust into a traumatic, challenging, unfamiliar world with no one to guide them.

One of the most challenging arenas we've had to navigate has been working with the home health care system.

During this period since the accident, we've met some home health nurses (HHN) who were wonderful and some who made our lives worse. Most HHN are neither amazing or terrible but excel or fail, respectively, based on how we interact with them. Unfortunately, it took years before we understood the appropriate way to create a positive environment that fostered success with our HHN.

The purpose of this book is to show you how to turn your home into a professional miniature hospital with a positive environment for everyone. An environment that helps you hire, retain, and bring out the best in your nurses.

I'm writing this as a parent and also as a professional educator and consultant in the field of home health and brain injury.

In addition to professional consulting and speaking, I work as a special education case manager in a large public high school and provide support to students with all types of disabilities, and their parents. I am also a certified brain injury specialist and have completed a doctorate degree in education.

With respect to home health, here is what I've learned:

1. The dynamics between families and home health nurses create inevitable but predictable obstacles. Those obstacles often lead to conflicts if not intentionally prevented.

2. Inviting a stranger into your home to care for a vulnerable family member is risky. You can protect your family by screening, monitoring, and preparing for misconduct.

3. There is a critical shortage of home health nurses. You can attract and hire good nurses if you create a comfortable and convenient work environment.

4. Home health nurses usually leave their cases in less than a year. Families can retain good nurses by creating a positive and professional environment.

5. You can avoid conflicts through clear communication and minimize their effects by implementing conflict resolution strategies.

Perhaps someone in your family has experienced a brain injury. Or perhaps, if you are working with home health care professionals, someone in your family has suffered a stroke, has dementia, or has cancer or heart disease.

Positive and productive outcomes with home health care are possible, but they occur only when family members know how to interact with nurses in their homes. Wherever you are in your journey, I want these pages to leave you informed, empowered, and prepared.

1 Understand the Imperfect Partnership

I do this stuff every day.

—**FIRST RESPONDER**

I started performing mouth-to-mouth resuscitation on my ten-year-old daughter right after she was struck by lightning.

As I bent over her, I was surprised by the smell of smoke. Already, her body was cold and turning greyish. She made sporadic gasps about every twenty seconds, which confused me because agonal breathing wasn't something covered in the CPR class I had taken the year prior.

I held her nose and breathed into her mouth.

The first responder was an off-duty firefighter who lived a few houses down from us. He arrived and began pumping violently on her chest.

"She has a pulse. Is that necessary?" I asked. "And shouldn't we keep breathing for her?"

"I do this stuff every day," he said. "I know what I'm doing."

The off-duty firefighter violently pumped her chest until her left lung collapsed and blood poured out of her nose.

When the emergency vehicles arrived, things continued to go awry.

Paramedics and volunteer firefighters moved around Evelyn's body slowly and without any sense of urgency. They sent a foreign exchange student who lived with us to their truck to get a defibrillator from the ambulance, then shocked Evelyn's body with a defibrillator over and over.

They were all wrong.

Evelyn was in a state of respiratory arrest, not cardiac arrest. She didn't need her heart started through chest compressions—she needed oxygen.[1] The Merck Manual and CPR training programs makes it clear: "For the purposes of respiratory arrest, the patient will have circulation and thus there is no need to defibrillate. Indeed, there is no need for chest compressions or formal CPR for that matter. Respiratory arrest management, at least initially, centers on successful ventilation."[2]

He should not have performed chest compressions at all; we should have just continued mouth-to-mouth breathing and transported her to the hospital immediately (incredibly, it took them over twenty minutes to load Evelyn into the ambulance).

The failure to breathe for Evelyn led to cardiac arrest due to a lack of oxygen and a severe anoxic brain injury that devastated my little girl.[2]

Once Evelyn was admitted into the pediatric intensive care unit (PICU), I continued to observe medical decisions that didn't sit right in my gut as a parent and that ultimately made me skeptical of all future decisions made by medical professionals on behalf of my daughter.

For instance, doctors cooled Evelyn's body, creating mild therapeutic hypothermia, by laying her on an ice-cold refrigerated mattress and administering drugs that prevented her body from shivering.

Nurses checked Evelyn consistently to ensure that her body temperature was between 89 and 92 degrees Fahrenheit. I cringed every time I saw the thermometer and can only imagine how horrible it was for her to endure a freezing body temperature for over a week.

Later, I would find journal articles that supported my unease. One study of people with acquired brain injuries showed that "long-term mild hypothermia did not improve the neurological outcome."[3] Other researchers found that patients treated with mild therapeutic hypothermia experience "increased in-hospital mortality and poor neurologic status on hospital discharge."[4]

A week after her admission to the PICU something else happened that made me question the care she was receiving. I

questioned a senior doctor why Evelyn's head was still locked in a neck traction brace. It looked uncomfortable and seemed unnecessary since Evelyn hadn't sustained a neck or spine injury.

"I understand your concern," the doctor responded, "but using a neck brace is a standard practice used out of an abundance of caution."

Two weeks later, green drainage flowed down Evelyn's pillow one evening. Unfortunately, the neck brace had prevented shifting the point of pressure and an unstageable (the worst level) bed sore the size of a golf ball had developed on the back of her head.

I also had questions about nutritional care. According to research, patients with brain injuries need an increase in calories and protein and have better outcomes when they are given food before forty-eight hours upon admission.[5] And yet Evelyn wasn't fed for three to four days—and then a product that was essentially sugar water.

Within three weeks we were informed that Evelyn would not make meaningful recovery and that we could let her "be a hero" and donate her organs or take her home and care for her ourselves there.

We couldn't imagine giving up, and we went home with a ten-year-old on the edge of brain death. Evelyn was ventilator dependent and struggled to make the slightest of movements. She couldn't swallow and had difficulty blinking. And I was

haunted by the thought of how not breathing for her during the first hour after her injury and all of the mistakes made afterward had contributed to the tragedy of her condition.

Starting from a Place of Crisis, Hurt, and Distrust

Is it any wonder that, when we began our journey with home health care, we did so from a place of woundedness and distrust? Is it understandable that I will never again place blind trust in medical experts or defer to them when I am uncomfortable with their actions regarding my daughter?

Let me continue by saying this about the nursing profession: working with home health nurses (HHN) is similar to encounters with police officers.

Most police officers are heroes who bravely risk their lives every day to keep the rest of us safe. And although the vast majority of interactions with police officers are unremarkable, tragedy has a way of compounding during times of crisis, and sometimes innocent people get hurt.

Consider Richard Gary Black who awoke to his grandson's screams in the middle of the night on July 30, 2018.[6] Mr. Black discovered that two crazed and drugged men had broken into his home. One intruder was naked and trying to drown his grandson in the bathtub. After a violent struggle Mr. Black, a highly decorated Army veteran, shot one assailant. Moments later, with his daughter-in-law screaming wildly behind him, police blared their tactical lights into Mr.

Black's face through the open front doorway and yelled for him to drop his gun. The seventy-three-year-old Mr. Black raised his flashlight toward the police officers who, fearing for their own safety, fatally shot him.

Mr. Black and his family went to bed on July 29 as a happy family. The initial nightmarish assault on their grandchild was followed by a preventable attack from responders who compounded the tragedy instead of helping the Black family.

In the same manner, families are in a state of crisis when a loved one needs home health nursing. These stressed families tend to respond inappropriately to the guidance of home health nurses, who may assault the families during their efforts of self-preservation.

Although interactions with home health nurses are usually unremarkable, there is a constant silent conflict between HHN and families. Unfortunately, families are usually ignorant about the professional medical environment. They are inexperienced at providing care for someone chronically ill. They also tend to lack resources and feel alone. In contrast to the families, HHN prioritize restricting care activities only to those in the plan of care and protecting their nursing licenses.

Medical care providers are integral in the recovery of your loved one, but your interactions and relationships with them can become counterproductive if you are not prepared to

transform yourself into a positive and professional supervisor of a home health work space.

You must learn how to protect yourself and establish an environment that promotes the health and well-being of your injured or ill loved one, despite being in a setting in which you may be viewed as incompetent, a liability, or even a threat.

Lest anyone think that I am nurse-bashing, I want to acknowledge all of the training that nurses receive and the hardships they experience in order to serve others.

Nursing is an incredibly tough career choice, and I respect them for their accomplishments and acknowledge that their profession is the backbone of our medical system. In fact, I love this quote by Dr. William Osler, one of the founders of Johns Hopkins Hospital: "The trained nurse has become one of the greatest blessings of humanity, taking place beside the physician and the priest."

It is extremely difficult to become a nurse. Nursing students are required to pass up to four years of extremely difficult science courses. My impression from nurses is that college professors seem to try to fail their nursing students through unreasonably strict expectations. In addition to their demanding coursework, nursing students complete rigorous clinical training in which the slightest rule infraction can get them removed from the program.

Impeccable criminal records are another requirement for nursing candidates. I heard of a woman who completed her four years of nursing college coursework as well as her clinical internship but was denied a nursing license by the state board due to hit-and-run charges against her following a fender bender when she was seventeen years old.

After nursing students complete the monumental requirements to become a nurse, the challenges are just beginning. I observed that nurses in hospitals endure a relentless work schedule and work at a frantic pace during their twelve-hour shifts.

Most of the nurses we encountered in a hospital setting were professional, caring, and diligent.

That said, our daughter, Evelyn, and my wife and I have experienced a great amount of hardship when working with nurses in our home.

I want to help others avoid the same.

I'll be the first to admit that part of the hardship came as a result of our ignorance. Another part came from our distrust of the medical profession based on mistakes we believe were made in the critical hours after our daughter was struck by lightning.

And part of the hardship simply came because we were reeling from indescribable pain and tragedy. After my daughter was devastated by a lightning strike, I was an emotional mess. I was depressed and fearful she would die. I felt guilt and was physically drained from a lack of sleep.

Let's face it, family members in crisis aren't in a good emotional state. They are sleep deprived. They're stressed. They're afraid. They're going to make mistakes too.

All of these things contribute to making the relationship between HHN and family members one that can be fraught with tension. In fact, terrible experiences with home health nurses are common.

But it doesn't have to be that way.

A critical perspective of nursing in the home health care environment is necessary to improve outcomes. Families who care for a loved one in a home health setting need insight from those who have experienced the same devastating journey.

The following chapters focus on common points of conflict and misunderstandings, and give specific steps you can take as a family member to minimize problems and receive the best possible care for your loved one.

2 How to Protect Your Family

The abuse, anger, and stress caused by home health nurses has been the worst part of our experience apart from the actual injury to my daughter.

—**BEN COCKERHAM**

Home health nurses (HHN) are strangers you let into your home. You must trust them to provide care for your injured loved one while you and your family are in a state of crisis, vulnerable, asleep, or away from the home.

As with any stranger you allow to have intimate access into your life, nurses can wreak havoc if you are not prepared.

For example, they can leave you stranded if they quit your case, physically abuse you or your family members, make false accusations to Child/Adult Protective Services, manipulate other nurses to turn against you, frustrate you with inadequate care, steal from your home, have an affair with your spouse, and abuse prescribed medications.

We experienced many of these within the first two years of having HHN in our home, but we have prevented similar experiences in the years since.

These assaults on your family can make you resentful and angry, which disrupts the environment and care provided to your child. You need the support of a team of people to care for your loved one. Anger and bitterness destroy the environment needed to foster productive teamwork.

Nurse Abandonment

From a nurse's perspective, abandonment occurs if she deserts her patient during her shift. However, you will feel abandoned if a nurse quits your case without warning. Abandonment is the most common result of a failed relationship with a HHN. It is exhausting and emotionally depressing when nurses abandon you and leave you to scramble to cover nursing shifts. Imagine that it is nine p.m. on a workday and your nurse hasn't shown up. She doesn't respond to your texts, so you call the home health agency, who informs you that the nurse quit your case that day.

You are forced to call and beg in vain for other nurses, friends, or family members to help you cover a shift without giving them notice. You were about to get ready for bed but now must stay up all night with your loved one, then go to work in the morning.

How to Prevent Nurse Abandonment

Hiring nurses who are a good match for your case is the first step in avoiding nurse abandonment. Guidance on the hiring process is covered later in this guide. In short, screen nurses as much as possible, look into their work background, set your expectations during the meet and greet, and avoid nurses who express significant concerns during the meet and greet.

We learned that when a nurse seems hesitant to take our case during the meet and greet, she will not stay long. If a potential nurse expresses concerns—such as the drive being too far, the shifts available not being what she expected, or our daughter being bigger than their preferred size for a pediatric patient—we don't hire her.

During the meet and greet and the first day on the job training, we clearly express our expectations and make sure the nurse is willing to work with us. For instance, we explain that we expect her (all of our HHN have been women) to follow company standards that prohibit cell phone use, and we do not allow them to complete college work during shifts either. We also explain that we expect them to provide us with fair notice before taking another case.

We hold biweekly phone meetings with nurses and attendants and allow them to communicate their concerns, needs, or frustrations. Regular meetings are an important opportunity for nurses to share their perspectives on how care

can be improved. In addition to providing a forum for nurses to communicate, we also share any concerns we have about the nurses with the home health agency. The agency is often able to serve as an intermediary between us and the nurses. The home health agency is the most important resource to help families succeed with nurses.

If we know that a nurse just isn't working out, we take initiative and look for her replacement. We communicate with the agency that we anticipate needing a replacement for a given nurse and allow them to recruit for us.

How to Respond to Nurse Abandonment

If a nurse quits your case before you are able to replace her, you need to do two things. First, sustain a positive attitude and atmosphere. Do not bad-mouth the nurse who left you or project negativity on the remaining support staff. When you are short staffed, you cannot afford to drive off your remaining help. Second, learn from the relationship failure. Find out why your nurse left your case and try to improve on your part in the future. Do you need to improve your hiring and screening process? Did you ignore her needs?

Nurse Abuse

Protecting your loved one is the first priority in your household. About eight months after we brought Evelyn home from the hospital, we hired a new night nurse who I will refer

to as "Tammy." Tammy was experienced, a mother in her midforties, and the spouse of an army veteran. She seemed like a decent person and a good nurse. We were excited because she was scheduled to cover weekend night shifts.

When I entered Evelyn's room Saturday morning at the end of Tammy's shift, I noticed that Evelyn had an unusually high heart rate and seemed very upset. Tammy seemed unconcerned and had no idea what was wrong. After Tammy left, I checked the trash and determined that Evelyn had only been changed twice during the night shift, which was not sufficient. I made a note to myself to check on Evelyn and the nurse again the next weekend, but didn't.

The third weekend, Evelyn's heart rate was extremely high again. When I asked her about it, Tammy claimed she had no idea what was wrong with Evelyn and quickly gathered her belongings and left our house.

Again, the trash indicated that Evelyn had only been changed twice during a ten-hour shift. Evelyn's face was flush, and she had tears in her eyes. I peered into her eyes and asked her if the nurse had been mean to her. Evelyn responded with intentional eye blinks. I asked several times, and her responses were faint but consistent.

I shared my concern with my wife, who questioned Evelyn alone and came to the same conclusion.

That evening, another nurse questioned Evelyn alone and determined that Evelyn was trying to tell us that the

night nurse was hurting her. I was so angry and upset. I had been given a security camera when Evelyn was in the ICU, but I hadn't taken the time to install it. An hour or two of effort would have protected my helpless little girl.

How to Prevent Abuse

You can prevent the abuse of your loved one by using wise hiring practices, installing security cameras, and using a health monitoring system. Let me expand on each of these below.

Screen Out Abusers during the Hiring Process

The first step in preventing abuse is to conduct due diligence when hiring nurses.

1. Laws regarding public record checks vary by state but can only be conducted by an employer and always require written consent of the person vetted. Ask your home health agency everything they know about a potential hire and find out if they have conducted a background check.

2. In addition, interview previous employers, other nurses, and families for whom the candidate has worked in the past. I regret my failure to ask Tammy why she left her previous case.

3. Tammy's social media account also would have likely thrown red flags. You can look through a

potential hire's social media profiles to learn more about her and to determine if she is going to be a good fit for your family and care team.

You need absolute confidence in your night nurse. If anything about the nurse seems "off," wait before hiring. Keep looking for the right fit. You can catch up on sleep later, but you can never undo abuse.

One red flag that we should have paid more attention to was the fact that Tammy's daughter, whom we hired as an attendant the same time we hired her mother, was irresponsible and a totally wrong fit. The daughter came to work in cutoff jeans so short that they were almost up her rear end, and she smelled badly from terrible hygiene; she also had a mouth full of rotten teeth at the age of twenty. Perhaps that should have alarmed us enough to look into Tammy's background, but we didn't.

Use a Camera Monitoring System

The second layer of defense is a pair of motion-activated cameras. Cameras provide at least four important benefits:

1. They record HHN to prevent abuse.
2. They serve as a witness to protect you from accusations of abuse.
3. They improve care by serving as an accountability tool.

4. Their presence scares off many crummy nurses before they take your case.

Video systems can be either professionally installed or do-it-yourself (DIY). Advantages of DIY monitoring systems include the following:

1. They are much less expensive to purchase.
2. They are easy to install and therefore more likely to get up and running in a timely manner.

Do-it-yourself home-monitoring systems range from $300 to $500 for the equipment and may include monthly service fees of ten to thirty dollars.

The cameras and data box for a professional system will average $700–$1,400 depending on the number of cameras you purchase. The labor for installation averages $400–$1,000 depending on the number of cameras installed. Professional video systems do not require an internet connection, cannot be tampered with or hacked easily, provide more storage for recordings, and use cameras with better resolution.

Here are the downsides to DIY systems:

1. They require good wireless internet to operate well.
2. They often require a monthly subscription.

3. They often provide significantly less storage data for recordings.
4. They can be hacked and tampered with more easily than professional systems.

A professionally installed video system is better in every aspect except for its initial cost; however, any sort of video system is far better than nothing. Even a broken or nonoperational camera plugged into the wall is much better than no system at all. At least a broken camera will give nurses and care providers the impression that they are being monitored.

If you choose the DIY route, there are several brands to choose from. When I asked for advice from a professional installer, he spoke well of video systems provided by Ring, Nest, and Alarm.com. He reported that the battery life and reliability of Arlo were very poor. According to several online reviews, Eufy seems to make very good video systems as well.

Whatever system you use, install at least two cameras in order to ensure that your loved one is recorded from multiple angles. A care provider can easily block the view of one camera with her body if only one is installed. Consider installing a camera in other rooms as needed to provide ample coverage.

Monitor and Record Your Loved One's Vital Signs Remotely 24/7

Health-monitoring devices provide another layer of security for your loved one who needs HHN. There are devices that monitor vital signs such as oxygenation, heart rate, and respirations, and transmit that data to a smartphone. Some monitors can also measure blood pressure and ECG (electrocardiogram) data.

Health monitors improve the care and safety of your loved one in several ways. Monitors alert you when their vital signs are too low. Wearable vital-sign monitors serve as an accountability tool to inform you if vitals become abnormal during night shifts or other times when you are not present. For instance, if you wake up in the morning and see that your child had an abnormally high heart rate at 3:00 a.m., you can check your video recording system to see what occurred in the room at that time. These devices also provide insight to your loved one's health by recording patterns and trends that you can share with physicians.

Some monitors, like the Wellue wrist oxygen monitor, records and transmits vital signs to your smartphone. It is intended to monitor patients during sleep and requires charging every sixteen hours. There are also watches that monitor vital signs, such as the Fitbit and Apple Watch, which provide a limited ability to monitor your loved one's health. The Embrace2 is a wrist-worn wearable that detects and alerts

for seizures. This device has a forty-eight-hour battery life but does not measure other vital signs.

In addition to wearable monitors, baby monitoring devices can improve the safety of your loved one. Baby monitors provide video and audio monitoring of your loved one when you are not in their room. Certain baby monitors can also track the number of times their bed is visited, their sleep patterns, and their temperature.

Action Steps If You Suspect Abuse

Dr. Nora Baladerian provides the following ten guidance steps on how to respond to suspected abuse of people with disabilities.[7]

1. Know and believe that abuse can happen to your loved one.
2. Become familiar with the signs of abuse. Any signs of injury, changes in behavior, mood, communication, sleep or eating patterns are included.
3. When you suspect something is wrong, honor your feelings and take action immediately. See #4.
4. When you suspect abuse, call a Child or Adult Protective Services agency and the police.
5. Do not discuss your suspicions with anyone at the program where you believe abuse is occurring, as

they may deny any problem, punish your loved one, and attempt to destroy any evidence that may exist.

6. Remove your loved one from the program immediately.

7. If there are injuries or physical conditions, take your loved one to a physician, not only to diagnose and treat the condition, but create documentation of your visit and the findings. Take your loved one to a mental health practitioner who can document the changes in his or her behavior and mood, and who can document what your loved one's memories are of the abuse.

8. Create a document in which you write all of your activities. Begin with when you first suspected abuse or neglect. What were the signs or signals you noticed? Write the dates of these, and if there were injuries, detail what they were, their appearance, and where on the body you saw them. If the staff gave an explanation, record this in your file. Write down when you called the police or protective services agency, the name of the representative, time and date of the call and what was said. If a staff member discussed this with you, write down what they said and their name and the date and time of the discussion.

9. Notify the Regional Center representative of your findings, suspicions and actions or your disability program in your state.

10. Get a police report. Contact the Victims of Crime program in your area and seek their support for reimbursement of costs and therapy for the family.

Harassment from Child Protective Services (CPS)

Having a nurse use CPS as a weapon to harass or a tool to establish distance from you is another result of failed hiring and relationship building with HHN. We experienced multiple CPS complaints filed against us by nurses. According to the CPS investigators that I encountered, it is very common for families of chronically ill children to experience CPS complaints.

After months of conducting interviews, looking at health and medical records, questioning my children at their schools, and reading statements from friends, family, and service providers, the last CPS investigator stated to my wife and our lawyer that we "were being harassed by nurses."

That's how bad relationships with nurses can become. We met other couples with medically needy children who reported similar and even worse attacks from hospitals and nurses who used CPS to punish them and control them and their children.

Reasons Why Nurses Call CPS

There are several reasons why a home health nurse would file a CPS complaint against you:

1. You are not implementing the plan of care. For instance, you notice an adverse reaction to a medication and stop administering the medication before a physician officially changes the plan of care.

2. You are providing care not ordered. For example, you add a blend of essential oils designed to improve respiration to your child's nebulizer or perform hyperbaric oxygen therapy.

3. Calling CPS gives nurses a voice and punishes the parent. CPS gives nurses power! Complaints to CPS are anonymous, meaning that CPS caseworkers will not reveal who made a complaint against you, and the hospitals and nurses filing the complaint are protected from retribution even if the allegations are without substance. Multiple CPS complaints against us seemed to be a means to gain control or revenge. We had a nurse who really hated that I used an essential oil diffuser in Evelyn's room. She was also extremely frustrated after I voiced concern over her excessive tracheal suctioning and the correction that she received

later by a doctor. She found another job, gave notice, and then filed a report with CPS before she left.

4. Nurses and hospitals benefit in several ways when they involve CPS. Nurses are mandatory reporters, which means that they are legally required to report any suspicion of neglect, abuse, or medical abuse. A report to CPS can make hospitals and nurses appear as if they are diligent care providers who heroically enforce medical practices.

I interviewed a specialist, who will remain anonymous, who advocates for parents when they've been harassed by CPS and hospitals. She shared that children's hospitals sometimes use CPS investigations to cover up medical errors or to punish parents who refuse to participate in research programs.

Children's hospitals often employ a team of social workers and medical staff who work together supposedly to support parents and prevent abuse. We felt harassed by this team. To us, they were just watchdogs used as a tool by a nurse who aggressively lied and badgered us.

For example, my daughter, Evelyn, was readmitted to the pediatric intensive care unit about two and a half years after her initial injury. It was incredibly stressful readmitting Evelyn to the hospital because her heart was racing at 140–154 beats per minute and she was coughing up blood.

After two days in the hospital, she began shuddering so hard that her hospital bed shook with every breath. We were stressed and terrified that Evelyn wouldn't live.

After four days, Evelyn stabilized. We focused on managing our stress and thinking optimistically about release.

During the fourth evening in the PICU, Evelyn's nurse, "Jennifer," happened to be a friend of the very first nurse to call CPS on us. In fact, I observed them hugging in the hallway before Jennifer entered Evelyn's room. I naively assumed that Jennifer would act with decency and professionalism while serving as Evelyn's nurse that night.

Jennifer observed that I used the cough assist device on Evelyn when I needed to clear mucus from her lungs, and told me in a direct and flat tone that I was not permitted to perform this procedure without the immediate supervision of a respiratory therapist. Despite having performed this procedure unsupervised repeatedly during the past four days, I agreed to her request, making sure that the respiratory therapist was at my side a few minutes later when we performed the cough assist.

About fifteen minutes later, hospital security and one of the social workers entered Evelyn's room and threatened to remove me from the hospital if I "continued to ignore hospital rules by disconnecting Evelyn from her ventilator."

I explained that the respiratory therapist was present and that disconnecting Evelyn from the ventilator while using

the cough assist was a necessary, normal, and safe part of the procedure.

The social worker did not acknowledge anything that I said and repeated her threat to have me removed.

The following evening, a CPS investigator informed us that a new CPS complaint had been filed against us (presumably by Jennifer). I argued that accusations that I was abusively removing Evelyn from the ventilator were not true. The CPS worker then threatened that even if the reports against us were false, they were still kept on record. She said that the complaints and investigations would follow us wherever we moved, and that they would eventually add up to significance. The CPS worker then warned us that she was going to interview hospital staff immediately and determine if we would be allowed to take our daughter home as scheduled that evening.

How to Prevent CPS Complaints

1. Be aware that innocent and normal interactions may be interpreted as inappropriate by the strangers in your house.

Some nurses expressed that they were uncomfortable with me (a father) diapering and caring for my daughter (ten years at the time of injury). I think it is hypocritical that those same nurses support male gynecologists and male obstetricians and

would support a random male nurse caring for my daughter alone during day or night shifts.

Many of the nurses we had conflicts with shared with us that they had been sexually abused by men. Perhaps they had an unhealthy view of men and lacked the ability to interpret normal father-to-child interactions. Innocent kisses on your child's face, physical therapy, massages, or diapering may appear diabolical to some nurses. Consider refraining from those activities in the presence of nurses.

2. Don't try to resolve your conflicts with nurses alone!

If your nurse expresses concern about anything in your home health environment, meet with the management of the home health nursing agency. Agency directors are experienced at dealing with nurses and resolving conflicts. It is in their interest to keep you as a client and to maintain the employment of the nurse in question. The nurse has little to lose from leaving your case for another.

We discovered that the office managers are often unaware of nurse conflicts and are not necessarily informed when nurses call CPS on families. Communicate regularly with office staff and management at the home health agency to express concerns and solicit advice.

3. Do not perform or discuss care or therapies around your HHN that are not part of the official plan of care.

They do not want to know if you are doing any unapproved types of care. If they are aware, you are forcing them into a predicament where they have to either report your unapproved medical care or accept liability for allowing it.

Terminate relationships if they become tense or hostile before the nurse takes action against you.

We didn't want to terminate relationships with nurses once they became tense because we were desperate for help and hoped that the nurses would remain professional and considerate. It is better to take initiative and end the relationship. This allows you to prepare for the breakup and recruit a replacement instead of getting caught off guard. Part ways with a disgruntled nurse in order to prevent malicious attacks that may occur.

Give nurses opportunities to voice concerns in ways that do not involve CPS.

Providing multiple avenues of communication may give you the chance to diffuse conflict or misunderstandings with a disgruntled or concerned nurse before CPS is involved. Hold regular meetings with nurses where together you discuss your loved one's care and share concerns. You can also request that they take concerns to the home health agency's leadership first before contacting CPS.

Prepare for CPS Complaints

In addition to HHN, hospital nurses and staff can also file CPS complaints against parents. Hospitals employ teams

of risk management personnel, social workers, and lawyers who play a role in investigations every week. They are well funded, well rested, and not in a state of crisis. In contrast, you are alone, without free legal representation, tired, emotionally broken, and lacking the knowledge and experience to defend yourself.

Hospital social workers may pretend to be your friend in order to get you to share information about your family and child. When they visit you in the hospital, they may be collecting data, perhaps for an active investigation.

A parent advocate explained to me once how hospital social workers operate. She said that during their first visit, social workers attempt to build rapport with you by asking how you are doing and helping you with basic concerns. They pretend to be a warm and caring resource so they can gain your trust. They want you to view them as a counselor and confidant so you will share your concerns and heartaches.

However, hospital social workers may be collecting data without your knowledge to create a psychological evaluation of you that they will include in a CPS report. They can collect data and submit the psychological evaluation of you without your consent or knowledge that it was ever done.

Even though CPS allegations can lead to the involuntary removal of children from your home, "Families involved in non-legal FBSS [family based safety services] cases and CPS

investigations are not entitled to any kind of free, court-appointed legal representation."[8] This means that unless you prepare in advance, you will lack professional or competent help when the CPS worker makes a surprise visit to your front door.

Here are four things you need to do before a CPS worker rings your doorbell and asks to enter your home:

1) Select and retain a medical attorney.

After CPS complaints piled up and an investigator threatened to retain Evelyn in the hospital, we decided we needed an attorney. It took us three weeks to find a list of medical attorneys, set up appointments, conduct consultations, and then finally select a lawyer. Finding a good lawyer while under the pressure and stress of an investigation is difficult.

This can be avoided if you select and retain an attorney before you need one. If you never need his or her services, your retainer will be returned. And if a complaint is filed, you can receive immediate counsel if you need it.

2) Keep updated copies of your child's medical records.

Medical records are the legal documents that hospitals use to record their personal observations, thoughts, and interactions with your loved one. Medical records provide insight into the perspectives and actions of the hospital and its staff. Records will expose what doctors think about you.

They also provide essential facts if a CPS complaint goes to court.

You should request medical records so frequently that the hospital clerks are annoyed at the mention of your name.

Your medical attorney will request your child's medical records prior to going to court, but you can only ensure that your attorney receives complete and unaltered records if you possess your own copy of the records before an investigation begins.

Your child's medical records are the most important document that you can maintain.

3) Keep a medical diary.

Use a Microsoft Word document or a digital calendar to record interactions with medical service providers. A digital record is more organized than a handwritten journal, and entries can be easily shared.

Your medical diary is valid documentation that presents your perspective and is also admissible in court. Your diary will also assist your attorney if you need to go to court. Be open and honest with medical service providers, and inform them that you keep a medical diary. They will be slower to file a frivolous CPS complaint if they perceive that you are alert and prepared. A medical diary is a tool to collect your own evidence and to hold nurses accountable. It will also serve as a record so you won't need to rely on your memory.

Include encounters, arguments, behavior, personal concerns, and anything that could be relevant should a nurse file a complaint against you.

4) Mentally prepare for a CPS visit.

The Fourth Amendment of the United States Constitution states, "The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no warrants shall issue, but upon probable cause, supported by oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized."

You need to get into a mind-set of self-preservation and wisdom. We were naive and ignorant about interacting with nurses and CPS investigators. We were eager to vindicate ourselves and show CPS investigators that we had nothing to hide, so we let them enter our home instantly. Now, we would not give up our Fourth Amendment rights so easily.

Now I would not allow a CPS investigator to enter my home without a warrant. CPS investigators do not issue Miranda warnings, but all evidence they collect will be used against you criminally. They do not reward your attempts to cooperate. When they enter your home, they are searching it for evidence of abuse of any type, even if it is not related to the actual complaint filed.

I would begin video recording the interaction as soon as they knock on your door. Ask the investigator to tell you the specific complaint filed against you. A transformation of your mind-set from naivete to one of self-preservation and caution is essential. You need to prepare and act as if the worst-case scenario can happen. Be extremely reluctant to trust nurses, investigators, social workers, and every other professional that you encounter. They are strangers in your home.

Action Steps When a CPS Complaint Is Filed Against You

Here are some of the steps to take as soon as a CPS complaint is filed against you:

1. Contact your medical attorney and request guidance.
2. Get the most current version of your child's medical records.
3. Prepare your children. A CPS worker went to our children's schools, pulled them out of class, and interviewed them privately. Knowing beforehand this was going to happen, we sat with our children before they were pulled out of class and told them what to expect. We explained why they were going to be questioned and encouraged them to be honest with the investigator, but to be careful how

they communicated. You can allow your children to record the interview on their smartphones.

4. Write a statement of facts that explains the details and circumstances from your perspective. We have asked several nurses to write notarized statements testifying to our good care.

Resources to Help You

FightCPS.com has samples of several resources that you may need to fight an attack from CPS. For example, this website provides guidance on how to write numerous useful documents such as appeals, complaints, and declarations of facts. This site also provides guidance on how to acquire kinship care, which would allow grandparents to watch your children as opposed to sending them to foster care.

Jon Scott, a parental rights defense expert, offers services through his website, ReturnMyChild.com. His website describes some cases of fraud and abuse conducted by CPS investigators and judges in cases that he has represented.

Before our daughter was injured, a family we knew of through close friends in another state was experiencing a nightmare with their daughter "Emmy." Emmy developed a condition in which she felt extreme pain in her abdomen after every meal. Doctors were not able to diagnose the condition, and the treating hospital staff accused Emmy's parents of abuse. The hospital colluded with local agencies

and removed Emmy from her home and forced her into residential care for psychological treatment. The facility restricted visits from Emmy's family, kept her drugged, and restrained her to force-feed her. Emmy's family retained the service of a parent advocate who provided guidance for several years until Emmy's condition was diagnosed and successfully treated.

After we experienced attacks from hospital staff in our state, we obtained the service of the same parent advocate mentioned above. She helped us to understand the investigation process and the perspectives and motives of those who were part of the process. Her website, ParentGuidanceCenter.org, is worth checking if you need assistance.

Nurse Neglect

Nurse neglect is defined as nurses failing to provide care needed to avoid mental or emotional distress, physical pain, or harm. Here are two of the many times my daughter Evelyn has experienced neglect.

When we first brought Evelyn home from the hospital, we had two night nurses. One of them was terrific and the other was terrible. "Gale" was young, very obese, and from a city in another state. I woke up in the middle of the night and checked on Evelyn.

The cold November air was billowing through the open window into the small room. The obese nurse was bundled

in her winter coat, reclined in the chair, and fast asleep. Evelyn was uncovered and wet from drool that had run and pooled down her neck and side. Evelyn's skin was ice cold and covered in goosebumps. Gale looked comfortable bundled in her winter jacket with her eyes shut and her feet propped up.

We made the mistake of giving Gale second chances instead of getting rid of her. She continued to sleep on the job until we let her go.

About a year later, I awoke to the high-pitched alarms from Evelyn's ventilator and pulse oximeter, and rushed to check on her. Evelyn's head was turned to the side, and her mouth was open in an effort to gasp for air. Her lips were purple, and her oxygen level was very low according to the pulse ox. Evelyn had vomit running down her mouth and neck and onto her chest.

The nurse was standing in Evelyn's closet and looked surprised when she noticed me by Evelyn's bedside. She told me that Evelyn had vomited, so she was looking for a shirt to change her in. I didn't bother asking the nurse why she prioritized changing Evelyn's clothes as opposed to helping her to breathe.

We let the nurse go that day. The home health agency director called me that afternoon and tried to convince me that I misunderstood the nurse's actions and that I should take her back.

If your loved one experiences neglect, you need to remove the nurse from your home and report the incident to the home health agency immediately. If you believe it is appropriate, you should follow the same steps that you would for an incidence of abuse as outlined previously in this chapter. Such actions may include a report to the police or the state board of nursing.

Nurse Theft

Nurses are total strangers in your home. Some nurses will steal from you. For some odd reason, the idea that nurses would steal from us did not occur to me. The first instance that I am aware of was about one and a half years after Evelyn was hurt. We left Evelyn at home with the nurse while we went for a walk.

After our walk, I entered Evelyn's room and the nurse was busy grabbing her belongings. I noticed that the nurse seemed flustered as she grabbed her bags and made for the door. Minutes later I entered my bedroom and noticed one of my wife's diamond earrings was lying on the floor. My wife doesn't ever wear these earrings, so I instantly suspected the nurse of attempting to steal them. But what could I prove?

I recommend keeping valuables locked and hidden. I would not let nurses know if you have valuables in the home. I would not allow nurses to have a key to the home. I would

consider extending your video monitoring system into other areas of the home as well.

The Risk of Affairs

Your relationship is vulnerable to an affair during a time of extended crisis. You and your spouse are in a weakened state. You are physically tired and emotionally hurt. You may feel guilt or blame each other for your circumstances. You likely have less time, energy, or money to invest in your relationship. You need to take conscious steps to protect your relationship from an affair, including one with a nurse.

Since my daughter Evelyn was hurt, I have experienced two times when a nurse expressed a desire to have an affair with me. In retrospect, I think I could have prevented those encounters if my wife and I would have made a habit of speaking with nurses about our expectations for professional relationships and behavior. We would now say something to the effect of, "We appreciate your care and service, but we believe strongly in limiting our relationship to professionally distant. Please help us keep interactions and conversations focused on providing care to our daughter. We have a strong marriage and will not engage in inappropriate conversations."

It is a good idea to lay ground rules for nurse behavior, but you are responsible for maintaining fidelity and avoiding unfaithfulness. There are several ways you can strengthen

your relationship to prevent an affair. You can invest in your relationship to ensure it is positive and healthy. Plan regular date nights. Find resources that provide respite care so you can be alone. Consider attending couples counseling to work out feelings of guilt and blame.

Do not allow a schedule that places one spouse alone with the nurse. Talk with your spouse openly about the risk of an affair and recommit to your vows of faithfulness.

Don't be naive! The people who provide services in hospitals or care in your home are strangers. Don't assume they are considerate, professional, or ethical. I believe that most HHN are professional and ethical, but not all of them are. Abuse, harassment from CPS, neglect, theft, and affairs are severe enough to make sure you prevent them at all costs. I've never been in a house fire, but I have smoke alarms. I'm a good swimmer, but I still wear a life jacket when I'm in a boat. Protect your family by preventing and preparing for these worst-case scenarios.

3 How to Attract and Hire Good Nurses

The average child going home for the first time with an order for in-home nursing care spent nearly 54 additional days on average in the hospital due to the lack of in-home nurses to provide care after discharge

—ROY MAYNARD, MD

About two weeks after the accident, medical staff in the hospital told us we had three options. We could take Evelyn home and provide twenty-four-hour care, remove her from the ventilator and let her die, or "let her be a hero" and allow the hospital to harvest her organs for donation and then let her die.

We were invited to a small room where medical staff from numerous departments sat and stood shoulder to shoulder. The departments took turns explaining Evelyn's condition and poor prognosis. I didn't realize until several minutes into the meeting that we were there to make a decision about

Evelyn's life. After my wife and I stated that we didn't want our daughter to be a "hero," we had to prepare to take care of her at home. We were cautioned that at some point we would potentially not have home health nurses to assist us.

Really? I thought to myself. *It must be a rare occurrence that we will have to care for Evelyn at home by ourselves without any help*.

The hospital staff at the PICU was so organized and focused on their responsibilities. We could never have imagined how different the home health environment would be.

About two weeks before Evelyn was released to go home, we had to choose a home health company to provide nurses. We were given a piece of paper with a list of companies in the area and a few tidbits of data about each company.

Some of the tidbits didn't seem very encouraging. They included observations like "This company has a lot of nurses but doesn't pay them well and has a high turnover," "This company has bad management," and "This company is new, and I don't know anything about them."

We chose a small company that prided itself on trying to hire nurses to fit each case and emphasized individualized care and service.

The difference between life at the PICU and the medical support we received at home was like the difference between staying in a hotel and staying at a homeless shelter.

At the hospital, Evelyn had a nurse and doctors available within feet. If we had a question, concern, or needed something, a nurse was available to provide and supply her needs. Specialists could be summoned and were available the same afternoon. New cartoon pictures were colored in marker by her door every week, and warm blankets were delivered on a whim.

The ugly side of home health care became apparent immediately upon taking Evelyn home.

Our first day nurse seemed like a nice lady. She was in her late fifties and had the face and voice of a wrinkled smoker. I'll call this nurse "Linda." Linda had the same name as one of my aunts, and most of the nurses in the hospital had big hearts, so I assumed Linda must also be a nice person.

Linda seemed surprised that Evelyn was not "on meds" or prescribed many drugs. Linda insisted that we administer Evelyn ibuprofen since her heart rate had been elevated since coming home two days earlier. We told Linda that we wanted to wait and try to determine why Evelyn's heart rate was elevated before giving her any meds. Linda became irate and stayed that way.

When I came home from work the next day, the owner of the home health company was waiting for me in the kitchen. He sat down with me at the kitchen table and warned me that if my wife and I couldn't get along with nurses they were going to have to let us go.

In less than a week we had gone from feeling like customers in a prestigious restaurant to beggars standing in a food line and being warned that if we made any trouble we would be kicked out of line.

Eventually we began to suspect that the grumpy day nurse wanted Evelyn prescribed drugs for her own reasons. Did Linda want access to prescription drugs? Based on self-reporting, substance abuse rates among nurses average around 10 percent.[9] Some researchers estimate that the actual addiction rates are actually between 14 and 20 percent.[10]

I observed that many of our home health nurses smoked. I often wondered if they choose to work in the home health setting because it allows them the opportunity to smoke while on the job. I also speculated that nurses with other drug addiction issues might gravitate to home health because there is less supervision and easier access to prescription drugs.

Linda stuck around a few weeks until Evelyn's first appointment back at the hospital. During the consultation with the primary care doctor, Linda interjected several times that Evelyn needed to be on meds. We didn't put Evelyn on meds, and Linda quit our case the next day. And so, we lost a nurse for the first time.

When we first brought Evelyn home from the hospital, "Rosie" was one of the nurses who provided care during the evenings. Rosie was a warm and soft-spoken Hispanic lady in her early fifties who provided great care. Rosie was gentle and

attentive to Evelyn. She was full of knowledge and was able to guide us on how to provide care and respond to Evelyn's needs. We trusted her and slept peacefully at night with her on duty.

Unfortunately, after about three months, Rosie said that her back was bad and that she needed a patient smaller than our daughter.

And so began our journey of taking care of Evelyn at night while going to jobs and caring for Evelyn and other children during the day.

Turnover in home health nursing has had a severe impact on our daughter's care and our quality of life. The revolving door of nurses means that we must constantly train nurses and learn how to work with them. Because there are so many new faces, the nurses always feel like strangers in our home. Because we expect our nurses to leave at any point or just not show up for work one day, we remain distant from them.

Nurses can earn 200–300 percent more money working in a hospital as opposed to a home health environment.[11] This means that your home health nurse has chosen this setting for specific reasons.

For example, some nurses choose home health because they prefer the flexibility in hours, reduced workload, reduced physical demands, or an environment free of supervision. The tremendous shortage of home health nurses means that you need to hold on to good nursing assistance when you have it.

According to one source the turnover rate in home health care was 82 percent in 2018.[12] This means that fewer than two out of ten nurses provided care for a patient for more than one year. When a nurse leaves your case, there is often a period where you lack a replacement and are forced to cover shifts without help.

Two key strategies for reducing nursing turnover in your home include using consistent respectful communication and creating a professional work environment. In addition, you can reduce turnover by implementing good hiring practices and accommodating the needs and preferences of your nurses.

Choosing a Home Health Nursing Agency

The first hire that you make after coming home from the hospital is the home health nursing agency. We initially thought we would be better served using a small company that paid higher wages and managed more intensively. Generally, we now favor larger companies because they can access a larger pool of nurses and seem more capable of staffing us. Here are a few things to consider when choosing a home health nursing company:

1. Speak with other local parents in the same situation, and get some advice on which home health companies to go with. Gain insight from support groups, staff from the hospital, or social

media to find other parents who use home health nursing in your area.

2. Speak with an office manager at a prospective home health company and find out how well they can staff you. Except for a time when a company had just lost a patient and had four nurses without a case, home health agencies were never able to immediately staff us at night. If a company guarantees they can staff you at night, make them justify that commitment. We value honesty from home health agencies and are leery of empty commitments.

3. Speak with nurses who work for the company in order to gain an inside perspective on the company. Are they happy with the pay and benefits? Do they report a high turnover of nurses or staff in the company? How well can the company staff its patients? What is their overall opinion of the company?

4. We prefer a company with a large pool of nurses. They recruit and hire more nurses, which improves the odds of finding a good nurse or a replacement when one leaves. There are, however, many parents who work with small companies and are very happy.

5. Often the office manager or owner of the company is the most important person to meet and get to know. You and the office manager should be a good match for each other. My two favorite office managers were honest and compassionate. I felt like one of them made a very bad call in one situation, but I knew he was doing what he thought was right, so I forgave him and continue to hold him in high regard. In contrast, we worked with one owner who seemed manipulative from the first time we met him. I wish I would have been more cautious and never worked with his company. He continued his manipulative ways and ended up as one of the few people that I disdain. I sometimes wonder if he was billing our insurance for shift hours that were not covered. Also consider that the owner of a small company will likely hire nurses and staff that share similar values and culture.

Attracting Nurses with a Comfortable and Convenient Workplace

As author Jim Butcher says, "You don't have to run faster than the bear to get away. You just have to run faster than the guy next to you."

You are competing with other families to keep good nurses working in your home. If you provide an appealing

environment, your nurses are more likely to continue providing service.

Usually in life when I pay money for a service, the people who provide that service act as if they appreciate my business. The manager of a restaurant or a hotel treats patrons with respect and care. The contractor who paints the house or cuts the grass treats the home owner with gratitude and courtesy. Not so in the world of home health nursing! Nurses and the nursing companies keep in the back (or front) of their minds that you are lucky to receive their service. There is a greater demand for home health care than the availability of nurses. Some other family is going to go without a night nurse tonight and would be glad to take your nurse.

Those within the field of HHN are aware of the extreme shortage of nurses, and the behavior, attitudes, and standards of nurses often drops accordingly. There are several factors you can control that will help keep your nurses content. If nurses believe that your case is significantly better than others, they are more likely to stay and will also provide better care. There are several factors you can influence in order to make your home more comfortable and convenient to HHN.

Long Orientation. Ensure that your nurse is comfortable having full responsibility for your loved one before you leave her alone. If she needs a few shifts to feel confident working on her own, do everything in your power to give her the

needed experience and time. This protects your loved one and creates a positive experience for the nurse.

Location. A centrally located home is a shorter commute for more nurses. Some nurses don't mind a forty-five-minute commute, but it is a significant advantage if your home is a short, easy drive. When we first needed home health care, we thought the idea of moving close to the city was absurd. After countless days and nights without nursing support, we realized that moving close to a hub of people is totally worthwhile and logical.

We also discovered that many nurses are uncomfortable with driving in the country. Although our home was less than twenty minutes from a major hospital, it felt remote to many nurses. Some nurses hate the outdoors. One nurse almost dropped Evelyn's ventilator because she was frantically swatting at a gnat while we were on the porch. She was quick to find another case after that gnat incident.

Your home needs to be easy to locate. Make identifying marks on your mailbox and on the front of your house. Nurses may come to your home for their first meet and greet while it is dark outside. Several potential nurses who had trouble getting to our home for the initial meet and greet turned back never to return because they couldn't easily find our house. We eventually wrapped our mailbox in reflective stripes and offered to meet nurses on the road in order to guide them to our house.

Organized Work Area. Nurses need and appreciate an organized and functional area to work. They need a desk to write on, file space for paperwork, and easy access to commonly used items. They also like a safe area to keep their personal belongings. We provide an office chair that is comfortable but one that does not recline because we have had nurses fall asleep in reclining chairs.

Shift Flexibility. Nurses can be very much like hens. If you have ever raised hens, you recognize this is a bad thing. Hens claim a spot and a clutch of eggs, and they become territorial. Your nurses will likely cling to their favorite shift schedule and expect incoming new nurses to work around their ideal schedule. You should ensure that the HHA offers reasonable shifts to potential incoming nurses. Insist on flexibility from all nurses.

Flexibility. If a nurse wants her shift hours to end sooner than you want, let the nurse leave early. If you want her to stay, accommodate her. We had a really terrific nurse that wanted to leave about an hour before we wanted her to, and she refused weekends. We let her go, but did not find a nurse nearly as good as she was and never filled the weekend shifts anyway. We should have compromised and kept the great nurse; they are rare!

Left Alone. Again, a nurse caring for your loved one is like a hen sitting on her eggs. She doesn't want you in "her" space, and she does not want to feel like you are checking on

her or telling her how to do "her" job. Many parents are eager to leave all care to the nurse and do not check on their child when a nurse is on duty. We believe that we are 100 percent responsible for the care of our daughter at all times.

We view a nurse as our assistant. We enter our daughter's room frequently to spend time with her and see if anything can be done to make her comfortable. Nurses *hate* this. They view our attention and care for Evelyn as a sign that we are checking on them and don't trust them (by the way, we usually don't). Try to create a positive environment when you are with your nurse and the patient. Start the conversation by thanking her for something she's done. Use the time to ask your nurse if she has anything she wants to bring up. If you have concerns, rather than mention them now, instead bring them up at a scheduled phone conference with all nurses attending. The nurse should enjoy your presence and not dread it.

Lifts. Ensure that nurses are not expected to lift your child by themselves. Ensure that a floor lift is easy to access. A ceiling lift is even better if you can install one. Ensure that she doesn't lift the patient off the floor during therapy or into a bathtub. Protect your nurse from injuries.

Electric Hospital Bed. You can purchase a used fully electric hospital bed for a reasonable price. Nurses appreciate a fully electric bed as it reduces bending over and physical labor. Some hospital beds offer lateral rotation, which is

also appreciated and increases how often your child will get turned.

Comfortable Temperature. Ensure that your nurse does not feel too hot or cold. Each home health nurse is a unique individual with specific needs and preferences. Find out what temperature they prefer to work in, and make their comfort the priority. A space heater, oscillating fan, or adjustment to the thermostat is worth your effort.

Personal Fridge. Nurses appreciate a separate refrigerator to keep their meals. This also ensures that their meals will not be accidentally eaten by family members. If you routinely stock the fridge with snacks, nurses will really appreciate the gesture.

Pet Free. Some nurses may be afraid of dogs, allergic to cats, or just not a fan of pet hair on their clothes. I wouldn't get rid of a family pet to suit nurses, but having one will exclude a small percentage of nurses.

Child Free. Of course, you cannot get rid of your children to accommodate nurses, but nurses often prefer to work in an environment in which other children are quiet and out of the way.

Peaceful Home. Families that experience an acquired brain injury (ABI) are under duress. Nurses, however, do not want to hear couples fight or yell at their kids or each other. Keep arguments away from nurses, or your stress will become even worse when they leave for a more peaceful

work environment. We received several nurses who left their previous cases because they did not want to work in a home with couples who argued and fought.

Compatible Culture. We know that some of the absolute best care can come from people who are different from the family they work with. However, we experienced that nurses are generally more comfortable with people who are similar to them.

Initially we had the idealistic vision that if we welcomed all nurses and attempted to foster an inclusive environment, nurses from different cultures than ours would feel comfortable. There were some exceptions, but on a consistent basis, nurses with significant differences in our home or work our case for very long.

Nurses from other countries are one of the exceptions. They often seemed comfortable in our home regardless of differences. You cannot change your culture, but you can avoid discussions that highlight cultural differences. You should make efforts to openly welcome your nurse and whatever cultural difference she brings.

Avoid conversations on sensitive topics that highlight differences or raise emotions. I don't talk about politics or religion at work. I don't have these types of conversations at home with nurses either, because they are both professional environments.

Smoker Friendly. Many nurses choose home health because they are not able to smoke while at a hospital. Hospitals often prohibit smoking on the property, and nurses lack the time to leave hospital property during breaks. If you permit smoking on your property, some nurses will be more likely to work your case.

Appreciation. Make a conscious effort to express your gratitude and appreciation to your nurses. Everyone deserves and enjoys recognition for hard effort and a job well done. Birthday, thank-you, and seasonal cards are also appreciated. We provide cash bonuses to attendants who step in on short notice.

An Effective Meet and Greet

Home health nurses are not your employees, but as the parent and resident of the home, you are responsible to determine who is allowed to enter your home and care for your loved one. Many of the conflicts, sleepless nights, and heartaches that we experienced could have been avoided had we followed wise hiring practices. In addition to the safety screening practices discussed in chapter 2, we recommend the following guidelines and practices during the meet and greet:

1. Home health agencies are similar to a matchmaking dating app. If the nursing company understands your values and your expectations, they are more

able to make a lasting match. For instance, my wife and I don't mind if a nurse shows up late, but if they fail to show up without a legitimate reason, we don't give them a second chance. The HHA should be aware of our tolerance levels in order to help them send the right nurse over in the first place.

2. Explain your ground rules when nurses come over for a meet and greet. If, for example, you are lenient when a nurse shows up a little late, you can tell her that you are okay if she arrives late to work occasionally. Perhaps the nurse makes a long commute and or drops off a child at day care before coming to your home. Or perhaps you need to leave for work promptly and cannot wait for them to show up a few minutes late. A potential hire needs to know what type of working environment and culture she can expect. She will likely quit your case if the environment is not what she expected.

3. My wife and I do not accept nurses who spend time on their phones or conduct other business, such as completing college work, during their shifts. Several nurses refused our case when they became aware of this expectation. In contrast to

us, many families don't mind if nurses spend time on their phones or read textbooks.

4. Listen to the nurse during the meet and greet. Nurses are usually reserved during a meet and greet, but we do our best to get to know what their needs and expectations are. We ask them about what their needs and likes are in relation to providing service. Does the nurse have a bad back and doesn't like to lift a patient? Is the nurse allergic or afraid of pets? Is the nurse content with the proposed schedule and location?

5. Nurses are usually reluctant to share their concerns, needs, or preferences during the meet and greet, so you have to listen attentively. Do your best to identify issues and concerns that your nurse has during the initial meet and greet. If a nurse has any significant dislikes about our case, they will eventually leave. If I hear an expression of dissatisfaction such as "It's a long drive out here" or "I usually work with smaller patients because of my back," I know it is just a matter of time before that negative thought cements in the nurse's mind and results in her departure for another case. So I save everyone's time by not hiring her in the first place.

6. Directly ask the nurse to tell you about her concerns and what type of home environment that she likes to work in. If appropriate, diffuse her concerns. For instance, if she left her previous case because the couple fought often, let her know that you have a stable relationship and never argue in front of others.

7. Inform the nurse during the meet and greet that you maintain a professional environment. Tell her that you value her nursing license and won't expect her to perform care that is not part of the plan of care. Let her know that you will treat her with respect and value her perspective.

8. Nurses typically come to your home and receive an orientation and training day after the meet and greet. Use this training day to screen the nurse. If we observe that a nurse is physically struggling, constantly seated, or has a bad attitude, we part ways before the relationship continues.

Remember, you are competing to attract and retain good nurses. Your HHN chooses every day to work your case. She receives offers on a daily basis from recruiters who offer her money, paid time off, and other incentives to leave your case for another. You will retain nurses better if you

create a comfortable physical and social environment. You need to prioritize making your home a professional working environment. Her work area should look organized and professional. Give nurses reasons to stay with you, or they will leave.

4 How to Reduce Nurse Turnover and Improve Care

You either get bitter or you get better. It's that simple. You either take what has been dealt to you and allow it to make you a better person, or you allow it to tear you down. The choice does not belong to fate, it belongs to you.

—**JOSH SHIPP**

With regard to home health care, you must put your own mask on first. You are the leader and advocate for your loved one who needs home health nursing. If you are emotionally or physically weak and broken, your loved ones will suffer worse outcomes. Just as parents are instructed in the case of a flight emergency to make sure their own oxygen masks are in place before assisting their children, you must prioritize and guard your own emotional and physical health before you can tend to that of your loved one.

If you allow the circumstance of a medically needy family member to make you angry and hostile, you will ruin your relationships with the HHN who are employed to help you. Remember, your home is a public work area when home health workers are present. Fighting, profanity, or a bad attitude is not appropriate in a public work environment. Bitterness and negativity create a hostile work environment for HHN that inevitably cascades into a myriad of problems.

The best advice I received about home health care came during a phone call from a mother named Liz whose son suffered a near-fatal drowning:

> Develop the most normal life that you can, surround yourself and your child with activities, make sure you are taken care of. We cannot just be a special needs parent who becomes isolated. Good comes from being around the normal world. Surround yourself with people who can help with your child. Some people help and are drawn to help. . . . The more you are out, the more people have an opportunity to help and contribute to your life.
>
> Incorporate your child into your day, let them sense that you are happy. They need to feel the sense of joy in your life. Not responsibility, but joy. How do you enjoy your life? Integrate your child into

your life. Everyone has problems, their problems are significant too.

We can be a source of hope and inspiration to others when we are not victims. Our example can quietly encourage others. Allow this to become part of a normal life instead of taking over your life, or you can't attract the positive.

You have to be the kind of person that can be helped. Friends, family, you need them, or you get tired, overwhelmed and angry.[13]

Nurture Your Physical Health

Since Evelyn's accident, I have experienced multiple injuries in caring for her. I have had back strains so severe that I could hardly stand up. I slipped on the stairs once while checking on her at three in the morning and knocked my hips out of alignment. Another time, I partially tore my hamstring picking her up in her wheelchair and was bedridden and in agony for over a week. I used to go to the dentist one or two times a year, but in the last five years I have had time to go just once. I have experienced weeks without a good night's rest.

My wife has experienced similar injuries and physical hardships. Our family does not eat the same quality of meals because we are too tired and busy to cook.

In other words, caring for a medically needy loved one is physically hard, and if you don't take care of your body,

you may reach a point where you are unable to provide care at all.

Get regular exercise.

You need a regular exercise routine. I enjoy hitting a punching bag and riding my mountain bike. I also try to include my wife or children when I exercise to keep our friendships strong.

Give your body the nutrients it needs.

My diet isn't very healthy, so I take supplements. I discovered that DHA supplements from fish oil or flaxseed keep my joints from aching. I also feel like my sleep is more restful when I take DHA. Some brands of B vitamins give me energy, and some brands don't seem to help. I also take multivitamins and magnesium. A weekly meal schedule improves meal quality and simplifies grocery shopping.

Nurture Your Emotional Health

I suffered from a broken heart for several years after Evelyn was hurt. My chest ached and felt like a collapsing void of sorrow. I cried intensely almost every day, three to five times a day, for the first year. Eventually, I cried less frequently, but I still had that deep ache almost all the time.

My wife and I took Evelyn to a small charismatic prayer group before the COVID-19 pandemic. Ten women gathered

around us, prayed, asked questions, and prayed some more. The women prayed in English, and they prayed in tongues for about an hour and a half. Two days later I realized that the ache in my chest was gone. Although still very upset, I felt significantly better for two months after that day of prayer. Evelyn's heart rate also dropped significantly for months after that day.

I believe that every family enduring a medical crisis needs support. Consider support groups, counseling, prayer, or respite care. Anger, regret, and blame are some of the negative emotions that can destroy you when you have a sick loved one.

Create Good Memories

Your nurse is more likely to keep working your case if you make opportunities for good memories. Memorable events create positive emotions around your case, which encourages nurses to stay.

Several years ago my family and our night nurse were driving around town in our van. It was our nurse's birthday. I thought it would be nice to buy her something to eat, so we bought everyone burgers. During the following months, we experienced severe tensions and conflicts with that nurse. One evening, I overheard the nurse tell Evelyn that the only reason she was still working our case was because I bought her food for her birthday.

A few years later, a different night nurse bought my wife and me gift cards to a restaurant for Christmas. Even though we had a tense and upsetting relationship with her, when I remember her, I think of her generous heart as opposed to the way she sometimes frustrated me.

Share Meals and Offer Treats

People love to eat, and sharing a meal is a terrific way to bond. Going out to eat is the classic way new couples begin a relationship. Because some nurses consider accepting food from the family unprofessional, consider offering to pick up some fast food for your HHN. It's okay if you don't pay for the meal; your nurse will still appreciate it if you offer to pick it up.

You can also consider providing snacks for your nurses. I know of one mother who kept the nurses' fridge stocked with drinks, energy bars, and other snacks. She told me that she was doing everything in her power to create the kind of environment in which nurses would enjoy working.

Give Small Gifts

Gifts that cost fifteen dollars or less are appropriate and appreciated (more expensive gifts may not be allowed by home health agencies). What if your gift is the only one she receives on her birthday? The small effort of purchasing a gift for Mother's Day or a birthday will display appreciation and

contribute to a sense of loyalty between your nurse and your family.

Celebrate Holidays Together

Remember, your home is a *public* workplace. Bring the cheer, and celebrate holidays as a work group. Decorate the inside of your home, for sure. You can invite nurses to contribute to the decorating. Everyone enjoys a wrapped present or a Christmas stocking with their name on it. Holidays are a shared cultural experience. Actively celebrating these holidays with your care team creates shared experiences and bonding.

Create a Positive Atmosphere

Wayne Sotile, an expert on creating relationships that last, advises avoiding living in a self-focused haze.[14] He directs people to focus on the well-being of others and create relationships and emotional experiences in which others feel safe in your presence.

You cannot become an authority figure who dictates rules and expectations. Rather, become a hero in the eyes of your nurses by creating an environment where you are gracious and generous. Let your nurses see you as an overcomer and a terrific parent. According to Dr. Sotile, "A pat on the back, voice mail, email, word of praise in front of other people, word of thanks, an apology" goes a long way. He adds,

"When in doubt, be gracious and generous. Be generous when providing forgiveness, praise, or acknowledgment."

Repeat Good Acts

Agnes is a Yale-educated pediatric nurse practitioner and currently serves as a director for a home health agency in the Midwest. She compares the relationship with your home health nurse to a marriage. She explains, "Just as in a marriage, you need to repeat positive and important messages. . . . See the pearl inside of everyone." She also encourages families to keep in mind that nurses are also dealing with personal stress and fears.[15]

Acknowledge Effort and Progress

If your nurse does anything above and beyond the plan of care, you definitely need to acknowledge and thank her. If nurses are punctual, work hard to keep the plan of care up-to-date, or show up to work during bad weather, acknowledge and thank them.

Sure, those are all part of their job expectations, but effort and excellence deserve acknowledgment and thanks. Nobody likes to work around people who only notice or point out the negative.

Keep a Flexible Mind-set

Agnes also shared with me insights from the Positive Approach to Care model taught by Teepa Snow. This model

emphasizes the need for caregivers to maintain a flexible mind-set.[16]

In your home, a flexible mind-set can mean accepting things that are adequate even if they are not what you prefer. For instance, if a nurse needs to end her shifts at an inconvenient time, maybe you allow that. If the nurse likes to finish her routine of care uninterrupted, maybe you can schedule activities that are not part of the plan of care, such as going to the park, around your nurse's routine.

I used to take Evelyn outside to the playground on warm days in the spring. If I noticed a break in the clouds, I would barge into Evelyn's room and demand that the nurse get Evelyn packed up and into her wheelchair immediately. The nurses would often protest that some care routine or another hadn't been done yet.

I always seethed inside because I viewed their protests as evidence of a lack of concern that Evelyn rarely got to go outside and an overall ambivalence to Evelyn's quality of life.

With this perspective, part of me enjoyed making the nurses get off their duffs and help me take my daughter outside. My mind-set was unproductive and wrong. I should have made a conscious effort to protect the routines that the nurses valued.

I should have planned ahead and tried to take Evelyn before or after the nurses completed their routines. Or I should have at least warned nurses in advance by telling them

of my goal to go outside, weather permitting. Ultimately, those nurses hated me and left our case. For Evelyn's sake, was it worth it? I think not.

Create a Professional Work Atmosphere

When you have home health care, your home is a workplace for medical professionals. Your home is a professional work environment. It is up to you as the home owner to ensure that you safeguard a professional experience for the benefit of everyone involved.

I am embarrassed to admit it, but my wife and I made huge mistakes regarding our home environment. We viewed nurses as care providers for our daughter Evelyn, and we welcomed them with open arms into our family. We thought that if we treated nurses like family, they would take better care of Evelyn and be more willing to stay with our case. We also genuinely appreciate anyone who takes care of our daughter and want to express our gratitude.

With one particular nurse—I'll call her "Tina"—who cared for Evelyn for almost two years, we let her children spend the night while she worked night shifts, accommodated her shift needs without question, considered her a trusted friend, and loaned her several hundred dollars for car repairs. We were completely open with her and shared all of our alternative care routines.

We never could have imagined the terrible consequences of letting our guard down and inviting a stranger so close into our family circle.

Ultimately, Tina took emotional ownership of our daughter, called CPS on us, and convinced other nurses and attendants to call CPS on us as well. As the weeks wore on, my wife and I were insanely frustrated by nurse-instigated CPS harassment, and we had no idea it was our "favorite" nurse orchestrating the entire ordeal.

We still don't understand Tina's goal. Perhaps she hoped to remove our daughter from our home so she could care for her at another location? Maybe she wanted me removed from the home so she could take over? We don't know why Tina hated us so much. We don't understand why Tina was willing to risk sending our daughter to the nearest institution for medically fragile children, which was a three-hour drive from our home. A location where she was truly at risk of neglect and abuse.

We learned our lesson. My wife and I are a team. Nurses can support our daughter and our shared goal of recovery for Evelyn, but now they are never part of our family. They are professionals assigned a shift in our home. Conversations and expectations should always remain professionally distant.

All questions, conversations, or concerns should involve the home health agency. Tina wasn't the only villain during that experience. The attendant and nurses who also agreed

to call CPS were guilty of harassment and endangering our daughter as well. Several nurses stood up for us and wrote letters on our behalf, but the fact that several nurses joined the assault on us illustrates the dangerous side of allowing strangers into your home.

In regard to establishing a professional environment, there are several areas that get nurses and families into trouble. Below are some recommendations for keeping things professional in your home.

Don't Discuss Nurse Pay

Nurses are constantly solicited by home health agencies to leave your case for another company. If the nurse likes your case, she may attempt to get you to follow her to another agency. Don't do this. The act of taking a family to another agency for higher pay is called "solicitation," and it is a crime if the nurse does it.

What is your nurse's motivation? Is the new agency a better run company that is more capable of providing quality nursing support? Is the new company's staffing coordinator, director of nursing, or director more effective? Does the nurse want to switch companies because it will benefit your loved one? If not, be cautious before switching.

Be Transparent with the Agency

Nurses and families often don't trust home health agencies or feel any sense of loyalty toward them. Regardless

of how you feel about the agency, they are the foundation that maintains the relationship between you and the nurses. They are interested in the welfare of your family and the nurse. They safeguard all parties and ensure that all services and activities are legal and appropriate. Bring any concerns to the agency.

Insist That the Agency Allocate Fair and Practical Shifts

Your nurse may not have your needs as her top priority. She wants and may insist on getting her ideal shifts. She won't mind if insistence on her ideal shift schedule leaves uncovered shifts at odd and unpopular times that other nurses won't take.

Staffing coordinators may not prioritize your coverage either. In theory they care, but from our experience, staffing coordinators don't usually bother to call when nurses have called in sick or even quit our case. Staffing coordinators at our agencies have seemed more than happy to leave shifts allocations alone if the nurses and families did not complain. Staffing coordinators seek contentment among their nurses, not necessarily what is best.

Only Allow Work-Related Tasks

If someone is employed as a teacher in a public high school, the principal doesn't expect him to mop the halls

or to repair the school bus. Your nurse was hired to provide professional medical service for a specific patient. Do not expect or allow your nurse to babysit your children. Do not expect or allow her to cook, clean, or handle arguments between members of your family. This is an inconsiderate expectation, and the nurse will fear losing her license if something happens to your children or your home while she is carrying out tasks not related to her work.

Keep the Atmosphere Safe and Professional

I know several nurses that switched cases because the couple in the home argued frequently. Couples who need medical care in their home are under a tremendous amount of stress. They are probably physically tired as well. If you fight and argue around your nurses, you will likely lose critical help, which will put even more strain on your household and marriage. Get support and counseling for your family, but do not argue or raise voices around your nurse. It is inconsiderate and will drive HHN away.

How to Improve the Quality of HHN Care

Everyone who provides home health services to your loved one is part of your team. It isn't fair to expect home health service providers to provide the same quality of care that you provide, but you can create an environment that brings out the best in everyone.

Set Realistic and Objective Expectations for HHN

Here's what I have experienced in terms of the quality of care from our HHN.

Nurses spend five to ten minutes performing range-of-motion exercises with their patient, if they do them at all. They typically expect my wife to perform basic tasks like making Evelyn's food or wiping her bed down. They don't often initiate taking Evelyn outside or putting her in her wheelchair. They rarely heat up her food or put a movie on for her unless we ask.

All of this leaves me disappointed. In fact, my disappointment makes me feel bitter towards many HHN. Because I judge most HHN, I often experience tense relationships with them that don't last.

Even though I feel my frustration is justified, my outlook doesn't consider the nurse's perspectives and is counterproductive.

I realize that HHN staff expect to perform only the specific tasks on their patient's plan of care. Wiping the bed, performing range-of-motion exercises, putting on a movie, and many of the other tasks that improve Evelyn's quality of life are not on their official "to-do list." A good nurse will likely perform those jobs, but I need to accept that nurses are medical care providers. I don't expect a mechanic paid to fix my car's brakes to also vacuum the interior. My wife doesn't expect her dentist to style her hair.

I still feel that, because we are talking about the quality of life for a human being, if going above and beyond the official "to-do list" provides comfort, it should be done. But I don't make the rules. As a result, I need to accept that nurses are not going to care about my daughter nearly as much as I do. Some of the few nurses who seemed to care a lot about Evelyn became controlling and combative. To an extent, I should be thankful that most HHN are detached from Evelyn and her outcomes.

Humanize Your Medically Needy Loved One

Displaying pictures of Evelyn before she was hurt and telling stories about how kind and unselfish Evelyn was can help humanize her to the nurses. I want them to view her as she really is. Evelyn is a beautiful and unique girl. She deserves to be treated like a person and not just a patient. It is up to me to convey her as a human to the nurses. Perhaps, if they view her as a person, they will treat her humanely while providing better care.

Post a Detailed Hourly Schedule

Schedule everything in order to get more done. If my wife and I truly value our position as the responsible leaders in the home, we need to make a detailed daily schedule and communicate it to everyone involved.

I use an Excel spreadsheet for Evelyn's schedule. I laminate the schedule so nurses can keep track of what

tasks are complete and which are left to do. Nurses seem to appreciate the to-do list and the fact that our expectations are clearly defined and posted.

The template that I use is available on my website, EducationLighthouse.com.

Implement the Extender Model of Care

If you are serious about making progress with your patient's goals, therapies need to occur frequently. Evelyn's physical therapist comes twice a week. If someone wants to become a successful bodybuilder, is working out twice a week sufficient?

The Care Extender Model is practiced in some rehabilitation settings in order to increase the amount of time patients receive care. In this model of care, specialists incorporate nurses, families, or volunteers into the team, training them how to perform basic therapies.

In the beginning, I naively thought that physical and speech therapists didn't do anything special. Bending a leg or elbow seemed simple. After observing and asking questions, I learned that therapy is a very complex skill that will definitely lead to improved outcomes if done consistently.

Your therapists can teach you, family members, and the HHN how to perform therapies safely and properly. We post Evelyn's goals for each area of care along with the contact information for the specialist in charge and boxes to indicate when therapy is performed.

Therapists are always very supportive of our tracking system for therapy goals and appreciate that the entire care team takes responsibility for outcomes.

Nurses are hesitant. In order to get nurses on board with participating in therapies, we speak with the home health agency. We explain that the Care Extender Model is commonly used to involve laypeople in rehabilitation efforts and that Evelyn's therapists are excited and ready to begin. We let the agency know that nurses will receive instruction from the therapists.

Acknowledge Nurses' Effort and Good Care

Acknowledging effort and good care is another method that I use to improve the working environment in our home. Every nurse seems to do something really well. It is easy to criticize, but what good does that do? Nurses deserve recognition and thanks when they do a good job.

Judith Umlas shares insight from her book *The Power of Acknowledgment* on her website: *"Recognizing good work leads to high energy, great feelings, high-quality performance and terrific results. Not acknowledging good work causes lethargy, resentment, sorrow and withdrawal. Recognize and acknowledge good work, wherever you find it."*[17]

In the past, I sometimes wanted to tell a HHN that I appreciated her, but I was afraid that my words would come out wrong or that the nurse wouldn't think that I was sincere.

I often told myself that I would acknowledge the nurse sometime in the future and then never did. Now, I let my positive feelings and thoughts flow when they arrive.

Recently, our daughter's nurse took over care for the night shift. I said, "Kelly, I am so thankful that you are Evelyn's nurse. I appreciate how gentle and loving you are toward her. We sleep well at night because you are watching her." I could tell, when Kelly looked in my eyes and said, "Thank you for saying that," that my words meant a lot to her.

You are the leader of the team providing care for your medically needy family member. Be the kind of leader who inspires your team. Foremost, you must take care of yourself. If you are physically exhausted or injured, it will be difficult for you to maintain a positive or professional attitude. You must also prioritize sustaining healthy emotions and attitudes. It is difficult to stay positive in the middle of a heartbreaking crisis, but negative emotions will only drive people away from you.

You need to inspire the care team to provide terrific care. You can do that by reminding HHN that they are caring for a special person and not simply a patient. You can improve the quality of nurse care by organizing care with a twenty-four-hour schedule and ensuring that everyone who provides care uses the Care Extender model.

5 How to Prevent and Resolve Conflicts

If there is no communication then there is no respect.

—SHANNON L. ALDER

The dynamics of a stranger in your home providing medical care to someone you love is unnatural and will likely lead to frustration at some point.

Home health nurses are professionals who show up in your house to provide medical care. They are legally obligated to implement a medical plan of care and nothing else. They are afraid of losing their nursing license, and they don't have a personal connection to your ill family member who needs their nursing support.

It is incredibly easy to become frustrated with a HHN or to cross professional boundaries with a nurse working in your home. In fact, unless you are informed and make conscious decisions when interacting with your nurses, you will likely experience conflicts.

Home health nurses and families are different in several aspects. These differences often lead to conflicts. The next section describes three key differences and how they can lead to tension or result in nurses leaving your case.

Understand Differences between Home Health Nurses and Parents

Sources of Conflict	Parents	Home Health Providers
Goals and Priorities	Do as much good as possible for the patient.	Implement plan of care and avoid harming the patient.
Authority	I am the authority as the experienced parent, care-giver, and home owner.	Medical professionals and the plan of care are the authority.
Commitment Level	Unconditional love	Professional responsibility

Conflicting Goals and Priorities

Different goals and priorities is one of the most common areas of conflict between families and HHN. On one hand, families prioritize "beneficence," which is the obligation to do good to the patient. In contrast, home health nurses prioritize

"non-maleficence," which is the obligation to do no harm to the patients they care for.

Nurses are only responsible (or permitted) to implement a medical plan of care as detailed by physicians. For example, if a parent believes that their child is not responding well to a prescribed medication, they may want to stop administering it before consulting a physician. The on-duty nurse will want to continue administering the medication until a physician changes the order.

We experienced conflict when we added probiotics to our daughter's food formula to aid her nutrition. Nurses, however, are not comfortable providing food with additives that are not prescribed. This kind of situation can cause conflict.

As a parent, I can choose one of the following:

1. Add the probiotic to the food without the nurse's knowledge.
2. Inform the nurse of the probiotic and take responsibility to feed my daughter.
3. Not let my daughter receive probiotics until completing a scheduled visit with a physician, who can officially prescribe probiotics with the food.

Waiting for a doctor's order is ideal, but will you let your child go without something you believe they need because

it makes a nurse uncomfortable? The nurse may choose to document the request to provide food that is not in the plan of care and report it to her supervisor. She may also choose to leave your case in hope of being assigned to a family that doesn't try to force her to provide unauthorized substances to a sick child.

You need to accept that nurses are medical professionals. They are bound by very clear restrictions on what type of care they can and cannot provide. If a nurse missteps, the home health head of nursing will forward a report to the state's board of nursing who will investigate.

Do not pressure your nurse to provide care that she is not comfortable with. Accept that she is forbidden from providing care that is not part of the plan of care. Furthermore, let your nurses know that you will never intentionally ask them to provide inappropriate care and that you welcome their correction if you unintentionally do so.

Opposing Views on Who Is the Authority

Having opposing views on who is the authority is another major source of conflict between parents and nurses. In respect to their child, parents view themselves as the most knowledgeable and experienced care provider. Especially within their home, parents view themselves as the authority.

In contrast, nurses are professionally educated and trained medical providers with years of experience in hospitals.

Nurses view themselves and the doctors who create the plan of care as *the* medical authority.

For example, nurses are trained to elevate the head of the bed (HOB) to at least thirty degrees after eating as a standard practice to prevent patients from vomiting. My daughter has a severe curve in her spine that sometimes places pressure on her abdomen when she is elevated in her bed. The only times I have observed her vomit after eating happen to have been when her bed was elevated thirty degrees. As you can imagine, I do not like to elevate the HOB after she eats. After a nurse feeds Evelyn, either I or the nurse will not be comfortable with the elevation level of the HOB.

As a parent, I can choose one of the following:

1. Insist that the HOB not be elevated to thirty degrees.
2. Mention that I prefer the bed elevation stay below thirty degrees, but allow the nurse to implement a "best practice."
3. Not mention my concern and hope that Evelyn doesn't vomit.

If I insist on what I believe is best, I create a professional conflict that the nurse must deal with. I challenge her as *the* medical authority in the home. If I even mention my concern, I create conflict with the nurse.

Different Commitment Levels

The disparity in levels of commitment to the patient are an additional source of conflict. Parents and immediate family members are more invested in the outcome and care of their loved one. Visiting nurses will not love your child, spouse, or sibling as much as you. It is still difficult and upsetting when we observe and feel that nurses just don't care as much, but this is our problem, not theirs.

We set ourselves up for disappointment when we place unrealistic expectations on others. For example, I was astounded and frustrated countless times by HHN failure to make sure Evelyn was warm at night.

As a habit, I ran my hand across her legs and arms to check her temperature in the mornings. More times than not, she was covered by a single thin blanket and her skin was cool to the touch. When I asked nurses to do a better job of covering Evelyn at night, they usually replied that her cool body temperature was a result of the brain injury, or they didn't respond at all. I often wondered if they allowed their own children to get cold at night.

Another example involved turning Evelyn in her bed. My daughter is not mobile and requires regular rotation on her bed in order to prevent pressure sores. I was disappointed that nurses only turned Evelyn every two hours. It is a minimum standard, but sometimes she becomes uncomfortable and needs to turn more frequently.

I also haven't liked that nurses do not heat up her food prior to giving it to her unless I insist. Nurses don't eat cold food or serve cold food to their children. Why would they get upset when I ask them to heat up Evelyn's food?

If nurses aren't performing care in a sufficient manner, you need to address that specific concern with the home health agency. But you should accept that nurses are only required to provide a minimal level of care. For instance, turning a patient every two hours is a common best practice and is considered an acceptable level of care.

Even though repositioning my daughter every two hours is considered medically acceptable, I know that she likely becomes uncomfortable before a two-hour time lapse, and I turn her more frequently. I should be very cautious before demanding that a HHN turn her as often as I do, though. Many nurses are prepared to meet the standard but unwilling to go beyond that.

Your expectations should be realistic. This means you should only expect a nurse to perform duties on the plan of care. Any expectations outside the plan of care are requests that nurses may bristle at. This is an area where you need to be flexible. It's hard for me to like a nurse on a personal level who isn't willing to turn Evelyn frequently or brush her hair, but is this a deal breaker for me? No.

Prevent Conflict Through Clear Expectations

Employees in professional work environments understand their job duties and expectations. Establishing clear expectations and a delineation of roles was the central theme to conflict prevention during my interviews with agency directors Martin and Agnes.

People become disappointed when reality is different from their vision and expectations. People become angry when they expect one thing and receive another. You need to let your nurses know exactly what taking your case and working in your home will look like. They need to see reality, so do not set a false image in order to entice your nurse to take your case during the meet and greet.

For instance, Martin said that if dogs run around the house typically, don't hide your dogs in a back room when a nurse comes over. Agnes also advised that families clearly express their expectations for nurses during the meet and greet.

During the meet and greet, you also need to determine what expectations your nurse has for you. A minority of nurses want to learn from you and will view you as a co-caregiver. They may even feel stressed if you leave them alone in the house to care for your loved one until after a few days of orientation.

Most nurses, however, will consider you as another person who also works shifts when they are not there. They

don't want you in the room when they are on shift. They don't want your advice, and they definitely do not want criticism. If you are a hands-on "helicopter parent," you need to stop. Instead of barging in the room, for example, check on your loved one through the camera system. Let HHN know that any insecurity on your part is your problem and not a reflection of them.

Practice Safe Communication and Conflict Resolution

Agnes, one of the home health agency directors we spoke with, said, "Your relationship with your home health nurse is like a marriage—you get along through good communication." Most HHN are reluctant to share their thoughts with you even when they are bursting with frustration.

It is incredibly easy for a HHN to find another case to work. Rather than work through issues with you, the nurse will likely leave you. Therefore, you must ensure that you and the HHN communicate professionally and regularly. Couples need a routine or regular date nights to talk with each other. You need to create an environment in your home that fosters healthy communication. Below are some suggestions for developing good communication with your nurses.

Know Your Audience

How do your nurses view you? They may see you as a tired, stressed-out mother who struggles to make ends meet.

Your nurse may view you as an insecure and out-of-shape dad who missed reaching his potential in life. Or they may view you as a petty micromanager who overcompensates for shortcomings. However nurses view you, they do not view you as a medical expert or an authority figure. And truthfully, you are not the nurse's boss. From the nurse's perspective, you cannot communicate from a position of authority, so try to get your nurse to view you as a teammate.

Acknowledge Your Nurse Often

You can create a sense of camaraderie in a few ways. First, acknowledge your nurse's worth and value. Your nurse has worth because she is skilled and educated. Unless she proves otherwise, assume she is a competent person with positive motives and significant capacity.

Your nurse has value because she is a unique and sought-after commodity. She can improve the quality of life for your child. Your nurse is valuable because her presence and care in your home enable you to care for all the other people who need your time and attention. Make a conscious effort to notice the unique and special things that your nurse does. Let her know that she is appreciated.

Conduct Weekly Meetings

Nurses view your home as a work environment, and your child's case is their profession. You need to create a space

and a time when the entire care team can share their voices. Weekly or biweekly conference calls create the space and the opportunity for everyone to solve problems and sustain what is going well.

We've found that almost all our nurses have been eager to participate in conference calls as long as they were scheduled well in advance and focused during the meeting time. I've allowed nurses to speak and voice themselves first. I try to keep meetings to thirty minutes.

Focus on the Mission

Create a spirit of teamwork by acknowledging the common goal and mission that you share with your nurses. Communicate that your priority is quality care and positive outcomes for your child. Remind your nurses of the shared priority and tell them that you are glad they are focused on your child's outcomes.

Consider bringing up this common mission during weekly meetings or when you need to share a concern with nurses. For example, say to the group, "Thank you for joining the conference call today. We can use this opportunity to collaborate on how we can provide the best possible care for Evelyn. Does anyone want to share what we are doing well and how we can sustain that? Does someone want to share ideas on how we can improve our care for her?"

Listen Well

You have two ears and one mouth. Nurses are often slow to share their frustrations or thoughts. They don't want to create conflicts. They will usually leave your case or shut down before they bring up a concern in a healthy, adult-like manner. Unless you create a time and space where they can share their issues comfortably, such as during regular team meetings, they will likely never speak up. When they share something or speak, take serious note of every word they share.

Choose a Good Time to Speak

Choose the best time for meaningful conversations with your nurse. Avoid conversations when she is tired, hungry, or stressed. Avoid conversations when you are tired, hungry, or stressed. Rather, look for opportunities when your nurse has free time and is relaxed. Consider bringing up a topic by first inviting your nurse to share her opinion on that topic. This will enable you to hear her perspective and insight before you speak. Regardless, make sure the time designated for conversation is opportune.

Be Kind and Respectful

Monitor your emotions and ensure that your voice tone is always kind and respectful. According to a website that quotes a 2015 study from the University of Southern

Colorado, a computer program can predict with 79 percent accuracy the outcomes of couples in counseling by simply analyzing the tones of their voices. According to the same website, the computer analysis of voice tone is a more accurate predictor of relationship outcomes than the counselors who provided the therapy.[18]

Many of the HHN who have cared for our daughter seemed very sensitive to my personal emotions. One time, we had a new day nurse named "Joan" who was engaging and seemed to get along well with me and my wife. Joan lifted Evelyn up using an electric ceiling lift in order to transport her to the shower. Joan was unfamiliar with using the sling with Evelyn and mistakenly positioned her too high. The sling forced Evelyn's head sharply downward, which cut off her breathing until I intervened.

I was fuming mad with my wife because I suspected that she did not train Joan on how to lift Evelyn using the sling. I made the mistake of making a comment under my breath, which Joan assumed was directed to her. The next day Joan told my wife that she would leave shifts before I came home in order to avoid me. I thought Joan was being thin-skinned and immature. Naturally, Joan left our case shortly afterward.

How to Resolve Conflict

You are probably going to experience conflict with your nurses. Conflict occurs when expectations or desires are not

fulfilled. Your response to conflict will determine if your nurses continue providing care to your loved one in need or if they leave your family for another case.

Nurses are constantly badgered and solicited by recruiters to leave your case and work for another company. A nurse once showed me the list of about thirty email solicitations she'd received from nursing recruiters. She received around thirty offers a day. Nurses are in short supply and high demand, so you need to resolve conflicts wisely because they are a regular occurrence when working with HHN.

During an interview, I asked Martin, a HHA director, how to handle conflicts with nurses. He said that if the family is comfortable talking to the nurse, they can do so. However, he said, "if the family feels uneasy about having a conversation with the nurse, they should give [the situation] to the agency. That's what they're there for."

Martin emphasized the importance of weekly open communication between families and nursing agencies. Agencies know your nurses better than you, and they understand the professional environment and the norms of home health. They contract and employ the nurses. Generally speaking, they are far more adept and experienced at handling conflict.

If you are not comfortable or are unable to resolve the conflict quickly, you need to communicate your needs and ask for assistance from the nursing agency as soon as possible.

As Martin said, it is their job to navigate these conflicts. The nursing agency loses money and time when nurses leave your case. Nursing agencies are equipped, experienced, and eager to resolve conflicts.

When responding to conflict, Agnes emphasized the similarity of the nurse family relationship to that of a marriage. When I asked her how to handle conflicts with nurses, Agnes responded, "All parties must realize that people say stuff that can be hurtful when under stress. Remember that all are here for the betterment of the patient. Don't handle conflict by giving up. Like in a marriage." Married couples often "stick it out" for the betterment of their children. Remind yourself and your care team that everyone is there for the health and well-being of your child.

Agnes also discussed the dangers caused by stress. She explained that parents and nurses say negative things when under stress. If there has been an argument, Agnes advised the following:

1. Allow everyone time (up to a few days) to cool off before talking.
2. Write down points on how you contributed to the conflict.
3. Start out by texting the nurse and asking her, "How do you think the last shift went?"
4. Invite a phone conversation outside a shift.

5. Have an in-person conversation if needed.
6. If you cannot calm down enough for a peaceful conversation, consider asking your spouse or representative from the agency to speak for you.

We spoke with Kate, a nonprofit director for youth services as well as a registered nurse who has extensive experience working with families dealing with brain injury, and she shared her advice as well.[19] Kate encourages parents to communicate openly and up-front in order to mitigate conflict.

I shared with Kate that almost all of our nurses felt uncomfortable when I walked into Evelyn's room and checked on her. Nurses feel like I am checking on Evelyn because I don't trust them or think they know how to care for my daughter. Kate said that I should tell nurses early and often, "I check because I care about my daughter, not because I care about you."

Kate also emphasized that nurses are under tremendous pressure and feel liable for everything that happens in your house while they are on shift. Kate said that families should not take negative words or actions from nurses personally. Families should keep in mind that home health nurses are flawed people with shortcomings too.

It is difficult to entertain a guest in your home peacefully for a long period of time. Most of us get tired, at least after a

while, of having guests in our homes even when they are close friends or family members. A HHN is similar to a long-term guest. In addition to just getting tired of having a stranger in your home, you expect the HHN to be responsible in caring for someone you love. That expectation, however, can lead to disappointment and frustration.

It is incredibly easy to become dissatisfied with your nurse, and it is just as easy for her to become angry with you. Keep in mind that HHN are visiting professionals who are contracted to enter your home and provide a limited service.

Your communication with HHN should be cordial and professional. Establish regular phone meetings with nurses so they have an opportunity to share their ideas and concerns. Ask the home health agency to provide guidance or intervene if tension develops between you and a HHN. Treat nurses as if you are fortunate to have their service, because you are. Ultimately, the success of your communication with your nurses is up to you.

Conclusion

Home health care makes your home feel like a reality TV show. Strangers come and go out of your house at all times until their services are no longer required. It never becomes comfortable running into a complete stranger in your living room when you walk out of your bedroom to go to work.

The awkwardness of home health care will become the least of your problems if you are not cautious and wise in your interactions with care providers. People who need home health care have a difficult situation. You must hire and retain good nurses despite the national shortage of nurses. Home health agencies face the same challenge, and they want to support you. Nurses have good intentions and want positive experiences in your home.

You have the ability to create a positive and professional health care environment in your home—the kind of environment that encourages and inspires nurses to do their best and results in better care and outcomes for your loved one in need.

—DR. BEN COCKERHAM

Endnotes

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Dr. Ben Cockerham is an educator, consultant, and author of guides for families that need home health nursing support.

Ben consults with home health agencies and families to reduce turnover and improve outcomes for nurses and families. Ben educates and helps implement systems that improve communication and create positive and professional home healthcare environments.

Ben and his family have required home health nursing since the injury of his daughter in an accident in 2015. Ben is a doctor of education with a background in special education. He learned from personal experience and the guidance from healthcare professionals how to transform a home health experience from frustration to success. Access to Dr. Cockerham's resources and consulting services are available at: educationlighthouse.org.