ICU Mom is a self help, inspirational guide for parents facing a child's admission to a Pediatric Intensive Care Unit. The author shares experiences from her teenaged son's prolonged hospitalization in the ICU, and offers guidance, common sense, and some advice to parents who find themselves in the same situation. She hopes to help families understand "life" in the ICU, and prepare them for their next step, whatever it is.

ICU MOM: 40 Days and Nights in a Pediatric Intensive Care Unit

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40 Days and Nights
in a Pediatric Intensive Care Unit

An Inspirational Account for Parents to Use in ICU

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CHAPTER ONE: THE SHOCK

There are few things that make a parent's blood run cold. Paramount among those things is the phone call late at night, the ring of the doorbell after 11 p.m., or the text from one of your child's friends past midnight. You will never be prepared for it, and will never be the same afterward.

When the message gets to you, your brain is frantic – what to do first? The answer: take a deep breath. Assess the situation. Try to remember the message in its entirety.

Did the messenger tell you that your child was in an accident? Was he hurt? Is she on her way to the hospital? Which hospital? Did anyone mention what injuries he had suffered?

If you have younger children, arrange for some long-term child care. Do not just leave them in the care of your eldest child. It may be quite some time before you come back to your home. Is there a neighbor who can come over and watch them, get them ready for school, etc?

Is one of your parents willing and able to come to the house and take over your other children's care for a few days? Once the rest of your family is taken care of, get yourself to the hospital, clinic, or wherever mentioned, as quickly as possible.

Do not go to the accident site. You may get in the way of any emergency workers still busy there. It is best to go to the hospital and wait for your child to be brought there by the emergency team, if they aren't there already. You do not want to go all the way to the accident site only to find out that your child has already been taken away by ambulance. You will be shocked at the image of the scene and imagine all types of possibilities about your child's injuries. It is best not to speculate, just get to the hospital.

Once at the hospital, check in at the emergency department. They will probably be waiting for you. A nurse or doctor will come out pretty quickly to talk to you, and most likely take you to a private room for a detailed conference.

When you speak to the doctor, find out what tests have been run, as well as the significance of the results.

Learn exactly what injuries your child has suffered; which are major and which are minor; what needs to be treated first, what can wait.

The doctor will want to ask you other questions as well, but many of them can wait. Now is the time to ask for your first visit with your child. The doctor may say that you are better off not seeing him right now. Turkey stuffing! You have bandaged him many times, sat up all night when he had an earache, held him when he was throwing up all night with the flu, gently dabbed lotion on every chicken pox. You must insist on seeing him. You are feeling not only helpless, but out of control. You need to see your child in order to reassure yourself, and be able to get the process of her healing underway.

Before going into the room where they are treating your child, take a deep, deep breath. Exhale slowly. Command your muscles to relax. Whatever is in that room may not be a pretty sight, but you need to see him for your sake. I have found that the imagination is often more lurid than reality.

Seeing my son with a swollen face, a crumpled hand, and covered in blood with a technician pumping air into his mouth and tubes connected everywhere, should have been the worst nightmare I had ever seen. I realized when I saw him that he did not look as “damaged” as I had imagined from speaking to the doctor. (Most of his injuries were internal, and did not show).

The nurse will take you to a place you can stand and watch as they work on your child. It will hurt as you see them putting in needle after needle, drawing blood, starting more IV’s, inserting medication, etc., but at least you will see that they are doing literally everything they can to help your child.

One of the staff will give you a bag filled with your child’s clothes and personal objects. It will be hard to see that hundred-dollar jacket in shreds because the paramedics had to cut if off him. Most of the clothing will be covered with blood, maybe even vomit. Just take the bag. (My son’s bag stayed unopened in my car for several weeks.) Once you have seen enough, and convinced yourself that you personally can do nothing else for him at that time, it is time to have a long conference with the emergency room doctor.

The First Decision – Where to Care for your Child

If you are reading this, perhaps your child has had a bad injury. Maybe the book was recommended by one of the staff in the ICU. Possibly you picked this book up to help you be prepared for such an incident. From here on, the book is written in the present tense, as if the experience is currently taking place.

The doctor will want to explain as much of the situation as he can. It is your duty, as a parent, to find out if this hospital is one that can take care of your child. If he suffered a mild concussion, it can probably be treated at that hospital. If, however, there is significant internal bleeding, a bad head injury, or some other kind of serious injury, be sure that the hospital is large enough to give the best care for your child. This is NOT the time to be loyal to a hospital. Your first loyalty is to your child. The doctor may want to transfer her to a different hospital, but again, make sure it is the absolute BEST hospital for your child.

In most cases, it would be best to have your child transferred to the nearest children's hospital. They have extensive equipment, experienced staff, and, most of all, work ONLY with children. Pediatrics is not just adult medicine for kids. Children are constantly growing, making treatment more challenging. Your child is much better off in an institution which has seen that type of injury in children before. They will know how to handle it, and have the best doctors in the area.

Every children's hospital has a Pediatric Intensive Care Unit (PICU), reserved for the sickest children. In charge of the unit there will be an intensivist, a physician who specializes in treating critical-care injuries. He has had more than eight years of training in this specialty AFTER medical school. He will also have a list of various specialists who can handle whatever problem comes up – kidney, gastroenterology, dermatology, burns, orthopedic, pulmonary (lung), neurology and neurosurgery. He is backed up by several physicians who are training to be intensivists, his "fellows" who are in their last years of training after medical school. In addition, he will have residents learning all about pediatrics, as well as nurses, and nurse practitioners, who have considerable training after becoming a nurse and can keep track of the patients for the doctor.

In short, a children's hospital is a very well-oiled machine, functioning on a very efficient level, and able to treat the worst injuries that may come their way. It makes sense to trust your child to that type of hospital, rather than a large hospital that happens to have a pediatric unit.

If, as does happen, there is no children's hospital near you, and no way to get your child to one (by air ambulance or medical plane) choose the largest hospital you can find that has a large pediatric unit (at least 15-20 beds would be best). Only then can you begin to get the care for your child that she deserves. This is the type of care that she will need to recover.

Make your decision clearly known to the emergency doctor. He may try to get you to change your decision, but he must have your permission. Trust your instincts. If you have to, call a friend and ask where they had their child taken in an emergency. Call your child's pediatrician to get a recommendation. This is not the time to be polite and wait until morning to "interrupt" people. It is, quite literally, a matter of life and death: your child's.

Arrangements will be made to transport your child to the new facility. Most children's hospitals will send their own ambulance, or even helicopter. Stay with your child while you wait. He may not be aware that you are there, but you will feel better that he is still breathing. Hold his hand or stroke his arm or another exposed piece of extremity. He may not feel it, but you will feel better at the touch.

When the children's hospital ambulance or transport gets to your local hospital, the staff from the children's hospital will have you sign all kinds of permission slips. They need to do this in case something more serious happens with your child on the way to the hospital. This is not the time to insist on reading and evaluating all the risks.

(I had to sign permission for a craniotomy, where a hole is made in the skull. It is a very risky procedure in a sterile operating room, much less in a moving ambulance, which terrified me. However, if my son's brain continued to swell, the options were to drill a hole in the skull to relieve the pressure, or have his brain swell up so much it could not get blood or oxygen and would die. Obviously, I had no problem making that decision.)

Another thing to take into consideration is that, if the ambulance was sent by the children's hospital, all the staff are certified in emergency pediatric care. They are not college kids with a summer job to "haul the bodies to the hospital". Your child is in much better hands in the ambulance, and on his way to the hospital, with them, than staying where he is. Sign the forms.

Before the ambulance leaves, make sure someone tells you what the new hospital's name is, the exact location, possibly even directions. If you live in a small town, the children's hospital may be several hours away, so get the telephone number, as well.

Watching the ambulance leave may well be the hardest thing you have ever done. There is absolutely nothing you can do for your child at this point, but pray and hope. You weren't invited to sit in the ambulance with him, because there is a chance they may have to perform one procedure or another on the way. This is not anything a parent needs to see.

Hard as it is, it is time to walk away, get in the car, and ultimately get to the hospital, where your child will get the best treatment possible.

Time for a Short Respite

It is time to go home and pack a bag. No matter how close you are to the hospital, you will most likely be spending a lot of time there while your child is being treated. If you were lucky enough to find a children's hospital, you should know that most of them take excellent care of the parents as well.

There is no way to know in the beginning how long you will be staying at the hospital. (In my son's case, I was at the hospital for 40 days and nights. I only went home to feed my cats; and whenever the nurses "forced" me to go home to get some healthy sleep. A PICU is noisy 24 hours a day, and will not be the place to get a restful sleep.) Basically, you will not want to leave your child's bedside for more than a few minutes at a time, and need to be prepared for that. The PICU at a children's hospital has foreseen that possibility and made accommodations for parents. Take advantage of everything you can to make the experience easier on you.

Some hospitals allow one parent to actually stay in the room all the time. Others may kick the parent out at 11 p.m., and send them downstairs to the parent's sleeping room. When you get there, they will quickly tell you which procedure your hospital follows.

There is typically a parents' waiting room, with several bathrooms. Some even have showers for the parents, and can furnish a toothbrush and toothpaste, shampoo and other necessities. If you remember, pack them in your bag. But if all you do is throw in a change of clothes, that's fine too.

Unfortunately, every minute you spend packing seems like an eternity. You will be terrified that you are taking too long and that your child might not make it before you get to the hospital. That is a normal feeling, but take time to slow down. From this point on, everything is uncharted territory, and you will need to be in good shape physically as well as emotionally.

If your child has a favorite blankie or stuffed toy, take it with. (I took a baseball!) The occupational therapists at the hospital have found that something familiar to the child helps in recovery, especially at the very beginning of treatment.

If you have a laptop computer, or iPad, it would be a good idea to take it with you. There will be a lot of "spare time", and you can use the laptop to make notes, do research, or simply play games to keep you from screaming in frustration. Be sure to take the power cord with you – batteries only last a few hours.

As you drive to the hospital, please drive carefully. You may be tempted to speed 90 miles an hour to get there faster, but don't. You do not want to end up as a patient at another hospital, unable to see your child.

It would be even better if you have someone else drive you to the children's hospital initially. The next day you can get someone to drive your car to the hospital. (It is doubtful you will be going anywhere so soon after admission to the PICU.)

Hospital First Impressions

Most PICU admissions seem to be in the wee hours of the morning. You may be rushing to the hospital at 4 a.m., entering through the Emergency Room. They will be expecting you. A hospital social worker will be already there, waiting to clue you in on your child's condition, and to acclimate you to the hospital's policies, what to expect, etc.

The social worker, (or whoever the hospital appointed for you,) will be of immense help. They will sit with you and answer whatever questions you have. They will find out when the emergency room doctors will have your child ready for a visit. The staffer will help you fill out all the paperwork, admission forms, insurance forms, etc. She will find out if there is anyone you want them to call, what child care arrangements you need to make for your other children, and in general make the waiting as painless as possible. You will be issued a parent's badge, which you must keep safe. *It will allow you to wander the halls of the hospital at any time without being challenged.* (There will probably be several times you want to just walk away from the unit to get a change of scenery, go to the chapel, the meditation garden etc. The badge will allow your safe passage, free from security guards asking you what you are doing.)

When the word comes that you can visit your child, it is time for another deep breath. Remember how she looked in the first hospital's E.R., and know she will look a little better in this one. They will have cleaned up most of the blood and other fluids, will have her in a hospital gown, and looking much more normal. There will still be IV tubes, maybe some new machines and bandages, but she will be more presentable. Just that slight change in appearance is where most parents get the strength to continue on this long, unknown journey.

Soon they will tell you that they are moving her from the ER and taking her to her room. If this had been a minor thing, you would accompany the gurney and your child right to her room. The situation is very different, however. The social worker will lead you from the emergency room back to the waiting room you were in earlier. She will try to tell you how to get around the hospital, and then lead you up to the PICU. You will be deposited in the Parents' Waiting Room while she goes to check on your child.

The odds are that you will not be able to go right in and see her. Once in the ICU room, the doctors and nurses need time to get her hooked up to all the machines. There will be IVs for fluids and medications; there will be monitors to track her heart rate, blood pressure, pulse, breathing rate, and any other conditions they need to monitor. (They needed to monitor my son's brain swelling, so yet another machine.) These procedures will take anywhere from a half hour to several hours, depending on what needs to be done.

You will be sitting in the waiting room for what seems to be a lifetime. If it is still night shift, there is no one at the desk to give you updates. You just sit and wait, worry and pray.

This would be a good time to send text messages to friends and family who need to know about this event. Most cell phones allow you to text ten people at a time. You can then use the forward feature and send the same message to ten more people. You can also call people from the waiting room, but remember how many minutes you have in your “allowance”. (I well exceeded my monthly “voice” limit by the second day my son was in the hospital.)

You can try to sleep, but it may not be possible. You will probably be constantly visited by doctors who are working with your son, coming out to the waiting room to have you sign the permission forms for one procedure or another. They will explain the procedure, and how it will help your child. It may be more of a “we don’t need to do it now, but we may have to later” kind of procedure, but they need your permission so that they can do it right away if the situation arises.

Sign the forms. Do not keep the doctor waiting – he wants to get back with the form so that they can do something else for your child that may possibly save her life. Remember, at a dedicated children’s hospital, they have specialists present on all shifts. They have super-specialists (like the best brain surgeon in the state) they can call if they need to. Do not question this emergency care, just allow it to happen. These are the experts, who can do a lot, much more quickly than your family doctor, since they do it more often. Their “job” is to get your child healed; put your trust in them.

While you are waiting to see your child, people may be coming and going. This may be frustrating to you. You may even be surprised suddenly by someone dropping into the chair next to you. Odds are it is one of the hospital’s chaplains. He will try to unravel some of the “med-speak” you have been hearing, since hospital chaplains have had extensive training in being around hospitals (they are not just neighborhood ministers who take turns visiting the hospital.). They may ask you about how you are feeling, what this injury means to you, etc. Even if you are not a dedicated churchgoer, this resource is valuable. He can get enough information from you to use in helping tame your emotions.

(After I had waited over three hours with no updates, I was so angry I hated every nurse and doctor in that hospital. I took that anger out on him, and he just nodded his head. He knew I needed to explode at someone, to release some of the churning emotions I felt, and offered his shoulder. Take advantage of such an opportunity if offered.)

When you are finally allowed into your child's room, you will be shell-shocked. Up to this point, you have probably half-reassured yourself that he is not really that badly-injured, that the doctors are just taking extra precautions. Your first visit to the unit will dispel that notion quickly.

You will see a number of machines in the room, some beeping, others flashing on monitors throughout the room. There will be tubes connected to various parts of your child's body. A quick run-through:

Monitors – there will be monitors displaying every significant function of your child's body:

Oxygen saturation – making sure your child's brain and heart get sufficient oxygen to maintain normal operations

Blood Pressure

Heart Rate

Temperature

Brain Pressure – if there was a head injury, an Intra-Cranial Pressure monitor has been inserted into your child's skull

Ventilator rate – if your child needs help to breathe

Respiration – breathing rate

Medication rate – how many drips per minute or hour per medication

IV's – there will be multiple IV bags filled with different medications and fluids dripping into one of your child's veins. These are all connected to a special "Central line" the doctors established near one of your child's major veins. It allows multiple medications and solutions to drip into your child's vein at the same time. If there was only a basic IV cannula, the input would be too much for your child's veins to absorb.

There will most likely be another IV in your child's arm, which is known as an "arterial line". This allows the medical staff to get easy access to the arterial blood of your child (known as "*blood gases*". This will tell the medical staff how well the oxygen and carbon dioxide are being distributed throughout your child's body.

Ventilator – Your child may need some extra help to breathe. It may be only a facemask or nose tubes to help the oxygen flow. Sometimes an injury or illness reacts badly with the lungs, or brain, and your child needs help to keep breathing. The ventilator has a tube placed in your child's windpipe, usually through his nose, which is connected to the machine. The machine will push air into your child's lungs at the rate requested by the doctors and staff.

Your child can also breathe on his own while on a ventilator; in that case the doctor will have the vent set to assist breathing. If your child suddenly forgets to breathe (as in sleep apnea), the machine will kick in and breathe for him. Usually he would breathe on his own after that first "pump".

There will most likely be a nurse in the room, or literally just outside, with your child. Most PICUs have a one patient-one nurse policy. The nurse will be in the room the entire shift, checking numbers, adjusting meds, and doing what the doctor requested. He might be friendly, but his first priority is your child.

You will be “introduced” to all the machines and monitors, and their significance to your child. The various flashing numbers will be explained. The nurse will try to break down that huge collection of equipment so that you can understand as much as possible. If you can manage to think of it, ask the nurse what the numbers should be, and write them down. That way you can, with a quick glance, see how well your child is progressing.

You will be shown where you can sit or rest. The ICU rules will be explained at length. They are very, very important, so listen as intently as possible. Your child’s life may depend on it.

Some of the rules may be evident to you, such as “no smoking”. However, if the patient next door was a visitor from a European or Asian country where smoking is very common, the visiting parent could start a fire if not told about the oxygen catching fire from the flame of a cigarette or match.

If your child has a brain injury, there may be a “no stimulation” sign on the door. The brain is swelling, and any loud noise will cause it to work harder, making it swell more. It seems minor, but if another patient's family has brought their other children to see their brother, and they run down the halls screaming, it would not do your child any good.

The hardest rule to follow, and maybe the most dangerous, is "no cell phones". It may seem silly, since even airlines are allowing calls to be made now. However, the machines that your child is depending on are different. Many of them are hooked up to the hospital's computer network so that their numbers and settings are transmitted wirelessly to the nursing station. I know that I would not want to be the one that interfered with the signal to keep the ventilator breathing for my child.

You will quickly learn to go out to the parents' waiting room to make calls (even text messages). Much better to be safe than sorry when you are gambling with your child's life.

This is NOT the time to be independent, thinking you can manage this situation by yourself. Trust me, you cannot. If your spouse accompanied you, it is time to discuss how to divvy up the various chores. Notifying people, determining who will be at the hospital for what times.

Some spouses cannot get off work without a financial penalty, so maybe you can decide that one will take the day shift, the other the night shift, sleeping in the room.

Most ICUs have a definite policy of how many visitors can be in a room at the time (typically only two). You can pretty well count on others coming to the hospital to try to get information, or overloading the hospital switchboard with requests for status updates.

Some hospitals will not, under any circumstances, release information on a patient to anyone except the parents. Others accept the fact that the patient did not live on an island, and has many people interested in his condition. They have established a "family password" system. If someone calls for information, they will be asked for the family password. If they can furnish it, they will be given the information. If they do not know it, they will be told that the information cannot be given. It is wonderful for grandparents and others to call in and feel connected, without making the journey to the hospital.

This password will also be used for visitors. If they know the password, the front desk will permit them to enter the unit, as long as there are not already two visitors.

Otherwise, the front desk will not permit them into the unit until the clerk speaks with you personally and gets verbal permission.

This is probably the most important password you can invent. It needs to be something that family members can remember, but casual friends will not be able to guess. “Kenilworth Avenue” may be too general, since a lot of people know you live on that street. But if your password is “Frank Lloyd Wright”, who happened to design the house across the street from you, it is unlikely others can guess it. Family members, however, will remember it because you surely pointed out that aspect of your neighborhood to them when you moved in.

Remember, you are protecting access to your very sick child. He will not need the entire football team barging in his room just because they are curious to see him with all those machines.

Make sure the nurse has all the necessary cell phone numbers, but also designate one as your main contact number. If something happens while you are not in the room, they can call that number and pass along the information needed. It is preferable for this number to be the person who stays at the hospital for most of the time.

Find out the visitor policy at the hospital. Visiting hours are very strongly observed in an ICU. They may not allow any visitors under 16. They may accept siblings under 16 if accompanied by the parent. Always check.

The parents' waiting room policy is most likely included in that pamphlet the social worker or nurse handed you down in the ER. The waiting room is open 24 hours, but lights may be dimmed at a particular time. You may be allowed to bring in only three or four friends to chat with in the waiting room. There may be specific limits on how bad a cold or sneezing may be to even get into the waiting room.

The waiting room facilities may include showers, washing machines, dryers, a kitchen, even lockers. Make sure you find out about those before the day shift goes off duty.

Sleeping arrangements can most likely be made at the waiting room front desk. The sleeping room may not be on the same floor as your unit. Remember, there are neonatal intensive care units, burn care units, and cardiac care intensive care units as well as your unit. Sleeping chairs fill up fast, so investigate these as quickly as possible. That way, one parent can be in the sleeping room, while the other is in the room at your child's side. (The sleeping room may allow more rest. Your sleep there will not be interrupted.) The couch in the ICU may be uncomfortable; there will be constant noise as the machines beep and whir and make themselves known; the nurse is there, and doctors slip in and check patients in the wee hours of the morning.)

With these logistics determined, it is now time to sit back, listen, observe, and wait it out.

JOURNAL EXCERPT – DAY ONE

I am sitting in the waiting room of the ICU at Arkansas Children's Hospital, waiting, waiting, waiting. Hard to believe it was only six hours ago when my life was shattered.

In fact, I think I can separate the segments of my life to "BEFORE ACCIDENT" and "AFTER ACCIDENT".

Six hours ago. I never would have dreamed my life would change so drastically, and permanently, in a few hours. Jared, *his friend N. and I were having supper (okay, I am not the most nutritionally aware mom; we had sloppy joes and potato chips). We laughed over inconsequential things, and the boys were discussing what they were going to do that night.*

It was a nice, normal, regular end of day. The boys finished their meal and did their homework. Then they wanted to go sit in my car to listen to music, since it has a great sound system. No problem there.

Then Jared asked if they could go for a drive. I asked if they would stay in town, and he said yes. I sent him away with my usual "Be Safe; I love You". He mumbled "Love you too, Mom" as he ran out to his friend's car.

I had a pleasant quiet couple of hours, watching TV, working on the computer. I noticed the time, it was almost 10:30 pm. I had told the boys to be back before 11, since it was a school night. I figured they would be heading back, noisily, any time now.

The pounding on the door, the incessant doorbell ringing, at 10:45 p.m. gave me some clue that life had changed.

When the policeman at the door asked if I was Jared Thomas' mother, my only thought was "what trouble has he gotten into now?"

At his age, 16 going on 17, he was always pushing his limits, finding out just what he could get away with. We had had a very serious clash just the week before. His mantra up to that time had been "guilty only if I get caught." I wondered what he had finally done to catch the police's attention.

Then the officer told me that Jared had been in a car accident and taken to the closest Medical Center. I admit to a moderate amount of worry, thinking Jared had broken his leg, or finally given himself a bad concussion. I was already thinking of ways to turn this injury to my advantage, to use it as a means to curb his "wild" behavior.

Then the officer disappeared and I began looking for my car keys. I could not locate them. A friend of Jared's dropped by, looking for the two boys. When he heard the news, he was instantly on his cell, to his mom. She was at the apartment in minutes, getting me in her car and on the way to the hospital (20 miles away) before I could even think about what was going on.

When I got to the hospital, I was more worried, but mainly because I knew that whatever injury Jared had suffered, it was going to mean a serious limitation of sports. The end of school was in sight, and he was so looking forward to playing on the summer baseball team. Since he lives for baseball, I wasn't *sure how well he would take it if he couldn't play for the school. That was one of the reasons he wanted to move to Arkansas -- to be "spotted".*

At the hospital, while filling in the copious forms, I heard my name (well, one of them. They were asking for "Jared's mom", a name I always delighted in hearing.)

I figured they were taking me to see Jared. Instead, it was a little waiting room, and she said the doctor wanted to speak with me "while they were getting Jared settled". No twitch of precognition, no premonition. I did wonder vaguely if his leg break, (because that was what I had convinced myself the injury was), was compound, or maybe even an open fracture.

The doctor said that Jared was currently getting a "Cat scan" and that I would be able to see him as soon as he got back. Again, no real trepidation. Then the doctor said "We need to get your son to another hospital as quickly as possible, because we don't have a neurosurgeon here."

It really is true-- the world does stop spinning and everything stops moving; time does indeed stand still. I just stared at the doctor and tried to make sense of the words he just said. I could not have heard him correctly. Neurosurgeon meant brain damage, brain swelling, bleeding on the brain, brain surgery, imminent death.

Jared's head injuries had always been relatively minor -- a hematoma, a goose-egg, a bruise, a stitch here and there. He couldn't have gotten hurt THAT bad! N. was a very careful driver. Even though it had started raining unexpectedly after they had left, he wouldn't have been doing anything that could cause an injury like that. There is no way he was talking about MY son! He was confusing Jared with somebody else.

The doctor began speaking again, telling me he wanted to transfer Jared to University Med Center. I still don't know why I didn't just agree with him. I had always heard that Arkansas Children's Hospital was awesome. If there were miracles needed, they usually took place at Children's.

I stated my preference, and he told me that since Jared was 17, he should go to University. I argued that he was 3 1/2 weeks shy of 17, and that I would only allow him to go to Children's. He gave up and walked away to make some calls to prepare for that.

The nurse came and took me to Jared's trauma room. There was no amount of preparation by the nurse that could have readied me for the sight that greeted me. I knew instantly that Jared was fighting for his life. There was a tech squeezing a bag, meaning he had already been intubated and could not breathe for himself (an ominous sign of bad brain damage). The *nurses were trying to get blood samples, and he was rolling around, trying to punch them, to avoid the needle (he always hated needles.)*

His arms were beginning to turn inwards, a classic sign of brain injury referred to as "posturing". I noticed his tongue badly swollen and protruding from his mouth. The right side of his face was already badly swollen, yet you could see an indentation just above his eye, which indicated a possible skull fracture. He was still covered in blood, since they were too busy trying to save his life to bother washing his face yet. This was NOT my baby, not the boy I had sent outside four hours earlier.

They wanted me to speak to him, try to get him to calm down. Much easier said than done, since there was no part of him I could even touch. I tried, switching from one side to the other as the nurses kept trying to perform one procedure after another. Finally someone managed to get him sedated, so the job went a bit smoother.

I remember thinking that all was finally well, when the nurse asked about my husband. I explained that we had just moved to Arkansas four weeks earlier, and that he was back in Los Angeles.

She said to call him. I told her I already had. She said "Tell him to get the first flight out here."

I guess my brain was already shutting down, because I assured her that I could sign any medical papers. She looked me in the eye, made contact, and said "He needs to get here as quickly as possible".

I knew from my days of medical social work that nurses NEVER say that unless the patient is not expected to survive the next 24 hours.

That was the first time I began to understand what I was up against. Jared had always accused me of watching too much Discovery Health Channel. I wish he wasn't correct. I now had an idea of my future, at least for the next week or so. Jared and I would be in an ICU room, fighting to save his life. I didn't like the picture. I also knew that I had no way to buck the trend, so took the first step of that wild ride that has led me to this spot in time.

The doctor found me. He said that Children's Hospital had "accepted" Jared and were on their way. The weather might still be a problem, preventing their Angel One helicopter from making the journey. If they were grounded, they would send their own ambulance to get Jared.

It seemed forever, but was only about an hour when the ambulance from Children’s arrived. Suddenly Jared's treatment room was filled with blue jump-suited people, all going to Jared's side and taking control. Turns out they send a resident (or maybe fellow) in emergency medicine on the ambulance, so if Jared needed any type of procedure during his journey to their hospital, he could get it.

The only faint feeling I got was when she asked me to sign a consent form for a possible craniotomy. That would have to be done if Jared's brain continued swelling out of control, and they needed to remove the top of the skull to allow more swelling. If the brain was swelling and had no more room, Jared would die. Obviously I signed the permission.

The ER nurse caught my attention and asked if I wanted Jared's belongings. She pulled out a bag and clothing from it. These were the clothes that had literally been cut from Jared by the paramedics. The keys to my car appeared in her hand, my cell phone, his "Axe" cologne, his gigantic shoes, the “hoodie” he always wore, and the remnants of his clothes. I needed a reason to leave the room before I started crying hysterically.

While they were working on getting Jared ready for the ambulance, I snuck down the hall to check on Jared's friend. Poor N was in a room with a hand covered in stitches. He said *the engine had pushed into the car interior, and cut up his hand. His dad said it was cut to the bone, and took 36 stitches, not to mention more stitches on his fingers and chin as well. N. asked if Jared "was going to make it". I so desperately wanted to tell him yes, but didn't want to lie to N either. He saw the answer in my face, and knew Jared was fighting for his life.*

Eventually Jared was ready to be transported to Arkansas Children's. He looked so tiny on that gurney surrounded by all those machines. I was so afraid I would never see him alive again, and was anguished that I hadn't been able to have any real communication with him here. The one thing I am pretty proud of was stopping the ambulance crew, and letting N. step up to the gurney. Jared may not have looked quite so beautiful now, but N. was able to see his chest rise in breaths, and knew Jared was still alive.

Now, hours later, I am waiting in a darkened waiting room in an unfamiliar hospital. Several doctors have run in, asking for this approval or that, but I haven't seen Jared yet. I don't know what his prognosis is, what his total injuries are, and I am anxious being so far away from him.

Since I can do nothing more productive, I will sit here and write out my thoughts. Once I can see Jared, I am sure I will feel better.

The hospital chaplain just left. How interesting. He has access to everywhere. When he asked why I was there, I practically screamed at him that they were working on my son and had not seen fit to even tell me how he was doing. He patted my hand and said that meant they were too busy saving him to leave his side. It was a horrible thought, but cast light on the situation.

He then offered to go to Jared's room to find out when I might go in. I accepted that offer so quickly I don't think he had finished speaking!

When he came back, he sat beside me, and took my hand. Instinctively I knew there was not going to be good news. He told me that Jared's brain was still swelling, and they had to insert a "bolt", some type of measuring device that keeps track of how much pressure there is in the brain. If it swells to the top of the skull, they will need to operate and take the top off his skull, to allow more room for the brain to expand. I know just enough medicine to be dangerous, and I knew that Jared was in serious trouble….much more than I had thought.

The chaplain added that the nurse told him that this was a bad case. He informed me that based on Jared's condition when he was brought to the Children's Hospital ER, they were not sure he would survive the first 24 hours. I think my heart stopped as *well as my breathing at that point. Surely God would not be that unfair! We had waited so long for Jared. There was no way that I could let God take him from me.*

That poor chaplain. I have no idea if other parents were as obnoxious as me. I told him that no matter what God's will was for Jared, MY decision was to get him well and ready for a career in the baseball major leagues. Period, end of story.

But at long last I had a target for my anger – God. He was not going to do this to me. I would not allow Him to take Jared from us. That would be cruelty as horrendous as anything on earth.

It was after nine o'clock before they came to get me. By then I was so drained of emotion that nothing they said registered. They brought me to a glass fronted room, with a table in front of a hospital bed. The bed contained my son, tethered to so many machines the tears just started coming down my cheeks. I wanted this all to be some nightmare from which I would wake up quickly. I pinched myself, but it hurt, meaning this was real.

When the engine had crashed into the passenger compartment, it had injured Jared's left hand, since he was in the passenger seat. Unfortunately, he is a southpaw, so that is his pitching hand. They had it bandaged up so that I could not see how bad the injury was. (At the local ER his hand had already swelled up to twice its size, all curled up). My heart truly sank. Playing *baseball was the only career Jared wanted. And he was good – his fast ball was already 65 mph, at age 16. It was bad enough that his brain was hurt. The sight, and thought, of what that injured hand represented was incredibly painful.*

The nurse on duty tried to get me settled and acclimated. She explained every single machine, what it did, what Jared's numbers on that machine meant. She was so wonderful – she knew I was way out of my league here. (I really felt blessed that we were assigned her. By keeping me calm, she was helping keep Jared calm. Not a lot of nurses realize that.) She let me touch him, and I lightly stroked his right arm, which had fewer tubes and needles than the left. I was afraid to talk to him because I was breaking up inside. I had always heard that hearing was the last sense to go, and I did not want Jared to hear me crying.

The nurse explained the sign on the door "No Stimulation". I had thought it meant that he wasn't to get physical therapy stuff. What it meant was that it was very important that as little noise as possible was made in the room. No beepers, cell ringtones, not even shouting across to the nurse. I realized that this was a very serious injury to my son, and very life-threatening. I turned down the ringer on the room phone as well. No one was going to hurt MY son by calling.

I found a little couch in the back of the room, just behind Jared's bed. That was placed so that the parent could actually stay in the room with him. I had been hoping for that. It didn't matter how comfortable I was, as long as I was in proximity to Jared. I could also eavesdrop on his caretakers as well!

Then the social worker for the unit came in. There were pamphlets about "life" at Children's, and a separate little book about how parents should work with the ICU staff, some rules etc. I am glad she left the pamphlet because I retained almost nothing from that conversation. I would have flunked the quiz for sure.

She made a suggestion, seconded by the nurse. I should find a photo of Jared, and tape it somewhere on his bed for him to see. When he regained consciousness, that picture would help them determine what, if any, brain or memory damage he had suffered due to the injury. If he couldn't even remember himself, it would take a different type of therapy than if he did have his memory intact.

I sat on the little couch, overcome emotionally, and overloaded with information. I knew this was going to be a rough experience. With Dean back in Los Angeles, I had no one to help me talk to the doctors, research the various things I was hearing, keep everyone updated on Jared's condition. I sat *there, feeling very sorry for myself, feeling helpless, and started my vigil.*

Now that you are settling into the unit, it will be important to become a “social animal”. You will find it so much easier to find eating places and grocery stores near the hospital, hiding places in the hospital, and safe havens to cry by talking to some of the other parents. This will happen if you occasionally make a trip to the waiting room by yourself. Another parent sitting by herself will no doubt strike up a conversation – “who do you have in the unit? How is he doing? What nurses have you had?”

It will always be easier to talk to someone in the same circumstances, and a PICU is a great leveler. The other parent may be the president of a company, or a farmer from the rural area of your state, but the most important thing in their life right now, as in yours, is getting their child better.

As you get used to being in the PICU, you will notice a number of rooms, typically more than 20. The child in each room will have one (or more) of a variety of critical problems, including:

Severe infection
Poisoning
Drug overdose
Trauma
Extensive surgery
Congenital anomalies
Immune disorders

The other parents will quickly fill you in on the best times to do things, such as washing clothes or taking a shower. They know when the waiting room fills up so bad that no one else can get in. They can tell you about a specific social worker or chaplain that is easy to talk to. Listen to all the advice they give – they have already been through the stage you are in, and are conquering newer ones.

By this time, you may be getting a lot of telephone calls, texts, etc., from concerned friends and relatives. Their first question is usually: “Do you need anything?” After five or six times, the question begins to drive you crazy, because the only thing you want is to have time rolled back to before the accident or injury. No one can do that.

Those asking the question are doing so because they feel utterly helpless. They, too, love your child and feel they should do something to help you out. They understand that your life has gone topsy-turvy and want to help.

Easy answers to that question may seem stupid, until you analyze them.

If your PICU has a shower, do you need shampoo, razor, shaving cream, toothpaste, etc? It would help your friends immensely to do something, so let them go to the local grocery store and get these items for you.

If you don’t want to use the hospital-supplied towels in the shower, ask them to go to your house and get a couple of yours. How about that special pillow you have? Wouldn’t you be more comfortable sleeping on it? Ask them to get it.

This would be the perfect time to ask them to get you a notebook and a couple of pens. You will need to take notes any time you hear anyone speaking about tests, lab results, or status on your child. If you write down any questions you have, you can ask the doctor the next morning.

You may have already decided that the hospital cafeteria is too far from the Unit to get there and back quickly. Ask one friend to bring you a case of whatever soda or drink you use. Ask another to get a box of those cracker and cheese sandwiches. This way when you are able to leave the room, it will only be for the time it takes to eat a pack of crackers and sip your drink. It will be a short break, but necessary for your physical and mental health. You will not feel guilty at being down the hall in the waiting room for five minutes. (Most units have little lockers the parents can use to store these items.)

Journaling is a great release for your emotions. It may seem as if you will never forget any detail about your experiences in the ICU, but time will fade those memories. Write them all down (on that notebook your friend brought you) so that you can feel better at the time, and also have something to share with your spouse if he is not there.

As you get settled in, it is important for you to find a rhythm, or routine, in the way your unit works. Some units have twelve-hour nursing shifts, others have ten or eight hour shifts. You will find it much easier to get a comprehensive idea of how your child is faring if you manage to be around the room when the nurses prepare to change shifts. The outgoing nurse gives the “report”, bringing the incoming nurse up to date on the highs and lows of the shift, which may fill in some of the gaps you had. (I had been wondering why my son’s blood pressure was so low. It turned out they were giving him medication to keep it low because some of the other meds he was on tended to raise it. I would have fretted for days if I hadn’t found out by “eavesdropping” at the shift change.)

The highlight of your day will always be in the morning hours, usually around 7 or 8 a.m. Do NOT even think of going to breakfast or leaving the unit until after then.

That is the time of Grand Rounds. The doctor in charge of the unit (the intensivist) will go to each room in the unit, and get a report on the patient for the past 24 hours; any lab or radiology results, and anything noticed or noteworthy from the nurse or the various residents and fellows involved in your child's care. (If you do not know when Rounds take place, ask your nurse. This is the time that the doctor is available to answer just about any questions you may have about your child's care and recovery.)

If you are visibly in the room, sitting or standing some place where he can see you, the doctor may come in at that time for a few words with you. If he is going to need more time with you to discuss your case, he will tell you an exact time he will return to speak with you.

When the doctor leaves to go see the next patient, one of his staff may stay in the room and tell you what was discussed. He will talk about tests for the day, how your child's recovery is doing, or perhaps ask some background questions.

For this reason, it is important you are there on the doctor's time. If you miss Grand Rounds, the Nurse Practitioner will eventually come to the room and tell you about them, but it is always nice to hear it directly from the doctor who is supervising your child's care.

There are some hospitals with a specific policy regarding doctor-parent talk. Some refer to it as the "No Secrets" policy. Essentially, it means that the doctors, nurses and others will always answer any questions you have, no matter whether the answer is good or bad. This is a wonderful concept of practicing medicine, a true "team" approach which includes all people concerned. Unless you tell them specifically not to tell you, they will be open and upfront with all the medical information. They will also inform you of tests and procedures coming up, explain why they are necessary, and even advise you of any possible side effects.

(This pertains to the specialists as well. I had a question about my son's growth potential, and the orthopedist showed me the x-rays that indicated his growth plates. This way I knew that he still had three inches to go before he finally attained his "grown-up" height.)

If this is your first day in the unit, the Intensivist will come in for an extensive talk with you. He will explain exactly what your child's condition is now, and what they hope he will be when he is discharged from the unit. They will also clue you in on what happens if a particular treatment does not work. It is not easy to hear, but necessary. It is always better to be prepared than surprised.

He will discuss your child's complete recovery, not just in the Unit. If there is going to have to be Rehab (such as in brain injuries and bad orthopedic injuries), he will tell you what to expect, and approximately how long the rehab will take. He will also remind you that your child has just suffered extensive trauma, and when he returns home, he will be different, no matter how well they have "patched him up".

Do not be surprised if, shortly after that "talk", the unit social worker appears. She will be very experienced in helping people who are affected by trauma. She will undoubtedly have a medical background, and has access to the doctor's notes to help explain something to you in "layman's terms". She will be an important resource for you whenever you feel your emotions getting the best of you. Not only does she have keys to the various sitting rooms, she will know who to call to help you out with whatever crisis is going on. (When I was getting so frustrated with not knowing how his brain injury would affect him, the social worker contacted the local Brain Injury Society, and they came to speak to me. I could much better handle the circumstances by talking to someone who had already been walking this particular path.)

If you are a single parent, this is a dreadful time for you. You are so used to taking care of your child by yourself that you will try to do it here as well. You can't. Period. This is the wrong time to be independent, because you are on an unknown journey, with no road map, and all by yourself. There is no way to delete the first two, but there is definitely a solution to the last.

You need to ask someone to come to the hospital every day and help you. It may stick in your throat to do so, but it is vital. This burden cannot be borne by just you, or by the time your child is better, you will be ill, or having a breakdown.

Think about this person carefully. It is not the time to play loyal daughter or son and call your mother, if you know your mother gets on your nerves about the way you raise your child. You do not need to hear a bunch of "I told you this would happen if you let her…"

Who is one of the closest adults to your child? It may well be one of his grandparents, or a favorite aunt. His godmother, or coach? Someone you know well, can trust implicitly, who can spare a couple days at least to stay with you. In fact, maybe compile a list of candidates and ask them to volunteer their time for five days, then bring in another, etc. It would help if they knew something about medicine, or the body.

One of the main reasons you need a second person is that you are totally emotionally involved with your child. Even though a staff member is telling you something in plain English, you may just blank out that conversation if it affects your child adversely. However, if your second person hears the same conversation, they will "hear" more of it, and be able to act on it quicker than you can.

This is especially important when the doctor calls a conference. The hospital is represented by the doctor, chaplain, social worker, Chief Unit Nurse, Nurse Practitioner, Fellows, and residents, while you are represented only by you. Would you even know what questions to ask?

When your “second person” comes in the first time, give them a while to adjust to seeing your child the way he looks right now. You have been looking at him for almost 24 hours now, and the shock and pain have diminished a bit. In order to be a help to you, your care teammate must be able to stay around your child. They will quickly become acclimated, and you will share the routines with him, treatments, etc. Then you can devise a schedule for when you can leave your child alone with him to take a break yourself. (This is why it HAS to be someone you trust implicitly. You are literally leaving your child in his care until you return. If this individual is not devoted to your child, he may act like a baby-sitter and sit in the back reading a book without being aware of what is going on.)

So much for practicality. The big question in your mind is – when will he get better? The doctor will already have spoken to you, but you're the parent. You have seen this child through measles, chicken pox, numerous flu's, possibly tonsillitis, whooping cough, hundreds of colds. Why isn't he showing any signs of improvement? Why is he just laying there, so still?

If one of the parents you meet in the waiting room has a child with a similar injury, talk to them. Find out what went on their first couple of days. (If they said they wanted to scream, trust me, they really wanted to.) They may offer suggestions on ways to help the nurse, Internet resources, best way to get the word out. (My best hint was to get something of my son's that he could smell. It turns out that smell triggers memory as well. Since my son was so "into" baseball, I put his pitcher's mitt just next to his face, so he could smell the leather. I do not know if it did any good, but I felt I was contributing toward his recovery by trying to trigger a memory.

Can you remember the first sight of your son or daughter in the PICU? All kinds of tubes and needles and machines around him, and no idea what they were there for? What do you think the reaction will be when her grandparents come by? Or her friends?

Some hospitals do a special visitor service automatically, but find your social worker and ask her. If so, the social worker (or Family Service worker, if they have one), will go into your child's room and take a number of digital photos. One will be a view of the entire hospital room, showing all the machines, etc., and your child in the bed. She will then take a number of photos of all the machines and equipment individually, and then a close-up of your child.

Once the photos are printed, she will show them to you and ask if they are representative. (They usually are, since she does this all the time.) She will have the photos at her desk. When a visitor, who has not seen your child since the accident or injury, comes by, inform the social worker. She will take you, and your visitors, to a small private room.

There she will speak a little bit about the injuries, and explain that there is a lot of equipment designed to help get him better. She then will show the photos, beginning with the close-up of the equipment and machines. She will explain what each and every machine in the photo is, and why it is being used. Once they understand that, she will show them the entire room. Your child can be seen, but not in a lot of detail, just surrounded by all the machines. She will then ask if they really want to see him, because no one wants them to faint away, or get sick in the room. If they still insist on going to the room, she will show the final photo – the close-up of your child. (At this point, most of his friends will decide they do not need to go in.)

If they still want to go in, and you are hesitant about them actually touching him, there is always the option of seeing him through the glass. This “excuse” can be used easily if your child has suffered a brain injury and has a “No stimulation” notice on the door. You can explain that they cannot talk to him even if they are in the room. This usually satisfies them.

This procedure is WONDERFUL if you have grandparents or other elderly relatives/friends stop by. The photos get them used to it. Many grandparents may decide to sit with you in the waiting room and talk, rather than see their grandchild looking like that.

JOURNAL EXCERPT – DAY TWO

Now I know what it feels like to be stuck inside a whirlpool. Everything is just spinning around and around, in my head and when I am in the unit.

Jared still is not stable, which worries me greatly. It has been 24 hours since they brought him in, and I thought he would have woken up by now. It may be just me, but I think the nurses feel the same way.

At least I am not alone now. I still can't believe it. Yesterday morning, when I was still waiting for them to let me in his room, I started texting everyone I thought needed to be told. It turned out to be a huge list, but it kept me doing something while I was waiting. Around 7:15 am, I called Bean, who is Jared's godmother, and about as close to him as I am. And that feeling is very mutual – he adores his Aunt Bean. I hated to wake her up with this kind of news, but I also knew I would be physically injured when she finally caught up with me if I hadn't called her first. In addition, she is a funeral director, and has a daughter who is a nurse, so she can dig the truth out of anyone.

We have known each other since high school, so we have no secrets. I believe she knows me better than I do myself.

I was out in the waiting room, probably around noon Tuesday, when I looked up to see a whirlwind in the room, coming straight to me. I thought I was hallucinating, until I heard a familiar voice say "Hey, Meem, how's our boy doing?" Who knew a nice voice would cause me to cry for the first time in these horrid 24 hours. She hadn't told me she was coming; she just knew she was needed. Unknown to me, she hung up the phone on our conversation, explained the situation to her husband, called the airlines, found a flight, and came in from Chicago. After some hugs and tears, we went in to see Jared.

I tried to warn her, but she waved me off. She wanted to see him as he was. There was a long indrawn breath when she saw him through the big glass doors; but she opened the door and went in.

It about broke my heart to see her with him. She rubbed his arm, and told him she was there, and that even though she loved him dearly, he didn't need to go to such great lengths to see her again. I explained what some of the tubes and machines were, especially the funny shaved part of his hair with the cranial pressure monitor in it. I knew I finally had someone to lean on, and already felt better about facing this battle.

The ICU here does not allow cell phones in the unit. Since Jared is connected to so many machines, there is no way I will take a chance of anything going wrong. At least with Bean here I can go out into the waiting room and text more people. Their reactions thus far have pretty much been disbelief. How can I explain to them what I don't know? In fact, one of his cousins thought I was pranking her (turns out one of her "friends" had already done that to her.)

What really hurts is when people close to him tell me that they want to be called if it looks like he is "going", so that they can be here with him. That is telling fate that it can happen, and "puts it into the air". It is hard to be around Jared, and so hard not to be around him.

I never before knew what a real intensive care room looked like. Don't ever believe what you see on television again.

When you look at him from the side (his left side), he looks almost normal. His cute curly hair looks just fine, and except for a couple of tubes in his mouth, he seems okay.

A closer inspection shows a shaved area in the middle of his head, with that icky thing sticking into his skull. I know it is helping him --- it measures the pressure of the brain, telling them if it is starting to swell , but it is very disturbing to look at.

Looking at Jared from his right side can make your knees wobble. His face is all swollen, way swollen, and bruised pretty much all over. There are little cuts all over his face, which I assume were from the windshield glass. And the pressure monitor with its shaved spot becomes very obvious from this side. It is hard to believe this is the same kid who just this past Monday night was helping me choose colors for the new house.

Jared has two tubes in his mouth -- one for the ventilator, which I think goes down all the way into his lungs, and an NG (nasal-gastric) tube, of which I am quite familiar. It helps keep the stomach and gastric juices from settling in, and keeps suctioning them out. It looks weird going into his mouth; mine were always through the nose (hence the name "nasal" gastric.)

I guess I am always a mom. The tubes in his mouth are bothering me. They seem to be pushing up, which is going to misplace and misalign all those years of Jared's orthodontia. Who knows what this is going to do to his overbite? Just one other bill I will be facing when he gets out of here -- another 40 months of braces. Sheesh.

I remember that when they first brought Jared to Children's, they asked me to sign consent to prepare a central line. I know it was to make it easy to give him IV's, and obtain blood samples, but it is pretty overloaded. At this time I am counting about five IV's connected to this line. A bunch of them are *various antibiotics to counter any infection from the accident scene; there is a line where they are giving him an IV with stuff for his brain swelling (I think it is called manitol); and the line they keep open for anything extra. At least the central line is keeping him from being a pincushion.*

And he still has more connections. Another permission slip I signed was for an arterial line. The blood samples they get from a regular "stick" is venous blood. Sometimes they need to know more blood chemistries, so they need blood directly from an artery , which carries oxygen and carbon dioxide in the blood. I remember Monday night at the local hospital they kept trying to get arterial blood, and he kept punching the nurses. When my dad had open heart surgery, they always tested arterial blood, and he said that it hurt way more than a regular blood sample. This special fixed line will prevent all that pain again and again. I guess that is good.

I keep waiting for the doctors to tell me something substantial. They keep saying that brain injuries take time, that up through day five, anything can happen, etc. They warn me that there are always backward steps in situations like this. It is getting incredibly frustrating to hear the same thing again and again.

I am also very irritated by the neurosurgeons on the case. They come in, I think deliberately, at 3 or 4 a.m., so that when I wake up they have already been there, made their exam, and *changed their orders. It would be very nice to actually speak with one of them, instead of having to wait for Dr. A. to interpret their orders.*

I don't think I am sleeping much, at least that is what the nurses are saying. I think they are worrying about me. I am lying down and in a haze. I can at least lie down and relax since Bean is here, maybe even a catnap. She is the one listening to the docs and nurses, and making comments, and then checking with her daughter.

I hope I do not have too many days and nights like this. Jared – are you listening? WAKE UP! We need to get out of here.

GETTING USED TO HOSPITAL LIFE

As you are getting used to life in the goldfish bowl known as ICU, you will start noticing all the comings and goings in your room. The respiratory therapist, the physical therapist, the occupational therapist as well as the myriad of specialists who are treating your child and keep checking in on her.

It can become nerve-wracking to see all these people examine your child, or do a treatment, write something down on the chart, and then leave without saying anything.

Remember your rights as a parent. You are entitled to know EVERYTHING about your child. You may not want to ask the nurse in the room itself (your child may be able to hear everything. You do not want him to hear anything pessimistic or disheartening.) Ask the nurse to step out of the room, and ask why the numbers on the monitor are changing. Is it a good or bad sign? Trust your parental instincts. If you sense that something is happening, talk to the nurse.

No one knows your child better than you. If she was always restless when sleeping, and now is not moving at all, tell the nurse. He wouldn't know about that, and it could be a vital clue. If her blood pressure was always very low, and now it is sky-high, make sure the nurse knows. He will know what the blood pressure should be for that injury, but it could be, coupled with your information, the nurse will be more alert to what is happening in that area of your child's health.

Make sure you are still taking mini-breaks away from the unit. By now, you may feel more helpless than you have ever been in your life. You need to remember there is a real world outside the ICU.

In fact, you may start getting angry at your care team, justified or not. It is just your emotions finding a way to express themselves. The staff is used to this, and have grown thick skins. Yell at them if you think they deserve it (sometimes they do).

Ask the social worker where the meditation garden is – most hospitals have them. Go there for fifteen minutes. It is remarkable what a little sunshine and commune with nature can do for your mental health. Get someone you trust to stay with your child and go outside. Get wild and crazy and go to the local fast food joint. Bring the food back, and eat it in the parents' waiting room. You will feel better, and be a better guardian for your child, if you watch out for your mental health as well as his physical health.

JOURNAL EXCERPT - DAY THREE

Another day and no progress with Jared. I am getting VERY concerned.

The nurses say his brain is still swelling. The room is under a super-quiet alert. Every tiny sound means his brain has to work, and they want it to work as little as possible. I can't even talk to him. I hadn't realized that I spoke to him a lot until his nurse pulled me aside and explained what the low brain stimulus sign meant.

I am afraid to move, in case I make too much noise. All I want is to have Jared back. I seem to be bursting into tears all the time. I don't want Jared to leave me. I keep wondering what I have done to cause this. Why is this being inflicted on my poor boy, when he hasn't had more than a couple of years with us? It is not fair! We were just talking about college, and baseball, and now he is here in the hospital. I watch too much documentary television; I don't want him to be brain damaged and unable to play baseball.

With Bean here, I can talk to her about it, because she shares my love for him. He has just gotten a chance at a normal life, and now this. I always tell Jared that "life isn't fair" whenever he complains about something. That doesn't mean that I wanted him to learn it this way.

Dean is on his way here from Los Angeles. I don't know what he is going to think, since he hasn't really been prepared. I am hoping to meet him downstairs before he comes in the room, or else he will be very taken aback.

Obviously I am not going to get much sleep, what with debriefing Dean and just being worried sick. I hope this will end soon.

ICU Mom is a self help, inspirational guide for parents facing a child's admission to a Pediatric Intensive Care Unit. The author shares experiences from her teenaged son's prolonged hospitalization in the ICU, and offers guidance, common sense, and some advice to parents who find themselves in the same situation. She hopes to help families understand "life" in the ICU, and prepare them for their next step, whatever it is.

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