



Complex Child E-Magazine

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Advocating for Your Child While Inpatient by Susan Agrawal

Being in the hospital is stressful for everyone, and it can be incredibly stressful for the parent staying with the child in the hospital. Despite your own high level of stress--which can sometimes approach insanity--it is vital to focus on the needs of your child. You are the only person whose entire attention is directed toward your child, and you must advocate for your child to get what your child needs.

Hospitals are busy places that are commonly underfunded and understaffed. Your child's nurse may be taking care of as many as six patients at once, and the resident physician, nurse practitioner, or attending may be caring for as many as 15 or more patients. While ideally all of the people caring for your child while inpatient will be intimately familiar with her needs, diagnoses, medications, and problems, it is often difficult for this to happen. As a result, you need to advocate carefully and effectively for your child to ensure her needs are met while inpatient.

In the rest of this article, I will make some suggestions based on my experiences with several long stays in the hospital. Not all of our stays have gone well, but over the years I have developed some strategies that have improved her care and our overall inpatient experience.

Hint #1: Stay with your child

The best way to advocate for your child is to simply be with him all of the time. While I understand this can be impossible logistically for some families, make use of every possible resource available to you to have someone with your child as much as possible. Extended relatives, friends, home nurses, and members of your church or temple may be more than happy to sit with your child while you take a break, go to work, or attend your other child's school performance. It is a simple fact that children who have an adult present while they are in the hospital receive better care. You will be able to answer care management questions and queries about medical history as necessary, oversee your child's care, and make sure the staff is taking care of your child appropriately.

But more importantly, you are the top expert in the world on your child. While some of your child's physicians may be experts on your child's medical condition, they are not experts on your child as a whole person. You are that expert. You will likely be the one to spot subtle changes in your child or interpret what may seem like a hazy set of

symptoms to your child's medical team.

It is important to be with your child as much as possible, and to participate in rounds if at all possible. If you must leave your child, call in for updates frequently, and try to arrange for someone else to keep an eye on him. Your child will, of course, be comforted by your presence. The hospital can be a very scary place, even for an older child.

Hint #2: Write down EVERYTHING

Unless you are one of those parents blessed with an exceptional memory, it is vitally important to write down everything that happens during your child's hospital stay. I suggest keeping a small notebook handy or create a file in your computer or smartphone. You need to keep track of every test result, note any changes in vital signs or your child's appearance/behavior, and keep a careful accounting of your child's daily plan.

Even with the best care in a top hospital, things tend to be missed. For example, during my daughter's most recent stay, a lab that was supposed to be performed was inadvertently left off the order. Because the team did not see the test result--which ended up being abnormal--they did nothing to address the resultant issue. I was able to point out that the lab was needed, and the result led to changes in my daughter's plan that ultimately prevented her from becoming sicker. While in an ideal world doctors and nurses would be able to keep track of every test and medication, it simply does not happen, due to human error or overextended staff. You need to make your best attempt to keep track of everything happening with your child to make sure nothing is missed or overlooked.

I find it helpful to star, bold, circle or underline things that need to be discussed the next day. When your child's team rounds the next day, I make sure to ask about any of the issues that require further action or resolution. I similarly highlight any parts of the care plan that have not been implemented for discussion on rounds.

If a doctor gives you a new diagnosis or recommends a new test for your child, write down the name of it (ask for them to spell it if needed). When you have some free time, use the internet or hospital medical library to look up further information so you are educated about the issues facing your child.

Hint #3: Be kind and polite to everybody

Your mother always told you to follow the Golden Rule, and there is no time better to put it into practice than while hospitalized. It is critically important to be kind and respectful to everyone involved in your child's care. This includes everyone, from the attending all the way down to the people who clean your room and keep the lounge and playroom clean. Say please and thank you to all of them at the beginning and end of every encounter.

You will always encounter difficult people, such as clueless residents, physicians with terrible bedside manners, or nurses with issues. It is best to just swallow your pride, avoid confrontation, and be nice to them, no matter what. If you are kind and have a good attitude all of the time, they will be much more likely to listen to you when there are concerns that need to be addressed.

I have also found that kindness gets you much better service--housekeeping puts more effort into your child's room, nurses work harder for you, and doctors are much more willing to work with you in a partnership. Kindness may also get you better nursing staffing while inpatient, as nurses who enjoy working with you and your child will request to continue caring for your child during the duration of your stay.

Hint #4: Check your attitude at the hospital door

We are all very aware that the average savvy medical mom or dad knows significantly more than the average first or second year resident physician. Residents, however, are not always aware of this fact, and some have over-inflated egos and a know-it-all complex that is usually overcompensation for their lack of knowledge. It is always very difficult to interact with residents and other medical professionals when there is constant tension. You think THEY know nothing and are incapable of making decisions for your child. They, on the other hand, think YOU know nothing and are not medically trained enough to make appropriate decisions for your child.

This conflict can be avoided easily by taking a careful look at your own attitude and approaching the medical team with respect, even if they may not have fully gained your trust. It is all a matter of how you say things, and not really what you are saying. Most doctors and nurses will be more than willing to listen to your opinions and impressions if you present them humbly and without a superior attitude. They will then respect you as a partner and will take your opinions into much greater consideration than they might otherwise. It is much better to say, "I know I am not a medical professional, but this fever is significant for my child and I think it needs to be addressed," than to say, "Why are you ignoring my kid's fever? You need to treat him." The first is respectful and requests their assistance without being overly assertive. The second is confrontational and demanding and will make your medical team defensive.

As in any situation, you need to pick your battles. If a member of your child's team wants to make a change that you disagree with but that will not hurt your child, cause him pain, or otherwise make any major difference in his care, it is sometimes best to just let it go. Of course it is important to speak up when you think a decision or test will negatively affect your child. But your opinion will be listened to much more readily if you have already established a partnership based on mutual respect.

Hint #5: Make sure you are on the same page

There is nothing more frustrating than a hospital stay that seems never-ending, with no sense of a plan or goals. It is critical to sit down with your child's team and come up with a set of goals and a plan to reach those goals so your child can ultimately be discharged. Of course, the plan is likely to change over time as your child progresses, but it is very important to make sure you and your child's team are on the same page regarding your goals and concerns. If you think your child is inpatient to come up with an adequate pain control plan and all the medical team is doing is performing more and more tests irrelevant to your child's pain, you need to respectfully request a meeting to make sure everyone is working toward the same goal.

Sometimes it can be hard to even know what your goals are, especially if your child is critically ill or newly diagnosed. It can be valuable to spend some time by yourself thinking about which concerns are most important and which ones are not, and create care goals based on your priorities. Once you have sorted these things out for yourself, you may find that some things that you thought were important can really be addressed later on an outpatient basis, while other more critical concerns that need resolution have been neglected.

The amount of time and effort you put into communicating effectively with your child's team will determine whether or not your child will experience the best care possible during an inpatient stay. Make it a priority to determine your goals and concerns and develop a plan in partnership with your child's team.

For information on resolving conflicts, see “When No One is Listening: Advocating Successfully with Your Child's Medical Team,” a previous article by Deb Millard.