

When in the Hospital - Tips for a Safer Hospitalization

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Frequent trips to the ER with subsequent hospitalization for illness such as pneumonia, and admissions for surgeries are common occurrences for children with trisomy 18 or 13 as well as many of the children with related disorders. Being aware of the following tips might make a hospital stay safer.

Admission paperwork. Do not sign an arbitration clause. An arbitration clause is written to protect the hospital from lawsuits. Your right to sue will be lost if you sign an arbitration agreement. The person who presents the admission paperwork for signature is supposed to let you know that you do not have to sign it. Hospitals can hold you forever to an arbitration agreement signed from a prior hospitalization, even if done years ago.

Your child's Life Support order. "Do you want a DNR?" or the question might be "Do you want her intubated?" Often there is no further discussion and a parent might not realize the doctor has asked about life support wishes for their child. What the doctor wants to know, is do you want your child to be resuscitated or not, in case your child has a cardio-pulmonary crisis while hospitalized.

A Do Not Resuscitate (DNR) order means that no cardio-pulmonary resuscitation (CPR) is to be done. The doctor must write and sign a DNR, in order for it to be followed by medical personnel. An attempt to resuscitate will be done if there is no written and signed order for a DNR. In some hospitals you can choose to have only portions of CPR attempted such as give medications, do chest compressions but don't use a ventilator. This kind of order will be viewed as having parental consent for a DNR limited specifically to no resuscitation by ventilator use.

The question about life support will be asked with each visit to the ER and again when a new attending physician takes over your child's care. A patient transferred out of the ER and to the PICU will have a new attending physician in the PICU where the question should be asked again. At any time, parents can *change their minds*, and ask that a new order be written, invalidating the previous order. If your child's condition changes, the life support order will be reassessed by the doctor and this should be discussed with you, the parent. Always check the status of your child's life support order, if any of these situations occur. A DNR is a life support order. It is possible for a life support order to be written (or changed) without a parent's knowledge or consent. A DNR affects the approach to care for your child in the hospital.

All patients need advocates. Our children, who cannot speak for themselves, need an advocate at all times. The Joe and Terry Graedon book *Top Screwups Doctors Make and How to Avoid Them [2011]* www.PeoplesPharmacy.com includes a chapter of practical tips for decreasing mistakes in a hospital. Adapted for our SOFT families below are some tips from this chapter and more.

Do not leave your child alone in the hospital. Neonatal and pediatric intensive care units (NICU and PICU) have rules about who can visit and when, but be there as often as possible. Parents know their

child best and their intuition about how their child is feeling and reacting is important. Swap off shifts with your spouse, relative or friend who knows your child and can advocate when you are not there.

Is it the right drug, right dose, right patient, right time? Each time a nurse brings your child medication, including IV solutions, ask for the name of the drug, and if the dose is correctly calculated. The nurse should check the name band of your child to confirm your child is the right patient before she gives the drug or hangs the IV.

Insist on being kept informed. Ask every day about lab results and what do they mean. Ask about procedures, what to expect, who will do it and why it needs to be done and *can you stay with your child*. If you don't understand what you are being told, ask that the attending physician come and explain.

Parents have a right to say NO! If you suspect a medication is not right or a procedure is not in your child's best interest, just say no. Parents can refuse a medicine or treatment for their child and if you want an explanation, insist it come from the attending physician.

If you are not happy with the care a nurse provided your child, ask the nurse in charge to assign your child a different nurse tomorrow or sooner if needed. If the person assigned to care for your child happens to come to work with cold symptoms, let the nurse in charge know that you do not want someone with a cold to care for your child. Even if they claim "it's just allergies" insist they assign a different nurse.

Be a part of transitions. Whenever there is a shift change or a transfer to a new unit or even if the patient leaves the room for a test, it is possible that relevant information might get lost in the shuffle. An advocate who is there can often be a part of the transition and conversation.

Call for help. Immediately alert the nursing staff if you suspect something bad is happening with your child. If their response is not resolving the situation ask them to call for a rapid response from a team to assess what is happening. Hospitals have special teams of experts and a system of codes for a crisis.

Red Flags. If a doctor discourages your obtaining a second opinion or when you hear words such as "too risky to do," "not for this child," "not in this hospital," "wait 6 months" or "wait until she gains weight," don't let the discussion end there, insist on an explanation from the attending physician.

Second opinions can make a difference. If you are struggling with a decision or are not comfortable with what you are being told; ask for a second opinion from another service. When in the NICU your child's attending physician will be a neonatologist. If that doctor says they are having trouble getting your child off a ventilator and recommends a DNR status, you can ask for a pulmonologist (a lung specialist) to evaluate the situation.

Discharge. It can be scary and exciting to finally be able to leave the hospital with your child. The hospital wants patients to leave as soon as possible, yet not so soon that they return sicker because they were discharged before they were really well enough to go home. New parents might have to learn about how to use an NG tube and more. The hospital nurses should provide training for parents about

any medical device a child will need to use, before discharge. If you do not feel comfortable with taking your child home, speak up and let the attending physician know.

Before leaving the hospital with a newborn. It is in a parents' best interest to insist that the hospital social worker provide them with information about Medicaid and the Medicaid waiver program for their state, and if possible, help them apply for such benefits. Also needed is an explanation about the benefits of Palliative care or Hospice, as these programs are routinely advised for newborns with trisomy 18 or 13 and are sometimes recommend for survivors who are not doing well. More benefits are reported to be available when on palliative care.

Pay attention to discharge orders. If there is any change to your child's usual medications, ask why. Confirm dose, times to give, how to give (with nourishment or not) and any possible side effects. Ask who to contact if a problem occurs. Usually the discharge planner arranges a follow-up appointment with your local health care provider. Ask if the medical records can be given to you to share with the local doctor. You will probably have to pay a charge to get them.

Mistakes happen. This happened with our daughter at a well-known teaching hospital. Megan was getting better, IV's were stopped and she was put back on her usual medications with discharge plans for the next day. But I noticed she was becoming increasingly tired and sleepy that day and the next. The staff was not concerned. Most had never cared for a child with trisomy 18 and perhaps assumed this was her norm. The problem was discovered when I reviewed the discharge medication orders and found that Potassium (KCL) was not on the list. Oral potassium was correctly held when she was getting it through the IV but restarting it after the IV was discontinued, was overlooked. Fortunately the problem was discovered before any dire consequence occurred.

My baby/child did not make it home. If there are unanswered questions afterwards, about what happened during your child's hospitalization, you can request a copy of your child's medical records.

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