



Complex Child E-Magazine

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Keeping Your Child Out of the Hospital: Treating Serious Illnesses at Home

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DISCLAIMER: Do not try to treat your child at home on your own. Being able to treat at home requires the commitment of a specialized doctor, such as a Palliative or Complex Care doctor, and a considerable amount of pre-planning, support services, and equipment. Without these in place, it is not safe to treat at home.

For certain children who are very medically complex, a primary goal of many families is to keep the child at home as much as possible. This can be difficult when your child experiences frequent serious illnesses that typically would require hospitalization. Some children are routinely admitted every few weeks for fluids or infusions, or are hospitalized for every fever if they have a central line. While standard protocol does suggest admission in these cases, it may be possible for these children to be treated at home with a lot of forethought and the commitment of a specialized doctor.

In most cases, only children in Palliative Care programs or children followed by Complex Care physicians or teams are able to stay home through the most serious illnesses. Other children with moderate illnesses may also stay home if they have a good team of doctors willing to work with their families.

The most important step to take if you want your child to be treated at home is to develop a plan in advance with your child's physician. This plan will help you to determine what equipment and medications you may need to have on hand, what nursing support needs to be available, and when an illness is simply too complicated or risky to be treated at home. Obviously, the plan will be individualized for each child, but the following steps can be taken as general guidelines.

Step 1: Talk to Your Doctor In Advance

The first step in developing a plan is discussing the idea with your child's primary doctor. Focus on how staying home will positively impact both your child's quality of life and her health. Children usually heal faster at home, if the right care can be provided.

It is not uncommon for a doctor to simply say no. The doctor may feel your child is not stable enough to be treated at home, or that the equipment available in the home is not adequate to monitor and treat your child. Your doctor may also feel you do not have enough support in the home, such as nursing care or multiple trained caregivers.

In some cases, you must prove yourself to the doctor. The doctor needs to feel confident that you, as the caregiver, have the necessary skills to both treat your child and make appropriate decisions about his care. It may take your doctor awhile to reach this point of comfort. The doctor may also want you to do a "trial run" providing your child's care in the hospital to make sure you are confident and able to provide appropriate care.

Step 2: Talk to Other Service Providers

You also need to make sure that other service providers, such as your nursing agency, home health company, pharmacy, insurance company, and durable medical equipment providers, are able to meet your child's needs at home.

In general, if your child receives nursing care, enough hours need to be in place to care for your child when ill. While it is not always possible to fill last minute shifts, it is wise to discuss in advance with your agency whether they have fill-in nurses available or whether they are willing to pay your regular nurses overtime to cover shifts during an illness.

Your home health company needs to be able and willing to provide you with the appropriate equipment to stay at home. This may include a pulse oximeter, oxygen tanks and supplies, a feeding pump and supplies, an IV pump and supplies, a resuscitation bag, a ventilator, or other similar items. You also need to make sure that they can provide 24 hour emergency service, so that urgent needs, such as an IV antibiotic or additional oxygen, can be available on a few hour's notice. The same is also true for your pharmacy. You need the ability to pick up an urgently needed drug 24 hours a day.

You may also need to get approval from your insurance company for coverage of certain emergency equipment or supplies. Sometimes it can be difficult to convince insurance that certain items are needed if they are not used on a daily basis. This is particularly true for pulse oximeters, for some reason. The best argument to use in this case is that treating your child at home will save the insurance company enormous sums of money.

Step 3: Get Trained

Every adult and competent child in your home needs to be fully trained in infant and child CPR. If possible, try to take a more advanced course that also discusses first aid, universal precautions, use of oxygen and a resuscitation bag, and so on. Remember it is wise to do a refresher course every few years. The Red Cross offers courses in many locations, and hospitals nearby may also provide training programs. In addition, the Red Cross is now offering online courses at <https://www.redcrossonlinetraining.org/>

Depending on your child's needs, you may want to do some more advanced training on a formal or informal basis. Some hospitals offer classes on topics such as feeding tube use, ventilator use, cathing, or IV care. It is also common for your home health company to

send out a nurse or other individual to help get your equipment set up and train you on its use. Get as much training as you possibly can.

Remember also to practice! You need to be prepared when an illness or emergency strikes, and the only way to be completely ready is to have practiced the skills you need multiple times in advance.

Step 4: Develop the Boundaries of Your Plan

It is very important to have very clear boundaries as to what illnesses can be treated at home and what symptoms require admission or at least an ER or doctor's visit. This will, of course, be different for each child, and varies widely based on your child's medical technology and available equipment.

Take, for example, a child who has a G-tube with a pump and a nebulizer. This child would likely be able to ride out a bad stomach virus or cold at home, using the G-tube and pump to slowly and continuously hydrate him with pedialyte, along with the nebulizer for respiratory symptoms. But this child would probably need to be hospitalized for any significant respiratory problems or severe dehydration.

My child, on the other hand, has much more equipment available at home. She has three IV pumps, monitors, a suction pump, oxygen, and resuscitation equipment. She also has emergency medications available, including IV fluids and antibiotics, respiratory medications and inhalers, seizure medications, and medications to treat autonomic crises. She has been able to stay home through multiple episodes of sepsis, extremely severe respiratory illnesses, and very significant autonomic or pain crises.

Each of these children has boundaries. For the child with the G-tube, the boundaries are pretty tight, and this child will need to go to the hospital with most serious illnesses. For my daughter, on the other hand, the boundaries are much wider due to her having constant IV access and oxygen at home. In general, her boundaries are as follows: Oxygen levels under 90 on three liters of oxygen usually earn her a trip in. Extremely abnormal vital signs that cannot be resolved with crisis medications also tend to get her admitted. Certain lab values, such as a very low hemoglobin or critical platelets, usually mean a trip to the hospital. Sometimes high fevers with very unstable vital signs require a trip to the ER, at least until a surgical cause is ruled out or treatment is started. In her case, however, we rarely need more than a few hours in the ER to sort things out, unless she needs ICU-level care, surgery, transfusion, or intubation. She can be treated at home for most serious illnesses.

Step 5: Develop Specific Care Plans or Protocols

It is best to think about your child's typical illnesses. Does she often get respiratory infections? Is severe vomiting an issue? Does she commonly get infections of her feeding tube, line, or trach? Does he have seizures? Thinking about these illnesses in advance will help you to determine what types of illnesses you need to plan for.

In my daughter's case, we have several specific protocols for certain types of illness. Some of these, such as her plans for seizures and anaphylaxis, are pretty straightforward, and just require giving medication. Other plans, such as her line infection/sepsis protocol, are much more complicated. The latter plan requires drawing blood, monitoring vital signs, giving IV fluids, and treating emergently with an IV antibiotic if needed. Her respiratory plan, for severe respiratory illnesses, is also more complex and involves monitoring, multiple medications, and oxygen. Each plan or protocol specifies what symptoms would indicate calling 911 or going to the ER.

We have also chosen to post Karuna's emergency protocols in a visible location in the home so they will be readily available if they are needed. Copies are also kept in her Carebook and her school backpack.

Step 6: Assemble Equipment, Supplies, and Medication

Once you have a plan in place, you need to make sure you have everything on hand to make it happen. You will most likely need to obtain at least some pieces of equipment, such as a resuscitation bag and mask, and several medications. It is also important to make sure that you stay on top of your equipment and supplies, checking that they are fully functional, charged, and that you have enough supplies and medication for at least two days. Make sure medications have not expired. Sometimes using an equipment and supply checklist can make this process a little easier. We also use a special shelf to house emergency medications.

Step 7: Go Over the Plan with Your Doctor

Finally, go over the plan with your doctor and your child's other caregivers, revising as necessary. It may be necessary to revisit the plan after you have gone through an illness at home or your child's needs have changed.

Step 8: Hope You Never Have to Use It!

There are several of my daughter's protocols, such as her anaphylaxis protocol, that we have never had to use. Hopefully this will be the case for many children!

But having a plan in place may allow your child to be treated in the comfort of the home, dramatically improving your child's quality of life, and the entire health and functioning of your family. It is well worth investing the time to develop an appropriate plan if staying home can make such a difference for your child and family.