

Getting Ready: Are You Ever Really Prepared?

Welcome to The Nebraska Medical Center! You are about to start a rollercoaster of a journey! We'd like to say we can prepare you completely after going through this tool, but we are not going to say that; can you ever really prepare for something like this? Most parents will say no. What we want to do is inform you about the place you are headed to, and maybe clear up a few questions you may have. There is a tool similar to this for your child. We encourage you to look at it together and answer as many of your child's questions as you are comfortable with. If there are questions you both have, keep them in mind, because your doctors and nurses are going to be there to answer those for you!

If you are new to Omaha, there is a lot you can learn through our convention and visitors bureau (<http://www.visitomaha.org>). They have lists of places to stay, things to do, special events in the area, and even where to eat. You may not have time for this right away, but chances are you will be spending a little bit of time here, so it is a good resource to keep in mind. We might be biased but we think Omaha is a pretty great and welcoming place!!

Each transplant is different in certain ways. More than likely, you have already become a pro with a lot of the medical things your son/daughter is going through. Some parents have felt that the best way to prepare is to be informed. If you need more basic information visit our website: [The Nebraska Medical Center Organ Transplant Program](#).

If you have been to the hospital for the evaluation process, you may have already met some of the people you will encounter. Do not hesitate to ask questions or ask for help. Whether it's a doctor, a nurse, a social worker, or a child life specialist, we are all here for you, your family, and your child. You should know too that while your child is in the hospital there is a team of people working for his/her recovery. There are weekly team meetings that include nurses, physical and occupational therapists, child life specialists, social workers, and even teachers. At each meeting everyone is updated on your child's condition in order to stay 'on the same page' and working toward the same goal: a steadfast recovery!

There are a lot of options as to where you and your family stay; you will have the opportunity to work with a transplant coordinator to figure out living arrangements; in addition you will have the opportunity to meet with someone on the financial side to help in your planning. There is a lot of information about accommodations (including directions, maps of The Medical Center, and pricing information) associated with the hospital on The Medical Center's website. Just click on this link to go directly to information on housing: [The Nebraska Medical Center Organ Transplant Program](#). Basically, there are a lot of options for you and/or your family:

1.) While your child is still in the hospital there is the option of the Nebraska House, located in the Lied Center. The link above gives more detailed information and even a virtual tour. Since it is attached to the hospital a lot of parents choose to stay here; it's convenient and close! Here are just a few pictures to let you see what it has to offer:



At some point, your child may be moved into “cooperative care” which is a floor at that Nebraska House in which patients and one caregiver stay with close monitoring and assistance from the hospital staff. It is a sort of transition “level” before being discharged.

2.) Another option is the Ronald McDonald House. It costs less than \$10 a night to stay here and is only up the street from the hospital. It houses a number of families that either have a child in the hospital or have a child that has just been discharged but needs to be close for check-ups. Here are a few pictures of the house to give you a general idea, but again there is more detailed information included in the link above.



At both the Nebraska House and the Ronald McDonald House you are going to meet other parents and families like yours. You can serve as a source of support and understanding for each other, because nobody understands what you are going through better than these other families.

3.) As a third option, some families prefer to seek out housing on their own in the community. Basically, do whatever works best for you and your family!

Other Questions you might have:

-What should I bring for my child?

You should bring any comfort items that your child is used to having around (stuffed animal, baby blanket, pacifier, etc.). The hospital gives you pajamas, but it may be more comfortable for your child to have his/her own 'jammies'/clothes with them. In addition, it's a good idea to bring email addresses and addresses of family/friends. It is a great way to stay in touch while you are away (yes, there is wireless internet and laptops to use but if you have a laptop you prefer you can bring it along too). The play rooms have movies for you to check out, but again, if your child has a favorite, you may want to bring it along. Basically, anything that you feel is going to help your child while in the hospital, bring it and label it with your child's name; you can always send it back home if you find you don't use it!

-What about keeping up with school?

If your child is school-aged and he/she will be in the hospital for an extended stay Eva, from the Too Cool Hospital School Program, will contact you upon admission. Eva has been a teacher here at the Med Center for almost 20 years, so she can get things 'rolling' right away. Usually, the process starts with getting a release signed so that your child's school can be contacted to set up a plan to help your child stay on track. In a best case scenario you should contact teachers before your child is admitted. The teachers can be told that someone will be working with your child during hospitalization. Also, bring books and enough assignments to get started with Eva. If you have an IEP (Individualized Education Plan) bring a copy of that as well.

The idea of "staying on target" does depend on how sick your child is; if he/she is well enough, Eva can work with him/her daily, but if your child is very ill and needs time to just rest, there is no need to push it. If a school is willing to adapt to a child's medical condition, it is reasonable to assume he/she can stay close to "on target" with the rest of his/her class. Older kids that have lab classes such as chemistry and woodshop may need a little more time to "catch up" when they return to school since those classes are hard to adapt to the hospital. If you have additional questions email Eva at emeinke@nebraskamed.com

-What if my child is very young? Are there teachers for the younger children as well?

Along with the school program for children five years of age and over, The Nebraska Medical Center has an Early Learning Program which offers a variety of services to their youngest patients and their families.

Our Developmental Specialists have backgrounds in child development and early education and are certified infant/toddler/preschool teachers in the state of Nebraska; they are here to support you as a parent with information on how children learn and grow as well as provide individual learning sessions to those young children who would benefit from developmental support during their hospitalization. The specialists will talk with you about your child's strengths, their current skills, and their interests. For children who will be in the hospital for an extended time, they develop Bedside Notes which are posted in the child's room. This family friendly tool is a way of acquainting caregivers, nurses, and other staff with your child's likes and dislikes, how they communicate, and ways to provide comfort.

Sometimes parents of children who have had medical challenges are interested in having a standardized developmental assessment completed. Other times, information is gathered through play sessions with your child so individual early learning activities can be tailored to meet the needs of your son or daughter. If your child is already receiving intervention services through a local school district or agency, their current Individualized Family Service Plan(IFSP) or Individualized Education Plan(IEP) might be helpful in developing their hospital program. Feel free to share the plan with your developmental specialist when you meet. Then, as discharge approaches, help is available in locating programs for your child in your home community.

For further information email either JLohmeier@nebraskamed.com or Megan@nebraskamed.com

-Will my child be sharing a room with another child?

At The Nebraska Medical Center each child normally gets his/her own room, but it is not a guarantee that this will be the case. There are times (particularly during the winter) that there is such a demand for pediatric beds that there may be two children sharing one room.

In the ICU each child does get his/her own room.

-What are the visiting hours?

Technically, visiting hours for the hospital are over at 8:30 PM. However, while your child is in the hospital you are not going to be asked to leave their side. The Nebraska Medical Center allows one parent to stay at the child's bedside overnight (there is a recliner in each room) as long as the staff can carry on with your child's medical care. There are not, however accommodations provided for you to sleep there. There is a family waiting room that has a kitchen (microwave and refrigerator included) as well as a bathroom complete with a shower, so if you do need to step away but don't want to be far, this is a great option! These are some pictures just to give you an idea of what to expect:



-What about a bedtime?

Adequate sleep and rest are very important in any recovery, so during the week bedtime is 10:30 (this means lights dimmed, TV off, and no loud voices or music). As a parent though, if you have something else in mind you can suggest it. The nurses do their best to enforce it, but are busy as well, so your help in enforcing bedtimes is appreciated.

-What can I do to help my child heal faster?

You know your child best so let a nurse know when your child is in pain, find things that your child likes to keep him/her busy, recognize cues when he/she is having a bad day and be there for him/her. The best things you can do are to be a parent and be present, but remember to take care of yourself because you are not much help to the team if you get sick or cannot function properly.

-I feel like I need to talk to someone, what kinds of services are available for my support?

It is normal to be overwhelmed and feel like you don't have a lot of control over what's happening right now. The "team" of doctors, nurses, social workers, and child life specialists are there for your support so talk to them frequently. In addition, pastoral care is available with various non-denominational services and even as someone to talk to for spiritual support.

There are various support groups for families with transplant children. The social workers and chaplains working with your team can connect you with a group that fits your needs. One such support group is the "Lunch Bunch". It is a group of parents that meet bi-weekly to eat lunch together and learn from staff members about a variety of topics that are pertinent to your child's care. It is not a requirement to go each time, so if something comes up you have nothing to worry about, it's just a place to go if you need some additional support!

Caring Bridge and Care pages are two resources that parents have talked about being extremely helpful for communicating with friends and family that cannot be at the hospital with you. They are free services in which you can post pictures and write about your child; others can then have access to it if they have the internet. Both sites provide stories, words of hope, information about some illnesses, and even tips for coping. In addition, it connects parents that are struggling through the same day to day

issues as you and can be an amazing source of support. You can visit the sites by clicking on these links: [CarePages - Support and community for everyone coping with illness](#) or <http://caringbridge.org/>. You will get step by step directions for starting your own “site” and sharing it with others.

-What about transportation if I am not bringing a car?

There are taxi services in Omaha, so at any time you can independently arrange for a ride if you need one, but there are a few services offered through the hospital that you should know about:

The Lied Center has a driver that can pick you up at the airport and bring you to the hospital upon arrival in Omaha. In addition, you can arrange for them to pick up family members and other visitors as well, but you need to give the office 48 hours notice so if you know someone is coming to visit, it’s best to plan ahead!

Further, there are volunteers that take guests of the Nebraska House to No Frills and Kmart once a week. There is a sign-up sheet at the front desk in the Lied Center if you are interested. There are various fast food restaurants and gas stations within walking distance of the hospital too, so if you just need a break and it’s a nice day there are places to go without having a vehicle.

There is a program called the transplant companion program (your social worker is the one who sets this up) in which a “companion” can show you around Omaha a little bit, take you to the mall, the zoo, a museum, or other places in Omaha. They are not available 24 hours a day, 7 days a week though, so arrangements need to be made ahead of time.

We asked a few parents currently at the transplant center what their thoughts were about the overall process and these are some of the things they had to say:

***“The days get really long sometimes, so I like to go to the resource room and find new books or use the workout room in the Lied Center. It’s a good way to be distracted and get rid of stress” Other suggestions are to find something you really enjoy and didn’t have time for previously, like finish a good book. It’s hard to focus, but atleast it is something to keep you preoccupied, even if for a little bit. There are also activities that the Child Life Specialists plan that are going to include you. Once a month the Lollipop Theater brings in a movie that is still in theatres for families to see; on Tuesdays a dog comes to visit and families are welcome; you can get a haircut for free once a month; and there are always the activity rooms. You can go in and play with your child or get activities for the two of you to do together in his/her room. You will be made aware of these activities as they come up. There may even be times that your**

child does not feel up to it, but if there is something going on, it is sometimes good to join in just to 'get a little break'

***"It's hard to be able to relay information to everyone back home, because if they are not here, it is hard to understand! But, it is nice to know that people are concerned and there for you."**

***"The people you meet at the Ronnie house and the Lied Center are people that understand what you are going through; they become people you never forget! So go to the support groups and meet other parents they can be a great source of information and even a release."**

***"It's very obvious that the doctors and nurses love what they do. They showed so much respect for our family and our son, and never acted annoyed when we asked questions."**

Each day is going to be different. Your child may feel like things are out of their control and you may too. Give your child choices in small things such as which activity to play so they can feel a sense of responsibility. And, set up activities that allow them to succeed and gain confidence. Basically, control the things you can and learn to ease up on the things you can't. Unfortunately there's not a lot to do to prepare you for that other than to tell you that each day will be different and to expect the unexpected.