Pediatric Intensive Care Unit

Parent Handbook
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INTRODUCTION

A Letter from Parents

Dear Fellow PICU Parent,

While every person’s and every family’s situation differs, we have been where you are now; at least to some extent. We did not have the benefit of a manual like this one to help us through and we, as parents who survived similar ordeals, wanted to give you the benefit of our experiences.

Not everything in this booklet will be relevant for you and some will become important at different times of your stay. Don’t feel that you have to read it all at once. Skim through it when you have a calm moment. Read what you find to be of interest then and keep it nearby in case you want to reference it down the road or even during future PICU visits if they become necessary. We’ve tried to incorporate useful information and resources to make your stay a bit easier than what many before you have faced.

There are many suggestions and ideas included, ranging from ways to take care of yourself, to what you might encounter during your stay, to how to interface with friends and family during this time. Not every suggestion will work for everyone. The encouragement to ask whatever questions you need to ask so you feel that appropriate care is being provide for YOUR child is, however, universal. You are the one who knows the most about your child, your beliefs, and your desires. These all need to be taken into account in planning care.

Your journey, whether brief or extended, will have its own unique series of bumps, blind curves, and possibly even stretches of clear sailing. We hope this document will help you to navigate your personal path with strength and success.

Don’t forget to keep breathing!

With Best Wishes,

PICU Supports Parents Advisor Team
ACKNOWLEDGMENTS

Parts of this handbook were adapted from information found on the “Patients and Families” page of the Society of Critical Care Medicine website. Please see www.sccm.org for additional details.
What can you do for your child in the PICU?

While the PICU is a very busy place and there are a lot of people taking care of your child, you remain at the center of what is happening for your child. No one knows your child better than you, so you are a very important part of your child’s care! There are many ways that you can be involved in your child’s care.

*Join in during morning rounds.* Every morning your care team will come by your child’s bedside, review how your child is doing, and discuss what kind of care your child will need. This is called *rounds*. This is a great time for you to share any observations you have about your child, let the team know about any ideas you have to help your child, and tell the team if you have a particular preference about your child’s care.

*Keep asking questions until you understand.* You have a right to understand what is going on with your child. If you cannot understand something, ask the physician or nurse to explain what is happening. If you still cannot understand, please ask again—and again, if necessary. As they say, “there are no stupid questions.” If the amount of information you are receiving is starting to feel overwhelming, try keeping a journal at the bedside to jot down notes and questions as they come up.

*Ask for ways in which you can “parent” your child.* Often times, parents are afraid to touch, cuddle, or help out with their child’s care and miss interacting with their child while in the PICU. However, you can do things to help take care of your child, like do diaper changes, help with physical therapy, or help the nurse move your child into a different position in bed. Ask your nurse what you can do to be involved.

*Help make the setting more comfortable for your child.* Even if your child is too sick for you to help with some of the more common tasks you usually do for him or her, you can still help by:
- Touching your child in a soft, soothing way.
- Bringing in items from home that will help your child feel more comfortable with the environment, like toys, pictures, a favorite blanket, or a stuffed animal.
- Playing soothing music for your child or music that you know your child likes.
How can you take care of yourself?

Being the parent of a child in the PICU can be one of the most stressful experiences a parent can face. Caring for yourself may not be the first concern on your mind, but taking care of yourself is important so that you can be there when your child needs you. It is kind of like being on an airplane and knowing that you need to put your oxygen mask on first before that of your child. Below are some things you can do to take care of yourself, both emotionally and physically.

**Know that it is okay to leave the bedside.** Many parents feel like they are not “good” parents if they leave their child, even for a few moments. This is not the case! Leaving the bedside can often help a parent process, cope, and re-energize. To ease your anxiety, you may want to ask your nurse when a good time might be to step out — when your child is sleeping, being taken for a test elsewhere in the hospital, etc. You can also ask about having a staff member or volunteer sit with your child while you are away, which may be possible in some cases.

**Don’t forget to eat.** Even though you may not feel like it, eating will help you stay strong and energized. Even something as simple as remembering to drink plenty of water and trying to eat at least one fruit and vegetable a day can be helpful. Also, if you find yourself always eating in the cafeteria (or not eating because you do not like or are tired of the food in the cafeteria), see if a friend or family member would be willing to bring you food from outside the hospital.

**Don’t forget to sleep.** No doubt it can be hard to sleep in the PICU. You may already feel exhausted from caring for your child at home, find that worrying keeps you awake, or simply find it too noisy to sleep in the PICU. However, sleep is another one of those things that will help you stay strong for your child. Some simple ideas for helping with sleep are using earplugs, a sleep mask, or headphone with soothing music.

**Get exercise when you can.** It may seem crazy to think that exercise can give you energy, but sometimes moving around is just the thing to help you rejuvenate, both mentally and physically. Even a short walk or stretching for 10 minutes in the family break room can be a big help.
Ask for help! We know that life does not stop just because your child is in the hospital. Do not feel like you have to manage your child’s hospitalization on top of everything else in your life. Often times, friends and family are looking for opportunities to help you — take them up on it! Check out our thoughts in *What can you do for family and friends?* for suggestions about how others can help you.

Know that having a range of emotions is normal. Being in the PICU can be scary, frustrating, exhausting, overwhelming, and more. At times it may feel like an emotional roller coaster. You have a right to feel all of the emotions you are feeling. There are people in the hospital, including social workers, chaplains, nurses, and others who can help you process whatever emotions you experience. Feel free to ask someone on your care team about help with this.

Be alert to depression and post-traumatic stress disorder (PTSD). Both during their stay, and even after leaving the PICU, many parents are vulnerable to depression and post-traumatic stress disorder. Be aware of changes in your mood, sleep patterns, and/or appetite, as well as the presence of nightmares or recurring thoughts about the PICU. Alert family members too. Sometimes a family member will notice signs and symptoms before you do. Again, feel free to ask someone on your care team for a referral for additional assistance.

Talk with other parents. Many parents find it extremely helpful to connect with other parents who have been in a similar situation. If you feel this might help you, ask someone on your care team if they can help identify appropriate people.

Use faith and spiritual support if it feels right. For some, it helps to turn to faith by involving people from their religious group or turning to prayer. For others meditation is a way to find spiritual solace.

Keep a journal. For some, keeping a journal is a good emotional outlet. Writing about what your child is going through can also help you keep track of their child’s progress and the medical information you are getting from the healthcare team.

Celebrate the small victories! We believe that positive thoughts go a long way. Try to enjoy the victories whenever they happen.

At times, being in the PICU may feel like you are on an emotional roller coaster.

Quite often, being in the PICU is more like a marathon than a sprint.
What can you do for your other children?

When your child is in the PICU, the whole family can be affected, even brothers, sisters, or other children close to your child. Here are some things that might help you understand and support your other children and/or other children around you.

Help children understand what is happening. It is important to be honest and explain to children (using words they can understand) why their brother or sister or friend is in the hospital. Children are often aware of more than we know. Without information about what is happening, children may make up things that can be scary. Helping children understand what is going on can help them feel less afraid.

Try to keep routines. Most children like routine. Normal day-to-day activities such as going to school or daycare will help children feel safe when separated from caregivers and family.

Try to provide opportunities for children to express their feelings. Expressing feelings can help children as they try to cope with what is happening, and they need lots of opportunities to do so. One way to help children express their feelings is simply by talking with them. Other children might find it easier to express their feelings through art and music. If you would like ideas about how to help children express themselves, please ask your healthcare team.

Look out for changes in behavior. Each child may react differently when another child is sick. Fear, guilt, anger, confusions, and loneliness are just some reactions you may see from children. Some behaviors you might see are:

- Acting out, and/or aggressive play
- Becoming more clingy or quieter than usual
- Regression to behaviors of their younger years (thumb sucking, bed wetting)
- Complaints of stomach aches, headaches, or other sickness
- Changes in sleeping or eating habits
**Involving your children at home can help.** Some children will not want to come to the hospital or may not be able to come to the hospital for one reason or another. Here are some activities you can do at home to keep other children involved:

- Draw pictures or write letters to take to the hospital
- Talk on the phone, video chat, email, send mail
- Ask siblings to help pack favorite items to send to the hospital such as favorite stuffed animals, DVDs, music, or games
- Make decorations for the hospital room (signs, pictures)
- Create a webpage. See *What websites can you use to stay connected?* for some website ideas.

**Ask for help.** If you want help talking to your other children or helping them in any way, ask someone on your healthcare team.

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Open communication with children can help them cope.
What can you do for family and friends?

Communicating with family and friends can be a challenge during a PICU stay. For many people, it is important to keep your loved ones informed and involved because they can provide much needed support. As you interact with family and friends, it may help to remember that this is a time for you to focus on your child, and surround him/her and yourself with caring and supportive people. Here are some ideas that may help you get support from your family and friends.

*Don’t be afraid to ask for help.* Many times friends or family will want to do something to help you, but don’t know what you need. Do not be afraid to express your needs and offer loved ones an opportunity to help you during this challenging time. Some things to consider asking for might include:

- Watch your other children
- Take in your mail
- Take in/out garbage cans
- Water plants/yard
- Bring you additional clothes/snacks/magazines, etc.
- Make calls on your behalf to update family and friends
- Sit with your child at the bedside so you can get some fresh air
- Drop off meals at home
- Help take your other children to their regular activities
- Feed pets at home

*Friends and family from out-of-town can also help.* People who live out of town may want to help out as well. For these people some options include:

- Use video chat (like Skype or Facetime) to entertain you or your child during quieter times
- Pay for a cleaning service to help maintain the house
- Send cards and letters to your child and/or other siblings and children at home
- Make a charitable donation in honor of your child
- Provide pre-paid meals/gift cards for restaurants near the hospital

Surround yourself with the best people to help you and your child during this time of need.
Not everyone may react as you expect. Your child’s illness may cause unexpected reactions in people, which can be frustrating. Here are some reactions you might encounter:

- Some people may not know what to say or may freeze up and be uncomfortable saying (or doing) anything at all.
- You might hear people make references to when their grandparent, co-worker, or even pet had a serious illness. No, those experiences are not remotely similar to when a child is sick. You might also hear people reference religious verses or motivational sayings that may not be supportive to you. In these situations, it may be helpful to recognize that people are trying to say the right thing, or are saying what they think they would want to hear if they were in your situation.
- Your circle of close family, friends, and support may change during and after your child’s illness— and that’s okay! (Trust us, it happens all the time in these circumstances.) For every person that might fade away during this time, parents often find that other people step up and provide enormous support.

People may react in ways you don’t expect.

Consider setting limits on visitors. You may or may not want people to visit you and your child while in the hospital. It may help ask your friends and family to contact you in advance if they would like to visit you and your child, that way you can let them know if and when it would be best for them to visit.

Set up a website. Websites can help you give updates and information to lots of people at the same time. Such sites can also be a great way to let people know what kind of help you need or to let people know if you have specific requests (like how you feel about having visitors). See What websites can you use to stay connected? for some website ideas.
**Who are the people in the PICU?**

There are many providers involved in your child’s care. Below is a list of the different people you may see and a brief description of who they are and what roles they have in your child’s care. Remember that because every child’s case and needs are different, every person on this list may or may not be a part of your child’s care. We hope this will help you as you meet the various people on your care team.

**PICU Attending Physicians** are the doctors who lead the PICU team.

*Attending Physicians from other specialties (non-PICU Attending Physicians)* are doctors from other services (like surgeons, kidney doctors, or neurologists) who lead a team of specialists helping to care for your child.

**Fellow Physicians** are doctors training to be an attending in a particular specialty, like PICU or cardiology. Fellows have completed a residency in a more general area, like pediatrics.

**Resident Physicians** are doctors in training. Most residents you meet are training to be pediatricians. These doctors may decide to become a general pediatrician or go on to be a fellow and train in a particular specialty.

**Medical Students** are training to become doctors and have not decided what kind of doctor they will be.

**Advanced Practice Nurses (APNs)** are nurses with Master’s degrees who are healthcare providers and work collaboratively within the healthcare team. Some APNs work only in the PICU while others work with other specialties like neurology.

**Bedside Nurses** are the nurses at your child’s bedside 24 hours a day/7 days a week and provide constant care to your child. PICU bedside nurses have been specially trained to care for critically ill children.

**Pharmacists** monitor the medicines given to your child.
**Dietitians** help manage your child’s nutrition, including nutrition given through a feeding tube or an IV.

**Respiratory (breathing) Therapists (RTs)** use oxygen and other therapies to help your child breathe. These therapists manage breathing machines at your child’s bedside.

**Physical, Occupational, and Speech Therapists** focus on increasing your child’s strength, flexibility, and function, and reducing risk during activities such as swallowing or transferring out of bed.

**Child-Life Specialists** help your child cope with being in the PICU. They are experts in child development and can also help with siblings or other young family members.

**Social Workers** provide emotional support and can guide you and your child to resources that you may need during your child’s stay in the PICU.

**Chaplains** provide spiritual and emotional support for you and your child. They are highly trained to work with people of all faiths or people who do not consider themselves part of a particular faith group. They can help to connect you with resources from your religious tradition.

**Case Managers** work closely with you, your child, and other members of the medical team to coordinate your child’s discharge plan. These professionals also serve as the link between the hospital and your insurance plan.

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**If you are not sure what someone’s role is, ask!**

Every member of your child’s care team serves a special purpose, but you are also a critical team member.
What are some of the tests and equipment a child may need in the PICU?

Many people think of the PICU as a place filled with machines that can be scary and overwhelming. For some, it can be helpful to understand why tests are ordered and what the different machines do. Below is information about many procedures, processes, and equipment used in the PICU. However, it is important to remember that children are admitted to the PICU for many different reasons. Since each child is different, the care and treatment your child needs may be very different from what another child needs. Some children may need only a few of these tests or equipment, while others may need many.

**Laboratory Tests.** Doctors may order tests on your child’s blood, urine, and sometimes cerebral spinal fluid (the fluid that surrounds your child’s brain and spinal cord). These tests can help the care team figure out what is wrong with your child and how to best help your child get better. In order to make plans for your child’s day, these tests may be done in the early morning. In some cases they are repeated throughout the day.

**Images or pictures of your child’s body.** Getting images of your child may be necessary to determine what is wrong with him/her or to follow his/her progress. Some examples include X-rays, ultrasounds, computed tomography (CT or CAT scan), or magnetic resonance imaging (MRI). In some cases these procedures can be done in your child’s room; in other cases, your child will have to go to another location to have them done.

Be prepared, some test may be done early (like at 4AM) or overnight.
Monitors. To help your care team keep a very close eye on your child, monitors are used. These monitors allow the care team to follow statistics like your child’s blood pressure, heart rate, respiratory rate (how fast or slowly your child is breathing), and oxygen level in the blood. Sometimes these monitors will cause a light to flash or an alarm to go off, helping your care team know that something has changed. Ask your healthcare team what each monitor means and what kinds of sounds or alarms mean that there is a problem.

Catheters and IVs. Most children in the PICU need to have medications or fluids given via their veins. For some children, a peripheral IV (a very small “straw” that goes into a vein near the surface of the skin) can be used to give medications or fluids in the veins. Other children may need a catheter (a larger “straw”) that goes into larger veins. These catheters are often called central venous catheters, central venous lines, or central lines. They are often placed in the groin or neck of a child.

Urinary catheter. In some cases it is important to know how much a child is urinating. In such cases a urinary catheter (sometimes called a foley catheter) is placed. This is also like a small “straw” that goes into the bladder.
Breathing machines. Many children admitted to the PICU have problems with their breathing. There are a number of different machines that can help children breathe better. Below is a list of some equipment that your child might use to breathe better.

Nasal Cannula. This is a small plastic tube with short prongs that go into the nose and give extra oxygen. Sometimes a “high flow” nasal cannula is used to help your child breathe more easily by giving extra oxygen.

Face mask. This plastic mask is placed over your child’s nose and mouth and delivers oxygen.

Positive Airway Pressure (For example BiPAP or CPAP). These machines can help your child breathe by giving them pressured air through a special face mask or mask on the nose.

Ventilator (also called a respirator, “vent,” breathing machine, or mechanical ventilator). This is a machine that can either help a child breathe or breathe entirely for a child. The ventilator is attached to a child through a tube called an endotracheal tube. This tube is place into the mouth or nose and ends in the trachea (the part of your child’s body that leads to the lungs). If a child has a tracheostomy tube (a tube placed in the neck by a surgeon in the operating room) a ventilator can be attached to the tracheostomy tube. There are different kinds of ventilators used in the PICU. Your healthcare team can explain to you what kind of ventilator is being used, if you child needs one.

The tests and treatment that your child needs may be very different from those of another child.
**Kidney machines.** Some children in the PICU experience problems with how their kidneys function. Sometimes, the kidneys don’t work as well as they need to, and other times they are not working at all. There are a couple of different ways to help your child if his/her kidneys are not working well. There are some situations when these treatments are used for other medical problems (not just problems with the kidneys) as well.

**Continuous Renal Replacement Therapy (CRRT).** CRRT takes over for the kidneys. It is used when a child needs treatment continuously (24 hours/day). It is done by placing a special catheter in a blood vessel (usually in the neck or groin) and attaching the catheter to a machine that cleans the blood and removes fluid.

**Hemodialysis.** Hemodialysis is done by attaching a special catheter to a machine that cleans the blood and removes fluid. Typically, hemodialysis is done every few days.

**Peritoneal dialysis.** Peritoneal dialysis requires the surgeons to place a catheter into the abdomen. This catheter is attached to a machine which fills the belly with fluid and then removes the fluid from the belly. Through this process, which typically occurs nightly, the machine is able to clean the blood and remove extra fluid from a child.
What kinds of medicines are used in the PICU?

In the same way that different treatments or therapies are used to help different children, a variety of different kinds of medications may be used to help your child get better. Some children may need only a few medications, while others may need many. Below is some information about medications that are frequently used in the PICU. Please talk with you healthcare team about the medications that your child is receiving.

Medications for pain. Medications to control pain are sometimes called analgesics. Pain medications can be given in a variety of ways (for example, by mouth or into an IV) depending on your child’s situation. Some commonly used pain medications in the PICU include: morphine, fentanyl, and hydromorphone (Dilaudid®). Acetaminophen (Tylenol®) and ibuprofen (Advil®) are also used. Often pain medications are given in combination with sedation medications. Your child will be monitored regularly for pain.

Medications for sedation. There are times when children in the PICU need medication to help them calm down and feel more comfortable. This can occur because of your child’s illness, because the PICU environment can be scary to some children, or because a treatment that your child needs may be uncomfortable or scary. Most children who need a ventilator (breathing machine) to help them breathe require medication to keep them comfortable. Some sedation medications commonly used in the PICU include: lorazepam (Ativan®), midazolam (Versed®), and dexmedetomidine (Precedex™). Often sedation medications are given in combination with pain medications. Your care team will do their best to make sure your child remains as comfortable as possible throughout his/her stay in the PICU.

Medications to manage blood pressure. Some children in the PICU have problems with their blood pressure. Some children may have high blood pressure, while others may have low blood pressure. Medicines to help children with low blood pressure are often called pressors and are usually given through a central line. Some commonly used medications to treat low blood pressure include dopamine, norepinephrine, epinephrine, and vasopressin. There are a number of medications to treat high blood pressure. Some of these medications can be given through and IV or central line, while others can be given by mouth. A medication commonly used to treat high blood pressure is nicardipine, but there are a variety of other medications that may be used for high blood pressure as well.
Medications to protect the stomach. Being in the PICU can increase your child’s risk of developing stomach ulcers or reflux. Reflux happens when stomach contents move up your child’s esophagus instead of going into the intestines. These may happen because of the stress on your child’s body or because of medications he/she is receiving. Some commonly used medications to protect the stomach include famotidine (Pepcid®), ranitidine (Zantac®), omeprazole (Prilosec®), or pantoprazole (Protonix®).

Medications for constipation. Constipation (trouble having a bowel movement) is a common problem in the PICU. Constipation can be a side effect of medications that your child is receiving. It can also occur because children in the PICU are not moving around as much as they usually do. Some commonly used medications to prevent constipation include docusate (Colace®), bisacodyl (Dulcolax®), senna (Senokot®), and polyethylene glycol-electrolyte solution (MiraLax™)

Medications to fight infection. Infections may make children so sick that they need to be in the PICU. Infections can be caused by bacteria, viruses, fungi, and in rare situations, other organisms. Antibiotic medications are used to treat infections caused by bacteria. Antiviral medications are used to treat infections caused by a virus. Antifungal medications are used to treat infections caused by a fungus.

Medications to prevent clots. Some children in the PICU may have an increased risk of developing clots in the blood. Medications that prevent clots from developing are sometimes called “blood thinners.” Some examples of blood thinners are heparin and Enoxaparin (Lovenox®).

Medications to control blood sugar. When a child’s body is stressed, which is the case for some children in the PICU, the level of sugar in the blood may be higher than normal. In some cases it will be important to keep your child’s blood sugar level normal using medications. Insulin is a common medication used to keep your child’s blood sugar normal if it is necessary.
Because children in the PICU may be too sick to take their medication by mouth, your child may receive medications in different ways. Below is a list of some ways that different medications may be given.

**By mouth.** You may hear healthcare providers using the abbreviation “PO” to refer to medications given by mouth or orally.

**Into a tube that goes to your child’s digestive track.** Your healthcare team will determine which of the following options is most appropriate for your child: a **nasogastric tube (NG tube)** inserted into the nose and ends in the stomach; a **nasojejunal tube (NJ tube)** inserted into the nose and ends in the small intestines; or a **gastrostomy tube (G-tube)**, a tube placed by a surgeon in the operating room that goes directly into the stomach. Most medications that can be given by mouth can also be given into a NG tube, a NJ tube or G-tube.

**Into an IV.** Some medications will be given directly into your child’s IV.

**Into a central venous catheter.** Some medications will be given directly into a **central venous catheter**. Usually, if a medication can be given into an IV it can also be given into a central venous catheter.

**Into the rectum.** Some medications given as a **suppository** (inserted into the rectum).

**As an injection or “shot.”** Some medications are given as a “shot” that delivers the medication under the skin or into your child’s muscle.

**As a patch.** Some medications are placed on your child’s skin like a patch or “sticker” and the medication is absorbed through the skin.
How will your child get nutrition while in the PICU?

Making sure that your child gets the right kind of nutrition in the PICU is important. A sick child may have different nutritional needs than a well child. In the PICU, your child’s nutrition can be supported in different ways.

Nutrition given orally. Some children are well-enough to take their food by mouth. However, there may be situations when the foods your child needs or is allowed to eat or drink are different from those at home.

Nutrition given into the digestive track. Some children are not able to take their food by mouth. In certain cases, food (in the form of “formula” or liquid nutrition) will be given via a tube into the digestive track. Typically this is done using an NG tube, an NJ tube, or a G-Tube.

Nutrition given into the veins. Some children cannot take food by mouth or into their digestive track. In such cases, nutrition can be given with specially prepared fluids into the veins. This type of nutrition is called total parenteral nutrition (TPN). Total parenteral nutrition may include two types of fluid, hyper alimentation (HA) and interlipids (IL). Most of the time a child who needs TPN must have some kind of central line because TPN is best given into the larger veins.

Fluids given into the veins. There are times when the nutritional support a child in the PICU may receive is limited to fluids given into their veins (sometimes through a peripheral IV and other times through a central line). Typically these fluids will contain needed electrolytes (like sodium and potassium) and sometime sugar.
What happens when your child is ready to leave the PICU?

Most of the time leaving the PICU means that your child is getting better. That can be a great and exciting time! But for some, leaving the PICU can also be a scary time because it means getting used to a new situation and, sometimes, new people. It can also be a difficult time because it may mean that you will need more time for taking care of your child. As all this is going on, we would like to remind you to **take care of yourself too**. Just as it is important to take care of yourself when your child is in the PICU, it is important to take care of yourself when your child goes home.

- Having a range of emotions is normal. Some parents may feel scared, frustrated, overwhelmed, and out of control when their child is leaving the PICU. All these feelings are normal.
- It is still okay to ask for help, even when your child is well-enough to leave the PICU.
- If possible, try to carve out time for yourself.
- Eating, sleeping, and getting exercise can help you stay strong.
- As mentioned before, even after leaving the PICU, many parents are vulnerable to depression and post traumatic stress disorder. Be aware of changes in your mood, sleep patterns, and/or appetite, as well as presence of nightmares or recurring thoughts about the PICU. Alert family members, too. Sometimes a family member will notice signs and symptoms before you do.

Many parents have a range of emotions when it’s time for their child to leave the PICU.

From the PICU your child might be transferred to a regular floor, discharged to home, or discharged to a transitional or long-term care location. On the following pages is some information about each of these situations.
Going to “The Floor.” When your child is getting better and does not need such close monitoring, he/she may be transferred out of the intensive care unit. Here are some changes you and your child might notice when you are moved out of the intensive care unit.

- **You may meet new doctors and nurses on the floor.** The PICU physicians, PICU APNs, and PICU nurses will no longer be involved in your child’s care. Your child’s attending physician and care team may be new to you. The PICU care team will communicate directly with the floor care team so they have the information they need to take care of your child.

- **You may not see your bedside nurse as often as you do in the PICU.** Nurses on the floor generally take care of more patients than PICU bedside nurses do, but you will still be able to contact a nurse if you or your child needs help.

- **The pace may seem a little slower on the floor.** Because your child is getting better, there are often fewer things that your child needs. You may experience longer stretches of time where you can just be together with your child without the constant flow of medical personnel. These “slower times” can be an opportunity for you and your child to start getting back into more normal routines. However, just because you may see the healthcare team less, that does not mean they are unavailable.

Going to Transitional or Long-Term Care. Sometimes a child may not need to stay in the PICU, but is not ready to go home and needs a different kind of care than can be given on the floor. In such cases a child may be discharged to a Transitional or Long-Term Care facility. This could happen for a variety of reasons, including but not limited to:

- The family needs more time to learn how to manage new medical equipment.
- Revisions need to be made in the home to accommodate the child’s needs, whether increased electrical capacity for new machinery, ramps, or other needs.
- The medical needs of the child are beyond the capabilities of the family to manage at home.
- Necessary home health care needs to be arranged before the child goes home.
- The child needs intense rehabilitation that is best provided at another facility.

The hospital discharge planner and a representative from the care facility will be available to discuss the transition, as well as any medical care questions you may have.
Going Home from the PICU. While many parents look forward to the day when they can bring their child home, going home also can be a stressful time. In some cases, your child may need new medications or different care. It is important for you to understand how to take care of your child and feel comfortable about what you will need to do at home. Consider the following as you get ready to go home:

- **Review your discharge instructions.** Before you go home you will be given information about how to help care for your child at home. Everyone who will be helping take care of your child should understand the information on the discharge instructions. If you have any questions about what is on the discharge instructions, please ask.

- **Know who to call if you have questions at home.** You may find that you have new questions after you get home or just need a little refresher on information that you got in the hospital. Knowing who to call in these situations will be helpful. Please do not hesitate to call someone on your child’s team, even in the middle of the night, if you need help.

- **You may need additional help at home.** Just because your child is well-enough to go home doesn’t necessarily mean you will be able to get back into your regular routine immediately. In some situations, you may need more help now that your child is going home and you will be taking charge of helping him/her continue to recover. This is a great time to reach out to friends and family for help or to ask to talk with someone on the healthcare team who can help you prepare for caring for your child at home.

- **Try to be patient.** It takes time to develop a new routine or get back to your previous routines. Generally, each day will bring more confidence and comfort with your situation.

- **Don’t forget about yourself.** Just as it is important to take care of yourself when your child is in the PICU, it is important to take care of yourself when your child goes home. If possible, try to carve out time for yourself. It is still okay to ask for help, even when your child is well-enough to go home. Eating, sleeping, and getting exercise can help you stay strong. As mentioned before, even after leaving the PICU, many parents are vulnerable to depression and post-traumatic stress disorder. Be aware of changes in your mood, sleep patterns, and/or appetite, as well as the presence of nightmares or recurring thoughts about the PICU. Alert family members, too. Sometimes a family member will notice signs and symptoms before you do.
What are Palliative care and Hospice care?

Palliative care is an overall approach to care that is focused on maximizing your child’s quality of life. “Quality of life” can mean different things depending on your child’s illness and your family’s beliefs. However, the general goal is to keep the child comfortable and minimize pain and suffering. Palliative care can be appropriate for children with a wide range of medical problems and can be combined with care that is aimed at curing disease and maximizing the length of life. Here are some facts about palliative care.

Your child’s comfort is a priority. The palliative care team has tools and resources to keep your child comfortable. The goal is to help your child be comfortable and enjoy life as much as possible.

Palliative care does not mean you—or your child’s doctors—are “giving up.” Even with the most advanced medical care there may be uncertainty about the future. The palliative care team helps support you, your child, and your family as you face that uncertainty, and will be a resource to you when difficult decisions have to be made.

You are not alone. While you may not have heard many people talking about palliative care for children, there are many children and families involved in palliative care programs. Talking with other parents of children in palliative care programs may be helpful. Your healthcare team can help you find someone appropriate with whom to speak.

Palliative care is a team effort. Palliative care is typically a collaborative team effort that includes different healthcare providers. Each member of your child’s healthcare team will tailor their care approach to meet the needs and goals of you, your family, and your child. Your child’s palliative care team may include or coordinate with:

- Your child’s pediatrician, general physician, or subspecialty physician
- Specialists in treating pain and other uncomfortable symptoms
- Providers of functional therapies (e.g. physical, respiratory, speech, etc.)
- Support services for your child and family (e.g. psychologists, chaplains, music and art therapists, child life specialists, etc.)

Palliative care supports you in making decisions that are right for your child and your family. The goal of the palliative care team is to ensure that you have all the information you need and to help explain how different care paths may affect your child’s comfort and quality of life. The team will always support the decisions you make, and if you change your mind, or if new information becomes available, they can help you consider other options.

Palliative care does not mean you are giving up.
Palliative care can continue after your child leaves the PICU. The palliative care team can continue to follow and support you even after your child leaves the PICU. They can also explain options for palliative care services at home.

Details on hospice. Hospice care is a subset of a palliative care plan that is specifically focused on end-of-life care. This end-of-life care is designed to support children and families in the final phase of life with a continued focus on comfort, quality-of-life, and a painless and dignified transition to death.

There may be financial support for palliative care and/or hospice care. Medicare, Medicaid, and most private insurance companies provide both palliative care and hospice benefits.
What about medical research?

Someone may talk to you about including your child in a research study. There may also be research studies in which you can participate. Doing research is one way for healthcare professionals to learn about how to take better care of future patients and to support their families. The following are a few important things you should know about research.

*The institutional review board (IRB) approves all research that involves people.* Any research that includes people is reviewed by a group of experts called the Institutional Review Board (IRB). The purpose of IRB review is to make sure that any research that involves people includes all the appropriate steps needed to protect the rights of those participating in the research and to make sure that the research complies with all federal regulations.

*Not everyone can participate in a research study.* Research studies focus on specific groups of patients or people. These groups are determined by the goals of the research. You may find that someone you know was asked to include their child in a research study, but you were not asked to include your child. This may be because your child does not meet the criteria to be included in the research. Ask your healthcare team if you have questions about this.

*Participating in research is voluntary.* You are never required to give your permission to include your child in research or to participate in research yourself. You can always say “no.” If you choose not to give permission for your child to participate in a research project, please know that the care your child receives will not change in any way.

*If you don’t understand something about a research study, please ask.* If you would like to know more about research in general or about a particular study, please ask your healthcare team.

If asked, it is always your choice whether or not to participate in research.
What words might you hear in the PICU? (A Glossary)

--- A ---

**Advanced Practice Nurse (APN):** A nurse with additional training that works collaboratively within the healthcare team.

**Analgesics:** Medications that reduce pain.

**Antibiotics:** Medications that treat bacterial infections.

**Antivirals:** Medications that treat viral infections.

**Antifungals:** Medications that treat fungal infections.

**Attending Physician (Attending):** A doctor that leads a team of specialists (examples include PICU, surgeons, kidney doctors, etc.)

--- B ---

**Bedside Nurse:** The nurse at your child’s bedside.

**Bilevel Positive Airway Pressure Machine (BiPAP):** A breathing machine that helps a patient get more air into his or her lungs. It uses different levels of pressure depending upon the patient’s needs. Air is given through a mask that fits snuggly to your child’s face. BiPAP is a proprietary term of a company called Respironics

**BiPAP:** See Bilevel Positive Airway Pressure Machine.

**Blood Gas:** A blood test that helps the doctors and nurses know how well a patient is breathing by measuring the amounts of oxygen and carbon dioxide in the blood.

**Blood Pressure:** The pressure exerted by the blood in the arteries. It is recorded by two numbers: the pressure after the heart contracts (when it is at its highest) and the pressure after the heart contracts (when it is at its lowest).

**Blood Sugar:** A measure of the amount of sugar present in a patient’s blood.

**Blood Thinners:** Medications that decrease the amount of clotting in the blood and therefore reduce the formation of blood clots.

**Bradycardia:** A medical word that describes a slower than normal heart beat.
**Cardiac Monitor:** A screen that shows a patient’s vital signs (heart rate, blood pressure, oxygen levels, breathing rate). Your child will be connected to this monitor by several wires and cables.

**Cardiopulmonary Resuscitation (CPR):** A procedure that tries to restart the heart if a patient has a cardiac arrest (the patient’s heart and breathing stop). This procedure combines pressing on the chest, giving rescue breaths, administering medications, and sometimes electric shocks.

**Case Manager:** A member of the healthcare team that works closely with patients, families, and other members of the medical team to coordinate each patient’s discharge plan.

**CAT Scan:** See *Computed Tomography Scan*

**Catheter (tube, line, drain):** A plastic tube placed in a blood vessel (vein or artery) or another part of the body (such as a bladder catheter to drain urine).

**Central line (IJ, femoral line, subclavian):** Special intravenous catheter placed in a large vein (usually near the neck or groin) to give fluids, medications, or nutrition and to draw blood samples for laboratory testing.

**Cerebral Spinal Fluid:** The fluid found around the brain and the spine.

**Chaplain:** A healthcare team member that provides spiritual and emotional support for the family and the patient. The chaplains work with people of all faiths or people who do not consider themselves part of a particular faith group.

**Child-Life Specialist:** A healthcare team member that is an expert in childhood development and focuses on helping patients and young family members cope with being in the PICU.

**Clot:** Clumps that occur when blood hardens. When they form inside a vein or an artery they can cause heart attacks, strokes, and other conditions.

**Computed Tomography Scan (CAT Scan, CT Scan):** An imaging technique that takes many pictures and compiles them to create a cross-sectional and/or three dimensional image of different parts of a patient’s body.
**Continuous Positive Airway Pressure Machine:** A breathing device that pushes air through a patient’s passageway using positive pressure. Air is given through a mask that fits snugly to your child’s face.

**Constipation:** A condition that occurs when a person doesn’t have regular bowel movements or when their stool is hard and dry.

**Continuous Renal Replacement Therapy (CRRT):** A temporary form of dialysis that runs continuously through a central line. CRRT can be used to filter toxins from the blood and to remove extra fluid from the body.

**CPAP:** See **Continuous Positive Airway Pressure Machine**.

**CPR:** See **Cardiopulmonary Resuscitation**.

**CT Scan:** See **Computed Tomography Scan**.

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**D**

**Dietitian:** A doctor that helps manage nutrition (whether through a feeding tube or through an IV).

**Defibrillator:** A machine that delivers an electric shock to attempt to reset an abnormal heart rhythm.

**Depression:** A psychological disorder characterized by persistent feelings of sadness, hopelessness, lack of motivation and disinterest.

**DNAR:** See **Do not attempt resuscitate**.

**Do Not Attempt To Resuscitate (DNAR):** An order telling doctors and nurses not to perform cardiopulmonary resuscitation (CPR) if the patient stops breathing or if their heart stops.

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**E**

**EKG:** See **electrocardiogram**

**Electrocardiogram (EKG):** A tracing of the electrical signals of the heart.

**Electrolytes:** Substances in the fluid of your body that control the body’s metabolic processes, like the flow of nutrients into the cells and the waste products out of the cells.
**Endotracheal Tube (ETT):** A tube that is placed in the patient’s airway (trachea) through the mouth or nose and then attached to a breathing machine to help the patient breathe.

**Esophagus:** The tube connecting the mouth to the stomach.

**ETT:** See *Endotracheal Tube*.

**Extubation:** A process by which an endotracheal tube is removed from a patient.

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**Face Mask:** A plastic mask that is placed over a patient’s nose and mouth and delivers oxygen.

**Fellow Physician (Fellow):** A doctor training to be an attending in a particular specialty.

**Functional Therapy:** Rehabilitation therapy that focuses on increasing and restoring function after an injury.

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**Gastrostomy Tube (G-tube):** A feeding tube that is surgically placed directly from the surface of the belly into the stomach.

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**HA:** See *Hyper alimentation*.

**Heart rate:** The rate at which a person’s heart beats. It is usually measured as beats per minute (BPM).

**Hemodialysis:** The process of using a machine to filter wastes from a person’s blood when their kidneys are not healthy enough to do so.

**Hospice Care:** End-of-life care that focuses on patient and family comfort and quality of life.

**Hyperalimentation (HA):** Nutrients and vitamins given to a person in liquid form through a vein.

**Hypertension:** A medical word that describes high blood pressure.

**Hypotension:** A medical word that describes low blood pressure.
**IL:** See *Intralipids*

*Injection:* A “shot” that delivers fluid medication into a patient’s body.

*Institutional Review Board (IRB):* A committee that has been formed to approve, monitor, and review human research that is occurring for all ethical and/or risk concerns.

*Intralipids (IL):* Fats given to a patient through the veins for nutrition.

*Intubation:* The process by which an endotracheal tube is placed when a patient is unable to breathe on his/her own and needs a breathing machine.

*IRB:* See *Institutional Review Board*.

**L**

*Long Term Care:* Care that includes a variety of services and resources to help with the medical needs of a patient that is chronically ill or disabled and unable to care for themselves.

**M**

*Magnetic Resonance Imaging (MRI):* An imaging technique that uses magnets to create an image of the organs and tissues in the body.

*Medical Student:* A student that is training to become a doctor and has not decided what kind of doctor they want to be.

*MRI:* See *Magnetic Resonance Imaging*

**N**

*Nasal Cannula:* A plastic tube that fits around the head with two short prongs into the nostrils. It provides the patient with oxygen (from a tank or wall source).

*Nasogastric Tube (NGT, NG), Orogastric Tube (OGT, OG):* A tube placed through the nose or mouth into the stomach. It is used temporarily to give medicines and feedings or to drain stomach contents.
- - - - - O - - - - -

**Occupational Therapist:** A member of the healthcare team that helps patients develop, recover, or maintain daily living and work skills.

- - - - - P - - - - -

**Palliative Care:** Care that focuses on reducing pain and discomfort and increasing quality of life.

**Patch:** A “sticker” that is usually placed on a patient’s arm and allows medications to be absorbed through the skin.

**Peritoneal Dialysis:** The process by which a machine removes waste products from a patient’s blood when their kidneys are not functioning properly by giving and then removing fluid from the abdomen (the peritoneal space).

**Pharmacist:** A member of the healthcare team that monitors medications.

**Physical Therapist:** A member of the healthcare team that focuses on increasing the patient’s strength and flexibility to reduce risk during activities.

**Post-Traumatic Stress Disorder (PTSD):** A psychological disorder that can develop in response to a traumatic or extremely stressful event. Symptoms include flashbacks, nightmares, severe anxiety, emotional numbness, and difficulty sleeping.

**Pressors:** Medications that cause vasoconstriction, or the narrowing of blood vessels.

**PTSD:** See *Post Traumatic Stress Disorder*.

**Pulse Oximeter:** A device that measures the amount of oxygen carried by the blood (oxygen saturation) using a special sticker wrapped around a finger or toe.

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**Reflux:** When the contents of the stomach leak from the stomach into the esophagus.

**Rehabilitation:** Treatments that are designed to help with physical healing and recovery from injury, illness, and disease.

**Respiratory Rate:** The rate at which a person breathes. It is usually measured as breaths (inhalation and exhalation) per minute.
**Respiratory Therapist:** A member of the healthcare team that uses oxygen and other therapies to improve the patient’s ability to breathe.

**Rounds:** When healthcare teams go to each patient’s bedside, review how the patient is doing, and discuss treatment plans for the day.

**Resident Physician:** A doctor training in a particular field like pediatrics.

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**Sedation:** Medicine that makes patients sleepy, relaxed, and less aware of uncomfortable or distressing conditions.

**Social Workers:** Trained professionals that provide emotional support and guidance.

**Speech Therapist:** A member of the healthcare team that focuses on increasing the patient’s strength and flexibility in all muscles involving the mouth and throat to reduce risk during activities such as swallowing.

**Stomach Ulcers:** A painful sore that results when acid in a person’s digestive tract degrades the lining of the stomach.

**Suppository:** A medication delivery system that is inserted into the rectum, and allows medications to dissolve and be absorbed into the blood stream.

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**Tachycardia:** A medical word that describes a faster than normal heart beat.

**Tachypnea:** A medical word that describes a faster than normal breathing rate.

**Total Parenteral Nutrition (TPN):** A solution that provides nutrition and is given into the veins. It is made up of a combination of sugar, carbohydrates, proteins, lipids, and electrolytes. It may include two types of fluids: hyperalimenation and interlipids.

**TPN:** See Total Parenteral Nutrition

**Transitional Care:** Care that must be coordinated during a movement from one healthcare setting to another.
**Tracheostomy Tube:** A tube that is placed in the neck by a surgeon in the operating room and attached to a ventilator to help a patient breathe easier.

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**Ultrasound:** An imaging technique that uses ultrasonic waves to create images of structures within a patient’s body.

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**Vasoactive Medications:** Medications that are given continuously into the bloodstream to raise or lower the blood pressure.

**Ventilator:** A breathing machine that moves air into and out of the lungs for patients that are unable to breathe or are having difficulty breathing.

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**X-ray:** An imaging technique that uses x-ray waves to take a picture of a patient’s bones and soft tissues.
What are Some Questions You Might Want to Ask?

Below is a list of sample questions that you can use to talk to your child’s doctors, nurses, and other healthcare providers. Not all of these questions will apply to your child’s situation. We encourage you to ask to speak to your child’s team at any time. Feel free to ask questions as many times as you need.

Logistics in the PICU

Becoming familiar with the room
- What are the numbers on the monitor?
- What are the normal numbers for what is shown on the monitor?
- What does it mean when the monitor makes noise or an alarm goes off?
- What are the buttons on the wall for?
- What are the yellow gowns and masks and why are they necessary?

Visiting the PICU
- What are visiting hours?
- Can exceptions be made to visiting hours?
- Can my other children visit?
- Can I have another trusted adult stay with my child?
- Is it OK for me to leave? Who will be with my child if I need to leave?

Working together
- English is not my first language. Is an interpreter available?
- I don’t understand the medical terms being used. Can you please explain?

The People Involved

Doctors and Nurses
- Who are the people taking care of my child?
- Who makes the final decisions about my child’s care?
- Who can I talk to if I have concerns about my child’s medical care?
- Can I meet with all of my child’s doctors at once?
- What should I do if my child’s primary team and specialists are giving me differing information?
- How do different doctors and nurses communicate?
- Is it possible for my child to have a consistent team of nurses?
- Can I ask to have a different doctor or nurse?

My role as the parent
- Can I participate in medical rounds?
- What is my role during rounds?
- When can I ask questions?
- Is it safe for me to touch my child?
- How can I help take care of my child while s/he is in the PICU?
Understanding my Child’s Illness and Treatment:

The basics
  What is making my child sick?
  Why does my child need to be in an intensive care unit?

Getting more information
  How is my child doing today?
  Can I see my child’s x-rays?
  What are the results of my child’s tests? What do the results mean?

If my child has a procedure or test:
  What is going to happen during the procedure/test?
  When they do this procedure, what are they looking for or trying to do?
  What are the risks of doing the procedure?

If my child has surgery:
  What exactly are they doing in the surgery?
  How long will it take?
  Where do I (we) wait?
  Will anyone tell me how things are going during the surgery?
  Who will talk to me about what happened after the surgery is finished?
  What will my child need after the surgery?
  How long does it take to wake up from the anesthesia?
Caring for My Child

Keeping my child comfortable
  Why is my child irritable? What can be done to help?
  What is the plan for addressing my child’s pain?
  Can I bring in my child’s things from home that comfort him/her?

Eating and Drinking
  Why can’t my child eat? When will he/she be able to eat/drink?
  Is not eating dangerous for my child? Is not eating uncomfortable for my child?
  What are the risks of IV fluids and IV nutrition?
  If my child is receiving IV fluids or nutrition, will he/she still be hungry?
  If my child is unable to eat by mouth, how will he or she be fed?

Medications
  What medicines is my child receiving, and what are they for?
  How long will he/she need to take these medications?
  What are the risks or side effects of the medications?

Lines and Tubes
  What lines/tubes does my child need? Why?
  When can these lines be removed?

Breathing
  What if my child needs a breathing tube and a machine (ventilator) to help with breathing?
  What is the reason for the breathing tube?
  How much is the machine breathing for him/her?
  Is this machine keeping him/her alive?
  How long will my child need to be on the machine?
  Will there be any lasting effects from the breathing tube?
**Plans and Goals**

Making Plans
- How long is my child going to be in the PICU?
- How long is my child going to be in the hospital?
- What is the plan today?
- What needs to happen for my child to be able to leave the PICU?
- Is my child going to be OK? Is there a chance that my child will die?
- What needs to be done to figure out how to make my child better?
- Why are things not getting better? What is the next plan?
- I notice a change in my child that is concerning. Is he/she getting sicker? Why is this happening?

Looking Ahead
- Is my child going to have problems in the future because of his illness now?
- What can we expect things to be like at home?
- What do I do if my child gets sicker after we leave here?
- How will this hospitalization affect my child as a person?
- Will my child remember being in the PICU?
- How can I help my child recover emotionally from this hospitalization?

**Hospital Resources**

- Where can I get food or drinks?
- What services are available to help support my child and family during this hospitalization?
- I’m worried about finances, work, my kid’s school, etc. Can someone help me?
- How can a social worker help me while my child is in the hospital?
- What is a Child Life Specialist and what can he or she offer?
- What is the role of volunteers in the hospital?
- Can I talk to another parent who is dealing with similar issues?
- What is the role of palliative care?
- My child receives developmental services at home. Are these available in the hospital?
- Is there somewhere I can do laundry?
- Is there somewhere other than my child’s hospital room where I can sleep?
Where else can you get information?

**All Kids**
Phone: 866-255-5437  
www.allkidscovered.com

All Kids is an Illinois Medicaid program that offers comprehensive healthcare to many Illinois children, regardless of immigration status or health condition. Children are eligible if:
- They live in the state of Illinois
- Are 18 years old or younger
- Meet insurance requirements
- The family meets the family income requirements

**American Cancer Society**
Phone: 800-227-2345, #1  
www.cancer.org

The American Cancer Society (ACS) is a nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy and service. Services include:
- Information--cancer diagnoses and treatment options
- Transportation--for radiation, chemotherapy and surgery appointments, including airline miles, if applicable
- Pain/Nausea Medication--assistance for those with no health insurance or no precription coverage
- Clinical Trials--matching services for various clinical trials aimed at developing improved treatments
- Lodging--reduced cost lodging (rates vary based on location)

**Bear Necessities Pediatric Cancer Foundation**
Phone: 312-214-1200  
www.bearnecessities.org

The mission of the Bear Necessities Pediatric Cancer Foundation is to eliminate pediatric cancer and to provide hope and support to those who are touched by it. Services include:
- Bear Hugs--special experiences for pediatric cancer patients living and/or being treated in Illinois, ages 0-19
- Family Support Services--financial assistance for families struggling economically
- Child/Family Events--Creative Collaborations/patient art day and various social events

**Courageous Parents Network**
www.courageousparentsnetwork.org

The Courageous Parents Network is a web and video-based network, conceptualized by a bereaved parent and overseen by a board of MDs, fellow parents, social workers, and a psychologist, that provides parents caring for critically ill and medically complex children with tools and virtual support. With 180 short videos featuring fellow parents sharing their experiences, the Courageous Parent’s Network provides education and support.
The Cystic Fibrosis Foundation (CFF) is the leading organization committed to finding new therapies and ultimately a cure for CF, and to improving the lives of those with the disease. Services include:

- CF Care Center Network—support and accreditation for 115+ specialized treatment centers across the country
- CF Patient Assistance—financial assistance for select FDA-approved medications and medical devices for CF lung disease
- CF Services Pharmacy—personalized services, patient advocacy and reimbursement support
- CF Tax Advice—how to deduct a portion of a CF patient’s food expenses that exceed what healthy people spend on food

Services—CF Legal Hotline, Advocacy efforts and Clinical Trial participation information

Illinois/National

The Cystic Fibrosis Institute (CFI) supports those affected by cystic fibrosis in the Chicagoland area and tries to make a difference by being an active source of assistance and advocacy in dealing with the everyday challenge of cystic fibrosis. Services include:

- Clinical Assistance—programs including mentoring, medication and supplement assistance, and contact information for services such as clinical care, genetic counselors, dietary consultation, exercise consultation and social services
- Education—materials, newsletters and an annual conference aimed at educating patients, families and the public
- Clinical Trials—hosting independent, federally sponsored NIH research, and pharmaceutical-based multi-center clinical research studies to test the latest treatments to help discover and develop new and more effective treatment strategies
- Advocacy—support/involvement in local, regional and national advocacy efforts, including fundraising events, influencing public policy, and increasing awareness

Illinois

The Children’s Neuroblastoma Cancer Foundation (CNCF) is a non-profit national health organization committed to finding a cure for neuroblastoma through research, education, awareness and advocacy. Services include:

- Parent Handbook—a comprehensive guide written by parents to help maneuver a neuroblastoma diagnosis.
- Community Awareness—help to increase awareness of neuroblastoma through fundraising events/marketing
- Annual conference—an educational program for parents and caregivers to discuss current treatment options, results of new research projects and to provide emotional support for children and families

Illinois/National

Children’s Oncology Services, Inc. (COSI) believes that a diagnosis of cancer should not prevent a child from experiencing the simple joys of childhood. Our programs offer fun, friendship and support in a safe and nurturing environment. Services include:

- Camp—Summer Camp, Winter Camp, Sibling Camp, and Family Camp
- Excursions—Utah Ski Trip, Dude Ranch, Whitewater Rafting and Outdoor Adventure, etc.
- Education—advocacy programs (Springfield and Washington D.C.)
- Scholarships—Tuition Reimbursement scholarships for cancer patients and survivors

Chicagoland
Specialized Care for Children has been offering free care coordination for families of children with special health care needs throughout Illinois for over 75 years. They are a division of the University of Illinois, Chicago. Services include:

- Specialized care coordination, according to your child’s medical needs and location.
- Communication coordination with health care providers, schools, and other groups/individuals
- Transition support to help you prepare for/manage the changes your child will go through over time
- Financial support for families who qualify ranging from care-related travel expenses to medical equipment

Gilda’s Club Chicago is a community where men, women and children who are living with cancer and their families can find support and resources. The center is located in Chicago. Services include:

- Noogieland-- program for children/teens with cancer, with cancer in the family, or have lost a loved one to cancer
- Kid Support--10-week group for children ages 4-12 to help learn to live with the stresses of cancer
- Kids Bereavement--grief group for children ages 4-12 who have lost a loved one to cancer
- Kids/Teen Camp--summer day-camp
- Family Activities/Social Events—workshops, seasonal parties and outings for children, teens and their families
- Psychosocial Support—wellness sessions/classes including yoga, meditation, art, cooking demos, etc.

Gilda’s Club Quad Cities is a cancer support community providing people living with cancer, and all who touch their lives, access to other people going through the same experience. The center is located in Davenport, IA (but also serves Illinois). Services include:

- Noogieland--a program for children and teens with cancer, with cancer in the family, or have lost a loved one to cancer
- Kid Support--10-week group for children ages 4-12 to help learn to live with the stresses of cancer
- Family Activities/Social Events—workshops, seasonal parties and outings for children, teens and their families
- Psychosocial Support—wellness sessions/classes including yoga, meditation, journaling, massage, etc.

The Greater Illinois Pediatric Palliative Care Coalition (GIPPC) is a group of organizations and individuals working to improve access to community-based support for Illinois children with serious illnesses and their families. Pediatric palliative care teams work in cooperation with a child's primary medical team to provide support within the home setting, including:

- Nursing Care--focus on pain and symptom management, under the guidance of a pediatrician
- Counselling--services for children and family members provided by a social worker, chaplain and/or art/music therapists

Specialized Care for Children (University of Illinois Chicago)
Phone: (217) 558-2350
www.dssc.uic.edu

Gilda’s Club Chicago
Phone: 312-464-9900
www.gildasclubchicago.org

Gilda’s Club Quad Cities
Phone: 563-326-7504; 877-926-7504
www.gildasclubqc.org

Greater Illinois Pediatric Palliative Care Coalition
Phone: 312-733-8900
mrudnik@mindspring.com

Illinois

Chicago

Quad Cities

Illinois
Illinois Department of Human Services – Early Intervention
Phone: (217) 524-1596
http://www.dhs.state.il.us/page.aspx?item=31889

Illinois’ Early Intervention program helps provide resources and support to families with children birth to age three that have diagnosed disabilities, developmental delays, or substantial risk of significant delays. Services include:
• Access to a robust lending library of books, videos, and periodicals that are specific to early childhood intervention issues.
• Connections to vendors and community resources
• Assistance creating a care plan

Leukemia & Lymphoma Society
Phone: 312.568.7728
www.lls.org/il

The mission of the Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin’s disease and myeloma, and improve the quality of life of patients and their families. Services include:
• Patient Services—diagnosis information, resources and support
• Financial Support—assistance with medical costs/household finances, insurance issues, and employment rights
• School Re-entry—facilitation of communication between physicians, parents, and school personnel to ease the transition of children/teens back to school

LivingWell Cancer Resource Center
Phone: 630-262-1111
www.livingwellcrc.org

LivingWell Cancer Resource Center is dedicated to providing people living with cancer and their loved ones the support and educational services they need when faced with a cancer diagnosis. The center is located in Geneva. Services include:
• Support Groups—groups for children/teens with cancer, parents/guardians, siblings, relatives, and friends
• Wellness—programs to promote mind, body and fitness for cancer patients and caregivers (ex—yoga, reiki, etc.)
• Creative Arts Expression—art/recreation programs such as The Smile Within, Teen Art Studio, and Time Out
• Education—programs for cancer patients and caregivers such as journaling, cooking, knitting, collage-making.

Make-A-Wish® Illinois
Phone: 312-602-9435; 800-978-9474
www.illinois.wish.org

Make-A-Wish® Illinois grants wishes to children with life-threatening medical conditions to enrich the human spirit with hope, strength & joy. Eligibility requirements include:
• Age—children ages 2½ to 18 (referred prior to 18th birthday) who live in Illinois or who are here for treatment
• Diagnosis—child is diagnosed at time of referral with a life-threatening medical condition; confirmed by physician
• Previous wish—child may not have received a wish from any other wish-granting organization
• Referral source—child can be referred by a parent/guardian, by the child, or a treating medical staff member

The HIPP Program is a state-run program that subsidizes the cost of health insurance premiums for families who either have private health insurance or are eligible to enroll in private health insurance and who have high medical expenses.

Imerman Angels (IA) mission is to provide personalized connections that enable one-on-one support among cancer fighters, survivors and caregivers. Services include:
• 1-On-1 Cancer Support—a person fighting cancer is partnered with someone who beat the same diagnosis, providing the fighter the opportunity to receive encouragement and guidance from someone uniquely familiar with the situation
• Caregiver Support—a caregiver of someone fighting cancer is partnered with a caregiver who relates to and can understand their situation

Illinois/National
The Muscular Dystrophy Association raises funds to defeat more than 40 forms of neuromuscular disease through programs of worldwide research, medical and support services, health education, and advocacy. Services include:

- **Clinics**—funding two pediatric, multidisciplinary clinics in Chicago with experts that specialize in the diagnosis and management of neuromuscular diseases; providing financial coverage of up to four visits a year
- **Summer Camp**—kids ages 6-17 can attend a free week of camp in an accessible setting with modified activities
- **Support Groups**—provide emotional and practical support to families affected by neuromuscular disease
- **Medical Equipment**—offer financial assistance with equipment repairs and maintain a supply of loaner equipment
- **Resources**—connection to a community offering referrals, education, advocacy, and general assistance

The MFTD Waiver is a home and community based services waiver run though the Division of Specialized Care for Children. It is a Medicaid program granted to the state of Illinois by the government that waives standard Medicaid rules about child eligibility and allows for more coverage for children who would normally require permanent hospitalization to receive their care. Children in the state are eligible if:

- They are under 21
- They are medically eligible
- They require ongoing home nursing
- They can be cared for safely at home
- The cost of caring for them at home is less than it would be in a hospital or nursing facility.

This also includes help with home modifications if necessary.

Miracles from Mia began as Miracles for Mia, an effort to raise money for Mia Clements. Following Mia’s death, the organization was reformed to Miracles from Mia, and is an organization that raises money for families with any medical crisis and financial need. To do so, they host events, sponsoring a certain number of families, and give the entirety of the funds raised to those families so that it can be used for any expense it needs to be.

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- Resources—connection to a community offering referrals, education, advocacy, and general assistance

Nursing and Personal Care Services (NCPS) is a nursing program for children under the age of 21 who are not as medically complex, or have fewer nursing needs. Children typically qualify for around 50 hours of nursing. NCPS only covers children who are Medicaid-enrolled.
Ronald McDonald House Charities of Central IL  
Phone: 217-528-3314  
www.rmhc-centralillinois.org

**Ronald McDonald House**  
Charities of Chicagoland & Northwest Indiana  
Phone: 708-423-5285  
www.rmhccni.org

**Starlight Children’s Foundation Midwest**  
Phone: 312-251-7827, x12  
www.starlight-midwest.org

**The Cancer Support Center**  
Phone: 708-798-9171, x204  
www.CancerSupportCenter.org

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This Ronald McDonald House provides a temporary "home away from home" for families whose child is receiving treatment for a serious illness at a medical facility in the Springfield area in an effort to reduce stress, keep the family intact, and enhance the quality of life for families. Services include:

- Convenient Location—located in the heart of Springfield’s medical community
- Comfortable Environment—private bedrooms, home-cooked meals and playrooms for children

**Central Illinois**

This Ronald McDonald Houses provide a “home away from home” for families of pediatric patients receiving treatment in Chicagoland hospitals in an effort to reduce stress, keep the family intact, and enhance the quality of life. Services include:

- Convenient Locations—near Lurie Children’s Hospital in Chicago, near Hope Children’s Hospital in Oak Lawn, near Loyola University Medical Center in Hines, and near University of Chicago Comer Children’s Hospital in Chicago
- Comfortable Environment—private bedrooms, home-cooked meals and playrooms for children
- Support—non-clinical and sibling support services, and recreational activities

**Chicagoland**

This Ronald McDonald House provides a temporary "home away from home" for families whose child is receiving treatment for a serious illness at a medical facility in the Springfield area in an effort to reduce stress, keep the family intact, and enhance the quality of life. Services include:

- Convenient Location—located in the heart of Springfield’s medical community
- Comfortable Environment—private bedrooms, home-cooked meals and playrooms for children
- Support—non-clinical and sibling support services, and recreational activities

**Central Illinois**

The Starlight Children’s Foundation helps seriously ill children and their families cope with their pain, fear and isolation through entertainment, education and family activities. The main program is called Great Escapes:

- A program for children birth to 18 that provides families with a chance to spend recreational time together to relax, regroup and return home with a renewed sense of strength and hope
- Family Activities: movie screenings, circus trips, mother-daughter makeovers, spa days, sporting events, picnics
- Families have reported the program provides valuable connections with others facing similar challenges and "emotional companionship: for the journey, priceless family memories away from hospital or clinical settings, and rare opportunities for social and interpersonal interaction

**Chicagoland**

The mission of the Cancer Support Center is to provide free, comprehensive resources that help people affected by cancer and their family’s process through their experience in a way that is as supportive and healing as possible to achieve the highest quality of life. The center serves south Chicagoland and has two convenient locations--in Homewood and Mokena. Services include:

- Connections/Family Support—programs including diagnosis information, individual and family counseling, support and networking groups, caregiver support, and grief/bereavement programs for all ages
- Wellness—programs including survivorship celebrations, yoga, massage, Reiki, tai chi, meditation and crocheting
- Resources—library with information and resources on types of cancer, treatment options, grief/bereavement, caregiver resources, guided imagery, relaxation, children’s resources, etc., that may be checked out for three weeks at a time

**South Chicagoland**
Wellness House offers psychosocial support and information as a complement to medical treatment to improve the quality of life and to provide comfort and community so those affected by cancer feel less alone and more empowered. The center is located in Hinsdale. Services include:

- Information/Education—classes, workshops, and speakers about various effects of cancer and ways to cope with the challenges presented by a cancer diagnosis (ex. ‘How to answer kids’ questions about cancer’)
- Family Matters—educational and supportive program to normalize and validate the feelings of children and teens
- Support/Networking—support groups to express thoughts/feelings, and to meet others in similar situations

West Chicagoland

Wellness Place
Phone: 847-241-5977
www.wellnessplace.org

The mission of Wellness Place is to provide individualized education, support and understanding to those affected by cancer as a complement to medical treatment. The center is located in Palatine. Services include:

- Counseling/Support/Networking—group or individual support or counseling, social networks, Art therapy, medical play for the cancer patient, family, siblings, etc.
- Education—information about cancer, treatment options, resources, events, etc. for cancer patients and families
- Integrative services—massage, Reiki, Healing touch, and expressive arts for pediatric patients and families
- School Re-entry—support and education for the child, parents and school personnel to ease the transition back to school

North Chicagoland

Twelve Oaks mission is to provide a resource that will help defray the cost of sports and community programs for children of families suffering financial hardship, with a focus on families struggling with the burdens associated in fighting cancer. Working with local organizations, the 12 Oaks Foundation will provide grants to families in need so their kids won’t have to miss some of the best parts of childhood. Funds are paid directly to the child’s designated organization. Services include:

- Grants that support families battling cancer. We provide financial aid to patients or their siblings (children ages 8-18) whose participation in an athletic or artistic extracurricular activity has been or is at risk of being interrupted by the financial strain of cancer.
- Support may be granted to multiple children in a family. Grants are capped at $500 per child and $2000 annually per family.

Illinois

A special thanks to the Pieces of the Puzzle Collaborative for providing information on many of these resources. The Pieces of the Puzzle Collaborative is an alliance of various non-profit organizations partnering together to minimize/eliminate obstacles to service and to facilitate increased access to quality psychosocial, supportive care for all children with life-threatening medical conditions, as well as for their parents/guardians and siblings.
What websites can you use to stay connected?

**Blogging Sites** to help you share and communicate with others:

- CarePage: [www.carepages.com](http://www.carepages.com)
- Caring Bridge: [www.caringbridge.com](http://www.caringbridge.com)
- Blogspot: [www.blogspot.com](http://www.blogspot.com)
- Wordpress: [www.wordpress.com](http://www.wordpress.com)
- Blogger: [www.blogger.com](http://www.blogger.com)
- Weebly: [www.weebly.com](http://www.weebly.com)

**Video Chat**

- Skype
- FaceTime
- Google Hangout
What should you know about Ann & Robert H. Lurie Children’s Hospital of Chicago?

**FAMILY SERVICES RESOURCES at LURIE CHILDREN’S:**
Below is information about some of the services available to all patient and their families at Lurie Children’s Hospital.

**ParentWISE (Parent Wisdom in Shared Experience):** Connects parents with other parents whose child has had a similar experience. Parent volunteers can either visit you at the hospital or reach you by telephone.

**Spiritual Care:** Helps children and families attend to religious and spiritual needs for prayer, ritual, and familiar items that may help bring comfort. Chaplains are available 24 hours a day to provide support and care. Chaplains serve people of all faith traditions as well as those who just wish to talk. The Chapel is located on the twelfth floor of the hospital.

**School Services:** Through onsite teachers, tutors, and classrooms, School Services provide learning experiences for pre-K through grade 12. They also connect with your child’s school and teachers, when appropriate. The school room is located in the Family Life Center on 12th Floor.

**Interpreters:** Interpreting services via the telephone and in person are available to non-English speaking children and their families.

**Family Life Center:** Is located on the 12th Floor of the hospital and is available to all inpatients, their siblings, and families. Amenities offered include: playgroups, teen lounge, infant/toddler play space, school room, toys, books and DVD lending, business center, parent quiet room, and salon.

**Ronald McDonald House (312 888 2500):** is a 60 bedroom house for families that live at least 10 miles away from Lurie Children’s. The House is located 5 blocks south of Lurie Children’s and offers a place for families to get some rest while remaining close to hospital. Initial referrals to stay at the house are made by your social worker. Visit: http://rmhccni.org/pageslurie-ph/

**Sarah & Peer Pedersen Family Learning Center (12th floor behind the red fire truck):** The PFLC is a resource space where all patients and families can access educational resources, learn more about their services, and read through consumer health materials.

For schedules and additional information, please contact Suma Rao-Gupta at: sraogupta@luriechildrens.org or 312-227-4709.
General information about Lurie Children’s Hospital and the PICU

Location and contact information:
Ann and Robert H. Lurie Children’s Hospital of Chicago
225 E. Chicago Ave, Chicago IL 60640
16th Floor
Main Phone: (312) 227-1600

PICU Leadership:
Critical Care Division Chief: Z. Leah Harris, MD
Medical Director: Craig M. Smith, MD
Nursing Director: Lora Byrne, RN

Hours and Visitation: For parents or guardians, visitation is available 24 hours. For family members or friends, visitation hours start at 10am and end at 8pm. Exceptions are sometimes made to this rule, but they will need to be discussed with the healthcare team and charge nurse.

Isolation and Visitor Restrictions: Our patients are vulnerable, and even a common cold could make them very ill. To help protect them, during the winter no visitors under the age of 14 are allowed, and only two people at a time may be in your child’s room. No one who feels sick should visit. If your child has symptoms of a virus, you will be asked to wear a gown and a mask when you are in the room.

Sleep: Parents may stay with their child 24/7, and there is a pull-out sofa and a recliner in each room. If you live far away and your child will be hospitalized for a while, ask your nurse or social worker for more information regarding rooms that may be available to you.

Showering: In many cases you can shower in your child’s room. Simply ask your nurse for towels and toiletries, give him/her a head’s up, and lock the door so no one accidentally walks in or disturbs you.

Laundry: Washers and dryers are available on the 12th floor of the hospital to all families. Detergent and softener are provided.

Getting food: The Sky Café is located on the 11th floor, and can be accessed in person or via room service (dial extension 12345 to place your order).

In addition, families can walk to Northwestern Memorial via the second floor of Lurie Children’s to access an array of food options, including Au Bon Pain, GRK Greek Kitchen, Saigon Sisters, Protein Bar, and more.

Gifts: Live flowers are not allowed in the PICU.

Lab Coats at Lurie Children’s Hospital: You will see staff at Lurie wearing different color lab coats to help you identify the roles of some staff members. Attending Physicians and Fellow Physicians typically wear gray coats. Resident physicians, advance practice nurses, and other staff wear long white coats. Medical students wear short white coats.
Parking at Lurie Children’s Hospital

For Appointments and Short Stays

- Huron-Superior Garage with access to Lurie Children’s via bridge
  - Enter on Huron or Superior east of St. Clair, follow signs
  - Up to 7 hours = $10 with validation
  - 7-24 hours = $15 with validation
  - Validate at Lurie 2nd floor security desk
- Street Parking
  - Free with handicap tag
  - $7 for two hours regular rate, two hour limit
  - Read posted signs carefully for restrictions
  - Meters accept credit/debit and quarters only
- Web search services for low daily rates in the area:
  - www.parkwhiz.com – Lurie Children’s search feature
  - www.bestparking.com – use Streeterville neighborhood search

For Extended Stays (may be economical if staying more than 10 days)

Consider purchasing monthly passes – garages not managed or endorsed by Lurie Children’s

- 5 W. Erie — $200/month – (312) 643-7275
- Ohio/Fairbanks surface lot — $225/month – (312) 617-5019
- Erie/Ontario — $275/month – (312) 642 – 6062
- 820 N. Orleans — $180/month (15 min. CTA bus ride) – (877) 909-6199

Use www.bestparking.com to find other monthly rates
CTA Bus Routes to Lurie Children’s

Lurie Children’s Hospital of Chicago can be accessed several ways via public transportation. There are a few CTA options available to those who will be using the CTA.

**CTA “El” Train:**

Located at Chicago Avenue and State Street, the **Chicago stop on the CTA Red Line** is the closest train and the hospital is 0.3 miles (approximately a 7 minute walk) heading east on Chicago Ave. The “66 Chicago” bus leaves from the Chicago Ave stop that heads east and stops a few feet away from the hospital.

Located at Chicago Ave and Franklin Street, the **Chicago stop on the Brown/Purple line** is the next closest train. This stop is 0.7 miles away and is approximately a 15 minute walk. There is a “66 Chicago” bus that leaves from the Chicago Ave stop that heads east and stops a few feet away from the hospital.

**CTA Bus**

*Stopping at Chicago Ave. and Mies Van Der Rohe (in front of Lurie Children’s)*

#3 - King Drive (North Bound & South Bound)  
#10 - Museum of Science and Industry (North Bound)  
#26 - South Shore Express (South Bound)  
#66 - Chicago Ave. (West Bound & East Bound)

*Stopping at either Michigan & Huron*

#143 - Stockton/Michigan Express  
#144 - Marine/Michigan Express  
#145 - Wilson/Michigan Express  
#146 - Inner Drive/Michigan Express  
#147 - Outer Drive Express  
#148 - Clarendon/Michigan Express  
#151 - Sheridan
TIPS for FAMILY and FRIENDS

Here are some suggestions for that first dreadful moment when you learn that someone you care about has a child in the PICU.

DO...........

- Send cards and emails. Just a short little note will do. They aren’t scrutinizing your words; they are just happy to know that another person is rooting for their child.
- Make sure they know you do not expect a reply to emails or phone calls.
- Take their other kids somewhere fun so they can be with their child without worrying about their other kids.
- Offer to spread the word for them to anyone in particular they want to know. It may ease their mind if you can call special friends and gently share their news.
- Volunteer to do specific tasks, like bringing dinner by or dropping off some groceries.

DON’T...........

- Be afraid to reach out even if you don't know them well. A card is always appreciated.
- Ask for too much detail or explanation; they are reporting out to many people and may need a break.
- Expect them to call you back promptly.

BE AWARE...........

- In the early days, they may feel cut off by comments like: "My friend’s kid was in the PICU a couple years ago and they’re fine now!"
- Every message counts. Your note or call may not feel like much to you, but combined with every other note or call they get, it becomes a tidal wave of support to carry them from the initial shock into and through treatment.
TALKING TO YOUR FRIENDS

If you feel nervous about talking with your friends, here are some pointers from parents:

*Be yourself and don’t be afraid.* Your friend doesn’t expect perfection. Some people have a knack for expression, some people are lost. Your friend sees that you care and that you are doing your best.

*Don’t push advice.* You probably don’t know enough about their case to really be useful. It can be tiresome to hear "My friend Paula had the same experience and she said that her doctors recommended..."

*When in doubt, email an offer of help or companionship.* Unreturned phone calls can be a weight on your friend. Always end a message with "No need to reply; I am just thinking about you."

*Listen more than you talk.* You are there for them. Give them some space to talk about whatever's on their mind: an annoying insurance problem, a funny card they got, an aching back, their old car that isn’t selling, whatever they want.

*Don’t force the conversation.* If they’re trying to talk about something going on in their life besides what is happening to their child, and you came to get the latest update on their child’s treatment, stick with the story they are telling. Treatment isn't the only thing going on in their life.

*Don’t expect them to follow up on every suggestion.* Many people will suggest that they call their friend who had a similar experience or read a new article about an ongoing clinical trial. These can be very helpful, but can also feel like another thing for the To Do list. Just pass the information along in a card or email and leave it there.

*Focus.* Take off your coat, sit down, turn off your cell phone. If your friend starts to open up and vent, stay with them. It helps to tell your friend up front how long you can spend so they don’t worry that their mood sent you packing.

*Don’t rush them through the hard stuff.* Your friend may be scared, uncomfortable, and tired. Try not to quickly stifle these truths with platitudes like, "You've got to stay positive" and "This is going to be over soon." Let them complain and cry and feel a little self-pity before you start to help them put themselves back together again.

*Respect their experience.* Don’t say, "I know how you feel!" unless you actually do. Don’t say "My friend went through the same thing and she's doing great." Every case has unique elements.
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