

# Heart to Heart

A guide to help families through heart surgery



## Heart surgery for your loved one requires special preparation

Preparing your family for heart surgery can be challenging. Everyone involved needs assistance and information to help them cope. Parents maybe unfamiliar on how to cope with the emotions surrounding this type of procedure.

### In this guide

What to know before surgery/Anesthesia  
Communicating with Hospital  
During Surgery and Recovery  
Additional items & reminders  
Extended Family/ At home  
Working with your Employer/Resources

This booklet will walk you through the process of what to expect before, during and after surgery and provide information, resources and tips to help you and your family through this difficult time.

### Parent to Parent

It is often beneficial to get advice from other people that have been in the same situation and experienced similar fears.

DSG can facilitate Parent to Parent visits pre and post surgery if desired. This is a great opportunity to have your questions answered on a personal level.

Email [info@kcdsg.org](mailto:info@kcdsg.org) or call 913-384-4848 to request a parent to parent match.

### Updating Family & Friends

Parents will be very busy before, during and after surgery so it is helpful to designate someone to communicate updates to your extended circle of support so you are not inundated with messages.

Facebook, CaringBridge, or Care pages are great ways to keep everyone in the loop. Create a call list for the messenger in case you have any urgent information which needs to be shared via phone.

# What You Should Know Before Surgery

Helpful tips from families who have walked in your shoes

**Ask for and schedule a pre-surgical visit/tour of the hospital and NICU/CICU units.** Familiarizing yourself with the hospital, the surroundings and what and how things work is one less thing to have to think about so all the focus is on your child surgery and subsequent recovery. Ask for all of the names of any doctors/staff who will be operating on/caring for your child and if possible, meet with them, even briefly; bring a notepad and take notes. Know who your main point of contact is for any questions you may have leading up to the surgery.

The hospital may offer **nursing mothers daily meal vouchers** redeemable at the cafeteria so be sure to ask ahead of time for these and know how and when you should go about obtaining them. Knowing this ahead of time is helpful for budgeting purposes and in planning your daily meals. If the hospital doesn't offer vouchers, ask if they'll consider it for you. Give them time to process your request in order to take full advantage of the benefit—know who and when you should ask for them.

Most children's hospital families have access to a **Ronald McDonald House** where you can stay for a much reduced rate. Ask hospital staff at your pre-visit or visit <http://rmhc.org/who-we-are/chapter-search> to search for a house. If there are no Ronald McDonald houses nearby, the hospital may still have arrangements for reduced rates for family members of surgical patients at area hotels.

**Bring things from home** such as pictures of siblings, Mommy and Daddy, grandparents, etc, that you can tape up to the bed/crib post-surgery. You could also consider bringing colorful "Get Well" signs or artwork. On another note, with twins or a young sibling (baby/toddler) left at home with family, leave

clothing that Mom and Dad have recently worn so they can at least be near your scent, it may provide comfort and familiarity.

As hard as it might be, **consider reducing contact with individuals outside the child's immediate family** and do everything in your power to keep yourselves and your child's siblings as healthy as possible.

Get to bed earlier than usual so as not to get run down and eat healthy. If necessary, limit therapy appointments and social engagements, such as family functions, church, going to the mall two weeks before the surgery. Also, it could be important to aunts, uncles, grandparents, and other family and friends to visit with your child before surgery, but do this two weeks prior and only as long as everyone is healthy.

**Talk to your pediatrician about your plans for "social isolation"** before the surgery and make sure you won't miss any important inoculations or vaccinations or get them scheduled in advance of the two week time period prior to surgery.

If your child is bottle-feeding from **a special bottle or pacifier**, bring them with you. Do not leave it to chance that the hospital will have what you need. This goes for formula or any **special dietary needs** your child may have. You don't want their digestive system at risk when focusing on recovery.



**Keep your home as germ free as possible leading up to surgery!**  
**Limit family visits and outings.**

## Anesthesia: What does it mean for my child?

If your child is agitated, it may be very difficult for the anesthesiologist to get an IV line for surgery. Dialogue with all pertinent professionals on the surgery team about your concerns and ask what their protocol is if they have difficulty getting an IV line.

How many "sticks" is considered too many? If they do experience difficulty getting an IV line, you should be prepared to see visible stick marks that will begin to bruise a few days after surgery.

Your child may experience a rough time coming out of anesthesia but it is temporary. Do whatever you can to keep your child calm, such as gently holding the child's hand, singing their favorite songs or lullabies or providing a favorite toy or blanket.

Remember your child will not have eaten anything since the night before surgery and will likely get hungry as they begin to awaken from anesthesia. Try to ensure a last minute feeding before the cut-off time the doctor indicates your child should have no more food prior to surgery.

As your child begins to wake up from anesthesia, calm them as best as possible and **DO NOT** be shy about strongly urging the nurses to allow you to breastfeed or bottle feed as soon as possible. They will likely have to get an order from the doctor and this could take time.



## Communicating with Hospital Staff

Ask ahead of time, preferably at the pre-surgery visit and write down the names of every doctor who will be in the OR/assisting during surgery. Find out each day which doctor is “on” in the NICU/CICU and is responsible for your child and write it down in a notebook. Always ask who is in charge each day so it is clear who you need to ask for if there are unanswered questions or problems. Find out from the nurses when a shift change will occur and make a note of it; remember to ask for things well before a nurse will be signing off for the day so there is no lag in your child’s care. Above all, write it down, and jot down notes if necessary at the end of the day for your reference, just in case.

Remember that this is your child and no one knows them better than you do. Do NOT be shy about making your concerns, thoughts, ideas, wishes, etc. known. You are not only the parent but your child’s advocate. If you want to be told/asked what tests, procedures and medications will be given/performed and when, make this known to everyone who is caring for your child and stay involved. Good communication goes both ways so it’s probably a good idea to simply inform the nurses/doctors when you’ll be taking a meal break or leaving the hospital for a period of time.

## Additional Reminders and Items to Bring

- Formula; If you are breast feeding, bring a supply of your milk and keep in the CICU freezer
- Bring your child’s favorite toys, stuffed animals, pacifiers and blankets
- Pack easy to dress clothing; front snaps, one piece outfits, pajamas for your child
- Take a CD player; Music for your child and for mom and dad
- Comfortable shoes
- Travel pillows
- Baggies for personal items, sanitizer
- Address book /notepads and pen
- Camera to document the surgery
- Educate childcare provider about procedure, recovery and anticipated return date
- Coordinate childcare for siblings
- Notify your insurance company of the procedure to determine the level of coverage and any expenses you will be personally responsible for paying
- Phone charger
- Thank you notes
- Healthy snacks
- A good book to read
- Important phone numbers
- Contact DSG at 913-384-4848 to request a hospital visit and meal voucher check

## What to expect at the hospital

### *Handing Your Child Off*

A flood of emotions. Emotions peak just before handing your child over to the anesthesiologist, nurses, and doctors. Soon numbness settles in but try to remember you will be absolutely elated after getting the “all clear” from the surgical team post-surgery. Sleeping in shifts will help both Mom and Dad stay alert.

### *During Recovery*

Your child will have a number of drains and lines attached and it can be quite startling to see and can make it difficult to get close and hold your child. Watch how the nurses do it and emulate them. Above all, DO NOT let it keep you from holding and feeding your child, it takes getting used to but if you’re gentle and careful it’s what your child needs.

Your child will probably experience feeling cold, groggy, irritable and hungry when waking from anesthesia. It can be hard to handle but do your best to comfort them and know that it will pass. Keep urging the nurses to allow you to try and feed your child as soon as the doctors say it’s possible.

Your child may be very sleepy the rest of the day but you will probably be pleasantly surprised at just how quickly the color comes back into their cheeks and how much more energy they will begin to exhibit in the coming days now that their heart is pumping and oxygenating blood properly.

Your hospital stay could be 4-10 days depending on any complications with the surgery or during recovery.





## What to Expect at Home

Your child may not be his “typical” self for several weeks, or more, following surgery. If your child was an excellent sleeper prior to surgery don’t be shocked if he/she now needs to be rocked to sleep, tosses and turns, or wakes up several times throughout the night. Your child may also develop an attachment with you. Your child may get upset when you lay them down or are out of line or sight or refuse to go to others. Tell grandparents and close friends not to be offended if your child is hesitant to go to them or be held by anyone but mom or dad during the first few weeks following surgery.

You may also notice a change in your child’s stools. Don’t hesitate to ask your pediatrician about adding MiraLAX or another stool softener to your child’s diet for a while.

Don’t worry about spoiling them by holding them more than usual, taking them from their crib at night or giving in to their every whim. Your child has been through an experience most of us can’t begin to imagine the need for extra support. It won’t take long to get through this transition stage and your child will be back in their routine before you know it.

## Working With Your Employer

Request a meeting with your supervisor to explain that your child will be having heart surgery. Discuss the scheduling and how much time you anticipate being off from work. After speaking with your boss, you should put your request in writing. Make sure your employer understands there can be last minute changes based on your child being ill or the surgeon’s schedule changing.

## Family Medical Leave Act (FMLA)

FMLA is a federal law requiring employers to provide employees job-protected unpaid leave due to a serious health condition that makes the employee unable to perform his or her job, or to care for a sick family member, or to care for a new child. Check your company’s policy on FMLA to verify your eligibility and benefits.

**For additional resources or questions:**

**Down Syndrome Guild of Greater Kansas City**

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## What Do I Tell My Family

Every family communicates differently, so you need to make the right decisions for your family. It’s important to explain what will happen before, during and after the surgery to siblings in a way that they can understand. Reading them books about surgery in general, then some on heart surgery could be a good way.

Make sure your children know they can ask questions. Questions like, is my sister going to die or will she look different – are very typical. Answer as honestly as possible and to the best of your knowledge.

Make your family aware that not everyone will be allowed to visit after the surgery due to hospital restrictions. Provide your family with a list of other ways they can help such as childcare for siblings, cleaning your house, providing a meal etc.

## Helpful Resources

- Request a DSG parent to parent match so you can visit with other parents who have been through heart surgery
- Request a DSG hospital visit and Hospital Meal Voucher Check to help cover some of the costs related to the hospital stay
- Visit the DSG website and watch the Heart to Heart Video which highlights one family’s experience with surgery from start to finish
- Check out Lily’s Heart from the DSG lending library
- <http://groups.yahoo.com/group/Downs-Heart>
- <http://www.dhg.org.uk/links.aspx?medical-uk>
- <http://www.mendedhearts.org/mlh/frame-mlh.htm>
- <http://kidswithheart.org/>