

*Heart Defects Society of Windsor and Essex
County*



*Hearts weren't
meant to be
born broken*

**Tips for Families Newly Diagnosed with
Congenital Heart Defects**

November 30, 2011

Registered Charity #89893 7818 RR0001

Heart Defects Society of Windsor and Essex County

We are a non-profit charitable organization dedicated to assisting families affected by congenital heart defects. This booklet was created as a reference guide to help you throughout your child's treatment, by Windsor area parents who have been through similar experiences. Please refer to it whenever you need information or advice. Our thoughts will be with you during your journey.

Please note: The website for the London Health Sciences Centre can be found at

www.lhsc.on.ca.

The website for Toronto Hospital for Sick Children (Sick Kids) can be found at

www.sickkids.ca.

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Preparing/packing for your trip to London

What to bring:

- ♥ If your child is an infant likely to sleep most of the time, you may wish to bring a book or magazine (whatever you would normally take to a waiting room). You may have a bit of wait time in between procedures (echo, ECG, blood work, etc.)
- ♥ Familiar toys or security objects for your baby or child – blankets, stuffed animals, etc. to comfort them during procedures.
- ♥ If your child has a favorite TV show or movie, you may wish to bring the DVD. It can be played to distract your child during their echocardiogram. (They also have a selection of movies available at the hospital.)
- ♥ Notebook or journal and pen. Even if you don't wish to record your thoughts on your child's experience at the hospital, a notebook is a good place to jot down notes, names of doctors, questions you have about your child's condition or care, etc.
- ♥ Snacks and beverages if you wish. Depending on the time of your appointment, it may run into lunch time. If you wish to grab something quick at the hospital, there are vending machines available directly outside of the Pediatric Cardiology waiting room (next to the elevators), and a Tim Horton's down the hall (turn right when exiting the waiting room, and go all the way to the end of the hallway).
- ♥ Your cell phone, if you need to keep in touch with people at home.
- ♥ A change of clothes for yourself and for your child. (better be have then to be without)

Directions to London Children's Hospital and where to park

How to get to the hospital:

- ♥ From the Windsor area, take the 401 East. Exit at Wellington Road (Exit #186), and turn left (north). After 4.6km, turn right on Commissioners Road East. Turn left at the first set of traffic lights, into Victoria Hospital (where the Paediatric Cardiology department is located). This trip will take you approximately 2 hours, depending on traffic, construction, etc.

Where to park at the hospital:

- ♥ Once you have turned off of Commissioners Road into the hospital complex, take an immediate left to get to the visitors parking lot. Follow the road to the front of the hospital until you find Zone C (these are the doors where you will enter the hospital). The parking lot will now be on your left. Follow the road to the end of the parking lot, turn left, and then turn left again into the parking lot. You will need to take a parking stub in order to enter – keep this with you when you exit your vehicle. There is a booth with an automated machine where you can pay (with cash or a credit card) before returning to your vehicle.
- ♥ The parking lot is slightly elevated, compared to the hospital. There is a stairway down to the street level, which is located near the parking booth. If you have a wheelchair or stroller, it may be easier to go to the far end of the parking lot before crossing to the hospital entrances.

Getting into and around London Children's Hospital

How to get into the hospital and where to go once you get inside:

- ♥ Look for the Zone C entrance that you passed when entering (it is clearly marked). Once you enter this door, turn left and follow the hallway around to your right. When you get to a junction, turn right and the Pediatric Cardiology clinic will be immediately on your right. It is easiest to check in here first, even if you have to go somewhere else (e.g. for blood work). The receptionist at the Cardiology clinic will tell you where you need to go.

Where to go to feed or change your baby:

- ♥ There is a quiet room in the Pediatric Cardiology clinic for this purpose. Ask the receptionist where it is located. Comfortable chairs are provided for nursing, and there is a change table with clean blankets for diaper changes.

London Hospital Staff and their roles in your child's treatment

Medical personnel your child may encounter during their visit:

Your child may undergo several procedures during their checkups in London. These procedures may all be completed before you speak with your child's cardiologist, or the doctor may speak with you during or between procedures, depending upon their schedule and the seriousness of your child's condition. Other personnel you will encounter may include:

- ♥ Technicians. During each visit, your child will likely have an Echocardiogram (Echo) and an Electrocardiogram (ECG). These will take place in separate rooms within the Pediatric Cardiology clinic, by separate Technicians.
- ♥ Nurse Practitioner. You will likely meet with this person during every visit. She will listen to your child's heart and may take vital statistics such as blood pressure and oxygen saturation. She may also measure your child's height and weight and discuss with you any changes to your child's condition since your last visit.
- ♥ Medical Students. From time to time, a medical student may perform some of the duties normally performed by the Nurse Practitioner. A med student may also be brought in to listen to your child's heart or may "shadow" the doctor for educational purposes.
- ♥ Cardiologist. The Cardiologist will typically visit your child once all of the procedures are complete and the results have been reviewed. They will then discuss with you your child's current condition and any concerns that either of you may have. They will also caution you of any restrictions or limitations your child may have, or any warning signs to watch for. If your child is going to be having surgery, they will also be able to help you understand what is going to take place. Finally, they will let you know when you will need to return for your child's next "checkup". This can then be scheduled directly by the receptionist. (The Nurse Practitioner may take care of setting up this appointment for you, if you don't have any scheduling conflicts.)

You may also have to go to other areas of the hospital for procedures such as blood work or x-rays. If this is the case, the receptionist or Nurse Practitioner will be able to direct you to the appropriate location.

Procedures your child may undergo in London

What procedures your child will likely undergo during their visit:

During each visit, your child may undergo the same procedures, or they may vary depending on your child's age and condition. Between procedures, you may be asked to return to the waiting room, or you may be taken directly from one room to another. These procedures include:

- ♥ Echocardiogram (Echo). This is basically an ultrasound of your child's heart. Your child will be asked to lie down on a cot, with their chest and stomach bared. The Technician will hold a probe coated with warm lubricant which they will slide around on your child's chest to view the anatomy, structure and functioning of their heart. A series of readings will be recorded for your Cardiologist to review. The results will give them a picture of how your child's heart is working, how blood is flowing, etc. This procedure is not painful, but many children are uncomfortable or afraid because they have to lie still. If your child is an infant, it is best to try to get them to sleep before the procedure begins. For older babies and children, they have mobiles, toys and a DVD player to try to distract them during the procedure. The length of time it takes to complete depends on several factors, including the complexity of your child's defects, and their willingness or ability to lie still. (The more they move, the longer it will take.) In extreme circumstances, if the Technician is unable to get the information needed to properly assess your child's condition, you may be asked to return for another Echo, prior to which your child will be sedated.
- ♥ Electrocardiogram (ECG or EKG). This is a very brief, painless procedure that records the heart's electrical activity. It shows the speed and rhythm of your child's heartbeat, among other things. A series of electrodes will be connected to your child's body with stickers. They will be asked to remain still for approximately 5-10 seconds, while the readings are being recorded. **Don't worry – they won't feel a thing.** When they are done, the stickers will be gently removed.
- ♥ X-ray. Your child may be sent to another area of the hospital for a chest x-ray, especially if they have previously undergone surgery and have any synthetic or artificial components or devices in their heart. If your child is an infant, they will likely be placed in an upright position within a tube-like device. You may be asked to assist with positioning them. They will be "sitting" on a seat similar to a bicycle seat, with their arms positioned straight up over their head. The clear "tube" will then be closed around them to hold them in this position until the x-ray is taken. If it is your first time witnessing this as a parent, it can be quite traumatic. Even if your child becomes very upset, rest assured that this will cause no harm to them. Once your child is old enough to lie relatively still on their own (even if you are there holding their arms), they will be able to lie on the table for their x-rays.
- ♥ Blood work. Your child may be sent to another area of the hospital for blood work for a variety of reasons, especially if they are on blood thinners or other medications. Depending on what tests need to be performed, several vials of blood may be collected. You may be asked to assist with holding your child in a position that facilitates this. Keeping your child as still as possible will likely lessen the discomfort they will feel.

Preparing/packing for your trip to Toronto

What to pack:

- ♥ One suitcase for yourself (parent) with about a week's worth of clothing. You may not know how long you will need to be away from home. Choose comfortable, weather appropriate items that can be layered, mixed and matched for versatility. Pack extra underwear if possible, and comfortable shoes. Please note that laundry services are now available at the hospital. Washing machines and dryers are located in room 4308 (next to Marnie's Lounge on the 4th floor). Ask your Social Worker for details.
- ♥ Your favourite toiletries, but there is a Shoppers Drug Mart in the hospital where you will be able to pick up essentials as needed.
- ♥ A pillow from home, for nights that you spend at the hospital, or naps during the day.
- ♥ Weather-related items, like an umbrella or snow-boots, appropriate to the season. Depending on where you are staying (hotel, Ronald McDonald House, etc.) you will need to walk at least 5 minutes to get to the hospital. (Don't plan to drive back and forth unless absolutely necessary – parking costs are very high all over Toronto.)
- ♥ A comfortable backpack or messenger bag that you can take back and forth to the hospital with whatever you will need for each day (books, snacks, drinks, etc.)
- ♥ Familiar items for your baby or child, if you wish – blankets, stuffed animals, etc. Although the hospital does provide sleepers for babies, you may wish to bring your own. (Make sure they snap all the way up the front – zippers are not practical.) If you have an older child, two-piece pajamas with a button-front top are best.
- ♥ Books, crossword puzzles, games, crafts or whatever you like to do to keep busy. If your child is an infant, they will be asleep most of the time. You will want to be with them, but will need something to do. You will have limited space, and the lighting is sometimes dim (bring a book-light if you have one).
- ♥ Notebook or journal and pen. Even if you don't wish to record your thoughts on your child's experience at the hospital, a notebook is a good place to jot down notes, names of doctors, questions you have about your child's condition or care, etc.
- ♥ A camera. You may not think of taking pictures when your child is ill or recovering from surgery, but you may want them later (especially if your child is a newborn infant).
- ♥ If you are a new mom, recovering from delivery of your baby:
 - Be sure to bring the perineal care bottle that you received at the hospital, and a good supply of sanitary products. You will need to cleanse yourself in a public washroom during the day, but the good news is that most of the washrooms at SickKids are private. They have a toilet and sink in the same room, with a locking door. Pay attention to the instructions near the lock though – they don't always turn the way you think they would.
 - Bring any prescriptions you were given (stool softener, Tylenol 2, Midol, etc.)
 - Prenatal/postpartum vitamins. You should continue taking these, as it may be hard to maintain a well-balanced diet in the hospital.
 - Bring a comfortable pillow to sit on for the car ride, and at the hospital. You will be doing a LOT of sitting, and you may be very sore for awhile, especially if you had an episiotomy. Some new moms like the nursing-type pillow with the hole in the middle.
 - Bring nursing pads. Especially if you are pumping/breastfeeding, you will likely have some leaking once your milk comes in.

- ♥ A breast-pump if you have one and are planning to breastfeed your baby. (There are pumps that you can use at the hospital, but you may wish to pump during the night while you are at your hotel, etc.)
- ♥ A water bottle. The air in the hospital is very dry and you will be thirsty. There are fountains and sinks where you can fill it as needed.
- ♥ Your favorite hand cream/lotion. You will be washing and sanitizing your hands on a regular basis. Combined with the dry air, you may find your skin dryer than normal. Lip balm is a good idea too.
- ♥ Snacks and non-perishable food items, like granola bars, energy bars, canned or powdered soups, tea-bags or powdered drink mixes etc. Food and beverages can get very expensive and the cafeteria hours may not coincide with your schedule during the day. There are kitchen areas with microwaves, kettles, sinks and fridges that can be used by the families of patients. A microwave-safe mug, bowl or other container may also come in handy.
- ♥ Your cell phone (don't forget your charger!) There are some areas of the hospital where they are allowed to be used, and may be a cost-effective alternative to using payphones, depending on your phone plan. If not, bring a list of phone numbers of people you want to keep in contact with, and buy a phone card in the hotel lobby. (Look for the Ci-Ci card – most cost-effective.)



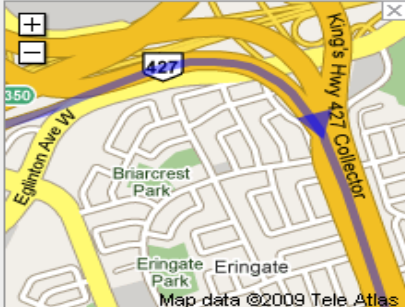

General notes:

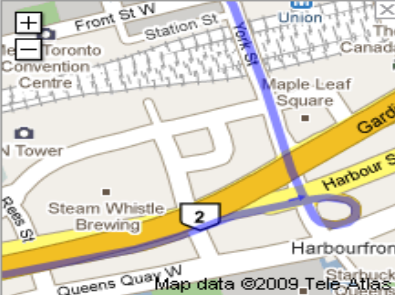
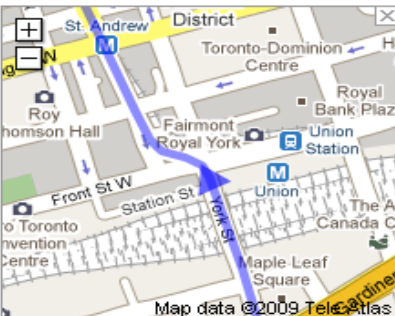

- 1. If you are concerned about bringing large or bulky items to the hospital (such as pillows), there are lockers in the critical care waiting room where you can leave items during the day, or overnight. There is a key system available – register with the CCU desk upon arrival. Once your child has a room in the ward, you may wish to leave these items there instead.**
- 2. Do NOT bring valuable items, such as expensive jewelry, electronics, etc. unless you can keep them on your person at all times. The hospital is not responsible for any lost or stolen items.**

Directions to Sick Kids and where to park

How to get to the hospital:

- ♥ How to get to Sick Kids by car (driving from Windsor):
 - 401 East to 427
 - 427 to Gardiner Expressway
 - Gardiner to York Street Exit
 - Veer left on York Street to University
 - University to Elm Street on right hand side immediately before the hospital. If you miss Elm, turn right after passing the hospital and go around back of hospital to Elm Street. The hospital fills the entire block.
 - Turn into the underground parking garage.

1. Head southeast on Ouellette Ave toward Tuscarora St About 4 mins		go 3.9 km total 3.9 km
 2. Slight left at Dougall Ave About 9 mins		go 5.7 km total 9.6 km
3. Take the exit onto King's Hwy 401/MacDonald-Cartier Fwy About 3 hours 26 mins		go 337 km total 347 km
4. Take the ON-427 exit About 1 min		go 1.1 km total 348 km
5. Merge onto King's Hwy 427		go 0.8 km total 349 km
6. Continue on King's Hwy 427 Expy About 4 mins		go 7.2 km total 356 km
7. Merge onto Gardiner Expy About 8 mins		go 13.1 km total 369 km

<p>8. Exit onto York St About 4 mins</p>		<p>go 1.4 km total 371 km</p>
<p>9. Slight left at University Ave About 3 mins</p>		<p>go 1.4 km total 372 km</p>
<p>10. Turn right at Elm St</p>		<p>go 0.2 km total 372 km</p>

♥ Alternate directions and maps can be found on the SickKids website at <http://www.sickkids.ca/VisitingSickKids/Getting-to-SickKids/index.html>

Where to park at the hospital:

- ♥ The easiest place to park is in the underground garage attached to the hospital. The entrance is on the South side of the hospital (enter from Elm Street, between University Avenue and Elizabeth Street). You will need to take a parking stub upon entering the garage. **Please note that the parking garage only accepts CASH payment.** If your child is a patient at SickKids, you can get your stub validated for a discounted parking rate. Current details and rates can be found at www.sickkids.ca/VisitingSickKids/Getting-to-SickKids/Parking/index.html. Special extended parking rates may also be available depending upon financial need – ask your social worker for details.
- ♥ Park as close to the elevator as possible, even if you have to go down to the lower levels. This makes it easier to store and retrieve things from your vehicle as needed, such as food, umbrellas, heavy coats, etc.
- ♥ Once you have parked, plan to leave your car there if possible. Walking to your hotel or other accommodations, restaurants, or anywhere else you need to go will save you a lot of money in the long run, since parking rates are high everywhere in the downtown area.

Where to go in Sick Kids to see your child

Where to go once you get inside the hospital:

- ♥ From the parking garage, take the elevator up to the lobby level. When you exit the parking elevator, the information desk will be on your right. The elevators to the higher floors and the cafeteria are clearly visible from this vantage point. A layout of the main floor of the hospital can be found at <http://www.sickkids.ca/VisitingSickKids/Getting-to-SickKids/index.html>.
- The Critical Care Unit is on the second floor. If your child was flown to Toronto in a plane or helicopter, this is probably where they will be initially. Take the elevator to the second floor and turn toward the back of the hospital (away from the front windows). When you reach the hallway, turn left. You will find a desk with a telephone at the entrance to the CCU waiting room. You will need to call in to the main desk each time you wish to enter this area (instructions are posted near the phone). You will be asked to identify yourself, and then will be instructed as to whether or not you may enter at that time.
- The Cardiac Ward is on the fourth floor (4D). When you exit the elevator, turn toward the back of the hospital (away from the front windows). When you reach the hallway, turn left. The ward desk will be directly in front of you. Your child will likely be staying in the ward if they are preparing for or recovering from a catheterization or surgical procedure, but not in critical condition.
- The Neonatal Intensive Care Unit (NICU) is located on the third floor. When you exit the elevator, turn toward the back of the hospital (away from the front windows). When you reach the hallway, turn left.
- If you need to report first for an x-ray, blood work or other procedure, it is best to report to the information desk for directions, if they have not already been provided to you. These procedures are carried out in various locations, mostly on the main floor.

General Note: If you are arriving outside of regular hospital hours, please be aware that you will need to check in with hospital security in the main lobby prior to proceeding. They will be able to locate your child for you and direct you to the appropriate area.

Accommodations in Toronto

Where to stay while in Toronto:

If your child is going to be having a surgical procedure, you may not know how long you will need to stay in Toronto. It is difficult for the medical personnel to give you an accurate estimate, as many factors may affect your child's recovery. There are several options for accommodations, which may change as your child progresses.

- ♥ Ronald McDonald House (416) 977-0458. This is a popular choice for families of patients from the Windsor area due to its low nightly rate (\$15 per family) and many amenities. Unfortunately, it is always operating at full capacity. If you wish to stay there, a referral from hospital staff is required for your first visit (usually a social worker). Please see their website at www.rmhtoronto.org for full details. Once they have your referral, beginning the day before you travel to Toronto, be sure to call EVERY MORNING to see if any rooms have opened up. Since they never know how long a family will be staying, they operate on a first come, first served basis. (Note that maximum stay is 30 days at one time.)

- ♥ There are several hotels nearby
 - Courtyard Marriott, 475 Yonge St , 416-924-0611
 - Delta Chelsea, 33 Gerrard St W , 1-800-CHELSEA, (416) 595-1975
 - Super 8 Hotel, 222 Spadina Avenue, 1-877-605-7666

When calling any of these hotels to make a reservation explain that your child is being treated at SickKids and you may receive a discounted "hospital rate".
- ♥ For more ideas on where to stay, call Tourism Toronto 1-800-499-2514 or visit www.toronto.com
- ♥ There are a limited number of "rooms" available in the hospital (with cots or padded benches and proximity to one of the public restrooms). These are usually given to families of newborns who have just arrived at the hospital, or to families of children who have undergone a surgical procedure that day. If your child is going to be having surgery, ask your social worker or the clerk at the 4D ward desk if a room is available for that night. These people can also assist you with hotel reservations if you have just arrived.
- ♥ If no rooms are available at the hospital, but you wish to stay to visit your child during the night, you are permitted to sleep in the Critical Care Unit waiting room, located on the second floor. Clean sheets and blankets are typically available in a cupboard there for that purpose. Many parents also nap here during the day. Lockers are available here for storing any personal items, such as toiletries, coats, etc. (Don't leave valuables unless you have a lock.)
- ♥ Parents are generally permitted to stay in the room with their child for as long as they like (in critical care or the group-ward rooms) but there is no place to sleep. In any case, this should be a last resort, as you need your rest too, in order to help care for your child during the day, and be alert to discuss their condition with medical personnel. You may also be asked to leave during certain times, such as when your child or another patient is undergoing a procedure, or when the medical staff is making their "rounds". This is to protect the privacy of the other patients and their families.
- ♥ Once your child's condition has improved to the point where they no longer require continuous monitoring, they will be moved to a private ward room (if space is available). These rooms have a "bed" (padded bench), linens and a private washroom, so that you may stay with your child around the clock. On the 4D Ward, if both parents are staying, a cot may be able to be brought in at night for the second parent, but be aware that these rooms are very small. Nurses will still be coming into the room at regular intervals during the day and night to check vitals and monitor your child's condition.

Breastfeeding at Sick Kids

What to do if your child is an infant and you plan to breastfeed (or if your child is an older breastfed baby who will require surgery):

- ♥ If you have just given birth and wish to breastfeed your child, but are not able to because of your child's condition, ask for information at the CCU desk or Ward 4D desk **as soon as possible** after arriving at the hospital. In order to ensure that your milk comes in, you will need to start pumping on a regular schedule.
- ♥ If your baby is older and you have already been breastfeeding, and wish to continue after your child recovers from surgery, be sure to ask your child's doctor for specific instructions. Pump your breast milk until your child is able to nurse again.
- ♥ If your child is in CCU, there is a room available directly next to the CCU front desk where commercial grade breast pumps are available. Attachments for the pump are sterilized after each use, and are available at the desk (you will need to "sign them out"). Sterile collection containers are available in the room as well. You can ask any available clerk or nurse for

directions on how to assemble and use the pump. **Also, be sure to ask what to do with the collected breast milk.** Label your containers carefully, and return them to the desk. Your milk will be frozen, stored, possibly fortified (if your child needs more calories, but is on a fluid-restricted diet), and sent back as needed to be fed to your child (possibly through a tube in their nose or stomach).

- ♥ If your child is on 4D (ward), pumps are available near the main desk. Ask at the desk for the attachments. You can then take the pump directly to your child's bedside and use the privacy curtains.
- ♥ Another breast pump room is also available on the fifth floor, directly adjacent to the elevators, toward 5A.
- ♥ If you are having any difficulties operating the breast pumps, or if you have questions regarding the frequency of pumping, the amount of milk you are getting, or any other issues, ask your child's nurse to request a meeting with a lactation consultant.
- ♥ If you do not own your own breast pump, you may wish to rent one to take back to your hotel (or other accommodations) at night. Pumps are available for rental at the Specialty Food Shop on the main floor. Ask a nurse or lactation consultant for details.
- ♥ Make sure that your child's nurses and doctors are aware of your desire to breastfeed, so that they will allow you to try as soon as your child is physically ready.

When your child is discharged from the hospital, be sure to take any remaining breast milk home with you. If you will be driving directly from Toronto to Windsor, ask if dry ice is available to keep it frozen. You can then use it at a later date, when you need to give your baby a bottle.

Staying in touch with home when you are at Sick Kids

How to keep in touch with family/work, etc.

- ♥ Internet access is available at the hospital. There is a resource room on the ground floor, down the main hallway toward Shoppers Drug Mart. This room is only open during certain hours, but computers with Internet access are available free of charge. This is also a good place to research your child's condition.
- ♥ There is also a very small lounge on the third floor, directly across the hall from the NICU waiting room with a single computer that is available free of charge. (This is directly underneath the Ward 4D desk area.) Note that this room may be occupied. Although there are sofas available here as well, please be considerate and wait outside if you wish to use the computer.
- ♥ Internet access is also available in Marnie's Lounge on the 4th floor.
- ♥ Pay phones are available in various locations throughout the hospital, including the lobby and the hallway directly outside of the CCU waiting room. Phone card vending machines are available in the lobby. Read the rates carefully before choosing – some are a much better deal than others.
- ♥ If you wish to use your cell phone, familiarize yourself with the areas where they are and are not allowed. Please be sure to turn off your phone when entering an area where they are restricted.
- ♥ There is a website called www.carepages.com that allows families to post updates and photos for their friends and family to share. This is also a good resource for support and information from families in a situation similar to your own.

Sick Kids Staff and their roles in your child's treatment

People who may approach you at your child's bedside:

- ♥ Medical personnel – surgeons, staff cardiologists, fellows, nurse practitioners, nurses, etc.
- ♥ Other hospital staff – see bottom of page.

How to understand the hierarchy of medical personnel:

The medical staff at SickKids is comprised of much more than simply “doctors” and “nurses”. Here are some of the people you can expect to encounter on a regular basis.

- ♥ Surgeons. At some point you will be visited by or meet with the doctor who will be performing your child's surgery or catheterization. The surgeon will also meet with you when your child's procedure is complete. Please be aware that each surgeon may have his or her own preferences for discussing the surgery with you. Some surgeons may come and sit with you in the Surgical Waiting Room to let you know how things went, and some may ask you to accompany them to a private room, or out into the hallway. Being asked to go to a private room is NOT necessarily “bad news”, so don't panic. You may wish to discuss this with your surgeon before the surgery so you know what to expect.
- ♥ Staff Cardiologists. There is one staff doctor on duty during each shift. This doctor will make rounds each day with a team of medical personnel. (Find out what time this is done so you can be present to discuss your child's condition.) There is also one Cardiologist who will be “assigned” to your child for the duration of their stay. This doctor will “check in” with you on a regular basis, but will probably have no direct involvement in your child's care.
- ♥ Fellows. These are medical doctors who are learning different specialties, in this case cardiology (SickKids is a teaching hospital). This is often the doctor who will be able to spend the most time with you discussing your specific concerns. They will be present on rounds as well, so you will see them on a daily basis.
- ♥ Nurse practitioners. With extensive training in cardiac care, these personnel can provide you with most of the information that a doctor can (in some cases, more) and they are often more readily available.
- ♥ Nurses. Your child will be assigned a different nurse during each shift. Nurses will perform checks of your child's vital statistics (temperature, blood pressure, etc.), administer any medications and respond immediately to any changes to your child's condition. They will also provide regular care such as feedings, diaper changes, etc. when you are not present.
- ♥ Dietitians. Their job is to ensure that your child's nutritional needs are being met, whether you are breastfeeding, formula feeding, feeding solid foods to an older child or your child is being fed through a tube. They may have recommendations on feeding methods and quantities and will be available to you during the daily rounds, or upon request.
- ♥ Pharmacists. They can provide you with information on any prescriptions your child may have.
- ♥ Occupational Therapists
- ♥ Physical Therapists

In addition to the medical personnel who will be checking your child on a regular basis, there are some other people who may visit you during your child's stay:

- ♥ A Social Worker. This person may be one of the first that you meet, and will be available to you during your child's stay. In addition to guidance regarding your child's care, they can assist you with accommodations and any information you may need regarding financial assistance that may be available to you.
- ♥ A Child Life Specialist. This person may ask if there is anything that you would like for your child to help make their stay more comfortable or enjoyable. They have age-appropriate developmental toys, such as mobiles and crib toys for infants that you can borrow during your stay. These are carefully sanitized prior to each use.
- ♥ An RSV Representative. RSV stands for Respiratory Syncytial Virus. Most children will be exposed to this virus by the age of two, and "healthy" children will simply exhibit symptoms similar to the common cold, or none at all. But due to your child's increased risk for respiratory infections, a series of shots will be available to your child through a government-funded program. These shots are administered at Windsor Regional Hospital, Metropolitan Campus, and are given once a month during the "RSV Season", which typically begins around November. **This is an optional program.** This representative can answer any questions you may have about the virus, its symptoms, and any potential risks/side effects.

A representative of the Chaplain's Office. This person may visit to offer emotional support, to encourage you to take care of yourself and to talk or pray with you if you so desire. If you do not appreciate faith-based support, you can simply politely decline to speak with this individual. They are there to help, not to intrude or make anyone feel uncomfortable.

Who to ask if you have questions about your child's condition or care:

- ♥ The person who will have the answers to your question(s) will vary depending on what you need to know, but the best person to start with is your child's nurse. He or she will always be available to you during their shift and if they don't have an answer for you, they will be able to direct you to the person who will. They can also contact other medical personnel such as surgeons or lactation specialists and request a visit if appropriate.
- ♥ The clerks who sit at the desks (both in critical care and on 4D) can also be very helpful with questions that are not of a medically technical nature. For example, they can inform you of the timing of doctors' rounds, locations of different facilities within the hospital, etc.

Taxes

Traveling out of town for medical treatment can become very expensive with the costs of travel, accommodations and food while you are away from home. While it may seem difficult to plan up to a year ahead of time, the Government of Canada has put together very simple guidelines allowing families to deduct the costs of travel from their incomes in order to lower the overall tax burden and therefore costs of medical treatment.

Below is a brief summary of the tax code. See the end of this section for links to detailed information from government sources.

- ♥ If you must travel greater than 40km for treatment, you may deduct travel expenses (i.e. fuel, wear and tear on your vehicle).
- ♥ If you must travel greater than 80km for treatment, you may also deduct meal costs for the treated person and one additional person (such as a parent or spouse) if they are required to assist the patient who is not capable of traveling alone.
- ♥ If you must travel greater than 80km and you must stay overnight (e.g. in a hotel), this will also be covered **provided you retain your receipt**.
- ♥ You may deduct the cost to park your vehicle.

It is very important to note that you are able to claim medical expenses for any 12 month continuous period of time ending in the respective tax year. For example, if your child was born in September 2008 and immediately transferred to Toronto for surgery and you had repeated follow-ups to an additional surgery in May 2009 with more follow-ups to come, you may select the September 2008-September 2009 as your 12 month period for tabulating total expenses.

Currently the CRA treats vehicle costs and meals as listed below. However, this is subject to change and is something that you should review in detail with whoever handles your taxes.

- ♥ Vehicle expenses – There are 2 ways to calculate this expense:
 - Simple method - track the exact number of kilometers you drive to and from hospitals as needed for treatment outside of your region (i.e. All trips to London and Toronto) and multiply by the flat rate per kilometer for Ontario for the given tax year. This rate can be found at <http://www.cra-arc.gc.ca/travelcosts/>
 - Detailed method – track **ALL** vehicle expenses for the one year time period (gas, oil changes, tires, maintenance, insurance, licensing and vehicle depreciation), total km driven and km driven for medical treatment. You may deduct the total portion of the km driven simply for medical treatment. This may prove advantageous for newer vehicles.
- ♥ Meals - You may claim \$17 per meal, up to \$51 per day per person without receipts. However, only one accompanying person (e.g. one parent) may make this claim.

We have provided an envelope in the back of this folder for you to maintain your receipts in one place. Collect all of them and your tax advisor can assist you with what exactly is needed. Also, begin recording kilometers traveled as soon as possible.

Detailed information is available at

- ♥ <http://www.cra-arc.gc.ca> – Canada Revenue Agency
- ♥ <http://www.cra-arc.gc.ca/E/pub/tg/rc4064/README.html> - Medical and Disability-Related Information (Includes Form T2201, 2008)
- ♥ <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/menu-eng.html?slnk> - Line 330 - Medical expenses for self, spouse or common-law partner, and your dependent children born in 1993 or later