# Checklists for Infant or Child Heart Patients ©

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These lists are as all-inclusive as possible, so you can just pick out the items that pertain to you. We hope you find them helpful, and if you have anything to add, please let us know here authors@congenitalheartbook.com

# TODO-General

-review this list every year on your child’s birthday

-tell your loved ones that you love them

-tell them it’s nobody’s fault

-write down your questions and concerns

-tell your child no questions are off limits, and ask if they have any questions

-make a special question list for them to write down their questions if you’re not there

-keep and update your summary sheet of all significant cardiac procedures

-write down their allergies and make sure your team knows about them

-help them understand why their medications are important, so they continue to take them when they get older

-help them learn the name of their defect and major interventions and medications in case they have an emergency without you

-consider a medial ID bracelet

-teach them the name of their cardiologist

-program their cardiologist’s on-call phone number into your phone and theirs if they have one

-tell everyone who’s helped that you appreciate their help

-assess need for counseling for yourself or the child

-have a good cry if you need it

-set alarm on your cell phone for administering meds (or pill reminder/medisafe app)

-make a special journal for the child to write down their thoughts, maybe trade it back and forth with stories/notes

-consider journaling to record your thoughts/concerns

-take care of yourself. You can’t help them if you aren’t in good shape.

-let teachers and caregivers know what’s going on so they can understand and maybe help

-ask teachers if you should come to the school to explain why your kiddo is different

-take lots of pictures and videos for chronicling everything

-tell your kids what you know, or they may stop trusting you or fill in their own (worse) version

-remember it’s ok to say “I don’t know, but we can ask the doctor”

-replace difficult terms like “heart failure” with “heart having trouble pumping blood”

-breathe

-get copies of all your child’s records, keep a photo of ECG on your phone

-make time to just enjoy your child’s company

-make sure your healthy kiddos know you love them just as much, even if sometimes you’re preoccupied with your sick child

# TODO - before a Regular Cardiology Appointment

-write down your needs and expectations from your cardiology team

-talk to your child and their siblings ahead of time, finding an age-appropriate way to let the whole family know what’s going on

-put a voice recording app on your phone to record the doctor visits to review later

-watch videos of blood draws/blood pressure tests/echos/MRI’s etc. with your child to prepare them

-read your child’s records, make questions for anything you don’t understand

-list all events since the last appointment-date, time, duration, how your child felt

-see if they need a refill for any medications

-assess need for counseling for yourself or your child

# What to Take to a Regular Cardiologist Appointment

-your list of what you expect/need from your cardiology team

-a family member or friend (if you want to) to help listen and ask questions

-your charged phone to record the visit

-your health insurance card

-your child’s medications (or at least a list of names and dosages), including over the counter

-the name and address of your primary care provider / family doctor

-names of any doctors/hospitals where your child received any treatment since last appointment (ex. pulmonologist, gastroenterologist, etc)

-a list of questions or issues you want to talk about

-a book/magazine/music/videos/toys for you and your child in case of a long wait, or to distract them during a procedure

-a snack/drink (or money to buy them)

-your child’s health summary

-if your child wore a Holter or have an implanted device, bring your calendar/daybook to your appointment to identify what they were doing during any flagged events

- a ribbon to tie around an arm after a blood draw to show everyone they shouldn’t be touched there

-treats for your child

-notepad for pictures and notes

# Questions for Cardiologist at Regular Appointment

-do you mind if I record this conversation

-what caused this defect

-what over-the-counter drugs are not compatible with what my child is now taking

-what do I do if we miss a dose of meds

-what do I do if my child vomits up the meds

-is it ok to mix the med with sugar to make it more palatable

-how do we know if the medication(s) is/are working

-how often do we need to come back for check-ups/tests

-what number do I call/email do I use if I have new questions

-what limitations are there on life

-what are all the treatment options

-when can we expect to next need an intervention

-how many interventions might be needed over the lifetime

-what are you looking for in each of the tests you recommend

-what symptoms should we look for/take note of

-how many patients like my child do you see, what is their general progression

-does my child have any exercise restrictions

-where’s the best place to get a second opinion

-what if I’m really bad at taking giving my child their meds, is there anything we can change that will help

-should we buy a pediatric O2 monitor, or does the hospital have a loaner

-when is the cardiologist in charge and when is the pediatrician? Who do we call for what

# Questions before Surgery/Intervention

-do you mind if I record this interview (audio record app)

-what other surgical/non-surgical options are available

-which option do you recommend and why (what is the risk/benefit of this)

-what are the risks and what are the odds of each of them

-of the most common complications, what do they look like/what signs do we watch for

-would you walk us through the process/procedure

-how many of these surgeries/interventions have you done

-how many hospitals in this country do this kind of surgery, and who’s the best

-where’s the best place to get a second opinion, if needed

-what are the average survival rates, rates at this hospital and your rates with this exact procedure

-how long will the procedure take, and how will I/we be updated during it

-when will we be able to visit our child after the procedure, are there limits to visits after that

-does our child need to wash specially before, and avoid lotions

-will we see our cardiologist that day

-what kind of anesthesia will my child receive

-when can we meet the anesthesiologist

-what resources are available that can help us (financial, social, home care, rehab, mental health)

-what additional tests will my child need after this, how do we measure the results

-what time should we arrive, and where

-what limitations will my child have after the procedure, for how long

-what will my child be hooked up to during the surgery

-what will my child be hooked up to after the surgery

-how many days before my child can come home, what will recovery look like

-do I have to stop giving my child any of their current meds before or after the procedure, if so, how long before, after

-if they do need to take their meds before surgery, can they take them with a sip of water

-what if I’m really bad at taking giving my child their meds, is there anything we can change that will help

-what’s the likelihood of my child getting blood transfusion/how much blood is normally lost during this procedure

-what will be used for stiches, will they need to be removed

-will anything be implanted and why? Who’s the manufacturer, what is their success rate, are there any recalls on this device, how long does it normally last

-can parents/family stay overnight with the child, where and will they be able to shower/do laundry /is there a sleeping room for family at the hospital, or subsidized housing nearby (Ronald McDonald house, hotel discounts)

-what do you use for pain control, how long will my child be on it

-what happens if the surgeon is unexpectedly unavailable the day of surgery

-what resources are available to help us after we go home

-will there be any dietary restrictions when we go home

-what number do we call if we have questions after we go home, will someone answer 24/7

-what warning signs warrant an emergency room visit?

-when do we come back for a post-op check-up

-how often will we need to return for tests/appointments after that

-what meds will I have to take afterwards for the short term? the long term

-what will we have to help our child with once they come home

-how long before our child can go back to school or play sports

-will there be any dietary restrictions when my child comes home

-what do we need to bring to the hospital

-where do we park to stay overnight, can we be reimbursed for parking

-are there any discounts at the hospital cafeteria for families of long-term patients

- what will insurance cover and what will we have to pay

-does insurance company have a case worker that can be assigned to you so you can always talk to the same person

-ask for the consent forms ahead of time so you can actually read them

-what facilities the hospital has for pumping and storing breast milk

-when will I be able to breast feed my baby

-when will we be able to hold our baby/child

-what toys will be available for our baby/child

-does the hospital have child life specialists or volunteers who can play with our child to give us break

-does the hospital have a councilor to help with our stress/anxiety

-are there any discounts at the hospital cafeteria for families of long-term patients, (especially if a mom is breastfeeding, meals are sometimes free)

-what else do we need to know

# TODO for Surgery/Intervention

-write down your questions and concerns

-take pics of all the docs you meet with and record their names, there may be many of them

-write down your child’s allergies (esp. contrast dye, shellfish or latex), medical history, medications, supplements and illegal drug use and make sure your team knows about them

-remember you are hiring your medical team like any other service provider, and you can fire them too

-arrange someone to attend the pre-op visits with you to help ask questions and understand

-have your child remove all jewelry and leave it home

-get help from family, friends, neighbors, kids’ friends’ parents. Give specific requests, like babysit for a week, bring meals for 3 days, or bring the other kids to their events for a week

-get help from school counselor, pastor, hospital social worker/psychologist/child life specialist

-get large pill organizer if you don’t have one already

-thank all your child’s caregivers

-consider fan/heater for patient’s room

- take lots of before and after pictures and videos of your kiddo, you never know when they might come in handy (make sure you get permission if anyone else is in the shot)

-consider extra pillows for home if you don’t have them, for propping up in bed

-talk to your child and their siblings ahead of time, finding an age-appropriate way to let the whole family know what’s going on

-let them know they’ll probably be

-asked to remove all their clothes and change into a special gown

-visited all the time and often woken up by lots of nurses and doctors

-hooked up to tubes in their arms and chest, one for pee, maybe even in their throat to help breathe, or blowing air in nose, a cuff on their arm, a clip on their finger

-surrounded by noisy equipment, maybe a machine squeezing their legs

-in pain/feel sick/be thirsty

-tired and not able to walk very far for x hours/days

-get a special bed that they’ll be able to adjust up and down, and their own tv

-be in a different room alone/with a roommate

 -how long before their friends/siblings will be able to visit

 -how long before they’ll be able to come home

 -how life will be different when they come back home

 -the possibility that they won’t come home

-ask the child -Do you have any questions?

-What is your understanding of why you’re going to the hospital?

-Does anything scare you?

-Is there anything you want us to know?

-Is there anything you’d like to bring?

-try to arrange to keep siblings on a routine

-involve siblings in the care, give them tasks like making cards or gifts, or decorating a room, or explaining the defect to people

**-**ensure you make time just for other children, even schedule it if you need to, they are probably as worried as you are

-give out awards for best helper, best laugher, best question asker

-let siblings know that it may seem like the adults forget about the kids during this, but they still love them. Plan a special event for siblings when you can

-reward all the kids in the family when one kiddo does something kind or brave, so they become a team

-make a list of movies your kiddo wants to watch

-plan to take longer than you expect from work, just in case

# What to Bring for Hospital Stays

-ID and insurance card

-medications

- coffee maker to the room (makes the doctors and nurses want to linger longer)

-buy some special new toys/gifts to surprise your kiddo(s)

-toiletries, lip balm, skin cream, dry shampoo

-diapers and wipes

-bottles, pump, warmer, soap and cleaning brushes

-phone and phone charger with long cord, tablet

-protective case for eyeglasses, dentures, hearing aids, contact lenses and solution, eye drops

-hearing aids, canes, other special tools

-decorations for their room

-special toys

-jam/jelly for pacifiers

-books/magazines/videos/music/word puzzles

-go home outfit

# Questions before Traveling

-where’s the congenital clinic in the city you are traveling to

-can child go through security detectors

-can liquid medications be taken in carry-on

-can oxygen be brought

-who to call if lost medications

-plan for extra time to go through security

# Questions for the Healthy Siblings

-How do you understand what’s happening to your brother/sister?

-What are your feelings about it?

-What do you think this means for the family?

-Is there anything you’re afraid of?

-Is there anything you don’t understand?

-Do you have any questions for the doctors?

-Would you like to talk to a mind doctor about your feelings?

# How to Help a Patient’s Siblings

-revisit this list often as circumstances change

-prep a talk ahead of time, finding an age -appropriate way to let them know what’s going on

 -Include how long the loved one expects to be in the hospital

 -how long before kids will be able to visit

 -if they will be able to visit, how the patient will look

 -how life will be different when the patient comes back home

 -the possibility that the patient won’t come home -see Prepare for End of Life

-replace difficult terms like “heart failure” with “heart having trouble pumping blood”

-do tell them what you know, or else they may stop trusting you and/or fill in their own (possibly worse) version

-it’s ok to say “I don’t know”

-tell that you love them

-tell them it’s nobody’s fault

-tell them no questions are off limits

-try to keep some routine in their lives for normalcy

-skype/facetime/zoom if visits aren’t allowed

-let them know that it may seem like the adults forget about the kids during this, but they still love them, and will keep them safe

-get help from school counselor, pastor, hospital social worker/psychologist/child life specialist

-make a special question list for them to write down their questions

-make a special journal for them to write down their thoughts, maybe trade it back and forth with stories/notes

-give them tasks like making cards or gifts, or decorating a room

-let your kids know that it may seem like the adults forget about the kids during this, but they still love them

-try to arrange to keep some routine in their lives for normalcy

-pre-record bedtime stories they can listen to in an adult’s absence

-make a special handshake for the patient and siblings to show you’re all in this together

# Tips for Giving Medications

-buy a pill organizer

-administer the liquid as far back in the mouth as possible

-blow in your child’s face after giving the medication

-reserve a special toy/device as a reward for taking the medication

-if child has trouble with pill medication, ask if there’s a liquid version available

-make a special calendar/spread sheet just for medications