# Checklists for Teen and Adult 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 - Teen Patient

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

-ensure your teen knows the name of their defect and the major interventions they’ve had

-help your teen create a list of highlights of their CHD in their phone, and a picture of latest ECG

-help them start a journal if they want to

-ensure they have their cardiologist’s contacts and on-call emergency number(s)

-make their phone has In Case of Emergency apps that include emergency contacts and medications

-make sure your teen understands the risks of pregnancy, and understands the dangers of piercings and tattoos, alcohol, smoking, and drugs (you can ask your cardiologist for help)

-ensure they understand any medications they should avoid, or are allergic to

-ensure they understand the need to take antibiotics for dentist appointments (if applicable)

-congratulate them. Life is hard

-ask them if they have any questions, and let them know no questions are off limits

-ask them what scares them, or what concerns they have

-ensure your teen knows which medications they are taking, and understand why they are important

-ensure they understand any exercise restrictions, and the importance of exercising daily within any limits

-consider a medial ID bracelet

-assess the need for counseling

-put a voice recording app on your phones to record doctor’s visits to review later

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

-let siblings know that it may seem like the adults forget about them when the patient is going through a scare, but that you still love them

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

# TODO – Preparing for Transition

-ensure your teen understands their need for lifelong follow up care, even if they feel fine

-encourage your teen to ask their own questions in clinic visits

-let your teen start booking their own appointments

-let them start refilling their own prescriptions, and keep track of when they need the next refill

-let your teen have time alone with their pediatric cardiac specialist to get used to it

-discuss when your teen will be ready to transfer to an adult specialist, and accompany them on early visits as they wish, and ensure they get some visit time and entire visits on their own

-help your teen start to learn their critical numbers-LDL, HDL, EF, BP, hr, gradient, as applicable

-celebrate their transition to managing their own care

-ensure your teen has access to their own medical records, and encourage them to keep a copy of everything

-help them learn where to get help if you’re not available

-ensure your teen knows what insurance they have and how to contact them

# TODO – Adult Patient

-review this list every year on your birthday

-download In Case of Emergency app and include emergency contacts and medications

-program nearest hospital address into your phone’s map app

-keep and update a summary sheet of all significant events and procedures, keep a photo of latest ECG on phone

-consider starting a journal

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

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

-get your cardiologist’s on-call phone number in your phone

-congratulate yourself. Life is hard

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

-get a copy of all your test and procedures reports

- exercise daily within any limits your cardiologist imposes

-understand your work-leave/disability policies

-know your critical numbers-LDL, HDL, EF, BP, hr, gradient, as applicable

-know the names of your medications and doses

-know why you are taking each medication and how it is helping you

-program reminders of when you need medication refills into your phone

-have a good cry if you need it

-make a living will/advance directive, power of attorney and talk to your loved ones about it and give a copy to your medical team- <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

-make a will and talk to your loved ones about it

-summarize your assets, liabilities, account numbers, share with a loved one

# TODO before a Regular Cardiology Appointment

-line up a loved one to join you if desired (warn them you may ask them to leave the room at time) to help listen and ask questions

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

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

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

-note any changes in physical ability, diet, weight, sleep patterns, energy levels

-write down your questions

-see if you need a refill for any medications

-assess need for counseling

# What to Take to a Regular Cardiologist Appointment

-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 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 you received any treatment since last appointment

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

-a book/magazine/music/videos in case of a long wait

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

-your health summary

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

-bring notepad for pictures and notes

# Questions for Cardiologist at Regular Appointment

-do you mind if I record our conversation

-what caused this defect

-what over-the-counter drugs are not compatible with what I am now taking

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

-what do I do if I vomit up the meds

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

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

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

-what’s a normal lifespan

-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 my lifetime

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

-what symptoms should I look for/take note of

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

-do I 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

# 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 me through the process/procedure

-how many of these surgeries/procedures 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

-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 my loved ones be updated during it

-when will visitors be able to see me afterwards, are there limits to visits after that

-do I need to wash/shave specially before the procedure, or avoid lotions

-will my cardiologist be there/what’s her/his role once we schedule the surgery

-what kind of anesthesia will I receive

-when can I meet the anesthesiologist

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

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

-what time should I arrive, and where

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

-what will I be hooked up to during the surgery

-what will I be hooked up to after the surgery

-how many days before I can go home, what will recovery look like

-how much will I be able to do physically the first 3 days? the first week

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

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

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

-what’s the likelihood of getting a 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 a loved one stay overnight with me, where and will they be able to shower/do laundry /is there a sleeping room for family at the hospital, or subsidized housing nearby/hotel discounts

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

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

-what resources are available to help me after I go home

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

-what warning signs warrant an emergency room visit?

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

-how often will I 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 I need help with once I come home

-how long before I can go back to work/school or play sports/have sex/drive

-will there be any dietary restrictions when I go home

-what do I 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 I 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 before the day of the procedure so you can actually read them

-what else do I need to know

# TODO for a 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 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

-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 kids to their events for a week

-get help from pastor, hospital social worker/therapist

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

-designate a caregiver/coordinator

-thank all your caregivers

-consider fan/heater for patient’s room back at home for extra comfort

-have someone take lots of before and after pictures and videos, you never know when they might come in handy

-have someone ready to drive you home, you may not be able to drive

-consider renting a powered recliner, you can rent from many medical supply companies

-consider a house cleaning service while your recover

-see if your car insurance company will suspend your insurance since you won’t be driving it

-do any heavy lifting at home (heavier than a gallon of water) before the operation

-practice getting out of chairs without using your arms

-consider buying a raised toilet chair if getting up without arms is a problem and shower stool if balance might be a problem

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

-get stool softeners in case they don’t send you home with them

-call your medical insurance company and understand exactly what you’ll be on the hook for (ask your insurance company if they have a case worker that can be assigned to you so you have always talk to the same person)

-ask a friend or neighbor to watch your home and collect your mail

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

# What to Bring for Hospital Stays

-ID and insurance card

-medications

-button up shirts

-zip up sweatshirt/button up sweater

-front clasp bras, feminine hygiene products

-favorite pillow

-phone and phone charger with long cord, tablet

-slippers and favorite pajamas

-toiletries, including dry and regular shampoo, lotion and lip balm

-headphones, earplugs, eye mask, laundry soap

-books/magazines, word puzzles

-sunglasses for the way home

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

-hearing aids, canes, other special tools

-decorations for your room

-water bottle

-notebook/pen for your own memories

-notepad /pen in case you can’t/don’t want to talk

-your own toilet tissue if you’re picky

-go home outfit

# Questions before Traveling

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

-can I 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 Patient’s Children or Siblings

-How do you understand what’s happening to your parent/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 Children or Younger 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

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

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

-let them know that you’re ok now, but may get worse for a while, or maybe forever

-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

# Prepare for End of Life

-tell your family you love them

-tell them this is nobody’s fault

-ask them their thoughts, feelings and questions, often

-talk to all your kids about how the future might be different

-have children help plan the ceremony

-plant a tree together in remembrance

-leave a special piece of jewelry

-write a special letter to your loved ones

-designate a special place where they can go to talk to adult

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