

The Road to Transition

Your Life with Congenital Heart disease



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This Workbook Belongs to:

This workbook contains general information and advice relating to congenital heart disease and is provided for educational purposes only. It is not intended to replace personalized medical advice and should be used to inform patients and supplement the regular care of a physician. We strongly recommend that you consult with your doctor about questions and concerns specific to your heart health. The author and publisher expressly disclaim responsibility for any adverse effects that may result from the use or application of the information contained in this workbook.

**Written by Heather Anderson and Jamie Gulick, co-founders of the 2HEARTS organization.
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The Road to Transition

This workbook was designed to support pre-teens and young adults living with congenital heart disease through the medical transition process. We at 2HEARTS think it's important that you experience a fluid and fruitful move from pediatric-focused to adult-focused health care.

This workbook is truly about you and your journey. You are more than your congenital heart disease and it is only fair that you understand your medical history and that your medical care team understand you as a person.

Filling these pages can be an exciting journey, so be attentive about everything new you are learning or discovering as you write your story. Not all questions will apply to you personally, so feel free to disregard whatever items you need to.

This workbook is an opportunity to uncover your inner power as you take charge of your future.

Only you can be the expert on you.

Enjoy the journey and congratulations!

2HEARTS would like to acknowledge Dr. Laura Pickler and her previous work in transition, which inspired this workbook. We would also like to thank Dr. Jeremy Nicolarsen, Dr. Joseph Kay & Dr. Liz Yeung for their valuable contributions.

The price of greatness is responsibility.

-Winston Churchill

Fun (& Good) to Know

What is congenital you ask?

CONGENITAL (con-gen-i-tal) A disease or physical abnormality present from birth. Having a particular trait at birth.

Why is that important, you wonder?

Because as you grow up and gain independence you will start making very important decisions about your medical care team. When picking a doctor, always remember that it's not advisable to go to any ole adult cardiologist. You should pick a doctor who is an Adult CONGENITAL Cardiologist. Be sure to refer to page 14 of this workbook when interviewing perspective Adult Congenital Cardiologists.

Is that it, you say?

No, just one more thing - be sure to tell all the other doctors you may have that you have congenital heart disease. It's important for them to know and they will be grateful you told them.

Yup, they have it too.

Celebrities with congenital heart disease

Shaun White - American professional snowboarder, skateboarder and a two-time Olympic gold medalist. **Tetralogy of Fallot**

Lauren Cheney - Soccer player on the USA Olympic Team. **Atrial Septal Defect**

Aaron Boone - Professional baseball player, Houston Astros. **Bicuspid Aortic Valve.**

Joe Ziegler - Lead singer in the band Leftmore and shoe designer. **Aortic Valvular Stenosis**

Bret Michaels - Lead singer in the band Poison and TV Host. **Atrial Septal Defect.**

Jesse J - Singer/Pop Star. **Wolff-Parkinson-White syndrome**

Brian Littrell - Singer in the band Backstreet Boys. **Ventricular Septal Defect.**

Robby Benson - TV & Film Writer/Director/Producer. **Bicuspid Aortic Valve.**

Mark O'shea - Country music singer. **Tetralogy of Fallot**

John Fox - NFL, Broncos head coach. **Bicuspid Aortic Valve.**

My Family

My

Parent: _____ Phone# _____

Work/Home# _____

Parent _____ Phone# _____

Cell# _____

Guardian _____ Phone# _____

Cell# _____

Other Important Family:

Name: _____ Phone# _____

Name: _____ Phone# _____

Name: _____ Phone# _____

Name: _____ Phone# _____



Just in Case - My Heart Team

The name of my defect/s or diagnosis is:

Brief Description (in your words):

My medications:

Name: _____
(Dosage) _____ For _____

Name: _____
(Dosage) _____ For _____

Name: _____
(Dosage) _____ For _____

Name: _____
(Dosage) _____ For _____

Name: _____
(Dosage) _____ For _____

(If you do not know, please ask your parent or doctor and find out)

Just In Case - The Facts

I have had _____ surgeries

Dates, names and locations of those surgeries:

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____
- 6) _____
- 7) _____

My Allergies:

If I am exposed to something I am allergic to, I: _____

Name of my cardiologist: _____

Phone # _____ Email _____

Name of my cardiologist's PA/NP: _____

Nurse: _____

Phone # _____ Email _____

Name of my primary care provider: _____

Phone # _____ Email _____

My hospital: _____ Patient ID #: _____

Hospital Phone # _____

Name of my surgeon: _____

Phone # _____ Email _____

Name of my transplant coordinator (if applicable): _____

Phone # _____ Email _____

Name of my social worker: _____

Phone # _____ Email _____

My other Doctors:

Name: _____ Phone # _____

Email _____

My other Doctors (cont:)

Name: _____ Phone # _____

Email _____

Name: _____ Phone # _____

Email _____

I have the following implanted devices (if applicable):

My device needs to be checked every _____ months.

To get it checked I have to _____

Nearest Urgent Care/Emergency Department: _____

Phone# _____

Other important people I should remember:

My Story

My favorite things to do/hobbies are:

Right now, my favorite

Song/Band: _____

The runner up: _____

Movie: _____

The runner up: _____

Book: _____

The runner up: _____

TV Show: _____

The runner up: _____

Sport: _____

The runner up:

**Pro
Team/Athlete:** _____

The runner up:

When I am really hungry, my favorite meal is:

My favorite subject in school is:

In five years I see myself:

In college, I would love to study and learn about:

When I'm an adult I would like to:

I am truly unique because of:

What I think is totally awesome about myself is:

The first time I was told or realized I had heart disease, I was:

Something interesting I would like my future new cardiologist to know about me:

"The greater the obstacle, the more glory in overcoming it."

My Smile

Dental care is very important to everyone, especially for those living with congenital heart disease. It is recommended that you brush and floss twice a day and visit the dentist twice a year.

Before a dental appointment, some people are required to take an antibiotic. You may hear your provider call this "prophylaxis" or "SBE prophylaxis". These antibiotics can help prevent endocarditis, a bacterial infection that spreads through the bloodstream and may damage the heart. It is very important to understand the seriousness of endocarditis as it can harm or kill a congenital heart patient who has otherwise been thriving.

People at greatest risk of endocarditis have damaged or artificial heart valves or complex congenital heart defects. Please consult your cardiologist to find out if you need to take antibiotics before your dental appointments.

The name of my dentist: _____

Phone# _____ Email _____

The name of my pre-medication:

I take my pre-medication before a dental appointment.

YES _____ NO _____ NOT SURE _____

Tattoos and Piercings may also require pre-medication. Please consult your cardiologist before making your appointment. It's a very simple step before adding a colorful piece of artwork to your skin.

Please sign the agreement below if you answered "YES" above.

I fully understand that good dental hygiene and taking an antibiotic before a dental appointment (or receiving a tattoo or piercing) is essential and I promise to do so from now on.

Sign _____ Date _____

My Truth

Having a heart defect worries me because:

Some of the good things about having a heart defect are:

Going to a new adult congenital cardiologist worries me because:

I'm nervous and/or excited about taking responsibility of my heart health because:

I know it is normal to feel a little depressed at times and when I do I like to talk to:

So far I have met _____ others who are living with congenital heart disease and the experience has been:

Courage is what it takes to stand up and speak; courage is also what it takes to sit down and listen.
-Winston Churchill

Taking Charge

“Responsibility is the price of freedom.”

-Elbert Hubbard

Just like every single person living with congenital heart disease, it's important to learn all you can about your future heart care.

Here are some questions you should ask your pediatric cardiologist and your adult congenital cardiologist at your next visit.

They get to learn all about you, you deserve to learn about them.

- #1 *Where did you train/go to medical school to become a cardiologist?*
- #2 *How many of your patients are young adults?*
- #3 *How many of your patients have my diagnosis?*
- #4 *In my case why is it important that I follow up with an adult congenital cardiologist?*
- #5 *Can young kids go to adult congenital cardiologists?*
- #6 *Who do I call if I am not feeling well, but it's not an emergency?*
- #7 *How often should I visit you each year?*
- #8 *How often will I need to have an XRAY? Echo? EKG? Blood work?*
- #9 *When or if I need it, can you advise me on birth control?*
- #10 *When or if I need it, can you advise me if I start to feel sad, depressed or frustrated with my heart disease?*

Make It Fun Too

Your doctor is just like you. He or she has a story and hobbies. Ask them some fun questions. It's a great way to bond with your caretaker - plus it makes doctor visits much more comfortable.

Find out your doctor's

- Favorite Color: _____
- Favorite Food: _____
- Favorite Song: _____
- Favorite Book: _____

And most importantly, what does he or she love most about his/her career?

Grown-up Responsibilities

Currently, what I understand about health insurance is:

The reason health insurance is so important for a person like me is because:

Right now my health insurance is:

It's not set in stone yet, but after discussing it with my family, I plan to obtain health insurance in the future by:

Nutrition and Exercise

Exercise is important for all people, especially people living with congenital heart disease.

For exercise I like to:

Some limitations I have are:

Eating healthy is great for the heart. Plenty of fruits, vegetables, and lean meats should be a part of everyone's diet.

I know I should limit my intake of:

Just So You Know

Visiting your doctor regularly is the key to staying healthy, and when you are healthy the world is your oyster.

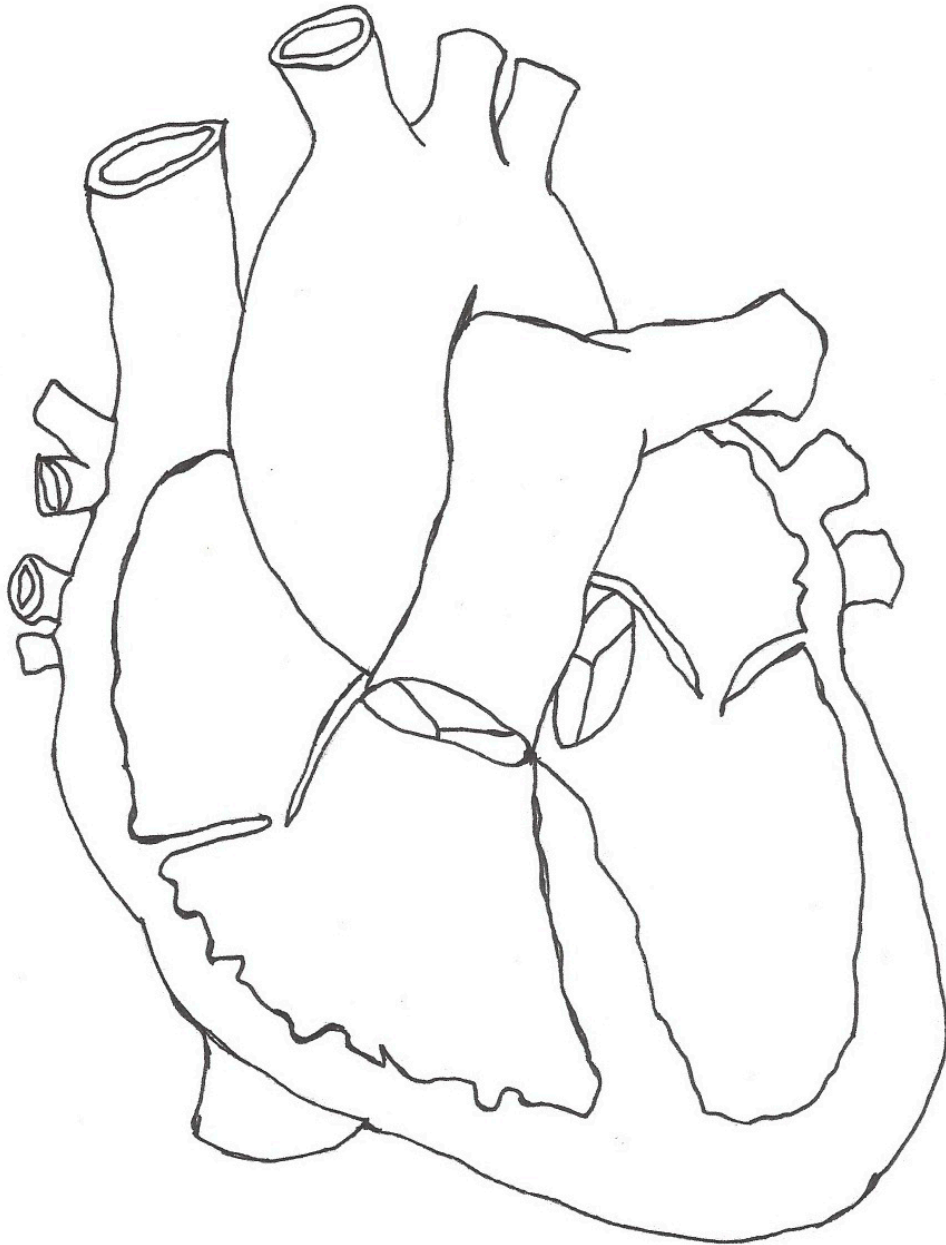
If I miss a doctor's appointment, I should:

If I forget to take my medication, I should:

Storing your medical records on a thumb drive or an online registration service is highly recommended so that you can access your information easily and share it with your new doctors. You may also keep your records in a paper binder, but digital record-keeping takes up less space and is easily carried around. Doctors heavily rely on medical records so that they can better assess your current health and care plan. If you have them, it's helpful to keep procedure/surgery reports, MRI/echo/stress test reports, discharge summaries. Your doctors are good at finding this information, so don't be upset if you don't have old documents. Try to keep some of these as you go forward.

I plan to store my medical records by:

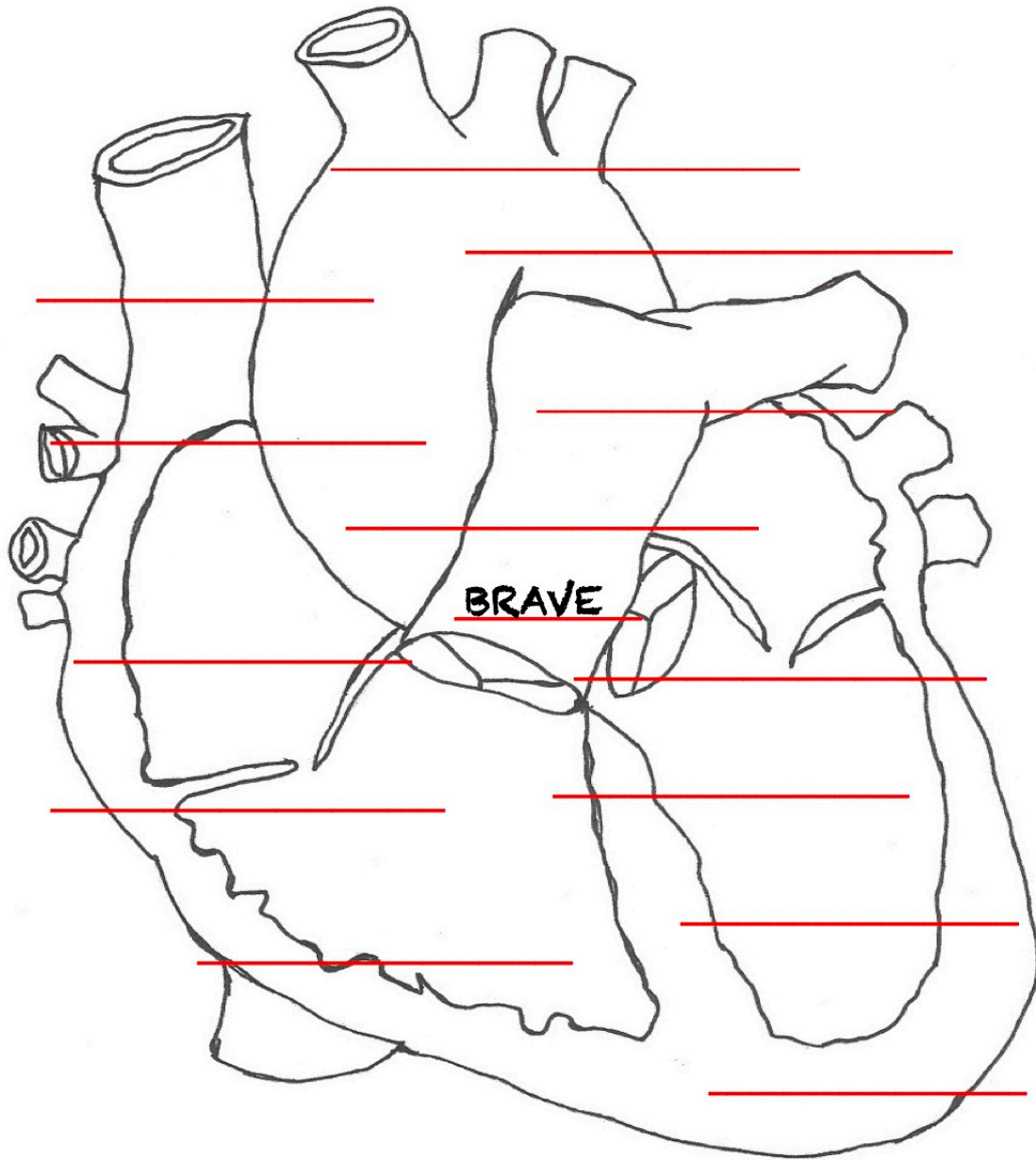
How My Heart Works



At your next cardiology visit, please have your doctor draw your heart's correct anatomy within this diagram.

If you are already familiar please mark the differences your heart has on this diagram.

I am



Please write down all the wonderful qualities about yourself that come from your heart

My Workshop/Camp

Connections & Friends:

1) Name: _____ Phone: _____

Email: _____

2) Name: _____ Phone: _____

Email: _____

3) Name: _____ Phone: _____

Email: _____

4) Name: _____ Phone: _____

Email: _____

5) Name: _____ Phone: _____

Email: _____

6) Name: _____ Phone: _____

Email: _____

7) Name: _____ Phone: _____

Email: _____

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Last minute thoughts & ideas

Thank you for sharing.

This workbook was brought to you by



WHO IS 2HEARTS?

2HEARTS is a nonprofit organization founded by two adults living with congenital heart disease. Having experienced the challenges of growing up with heart disease, the founders felt the road to independence could be smoother and safer.

The journey to adulthood is more complicated for those living with heart defects, so 2HEARTS' main goal is to guide a tween/teen through the gauntlet of responsibilities it takes to create a strong, active, and successful life.

For more information please visit: www.2-hearts.org



To request more workbooks please email info@2-hearts.org or call (720) 263-2593

The mission of 2HEARTS is to provide an open and supportive environment for children and young adults with congenital heart disease and their families. 2HEARTS aims to minimize the emotional burden on the CHD youth by educating and supporting their journey from childhood to adulthood.

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