



Taking Care of You and Your Heart: What *You* Need to Know



Seattle Children's
HOSPITAL · RESEARCH · FOUNDATION



Adolescent and Young Adult (AYA)
Heart Center Booklet

Contents

I. About this booklet

Letter from the Heart Center

Contributing authors

II. Keeping track of my health

My medical treatment

Appointments, health changes and questions log

III. Learning about my heart

Preparing for Your Heart Surgery

Your Scar After Heart Surgery

Life After Heart Surgery

Heart Disease, Sexuality and Social Pressure

Heart Diagrams

IV. Journal Pages

About This Booklet

.....

.....

About this booklet

Welcome to the Seattle Children's Heart Center Handbook for adolescents and young adults with heart disease. Living with heart disease and having procedures on your heart can be frightening, and we hope that this handbook will help answer a few of your questions and address a few of your concerns about your heart.

This handbook was put together by people just like you – adolescents and young adults who have personally experienced many of the same feelings and events that have been a part of your life. We hope you will find the content useful. And we hope that it will help you see that, although life with heart disease can feel pretty overwhelming at times, especially when talking about surgery or other procedures, it can also be really rewarding and truly unique.

Let us know what you think if you have time. Like it says above, this material would not be possible without people just like you.

Contributing Authors:



Katie Kemp

Katie, age 18, has Hypertrophic Cardiomyopathy. She received an Implantable Cardioverter Defibrillator (ICD) at the age of 15 after having a sudden cardiac arrest in gym class. She is a high school senior and will be attending the University of Washington in the fall of 2012. In her free time she enjoys reading and dancing.



Brady Thompson

Brady age 18, has Tricuspid Atresia, Atrioventricular Septal Defect, and, ironically as he says, Bradycardia. He had three open heart surgeries when he was a child and has had a pacemaker since he was three years old. In the winter he loves to go bowling and skiing, and enjoys swimming and knee boarding at his lake cabin over the summer months.



Kelsey Stamnes

Kelsey, age 17, had open heart surgery at the age of 15 to correct a congenital defect called Partial Anomalous Pulmonary Venous Return (PAPVR). She currently takes a daily medication to control a condition she developed after surgery called Chronic Pericarditis. She loves to stay active, so she practices yoga, ski races competitively for Crystal Mountain, and is involved with activities at her high school.



Lisa Giamberso

Lisa, age 21, had an Arterial Switch at when she was 6 days old to correct Transposition of the Great Vessels. Lisa is now a sophomore at the University of Oregon and loves to hike, dance, and is excited to study abroad in South America next year!



Raegan Young

Raegan, age 17, was born with a double outlet right ventricle (DORV) deficiency as well as several other cardiac complications. She had open heart surgery as an infant as well as another open heart surgery in 7th grade to remove scar tissue that was interfering with the pumping of her heart. Raegan attends Mercer Island High School and loves to sing, dance, play the trumpet and volunteer.

About this booklet

Keeping Track of My Health

.....

.....

My Medical Treatment

My history

Date I was diagnosed

Other important information

Allergies

Adverse reactions or events

Explain if you had to go to the hospital for these, and if your healthcare provider changed your medicine dose because of it.

Where I got treatment

Surgery

Where my surgery took place

Address

Phone contact

Medical Record Number

Medical Treatment

My healthcare team

My social worker's name
and phone number:

My nurse or nurse
practitioner's name and
phone number

My cardiologist's name and
phone number

My surgeon's name and
phone number

My nutritionist's name and
phone number

Other team members and
contact information

Local pharmacies

Pharmacy

Phone

Address

Pharmacy

Phone

Address

Medical Treatment

My surgeries and procedures

It is best to keep copies of records, especially:

- Discharge summary (after surgery) and all operative report
- Cardiac cath reports and your most recent clinic visit summary
- Echo reports, EKG's, Cardiac testing such as exercise testing and Holter monitors
- Any other related documents such as cardiac MRI's, CT scans, pacemaker checks

Surgery/procedure date _____

Kind of surgery/procedure
I had _____

Person who did the
surgery/procedure _____

Any problems with
surgery/procedure _____

Surgery/procedure date _____

Kind of surgery/procedure
I had _____

Person who did the
surgery/procedure _____

Any problems with
surgery/procedure _____

Medical Treatment

Surgery/procedure date

Kind of surgery/procedure
I had

Person who did the
surgery/procedure

Any problems with
surgery/procedure

Surgery/procedure date

Kind of surgery/procedure
I had

Person who did the
surgery/procedure

Any problems with
surgery/procedure

Surgery/procedure date

Kind of surgery/procedure
I had

Medical Treatment

Person who did the surgery/procedure

Any problems with surgery/procedure

Surgery/procedure date

Kind of surgery/procedure I had

Person who did the surgery/procedure

Any problems with surgery/procedure

Medical Treatment

My medicines

Print out as many pages of these as you need. There are extra sheets that you can print at www.seattlechildrens.org.

Do I need medicine before dental work? Yes No

Medicine name _____

How I take this medicine _____

Dose that I get each time: _____

Medicine name _____

How I take this medicine _____

Dose that I get each time: _____

Medicine name _____

How I take this medicine _____

Dose that I get each time: _____

Medical Treatment

Do I need medicine before dental work? Yes No

Medicine name

How I take this medicine

Dose that I get each time:

Medicine name

How I take this medicine

Dose that I get each time:

Medicine name

How I take this medicine

Dose that I get each time:

Medicine name

How I take this medicine

Dose that I get each time:

Medical Treatment

Do I need medicine before dental work? Yes No

Medicine name

How I take this medicine

Dose that I get each time:

Medicine name

How I take this medicine

Dose that I get each time:

Medicine name

How I take this medicine

Dose that I get each time:

Medicine name

How I take this medicine

Dose that I get each time:

Medical Treatment

Medicines I take for
side effects (nausea,
constipation, etc.)

Medical Treatment

Blood tests

Dates and results of any blood testing:

Date	Test	Result
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Medical Treatment

Notes

Multiple horizontal lines for writing notes.

Appointment, health changes and questions log

This is a place to list appointments you have had, changes in your health, or any questions you have for your healthcare team so you don't forget what you needed to ask. It can be helpful to find patterns about how these changes might be related to your treatment. If you need more pages, you can print out extra copies of these sheets from the website at www.seattlechildrens.org. To get to the Adolescent and Young Adult, search for "AYA Heart Center" from the main page.

Date

Appointment (for what? with who? any important things to note), changes to your health (physical, emotional or both), or any questions that you want to ask your healthcare team.

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Appointment, health changes and questions log

Date

Appointment (for what? with who? any important things to note) or changes to your health (physical, emotional or both)

Appointment, health changes and questions log

Date	Appointment (for what? with who? any important things to note) or changes to your health (physical, emotional or both)
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Appointment, health changes and questions log

Date

**Appointment (for what? with who? any important things to note) or
changes to your health (physical, emotional or both)**

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Learning About My Heart

.....

.....

Journal Pages

.....

.....

Journal

You can use these pages to write down any thoughts or feelings you are having. You can also use them for notes or whatever else you would like.

