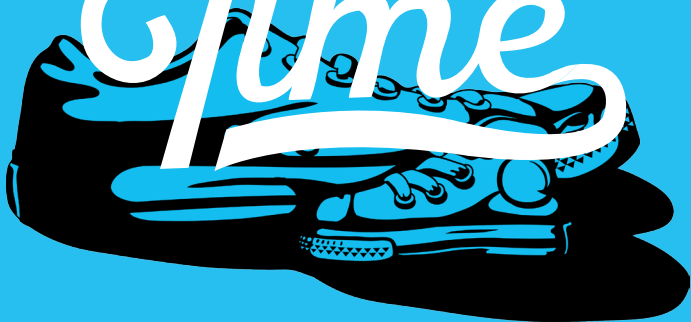




**Boston Children's Hospital**  
Until every child is well™

# One Step at a Time



**Your Guide to Making the Move from  
Pediatric to Adult Care**

written by the Teen Advisory Committee

# Read This!

**This guide was created to help teens and young adults in their transition from pediatric to adult care providers. We know that this move can be scary and confusing, so we wanted to help make the process a little easier by giving some tips and tricks.**

**The Teen Advisory Committee has been working on this project for the last few years (while adding a few side projects along the way). To create the content for this guide, we drew upon the lessons we learned from interviews with doctors, nurses and other medical professionals in pediatric and adult care settings. We also reviewed a multitude of transition guides available from other hospitals and organizations.**

**This tool is meant to serve as a guide, not as a list of rules. We hope it helps you on your journey.**

**Best of luck,  
Members of the Teen Advisory Committee**

# **ABOUT THE TEEN ADVISORY COMMITTEE**

FORMED IN 2002, THE TEEN ADVISORY COMMITTEE (TAC) CONSISTS OF MORE THAN 20 ADOLESCENTS AND YOUNG ADULTS RANGING IN AGE FROM 14 TO 22 YEARS OLD WHO RECEIVE CARE AT BOSTON CHILDREN'S HOSPITAL. MEMBERS OF THE TAC SIT ON HOSPITAL-WIDE COMMITTEES AND GIVE ONGOING INPUT ON SPECIFIC PROJECTS. OUR ROLE IS TO REPRESENT THE ADOLESCENT PERSPECTIVE.

SOME OF THE WORK WE'VE DONE INCLUDES:

- QUALITY IMPROVEMENT PROJECTS
- ADVOCATING FOR SPECIFIC LEGISLATION
- HOSPITAL AND INTERNATIONAL PRESENTATIONS ON TRANSITION OF CARE
- CREATION OF VIDEOS FOR ADOLESCENT PATIENTS ON PREPARING FOR INPATIENT AND OUTPATIENT VISITS

TO LEARN MORE ABOUT THE TEEN ADVISORY COMMITTEE, PLEASE VISIT [WWW.CHILDRENSHOSPITAL.ORG/TAC](http://WWW.CHILDRENSHOSPITAL.ORG/TAC).



# TABLE OF CONTENTS

2 WHEN DOES IT HAPPEN?

4 HAVING THE CONVERSATION

6 EVERYONE'S ROLE

8 FINDING SUPPORT

10 GETTING ORGANIZED

12 MAKING IT WORK

14 ADDITIONAL RESOURCES

16 TOOLS YOU CAN USE

# WHEN DOES IT HAPPEN?

TRANSITIONING TO AN ADULT CARE PROVIDER DOESN'T HAVE A SET TIME FRAME; HOWEVER, THE PROCESS TYPICALLY STARTS IN YOUR TEEN YEARS (IF IT HASN'T YET, DON'T WORRY!). THE DECISION TO TRANSITION SHOULD BE BETWEEN YOU AND YOUR PEDIATRICIAN. YOU SHOULD FEEL COMFORTABLE ENOUGH WITH YOUR CURRENT SITUATION TO BE ABLE TO MANAGE YOUR OWN HEALTH CARE. IT'S A GOOD IDEA TO START PLANNING YOUR TRANSITION WHILE YOU ARE IN HIGH SCHOOL AND STILL HAVE A SAFETY NET. THAT WAY AFTER GRADUATION, YOU'LL ALREADY HAVE EXPERIENCE WITH INDEPENDENTLY MANAGING YOUR HEALTH CARE.



HOME



WORK

TRAVEL

COLLEGE



# ARE YOU READY TO TRANSITION?

1 CAN YOU DESCRIBE YOUR **MEDICAL CONDITION** TO SOMEONE ELSE?

2 DO YOU KNOW THE MEDICATION AND/OR EQUIPMENT YOU USE TO **MANAGE YOUR CONDITION**?

3 DO YOU **RELY ON YOUR PARENTS** TO SPEAK FOR YOU WHILE MEETING WITH DOCTORS?

4 CAN YOU **SET UP AN APPOINTMENT** BY YOURSELF?

5 DO YOU UNDERSTAND **HOW INSURANCE WORKS** AND HOW IT AFFECTS YOU?

# HAVING THE CONVERSATION

Today 12:07 PM

So, Dr. \_\_\_\_\_, I would like to talk to you about the process of transitioning. I've been with you for \_\_\_\_\_ years and I would like to know if you think it is time for me to move on to an adult provider.



It's a whale.

Delivered



Send

# WHAT KIND OF ADULT PROVIDER DO I WANT?



Female



Male



Location

# WHAT SHOULD I ASK MY CURRENT DOCTOR?

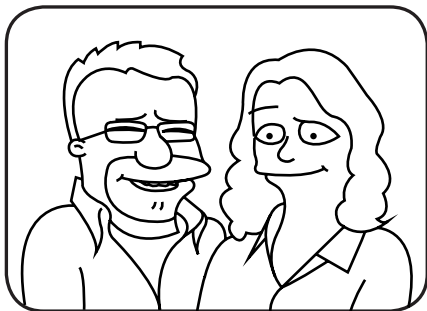
- RECOMMENDATIONS OF REPUTABLE ADULT PROVIDERS
- STEPS TO FINDING A NEW ADULT DOCTOR
- HOW TO TRANSFER MEDICAL RECORDS
- MATERIALS NEEDED FOR FIRST APPOINTMENT WITH ADULT DOCTOR
- INFORMATION TO PROVIDE TO SCHOOL OR JOB ABOUT DIAGNOSIS

# EVERYONE'S ROLE



## YOU

TAKE INITIATIVE BY MAKING YOUR APPOINTMENTS. KNOW THE TYPE OF INSURANCE YOU HAVE, THE MEDICATIONS YOU TAKE, THE ALLERGIES YOU HAVE AND YOUR FAMILY HISTORY. HAVE ONE-ON-ONE TIME WITH YOUR PROVIDERS (WITHOUT YOUR PARENTS).



## YOUR PARENTS/ GUARDIANS

REMIND YOUR PARENTS/GUARDIANS THAT TRANSITIONING DOESN'T HAPPEN OVERNIGHT. THEY SHOULD EDUCATE YOU ABOUT YOUR HEALTH CONDITION AND HISTORY. THEY SHOULD BE PROUD OF YOU FOR TAKING THE INITIATIVE TO MANAGE YOUR OWN HEALTH CARE, AND SHOULD SUPPORT YOU THROUGH THIS PROCESS.



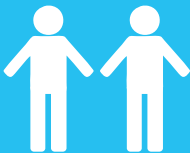
## **PROVIDER**

YOUR PEDIATRIC HEALTH CARE PROVIDER SHOULD START THE CONVERSATION ABOUT TRANSITION WITH YOUR FAMILY. HE OR SHE SHOULD START TALKING DIRECTLY WITH YOU DURING APPOINTMENTS AND HELP YOU TO FIND THE RIGHT ADULT CARE PROVIDER WHEN YOU ARE READY.

## THINGS TO DO

- MAKE SURE RECOMMENDED PROVIDER IS IN YOUR HEALTH INSURANCE NETWORK
- SCHEDULE INFORMATIONAL INTERVIEWS WITH ADULT CARE PROVIDERS
- WHEN MAKING AN APPOINTMENT, ASK STAFF:
  - WHAT TO BRING
  - HOW LONG APPOINTMENTS TYPICALLY LAST
  - FOR DIRECTIONS
  - IF THERE IS A PATIENT PORTAL
- BRING MEDICAL RECORDS TO APPOINTMENT, IF NEEDED

# FINDING SUPPORT FOR YOUR FIRST APPOINTMENT



It is personal preference whether you want a support person at your first adult care appointment. Here are some options to consider:



HAVE A SUPPORT PERSON AVAILABLE TO YOU BY PHONE, OR ASK HIM OR HER TO WAIT IN THE WAITING ROOM

2

ASK YOUR SUPPORT PERSON IF THERE'S ANYTHING THEY THINK YOU SHOULD BRING UP DURING YOUR APPOINTMENT

3

TRY TO ANSWER ALL QUESTIONS YOURSELF AND HANDLE THE APPOINTMENT ON YOUR OWN AS MUCH AS POSSIBLE

# PLAN AHEAD

S	M	T	W	T	F	S
12	13	14	15	16	17	18

- KNOW AS MUCH AS POSSIBLE ABOUT YOUR MEDICAL HISTORY (E.G. PAST PROCEDURES, MEDICAL EQUIPMENT).
- FIND OUT HOW TO SEND YOUR MEDICAL HISTORY TO YOUR NEW PROVIDER A FEW WEEKS IN ADVANCE.
- ASK HOW LONG THE FIRST APPOINTMENT WILL BE.
- GET TO YOUR APPOINTMENT EARLY TO AVOID MISSING IT AND TO ALLOW FOR TIME TO FILL OUT FORMS.
- BE SURE TO CHECK IN AT THE FRONT DESK AND SHOW YOUR INSURANCE CARD/PAY A CO-PAY.

Today

Calendars

Inbox

# GETTING ORGANIZED BEFORE YOUR FIRST APPOINTMENT

IT MAY BE HELPFUL TO HAVE A WRITTEN LIST OF THINGS YOU WANT TO COVER DURING YOUR APPOINTMENT, BUT DON'T FEEL LIKE YOU NEED TO STICK TO A SCHEDULE.

## HELLO

my name is

- LIST OF MEDICATIONS YOU ARE TAKING
- ANY SUPPLIES/EQUIPMENT YOU USE
- ANY URGENT OR MAJOR CONCERNS YOU MAY HAVE GOING ON (FOR EXAMPLE: HOW TO GET REFILLS OF MEDICINE, SUPPLIES SENT TO YOU, ETC.)
- BASIC OUTLINE OF YOUR MEDICAL HISTORY
- HOW YOU BEST LEARN INFORMATION



# HELPFUL TIPS



DON'T BE AFRAID TO ASSERT YOURSELF AND ASK FOR HELP.



SPEAK UP AND ASK AS MANY QUESTIONS AS YOU NEED (FOR EXAMPLE: DON'T BE AFRAID TO SAY THAT AN APPOINTMENT TIME ISN'T GOOD FOR YOU OR ASK FOR DIRECTIONS).



KNOW THE OFFICE HOURS JUST IN CASE YOU HAVE AN URGENT QUESTION OR CONCERN.



DON'T FORGET TO CHECK OUT AND MAKE A FOLLOW UP APPOINTMENT BEFORE YOU LEAVE.

# MAKING IT WORK



BUILDING A NEW RELATIONSHIP CAN BE SCARY, ESPECIALLY WITH A NEW DOCTOR. HERE ARE SOME WAYS TO BUILD A BETTER RELATIONSHIP:

- TALK ABOUT IT WITH SOMEONE YOU TRUST.
- KEEP AN OPEN MIND.
- GIVE TIME FOR THE RELATIONSHIP TO DEVELOP.
- TALK TO YOUR NURSE PRACTITIONER OR PHYSICIAN'S ASSISTANT. THEY WILL BE WORKING CLOSELY WITH YOUR DOCTOR AND CHECKING IN WITH YOU DURING APPOINTMENTS.
- LET YOUR NEW DOCTOR KNOW WHAT MAKES YOU FEEL COMFORTABLE AND UNCOMFORTABLE.

Like · Comment · Share

IF YOU STILL ARE NOT SATISFIED WITH YOUR NEW CARE PROVIDER, ASK YOURSELF THESE QUESTIONS:

- SHOULD I GIVE IT MORE TIME?
- WHAT IS IT SPECIFICALLY I DO NOT LIKE?
- DID I TELL MY DOCTOR HOW I BEST TAKE IN INFORMATION?
- AM I ABLE TO UNDERSTAND WHAT THE DOCTOR IS TELLING ME?
- DO I HAVE THE OPPORTUNITY TO ASK QUESTIONS?

[Like](#) · [Comment](#) · [Share](#)

REMEMBER, NOT EVERY FRIENDSHIP WORKS OUT IN THE END. IF YOU HAVE GIVEN IT TIME AND YOU ARE STILL GETTING NOWHERE, YOU SHOULD CONSIDER FINDING A NEW ADULT PROVIDER.

# ADDITIONAL RESOURCES



BOSTON CHILDREN'S HOSPITAL'S  
TEEN RESOURCES

[www.childrenshospital.org/patient-resources/teen-resources](http://www.childrenshospital.org/patient-resources/teen-resources)



TIPS FOR TEENS  
VISITING THE HOSPITAL

[www.childrenshospital.org/patient-resources/teen-resources/tips-for-teens](http://www.childrenshospital.org/patient-resources/teen-resources/tips-for-teens)



## CHILDREN'S MEDICAL SERVICES: HEALTH CARE TRANSITION GUIDE FOR YOUNG ADULTS

[www.region10.org/r10website/assets/File/whenyouare18brochure.pdf](http://www.region10.org/r10website/assets/File/whenyouare18brochure.pdf)



## HEALTH EDUCATION RESOURCE EXCHANGE: YOUR LIFE, YOUR HEALTH, YOUR WAY

<http://here.doh.wa.gov/materials/life-health-way>



## GOT TRANSITION?

[www.gottransition.org](http://www.gottransition.org)



## PENNSYLVANIA DEPARTMENT OF PUBLIC HEALTH: TRANSITION HEALTH CARE CHECKLIST

[www.pbsd.k12.pa.us/Downloads/healthcare-checklist.pdf](http://www.pbsd.k12.pa.us/Downloads/healthcare-checklist.pdf)

# TOOLS YOU CAN USE

## CURRENT LIST OF HEALTH CARE PROVIDERS

Name	Specialty

# of years you've worked with MD	Contact Information

# DISEASE NAME AND SYMPTOMS

Disease Name



Symptoms

# SURGICAL HISTORY

Date (oldest first)	Surgery	Surgeon

Cause	Other Details

# MY MEDICATIONS

Name of Medicine	Why do you take it?	Dose

How many times do you take per day?	When do you take it? (morning, noon, night)	Name of doctor who prescribed medicine

# ALLERGIES

Allergy (for example: food, medicine, etc)	Type of reaction (for example: trouble

e breathing, swelling, rash, etc.)	Years that you've had allergy (if known)

# MEDICAL EQUIPMENT

Type of equipment	Prescribing doctor's name



Prescribing doctor's contact information	Special instructions/ details

# INSURANCE (SUCH AS MEDICAL, DENTAL, MENTAL H

Name of Insurance	Member ID

Insurance Policy Details: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# HEALTH, VISION OR PRESCRIPTION)

Deductible/Copay	Contact information

---

---

---

---

---



**Boston Children's Hospital**

Until every child is well™

## **Teen Advisory Committee**

Hale Family Center for Families

Boston Children's Hospital

300 Longwood Avenue, Boston, MA 02115

[TeenAdvisory@childrens.harvard.edu](mailto:TeenAdvisory@childrens.harvard.edu)

[childrenshospital.org/tac](http://childrenshospital.org/tac)

Special thanks to the Boston Children's Hospital League for its fiscal support of the Teen Advisory Committee

