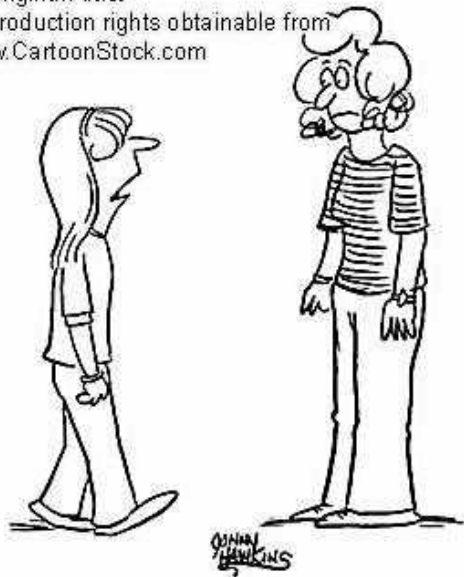


Understanding Health Care Transition

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search ID: jhan410

"Don't call me a teenager. From now on, I want to be referred to as a pre-adult."

Parag Shah, MD, MPH
Medical Director, Chronic Illness
Transition Team
Lurie Children's Hospital
Chicago, IL

Disclosures

- I work as a physician at Ann and Robert H. Lurie Children's Hospital of Chicago, and I have no financial or commercial disclosures relating to this presentation.

Objectives

- **What do we mean by “Transition”**
- **Some facts, challenges, barriers**
- **What can you do to help prepare**
- **Tips and Resources**



Transition Is Exciting

- Independence
- Less Mom and Dad
- People talk directly to you
- People give you more responsibility



Transition Is Scary



- Independence
- Less Mom and Dad
- People talk directly to you
- People give you more responsibility

SELF ADVOCACY



Fancy Transition Definition

HEALTH CARE TRANSITION

“the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”

(AAP Clinical Report 2011)¹

SOME FACTS ABOUT TRANSITION

- 12-20% of youth in IL are thought to have special health care needs
- Over 90% of youth with chronic illnesses survive into their 20's
- Outcomes including clinical markers (HgbA1c etc.), utilization, and morbidity and mortality increase during the transition period
- A systematic preparation leads to better clinical outcomes (adherence, hospitalizations, clinical markers etc.)
- High priority for IOM. MCHB, AAP, AAFP etc.
- Most make this transition without systematic preparation
 - Only 16% of children claim transition services discussed explicitly
 - 60% of parents with YSHCN reported not receiving necessary services to make appropriate transitions
 - Less than 50% of pediatricians report assisting in transition of CYSHCN most of the time
 - (CMH) 11% with portable medical summaries, 23% with adult care plan



*American Academy of Pediatrics. Survey: Transition Services Lacking for Teens with Special Needs. *AAP News*. Vol 30; 2009.

Issues

■ Pediatric Providers have reported

- Lack of adult physicians who are willing and have knowledge of pediatric conditions
- Poor reimbursement
- Their own reluctance

● Adult Providers have reported

- Lack of training
- Difficulty meeting psychosocial needs
- Lack of time and reimbursement
- Lack of coordinated transfer from pediatric practices

● Families and Patients have reported

- Differences in culture between pediatric and adult health care models
- Nervousness about going to somebody that “doesn’t know anything about me”





Pediatric vs Adult Life

Pediatric

- Developmental Focus
- Checkups important
- Ask you about your needs

Adult

- Job Functioning Focus
- Self checking important
- You ask about your needs



Pediatric vs Adult Health Care

Pediatric

- Provider & parent controlled
- Comprehensive, multi-disciplinary clinics (one-stop-shopping)
- Case management & social work support
- Families supported through process

Adult

- Patient responsible
- Multiple providers each caring for separate issues
- Less social work or case management assistance
- Patient must be proactive to get services

When Should Transition Begin?

- Ages 11-13
- Youth most receptive to future planning
- Less gap between peers



What To Ask Your Pediatric Providers

Transition policies

- Timeline
 - Initiation
- Outcomes
 - What should the youth know and do before they leave my office
- Transfer
 - Practice processes
 - Communication

PREPARING YOURSELVES

- Knowledge/Skills/Responsibility
- Finding Adult Doctors
- College/Work
- Health Insurance
- Guardianship
- Financial Planning/Benefits
- Transportation
- Recreation
 - Community participation has strong association with successful transition



Use A Checklist

elect Flowcharts to View

MMC TRANSITION PLANNING [58]

Transition Planning	4/8/2013
formant	Parent alone
owns the name of all major conditions	Y
an explain each of the conditions in 3 sentences or less	Y
an explain physical and cognitive limitations and disabilities	Y
owns the names of medications	Y
owns the purpose of each medication	Y
owns the name of each specialist provider	Y
owns the basic function of each specialist provider	Y
owns any activity/behavior limitations	Y
owns a med-alert bracelet (conditions, allergies)	N
akes appointments independently	Y
owns where to go for emergency care	Y
/here?	Concerned about emergency transition
omfortable making major medical decisions	Y
ommunicates independently during visit	Y
owns when to take medications	Y
akes medication independently	Unable
urrently compliant with medical treatment	Y
atient/family have arrangements for living?	Y
/hat are they?	With family
atient/family have arrangements for finances	Y
/hat are they?	SSI and should continue
atient/family have arrangements for education/vocation	Y
/hat are they?	School until 22
atient/family have arrangements for recreation	Y
/hat are they?	Through school
ssessed need for guardianship	Recommended
itiated discussion about eventual transfer to adult care	Y
iscussed plan for adult primary care	Y
iscussed plan for adult specialty care	Y
nderstands their insurance	Y
as adult insurance (or plan) in place	Y
nderstands government benefits for adult	Y
reated a Medical Summary/Personal Health Record and maintains this independently	In progress



Patient Name: _____ Birthdate: _____ Ago: _____
Completed By: _____ Date: _____

Transition Checklist for Teens

This **Transition Checklist for Teens** is about the skills you need to learn to take care of your health when you become an adult. Your doctor or nurse will talk with you about the areas where you want help. Please complete this checklist by marking the box or boxes that describe you the best. If you do not understand a question, please ask your parent, nurse, or doctor for help.

ACCESSING HEALTH CARE - Skills and Abilities:	YES, I do	NO, I will learn	Someone will need to do this for me	N/A, Will not be needed	Need more info
△ Do you wear or carry a medical alert (list of allergies, conditions)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you speak up for yourself in your doctor's office?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you help make health care decisions with your family or doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you see your doctor without your family/parents in the room?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know your rights to keep your health information private?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you call your doctor(s) on your own if you have a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know how to schedule your own doctor appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you have an updated portable medical summary and/or care plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you have an adult doctor (or a doctor for while you are at college)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MANAGING YOUR CONDITIONS AND TREATMENTS - Skills and Abilities:					
△ Do you know how to describe your own health conditions/disabilities and do you know how they affect your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know the names of your medicines and why you take them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know what can happen if you skip your treatments or medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you almost always take your medicines correctly on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know when and how to fill your own prescriptions (knowing who prescribed and where to call, getting refills on time)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you use and take care of your own medical equipment and supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know when to call for routine checkups, urgent care, and when to go to the emergency room or call 9-1-1?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
STAYING HEALTHY - Skills and Abilities:					
△ Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you understand how smoking, drinking, and/or using drugs can affect your condition (worsen symptoms, react with your medicines)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know how your condition affects sexuality (the need for closeness, caring, and touch, sometimes involving sexual activity)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know what you'll do for birth control, safe sex, and reproductive concerns (genetics, pregnancy)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
INSURANCE - Skills and Abilities:					
<input type="checkbox"/> Do you know how to use your health insurance benefits (co-pays, referrals)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know who to call for questions about your insurance coverage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know how you will maintain health insurance as an adult?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OTHER AREAS OF TRANSITION - Skills and Abilities:					
<input type="checkbox"/> Do you know what you will do after high school (job, more school, recreational options, volunteer, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know of resources that can help you to find adult services (job support, transportation, assistive technology, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know how your condition might affect your job choices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know what government benefits you might qualify for (SSI, SSDI, Health Benefits for Workers with Disabilities, Home & Community Based Services, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know about guardianship or power of attorney for health care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know your options for housing as an adult (on your own, group home)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know how to manage your money and pay your bills?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

KEY: ☐ ET ☐ MT ☐ LT

KNOWLEDGE

- Name of your condition
- Name of associated medical problems
- Names of your medications
- Knowing how your NF affects you specifically
- Names and contact information for your provider
- Routine, Urgent, and Emergent Care
 - Know the difference, and where to go for each
- Important symptoms – “red flags”
 - Intractable pain
 - Change in skin findings
 - Sudden/unexplained neurologic symptoms
- Reproductive counseling
 - Birth control pills effect on NF
- Basic insurance information



Examples - Knowledge

- You are about to transfer your care to a new adult doctor. What are some things you can do to make sure your visit goes smoothly?
- Try and describe each of your medical issues in 3 sentences
- Make sure you know how your illness affects you
- Learn about your medical history from your parent, major hospitalizations, surgeries, medicines etc.
- Create a portable medical record

Portable Medical Summaries

DOB 5/24/73 SS# 289-XX-XXXX ALLERGY: Sulfa Drugs, Adhesive Tape

- High intelligence (130 IQ), compliant patient, high tolerance to pain
- Incomplete Quad (has sensation), only movement left index finger 10 cm
- Need to explain EVERY procedure, when possible, ask for consent prior to doing
- If unable to talk => one blink = yes / two blinks = no - Read his lips - OR - letter/word board to direct his care.

PRIMARY DIAGNOSIS	AGE: 30	HEIGHT 4'3" (51inches)	WEIGHT 80lbs approx
1. NEURO/MUSCULAR 359 Muscular Dyst/335.1 SMA	Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, 3/74)		
2. RESPIRATORY V44 Trach, 518.81 Respir Failure 486, Pneumo Org NOS	incomplete quad (has full sensation), no functional movement Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis, Recurrent pneumonia (last hospitalization, 9/01) Respiratory insufficiency, poor residual functions and reserved capacities Decreased esophageal motility, s/p feeding gastrostomy tube (7/83)		
3. GASTRO V44.1 Gastro Status			
4. ORTHOPEDIC 737.4, 754.89, 754.81	Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips flexion contractures, spinal fusion (3/82 Lueke Rod), pectus excavatum		
5. UROLOGICAL 752.51	Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr, Cystoscopy/left ureteral stent (10/01), IVP (6/90)		
6. BLOOD TYPE	A + (positive)		
7. SPECIAL NOTES	IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36H1124)		

MEDICAL			
ACUPUNCTURE PHYSICIAN Barbara XXXXX RN, AP, Ocala, FL O: 352-xxx-xxxx		HOSPITAL North FL Regional Medical Center, Gainesville, FL 4/95, 1/97, 5/01, 9-10/01	
INTENSIVIST: Melvin XXXX, MD, Ocala, FL O: 352-622-xxxx		IMMUNIZATIONS Flu 02 Pneumo 79, 01 Tetanus 85 DPT 73, 79 Measles 74 Mumps 74 TB 78, 87	
PULMONOLOGIST: Robert xxx MD, Gainesville, FL O: 352-xxx-xxxx Bpr: 352-xxx-xxxx		ENTERAL Pulmocare (237ml) x 2 cans, nocturnal 70 ml/hr	
MEDICATIONS		HERBS / DROPS	VENT / TRACH / 02
Rx_DAILY 1. Alprazolam (xanax) 0.5 mg QID anxiety 2. Aspirin-Child 81 mg 1 x prevent clots 3. Temazepam 15 mg H S sleeping pill 4. DuoNeb 1 vial QID nebulizer (Ipratropium, Bromide & Albuterol)		1. Lymphatic 5 2X 2. Flu Balancing 10 2X 3. Respiratory 7 2X 4. Allertox -airborne 5 2X 5. " " Aleer-Total 3 3x 6. " " Allerdrain 10 4x 7. Immune 6 2X 8. Acute Rescue 5 2X 9. Urinary 8 2X 10. Digestive 3 2X 11. Mucous 5 2X 12. Cell 7 2X 13. Muscular 4 2X 14. Integumentary 8 2X 15. Er Cheng Tang 1 tsp 2X	VENT - Pulmonetic LTV 900 Breaths 05 Tidal Volume 310 Inspiration 1.1 Pressure Support 13 Sensitivity 02 High 40 Low 02 TRACH: Shiley 6 cuffed (deflated)
Rx_MONTHLY 1. Thiamine 100 mg monthly vitamin 2. Cyanocobalamin 1000 mcg/ml monthly (B12) vitamin		SPEAKING VALVE: Passy-Muir PMV007	
Rx_PRN 1. Darvocet-N pain 2. Zithromax SUS PFIZ 200/5ml 45ml antibiotic 3. Diphenoxylate/atropine 1-2 tablets diarrhea		OXYGEN 1.5 liters	

INSURANCE	
BlueCross BlueShield of Massachusetts Primary Subscriber: xxxxx xxxxx BC/BS PPO Plan Code 200 Customer service: 800-296-xxxx XXP XXXXXXXX 10 PPO	BlueCross BlueShield of Massachusetts Secondary Subscriber: xxxxx xxxxx BC/BS Blue Choice Plan 2, POS Code 200 Customer service: 800-222-xxxx XX XXXXXXXX 10
HEALTH SURROGATE P H (mother) c 352-xxx-xxxx h 352-xxx-xxxx	

PORTABLE MEDICAL SUMMARY

Name:
Address:
City, State, Zip:
Phone:

DOB: Gender: Male Allergies:
Insurance:

Primary Diagnosis:

Age at Onset	Date of Onset	History

Other Diagnoses:

Age at Onset	Date of Onset	History

Other Diagnoses:

Age at Onset	Date of Onset	History

Current Medications:

Medication	Dose	Started	Response

Past Medications:

Medication	Dose	Started	Response

Annual Testing:

Test	Date	Result

Medical Providers:

Name	Specialty	Contact No.

Portable Medical Summaries

Ann & Robert H. Lurie
Children's Hospital of Chicago
Chicago, IL 60611
Portable Medical Summary

Medical Record No.
Patient Name
Birthdate
Physician
Please align patient label to the right

Ann & Robert H. Lurie
Children's Hospital of Chicago
Chicago, IL 60611
Portable Medical Summary

Medical Record No.
Patient Name
Birthdate
Physician
Please align patient label to the right

Disclaimer: This document was created for me with the help of my providers based mainly on information I provided. It does not represent official health information and is made only for the purposes of convenience. It is my property and not the property of Ann and Robert H. Lurie Children's Hospital.

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Ann & Robert H. Lurie
Children's Hospital of Chicago
Chicago, IL 60611
Portable Medical Summary

Medical Record No.
Patient Name
Birthdate
Physician
Please align patient label to the right

Disclaimer: This document was created for me with the help of my providers based mainly on information I provided. It does not represent official health information and is made only for the purposes of convenience. It is my property and not the property of Ann and Robert H. Lurie Children's Hospital.

MY NAME'S MEDICAL SUMMARY

ABOUT ME			
Address:		County:	
City:	State:	ZIP Code:	
Email:	Phone:	Cell Phone:	Gender: <input type="checkbox"/> M <input type="checkbox"/> F
ALLERGIES:		EMERGENCY CONTACT:	
Primary Care Giver/Decision Maker:		Relationship:	
Legal Status: <input type="checkbox"/> Guardian <input type="checkbox"/> Power of Attorney <input type="checkbox"/> Informal Rep <input type="checkbox"/> Other			
Advance Directive <input type="checkbox"/> DNR <input type="checkbox"/> Organ Donor <input type="checkbox"/> N/A <input type="checkbox"/> Specific Info:			
TO KNOW ABOUT ME:			
MY HEALTH CARE PROVIDERS			
Primary Care Provider:		<input type="checkbox"/> Peds <input type="checkbox"/> Adult	Phone: Fax:
Address:		County:	
City:	State:	Last visit:	
Specialist Names:	Specialty:	<input type="checkbox"/> Peds <input type="checkbox"/> Adult	Phone #'s:
Therapists Name:	Specialty:	<input type="checkbox"/> Peds <input type="checkbox"/> Adult	Phone:
Medical Equipment Company/Contact:		Phone:	Fax:
Home Care Company/Contact:		Phone:	Fax:
Community Agency Contact:		Phone:	Fax:

MY IMMUNIZATIONS					
Influenza (last)	Date(s):	Meningococcus	Date(s):	HPV	Date(s):
Td or Tdap	Date(s):	Pneumovax	Date(s):	Varicella	Date(s):
Hepatitis B	Date(s):	Hepatitis A	Date(s):	MMR	Date(s):
Polio	Date(s):	PPD (last)	Date(s):		Date(s):
MY FAMILY HISTORY					
Who?	Condition		Who?	Condition	
MY PAST HOSPITALIZATIONS					
Date:	Hospitalization:				
MY PAST SURGERIES/PROCEDURES					
Date:	Surgery:				
MY INSURANCE					
Primary Insurance:		ID number:	Good Until:		
Secondary insurance:		ID number:	Good Until:		
<input type="checkbox"/> Waiver	Type:	<input type="checkbox"/> Waiting List	Type:		
Waiver Case Manager:		Phone number:			

MY MEDICAL PROBLEMS				
DIAGNOSIS/PROBLEM:	DESCRIPTION:			
MY MEDICATIONS				
Medication	Dose	Times	Purpose	Comments
Other medications/treatments I have tried:			What Happened?	
My Pharmacy:	Phone:	Fax:		
MY EQUIPMENT				
Current Equipment:	Specs/Settings:	Equipment Needs:		
MY DIET				
MY IMPORTANT TESTS/NUMBERS				
Test:	Date:	Result:		

Skills

- Maintaining your medical record
- Make an appointment
- How to contact your doctor
- Filling prescriptions
- Ordering meds & supplies
- Self examination

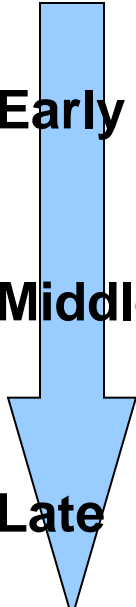


Examples - Skills

- **It has been a year since your last appointment with your specialist, you want to start teaching your child to become more independent. What can you do?**
 - Make sure the provider speaks to your child directly
 - Make sure your child answers the questions to the best of their ability
 - Make your own appointments
 - Prepare some questions to ask the doctor about your condition

Responsibility

- Gradual shift in responsibility from caregiver to teen
- Teen going from consultant to manager to CEO

	Provider	Parent/Family	Young Person
 Early Middle Late	- Major responsibility	-Provide care	-Receives care
	-Support to parent/family & child/youth	-Manages	-Participates
	-Consultant	-Supervisor	-Manager
	-Resource	-Consultant	-Supervisor

ADHERENCE

- You are trying to become more compliant with your medications. What can you do?
- What exactly is the barrier
 - Forgetting
 - Side Effects
 - Scheduling
 - Social stigma
- Use resources (technology, pill boxes) to help improve compliance

FINDING ADULT DOCTORS

Finding Adult Doctors



- Ask your current doctor for a referral
- Consider your parents' doctor
- Call your insurance company
- Check with your local support groups
- Call large medical and specialty rehab hospitals and ask for referral line
- Ask your Care Coordinator or Case Manager
- Ask a friend for suggestions

Questions to Ask



- Are they familiar with NF
- What are the office hours
- Do they take your insurance
- How do they communicate
 - Email, Phone, Electronic patient portal
- Do they have physical facilities to meet your needs
- Are they willing to talk with your pediatric provider
- What hospital are they with

COLLEGE/WORK

Preparing for College

- Create a plan to receive your medical supplies away from home
- Check in with the school health clinic. Ask what services they offer? Consider having your providers write a letter to the school
- Discuss risk-taking behaviors (such as drinking, smoking, and drug taking) with your medical team
- Check with your insurance provider regarding out-of-state coverage



College Accommodations

- Rights are defined by Section 504 of the Rehabilitation Act and the ADA of 1990
- You must ask for accommodations in college to receive them
- “Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities”
 - <http://www.ed.gov/about/offices/list/ocr/transition.html>
- Colleges not required to change substantive content
- Examples of accommodations
 - Extra time
 - Front seats
 - Priority registration
 - Substituting one course
 - Note taker

Parent to Parent Advice

"The one thing I wish I knew..."

- Network with other parents and families of children with special needs for ideas and support
- Talk with your child and make sure he or she is really prepared to be away from home.
- Know your rights. In hindsight, I would have gone right to the dean for working out special accommodations.
- I wish I knew that my daughter could have had her car at school in a handicapped spot. It certainly would have saved her struggles with medical equipment up the stairs to public transportation, etc.
- I wish I knew that taking one less class made things much easier one semester when my daughter had missed quite a bit of school. The one less class still kept her as a full-time student
- I wish I knew that medical supplies could be sent in the mail.

ADA (Americans with Disabilities Act) 1990

- Employers must provide “reasonable” accommodations to qualified employees and applicants with disabilities
- Unless such accommodations would pose an undue hardship
 - Too costly, too substantial, too disruptive
- YOUR RESPONSIBILITY TO ASK
 - Does not have to be in writing
 - Can be a formal letter (examples exist)

Sample Accommodation Request Letter

The following is an example of what can be included in an accommodation request letter and is not intended to be legal advice.

Date of Letter

Your name
Your address

Employer's name
Employer's address

Dear (e.g., Supervisor, Manager, Human Resources, Personnel):

Content to consider in body of letter:

▼ Identify yourself as a person with a disability

▼ State that you are requesting accommodations under the ADA (or the Rehabilitation Act of 1973 if you are a federal employee)

▼ Identify your specific problematic job tasks

▼ Identify your accommodation ideas

▼ Request your employer's accommodation ideas

▼ Refer to attached medical documentation if appropriate*

▼ Ask that your employer respond to your request in a reasonable amount of time

Sincerely,

Your signature
Your printed name

Cc: to appropriate individuals

▼ You may want to attach medical information to your letter to help establish that you are a person with a disability and to document the need for accommodation (Taken directly from: <http://www.jan.wvu.edu/media/accommrequestltr.html>)

REMEMBER

YOU ARE ENTITLED TO

- Be treated with respect
- Confidentiality
- Choose to disclose at any time during the employment process
- Receive accommodations for an interview

YOU HAVE RESPONSIBILITY TO

- Disclose your need to receive any accommodations
- Be truthful, determined, and proactive
- Work your hardest with the skills and merits you have

HEALTH INSURANCE

INSURANCE: THE GOOD, THE BAD, THE UGLY

- Insurance can be a significant barrier of transition
- There are a variety of insurance options for children and adults
- Learn how to read benefit plans

Health Insurance



Health Insurance Options

- All Kids/Family Care (Up until 19th Birthday)
- Adult Medicaid- no longer based on disability
 - Available for those earning less than 138% of FPL
- Medicaid- Blind, aged, disabled adults moving to managed care
 - Integrated Care Program
- Medicare (Certain medical conditions and DAC status)
- Private Insurance
 - Group plan
 - Exchange
 - Parents until 26
- College/university insurance

Supporting patients who lose insurance

- Provide anticipatory guidance to plan for insurance needs as an adult. www.Healthcare.gov
- Social workers can provide resources to legal/advocacy support
 - Ex. Health & Disability Advocates can help appeal a SSI and Medicaid denial.
- Patients without insurance may be eligible for medication prescription programs
 - Ex. www.needymeds.org

GUARDIANSHIP

Guardianship Process

- Start considering around 17th birthday
- IL state guardianship guide
 - <http://gac.state.il.us/osg>
- Do not need an attorney but can use one if you would like
- In IL, forms are filed through County Circuit Court. They would be filed on the child's 18th birthday
- Forms are found on Circuit Court website under Probate
- Physician will need to fill out form within 3 months of filing
 - Multiple physicians can collaborate and sign form for Cook County
 - Physicians can use IEP, IQ tests, and other school evaluations

Guardianship

- Guardianship is when one person will have the legal power to make decisions
 - Court assumes that anybody age 18 can be their own legal guardian until proven otherwise
- Alternatives to Guardianship - For some individuals with disabilities, less restrictive options to legal guardianship may provide the protections needed. Examples include
 - Joint Bank Account
 - Power of Attorney



Tools: Transition Resources

- Transition Websites
- Transition Videos



HealthVault

<https://www.healthvault.com/us/en>

What is HealthVault?

Microsoft HealthVault is a trusted place for people to gather, store, use, and share health information online. [Learn more](#)

Organize your family's health information.

Be better prepared for doctor visits and unexpected emergencies.

Create a more complete picture of your health, with you at the center.

Achieve your fitness goals.

Connect anywhere



Connect from the [web](#), [Windows](#), [Windows Phone](#), [iPhone](#), and [more](#).

Privacy

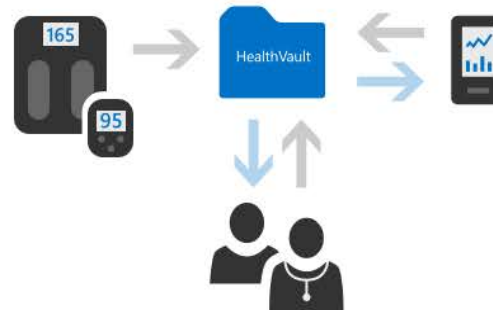
It's your HealthVault account

You decide who can see, use, add, and share info, and which health apps have access to it.

HealthVault won't provide your health information to any other app or service without your permission.

[Read the HealthVault Account Privacy Statement](#)
[PHR Privacy Notice \(PDF\)](#)

Connect your health data



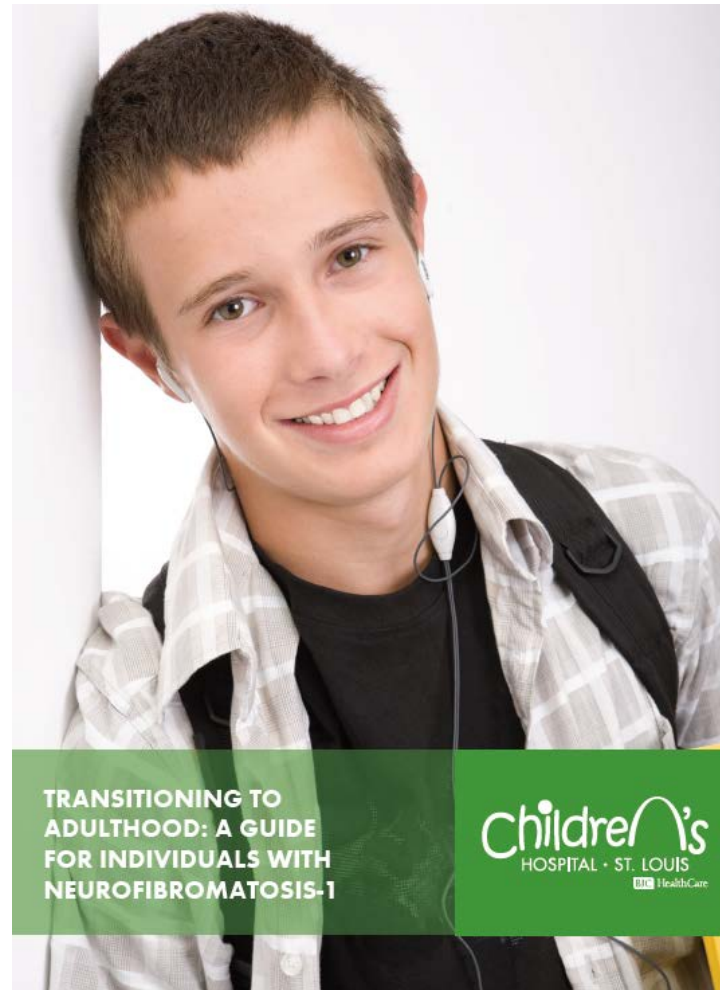
Learn [how HealthVault works](#) with connected apps and devices and helps you share information with people you trust.

Health IT for you

Watch [this cool video](#) from [healthit.gov](#) to see how you benefit from access to your medical records.

NF Transition Brochure


<http://www.nfarizona.org/Transitioning-to-Adulthood-Brochure.pdf>



NF Network






<http://www.nfnetwork.org/home>

screenshot

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www.mymedschedule.com

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Step 3: Review the Schedule [Back to Step 2](#) [Save Schedule](#) [Print Page](#)

MyMedSchedule Checklist Instructions English

MyMedSchedule.com® Helping you take the right dose, at the right time, every day.™

Rebeccas Revised: 12/12/2008 at 11:37 AM

Take These Medications	At These Times		Purpose
	8am	9pm	
 Ditropan XL® (Oxybutynin chloride) 10mg Extended release tablet(s)		2 Extended release tablet(s)	Treats overactive bladder
 Tylenol® (Acetaminophen) 325 mg Tablet(s)	2 Tablet(s)		Pain reliever
 Catheter			

The pharmacist may make a generic substitution for the medication shown in your Daily Schedule. The medication name, dosage strength, shape, color, and size may change as a result of this substitution. Please check dosage strength on your prescription bottle against

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ICAAP Transition Handouts

<http://illinoisaap.org/projects/medical-home/transition/>

Resources and Tools for Families


File Name	Size	Link
TransitionAdulthoodTeen.pdf	571 KB	Transition to Adulthood Handout for Teens
HealthCareTransition.pdf	457 KB	Health Care Transition Handout
ChecklistTeens.pdf	284 KB	Transition Checklist for Teens
ChecklistCaregiver.pdf	242 KB	Transition Checklist for Parents/Caregivers
HowWellKnowHCNeeds.pdf	239 KB	How Well Do You Know Your Health Care Needs?
TransitionAdulthoodParent.pdf	884 KB	Transition to Adulthood Handout for Parents and Caregivers
DifferencesInCare.pdf	559 KB	Differences In Care
TransitionTimeline.pdf	1,366 KB	Transition Timeline
TransitionIssuesSpecialNeeds.pdf	915 KB	Transition Issues for Adolescents with Special Needs Brochure
GuideToAdultBenefitsReadOrder.pdf	1,270 KB	Guide to Adult Benefits, Services, and Resources
GuideToAdultBenefitsPrintOrder.pdf	1,209 KB	Guide to Adult Benefits, Services, and Resources (for print orders)
Guardianship.pdf	761 KB	Guardianship and Alternatives
DoYouUnderstandInsurance.pdf	347 KB	Do You Understand Insurance?
FillingPrescription.pdf	456 KB	Filling a Prescription
MedicalEmergency.pdf	431 KB	What To Do In A Medical Emergency
TakeMedsAsDirected.pdf	337 KB	Take Medications As Directed
WorkingWithDoctor.pdf	477 KB	Working With Your Doctor
FindingAdultProviders.pdf	443 KB	Finding Adult Providers
PortableMedicalSummary.pdf	137 KB	Portable Medical Summary

Transition Videos-Nemours Hospital

- Legal and Financial:
 - <http://youtu.be/CpvIyfiRjRM>
- After High School
 - <http://youtu.be/gdFb4NsifAM>
- Where to Live:
 - <http://youtu.be/8bBp3VX71Hs>
- Medical:
 - <http://youtu.be/cjXurYrFMZM>


LURIE CHILDREN'S SITE


[HTTP://WWW.LURIECHILDRENS.ORG/EN-US/CARE-SERVICES/FAMILY-SUPPORT/TRANSITIONING-TO-ADULT-CARE/PAGES/DEFAULT.ASPX](http://www.luriechildrens.org/en-us/care-services/family-support/transitioning-to-adult-care/pages/default.aspx)



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Care & Services > Research > Get Involved > Community >





Transitioning from Pediatric to Adult Care

For teen-agers living with a chronic illness, gaining more responsibility for their health, their life and moving towards adulthood can be an exciting and challenging time.

LurieChildrens.org > Care & Services > Family Services & Support > Transitioning from Pediatric to Adult Care

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Transitioning from Pediatric to Adult Care

For teen-agers living with a chronic illness, gaining more responsibility for their health, their life and moving towards adulthood can be an exciting and challenging time.

Key Points

During the transition process, key points to remember:

1. Start early – begin planning by age 14
2. Remember that "transition" is a process, not an event
3. Get help from your current pediatric healthcare team
4. Involve teens in decisions, and empower them with more independence
5. Transfer to adult care should not happen during a medical crisis

For Healthcare Professionals >

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- [Get Directions/Parking >](#)
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Related Stories

DIRECTIONS

- Developing formal checklist of knowledge and skills for NF
- Development of a comprehensive resource website such as foundation website etc. for families
- Development of 1 page fact sheets for providers surrounding issues of NF such as what to look for, yearly tests and scans, and complications
- Understand the most common issues surrounding issues such as guardianship, driving, insurance coverage and develop letters and forms that providers can use to help their families
- Locate community resources that can help your children meet peers and engage in their community to the fullest extent



THINGS TO REMEMBER...

- **Transition involves learning about yourself, your medical condition, and planning for school and work, community, relationships and more**
- **Transition is a process not an event**
- **Start early!**

SELF ADVOCACY



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4. Cooley C et al. Got Transition. Center for Medical Home Improvement.
<http://www.gottransition.org/6-core-elements>