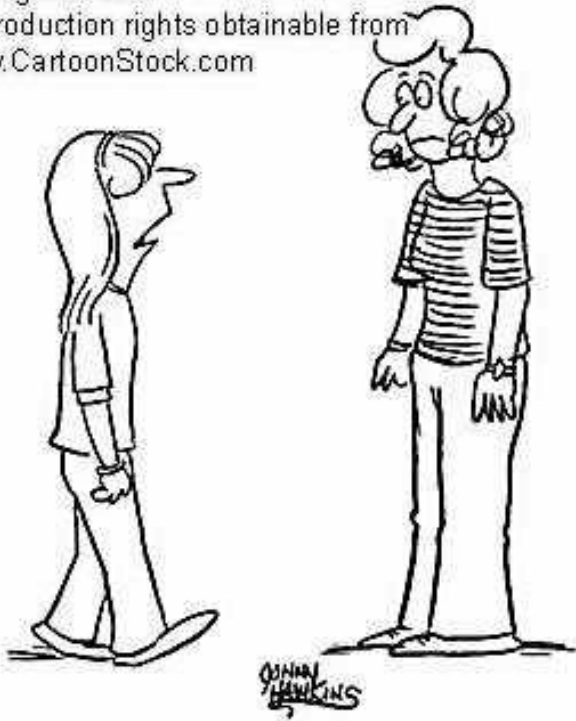


Understanding Health Care Transition

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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
Medical Director
Chronic Illness Transition Team
Lurie Children's Hospital
Chicago, IL

DISCLOSURE SLIDE

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”**
- **Facts, Challenges, Barriers**
- **Tips and Resources**



Transitions

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)

Facts About Transition

- 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

Known Barriers

- **Pediatric Providers have reported**
 - Lack of adult physicians to care for young adults with chronic illness
 - Lack of adult physicians with knowledge of pediatric diseases
 - 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 Models of 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



Assessing and Preparing Youth

- Knowledge
- Skills
- Responsibilities

USE A CHECKLIST TO HELP
(CREATE ONE FOR YOUR POPULATION)

Checklist Example

Patient Name: _____ Birthdate: _____ Age: _____
 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	NA, 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"/>
□ 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"/>
□ 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"/>
□ 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"/>
○ 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"/>
○ 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"/>
□ 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"/>
□ 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"/>
○ 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"/>
○ 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"/>
○ 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"/>
○ 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"/>
□ 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"/>
□ 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:					
□ 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"/>
○ 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"/>
○ 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:					
□ 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"/>
□ 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"/>
□ 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"/>
○ 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"/>
○ 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"/>
○ 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"/>
○ 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
- Names of your medications (Bring medication list with specific instructions from pharmacy)
- Names and contact information for your providers
- Importance of hand washing
- Anesthesia precautions
- Hydration protocols
 - E.g. No Lactated Ringers



Examples - Knowledge

- You are about to transfer care of a patient to a new adult doctor. What are some things you can do to ensure your patient knows about their condition?
- Have patient describe their illness in 3 sentences
- Have them learn about their medical history from their parent, major hospitalizations, surgeries, medicines etc.
- Have patient create a portable medical record

Skills

- Make an appointment
- Filling prescriptions
- Ordering meds & supplies
- Care and access of central lines or enteral feeding tubes

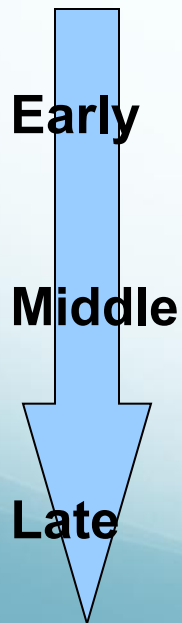


Examples - Skills

- **It has been a year since your patient's last appointment with their specialist, you want to start teaching your patient to become more independent. What can you do?**
 - Speak directly to patient so they can learn to communicate
 - Direct patient to front desk to make the appointment themselves
 - Have patient prepare some questions to ask the doctor about their condition

Responsibility

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



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

ADHERENCE

- You are trying to encourage more compliance with your patient. What can you do?
 - Ask directly about barriers
 - Use resources (technology, pill boxes) to help improve compliance

Assessment of Youth OTHER ITEMS

- Guardianship
 - Power of Attorney vs Guardianship
 - Financial, health care, estate
- Insurance, Benefits, and future financial planning
- Community Resources
 - Pediatricians feel lack of knowledge of community resources is large barrier to transition
 - Community participation has strong association with successful transition

Portable Medical Record

DOB 5/24/73

SS# 289-XX-XXXX ALLERGY: Sulfa Drugs, Adhesive Tape

PORTABLE MEDICAL SUMMARY

- 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.

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

DOB: Insurance: Gender: Male Allergies:

PRIMARY DIAGNOSIS AGE: 30 HEIGHT 4'3" (51inches) WEIGHT 80lbs approx

- NEURO/MUSCULAR** Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, 3/74) incomplete quad (has full sensation), no functional movement
- RESPIRATORY** 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)
- GASTRO** V44.1 Gastro Status
- ORTHOPEDIC** Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips flexion contractures, spinal fusion (3/82 Lueke Rod), pectus excavatum
- UROLOGICAL** Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr, Cystoscopy/left ureteral stent (10/01), IVP (6/90)
- BLOOD TYPE** A + (positive)
- SPECIAL NOTES** IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36H1124)

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.

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
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)	VENT / TRACH / O2 VENT - Pulmonic 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	CELL 11. Mucous 5 2X 12. Cell 7 2X 13. Muscular 4 2X 14. Integumentary 8 2X 15. Er Cheng Tang 1 tsp 2X
Rx PRN 1. Darvocet-N pain 2. Zithromax SUS PFIZ 200/5ml 45ml antibiotic 3. Diphoxylate/atropine 1-2 tablets diarrhea	SPEAKING VALVE: Passy-Muir PMV007 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

BC/BS Case Manager Debra XXXXXXX 800-222-xxxx ext xxx

My Health Passport

<http://www.sickkids.on.ca/myhealthpassport>

The screenshot shows a Microsoft Internet Explorer browser window displaying the 'Spina Bifida' form on the SickKids website. The browser's address bar shows the URL: <http://www.sickkids.ca/myhealthpassport/FormPassport.aspx?FormId=50>. The form is titled 'Spina Bifida' and includes a 'SickKids' logo and a 'G2G' logo. The form text reads: 'This is where you put in your health information. Much of it you will know and the rest is available to the health care provider you are completing this with. If something doesn't apply to you, skip to the next section. There is no need to enter "none" or n/a, unless you want the section to print on the final version. An example of this would be if you want your card to say "Drug Allergies: None". At the end, there is a place you can put in anything that you would want an adult health care provider to know about you.'

The form fields include:

- Name: [Text Box]
- Date of birth: [Text Box]
- What kind of Spina Bifida do you have? [Radio Buttons: Myelom, Sacral]
- Level of Spina Bifida [Radio Buttons: Sacral]
- I have hydrocephalus [Radio Buttons: yes, no]
- Controlled by [Radio Buttons: VP sh, VA sh]
- I have a syrinx [Radio Buttons: yes, no]
- At what level? (ex: C2-C4, T2...) [Text Box]
- It is controlled by a [Radio Buttons: Right, Left]

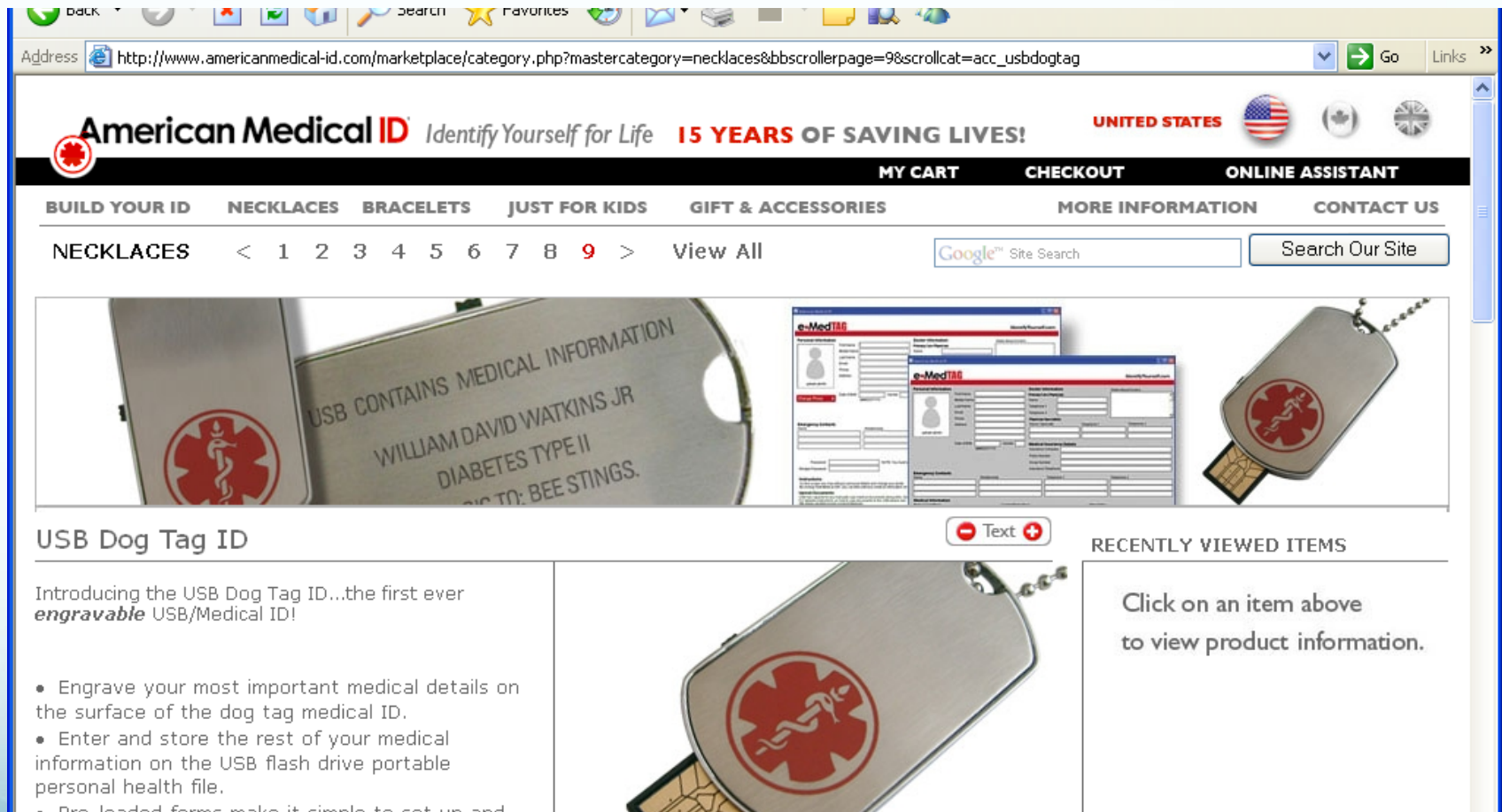
An Adobe Reader window is open over the form, displaying the completed PDF. The PDF content includes:

Please, cut passport and fold it to wallet size.

Name	Rebecca Smith
DOB	July 10, 1984
Diagnosis	Myelomeningocele -Lumbar
Hydroceph	hydrocephalus- Right VP shunt. Shunt malfunction- 1984. Shunt revision- May 1990, June 1999, August 2004. Tethered Cord Release- October 1995
Transfers	Self-transfer
Medicity	Braces-AFO, Orthoses
Ortho	None
Gender	4x per day, 6 Fr
Bladder Ops	Myelomif
Bowel	Bowel movement every other day_MACE
Medical problems	Asthma Depression
Operations	Wisdom teeth removed in Summer 2001
Vaccs	Miracle Dirospan 5 mg Bactrim
Drug allergies	None
Other allergies	LATEX ALLERGY
Other allergies	Dairy
Immunization	SOPE, MMW, Hib, HDU, Hep A
Coverage	Blue Cross Blue Shield PPO ID # 13324200 Group # 00000 Customer Service Number: 800-334-8388
1st provider	Dr. Gupta, 773-933-1111, Northwestern Memorial
Referral	Dr. Mukherjee, 773-327-1133, Children's and RIC
Paed Urol	Dr. Yarkas, 773-333-3333, Children's, Kelly
Adult Urol	Dr. Karp, 312-926-4200, RIC/Northwestern
Paed	Dr. Bowman, 773-490-4200, Children's
Neurology	
Adult Neurology	Dr. Ganja, 312-926-3000, RIC/Northwestern
Paed Neuro	N/A
Adult Neuro	N/A
Paed Ortho	Dr. Dias, 773-327-1000, Children's
Adult Ortho	Dr. Dias, 312-938-1000, RIC
Paed Cardio	Dr. Reynolds, 773-880-1000, Children's
Adult Cardio	N/A still with Dr. Reynolds
Endocrin	Rebecca 773-327-2142
Psych	Mary Johnson, Northwestern Psych, 312-926-1900
PT	N/A
OT	N/A
Aud	Kater Orthotics Randa Tadi
Emergency Contact	Jocaine Smith- Mom W: 773-626-2333 John Smith- Dad W: 773-268-2658
Date Created	3/11/2008

Electronic Health Record

<http://www.americanmedical-id.com>



The screenshot shows the American Medical ID website. The header includes the logo, tagline "Identify Yourself for Life", and "15 YEARS OF SAVING LIVES!". Navigation links include "MY CART", "CHECKOUT", and "ONLINE ASSISTANT". A secondary navigation bar lists categories like "BUILD YOUR ID", "NECKLACES", "BRACELETS", "JUST FOR KIDS", "GIFT & ACCESSORIES", "MORE INFORMATION", and "CONTACT US". The main content area features a "USB Dog Tag ID" product. The product image shows a dog tag with a red medical symbol and engraved text: "USB CONTAINS MEDICAL INFORMATION", "WILLIAM DAVID WATKINS JR", "DIABETES TYPE II", and "ALLERGIC TO: BEE STINGS.". Below the image, there is a "Text" button and a "RECENTLY VIEWED ITEMS" section with a prompt to click on an item to view product information.

American Medical ID Identify Yourself for Life **15 YEARS OF SAVING LIVES!** UNITED STATES

MY CART CHECKOUT ONLINE ASSISTANT

BUILD YOUR ID NECKLACES BRACELETS JUST FOR KIDS GIFT & ACCESSORIES MORE INFORMATION CONTACT US

NECKLACES < 1 2 3 4 5 6 7 8 9 > View All

Google™ Site Search Search Our Site

USB Dog Tag ID Text

RECENTLY VIEWED ITEMS

Click on an item above to view product information.

- Engrave your most important medical details on the surface of the dog tag medical ID.
- Enter and store the rest of your medical information on the USB flash drive portable personal health file.
- Pre-loaded forms make it simple to set up and

INSURANCE: THE GOOD, THE BAD, THE UGLY

- Insurance can be a significant barrier of transition. Uninsured rates are 29% for young adult compared with 14% national average
- There are a variety of insurance options for children and adults
- Insurance will change for our adult patients
- Most dependents can now stay on insurance until they are 26 years old

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

Tools: Transition Resources

- Health Care Checklists
- Medical Health Summaries
- Transition Websites
- Transition Videos



My Med Schedule

www.mymedschedule.com

MyMedSchedule® - Easily create free, printable, medication charts and daily pill reminders - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Address: <https://secure.medactionplan.com/mymedschedule/>

MyMedSchedule.com My Account | Find a Pharmacy | Log Out | Help




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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Proprietary technology. Patent pending. The brands and trademarks included herein are the trademarks of their respective owners.

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LURIE CHILDREN'S SITE

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

[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)

 Lurie Children's Hospital of Chicago™

Formerly Children's Memorial Hospital

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[Research >](#)

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[Community >](#)



Enter Keyword(s)

SEARCH



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](#)

[Our Culture of Care](#)

[Conditions & Treatments](#)

[Find A Doctor](#)

[Appointments](#)

[Your Visit](#)

[Hospital & Visitors Guide](#)

[Parking & Locations](#)

[Billing & Medical](#)

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 >](#)

I Want To:

[Find a Doctor >](#)

[Get Directions/Parking >](#)

[Request an Appointment >](#)

[Related Stories](#)

FUTURE DIRECTIONS

- Developing formal checklist of knowledge and skills for your population
- Development of a comprehensive resource website such as foundation website etc. for families
- Development of 1 page fact sheets for providers surrounding issues of mitochondrial diseases
- 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 young adults meet peers and engage in their community to the fullest extent (local)

THINGS TO REMEMBER...

- **Transition involves planning for teens' future in school and work, community, relationships and medical care**
- **Transition is a process not an event**
- **Start early!**

Contact Information

- Rebecca Boudos, LCSW
 - rboudos@luriechildrens.org
- Parag Shah, MD
 - Pshah@luriechildrens.org