UNDERSTANDING HEALTH CARE TRANSITION

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Presentation courtesy of:
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Transition Specialist

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OBJECTIVES

- What do we mean by “Transition”
- Facts, Challenges, Barriers
- Implementing Transition
- Tips and Resources
“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)
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
**KNOWN BARRIERS**

- **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
## SIX CORE ELEMENTS FOR PROVIDERS

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td><strong>1.</strong></td>
<td>Develop a transition policy</td>
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<td><strong>2.</strong></td>
<td>Identify youth that are going to be difficult to transition</td>
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<td><strong>3.</strong></td>
<td>Assess youth for transition readiness</td>
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<tr>
<td></td>
<td>CHECKLIST</td>
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<td><strong>4.</strong></td>
<td>Develop tools for transition</td>
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<tr>
<td></td>
<td>a. Portable medical summary</td>
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<td></td>
<td>b. Emergency plan</td>
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<td><strong>5.</strong></td>
<td>Transfer care</td>
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<tr>
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<td>a. Summary</td>
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<td>b. Communication with new provider</td>
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<td></td>
<td>c. Condition fact sheet if necessary</td>
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<tr>
<td><strong>6.</strong></td>
<td>Completion of Transition</td>
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<td>Continue to be a resource for patient and adult provider</td>
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WHEN SHOULD TRANSITION BEGIN?

- Ages 11-13
- Youth most receptive to future planning
- Less gap between peers
STEP 1: HEALTHCARE PROVIDER’S TRANSITION POLICY

- Timeline
  - Initiation
- Outcomes
  - What should the youth know and do before they leave the office
- Transfer
  - Practice processes
  - Communication
STEP 3: ASSESSING AND PREPARING YOUTH

- Knowledge
- Skills
- Responsibilities

USE A CHECKLIST TO HELP
CHECKLIST EXAMPLES

See transition resources at end of slide presentation
What to do in an emergency
Learning to stay healthy
How to get health insurance
What could happen if condition gets worse
Name of condition
Symptoms of condition
Names of medication and purpose
Names of doctors and purpose
How risk taking behaviors may affect medical condition
Where to go in an emergency
Basic information on insurance plan
A pediatric rheumatologist is about to transfer care of a patient to a new adult doctor. What are some things the doctor can do to ensure the 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

- Speak directly to your medical team
- Meet alone with your medical team
- Call the nurse yourself
- Make an appointment
- Manage self care and medical skills
- Fill a prescription or medical supplies
- Take medications
It has been a year since your last appointment with your specialist. Your doctor wants to start teaching you to become more independent. What can your doctor 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
Gradual shift in responsibility from caregiver to teen
Teen going from consultant to manager to CEO
Following recommendations to medical treatment (medications, regimens, restrictions)
Take ownership of your body
<table>
<thead>
<tr>
<th>Stage</th>
<th>Provider</th>
<th>Parent/Family</th>
<th>Young Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>Major responsibility</td>
<td>Provide care</td>
<td>Receives care</td>
</tr>
<tr>
<td></td>
<td>Support to parent/family &amp; child/youth</td>
<td>Manages</td>
<td>Participates</td>
</tr>
<tr>
<td>Middle</td>
<td>Consultant</td>
<td>Supervisor</td>
<td>Manager</td>
</tr>
<tr>
<td>Late</td>
<td>Resource</td>
<td>Consultant</td>
<td>Supervisor</td>
</tr>
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</table>

Gall, Kingsworth, and Healy, 2006
Your doctor is trying to encourage you to become more adherent with your medical treatment. What can your provider do?

- Ask directly about barriers
- Use resources (technology, pill boxes) to help improve compliance
ASSESSMENT OF YOUTH

- Guardianship
- Insurance, benefits, and future financial planning
- Patient confidentiality rights
- Community Resources
  - Community participation has strong association with successful transition
  - Pediatricians may not know about community resources that are available
- Career/Vocation support
95% written summary and support from specialists,
91% want to speak w prior provider,
84% written educational info about condition

PORTABLE MEDICAL RECORD

**NAME**

DOB: 5/26/73  
Address, Home Phone, Cell Phone, Email  
SS# 259-XX-XXXX  
ALLERGY: Sultra Drugs, Adhesive Tape

- High Intelligence (130 IQ), compliant patient, high tolerance to pain  
- Incomplete quad (left sensation), only moved with left hand longer 10 cm  
- Unable to talk - yes/no concept - yes, two items no - Rapid hand tips - OR, with-ward board to direct his care

**PRIMARY DIAGNOSES**

- **NEUROMUSCULAR**  
  Myasthenia Gravis  
- **RESPIRATORY**  
  COPD, Pneumonia, Chronic Rhinitis

**MEDICAL**

**HOSPITAL**  
North FL Regional Medical Center, Davenport, FL  
4515, 2-07-05, 5-01-01

**IMMUNIZATIONS**  
- Varicella  
- Mumps  
- Hepatitis A & B

**ENTRAL**

**VENTILATOR/ICU**

**MEDICATIONS**

<table>
<thead>
<tr>
<th>Rx</th>
<th>DAILY</th>
<th></th>
<th>QNT</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levodopa</td>
<td>0.1 mg</td>
<td>QID</td>
<td>100 mg</td>
<td></td>
</tr>
<tr>
<td>Antihypertensives</td>
<td>10 mg</td>
<td>8 AM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dexamethasone</td>
<td>1 mg</td>
<td>12 PM</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**INSURANCE**

BlueCross BlueShield of Massachusetts  
Primary Submitter: BCBS PPO Plan Code 300  
Secondary Submitter: BCBS Blue Cross Plan 2, PPO Code 200  
Consumer Services: 800-224-4656  
Fax: 205-373-7329

**HEALTH CARE**

P.H. (mother) c 352-xxxx-xxxx  
Health Care  
Home Health Care  
Pharmacy

**PORTABLE MEDICAL SUMMARY**

Name:  
Address:  
City, State, Zip:  
Phone:  
DOB:  
Gender: Male  
Allergies:  

**Primary Diagnosis:**

- Age at Onset  
- Date of Onset  
- History

**Other Diagnoses:**

- Age at Onset  
- Date of Onset  
- History

**Current Medications:**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Started</th>
<th>Response</th>
</tr>
</thead>
</table>

**Past Medications:**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Started</th>
<th>Response</th>
</tr>
</thead>
</table>

**Annual Testing:**

<table>
<thead>
<tr>
<th>Test</th>
<th>Date</th>
<th>Result</th>
</tr>
</thead>
</table>

**Medical Providers:**

Name  
Specialty  
Contact No.

7/28/09 PM
My Health Passport
http://www.sickkids.on.ca/myhealthpassport

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.
ELECTRONIC HEALTH RECORD

HTTP://WWW.AMERICANMEDICAL-ID.COM

USB Dog Tag ID

Introducing the USB Dog Tag ID...the first ever engraveable USB/Medical ID!

- 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 update.
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 may change for our adult patients.

If a child received Medicaid/All Kids as a kid, it does not guarantee that they will be eligible as an adult.

Most dependents can now stay on insurance until they are 26 years old.
How Providers Can Support 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.

- Provide patient with health care clinics that see uninsured patients

- Patients without insurance may be eligible for medication prescription programs
  - Ex. www.needymeds.org
HEALTH INSURANCE OPTIONS

- Differs depending on state of residence
- Illinois: All Kids/Family Care (Up until 19th Birthday)
- Adult Medicaid (Income and Disability- SSI Definition)
- Medicare (Certain medical conditions)
- Private Insurance
  - Group
  - Individual (2014 can not be denied on pre-existing)

- College/university insurance
- Illinois Comprehensive Health Insurance Plan (ICHIP) (Anyone can apply, high premiums)
- Illinois Pre-Existing Condition Insurance Plan (IPXP) (Must be uninsured for 6 months)
TOOLS: TRANSITION RESOURCES

- Lurie Children’s Division of Rheumatology Transition Documents
  - Word Documents available – we will let you know how to access

- Health Care Checklists
- Medical Health Summaries
- Transition Websites & Videos
MEDICATION REMINDERS
# My Med Schedule

[www.mymedschedule.com](http://www.mymedschedule.com)

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## Step 3: Review the Schedule

[MyMedSchedule.com](https://secure.medschedule.com/mymedschedule)

**Helping you take the right dose, at the right time, every day.**

### Rebecca's Schedule

Revised: 12/12/2006 at 11:37 AM

<table>
<thead>
<tr>
<th>Take These Medications</th>
<th>At These Times</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ditropan XL®</td>
<td>8am</td>
<td>2 Tablet(s)</td>
</tr>
<tr>
<td>(Oxybutynin chloride)</td>
<td>9pm</td>
<td>Treats overactive bladder</td>
</tr>
<tr>
<td>10mg Extended release tablet(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tylenol®</td>
<td>2 Tablet(s)</td>
<td>Pain Reliever</td>
</tr>
<tr>
<td>(Acetaminophen)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>325 mg Tablet(s)</td>
<td></td>
<td></td>
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<tr>
<td>Catheter</td>
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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 the medication as it is actually dispensed.
**WEBSITES AND VIDEOS**

- **Got Transition**
  - Got Transition/Center for Health Care Transition is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health
  - www.gottransition.org
  - http://www.gottransition.org/youthfamilies/index.cfm

- **Arthritis Foundation**
  - Website is designed to prepare youth with rheumatic diseases and their families for the transition to healthy adulthood
  - www.jatransition.org
WEBSITES AND VIDEOS

- http://illinoisaap.org/projects/medical-home/transition/resources-for-physicians/
- http://depts.washington.edu/healthtr/
All of us go through transitions in our life, from infancy to childhood, from preschool to primary school to high school, and from teenagers to adulthood. The journey to adulthood is often filled with joys and challenges, hurdles to cross and paths to choose. Planning ahead and preparing for these changes will help you to take full advantage of the choices that lay before you.

Planning for the transition from pediatric doctors to adult doctors, moving from school to work, and achieving the highest level of independent living can be exciting and challenging. It is never too early to begin thinking about and preparing for your child’s future. The materials listed below can help guide you and your child as you experience life’s transitions.

**Transition Fact Sheet and Worksheets for Parents & Youth**

The Transition Information Sheet for Families explains what medical transition is and why it is important. This fact sheet also identifies the key issues that must be considered as your child grows and matures and takes on more responsibility for their own health and well-being. The Transition Information Sheet for Families is available in both English and Spanish.

The Transition Worksheet for Parents can be used to help you identify what you and your child have thought or planned for their life as an adult. It can be used to help you prepare for all aspects of independent living including transportation, employment, financial resources, medical care and many others. The Transition
HEALTH CARE TRANSITIONS
HTTP://HCTRANSITIONS.ICHP.EDU/HCT-PROMO

Health Care Transitions

Print Resources

Since You're Not A Kid Anymore
It's Time To Be More In Charge Of Your Health Care

Now That You're In High School
It's Time To Be More In Charge Of Your Health Care

When You're 18
You ARE In Charge Of Your Health

These 30-page health care transition guides include information and activities designed to help teens with special health care needs take a more active role in their own health care. All are available for download as a full color PDF document.

Streaming Videos

Talking With Your Doctor
This 18-minute video teaches teens how communicate effectively with health care providers so that they answer teens' questions and give the information and supports teens need to be more in charge of their own health. Teens will also learn how to prepare and give health care providers the information they need to give teens the best possible medical care. (2008)

Streaming Video and Download Page
Available on a DVD for $5. To order email John Reiss at jreiss@ichp.ufl.edu.

This is Health Care Transition
Growing up and becoming an adult is difficult for all youth, but can be especially challenging for youth with special health care needs (SHCN).
Transitioning from Pediatric to Adult Care

For teenagers 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
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!

- Follow your provider’s transition policy

- Use checklists and resources

- Talk with your doctor about health care transition
CONTACT INFORMATION

- Megan Curran, MD
  - mcurran@luriechildrens.org