Understanding Health Care Transition

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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

Your Voice

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)
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.

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

### MNC TRANSITION PLANNING [GB]

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<td>Name of all medical conditions</td>
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<tr>
<td>Explain each of the conditions in 3 sentences or less</td>
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<td>Explain physical and cognitive limitations and disabilities</td>
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<td>Name the medications</td>
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<td>Purpose of each medication</td>
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<td>Name the basic function of each specialist provider</td>
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<td>Any activity/behavior limitations</td>
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<td>Met and addressed (conditions, allergies)</td>
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<tr>
<td>Schedules appointments independently</td>
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### ACCESSING HEALTH CARE - Skills and Abilities

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<td>Do you help make health care decisions with your family or doctor?</td>
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<td>Do you call your doctor/Google only if you have a problem?</td>
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<td>Do you have all your medications with you when you see your doctor?</td>
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<td>Do you know what to do if you miss a dose?</td>
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<td>Do you know when to call your doctor (or clinic)?</td>
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<td>Do you know how to call your doctor (or clinic) if you have a problem?</td>
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<tr>
<td>Do you call your doctor when you have a problem?</td>
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<td>Do you know how to get your medications at home?</td>
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<td>Do you know what to do if you need more than one medication?</td>
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<tr>
<td>Do you know how to take medications independently?</td>
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<td>Do you know how to manage your medications?</td>
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### MANAGING YOUR CONDITIONS AND TREATMENTS - Skills and Abilities

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<td>Do you know how to explain them to your doctor?</td>
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<td>Do you know how to manage your medications?</td>
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<td>Do you know how to manage your medications effectively?</td>
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### STAYING HEALTHY - Skills and Abilities

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<td>Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?</td>
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<td>Do you understand how smoking, drinking, and/o...</td>
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<tr>
<td>Do you know how your condition affects your daily life?</td>
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<tr>
<td>Do you know how to prevent accidents and injuries?</td>
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<tr>
<td>Do you know how to prevent infections and...</td>
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<tr>
<td>Do you know how to prevent falls and injuries?</td>
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<tr>
<td>Do you know how to prevent accidents and injuries?</td>
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<tr>
<td>Do you know how to prevent infections and...</td>
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### INSURANCE - Skills and Abilities

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<tr>
<td>Do you know how to use your health insurance benefits (co-pays, referrals)?</td>
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</tr>
<tr>
<td>Do you know who to talk to about your insurance?</td>
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<tr>
<td>Do you know how to maintain health insurance as an adult?</td>
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### OTHER AREAS OF TRANSITION - Skills and Abilities

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<tr>
<td>Do you know how to set up your own doctor’s appointment?</td>
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<tr>
<td>Do you know how your condition affects your daily life?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Do you know how to manage your money and pay your bills?</td>
<td>☐</td>
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</table>

**KEY:** Y = Yes, N = No, NA = Not applicable
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 providers
- 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 SUMMARY

DOB: 5/24/73  SS#: 289-XX-XXXX

APPROXIMATE AGE: 30  HEIGHT: 4'3" (51 inches)  WEIGHT: 80 lbs

ALLERGIES: Sulfur Drugs, Adhesive Tape

PRIMARY DIAGNOSIS:
- Neuro/Muscular: Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, 3/74)
- Respiratory: Incomplete quad (has full sensation), no functional movement
- Gastro: Decreased esophageal motility, slip feeding gastrostomy tube (1/87)
- Orthopedic: Severe deformities, thoracic, pelvic obliquity, bilateral dislocated hips
- Urological: Undescended testicle (since birth), intermittent cath (1/01), cist 10 Fl.
- Blood Type: A (+) positive

MEDICAL

ACUPUNCTURE PHYSICIAN
Barbara XXXXX RN, AP, Orlando, FL
C: 352-xxxx-xxxx

INTENSIVIST
Melvin XXXX, MD, Orlando, FL
C: 352-622-xxxx

PULMONOLOGY/Neurology: Robert xxx MD, Gainesville, FL
C: 352-xxx-xxxx

HOSPITAL
North Fl Regional Medical Center, Gainesville, FL
4/95, 1979, 5/01, 5-1/01

IMMUNIZATIONS
- Pneumonia 01
- Tetanus 65
- Mumps 74

ENTERAL
- Pulmocare (237ml) x 2 cans, nocturnal 70 ml

RX DAILY
- Ativan: 0.5 mg x 2 daily
- Captopril: 81 mg x 1 daily
- Temazepam: 15 mg x 1 sleeping pill
- Dutro: 1 tablet x 120 mg

RX MONTHLY
- Thiamine: 100 mg monthly
- Cefuroxim: 1000 mg monthly (B12)

RX PRO
- Dexamethasone: 10 mg x 1 daily
- Zithromax: 200mg x 1 daily
- Diflucan: 1 tablet

INSURANCE

Blue Cross Blue Shield of Massachusetts
Primary Sub: XXXXXXXXXXX
Secondary Sub: XXXXXXXXXXX

BLUE CROSS BLUE SHIELD OF MASSACHUSETTS

MEDICINES
- VENT: Pulmocare LTV 900

INTERNIST

MEASUREMENTS

DOB: Gender: Male

Primary Diagnosis:

Other Diagnoses:

Current Medications:

Past Medications:

Annual Testing:

Medical Providers:

Name: Specialty: Contact No.

Policy: Special: Contact:

Phone: City: State: Zip:

Insurance:

DOB: 5/24/73  SS#: 289-XX-XXXX

APPROXIMATE AGE: 30  HEIGHT: 4'3" (51 inches)  WEIGHT: 80 lbs

Allergies: Sulfur Drugs, Adhesive Tape

Primary Diagnosis:

Other Diagnoses:

Current Medications:

Past Medications:

Annual Testing:

Medical Providers:

Name: Specialty: Contact No.
### Portable Medical Summaries

**MY NAME'S MEDICAL SUMMARY**

**ABOUT ME**

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<th>County:</th>
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**ALLERGIES:**

**EMERGENCY CONTACT:**

**Primary Care Giver/Decision Maker:**

**Relationship:**

**Legal Status:**

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<th>Informed Rop</th>
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**Advance Directive:**

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<th>WIA</th>
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**TO KNOW ABOUT ME:**

**MY IMMUNIZATIONS**

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<tr>
<th>Vaccine (see)</th>
<th>Date(s)</th>
<th>Measles, Mumps, Rubella</th>
<th>Diph</th>
<th>Hep A</th>
<th>Rabies</th>
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**Hepatitis B**

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<th>Date(s)</th>
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**FORE**

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**MY FAMILY HISTORY**

<table>
<thead>
<tr>
<th>Who</th>
<th>Condition</th>
<th>Who</th>
<th>Condition</th>
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<tbody>
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**MY PAST HOSPITALIZATIONS**

<table>
<thead>
<tr>
<th>Date</th>
<th>Hospitalization</th>
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<tbody>
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</table>

**MY PAST SURGERIES/PROCEDURES**

<table>
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<tr>
<th>Date</th>
<th>Surgery</th>
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**MY INSURANCE**

<table>
<thead>
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<th>Primary Insurance</th>
<th>E number</th>
<th>Good Until</th>
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<tbody>
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<table>
<thead>
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<th>Secondary insurance</th>
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<table>
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<tr>
<th>Waiver Type</th>
<th>Waiting List</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

<table>
<thead>
<tr>
<th>Waiver Care Manager</th>
<th>Phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent/Family</th>
<th>Young Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Major responsibility</td>
<td>-Provide care</td>
<td>-Receives care</td>
</tr>
<tr>
<td>- Support to parent/family &amp; child/youth</td>
<td>-Manages</td>
<td>-Participates</td>
</tr>
<tr>
<td>- Consultant</td>
<td>-Supervisor</td>
<td>-Manager</td>
</tr>
<tr>
<td>- Resource</td>
<td>-Consultant</td>
<td>-Supervisor</td>
</tr>
</tbody>
</table>
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](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 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


- 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](http://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**


**What is HealthVault?**
Microsoft HealthVault is a trusted place for people to gather, store, use, and share health information online. [Learn more](https://www.healthvault.com/us/en)

- **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
Step 3: Review the Schedule

<table>
<thead>
<tr>
<th>Medication</th>
<th>At These Times</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ditropan XL&lt;sup&gt;6&lt;/sup&gt;</td>
<td>8am 2 tablets</td>
<td>Treats overactive bladder</td>
</tr>
<tr>
<td>(Oxybutynin chloride)</td>
<td>9pm 2 tablets</td>
<td></td>
</tr>
<tr>
<td>(Extended release tablet(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TYLENOL®</td>
<td>2 tablets</td>
<td>Pain reliever</td>
</tr>
<tr>
<td>(Acetaminophen)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>325 mg Tablet(s)</td>
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</table>

Rebecca's Schedule

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

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

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

MyAccount | Find a Pharmacy | Log Out | Help

For more information, visit www.mymedschedule.com
# ICAAP Transition Handouts

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

## Resources and Tools for Families

<table>
<thead>
<tr>
<th>File Name</th>
<th>Size</th>
<th>Link</th>
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<tbody>
<tr>
<td>TransitionAdulthoodTeen.pdf</td>
<td>571 KB</td>
<td>Transition to Adulthood Handout for Teens</td>
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<tr>
<td>HealthCareTransition.pdf</td>
<td>457 KB</td>
<td>Health Care Transition Handout</td>
</tr>
<tr>
<td>ChecklistTeens.pdf</td>
<td>284 KB</td>
<td>Transition Checklist for Teens</td>
</tr>
<tr>
<td>ChecklistCaregiver.pdf</td>
<td>242 KB</td>
<td>Transition Checklist for Parents/Caregivers</td>
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<tr>
<td>HowWellKnowHCNeeds.pdf</td>
<td>239 KB</td>
<td>How Well Do You Know Your Health Care Needs?</td>
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<tr>
<td>TransitionAdulthoodParent.pdf</td>
<td>884 KB</td>
<td>Transition to Adulthood Handout for Parents and Caregivers</td>
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<td>TransitionIssuesSpecialNeeds.pdf</td>
<td>915 KB</td>
<td>Transition Issues for Adolescents with Special Needs Brochure</td>
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<td>GuideToAdultBenefitsReadOrder.pdf</td>
<td>1,270 KB</td>
<td>Guide to Adult Benefits, Services, and Resources</td>
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<td>GuideToAdultBenefitsPrintOrder.pdf</td>
<td>1,209 KB</td>
<td>Guide to Adult Benefits, Services, and Resources (for print orders)</td>
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<td>Guardianship.pdf</td>
<td>761 KB</td>
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<td>DoYouUnderstandInsurance.pdf</td>
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<td>Do You Understand Insurance?</td>
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<td>FillingPrescription.pdf</td>
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<td>MedicalEmergency.pdf</td>
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<td>What To Do In A Medical Emergency</td>
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<td>TakeMedsAsDirected.pdf</td>
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<td>WorkingWithDoctor.pdf</td>
<td>477 KB</td>
<td>Working With Your Doctor</td>
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<td>PortableMedicalSummary.pdf</td>
<td>137 KB</td>
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</tr>
</tbody>
</table>
Transition Videos-Nemours Hospital

- **Legal and Financial:**

- **After High School**

- **Where to Live:**

- **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
DI RE CTI ONS

• 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

Your Voice

Advocacy
Contact Information

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