What is transition?

“Transition in health care for young adults with special health care needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood”

American Academy of Pediatrics, 2002
What is Transition?

- A process
- More than a “transfer* of care”
- Patient-focused (not parent)
- Individualized
- Involves learning knowledge and skills

* Transfer of care is when you actually move to adult care for appointments

Progression of Responsibility

Health Care Provider = HCP

- (medical doctor, physician assistant, nurse practitioner)
- Parent
- Youth
Transition Timeline

• Should start between 11-13 years old
  – Start small: learning names of meds, answering some questions

• Gradually add to knowledge & skills

• Should include other aspects of life, not just health

• Time of transfer of care varies
  – Best to be done when healthy, not during a flare
  – Some hospitals require transfer at age 18
  – Going to college near home vs far away
<table>
<thead>
<tr>
<th></th>
<th>Pediatric Care</th>
<th>Adult Care</th>
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</thead>
<tbody>
<tr>
<td>Person-focused</td>
<td>Patient, parents, family</td>
<td>Patient: you &amp; only you</td>
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<tr>
<td>Doctor-patient relationship</td>
<td>Ongoing relationship</td>
<td>New relationship, get to know each other</td>
</tr>
<tr>
<td>Members of healthcare team</td>
<td>Multiple</td>
<td>Fewer</td>
</tr>
<tr>
<td>Resources</td>
<td>More</td>
<td>Fewer</td>
</tr>
<tr>
<td>Patients per doctor</td>
<td>Fewer</td>
<td>More</td>
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<tr>
<td>Office visit length</td>
<td>Longer</td>
<td>Shorter</td>
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<tr>
<td>Pain management for procedures</td>
<td>Sedation, high focus</td>
<td>In the office, no sedation, lower focus</td>
</tr>
<tr>
<td>Time perspective</td>
<td>Focus on future</td>
<td>Focus on “right now”</td>
</tr>
<tr>
<td>Patient and parental responsibility</td>
<td>Pt must take meds and do tests - doctor follows up if not</td>
<td>Patient may or may not follow doctor’s recommendations</td>
</tr>
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</table>
Challenges for Pediatric Providers when Transitioning Patients

• Finding time in clinic to teach transition knowledge and skills
  – We can utilize nurses and other staff to help

• Spending time alone with patients
  – Time constraints in clinic
  – Discomfort with discussing sexuality, drugs
  – Parents want to know what’s going on
  – You can specifically ask to talk alone

• Enlisting parents to let their kids take charge
  – We should educate parents about transition, not just kids
Challenges for Adult Doctors Who Inherit Pediatric Patients

- Giant stacks of medical records
  - Pediatric doctors should send a summary of care
  - Best for doctors to communicate directly to hand off patient
  - Helpful when patient can summarize for the new doctor

- Some adult doctors feel bad that they can’t provide a similar level of care
  - Time constraints
  - Pediatric providers provide more “hand-holding” and reminders
Challenges for Adult Doctors Who Inherit Pediatric Patients

• Low familiarity with pediatric rheumatic disease
  – Differences between disease presentation in a child versus in an adult
  – Medications used differently
  – Monitoring labs and studies may be done differently, less frequently
Juvenile vs Adult Myositis

**Juvenile myositis**
- Onset of disease is not associated with cancer
- Disease and treatments affect growth and development
- Disease might last longer

**Adult myositis**
- Myositis often develops as a symptom of having cancer
- Patients are already fully grown and developed
- Disease might go away when cancer is treated
- Disease might be more severe

**Similarities**
- Similar findings: rashes, weakness
- We use the same medications for treatment
Breakdown of Transition Process
Disease Process

**Knowledge**
- What disease you have
- What goes wrong in people with this condition
- Time course of your illness & treatments
- Signs of a flare
- Purposes of tests
- When to call the HCP
- Which HCP to call for what symptoms

**Skills**
- Describe disease in your own words (3 sentences)
- Describe your medical history
- Call HCP when having new/worrisome symptoms
Medications

**Knowledge**
- Names of previous and current medications and doses
- Purpose of medications
- Side effects
- Interactions with other medications, alcohol, drugs

**Skills**
- Keep a list of medications
- Take medications on own without reminders from parents
- Refill your prescriptions
- Call HCP about worrisome side effects
## Healthy Practices

### Knowledge
- Importance of exercise/healthy eating
- Effects of alcohol, drugs, and tobacco on health and with medications
- Reproductive health
  - Effects of medication
  - Sexually transmitted infections
  - Risks of pregnancy

### Skills
- Make good diet choices
- Stay active (to best of your ability)
- Talk to HCP about use of drugs & alcohol
- Talk to HCP about sexually transmitted infections & birth control options
Office Visits/Adult Care Model

Knowledge

- Role of each HCP
- Paperwork required for appointments
- Privacy & confidentiality rights
- Medical & surgical history

Skills

- Keep a list of questions
- Talk to HCP by yourself
- Attend appointments by yourself
- Schedule appointments
- Sign consents
- Keep a portable medical/health record
Insurance

Knowledge

- Insurance coverage
- Copays/deductibles
- When insurance ends
- How to apply for health insurance

Skills

- Bring insurance card to appointments
- Complete necessary paperwork
- Pay copays
- Ask and apply for assistance and resources
Transition Resources

- **Adolescent Health Transition Project** - A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities. [http://depts.washington.edu/healthtr/](http://depts.washington.edu/healthtr/)


- Ask Amy & Morgan Gleason about app for medical records
Transition Resources


- **JA Transition Tool Kit** – An individualized tool kit that provides information on how develop transition skills specific to juvenile arthritis. [http://www.kidsgetarthritistoo.org/resources/transition-toolkit.php](http://www.kidsgetarthritistoo.org/resources/transition-toolkit.php)

- **State of Illinois Division of Specialized Care for Children (DSCC)** – Their website has a section dedicated to transition with information for adolescents and parents [http://internet.dscucc.uic.edu/dsccroot/parents/transition.asp](http://internet.dscucc.uic.edu/dsccroot/parents/transition.asp)
References


