

Transitioning from Pediatric to Adult Care

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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

	Pediatric Care	Adult Care
Person-focused	Patient, parents, family	Patient: you & only you
Doctor-patient relationship	Ongoing relationship	New relationship, get to know each other
Members of healthcare team	Multiple	Fewer
Resources	More	Fewer
Patients per doctor	Fewer	More
Office visit length	Longer	Shorter
Pain management for procedures	Sedation, high focus	In the office, no sedation, lower focus
Time perspective	Focus on future	Focus on "right now"
Patient and parental responsibility	Pt must take meds and do tests – doctor follows up if not	Patient may or may not follow doctor's recommendations

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/>
- **American Academy of Pediatrics, Illinois Chapter** – Resources and tools for families working on transition.
<http://illinoisaap.org/projects/medical-home/transition/resources-for-families/>
- Ask Amy & Morgan Gleason about app for medical records

Transition Resources

- **Got Transition? National Healthcare Transition Center**
– A national resource with information and tools for youth and for families. <http://www.gottransition.org/>
- **JA Transition Tool Kit** – An individualized tool kit that provides information on how develop transition skills specific to juvenile arthritis.
<http://www.kidsgetarthritis.com/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.dsccl.org/dscclroot/parents/transition.asp>

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