Growing Up on Nutrition Therapy: Transitioning from Pediatric to Adult Care

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Growing Up on Nutrition Therapy

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Brief medical history from childhood to adulthood

- Diagnosed with Crohn’s Disease at age 9 in 1979
- First hospitalization at age 12
- On NG-tube feeds briefly and then home TPN from age 14 to 31
- Independence increased during college years from age 18 to 22
First time in the hospital - 1982

• Fear at the beginning
• Learned to more effectively communicate with nurses and doctors
• Big change in attitude by the end of the six-week stay
Teen years – Learning to do it myself

- More involved in self care
- Became a more critical thinker
- Weighed health decisions
College years – taking charge

- Overcame fear of administering TPN without family around
- Called the nurse or doctor on my own when problems arose
- Made friends who were sympathetic and not averse to helping me if I had a problem
- Became the primary decision-maker in issues involving my health
Looking back – lessons learned

- Keep an open mind.
- It’s OK to pull away from your parents, but don’t shut them out.
- Find health care professionals you are comfortable with.
- Accept help that will make your life easier.
- Join groups like the Oley Foundation and the Feeding Tube Awareness Foundation.
- Don’t let your care slip!
Transitioning from Pediatric to Adult Care – The Physician’s Perspective

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Agenda

1. Goals of successful transition
2. Barriers
3. Algorithm
4. Checklists
5. Expectations
6. What Parents Can Do
Goals of Successful Transition

• To ensure that “high-quality, developmentally appropriate health care services are available in an uninterrupted manner”
• Process starts in early adolescence
  – Timing is individualized
• Ideally is completed between 18-21 y/o
• Provide a structure for training and continuing education
Barriers to transition

• Complex, unique process
• Lack of transition support & preparation:
  – Limited office staff training
  – Lack of identified, healthcare team/ staff members responsible for transition
• Financial/ insurance barriers
• Paucity of adult providers for medically complex patients with chronic conditions
• Anxiety regarding planning future health care
Algorithms for Transition

CLINICAL REPORT – SUPPORTING THE HEALTH CARE TRANSITION FROM ADOLESCENCE TO ADULTHOOD IN THE MEDICAL HOME

Algorithms for Transition

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Algorithms for Transition

CLINICAL REPORT – SUPPORTING THE HEALTH CARE TRANSITION FROM ADOLESCENCE TO ADULTHOOD IN THE MEDICAL HOME

Transition of Children with Special Health Care Needs

• An important feature of transition planning is individualization & recognition that certain tasks that lead to patient self-management are beyond the capability of some young adults whose medical conditions include physical or cognitive challenges.
  – It is important to discuss this as a team early on in the process
  – Equally important to assess transition readiness
Pediatric to Adult Care: Transition Planning Checklist

• 1 to 2 years before anticipated transition to new adult care providers
  – Introduce the idea that transition will occur in the future
  – Encourage shared responsibility between the young adult and family for:
    • Making appointments
    • Refilling prescriptions
    • Calling health care providers with questions or problems
    • Making insurance claims
    • Carrying insurance card
Pediatric to Adult Care: Transition Planning Checklist (continued)

• 6 to 12 months before anticipated transition
  – Discuss health insurance coverage and review options with family
    • Make an appointment with a case manager or social worker
  – Prepare health information to provide to the adult care team
    • Review specifics of underlying condition: (e.g. for intestinal failure patients: TPN calories, hydration, CVC access, IFALD)
  – Provide information about differences between pediatric and adult health systems and what the young adult can expect at first visit
    • Patient's responsibilities
    • Confidentiality/parental involvement (e.g., HIPAA Privacy Act and parents need permission from young adult to be in exam room, see test results, discuss findings with health care providers), health care proxy
  – Help identify next health care providers if possible
  – Discuss upcoming changes in living arrangements (e.g., dorms, roommates, and/or living alone)
Pediatric to Adult Care: Transition Planning Checklist (continued)

• 3 to 6 months before anticipated transition
  – Review and remind of above health insurance changes, responsibility for self-care, and link to resources
  – Obtain signature(s) for release for transfer of personal medical information and for pediatric care providers to talk with the new adult health care providers
  – Identify new adult care physician
Transitioning from Pediatric to Adult Care: Transition Planning Checklist

### Transition Checklist for Teens

**Accessing Healthcare: Skills and Abilities**

- Do you have a medical home for ongoing medical conditions?
- Do you schedule appointments for yourself?
- Do you help make healthcare decisions with your family or doctor?
- Do you understand your role in your healthcare?
- Do you know your rights to keep your health information private?
- Do you know who to call if you have a problem?
- Do you know what your healthcare providers are doing for you?
- Do you have an updated medical summary and contact information?
- Do you have a current email address?

**Managing Your Conditions and Treatments: Skills and Abilities**

- Do you know how you can affect your health conditions and do you know how they affect your daily life?
- Do you know the name of your medicine and why you take them?
- Do you know what can happen if you stop your treatment or medication?
- Do you know how to control your condition (medication, activity, lifestyle)?
- Do you know what to do if you get adverse reactions?
- Do you know what to do if you forget to take your medicine?
- Do you know what to do if you get symptoms?

**Staying Healthy: Skills and Abilities**

- Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?
- Do you understand how smoking, drinking, and using drugs can affect your condition (e.g., exercise, smoking, etc.)?
- Do you know your health condition affects the use of food or exercise?
- Do you know what foods are good for your health?
- Do you know how to set up a system for daily activities?

**Transitioning Care: Skills and Abilities**

- Do you know how to use your health insurance benefits (co-pays, deductibles)?
- Do you know who to call for questions about your insurance coverage?
- Do you know how to call for appointments for your doctor appointment?

**Other Areas of Transition: Skills and Abilities**

- Do you know what you will do after high school (job, college, etc.)?
- Do you know what healthcare resources are available for you?
- Do you know how your medical condition might affect your job choices?
- Do you know about health benefits (e.g., Medicaid, Medicare, etc.)?
- Do you know about eligibility for senior or low-income healthcare benefits?
- Do you know your mental health resources?

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**References**


Transitioning youth to adult healthcare: new tools from the Illinois Transition Care Project
### Managing Expectations: Differences in Adult and Pediatric Culture of Care

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<thead>
<tr>
<th>PEDIATRIC</th>
<th>ADULT</th>
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<tbody>
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<td>• Individual-based</td>
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<td>• Developmentally oriented</td>
<td>• Disease focused</td>
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<td>• Nurturing, high level of psychosocial support</td>
<td>• Depends on patients to be autonomous/ independent</td>
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<td>• Interdisciplinary</td>
<td>• Multidisciplinary</td>
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What Parents Can Do in the Transition Process

• Ask your child’s pediatrician and other pediatric physicians at what age they typically transition patients to adult clinics.

• Understand that transition can lead to feelings of nervousness, excitement, hope, and frustration for all family members involved. It is important to have patience and provide support to each other during this process.

• Work with your pediatric clinic to develop a list of goals for transition, and check in on these goals at each routine visit.

• Talk with your child early and often about his or her role as a patient and that he or she will take an increasing role in his or her own health care over time. Provide positive reinforcement when your child shows independence in his or her own health care.
## Resources

### General Resources
- National Health Care Transition Center, [www.gottransition.org](http://www.gottransition.org)
- Family Voices, Inc., [www.familyvoices.org](http://www.familyvoices.org)
- Family-to-Family Health Information & Education Center, [www.bridges4kids.org/f2f](http://www.bridges4kids.org/f2f)
- Kids as Self Advocates (KASA), [www.fvkasa.org](http://www.fvkasa.org)
- National Alliance to Advance Adolescent Health, [www.thenationalalliance.org](http://www.thenationalalliance.org)

### Transition Care Plans
- AAP/National Center for Medical Home Implementation ([www.medicalhomeinfo.org/how/care_delivery/transitions.aspx](http://www.medicalhomeinfo.org/how/care_delivery/transitions.aspx)).
- University of Washington, Adolescent Health Transition Project, [http://depts.washington.edu/healthtr](http://depts.washington.edu/healthtr)

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Resources

Transition Assessment and Evaluation Tools

- JaxHATS, evaluation tools for youth and caregivers and training materials for medical providers, www.jaxhats.ufl.edu/docs
- Texas Children’s Hospital transition template, http://leah.mchtraining.net/bcm/resources/tracs
- Carolina Health and Transition Project (CHAT), www.mahec.net/quality/chat.aspx?a10

Portable Medical Summaries

- Sick Kids, www.sickkids.ca/good2go

FEEDING TUBE
AWARENESS FOUNDATION

Traci Nagy
Founder, Feeding Tube Awareness Foundation

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Organization Mission

The organization has a dual mission.

1. To provide parents with the practical information they need to navigate day-to-day life with a child who is tube-fed.

2. To raise positive awareness of tube feeding as a life-saving medical intervention, so that parents get the support they need.
How do we support parents?

• We are an unparalleled resource for pediatric tube feeding.
  – Newly designed website (www.feedingtubeawareness.org)
    • Comprehensive
    • Easily navigated
  – Parent education materials
  – Largest online support forum – Facebook page
    • More than 35K followers, significant reach, thousands engaged
Feeding Tube Awareness Week

• In 2011, we held the first Feeding Tube Awareness Week®, which highlighted the positive benefits of tube feeding.

• Millions have been reached through newspapers, TV, social media and company outreach.

• We changed the dialogue about tube feeding, empowering parents and tube feeders.

Get involved!
www.feedingtubeawarenessweek.org
Transitioning to Adult Care

• On the Feeding Tube Awareness Facebook Page, we asked parents to tell us about their experiences with their transition and tips for other parents making the transition from pediatric to adult care.
Challenges

• **Starting Over.** It feels like having to start over after having mastered everything.

• **Finding a good PCP.**

• **Coordinating Care Across Hospitals.** Some doctors will keep pediatric patients into adulthood, but some will not. This leaves parents coordinating care between Children’s and Adult hospitals.

• **Knowing Your Child.** Having new doctors understand the capabilities/limitations of your child.
Who Can Help?

Pediatricians:
- Some pediatricians (and Children’s Hospitals) will keep their special needs/medically complex pediatric patients beyond 18 or 21.
  - However, there can be insurance complications, so make sure those are worked out in advance.
- Pediatricians may be able to help find a PCP

Your Children’s Hospital/Specialists:
- If your child needs to transition, make sure that the Children’s Hospital will continue to see them until the transition is complete and all adult care providers are in place.
- Some hospitals have transition or bridge programs in place.

Palliative Care:
- One parent, who is currently transitioning, is getting help from Palliative Care to find a new medical team.
Tips From Those Who Transitioned

• Start the process early if you need to switch.
  – Find out which doctors will maintain relationships into adulthood and which will not.
• Ask your trusted pediatric doctors who they see.
• Try to find a family practitioner who sees both pediatric and adult patients.
• Try to transition at a time when your child is more stable, not in an emergent situation.
• Stick with a University Hospital that also has a NICU, that way there are pediatric specialists on staff to consult with.
• Be emotionally prepared for the “adult” environment, which can be more bleak and less cheery than pediatrics.