

Searching for a cure



Cystinosis Research Network

Bridging the Gaps:

Transitioning from Pediatric to Adult Care

Texas Children's Hospital

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Presentation Objectives

- Definition and Goals of Transition
- Obstacles
- Recommendations
- Stages of Adolescence
- Specific conditions
- Advances in transitioning



What is Transition?

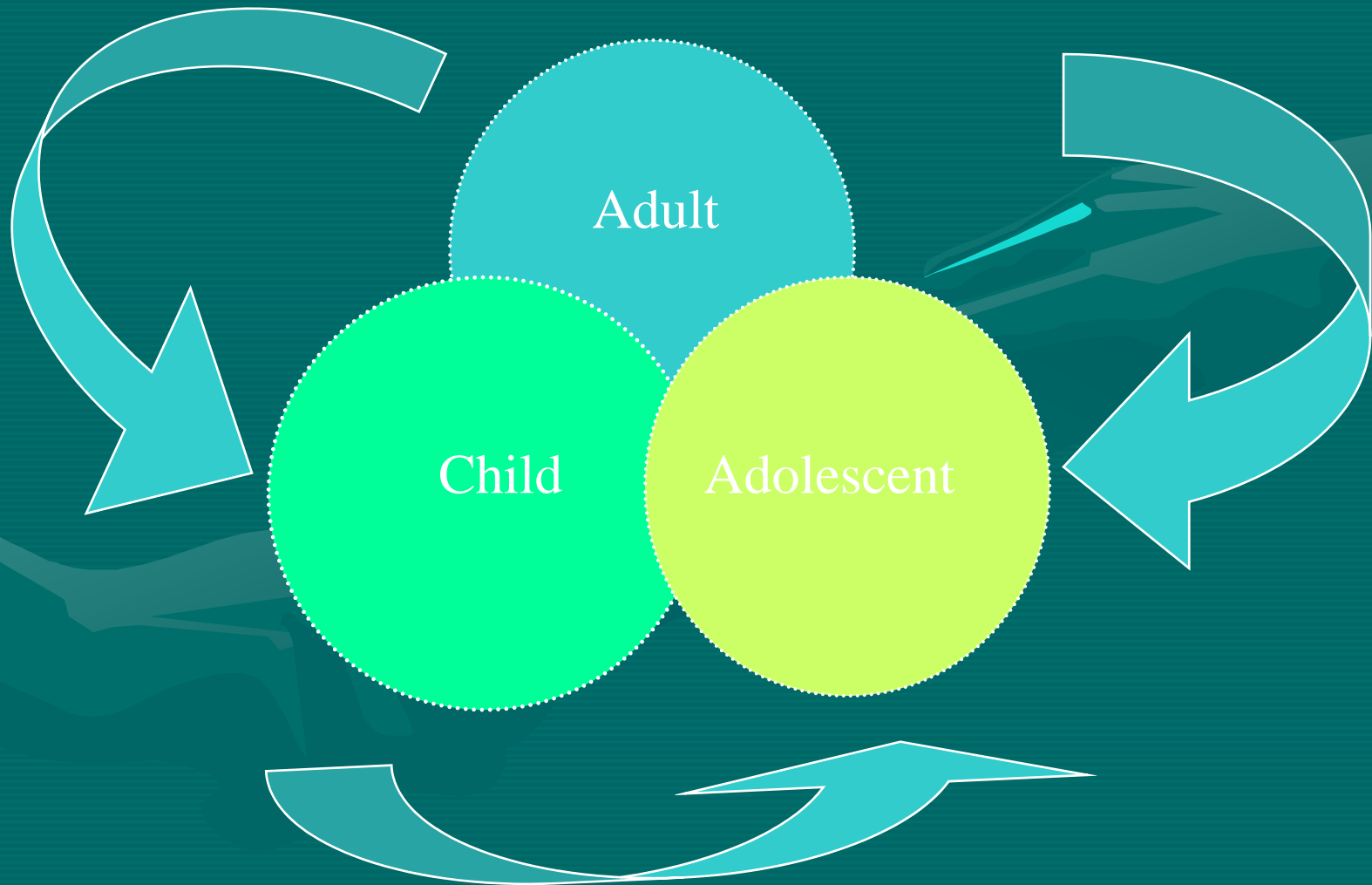
“Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system”

Goal of Transition

To maximize lifelong functioning and potential through the provision of high quality, *developmentally appropriate* health care services that continue uninterrupted as the young adult moves from adolescence to adulthood.



Transition is a Process

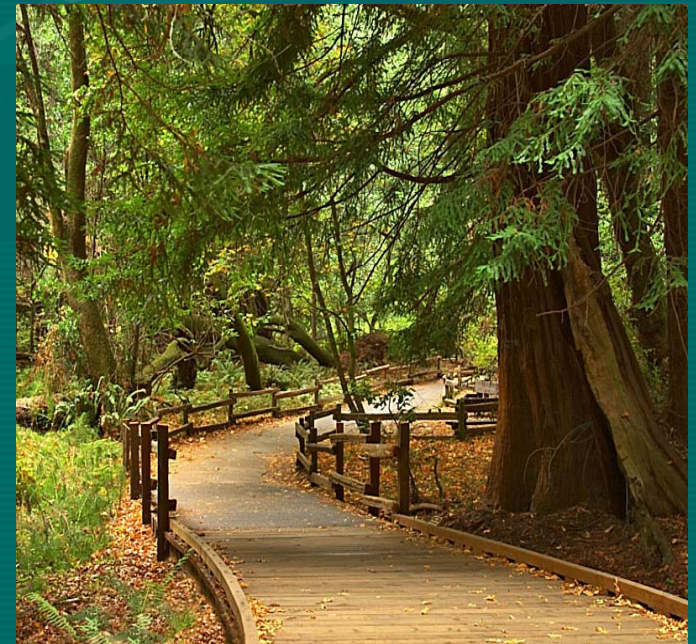


Transition is a Journey

- Childhood to adulthood characterized by:
 - Anger, confusion, hope and despair, mastery of essential life skills for independence.

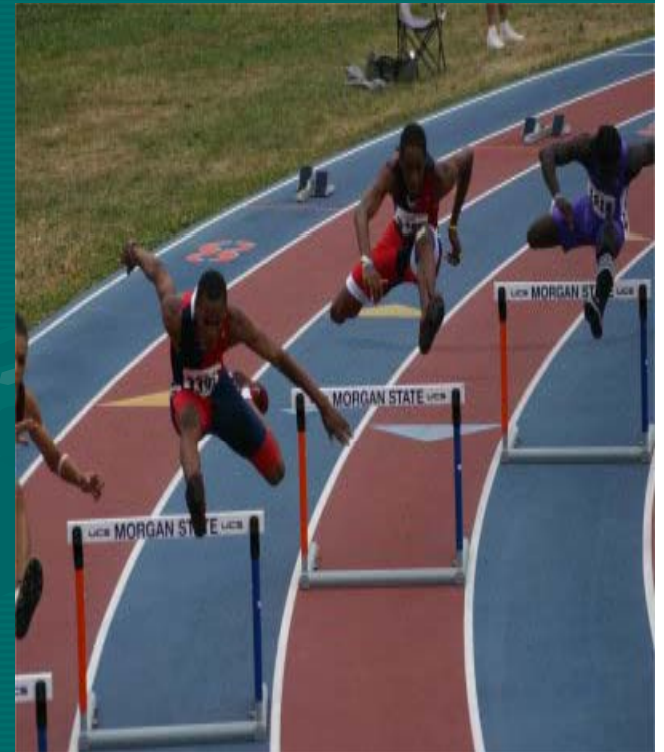
For youth with chronic illnesses this process can be delayed.

- Exploring limits
- Reality testing
- Self-image development



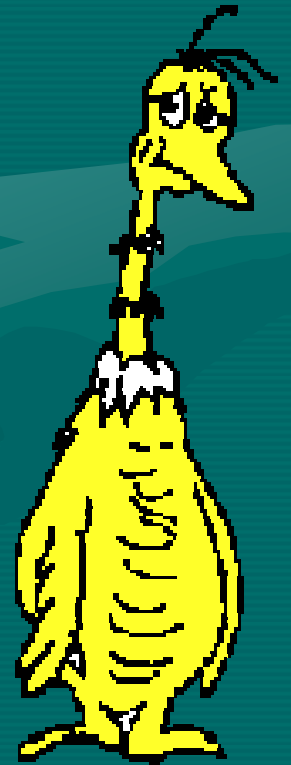
Obstacles to Transition

- Prognosis of patient's diagnosis
- Understanding need for transition by patient and family
- Environmental or familial stressors
- Need to control by either parents or health care team
- Distorted perception of patient outcome



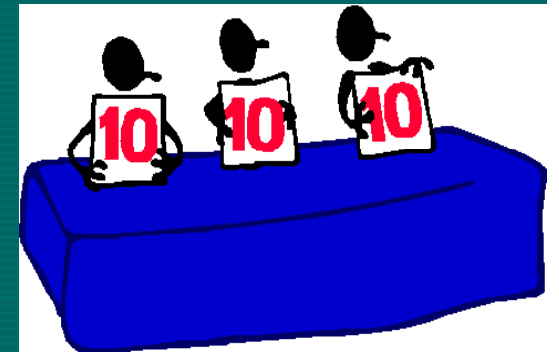
Negative Messages

- Patient/Child is incapable of independent care
- Patient/Child is not expected to assume self-responsibility and will be taken care of
- Patient/Child is very different from his or her peers
- The medical prognosis is too poor to warrant planning for the future



Importance of Transition- *Consensus*

- Identified health care provider (HCP) to partner with youth/families during transition
- HCP with core knowledge and skills
- Maintain current medical record
- Create written plan by age 14
- Apply preventive and primary care to youth with/without special health care needs
- Ensure affordable and continuous health insurance coverage



Transition Framework

Healthy People 2010- Department of Health & Human Services

Goal- All young people with special health care needs will receive the services necessary to make the necessary transition to all aspects of adult life

- Health care
- Work
- Independent living

Steps to achieve goal

- Knowledge
- Medical summary
- Written plan for family



Where to Begin?

- Need to understand the stages of adolescence
- Health care transition process
- Responsibilities of the patient, family, and health care team
- Tools for gaining knowledge of ‘what and when’ the patient needs to know in order to complete the transition *successfully*



“Ingredients” of Transition

- Getting consent and cooperation of the patient
- Enlisting active support of the family
- Getting the support of **all** the medical professionals
- Instituting a policy on timing of transfers
- Establishing a preparation and education program prior to transition
- Define expectations
- Gather information about available adult services
- Consider having pediatrician and adult M.D. as co-managers for a period of time.



What You (Patient/Family) Expect

- Medical regimen and clinic visits that promote adherence, education
- Educational tools
- Monitoring for side effects/complications
- Support and promote healthy lifestyle
- Identification as an unique individual
- Guidance for long term care
- Identification of long term care providers
- Support for insurance issues
- Support for career planning



Know your health care team members!

- Take full advantage of the various health care team members

- MDs, RNs, TX RNs, CCLS, LMSWs, RDs

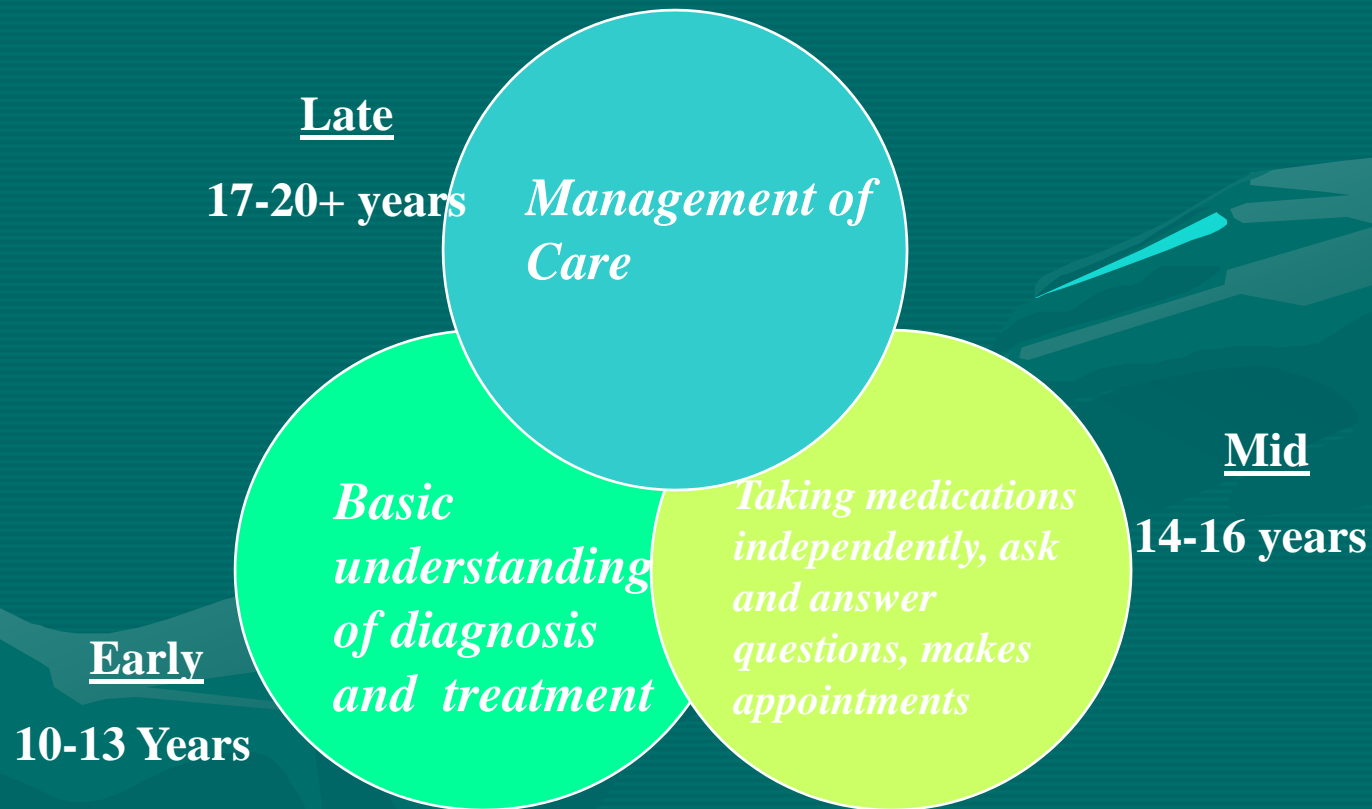
Wealth of information and tools at your reach!

Ask questions? You are the best advocate!



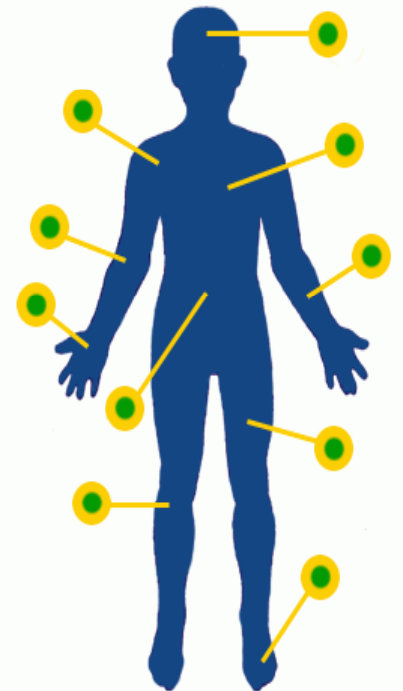
Social Workers
Help starts here.

Stages of Adolescence & Medical Tasks



Early Adolescence (10-13 years) & The Medical Team

- Learn about normal body function
- Describe the diagnosis in age appropriate terms
- Name medications taken
- Manage tasks at school



Mid Adolescence (14-16 years) & The Medical Team

- Recognize symptoms that indicate a need for immediate treatment
- Seek help when problems arise
- Keep a medical journal or personal health notebook
- Call for prescription refills
- Take charge for scheduling appointments
- Acknowledge understanding of changes in medications and treatment
- Know the difference between primary and specialist care
- Assents to medical care (age 15)
- Understand they will be transferring to adult care

For children age 13-14 years with a chronic illness,
which statement is a good indicator that they will
have a successful transition?

- A) “I have told my best friend about my diagnosis”
- B) “I have a supportive family”
- C) “I do chores around the house”



Late Adolescence (17+ years) & The Medical Team

- See medical team members independently
- Know common complications of diagnosis
- Call for lab results
- Discussions regarding plan of transfer should become more frequent
- Manage all regular medical tasks– self advocate!
- Aware of medical insurance coverage
- Identifies rights and responsibilities of being a patient
- Signs consents (18 years of age)
- Learn about the systems that will apply to them as adults (i.e. insurance, social security, guardianship, advanced directives)

Insurance Issues

- Types of coverage varies state by state (Medicaid, MediCal ,CSHCN, etc.)
 - Some commercial insurances will cover until 25 years of age if a full time student
 - Limitations or restrictions
 - “Preexisting” clause ☹
 - Supplemental Security Income (SSI)
 - Means tested along with diagnosis
- Check eligibility for SSI month she/he turns 18
- Their financial resources are evaluated; not parents/guardians

Read the fine print!



Questions to Ask

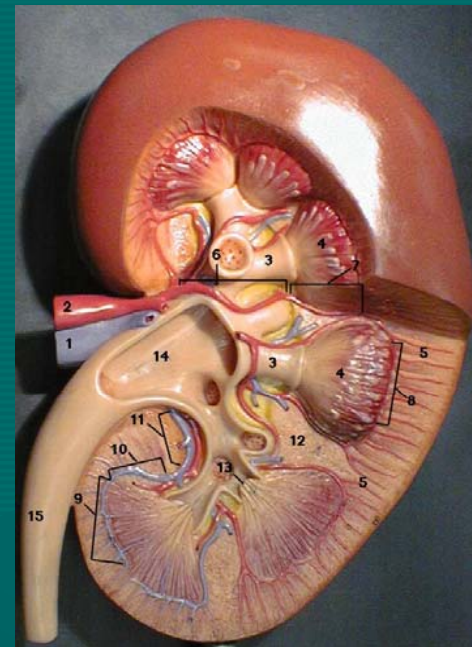
- How often should I see the physician/ medical team?
- Will my appointments have a major impact on my education and or employment?
- How will I find out test results?
- How will I obtain prescriptions?
- Who do I call if I become ill between visits?
- What do I do if I have trouble with insurance?
- If I need surgery, who will be consulted?
- What will the effects of aging have on my condition?
- Will my condition affect my ability to have children?

Considerations

- Process should be gradual and individualized
- Discussions should be held at regular intervals (i.e. Care Plan Meetings) starting early in adolescence
- Progress and limitations noted
- Transfer should occur by the age of 18-21 years
 - AAP have “floating recommendations”
 - “Special circumstances” such as chronic illness may make pediatric care optimal for some beyond age 21

Transitioning for the Renal Patient

- CKD
- Dialysis
- Transplanted
- Transplant list



Expectations of Adult Practice

- Patient has the knowledge of condition, treatment and plan of care
- Knows medications
- Written summary
 - Can be done with dictation of last visit
 - Last set of labs, x-rays, ultrasounds, etc.



Attachment

Transition Timeline for Children and Adolescents with Special Health Care Needs: Chronic Illnesses/Physical Disabilities

Parent and Child Interactions that Encourage Independence

Birth to 3-5, or according to your child's developmental ability

- Assure your infant the world is a good place in which to live. The development of a sense of trust is vital to the development of a healthy personality.
- Allow your child to develop at his/her own individual rate.
- As a parent it is important to take short breaks from your child to renew energy with which to enjoy him/her.
- Begin keeping a record of your child's educational and medical history, including immunizations.

By ages 3-5, or according to your child's developmental ability

- Assign your child chores appropriate for his/her ability level.
- Encourage decision-making skills by offering choices.
- Teach consequences of your child's behaviors and choices.
- Continue involvement in community and recreational activities that include children with and without special needs.
- Begin asking "What do you want to do when you grow up?"
- Begin teaching your child about his/her special health care need.
- Begin teaching your child self-care skills: normal skills and those related to his/her special health care need.

By ages 6-11, or according to your child's developmental ability

- Begin helping your child interact directly with doctors, nurses, therapists and teachers.
- Assess your child's perception and basic knowledge of his/her special health care need. Build on their understanding.
- Continue teaching your child normal self-care skills as well as skills related to his/her special health care need.
- Determine whether reasonable accommodations are needed to ensure equal access to school programs; if so, ask if your child qualifies for a 504 plan.
- Encourage hobbies and leisure activities; include exploring community and recreational activities, clubs, 4-H, Scouts, Campfire, YMCA, sports, etc.
- Continue to encourage decision-making skills by offering choices.
- Continue assigning your child chores appropriate for his/her ability level.
- Take your child shopping whenever possible so he/she can help in choices.
- Let your child choose how to spend some or all of allowance.
- Teach your child the consequences of his/her behaviors and choices.
- Allow your child to experience the consequences of a poor choice as well as a good choice.
- Begin teaching your child self-advocacy skills.
- Begin asking your child "What will you do when you grow up?"

By ages 12-18, or according to your child's developmental ability

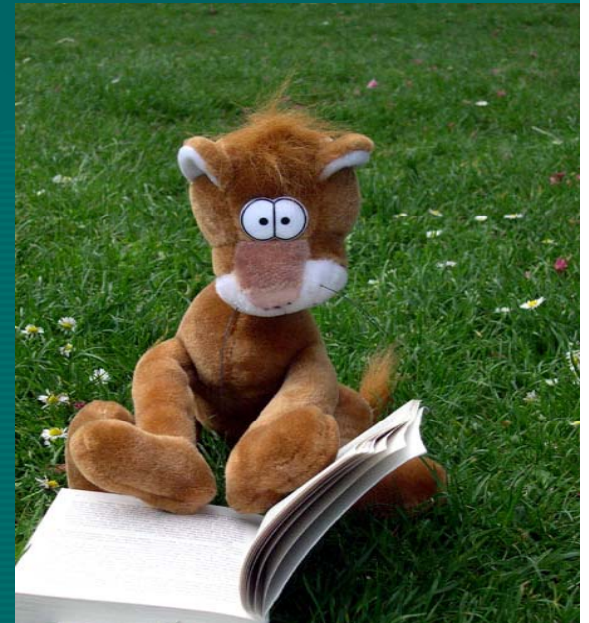
- Assess your teen's perception and basic knowledge of his/her special health care need. Fill in gaps in understanding.
- Continue teaching your teen normal self-help skills as well as skills related to special health care need.
- Begin helping your teen keep a record of his/her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and 504 plan if he/she has one.
- If has a 504 plan, encourage teen to participate in any 504 meetings.
- Begin helping your teen take responsibility for making and keeping his/her own medical appointments, ordering their own supplies, etc.
- Begin exploring health care financing for young adults at age 17.
- Discuss sexuality with your teen.
- Help your teen identify and build on his/her strengths.
- Explore support groups, if teen is interested.
- Begin to explore and talk about possible career interests with your teen.
- Help your teen find work and volunteer activities.
- Continue to allow your teen to help with family chores.
- Continue to encourage hobbies and leisure activities.
- Help your teen identify and be involved with adult or older teen role models.
- Begin, with your teen, looking for an adult health care provider.
- Encourage teen to contact campus disabled student services to request accommodations if he/she will be attending college.
- With teen, check eligibility for SSI the month he/she turns 18. At age 18, the teen's financial resources are evaluated, not the parents/guardians'.

By ages 18-21, or according to your child's developmental ability

- Act as a resource and support to your young adult.
- Encourage your young adult to participate in support groups and/or organizations relevant to his/her special health care need.
- Finalize health care financing with your young adult.
- With your young adult, finalize transfer of medical care to adult provider.
- For young adult attending college, encourage continued contact with disabled student services as needed for accommodations.
- Encourage young adult to investigate services provided by Division of Rehabilitation Services (DRS) if he/she has not already done so.

Advances in Transition Programs

- More and more pediatric centers developing their own programs for transitioning
- Creating “toolkits” and “passports”
- Connecticut Children’s Medical Center’s Kit:
 - File Folder, ongoing use and update at every visit
 - Check list according to 3 stages of adolescence
- Knowledge of condition
- Healthcare
- Bone Health
- Lifestyle Issues
- Psychosocial
- Sexual Health
- Education/Vocation
- Implementation of transition



Resources

Build your own care notebook

www.medicalhomeinfo.org/tools/care_notebook.html

CMS Health Care Transition Workbooks

hctransitions.ichp.ufl.edu/resources.html

National Dissemination Center for Children with Disabilities

www.nichcy.com

National Center in Secondary Education and Transition

www.ncset.org

Youthhood. Transition planning for youth with & without disabilities.

www.youthhood.org

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Start small. Start slow. Start now!

