Transition from Paediatric to Adult Care for Young Adults With Childhood Onset Chronic Disease

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Purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of young people with chronic medical conditions, as they move from child-centered to adult-oriented health care system.
Transition from Pediatric to Adult Care for Young Adults
With Childhood Onset Chronic Disease – Who are we talking about?

Age: 15–25 years

US: 39.2 million

5–10% (4 million) have serious chronic conditions

0.5 million young adults transition from pediatric to adult care every year

2010 US Census Data

Cerebral palsy
Type I Diabetes
Cystic Fibrosis
Congenital heart disease
Transplants
Rare genetic and metabolic disorders
Severe asthma
Spina bifida
Inflammatory bowel disease
Lupus
Sickle Cell Disease
Muscular Dystrophy and many others…
“Transition readiness is the capacity of the adolescent and those in his/her primary medical system of support...to prepare for, begin, continue and finish the transition process. In contrast, transfer is a discrete event.”

- Tuchman LK, Schwartz LA, Sawicki GS, Britto MT: “Cystic Fibrosis and Transition to Adult Medical Care.” Pediatrics 2010; 125; 566-573
Barriers to Successful Health Care Transition – Youth/Family

- Little family awareness & knowledge of HCT
- Lack of preparation of youth for HCT
- Adult oriented medical providers lack of knowledge of childhood onset chronic conditions
- Transition often prompted by age or behavior rather than readiness
- Differences in Child and Adult Medicine

Health Care Transition Study: 34 focus groups and interviews with youth/young adults, family health care providers

(Institute for Child Health Policy)
System for Adolescent to Adult Health Care Transition

- The Key to Understanding the System for Adolescent to Adult Health Care Transition....

- In most cases, there is no system.
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Culture of Care: Pediatric Provider

- Family-centered
- Developmentally oriented (School and life progress)
- Nurturing, high level psychosocial support
- Interdisciplinary
- Involve parent direction and consent
- Flexible

*The best way to care for patients, right?...Maybe.*
Transitional Program Approach

1. Help patient select site for care
2. Meet with medical/social support staff at transitional care site
3. Address Vocational issues
4. Insure adequate care for children/other family members
5. Ensure cooperation of “support persons.”
6. Arrange/accompany for first visit to new provider.
Key points for transition from paediatric services to adult services

- Transition preparation is an essential component of high quality health care in adolescence
- Every paediatric general and specialty clinic should have a transition policy; more formal transition programmes are needed if large numbers of young people are being transferred to adult care
- Young people should not be transferred to adult services until they have the skills to function in an adult service and have finished growth and puberty
- Preparation for transition should start early—well before entering adolescence
Key points for transition from paediatric services to adult services

• Personalised transition plans are needed for each young person
• An identified person (ideally a nurse specialist) in the paediatric and adult teams must be responsible for transition arrangements
• Management links must be developed between the two services
• Transition arrangements should be evaluated
1. Adolescent Health Transition Project–U. of Washington
   http://www.depts.washington.edu/healthtr
2. Blum, R. Ed. “Improving Transition for Adolescents With Special Health Care Needs from Pediatric to Adult–Centered Care.” Pediatrics Vol. 110 No. 6 12/02 (supplement)


