Partnering For Care: Transition to Adult CF Care

August 19, 2010

[Image: Cystic Fibrosis Foundation]

| Adding tomorrows every day.

[Image: JOHNS HOPKINS MEDICINE CYSTIC FIBROSIS CENTER]

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Michael Boyle, MD
Johns Hopkins Hospital
Transition should start at the time of diagnosis!
Trends in Number of Patients, 1986–2009

- Pediatrics (< 18 years old)
- Adults (≥ 18 years old)

Year: '86, '88, '90, '92, '94, '96, '98, '00, '02, '04, '06, '08

Number of Patients:
- Pediatrics: 15,000
- Adults: 12,000

Chart shows an increase in the number of patients over the years for both Pediatrics and Adults.
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Johns Hopkins Hospital
The Goal:

Developing a Sense of Self-responsibility
Ideal Transition to Adult CF Care

Responsibility

Parents/Family

Child

Age

21
Goals for 12 - 14 Year Olds

• Knows what causes CF and how the body is affected
• Knows the names medications and when to take them and actually does take them
• Understands the purpose of each medication
• Performs airway clearance without help (most of the time)
• Understands choices about smoking and drinking and effect on health in CF
Goals for 16 – 18 Year Olds

- Ability to recognize symptoms and describe them
- Awareness of the dates of clinic appointments and other tests and can schedule them
- Awareness of medication supply and participates in refilling prescriptions
- Speaks directly to CF healthcare providers to discuss changes in health
- Learns to maintain own equipment
Goals for 21 Year Olds

• Contact CF healthcare providers directly to discuss changes in health
• Schedule all appointments and tests
• Refill prescriptions independently
• Awareness of details about insurance and strategies for future coverage

Boyle MP. “Transition from Pediatric to Adult Care: It’s a Transition for Parents As Well!”, 2007.
“The worst thing you can do for someone you love is to do that which they could and should do for themselves.”

— John Wooden
Partnering in the Transition to Adult CF Care

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Learn More...

• Talk with your CF Team members
• “Building Life Skills to Manage CF” Web cast on CF Foundation's Web site
• NIH – www.medlineplus.gov
• www.hopkinscf.org
• Kidshealth.org - search “transition”
Partnering for Care Series

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Cystic Fibrosis Foundation

JOHNS HOPKINS MEDICINE CYSTIC FIBROSIS CENTER
Archived CF Education Webcasts

www.cff.org/LivingWithCF/Webcasts

• CF Research
• Lung health and lung disease
• Nutrition for kids and adults
• Germs, infection control and people with CF
• CF healthcare coverage – insurance and government programs
• Fertility information
• Building life skills to manage CF and more
Thank You

• …for watching & submitting questions
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• The CF Foundation
• Genentech