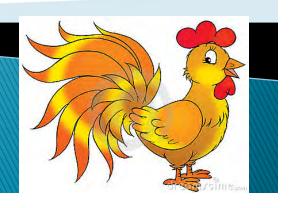




Navigating the Path from Pediatric to Adult Care of Type 1 Diabetes

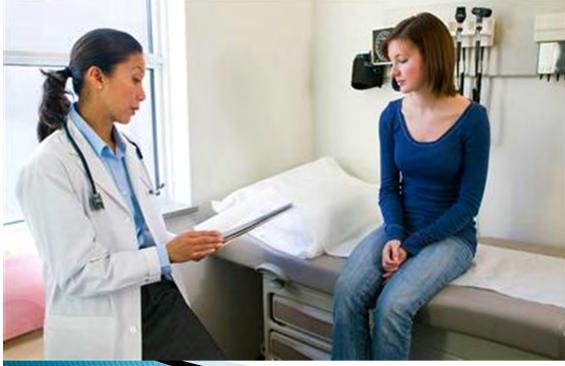
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July 18, 2012
New Orleans, LA















Goals and Objectives

- To describe how type 1 diabetes carries unique and particular vulnerabilities among "adult diseases of childhood," as evidenced in increased morbidity and mortality during the critical time of emerging adulthood
- To describe the difference between transfer and transition to adult care, specifically relating to type 1 diabetes
- To provide a checklist of elements necessary for effective transition from pediatric to adult care, including useful web links and resources

Perspectives

- ▶ 13% of US Children with Special Health Care Needs
- ▶ 90% reach adulthood (no longer only the hardiest or those with the simplest problems surviving).
- ➤ Tidal Wave of YA with complex diseases: cancer, diabetes, CHD, asthma, CF, rheumatic disease, mental health and cognitive disorders (Are Internists Prepared to Meet the Demand?)
- Yet Minimal attention is given to preparing youth for an increased level of responsibility
 - Health insurance
 - Communication skills
 - Taking Medications independently
 - Being able to describe Medical Condition/Special Needs
 - Knowing of/Accessing Community Resources
 - Legal Implications of Emancipation/Making Decisions

Straub, et al "Factors Affecting Health Care Transition," JAH Abstracts 36 (2005) 95-110 Williams, "Fumbling the Handoff: Managing the Transition to Adult Care for Adolescents with Chronic Conditions," JAH 44 (2009)s 307-308

Definitions

- Adolescent: Pubarche-Age 18
- ▶ Emerging Adulthood: 18–25 years
- ▶ Young Adulthood: 25–30



Of note is that chronological age does not necessarily correlate with the developmental tasks of these delineations.

The ADA's Position Statement (October 24, 2011) uses 18–30 as its working definition.

Immaturity's Significance



- The state of immaturity aides in creating an acceptable space and time to develop the skills and education necessary to function as a successful adult. The process of moving from immature young adulthood to full adulthood is an opportunity for the body and mind to fully develop while responsibility for actions and consequences shifts from dependency to independence. For the young adult, this process can sometimes feel like a confusing struggle. How to Stop Being Immature | eHow.com http://www.ehow.com/how_5129762_stop-being-immature.html#ixzz1f3f36EFD
- Pat Stansik: I'm 24://www.funnyordie.com/videos/f0ae55c320/i-m-24 Pat Stansik: I'm 24

Prevalence of Type 1 DM in Youth

- Diabetes is one of the most common chronic diseases in children and adolescents; about 151,000 people below the age of 20 years have diabetes.
- Each year, more than 13,000 young people are diagnosed with type 1 diabetes

CDC data: SEARCH for Diabetes in Youth

1-877-CDC-DIAB (1-877-232-3422) or visit the following Web

site: http://www.cdc.gov/diabetes/projects/diab_child.htm.

Survival of Youth with T1D

- By 1941: 24 had gone beyond 20 years with diabetes
- **By** 1948:
 - more than 385 beyond 20 years
 - 161 more than 25 years
 - 14 more than 30 years
 - Life expectancy for a child with diabetes was 45 years (Metropolitan life insurance actuarial table for a child of ten years in 1948).

Elliott P. Joslin, "Diabetic Manual for Doctor and Patient," eighth edition, 1948

Joslin Medalists: DM of long duration

Those greater than or equal to 50 years: >3000 since 1970

Those greater than or equal to 75 years: 34 since 1996



Adults with Childhood Illness: The Joslin Fifty Year Medal

"Joslin Diabetes Center established his award in 1970 to recognize the remarkable achievement of those individuals who have lived with insulin-dependent diabetes for fifty years or more. We now extend this tribute... for ... conscientious and courageous attention to the many difficult details involved in successfully living with diabetes over these many years."

Thoughts from Joslin,

- The diabetic child I believe to be a superior being.
- ...that his bringing up, if properly conducted gives him self confidence, a sense of responsibility and self-control and unusual knowledge .Environment, I agree, is an important factor.
- Intelligence is inborn in the diabetic child. At the age of ten years he acquires a knowledge of diabetes far more readily than the average diabetic of fifty years. It is true he lacks judgment and has not learned to reason, largely because he has not had the opportunity to study in the school of experience. He knows the Benedict test and is well aware of its significance. He understands the reckoning of his diet and recognizes errors in the same. He can administer his own insulin and occasionally prefers to do so. After a few experiences, he detects the advent of an insulin shock almost intuitively.
- Diabetic children are more sinned against than sinning and it is because of this that they do not give a fair show.
- Diabetic children mean to be honest. If they break a rule of diet because they follow their instinct of self-preservation and sense of hunger, be careful what you say and do.
- Never ask a diabetic child if he has broken his diet any more than you would ask your best friend if he had been dishonest.....Instead proceed in the most logical manner to seek the truth. Express wonder and surprise about what has happened.....The poor little child is punished enough by his own conscience and far more than as if you blamed him.
- Every diabetic child has his three mischievous ponies to drive and their names are Diet, Exercise, and Insulin. It is no joke for a child to manage one willful pony, but a real struggle, and to harmonize the capriciousness of three such ponies is a tremendous triumph.

Goal 1

To describe how type 1 diabetes carries unique and particular vulnerabilities among "adult diseases of childhood," as evidenced in increased morbidity and mortality during the critical time of emerging adulthood

Morbidity and Mortality

- YA with T1D: increased risk for premature morbidity and mortality over the general population
 - 3 fold in men
 - 6 fold in women
- In a study of 20-29 year olds, Major Causes
 - ACUTE complications
 - Hypoglycemia
 - Ketoacidosis
 - Contributing PSYCHOSOCIAL Factors
 - Living alone
 - Past drug abuse
 - Previous psychiatric referral



Laing et al, "The British Diabetic Association Cohort Study, I: All-cause mortality in patients with insulin-treated diabetes mellitus. Diabet Med 16: 459-465, 199a Laing et al, "The British Diabetic Association Cohort Study, II: Cause-specific mortality in patients with insulin-treated diabetes mellitus, Diabet Med 16: 466-1999b

Levels of DM Control as reflected in HbA1C by Age Group

- ▶ Ages 13–18 years: 32% achieved ADA goals
- Adults: 56 % achieve target A1C values of <7 percent.</p>
- Majority of youth in poor control (A1C > 9.5%) were teens

Isolated and Unseen Disability

- ISOlation: Many adolescents and young adults who have felt isolated by chronic disease during childhood wish to as they move away from home.
- **Seen Disability**: Patients who are more symptomatic or developmentally dependent have the best record of continuing care
- Unseen Disability: asymptomatic patient with residual abnormality that requires proactive management to avoid secondary disability is the most likely to come to avoidable and regrettable harm

This is the group that is most likely to fail successful transfer



R.G. Williams,"Fumbling the Handoff: Managing the Transition to Adult Care for Adolescents with Chronic Conditions," JAH, 44 (2009) 307–308

DM Complications of YA

- Microvascular
 - Nephropathy: macro and micro albuminuria, 6%
 - Retinopathy: moderate non proliferative 5%, 2% proliferative at 10 years after diagnosis

Behavioral

- Diabulimia: more diabetes-related complications and a 3x greater risk of death than those who did not restrict
- Depression: 1-2 x higher than general population

Warner D, McKinney P, Law G, Bodansky H. Mortality and diabetes from a population based register in Yorkshire 1978-93. Arch Dis Child 1997:78:435

Swerdlow A, Jones M. Morta. Suring 25 years of follow-up of a



The Downward Mental Cycle of Complications

- Self-blame
- Despair
- Lack of Motivation
- Withdrawal from both self care and followup

There is an inherent burden of fear and anxiety about complications and disability that is made unwittingly worse by physicians and pamphlets that are read.

Predictors of Complications

- Significantly worse mean HbA1C during the 11 years prior to evaluation (9.9 vs 8.0)
- Behavioral Problems During Adolescence
- YET, Intensive treatment treatment during adolescence doe NOT necessarily set the stage for optimal glucose control during young adulthood (DCCT data)
- A high level of family support during this key developmental phase is the best predictor of adherence to the DM regimen

Gillibrand, et al The Extended Health Belief Model Applied to the experience of diabetes in young people. Br J Health Psychol 11: 155-169,2006.

Goal 2

To describe the difference between transfer and transition to adult care, specifically relating to type 1 diabetes

Defining Transition

"a multi-faceted, active process that attends to the medical, psychosocial, and educational and vocational needs of adolescents as they move from child-focused to the adultfocused health-care system."

Blum et al "Transition from child-centered to adult health-care systems for adolescents with chronic conditions." A position paper of the Society for Adolescent Medicine. J Adolesc Health 1993;14: 570-6

The term "transition"

- "The process before and after the event of transfer,"
- That is the actual shift from pediatric to adult health care
- Encompasses specific decisions made and actions taken for building the capacity of an adolescent, the parents and the providers to
 - Prepare for
 - Begin
 - Continue
 - Finish the process of transition

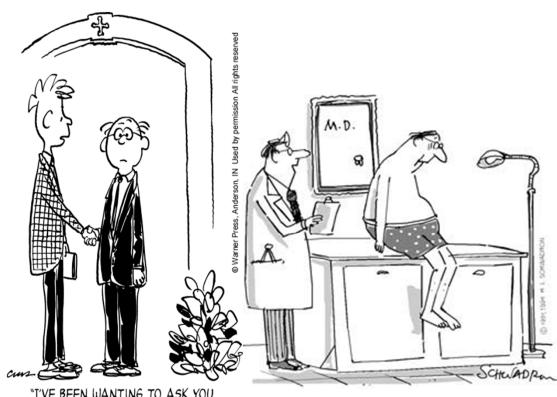
CA is NOT a sufficient criterion τον transver because physical and psychological criteria should be met as well

AnneLoes vanStaa, et al, Rotterdam, The Netherlands, "Readiness to Transfer to Adult Care of Adolescents with Chroinc Conditions: Exploration of Associated Factors," Journal of Adolescent Health 48 (2011) 295-302

The term "transition"



"We now feel it's best that baby keeps her security blanket until she's old enough for a cell phone."



"I'VE BEEN WANTING TO ASK YOU SOMETHING, REVEREND PALMQUIST. AT WHAT AGE DID YOU DECIDE TO BECOME STRAITLACED?!"

The Pediatrics Consensus Statement on Timing of Transition

- Developmental Readiness
 - Self manage Care (more important even than level of knowledge or age): SELF-EFFICACY
 - Understand disease process
- Complexity of the Health Problem
- Characteristics of the Adolescent and Family
 - SES
 - Severity and Effect of the Chronic illness
 - Ability to self manage
 - Attitude toward the transition
- Availability of Skilled Adult Health Care Provider

AAP, AAFP, and ACP, "A Consensus Statement for Health Care Transition for Young Adults with Special Health Care Needs," Pediatrics 2002; 110: 1304-6.

Challenges

- Unrealistic demands/expectations of the new physician who may wish to make changes in DM management (perhaps lack of MD training in psychosocial development of this age group)
- Bond of confidence and trust not yet made
- Intrusion on sense of autonomy and personal control
- Result: Estrangement from follow up
- 24-69% lost to follow-up, mostly those with
 - Poorer metabolic control
 - More frequent hospitalizations

Pacaud et al "Problems in Transition from Pediatric to Adult Care for individuals with diabetes. Can J Diabetes 2005;29 (1): 13-8

Bartsch C et al, "Where did they go? Life after teen diabetes clinic. Diabetes 1989; 38(2): 40A Frank M, "Factors associated with noncompliance with a medical follow-up regimen after discharge from a pediatric diabetes clinic. Can J Diabetes Care 1996; 20(3):13-20

Transition: Much more than Medical Aspects of Self-Care

- Complex negotiations around
 - SELF: ordinary aspects of adolescent development:
 - Identity development
 - Educational experiences
 - Social interactions
 - HEALTH: extraordinary health -related circumstances
- Both PRIVATE and PUBLIC faces



How T1D differs from other chronic disease

UNSEEN unless in acute distress

Therefore under the radar with regard to others

Often MISPERCEIVED by others

Often NOT COMMUNICATED to otners for tear of lack of acceptance or even discrimination socially and in the workplace

CHAPTER 25

DOGS, DIABETICS AND THEIR FRIENDS

A DOG is a diabetic's thoughtful friend.

A dog never says to a diabetic "You are thin," never speaks about his diet, never tempts him to break it and to eat a little more, never refers to the delicacies he himself



Case No. 2007

	1928	1933
Age, yrs	13.8	18.8
Diabetes, yrs	8.0	13.0
Height, in	63.2	68.0
Weight, lbs	112.5	146.0
Carb., gm	141	220
Protein, gm	79	121
Fat, gm.	94	114
Insulin, units	76	80
	1940	1949
Age, yrs.	25.8	34.0
Diabetes, yrs	20.2	28.3
Height, in.	68.0	
Weight, lbs	162.0	166
Carb., gm. ,	215	
Protein, gm	96	
Fat, gm.	97	
Insulin, units	63	65

Fig. 44.—Case No. 2007. A diabetic child and his dog, Bob, in 1923.

has eaten or the good bones he expects to eat, in fact never implies by any signs or action in public or in private that he knows his master has diabetes. A diabetic is never embarrassed by his dog. How often he wishes his friends were as considerate!

Importance of Building Social Networks

- One study showed that YA with DM have fewer numbers of social networks yet were psychosocially mature
- Camping experience can build resilience and networks
- Residential weekend programs have been designed for adolescents with diabetes to increase independence through
 - Peer support
 - Education
 - Friendship-building activities
 - Small focus groups on
 - Meal preparation
 - Substance use
 - Driving
 - Sexual Health



Psychosocial Maturation

- "Young adults with T1D did not show delayed psychosocial maturation when compared with healthy young adult controls."
- "Health care providers are still faced with the challenge of meeting the needs of a fairly poorly understood age group."

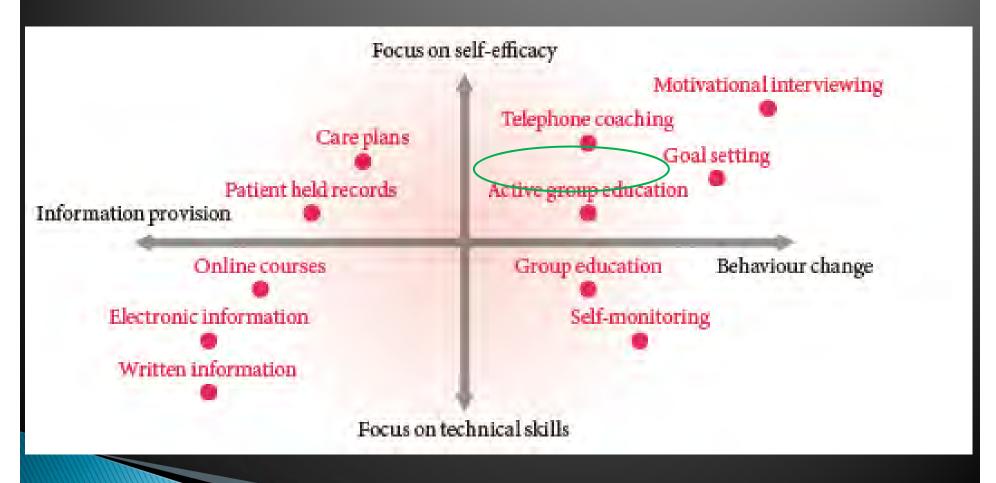
Pacaud, et al, (University of Calgary, Calgara, Alberta, Canada, "Effect of Type 1 Diabetes on Psychosocial Maturation in Young Adults," Journal of Adolescent Health (40) (2007) 29-36

Education and Health

This research shows that there are significant implications for policy and practice development in both EDUCATION and HEALTH sectors

Drew, et al "Teenagers and Chronic Condition-Self Management: Much More than Medical Aspects of Self-Care," University of Melbourne. JAH Absracts44 (2009) S14-S47

Self-management Support



Sourced from: Da Silva, D. Evidence: Helping People to help themselves - A Review of the evidence considering whether it is worthwhile to support self-management, May 2011, The Health Foundation

Education

"The most important education for a diabetic child...is his diabetic education, because upon that his life depends. No matter how devoted his parents, no matter whether wealth allows a nurse, nothing will take the place of a child acquiring for himself the fundamentals of his disease and how to combat it successfully. To do this encourage association with other diabetic children so that their successes or failures will serve as examples."

Current Intensification of Care

- More flexibility with regard to schedule and meal planning BUT
- More complex management, including carbohydrate counting, frequent blood glucose monitoring and analysis, and multiple daily injections or CSII

Barriers to Intensive Therapy

- Fear of Hypoglycemia
- Unrealistic expectations leading to perfectionism

Concerns about Weight Gain Associated with this (2.4 x risk of disordered eating with T1D,

Jones et al 2000)



How to Overcome Barriers

- Set realistic goals
- Minimize performance pressure re Glycemic control
 - A tool
 - A target
 - Non judgmental
- Recognize Impact of Changing Family Roles and Social Relationships
 - Fostering Positive Involvement of Parents as Independence grows
 - Behavioral Changes with regard to Dating
 - Fostering improved control in the context of marriage/future goals
- Recognize Impact of Mental Health of patient and how the physician patient relationship can prevent
 - Depression
 - Lack of Motivation
 - Disengagement from Care

Flaws of the Past Studies

- DM management more rigid/regimented
- Measurements of Maturity were
 - financial independence from parents,
 - employment
 - marital status rather than
- Responsibility and Independence
 - Psychosocial Maturation
 - Social Support Networks
 - Locus of Control



Goal 3

To provide a checklist of elements necessary for effective transition from pediatric to adult care, including useful web links and resources

The Checklist

- Role of the Health Care Provider
- Adolescent Skills required for Diabetes
- Transition/Participation in Health Care Visits
- Diabetes Knowledge
- Diabetes Management Skills
- Social Responsibility



Necessary Elements for Successful Transition

- Availability of Adult Care that Addresses the Specific Developmental Needs of the YA
- Early start in Preparation (both with Peds and Adult Care)
- Coordination of Care with appointment of a specific transition coordinator
- YA needs to be both trained and empowered to become an effective partner in his own care



Skills for Moving from Pediatric to Adult Care

- Scheduling an Appointment
- Getting Health Insurance
- Deciding about Guardianship
- Speaking up at the Doctor's Office
- Understanding Diabetes (including a Sick Day and Emergency Plan)
- Managing Medications
- Keeping a Health Summary
- Looking into Service Coordination
- Setting realistic Health goals

Written Transition Plans

- Knowledge and Self Management Skills and participate actively in health care decisions
- Clear Goals for Patients and Providers
- Periodic Assessment of Progress to determine readiness for Transfer
- Coordinated by both transferring and receiving physicians: eg meet the new provider BEFORE transfer occurs. During disease stability and not during crisis, initial visit with orientation to new system of care, availability of evening or weekend appointments ideal

Where are our YA's re their care

- Pediatric
- Blended care from both Pediatric and Adult
- Adult
- Continuous Care from FP or Med-Peds
- Drop out of health care system and fail to receive structured care

Expressed Needs by YA with T1D

- Stress Management
- Finances
- Sexual Health and Impact of Diabetes on Pregnancy
- Alcohol and Drug (and risks associated with DM specifically)
- New Developments in Diabetes Research
- Healthy Cooking





Concerns of the Adolescent

- Fear of the unknown: important for there to be involvement of the patient in planning as well as for annual review, as early as about age 14
- Being lost in the shuffle: a fumbled ball
- Growing responsibilities as a distraction from the "many difficult details" of DM management

Guidelines/Position Statement from the ADA (multi-disciplinary)

- Although these guidelines are a summary of the current knowledge, there remains a pressing need for re- search to examine
 - the medical,
 - psycho- social
 - cost-effectiveness outcomes of different models for transitioning care from pediatric to adult medicine
 - to identify potential strategies for engaging young adult patients in self-care.
 - Emphasizes the special but changing role of the family

Goal 4

To explain the need for a position statement specifically for transition of adolescents with type 1 diabetes, (highlighting the need for a data base in development of solid guidelines for safe and compassionate care of "emerging adults")

Survey of ISPAD



- Only 50% of responders had structured transition programs and transition approaches varied widely including
 - telephone calls or letter to notify patients of transition ,
 - joint clinics with pediatric and adult provider and
 - group transfers.
- And only 35% of these had evaluated outcomes of the program

de Beaule Cet al: "Transition from pediatric to adult diabetes care: smooth or smooth or Pediatric Diabetes 11:244-27, 2010

What will be needed for Comprehensive Health Care Transition Programs in Diabetes

- Systematic Changes in Health Care
- Chronic Care Model for longitudinal, patientcentered care
- An infrastructure capable of providing continuous relationships with a health care team, individualization according to health care needs and values, anticipation of patient needs, cooperation among clinicians, and evidence-based care.
- All with an ADOLESCENT and YA focus

With regard to Adolecents: understanding of the following are critical

- Social Networks
- Goals
- Beliefs





Expectations of glycemic control







As Yet

- Essential components
- Optimal organization
- Best approaches to transition of care

are unknown.

More evidence is needed re both successful and unsuccessful approaches to transition to determine the effectiveness of existing programs and inform the design and evaluation of future transition efforts....

The Actual Transfer: in the context of Transition

- Few Published studies have combined multiple transition recommendations into programs and evaluated outcomes.
- One successful program offered
 - Transition coordinator
 - Transition appointment involving the PCP, Both PED and Adult Diabetes Specialist
 - Participation of the pediatrician in the initial appointment in the adult health care system

Bowen, et al, "Health Care Transition in Adolescents and Young Adults With Diabetes," Clinical Diabetes, Volume 28, Number 3, 2010

In Summary

- Vulnerable Population: DEVOLPMENTAL and BEHAVIORAL issues are paramount in the evaluation and care of the young adult with diabetes shown epidemiologically to be the primary underlying causes of
 - accelerated microvascular complications
 - acute metabolic decompensation
- Multi-faceted program necessary
- Existing literature with regard to transition of the YA with diabetes is thus far scant/greatly needed

Useful Resources

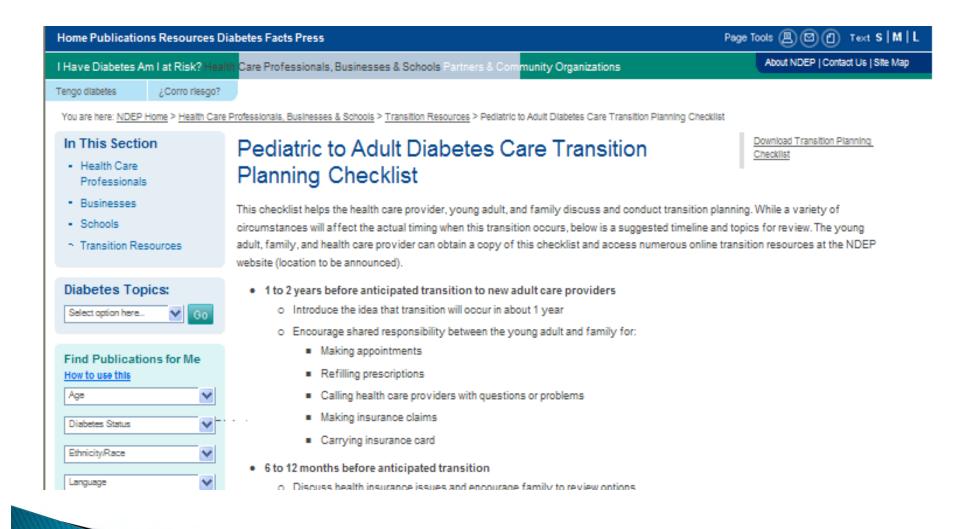
- Wolpert, Anderson, and Weissberg-Benchell, Transitions in Care, Meeting the Challenges of Type 1 Diabetes in Young Adults, 2009, The American Diabetes Association
- Bowen, Henske, and Potter, "Health Care Transition in Adolescents and Young Adults With Diabetes," Clinical Diabetes, Volume 28, No. 3, Nov.3, 2010
- October 24, 2011: Recommendations for the Transition of "Emerging Adults" With Diabetes From Pediatric to Adult Diabetes Care Systems: New Position Statement, American Diabetes Association (position statement release)
- Peters, Laffel, et al. The American Diabetes Association Transition Working Group, "Diabetes Care for Emerging Adults: Recommendations for Transition From Pediatric to Adult Diabetes Care Systems," Diabetes Care, Volume 34, November, 2011, pages 2477-85
- Rosen, "Between Two Worlds: "Bridging the Cultures of Child Health and Adult Medicine," Journal of Adolescent Health, Volume 17, No. 1, 1995.
- NDEP (joint effort of the CDC and NIH has developed a useful template):
 - http://ndep.nih.gov/transitions/index.aspx
 - http://ndep.nih.gov/transitions/ResourcesList.aspx (resources for the college transition)
- Http://www.gottransitions.org/
- http://healthytransitions.org/skillmedia/tool show (This link is from NY and includes a checklist.)
- www.jdrf.org
- www.childrenwithdiabetes.org
- www.diabetes.org The ADA has a teen and young adult message board: http://community.diabetes.org/
- www.joslin.org http://www.joslin.org/phs/for-teens-with-diabetes.html

Transitions: Online Tool

www.YourDiabetesInfo.org/transitions



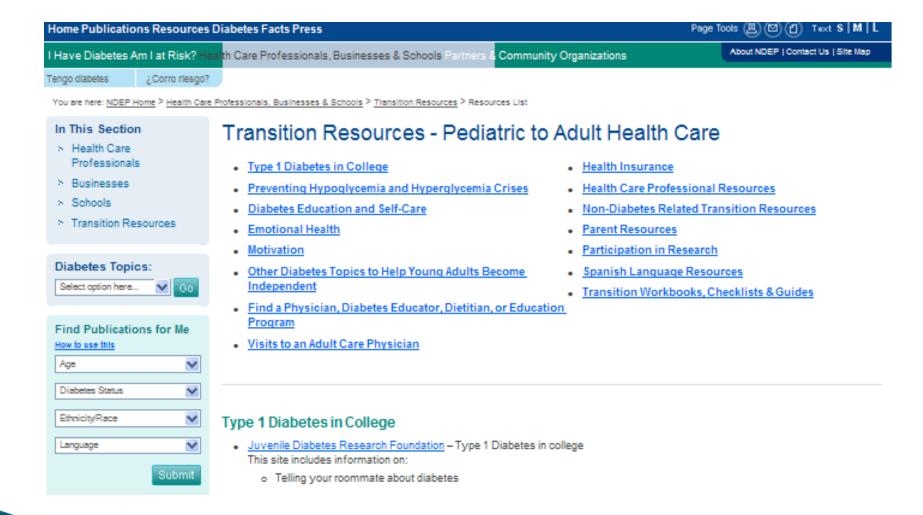
Transitions: Checklist



Transitions: Clinical Summary Page

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Transitions: Resource List



Smooth Flying....



Thank you! Questions??

