TRANSITION OF ENDOCRINE CARE FROM PEDIATRIC TO ADULTHOOD

CARLOS A. LEYVA JORDÁN, M.D.
PEDIATRIC ENDOCRINOLOGIST
• No potential conflict of interest
OBJECTIVES

• Review timing considerations for transition from pediatric to adult-centered care
• Identify challenges faced by the emerging adult with endocrine disorders
• Describe ways to create a successful transition from pediatric to adult-centered care
• Discuss key factors that should be considered when developing a transition in care program
• Provide information on helpful resources for transitioning care
DEFINING TRANSITION OF CARE

• What is a transition of care?
  – “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to an adult-oriented health care system.”
    – Society for Adolescent Medicine

• What is it not?
  – Transition is not merely the transfer of care but a long-term process. It is not a one-time event, but begins long before the actual transfer of care occurs.

• Ideally, the timing of transfer to adult care should be determined by patient readiness and not defined by age.

CURRENT TRANSITION OF CARE

PEDIATRIC CARE → Good Luck! → ADULT CARE
CHALLENGES TO TRANSITIONING THE EMERGING ADULT

CHALLENGES TO TRANSITIONING THE EMERGING ADULT

• LIFE
  – No routine and unpredictable schedules/ Late nights
  – Stress
  – Alcohol and drugs
  – No stable support system, new friends
  – Social pressures
  – Wanting to be normal
  – Limited food options
  – Desire for spontaneity
  – Financial concerns
  – Priorities evolve throughout college years

• CHRONIC CONDITION
  – Transition of care
  – Transition of independent management
  – Increased responsibility
  – Less parental involvement
  – Registration with “Disabilities services”
  – Responsibility for informing professors/bosses
  – No support resources or education typically available
CHALLENGES TO TRANSITIONING THE EMERGING ADULT

• Due to prolonged supervision under parents or guardians, the patient “does not feel ready” to take full responsibility of her/his condition
• Chronicity of many endocrine disorders needs continuity of care
  – Diabetes
  – Growth Hormone Deficiency
  – Turner Syndrome
  – CAH
  – etc.
• In 2002, a consensus statement coauthored by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine was published, stating the importance of supporting and facilitating the transition of adolescents with special health care needs into adulthood. The consensus statement articulated 6 “critical first steps” to ensuring the successful transition to adult-oriented care.
1\textsuperscript{st} CRITICAL STEP

- Ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning.

IDENTIFY ADULT ENDOCRINE PHYSICIAN
2\textsuperscript{ND} CRITICAL STEP

- Identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs; and to make them part of training and certification requirements for primary care residents and physicians in practice.

PROVIDE TRAINING TO RESIDENTS AND FELLOWS
3rd CRITICAL STEP

• Prepare and maintain an up-to-date medical summary that is portable and accessible, providing a common knowledge base for collaboration among health care professionals.

CREATE AN ENDOCRINE MEDICAL SUMMARY TEMPLATE
3° CRITICAL STEP
(ENOOCRINE MEDICAL SUMMARY TEMPLATE)
4th Critical Step

- Development of up-to-date and detailed written transition plans, in collaboration with young people and their families.

Create Transition Plan/Timeline for the Patient
5th Critical Step

• Ensure that the same standards for primary and preventive healthcare are applied to adolescents.

Maintain Similar Treatment Plan
6th CRITICAL STEP

• Ensure that affordable, comprehensive, and continuous health insurance is available to young people with chronic health conditions throughout adolescence and into adulthood.

CONTINUED INSURANCE COVERAGE
6th CRITICAL STEP

• Proyecto de la Cámara 1755
TRANSITION OF CARE

DIABETES
SUMMARY OF ISSUES GIVEN BY ADULT PATIENTS WITH TYPE 1 DIABETES IN PR (CEBNAD 8/13/2017)

• Getting appointments
• Knowledge of latest type 1 diabetes technology in adult endocrinologists
• Create a transition protocol
• Insurance coverage
EMERGING ADULTS WITH TYPE 1 DIABETES FACE ADDITIONAL DEMANDS

• Normative Choices
  – Relationships
  – Occupations
  – Living arrangements
  – Financial management

• Diabetes Care
  – Finding appropriate care providers with experience treating type 1 diabetes
  – Access to diabetes supplies
  – Access to insurance coverage

Young Adults with Diabetes

Average HbA1c significantly higher than ADA guidelines & increasing

Mean HbA1c (%)

T1D Exchange Data, 2014

https://t1dexchange.org
Young Adults with Diabetes

Only population with no increase in insulin pump use

Age (years)

Overall  6-13  13-18  18-26  26-50  ≥50

Enrollment

Current

T1D Exchange Data, 2014

https://t1dexchange.org
Young Adults with Diabetes

Only population with no increase in CGM use

![Bar chart showing CGM use by age group and enrollment status.](https://t1dexchange.org)
PSYCHIATRIC ISSUES MORE COMMON IN EMERGING ADULTS WITH TYPE 1 DIABETES

- High risk group for psychiatric disorders, similar to children that have other chronic diseases.
TYPE 1 DIABETES AND COLLEGE

• There are an estimated 53,000 college students with type 1 diabetes in the United States
• The majority of college students with diabetes do not leave home when it is time to go to college
• 71% of college students report having difficulty managing their diabetes while at school

Questionnaire given to students participating in the College Diabetes Network (CDN) reported the following recommendations for clinicians:

- Ask me about my life outside of diabetes
- Be positive! Avoid criticism, judgment, and negativity
- Don’t be afraid to bring up “taboo topics” such as alcohol, sex, and drugs
- Peers are an important piece of the diabetes care team
- Acknowledge the spontaneity and lack of routine of college and help make a plan of attack
TEAM-BASED CARE OF ADOLESCENTS AND YOUNG ADULTS WITH TYPE 1 DIABETES

• Developed at Barbara Davis Center for Childhood Diabetes in Denver, Colorado
• Change clinical care structure
  – Shared medical appointments
    • Improved patient outcomes
    • Increased satisfaction
    • Improved efficiency
      – Including billing
    • More comprehensive visits
  – Multidisciplinary team
TEAM-BASED CARE OF ADOLESCENTS AND YOUNG ADULTS WITH TYPE 1 DIABETES
TEAM-BASED CARE (ADOLESCENTS’ RESPONSE)
TEAM-BASED CARE (PARENT’S RESPONSE)
TEAM-BASED CARE (YOUNG ADULTS’ RESPONSE)
Online Tool from the National Diabetes Education Program Helps Youth Transition from Pediatric to Adult Care

*Transitions from Pediatric to Adult Care* from the National Diabetes Education Program (NDEP) helps teens with diabetes make a smooth transition to adult health care. Families and health care professionals will also find these materials very helpful.

The online tool contains the following materials:

- **Transition Planning Checklist**: suggests a timeline, topics to review, and key action steps to support various aspects of the transition process
- **Patient Clinical Summary**: provides a summary of the teen’s health status to be completed by the pediatric health care team and provided to the adult health care team
- **Resource List**: offers hyperlinks to additional resources such as videos, message boards, social networks, workbooks, checklists, guides, and books and can be viewed by category


HHS’ National Diabetes Education Program (NDEP) is jointly sponsored by the NIH and CDC with the support of more than 200 partner organizations.
Purpose of Transitions

Transitioning from pediatric to adult health care can be a challenge for teens and young adults with diabetes, their parents, and pediatric and adult health care providers. The NDEP has developed the Transitions from Pediatric to Adults Care online tool to help with the following:

• Encourage teens and young adults to assume more responsibility for diabetes self-management and make more independent judgments for their health care needs
• Help teens with diabetes make a smooth transition to adult care
• Provide families and health care professionals with guidance in helping teens with diabetes transition to adult care
Transitions: Checklist

Pediatric to Adult Diabetes Care: Transition Planning Checklist

This checklist helps the health care provider, young adult, and family discuss and plan the change from pediatric to adult health care. While a variety of events may affect the actual timing when this change occurs, below is a suggested timeline and topics for review. The young adult, family, and health care provider can obtain a copy of this checklist and access many online transition resources at the NDEP website [www.YourDiabetesInfo.org/transition].

1 to 2 years before anticipated transition to new adult care providers
- Introduce the idea that transition will occur in about 1 year
  - 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
    - Reviewing blood sugar results with provider between visits
  - Discuss with teen alone:
    - Sexual activity and safety
    - How amending, drugs, and alcohol affect diabetes
    - How depression and anxiety affect diabetes and diabetes care

6 to 12 months before anticipated transition
- Discuss health insurance coverage and encourage family to review options
- Assess current health insurance plan and new options, e.g. family plan, college plan, employer plan, and health care poy
- Consider making an appointment with a case manager or social worker
- Discussion of career choices in relationship to insurance issues
- Encourage family to gather health information to provide to the adult care team (See Clinical Summary for New Health Care Team [www.YourDiabetesInfo.org/clinical])
- Review health status, diabetes control, retina (eyes), kidney and nerve function, oral health, blood pressure, and lipid (cholesterol)
- Discuss with teen alone:
  - Sexual activity and safety
  - Smoking status, alcohol, and other drug use
  - Issues of independence, emotional ups and downs, depression, and how to seek help
Transitions: Resource List

Transition Resources - Pediatric to Adult Health Care

Resources for Teens and Families
- "Understanding Diabetes" for teens with type 1 or type 2 diabetes, by H. Felar Chace, MD, Barbara Davis Center for Childhood Diabetes
- "Diabetes in Teens" for teens with type 1 or type 2 diabetes (See the tip sheets in English and Spanish about what diabetes is and how to be active, stay at a healthy weight, make healthy food choices, and deal with the ups and downs of diabetes.)
- Be Healthy, Too: Be Healthy For Life! or for teens with type 2 diabetes
- Everyday Wellness Kit or for teens with type 1 diabetes

Managing Diabetes
- "Understanding Diabetes" for teens with type 1 or type 2 diabetes, by H. Felar Chace, MD, Barbara Davis Center for Childhood Diabetes
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- Everyday Wellness Kit or for teens with type 1 diabetes

Preventing Hypoglycemia and Hyperglycemia
- Hypoglycemia and Diabetic Ketoacidosis (DKA)
  - "What You Need to Know about High Blood Glucose"
  - "Diabetic Ketoacidosis: What It Is and How to Prevent It" from the American Academy of Family Physicians
  - "Sick Day Management" from Kaiser Permanente
- Hypoglycemia
  - "What You Need to Know about Low Blood Glucose"

Insulin Pump and Continuous Glucose Monitoring Systems (CGMS) Help
- Contact the toll-free phone number or website on the back of your insulin pump or CGMS.
- Find more information about diabetes technology in the Diabetes Forecast Consumer Guide.
Transitions from Pediatric to Adult Care Tool Promotional Tools

Use these promotional tools to promote NDEP's Transitions Tool.

Transitions Article
Transitions Byer
Transitions Half Page PSA

Application Required
DOC and DOCX require Microsoft Word or the free Microsoft Word Viewer application for viewing.
PDF files require the free Adobe Acrobat Reader application for viewing.

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TRANSITION OF CARE

GROWTH HORMONE DEFICIENCY
TRANSITION OF CARE

TURNER SYNDROME
TURNER SYNDROME

• Many young women with Turner syndrome are lost to follow-up.
  – An Australian study of 39 adult women with the syndrome found that only 24 (63%) received regular follow-up and only 17 (44%) had adequate health surveillance, even though 87% were identified with one or more associated disorders.
  – The study concluded that adult care was suboptimal and sporadic.
  – A questionnaire survey of 160 young women with Turner syndrome in Belgium, who had all been identified and treated during childhood, found that 41 of 102 responders (40%) reported health problems, yet 13 (13%) did not receive regular medical care.
  – Of the 76 women with primary amenorrhea and induced puberty, 11 (14.5%) were no longer taking estrogen. The average age of this cohort was 23 years.

TURNER SYNDROME

• There is significant morbidity and early mortality among adult women with Turner syndrome. Reduced life expectancy is mainly caused by cardiovascular disease. Hypertension is common. The risk of atherosclerosis is shared by other women with ovarian failure.

• Transition is a staged process. During adolescence, the focus of medical care changes from growth to feminization and then to the maintenance of health. When final height is achieved and pubertal induction is completed, clinic visits become less frequent and the emphasis shifts to health surveillance, review of existing conditions (e.g. hormone replacement), and early identification and treatment of new ones (e.g. hypothyroidism).

TURNER SYNDROME (CARDIOLOGY)

• Cardiology review may be appropriate at the time of transition to adult care, at the onset of hypertension, and in women considering pregnancy.

• Magnetic resonance imaging of the aortic arch and valve may be more sensitive than echocardiography.

TURNER SYNDROME (FERTILITY)

• Discussing plans for fertility is important: maternal deaths from aortic dissection have been reported in Turner syndrome, and assisted reproduction (egg donation) should not be offered without adequate pre-pregnancy assessment.

• Some women with structural cardiac anomalies may be advised against pregnancy. There is also an increased risk of pregnancy-induced hypertension and gestational diabetes, and caesarean section delivery is the norm.

• Multiple pregnancies should be avoided.

TURNER SYNDROME

• During the transition period, there is a change in emphasis from treating the child within the family, using the parents as intermediaries, to supporting the adolescent in developing independence and taking responsibility for her health. These young women will require life-long care; it is crucial that they have a good relationship with their health professionals and a full understanding of their condition, as these factors contribute to compliance and minimize drop-out.

PEDIATRIC ENDOCRINE SOCIETY: RESOURCES

- https://www.pedsendo.org/patients_families/transition_toolkit/index.cfm
TRANSITION OF CARE

CONGENITAL ADRENAL HYPERPLASIA
CONGENITAL ADRENAL HYPERPLASIA

- Patients aged 16+ years with CAH who had attended the adrenal clinic at Royal Manchester Children's Hospital between 1992 and 2009 were identified.
  - A total of 61 patients (27 men) were identified. Thirty-six patients were referred to specialist adult services from the pediatric service; eighteen of these (50%) were lost to follow-up (two were never offered an appointment). Only 53% of the whole group attended their first new and subsequent second appointment (i.e. good early attenders). Good early attenders were less likely to get lost to follow-up compared with poor early attenders (11–33% lost to follow-up compared with 63–71%).

# CONGENITAL ADRENAL HYPERPLASIA

- Clinical manifestations in children
  - Salt wasting
  - Ambiguous genitalia
  - Postnatal virilization
  - Short stature
  - Non-classic

- Clinical manifestations in adults
  - Psychosexual
    - Gender identity
    - Impaired sexual function
  - Infertility
  - Metabolic abnormalities
    - Obesity
    - Diabetes
    - Decreased bone mineral density

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<table>
<thead>
<tr>
<th>Age and Time</th>
<th>Provider</th>
<th>Parent/Family</th>
<th>Youth</th>
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</thead>
<tbody>
<tr>
<td>Major responsibility</td>
<td>Provides care</td>
<td>Receives care</td>
<td></td>
</tr>
<tr>
<td>Support to Parent/family &amp; child/youth</td>
<td>Manages</td>
<td>Participates</td>
<td></td>
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<tr>
<td>Consultant</td>
<td>Supervisor</td>
<td>Manager</td>
<td></td>
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<tr>
<td>Resource</td>
<td>Consultant</td>
<td>Supervisor/CEO</td>
<td></td>
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</tbody>
</table>
Parent/guardian
- Fostering patient's independence while ensuring ongoing care
- Resolving issues of overinvolvement and overprotection
- Separating from paediatric-care providers/institution

Paediatric-care provider
- Separating from close relationship with patient/family
- Resolving financial and academic barriers
- Developing skills and resources for transition preparation
- Building confidence in adult-care providers

Patient
- Developing and negotiating independence and interdependence
- Resolving lack of knowledge and misperceptions
- Taking responsibility, developing self-advocacy
- Developing mature roles and relationships
- Separating from paediatric-care providers/institution

Adult-care provider
- Developing a supportive relationship with the patient
- Recognizing the developmental stage of the emerging adult patient
- Fostering shared responsibility with stakeholders
ENDOCRINE SOCIETY: RESOURCES

- Provider assessment of patient skills
- Clinical Summary
- Patient self assessment of worries, burdens, concerns of his condition
- Recommended Approach for Transition
- Guideline for Pediatricians for Transition
- Educational Fact Sheets (about condition)
- Welcome Guideline
- Visitor Information Sheet
A Successful Approach to Managing Pediatric to Adult Transitions of Care

Transitioning from a pediatric to an adult provider can be a challenge for all members of the care team. Transitions toolkits have been developed for a variety of endocrine conditions to help ease this transition. Click on the relevant condition on the right to view these toolkits.

http://www.endocrinetransitions.org/
THANK YOU!