HOW TO BREAK UP WITH YOUR ADOLESCENT PATIENTS GENTLY – IT'S YOU, NOT THEM

SUPPORTING SUCCESSFUL HEALTHCARE TRANSITIONS

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CEU CREDITS

- This nursing continuing professional development activity was approved by the Georgia Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

- To receive contact hours, you must complete the recorded presentation(s) and evaluation via the SurveyMonkey link by June 1, 2021. Upon completion, a certificate of attendance will be emailed June 2, 2021.

- Completion of all three 45-minute presentations for the Georgia Pediatric Nurses Association Spring 2021 Meeting and the 10-minute evaluation has been approved for 2.5 contact hours.

DISCLOSURES

- No conflicts of interest

OBJECTIVES

- At the conclusion of this presentation
  - Discuss the current status of healthcare transitions for youth with and without special health care needs
  - Describe the successful youth healthcare transition from pediatric to adult oriented care
  - List resources to support youth healthcare transitions from pediatric to adult oriented care

WHAT ARE THE GOALS OF TRANSITION?

- Ongoing and focused planning starting at an early age
- Continuity of insurance coverage
- Helping youth gain independent health care skills
- Understanding health care systems available for adults with and without disabilities
- Moving from pediatric care to physicians trained in adult medicine

PEDIATRIC VS. ADULT CARE

Pediatric Care

- Family Centered
- Multi-disciplinary
- Parent primary caregiver/decision maker
- May not address growing independence and increasingly adult behavior

Adult Oriented Care

- Patient Centered
- Physician and Patient decision making
- Physician acknowledges patient's autonomy and independence in care plans
- Family involvement only with patient consent

- Transition planning should begin early in adolescence
- Continue into young adulthood for both those with and without special health care needs.
- Got Transition & Six Core Elements of Health Care Transitions

SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

1. **POLICY/GUIDE**
   Develop, discuss, and share transition and care policy/guide
   AGE 12-14
2. **TRACKING & MONITORING**
   Track progress using a flow sheet registry
   AGE 14-18
3. **READINESS**
   Assess self-care skills and offer education on identified needs
   AGE 14-18
4. **PLANNING**
   Develop HCT plan with medical summary
   AGE 14-18
5. **TRANSFER OF CARE**
   Transfer to adult-centered care and to an adult practice
   AGE 18-21
6. **TRANSITION COMPLETION**
   Confirm transfer completion and elicit consumer feedback
   AGE 18-23

Transition and Care Policy/Guide

Tracking and Monitoring

Transition Readiness

Transition Planning

Transfer of Care

Transfer Completion

What do we know about pediatric to adult health care transitions?

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Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review

Annie Schmidt, MPH [a,*,1], Samhita M. Ilango, MSPH [a,1], Margaret A. McManus, MHS [a], Katherine K. Rogers, MPH, PhD [b], Patience H. White, MD, MA [a]

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CONCLUSIONS OF THIS STUDY

- This review strengthens the evidence that a structured HCT process for youth with special health care needs can show improvements in

  - adherence to care
  - disease-specific measures
  - quality of life
  - self-care skills
  - satisfaction with care
  - health care utilization

HOW DO YOU GET THERE?

WHO IS INVOLVED?

- Youth
- Parent/ Caregiver
- Family members

- Pediatrician
- Practice Administrator
- Clinical Staff
- Front Office Staff
- Referral Staff

What is in your toolbox?

TRANSITIONING YOUTH TO AN ADULT HEALTH CARE CLINICIAN

For use by Pediatric, Family Medicine, and Med-Peds Clinicians

Download Full Implementation Guide

Transition and Care Policy/Guide
Guide | Examples

Tracking and Monitoring
Guide | Examples

Transition Readiness
Guide | Examples

Transition Planning
Guide | Examples

Transfer of Care
Guide | Examples

Transfer Completion
Guide | Examples

TRANSITIONING TO AN ADULT APPROACH TO HEALTH CARE WITHOUT CHANGING CLINICIANS

For use by Family Medicine and Med-Peds Clinicians

Download Full Implementation Guide

Transition and Care Policy/Guide
Guide | Examples

Tracking and Monitoring
Guide | Examples

Transition Readiness
Guide | Examples

Transition Planning
Guide | Examples

Transition to Adult Approach to Care
Guide | Examples

Ongoing Care
Guide | Examples

INTEGRATING YOUNG ADULTS INTO ADULT HEALTH CARE

For use by Internal Medicine, Family Medicine, and Med-Peds Clinicians

Download Full Implementation Guide

Transition and Care Policy/Guide
Guide | Examples

Tracking and Monitoring
Guide | Examples

Orientation to Adult Practice
Guide | Examples

Integration into Adult Practice
Guide | Examples

Initial Visits
Guide | Examples

Ongoing Care
Guide | Examples

[Pediatric Practice Name] cares about you.

We will help you move smoothly from pediatric to adult health care. This means working with you, starting at ages 12 to 14, and your parent/caregiver to prepare for the change from a pediatric model of care to an adult model of care. A pediatric model of care is where parents/caregivers make most choices. An adult model of care is where you will make your own choices. We will spend time during visits without your parent/caregiver in the room to help you set health goals and take control of your own health care.

By law, you are an adult at age 18. We will only discuss your health information with others if you agree. Some young adults choose to still involve their parents/caregivers or others in their health care choices. To allow your doctor to share information with them, consent is required.

We have these forms at our practice. For young adults who have a condition that limits them from making health care choices, our office will share with parents/caregivers options for how to support decision-making. For young adults who are not able to consent, we will need a legal document that describes the person's decision-making needs.

We will work with you to decide the age for moving to an adult doctor. We suggest that this move take place before age 22. Our office policy is to prepare you to move to an adult doctor. This includes helping you find an adult doctor, sending medical records, and talking about any special needs with the adult doctor. We will help you find community resources and specialty care, if needed.

Your health matters to us. As always, if you have any questions, please feel free to contact us.

SAMPLE TRANSITION POLICY

TRANSITION TRACKING & MONITORING

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Transition Registry

A transition registry can be used to track and monitor youth throughout the pediatric-to-adult health care transition period. This sample registry can be customized as needed. A registry can be on paper, an Excel spreadsheet (see below), or — if possible — integrated into the electronic medical record.

Name	DOB	Appt	Age	Primary Diagnosis	HCT Policy/ Guide Shared with Y/YA/ Parent/ Caregiver	HCT Readiness Assessment Conducted	HCT Readiness Education/ Counseling Provided	HCT Plan of Care Shared with Y/YA/ Parent/ Caregiver	Medical Summary and Emergency Care Plan Shared with Y/YA/Parent/ Caregiver	Age 18 Privacy and Consent Changes Discussed	Supported Decision-Making Discussed (If Needed)	Adult Clinician Selected	Adult Clinician Contacted	Transfer Package Sent to Adult Clinician	Feedback About HCT from Y/YA/ Parent/ Caregiver	First Appt with Adult Clinician	Initial Adult Appt Attended
(Instructions)		(Date or Blank)	(At Time of Appt)		(Yes or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Date or Blank)	(Yes or Blank)	(Date or Blank)	(Date or Blank)	(Yes or Blank)	(Date or Blank)	(Date or Blank)
Mary Smith	03/04/03	06/01/20	17 Y	Asthma	Yes	06/01/20	06/01/20	06/01/20	06/01/20	06/01/20		Yes	06/15/20	06/15/20	Yes	04/01/21	
Mary Smith	03/04/03	04/01/19	16 Y	Asthma	Yes		04/01/19	04/01/19	04/01/19								
Mary Smith	03/04/03	04/01/18	15 Y	Asthma	Yes		04/01/18	04/01/18									
Taye Davis	01/17/01	01/10/20	19 Y	Epilepsy	Yes	01/10/20	01/10/20	01/10/20	01/10/20	01/10/20	01/10/20	Yes	01/21/20	01/21/20	Yes	06/07/20	
Taye Davis	01/17/01	01/21/19	18 Y	Epilepsy						01/21/19							
Sasha Jones	02/14/01	03/01/20	19 Y	Autism	Yes	03/01/20	03/01/20	03/01/20	03/01/20	03/01/20	03/01/20	Yes	03/24/20	03/24/20	Yes		
Sasha Jones	02/14/01	03/01/19	18 Y	Autism													
Sasha Jones	02/14/01	04/01/18	17 Y	Autism													
Sasha Jones	02/14/01	03/01/17	16 Y	Autism													
Jesus Garcia	11/03/05	12/01/20	15 Y	Diabetes	Yes	12/01/20	12/01/20	12/01/20	12/01/20								

HCT - health care transition, Y/YA - youth/young adult

Use a flow sheet, registry or the electronic health record if possible to track and monitor the progress of transition age patients (14-26) as they move through the six core elements of transition

TRANSITION READINESS

Sample transition readiness assessments:

- Youth
- Parents/Caregivers
- Youth With Intellectual and Developmental Disabilities
- Students with an Individualized Education Program (IEP)

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	0	1	2
I know how to ask questions when I do not understand what my doctor says.	0	1	2
I know my allergies to medicines.	0	1	2
I know my family medical history.	0	1	2
I talk to the doctor instead of my parent/caregiver talking for me.	0	1	2
I see the doctor on my own during an appointment.	0	1	2
I know when and how to get emergency care.	0	1	2
I know where to get medical care when the doctor's office is closed.	0	1	2
I carry important health information with me every day (e.g., insurance card, emergency contact information).	0	1	2
I know that when I turn 18, I have full privacy in my health care.	0	1	2
I know at least one other person who will support me with my health needs.	0	1	2
I know how to find my doctor's phone number.	0	1	2
I know how to make and cancel my own doctor appointments.	0	1	2
I have a way to get to my doctor's office.	0	1	2
I know how to get a summary of my medical information (e.g., online portal).	0	1	2
I know how to fill out medical forms.	0	1	2
I know how to get a referral if I need it.	0	1	2
I know what health insurance I have.	0	1	2
I know what I need to do to keep my health insurance.	0	1	2
I talk with my parent/caregiver about the health care transition process.	0	1	2
MY MEDICINES *If you do not take any medicines, please skip this section.*			
I know my own medicines.	0	1	2
I know when I need to take my medicines without someone telling me.	0	1	2
I know how to refill my medicines if and when I need to.	0	1	2

TRANSITION READINESS

The purpose of the transition readiness assessment is to begin a discussion with youth about health-related skills. Scoring is optional and can be used to follow individual progress on gaining these skills, not to predict successful transition outcomes

NAVIGATING THE PROCESS

Encourage	Acknowledge	Consider	Discuss
Encourage one on one time with youth/young adult without parent's presence develop and plan of care with joint goals and actions	Acknowledge parent/caregiver's request to support their youth's transition efforts	Linkage to community resources, identify adult oriented physician or specialist, condition sheets or legal documents, if needed	Discuss best timing of transfer to adult provider/model of care, supported decision making, medical summary, and emergency care plan as needed

TRANSITION PLANNING

- Plan of Care
- Medical Summary and Emergency Care Plan
- Sickle cell disease SMART Phrase resource for incorporating a Medical Summary into a transfer letter

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Plan of Care

This sample plan of care is created jointly with youth and their parent/caregiver to set goals and outline a plan of action that combines health and personal goals. Information from the transition readiness assessment can be used to develop goals. The plan of care should be updated often and sent to the new adult clinician as part of the transfer package.

Preferred name | *Legal name* | *Date of birth*

Primary diagnosis | *Secondary diagnosis*

WHAT MATTERS MOST TO YOU AS YOU BECOME AN ADULT? HOW CAN LEARNING MORE ABOUT YOUR HEALTH NEEDS AND LEARNING HOW TO USE HEALTH CARE SUPPORT YOUR GOALS?

Youth's Prioritized Goals	Transition Issues or Concerns	Actions	Person Responsible	Target Date	Date Completed

Clinician/Care staff name | *Date plan created/Updated*

Clinician/Care staff contact information | *Clinician/Care staff signature*

Youth signature | *Parent/Caregiver signature*

got transition.

PLAN OF CARE

Incorporating Health Care Transition Services into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians

Patience White, MD, MA
Annie Schmidt, MPH
Margaret McManus, MHS
Charles Irwin, Jr., MD

June 2018

got transition
The National Alliance to Advance Adolescent Health

Adolescent & Young Adult Health
National Resource Center
University of California, San Francisco

ANTICIPATORY GUIDANCE

- How important is it to you to manage your own health care (e.g., filling a prescription and taking your own medications, carrying around an insurance card, and scheduling your appointments)?
- How confident are you about managing your own health care (e.g., filling a prescription and taking your own medications, carrying around an insurance card, and scheduling your appointments)?
- What questions do you have about your health, medical summary, or, if needed for adolescents with special health care needs, plan of care?
- How comfortable do you feel asking your clinician questions?

CONVERSATION STARTERS: THE ADOLESCENT

- What questions or concerns, if any, do you have as you transfer to a clinician who cares for adults?
- How can our practice help you find an adult health care clinicians you feel comfortable with? Do you have any preferences about your next clinician (e.g. gender, location?)
- Will you need help finding other clinicians? (e.g. for reproductive health care, specialty care, mental health)?

CONVERSATION STARTERS: PARENT/CAREGIVER

- How are you encouraging your adolescent to build skills for managing their own health?
  - Is your child able to talk about their medical condition to others?
  - Do they know what medications they take
  - Do they know when to take their medications?
  - Do they take their medication on their own?

ADDRESSING GUARDIANSHIP, ALTERNATIVES IN TRANSITION PLANNING - *BEFORE THE YOUTH TURNS18*

Current formal tools for people who need help with decisions

Release forms

- Person signs release forms authorizing a specific person(s) access to certain kinds of records (health, financial, etc.).
- Some release forms may allow a person to select certain records to be released while retaining privacy over others.
- Some release forms may provide one-time or time-limited access to records, others releases may remain in effect in perpetuity.

Supported Decision Making agreements (Wisconsin)

- Person makes all their own decisions. Person identifies area of the life in which they want support, identifies a Supporter(s) to help them gather information, compare options, and communicate their decisions to others.
- The Supported Decision-Making agreement outlines what types of decisions the Person wants support and the role of the Supporter.
- Agreement can be changed or stopped at any time by the Person or Supporter.

Representative payee

The Social Security Administration (SSA) appoints an individual/organization to receive SSI/SSDI benefits for a person who cannot manage or direct the management of their own benefits.

To change a Representative Payee, the Person must complete an application process with the SSA.

Power of Attorney, medical proxy

- Formal legal arrangements that permit others to act on the Person's behalf.
- Powers of Attorney (POA) designate another (a POA) individual to make certain decisions (generally health care or financial) on the Person's behalf. POAs can be set up in different ways. Some POAs are activated only when a person is incapacitated. Or a POA can be written so an individual other that the Person is always the designated decision maker in certain areas.
- Medical Proxy documents appoint a proxy/agent to express a person's wishes and make health care decisions for the person if the person cannot speak for themselves.

Limited or Full Guardianship

- Transfers some or all decision-making authority from the Person to a court-appointed Guardian.
- Once guardianship is granted by the courts it is difficult (and costly) to modify or reverse the guardianship; any changes must be made through a formal court process.

The Arc Wisconsin

Less Limiting

More Limiting

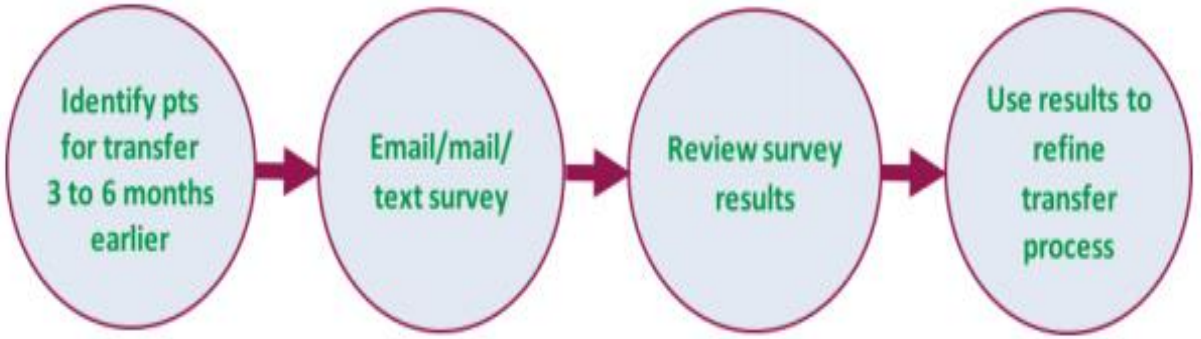
TRANSFER OF CARE

- Transfer checklist
- Transfer letter

TRANSFER CHECKLIST

Prepared transfer package including: _____ *Date*

- ☐ Transfer letter, including date of transfer of care
- ☐ Final transition readiness assessment
- ☐ Plan of care, including transition goals and prioritized actions
- ☐ Medical summary and emergency care plan
- ☐ Guardianship or health proxy documents, if needed
- ☐ Condition fact sheet, if needed
- ☐ Additional clinician records, if needed



TRANSITION COMPLETION

TRANSITION COMPLETION

- Feedback survey
  - Youth/Young Adults
  - Parents/Caregivers
  - Clinicians

TRANSITION COMPLETION

DID YOUR PAST DOCTOR OR OTHER HEALTH CARE PROVIDER... *Please check the answer that best fits at this time.*	YES	NO
Explain the transition process in a way that you could understand?	☐	☐
Give you guidance about the age you would need to move to a new adult doctor or other health care provider?	☐	☐
Give you a chance to speak with them alone during visits?	☐	☐
Explain the changes that happen in health care starting at age 18 (e.g., changes in privacy, consent, access to health records, or making decisions)?	☐	☐
Help you gain skills to manage your own health and health care (e.g., understanding current health needs, knowing what to do in a medical emergency, taking medicines)?	☐	☐
Help you make a plan to meet your transition and health goals?	☐	☐
Create and share your medical summary with you?	☐	☐
Explain how to reach the office online or by phone for medical information, test results, medical records, or appointment information?	☐	☐
Advise you to keep your emergency contact and medical information with you at all times (e.g., in your phone or wallet)?	☐	☐
Help you find a new adult doctor or other health care provider to move to?	☐	☐
Talk to you about the need to have health insurance as you become an adult?	☐	☐

RESOURCES

- Georgia Department of Public Health Transition Page
- Got Transition
- AAP Transition ECHO project
- Parent to Parent of Georgia Health Care Transition Workshops

VIDEOS….

- Dr. Right: the right way to discuss transition
- Making Health Care Transition Work for Youth with Autism

THANK YOU!

If you need additional information or if you believe your practice may be interested in an interactive version of this presentation, please contact Fozia Khan Eskew at the Chapter office at feskew@gaaap.org