Co-Management and Transitions for Patients with Genetic Conditions

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Integrating Genetics into Your Practice Webinar Series
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Learning Objectives

1. Discuss formation of care teams integrating primary care providers, genetic counselors, geneticists and others for persons with genetic conditions

2. Review clinical management materials for specific genetic conditions and their use

3. Present tools used in transition planning and review their implementation for patients and providers
Resources

- www.geneticsinprimarycare.org
- www.medicalhomeinfo.org
- www.gottransition.org
- www.region4genetics.org
Why Are These Topics Important?

• Increasing *numbers* of medically complex children
• Increasing *degree of complexity* of care
• Increasing patient and family *desire for comprehensive and coordinated care*
• Increasing demands on *provider’s time*
• Increasing concerns about *reimbursement*
• Increasing adoption of *medical home model*
Children and Youth with Special Health Care Needs (CYSHCN)

- Approximately 10.2 million children in the US (15% of all US children) have special health care needs based on the MCHB definition.¹
- More than 1/5 of US households with children have ≥1 child with special needs.
- 16% of CYSHCN are reported to not receive all the services they need.
- >94% of CYSHCN have a regular source of care when they are sick: 78% in private doctor's office; 13% in clinic or health center; and for almost 4% another setting.
- 0.67% are children with medical complexity (CMC), who account for 33% of health care costs for children.²


² Cohen, E; Berry, JG; Camacho, X; et al. Patterns and Costs of Health Care Use of Children with Medical Complexity. Pediatrics. 2012 Dec; 130(6)e1463-70.
Goal

Develop a systems-based approach to co-management and transitions to improve *efficiency* and *quality* of care for patients with genetic conditions
Co-Management

Shared, delegated care of a patient's medical condition among providers with either similar or disparate clinical expertise and/or professional credentials

Jonathan Talamo, MD
Principles & Practice of Ophthalmology, 2013
AAP Medical Care Model

Care that is

• Accessible
• Continuous
• Comprehensive
• Family-Centered
• Coordinated
• Compassionate
• Culturally effective

Essentials of Co-Management

- Wish to pursue a team approach to care
- Good communication
- Agreement on how to divide care
- Means to negotiate concerns
- Mutual respect
- Reliability
- Ownership of problems
Consider Ongoing Co-Management for

- Complex or multisystem medical issues
- Conditions requiring providers with specific technical skills
- Conditions which require specialty teams, such as metabolic diseases
- Rare conditions
- Patients and families with many questions about diagnosis and cares
- Any case in which the patient, family, PCP or specialist feels co-management would benefit patient care

Even if a patient with genetic concerns is not actively co-managed, many still need periodic follow-up by a genetics provider
Why Involve Genetics in Co-Management?

We understand

- Diagnosis
- Inheritance pattern and recurrence risk
- Mechanism of disease
- Evolution of clinical manifestations with age
- Syndrome management
- Reliable patient information/support groups
- Updates in testing/discussion of biobanking
- Experience and comfort with rare conditions
- How to access genetics expertise
- Multisystem approach
- Preparation for end-of-life issues and post-mortem investigations
Limitation of Genetics Availability

2006 comprehensive national survey of genetics services and health workforce

- 610 clinical geneticists spending ≥5% of time in direct patient care services
  - 36% general
  - 28% pediatric
  - 15% reproductive
  - 14% metabolic
  - 7% adult

- Mean new patient visits 222-900
- Mean follow-up visits 155-405

Genetics Availability

Genetics evaluations are very time intensive.

Average total time spent (Clinical geneticist and genetic counselor) in real-time study

- New consult 7 hours
- Follow-up 3.5 hours


So much to do, so little time...
Determinants of Co-Management Model

- Geography
- Clinic systems
- Insurance limitations
- Specialty availability
- Multispecialty clinics availability
- Interest of specialist in management
- Frequency of need for specialty visits
- Buy-in of patients and family into team approach
- Family financial, time, and transportation barriers
A Few Caveats

• Many patients with genetic conditions are cared for by multiple other pediatric specialists, each of whom should have defined patient care responsibilities

• All members of the co-management team must be clearly identified for family and providers

• It is best to establish a relationship with specialty providers prior to referral, in person or by phone

• In my opinion, multidisciplinary clinic care is usually preferable due to better coordination of care
It can sometimes feel like herding cats...
Tools for Co-Management

- Meaningful use of EMR with shared access
  *e.g., Care Everywhere on Epic®*
- Nurse care coordinators
- Multidisciplinary clinics
- Published management guidelines for specific syndromes
- Written agreements for establish co-management and specify division of care responsibilities
- *Direct communication between providers*
Nurse Care Coordination Model

Preferably a skilled, experienced pediatric RN

• Establishes **ongoing relationship** with patient, family and all providers
• Provides **single access** for all medical needs and access for patients and family
• **Accompanies** patient and family to clinic visits
• Reinforces **understanding** of medical advice and medication
• Helps **schedule coordinated appointments** and **review purpose** of visits
• **Tracks** care team participants
• Aids in **gathering and disseminating** outside medical and school records to all providers
• **Documents** cares and changes in status and shares with providers
• Assists with **orders**, such as for durable medical equipment
• Promotes appropriate **involvement of non-medical providers**, such as Social Work
• Available for both **in- and outpatient** settings

*Proven to be cost-effective in adult setting*

Care coordination cuts admissions, ED visits, LOS. Hosp Case Manag. 2013 May;21(5):67-8

Syndrome-specific Health Management Guidelines

- Standard of care based on evidence or expert panels
- Guidelines must be individualized to patient and situation
- Source of recommendations (with date published) should be documented in note
- List of guidelines available on GPCI Web site: www.geneticsinprimarycare.org/
- Other sources:
  - AAP Clinical Reports www.aap.org
  - ACMG Practice guidelines www.agmc.net
  - GeneReviews http://www.genetests.org/by-genereview/
  - Search of medical literature
  - Syndrome-specific foundation or society Web sites
  - Genetic counselors or clinical geneticists

*Use of these guidelines can help you assess quality of care, and act as a foundation for interactions with the Genetics provider.*
Letter Template to Engage a Specialist in Co-management of a Specific Child

(Insert your practice name)

Dear _______

We are referring our patient to you for a consultation visit. It is our plan (the family and our medical home team) to obtain your expert opinion on the following aspects of their health and gain your guidance helping our community-based support of this child and family.

– Child’s Condition: ________________________________________________________________
– Particular Questions/Concerns: ______________________________________________________
– Needed Recommendations: _________________________________________________________
– Other Tests or Referrals (note person responsible for communicating with family): _____________
– Recommended Specialty Visit Intervals: _______________________________________________
– Needed Chronic Condition Management Parameters for Primary Care: ______________________

Would it be possible for you to address the above checked concerns or issues and/or provide answers to the questions below (by phone, fax, email or other means) within one week?
1) __________________________________________________________________________
2) __________________________________________________________________________

Our care team is available to you for communication, transfer of information and sharing of care responsibilities. Our lead clinician and/or care coordinator can be reached at _____________.

We appreciate your working with us to strengthen the care of children and families.

Sincerely,

(Your name and title)

Co-Management Agreement

(Clinician/Practice Name) is initiating this Co-Management Agreement with (specialist name or group) to clarify aspects of the provision of comprehensive care for:

- General Agreement – Children and youth with the following conditions or
- Specific Agreement – Name child/youth and their condition

We would like to establish a set of explicit co-management roles and clarify who will take the lead with each one.

- Core knowledge and services your practice/department will provide: ________________
- Timely access, communication, and methods of reporting findings to one another: ________
- Periodicity of visits to specialty care/primary care (e.g. one time, period of time, indefinite, etc): ______________________
- Establish methods to evaluate effectiveness together and with family: __________________
- Other: ______________________

This Co-Management Agreement is between the following primary care and specialty clinicians (include signatures):

Primary Care Clinician ______________________
Practice ________________________________ Date __________

Specialist _______________________________
Practice/Department ________________________ Date __________

PRIMARY CARE REFERRAL AND FEEDBACK FORM

Date: ____________________  ( ) Initial  ( ) Follow-up

Referring Physician Name:

Address: ____________________  ____________________  ____________________  ____________________  ____________________  ____________________

(Street/PO Box)  City  State  Zip

Fax: (________) ___________  Phone: (________) ___________

Patient’s Name: ____________________  DOB: ____________________

Parent’s Name: ____________________  Address: ____________________  Phone: ____________________

Date(s) Patient Seen: ____________________

Reason(s) for Referral:

Any Specific Questions or Requests

________ ________

Referring Physician’s Printed Name/Signature

Thank you for evaluating this patient. To facilitate communication and treatment, please make copies of this form to retain in the patient’s record; complete a form after initial assessment; complete additional forms periodically during treatment (as indicated) and when treatment is terminated; and mail or fax completed form(s) to the physician listed above. This is not a request for copies of psychotherapy notes, which require a signed consent to release. Thank you for your collaboration.

Consultant’s Report

Date(s) Patient Seen: ____________________

☐ Patient did not make appointment.  ☐ Patient made an appointment but did not keep appointment.

☐ Patient not seen within 60 days.

Initial Diagnoses:

1. ____________________
2. ____________________
3. ____________________

Recommendations:

Medications Prescribed:

Follow-up Arranged or Provided by Consultant:

☐ Further diagnostic testing  ☐ Group therapy

☐ Individual therapy  ☐ Lab tests

☐ Family therapy  ☐ Medication management

☐ Medication management by PCC  ☐ Referrals recommended

☐ Follow-up recommended  ☐ Other

Other Care Needed:

Name (type or print) ____________________  Signature ____________________

FAX to ____________________  # ____________________  contact person ____________________

Add disclaimer statement per your institution here:

doi: 10.1542/peds.2010-0788Q

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

Pediatrics 2010;125;S172
How to Be a Good Partner in Care

- Get release of information forms filled out as soon as possible
- Ensure medical records are sent in a timely fashion
- Designate a care coordination specialist for each complex patient
- Be sure to ask family for feedback on process
- Contact specialist if questions
- Maintain professional and cordial interactions, and expect the same from your specialty providers
- Discuss pathway for addressing disagreements
- Do not criticize other providers in front of patients and families
- Track referrals for Quality Improvement
- Give the specialists constructive feedback
Transitions

“Optimal health care is achieved when each person at every age receives medically and developmentally appropriate care.”

Transitions in Genetics Patients

- Prenatal to birth
- “Normal” to “Something’s Wrong”
- Unknown diagnosis to known Diagnosis
- Age-related manifestations
- Childhood to Adulthood
- Health to disease (or reverse)
- Ability to disability (or reverse)
- At risk to low / no risk (or reverse)
- Need for active co-management to decreased genetics involvement
- Observation to disease management to palliation
- Life to death
## Transition Preparation of CYSHCN

<table>
<thead>
<tr>
<th>Core Outcomes</th>
<th>Met Goal</th>
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</thead>
<tbody>
<tr>
<td>Child receives anticipatory guidance on transition</td>
<td>40%</td>
</tr>
<tr>
<td>Doctor discussed shift to adult provider</td>
<td>44%</td>
</tr>
<tr>
<td>Doctor discussed future health care needs</td>
<td>59%</td>
</tr>
<tr>
<td>Doctor discussed future insurance needs</td>
<td>35%</td>
</tr>
<tr>
<td>Caretaker reports child is encouraged to take responsibility for own health care needs</td>
<td>78%</td>
</tr>
</tbody>
</table>

National Survey of Children with SHCN 2009-2010

- **Most CYSHCN are not getting needed preparation**
- More education of providers, patients and families needed
- Further expansion of clinical tools and processes expected to help
Model Values & Goals

Establish a working alliance between the young adult, parent(s)/guardian(s) and professional(s) to enable the patient to

• Realize his/her potential
• Satisfy his/her needs
• Develop capacities needed to interact successfully with biological, physical and social environments
• Become a responsible medical consumer

Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction

AAP, AAFP and ACP Transitions Clinical Report Authoring Group

Pediatrics 2011 Jul;128(1)182-202
National Health Care Transition Center
6 Core Elements to Transition

Both Pediatric and Adult Health Care Setting have recommended tracks to follow.

1. Transition Policy
   - Develop transition policy
   - Share with providers, patient, and families.
   - Educate staff on best practices

2. Transitioning Youth Registry
   - Identify and enroll current and future youth in registry
   - Monitor preparation, planning, and outcomes (care coordination)

3. Transition Preparation
   - Use Transition Readiness Assessment to identify and address gaps in preparation, knowledge, and skills

National Health Care Transition Center-6 Core Elements to Transition

4. Transition planning
   – Address gaps in plan
   – Set goals with youth and family
   – Make the following:
     • Health Care Transition Action Plans
     • Portable Health Care Summary
     • Emergency Plan, if needed.
   – Notify adult practice 1 year in advance and arrange for visit.

5. Transition and transfer of care
   – Peds PCP to meet with adult PCP
   – Use Transfer of Care Checklist
   – Send Transition Package with cover letter and all materials in checklist
   – Coordinate specialty transitions as needed
   – Transition to Young Adult Model of Care

6. Transition Completion
   – Check in with adult provider at 3 months to ensure success
   – Remain available as needed for questions from new PCP

Transition Health Care Checklist:
Preparing for Life as an Adult

My Health Pocket Guide

Transition Planning:
For Children and Adolescents with Special Health Care Needs
### Transition Planning for Children and Adolescents with Special Health Care Needs

<table>
<thead>
<tr>
<th>Health</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Understanding your child’s diagnosis or condition</td>
<td></td>
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<tr>
<td>Discuss coping strategies for dealing with uncertainty</td>
<td></td>
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<tr>
<td>Establishing relationships and partnering with the Health care team</td>
<td></td>
</tr>
<tr>
<td>Navigating the health care system of specialists</td>
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<tr>
<td>Importance of establishing a primary care provider</td>
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<tr>
<td>How to access “My Care”</td>
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<tr>
<td>Anticipatory guidance for time of illness</td>
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<tr>
<td>Yearly mental health interview for parents &amp; child to address any emerging concerns</td>
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<table>
<thead>
<tr>
<th>Environment &amp; Access</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Day care considerations: family caregiver, in-home day care, day care center</td>
<td></td>
</tr>
<tr>
<td>Self care, activities of daily living, adaptive equipment, home safety, modification, home care-giving demands</td>
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<tr>
<td>Emergency home and transportation plan</td>
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<thead>
<tr>
<th>School &amp; Therapy</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Birth to 3 services: teacher, physical therapy, occupational therapy, speech therapy</td>
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<tr>
<th>Finances</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Consider family income and resources</td>
<td></td>
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<tr>
<td>Connect with county and/or medical social worker to review options</td>
<td></td>
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<tr>
<td>Consider applying for SSI and/or Medicaid programs</td>
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<tr>
<td>Private health insurance</td>
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<tr>
<td>Children’s Miracle Network</td>
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<tr>
<th>Social Support</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Parent to parent connection groups</td>
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<thead>
<tr>
<th>Behavior Management</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Developing positive interactions between parent and child</td>
<td></td>
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<tr>
<td>Recognizing your child’s cues</td>
<td></td>
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<tr>
<td>Developing positive feeding experiences</td>
<td></td>
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<tr>
<td>Establishing sleep routines</td>
<td></td>
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<tr>
<td>Play experiences</td>
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<table>
<thead>
<tr>
<th>Community Resources</th>
<th>Comments</th>
</tr>
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<tbody>
<tr>
<td>New Life Family Center</td>
<td></td>
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<tr>
<td>Respite Care</td>
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<td>Parenting Classes</td>
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<td>County Services</td>
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<table>
<thead>
<tr>
<th>Child &amp; Family Strengths</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Parents as advocates for your child throughout his/her life</td>
<td></td>
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</table>
Transition Planning for Children and Adolescents with Special Health Care Needs

<table>
<thead>
<tr>
<th>Age 12 to 13</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td><strong>Health</strong></td>
<td>Utilization of multi-disciplinary care conferences to address complex care decisions</td>
</tr>
<tr>
<td></td>
<td>Begin to discuss how transition of medical care will be done</td>
</tr>
<tr>
<td></td>
<td>Yearly mental health interview for parents &amp; child to address any emerging concerns</td>
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<tr>
<td></td>
<td>Receive current copy of Transition Health Care Checklist: Preparing for Life as an Adult</td>
</tr>
<tr>
<td><strong>Environment &amp; Access</strong></td>
<td>Plan transition to middle school</td>
</tr>
<tr>
<td></td>
<td>Before and after school care</td>
</tr>
<tr>
<td><strong>School &amp; Therapy</strong></td>
<td>Orientation to middle school setting and staff before school year starts</td>
</tr>
<tr>
<td></td>
<td>Begin to make formative plans for Transition planning starting at age 14</td>
</tr>
<tr>
<td><strong>Finances</strong></td>
<td>Consider family income and resources</td>
</tr>
<tr>
<td></td>
<td>Connect with county and/or medical social worker to review options</td>
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<tr>
<td></td>
<td>Consider applying for SSI and/or Medicaid programs</td>
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<tr>
<td></td>
<td>Children’s Miracle Network</td>
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<tr>
<td><strong>Social Support</strong></td>
<td>Establish peer friendship groups</td>
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<tr>
<td></td>
<td>Consider participation in Special Olympics</td>
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<tr>
<td></td>
<td>Look for social/recreation opportunities</td>
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<tr>
<td></td>
<td>Riverfront Services</td>
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<tr>
<td></td>
<td>Teach self-advocacy skills</td>
</tr>
<tr>
<td><strong>Behavior Management</strong></td>
<td>Establish independence through compromise and negotiation</td>
</tr>
<tr>
<td></td>
<td>Assess for the presence of withdrawn and isolating behaviors</td>
</tr>
<tr>
<td></td>
<td>Increased behavioral issues due to hormonal changes and puberty</td>
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<tr>
<td></td>
<td>Social difficulties related to peer group</td>
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<tr>
<td></td>
<td>Issues of sexuality</td>
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<tr>
<td><strong>Community Resources</strong></td>
<td>Community programs:</td>
</tr>
<tr>
<td></td>
<td>- Swimming</td>
</tr>
<tr>
<td></td>
<td>- UWL Mentorship program</td>
</tr>
<tr>
<td></td>
<td>- Martial Arts</td>
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<tr>
<td></td>
<td>- Horse Sense for Special Riders</td>
</tr>
<tr>
<td></td>
<td>- YMCA</td>
</tr>
<tr>
<td><strong>Child &amp; Family Strengths</strong></td>
<td>Encouraging individual interest &amp; independence</td>
</tr>
<tr>
<td></td>
<td>Providing a positive forum for all family members to express thoughts, feelings, and opinions</td>
</tr>
</tbody>
</table>

continued...
Transition Planning for Children and Adolescents with Special Health Care Needs

<table>
<thead>
<tr>
<th>Health</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• You have the right to make all your own decisions about health care. You may consider other decision-making options, including having someone else help you make decisions.</td>
<td></td>
</tr>
<tr>
<td>• Take action to transition to adult health care providers</td>
<td></td>
</tr>
<tr>
<td>• Enroll in adult long-term care program if you are eligible</td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td></td>
</tr>
<tr>
<td>• Guardianship, Power of Attorney, Power of Financial Attorney and Medical Directive* must be in place, if needed</td>
<td></td>
</tr>
<tr>
<td>• Contact private insurance companies about continued coverage, based on disability</td>
<td></td>
</tr>
<tr>
<td>• Apply for SSI, and reapply for Medicaid programs as an adult, if you may be eligible</td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
</tr>
<tr>
<td>• Make decisions about future plans for work, additional schooling, and living situations</td>
<td></td>
</tr>
<tr>
<td>• Males need to register with Selective Service</td>
<td></td>
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<tr>
<td>• Register to vote</td>
<td></td>
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</tbody>
</table>

*Also known as an advance directive. This is your written plan for end of life care. It states your wishes with regard to the use of extreme measures to keep you alive, such as cardiopulmonary resuscitation (CPR), machines to help you breathe, tube feeding and other methods.

(Adapted from Wisconsin Community of Practice on Transition Practice Group of Health, Transition Health Care Checklist: Preparing for Life as an Adult, March 2007, p. 2).

Notes

____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________

continued...
## Transitions

<table>
<thead>
<tr>
<th>What Genetics Wants from You</th>
<th>What You Want from Genetics</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How long will you remain the PCP for this patient?</td>
<td>• How does this condition change over time?</td>
</tr>
<tr>
<td>• What transition policies are you implementing?</td>
<td>• What kind of Genetics services will this patient need as an adult?</td>
</tr>
<tr>
<td>• Who will guide the transition process?</td>
<td>• Do you follow adults with genetic conditions?</td>
</tr>
<tr>
<td>• What transition processes need Genetics input?</td>
<td>• If not, who does?</td>
</tr>
<tr>
<td>• Who will see this patient after transition for primary care?</td>
<td>• Are there changes in insurance coverage for adults that would warrant addressing?</td>
</tr>
<tr>
<td>• Where will the patient live- at home, in a group home setting?</td>
<td>• Which adult PCPs do you work with?</td>
</tr>
<tr>
<td></td>
<td>• How does this condition affect need for guardianship?</td>
</tr>
</tbody>
</table>
Keys to Transitions to Adult Genetic Care

- Decide on your age (or other) cut-offs
- Ask Genetics specialists about their scope of practice
- Ask Genetics what management or follow-up is needed in adulthood
- Identify options for appropriate adult providers - Genetics and others
- Look into adult care coordination
- Let your patients and families know well in advance about transitions
- Have a written plan for transitions
- Discuss quality-of-life and end-of-life issues openly, as indicated
- Document and track transition process
- Ask for feedback from patients and families
Healthy & Ready to Work:
A Series of Materials Supporting Youth with Special Health Care Needs

Transition to Adult Health Care:
A Training Guide in Two Parts

http://www.waisman.wisc.edu/cshcn/cdrom.php
Helpful Materials

• Region 4 Midwest Genetics Collaborative
  www.region4genetics.org/Education/Families.html
  – Partnering with your Doctor: The Medical Home Approach brochure
  – Transition Web Application: online videos and resources packet for young adults, parents/guardians, and health care professionals
  – Care Coordination Training: Empowering Parents workshops (in pilot training 2013)

• Genetic Alliance
  www.genesinlife.org/

• Six Core Elements of Health Care Transition
  http://www.gottransition.org/home

• Transition to Adult Health Care: A Training Guide in Two Parts (PDF document)
  http://www.waisman.wisc.edu/cshcn/cdrom.php

• Medical Genetics in Pediatric Practice
  – New AAP handbook published 2013 (also on iOS® and Android® platforms)

• Off to College: A Guide for Young Adults with Chronic Illness
  http://www.uwppc.org/
Summary

• Keep the patient and family at the center of care.
• Cultivate good relationships with your Genetics colleagues.
• Communication is a two-way street.
• Use available tools and standard processes to ensure consistent co-management and transition.
• Practice makes perfect (for all of us)!
Questions
Thank you for your participation!

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