

Transition: Introduction and CNF Toolkit



Rebecca J. Schultz, PhD, APRN, CPNP
Associate Professor
Nelda C. Stark College of Nursing
Texas Woman's University



Assistant Professor
Baylor College of Medicine
Pediatric Nurse Practitioner
Comprehensive Epilepsy Program
Texas Children's Hospital

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Disclosures

- Member, CNF Transitions Project Advisory Committee

At The End Of Our Conversation This Evening I Hope You:

- Take an active role in transition planning for your adolescent--set expectations
- Utilize the transition toolkit to guide you through the transition process.

What is transition of health care?

- **Process** of moving from pediatric to adult health care system
 - Requires **preparation** of youth to receive care within the adult health care system. ** Includes caregivers
 - Planned, patient centered, developmentally appropriate, comprehensive, uninterrupted
 - Requires periodic assessment of transition readiness
- **Transfer—the final step of transition**

American Academy of Pediatrics, et al. (2002)

Goals of Health Care Transition

- Maximize lifelong functioning and potential
- Prevent “bridge to no where”
 - Good communication and uninterrupted services



Successful transition leads to . . .

- Continuity of care
 - Fewer gaps in clinical follow up
 - Improved access to care
- Improved adherence
 - With medications
 - Fewer emergency room visits
- Improved Quality of Life



Annunziato, et al. (2007); Bryden, et al. (2001); Bryden, et al. (2003)

Needs of Adolescents with Chronic Health Conditions

- Similar to youth without chronic health condition
 - Change as adolescent matures
 - Desire for independence
 - Need for identity and purpose
 - Often complex
 - Require individualized care



Adolescents with Cognitive Impairments

- Cognitive ability impacts the transition process & outcome
 - “Developmentally, she is 7”
 - Independent living skills
 - Additional support
 - Adult provider to accept care
 - 35% no adult neurologist



Barriers

- Patients, parents/caregivers unwilling to transition
- Adult providers lack experience
- Adult providers difficult to access
- Difference in pediatric vs adult culture
- Aging out, but still youth is unready/ unwilling to take adult responsibility
- Insurance changes
- Transportation/ Access
- Patient seen by multiple providers without a medical home (fragmentation of care)
- No time to discuss transition

Different Needs

- **Refractory, intellectual disability**
 - Complex health needs
 - Require multidisciplinary care –more resources and services
 - PCP, PT, OT, psychiatry
 - Behavioral issues
 - Social issues
- **Well controlled, normal intellect**
 - Self-management skills
 - AED teratogenicity
 - Alcohol & drugs
 - Driving
 - Mental health

All need individualized transition care plan



COMMON PRINCIPLES AND TOOLKIT FOR TRANSITION TO ADULT NEUROLOGY

**YOUR TOOL TO SETTING EXPECTATIONS FOR YOURSELF,
YOUR ADOLESCENT, AND YOUR NEUROLOGY PROVIDER.**

Brown, et al, Neurology® 2016; 87:1–6

Transition Takes

- Time
 - locate resources
 - learn new information

- Advocacy

- Tenacity



START EARLY

- Begin discussion at 12-13 years of age
 - Ask your neurologist when you will have to transfer to adult care?
 - 18 years
 - 21 years
 - Never
 - Will they help you with this process? How?
- Set expectations
 - Obtain optimal independence
 - Team



Learn Self-Care Skills

- Start early: 12-13 years
 - Depends on teen's abilities
 - Align with “training” in independent living skills
 - Advance with age/acquisition
- Baby steps: Starts with YOU!
 - Let your teen check-in for their clinic appointment
 - You may be surprised what your teen CAN DO!

Letting Go!

- Moving from “Advocate to Ally” Eileen Forlenza
- Tips to “letting go”
 - Remember, it’s about your child; Not about you.
 - Let go of the idea that your child will make the same choices as you did for them.
 - Professionals need to ‘let go’ too.
 - Encourage direct communication between your child and the provider
 - ‘Letting go’ might look different for each of us

Medical Condition

- Teach your teen about their medical condition
 - Name of condition
 - Signs of illness
 - Sex, drugs, alcohol
 - Signs of emergency; when to seek medical attention
 - Develop emergency plan



Emergency Plan

- Medical Alert bracelet/necklace or tag
- Wallet card
 - Diagnosis, seizure type
 - Medications
 - Allergies
 - Emergency contact information
 - Medical contact information
- ICE number on phone
 - Can include additional information about medical condition under the contact details

Managing Medications



- Know names and doses of medication
- Promote independence in taking medications
 - Talk to provider about side effects
 - Inconvenient dosing schedule
 - Medication reminders
 - Missed dose is #1 reason for breakthrough seizures
- Know how to refill prescription



Appointment Keeping/Insurance

- How to schedule an appointment
- Importance of following up on lab tests, check-ups, referrals
- Insurance coverage
 - What to do if lose current coverage
 - What does your health insurance cover?

Promote independence/self-advocacy

- Encourage your teen to participate in the clinic visit
 - Let them tell the doctor or nurse about their seizures; how they are feeling
 - Let them answer the questions
 - Encourage them to ask questions during the office visit
 - Time alone in clinic visit



Legal Competency

- Age of majority is 18 years in most states
 - Right and responsibility to make certain legal decisions
- Assess decision-making capacity
 - Begin discussion at age 14 years
- Capacity for making decisions may vary depending upon your teen's ability
 - Shared decision-making
 - Confidentiality waivers
 - Health care power of attorney
 - Guardianship

Assessment of Self-Care Skills

- Reassess annually
 - Celebrate successes!



- Resources

- www.childneurologyfoundation.org/transitions
- www.gottransition.org

Child Neurology Foundation Toolkit

<https://www.childneurologyfoundation.org/resources-for-young-people-with-neurologic-conditions-and-their-caregivers/>

Self-Care Assessment

PARENTS / CAREGIVERS

Young Adults with Neurologic Disorders

Decision-Making / Guardianship

- ☐ My young adult can make their own health care choices.
- ☐ My young adult needs some help with making health care choices. Name: Consent:
- ☐ My young adult has a legal guardian. Name:
- ☐ My young adult/I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care

- ☐ My young adult can care for all their needs.
- ☐ My young adult can care for their own needs with help.
- ☐ My young adult is unable to care for themselves, but can tell others their needs.
- ☐ My young adult requires help for all their needs.

Transition and Self-Care Importance

On a scale of 0 to 10, please pick the number that best describes how you feel right now.

How **important** is it for your youth/young adult to take care of their own health care?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 (not important)	1	2	3	4	5	6	7	8	9	10 (very important)

How **confident** do you feel about your youth/young adult's ability to take care of their own health care?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 (not confident)	1	2	3	4	5	6	7	8	9	10 (very confident)

Tool developed by the Child Neurology Foundation as part of the ACP HVC pediatric to adult care transition project.
Available at: www.childneurologyfoundation.org/transitions © 2020 CNF

Page 1 of 3

Understanding Young Adult's Health

Please check the box that applies to you right now.

☐ Check if none of the options below apply (for example, totally dependent care)

	Yes, they know this	They need to still learn this	I need to learn this
My young adult knows their medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult can tell other people what their medical needs are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows what to do if they have a medical emergency. My young adult has an emergency care plan documented.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows the medicines they take and what they are for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult can take their medicine by themselves.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult can take their medicine without a reminder.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows what they are allergic to, including medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult can name 2-3 people who can help them with their health goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care

Please check the box that applies to you right now.

☐ Check if none of the options below apply (for example, totally dependent care)

	Yes, they know this	They need to still learn this	I need to learn this
My young adult knows or can find their doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult makes their own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, my young adult thinks about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult has a way to get to their doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows they should show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows where to get care when their doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult has a folder at home with their medical information, including medical summary and emergency care plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult has a copy of their plan of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows how to ask for a form to be seen by other another doctor/therapist (i.e., referral).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult knows where their pharmacy is and what to do if they run out of medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care (continued)

	Yes, they know this	They need to still learn this	I need to learn this
My young adult knows where to get a blood test or x-rays if the doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult carries health information with them every day (e.g., insurance card, allergies, medications, and emergency phone numbers).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My young adult has a plan so they can keep their health insurance after 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please include here any other concerns or thoughts you wish to share with your health care team regarding the health of your young adult:

Self-Care Assessment

YOUTH/YOUNG ADULTS

Young Adults with Neurologic Disorders

Legal Choices for Making Health Care Decisions

- ☐ I can make my own health care choices.
- ☐ I need some help with making health care choices. Name: _____ Consent: _____
- ☐ I have a legal guardian. Name: _____
- ☐ I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care

- ☐ I care for all my needs.
- ☐ I care for my own needs with help.
- ☐ I am unable to provide self-care but can tell others my needs.
- ☐ I require total personal care assistance.

Self-Care Importance

On a scale of 0 to 10, please pick the number that best describes how you feel right now.

How **important** is it for you to take care of your own health care?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 (not important)	1	2	3	4	5	6	7	8	9	10 (very important)

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Page 1 of 3

Self-Care Importance (continued)

How **confident** do you feel about your ability to take care of your own health care?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 (not confident)	1	2	3	4	5	6	7	8	9	10 (very confident)

My Health

Please check the box that applies to you right now.

	Yes, I know this	I need to still learn this	I will need help with this
			Who: <input type="text"/>
I know what medical conditions I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what my medications are for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do if I have a medical emergency. I have an emergency care plan documented.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take my medicines without someone reminding me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I am allergic to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can name at least 2 people who can help with my health goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to people how my beliefs affect my care choices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

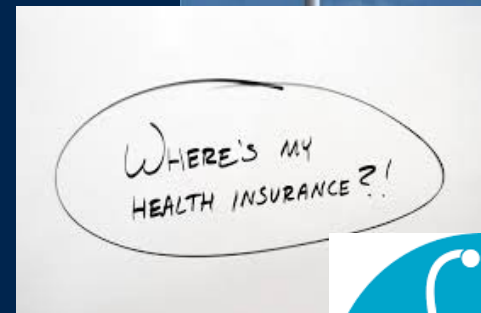
Using Health Care

Please check the box that applies to you right now.

	Yes, I know this	I need to still learn this	I will need help with this
			Who: <input type="text"/>
I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can make my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, I think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know I should show up 15 minutes before my visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comprehensive Plan – review annually

- Education
 - Review individualized educational plan (IEP)
 - Develop school educational plan/support
 - Remain in high school until 21
 - Vocational Training
 - College
- Assess support needs
- Health Care Providers



Post-HS Education?

- Check out student health center services
 - Health care provider on campus?
 - Refills?
 - Consider mail order pharmacy
- Develop emergency care plan
 - Share with roommate or resident advisor
 - Post seizure first aid on dorm fridge or door
 - Stopwatch
 - Wear medical alert bracelet
 - Program ICE into phone

Health Insurance

- Insurance coverage
 - Will it change?
- Medicaid
 - Will it change?
 - Do your providers accept your plan?
 - CHIP coverage ends after the 18th birthday
 - Assistance
 - Social Security Administration
 - www.healthcare.gov

Identify Adult Provider

- Finding a new provider
 - Referral from current provider
 - Friends/family
 - Health insurance directory

Identify adult provider

- What are your needs/expectations?
 - Location
 - Near home or at college
 - Transportation needs
 - Hospital affiliation/emergency care
 - Knowledgeable about TSC, epilepsy/co-morbid conditions
 - Communication style

Transfer Packet

- Between ages 17 and 18
 - Re-assessment of knowledge of medical condition and self-care skills
 - Decision-making capacity
 - Prepare Transfer packet
 - Summary of diagnosis/etiology
 - Current medication/laboratory results
 - Previous treatments and diagnostic evaluations
 - Significant past procedures
 - Emergency care plan



Brown, et al, Neurology® 2016; 87:1–6

Medical Summary

TRANSITIONING PATIENT

Young Adults with Neurologic Disorders

Patient Information

Patient Name:

Date Form First Completed:

Date/s Form Revised:

Form Completed by:

Principal Transition Medical Provider's Contact Information

Name:

Address:

Work Number:

Best Time to Reach:

Email:

Best Way to Reach: ☐ Phone ☐ Email

Transitioning Patient Contact and Insurance Information

Name:

Nickname:

DOB:

Preferred Language:

Address:

Cell #:

Home #:

Best Time to Reach:

Email:

Best Way to Reach: ☐ Text ☐ Phone ☐ Email

Parent (Caregiver):

Relationship:

Address:

Cell #:

Home #:

Best Time to Reach:

Email:

Best Way to Reach: ☐ Text ☐ Phone ☐ Email

Health Insurance Plan:

Group and ID

Limited Legal Status? ☐ Y ☐ I ☐ N ☐

Tutorship ☐ Y ☐ I ☐ N ☐

Guardianship ☐ Y ☐ I ☐ N ☐

****Legal documents to be provided by parents of primary caregivers** Please attach.**

Health Care Providers

Name	Phone/Fax	Email
Primary Care Provider		
Specialty & Name	Phone/Fax	Email
Specialty Provider		
Specialty Provider		
Specialty Provider		
Specialty Provider		
Specialty Provider		
Name	Phone/Fax	Email
Occupational Therapist		
Physical Therapist		
Speech Therapist		
Behavioral Health		
Other		
Other		
Other		

School and Community Information

Agency/School	Contact Person	Phone/Fax	Email

Emergency Care Plan

Name:		Relationship to Patient:	
Phone (Cell):	Phone (Other):	Email:	
Preferred Emergency Care Location:			
Special precautions (e.g., seizure action plan):			

Etiology (Check all that apply; describe)

<input type="checkbox"/>	Genetic/Chromosomal	<input type="checkbox"/>	Prenatal Substance Exposure	<input type="checkbox"/>	Prenatal Viral Exposure
<input type="checkbox"/>	Preterm Birth	<input type="checkbox"/>	Infection	<input type="checkbox"/>	Acquired (e.g., TBI, Submersion injury)
<input type="checkbox"/>	Metabolic	<input type="checkbox"/>	Other (specify)	<input type="checkbox"/>	Other (specify)
<input type="checkbox"/>	Unknown (specify)				

Diagnoses and Current Problem

Primary Neurological Diseases

Problem List	Details and Recommendations

Secondary Diagnoses

Problem List	Details and Recommendations

Associated Behavioral Issues

Please specify:

Allergies; Medications and Procedures to be Avoided

Allergies	Reactions
Avoid	Why?
Medications (List)	
Medical Procedures (List)	

Current Medications (For prior medications, please complete final page)

Medications	Dose	Frequency	Medications (continued)	Dose	Frequency
1.			7.		
2.			8.		
3.			9.		
4.			10.		
5.			11.		
6.			12.		

Prior Surgeries, Procedures and Hospitalizations (include imagery where available)

Date:	
Date:	
Date:	
Date:	
Date:	
Date:	
Date:	
Date:	

Adaptive Functioning Domains (current activities)

Communication	Verbal?		NonVerbal?	
Social				
Nutritional Issues				
Sleep Issues				
Mobility	Independent?		Aides?	
	Other? Describe			
Functional Academics	Functional Grade Level:		Date Tested:	
	FSIQ: (full-scale if available)		Date Tested:	
Self-care				
Leisure				

Care Notebook

- Resources
 - Texas Parent to Parent Care Notebook
 - www.txp2p.org/services/family-to-family-health-info/care-notebook

The Transfer

- Request current provider send a copy of medical records
- Request current provider send a summary of their recommended treatment
- Schedule appointment
- Call new provider's office before 1st visit to be sure they received records

Summary

- Transition is a process
- Planning for the future is essential
- Start early
- Takes time to learn self-advocacy and self-care skills
- Journey of Advocacy >>>> Ally
- Develop a Team. Be the Quarterback!
- Goal to maximize lifelong potential

Set Your Expectations!

- Stay informed:
 - <http://www.childneurologyfoundation.org/transitions>
 - www.gottransitions.org
 - www.medicalhomeinfo.org
- Begin dialogue with self, family, and youth regarding transition expectations (health care and social). How do you envision the future? What is your dream?
- Begin dialogue with your provider regarding transition expectations
- Reach out to your community – YOU ARE NOT ALONE!
- **Share your story!**

Thank you!

