



The A,B,C's of Transition Care: Patient Autonomy

Teresa Nam, MD

Midwest Region NMPRA

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CASE 2: PATIENT AUTONOMY/PREPAREDNESS

- Working in the ER, you see a JK, a 19 year old female with Crohn's disease coming in for dysuria. She is not able to tell you the names of her medications or why she is taking them.
- When you ask her if she has started to think about transitioning her care to an internist and adult gastroenterologist, she replies "I am never going to switch over from Dr. X."



AUTONOMY/ PREPAREDNESS CASE

- What ways are available to prepare this patient to move from pediatric to adult care?
- Are there tools available to do so?

SKILL AREAS

- Accessing health care
 - Ability to navigate the health care system
- Managing conditions and treatments
 - Knowledge of diagnoses and medications
- Staying healthy
 - Preventative practices
- Using health insurance
 - What kind of insurance, co-pays, coverage
- Other areas of transition
 - Housing, employment, finance, benefits, and guardianship



ACCESSING HEALTH CARE - Skills and Abilities:	YES, I do	NO, I will learn	Someone will need to do this for me	N/A, Will not be needed	Need more Info
△ Do you wear or carry a medical alert (list of allergies, conditions)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you speak up for yourself in your doctor's office?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you help make health care decisions with your family or doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you see your doctor without your family/parents in the room?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know your rights to keep your health information private?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you call your doctor(s) on your own if you have a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know how to schedule your own doctor appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you have an updated portable medical summary and/or care plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you have an adult doctor (or a doctor for while you are at college)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MANAGING YOUR CONDITIONS AND TREATMENTS - Skills and Abilities:					
△ Do you know how to describe your own health conditions/disabilities and do you know how they affect your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know the names of your medicines and why you take them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know what can happen if you skip your treatments or medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you almost always take your medicines correctly on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you know when and how to fill your own prescriptions (knowing who prescribed and where to call, getting refills on time)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you use and take care of your own medical equipment and supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you know when to call for routine checkups, urgent care, and when to go to the emergency room or call 9-1-1?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
STAYING HEALTHY - Skills and Abilities:					
△ Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
△ Do you understand how smoking, drinking, and/or using drugs can affect your condition (worsen symptoms, react with your medicines)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know how your condition affects sexuality (the need for closeness, caring, and touch, sometimes involving sexual activity)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know what you'll do for birth control, safe sex, and reproductive concerns (genetics, pregnancy)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
INSURANCE - Skills and Abilities:					
□ Do you know how to use your health insurance benefits (co-pays, referrals)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you know who to call for questions about your insurance coverage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
○ Do you know how you will maintain health insurance as an adult?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OTHER AREAS OF TRANSITION - Skills and Abilities:					
□ Do you know what you will do after high school (job, more school, recreational options, volunteer, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ Do you know of resources that can help you to find adult services (job support, transportation, assistive technology, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



BUILDING AUTONOMY



Assessment of patient's ability for self care/management

- **Medications:**
 - knows them, gives own meds, knows why taking, can order meds when running out, knows side effects/things to monitor with different medications
- **Self care/knowledge of disease**
 - Warning signs/ when to seek help/who to contact, troubleshooting, devices/procedures (self cathing, etc),
- **Navigating medical system**
 - Making appointments, filing insurance claims, who to call when sick, understanding specialists' roles
- **Finances and living**
 - Income, budgeting, living expenses, employment, IADLs, ADLs, education planning



Questions incorporated into your Adolescent Note

○ Transition Specific Questions

Insurance plans:

- Medicaid application
- Will remain on parental insurance
- Needs information regarding insurance plans

Guardianship:

- Requires referral to legal for assistance
- Special Needs Trust

Future Plans/Activities:

- Requires information about day programs/job training
- Life training program (RIC)





The A,B,C's of Transition Care: The Portable Medical Document

Rachel Caskey, MD

Midwest Region NMPRA
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PORTABLE MEDICAL DOCUMENT

All patients, especially those approaching transition, benefit from a basic portable medical summary that includes:

- Basic patient personal, social, and contact information, including emergency and guardian contact information (if applicable)
- Providers' contact information
- Diagnoses and baseline status
- Pertinent medical, surgical, and injury history
- Immunization record
- Allergies
- Current medications
- Transition goals
- Special notes

<http://www.healthvault.com/personal/index.aspx>



Expanded Portable Medical Summary or Care Plan

- Patients with complex chronic conditions may require a basic summary plus:
 - Therapies/other services, including contact information
 - Maintenance routines: bowel/bladder, respiratory, nutrition, etc.
 - Equipment and supply information (and ordering information)
- Portability and ease of access/update is particularly important



TRANSITION PORTABLE MEDICAL SUMMARY

Transition Summary

Name _____ DOB _____ SS# _____
 Address _____
 Phone _____
 Emergency Contact _____ Relationship _____ Phone _____
 Guardian/Medical Surrogate _____ Relationship _____ Phone _____
 Communication needs _____
 Assistive technology _____

Primary Insurance _____
 Secondary Insurance _____
 Health Care Insurance Plans _____
 if none, consider referral to social work

Physician	Address	Phone number/Fax
PMD:		
Future PMD:		

if none, refer to ICAAP physician network

Diagnosis	Managing Provider	Address	Phone
1.			
2.			
3.			
4.			
5.			

plans for sub-specialty transition?

Current Medications	Current Medications

Allergies: _____

Please attach recent labs, imaging and other studies.

Please attach most recent history and physical exam and immunization history.

Medical Equipment	Medical Supplies	Provider	Contact
Info			
1.			
2.			
3.			
4.			

Past Hospitalizations/Surgeries

Date	Hospital Name	Reason	Physician

Hospital records included

Functional Capabilities	
Upper Extremities	
Lower Extremities	
Speech/Language	
Cognitive/Problem Solving	
Services Receiving	Address
1.	
2.	
3.	

Brief medical history/prognosis/disease course: _____

School address _____ Phone _____

Hobbies _____

After high school plans _____

if none, provide informational hand-out or refer to social work.



Strategies for the Portable Medical Summary and the Transfer of Care

- Provide the portable medical summary to new physician(s) **before** the patient transfers
- Consider:
 - An e-copy that can be easily updated
 - Sending separately from the complete records
 - Potential opportunity to discuss with new physician(s)
- Format of portable medical summary
 - Note in EMR
 - Separate document – electronic or written



BUILDING SKILLS

- ICAAP Medical Home: <http://illinoisaap.org/projects/medical-home/transition/resources-for-physicians/>
- RIC Life Center: www.lifecenter.ric.org
- Illinois Centers for Independent Living: List of centers in IL: www.incil.org
- Family Resource Center on Disabilities (Chicago area): www.frcd.org/resources/transition
- Illinois Department of Human Services: Job training and independent living support:
www.dhs.state.il.us/page.aspx?item=29727

