

**AUA**  
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MAY 15-18

# Considerations for Transitioning from Pediatric to Adult Urology Clinical Care

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## Disclosures

- None

- APPs uniquely positioned to lead structured, patient/person-centered transitions



## Good Morning....

Appt Time	Patient	Age	Sex	Reason for Visit	Provider
8:30 AM	E.C.	16	F	Follow-up: Spina Bifida	Maryellen Kelly, DNP
9:00 AM	T.J.	14	M	Eval: Posterior Urethral Valves	Maryellen Kelly, DNP
9:30 AM	L.H.	8	M	Check-up: Hypospadias	Maryellen Kelly, DNP
10:00 AM					

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## Insert blank stare and UpToDate search

Think about each patient:

- 1- Medical Complexity
- 2- Social Support
- 3- Self-Efficacy and Autonomy

## Medical Complexity



### High Complexity

- Congenital Anomalies
- Neurogenic Bladder
- Catheterizable Channels
- Renal Insufficiency
- Recurrent Infections
- Follow-up: Spina Bifida
- Bladder Augmentation
- Catheterizable Channels
- Renal Insufficiency
- Prior Reconstructions



### Moderate Complexity

- Stable Congenital Conditions
- Intermittent Catheterization
- Mild Renal Involvement



### Low Complexity

- Resolved Childhood Issues
- Minimal Ongoing Management

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## Social Support

**Strong Support**

- Engaged Caregivers
- Reliable Transportation
- Stable Housing
- Consistent Follow-Through

**Moderate Support**

- Intermittent Caregiver Involvement
- Some Logistical Barriers

**Low Support**

- Unstable Housing
- Limited Family Involvement
- Unreliable Follow-Up
- Financial / Insurance Instability

## Efficacy and Autonomy

**High Autonomy**

- Manages Medications
- Schedules Appointments
- Understands Condition

**Moderate Autonomy**

- Partial Understanding
- Needs Reminders
- Inconsistent Self-Management

**Low Autonomy**

- Dependent on Caregivers
- Limited Understanding of Condition
- Difficulty Navigating Healthcare

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## Bringing it back to the patient

- Combinations
  - High complexity + low support + low autonomy
  - Moderate complexity + strong support + moderate autonomy
  - Low complexity + low support + high autonomy

## Priorities based on categories

- Ex: High Medical Complexity + Low Support + Low Autonomy
  - Direct communication with pediatric providers/clinic
  - Obtain **detailed** medical history summary
  - Set-up new case management/social worker preemptively
  - Focus on **one** skill for autonomy per visit
  - Use telehealth for more frequent check-ins
  - Confirm DME needs

## Priorities based on categories

- Ex: High Medical Complexity + Strong Support + Moderate/High Autonomy
  - Review long-term real and potential complications of condition
  - Reinforce self-management but shift responsibility away from caregivers
  - Discuss adult specific concerns: insurance, employment, living situation, sexuality, fertility
  - Identify gaps in condition related knowledge

## Priorities based on categories

- Ex: Moderate Medical Complexity + Low/Moderate Support + Moderate Autonomy
  - Review medication and follow-up adherence
  - Provide written and digital plan
  - Set up reminders (in EMR or their phone)
  - Screen for mental health concerns that could affect self-management
  - Connect to community (peers, transportation, financial assistance)
  - Reinforce important condition 'red flags'

## Priorities based on categories

- Ex: Low Medical Complexity + Low Support + High Autonomy
  - Focus on education and empowerment
  - Ensure patient understands when to return and 'red flags'
  - Confirm established primary care
  - Provide anticipatory guidance
  - Make sure they have an 'easy' way to reach you

## Checklist

- Identify immediate risks
  - Renal decline
  - Medication and insurance
  - DME
- Document achievable goal for next visit
- Set-up adult-focused support

## Reference Plan

- Medication list and pharmacy contact
- DME list and contact
- Emergency symptoms
- Clinic contact
- Next visit date/time/location

## Case

Pt: 19 year old with spina bifida, Mitrofanoff, MACE and history of bladder augmentation

## Case

Pt: 19 year old with spina bifida, Mitrofanoff, MACE and history of bladder augmentation

High complexity + moderate support + low autonomy

## Resources and Takeaways

- Transitional is a process
- Spina Bifida Association transition guidelines
  - Adolescent/Young Adult Self-Management and Independence Scale (AMIS II SB-SR)
  - Transition Readiness Assessment Questionnaire- Spina Bifida (TRAQ-SB)
  - Kennedy Krieger Independence Scale (KKIS)

## Resources and Takeaways

- Got Transition
- AAP Guidelines on Transition
- Transition Readiness Assessment Questionnaire
- STARx Questionnaire

Thank you

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