NephU™
Improving Awareness & Patient Outcomes

Transition Of Care From Pediatric To Adult Nephrology

The Need For Pediatric-To-Adult Nephrology Care Transitioning Is Increasing

500,000

More than 500,000 adolescents with chronic disease transfer to adult-focused health care every year in the United States[1]

85-90%

The number of young patients graduating from pediatric to adult renal care has progressively increased due to improved management resulting in patient survival rates of 85-90%[2]

25%

About 25% of all teenagers and young adults with advanced CKD present primarily to adult services[2]

The Management Of CKD Differs Greatly Between Adolescents & Adults

- Childhood CKD can result in irreversible developmental delays and impairments in cognitive functioning[1,3]
- The etiology of CKD differs between adults and adolescents
  - Although glomerular diseases are a leading cause of adolescent-onset CKD, congenital abnormalities and hereditary conditions are more commonly responsible for CKD in younger children, which may be less familiar to adult nephrologists
- Unlike adult treatment, pediatric treatment is family-oriented and based on parental involvement in the decision-making process[4]
- The integration of youth into academic, recreational, and social situations is an important aspect of their care[3]

The Core Principles Of Successful Nephrology Care Transitioning Are Youth-Focused[5]

1 Start transition planning early

- Regularly assess transition readiness with both patients and caregivers
- Ensure that adequate time is dedicated to coordinating a successful transition
- Understand each patient's potential and goals for activity, education, recreation, and vocation

2 Create an individualized transition plan

- Identify a transition "champion." Involve key multidisciplinary clinicians whenever possible, as well as primary care
- Solicit input on care needs from youth and parents. Address gaps in patient preparedness, autonomy, and confidence

3 Provide support before transition

- Provide education and peer support for patients and caregivers
- Support patients with a stepwise approach to increasing independence in care management
- Create a comprehensive health transfer summary based on patient and caregiver priorities
- Provide summary to patients, caregivers, and clinicians

4 Ensure ongoing support after transition to adult care

- Ensure patients attend appointments
- Assess each patient's connection to adult services
- Continue to involve caregivers as per the patient's wishes, with gradual weaning over time
- Measure outcomes routinely

References:
1. Bell LE, et al. *Adv Chronic Kidney Dis*. 2011;18(5):384-390.
2. Watson AR, et al. *Kidney Int*. 2011;80(7):704-707.
3. Scarponi D, et al. *Front Pediatr*. 2021;9:689758.
4. Močnik M, et al. *Children (Basel)*. 2022;9(7):959.
5. Toulany A, et al. *Pediatri Child Health*. 2022;27(5):297-309.
6. Levin A, et al. *Kidney Int*. 2024;105(4S):S117-S314.
7. Riar S, et al. *Indian J Pediatr*. 2023;90(12):1237-1244.

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Proper Timing & Preparation Are Critical To The Success Of Transitioning

Transferring from pediatric to adult nephrology services should occur only after the patient has been adequately prepared and critical patient information has been provided to the receiving adult service[2]

In preparation for transition to adult nephrology, patients should be[2]:

- Introduced to the concept of transition in early adolescence (12-14 years old)
- Given information gradually about transition in a manner that is appropriate to their developmental stage and intellectual ability
- Directed by lead clinicians who are designated to coordinate services and provide education on transition issues
- Assigned a specific team member who is responsible for coordinating transition from both pediatric and adult renal services

There Are Four Areas Of Competency The Patient Must Reach Before The Transition Process[3]:

1. **Recognition:** awareness of their disease process, the health care system, and the reason(s) for transition
2. **Insight:** awareness of their own emotional needs
3. **Self-reliance:** autonomous treatment planning and participation
4. **Establishment:** evidence of healthy lifestyle choices, life-long adherence to medication and follow-up, and the acquisition of psychosocial skills

Current Recommendations For Transitioning CKD Patients From Pediatric To Adult Nephrology[6]

Preparation For Transfer

Transition
Pediatric care

- Start early (11-14 years old)
- Use checklists to assess readiness and guide preparation
- See young person alone for at least part of each visit
- Comprehensive written summary and verbal handover, including cognitive ability and social support
- Follow-up after transfer

Transfer–when stable

Preparation For Regular Adult Care

Transition
Joint pediatric-adult care or young adult care

- Allow young people to visit the clinic before transfer
- Recognize that “emerging adulthood” is a period of high risk for adverse outcomes
- See emerging adults more frequently than older adults with same stage of CKD
- Include caregivers or significant others in patient visits, with permission of patient

Regular adult care

11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 Age (years)

Multiple Barriers May Compromise Patient Transition To Adult Nephrology[7]

Barriers To Transitioning Young Patients With Renal Disease

- **Neurocognitive developmental delay** — Children with CKD may have impairment in overall cognitive functioning, lower academic achievement levels for reading, writing, and mathematics, and deficits in memory and executive functioning.
- **Life-span changes in the immune system** — Immune system changes in early young adulthood may contribute to high renal graft failure rates at 17-24 years of age and have implications in long-term CKD care.
- **Social & psychological impairment** — Social isolation related to illness, pain, frequent medical visits, and body image issues may explain the high rates of depression and anxiety in young patients with CKD.
- **Financial & legal challenges** — Achieving legal autonomy and adjusting to increased self-determination and independent living create challenges after long-term dependence on parents.
- **Physician factors** — Providers of adult renal care may have limited knowledge, training, or experience in the management of pediatric renal disorders and adolescent development and behavior.

References:
1. Bell LE, et al. *Adv Chronic Kidney Dis.* 2011;18(5):384-390.
2. Watson AR, et al. *Kidney Int.* 2011;80(7):704-707.
3. Scarponi D, et al. *Front Pediatr.* 2021;9:689758.
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