

# Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)

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The transfer of young patients from pediatric to adult renal care takes place after a transition process which involves both sides. It is important that it is individualized for each young person, focusing on self-management skills as well as assessing support structures. The consensus statement has been developed by the panel of adult and pediatric nephrologists and endorsed by the councils of both ISN and IPNA. It is hoped that the statement will provide a basis for the development of locally appropriate recommendations for clinical practice.

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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%.<sup>1,2</sup> Adult renal services are being exposed to an increasing number of adolescent and young adult patients who have either transitioned from pediatric care or presented directly to adult services. It is recognized that there are substantial risks of non-adherence at the time of transfer from pediatric to adult care and among the cohort of patients aged <25 years who are managed in adult care.<sup>3,4</sup>

Recovery from acute kidney injury and increased detection of nephrourological problems on antenatal scanning means that there is also an increasing number of children with chronic kidney disease (CKD) 1–4 who are being followed by pediatric nephrologists.<sup>5,6</sup> There is general agreement that patients with CKD 3–4 should be transferred to adult services, whereas those with CKD 1–2 could most typically be followed in primary care with clear instructions to refer to nephrologists if there is evidence of progressive kidney damage and/or hypertension or proteinuria.

Growth and development are essential issues for all children. For children with a chronic condition like CKD, caretaking by a comprehensive multiprofessional team of clinicians, nurses, dietitians, social workers, play therapists, psychologists, and educators is the most effective way of minimizing disabilities and maximizing the potential of each child. Provision of support for children and families from a more diverse multiprofessional team is one of the major differences between pediatric and adult care.<sup>7</sup>

While the most frequent etiology of adolescent-onset CKD5 is glomerular diseases, younger children more frequently develop CKD from congenital abnormalities (e.g., renal dysplasia, reflux-associated damage) along with hereditary conditions.<sup>8</sup> Adult nephrologists may be less familiar with these latter conditions. The difficulties of dealing with adolescent patients who have chronic illness superimposed upon all of the other physical, psychological, and sexual changes of their development can make the management and transition issues challenging for the patient,

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families, and staff.<sup>9,10</sup> The position paper from the Society for Adolescent Medicine in 1993 uses the phrase ‘transition’ as a process that involves purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit.<sup>11</sup> In the most desirable format, therefore, transfer is an event that takes place at the end of a transition process and that is designed to be a more purposeful and concerted effort to prepare the young person with a chronic condition to accept responsibility for his/her disease management.<sup>7,12</sup>

Renal units in different parts of the world have variable experiences and plans for transition and management of adolescents and young adults with CKD 3–5. It is now recognized that the adolescent/young adult years embrace ages 14–24 years in terms of brain development and maturation. This may account for the increased risk taking, impulsive behavior, and non-adherence issues that are so common in this age group.<sup>13,14</sup> Approximately 25% of all teenagers and young adults with CKD5 present primarily to adult services usually after the age of 16 in many developed countries. In addition, in many developing countries there are no pediatric renal units, and older children may well be looked after from the outset by adult nephrologists.

Wherever managed, young people in the 14–24-year age group need special consideration, and it is important that their viewpoints are considered when transfer does take place between pediatric and adult units.<sup>15</sup> A number of these issues have been addressed at recent consensus meetings, particularly in the field of transplantation.<sup>16–18</sup>

Although the authors of this document have experience in the area of health-care transition (via research or clinical practice), there is minimal published evidence to validate many of the statements in this document. Rather it represents a consensus viewpoint on optimal clinical management developed by the panel via e-mail discussion and tele-conference.

The Councils of both ISN and IPNA endorse this consensus statement, describing the ideal care of young people with kidney disease during this critical phase of their lives. However, ISN and IPNA are global organizations and count among their members many nephrologists who practice in low-resource environments where it may be extremely challenging to achieve the standards of care described in this consensus statement. It is anticipated that this statement will provide a basis for the development of locally appropriate recommendations for clinical practice.

## CONSENSUS STATEMENT

Where appropriate, components are marked with an ‘A’ for essential; those that are desirable are marked with a ‘D’.

### 1. Transition to transfer

Transfer should occur from pediatric to adult nephrology services only after efforts have been made to assess and prepare the adolescent/young adult and necessary patient-care information has been delivered to the receiving adult service. (A)

2. Transfer from pediatric to adult nephrology should be
  - (a) individualized for each patient after he/she has completed a transition plan (It will depend upon completion of physical growth and, where possible, educational, social, and psychological attainment.); (A)
  - (b) agreed jointly by the patient and his/her family/carers in conjunction with the pediatric and adult renal care teams; (A)
  - (c) take place during a period without crises, especially if social support is unstable; (A)
  - (d) take place after completing school education; (A)
  - (e) take into account treatment plans by other subspecialties with particular reference to urological supervision; (A)
  - (f) take place with due consideration of financial factors and not be done abruptly without adequate preparation as a result of financial pressures. (A)

### 3. The transition process (Figure 1)

The most effective time to transfer an adolescent/young adult from a pediatric to adult renal service is after a transition process. Hence, young people should be

- (a) introduced to the concept of transition in early adolescence (12–14 years); (A)
- (b) given information about transition in a gradual manner that is appropriate to his/her developmental stage and intellectual ability; (A)
- (c) directed by lead clinicians (‘transition champions’) in pediatric and adult units who are identified to coordinate and educate them on transition issues; (A)
- (d) assigned to a nominated key worker who is responsible for coordinating transition from both pediatric and adult renal service (A) (Support professionals (nurses, youth workers, social workers, etc.) can be very effective in facilitating transition by providing access to ongoing support groups that can provide practical aid and advice to the transitioning young person.);<sup>19,20</sup>

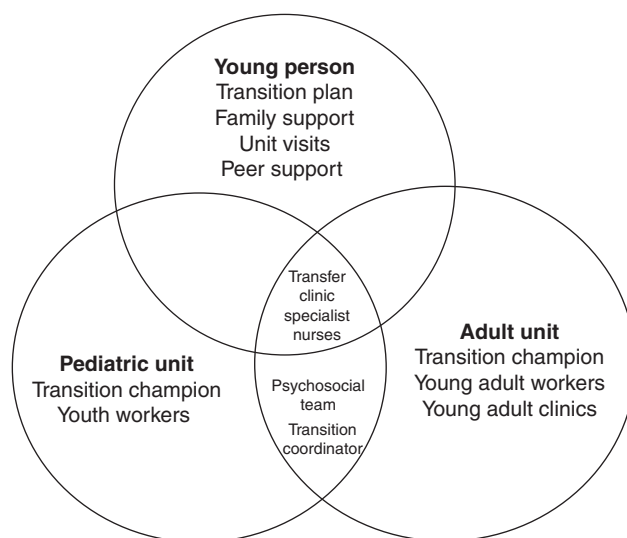


Figure 1 | Support for transition.

- (e) provided with a generic transition plan, which then can be individualized for each patient<sup>21</sup> (A) (Most transition plans have certain competencies to be achieved at a certain age (see the example in Table 1). Feedback from young people indicates that some like to follow a plan through different stages and some like to do it all in a short period before transfer.);<sup>18</sup>
- (f) include parents, other family members, and even boyfriends/girlfriends (if the young person agrees), as more information lessens anxiety; (A)
- (g) be offered the opportunity of an informal visit to the nominated adult service before transfer occurs; (A)
- (h) given the opportunity to participate in group sessions with other young people who are about to transition, for peer support experience (A) (Peer support can be complemented by establishing a local e-mail and social networking group.);<sup>18,19</sup>
- (i) able to receive tools to aid in the acquisition of disease self-management skills, such as the transition medical passport; a self-administered transition, readiness survey, and the TR<sub>x</sub>ANSITION Scale (TM) are useful adjuncts (D)<sup>12</sup> (see Appendix A for details on the TR<sub>x</sub>ANSITION Scale (TM).
- (b) An internal medicine specialist or nephrologist in each adult service should take special interest and be trained in managing young people with CKD 4–5; (D)
- (c) Specialist adult nurses who liaise with specialist nurses from the pediatric unit can ensure continuity of care; (A)
- (d) Transfer to adult renal care should include a comprehensive written and verbal summary of all the multidisciplinary aspects of the young person's care. This should include medical, nursing, dietary, social, and educational information; (A)
- (e) The young person should be prepared through a transition pathway to assert their autonomy and to be able to provide relevant information about themselves. (A)

An ideal method to promote the successful transition of young people is through the use of a transition clinic where the adolescent/young adult is seen jointly by pediatric and adult specialists on a number of occasions before being transferred to adult renal services, preferably in a young adult clinic. However, tertiary pediatric renal units may refer to several adult services. Patient choice and the logistics of distance, numbers, and cost make regular transition clinics less feasible.

#### 5. Continuity of care

A recurring point raised by young people who have been transferred is the lack of continuity of care and build-up of trust that they experienced in the pediatric unit. It is appreciated that many transition issues raised in these statements are aspirational, but two options could be considered.

*Option 1:* An ideal method to promote successful transition is by preserving continuity of care through the efforts of a small team of specific professionals responsible for assuring the care of the transferred young person. This may involve an adult nephrologist, nurse specialist, and one or more support staff (youth worker, social worker, etc.) in the adult service. This dedicated team should have training in managing teenagers and young adults and have knowledge of pediatric renal diseases. (D) The potential availability of such a team will vary according to the country and facilities resourced.

*Option 2:* Adult renal centers could develop young adult clinics that would incorporate both patients transferred from pediatric care and adolescents and young adults (aged <24 years) who may have presented with CKD 4–5 directly to the adult renal unit. (D)<sup>22</sup>

A recent survey of US internists found that many felt the need for better training in congenital and childhood-onset conditions, as well as concerns about psychosocial and financial issues.<sup>23</sup> Training of junior doctors on transition issues needs to be included in the training of adult specialists.<sup>24,25</sup> (D) This training is more imperative for the lead clinicians in the adult center.

#### CONCLUSIONS

Transition from pediatric to adult renal services is an individualized process that provides the young person with

The concepts of transition champions and transition coordinator deserve further delineation. A useful method to effectively develop a transition process for young people with CKD involves identifying specific transition champions—physicians in the pediatric and adult services who have special interest in organizing and leading the *transition process or program* for the young people in the unit. These transition champions will be most effective when they are able to work closely with a designated transition coordinator(s), typically a nurse, social worker, or youth worker, who would take responsibility for *coordinating the transition steps for the individual transitioning young people*.

#### 4. Transition or transfer clinic

- (a) A transfer clinic in either the adult or the pediatric renal unit with both adult and pediatric nephrologists in attendance is the optimal minimum standard; (A)

**Table 1 | An example of the competencies expected of a young adult being transferred to an adult renal unit**

● I understand my condition and can describe it to others
● I know my medications and what they are for
● I can make decisions for myself about my treatment
● I know what the adult clinic arrangements are and who will be reviewing me in clinic
● I know how to make my appointments
● I can make my own transport arrangements to get to the hospital for appointments
● I know who to call in a medical emergency
● I am able to talk about my worries concerning blood tests and other treatments
● I know the dietary advice that I have to follow and the importance of activity
● I have appropriate knowledge about sexual health matters
● I have discussed alcohol, smoking, and drug issues

appropriate self-management skills as well as assessing support structures. Since young people are in 'transition' from 14 to 24 years, it is vital that there be good communication between pediatric and adult services, especially at the point of transfer. Support for this age group should be developed on both pediatric and adult-focused sides. The consensus statements highlight developments that are necessary to ensure a successful health-care transition process.

#### DISCLOSURE

All the authors declared no competing interests.

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#### Appendix A

##### The TRANSITION Scale

The Transition Scale is a mechanism to assess and monitor progress in achieving the goals of transition—the ability of the adolescent/young adult to provide his/her own self-management and not be reliant on parental care. The components include the following:

- Type (of illness)
- Rx
- Adherence
- Nutrition
- Self-Management Skills

##### Informed Reproductive Health

Trade/school

Insurance

Ongoing Support

New Health-Care Providers

The score is determined by a professional member of the renal unit who provides for the young person a subscore of 0–1 (0 = no ability, 0.5 = partial ability, 1 = desired ability) for each component. This total score can be used to monitor progression over time and the subscores can be used to identify gaps that need to be addressed.