

The continuum of transition from paediatric to adult renal care

Alan Watson looks at the current transition arrangements for moving young people with renal disease from a paediatric to an adult renal unit. He outlines the competencies young people need before they can be transferred, and how they can be best supported on their journey.

■ transition ■ adolescent health care ■ young people health transition ■ transitional health plans

Paediatricians are experts in physical growth combined with social, psychological and educational development. Chronic kidney disease (CKD) has a major impact on the child and whole family, and the management of such children requires an expanded multiprofessional team incorporating nephrologists, surgeons, nurses, dietitians, social workers, psychologists, play therapists, teachers and youth workers.

Since the incidence of CKD stage 5 (dialysis and transplantation) in the paediatric population (0–18 years) is only approximately 3 per million population per year, it is understandable that the care of children and young people has been concentrated into paediatric renal units (PRU) serving large populations. The disadvantages of distance and travel to PRUs are balanced by the support and expertise available. There are only 13 comprehensive PRUs in the UK serving populations of 2–8 million, with 10 undertaking renal transplantation.

The aetiology of CKD in children is very different from that in adults. Children suffer predominantly from congenital abnormalities, e.g. renal dysplasia, reflux-associated damage, hereditary conditions and chronic glomerulonephritis such as focal glomerulosclerosis. This is a very different spectrum from adult renal units where uncertain aetiology, diabetes, glomerulonephritis, hypertension and autosomal dominant polycystic kidney disease predominate. Treatment of children has been successful, with over 90% 5-year patient survival in dialysis and transplant programmes (Lewis et al, 2008). This success has meant that children of

all ages have been accepted for dialysis, including newborn infants. Some of these children have comorbidities with other major system disorders, such as cerebral palsy, that will also require treatment into adulthood.

The net result of increased activity and expertise in PRUs since the 1980s has therefore been an increasing number of young people suitable for graduation or transfer to adult units. This includes not only transplant and dialysis patients but also those with CKD from either congenital or acquired kidney insults including haemolytic uraemic syndrome, Henoch-Schönlein purpura, reflux-associated damage and glomerulonephritis (Watson, 1996; Cameron, 2001).

Young people are transferring with different aetiologies and comorbidities and often to local adult units they have never visited. Many have been used to the support of a multiprofessional team in the PRU providing not only medical but close dietetic and psychosocial care (Watson, 2005). The differences between paediatric and adult units are important to recognize and discuss (*Table 1*) but the transition of young people along a continuum. All health professionals should promote young persons' self management skills and ensure that they receive appropriate social support to develop these (Bell, 2007; Viner, 2008).

Transition or transfer?

Transition has been defined as 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents with chronic physical and medical conditions as they move from child centred to adult orientated healthcare systems' (Blum et al, 1993). This definition has been helpful to focus the minds of clinical teams as it emphasizes that transition is a process which needs to be individualized with transfer taking place at some time during transition.

Transition does not stop once transfer to the adult unit has taken place. Indeed, recent research suggests

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Table 1. Differences between paediatric and adult renal units

Paediatric	Adult
Consultation with patient and family/carer	Individual consultation
Psychosocial support from team members	Limited psychosocial support
Fewer patients and more consultant-based care	Larger patient numbers and specialist nurse/junior doctor review
Specialist knowledge about rare conditions, e.g. cystinosis	Lack of experience with childhood onset chronic conditions
No waiting list for dialysis	Pressure on dialysis spaces
Young people waiting areas and peer support	Usually no young adult clinic
Medications usually free	Usually pay for medications

Table 2. Competencies expected of a young adult transferring to 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 sufficient knowledge about sexual health matters
- I have discussed alcohol, smoking and drug issues
- I know how to contact my primary care physician

that brain development for young adults continues until young adulthood (25 years) giving credence to some of the characteristics of adolescent behaviour such as impulsivity and risk taking (Durstun and Casey, 2005; Giedd, 2008). Hence transition could be regarded as the period from 14–24 years of age. We know this is one of the highest risk periods for non-adherence (Watson, 2000; Dobbels et al, 2010).

The need to incorporate transition planning into chronic illness management has also been embraced by other subspecialties with many examples of good practice that need to be shared (McDonagh et al, 2007; Viner, 2008; Khadr and Kelnar, 2008). All stress the need to improve the transition process and closer collaboration with adult healthcare providers.

What age should transfer to the adult unit take place?

Young people should have completed most of their growth and development in the paediatric unit. The usual age of transfer in the UK is when they have completed secondary education (between 17 and 19 years of age). Again, the exact timing should be individualized but previous surveys have indicated that some paediatric units are tied by the rules of the children's hospital who state that no patients over the age of 18 should be admitted. There are also paediatric units that have continued to dialyse young people into their 20s in order to maintain the viability of their haemodialysis facility. What is important is that young people themselves should have a major input into the decision-making (Bell et al, 2008; Webb et al, 2010). Transfer during 'crisis' of whatever nature should be avoided. If we expect the young person to be fully autonomous in the adult unit, i.e. capable of receiving and understanding information and making his/her own decisions, then we should ensure that young people achieve certain competencies before transfer as part of a transition plan (Table 2).

What is a transition plan?

Young people and their families should be made aware at an early age of the unit's philosophy regarding transfer to adult services. If children have been followed from early childhood then it is important to involve them in the conversation as much as possible rather than just talking to the adult carer. Some units have developed a written transition plan introduced by 14 or 15 years of age (Paone et al, 2006; British Association for Paediatric Nephrology (BAPN) and Renal Association, 2009). This covers areas shown in Table 2 and is an opportunity to review and update information and knowledge on an annual basis. The feedback from the young people themselves suggests that some individuals want information in small amounts at different times, whereas others want it all at one sitting (Webb et al, 2010).

The plan is only useful if its content has been reviewed with the young person by one of the members from the team. For transplant patients this has usually been the transplant specialist nurse, with discussion about transition often being incorporated into annual update visits. Being seen in the home has great advantages as young people are more relaxed and able to discuss matters alone in a confidential manner without their parents' presence.

For young people who are transferring on dialysis, it is the dialysis specialist nurse who will coordinate visits to the adult renal unit and make sure firm arrangements are in place before transfer takes place.

Paediatric nephrologists are usually more central in transferring young people with CKD and deciding

with their colleagues whether adult renal clinic follow-up is appropriate or primary care is more suitable.

Youth work support

Youth workers support mainly young people between 11 and 25 years of age in the community. Their brief is to promote personal and social development with a range of informal educational activities which combine challenge, learning and enjoyment. Our unit has had the benefit of youth work support since 1998. Many young people and their siblings have benefited from this support on the wards, and/or youth club and residential experiences (Hilton et al, 2004; Watson, 2004).

In recent years our unit has organized transition weekends or weekly residentials where young people approaching transfer to adult units have had the opportunity to discuss a wide variety of issues (Watson et al, 2010). The feedback has been very positive and the young people have particularly benefited from meeting young adults who have already undergone transition along with staff from the adult unit. This peer support is an important way of helping young people through difficult times and many young people have maintained e-mail and text contact to develop their own support network.

Figure 1. Current transition arrangements

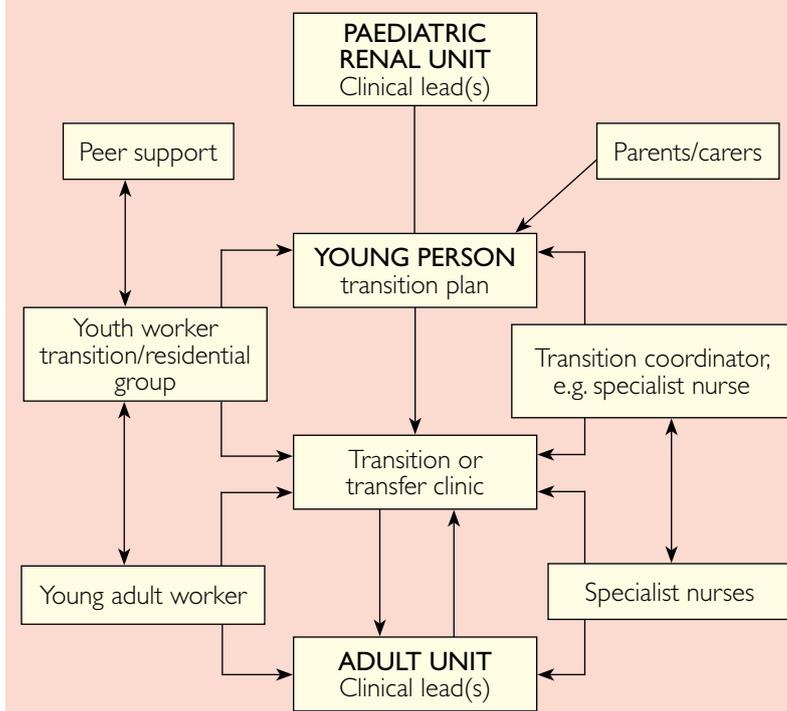


Table 3. Key statements of consensus on transition

A formal, national framework for enabling the seamless transition of transplant patients from paediatric to adult services should be defined, towards which all healthcare service providers should work

The age of transfer of a patient from paediatric to adult services depends on the individual's circumstances and is usually after completing growth and development (particularly educational). Transfer takes place during a transition process that spans an age range of 14–24 years

Every transplant recipient should be offered the opportunity of participating in a 'young adult' clinic of their choice up to the age of 24 years

Each paediatric unit, and similarly each adult unit, should identify a clinical lead who will have the key role of collaborating to establish an agreed transition service/process and enabling the multidisciplinary team from both units to work together to ensure the process of transition is optimal for each patient

The development and establishment of the transition service should include a process of consultation with patients, parents and their families, to ensure that the transition service provision meets the need of all

Young adults undergoing transfer during the transition process should have access to some form of support service tailored to their needs in the adult unit, ideally in the form of one or more 'young adult support workers'

A set of performance standards for operating a transition service should be established, against which the Care Quality Commission is able to assess the performance of individual NHS trusts, for the purpose of ensuring that the defined standards are being met and, where they are not, that appropriate measures are in place to address poor performance

Source: Webb et al, 2010

Transfer arrangements

The ideal model would be to invite young people to a transition clinic, on one or more visits before transfer, where they would be seen by both paediatric and adult nephrologists and specialist nurses. This is feasible when there is a large cohort of local patients such as those with diabetes and cystic fibrosis. Anecdotally other adult subspecialties such as diabetes, report significant benefit from meeting the young people some time before being seen on their own in the adult clinic.

However, the logistical issues pointed out in the introduction mitigate against such arrangements for nephrology patients. For instance, for 25 renal transplant patients transferred from the Nottingham paediatric renal unit in the last 3 years, 9 have been transferred to the local adult unit, 8 and 6 to units 40 and 35 miles distant and 2 to a unit 90 miles distant. Our unit serves a population base for 6 million and for each individual adult unit there can be 1–5 transplant patients transferred each year, plus 0–3 dialysis patients and 5–10 CKD patients. The recent joint UK British Association for Paediatric Nephrology/Renal Association (2009) document emphasizes a number of possible arrangements depending on local geography and enthusiasm. The report suggested the possible formation of a Young Adult Renal Unit (YARU) within each region serving a total population of 2–4 million.

What is important is that units establish a dialogue and collaborate in the best interests of young people. Preventing the tragedy of one young adult losing a transplant as a consequence of 'getting lost' in the system is well worth the effort (Watson, 2000). Graft loss may result in the young person needing years of dialysis with the associated high cardiovascular risks.

Transition champions

It is hoped that we have moved on from the era where paediatricians were accused of spoiling the children and adult nephrologists of neglecting them. Although the culture and arrangements may be different in the adult unit, the use of the transition plan and, if necessary, pre-transfer visits, allay many of the anxieties of both young people and their parents. What is needed are transition 'champions' or 'leads' on both sides of the 'false divide' to promote and facilitate transition. The evolution of our own centre's transition support is illustrated in *Figure 1*.

Specialist nurses are increasingly involved in running many adult and paediatric renal services and greatly assist in the transfer of patients. Social work and psychology support, however, are often



Youth workers aim to promote young people's personal and social development. To share their experiences, these young people from the Nottingham Renal Unit, led by their youth worker, are on a residential outing in Derbyshire.

lacking in adult units. The different groups are now looking at ways of improving the experience of young adults in transition.

Young adult support workers

There has also been powerful feedback from young people who have been through the transition process. They mention that being admitted to adult wards and clinics is a 'shock to the system'. At a recent conference one young adult patient vividly recalls being admitted to the adult unit with a dialysis complication and being in the middle of two elderly patients both of whom had had amputations and one of whom was blind. He immediately thought that this was the fate that awaited him.

Peer support and/or mentorship could be facilitated by the development of young adult clinics. A National Kidney Care project has been initiated to pilot the use of young adult support workers in adult units (Watson, 2009).

Other recent initiatives

Consensus statements on transition, particularly in the field of transplantation, have further raised the awareness and importance of the subject (Bell et al, 2008; BAPN and Renal Association, 2009). The most recent UK consensus from cardiac, liver and hepatic transplant centres incorporated the viewpoints of young people and parents/carers as well as professionals (Webb et al, 2010). Several consensus statements emerged from the meeting that are representative of the current opinion of families and the UK transplant community (Table 3). It is hoped the statements will form the basis of a best-practice framework for adoption and development. **JRN**

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Key points

- Transition planning for young people with chronic kidney disease (CKD) should provide them with the knowledge and skills to manage their own healthcare in an adult unit
- Transfer from paediatric to adult unit should be individualized depending on completion of a transition plan, patient choice and physical, social and emotional maturity
- There should be transition champions and support for young people/adults on both sides with active involvement of the patients themselves

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