



What I tell my patients about transition to the adult renal unit

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Treatment for children and young people with chronic kidney disease (CKD) is centralised in 13 children's units in the UK serving population bases of 2–8 million. The reason that there are so few paediatric units is that CKD is relatively rare in children compared with adults, so while in any one area there may be only one children's renal unit, there may be up to ten adult units.

As well as being experts in kidney problems, paediatric nephrologists are also specialists in growth and development. We are aware of the need to maximise the potential of every child and minimise the impact of CKD on growth as well as schooling, and psychological and social development. Thus, many paediatric units have a multidisciplinary team that consists not only of specialist doctors, surgeons, nurses and dietitians, but also of social workers, play therapists, psychologists, teachers and youth work support.

There comes a time when we agree with you and your family that it is appropriate for you to transfer from the paediatric to the adult renal unit, where another team will support you through your adult life. We believe that the transfer should only take place after a process known as transition.^{1,2}

What is transition?

Healthcare transition is a process that involves you moving from child and parent/carer-directed care to self-management of your condition in an adult-oriented healthcare system. Preparing for transition can take several years and in this article we will discuss the when, where and how of transition. Doctors now realise that although you will be transferred after a transition period in the paediatric unit, the actual process of transition continues into your mid-twenties and so paediatric and adult units need to collaborate closely.

With young children, all the information is usually given to, and care management carried

out by, parents or carers. Hopefully, as a young person/adolescent you have been increasingly involved in your own care and may have seen the consultant on your own. After you transfer, it is expected that you will be managing your condition yourself, although we appreciate that many, if not all, patients need support from families, partners and friends.

What are the differences between the paediatric and adult units?

Many paediatric patients get to see their consultant on a regular basis and the whole family may have built up a lot of trust with the paediatric team. We hope to transfer you to a nephrologist in the adult unit who will act as a 'transition champion'. However, different clinic arrangements may occur in the adult unit, with more reviews being conducted by specialist nurses and junior doctors (see Table 1). A lot of adult patients with CKD suffer from different diseases such as diabetes, hypertension and heart disease, and so some of the doctors you will meet may not be familiar with uncommon childhood illnesses. You may be used to using an adolescent or young people's room in the clinic or on the

Table 1. Differences between paediatric and adult renal units

| Paediatric | Adult |
|---|--|
| Consultation with parent/carer and, increasingly, the young patient | Individual consultation with patient |
| Psychosocial support from team members | Limited psychosocial support in terms of social work, psychology |
| Fewer patients and more consultant-based care | Larger patient numbers and specialist nurse/junior doctor review |
| Specialist knowledge about rare conditions eg 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 in clinic | Limited young adult clinic |
| Medications usually free | Usually pay for medications |



ward, but, unfortunately, in many adult units there is no young adult facility either in the clinic or on the ward. There will be access to dietitians in adult units, but there may be limited social and psychological support. Youth and young adult workers are few and far between, but work is being done to assess young adult support workers in adult units as well as young adult clinics where you can meet your peers (see Figure 1).

Having pointed out the differences, we wish the transfer to be a positive experience and hence the time spent on the transition process to provide you with all the information you require and allay the anxieties of you, your family and the clinical teams. As in a lot of things in medicine, it does often boil down to communication. Paediatric and adult nephrologists are actively looking at their transition arrangements and would welcome any observations and suggestions young people make.

When does the transfer take place?

There is no set time for transfer to the adult unit and it is a decision that we individualise for each young person. What we have learned is that we should be talking to you about transition years, and not just months, before the transfer (starting when you are 12–14 years old).^{3,4} We aim to avoid transferring you at any crisis time in your general health or if you are psychologically upset with family or other issues.

There is general agreement that the age of transfer should be about 18 years, when most people will have finished secondary school

education. However, you could be transferred at 17, or even sometimes 20 years if your growth has been very delayed because of CKD from an early age or you have other problems. If you are moving away to college or university, then it may well be worthwhile introducing you to an adult renal unit near to your home, which can liaise with you about provision during these further education years. Transfer may be delayed if you are receiving care from other specialties such as orthopaedic, endocrine or cardiac departments.

Transition should start at 14 years of age at the latest, and you should have been provided with a transition plan.⁵ Some of this can be in the form of a diary or a booklet – you have to complete certain tasks by certain ages. You can, of course, fill it in all at once near the end, but either way the nurse or doctor supervising your transition should review the plan with you.

The transition plan includes ‘competences’ or tasks that we expect of the young adult before transferring to the adult renal unit (see Box 1). You will be checked, via your transition plan, as to whether you have achieved these competences. Many young people need support and information from their peers. It may be that your unit organises for young people to meet as a group and have the benefit of input from young adults who have actually made the move across from paediatric to adult units. Such advice can often be invaluable.

A few units have youth workers or young adult workers who provide one-to-one support and also run youth clubs.⁶ Young people who are undergoing transition have been invited to residential weeks or weekends in youth hostels and again have benefited from sessions with peers and young adults who have been transferred.⁷ Support groups have then developed among young people themselves with e-mail and texting.

Where do I transfer after the transition process?

It has already been mentioned that paediatric units may be in a region where there may be several adult units. Sometimes, adult centres in major cities have satellite dialysis units or clinics in other towns/cities.

Obviously there are benefits to you transferring to a unit closer to your home, especially if this is a major teaching hospital. This is a place where there is likely to be a transition champion in the adult unit and the

Box 1. Competences expected of a young adult transferring to the 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

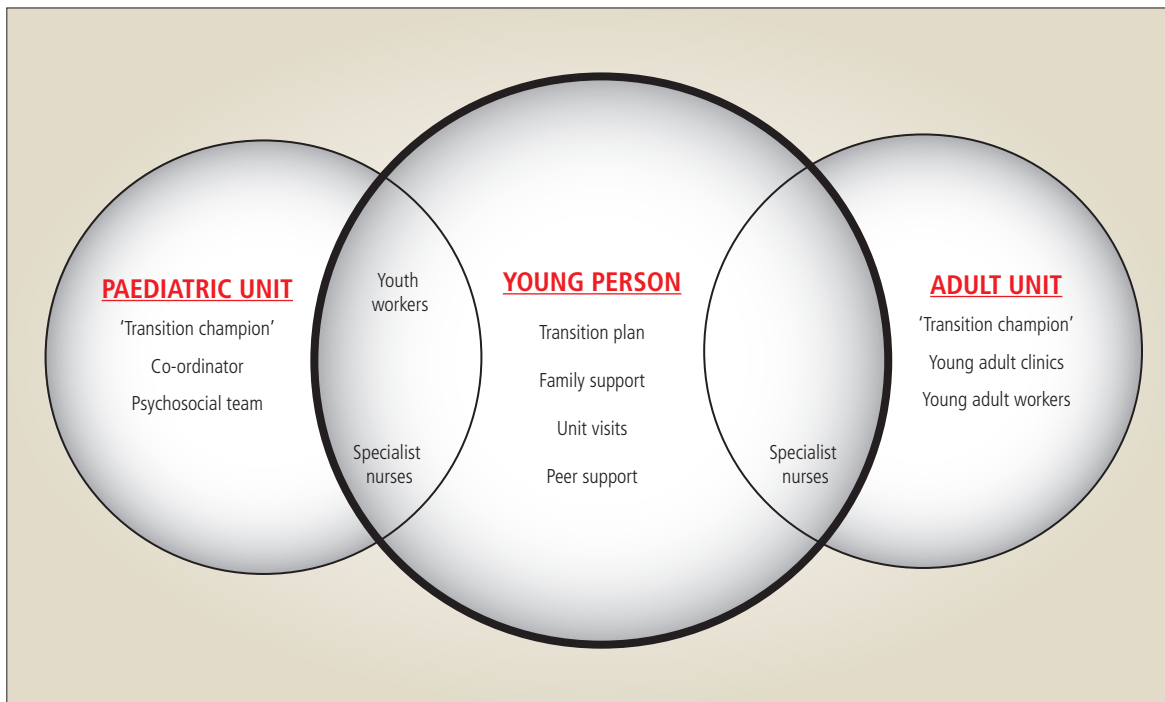


Figure 1. The different roles and availabilities within the paediatric and adult units, and of the young person

possibility of a young adult clinic where you might meet similar patients. Ultimately, the choice of adult unit is down to you, and it may be that you wish to visit a few units before settling on one. After all, you are likely to be with them for very many years!

You are probably aware that CKD may be mild (stage 1 or 2), moderate (stage 3 or 4) or severe (stage 5), when dialysis and transplantation are necessary. In the UK, patients with CKD stage 1 and 2 – all those with stable kidney function and a glomerular filtration rate above 60 ml/min/1.73 m² – who do not have high blood pressure or protein in their urine (proteinuria) are generally referred to their primary care physician (that is, their GP) for regular checks, with referral back to the adult unit if there is a rise in the plasma creatinine taken on a blood test, or if high blood pressure or proteinuria develop. Although you may have been followed in the paediatric unit for kidney problems, it may be that long-term follow-up will be with your GP if you are in the mild category.

If you have had a kidney transplant, are on dialysis or have CKD stage 3–4, then you will generally be followed in the adult transplant clinic, dialysis unit or general nephrology clinic respectively.

Some children with CKD also have problems with their bladder and have had operations on the urinary tract. They may therefore be under joint management with a paediatric urologist. Many bladder problems will also need to be

followed up in the long term. Young adult urology clinics are also developing and, before you leave the paediatric service, you should be clear as to who is directing follow-up for any bladder or surgical issues.

How is transfer to the adult unit arranged?

Ideally, before you transfer we would like to have introduced you to the adult renal physicians in a joint clinic where both paediatric and adult consultants and specialist nurses could attend.

However, you can appreciate that young people from the one paediatric unit are going to different centres, and hence the numbers transferred each year to each adult centre are relatively small. We therefore usually concentrate on a transfer clinic with the paediatric and adult nephrologists and nurses in attendance. The transfer clinic usually takes place on one or two occasions each year and is best organised in the adult renal clinic.

Before that transfer clinic, you would have completed a transition plan and may well have had a visit to the adult unit already. Such visits are certainly necessary if you are going to transfer on haemodialysis (HD) or peritoneal dialysis (PD). The timing of transfer on HD will often depend on the availability of a suitable dialysis time in the adult unit; pressure of numbers means that adult units often run three shifts – morning, afternoon and evening – each day. Hopefully you can negotiate a dialysis time that is convenient for you and any ongoing college



studies or work. Home therapies with automated PD or home HD are being actively encouraged.

One way that you can learn a lot about transition is by attending a transition residential weekend or weekday break. These have been organised by youth workers in some units and provide an opportunity to discuss many issues, often in the company of young people who have made the transition and can act as peer counsellors.⁷

What happens at the transfer clinic?

We would also arrange for specialist nurses to attend the transfer clinic. Many transplant and dialysis clinics in adult units are run by specialist nurses and it is important that you are introduced to such a nurse co-ordinator in the adult unit.

Parents or carers are welcome to attend the transfer clinic (in fact, you may still be dependent on them for transport), but the initial clinic interview should be between you and the paediatric and adult consultants, along with specialist nurses who may be involved in your future care. The paediatric nephrologist would have provided you, and his or her adult colleague, with a summary of your past treatment.

The adult consultant may check aspects of this with you, such as the medications and any future plans. There may be different

arrangements for blood taking (phlebotomy) and the provision and cost of prescriptions in the adult unit. It is important for everybody to realise that you and your family may have built up trust with the paediatric team over many years. It may take some time to build relationships in the adult unit⁸ and you need to be the main advocate for your condition.

What about the adult wards?

One of the important bits of feedback that we have received from young adults who have moved to the adult unit are that sometimes being admitted to the adult ward is a shock to the system, especially as adult units increasingly treat elderly patients. Hopefully you will avoid ward admissions, but it is suggested that your introduction to the adult unit should include a visit to the ward. You should be aware that such units are often very busy with many elderly patients, and at present have limited facilities for young adults in terms of computers and so forth.

Is that it?

We should consider transfer to the adult unit as a positive step in your life. We cannot make the CKD disappear, but again we would emphasise that we want to minimise its impact by providing you with information and support.

We know that issues with adherence (taking all of the medications and treatments all of the time) are more difficult over the young adult years, and if there are problems and issues you wish to raise, the clinic staff are there to help you with them.

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Key points

- Transition to the adult renal unit provides the young patient with the knowledge and skills to move from child/caregiver-directed care to an adult setting.
- Transfer takes place at the end of a transition process, which should be individualised depending on a transition plan, and patient choice and maturity.
- Improved communication and direction for transition should be promoted by transition champions.
- Transition does not stop with transfer to the adult unit, but encompasses the ages 14 to 24.



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