

# The “rocky road” of transition from paediatric to adult care in renal disease

J Stewart Cameron

Department of Nephrology and Transplantation  
Guy's Hospital, King's College, London, UK

Received for publication: 20/06/2007

Accepted: 25/06/2007

It was good to see recently the cover of the April 2007 number of *Nephrology Dialysis Transplantation*, the journal of the European Renal Association, which began in heavy type:

“Transitional medicine: an important topic in Nephrology.”

This note advertised a very welcome review article<sup>1</sup> by Lorraine Bell, Department of Nephrology at McGill University in Quebec, Canada, entitled “*Adolescents with renal disease in an adult world: meeting the challenge of transition of care.*”

This editorial was doubly welcome, as the many challenges of the transition of children from children's services to adult units has been persistently neglected in adult nephrology units, in their practice, in their teaching and in their publications, ever since its importance was first pointed out almost a quarter of a century ago<sup>2</sup>. Virtually all of the subsequent modest literature on the experience of transition in renal disease has appeared in the paediatric literature<sup>3-5</sup>, and in general nephrologists looking after these newly-fledged adults have ignored the topic. Hence the importance of the article on transition in this issue of the *Portuguese Journal of Nephrology and Hypertension* by Dr Sofia Jorge and her colleagues.

In the developed world today, most of the renal conditions affecting children are chronic, that is, they persist, and the great majority of children with renal disease (other than simple urinary infections) will thus

require care into and probably throughout adult life. Their needs are especially great during adolescence when they must, in addition to all the usual challenges of growing into an adult and the complications of their illness and its treatment, face the challenge of a change of management from the children's unit to the adult unit. Patient care is sliced and diced to suit the organisational needs of the hospital and the professions working within it, and least of all the needs of the individual patient.

This presents barriers when the patient has to transfer for care from one group of carers to another: some patients breeze through these difficulties, but others flounder. Particularly hazardous is the transition from paediatric to adult clinic, and evidence of graft failure in young transplant recipients after transfer<sup>5,6</sup> demonstrates how important this is in practice. One obvious solution is to create environments in which older children, adolescents and new adults differing widely in physical and psychological maturity and practical competence can best function and receive care – but such adolescent medicine units are all too rare, even in developed countries today.

Actual *transfer* of the young patient from clinic to clinic is only the final step in the process of *transition*. This requires considerable effort in terms of education – many adolescents know little or nothing of their condition, as hitherto communication has been largely through their parents. Watson has suggested a list of skills which need to be communicated to the young patients (Table I) and those in adults units need

**Table 1**

Suggested competencies to be achieved by the young adult before transfer

- I understand my condition and can describe it to others
- I can make decisions for myself about my treatment
- I know my medicines, what they are supposed to do, and their possible side effects and interactions with other treatments
- I know what the adult clinic arrangements are and who will be my responsible physician
- I know how to make clinic or other appointments
- I can make my own transport arrangements to get to the hospital
- I am able to talk about my worries concerning blood tests and other treatments
- I know who to contact in a medical emergency
- I know the restrictions that I have to follow, including diet and activity
- I have sufficient knowledge about matters of sexual health
- I have discussed alcohol, smoking and drugs issues with my carers

to re-check that their new young patients have indeed acquired - and retained - these skills.

Many older teenagers and young adults feel to begin with completely out of place within the adult unit, and these feelings should not be under-estimated. Adult units are so much larger than the average paediatric unit, and usually much less individual support is available. Often there is little knowledge in the local adult unit of some of the specialised conditions in paediatric renal disease such as (for example) cystinosis. The main impact however is one of the sheer age of the others attending the adult unit, particularly for those with chronic renal failure, which affects in the main these already at or near retirement age.

In addition, nephrologists have almost universally been slow to learn from the work on the management of transition by their colleagues in other fields, such as congenital heart disease, rheumatology, cystic fibrosis and other juvenile chronic medical problems which like many formerly fatal renal conditions, now deal with patients who routinely survive into adult life<sup>7,8</sup> or from general sometimes national guidelines on the subject<sup>9</sup>. Nevertheless, few detailed evaluations of any of the transition strategies have been performed, and none for those with renal disease.

The transition process reminds us yet again that we should learn from our patients as well as help and direct them. As Wickes noted recently in her description of living though to adulthood with cystic fibrosis<sup>10</sup>:

*“Health professionals may be experts in their field, but patients are experts in their lives. The best doctor-patient relationships are those in which both parties educate each other.”*

**Conflict of interest statement.** None declared.

## References

- 1 Bell L. Adolescents with renal disease in an adult world: meeting the challenge of transition of care. *Nephrol Dial Transplant* 2007;22:988-992.
- 2 Cameron JS. The continued care of children with renal disease into adult life. *Am J Kidney Dis* 1985;6:91-95.
- 3 Watson AR. Non compliance and transfer from pediatric to adult transplant unit. *Pediatr Nephrol* 2000;14:469-472.
- 4 Cameron JS. The continued care of children with renal disease into adult life. *Pediatric Nephrol* 2001;16:680-685.
- 5 Watson AR. Problems and pitfalls of transition from pediatric to adult renal care. *Pediatr Nephrol* 2005;20:113-117
- 6 Cochat P, de Geest S, Ritz E. Drug holiday: a challenging child-adult interface in pediatric transplantation. *Nephrol Dial Transplant* 2000;15:1924-1927.
- 7 McDonagh JE, Kelly DA. Transitioning care of the pediatric recipient to adult caregivers. *Ped Clin N Amer* 2003;50:1561-1583
- 8 Reiss J, Gibson R, Reiss J, Gibson R. Health care transition: destinations unknown. *Pediatrics* 2002;110:1307-1314
- 9 Department of Health. Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. London, Department of Health 2006. see also a discussion of this document: Jordan A, McDonagh JE. Transition: getting it right for young people. *Clin Med* 2006;6:497-500.
- 10 Wicks E. Cystic fibrosis: a patient's journey. *Br Med J* 2007;334:1270-71

## Correspondence to:

Prof. J Stewart Cameron  
 Emeritus Professor of Renal Medicine  
 Department of Nephrology and Transplantation  
 Guy's Hospital, King's College, London SE1 9RT, UK  
 e-mail: jstewart.cameron2@btopenworld.com