Supporting young people to move to adult services

In this article...

- Why transition from paediatric to adult renal services is tough
- How this can translate into poor outcomes
- How a support service can help young adults help themselves

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Abstract
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Young people with chronic kidney disease can have poor treatment outcomes and struggle to come to terms with their condition. They may also find the transition from paediatric to adult services difficult. A support service is taking an evidence-based approach to these issues, recording outcome data to measure the efficacy of its interventions.

Moving from paediatric to adult services can be challenging for young people who have long-term conditions. The East Midlands Renal Network (EMRN) is one of five networks that are approved by NHS Kidney Care to develop innovative ways of supporting young adults with chronic kidney disease (CKD).

NHS Kidney Care has recognised that young adults with complex health needs require specific support; it aims to identify approaches that are adaptable to different locations and can deliver:
- Greater concordance with treatment;
- Fewer lost transplants and patients returning to dialysis;
- Better clinical and psychological outcomes for patients;
- More efficient use of resources.

Supporting Young Adults (SYA) is a project set up by the EMRN. It is managed collaboratively by Derby Hospitals Foundation Trust and Nottingham University Hospitals Trust.

Needs of young adults with CKD
Children and young people with CKD have to cope with:
- Diet and fluid restrictions;
- Having to take various medicines at different times;
- Frequent clinic appointments;
- Invasive treatment;
- The effect on body image of the visible impact of dialysis.

Visible signs include unsightly arteriovenous fistulas to the arms, neck, chest or groin, as well as venous catheters or peritoneal catheters extending from the abdomen. Individuals may also experience profound oedema and/or a uraemic pallor due to being unable to excrete excess fluid and waste products (Lindsay-Waters, 2008). There is also the feeling of being “on call” for a kidney transplant and having everyday life determined and restricted by the use of machines.

As treatments improve, life expectancy has increased for young people with CKD, and more and more individuals are making the transition from paediatric to adult renal services. The change from paediatric care – which is often familiar, multidisciplinary and family focused – to unfamiliar adult services, which encourage independence, is difficult. Patients may feel nervous about their future and abandoned by their familiar service. This can lead to problems such as non-concordance with treatment or medication, poor attendance at follow-up clinics and reluctance to contact health professionals when problems arise.

Watson (2005; 2000) highlighted the importance of effective transition services and what can occur when young adults are not given the appropriate support. Young adults who present directly to adult services...
also struggle with adjustment issues and have problems with denial and concordance. This can have devastating consequences, including the rejection of transplants and a return to dialysis, which can affect many areas of life; patients may experience difficulties with education, finding and retaining employment, and developing and maintaining relationships with friends and potential partners (Lewis, 2010).

Literature suggests young adults with CKD are more likely to have reduced earning potential and those receiving renal replacement therapy are more likely to live with their parents (Bell, 2007). Young patients may also experience poor self-image, depression and anger (Querfeld et al., 1997).

Building on the transition programme
Nottingham University Hospitals Trust established a transition programme in 2005 to help young patients with CKD who are moving from paediatric to adult services. Working with their assigned health professional, patients initiate an annually reviewed individual transition plan when they reach the age of 14. This includes a series of goals and checklists to allow them to work through all areas of their health, social and personal development to enable the independence they will need when they reach adult services.

Young adults can attend a residential transition course where small groups spend a weekend with youth workers, a dietitian, social worker and renal nurse, and “expert” young adult patients who have already experienced transition. They participate in workshops, confidence-building activities and group discussions on topics such as alcohol awareness, sexual health and independent living. This allows patients to share experiences, provide peer support and form friendships. It also allows health professionals to identify any areas where extra support is needed.

The process has also included developing specific transition clinics for kidney-transplant patients. The first clinic patients attend in the adult unit is held jointly with the paediatric and adult nephrologists, paediatric youth worker and adult transplant nurse. The slot is 30 minutes long, allowing for a “get to know you” session and a chance to look around the unit.

For patients having a renal transplant, a twice-yearly young-adult transplant review clinic was also introduced, allowing patients under the age of 25 to attend as a separate group. This aims to help them feel more comfortable and relaxed, improve attendance rates and encourage better engagement with health professionals. It also offers an opportunity to meet peers and share experiences. However, we felt these initiatives could be built on to further improve the transition of young adults with CKD and avoid certain issues, such as missed appointments, and that health professionals could provide expertise for specific elements.

The group meets monthly and reports to the EMRN board, which has representatives from provider organisations, primary care trusts, commissioners and patients.

Project design
A steering group was established with representatives from Derby and Nottingham adult renal units and the EMRN; other staff provide expertise for specific elements.

The SYA Forum, funded by the British Kidney Patient Association, was established to gain input from young adult patients. Members preferred this form of involvement to membership of the steering group; the forum has provided valuable advice, support and encouragement.

The main strands of the project are:
» Employing an assistant psychologist to undertake a study to identify the needs of young adults;
» Employing a young-adult worker to provide support and education to enable young adults to make informed decisions and take more responsibility for their disease and its management in adult renal units;
» Collecting data at initiation and at intervals throughout the project to measure outcomes.

The steering group’s overall aim is to improve clinical outcomes for young adults with CKD by:
» Supporting them as they cope with the challenges they face as a result of having CKD;
» Empowering them to overcome and manage these challenges;
» Enabling them to access opportunities to reach their potential.

Young adults’ needs
The research conducted by the assistant psychologist explored the needs of young
adults (aged 18-25) with CKD, identifying whether these differed by treatment modality (peritoneal dialysis, haemodialysis, transplant) and by whether patients had transferred from paediatric renal care or entered adult renal care directly.

The researcher collected qualitative data through individual semi-structured questionnaires. Young adults with CKD participated in interviews exploring their support needs in different areas of their lives. Thematic analysis of the interviews is being undertaken to identify support needs, which will help to inform the future development of support services.

Emerging themes of the interviews to date relate to adversity and resilience, and some young adults felt their transition was rushed. Transition from paediatric to adult renal services, direct entrance to adult renal services, and change in treatment modality were experienced as acute adversities. Young adults were more likely to adapt if they had protective factors increasing their resilience, such as support from family and friends (Langham et al, 2011).

Support via the young-adult worker
After exploring who should deliver the support service and assessing the skills of the current renal teams, we recruited a young-adult worker with a background in youth work rather than healthcare. One of this worker’s first tasks was to visit the renal teams to explain the new service and any specialist input.

Issues raised include financial, educational and emotional concerns. This has resulted in a large number of referrals to internal and external services including educational establishments, grant-making trusts, clinical psychology services and volunteer centres. Young adults have been supported to make decisions about how they access healthcare and to improve health-related behaviours, such as stopping smoking. Some are being supported to access training and education to improve their prospects and reach their full potential.

Determining success
We collected baseline data at the beginning of the project, capturing information for a one-year period before the project started, including haemoglobin levels, estimated glomerular filtration rate, treatment modality and information about hospital admissions and clinic non-attendance. The same data will be collected throughout the project to assess whether the interventions have made a difference.

Young adults who access the one-to-one service are also asked to complete quality-of-life questionnaires so the intervention’s wellbeing benefits can be assessed. Alongside this, the young-adult worker provides regular information to the steering group about the amount and areas of support provided.

The SYA Forum will continue to be a great means of evaluating the project’s effectiveness, and the service is continually reviewed at steering group meetings. It is too early to tell whether the interventions now provided will have a lasting effect, but initial feedback is encouraging, as highlighted in Box 1.

Further analysis will take place as a result of the information obtained; outcomes and findings will be shared across the EMRN and published more widely via specialist publications and NHS Kidney Care. An in-depth understanding of the varying support needs of young adults with CKD will help adult renal units to develop their services appropriately.

**Conclusion**
This is an exciting project that builds on the regional pediatric renal unit’s existing transition pathway, provides a different approach to supporting young adults in adult renal units and complements the work of nurses and doctors. The project’s research findings will highlight the needs of young adults and enable appropriate interventions to take place in the most effective way. It is important that interventions really do make a genuine difference, and that the young-adult worker provides value for money. This will be demonstrated if we can empower young adults to live a more fulfilled life, with improved therapy concordance, leading to improved clinical outcomes.

**References**
Lewis H (2010) Impact of Paediatric Presentation of End-stage Renal Failure on Social Lives of Young Adults. Presentation to EMRN SYA Project Steering Group.

**Useful website**
www.kidneycare.nhs.uk