

HELPING ADOLESCENTS AND YOUNG ADULTS WITH END STAGE RENAL FAILURE

BRITISH ASSOCIATION FOR PAEDIATRIC NEPHROLOGY RENAL ASSOCIATION

1. Background

Adolescents and young adults with serious renal disease are a vulnerable group of patients. Adolescents with a history of significant renal disease from early childhood may have delayed physiological and psychosocial development, academic disadvantage and diminished self-esteem. The transfer from a paediatric to an adult renal unit is a move from a nurturing and familiar environment to a more business-like and apparently less empathetic clinical service due to work-load pressure. The majority of patients in adult units are considerably older making direct peer interaction difficult in an unfamiliar environment. Young and previously well adults also occasionally present to adult renal units with significant renal disease and, although less disadvantaged than those with a childhood of chronic ill health, have a similar need for support in an unfamiliar environment.

In 1985 Stewart Cameron published an article noting that the continuing care of children with chronic or relapsing renal diseases to units of adult internal medicine had received surprisingly little attention[1]. There have since been many publications concerning the lack of adequate facilities for adolescents and young adults in adult renal units and highlighting the inadequate preparation prior to moving from the paediatric unit. Cameron reviewed the situation in 2001 and concluded there had been little progress [2]. In our view there has been more than enough debate and discussion and the time has now come to act. This view is supported by the National Director for Kidney Care for England and follows on from the Renal Action Learning Sets based at Birmingham Children's Hospital and Great Ormond Street Hospital for Children, London [3]. The professional bodies for adult and paediatric nephrology, together with their respective Royal Colleges, have commissioned this report to

- Define a preferred pathway for transition
- Identify barriers to change which may delay implementation of the pathway

This document makes the case for transitional care as a quality improvement initiative that warrants commissioner support - the report by Lord Darzi 'High Quality Care for All – NHS Next Stage Review' has high quality health care at its heart. The first of seven steps to achieving high quality care is:

'Bring clarity to quality. This means being clear about what high quality care looks like in all specialties and reflecting this in a coherent approach to the setting of standards.'

This report defines high quality care both for adolescent renal patients preparing for transfer to adult renal units and for adolescent and young adults attending an adult renal unit, and identifies the essential components of that care. This clarity will allow paediatric and adult renal units to examine existing practice and introduce change where appropriate.

2. Methodology

This report was prepared following a one day meeting of representatives from paediatric and adult renal services and a patient and parent representative (Appendix 1). Attendees were provided with selected published material [3,4,5], the result of an electronic survey of transition arrangements in UK adult renal units (conducted by Professor Feehally), and transition documents in use at Birmingham Children's Hospital, Bristol Children's Hospital, Evelina Children's Hospital, Great Ormond Street Hospital and Royal Belfast Hospital for Sick Children.

3. Recommendations

3.1 Principle

Transition is a process that can begin at any time during paediatric care but generally should begin by the start of academic year 9 and can continue until the young adult is in their twenties. Transfer is an event that should occur at a time agreed by the adolescent and their parents, as well as by the paediatric and adult renal staff, during the transition process. The timing of transfer will be influenced by individual Trust policies but generally should not take place before the end of academic year 11.

3.2 Remit

Children in academic year 9 or above with a functioning renal transplant

Children in academic year 9 or above on dialysis

Children in academic year 9 or above with chronic kidney disease and anticipated to require renal replacement therapy within 1 year

Young adults less than 20 years of age presenting to an adult renal unit with end stage renal failure, or with chronic kidney disease and anticipated to require renal replacement therapy within 1 year

3.3 Organisation of services

- Each regional paediatric unit in the UK should identify a named clinical lead for transition
- A small number of adult renal units (2-3) within each region should be designated as regional Young Adult Renal Unit (YARU) and a named clinical lead for transition should be identified within each of these units. The number and location of YARU will vary depending on the regional population distribution and will require advice from commissioners.
- YARU will typically serve a total population of 2-4 million to allow referral of sufficient numbers of young adults to sustain separate young adult clinics, psychosocial support and other appropriate facilities for their use
- Transition leads (paediatric and adult) should agree a written transition document or pathway to include details of the transition process at both the YARU and paediatric centre (example in Appendix 2)
- The regional paediatric unit should establish an adolescent transition support team to implement the transition document and to provide continuing support for patients for at least one year after transfer

- Each adolescent should have an identified key worker from the adolescent transition support team to work with them through the transition process
- The key worker should liaise with appropriate members of the multi-professional team (transplant nurse, specialist dialysis nurse, consultant paediatric nephrologist, consultant transplant surgeon, social worker, counselor, youth worker, psychologist) to achieve the requirements specified in the transition process document
- Each YARU should appoint a young adult support worker to work with the adolescent transition support team before and after transfer of the young adult, and to support young adults presenting to the adult renal unit
- Dialysis patients transferring to adult renal units should be offered the choice of attending the unit closest to their home or traveling to a YARU
- Young adults (ie under 20 years of age) presenting to an adult renal unit with ESRF or anticipated to require renal replacement therapy within one year should be allowed to choose between remaining under the care of their local adult renal unit or transferring to the nearest YARU

3.4 Components of transition

Preparation

Transfer

Integration into the YARU/adult renal unit

Preparation

This phase, beginning in academic year 9, should aim to prepare the adolescent patient for transfer to the adult renal unit by ensuring they have

- An understanding of their renal disease, its treatment and related health issues
- Confidence to speak about their health in an outpatient clinic
- Resolved issues relating to venesection and procedures such as renal biopsy and line insertion
- Begun to acquire necessary skills to manage their health independently of their parents

Individual paediatric renal units will develop their own scheme to help their adolescent patients achieve these skills but there should be at least one review with the key worker and other appropriate members of the adolescent transition support team each year and this meeting should review an agreed minimum data set (see example Appendix 3) of recommended achievements. The discussion and suggested actions should be documented each year in a summary letter to the patient, a copy of which should be kept in the patient's health record and subsequently provided to the adult nephrologist at the time of transfer.

The following are examples of good practice that paediatric units should consider in devising their own transition process:

- A tour of an adult renal unit for adolescent patients and their parents (to include a visit to the outpatient department, haemodialysis unit and ward area, transplant ward) and an opportunity to meet members of the adult renal team
- Discuss venepuncture services in adult renal units and gradually introduce a change in practice through trial sessions in the paediatric unit, where any concerns or difficulties can be identified and resolved. This may involve the use of a hospital venesection service (if available) to help adolescent patients reduce their reliance on individual members of the team; reduce reliance on topical analgesia and the use of ‘butterfly’ needles for venesection
- Encourage partial ‘parent-free’ outpatient consultation, allowing the adolescent patient to conduct some of the clinic attendance on their own thereby developing confidence in reporting health issues and discussing treatment
- A transition clinic in the paediatric centre at which adolescent patients can meet members of the adult renal team and experience the ‘adult’ approach to out patient consultations
- A Transition Camp that carries out a wide range of interactive workshops covering: developing teamwork, building trust and support, planning, budgeting, raising self-confidence, developing life skills (communication, independence, work skills, managing stress, managing change), healthy living (diet, exercise, hygiene), health awareness (alcohol, sexual health), introduction to adult services and celebrating achievement. Activities led by the Youth Work Team, in conjunction with the medical specialist team that can be accredited by national schemes such as Open College Network (OCN).

Transfer

The timing of transfer to an adult renal unit or YARU should be agreed by the adolescent and their parents, as well as by members of the paediatric and adult renal medical teams. It is essential that there is absolute clarity regarding the date of transfer of medical care so that patients and parents know which medical team will continue to provide routine and emergency care. If the agreed date of transfer necessitates delayed discharge and continued attendance at the paediatric centre, it is essential the named consultant anticipates any conflict with Trust policy about age of transfer, and takes appropriate steps to resolve difficulties arising from this decision.

The meeting identified the following examples of good practice:

- Haemodialysis and peritoneal dialysis patients: have at least one outpatient attendance with the consultant nephrologist and members of the dialysis team at the YARU or adult renal unit prior to transfer; have at least one outpatient attendance at the regional transplant unit prior to transfer if they are transferring for dialysis at a non-transplanting centre and are on the deceased donor transplant list; have a member of the adolescent transition support team and appropriate specialist nurse attend these appointments
- Renal transplant recipients have at least one outpatient attendance at the YARU prior to transfer; a member of the adolescent transition support team and/or a paediatric renal transplant nurse should attend this appointment

Integration into the YARU/adult renal unit

The meeting recognized that adolescent and young adult patients form a small part of the patient load in any adult service, and that specialist adolescent medical services are unlikely to be developed in the majority of adult hospitals in the foreseeable future. Consequently, it was felt appropriate to stress the importance of developing awareness of the special needs of this group of vulnerable patients within adult renal services. Watson et al [6] have shown a high rate of transplant loss

following transfer to adult services, and high rates of graft loss have also been noted in adolescent and young adults in the West Midlands (Appendix 4), highlighting the potential health economic benefit of investing in support for this group of patients to improve transplant outcome. The YARU and the linked regional paediatric renal unit should work together to develop a shared vision for adolescent and young adult patients, supported by an adolescent transition support team and specialist young adult support worker. This should better prepare adolescent patients and their families for transfer from paediatric to adult services. However, there is a need for the momentum to be continued after transfer by:

- Establishing consultant delivered young adult clinics with support from the young adult support worker and also from members of the adolescent transition team for those who have recently transferred
- Facilitating networking between young adults to provide mutual support
- Providing personal health and career advice within the role of the young adult support worker
- Establishing a minimum data set of achievements to continue the process of integration into adult services (Appendix 5)

The meeting identified the following examples of good practice that may be used by YARU in devising their own transition document:

- Identify and train young adults to act as a ‘buddy’ for newly transferred patients
- Develop sources of information to provide education and careers advice, personal health promotion, travel advice – this could be web-based and shared by YARU across the UK
- Establish young adult residential courses and young people’s conferences to facilitate networking, sharing of experience and health promotion/disease prevention

4. Workforce

Paediatric Unit

Named clinical lead for transition: Consultant Nephrologist, 1PA activity.

Adolescent transition team: The implementation of a transition process fulfilling the detail recommended in this report requires additional funding and resources to establish a team comprising a psychologist (0.5 WTE), youth worker (0.5 WTE), social worker (0.3 WTE) for a region of approximately 5-6 million population linking with 2-3 YARU and a transfer rate of 5-8 adolescents per year.

YARU

Named clinical lead for transition: Consultant Nephrologist, 1PA activity

Transplant clinical nurse specialist (0.5 WTE)

Young adult support worker (1 WTE): this post could be recruited from a wide professional background including social work, youth work or counseling. The post will typically be based in the adult renal unit located with the regional transplant centre providing paediatric transplantation services, but other local arrangements may be more suitable. The young adult support worker should work closely with the adolescent transition team in the regional paediatric unit and with other local adult renal units (Appendix 6).

5. Implementation

These recommendations will result in significant improvement in the quality of service offered to vulnerable young adults with severe renal disease.

We seek endorsement for these plans from the National Clinical Director for Kidney Services in England, and anticipate that the necessary service developments be given priority by specialized renal commissioners in England and their equivalents in devolved regions of the UK.

We anticipate that YARUs and adolescent transition support teams within each region will be established by 2010.

6. Conflict of interest statement

Meeting expenses were supported by an unrestricted educational grant from the Astellas Transplant Foundation.

7. References

1. Cameron JS. The continued care of pediatric patients with renal disease into adult life. *Am J Kidney Dis.* 1985; 6:91-95.
2. Cameron JS. The continued care of children with renal disease into adult life. *Pediatr Nephrol* 2001; 16: 680-685.
3. Milford DV, Fisher D, Marks SD. Adolescent transfer to adult renal units. *Br J Renal Medicine* 2008. 13: 30-31
4. Bell LE et al. Adolescent transition to adult care in solid organ transplantation: a consensus conference report. *Am J Transplant.* 2008; 8:1-13.
5. Bell L. Adolescents with renal disease in an adult world: meeting the challenge of transition of care. *Nephrol Dial Transplant.* 2007; 22: 988-91
6. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol.* 2000; 14: 469-72.

Appendix 1

Attendees

Ms N Bandler, Transplant Nurse, Oxford Transplant Centre, Churchill Hospital

Mr M Beehan, transplant recipient and former paediatric patient

Mrs J Dargie, parent of paediatric transplant recipient transferred to adult unit

Mrs S Dolby, Consultant Clinical Psychologist, Bristol Children's Hospital

Professor J Feehally, Consultant Nephrologist, University Hospitals of Leicester

Dr J Hainsworth, Clinical Psychologist, Leicester General Hospital

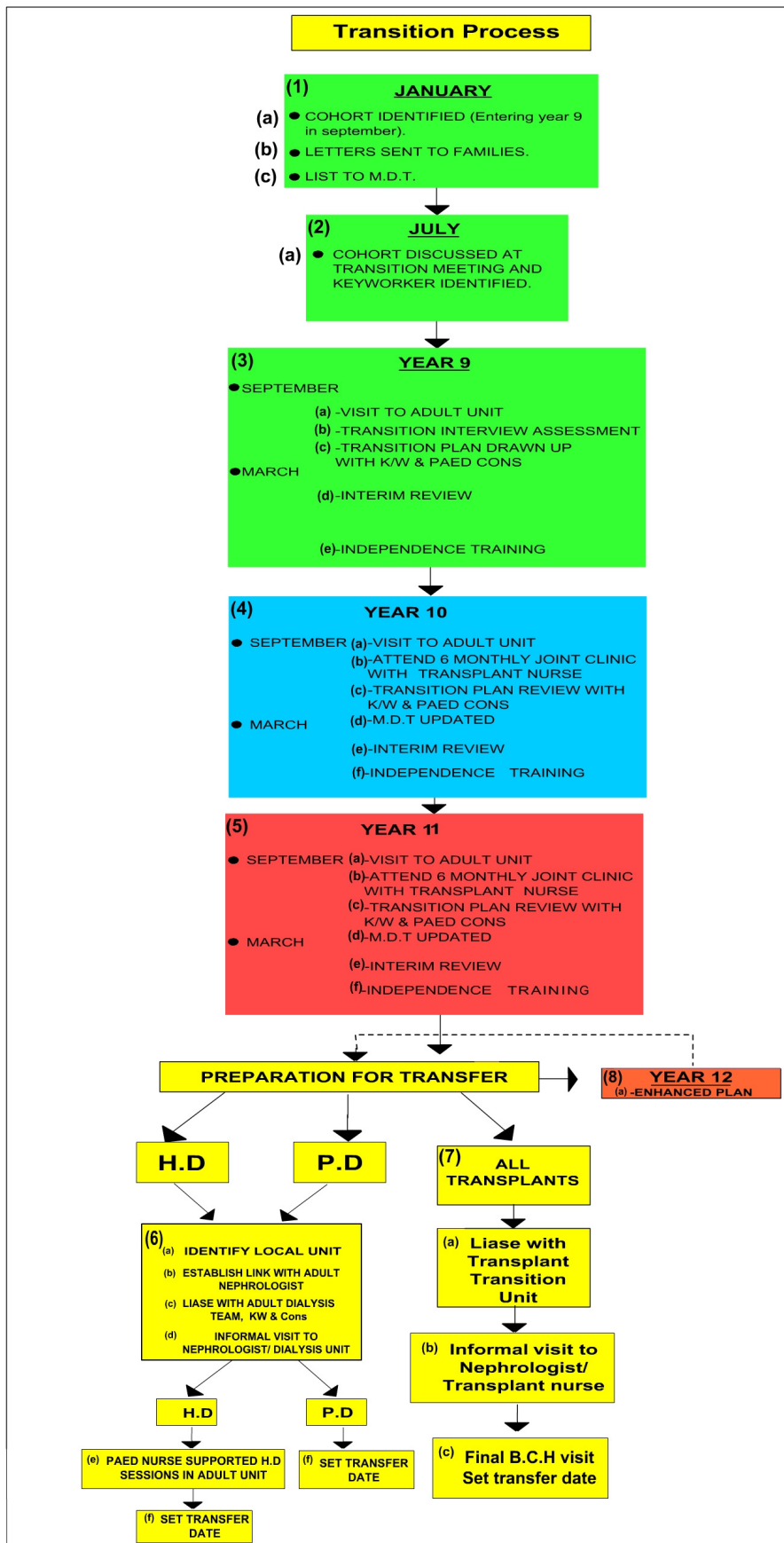
Dr P Harden, Consultant Nephrologist, Oxford Transplant Centre, Churchill Hospital

Ms D Hilton, Senior Youth Worker, Queen's Medical Centre, Nottingham

Dr S Marks, Consultant Nephrologist, Great Ormond Street Hospital, London

Dr D Milford, Consultant Nephrologist, Birmingham Children's Hospital

Appendix 2



Appendix 3

ASSESSMENT TOOL GUIDANCE FOR KEY WORKER BIRMINGHAM CHILDREN'S HOSPITAL

Please check the adolescent patient passes the assessment for the previous year before testing for the current year.

1. KNOWLEDGE AND UNDERSTANDING

- **Knows condition, its effects and prognosis**
 - Year 9: names their renal problem with prompting; is broadly aware of consequences of renal disease (eg 'I need to watch what I eat and drink while I am on dialysis'; 'I don't have to worry about what I eat/drink as long as my transplant works well.');
 - Year 10: names their renal problem reasonably accurately and with minimal prompting; knows if there is associated symptomatology eg 'my kidney problem is known to also cause deafness in later life'; understands that kidney transplants can fail/dialysis access can fail
 - Year 11: names their renal problem accurately without prompting; knows the consequences of renal failure and possible complications that may arise from dialysis or renal transplantation; understands dialysis or transplantation are the only ways to treat chronic renal failure.

- **Knows medication purpose and effects**
 - Year 9: knows broad purpose of treatments eg for BP, for bones, for kidney rejection. May know some side effects.
 - Year 10: can correctly name up to 3 medications; knows frequency and purpose of treatment; knows important side effects
 - Year 11: can correctly name most medications; knows dose frequency; knows drug purpose; and important side effects

- **Knows treatment regimes purpose and effects (dialysis patients only). This section relates to nutrition, fluid restriction and dialysis regimen, NOT medication.**
 - Year 9: knows frequency and basic purpose of whichever dialysis modality they are being treated with; knows fluid allowance; knows broad categories of food restrictions.
 - Year 10: knows either PD prescription or duration HD; knows dialysis influences biochemistry and fluid balance; knows how diet affects biochemistry
 - Year 11: confirm knowledge of PD/HD prescription; knows how manipulation of dialysis and diet influences BP, biochemical control

- **Knows key team members and understands their roles**
 - Year 9: understands that care is delivered by a team

- Year 10: can name usual consultant; can name nurse involved in their care and knows their role; may know the name of another health care professional and their role
- Year 11: confirm knows the name of their usual consultant and understands their role (eg prescription of treatment including drugs, fluids, dialysis etc; directing care; communication); knows the name and understands the role of all other health care professionals involved in their care

2. SELF ADVOCACY/INDEPENDENT HEALTHCARE BEHAVIOUR

- **Part/whole outpatient consultation on their own**
 - Year 9: attends the first 5-10 minutes of the clinic consultation on their own
 - Year 10: attends most of the clinic consultation on their own
 - Year 11: can conduct entire consultation on their own if necessary
- **Knows how to make/alter medical appointments**
 - Year 9: understands the importance of an outpatient appointment
 - Year 10: knows how their parents make/alter appointments with health care professionals
 - Year 11: knows how to make/alter appointments with health care professionals involved in their care
- **Understanding of confidentiality**
 - Year 9: knows what confidentiality is
 - Year 10: understands professionals share information but that patients can limit this
 - Year 11: understands professional and personal (ie as patient) issues relating to confidentiality and its limits (eg risk)
- **Takes some/complete responsibility for medication and other treatments**
 - Year 9: can take some medication/treatment when away from home but under supervision (eg school nurse)
 - Year 10: can reliably take all medication/treatment with adult supervision
 - Year 11: could reliably take all medication/treatment for a short period (eg a day) if necessary
- **Adherence**
 - Year 9: understands the concept of adherence
 - Year 10: knows the importance of adherence to medication/diet/treatment (eg dialysis, catheterisation etc)
 - Year 11: knows the importance of adherence to medication/diet/treatment and blocks to achieving this
- **Orders repeat prescriptions**
 - Year 9: understands continuous medication is obtained by repeat prescription
 - Year 10: understands medication may be prescribed by different doctors (eg hospital, GP surgery)
 - Year 11: knows who prescribes medication and how to obtain repeat prescriptions

3. HEALTH AND LIFESTYLE

- **Understands the importance of diet and exercise**
 - Year 9: understands how diet and exercise can affect health
 - Year 10: understands how their diet and level of exercise can affect their health
 - Year 11: knows components of a healthy diet and the value of exercise; check they have information leaflet

- **Understands the implications for them of smoking/alcohol/substance abuse**
 - Year 9: has a basic understanding of the impact of smoking, alcohol/substance abuse in general
 - Year 10: understands the impact of smoking, alcohol/substance abuse on their own health
 - Year 11: has a full understanding of the implication for their health of smoking, alcohol/substance abuse

- **Understands sexual health matters**
 - Year 9:
 - Year 10:
 - Year 11:

4. SELF CARE

- **Meal preparation**

Are they able to prepare a basic meal e.g. sandwiches/toast/ tea?

- **Understanding of financial issues**

Does young person have part time jobs, savings, gets pocket money, bank accounts, paying bills, applying for assistance for college (Educational Maintenance Assistance), do they know where to get it from?

- **Domestic tasks**

Does the young person have any responsibilities at home e.g. help with chores, jobs around the house?

- **Arrange transport/can travel independently**

Identify current travelling plans does young person travel on their own, do they feel confident travelling alone, how do they do this e.g. bus, train, taxi, do they pay bus fare, travel pass?

- **Personal hygiene**

What is their daily washing routine? dental care, use of toiletries, females using sanitary protection during menstruation, young men keeping clean during puberty

5. EDUCATIONAL AND VOCATIONAL PLANNING

- **Current and future education and career plans/impact of condition**
Record the educational, training and employment aspirations as stated by the young person : realistic goal plans, identification of course – college applications/prospectus/ open day/ qualifications required, job description – what job involves, What work experience have they had?
- **School attendance and performance**
How are they performing at school/ predicted grades/record of achievement, absence from school/ school report.
- **Knows how to access careers advice and work experience**
Do you know which local services provide relevant information on, advocacy & advice if needed do they have an assigned Personal Adviser at their school, do they know where the local careers office is located/opening & closing times
- **Outside school activities and interests**
Does the young person have any interest/hobbies, belong to any club association e.g. army cadets/scouts/guides/ part time job, gym, social life

6. PSYCHO-SOCIAL

Some guidance on questions to ask has been provided- please see below:

- **Body/Self Image**
 - How do you see yourself as a person?
-Look out for anything that demonstrates positive or negative self-image. -If not balanced or negatively skewed, highlight for discussion.
 - How do you feel about your body?
-Look out for anything that demonstrates positive or negative body-image. -If not balanced or negatively skewed, highlight for discussion.
 - Do you feel any different about your body or how you see yourself since you have known about your renal condition?
-Note any changes that potentially affect wellbeing or functioning.

- Has your condition/treatment affected your body in any way and how do you feel about this? Have you been able to discuss this with anyone at the hospital and has your treatment been changed because of your concerns?
-If issues are mentioned and not raised with anyone-can they be encouraged to discuss with someone?

-If they have raised them, do they feel this has been listened to and where possible addressed?
- Do you feel people accept you for who you are?
Look out for issues of negative perception by others and how might these be managed.

- **Self Esteem/Confidence/Mood**

- Do you think you are good at anything?
Draw out any positives- can these be built upon? Note any negative skew.
- How do you feel about your life?
-How satisfied are they with how things are for them.

-If there are a lot of dissatisfactions, can anything be done to support or address any of these?
- What do you do when you get upset or angry? Do you think this has changed since you found out about your renal condition/or since your condition got worse?
-Look for coping strategies- are these helpful or unhelpful strategies, do they make the problem worse or better (in the long and short term).

-Could they benefit from some new more helpful ones? How might this be done?

-Do you have any concerns about this young person's mood and if so how can these be addressed?
- Do you have any worries that you can't stop thinking about? What do you do with these?
-Find out about major concerns- is there a particular theme to them?

-Are these realistic concerns or are they disproportionate?

-Look for coping strategies to deal with worry- are these helpful or unhelpful strategies, do they make the problem worse or better (in the long and short term).

-Could they benefit from some new more helpful ones? How might this be done?
- Do you worry about the future?
-Are these concerns realistic?

-Do the concerns get in the way of current functioning or quality of life?

- Do you make friends easily?
-If no what gets in the way?
- Do you feel confident about yourself?
-Draw out strengths and insecurities if there are any.

-Are there any issues to be addressed or targets to build upon?

- **Peer Relationships/Bullying**

- Who are your closest friends and where do you see them?
-Look for balance or social network.
- Do you think your renal condition has affected your friendships?
-Are they isolated when off school or in hospital?

-If so is there any way around this?
- Do your friends know about your renal condition and if they do they do anything that is helpful/not helpful in managing your condition?
 - *Do they have any concerns about disclosing?*
 - *Are there people they would like to disclose to- would they like help in practicing telling people?*
 - *Any useful/unhelpful things they have experienced in relation to friendships related to their care?*
- Have you experienced any problems with young people your age?
 - *What sort of problems?*
 - *Who is aware of the problems?*
 - *Can the problems be addressed?*
- Have you experienced any bullying? If so where and what was the bullying about? Have you told anyone about this and if so how was it dealt with?
 - *Find out the impact this has had upon them and whether there are any unresolved issues.*

- **Family/Network Support And Relationships**

- Where they see themselves in the family- how close are they with their parents and siblings or other important family members?
 - *How do they view their position within the family and does their renal condition relate to this?*
- How involved are parents directly in their care & what are your feelings about that?

- *Are they or are their parents taking too much responsibility?*
- *Is everyone happy with who takes responsibility for the care.*
- *Will the current arrangement be ideal given the stage they are in their transition?*
- *Does this need to change?*
- *Do they need additional support and if so who from?*

- Does your renal condition get in the way of family life or your life as you want it to be?
 - *Are there any resolvable practical issues that are raised.*
 - *How might these be addressed?*

- Who do you talk to about your renal condition and treatment?
 - *Is the young person well supported?*

 - *Can they talk openly to at least one person in their family and one person in the hospital?*

- Do you feel you can trust people?
 - *Highlight any trust issues and the reason behind these.*
 - *Can any issues be resolved?*

- **Coping Strategies**
 - What do you do when you have a problem?
 - *Look at helpful and any unhelpful coping strategies.*

 - Do you think you are good at solving problems?
 - *If no is this a confidence issue or does this young person require extra help?*

 - What do you do to have fun?
 - *Is there a good balance between school/hospital/social life and fun in this young person's life?*
 - *If not can anything be done to address this and who can help?*

 - What do you do to take care of yourself?
 - *Does this young person have good self-care skills (look at all aspects of emotions and social wellbeing)?*
 - *If not how can this be addressed?*

 - What do you do to relax?
 - *Draw out preferences and emphasise the importance of stress management.*
 - *Are there other things they can do?*

7. TRANSITION

- **Attends transition clinic**
Yes/No for that year & discuss

- **Attends adult unit tour**
Yes/No for that year & discuss

- **Attends independence training**
Yes/No for that year & discuss

- **Transfer plan agreed**
Yes/No for that year & discuss

Appendix 4

All renal graft losses more than 3 months from transplantation in children transplanted 1.1.1995-31.12.2004 Birmingham Children's Hospital

| Graft survival (yrs) | Age graft loss (yrs) |
|----------------------|----------------------|
| 3.5 | 17 |
| 3.6 | 18 |
| 3.2 | 18 |
| 4.75 | 17 |
| 2.2 | 17 |
| ? | 17 |
| 3 | 16 |
| 9.1 | 16 |
| 1.4 | 16 |
| 3.1 | 15 |
| 3.6 | 16 |
| 2.1 | 14 |

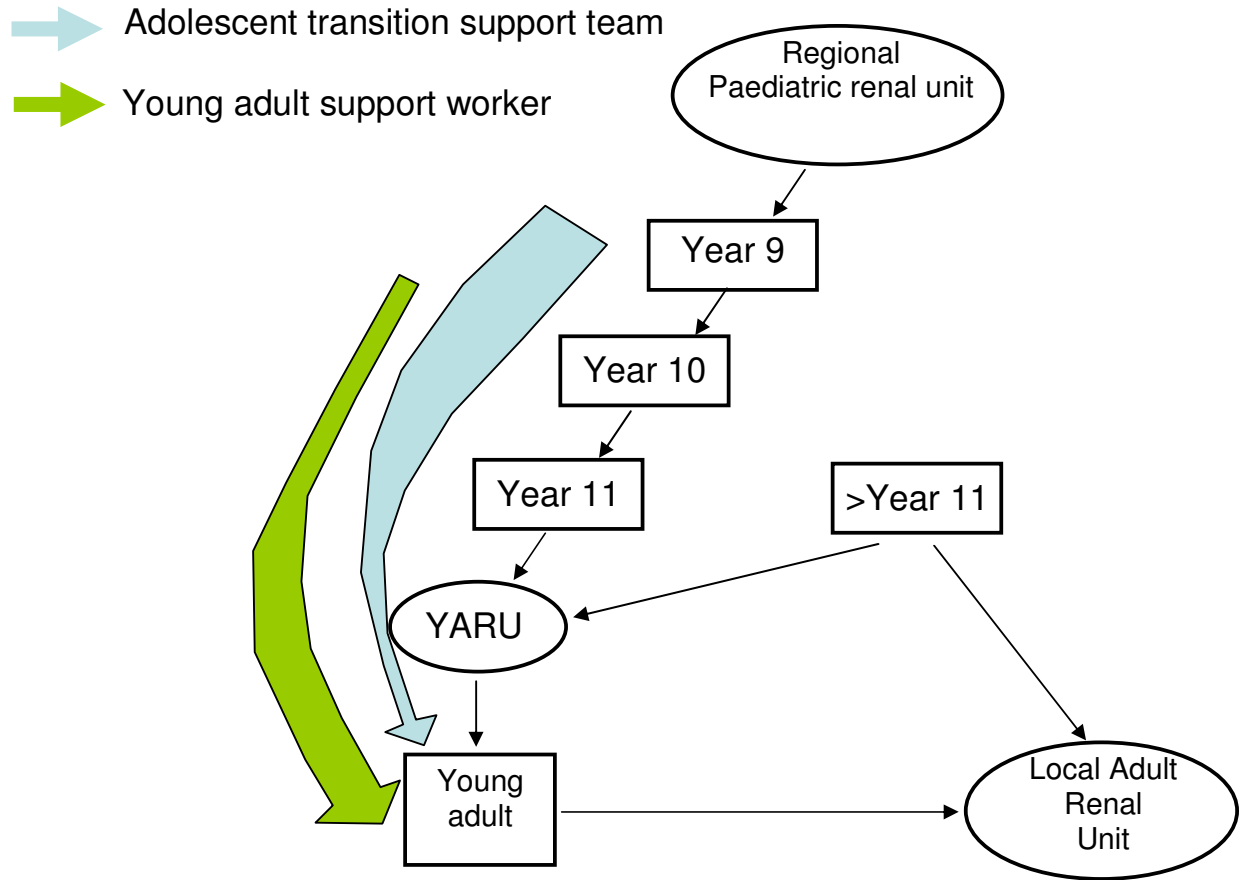
Appendix 5

The skills acquired during the transition pathway completed in the paediatric unit need to be further developed following transfer to a YARU or local adult renal unit. Important components include:

1. Complete independent successful management of treatments including knowledge of current prescription and common side-effects
2. Stable education or employment status
3. Knowledge of original renal disease, implications and consequences of dialysis and transplantation
4. Knowledge of the roles of the multidisciplinary healthcare team and how to access advice appropriately
5. Understanding of the importance of taking responsibility for personal and sexual health
6. Psychological maturity demonstrated by stable family/partner relationships; evidence of adherence to medical therapy; financial awareness

Appendix 6

Proposed model of care



Paediatric patients are supported by the adolescent transition support team (based in the paediatric renal unit) during academic years 9, 10 and 11 but with input from the young adult support worker (based in YARU) prior to transfer. Although there is continuing support from the adolescent transition support team after transfer, the young adult support worker will be mainly responsible for providing ongoing support. The young adult will transfer to the local adult renal unit after 20 years of age. Newly presenting young adults (academic year 12 and older) can elect to either attend their local adult renal unit or a YARU.