To start a transition program for teenagers and young adults with kidney transplants in Queensland

Anna Francis, Churchill Fellow 2015

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Signed Anna Francis

Dated 29/06/2016
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Introduction & Acknowledgements

I would like to gratefully thank the Churchill Trust for the amazing experience that I have had. It is only with the extensive support from the Trust that I have been able to travel overseas and visit multiple centres of excellence to gather experience in forming a transition programme for young adults with end stage kidney disease in Queensland.

The centres I visited (Heidelberg University Hospital, Nottingham Children’s Hospital and Boston Children’s Hospital) were incredibly kind and welcoming and I would particularly like to thank my lead contact at each centre, Dirk Bethe (Heidelberg University Hospital), Dr Martin Christian (Nottingham Children’s Hospital) and Associate Professor Michael Somers (Boston Children’s Hospital) for their kindness and enthusiasm for my project.

I would also like to acknowledge Associate Professor John Burke and Professor David Johnson, my referees for this scholarship. Their enthusiasm and mentorship have been invaluable in this project.
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Executive Summary

Dr Anna Francis, Nundah, Brisbane, 07 3068 1111

Advances in medical care mean increasing numbers of children with end stage kidney disease are surviving to adulthood and graduating from paediatric to adult care. As an adolescent becomes an adult, the primary responsibility of care moves from the parents (or care-giver) to the young adult. For youth with kidney disease, the path of transition to adulthood has added complexity. Their illness often hinders individuation, as the child may be reliant on parents for their day-to-day medical care. In addition, advanced kidney disease is associated with cognitive impairment and psychosocial maladjustment when compared to healthy controls.(1-5).

Currently in Queensland, we have no structured transition clinic for young people with end stage kidney disease. The purpose of this fellowship was to attend the American Transplant Conference and visit centres of excellence in Heidelberg, Nottingham and Boston to learn about their transition programmes in order to help start a transition programme in Queensland.

Transition is not a single event in time, but rather a planned, purposeful transfer of care over time between the paediatric to adult centre whilst fostering ownership of care in the young adult. There are multiple ways to foster this process. In Heidelberg, I learnt about the importance of a “transition lead”, having one point person to be the point of contact for the young person during the process and check that everything is on track. In Nottingham, I saw how integral youth workers are to the transition process. They support the young person, encouraging empowerment and the building of self-esteem. In Boston, I met with adult nephrologists who explained their strategies for easing parental anxiety around this time of change whilst building a primary relationship with the young person. In addition, I spoke with nurse specialists, pharmacists and social workers who provided insight on interventions to improve medication adherence and ways to smooth the path of transition. In all three centres I met with paediatric nephrologists who explained the history and current state of their transition programmes as well as practical aspects of setting up a programme. Sessions at the American Transplant Congress dedicated to transition discussed interventions to improve transition, like shared care clinics, formal assessment of transition readiness, using technology to increase treatment adherence and risk factors for non-adherence.

I will use the information I have gathered from this scholarship to work with other members of my paediatric nephrology team and with the adult nephrology team (particularly Dr Ross Francis who has put an enormous amount of work already into creating the clinic) to help create a transition clinic for young people with end stage kidney disease in Queensland.
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Programme: May 30 – June 24, 2016

Heidelberg University Hospital, Heidelberg, Germany
Key professionals who kindly gave their time to discuss transition:
• Dirk Bethe, Psychologist
• Dr Claus Schmitt, Paediatric Nephrologist
• Dr Suzi Riga, Paediatric Nephrologist

Nottingham Children’s Hospital, Nottingham, England
Key professionals who kindly gave their time to discuss transition:
• Dr Martin Christian, Paediatric Nephrologist
• Dr Fariha Hussain, Paediatric Nephrologist
• Ruth Prigg, Dietician
• Kim Helm, Specialist Nurse
• Shelley Jepson, Specialist Nurse
• Donna Hilton, Youth Worker
• Mark Howard, Youth Worker
• Terrence Green, Youth Worker

Boston Children’s Hospital, Boston, USA
Key professionals who kindly gave their time to discuss transition:
• Dr Michael Somers, Paediatric Nephrologist
• Dr Maria Ferris, Paediatric Nephrologist visiting from University of North Carolina Children’s Hospital
• Dr Melanie Hoenig, Adult Nephrologist from Beth Israel Hospital
• Roberta Hoffman, Social Worker
• Dawn Freiburger, Nurse, Lung Transplant Transition Service
• Jennifer Gilarde, Transplant Pharmacist

American Transplant Conference, Boston, USA
Speakers attended:
• Christina Spivey
• Seth Heldenbrand
• Julie Boucquemont
• Rachel Annunziato
Main Body

Improvement in medical care means increasing numbers of children with end stage kidney disease (ESKD) are surviving to adulthood and requiring transition to adult services. Transition is defined as ‘purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems’. (6) This transition mirrors other wider aspects of the young persons life, where parents start by providing all care for their child, but by adulthood the young adult (hopefully!) assumes all responsibility.

Adolescence is renowned as a stormy period of cognitive, emotional and psychosocial change. It is a time of self-definition, developing risk assessment and other complex executive functions and of emotional lability. Even for well teenagers, adolescence is associated with increased morbidity and mortality. In Australia from 2000 to 2013, mortality rates were 46.7 per 100,000 for 15-24 year olds, compared to 11.0 per 100,000 for 4-14 year olds. (7) Transition has long been recognised as a time of high risk for medical complications. (8) Poor medication compliance and increased rates of acute rejection and graft loss have all been described in the transition period. (8-10) Poor readiness for transition has also been associated with increased hospitalization. (11)

Increasingly, we have recognised the importance of a structured transition programme to guide young people through this time. (12) The purpose of this scholarship was to travel to centres of excellence throughout the world to learn about their approaches to transition of care from paediatric to adult care in young people with end stage kidney disease.
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Transition in Germany

Health system setting
Centre: Heidelberg University Hospital, Heidelberg, Germany
Population base: Large patient population (8 million) who will drive up to 180 km to come to the centre. Every year, eight to ten children are admitted to their dialysis and transplantation program and they perform around 20 kidney transplants per year.
Health care framework: In most German paediatric nephrology units, most transplant and dialysis patient are mostly run by non-profit dialysis organisation (KFH). There are around 200 adult dialysis units in Germany. These organisations are separate to the hospital. The units are situated on the hospital site and the KFH pays the hospital for the staff that comes from the hospital. They only accept patients to age 18. In Germany, the health care is around 10% private, some are funded through combined workplace and personal insurance and those on social security are covered entirely by the state.

Team:
- Paediatric Nephrologists: 6-8
- Dedicated transplant nurse: half time in this role and half time on the nephrology ward
- Social worker
- Psychologist
- Dietician

Transition programme set up
In Heidelberg, transition planning is integrated into every clinic visit.

Transition process:
1. Preparing for transition
   - 2-week yearly summer camp. To give the children the understanding that they are not alone. They cannot share their experiences with their friends and this is an opportunity for them to accept and learn about their disease and making a support network that will continue on after their transfer to adult care. During the camp, they have scheduled education sessions where they also do question and answers sessions. They also have adult graduates who have positive life stories to motivate and encourage the children. The children can share ways of coping with living with the disease – for example ‘what do you say when your classmates ask why you have a tube in your tummy’
   - Improving skills for living with the disease
   - Transition programme called “finally grown up” in Austria with one-week camp and then 2-3 weekends per year. They will play sports and give talk on profession, schooling, sexuality, drugs, disease, and treatment. They look at pig kidneys so the children can understand what a kidney is.
   - Fostering independence whilst ensuring safety. The dilemma of burgeoning independence is that we want to give them the opportunity to learn from their mistakes but with immunosuppression there is no room for mistakes.
2. Timing for transition: Evaluation of the situation for timing of the transition one year before the transition
3. Communication with the adult team

Criteria for transition:
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- Individual criteria for transfer NOT age based. The median age for transfer in Germany is 18.3 years. In Heidelberg, there is a dialysis unit, which belongs to KFH. These patients must be transferred at age 18. All transplant and general nephrology patients are treated in the general paediatric hospital and there is more leeway on time on transfer. Most other German units must transfer at age 18. In Heidelberg the average transplant patient is 21 at the time of transition.
- Finished school (this is between age 16 -19 in Germany depending on the level of their high school)
- Started vocational training and stable in this
- Able to negotiate with medical personnel
- Knowledge of disease and medication
- Some self sufficiency
- Not in medical or psychosocial crises i.e. just starting to study or just starting a job
- At least 1 year post transplant

Interventions to improve transition
- Clinical lead for transition: full time psychologist Dirk Bethe. The hospital also has a transition co-ordinator, not just for renal
- Psychological support for crisis of identity
- Ongoing support- not just one intervention per year!
- “Transition days” where the children can sit around a table in an informal environment and ask “what I have always wanted to ask my doctor”
- The doctor from paediatrics sometimes goes to the clinic at the adult clinic
- For 6 months or more they see the children as an overlap to the adult centre
- After transfer they can still call the paediatric unit if they have questions
- Encourage the children to know their medications themselves and they have primary responsibility for their medications and mum or dad is the back up. They also encourage them to have their dosette box.
- See the children individually with the parents coming in later.
- From 18 years the children are encouraged to find their own adult nephrologist closer to home
- Letter is the primary mechanism of transfer
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Transition in Nottingham

Health system setting
Patient population: Large population over an area the size of Scotland. People drive up to 150km to access the main nephrology centre. Cover 6 million people in the area, covering from East Midlands to South Yorkshire.
Health care system: Universal free health care is provided by the NHS. The age of transfer is not set for nephrology at Nottingham.

Transition team
- Paediatric nephrologists
- Youth workers
- Transplant nurse specialist
- Social worker
- Dietician

Criteria for transition
- Use the “ready, steady, go” programme (set up by Dr Arvind Nagra at Birmingham)
- Don’t transition in a time of medical or psychological/social crisis
- Transition away from big changes in education/vocation (finish school around 17)

Interventions for transition
- Youth workers (see more below)
- From the age of 11 have a few minutes alone with the consultant in each clinic
- The team use expert peers: older transplant patients to provide peer support to the younger ones
- CNC or youth worker and paediatric nephrologist goes along for the first 2 visits and the adult team come to the children’s hospital for 2 visits (up to an hour travel between the two hospitals)
- Multidisciplinary team meeting before the very first transition clinic for each person (both paediatric and adult consultant, paediatric nurse specialist, youth worker and young adult worker and any dietician etc. if needed
- Working on procedure phobias so that they don’t need general anaesthetic etc. for kidney biopsies – work on these phobias slowly over time so that they can function at an adult hospital level before they go across
- Transition workshops- both for children and parents and they have young adults and their parents who were post transition come along
- Parent tool in ready steady go
- Transfer letter- medical and nursing and social worker have input on the letter
- Tour of the outpatients / haemodialysis centre/ inpatient ward / imaging/ pharmacy/ phlebotomy/ social work/ admissions of the adult hospital
- Focusing on the positive side of adult hospitals- ‘finally an adult’, more flexibility in clinic times as there are more clinics

Youth Centre at Nottingham Children’s Hospital
4 youth workers and 10 volunteers, the volunteers do an “intro to youth work” course and get a qualification. Patients arrive at the centre from various avenues including hospital school, play therapists, nurses will call with a referral, self-referral and parents
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The centre serves 11 – 25 year olds and has a dedicated space in the hospital. They encourage the parents to leave so the kids can have peer interaction. It is also a medical staff free zone.

The aims of the youth centre are:

- Building a relationship with the kids and then assessing their needs
- Based on the children’s agenda
- Fostering independence and peer support
- Doing age appropriate activities
- Demystifying the language used in hospitals
- Seeing the young person as a person first as opposed to seeing their health condition first
- Fostering peer support

Programmes

- Have evening sessions – every Wednesday they rent out a ‘youth club” (like YMCA) and outpatients and the occasional inpatient comes along. Around 15 kids come each time
- Monday evening once a month- lego club
- Life skills course once a month ie budgeting
- Young adults evening for life skills ie CV writing, first aid
- Do day trips For the day trips they apply for grants but also get the kids involved in fundraising
- Youth forum: represent children at the hospital. For eg the renal team was developing a brochure
- Week long residential- once a year
- Preparation for work: managing their time, CV writing, building confidence, volunteering, talking through interview process, encouraging public speaking, practising the skills of working – like getting the kids to present ideas for making the hospital better, mock interviews for the kids

Website: nuhyouthservice.org.uk have their upcoming events

Issues with the transition process:

- Involving the whole team
- Tensions between paediatric and adult teams on the optimal timing of transition
- Less expertise on transition for the units where transfer is rare
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Transition in Boston

Health system setting
Population: Boston Children’s Hospital will admit children from all over the US and the rest of the world. They do 25-30 kidney transplants a year and have around 20 children on HD and 10 on PD.

Health care framework: Individual hospitals in the US have different rules on age of transition. At BCH they can keep children up to mid 30’s! Because there is a very different health system setting from the UK and Australia, there is no financial incentive to move patients to adult care, rather the longer the hospital keeps the patient, the more money they make. There is a young adult service within BCH and there is a young adult ward.

Team
- Nephrologists 8
- Nurse practitioners: 4
- Fellows: 2
- Social work: 2 support to parents, grieving the loss of a healthy child, the challenges of parenting a child with a chronic illness, community resources, funding support, liaison with school systems
- Dietician: 1
- Pharmacist: 1

Transition process
There are no formal transition clinics at BCH. They currently practice an integrated process where transition is brought up as part of routine visits but here are plans to move to a more formal transplant transition clinic. In regular clinic visits, the following interventions are used:
- getting the children to list their medications in clinic and what the medications are for (from age 12)
- Involving the children in making in the next appointment
- Directing initial questions towards the child
- Encouraging the child taking more responsibility at age-appropriate levels and modelling this for the parents to help them to help their children grow up. Starts at age 3!! How are you feeling? Age 6- why are you here, are there special foods you eat, age 9- how are your medications organised ie pill box, how many times a day do you have medication, age 12- how many medications a day
- Using tools: TRAQ questionnaire, which is a patient reported questionnaire developed at BCH initially for assessing transition in young people with cystic fibrosis.
- Assess the families coping style- what prior challenges have you had and how has the family come through it, did that coping style work for them?
- Assessing how they learn-writing things down, notebook, computer, pictures, recorded information, notes on phones.
- Every patient and their parents with end stag kidney disease meets the social worker to discuss coping, grief and loss and more concrete issues like finance/welfare, liaising with school (schools often think that the child can’t do things, when in fact they can), acknowledging the fear that the parents feel,
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supporting the parents in child in telling friends and family about the condition, understanding the cultural and religious background
• Family meetings have the social worker in the room and provide a road map for the course of transition. In the meeting, get the family to tell you when they have reached saturation and can’t take any more information in
• Having other families who are further down the track mentoring new families
• Emphasising the team are experts in nephrology but the parents and young person are experts in themselves and its going to be team work for the best results

As well as spending time with the paediatric nephrology team at BCH, I met with members of other teams and other hospitals to discuss their perspectives on transition.

Dawn Freiberger: Lung transplant specialist nurse, Boston Children’s Hospital
The lung transplant transition programme at BCH is based on the Cambridge transition programme.
Transition readiness is assessed by a tool that was developed for CF patients and has been modified for lung transplant patients, called the TRAQ tool (transition readiness assessment questionnaire). There have been some modifications specific to transplant like assessing patient knowledge of common interactions between immunosuppressive medication and common medications and food. The TRAQ is assessed yearly from the age of 12.
The also independently assess the children and their parents to compare their perceptions of the young persons transition readiness. They then launch an action plan based on the deficiencies identified in the TRAQ tool.
The adult provider comes to the paediatric hospital and they have a joint meeting with the whole multidisciplinary adult team and the young person and their family to discuss history, medication, future directions. The social worker then accompanies the young person for a tour of the adult hospital.
After the point of transfer, if the families contact the paediatric team, they refer them to the adults but then follow up with the families to make sure the issue has resolved.

Issues with transfer:
• No assigned adult lung transplant physician
• Biggest complaint from the families is the lack of personal care in the adult system

Indications with transition:
• Not before age of 21
• After college or well established in college
• No acute medical issues

Interventions to improve transition
• Meetings with transplant pharmacists at every visit!
• Identifying early with the families the tasks of transition
• Ensuring the young person has a good personality fit with their treating team
• Teen events offsite from the hospital so the kids can meet other children in the same position as them to help them normalise the lives

Maria Ferris: University of North Carolina at Chapel Hill (paediatric nephrologist)
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The transition programme at UNC Chapel Hill was started by Dr Ferris in the paediatric nephrology programme but has spread to all teams in the hospital. The programme is 10 years old. The programme was started by a 3 year grant. The initial programme was modelled on the work of Janet McDonough (rheumatologist in Birmingham). Initially, Dr Ferris and a transition champion, who is a psychologist, founded the team. Since then, the team has grown and developed two complementary tools to assess transition readiness as well as interventions to improve transition.

The team founded the International Health Care Transition Research Consortium in 2009. Tools to assess transition readiness they have developed over the time of 2 years:

- STARx: completely self reported, 18 question tool, similar to TRAQ
- TRxANSITION: based on a 7 minute interview between the patient and health care provider

Next, they initiated interventions to improve transition outcomes

- ALLYOUNEEDISLOVE
- One sheet scales

Melanie Hoenig: adult nephrologist (Beth Israel) and teacher at Harvard Medical School

There is no one adult nephrologist in Boston who accepts all the transferred patients.

Jobs for adult nephrologist

- Figuring out who has ownership of care in the family
- Always has some time in the appointment with just the young person in the room
- Finding the place for the parents in the care
- Taking time to build a relationship
- For women, say at the first visit that pregnancy (and contraception) is going to be a topic for discussion. The young adult may not be ready to discuss it fully, but at least the subject is opened
- Be very clear about where the current level of kidney function is and where the long term trajectory may be.
- Make it clear that if they move around, we will help them find another nephrologist
- Having an email path of contact is very important
- Making sure the young person knows how to contact the team, refill prescriptions
- Letting the parents and young person know that once the child is fully grown they don’t need regular ultrasounds as the kidney is fully grown
- Getting the young person to bring all of their pills in and going through them all and what they are for
- Building the relationship with the parents as well and acknowledging that this is scary from them too.

Her perspectives on ways to improve transition

- Simplifying medication regimes to improve compliance
- Encouraging ownership of health care needs ie knowing how to make an appointment, refill scripts
- Making sure the young person actually makes the appointment to see the adult staff and not doing the transfer until they have met the adult nephrologist
American Transplant Conference, Boston, USA

Monday June 13; Christina Spivey. & Seth Heldenbrand & Julie Boucqemont

Medication non-adherence in transitioning patients
Non-adherence may be intentional or non-intentional. Non-intentional non-adherence is associated with decreased problem solving skills and decreased social support. Intentional non-adherence may be due to lack of health literacy, confusion, lack of appropriate instructions, adverse drug events, impaired access to therapy (eg cost). Adolescence and the time of transition to adult health services is the most at risk period for non-adherence. The risks of non-adherence include rejection, infection, graft loss and death. Poor adherence is associated with increased medical complication, decreased health related quality of life, psychological distress, family dysfunction and economic/schooling/vocational consequences.

Assessment of adherence:
- Direct observation of medication taking
- Drug levels (may be affected by metabolism, drug-drug and drug-food interaction)
- Biological tracers (where a tracer is added to the drug and the tracer rather than the drug level is measured)
- Electronic monitoring ie chip in the bottle cap. This can be bulky and inconvenient and doesn’t work if the patient uses a pill box to increase adherence
- Pill counts
- Pharmacy refill records. These are correlated well with serum drug concentrations in renal transplant recipients.
- Self reports (may be of limited validity if they are reporting good adherence, but believable if they are reporting poor adherence)

Non-adherence risk factors:
- Non-modifiable: SES, urban vs rural
- Patient related factors: emotional behavioural functioning, coping strategies, personality traits
- Condition/treatment factors: ie complex medication regimes
- Environmental variables eg family factors, hospital level factors

Interventions to improve adherence include:
- Direct observation by the health care provider (often not feasible)
- Pre transplant and ongoing education on the medicines and reassessing their education levels intermittently
- Motivational interviewing: building rapport, understanding barriers, finding motivational points (ie wants to go to uni) and building on these to improve motivation to adhere to the routine
- Cognitive functioning skills intervention
- Changing medications that are unpleasant to take
- Addressing mood disorders
- Pill boxes
- Mobile app: eg MediSafe Meds & Pill Reminder
- A website to find quality med app is www.medappfinder.com (funded by a university, not by a company)
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- Internet-connected adherence monitoring technologies ie having the home PD machine upload dialysis data. also apps with medical social networking, that after several reminders to the person will send a text to someone else letting them know the meds have not been taken.
- Electronic pill cap reminders or pill box eg www.medminder.com which will text you if you forgot to open the box and take your pill
Conclusions and Recommendations

Receiving a Churchill Scholarship has enabled me to travel around the world, meeting leaders in the field of transition of health care from paediatric to adult services. In three different countries I met health care workers from five different hospitals, as well as attending the American Transplant Conference. All the teams worked in different health care systems, with varying levels of funding and staffing, but were similar in their enthusiasm and drive to achieve the best outcomes for their patients.

I saw a variety of different approaches to optimising transition. As with most things in medicine, there is both art and science to transition care. Based on my travels, I believe the optimal transition programme should include:

- One person who is the “transition co-ordinator” for the service, usually a nurse specialist. This person knows staff at the both the adult and paediatric sites, is the point person for patients and their families when they have questions and advocates for the patient as they make their journey.
- Joint clinics attended by both paediatric and adult nephrologists to facilitate optimal communication. This also allows the young person and their family to build a relationship with adult team (and vice versa) before the time of transfer.
- Multidisciplinary team at the clinic, with an opportunity to discuss the young person as a team. Team should include social worker, pharmacist, dietician, nursing staff and others as needed.
- Youth worker as part of the team, whose goals are to support the young person in their path to independence.
- Starting the conversation about transition from the age of 12.
- Assessment of the young person’s transition readiness and targeted interventions to the areas of weakness that are identified. This can be done by transition readiness assessment tools like TRAQ, TrxANSITION, or STARx.
- Support for the parents as they prepare to step back.
- The time of transfer should involve a meeting between the paediatric and adult nephrologist, transition co-ordinator, allied health, patient and parents to outline the current issues (medical and psychosocial), past major issues, medications, allergies, future planning (medical, surgical, vocational/educational, social) so that no vital information is lost. Before leaving this meeting, the young adult should know when and where their next appointment with the adult team is. There also needs to be a written transfer letter, a copy of which should go to the adult team, GP and young person.
- Before the young person fully transfers to adult services, they should have a tour of the outpatients / haemodialysis centre/ inpatient ward / imaging/ pharmacy/ phlebotomy/ social work/ admissions of the adult hospital.
- After the first visit with adult services, there should be a follow up phone call or outpatient appointment to check everything went smoothly. However, once they have transferred, any queries should be redirected to adult services, as they are now in charge.

Recommendations and plans for the future.
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1. To start a multi-disciplinary, combined adult and paediatric transition programme for young people with end stage kidney disease in Queensland that is based on the conclusions of this scholarship as well as other research and expertise.
2. Expand this programme to other disciplines in Queensland and throughout Australia
3. Participate in research on predictors of outcomes in transition and on interventions to improve transition
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References