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# Paedriatric Renal Service

## Transition Procedure Document

## Aim

This Transition procedure document details the successful and seamless transition and transfer process of young people from the Starship Paediatric Renal Service to Adult Renal services throughout New Zealand. This includes information relating to the timing of transition, the roles of clinical teams and the steps required in transition planning. A range of tools and resources are also provided.

### Reference Documents

| Type | Document Title(s) |
|---|---|
| Position Paper | The Royal Australasian College of Physicians (2006) Transition to Adult Health Services for Adolescents with Chronic Conditions. Online, available: http://www.racp.edu.au/index.cfm?objectid=B567F6BD-D4A2-C8EA-4D7BA9C2AABF5D03<br>The Royal Australasian College of Physicians (2014). Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services. https://www.racp.edu.au/docs/default-source/advocacy-library/transition-of-young-people-with-complex-and-chronic-disability-needs.pdf |
| Position Paper | The Paediatric Society of New Zealand (2003), Position Statement: Meeting the Care and Support Needs of Young People with Complex and Chronic Health and Disability Needs as they Approach Adulthood. http://www.paediatrics.org.nz/files/positionstatements/highhealthneeds.pdf |
| Standards | Northern Regional Alliance. (2017) Standards for Quality Care for Adolescents and Young Adults in Secondary and Tertiary Care. https://www.healthpoint.co.nz/download,693185.do |

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| Article | McDonagh, J. E., & Viner, R. M. (2006). Lost in transition? Between paediatric and adult services. *BMJ, 332*(7539), 435-436. |
| Article | Watson, AR, Harden P.N, et al. Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)<br>Kidney International (2011) 80, 704-707 |
| Article | Maria Ferris and John Mahan. Pediatric Chronic Kidney Disease and the Process of Health Care Transition.<br>Seminars in Nephrology (2009) 29:435-444 |
| Article | Marcus Weitz, Saskia Heeringa et al. Standardized multilevel transition program: Does it affect renal transplant outcome?<br>Pediatric Transplantation (2015) Vol 19, issue 7: 691-697. |

## Introduction

Children with chronic kidney conditions require ongoing healthcare into adulthood. Successful transition from paediatric to adult care is seen as an important goal and essential part of quality care for young people with chronic kidney disease.

The concept of transition implies a "planned, purposeful movement of the adolescent or young adult with a chronic disease from a child (and family) centred to an adult orientated health care system"(Janet E. McDonagh & Viner, 2006).

The transition from a paediatric to an adult orientated service is not a sudden unanticipated transfer but an organised process of preparation and adaptation.  The goal of which should be to "maximise lifelong functioning and potential through the provision of high quality developmentally appropriate health services, that continue uninterrupted as the individual moves from adolescence to adulthood" (American Academy of Pediatrics)

It is important to emphasize that transfer is not synonymous with transition: it is simply one of many events during the much longer process of transition (Shaw, K. L., Southwood, T. R., & McDonagh, J. E., 2004).

## Definitions

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| **Transition** | Transition is "the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult oriented health care systems." *(Society for Adolescent Medicine, 1993)* |
| **Transfer** | Transfer is the handover of care to adult services. |

# Transitioning a Paediatric Renal Patient

## Age of transition

Transition planning is flexible in timing but will commence early in adolescence to allow the young person where possible, time to increase their capacity for self-care.  Consideration will be given to education around their condition, promotion of self-management skills as well as assessment of their psychosocial needs.

Preparation for transition planning will commence from age 12-14 years with education towards self-management followed by active transition planning from age 15-16 years. Individual transition plans will identify areas where self-management is an achievable goal. Not all adolescents with kidney disease will be able to achieve independent care in all areas. The transfer of care to an adult renal service will generally occur between the ages of 16-18years. Occasionally transfer will occur for 15year olds, when local adult services can provide appropriate care closer to home. Completion of transitioning from a paediatric to adult renal service continues in the adult renal healthcare setting.

## Admissions Policy

In general, new patients will be accepted up until their 15th birthday. Patients previously treated at Starship may continue to be treated up to and including their 18th birthday for conditions for which they have previously been treated or related to their existing condition.

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# Core Principals for Transition Planning in Paediatric Renal

It is well recognised that there are challenges and barriers to successful transition of young people within renal services in New Zealand due to the differences between regions and District Health Boards. However the Paediatric Renal team aims to be guided by the following core principals in order to ensure that the young person will have the skills to manage their care and will be followed up in the adult system:

- **Early preparation** and planning is essential.
- Young people will be given the opportunity to be seen within a **developmentally-appropriate healthcare model** that values **confidentiality and privacy.**
- **Transition co-ordinators/key contact people** will be identified for all young people. For all end stage kidney disease youth it will be the renal clinical nurse specialists.
- Effective **communication** is key. Transition will be a multidisciplinary process with a co-operative working relationship between paediatric and adult services.
- Each young person will be involved in developing their own **Individualised Transition Plan** that focuses on all aspects of their life.
- Young people will be empowered, encouraged and enabled to achieve **self-management** wherever possible.
- Young people will need detailed information about the adult centre they are going to and wherever possible will have the opportunity to meet with the adult team and see the new environment.
- A clear and concise patient summary/referral letter will be written to ensure an **effective handover.**
- Where possible, transfer will occur at a time of disease stability.
- **Follow up** will be required to ensure that young people have engaged effectively with adult health care services.
- **Evaluation** of the transition process will be undertaken to inform future planning and policy.

# The Phases of Transition Planning

Transition takes place over a period of years.  It is a fluid process and therefore these phases are intended only as a **guide for practice**. The individuality of patients and clinical settings will mean that variation is inevitable.

There are generally 4 phases of transition; the planning phase, early, middle and transfer phase.

## Planning Phase  (12 years onwards)

This initial stage is from age 12 years. It is during this stage that the young person and their family are *introduced* to the transition process and the young person is encouraged to participate in his/her own care in the presence of his/her whānau.

- The concept of developmentally-appropriate care, confidentiality and privacy is introduced to prepare the young person and their family.
- Give the patient and the family a rough idea of likely timings but emphasise that this is flexible.
- Discuss the concept of an individual transition plan and explain that this will be developed within the next couple of years.
- Provide the young person and whānau with the "Transition information for young people in the paediatric renal service" and confidentiality pamphlets.

## Early Transition Phase (12—14 years)

In this phase the young person and their family gain an understanding of the transition process and the youth practices skills, gathers information and sets goals to participate in his/her own care.

- The young person and their parent/caregivers formally begin the transition process in routine clinics. This should include:
    - Evaluating self-management knowledge and skills
    - Introducing the youth health model including confidentiality and privacy
    - Introducing the HEEeADSSS assessment tool
    - Begin seeing the young person for part of the clinic on their own
- Introduce the concept of preparing to leave the paediatric setting by age of 16+ years
- Transition co-coordinator/key contact person allocated

## Middle Phase (14-15 years)

- Developing an Individual Transition Plan identifying areas where self-management can be achieved.
- The young person with whānau continues to be supported in developing self-management skills and gathers information about their condition, medications and how this impacts on their day to day life.
- Developmentally-appropriate education about condition, medication and specific adolescent health and risk issues occurs.
- Developmentally-appropriate care is provided that values confidentiality and privacy.
- Opportunities are provided for parents/caregivers to be supported to assist their young person in developing self-management skills.
- Encourage Kidney Kids camp participation to promote social skills, networks and self-esteem among peers with kidney disease. Camp KeeWee ages 8-15 then YAK (Young Adults Kidney camp) ages 16-21.

## Transfer Phase (15+ years)

The young person and whānau feel prepared to move towards adulthood and the adult setting.

Getting ready:

- Young person self-management knowledge review and final education provided
- Transfer checklist completed by healthcare team
- Patient and family fully informed about adult service including introduction to adult team members and new environment
- Date of transfer negotiated and documented on updated transition plan
- Transition Coordinator/key contact liaises with adult services and where possible arranges a meeting
- Referral/Transfer letter sent to adult service

Time of Discharge/Transfer

- Coordinator/key contact communicates directly with adult service and all allied health services involved to ensure all necessary information about patient is received and comprehensive referrals are made.
- Emergency plan discussed with YP (for acute support during transfer period)
- Consent to share information collected and documented
- The paediatric team will ensure that the young person's final visit at Starship is a marked occasion and recognition is given to the young person by the team
- ADHB transition to adult services note in the clinical portal completed

## Follow up after referral to adult services

Paediatric service closure occurs when the young person is actively engaged with adult services. Transition coordinator ensures a first adult clinic is attended.

## Integration into Adult Services Phase (15+ years)

The young person and whānau feel supported in their integration to the adult setting.

Getting to know a young person:

- Young person self-management knowledge review
- Transition and healthcare goals discussed
- Young person and family fully informed about adult service including introduction to adult team members and new environment
- Young person has contact details for key contact person with adult services

## Evaluation of the Transition Process

It is essential that the transition process is evaluated and success of transition planning is measured in both paediatric and adult settings. This can include:

- Monitoring the volume of completed individual transition plans, patients transferred to adult services and volume safely captured into adult renal services, annually.
- Feedback encouraged from youth and whānau throughout the transition journey and data analysed to drive service improvement.