

CKD: The Importance of Psychosocial Care and Transition



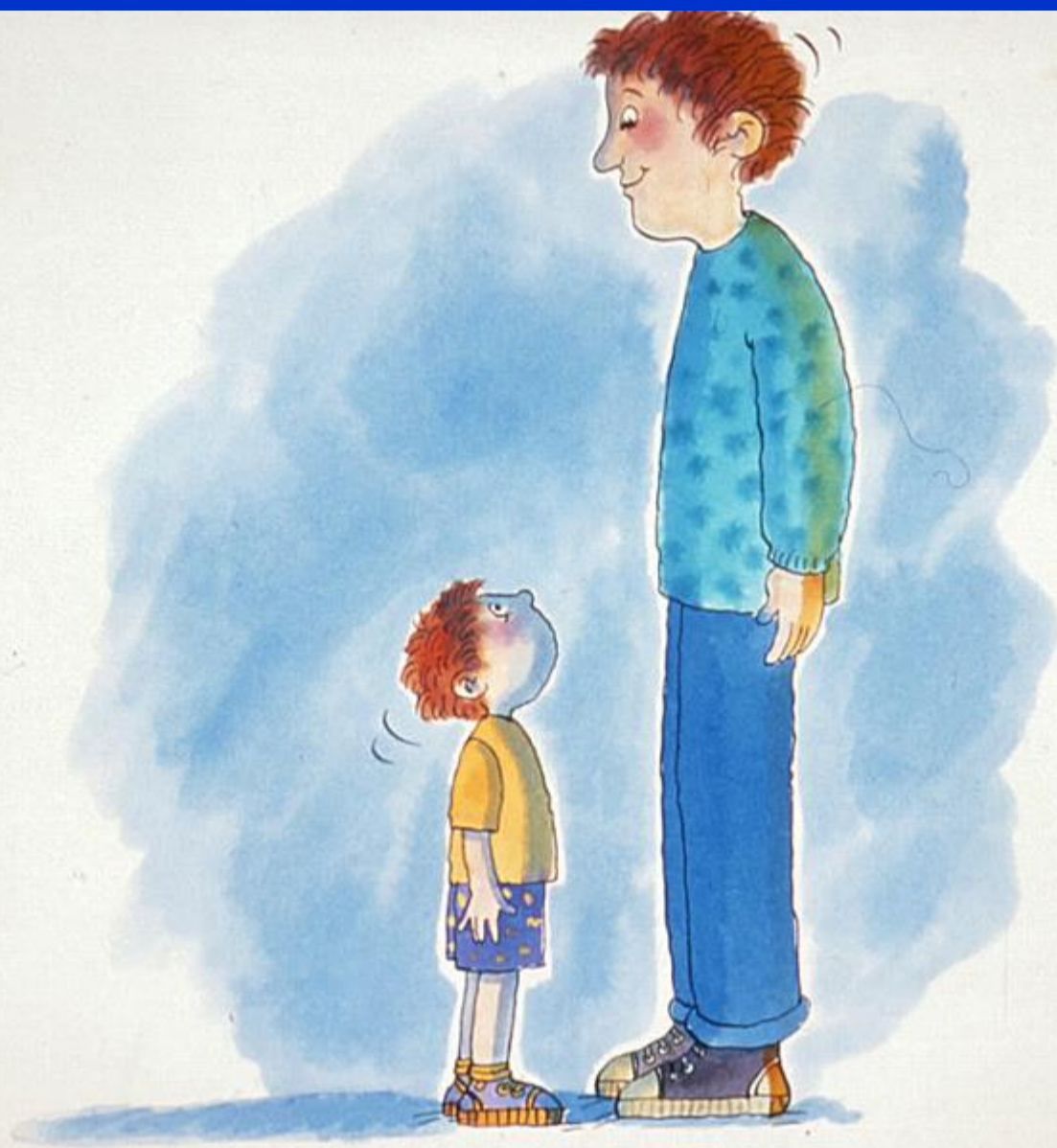
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Lodz, May 2015









GROWTH & DEVELOPMENT

- PSYCHOLOGICAL
 - SOCIAL
 - EDUCATIONAL



Chronic Kidney Disease



Pre-emptive



TRANSPLANTATION



Dialysis



Successful Dialysis

Requires

- Team and family discussion
- Preparation (including home visit)
- Good access
- Dedicated nurse trainers
- Home support

Co-Morbidity Factors in Choice of ESRF Therapy

- Physical Problems **13 (7%)**
 - Myelomeningocele (3)
 - Neonatal problems (2)
 - Ascites/Wilms (2)
 - Cardiac insufficiency
 - Glycogenosis
- Mental Retardation **11 (6%)**
 - Bardet-Biedl (4)
 - Downs (1)
 - Not specified (6)
- Mental Illness Parent **3 (2%)**

Principles of Peritoneal Dialysis

- Getting right the PRESCRIPTION
 - Surgical and Medical aspects
 - Nutrition
 - Psychosocial
- Individualised therapy in a family context

Psychosocial Support for Children and Families Requiring Renal Replacement Therapy

Watson. Pediatr Nephrol 2014;1169-1174

- Lack of adequate TIME
- Lack of COORDINATION of social, educational and respite care
- Lack of STANDARDS especially with comorbidities increasing

Burden of Care Takes its Toll!

- Depression commoner in caretakers of children on CPD
- Mothers of children with CKD lower HRQoL and higher psychosocial strains
- 30% of CKD patients 9-18 yrs of age met criteria for depression

Factors Influencing Choice of Renal Replacement Therapy in European Paediatric Nephrology Units

Watson et al. Pediatr Nephrol 2013; 2361-2368

- 14 units surveyed
 - Dietetic support in 6
 - Social worker in 11
 - Psychologist in 12
 - Play Therapy in 7
 - Teaching support in 10

Quality of Life (GCQ)

- Discrepancy measure of psychosocial QoL (GCQ)
- How children perceive their life versus how they would like it to be
- PEDS QL 3.0 ESRD module
 - 7 scales (eg general fatigue, treatment problems, physical appearance)

Nottingham Study

- Mean GCQ 76.3; SD 11.7 – NOT significantly different from norm (74.5; SD 9.9)
- No correlation of GCQ, PedsQL or CATIS with age or time since diagnosis
- No impact of gender on GCQ or PedsQL
- MALES showed less positive attitudes on CATIS
- PRE-EMPTIVE transplant patients had significantly higher scores on GCQ and PedsQL but not CATIS
- GCQ and PedsQL scores highly correlated

Quality of Life Issues

- QoL or health status?
- INFORMATION & INDIVIDUALISED APPROACH but note CHILD-PARENT discrepancy
- Use the QoL measure to track progress and adjustment of support necessary to achieve scholastic, psychological and social goals

Why Focus on This Age Group

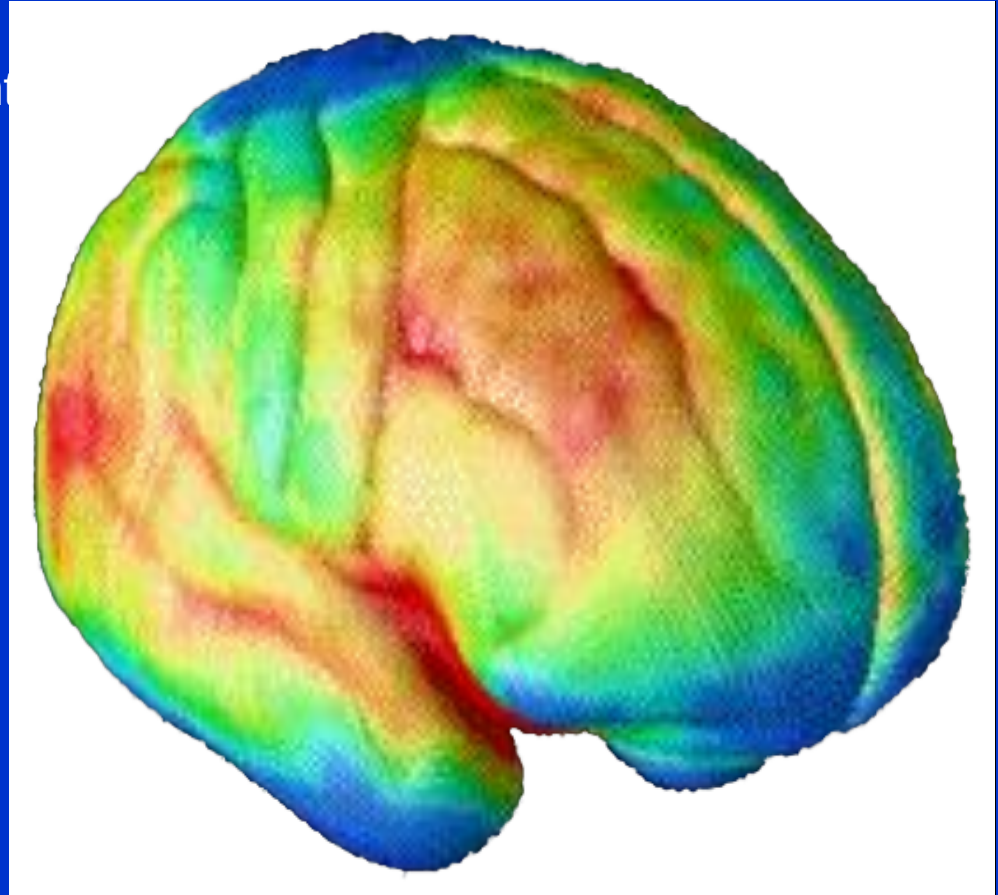


Brain Development

Maturation Occurs from Back to Front of the Brain

Images of Brain Development in Healthy Youth (Ages 5 – 20)

Blue represents maturing of brain areas

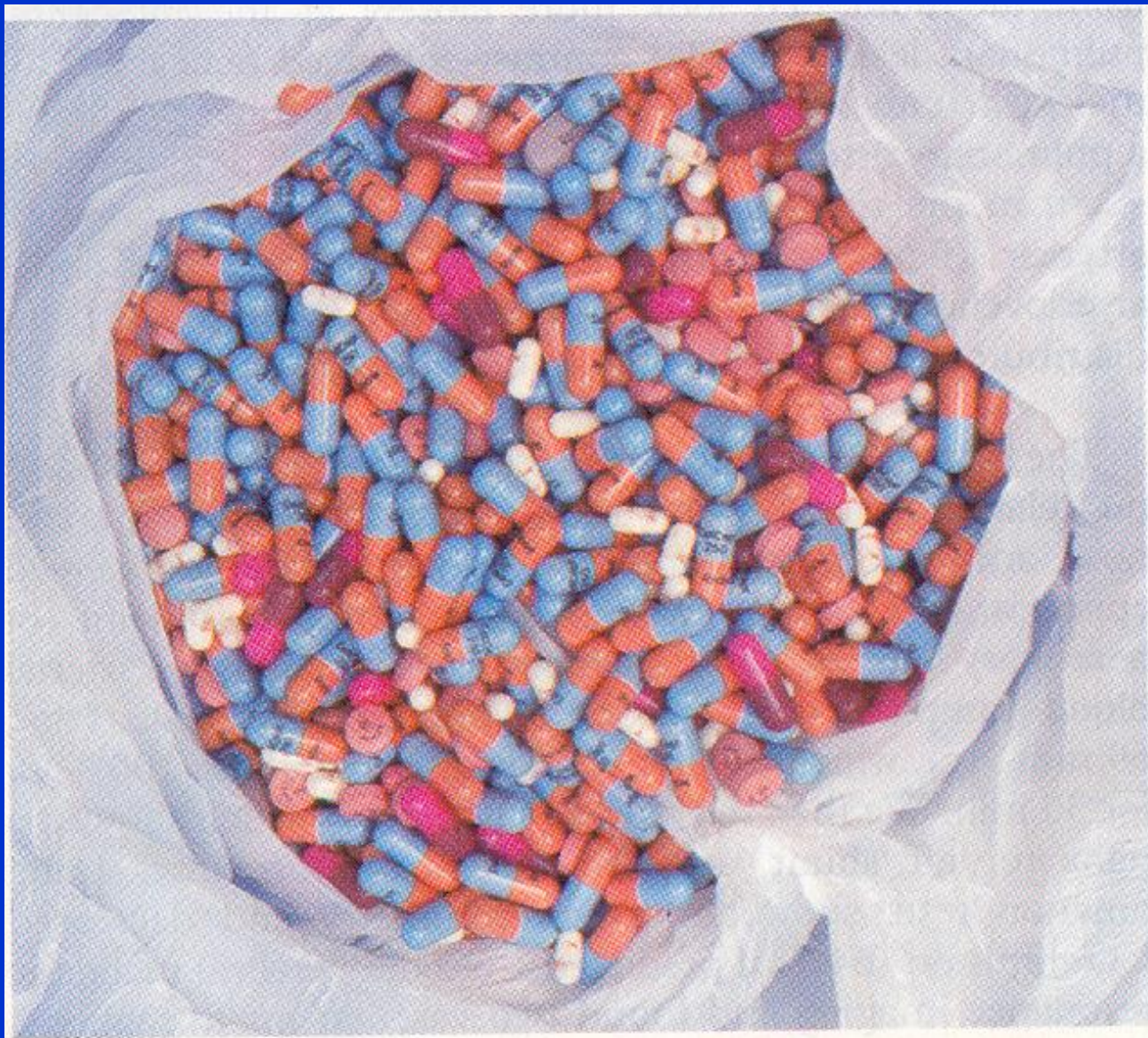


Source: Gogtay, Giedd, et al., 2004.

Copyright © 2004 The National Academy of Sciences, USA
Gogtay, N., Giedd, J.N., et al. (2004)
Dynamic mapping of human cortical development during childhood through early adulthood
Proceedings of the National Academy of Sciences, 101 (21), 8174 – 8179

Normal Adolescent Behaviour

- Experimentation
- Inconsistent behaviour
- Sense of invincibility
- Body image and peer acceptance of crucial importance



Non-Compliance and Transfer from Paediatric to Adult Transplant Unit

Pediatric Nephrology 2000;14:469-472

- 20 adults (9 female) transferred to 3 different adult centres at mean age of 17.9 yrs (15.7 – 20.9 yrs)
- Transplanted at mean age of 14.3 yrs (9.6 – 18 yrs)
- **7/20 (35%) transplants failed within 36 months of transfer**

Transition

Defined as a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems

Blum et al 1993

Transition for Chronic Illness

- ? When growth and schooling tasks completed
- ? 18 years or when funding stops
- Not at a time of crisis!
- Self-management skills and social support

Different Arrangements and Philosophies

Paediatric	Adult
Consultation with patient and family/carer	Individual consultation
Psychosocial support from team members	Limited psychosocial support
Fewer patients and more consultant based care	Larger patient numbers and specialist nurse/junior doctor review
Specialist knowledge about rare conditions, eg cystinosis	Lack of experience with rare paediatric conditions
No waiting list for dialysis	Pressure on dialysis space
Young people waiting areas and peer support	No young adult clinic
Medications usually free	Pay for medications



PAEDIATRIC



TRANSITION CLINIC



TRANSFER CLINIC



ADULT UNIT

How to Transition

Information

Paediatric Unit



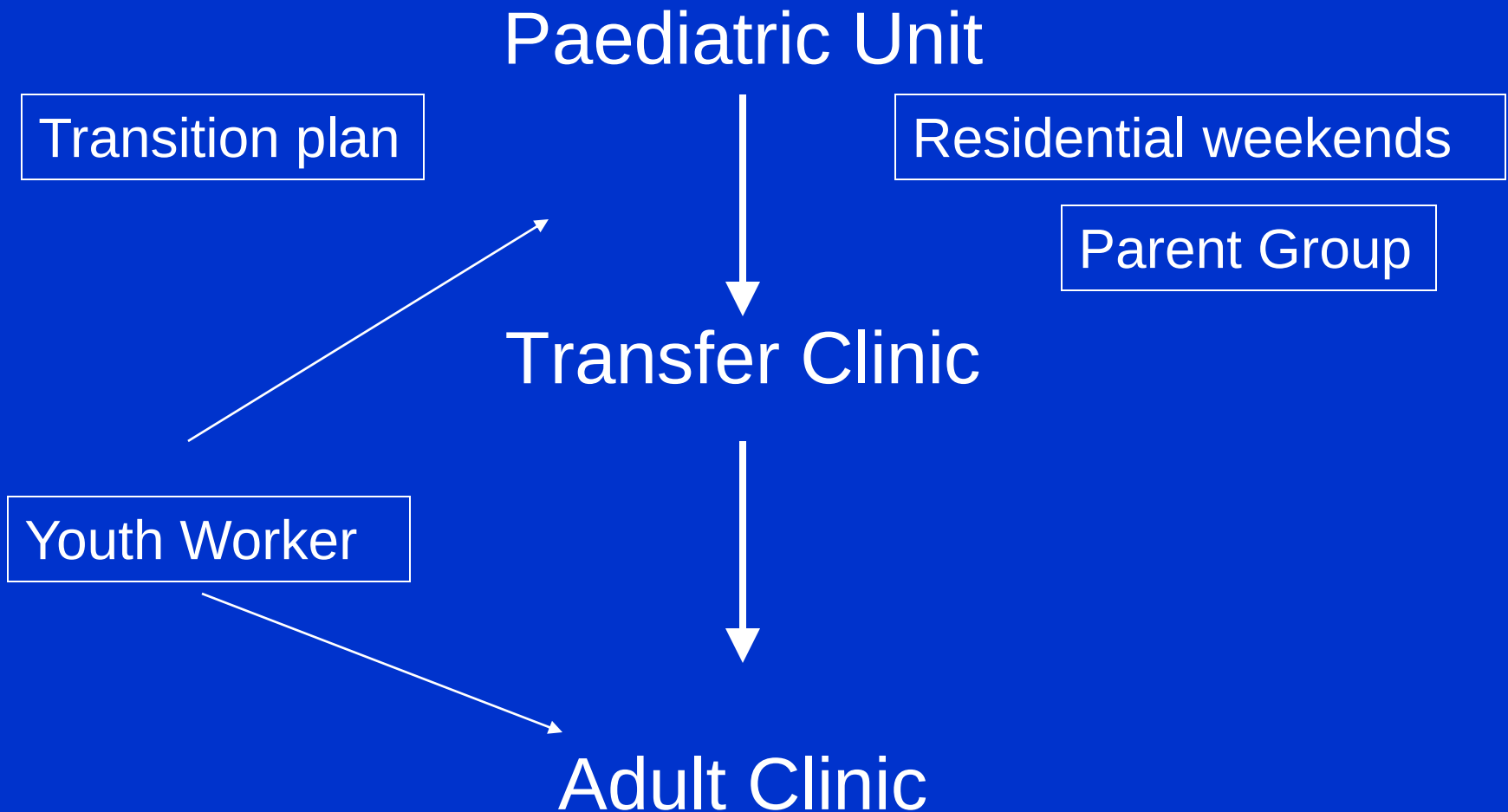
Transfer Clinic



Adult Clinic



Transition Process



Transition Plan

- Self management skills
- Long term social support

Competencies expected of a young adult transferring to adult renal unit

- I understand my condition and can describe it to others
- I know my medications and what they are for
- I can make decisions for myself about my treatment
- I know what the adult clinic arrangements are and who will be reviewing me in clinic
- I know how to make my appointments
- I can make my own transport arrangements to get to the hospital for appointments
- I know who to call in a medical emergency
- I am able to talk about my worries concerning blood tests and other treatments
- I know the dietary advice that I have to follow and the importance of activity
- I have sufficient knowledge about sexual health matters
- I have discussed alcohol, smoking and drug issues

The Nottingham Youth Work Project

- Help and support young people to build self-esteem through a diverse range of personal and social developmental opportunities
- To enable young people to have their voices heard in front of decision-making at different levels
- To offer support in transition from paediatric to adult services



Transition from Pediatric to Adult Renal Services

A consensus statement by the
International Society of Nephrology (ISN)
and the
International Pediatric Nephrology
Association (IPNA)

Kidney Int (2011;doi 10.1038/ki2011 209)
Pediatr Nephrol (2011;26:1753-1757)

Transfer from Pediatric to Adult Nephrology should:

- a) Be individualised for each patient after he/she has completed a transition plan. It will depend upon completion of physical growth and, where possible, educational, social and psychological attainment
- b) Be agreed jointly by the patient and his/her family/carers in conjunction with the pediatric and adult renal care teams
- c) Take place during a period without crises, especially if there is unstable social support.

- d) Take place after completing standard school education
- e) Take into account treatment plans by other sub-specialties with particular reference to urological supervision
- f) Take place with due consideration of financial factors and not be done abruptly without adequate preparation as a result of financial pressures.

Utility & Cost of a Renal Transplant Transition Clinic

Prestidge et al 2011

- 12 transition clinics (TC) vs 33 pre-TC
(0 loss) (24%)
- Average yearly per patient cost
C\$11-34,000 C\$17-39,000
- Return to dialysis
C\$41-61,000

Adherence to Transition Guidelines in European Paediatric Nephrology Units

EPDWG. Pediatr Nephrol 2014

- Survey of 15 units 2 years after consensus statement in 2011
 - 66% aware of guidelines
 - 33% integrated them into clinical practice
 - 47% transfer ≤ 5 patients with CKD5 to median of 5 adult units
 - 80% commenced transition planning >15 yrs of age

Barriers to Effective Transition

- Patient and parent attachment to the paediatric unit
- Difficulty in allowing the young person to perform self-care
- 73% of units mandated to transfer by certain age

They Need Our Help!



“It is not enough for physicians to do what is necessary, but the patient and the attendants must do their part as well, and the circumstances must be favourable”

Hippocrates fifth century BC