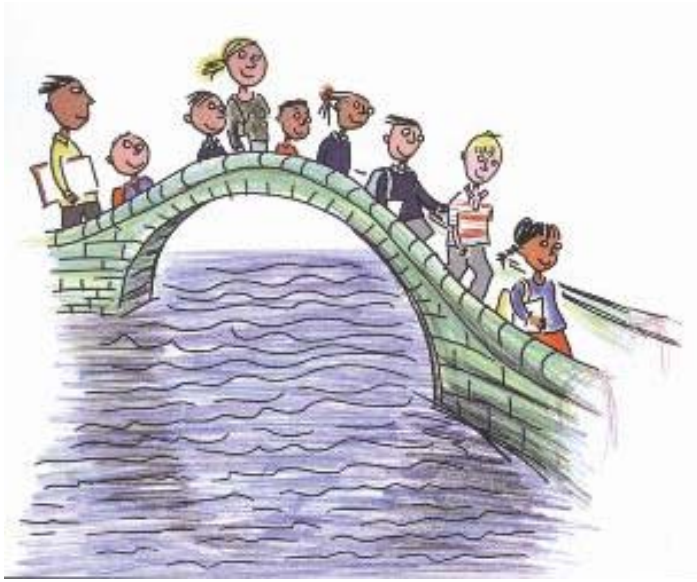
Lost in Transition:
Adolescence 2 Adulthood



Mina Matsuda-Abedini, MDCM, FRCPC

Clinical Assistant Professor

Pediatric Nephrology

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“ As a disabled child I was an infant. As an adolescent I was a child. In my adult years, I would finally pass through adolescence. Prolonged infancy encouraged dependency. This made the acceptance of personal responsibility difficult. As an adult aged patient I felt cast into a foreign sea. My boat had oars, but I did not know how to use them. ”

Margaret Stineman, MD

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Objectives

- To identify the challenges faced by youth living with chronic kidney disease
- To describe the concepts of the developmentally-appropriate care and transition planning
- Identify opportunities for better transition care and barriers that need to be overcome for improved transition care
- To describe the tools used in the clinical setting to support youth and their families through the process of transition from pediatric to adult health care settings

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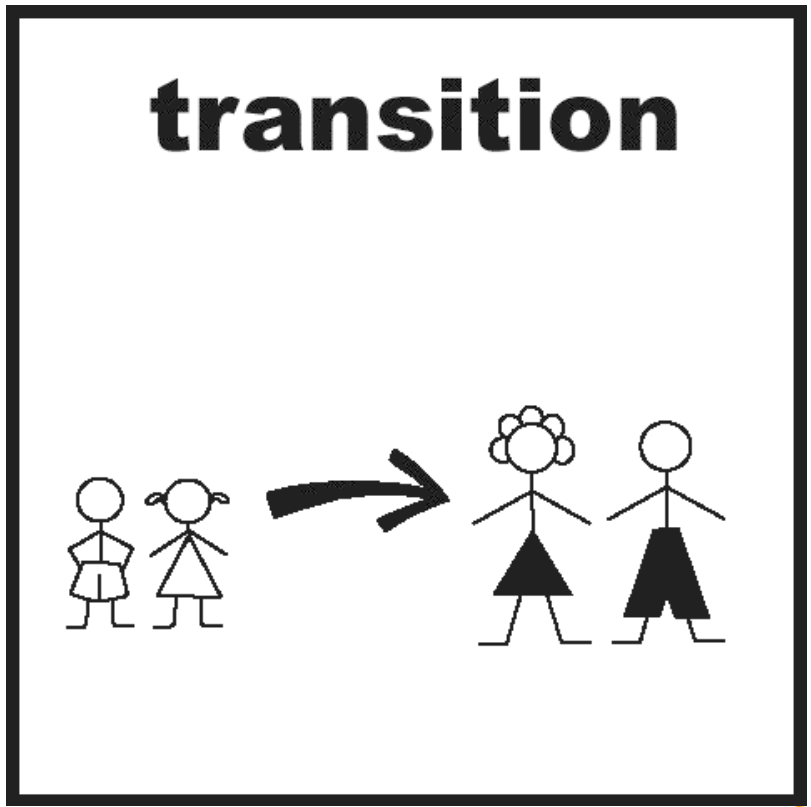
Transfer vs. Transition

- **Transfer** is an event in the **transition** process the timing of which depends on many factors other than chronological age, e.g. maturity, disease activity, independence, availability of adult specialty service.



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Transition

- “Transition is a process which occurs throughout pediatric care that educates and empowers youth and their families to become active participants in their own care. It is not just the transfer of care to the adult system.”

Rosen D. J Adolesc Health 1995;17:10-16

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Transition Goals

- Maximize lifelong functioning and potential
- Developmentally appropriate
- Ensure uninterrupted health care services as the individual moves from adolescence to adulthood

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Adolescence

- Concern over body image
  - May affect compliance with medications (e.g. Prednisone, CyA)

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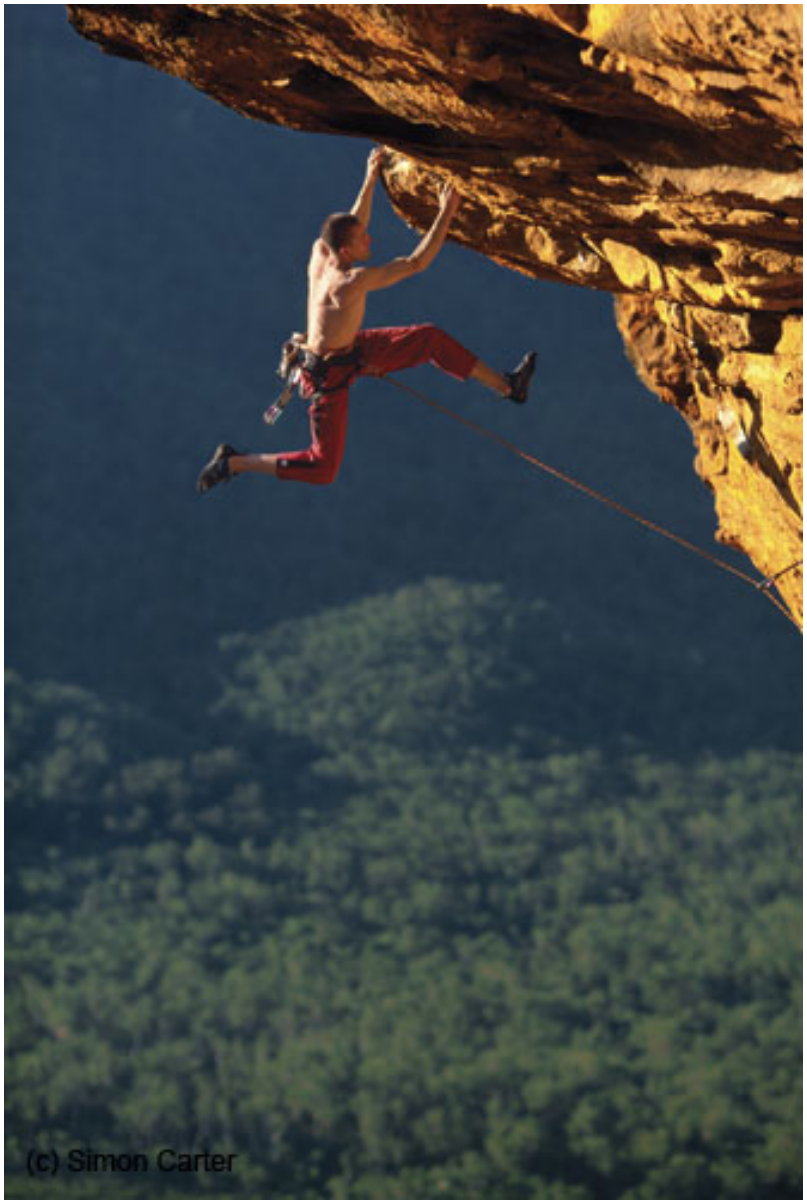

Adolescence

- Risk taking
  - Less long-term, future oriented thinking
- Sense of invincibility

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Adolescence

- Peer pressure
  - Don’t want to look or feel different from peers
- Health is often not a main priority

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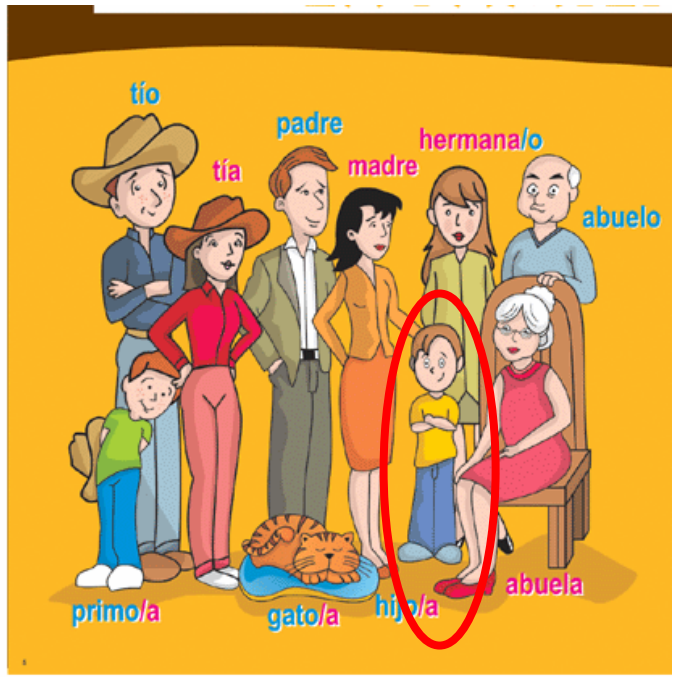
Challenges in Pediatrics

- Congenital malformations and inherited disorders
- Attached to patient/families since childhood
- Need lifelong interdisciplinary care
  - Nephrology, urology, neurology, GI and others familiar with “pediatric” conditions
- Complex social situations
- Summarizing years of care



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Challenges in Adult Medicine

- Limited resources for multiple needs patients
- Psychosocial development delay
- Patient's reliance on parents and pediatric interdisciplinary team vs. autonomy

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Graft survival rates

- What age group has the highest risk of graft loss at 5 years post-transplant?
  - ❑ <1 year olds
  - ❑ 1 -10 year olds
  - ❑ 11-17 year olds
  - ❑ 18-34 year olds
  - ❑ 35-49 year olds
  - ❑ 50-64 year olds

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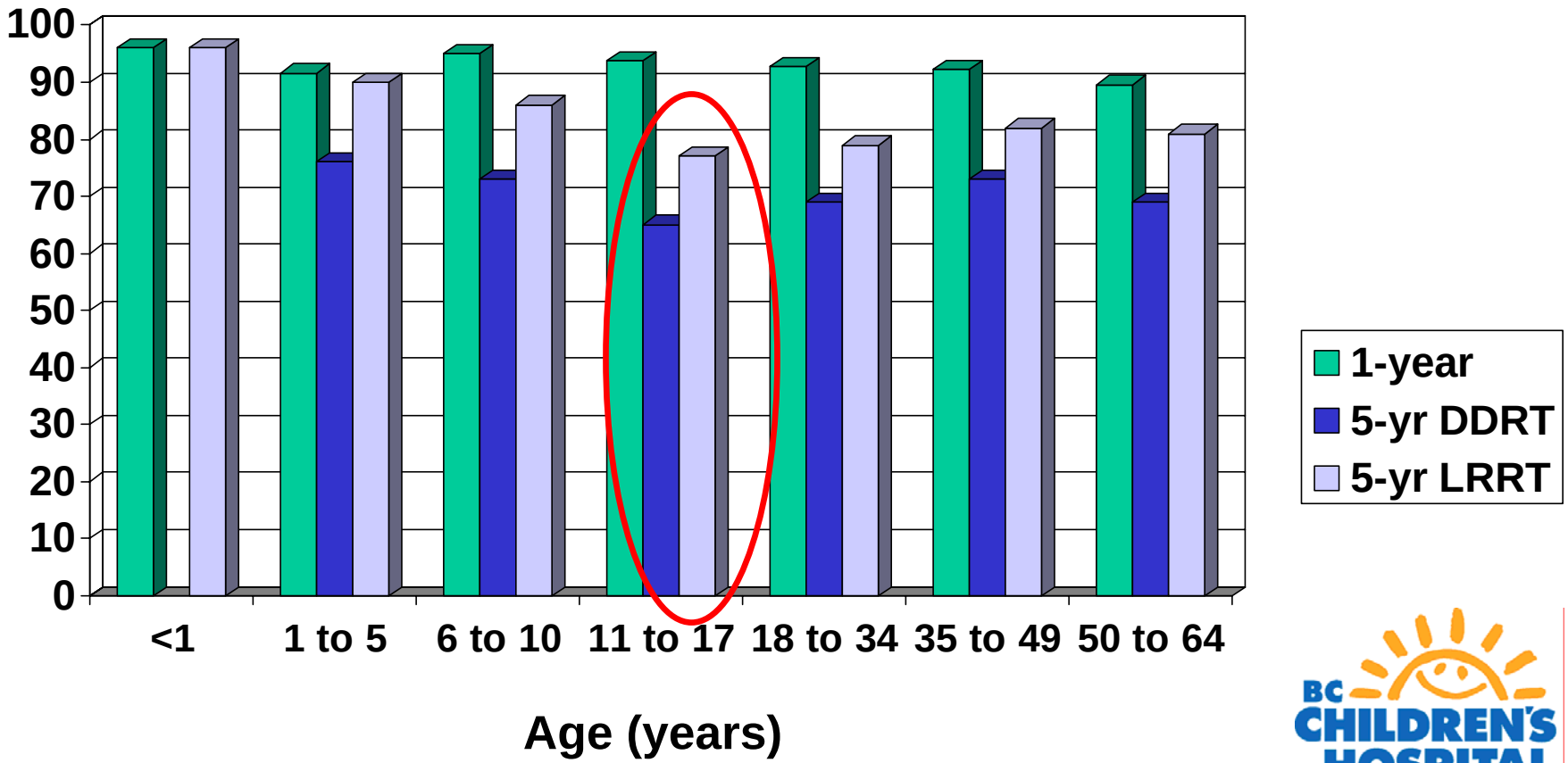
Graft survival rates: 1995 - 2004



OPTN Annual Report

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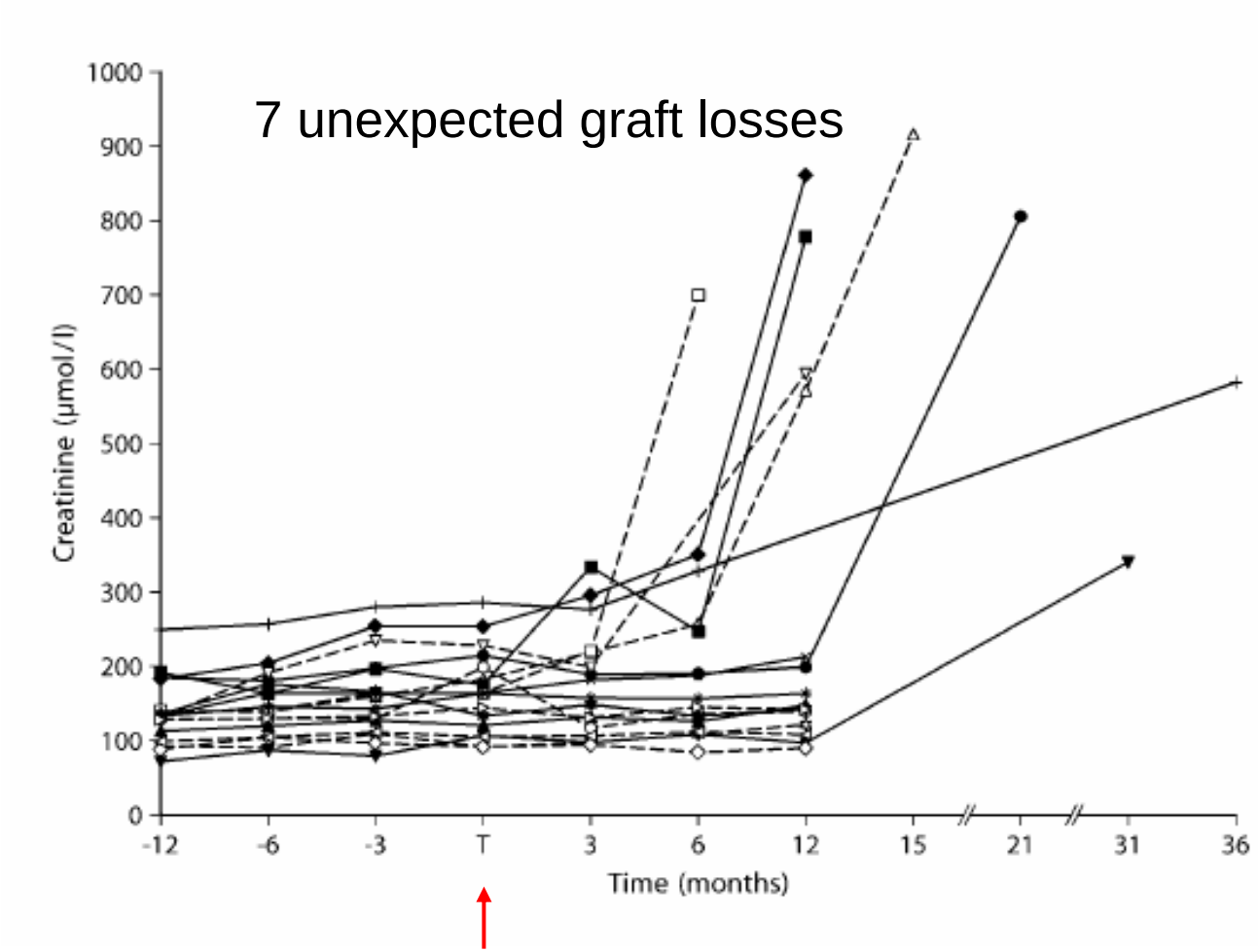
Creatinine before and after transfer in 20 patients



Watson AR Pediatr Nephrol 2000

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Outcomes of Patients Transferred from BCCH to Various Adults Centres in BC

BC Renal Agency
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Study Cohort

- Transferred period:
  - January 1 2000 and December 31 2006
- Outcomes of interest:
  - Survival Time
  - CKD patients: Time to Dialysis or Transplantation
  - Dialysis patients: Time to Transplantation
  - Transplant patients: Time to Graft Loss (defined as requiring dialysis or re-transplantation)
- Outcomes follow-up period:
  - Date of Transferred to August 31 2007

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Baseline Data

	Overall	CKD	Dialysis	Tx
N	66	23	8	35
Age *(in years)*	19.3±1.3	19.1±1.0	19.5±1.2	19.4±1.5
Male	39 (59%)	14 (61%)	4 (50%)	21 (60%)
Transferred to				
IHA	8 (12%)	6 (26%)	0	2 (6%)
FHA	9 (14%)	5 (22%)	2 (25%)	2 (6%)
VCHA/PHSA	33 (50%)	10 (43%)	5 (63%)	18 (51%)
VIHA	4 (6%)	2 (9%)	0	2 (6%)
NHA	3 (5%)	0	1 (12%)	2 (6%)
Unknown	9 (13%)	0	0	9 (25%)

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Outcomes Data

	Overall	CKD	Dialysis	Tx
N	66	23	8	35
Median Years of Follow-up [1st - 3rd quartile]	3 [2-5]	3 [2-4]	3 [2-4]	3 [2-5]
Observed Outcomes:				
Deaths	4 (6%)	1 (4%)	0	**3 (9%)**
Starting Dialysis*	16 (28%)	10† (43%)		**6 (17%)**
Transplantation	9 (14%)	6† (67%)	3 (38%)	0

* Applicable to only CKD and Transplant patients:

- N for Overall Column = 23 (CKD) + 35 (TX) = 58
- % Starting Dialysis for Overall Column = 16/58 x 100% = 28%

† There were 4 patients who started dialysis and then followed by transplantation

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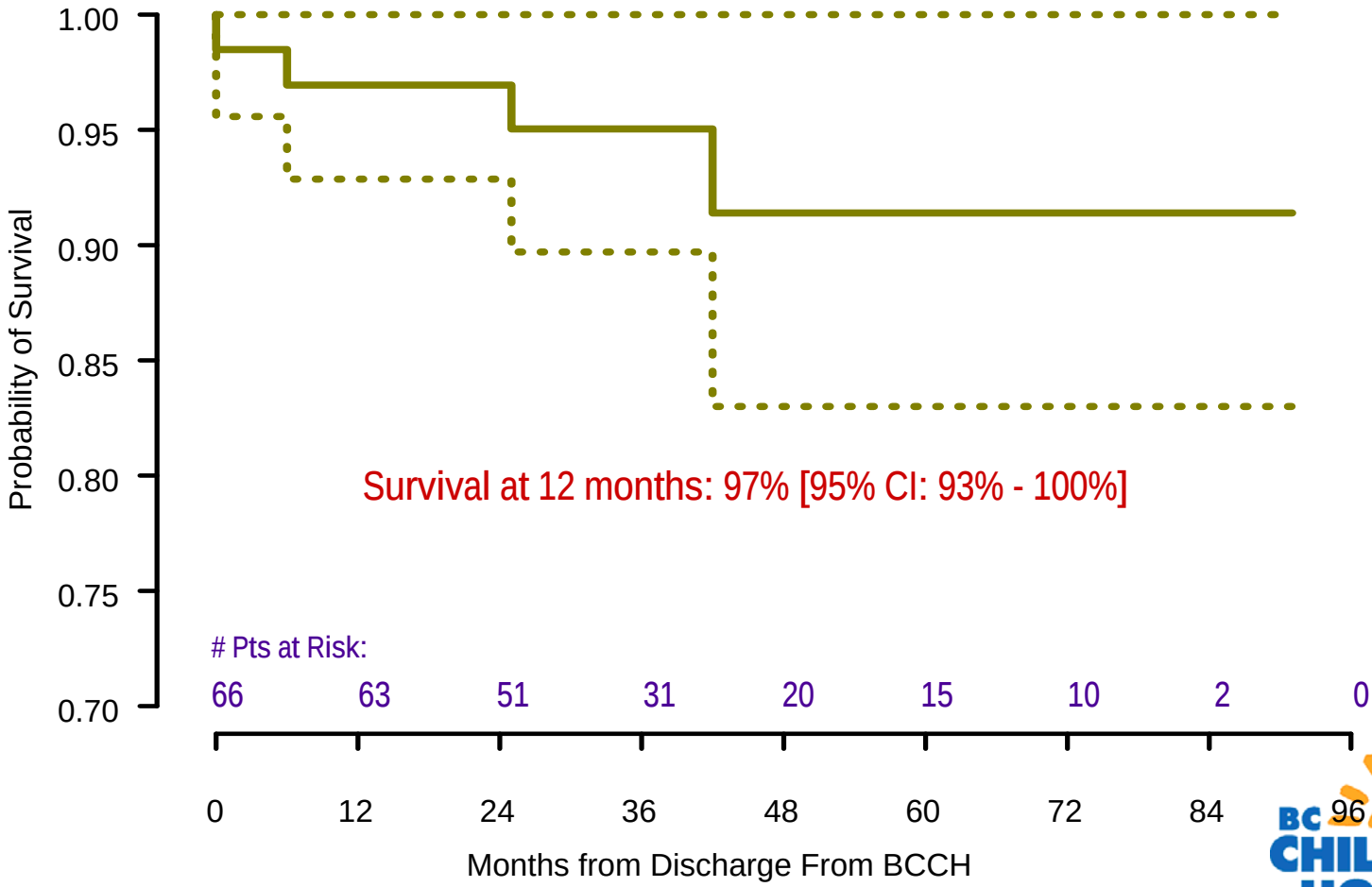
Kaplan-Meier Estimated Survival
(Overall Cohort)



Note: Results above remain similar when censoring at transplantation

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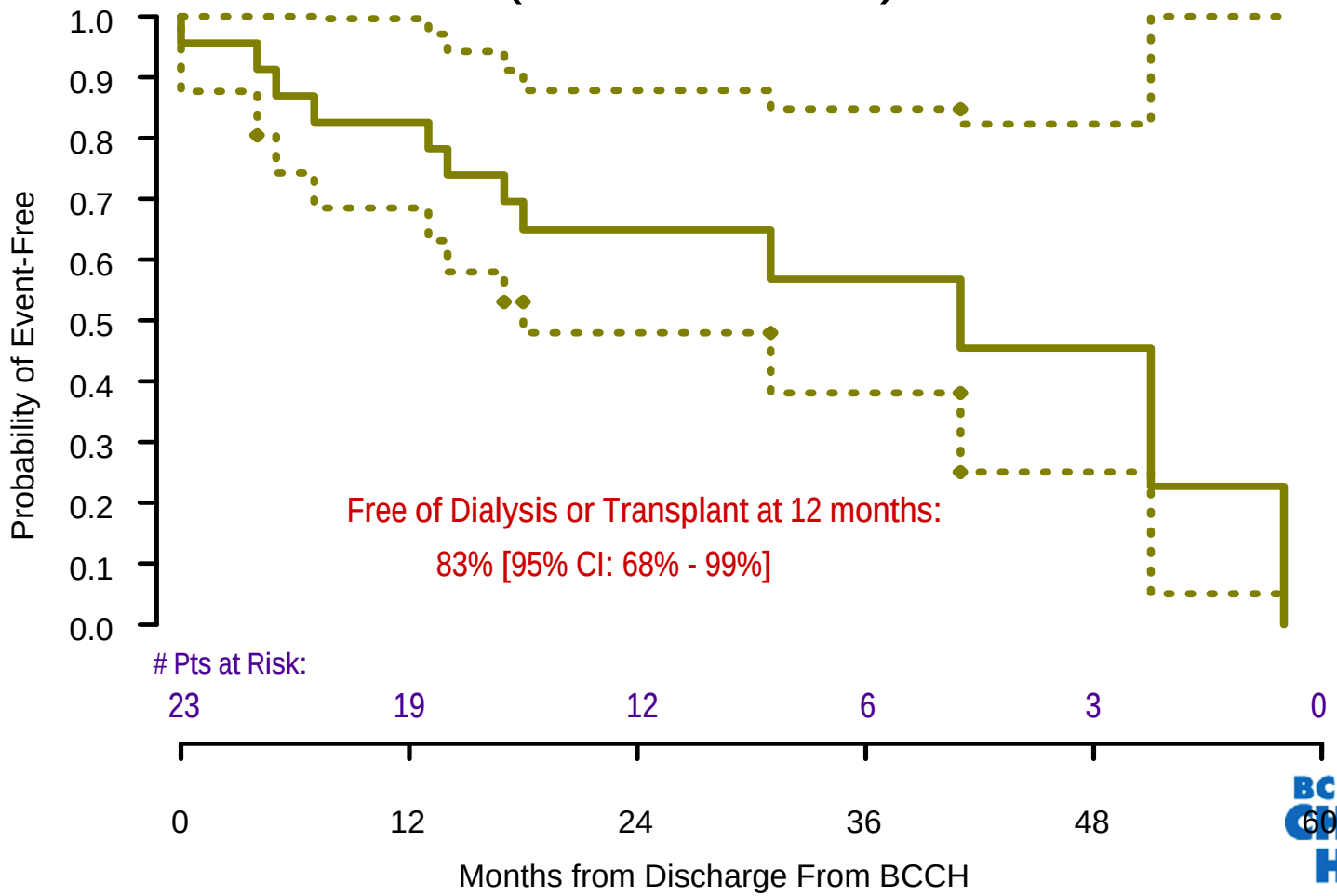
Kaplan-Meier Estimated Time to Dialysis or Transplantation

(CKD Patients)



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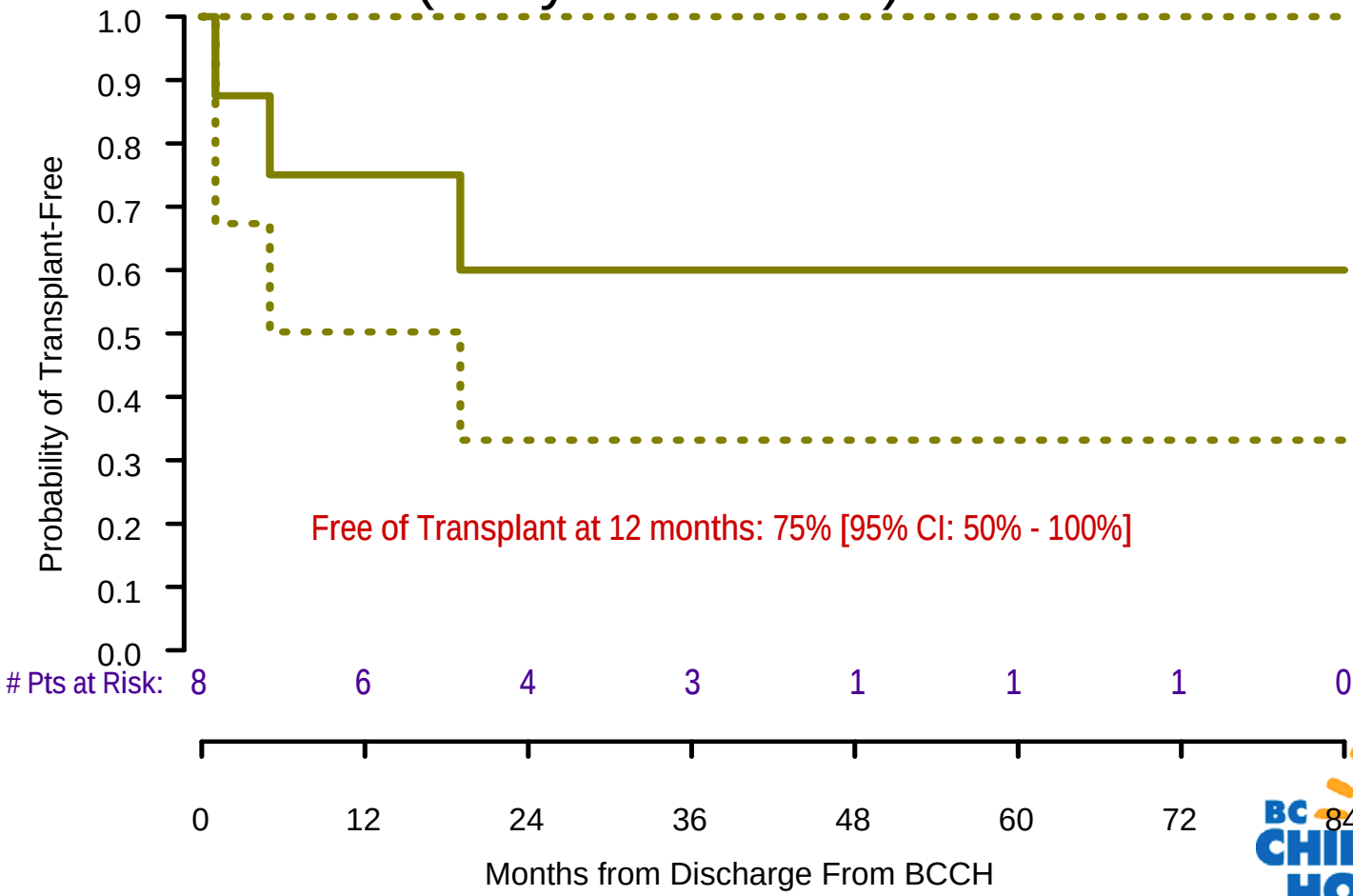
Kaplan-Meier Estimated Time to Transplantation

(Dialysis Patients)



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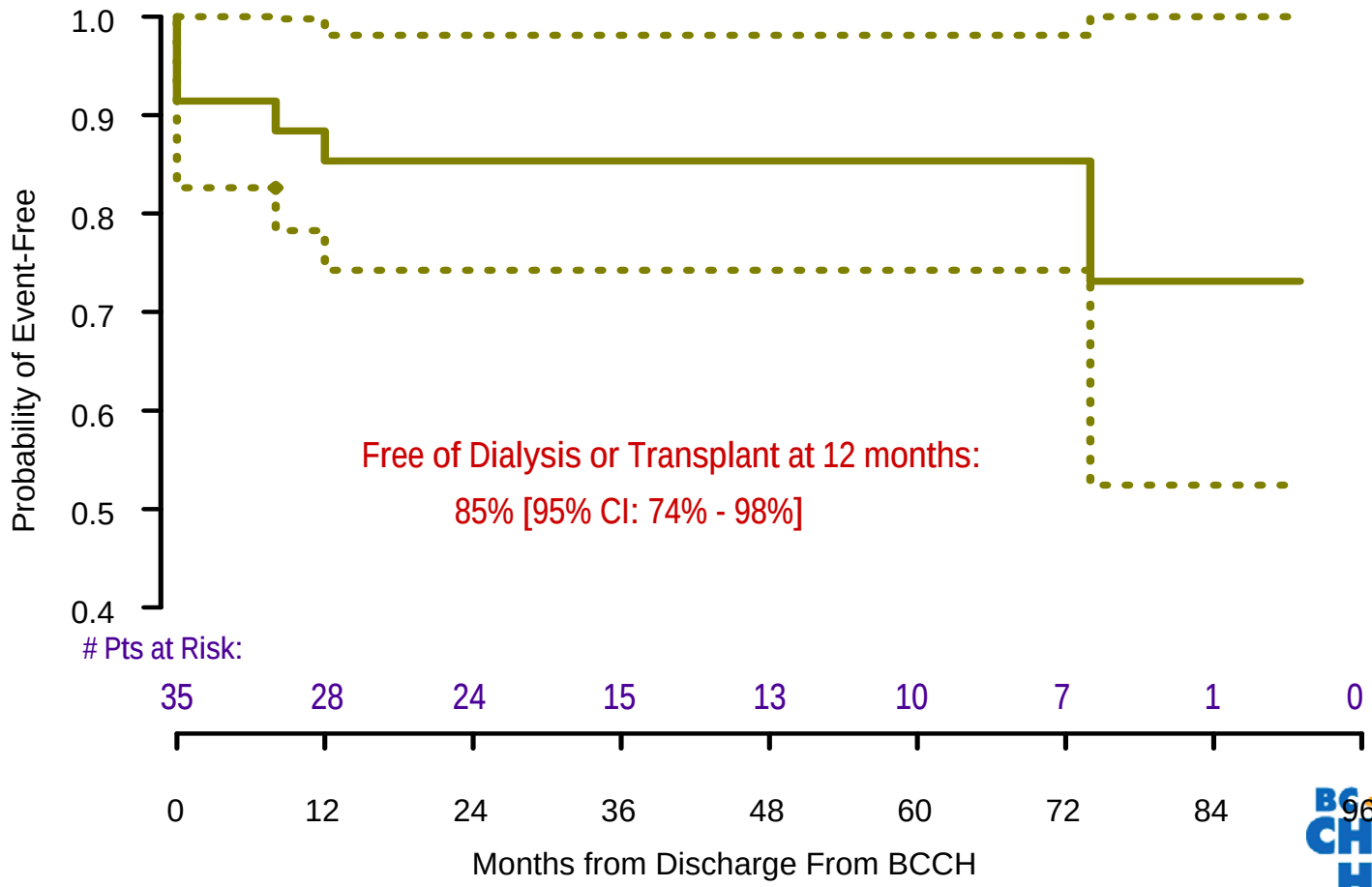
Kaplan-Meier Estimated Time to Dialysis or Transplantation

(Transplant Patients)



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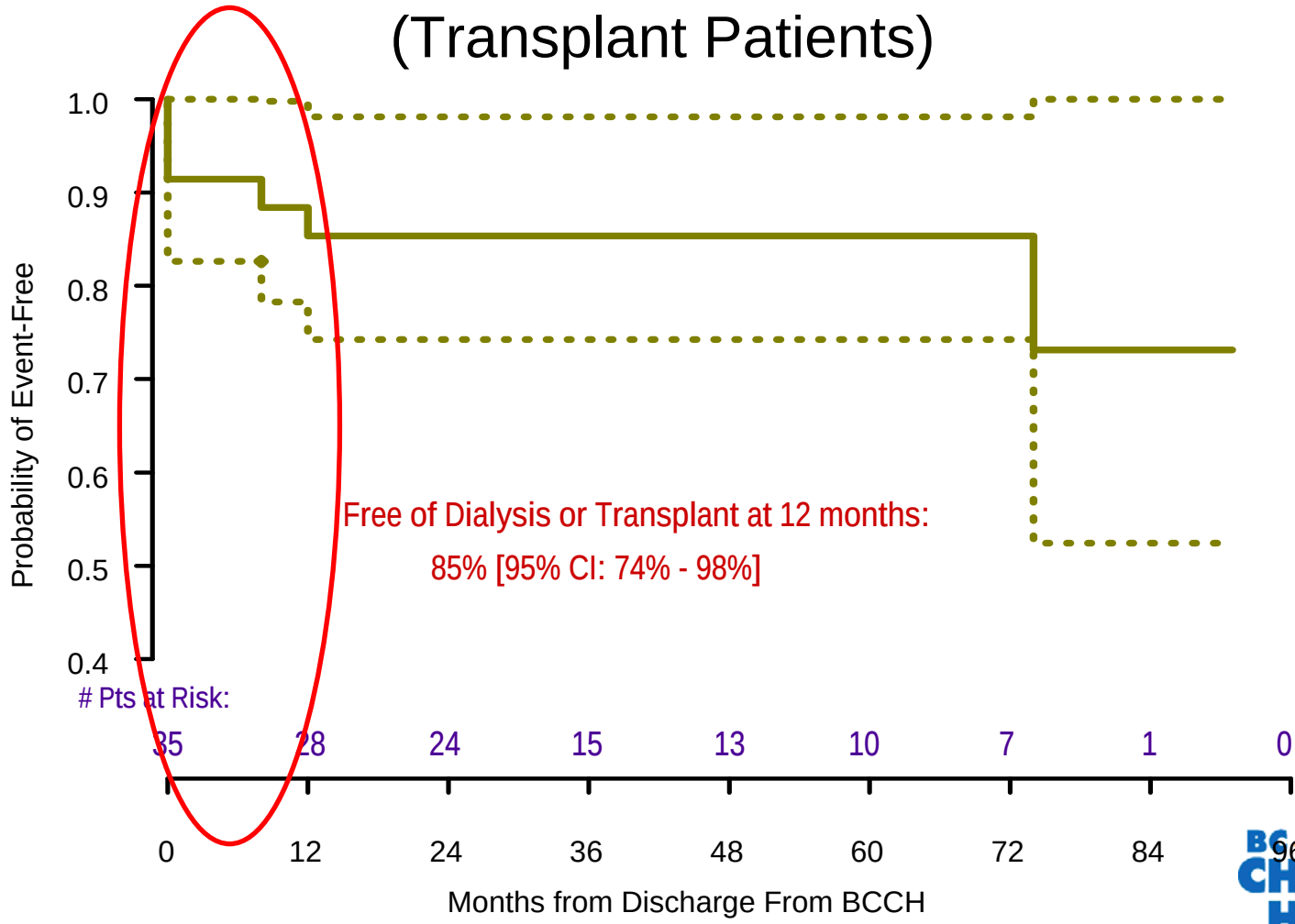
Kaplan-Meier Estimated Time to Dialysis or Transplantation

(Transplant Patients)



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Clinical: Transition Framework

Early Transition	Middle Transition	Late Transition
The youth and the family are introduced to the transition process and the youth begins to participate in his/her care	The youth and family gain understanding of the transition process and the youth practices skills, gathers information and sets goals to participate in his/her own care	The youth and family prepare to leave the pediatric setting with confidence and the youth uses independent health care behaviors and consumer skills into adult system

Years 10 ----------18
Grade 5 ----------12

M. Paone, et al. On trac: A transition service at British Columbia's Children's Hospital. Vancouver 1997

Clinical: Transition Framework

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Years 10 ----------18

Grade 5 ----------12

Depends on …

..Severity & exacerbation of condition

..Physical and cognitive abilities

..Psychological and emotional stability

..Family and social support

M. Paone, et al. On trac: A transition service at British Columbia's Children's Hospital. Vancouver 1997

Clinical: Transition Framework

EARLY ADOLESCENCE
Ages 10-12 Grade 5-7

MIDDLE ADOLESCENCE
Ages 13-15 Grades 8-10

LATE ADOLESCENCE
Ages 16-18 Grades 11-Graduation

Self-Advocacy
Independent Health Care Behaviors
Sexual Health
Educational ,Vocational, financial Planning
Social Supports
Health & Lifestyle

Developed in collaboration with the Building-a-bridge project for youth with endocrine conditions at BCCH

Clinical Pathway for Adolescent Transition Care

Youth Between 10 - 18 yrs of age

- Chronic health condition requiring ongoing adult care
- Minimum of 2 visits or 1 yr. from diagnosis

Initiate Clinical pathway on health care record. Review process with youth & family

Initiate transition tools as chosen.
Youth Planer, Family care book, Workshop

EARLY TRANSITION
Youth/family identify concerns. Pathway section completed

Early Transition needs met?

Yes

MIDDLE TRANSITION
Youth/family identify concerns. Pathway section completed

Middle Transition needs met?

Yes

LATE TRANSITION
Youth/family identify concerns. Pathway section completed

Transition Pathway Completed?

Yes

Complete Transition summary & transfer youth to adult care

Attend Transition Clinic/workshop
Complete transition process evaluation (youth, family, staff)

No

Refer to appropriate resources.
Make formal referral

No

Refer to appropriate resources.
Make formal referral

No

Communicate needs (foci) to Adult Care Providers

Youth Health Consultation Service
Genetic Counseling
GF Strong Adolescent & Youth Adult Program
Sexual Health Resource Center
Mental Health

BCCH Renal Transition Clinic

- Introduced in January 2007
- Vision:
  - Family-centered
  - Continuous
  - Comprehensive
  - Compassionate
  - Developmentally appropriate

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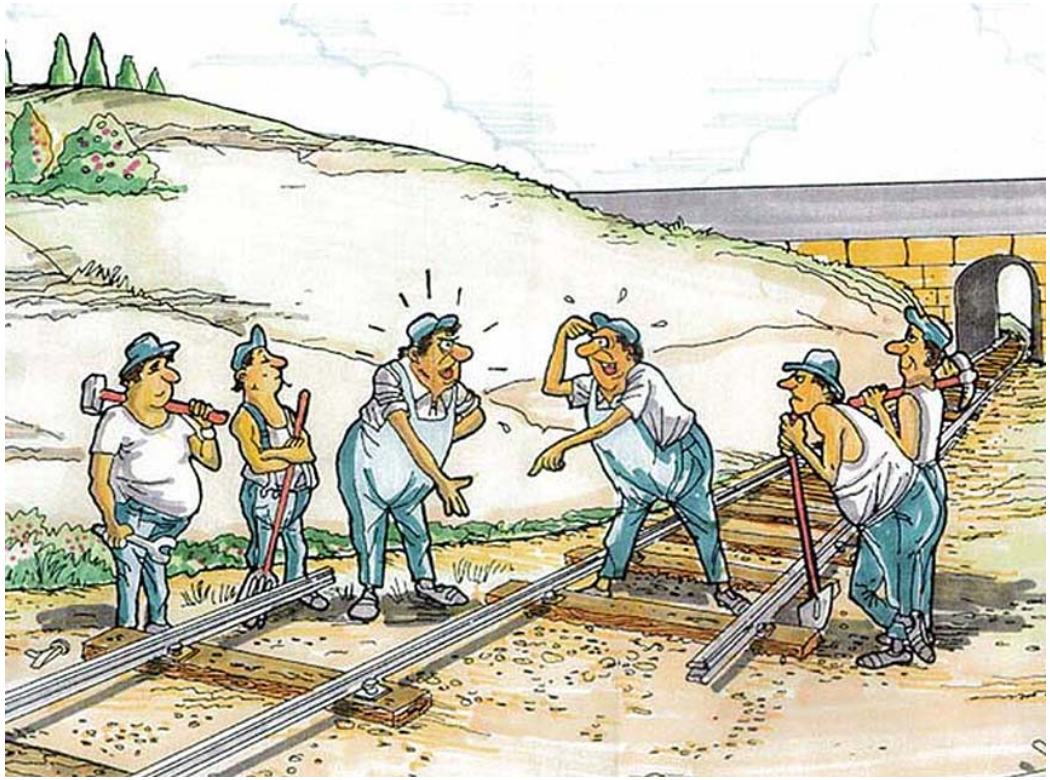
Transition Team



- Pediatric nephrologist and renal nurse
- Adolescent medicine physician and nurse
- Renal pharmacist
- Renal dietician
- Social worker
- Administrative clerk

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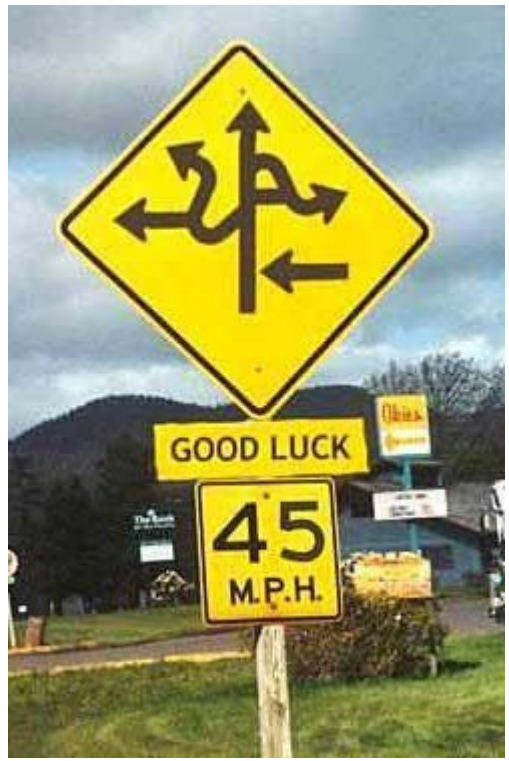
Readiness for Transfer

- Identifies primary care provider
- Youth knows and understands
  - Their renal disease & need for renal replacement/transplant
  - Impact on reproductive health and potential
    - Pregnancy, teratogenicity, fertility
    - Genetic risk of disease recurrence
    - Health care standards: cancer screening, immunizations, etc.

Readiness for Transfer

- Knowledge of consequences of non-adherence
- Youth's ability for disease self-management
  - Medications names, purposes, doses, refills
  - Making appointments, knowing where to go
  - Seeking medical assistance when needed
  - Knowledge of renal diet



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Components of Transition/Transfer

- Interdisciplinary teams
- Patient is medically stable
- Issues of non-adherence addressed
- Individual assessment of readiness
- Insurance coverage
- Transfer discharge summary
- Communication with the adult team

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Transition Summary

Name _____ _____ DOB _____ _____ PHN _____

Address _____

Phone _____ _____ _____

Home Work Cell

Emergency Contact: _____ Relationship: _____ Phone: _____

Family physician: _____

Allergies (meds & food):_____

Height: _____ Weight: _____

BP at last visit: _____

Diagnosis
1.
2.
3.

Current Medications	Current Medications
1.	5.
2.	6.
3.	7.
4.	8.

Medic alert bracelet Yes ☐ No ☐

Dietary/Nutritional Needs: _____

Most recent investigations	Date
1.	
2.	
3.	
4.	
5.	

Past Hospitalizations (including surgeries)			
Date	Hospital Name	Reason	

Psychosocial assessment
Home (Family, Housing, Transportation):
Education & Work:
Activities:
Drugs:
Sex:

Summary

Signature Nephrologist: _____ Date Completed: _____

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Gee Wigle, Transplant Nurse Coordinator
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Tanya Strubin, Social work
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Paula Woo & Nonnie Polderman, Dieticians
604-874-2345X7157

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Thank you

- Adeera Levin, MD BCPRA
- Douglas Matsell, MD
- Marg Turik, RN
- Gee Wigle, RN

  Jesse Ahuja, RN
- Jorge Pinzon, MD
- Sara Miles, RN
- Kathleen Collin, PharmD
- Tanya Strubin, MSW
- Paula Woo, RD

  Nonnie Polderman, RD
- Jennifer Leechik, RN

  Lorraine Nicado, RN
- Theresa Ferraro
- Lee Er, BCPRA

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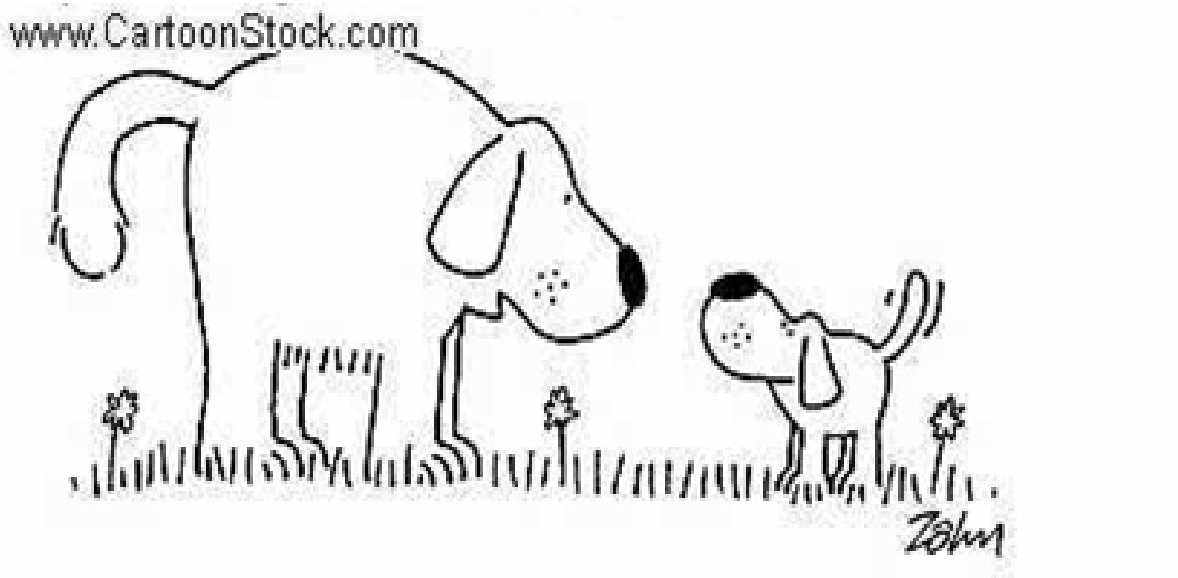

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