

Are Your Teens Good 2 Go?

Miriam Kaufman BSN, MD, FRCPC BC Nephrology Days October 2007



Transition

"The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from childcentered to adult-oriented health care systems"



(Blum, 1993)

Transition is a process, Transfer is an event.



The Adolescent Brain

► Frontal Lobe

- Last to fully develop sometimes 3rd decade of life
- Give rise to "executive functions"
 - ► Organization
 - ► Planning
 - ► Self-regulation
 - ► Selective attention
 - ► Inhibition

(Casey, et al., 2000; Sowell, et al., 1999)



The Brain and Implications for Transition

► Adolescent is expected to take on tasks

Self management of condition
Plan ahead for appointments
Arranging to be away from school or work
Focusing on dialogue in clinic
Management of medications and symptoms
Problem solving

All difficult to do without executive functioning!!



What Do Adolescents Need For Successful Transition?

- Knowledge and information in six domains:
 - Self advocacy & self esteem
 - Independent health care behaviors
 - Sexual health
 - Social supports
 - Educational/vocational/financial planning
 - Health & lifestyle

(Paone, 2000; Blum, 1998)





What Do Adolescents Need For Successful Transition?

Increased self-management skills (Paone, 2000)



Opportunities for growth & change



► Patience



Cultural Differences

► Paediatric

► Adult

- Family centered
 Fewer patients
- Peer support
- Physically appropriate for children
- Specialist knowledge of paediatric conditions
 Multi-D team & supports available

- Individually centered
- Large # of patients
- Limited peer support
- Physically appropriate for adults
- Potential for limited exposure to paediatric specific conditions
 Limited team support



Do teens make it to the adult healthcare system?

Cardiology study:

 53% of patients with CHD did not successfully transfer to adult care within the recommended time frame



(Reid, G., Irvine, M., McCrindle, B., Sananes, R., Ritvo, P., Sui, S., Webb, G, 2004)



Do teens make it to the adult healthcare system?

Diabetes study:

- Pre-intervention: 25% of patients did not attend their first appointment in adult healthcare system within 2 years of leaving pediatric center
- Post-intervention: 6% failed to attend adult appointment within 2 years.





(Frank, 2006)

Principles of Transition

- Skill acquisition is possible
- Early start!
- Planned, coordinated approach



- Progressive movement towards active participation in health management
- Transition planning should occur at the youth's pace dependent on:
 - Medical stability and cognitive development
 - Severity of illness
 - Personal goals and available social supports



The Long Road To Date

- Efforts of transition pioneers
 Anecdotal accounts of problems
 Transition Symposium 2002
 Adolescent Medicine
 Site visits

 - Literature reviews
 - Proposal to executive
 - Secured funding Good 2 Go Transition Program:
 - ► Transition Coordinator CNS 1.0 FTE
 - Psychologist .5 FTE
 - ► Paediatrician and Social Worker





Good 2 Go Philosophy

Believe that children and youth with chronic health conditions can acquire skills while in the paediatric system that will assist them in successfully managing their health care now and in the future.

Paediatric health care professionals are in a position to facilitate developmental transition in a number of different ways.



Shared Management Model

Development of therapeutic alliance

- Roles of players change over time as child grows and develops
- Planned, systematic approach to a gradual shift in responsibilities

Leadership of care is slowly transferred from provider to parent to young person



Shared Management Model (Kieckhefer & White, 2006)

Age & time	Provider	Parent/family	Young person
	Major responsibility	Provides care	Receives care
	Support to parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manages
	Resource	Consultant	Supervisor/CEO



Program goal

To prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to

- Advocate for themselves (or through others)
- Maintain health-promoting behaviors
- Utilize adult health care services appropriately and successfully



Methods of achieving our goal

► Education and staff support ► Resource identification and collaboration ► Evaluation of transition interventions Provision of direct transition services





Menu of interventions

- Clinical pathways-timelines of expectations
- Seeing teen on own for clinic visit
- ► 'MyHealth passport'
- 'Growing up ready' posters
- ► Marking "graduation" as an event
- ► Website
- Hospital wide psycho-educational transition groups for teens and parents



Menu of interventions

Facilitation of first appointment in adult setting
Processing of first adult healthcare system visit
'Transition clinic' in home clinic with adult staff
Patient and family education days
Staff training
Preparation for employment







Transition Readiness Survey

Good 2 Go Transition Program					CHECKLIST FOR							
Use the following	scale	to ran	k you	<i>yr æns</i>	wers to the statements below.							
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1	2	3	4	5							CHECKLIST FOR PATH	ENTS
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n the future	+	1	1	1		1	2	Τ.	-	-		_
My teen speaks up for him/her- and tells others what he/she needs	+	+	+		I can describe my chronic health condition to others	1	1	3	1	5	Comments	-
My teen has a family doctor he/she likes and will continue to see as an adult	+	+	+		I know what my health may bring in the future	+	-	-	-	-		
My teen knows the types of doctors he/she will need		-			I speak up for myself - and tell others what I need							
My teen knows he/she has the right to information about his cherself and his/her health		-+	_	6	I have a family doctor I like and will continue to see as an adult	\square		-				
My teen has a person who will help him/her with his/her health if our family cannot	-			1	know the types of doctors I will need to ee as an adult	1	+	+	+	+		
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Graduation Certificate

Good 2 Transition Pro		1010	SickKids
Cert	ificate Thi	of Achie s certifies that	venent
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MERIT	at The Hosp	ital for Sick Child	ren
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Website:





Transition Clinic

- Recently started within Adolescent Medicine
- Limited appointment slots at this time
- Assistance for patients with complex transition issues:
 - multiple medical issues and teams
 - non adherence
 - psychological factors interfering with utilization of healthcare



My Health Passport

A portable, customized, wallet sized document

Created by adolescent and HCP

Main goals are patient education, ownership of health information, self-advocacy

Communication of important information in new or emergency situations.

A tool that can be used without having to buy anything or download any software



How to Use

- Adolescent at keyboard with health care provider and chart
- Fills in information with help from HCP
- When document printed at end, cut out and fold (or it will just end up crushed in their knapsack)
- If you are just trying it out without a patient, please enter "100" as your age
- After printing, close window, which will take you back to program so teen can email passport to themselves



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Passport ✓ Select passport ✓ Select passport ✓ Heart transplant ✓ Liver transplant Liver transplant Lung transplant ✓	
Copyright © 2007 Multi organ transplant i rights reserved.	
Rheumatology Test Form	



Rejection history

March 2006

🗹 Pnuemovax 🗹 Prevnar 📃 HPV 🔲 Hepatitis A 🔽 Hepatitis B

2 mild rejection episodes--April 2004;



(150)

ew Passport

We'd like a bit of information from you for our statistics. We will not be saving the rest of the passport, so this information will not be linked to whatever information you put in your passport.

If you are a health care provider testing this out or showing it to a colleague, please enter "100" as your age.

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Patient Name John Smithkowski-Neuron		
Patient Phone 647-888-8888		
Patient E-mail Cooljohn66@hotmail.com		
Parent Name Cindy Smithkowski		
Parent Phone 647-999-9999		
Parent E-mail cindys@hideouswork.com		
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	-	Prednisone		
	-	Sirolimus/Rapamycin/Rapamune		
	-	Cyclosporin/Neoral/Sandimmune		
	-	Azathioprine/Imuran		
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	<u>P</u> aediatric provider name & phone number	Dr. Glo Merulus 416-813-C		
	<u>A</u> dult provider/transfer date phone number	Dr. N. Phron 416-999-9999		
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Internet

This printed small enough to be wallet sized when folded in half!

Cut and fold with patient. You can use a hospital card or other ID card to fold it around as a guide

Name	John Smithkowski-Neuron
DOB	January 5, 1990
Transplant	Kidney,December 2003, SickKids
Diagnosis	Prune belly
Immunization	DPTP,MMR,mening,Pnuemovax,Prevnar,Hep B
Rejection history	2 mild rejection episodesApril 2004; March 2006
Operations	Bladder augmentation 1990, multiple revisions
Current immunosupp.	Tacrolimus,MMF,Prednisone
Previous immunosupp.	Cyclosporin
Other	Fosinopril, Calcium, Vitamin D
Drug allergies	Penicillin
Dialysis	July 2003-December 2004
High/low creat	88 (84-92)
TFI	3,500
Bone status	Z= -1
EBV	positive
CM∨	positive
Blood group	AB+
Donor	B+
PTLD	No
Drug coverage	Parent's private plan
Exercise	Swim once a week
Paediatric provider	Dr. Glo Merulus 416-813-0000
Adult provider	Dr. N. Phron 416-999-9999
Other	I get diabetes when I take a lot of prednisone.
Emergency Contact	Cindy Smithkowski 647-999-9999 Adam Neuron 647-999-9998

Please, cut passport and fold it to wallet size.

Longer passport might need to be folded in thirds or twice

Can use glue stick to glue together after folding



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<u>2</u> . About how long did it take you to do it?	10 minutes		
<u>3</u> . Are you happy with the passport you printed?	🔿 Very Happy 💿 Happy 🔿 Neutral 🔿 Unhappy 🔿 Very Unhappy		
<u>4</u> . Would you have preferred to do it in another language?	🔿 No 💿 Yes		
If answer is "Yes" what language do you prefer?	Russian		
5. Do you think we should make any changes?			
Submit			

Getting Going....

Early Adolescence (12-14)

- ✓ Learn to describe health condition
- Learn about medication and treatments
- ✓ Begin to ask questions at appointments
- Responsibilities at home: chores, helping out
- Information about sexual health books, pamphlet, care provider.
- Learn how smoking, alcohol, drugs impact health
- Begin spending some time alone for part of clinic visit





On My Way....

Middle Adolescence (15-17)

- Support groups, internet, condition-specific associations to enable peer support
- Teen has someone to discuss contraception, sexual functioning, intimate relationships
- Continue to learn about medication –accept and fill prescriptions
- ✓ Discuss future goals: career, post-secondary education
 ✓ Youth meets with care provider alone for part of visit



Almost There.....

Late Adolescence (18-21)

- Discuss choices in adult specialist/hospitals
- Teen books medical appointments and keeps track of physicians (name, #)
- Discussion around sexual capabilities, fertility, genetics
- Discuss plans for employment options and health care benefits



Planning for your appointment

Write down questions so you don't forget to ask what is important for you.

If you don't understand what they tell you ask them to repeat their information and keep asking until you understand.

Summarize information received

Expect to be asked for your opinion and ideas in planning your care.





Take Home Points

- Start early
- Avoid transfer when unstable
- Use a variety of approaches
- Give patient opportunity to spend time alone with care provider
- Include all programs involved in patient
- Identify staff member to coordinate complex transfer
- Introduce to adult care providers
 Encourage feedback from patients and families.



Good 2 Go Transition Team



