Transitions: Becoming an Adult

16th Australian and New Zealand Haemophilia Conference
21-10-2011
Novotel
Sydney Olympic Park

We will be looking at a range of related topics including:

• Qld – How we currently manage Transition
• WA – The Transition Study
• Panel Discussion
HOW AGING AFFECTS BELT HEIGHT...

YOUTH ADULT MIDDLE- AGE OLD AGE

"First they make you button your own shirt, then they make you tie your own shoes...you gotta ask yourself — where's this all heading?"
Rent, taxes, death. I hate growing up.

I hate how hospital gowns never cover yur tail.
So many exciting decisions to make!

This one used to be a rose. This one used to be a butterfly. That used to be a horse. Um, this one...

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Transitioning in Queensland
From Teddy Bears to Apprenticeships

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and
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Qld Haemophilia Centre
Royal Children's Hospital
and
Royal Brisbane & Women's Hospital
Qld Haemophilia Centre
Adults and Paediatric teams
(plus additional physio and psychologist)

RCH Team

RCH team
• Clinical Nurse Consultant
• Haematologist (2)
• Registrar
• Psychologist
• Physiotherapist
Warm and Fuzzy!

- Occupational Therapy
- Haematology / Oncology Outpatients Centre
- Nutrition and Dietetics
- Music Therapy

RCH Day therapy and Outpatients ward
Defining “Transition”

• “A multi-faceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from child to adult centred care”
Stakeholders

- Child/young person
- Parents/ care-givers
- Referring paediatric care team
- Accepting adult care team
Transfer

- After finishing year 12 or finding employment
- Timing may vary depending on individual circumstances
- Planning starts early (no later than 12 years old)

**RCH Timeline**
- January: Review potential pts for transfer for following year. Draft patient list
- February: Commence monthly review of potential patients at QHC meeting
- March: Plan and initiate clinic appt to prepare patients for transition throughout the year
- April: Continuing review and discussion regarding potential transition patients in QHC meetings
- May: List of Transition patients finalised
- June: Referrals sent to Cancer Services Referral Centre
- July: RBWH transition day for identified patients
- August: RBWH transition day for patients identified in previous year
- September: RBWH transition day for identified patients
- October: RBWH transition day for identified patients
- November: RBWH transition day for identified patients
- December: RBWH transition day for identified patients
Key Differences

Children - Family-oriented
• Decisions made by parents, with input by young person as team communicates with parents
• Physical environment of hospital is bright and cheery

Adults - Individual-oriented
• Needs to develop self care and advocacy skills
• Team communicates directly with young person who is seen independently
• Physical environment is most often white and sterile

“Here comes the school bus, Mom. I guess you don’t get to drive me there after all!”
Challenges for the Young Person

• Developmental issues
• Resistance to transition resulting from anxiety/fear
• Inability to manage disease/self-infuse factor
• Poor organisational skills
• Other life issues

Potential Challenges for the Parent

• Difficulty letting go
• Anxiety about adolescent’s inability to manage care
• Anxiety about parent’s role in adult care
• Anxiety about new medical team, different culture
• Other life issues
Challenges for the RCH Team

• Difficulty getting some families in for final review.
• Affects quality of referral information to adult service
• Ensuring that the young person/ family is ready for independent care

RBWH Team

• Clinical Nurse Consultant
• Haematologist
• Psychologist (mainly RCH)
• Social Worker
• Clinical Nurse
• Physiotherapist
Royal Brisbane and Women’s Hospital and Royal Children’s Hospital – HERSTON COMPLEX

RBWH Day Therapy and Outpatient’s Unit
New Doctors!

New nurses!
New Physiotherapists!

"A little more work is needed on your broken Mr Smith!"

New Social Workers!

"This one looks good -- you climb trees and hurt for bugs and get chased by social workers..."

"The police brutality I can take, but those social workers..."
Potential Changes for the Young Person

Significant Impact of Growing Up

- Peers
- Housing
- Finances
- Education
- Health care
Challenges across the 2 Haemophilia Teams

- Lack of time to research
- Lack of time to plan
- Lack of time for discussion
- Lack of time to offer support
- Lack of resources

Potential Challenges in working with the young person

- Self management
- Mobility – housing, mobile ph
- Challenges of adult hospital
- Non-attendance
- Ability to plan
- Risk taking
- First significant bleeds
Achieving Success in Transition

- Plan and prepare
- Transition Day/Clinic
- Contact between visits including referral
- Maintain confidentiality
- Offer encouragement
- Address issues
- Partnership model - Empower!
- Be patient – “Not One Size”

THE END!