Mitochondrial Family Day – 18/11/2016

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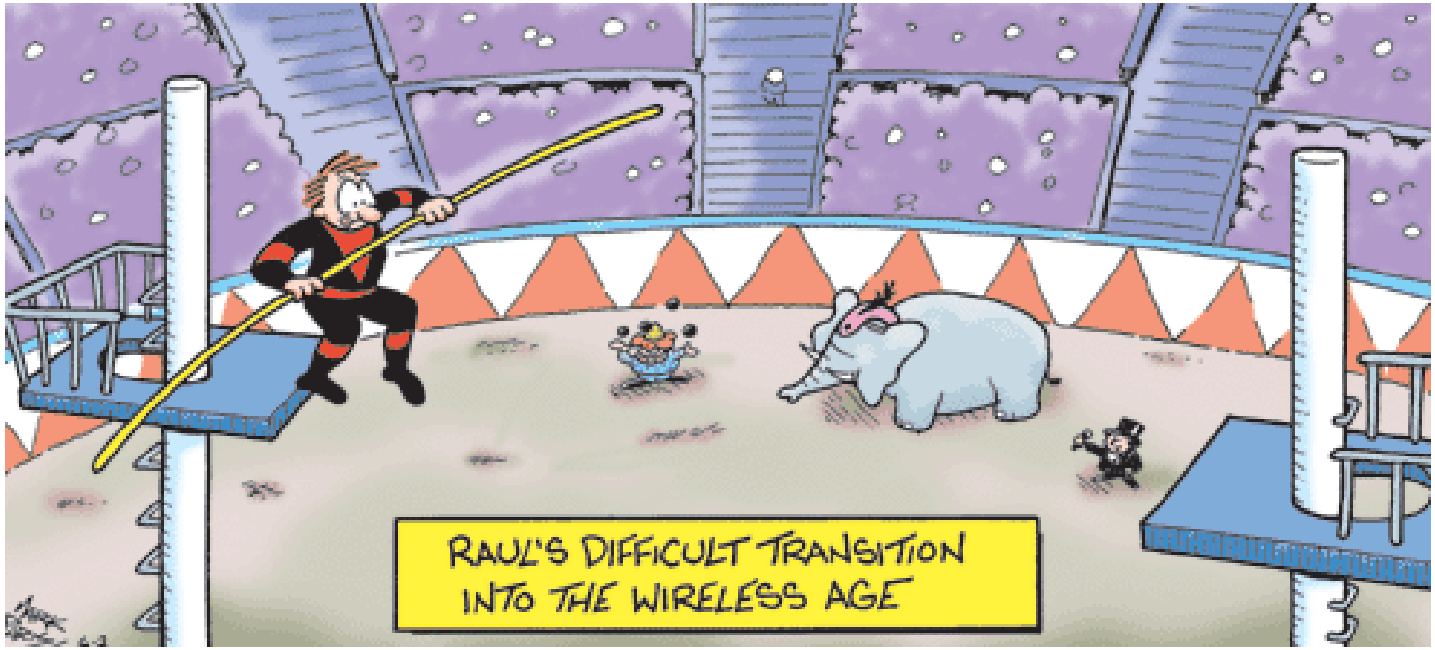
Transition

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

https://www.racp.edu.au/index.cfm?objectid=B567F6BD-D4A2-C8EA

The Facts

- >90% of children with chronic illness now reach adulthood
- There needs to be a bridge between the paediatric and adult services



Goals in Transition

- An active process
- Planned
- Co-ordinated
- Choosing the right time
- The right service
- Need to consider the emotional and social maturity of the adolescent

Lampe, 2014. Adult Transition Meeting

Transition

- Should be
  - Individualised
  - Age/developmentally appropriate
  - Affordable
  - Accessible
  - Fun

Hendriksz, 2013

Clinic Definitions

- Paediatric
  - The therapeutic relationship is focused on the parents and the medical team, with the child as a passive observer
- Transition
  - The therapeutic relationship shifts to the young person and the medical team, with the parent becoming the observer
- Adult
  - The young person is completely independent from parents and manages their own health care

Models of Care (MOC)

- Paediatric care
  - Family-centred
  - Protective/nurturing
  - Prescriptive
  - Focus on development and growth
- Adult care
  - Independence (emotional and financial)
  - Autonomy for health
  - Collaborative
  - Empowering for the adolescent

Lampe, 2014. Adult Transition Meeting

Clinical Goal of the Transition Consultant

1. Make the young adult socially independent as a first step
2. Make the young adult medically independent by the age of 25 years ready for referral to an adult service
   - This is based on the Manchester Health Service (UK) MOC where they have 3 metabolic clinics
   - Paediatric (0 – 16/18)
   - Young adult (16/18 – 25)
   - Adult (over 25)

Hendriksz, 2013

Common Models of Transition

- "Push"
  - Paediatric teams lead the transition process
  - Paediatric team share care from 16 – 18 years of age
  - Adult teams introduced over a number of appointments
  - Patients are pushed out of the paediatric service
- "Pull"
  - Adult team leads the transition process
  - Pull the young person into care
  - Adult services start the process
  - Need to have established a relationship in the presence of the paediatric team

Hendriksz, 2013

Phases of Transition

- Getting the Right Start
  - No right age for transition
  - Needs a flexible approach
- Preparation phase
  - Conversations to start around 10 – 14 years of age
  - Introduce transition team members around 14 years of age
  - Prepare a transition document completed by the child/young person with the support of the medical team

Hendriksz, 2013

Phases of Transition cont'd

- Introduction/active phase
  - Young person introduced to the new team over a series of appointments
  - Between the age of 14 – 16 years of age
  - Appointments must have attendance of both medical teams
  - Allow some time for the patient to be alone with the new team
    - Aim to increase the knowledge of the young person on their disorder. Management and care plans

Hendriksz, 2013

Phases of Transition cont'd

- Transfer phase
  - Actual transfer
  - Singel event that occurs on a designated date
  - Medical care officially handed over to the adult team
  - Around 16 – 18 years of age
  - Communication between teams is crucial to success
- Integration phase
  - Frequently forgotten
  - The young person is seen by the same person in the adult service until the age of 25 years old
  - Focus shifts to the medical condition and adult lifestyle diseases like alcohol, obesity, osteoporosis, pregnancy, cardiovascular health
  - These appointments are clinician to adult – no parents

Hendriksz, 2013

Barriers to Transition

- Funding
- Parents find it difficult to let go
- Challenges in accepting the changing of relationships
- Anxiety from the parent and young person on potential lack of information sharing

Hendriksz, 2013

Principles of successful transtion

- Services for adolescents and young people needs to be developmentally appropriate
- Services need to consider health issues outside their chronic illness
- Services need to be engaging and flexible enough to a young person's lifestyle and social circumstances
- Works best if the service is committed to transition through a case management model

Historical Perspective - Queensland

- Two stand alone services
  - Royal Children's Hospital
    - Paediatric/Adult (70/30%)
  - Mater Health services
    - Adult/Paediatric (70/30%)
    - Adult services at the time was unfunded activity
- Queensland Health (QH) amalgamated
  - Mater Children's Hospital
  - Royal Children's Hospital
  - Formed the Lady Cilento Children's Hospital – South Brisbane (LCCH)

This created a problem

- A large service gap
- No specialist staff available for the adult metabolic population in Queensland and Northern NSW
- No trained adult staff (medical and nursing)
- No funding
- 200 at clinical risk adults with a metabolic disorder

Model of Care - Options

- Cease to provide adult metabolic services in Queensland
- All services move to the new paediatric facility (LCCH)
  - No capacity for adult patients to be acutely managed in a paediatric hospital
- Set up 2 stand alone services
  - Expensive
  - No clinical expertise
- Set up a comprehensive state-wide metabolic service delivering care from cradle to grave

Service planning

- Churchill Fellowship to identify transition and service delivery options
- The development of a business case (8/12)
- The selling of the business case to the 2 hospital executives (5/12)
- Final agreement reached (in principle) after Queensland Health received multiple ministerial complaints from adults regarding service confusion – Qhealth and MHS committed to service delivery (12/12)
- Lifespan services began 1st January 2015 (with financial agreements still pending)
- No funding until March 2016

Queensland Lifespan Metabolic Medicine Service (QLMMS)

- Double Branded Service Level Agreement (clinical partnership)
  - Queensland Health
  - Mater Health Services
- Service covers the lifespan
- Children up to end of school
  - Seen at the Lady Cilento Children's Hospital
  - 16 – 18 in an adolescent clinic
- Over 18 years of age
  - Seen at the Mater Health Services (public, private, maternity)

QLMMS Staffing

- Medicine
  - 1.8 fulltime equivalent (FTE) metabolic paediatric physicians
  - 0.5 FTE adult physician
  - 1.0 FTE clinical fellow (recurrent funding)
- Nursing
  - 1 FTE metabolic nurse practitioner
  - 0.5 FTE clinical nurse
  - 1 FTE registered nurse
- Dietetics
  - 0.7 FTE adult metabolic dietitian
  - 0.6 FTE paediatric metabolic dietitian
- Social Work and Psychology services

Advantages of a Lifespan Model

- Comprehensive MDT
- Consolidate resources
- Cheaper health care delivery service model
- Sharing of workload
- Increased staffing numbers for on-call and succession planning
- Portal of teaching
- Prevents professional staff burnout

Advantages for the consumer

- Fewer patient number dropouts from the paediatric clinic to the adult service
- A smooth transition through the service
  - Specialist Paediatricians (with metabolic qualifications)
  - Specialist Adult Physician (training in metabolic medicine)
    - Medical staff working across the lifespan when on-call
  - Specialist Adult Metabolic Dietitian
  - Paediatric Metabolic Dietitian
  - Metabolic Specialist Nurses working across the lifespan

Problems

- Mitochondrial Disorders are multi-system
- Metabolic clinics don't have the sub-specialist skills to medically manage presenting systems
  - A one stop clinic is not possible
  - E.g. If the major symptom is neurological then the individual needs to be linked with neurologist (primary physician)
- Co-ordination of care
  - Use the metabolic service or may be a local general practitioner
- Gene Testing
  - Genetic testing for mitochondrial disease is vey expensive technology
  - Queensland government don't currently fund genetic testing

Conclusions

- Nothing is perfect
- It will never be a one size fits all
- All services should manage outcomes
  - Retention in adult services
- No-one likes change

"There is nothing wrong with change if it is in the right direction" Winston Churchill

"Optimal health care is achieved when every person at every age receives health care that is medically and developmentally appropriate"

A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. *Pediatrics* 2002; 110;1304

Queensland Lifespan Metabolic Medicine Service

- Postal address
  - Lady Cilento Children's Hospital
    501 Stanley Street
    SOUTH BRISBANE QLD 4101
- Metabolic Clinic Contact Details
  - Monday to Friday – 0800 – 16:30
    - Call 3068 4426
    - Non-urgent enquiries
      - Email metabolic-medicine@health.qld.gov.au
- Urgent critically unwell calls – after hours
  - Call 3068 1111 and the doctor should ask for the metabolic doctor on call
- Children's clinics are at the Lady Cilento Children's Hospital
- Adult clinics are at the Mater Adult Hospital