# Mind the Gap

***Transition planning from paediatric to adult care for those with MPHD.***

Bin Moore CNC
Coordinator, Growth & Endocrine Services
The Children's Hospital Westmead

The Sydney children's Hospitals Network
care, advocacy, research, education

*Conflict Of Interest Disclaimer Statement*

I have no conflicts of interest and accept full responsibility for the content of this presentation.

## Session objectives

- Review the difference between transition planning and transfer
- Understand the importance of planning in advance:
  - review of knowledge and understanding
  - timing of education
- Identify resources to assist young people navigate the adult healthcare system.

## Outline

- Background
- Current literature
- Case studies
- Discussion of issues related to transition

## Transition

*(Blum et al 1993)*

'purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from a child centred to adult oriented health care system'

Multidisciplinary process that addresses not only the medical needs of adolescents as they move from children's to adult health services, but also their psychosocial, educational and vocational needs.


## Chronic Disease in Adolescence

- 12% of young people in Australia have chronic health issues (RACP)
- **90% of young people with chronic disease are now living into adulthood**
- Patients with "paediatric diseases" now live into adulthood
- **Adult hospitals need to be prepared and resourced to cope.**

# 2018 Report on Transition

*The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians*

- Currently only **15%** of youth **receive transition planning assistance** from their health care providers. (National Survey for Children's Health)
- **6 critical first steps**
  - Identify health care professional who assumes responsibility for care coordination.
  - Identify core knowledge and skills required
  - Prepare and maintain up to date medical summary that is portable and accessible
  - Develop and update detailed written transition plans
  - Ensure the same primary and preventative health care plans are applied to all adolescents
  - Ensure that affordable comprehensive and continuous health insurance is available to all young people with chronic health conditions

# What works?

- Vertically integrated care + organised program most successful
  258 women - nil lost to follow up with organised care within same hospital
  *Transition in Turner syndrome European Journal of Endocrinology (2019)*
- Appropriate parent involvement, promotion of self advocacy, meeting the adult team most significant features of the transition process improved long term outcomes
  374 YP 3 disorders (DM ASD CP ) completed questionnaires annually over 3 yrs
  *UK Transition collaborative group*
- connection with adult health care provider and vertically integrated care + organised program
  - "On your own feet transfer experiences scale" OYOS-TES
    - qualitative review of adolescents experience
  - 50% felt prepared *Rotterdam study on satisfaction of transfer of care*

## If this is what it's like to learn Endocrinology……



## Challenges of Transition

- **Different models of care between hospitals**
- Developing independence whilst remaining dependant
- **Difficulty "letting go" of relationships (for patients, families and clinicians)**
- Timing- hospital policies use age instead of developmental readiness as an indicator

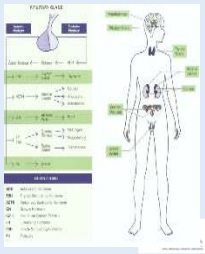
## Barriers to successful transition

- Poor decision making – by young person
- Young person doesn't prioritise the Medical Check or medications eg HRT
- Lack of awareness of available resources is a frequently reported barrier (Dept of Human Services, 2008).
- Young person doesn't trust the new people
- Communication difficulties -poorly understood by Adult Team
  - decision making, problem solving, assertiveness, self determination advocacy
- Parent/caregiver issues

Steinbeck & Kohn 2013

## Who do we need to Transition?

- **MPHD**
  - Congenital or acquired
- Syndromes
  - Turner Syndrome / PWS / Kleinfelters
  - bony dysplasia
- Adrenal insufficiency
  - CAH
- Thyroid
- DSD's
- Gender dysphoria/GID



## Connor:
### 11yr old male

- **Presented with**:
  - 12/12 history of occasional nocturia

    Seeing psychologist
  - 3/12 history of headaches/blackouts
  - 2 week history of torticollis
  - Obstructive hydrocephalus

## Continued…..

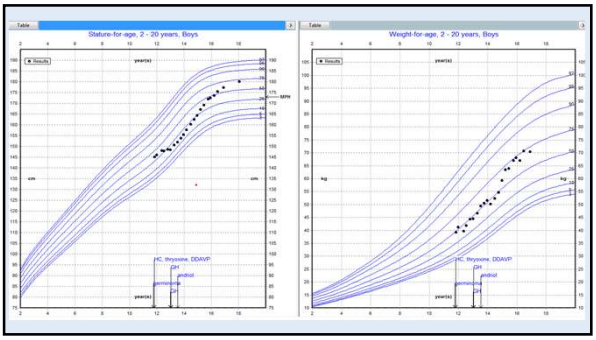
- MRI showed
  - Pituitary gland compressed by mass and pushed anteriorly
  - No definite pituitary bright spot
  - Distal portions of the optic nerve enlarged with infiltration to the optic chiasm
- Diagnosis:
  - Intracranial Germinoma
- Surgery likely to be unsuccessful

## Treatment

- Biopsy– Dec 2004
  - Intracranial Germinoma
- Chemotherapy – Jan –April 2005
  - 4 cycles of a cocktail of drugs
- Radiotherapy - June – Oct 2005
  - 30 Gy - Whole ventricles
- Endocrinology referral for management of hypopituitarism

## Medications

- Thyroxine and Hydrocortisone post biopsy
- DDAVP – Minirin
- Growth Hormone 2007-2011
- Pubertal Induction commenced 2007
  - Aged 13.5yrs
  - Initially with Andriol
  - IMI Reandron commenced May 2010




## Social Issues

- Single working mother
  - Parents separated shortly after diagnosis
  - History of Bipolar disorder
  - Medication non compliance
- Self image
  - Cognitive function and processing speed impacted
    - Medication non compliance
  - Emotionally immature and vulnerable when stressed
    - Loss of peer relationships
  - Dropped out of school and apprenticeships
    - Lost to medical follow up for some time

## Oncology Late Effects

- Survival leaves a legacy
- Effects may evolve over time
- Depends on
  - Volume of the brain treated
  - Part of the brain treated
  - The dose of radiation
  - Age at presentation
- Needs continual reassessment of cognitive function

## Long Term Follow up?

- No
- Missed appointments although reminded of the importance
- Moved away from the hospital he was referred to
- Eventually settled in one area (for a while) then moved again and was lost to follow up.
- Admitted in adrenal crisis and re-engaged with hospital
- Now sees an adult endocrinologist
- Feels competent to manage most aspects of care
- Continues to come to long term follow up (LTFU) clinic at CHW
- Case coordinator from Oncology continues to support him.
- 2019 Finally discharged from LTFU aged 25yrs

## Jessica:
### 4.5yr old female

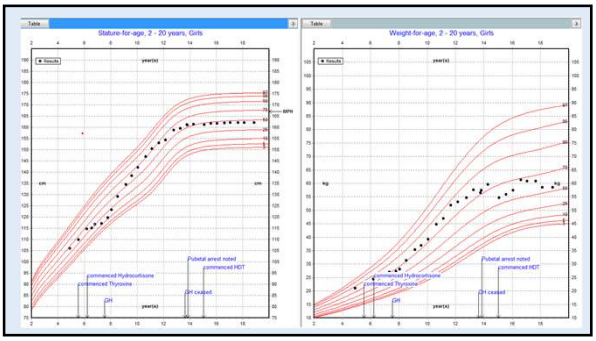
- Septo Optic Hypoplasia - Presented Dec 2003
  - History of blindness in Left eye + polydipsia
  - MRI showed optic nerve hypoplasia and an ectopic posterior pituitary
- Anterior pituitary testing
  - confirmed Panhypopituitarism
    - GH, TSH and Cortisol deficiencies
  - Commenced on replacement therapy
    - Thyroxine, hydrocortisone, GH Rx
    - GH ceased when BA 13.5yrs

## Continued…..

- Spontaneous onset of puberty
  - Did not progress to menstruation
  - required medical management
    - Commenced E2 patches/Progesterone replacement @15yrs
- Ongoing issues with HDT patches/gel
  - Discussed options with clinician
  - Moved to oral replacement as more acceptable to pt
  - All other replacement therapy continued
- Transitioned to Adult healthcare Dec 2017

## Social Background

- Nuclear family well educated
- Diagnosed young
  - Ongoing education of condition throughout adolescence
  - Understood medications and management plans
- Supportive mother
  - Encouraged independence
  - Willing to advocate for her child as necessary
  - Supported the move to adult healthcare




## Follow Up

- Left the care of the paed. team aged 18yrs
  - Felt ready to leave
  - Would have liked to have stayed
- Studying Nursing at University
- Engaged with adult clinician 6mthly
  - Feels reasonably confident to manage care
  - Mum still comes to appointments – Pt choice
- Aged 20 still worries about future.

## Our Challenges

- Getting transition to be part of each young persons care plan
- Getting families to "let go"
- Developing youth friendly services
- Involving adult colleagues to understand the "emerging adult"
- Ensuring ***sustainable engagement*** in any setting, including rural and regional areas

## What do we need?

- ✓ Services for young people need 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 coordinated management model

## Coordinated Management Model

- What do they need to know before they go
  - What is essential (e.g. medication dose and regimen)
  - What is helpful (e.g. financial advice)
- Who will help them explore options
  - Many more adult hospital choices
  - What services will they need
  - Not all services are under the one roof
- What's our role?
  - Get to understand the young person over time

## HEEADSSS Assessment

- Home
- Education & employment
- Eating
- Activities
- Drugs
- Sexuality
- Suicide
- Safety

"The idea is to speak privately with patients about stressors that may appear during adolescence, so they can practice taking responsibility for their health care needs."

With explanation, adults (usually) accept the need for confidential care.

Goldenring JM, Rosen DS. Getting into adolescent heads: an essential update. *Contemp Pediatr*. 2004;21(1):64-90.

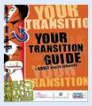
## The Flinders Program

A generic set of tools and processes enabling health professionals to support their clients to more effectively self-manage their chronic condition(s)

| Principle of self-management | Sample questions in the Cue and Response interview |
|---|---|
| Knowledge of treatment | • What can you tell me about your treatment?<br>• What other treatment options including alternative therapies do you know about?<br>• What does your family/carer understand about your treatment? |
| Sharing in decisions | • Does your doctor/health worker listen to you?<br>• How involved do you feel in making decisions about your health with your doctor / health worker? |
| Healthy lifestyle | • What are you doing to stay healthy as possible?<br>• What things do you do that could make your health worse?<br>• What aspects of your lifestyle would you like to change? |

©FHBHRU, The Flinders Program Flinders University 2017
http://www.flinders.edu.au/medicine/fms/sites/FHBHRU/Flinders%20Program%20Information%20Paper.pdf

## Get the TIK ✓




- ✓ Transition Plan
- ✓ Parent Checklist
- ✓ 14 –16 skills management checklist
- ✓ 16 - 18 skills management checklist
- ✓ Taking Charge of your healthcare
- ✓ Hints for finding a GP
- ✓ Financial Issues in the adult world
- ✓ Medicare application form
- ✓ Referral to Adult Transition Coordinator


## Consider…….

- What systems are affected
- What follow up is needed
- Who will coordinate ongoing care
- When should transition happen
- What other supports do they need

## Who will coordinate care?
## When should transition happen?

- The endocrine team?
- Oncology Team - long term follow up (LTFU)
- Clinical nurse consultant / Individual case manager?
- GP / Family / Other options - Trapeze Coordinators
- Should it be aged based
- Should cognitive development be considered?

## What do we need to address?

- Understand their condition
- Understand what hormones are missing & what they do
- Why medications are needed
  - When to take meds
  - Sick day management (of Adrenal Insufficiency)
  - Risk taking behaviour
- What other services they will need
- ***Adolescence!***

## Education is about...

### *Individualising care*

- Assessing the family and patient
- Planning with them what they need
- Providing them with knowledge and skills to manage their child's condition
- Evaluating you have been effective

## Resources

- Consider literacy level
- Tabloid newspaper (~ 11 years)
- Short sentences
- Use informal language
- Meaningful pictures

## Issues for young people

- Health transition one of multiple transitions happening at this time
- Adjusting to new teams, environment, protocols, rules
- Single to multiple care providers with no coordination
- Financial – changes in benefits, costs of equipment, medications
- Special considerations needed for patients with intellectual disability
- Records not easily transferrable

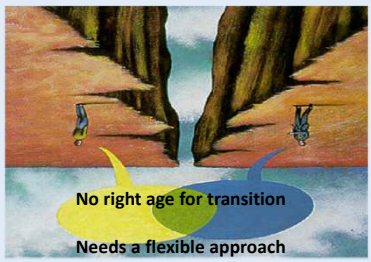
## Parents ……

### grown up children need Drs for grown ups

- Relationships
- Contraception
- Pregnancy / genetic risks
- Driving & other licences
- Employment
- Life &health insurance
- Legal issues
- Alcohol & smoking
- Drugs
- Hobbies & leisure pursuits

## Tips for Parents

- Recognise your adolescent has their own ideas about their health .
  - Teach them about their condition and how to manage it.
- Be supportive & encourage them to become confident in taking control of their health.
- Encourage them, to the best of their ability to see their Dr or other HP's on their own.
- Before an appointment take 5 minutes to talk together about what they may want from seeing their health team.
- When the doctor asks a question let them speak first.
  - Be patient and accept that they may make mistakes
- Help them find a good GP, & help them to get their own Healthcare Card
- Make sure they have emergency contacts to stay safe & well.
- Place trust in them and their ability to make choices for themselves.


**There is nothing wrong with change - as long as it is in the right direction**
*Winston Churchill*

Hand held Electronic Medical Record

## My Health Record
### Folder of the future



Does this allow for ongoing planning ?


## Take home message

- Oh…. You're turning 18 soon… time to move on
- This could be your last visit to hospital
- I will refer you to an adult hospital
- There are lots of choices
- You just need to ring and get an appointment
- Best of luck for the future

- Start early
- Plan well ahead
- Have yearly transition consultations from 14yrs
- Complete competence checklists annually
- Visit the adult facility prior to moving care
- Have the opportunity to say goodbye to team

## Knowledge versus Wisdom

**Knowledge is knowing that a tomato is a fruit**

**Wisdom is not putting it in a fruit salad**

# References


https://www.gottransition.org/about/index.cfm

*Steinbeck, K ., Kohn*, M. 2013 (Ed)A Clinical Handbook in Adolescent Medicine: A Guide for Health Professionals Who Work with Adolescents and Young Adults, edited by; 2013. New Jersey: World Scientific Publishing Co Pty Ltd. ISBN: 978-981-4374

Robards F, Kang M, Sanci L, Steinbeck K, Jan S, Hawke C, Kong M, Usherwood T (2017). *Access 3: young people's healthcare journeys, Preliminary Report*. Department of General Practice, Sydney Medical School Westmead, The University of Sydney in partnership with the Australian Centre for Public and Population Health Research, Faculty of Health, The University of Technology Sydney, Sydney, Australia.

Kang M, *et al. BMJ Open* 2017;7:e017047. doi:10.1136/bmjopen-2017-017047





http://www.flinders.edu.au/medicine/fms/sites/FHBHRU/Flinders%20Program%20Information%20Paper.pdf

http://www1.health.nsw.gov.au/pds/activepdsdocuments/gl2018