Mind the Gap
Transition planning from paediatric to adult care for those with MPHD.

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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)

A 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 + organized program most successful.
  258 women - nil lost to follow-up with organized care within same hospital.
  (Transition from Teen to Adult: European Journal of Endocrinology, 2018)

- 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 + organized 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

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
  - Emotional immaturity and vulnerability when stressed
  - Lost to 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
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

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 person's 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
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.


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)

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.
Adult services aim for long-term retention.

Children’s services need to prepare well.

Prevent rebound
Prevent falling through the gaps

No right age for transition
Needs a flexible approach

There is nothing wrong with change - as long as it is in the right direction.

Winston Churchill

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


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