TRANSITION PROGRAM IN WA

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William Oversby – patient perspective

Background

- Missing opportunities to educate through transitions throughout life
- Self management and home treatment
- Lack of an organised system of identifying education and support needed through transitions
- Anecdotal evidence of gaps in education

Method

- Parameters - diagnosed at PMH, now attending RPH clinic, up to age 30 years
- Demographics - 16/27, 14 males/2 females,15 from metro/1 regional.

1 haemophilia A mild	3 vWD mild
2 haemophilia A moderate	2 vWD severe
6 haemophilia A severe	
2 haemophilia B severe	

- an appointment made for the clinic

Method

- Consultation with staff at adult and paediatric HTC
- Registered as a Quality Improvement Activity at RPH.
- Questionnaires - 3 themes
  - RPH HTC – questionnaire at clinic appt
  - Physiotherapy – physical examination and questionnaire at clinic appt
  - Psychosocial interviews conducted outside of clinic appt

Some of the questions

What did you feel when you left PMH and the Haemophilia Care Team to move to RPH for your bleeding disorder care?

- *"scared and upset. I felt very attached to the staff at PMH"*
- *"uncertainty about where to go after PMH and what you have to do – confused and left in the dark"*
- *"Apprehensive, all new, I wasn't known to anyone – daunting"*

Q's cont.

Did you and your parents/guardians feel that it was an appropriate time for you to shift to an adult haemophilia centre?

- *"I felt very daunted having to leave and feel it may not have been an appropriate time to move across, however maybe no time would have been a good time"*
- *"it was weird staying at PMH because of my size"*
- *"I felt more mature and had also outgrown PMH beds"*

Q's cont.

How did PMH staff prepare you for your move to RPH?

- *"There didn't seem to be a lot of preparation. There was no real plan"*
- *"Brief chat, telling me it was happening"*

Do you feel the education and information provided to you about your bleeding disorder has been adequate, to date, to allow you to make informed decisions about your own care?

- *" Mum provided education but quite early. It was never double checked later on – would have been a good thing to reinforce the information later at PMH and again at RPH"*

Q's cont.

Prior to leaving PMH how involved in your care were your parents/guardian? Would you have liked them to be more/less involved?

- *"Mum was completely involved"*
- *"Mum was extremely involved. Perhaps if I was more involved I might have more knowledge, but at the time it was easier just to have mum do everything"*
- *"I wasn't mature enough to manage my own care or deal with speaking to Doctors on a one to one basis"*

Q's cont.

What differences did you notice between the treatment and care you received at PMH compared to RPH?

- "*PMH will send out appointments regularly. Due to my forgetful nature, I would go long(er) periods without attending clinics at RPH"*
- *"looked after at PMH"*
- *"treated with TLC at PMH while at RPH was not as caring"*
- *"ice creams after needles at PMH"*

Q's cont.

While at PMH, what opportunities were offered to you to consult with Doctors and other health professionals independently of parents/guardians?

- "*when I was 18 and staff were talking to my parents, not me, I felt like 'what about me?'"*

Has the genetic implications of your bleeding disorder been discussed with you at either PMH or RPH? What is your understanding?

- *"I possibly need to have it reinforced. Mum was misinformed"*

Questions

Other questions addressed:

- What was happening in the young person's life at the time they moved to the adult centre and what assistance had they received with schooling, vocation choices, peer support from others with bleeding disorders.
- How transitioning might be improved.
- How they managed disclosure of their bleeding disorder and/or viruses.
- What is their understanding of the roles of health professionals in the Haemophilia Care Team?

Findings

- No haemophilia carriers identified
- Most would have liked orientation to RPH
- Most thought the timing appropriate
- Most did not recall preparation - parents
- Most self-infusing prior to move
- Most understood they needed to be more independent
- Some with mild/moderate disorder had no transition

Findings

- Liked access to full-time haemophilia nurse
- Slack about 6-monthly reviews
- Remind of clinic appointments
- Satisfied with service at RPH clinics
- Minimal contact with others outside clinic
- Info on genetic inheritance inadequate
- Career choice affected

Findings

- 11/17 had ankle stiffness
- RICE: understand concept, not pathology of joint bleeds or consequences of not treating

Recommendations

1. Continue present clinic format
2. Send appointment reminders
3. Protocol for timing of clinic reviews
4. See mild/moderates at appropriate transition time to ensure they are referred to adult facility
5. How to care for adolescent haemophilia carriers?

Recommendations

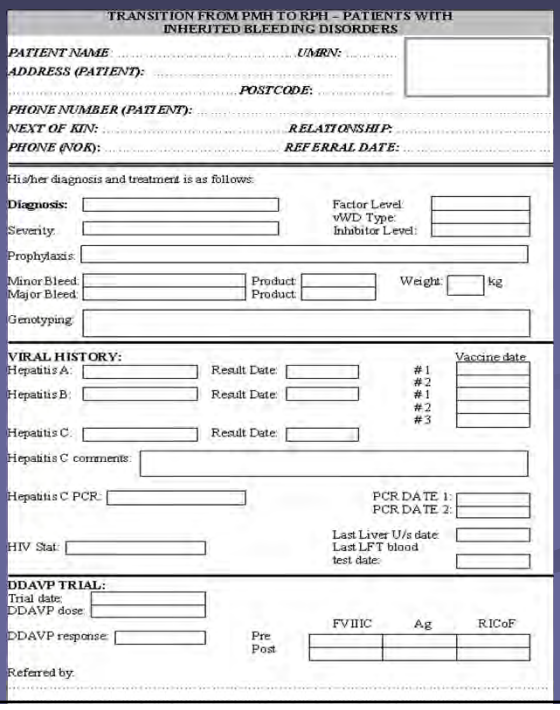
6. Develop a model of transition
   - written info on transition for families
   - early preparation by using a Skills Checklist
   - info on rights & responsibilities
   - orientation to adult facility
   - formal liaison between PHM & RPH prior
   - review of Skills Checklist at RPH

Recommendations

7. Further research into ankle stiffness
8. New patients to RPH receive education on pathology of a bleed
9. New patients to RPH assessed for base ranges of movement in all peripheral joints.

Implementation

- Referral



TRANSITION FROM PMH TO RPH – PATIENTS WITH INHERITED BLEEDING DISORDERS

PATIENT NAME: ..... *UMRN:* .....
ADDRESS (PATIENT): .....
..... *POSTCODE:* .....
PHONE NUMBER (PATIENT): .....
NEXT OF KIN: ..... *RELATIONSHIP:* .....
PHONE (NOK): ..... *REFERRAL DATE:* .....

His/her diagnosis and treatment is as follows:

Diagnosis: Factor Level:
Severity: vWD Type:
Inhibitor Level:
Prophylaxis:
Minor Bleed: Product:
Major Bleed: Product:
Weight: kg
Genotyping:

VIRAL HISTORY: Vaccine date
Hepatitis A: Result Date: #1 #2
Hepatitis B: Result Date: #1 #2 #3
Hepatitis C: Result Date:
Hepatitis C comments:
Hepatitis C PCR: PCR DATE 1: PCR DATE 2:
HIV Stat: Last Liver U/s date: Last LFT blood test date:

DDAVP TRIAL:
Trial date:
DDAVP dose:
DDAVP response: Pre Post — FVIIIC Ag RICoF
Referred by:

Health checklist

TRANSITION FROM PMH TO RPH – PATIENTS WITH INHERITED BLEEDING DISORDERS

HEALTH CARE SKILLS CHECKLIST

Patient details

Health Care Skills	Can Do Already Date	Needs Practice Date	Plan to Start Date	Accomplished Date
Able to describe inherited bleeding disorder.				
Able to recognise a bleeding episode and when to treat. Responsibility for when to treat prophylactically. Able to choose a vein, mix and prepare factor?				
Able to self-infuse. Know what product you treat with and dose. Can describe the consequences of untreated joint, muscle or major bleeds?				
Can identify target joints?				
Can identify physical abilities as well as restrictions and limitations related to bleeding disorder? Understand the benefits of exercise?				
Independently contact the Haemophilia Nurse when you have medical concerns?				
Know importance of annual visit to a haematologist.				
Can explain the genetics of bleeding disorder				

Health checklist

TRANSITION FROM PMH TO RPH – PATIENTS WITH INHERITED BLEEDING DISORDERS

Patient details

Health Care Skills	Can Do Already Date	Needs Practice Date	Plan to Start Date	Accomplished Date
Know which medications you can and cannot take				
Can order own factor and supplies Can ask questions and respond to questions of health care staff. Understand the importance of recording product usage and bleeding history				
Understand what to do when travelling. Have a plan for your move to the adult HTC and understand what might be different. Have had an appointment and orientation at the adult HTC?				
Feel ready to move to the adult HTC?				
Parents/guardians feel ready for your move to HTC? Understand your rights and responsibilities are in relation to medical care, education, employment and access to other services? Understand what services are available at the adult HTC? Understand the purpose of a Medic Alert bracelet?				

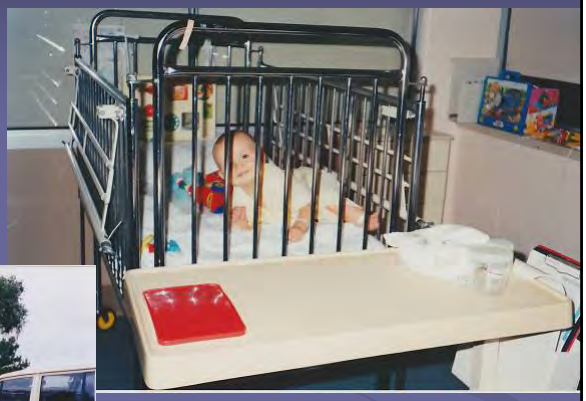
REFERENCE: Adapted from Adolescent Health Transition Project: www.depts.washington.edu/healthtr/checklist

Implementation

- Routinely completing genograms to identify possible carriers and providing information on how to access HTC
- SMS reminders unable to be implemented
- Letter sent to mild and moderate patients providing information about how to access the adult HTC.
- Recognition that learning is continual through life
- Recognition that knowledge needs to be continually reinforced.
- Recognition that information needs to be available and accessible in different forms.
- Morning teas at RPH welcoming and assist in orientation

My Transition

- I'm 18 years old
- Live in rural area in WA
- Uni next year



PMH first bleed 10 mths old 1994

Severe Haemophilia A

- First port around 1 year old
- Start of prophylaxis
- Last infusaport removed age 9
- Three ports in total

Port infusion 2000

Ayres Rock trip 2007

Playing in tennis tournament 2006

Mum, Dad and me after climbing the Porongurups 2009

Fox Glacier NZ 2010 with my brother Murray –he doesn't have haemophilia

My family on NZ trip

Year 12 Ball

Independence