

# The development of an Enhanced Family Based Transition Model from the adult hospital perspective : A WORK IN PROGRESS



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# WHAT IS TRANSITION?

- “Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems.”<sup>1</sup>
- “In the context of haemophilia, transition also refers to the continual process of learning about haemophilia and how to manage the many aspects of care. Transition is more complex for families living with haemophilia. Each stage of development involves extra learning for the parents and the child, and the comprehensive care team as well.”<sup>2</sup>
- “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.”<sup>3</sup>

1. Blum RWM. Chronic illness and disability in adolescence. *Journal of Adolescent Health* 1992;13:364-368.

2. ‘Transitions towards independence’. In: Canadian Hemophilia Society. *All about hemophilia: a guide for families*. 2<sup>nd</sup> edn. Montreal: CHS, 2010 <http://www.hemophilia.ca>

3. Spilsbury M, Chong D. Transitioning in Queensland: from teddy bears to apprenticeships! Presentation at the 16<sup>th</sup> Australian & New Zealand Haemophilia Conference, Sydney, 20-22 October 2011. <https://www.haemophilia.org.au/conferences>

# Stages of Transition – how we would like it to look!



## Transition program at the Royal Children's Hospital

- Thinking about the move to adult care, Transition Outpatient Clinic, Transition resources
- What are the differences between Adult and Paediatric care
- Thinking about developmental stage, type of care, physical environment, self determination, independence, level of family involvement, expectations from health care providers

## Pre-transition

- Planning with both teams
- Handover– a formal meeting
- What is the ideal format, is one clinic at each end adequate?
- Opportunity to get to know the adult team
- Chance to get to know the young people and their families

## Transition program at the Alfred

- Pre-transition information night
- Transition clinic
- The first year, try to see patients more frequently, about twice as often.
- follow up and feedback (including research about how the experience has been)

### Healthcare skills checklist

Transition Support Service

Name: \_\_\_\_\_ Date: \_\_\_\_\_

This checklist is for you to fill in with your Transition Lead or a member of the Transition Support Service team. It will help you to reflect what you know and identify any gaps in knowledge or skills that you will need to move smoothly to adult healthcare.

**My healthcare understanding**

Can I describe the different healthcare services I might need?

Can I describe the different healthcare professionals?

Can I describe the different healthcare settings?

Can I describe the different healthcare services I might need?

Can I describe the different healthcare professionals?

Can I describe the different healthcare settings?

Can I describe the different healthcare services I might need?

Can I describe the different healthcare professionals?

Can I describe the different healthcare settings?

### Readiness to transfer checklist

Transition Support Service

Name: \_\_\_\_\_ Date: \_\_\_\_\_

This checklist is for you to fill in with your Transition Lead or a member of the Transition Support Service team. It will help you to reflect what you know and identify any gaps in knowledge or skills that you will need to move smoothly to adult healthcare.

**My readiness to transfer**

Area	Yes	No	Not sure	Other
Can I describe the different healthcare services I might need?				
Can I describe the different healthcare professionals?				
Can I describe the different healthcare settings?				
Can I describe the different healthcare services I might need?				
Can I describe the different healthcare professionals?				
Can I describe the different healthcare settings?				

### Healthcare transition plan

Transition Support Service

Name: \_\_\_\_\_ Date: \_\_\_\_\_

This checklist is for you to fill in with your Transition Lead or a member of the Transition Support Service team. It will help you to reflect what you know and identify any gaps in knowledge or skills that you will need to move smoothly to adult healthcare.

**My healthcare transition plan**

Area	Yes	No	Not sure	Other
Can I describe the different healthcare services I might need?				
Can I describe the different healthcare professionals?				
Can I describe the different healthcare settings?				
Can I describe the different healthcare services I might need?				
Can I describe the different healthcare professionals?				
Can I describe the different healthcare settings?				

### Transfer to adult services passport

Transition Support Service

The Alfred Children's Hospital Melbourne

Name: \_\_\_\_\_ Date: \_\_\_\_\_

This passport is for you to fill in with your Transition Lead or a member of the Transition Support Service team. It will help you to reflect what you know and identify any gaps in knowledge or skills that you will need to move smoothly to adult healthcare.

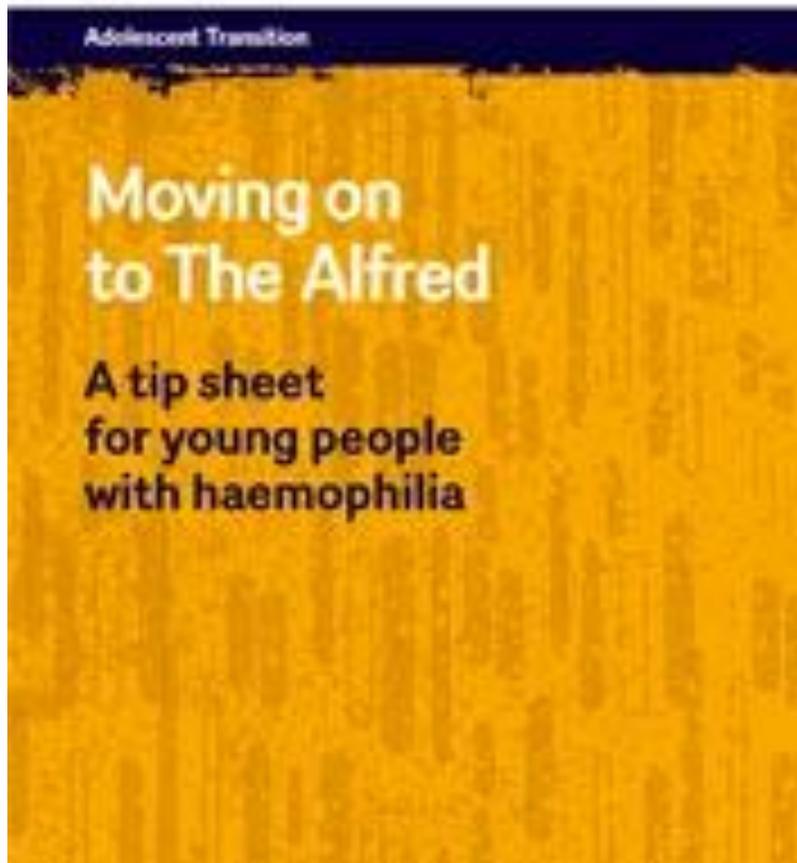
Area	Yes	No	Not sure	Other
Can I describe the different healthcare services I might need?				
Can I describe the different healthcare professionals?				
Can I describe the different healthcare settings?				
Can I describe the different healthcare services I might need?				
Can I describe the different healthcare professionals?				
Can I describe the different healthcare settings?				

[https://www.rch.org.au/transition/factsheets\\_and\\_tools/resources/](https://www.rch.org.au/transition/factsheets_and_tools/resources/)

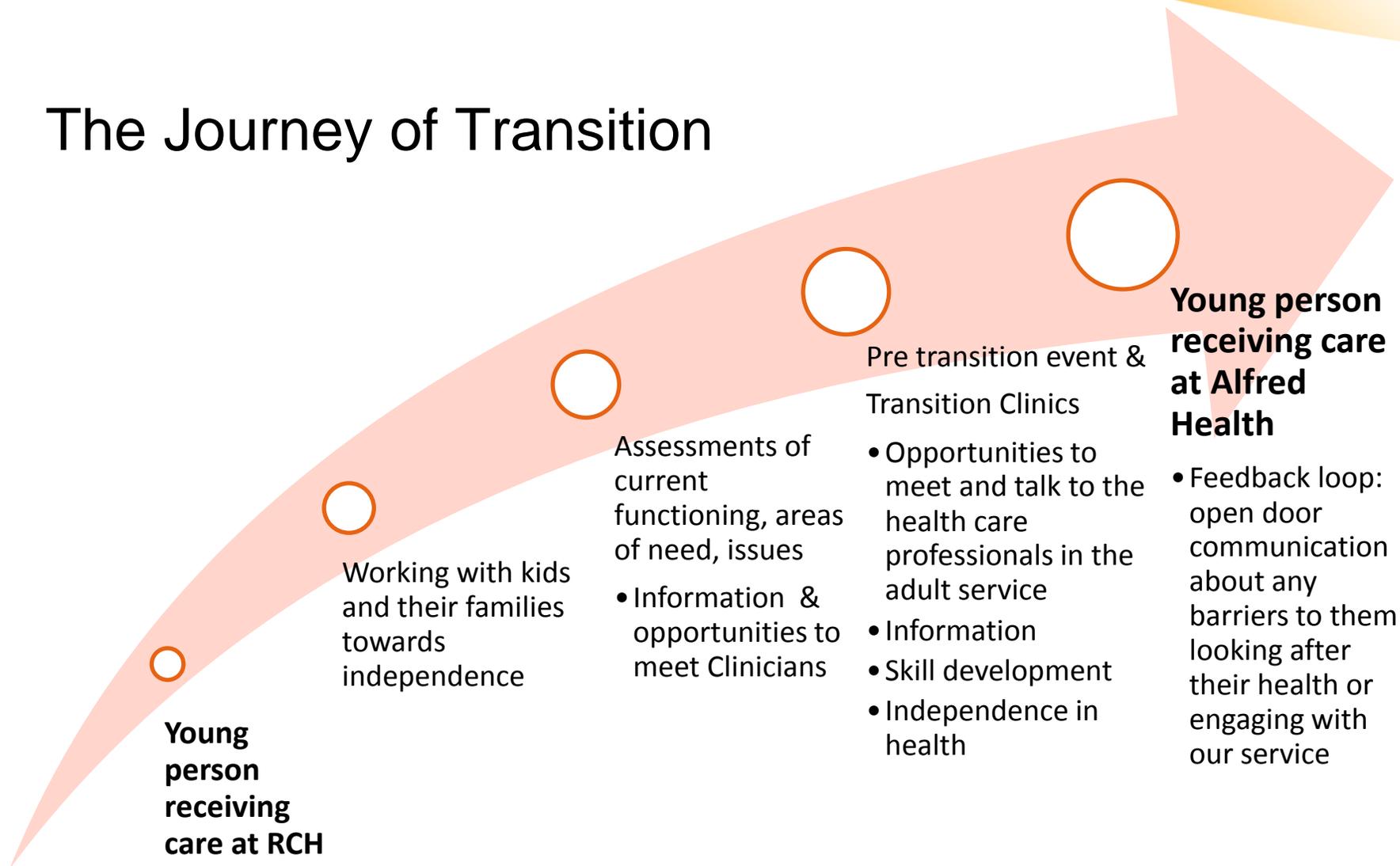


## Quick Tips

- Don't be afraid to ask questions or contact your new Haemophilia health care team as they are very helpful.
- Allow plenty of time for your first appointment and familiarise yourself with The Alfred and the clinic's new systems.
- Remember that you're at an adult hospital and most other patients will be a lot older than you may be used to.
- At the Alfred, be prepared to be treated like an adult.
- Enjoy your independence and don't be afraid if you make the occasional mistake because your health care team are there to support you.



# The Journey of Transition



# What the research tells us?



- A Cochrane Review found that “Transitional-care programmes led to little or no difference in health status, quality of life or well-being, or rates of transfer from child to adult health services.” (N 238 patients) However as there research was only short term, less than 12 months the benefits may not have been evident as yet. Campbell F, Biggs K, Aldiss SK, O'Neill PM, Clowes M, McDonagh J, While A, Gibson F. Transition of care for adolescents from paediatric services to adult health services. Cochrane Database of Systematic Reviews 2016, Issue 4.
- Studies have shown that up to 25% of young adults that have been transferred to adult health care do not regularly attend follow up visits in the hospital. (Sattoe JNT, Peeters MAC, Hilberink SR, et al, Evaluating outpatient transition clinics: a mixed-methods study protocol, BMJ Open 2016)
- “While adolescents become increasingly responsible for their own health, they generally show poor treatment adherence, which puts them at risk for poor health outcomes.” (Sattoe JNT, Peeters MAC, Hilberink SR, et al, Evaluating outpatient transition clinics: a mixed-methods study protocol, BMJ Open 2016)
- The experience of Renal care in the UK has been interesting as they have demonstrated that innovative, relevant transition programs are able to make a significant difference on health outcomes. (Harden, P, Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure, *BMJ* 2012; 344)

## The Canadian Model

# 13

Transitions Toward Independence

This chapter provides answers to these questions:

### PART 1 – Transitions from birth through the teenage years

- What is transition?
- Why is transition called an ongoing journey?
- What important transitions occur in the teenage years?

### PART 2 – Transition to adulthood and adult care

- How does care change with the transition to an adult hemophilia program?
- When does the transition to adulthood and adult care begin?
- What is the parent's role in the transition to adulthood and adult care?
- How does the care team facilitate the transition to adult care?
- What other resources are available to assist the transition to adult care?

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## What the TRxANSITION Index Measures

Type of chronic health condition

Rx/Medications

Adherence

Nutrition

Self-management skills

Issues of reproduction

Trade/School

Insurance

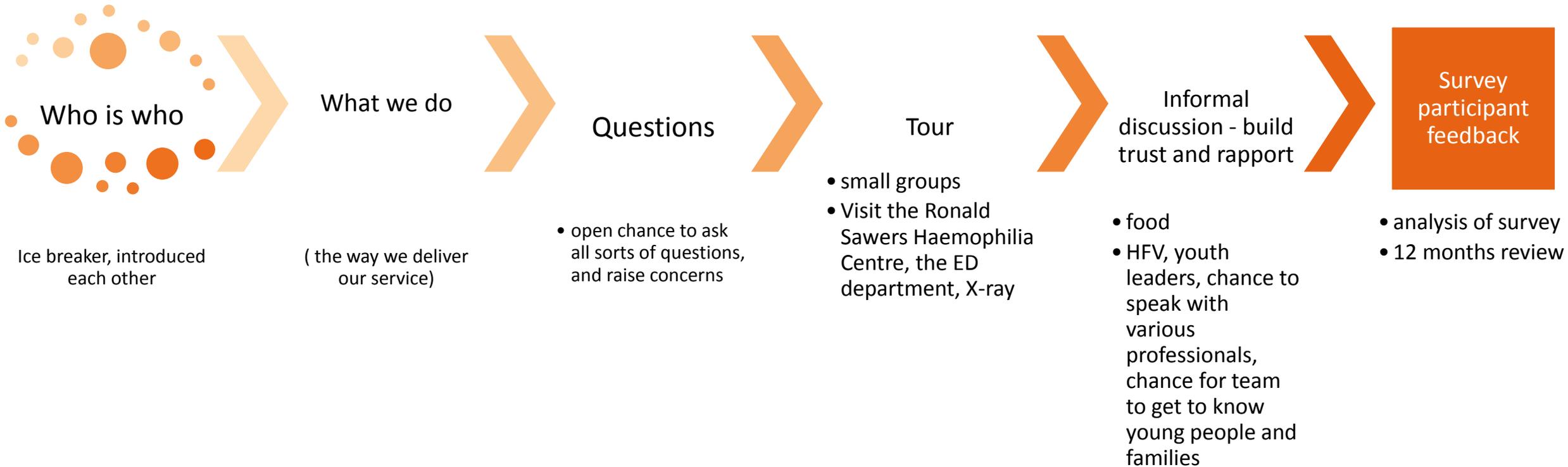
Ongoing Support

New health care providers

Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)

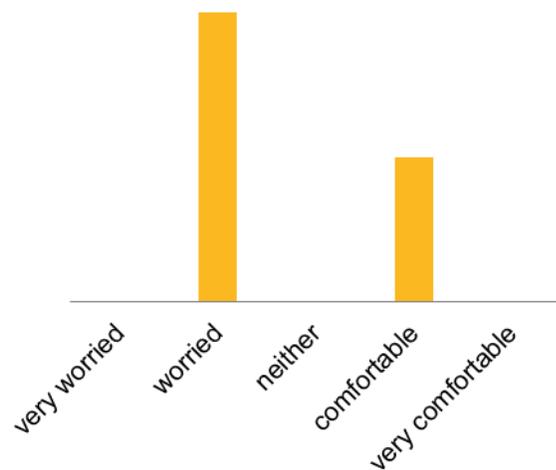
Watson, A.R., Harden, P., Ferris, M. et al. *Pediatr Nephrol* (2011) 26: 1753.

# The Pre Transition Night: ON THE NIGHT

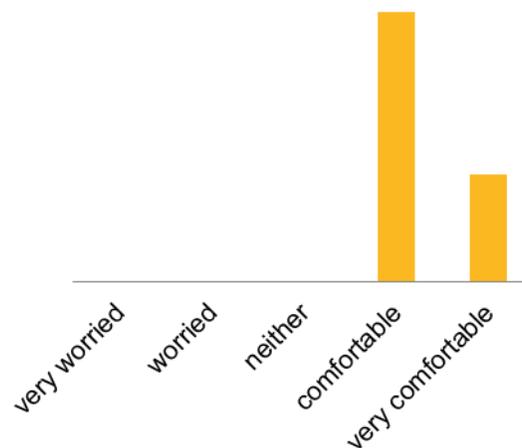


## Survey - Impact of Pre Transition session

**Prior to this session how did you feel about changing to the Ronald Sawers Haemophilia Centre?**



**After tonight how do you feel about changing to the Ronald Sawers Haemophilia Centre?**



n = 8 respondents

“Glad to be reassured we parents will still be involved to whatever level our son is comfortable with”

“learnt a lot about the condition – found some of my previous ideas wrong”

# Communication

## Key factors

- Tech savy
- Keep it short, get to the point
- Be authentic, respectful and listen,
- Recognize when they are doing well, praise
- Choose the best medium for communication (Millennials prefer text and social media communications over email, phone calls and face to face meetings)
- Be responsive
- Use visuals as well as words

<http://franchetti.com/communicating-with-millennials>



## Our current communication points

- Brochure
- Website
- Text messages
- Face to face
- Articles in HFV and HFA publications
- Input in forums on lineT
- Telehealth



Thanks

