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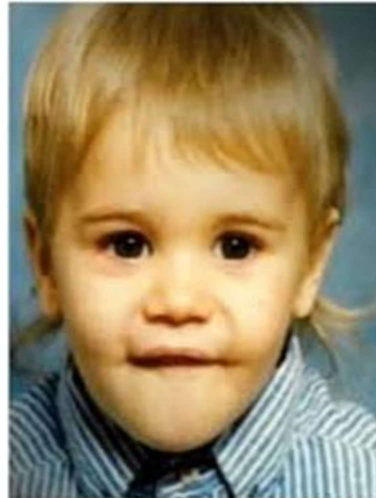
ACHD Symposium 30th November 2017

Paediatric care…



Adolescence & Young Adulthood

Hormones

Adherence issues

Risk-taking

Drugs
Smoking
Alcohol

Sexual health

Other life transitions

2013 CSANZ Recommendations for Standards of Care

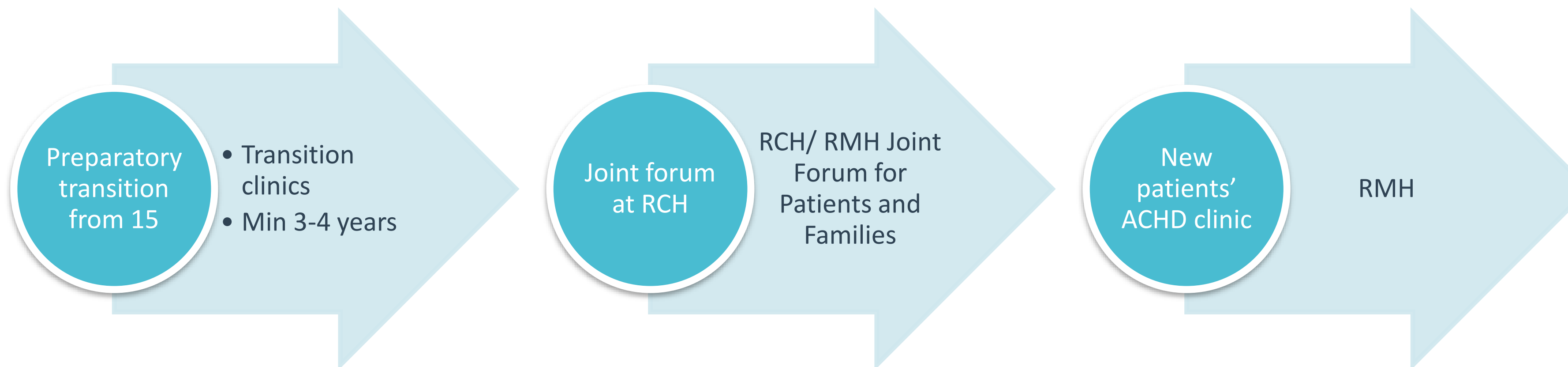
Key priorities:

1. Planning of Transition of Care from paed to adult CHD services
2. Establishing & maintaining Comprehensive and Regional ACHD services

Transition models of care (Melbourne)

Htx

Fontan and other CHD



Fontan Transition Study – Preliminary Findings 2013 (YP 15-18 n=13 + Parents n=14)

- Significant gaps in knowledge of health condition & treatment
  - 38% were unable to provide their correct cardiac diagnoses
  - 85% did not know what a Fontan circulation was
  - 46% were unable to provide detail about their medications/treatment
  - 23% had never had discussions with their doctors about smoking, alcohol or pregnancy

- Low levels of self-management with healthcare needs
  - 36% would not know who to contact or how to get in touch with their healthcare team
  - 92% saw their doctors always in the presence of their parents
  - 32% reported that they were not confident discussing their health condition

- Anxieties and concerns regarding transfer to adult care
  - 47% YP did not feel that they were well prepared for transfer
  - 61% YP reported they felt anxious about transfer
  - 93% parents felt anxious about transfer

Du Plessis, K., Culnane, E., Peters, B., d'Udekem, Yves., *'Adolescent and Parent perspectives prior to involvement in a Fontan Transition Program',* International Journal of Adolescent Medicine and Health, 2017

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International Journal of Adolescent Medicine and Health

Fontan and CHD Transition Developments across Australia and NZ

Victoria:

- Transition clinics for all Fontan patients 15+ years
- Online youth support group
- Phone interviews and surveys of transferred patients
- Fontan transition resources for patients & families
- CHD Transition Project (VCCN, VCPN, RCH and RMH)
- ACHD Transition Project (VCCN, RMH, RCH)
- Psychological support for Fontan (CHD) patients - study

New South Wales:

- Fontan (CHD) Transition nurse at Westmead Children's Hospital – adolescent clinic once a month (paed/adult cardiologist last paed appt)
- Workshops for young women with Fontan
- Transition resources and staff education

SA:

- Fontan (CHD) Transition nursing roles at Womens' & Children's Hospital
- Transition Policy (WCHN) and transition resources
- Pre-emptive transition planning

Transition model of Care (New Zealand)

- All major centres have paediatric cardiology outreach clinics
- Adolescents are referred from these clinics to adult cardiac services (often a specific cardiologist) at the local centre for ACHD follow-up
- Move to adult services at 15 years of age
- Regional outreach transition clinics
  - Regular transition clinics in Auckland
  - Outreach transition clinic in Christchurch

Auckland Transition Clinic Model

- Small numbers booked for the clinic
- No medical tests
  - Usually no formal medical assessment
- Sit down and have a conversation
- Meet the new team
  - Cardiologist(s), Nurse practitioner, Psychologist
- Usually ACHD clinic appointment 6 months later

What some of our young adults have told us about transition

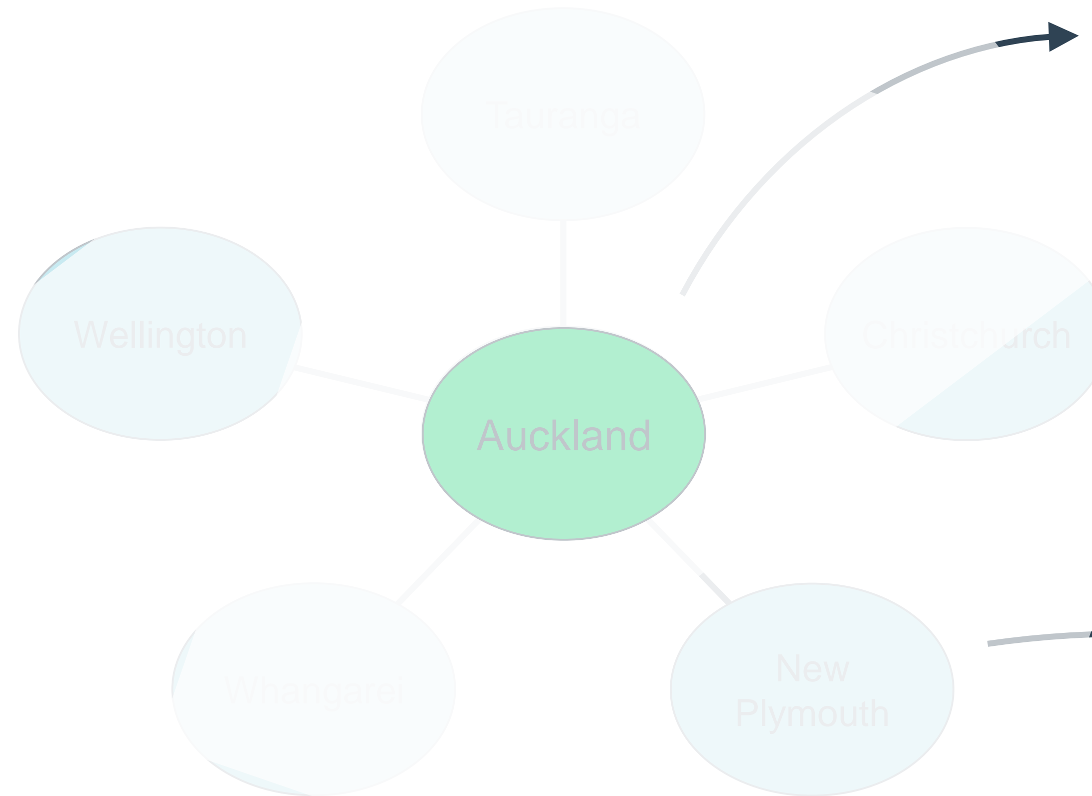
I’m excited to take on more, but my mum is spinning

I’m so scared about the future I could die

Congratulations you are going to adults is what they said…
is that it!

ACHD in New Zealand
Hub & Spoke Model

- General cardiology (large centre)
- Regular ACHD clinic
- MRI
- ACHD outreach clinic



- ACHD Cardiology
- Cardiac Surgery
- Catheterisation
- Transplantation
- EPS
- MRI

- General cardiology (Small centre)
- ACHD outreach clinic

Transition Enablers

- “Whole of Life” approach to care – including preparatory transition support and individualised follow up in ACHD service
- Close collaborations between paed and adult services
- Employment of Transition Nurse (in paed AND adult service)
- Holistic approach to transition care which includes access to psychological, psychosocial and educational/vocational supports
- Patient/family-held medical information
- Shared information amongst all care providers (national health record?)
- Regular and trusted GP

How do we achieve this?

- Pre-emptive transition processes and interventions commencing during early adolescence – screening, capacity building, patient & family centred
- Care coordination and early transition planning for complex patients
- Joint paed & adult transfer systems
- Ongoing evaluation of process and collection of data to assist with justification of ongoing resources for transition care – consumer feedback, outcome data post transfer (e.g. attendance rates, ‘avoidable’ ED presentations for cardiac complications) and building a sustainable funding model

Questions?

Melbourne Children's

A world leader in child and adolescent health