Your CF Transition from Child to Adult Care:
Challenges, Developments and Learnings

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What should good transition feel like?
What Should Good Transition Feel Like?

Supported, welcomed, clear about legal processes, needs met like comfortable, like high school transition, no pressure, timely, no pressure, transparent, informed, like high school transition, supported, best, sure, confident, safe, united, tailored, confident, prepared, compassionate, trust, informed.
Transition Support Service
(RCH Melbourne)

- The Team – Manager, Coordinator, Youth Mentors (2.4 FTE)
- Transition clinics across all departments (1300+ YP & Families each year)
- Early preparation, planning, support, care coordination
- Holistic focus with goals setting – emotional, educational, social
- Foster paed/adult service collaborations
- Projects and Research
- Clinician education & support
Take a deep breath for the future
Your continued cystic fibrosis (CF) care
Learnings

- Structured transition programs were associated with improved satisfaction, self-care and self-advocacy skills, independence and lower anxiety – positive experience.
- Young people were concerned about leaving behind paediatric CF providers, differences in care and infection risks.
- Lack of preparation for transition was a consistent theme.
- The most useful aspects of transition programs were:
  1. Meeting the adult CF teams
  2. Visiting the adult centre

Coyne et al., *Improving Transition to Adult Healthcare for Young People with Cystic Fibrosis: A Systematic Review*, Journal of Child Health Care, 2017 (London, Dublin)
Learnings

- **Cystic Fibrosis** – these elements lead to effective transition:
  1. Early transition planning
  2. Coordinated approach with all involved including young people and their families
  3. Detailed communication and transfer of information
  4. Feedback between paediatric and adult teams
  5. Ongoing audit of transition process

(*Towns & Bell, 2011*)
CF & Respiratory Transition

**CYSTIC FIBROSIS**
- Preparatory transition from 15
  - Transition clinics
  - Min 3-4 years
- Transition clinic at RCH (1-2)
  - ALFRED & MONASH
- Opportunity to visit adult service prior to transfer
- Orientation to the adult service
- Continue transition at the adult service
- OTHER??

**Other Respiratory**
- Preparatory transition from 15
  - Transition clinics
  - Min 3-4 years
- Joint clinics at RCH
  - ROYAL MELBOURNE & AUSTIN
- Feedback from patients, families, clinicians
  - Transfer to Adult Service
SO here I am, almost at the end of my RCH journey. If a journey of a thousand miles begins with a single step, then the journey that started 18 years ago will continue to be as eventful, thought provoking and challenging as it has been so far. I will take with some wonderful memories and am grateful that those who have been part of the journey have done such a wonderful job to prepare me for what is to come…
Transition has made me realise how much of a strong bond I had with my team at the Children’s and how different it’s been talking about the most personal thing in my life, my health with my brand new team.

It’s confronting and sometimes scary but I feel as though I’m equipped to do so after being involved in the transition clinics. So far I’ve made it a year on my own, so haven’t done too badly I guess??”
Where to next?

- Continual improvements in transition care
- International Interdisciplinary Transition Study 2018 – 2021: retrospective and prospective
Key messages

1. Increased knowledge, confidence, skills = empowerment

2. You have a voice; ask questions

3. Start transition discussions and planning early
THANK YOU