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# Adjustment Difficulties in Young People with Congenital Heart Disease

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# Paediatric Psychosocial Service @ RMCH

- Input into the Paediatric Cardiology Service as part of wider Paediatric Psychosocial Service – funded service from January 2020.
- Input from a range of clinicians (Clinical Psychologists, Psychological Therapists, Child Psychotherapist) who all work across many specialties as well as Cardiology.
- In 2020 we received 17 referrals for direct psychological support (14 outpatient and 3 inpatient).
- Indirect work has included liaison with cardiology team and hospital staff, outside agencies (school, social care, etc.) and occasional joint work in clinics.



# Psychological Effects of Chronic Illness

Research has shown...

- Children with a chronic illness are twice as likely to present with psychological difficulties
- Mothers of children with a chronic illness have poorer mental health
- Siblings of unwell children have higher levels of mental health problems
- Diseases with high probability of fatality are associated with higher levels of psychological disorder in both children and parents

*Ordinary people in exceptional circumstances (Eiser, 1990)*

## What does it Mean to Adjust to Chronic Illness?

### Process of Adjustment:

- Multiple life domains (home, school, social)
- Changes over time (age, stage of development)
- Heterogeneity of individuals

(Stanton et al. 2007)

### Adjustment Difficulties:

- Internalising Behaviour
- Externalising Behaviour

### Quality of Life:

Subjective perceptions of social, emotional and cognitive (and physical) functioning

## Risk Factors for Adjustment Difficulties

Avoidant coping  
strategies

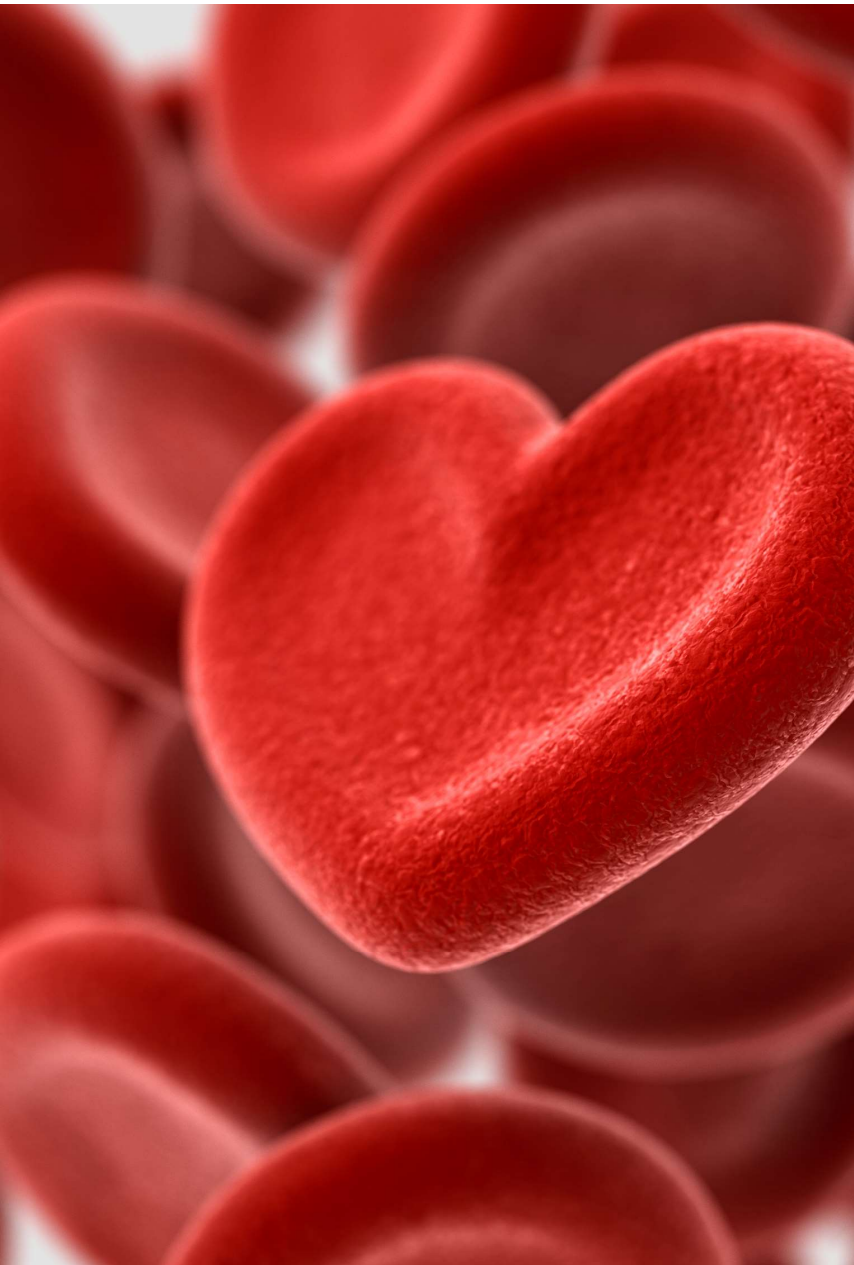
Higher levels of  
distress

Low levels of  
social support

Poor sense of  
control

Parental  
depression or ill  
health

Poor  
relationship with  
medical team



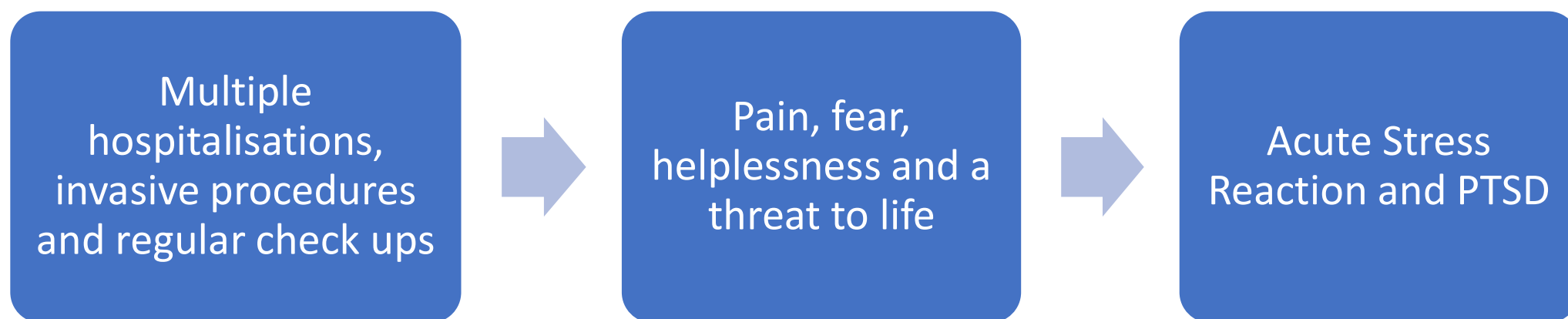
## Psychosocial Adjustment in CHD

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- Higher risk of developing emotional and behavioral problems
- Females show worse adjustment than males
- More severe CHD = worse adjustment
- Surgical procedures = worse adjustment
- Poor social support = worse adjustment
- Physical limitations = worse adjustment

(Freitas et al. 2013)

## Impact of Traumatic Events



*“In the face of a significant and potentially traumatic medical event, nearly all children & parents will experience a period of adjustment and challenge likely to include some acute stress reactions”* (Winston et al, 2002)



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## Impact of Trauma in Children with CHD

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**12-31%** children undergoing cardiac surgery develop PTSD

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**12-14%** experience post traumatic stress symptoms

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Negative impact on medical adherence

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Can lead to re-hospitalisations, sleep difficulties and reduced QoL (*Meentken, et.al 2017*)



## Protective Factors



Family's understanding of the illness



Opportunity to discuss and manage illness at a developmentally appropriate level



Opportunity to express feelings and concerns about illness



Open and honest communication with the family/medical system



Good social supports



Able to participate in normal childhood activities



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***“Apart from being unlucky enough to get ALS... I have been fortunate in almost every other respect. The help and support I have received... have made it possible for me to lead a fairly normal life...”***

Hawking 1988.

## Treatment Adherence

Non-adherence rates = approx. 50%



Evidence of selective adherence



Impacts on clinical care



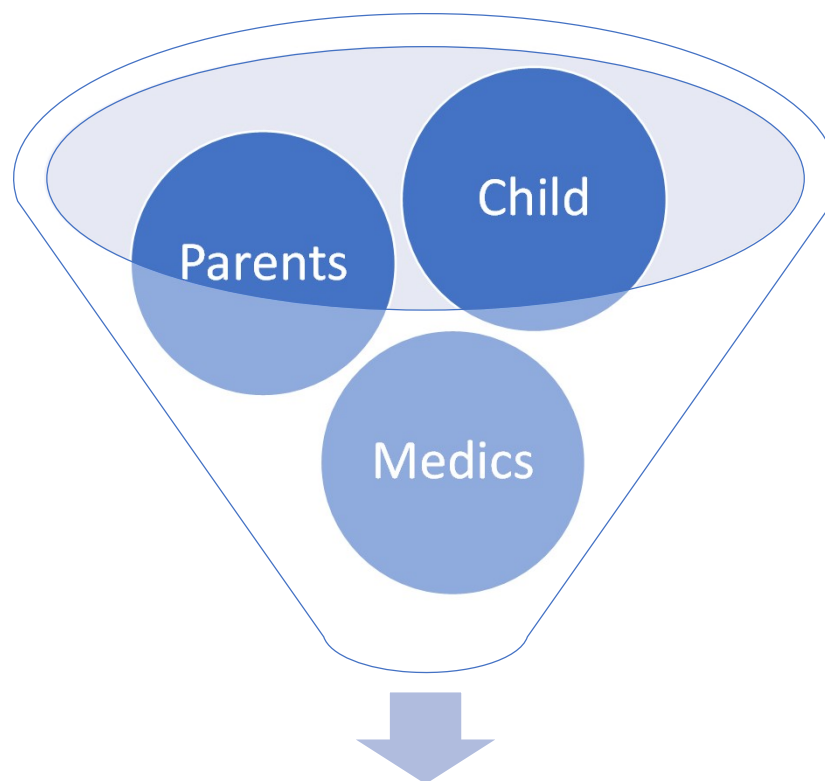
Financial and time cost



Major reason for psychological referral

## Treatment Adherence

Challenging problem with many views to consider...



More helpful to view adherence on a continuum and look at partial rather than complete/incomplete adherence

## Case Example

- Sophie (age 12) – Born with CHD (coarctation of the aorta) and has high blood pressure
- Mum, dad and younger brother at home – no health issues
- Referred due to concerns low in mood
- Recently had some time away from school due to number of hospital appointments
- Withdrawn and quiet, not going out with friends anymore
- Tearful and asking “why me?” in relation to heart condition
- Some non-adherence to medication
- Struggling to fall asleep and waking in the early hours

# Assessment

- Meeting with parents and Sophie
- Understanding the things that were important to Sophie – school, friends, interests, future plans
- Finding out what difficulties may have arisen in Sophie's life – both in relation to her heart condition and other aspects of her life
- Exploring Sophie's history of and understanding of her health condition
- Exploring Sophie's self-concept and self-esteem
- Exploring any concerns parents have
- Liaison with school with permission from family

## Formulation

- Changes in Sophie's friendship group have left her feeling more anxious and less confident in self – missed time from school meant less opportunity to be as “involved” with friends
- Nasty messages on social media between peers including judgements on appearance and “laziness”
- Worries about being different and not wanting people to know about medication
- Gaps in Sophie's understanding of her heart condition – worries that it will limit activities with friends, e.g. sleepovers, trampolining, and sad about managing a lifelong condition
- Mum very worried about Sophie's future and sad about limitations on her life due to heart condition – can lead to wanting to “protect” and keep her home
- School shared that new netball club has started but have prevented Sophie from attending due to her heart condition.

## Intervention

- Offered direct psychological therapy to Sophie
- Sleep hygiene information given
- Exploration of motivation to adhere to treatment
- Use of ACT (Acceptance and Commitment Therapy) to support Sophie to adjust to living with a long term health condition and still live a full and meaningful life in line with her values
- Brief therapy sessions with mum to support her with feelings of “loss” in relation to Sophie’s future and support her to allow Sophie’s independence
- Information given about charitable organisations and support groups for mum and Sophie to meet with other parents and children with heart conditions
- Consultation with the medical team around Sophie’s activity levels and what extent she can participate in sports in and out of school
- Liaison with school to explore other ways Sophie can be involved in netball, such as umpire



# ACT (Acceptance and Commitment Therapy)

- Improving quality of life by considering values and what is important despite difficulties faced.
- Changing the way we approach difficult thoughts and feelings
- Tug of war with a monster
- Walking in the rain
- Using values as a compass
- Finding ways to stay focused on what's important





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**Any questions?**