

The psychological impact of Congenital Heart Disease (CHD)



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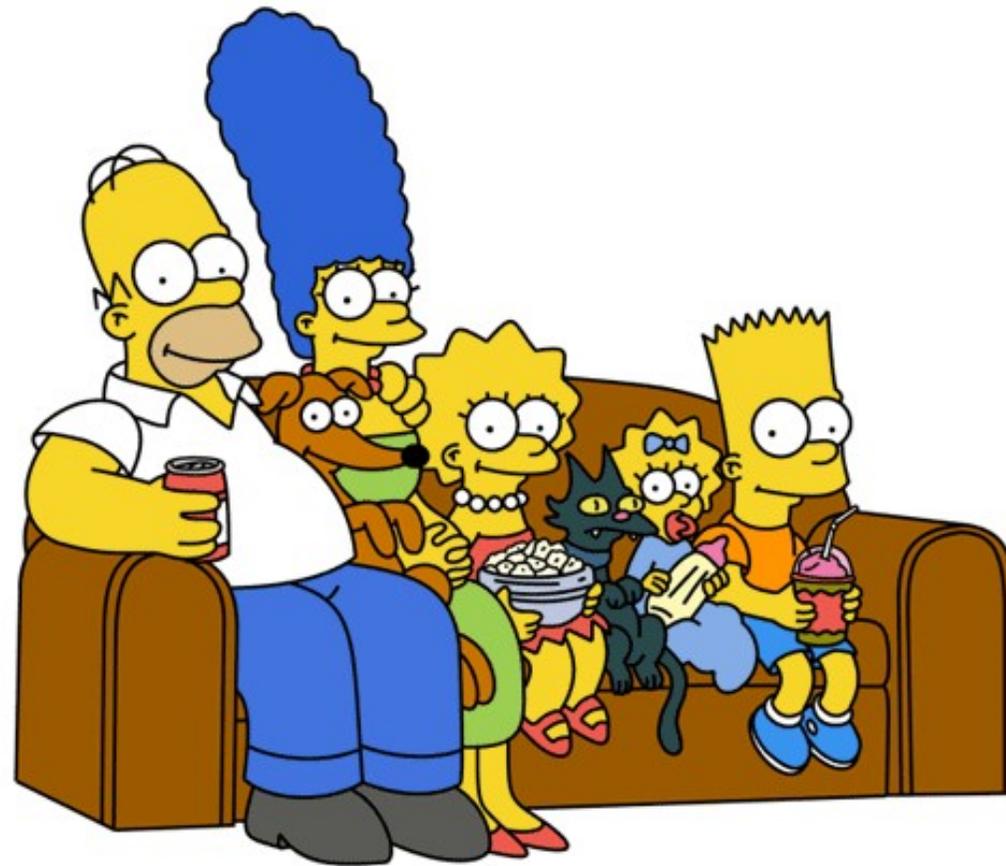
Inspired by Children

Aims

- **Enhance understanding of the psychological impact of CHD for children/young people, parents and siblings**
- **Case-study: Jennifer**
 - Assessment, Formulation and Intervention



CHD impacts the whole family...

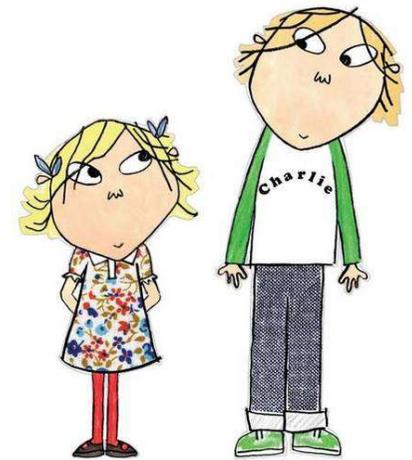


...throughout the lifespan



Psychological impact?

- Child/young person
- Parents
- Siblings



Inspired by Children

Child/young person

Social difficulties

Cognitive/
educational difficulties

Somatic complaints

Trauma

Adjustment to diagnosis

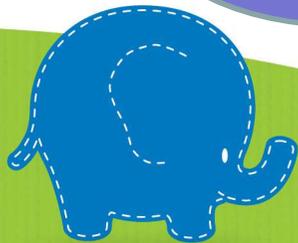
Self-concept issues

Externalising
(behavioural) difficulties

Attachment

Internalising
(emotional) difficulties

Hypervigilance



Parent/guardians

Adjustment to diagnosis

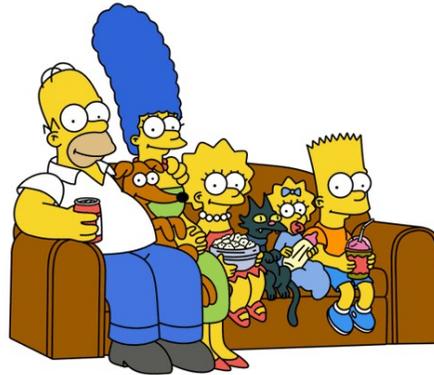
Loss/grief responses

Impact on parental relationship

Trauma

Parental mental health considerations

Attachment

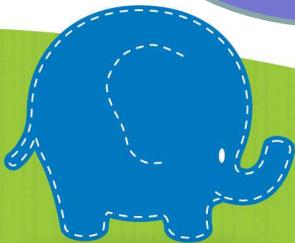


Practical concerns

Managing illness

Managing emotional/behavioural difficulties

Hypervigilance



Inspired by Children

Siblings

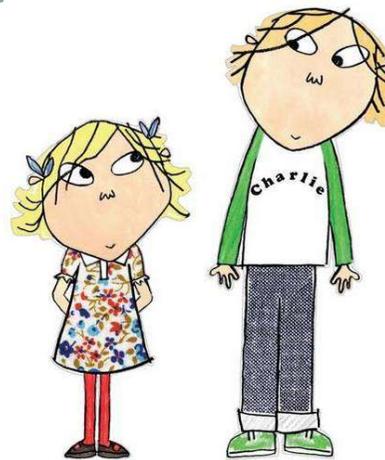
Positive impact

Loss/grief responses

Somatic complaints

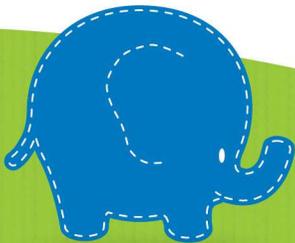
Internalising of problems

Externalising of problems



Genetic considerations

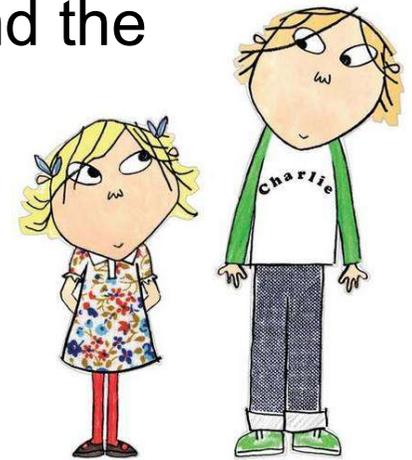
Changes to sibling relationships (e.g. jealousy)



Inspired by Children

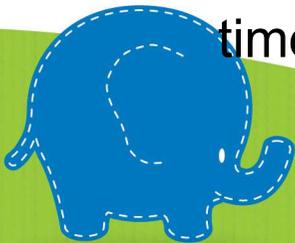
Case- Study: Jennifer

- 1 month old
- Post natal diagnosis of Tetralogy of Fallot (ToF).
- Mum was referred to psychology by the Cardiac Liaison Nurse for support due to mum's distress, but also due to difficulties in the relationship between mum and the medical team



Assessment

- Asking mum for a full history, including:
 - pregnancy experience, info given at scans, birth experience, when mum/parents first started to realise something was not right, mum's experience of Jennifer's diagnosis of ToF- initial thoughts/feelings, mum's understanding of ToF and what this means to her, the plan going forward for Jennifer- medication/surgery, experience of being in hospital with Jennifer, and of the hospital environment/medical team.
- Other:
 - Past mental health difficulties, employment, current support (family/friends), current mood (what have they found helpful/unhelpful in managing mood?), risk
 - Asking the question of what mum feels is needed from me at that time.



Formulation

Pre-disposing factors:

- Mum's pre-existing anxiety
- Mum's history of attachment difficulties
- Jennifer's post-natal diagnosis of ToF and subsequent distress associated with this

Protective factors:

- Good family support
- Good relationship with GP
- Keen to engage in psychology

Presenting issues:

- Mum's difficult relationship with the medical team:
Mum presenting as frustrated and distrusting of the medical team and expressing feelings of anger towards the team

Perpetuating factors:

- Perceived lack of communication from the medical team
- Feeling the medical team did not understand parental experience
- Mum not having any strategies to help manage anxiety
- Fear and distress about Jennifer's surgery

Precipitating factors:

- Mum's lack of, but desire for, control
- Mum wanting to attribute blame on something/someone for Jennifer's diagnosis- leads to shouting at the medical team

Intervention

Giving mum a space to offload and process

Coordinating meetings/ communication between parents and medical team

Responding to emotional distress

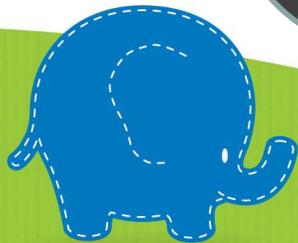
Validation

Anxiety management work

Preparation for surgery

Psycho-education

Sharing psychological formulation with the medical team



Welcome to Holland

by Emily Perl Kingsley

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills.... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.

Thank you for listening
Any questions?

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