

# The psychological impact of Congenital Heart Disease (CHD)



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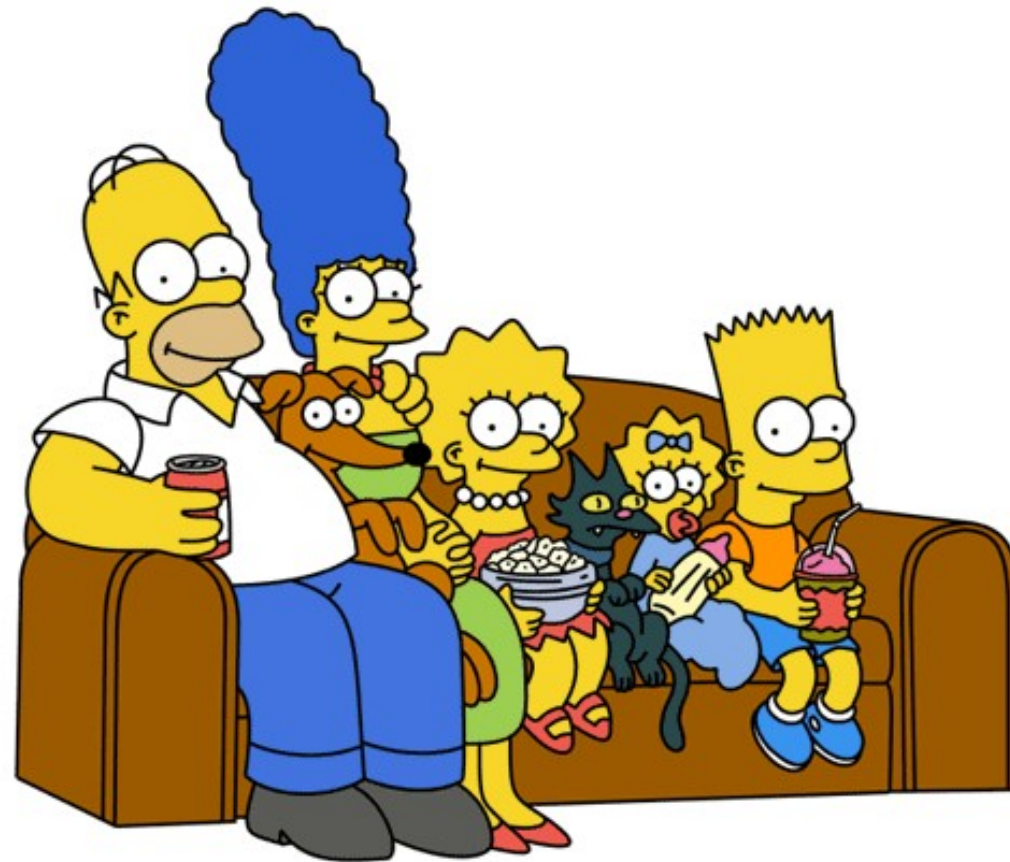
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# Aims

- **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...

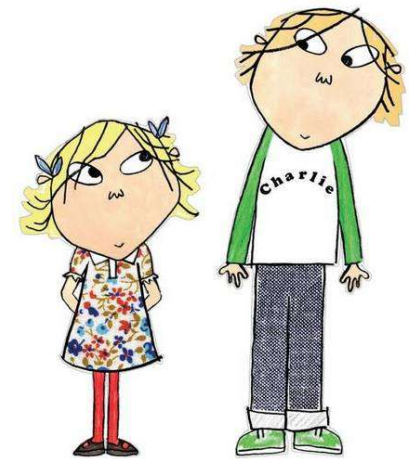


...throughout the lifespan



# Psychological impact?

- Child/young person
- Parents
- Siblings



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# Child/young person

Social difficulties

Cognitive/  
educational difficulties

Somatic complaints

Trauma

Adjustment to diagnosis

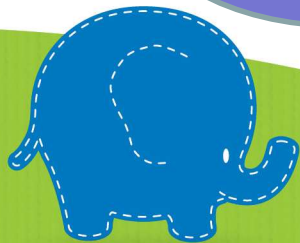
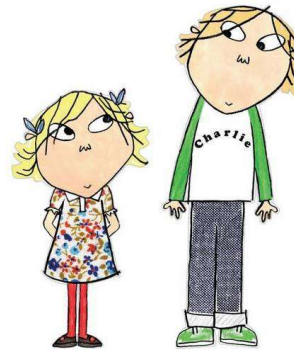
Self-concept issues

Externalising  
(behavioural) difficulties

Attachment

Internalising  
(emotional) difficulties

Hypervigilance



# Parent/guardians

Adjustment to diagnosis

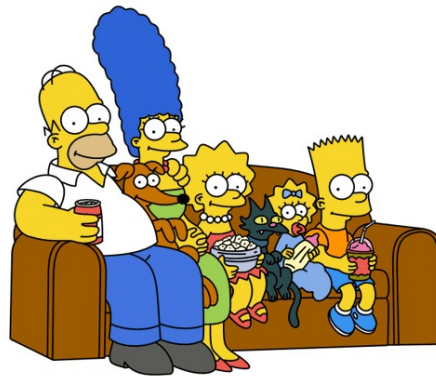
Loss/grief responses

Impact on parental relationship

Trauma

Parental mental health considerations

Attachment



Practical concerns

Managing illness

Managing emotional/behavioural difficulties

Hypervigilance



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# Siblings

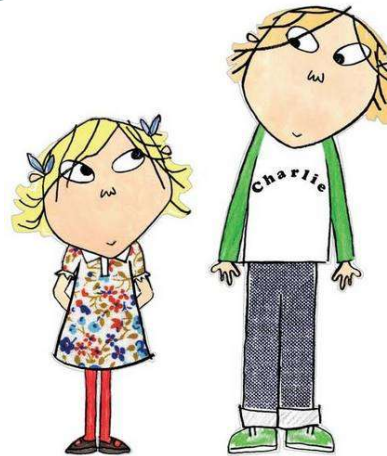
Positive impact

Loss/grief responses

Somatic complaints

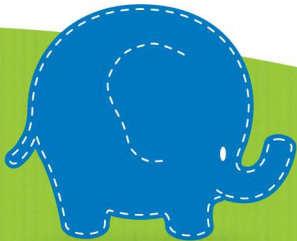
Internalising of problems

Externalising of problems



Genetic considerations

Changes to sibling relationships (e.g. jealousy)

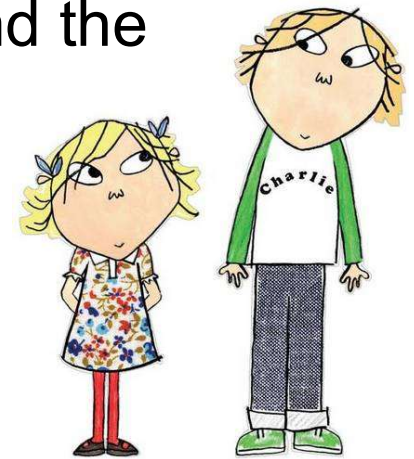


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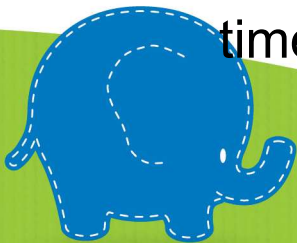
# Case- Study: Jennifer

- 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

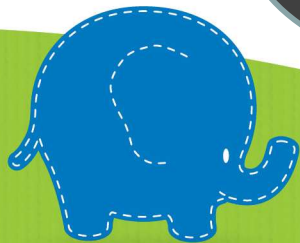
Validation

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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