

Psychological Impact of CHD: Early experiences matter

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CHD: Living longer, better.

- Those with Congenital Heart Disease (CHD) are surviving & living longer.
- Medical advances also mean improvement in severity of disease.
- But having a longer life and less severe disease does not actually correlate with increased psychological wellbeing of families and children with CHD (Utens & Levert, 2015).
- So how as HCPs can we support those living with CHD to have a good quality of life and support their future psychological wellbeing?; How can we help them Live Longer, Better?
- Huge scope of psychological impact of CHD from birth to adulthood, from diagnosis to end of life.
- Where to begin? Thinking about what impacts at the very beginning: supporting families to cope with diagnosis, and supporting the parent-child relationship, considering the impact of this later in the journey.

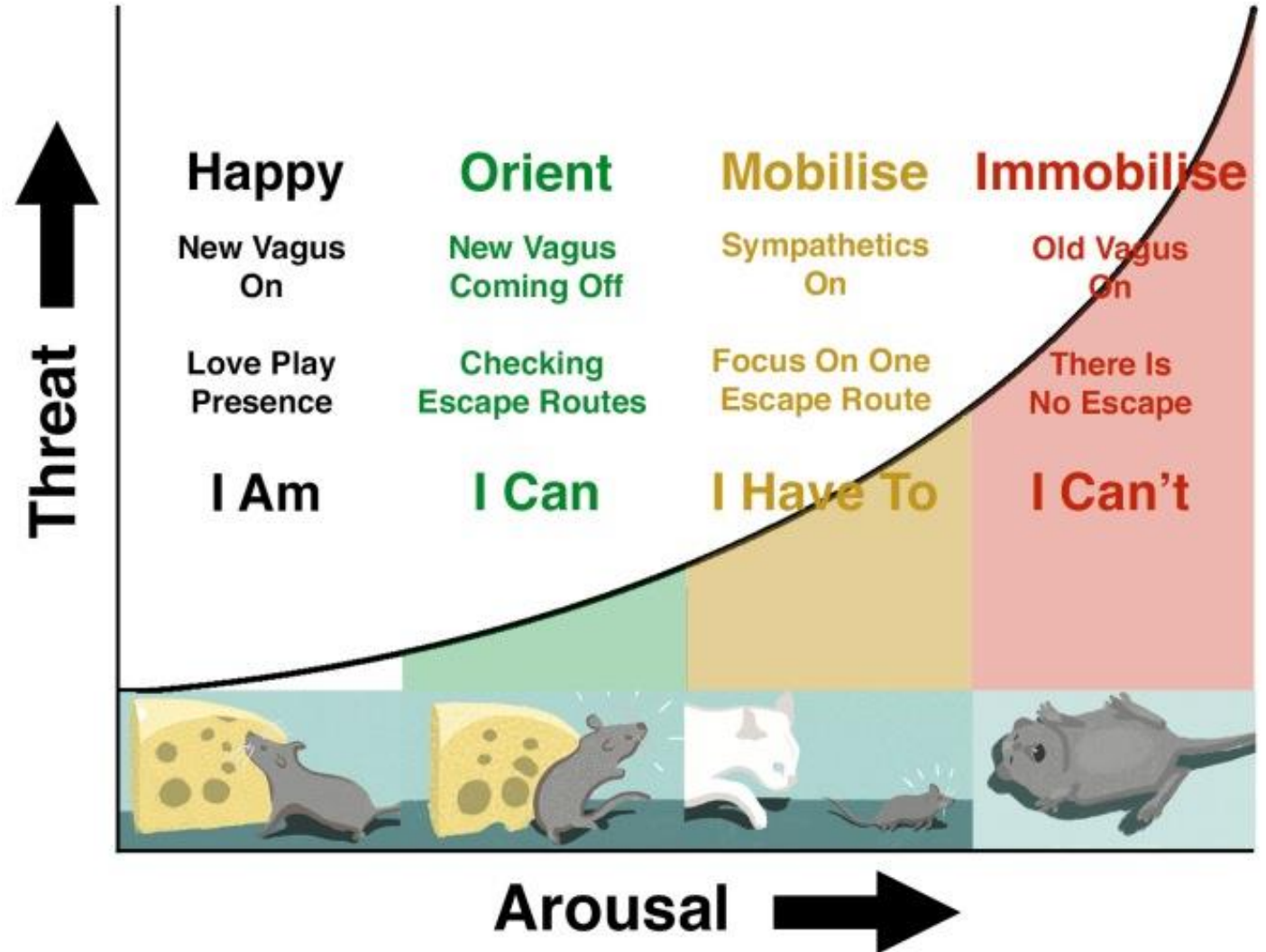
Diagnosis: parents dealing with a “broken heart”

- Parents speaking about their experiences: <https://healthtalk.org/parents-children-congenital-heart-disease/overview> (BHF interviews)
- The heart is symbolic; the meaning of having a child with a heart condition is unique to each parent.
- At CHD diagnosis overwhelming emotions and high stress (more than other chronic conditions) (Goldberg et al 1990).
- Antenatal or postnatal diagnosis- both traumatic. Different impacts for different families.
- Pregnancy and becoming a parent is stressful; plus shock & trauma of news, loss & mourning, fear & uncertainty, guilt & asking why, and understanding health care.

Trauma: Defence Cascade

Trauma responses (Porges, 2011):

- Orient (what is happening?)
 - Mobilise (fight/ flight, speed-up)
 - Immobilise (freeze/ dissociation)
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- Reactions normal & natural in context of stressor.
 - Impacts on processing of information and memory of events.
 - Difficulties occur long term when stuck in high arousal (“alarm system in brain switched on”).



Recommended book: Trauma Is Really Strange. Steven Haynes

Parental coping

- Parents as individuals and a couple- impact of trauma on how they function and are supported.
- Parent diagnosis reactions and level of stress not related to severity of cardiac defect (Lawoko & Soares, 2003).
- Reduced quality of life for parents related to financial concerns, time taken with child's health care, distress and social isolation (Lawoko & Soares, 2003).
- Post-traumatic growth- Long term, parents of children with stable CHD have better mental health and coping than parents of "healthy" children (Spijkerboer et al 2006).
- Each new traumatic event (hospitalisations, procedures or crises) needs to be processed and parents will go through further adjustment.

The Importance of Parent-Child Relationships

The parent-child relationship and interaction is crucial to the short and long term physical and emotional wellbeing and development of the individual. It impacts into adulthood.

- Early years brain development: Positive interactions (e.g. serve and return interactions) build the foundations in the brain for good emotional and physical health. Stressors (including absence of parent) negatively impact. Youtube video: <https://www.youtube.com/watch?v=hMyDFYSkZSU&list=RDCMUcZszRaJa7VomcD3yZd9leDw&index=6>
- Attachment is "a lasting psychological connectedness between human beings" (Bowlby, 1997)¹. In particular, attachment theory highlights the importance of a child's emotional bond with their primary caregivers. Disruption to or loss of this bond can affect a child emotionally and psychologically into adulthood, and have an impact on their future relationships. Attachment process begins before birth.
- Learning how to live with CHD: Health beliefs and behaviours; how we think about our health, the control we perceive we have and the actions we take are largely influenced by our caregivers. To help children have health beliefs that are likely to help their future health and quality of life we need to look at the interactions they experience.

CHD: Impact on Parent-Child Relationship

With CHD the parent-child relationship and interactions can be impacted by:

- Lack of bonding in pregnancy
- Trauma
- Parental mental health issues/ coping
- Parental attitudes to CHD (*perceived* severity of condition- under or over estimation)
- Separation from parent/s
- Feeding difficulties

Positively:

- Plasticity of the young brain allows for overcoming early adversity.
- There are opportunities for professionals to identify issues & support.

How health professionals can help?

Our roles as HCPs are different and we have varying amounts of contact with children, young people and adults and their families with CHD.

Considering early experiences is relevant throughout the journey.

Need to reflect individually on:

- How the start an individual has impacts on how they are coping now?
- How you could help support their current and future wellbeing within your role?

Need to understand other factors that impact on quality of life more than disease severity:

- Social support, isolation and family dynamics
- Financial situation and concerns
- Parental coping and mental health

To support a good start at diagnosis the following slides offer suggestions for clinical practice...

How to help: Meaning of CHD

Exploring the meaning of CHD:

- Give enough time to share clear information (verbal and written) about the medical condition and possible impact on life (Reid & Gaskin 2018).
- Signpost to peer support and information.
- Regularly revisit this discussion and check understanding.

This will help a parent going through this stressful experience to orient to what can be done, how life might be, and help them develop a more realistic idea of the possible impact and severity of their child's condition. This in turn supports bonding and the parent-child relationship, and living well with CHD.

How to help: Bonding & Interaction

Discuss the parent-child relationship

- Make talking about their relationship and interactions with their child a normal thing to think about alongside the CHD.
- Talk with parents about bonding and interaction and why this is important.
- Ask them about their experiences of bonding with their child and any barriers.
- In pregnancy and with new parents in hospital think with parents about how you/others/ward can help them interact (serve and return) and bond with their child. If parents are not present or not interacting discuss this concern.
- Talk to parents of young children about how CHD (and other issues) impact on how they parent their child.

Having these discussions will enable parents to bond with their child and be empowered to support their development through interaction.

How to help: Parents Wellbeing

Supporting emotional wellbeing of parents:

- Most parents do not require referral for psychological assessment and intervention for overwhelming feelings that are a normal response to a stressful event and part of the adjustment process, but talking to someone helps.
- Talk to parents individually and as a couple (where appropriate) about how they are coping.
- Help them consider how to talk further with others: family/friends, chaplaincy (inpatients), local HCPs e.g. GP, health visitor.
- Link them with peer support in person or via networks:
 - Childrens' Heart Association www.heartchild.info/web/
 - Childrens' Heart Unit Fund www.chuf.org.uk
 - North East and North Cumbria Congenital Heart Disease Network Engagement Projects

How to help: Parents Wellbeing

Supporting emotional wellbeing of parents:

- There are circumstances where referral for psychological assessment and intervention (usually via their GP*) would be beneficial:
 - Reactions seem out of proportion to the stressful event
 - Trauma reactions continue much longer than might be expected
 - There are other mental health issues that may impact on coping
 - There are concerns about risk to themselves or others (crisis team)

*For parents of inpatient children at the Freeman Hospital the Paediatric Psychology team can be contacted for discussion regarding support options

Supporting parents wellbeing supports the wellbeing of the child now and in the future due to the positive impact on the parent-child relationship and interaction.

Questions & Comments?

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