

# **Using psychologically informed care to improve mental health and wellbeing for people living with a heart condition from birth: A Statement Paper.**

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## **Abstract**

Over the last few decades medical and surgical advances have led to a growing population of individuals living with congenital heart disease. The challenges of this condition can reach beyond physical limitations to include anxiety, depression and post-traumatic stress disorder. To date these psychological outcomes have been neglected, yet they need not be inevitable. The factors contributing to these difficulties are considered here, drawing on current evidence and neuro-psychological theories including the novel application of Polyvagal Theory. Suggestions for developing psychologically informed medical and social care to improve mental health, wellbeing and recovery and influence policy and training are proposed.

## **Keywords**

**Congenital Heart Disease, Polyvagal Theory, Medical Trauma, Psychological Medicine, Psycho-cardiology, Trauma Informed, PTSD, Training.**

Word Count: 3195

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Congenital heart disease (ConHD) affects approximately 1% of live births, with similar prevalence worldwide (Chen *et al*, 2018; Triedman and Newburger, 2016). ConHD describes any cardiac anomaly present from birth and this heterogenous group comprises people with a wide range of cardiac conditions which vary widely in complexity. In the USA, approximately one quarter of infants born with ConHD will require medical intervention within the first year of life. Medical and surgical advances mean that 90% of infants with ConHD will survive into adulthood compared with just 20% in the 1940s (Warnes *et al*, 2001) leading to a demographic shift with more adults than children now living with this condition. There is no cure for complex ConHD and lifelong monitoring is indicated (Greutmann *et al*, 2015). In addition to the physical limitations of their condition and an increased mortality and morbidity burden, this growing population are at risk of mental health problems, psychosocial stressors and neurological sequelae (Bromberg *et al* 2003; Czosek *et al*, 2012; Kasparian *et al*, 2016; Kovacs and Utens, 2015; McCusker *et al*, 2010; Morton, 2011; Ringle and Wernovsky, 2016; van Rijen *et al*, 2003; Verstappen *et al*, 2006).

### **ConHD, Mental Health and Post Traumatic Stress**

It is well established that individuals with ConHD are at an increased risk of a number of psychological difficulties including anxiety, depression and post-traumatic stress disorder (PTSD) (Bromberg *et al* 2003; Czosek *et al*, 2012; Kasparian *et al*, 2016; Kovacs and Utens, 2015; McCusker *et al*, 2010; Morton, 2012; van Rijen *et al*, 2003; Verstappen *et al*, 2006). Meentken *et al* (2017) found that ConHD can result in acute stress reactions and PTSD in the long-term with 12–31% of children undergoing cardiac surgery developing PTSD and 12–14% showing elevated post-traumatic stress symptoms (PTSS). Adults living with ConHD are also at significantly higher risk of post-traumatic stress disorder (PTSD) than people in the general population. Deng *et al* (2016) found that between 11 - 21% of adults had PTSD compared to just 3.5% in the general population. PTSD also affects the wider family, Helfricht *et al* (2008) found that 16.4% of mothers and 13.3% of fathers had acute PTSD and 15.7% of mothers and 13.3% of fathers had PTS symptoms six months after their

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child had undergone cardiac surgery. Some of the factors contributing to these mental health outcomes are discussed below.

### *Medical Interventions & Events*

Whilst this population have benefited from significant medical advances, often gifting life, this has at times involved employing less humanised treatments (Todres *et al*, 2007). From infancy members of this population may frequently undergo medical procedures and hospitalisations such as Electrocardiograms (ECG), surgery, blood tests, insertion of a cannula, physical examinations, Cardiac Catheterisation, Echocardiograms (ECHO), Venogram, implantation of devices such as pacemakers and ICDs, pacemaker interrogations, stays in High Dependency (HDU) and Intensive Care Units (ICU) and a heart transplant. Studies have shown that medical procedures are often experienced as painful and frightening and can be overwhelming, cause feelings of helplessness and may give a sense of life threat (Meentken *et al*, 2017). Individuals with ConHD will often have experienced such procedures before knowing they will likely endure them again. Further, cardiovascular events, such as arrhythmias, heart failure, stroke and cardiac arrest can also contribute to post traumatic stress (Deng *et al*, 2016).

Children are often forcefully held for medical procedures, termed 'Clinical Holding'. Bray *et al* (2018; 2015) found that 81% of medical professionals report children being forcefully held, often by parents, for procedures *frequently or very frequently to get the procedure done quickly* despite potentially causing them to become scared of having future procedures and contributing to post traumatic stress. Healthcare professionals report finding it difficult to balance the different agendas, rights and priorities of the child during medical interventions. Further, parents report feeling uncomfortable about being asked to forcefully hold their child for such procedures. Professional guidance states that Clinical Holding should be a *last resort*, yet it remains part of everyday practice. Undergoing repeated, painful medical procedures may leave children

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psychologically distressed since younger children may have a 'moral' explanation for this treatment and interpret the medical professionals and their parents as intentionally punishing them for wrongdoing (Bibace and Walsh, 1981).

### *Neurophysiological Vulnerability to Psychological Distress: The Polyvagal Theory*

Individuals with ConHD may be physiologically more susceptible to post traumatic stress, when considered through a Polyvagal lens as a direct result of their cardiac condition (Morton, 2018). The heart plays a central role in regulating the autonomic nervous system (ANS). The Polyvagal Theory (PVT) proposes that the main function of the ANS is to assess and respond to threat, with the goal of establishing safety with others, termed Neuroception. Porges (2018; 2014, 2011, 2007, 2001, 1998) proposes three hierarchical, phylogenetic levels of threat response each managed by different branches of the vagus nerve. These modes can be traced to survival based behavioural and psychological reactions that have developed at different stages of our evolutionary history. To adapt to the changing environment we need to be able to transition between these modes to respond appropriately both when we feel safe (facilitating play, social interaction and sexual intimacy), as well as unsafe (enabling defensive mechanisms such as mobilization during 'fight or flight' and immobilization). When we feel safe the ventral vagal pathway of the parasympathetic nervous system (PNS) is activated. Porges terms this mode the emergent Social Engagement System (SES) which is our most evolved and healthy way of being. The tasks of this pathway include mastication, feeding, vocalizing, breathing, head tilt and turn, gaze, facial expression, voice perception and listening. The anatomical structures associated with the SES have neurophysiological interactions with the HPA Axis, social neuropeptides (such as oxytocin) and the immune system. As such, we need to be in this mode to grow, develop, learn, to feel a full range of emotions and socially connected.

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When we perceive threat the sympathetic nervous system (SNS) is activated triggering hyperarousal of the nervous system and an associated increase in heart rate, blood flow and heightened sensations. Psychologically we feel anxious combined with an urge to act in defence; termed the 'fight or flight' response. In this mode, cognitive processes are rigid, obsessive and biased to perception of risk.

Whereas, if we perceive a more serious threat to our lives a more primitive branch of the PNS, the dorsal vagal pathway, is activated. This branch of the vagus nerve is common in most vertebrates and it is associated with tonic immobility and extreme deceleration of the ANS. In this mode, individuals experience bradycardia which decreases blood flow to the extremities. Porges notes that this may be the mechanism underlying stress related defecation and syncope (Porges, 2018).

Psychologically this is experienced as an absence of sensation, dissociation of awareness, slowed cognitive processing and an urge to 'play dead' and 'freeze' for survival. Non-specific signs of shutdown include a flat facial expression, facial pallor and laboured shuffling movements with hypoaroused individuals frequently experience pervasive shame (Levine, 2018).

The ability to transition between these three modes depends on an efficient nervous system with the PNS modulating stress vulnerability via the vagal brake. Respiratory sinus arrhythmia (RSA) is a non-invasive measure of parasympathetic tone which can be used to monitor how the vagus nerve modulates heart rate activity in response to stress, emotional regulation and general wellbeing. As such RSA provides a marker for Neuroception (Porges, 2011). Chronic health problems, such as chronic fatigue syndrome and fibromyalgia, have been linked to pervasive stress and ANS dysregulation (Levine, 2018). Since the heart plays a central role in ANS functioning, it seems likely that ConHD may compromise the Neuroception of safety and leave such individuals more vulnerable to Neuroception of risk and consequently psychological distress and post-traumatic stress (Morton, 2018).

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### *'Orphans' of the healthcare system*

For many of today's adult survivors treatment was pioneering with expectations of survival uncertain and poor psychological awareness and support. Many grew up as *miracle baby* or as a *lost cause* and describe *feeling different* (Verstappen *et al*, 2006). Until fairly recently, it was not uncommon for children to stay in hospital without their primary caregiver, who visited weekly (Robertson, 1958). As such, adult survivors may have faced significant medical adversity, without the protective presence of their primary caregiver. Further, care provision has not evolved in time to meet the needs of the growing population of adult ConHD survivors and can be inconsistent and difficult to access leaving them feeling unsafe (Wray *et al*, 2012).

### *Challenges to Attachment*

As a result of their heart condition and in the name of treatment, babies with ConHD face significant challenges to fulfilling their biological need for connectedness with their attachment figure(s) (Morton, 2018). Under normal circumstances the baby and primary caregiver will engage in a biologically-choreographed dance and when this relationship is predictable, attuned and safe a secure attachment to each other is enabled. Such early interactions tone the infant's ANS providing the template on which future relationships are built, termed the 'Internal Working Model' (Bowlby, 1977). As such, over time, the infant develops the capacity to self-regulate and navigate their social world. Neurodevelopmental studies demonstrate that children with a secure attachment to their primary caregiver are more resilient to traumatic life events (Harlow, 1958; Rothschild, 2000; Spitz, 1945).

However, infants with ConHD may face physical barriers to their attachment figure such as being incubated, in ICU and HDU and attached to medical equipment. ConHD in infants is associated with increased energy expenditure, poorly developed oral motor skills, feeding problems, uncoordinated

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swallowing, high respiratory rate, fatigue and reflux (Arvedson and Brodsky, 2002; Einarson and Arthur, 2003; Kohr *et al*, 2003; Ringle and Wernovsky, 2016; St Pierre *et al*, 2010; Sundseth-Ross and Browne, 2002; Wolf and Glass, 1992) and a higher prevalence of low level developmental delay including cognitive, attention, executive functioning difficulties and problems with motor and language skills (Dittrich *et al*, 2003; Karsdorp *et al*, 2007; Mahle *et al*, 2002; Mussatto *et al*, 2014; Wernovsky *et al*, 2000; Wilson *et al*, 2015).

Autonomic attunement between the infant and caregiver is achieved through the tasks of the SES, namely, eye gaze, vocalizations, feeding, head tilt and turn, facial expressions and voice perception. To operate within this mode both baby and caregiver must feel safe to enable ventral-vagal activation. As described, such infants may be less likely to experience Neuroception of safety as a direct result of cardiac dysregulation heightened by enduring stressful medical experiences and Neurophysiological delay. Whilst the primary caregiver may in turn struggle to feel safe as a result of caring for an unwell child. Together, this may make co-regulation and the development of a secure attachment bond between baby and caregiver more challenging.

### *Psychosocial Challenges*

It is well established that such individuals face a range of additional psychosocial challenges. A recent systematic review of qualitative studies looking at children's experiences of ConHD identified six themes; disrupting normality (e.g. disrupting the family dynamic), powerlessness in deteriorating health (e.g. exhaustion from medical testing and preoccupation with impending mortality), enduring medical ordeals (e.g. disappointment by treatment failure) , warring with the body (e.g. distorted body image and testing the limits), hampering potential and goals (e.g. unfair treatment and limiting attainment) and establishing one's own pace (Chong *et al*, 2016). These findings are consistent with previous studies which report psychosocial challenges such as feeling different, uncertainty about prognosis, navigating a hidden disability, impaired peer relationships, parental overprotection,

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school absences, physical limitations, scarring and problems with body image, discrimination, difficulty having and raising a family and reduced quality of life (Dempster *et al*, 2017; Kovacs, 2009; Verstappen *et al*, 2006).

### **A Holistic Account: Psychologically informed medical and social care.**

The increased risk of mental health problems associated with ConHD could be mitigated by adopting more psychologically informed medical and social care grounded in a holistic understanding of ConHD to enable such individuals to live as normal a life as possible. This calls for an improvement across several areas of medical and social care to this end.

#### *Promoting a Soothing Presence.*

Individuals living with ConHD may face medical interventions and hospitalisations throughout their lives. Research suggests that enabling the soothing presence, by their side, of a loved one could mitigate against such adverse experiences. The reassuring touch and voice of a loved one can facilitate a secure attachment bond with caregivers for infants and enable Neuroception of safety across the lifespan. Research studies have demonstrated that touch facilitates the tasks of the vagus system by expressing compassion and providing feelings of reward, reciprocity and safety (Hertenstein *et al*, 2006). Further, preterm infants gain significantly more weight when touched (Field *et al*, 1986). Compassion is also expressed through vocalisation (Simon-Thomas *et al*, 2009). Skin-to-skin contact, such as *Kangaroo care* has been shown to reduce mortality, severe illness, infection, length of hospital stay, sleep organisation and the modulation of pain responses in preterm babies (Jefferies, 2012).

#### *Addressing the mental health needs of the wider family: Psychoeducation & Psychological Support*

To promote secure attachment and available social support it is important that the mental health of the wider family is also supported. To validate their experience a psychoeducation programme for

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parents may be indicated to teach them that, while it may take more effort to engage and feed their baby, their role is essential. Research suggests supportive input from a psychologist improves outcomes for both infants with CHD and caregivers (Kasparian *et al*, 2016; McCusker *et al*, 2010).

### *Providing Consistency of Care to Promote Feelings of Safety*

Healthy regulation of the ANS is shaped by social interactions during childhood and predicts whether we find connection with others safe or frightening (Hertenstein *et al*, 2006). Therefore, consistency of care from familiar medical staff is essential (Robertson, 1958). This remains a challenge for adults for whom care provision can be inconsistent and difficult to access calling for improved service provision, consistency of care and the development of Healthcare Standards to this end (Freeman, 2014; Sayburn, 2015).

### *Training Medical Staff to Provide Appropriate Emotional Support*

Empathic communication and compassion need to be considered essential components of training for all medical healthcare professionals including doctors, surgeons, nursing staff and other allied health professionals such as electrophysiologists. Psychological health and wellbeing depends on minimising medical disruptions to the biological need for safe social connection with survival rates increasing when doctors make eye contact and provide reassuring touch to their patients (Field *et al*, 2010). Clinical Holding should be minimized through training in alternative practices such taking a 'Clinical Pause' to explore the child's wishes and find alternative techniques such as distraction and taking time to spend time to inform and engage children in making choices about their procedure (Bray *et al*, 2018). Other aspects of routine medical practice need to be re-considered from a psychologically informed perspective such as the use of *bravery stickers*. Although it can be helpful to provide hope and compensation for painful medical procedures it is important such incentives are not framed as a reward for suppressing a normal emotional response to pain and discomfort (Morton, 2015a).

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### *Developing a Healing Environment*

During hospital stays patients are often exposed to unnecessary disruptions to sleep and recovery. Often the hospital setting can be stressful exposing patients to loud noises such as heart monitors, harsh lighting, poor privacy and multiple awakenings, often to suit the shift pattern of the attendant medical or cleaning staff rather than through medical necessity. Detsky and Krumholz (2014) suggest this atmosphere may contribute to a transient increase in vulnerability to further episodes of hospitalisation termed 'Post-Hospital Syndrome'. The development of a more healing environment by addressing these factors could improve patient experience and psychological and medical outcomes.

### *Empowering Patients*

It is important to address de-personalising aspects of care such as hospital gowns (Baillie, 2009) especially given that patients are frequently being asked to wear hospital gowns when there is no medical reason for them to do so (McDonald *et al*, 2014). As such the current author is leading a study exploring the impact of hospital clothing on patient wellbeing and recovery for adults with ConHD. Providing patients with a copy of clinical letters, access to their clinical notes and involving them in aspects of their care may also help to address any power imbalance between patients and medical professionals and enable self-management and a sense of autonomy and control over their condition.

### *Informing Therapeutic Practice*

Given the increased vulnerability to psychological trauma for both individuals with ConHD and the wider family a specialist psychologist should be embedded within the care team (Kasparian *et al*, 2016; Morton, 2015). Further, fostering links between psychological care and patient support groups could encourage peer-to-peer support and improve wider social support (Callus and

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Pracettoni, 2018). For children, touch, play and music therapies may be indicated. However, it is important to take into account their individual needs and any history of body trauma (Minton *et al*, 2006; Rothschild, 2000). Members of this population may benefit from trauma informed psychological interventions that incorporate 'Bottom Up' strategies such as Sensorimotor Psychotherapy (Ogden, 2018), Neural Exercises (Dana, 2018; Porges, 2018), a Relational Stance (British Psychological Society, The Division of Counselling Psychology, 2013) with a focus on compassion to challenge any hypervigilance to threat and develop self-soothing strategies (Gilbert, 2009). The concept of Neuroception can help clients make sense of confusing dysregulated behaviours and empower them by enabling them to make sense of their experience in light of their adverse history (Ogden, 2018).

It is important to recognise resilience factors which may mask more difficult psychological responses yet, when utilised carefully can be drawn on to facilitate healing, coping and empowerment. Many people report positive personal change following adverse life events including increased resilience, a more positive perspective, a deeper appreciation of life, closer relationships, increased empathy and personal strength (Hefferon *et al*, 2009; Sheikh, 2004; Staub and Vollhardt, 2008; Stellar *et al*, 2015).

### *Building Wider Understanding and Social Connection*

The growing number of people living with ConHD has created a relatively new population which coupled with the often hidden nature of this condition can lead to limited understanding and awareness in wider society. We should look to improve this to promote social inclusion and feelings of connectedness through projects such as the patient led photography exhibition Scarred FOR Life which aims to promote awareness about the unique needs of this hidden population and challenge negative perceptions about scars (Morton, 2015b). Further, working in partnership with wider systems, such as schools, patient groups and workplaces, to improve awareness and understanding should improve social inclusion and quality of life.

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### *Conclusion*

Medical advances have contributed to an increasing cohort of individuals living with ConHD. Yet, the challenges of this condition can reach far beyond any physical limitations to include an increased vulnerability to anxiety, depression and post-traumatic stress. To date these psychological outcomes have been poorly addressed, yet they need not be inevitable. By adopting a more psychologically informed approach to care provision health and social care providers could help to mitigate against these negative outcomes. To improve the quality of life and facilitate recovery and wellbeing, for this growing population, it is imperative that this approach influences the development of practitioner training and policy to this end.

The Author declares that there is no conflict of interest.

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