

# The Traumatic Stress Research Consortium (TSRC)

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## Medical Trauma: the Forgotten Adverse Childhood Experience



### In this issue:

The TSRC's mission centers on understanding how traumatic experiences and safety affect our psychological and body experiences. In this newsletter, psychologist and researcher Dr. Liza Morton shares her personal story and groundbreaking work on medical trauma, and offers insights on how therapists can better understand their clients' medical experiences and foster their resiliency.

# Medical Trauma: the Forgotten Adverse Childhood Experience

By Dr. Liza Morton

Lack of awareness and support for medical trauma is an issue I have felt my whole life. I was born with complete heart block and a hole in my heart (atrial septal defect). When I was 11 days old, I was fitted with a cardiac pacemaker, a world-first in 1978. My mum first held me when I was 6 weeks old, scarred with broken ribs and already fitted with a second pacemaker after the first one failed. She did her best to “love me better.” Since then, I’ve depended on pioneering medical treatment including countless cardiac surgeries, treatments, hospitalizations, and emergency trips to the hospital.

By the age of 7, I had been fitted with five pacemakers by thoracotomy, a procedure where the ribs are broken and the pacemaker is fixed to the heart. Early devices were set at a fixed rate, limiting me physically. I was unable to take part in gym lessons, active play, or keep up with my peers. I was relatively lucky. Only a few years before, children with a pacemaker had to carry around an external battery pack. Before that, the device was plugged into the mains electricity leaving the child unable to move around.

In the mid 1980s, during a family visit with my aunt in the US, I remember having to stand at the bottom of the garden each time she used her new microwave oven. I was not allowed on rides at the theme park or to go through the metal detector at the airport. Throughout my childhood, I focused on what I could do and enjoyed reading, drawing and quiet play. I had open heart surgery

## About the author:

Dr. Morton is a counseling psychologist in Scotland who has written extensively about the psychological impacts of medical trauma. Her research and clinical practice draws from her personal experience of living with a congenital heart condition. We are delighted to have Dr. Morton share her insights for providing support for clients impacted by medical trauma.



Dr. Liza Morton

to repair the hole in my heart when I was 13 years old. Around this time, I was fitted with a variable-rate pacemaker, enabling me to be more active. Congenital heart conditions are for life, and I was fitted with my eleventh pacemaker a few years ago, spending a month leading up to this surgery in the hospital awaiting a surgical slot with a specialist team. While I have always lived as full a life as possible, I have felt a lack of psychological support since childhood (Morton, 2015).

The reality is that medical experiences can be painful and frightening, particularly during childhood, and may occur in the absence of a loved

one. Cardiac symptoms can be abrupt and unexpected, leading to emergency care. Long term health conditions can mean living with uncomfortable physical symptoms and limitations, uncertainty about prognosis, and routine exposure to tests and procedures. It is unusual to face a traumatic situation that you've already experienced, knowing that you'll face it again. Yet, this is often the case for those of us living with serious lifelong health conditions. As I cross the threshold of the hospital entrance, even for a simple check-up, the 'hospital smell' takes me back to being a child.

From infancy, children with serious medical conditions may need to keep quiet and still for invasive, often painful, life-saving treatment. They also face medical barriers to early attachment such as being in an incubator in intensive care attached to an array of medical equipment. Understandably,



Dr. Morton in childhood

parental mental health can be challenged during this time too. 81% of medical professionals report children being forcefully held for medical 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. Often it is the parent who is asked to hold their child down (Bray et al 2018). Being rewarded from childhood to be brave, a "warrior," and a "good pa-

tient" can prevent children from voicing distress.

More broadly, living with a congenital heart condition can impact relationships, finances, education, career, self-esteem, sexual health, body-image, parenting and life choices (Morton, 2020). Many of us face discrimination and ableism. The risk to mental health for the congenital heart condition population increased during the COVID-19 pandemic, exacerbating post-traumatic stress. At the same time, media coverage added to feelings of marginalization and ableism (Morton et al 2022).

## The Paradox of Medical Care: Life-saving and Traumatic

During medical care, there is little choice but to entrust your life to your healthcare team. In this "patient role," many people report feeling vulnerable, dependent, frightened, and disempowered. These feelings can prevent us from articulating concerns and increase vulnerability to medically related trauma. This can be exacerbated by disempowering aspects of care such as being asked to wear a backless hospital gown (Morton et al, 2020) and waiting for different aspects of healthcare (Morton, 2021).

Over the last half century, medical advances have led to a growing population of people living with lifelong health conditions. Astoundingly, survival to adulthood for babies born with a heart condition has improved by 75 percent during this period. The most common birth defect, Congenital Heart Conditions (CHC), affect nearly 1 percent of babies and an estimated 12-million people globally (Zimmerman et al., 2020). It is very likely that someone you know, perhaps a family member, friend, colleague or client has a CHC. CHCs comprise a variety of heart conditions which range widely in severity and prognosis, approximately a quarter of whom will need cardiac surgery in the

first year of life. While treatments have developed rapidly, CHCs are incurable and lifelong specialist cardiac care is recommended. Despite this, the Adult Congenital Heart Association (ACHA) estimates that less than 10 percent of adults with a CHC are in specialist care (Arjuro, 2020; Wray et al., 2013). I have been involved in activism to improve care in Scotland for over ten years, following life threatening issues that occurred while trying to access services (Freeman, 2014; Morton, 2019). Although I am enormously grateful to be able to access free healthcare, I know many of my peers across the globe face the burden of paying for treatment.

The progress in treatments for CHCs has gifted life to many. However, living with a lifelong heart condition can involve exposure to medical procedures, unique life stressors and hidden barriers – often from infancy. Despite improved understanding about the impact of early trauma, the psychological impact of early and repeated medical experiences remains neglected and access to psychological support is poor for this population. This gap in care urgently needs to be addressed, since approximately 1 in 2 adults with a CHC will experience anxiety, depression, or post-traumatic stress during their life, two to three times higher than the general population (Kovacs et al., 2022).

## Mitigating Risk with Psychologically Informed Healthcare

While many of the challenges that contribute to these disproportionately high mental health outcomes for adults with CHC are unavoidable, there are many ways to mitigate their impact and to promote protective factors and positive adaptation. Grounding medical care in the most recent psychologically informed, holistic understanding is essential to this end (Morton, 2020). The devel-

opment of a more healing environment by addressing unnecessary waiting, harsh lighting, incessant noise, disempowering aspects of care such as clinical holding (iSUPPORT, 2022) and backless hospital gowns (Morton et al, 2020) could improve patient experience, psychological and medical outcomes (Morton, 2020).

As social beings, threat is often interpersonal while psychological safety with other people is communicated using compassion (Gilbert, 2017). This is why compassionate communication needs to be considered an essential component of training for all healthcare professionals rather than being left to the ‘bedside manner’ of the attending medic. Compassionate communication, within the context of a bounded professional relationship, can help to facilitate trust, mutual respect, and alleviate distress. Providing accessible information, avoiding the use of medical jargon, taking concerns seriously, promoting dignity, and making time to answer any questions are essential components of facilitating healthcare literacy and self-management of chronic health conditions (Livecchi and Morton, 2023). Repeated exposure to childhood medical trauma can negatively impact feelings of psychological safety throughout life (Morton et al, 2022; Morton, 2018). To feel as psychologically safe as possible, patients need to be able to trust

*“It is unusual to face a traumatic situation that you’ve already experienced, knowing that you’ll face it again. Yet, this is often the case for those of us living with serious lifelong health conditions.”*

that healthcare providers understand the limits of their competencies, will consult with specialist colleagues as required, acknowledge their lived experience, and take their concerns seriously. Consistency of care from familiar medical staff is also important to help build a trusting relationship, for example, by having a named point of contact, such as a specialist nurse.

Informing and engaging patients in making choices about medical procedures and facilitating coping techniques, such as distraction, can also help. Social support is one of the most protective factors for mental health and well-being especially during times of poor health. Therefore, facilitating the presence of loved ones can provide comfort and may improve outcomes. It can be difficult to distinguish between benign cardiac arrhythmias and more serious issues, especially if similar feelings in the past have indicated a serious problem, which can lead to heart-focused health anxiety (Roseman et al 2021). Understanding this and taking the time to validate and explore any concerns can help. It is also important to recognize the challenging work healthcare professionals do and the emotional and psychological impact this can have, especially post pandemic (Cogan et al, 2023). Providing clinical supervision from a team Psychologist could help to alleviate this burden and help to prevent vicarious trauma, moral injury, compassion fatigue and burnout (Morton, 2020).

## Therapeutic Work with Clients Who Have CHC

Of course, everyone's experience of living with a CHC is unique. Every single person, even with the same health condition, has a different story to tell. For clinicians, it is important to educate oneself about the client's condition, be curious, and ask questions to better understand what

living with a lifelong cardiac condition means for them.

It is important to validate a normal emotional response to unusually difficult life events and choices, discrimination, and barriers by focus-

### Issues relevant to working with clients who have CHC:

- PTSD (including trauma from medical experiences), post traumatic growth, and positive adaptation
- Medical barriers to early attachment
- Preparing for further medical care, transplant, or other interventions
- Health anxiety
- Living with physical symptoms (e.g. pain, arrhythmias, fatigue)
- Living with a cardiac device (Pacemaker, Implantable Cardioverter Defibrillator - ICD)
- Impact on exercise & functioning
- Losses (e.g. decline in health, ability to have children, normal childhood, goals or plans)
- Impact on relationships, career, finances, parenting, life choices
- Identity, feeling different, low self-esteem
- Feeling disempowered
- Body image and scarring
- Sexual health
- Discrimination, ableism, bullying
- Intersectionality
- Palliative care

ing on empowering the client to self-advocate, set boundaries and develop meaningful goals (Livecchi and Morton, 2023). Clients presenting with more complex medical trauma may benefit from a phased intervention model of psychological treatment (Herman, 1998) to ensure safety and stabilization, psychoeducation, a safe space to process traumatic experiences and losses, and to develop self-care and skills to manage stress and medical treatments. Clients may also benefit from support in managing chronic symptoms and developing self-compassion about their condition.

Being exposed to medical interventions, particularly if there are medical barriers to attachment may also impact on feelings of psychological safety across the lifespan. Polyvagal Theory offers a ‘Science of Safety’ and, as such, I have developed a standardized measure of psychological safety, ‘The Neuroception of Psychological Safety Scale’ (NPSS) with a team of international collaborators including Dr. Nicola Cogan, Professor Stephen W. Porges and Dr. Jacek Kolacz (Morton et al, 2022) to enhance clinical work and research in this growing field.

## Looking Forward

Medical trauma is often left out of conversations about adverse childhood experiences (ACEs) and while we now know that around 50% of adults with a CHC experience PTSD, anxiety and depression (Kovacs et al., 2022), support remains poor. Much more could – and should – be done.

To help address this gap, Tracy Livecchi, LCSW and I have written the first book to focus on the psychosocial, emotional, and practical challenges in living with a CHC. Our book ‘Healing Hearts and Minds: A Holistic Approach to Coping Well with Congenital Heart Disease’ aims to promote hope, connection and to normalize an understand-

able response to the often-cumulative challenges the growing CHC population can face from infancy. We provide evidence-based information to support people living with a CHC, their families, and healthcare professionals. Both Tracy and I are ‘dual experts’ as mental health professionals living with CHCs, dependent on pioneering cardiac care since birth. In *Healing Hearts and Minds*, we begin by sharing our personal stories, then explore the collective history of this medical population and the possible psychosocial consequences of CHCs. We hope the book may be beneficial to people living with other long-term medical conditions, anyone working therapeutically with medical trauma, or providers who want to take a psychologically informed approach to healthcare.



*Healing Hearts and Minds: A Holistic Approach to Coping Well with Congenital Heart Disease* published by Oxford University Press is [available now](#).

For more information, visit <https://www.drlizamorton.com/>

# About the Consortium

The TSRC is an international group of clinicians and researchers studying the science of safety and connection. We are committed to furthering our understanding of the personal trajectories of trauma survivors, including mental and physical health, social wellbeing, resilience, and personal meaning.

## Our Team



Jacek Kolacz, Ph.D.  
Managing Director &  
Chief Scientist



Erika Bjorum, LCSW  
Consortium  
Coordinator

Olivia Roath: Newsletter design  
and graphics

## Advisors

Stephen W. Porges, Ph.D.  
Founding Director

Deb Dana, LCSW  
Clinical Advisor

Gregory F. Lewis, Ph.D.  
Scientist

## Ways to get involved with the consortium

**Invite your clients to share their  
experiences:**

We continue to welcome new participants for our worldwide client survey. We invite you to help your clients share their experiences.

**Help grow our membership:**

Invite your colleagues to join the TSRC network. Register at [trauma@indiana.edu](mailto:trauma@indiana.edu)

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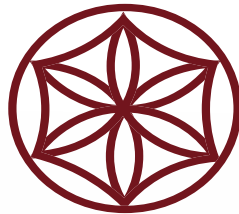
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## Newsletter Team

Jacek Kolacz: Editing

Erika Bjorum: Editing

Olivia Roath: Design



The Kinsey Institute  
Indiana University, Bloomington