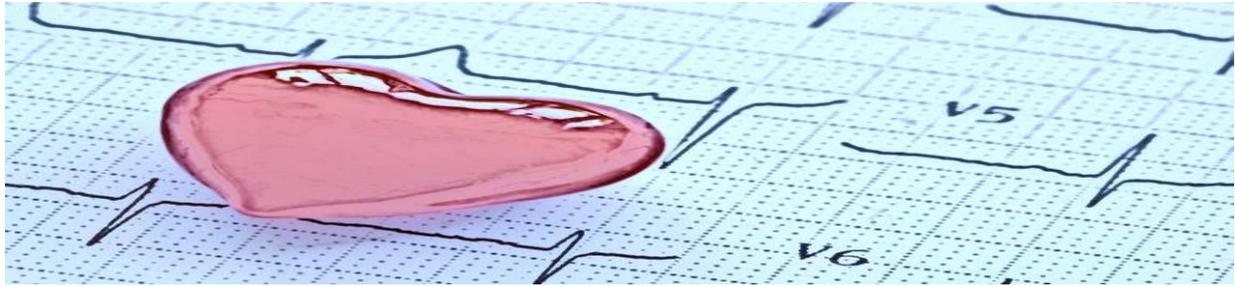


# An exploration into Psychology - could you benefit?

Dr Liza Morton



## Some Emotional Challenges of Growing Up with a Heart Condition

*“Nothing to me is more BEAUTIFUL. Every fissure tells story. Every blemish makes you more REAL. All my life I have been waiting for a heart like this, a heart that speaks the TRUTH.”*

From ‘Love Monkey’ by Edward Monkton

What truths do our hearts speak and do we have the courage to voice this story? We each face challenges in life as a result of being born with a heart condition. Difficult emotions are a normal reaction to tough life events. Yet, in the midst of dealing with physical symptoms, there is not always the opportunity to deal with these feelings and adequate support is not always available. Of course, not everyone who has grown up with a heart condition will feel like this. We are all different and we all have different experiences but some of the emotional difficulties that might arise are considered here.

### **Outsiders**

Given the cultural significance of the heart as a symbol of love (*with all my heart*), the keeper of emotion (*heartfelt*) and the essence of life, it is perhaps not surprising that knowing that this part of us is unique means that we may feel *different*. This is often reinforced by growing up with pioneering treatment as a *miracle baby*, *special* or a *lost cause*. Discrimination, which usually involves some kind of rejection, bullying or shaming, can also lead to us feeling different and alone. Shame, a social emotion, is increasingly being linked to the development of anxiety, depression and low self-esteem.

### ***Hidden scars***

Congenital heart disease (CHD) is an invisible disability and, although this has advantages, can create difficulties at school, work and socially (for example, being expected to take part in P.E.). During more acute periods of illness we risk more typical discrimination such as being treated as if we are dependent, childlike and being seen as our condition (e.g, being called “the girl with the heart condition”). As a result, revealing our health problems may put us at risk of discrimination yet hiding them can make us feel like a fraud and leave us without much needed understanding and support.

### ***Out of control***

The imbalance of power between doctors and patients can also leave us feeling out of control and dependent. At times this can leave us feeling dehumanised, ashamed and might lead to us expecting doctors to “fix” us rather than feeling empowered to manage some aspects of our health ourselves.

### ***Lost childhood***

Many of us grew up without knowing how long we would live, making childhood a less carefree experience. Some of us were painted an overly optimistic picture (e.g. that we were *cured* and could function *normally*) while others received an unduly pessimistic outlook.

Although cardiac care has developed rapidly, the impact of this on the body is less well understood perhaps leading to *unexplained medical symptoms*. Often, support within schools was poor and issues such as increasing awareness, educating teachers, bullying and missed schooling were not always addressed. Ongoing challenges may include making difficult decisions about treatment, enduring surgery and pain, managing physical limitations, living with implanted devices, not being able to have children, having a heart transplant and facing a reduced life expectancy. For some, specialist adult care is not available, presenting many challenges around transition and finding adequate care.

### ***Re-living hurts***

Early exposure to medical interventions can share common themes with other types of childhood trauma including lack of control, invasion of body boundaries, problems with trust, dissociation (feeling detached from your body), flashbacks and nightmares. Early trauma can make us more vulnerable to other health problems, unexplained bodily symptoms, anxiety and depression. Heart symptoms might trigger feelings of anxiety (and vice versa) if similar feelings in the past have indicated a serious problem.

## ***Feeling unsafe***

The importance of a secure early attachment (feeling safe and loved as a baby and child), to our main caregiver, for psychological and emotional health is well established. Yet, this can be more challenging for us since it is physically difficult to hold a baby who is attached to an array of medical drips and heart monitors, often in an incubator. For some, parents were not allowed to stay with them in hospital.

## ***Mental Health & Wellbeing***

The impact of living with a heart condition from birth can reach far beyond any physical symptoms. The fact that this condition is there from the start helps to shape who we are. For many of us it becomes part of our identity, impacts how we see our body, changes our experience of childhood, influences our relationships, and our education and career choices. It creates obstacles that we learn to navigate around from birth. Many of us live through more challenges in childhood alone than most people will face in a lifetime. This teaches us about the uncertainty of life and just how painful yet precious it can be. We learn to be strong, to cope, to laugh at adversity, to get on with it and to fight.

Not because we are brave or good at this (although we may be) but because we have no other choice. And this gets us through, most of the time. But sometimes, some of us, get overwhelmed by what we are expected to endure. Not because we are *crazy* or *weak* but because we have been strong for too long and we have been through so much. But it can be harder to voice these feelings than it is to seek help about our physical symptoms. It can also be more difficult to find support from others who understand and are able to help. Yet, the emotional impact of living with a serious medical condition, from birth to death, is surely worthy of attention. Especially if, for some, these emotions can develop into periods of low mood or anxiety and because emotional distress can hinder physical recovery.

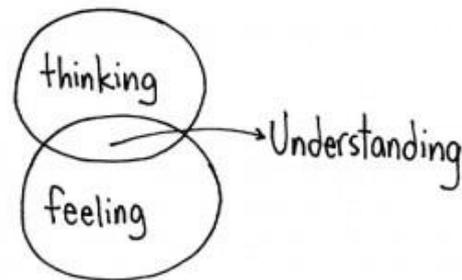
Perhaps then it is not surprising that a growing number of studies suggest that people who are born with a heart condition are at a higher risk of anxiety, depression and post-traumatic stress disorder. It seems likely this is a result of the additional stressors we face. [Although living with a heart condition itself may also contribute directly to these outcomes \(click here for more information\).](#)

Through medicine we survived. Understanding how our experiences have shaped us offers us the chance to thrive. Where medicine has gifted us life we may need to look to a different field, Psychology, to heal the emotional scars. If required, there are many different types of help available and different approaches will suit different people. Emotional Support, Self-Help, Counselling and Psychological therapies can offer the chance to process and manage these emotions leaving us free to make the most of our present and future. These kinds of help are considered in the next section.

## What can Psychology Offer People Living with a Lifelong Heart Condition?

In the previous section we explored some of the emotional challenges of growing up with a heart condition, suggesting that Psychology, the study of human mind and behaviour, may help to heal emotional scars. Of course, not everyone who is born with a heart condition will want or need this approach. We are all different, but there is no harm in being aware of the options available and deciding for ourselves.

Psychology helps us understand ourselves, why we think, behave and feel as we do. This understanding can help to free us from past pain, learn to manage difficult feelings in the present and embrace the future.



It is important to note that seeking support does not mean that we are *mad*, *crazy* or *weak*. It just means that we are human, that we feel a normal emotional response to unusually difficult life events, and that this can be overwhelming. We don't hesitate to seek advice when we experience physical symptoms so it's only sensible to seek help when we feel overwhelmed by emotional discomfort. Admitting that living with a heart condition can be difficult does not prevent us from being thankful to our doctors or mean that we are being disloyal to those who care for us.

We take for granted that those with other life-threatening health problems, such as cancer, will struggle at times. We know that this is because of their condition and treatment. It is only fair that we allow ourselves the same right to voice all sides of our story.

Acknowledging difficult emotions does not take away from the strengths that can come from growing up with a heart condition, such as increased resilience, courage, wisdom, humour, determination and a fuller appreciation of life and empathy. Rather, dealing with the difficult emotions frees us to make the most of our lives. Surely, this is the best way to express our gratitude to all who have contributed to our survival? It can also inform better support and make the experience easier for everyone. Recent studies indicate that emotional health can aid recovery from illness and improve physical health. So, a holistic account of living with CHD could offer better physical and emotional health and a better quality of life for us and for others.

## What can Psychology offer us?

### Self Help & Emotional Support:

For mild to moderate mood difficulties Self Help material could help. The Somerville Foundation continues to develop specific resources for ACHD patients and lists relevant reading materials and websites. You can find these resources on the Hearts and Minds section of The Somerville Foundation's website. The Somerville Foundation also has a range of contact points: Helpline (0800 854 759), email and a closed Facebook group. Your care may include a Cardiac Liaison Nurse who can offer emotional support.

### Psychological Therapies:

There are lots of different kinds of 'talking therapies' available.

#### Person-Centred Counselling

A Person-Centred Counsellor will listen to you in a warm and supportive way. You are given space to process difficult emotions, make sense of your story and feel heard without being judged. This could help you make difficult decisions or deal with surgical interventions and other difficulties, such as grief and loss (e.g. loss of "normal" childhood or a further loss of health). It is often easier to gain access to a Counsellor through the NHS. For private sessions, a Counsellor will charge less per session than a Chartered Psychologist.

#### Cognitive Behavioural Therapy (CBT)

CBT helps to change unhelpful patterns of thinking and behaviour that have become vicious cycles. Early therapy aims to understand how these patterns contribute to current mood difficulties and how they have developed. Work then focuses on breaking these patterns by challenging negative ways of thinking (e.g. always assuming the worst), unhelpful behaviour (e.g. staying in the house if you feel nervous about socialising) and managing physical symptoms (e.g. using relaxation techniques). CBT may help you to overcome health anxiety and panic attacks, challenge the unhelpful beliefs that may underlie low self-esteem and change unhelpful coping strategies (e.g. the use of alcohol or drugs).

CBT is advocated in NICE and SIGN guidelines for the treatment of anxiety and depression and is offered by most Chartered Psychologists and CBT therapists. See Part 3 in the next edition of the newsletter for information about some more kinds of Psychological Therapies and how to access them.

#### Interpersonal Psychotherapy (IPT)

IPT focuses on reducing mood problems by developing a more supportive social circle. Early sessions review the key people in your life. Therapy focuses on one of four areas; an Interpersonal Dispute (such as an argument with someone who is

important to you), a Role Transition (like moving house), a Grief or Loss and Interpersonal Sensitivities (general problems with making and keeping relationships). These four focus areas could be appropriate depending on the trigger for your current mood difficulties. A focus on Interpersonal Disputes might help if you are having problems navigating the medical system or if you are being bullied. Role

Transitions might benefit you during the move from childhood to adult care, adapting to having a cardiac medical device fitted, enduring surgery or having a heart transplant. Role Transitions could also be useful if you are recovering from post-traumatic stress disorder (PTSD). A focus on Grief or Loss may help following the loss of a peer, a further loss of health or not being able to have children. Interpersonal Sensitivities is generally considered useful if you have a limited social network. The goal of IPT is to improve your social skills and increase your social network and it is perhaps more appropriate when you suffer from health problems since it connects life events to emotions. IPT is advocated in NICE (National Institute for Health and Clinical Excellence) guidelines and is offered by some Chartered Psychologists and some other therapists both privately and within the NHS.

### **Body Psychotherapy**

Recent approaches within psychology offer a more holistic account of human experience than previous approaches. During a threatening situation the body reacts by preparing to defend itself through its fight, flight or freeze response. Sometimes even though the threat is gone the body is left stuck in this mode which can cause a number of physical and psychological symptoms including sleep disturbance, panic attacks, exhaustion, feeling unsafe, flashbacks and nightmares. This is known as post-traumatic stress. Body psychotherapy is an integrated method of psychotherapy that addresses thoughts, emotions and bodily sensations. The aim of therapy is to help you manage your anxiety, establish feelings of safety and process traumatic experiences. This kind of therapy could be useful if you are suffering from post-traumatic stress as a result of medical trauma.

### **The Human Givens**

The Human Givens approach is based on the idea that we each have a basic set of needs (such as security, attention, autonomy, emotional intimacy, status, meaning and purpose) and if they are not met then we feel emotional distress (see the [Human Givens Institute](#)). This approach works to help you adjust your life so that all these needs are being met with the aim of reducing psychological distress.

## Finding the right therapist

The quality of the therapeutic relationship is at least as important as the therapeutic method. Therefore, finding the right fit with a therapist that you feel comfortable and safe with is as important as finding the type of therapy that you feel would help you the most.

## How to access help

Referral to a Clinical or Counselling Psychologist, CBT Therapist or Counsellor in the NHS should be done via your GP or another doctor such as your cardiologist.

Therapists typically charge between £35-100 per hourly session for private work and your GP may also be able to advise therapists who do private work locally. [The British Association for Behavioural and Cognitive Psychotherapies](#) and [The British Psychological Society](#) list accredited private therapists.

In sum, living with a heart condition from birth can present many challenges. It is normal to have an emotional reaction to these adverse life events. However, there is not always the opportunity to deal with difficult emotions when you are also having to cope with serious medical problems. For some these emotions can develop into periods of low mood or anxiety. Emotional Support, Self-Help, Counselling and Psychological therapies can offer the chance to process and manage these emotions leaving us free to make the most of our present and future. There are many different types of help available and different approaches will suit different people.

## The Good News

*“We shall draw from the heart of suffering itself that means of inspiration and survival.”*

Winston Churchill

We have explored some of the emotional challenges in life that living with a heart condition from birth may present. When dealing with physical symptoms there is not always the opportunity to deal with these feelings and adequate support is not always available or known. As such, it seemed important to highlight these issues to promote understanding and an exploration into the various types of help available.

However, this does not mean that living with a heart condition from birth has only a negative impact on our lives. In fact, many studies suggest that a solely negative focus on the impact of congenital illness provides an incomplete picture of this experience.

In particular, such studies have found that many people report positive personal change following such adversity. This is known as post traumatic growth. Such positive factors include a more positive perspective, a deeper appreciation of life and increased personal strength. Further, enduring these dramatic life events can promote closer relationships with our families, friends and peers. Often we compensate for what we cannot do by making the most of what we can do with a keen determination. Many of us who have endured a difficult start in life develop a greater sense of empathy and altruism and feel driven to prevent others from suffering, explaining perhaps why so many of us are drawn to the caring professions (such as nursing, social work, advocacy or charity work). It is this resilience that can enable us to effect positive changes in light of difficult life events.

It is not the case that some of us respond negatively to adversity while others remain strong and resilient. In fact, studies suggest that the same people who report post traumatic symptoms can also experience post traumatic growth. These responses may become entwined, perhaps making it more difficult for others to understand and notice the hurt behind our stoicism.



However, several factors are known to provide a pathway to healing and personal growth following adversity. These include having the opportunity to share our story to feel heard and understood by others and ourselves. This is one of the main reasons that counselling or therapy can be helpful. Chatting with peers, reading similar biographical stories and writing about our experiences can also be

insightful and therapeutic for the same reason. Good social support and nourishing relationships can help to protect us from mental health problems and having strong role models may inspire us and help us to focus on positive goals. Creating meaning from our suffering also helps many of us to heal. Another important factor is feeling empowered to manage some aspects of what is happening to us, particularly regarding our health (e.g. by having a good understanding of our condition and feeling heard by our medical care providers).

In conclusion, a congenital heart condition has the potential to weave itself through most aspects of our lives, sometimes for worse, sometimes for better. This is certainly not an easy life. Perhaps few of us would choose it. Yet, that does not mean that life can't be lived fully, meaningfully and enjoyed. At times we may be tripped up by the emotional cost of living with such a condition. This is understandable. Taking the time to know the roots of this suffering can better equip us to meet such challenges and to find adequate support. As our lives move forward and we encounter challenges, and build the resources within ourselves to manage and succeed, we can enjoy a personal growth and build a resolve that can often really only come through navigating such obstacles from birth.

*This series of articles have been adapted by Dr Liza Morton for The Somerville Foundation from Morton, L. (2011) Can Interpersonal Psychotherapy meet the psychosocial cost of life gifted by medical intervention? Counselling Psychology Review, Vol. 26, 3, p 75-86. Updated by Liza Morton, January, 2018.*

Please consult the original article for a full list of references.

## About the Author



Dr Liza Morton, born with complete Congenital Heart Block, was recently fitted with her 11th cardiac pacemaker. She has also had an ASD repaired by Open Heart Surgery. Liza, a volunteer for The Somerville Foundation, is a Chartered Counselling Psychologist. She has studied Psychology for many years, an interest that was driven by her wish to understand how her heart condition and extensive medical history had shaped her. As part of her training

she has undergone therapy with both a Counselling Psychologist and a Body Psychotherapist work she feels has helped her process the challenges of living with a heart condition from birth.