

Sally's story

I was born in the 1960s and was diagnosed with Crouzon's Syndrome when I was two-years old. In those days knowledge of craniofacial syndromes was rare and it took a nasty fall and for me to be almost blind before my parents were taken seriously that something was very wrong. My intracranial pressure was extremely very high and my head and face misshapen.

Over the following 14 years I had around 30 surgeries to correct the effects of Crouzon's Syndrome, which included several major procedures to expand my skull and eye sockets initially, and then to restructure my face. Because of the success of my treatment and the astonishing aesthetic result I became an object of medical curiosity. Whenever I attended hospital, which was every month or two during childhood, I drew a large crowd of admiring and curious doctors. However, I have carried the psychological effects of this journey, not least the bullying I experienced at school due to my unusual appearance when I was young.

No one spoke to me directly about what was happening to me when I was young, perhaps because it was so unknown. I was encouraged to be strong and brave. The general opinion in those days was that talking about fears and sadness would weaken my courage and ability to survive. Until I was 11-years-old I never knew what surgery I was having or what state I would wake up in – not knowing was very scary. I vividly recall the horror of that first surgery when I was very young; not knowing what was happening, having my hair shaved off and not being able to see very well. Following that I detected major surgery was coming whenever I was asked to leave the consulting room so that doctors could talk to my parents.

I found out what was happening by listening to conversations. I often heard about my low chances of survival both from doctors talking at the end of my bed and from grave conversations amongst family members. I lived in constant fear, never knowing what was coming, never expecting to wake up from surgery or survive to adulthood. I was encouraged not to speak or even think of my fears – perhaps that's how everyone else coped with what was happening. I carried this trauma into adulthood where it revealed itself as pervasive fear and anxiety for many years.

I found strength and hope in my Christian faith when I was young; although my parents struggled to to reconcile my suffering with a loving God. Singing hymns and pondering life brought comfort. Chaplains at the various hospitals often made a point of seeing me whilst I was in hospital. They would hold my hand reassuringly and tell me they would pray for me; they seemed to be the only ones who could remain with my suffering without rallying me to be brave. That meant so much to me as most people kept their distance, not knowing what to say. I have since had the privilege of being a nurse, a hospital Chaplain, and now a psychotherapist; passing on that same presence and quiet strength to those in need.

As a child I struggled to speak clearly and eat without making a mess. There were no specialist units and sparse language support in those days. I therefore learned by watching others, listening carefully and so teaching myself. I also learned to manage the severe pain from headaches by myself, often by focusing on nature and others. I carry this skill of listening carefully today, which is perhaps why I became a therapist.

On the positive side, I have always been grateful for a new day. I loved making people smile when I was young, listening to their stories, caring and helping others where I could. Feeling so scared and isolated gave me a passion to relieve the suffering of others. I loved walking in the countryside and woodlands and pondering life, even at a very young age this was my way of coping with it all. From as early as I can recall I wanted to be a nurse; I wanted to give something back, buty mostly I wanted to make sure no one felt as alone and frightened as I did.

People say they can't tell I have Crouzon's these days. The aging process has been very kind to my facial features and I have a lot of curly hair, which hides a multitude of scars. Whilst people are being kind and genuine, this can sometimes feel invalidating as I endured so much and in some ways still struggle.

In my late 30s, I went into the new specialist unit craniofacial system for a few surgical revisions. I went armed with my medical notes, which helped inform the team of what I'd had done (techniques for treating crainosynostosis are very different to when I was young). Unfortunately, because I was deemed "a veteran of surgery", my psychological needs were again overlooked.

Throughout my life, I have struggled to speak about Crouzon's. Whenever I plucked up the courage I was often met with a recoil reaction from people. It's okay for people to acknowledge they don't know what to say. What is worse is when people try to minimise or diminish my experiences. In recent years though I've had the joy of meeting other people with Crouzon's and craniosynostosis, which has been so heartening to share similar experiences. Having a rare condition can feel very isolating, which is why Hannah's Fund and the Headlines charity can be so important.

Often people, especially therapists, are curious as to why I have never been angry about what I went through. I've never questioned 'Why me?' as I have always felt that in the grand scheme of life 'why not me'. I had fabulous surgeons who did their very best to correct things. I don't think anyone thought about the emotional or psychological impact it had on me then. Everyone did what they thought was best to save me, make me look good and keep brave. There continues to be a paucity of research on the psychological impact of these rare conditions, especially for older adults.

I bear the scars, physically and emotionally. I often still see Crouzon's when I look in the mirror; although, now I can also appreciate what my experiences have given me, and that it's good to be me. One of the most significant things that helped has been developing self-compassion and sharing my story. A few years ago I decided to write a letter to my old pal 'Crouzon's' so I could start to shake hands with this strange bedfellow. I have since written a 'sad letter', a 'compassionate letter', an 'I'm really frustrated with you' letter, and a 'thank you for everything you've given me' letter to Crouzon's. It helped me create a relationship with me, make peace within, and come to appreciate what I have gained from traversing this rocky road. Support from Changing Faces and fellow sojourners also helped enormously. Understanding and validation was key and I have since organised professional workshops on the importance of psychological support for people with visible difference.

Even though I still often feel the presence of my ancient fear, lack of confidence, and feelings of isolation, my experiences have given me so much. It has enriched my life with insight, compassion, courage, determination, humility, and a quite a measure of wisdom.

How Hannah's Fund can help:

For me talking about my experiences and fears was key. However, psychotherapy can be expensive and the search to find someone who will understand ones specific needs can be difficult. There are professional registers, yet finding the right person who understands the complexity of craniosynostosis and craniofacial syndromes is important. **Hannah's Fund** makes access to specialist help easy.

Hannah's fund would have made all the difference to me when I needed assistance to help me process what happened and to feel safe through my most difficult times with Crouzon's syndrome.

Hannah's candid and honest writings open an important dialogue of what it is like to endure a rare chronic health problem, particularly the complexities of having a craniofacial condition, and the silent suffering behind the brave exterior. With the provision of spaces to talk and share, people who get it, and the promotion of research, the mental health of young people and adults can be improved. Providing safe and welcoming spaces to talk is crucially important in promoting mental wellbeing.

I relate deeply with Hannah's writings, although I didn't suffer half as much as Hannah did. Being desperate to communicate, people's comments and reactions, hearing everyone around you yet being unable to speak or reach a level of consciousness, and above all the silent pain, which no words can tell. Shared experiences of many I am sure.

Yet, as one of Hannah's poems implies; there is always hope; sorrow can be embraced, life can be lived to the full, pain can offer meaning. Life is a song and, if we help each other along the way, we can learn how to sing it.