Living with craniosynostosis in adulthood

Contents

Living with a rare craniofacial condition can present a variety of different challenges in adulthood.

As part of a major project funded by the VTCT Foundation, a group of Headlines' adult members worked alongside a team of research psychologists from the Centre for Appearance Research (CAR) to produce a series of resources to help other adults with some of the key issues and concerns.

Each section in this booklet is accompanied by a short video focusing on the topics covered, which can be accessed via www.headlines.org.uk/for-adults

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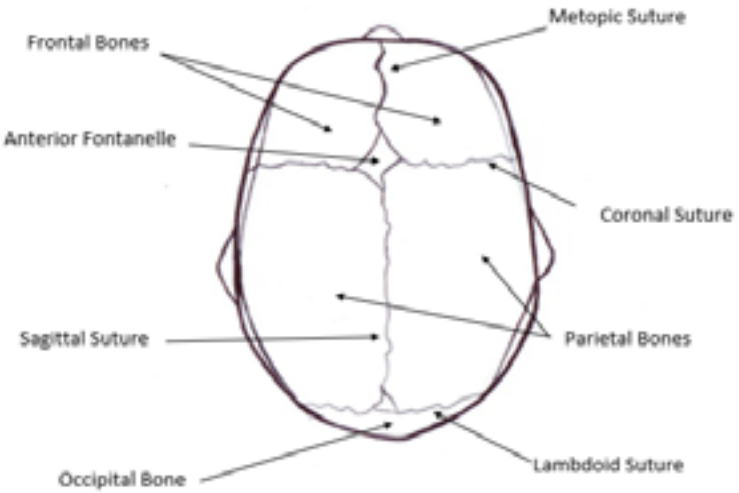
What is craniosynostosis?



The skull is made up of several plates of bone which meet at gaps (sutures), called the sagittal, coronal, metopic and lambdoid.

Normally, sutures join (fuse) during adulthood, when brain growth has finished. However, in a small number of babies, one or more of the sutures fuses before birth or early in childhood. This results in a condition called craniosynostosis, where the head is an unusual shape.

We generally talk about two main types of craniosynostosis:

Non-syndromic craniosynostosis typically involves one suture and does not normally affect other parts of the face or body. There may or may not be an underlying genetic cause.

Syndromic craniosynostosis can affect facial appearance and the appearance of the hands and feet, as well as the skull. A small number of children may also have learning difficulties, hearing impairments and/or problems with vision. There is often an underlying genetic cause, but in many cases there is no obvious family history. Examples of syndromic craniosynostosis include Apert syndrome, Crouzon syndrome and Pfeiffer syndrome.

It is estimated that craniosynostosis affects between 1 in 1,800 and 1 in 2,000 babies in the UK each year. Around 75% of these will be non-syndromic, and the other 25% syndromic.

One baby is born with some form of craniosynostosis almost every day in the UK

Treatment for craniosynostosis

Children born with craniosynostosis in the UK have the opportunity to be treated at one of five NHS Specialist Craniofacial Units, which provide coordinated treatment from a range of health professionals.

The specialist team is often referred to as the MDT (multidisciplinary team) and normally includes surgeons, clinical nurse specialists, clinical psychologists, speech and language therapists, clinical geneticists, orthoptists, and other specialists. The service provides treatment and support for families and individuals from the point of diagnosis through to early adulthood.

The five designated Specialist Craniofacial Units are based in:

- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital, Birmingham
- Great Ormond Street Hospital for Children, London
- John Radcliffe Hospital, Oxford
- Royal Hospital for Children, Glasgow

These Specialist Units were established alongside new standards for treatment published in 2014. This means that many of today's adults will have received treatment that is different to what is provided now.

Current treatment for adults with craniosynostosis

There may be occasions when adults with craniosynostosis need to return to treatment, or are curious about recent advancements in the way treatment is delivered. Unfortunately, specialist treatment for adults is not currently commissioned by the National Health Service. This means specialist treatment for adults is not provided in some regions of the UK, and is limited in others.

To find out what is your region offers, please contact your nearest NHS craniofacial team (listed above), who will be able to advise you on the best course of action. If resources within the craniofacial team are currently limited or unavailable for adults, the team may be able to direct you to appropriate community support. You can also contact your General Practitioner (GP), who should be able to signpost you to the most relevant source(s) of support.

If you are struggling to get a referral, or think you have been referred to the wrong place, you can seek help from Headlines Craniofacial Support by calling 07541106816 or emailing helpline@headlines.org.uk.

Social experiences

Modern appearance 'ideals'

In modern Western cultures, there are prevailing societal appearance 'ideals' which tend to dictate what is viewed as attractive. These ideals are determined and encouraged largely by the media, and the fashion and beauty industries that stand to profit from these ideals. As a result, anything that deviates from the ideal is typically seen as undesirable or 'different'. Even if a person doesn't place a lot of value on their appearance, everyone is likely to experience appearance-related pressures to some degree.

The impact of appearance 'ideals'

Over time, appearance ideals have become increasingly unachievable. When people compare themselves to these ideals, they may therefore feel that they fall short. This can have a negative impact on people's self-esteem. People may also feel pressure to conform to beauty standards from friends, family members, and the media. This may lead people to want to change the way they look, through daily practices, such as applying make-up, or through longer-term measures, such as invasive cosmetic procedures.

These pressures are felt by all people of all ages, whether they have a 'different' appearance or not. It is possible that for those with a condition which affects their appearance, these felt pressures may be even greater. There is an undeniable lack of diversity in appearances and abilities across many areas of society, which ultimately excludes people who do not see themselves represented.

"Some days it feels like everyone has something to say about my appearance".

Protecting yourself from unhelpful societal messages

Appearance pressures can come from many sources, such as advertisements, magazines, TV and film, and friends and family. Over the last decade, social media platforms have also become a key space for these types of messages. To protect yourself from unhelpful societal messages, you could try to only consume content that is aligned with your hobbies and goals, and makes you feel positively about yourself. On social media, it can be helpful to unfollow or mute any accounts that make you feel bad after you've viewed them. Be intentional with the social media feeds you create. Research finds that the more diversity we're exposed to, the better we feel about ourselves. Try to follow accounts that showcase all kinds of people, of different abilities, ages, body sizes, skin colours, and genders. Be sure to take a break - every now and again it can be helpful to unplug from socials and immerse yourself in real life instead.

Looking 'different'

Having an appearance-altering condition, such as craniosynostosis, can make people vulnerable to staring, and unsolicited comments and questions from others. Although other people may not mean any harm, it can leave the individual feeling upset or anxious in social situations. In other cases, more intentional social exclusion, teasing and bullying can occur. While these experiences are most often reported during adolescence, these difficulties can appear

in later life. Adults with craniosynostosis who have had negative social experiences in the past may continue to experience the ongoing effects.

"It's been hard to fit in. I've sometimes felt like an outsider".

Many different factors can impact how a person experiences and interacts with their environment, such as gender, ethnicity, or sexual orientation.

Managing difficult social situations

If you're caught off guard in the moment, it can be difficult to know how to respond. UK-based charity, Changing Faces, has produced a range of resources providing tips and tricks for managing difficult social situations. These include: coping with other people's reactions, how to respond to staring, how to respond to comments and questions, and dealing with abuse or harassment. Visit: www.changingfaces.org.uk/advice-guidance/relationships-social-life for more information.

Coping with social anxiety

For some people, these challenges may begin to impact their day-to-day life. This may lead to a fear and/or avoidance of social situations.

A challenging social encounter can promote feelings of self-consciousness, and initiate a negative loop that can result in social avoidance and isolation. Cognitive Behavioural Therapy (CBT) is a therapeutic approach that can help people to change how they think and behave. It is based on the idea that thoughts, feelings, physical sensations and behaviours are all linked and influence each other.

The CBT model can help identify different thought processes which are at play when we encounter challenges.

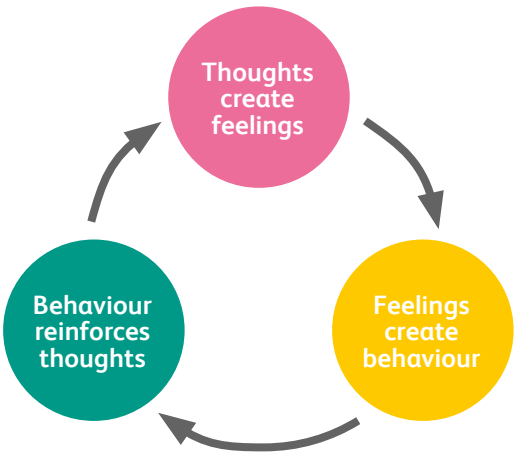
Situation: The trigger (e.g. a challenging social encounter)

Thoughts: Positive or negative interpretation of the trigger (e.g. "everyone is looking at me")

Emotions: Positive or negative feelings associated with the trigger (e.g. anxiety)

Physical experience: Bodily reactions (e.g. increased heart rate, feeling nauseous)

Behaviours: Reaction(s) (e.g. go home and avoid leaving the house for the next few days)



With an awareness of how our thoughts, feelings and behaviours are linked, it is possible to stop negative and unhelpful loops.

Challenging **thoughts:** Consciously catch and change any unhelpful thoughts in a given situation.

Challenging **emotions/physical experience**: Implement strategies to manage uncomfortable emotional and physical feelings.

For example, simple relaxation and breathing exercises can be effective. Tell yourself the feeling will pass.

Challenging **behaviour**: If it's possible and safe to do so, the 'graded exposure' technique can be helpful to tackle the behaviours that feel particularly difficult. This technique gradually exposes the person to the situation they are most worried about. For example, if the person's goal is to attend a social event, they could visit the venue in advance, get ready for the event with the support of a friend, or attend a smaller gathering with trusted friends to become used to being in a group situation.

To learn more about CBT and other therapeutic approaches, and to access resources to help you apply these approaches to your daily life, please visit www.getselfhelp.co.uk.

Changing Faces offer resources for feeling more confident in social situations. These include the role of body language in communication, improving conversational skills, and meeting new people. Visit www.changingfaces.org.uk/advice-guidance/relationships-social-life.

Romantic relationships

Meeting new people and opening up to being judged by others can be daunting. While navigating romantic relationships can be challenging for all adults at any age, people with craniosynostosis may be anxious about when and how to disclose their condition to a potential partner.

"In my late teens and early twenties, I was very self-conscious about being rejected and I thought I couldn't have relationships in the same way as my friends. I felt very low at that time, because I thought no one would want me".

In order to find a loving relationship, it's important that a person feels comfortable in themselves first. Having a condition such as craniosynostosis does not make a person any less 'loveable', and everyone has many brilliant qualities to offer a partner. Having a condition may even be helpful when navigating the dating world; if a potential partner responds negatively, it may indicate that the relationship is not worth pursuing.

"I was a late starter, but out of choice. A lot of my friends got in and out of bad relationships but I was a bit savvier about what I wanted from a relationship and was willing to wait for it".

Changing Faces offer resources on dating and relationships, as well as physical intimacy. Visit www.changingfaces.org.uk/advice-guidance/relationships-social-life

Khadeja is a 26-year-old British Pakistani with Crouzon's Syndrome. She was diagnosed as a baby and has since lived with the challenges it came with.

"Having a facial 'disfigurement' made me stand apart from all crowds. Not fitting in with society had a major impact on my personality. From a young age I was heavily dependent on family when facing the outside world. The constant stares and remarks caused conflict for both my personality and ultimately identity development. I was more than an Asian, Muslim female. I was also someone who society saw as having 'abnormalities'. The element of Crouzon syndrome was an additional identity for me - the accumulation of the physical impairments brought by my condition (minor visual, hearing), as well as others' reactions to it - felt like added weight. I can reflect now that society dictated my identity, before I ever got a chance.

I remember being called horrible names. Kids would usually nudge their parents whilst pointing at me. When they used to ask it was a difficult conversation to have. I would kindly excuse the question when it was hard to explain. Cartoons with googly eyes would often make me uncomfortable and I avoided any conversation that included them.

Growing up I learnt to become inspired and determined. This gene may be a part of me, but I wouldn't let it dictate my life. I wanted to be accepted by society - but after realising how society at times viewed me negatively – I pushed back and retaliated. Why I should care about what they think of me?

As an adult, I realise my condition was a strength. Dealing with psychological and medical hardships during my earlier years allowed me to gain more exposure, and I develop faster, for example in my confidence. During my undergraduate studies I used this confidence to achieve my goals. I did this while still working on my own identity and the way I was perceived in a crowd.

I learned how to cope effectively. I avoided an online presence and never displayed my appearance directly. This limited others people's pre-judgements of who I was, based only on how I look and before they even met me. It helped, especially in jobs and making friends.

For example, my friendships were mainly established in-person rather than online. I submitted job applications without any pictures, and didn't disclose my ethnicity or religion. I faced challenges head-on. I attended all job interviews and took them as an opportunity for growth both in my career and my personal life. I realised that some employers were uncomfortable with me on a front-end role. This, coupled with my introverted personality, meant I very quickly learned that non-customer-facing roles were more suiting.

Now, I often choose not to disclose my condition to others, for example, colleagues. I find this is effective, as it helps me to work on my identity and personality outside of Crouzon's.

Now I live life with the ability to do what anyone else does, I manifest my own future and set my own goals. If someone doesn't like me because of my appearance, they have the right to move themselves, but I won't move if I've not done anything wrong. I've learned that it's important to keep moving forward with life, and take each day as growth for a stronger future."

Treatment experiences

Previous experiences of healthcare

By the time an individual with craniosynostosis reaches early adulthood, they will likely have undergone several medical interventions. This will vary depending on their type of condition (e.g. syndromic or non-syndromic) and what treatment was available when the individual was born. For example, adults who did not have access to the craniofacial units while they were growing up may have a more varied treatment history.

Early childhood experiences can influence how people develop as adults. Some adults with craniosynostosis may therefore feel familiar with and comfortable in hospital settings, while others may become anxious. If previous treatment experiences were particularly distressing, adults may experience a range of difficult emotional reactions to medical environments, alongside other challenges, such as flashbacks or difficulties sleeping. These may be triggered unexpectedly, such as feelings of panic in response to hearing an ambulance siren. Some adults may avoid medical settings altogether.

"In all honesty, I would say I have been traumatised by my medical experiences".

It could be helpful for adults to reflect on how their early medical experiences may continue to impact them today, and speak openly about this with health professionals if they feel able to. It is the health professionals responsibility to ensure adults feel safe in a medical environment. If your medical experiences are impacting your day-to-day life, please contact your General Practitioner (GP) or your closest craniofacial team, who will be able to direct you to appropriate sources of support.

Previous medical experiences can also have a lasting impact on other members of the family, such as parents, grandparents, and siblings. Family members may find it helpful to access some of the links in this booklet, and connect with Headlines Craniofacial Support.

Transitioning to adult care

From the age of 16, individuals with craniosynostosis can expect to begin their transition into an adult model of care. This typically involves having more responsibility for medical decisions, and taking more control over the coordination of appointments. Specialist NHS treatment for craniosynostosis

in the UK also tends to end around this time. Many young people will have a positive experience of transition to adult care. However, like any major transition in life, this can be challenging to navigate.

"I would have liked better support to make my own healthcare decisions".

Young adults with craniosynostosis may feel frustrated they are not given enough say in their own care, or feel overwhelmed by the sudden expectation to make big medical decisions independently, something which their family members may have previously taken care of. Family members themselves may wonder when is the best time to let the young person have more autonomy over medical decisions.

Young adults should receive age-appropriate information about their medical care, and offered opportunities to share their views about treatment. These views should be taken into account by the health professionals, and the young adult should have the final say about whether a given treatment or surgery takes place.

Managing ongoing health needs in adulthood

Although the majority of medical treatment performed today in the UK will end around the age of 16 years, research has indicated that health-related concerns can persist into adulthood. These difficulties may include physical symptoms, such as migraines, and psychological concerns, such as anxiety. Adults born before the specialist craniofacial units were established may also find that the treatment they received then was quite different and has resulted in different outcomes.

Since specialist craniofacial care in adulthood isn't commissioned by the NHS in the UK, adults may need to lean more on primary care practitioners, such as General Practitioners (GPs). These healthcare professionals are likely to be less knowledgeable about craniosynostosis, which can feel frustrating.

"It would make me feel more secure and well looked after if my GP knew more about my condition than I do!"

"Health professionals don't seem to consider the causes or connections between symptoms".

Nonetheless, GPs are a great first contact for discussing any concerns.

Those impacted by long-term health difficulties, particularly in the case of 'rare' conditions, often feel they carry a burden of care. As well as the time it takes to arrange and attend medical appointments, adults with craniosynostosis may feel a need to teach health professionals about their condition, and fight hard to advocate for the care they need.

"I've had problems getting referrals. I've had to jump up and down quite a lot to be heard".

To support yourself through these challenges, you could consider trying the following approaches:

- If it feels beneficial to you, and if you are able to, try to become familiar with your medical history. Ask your family members or health professionals to help you gain access to your medical records, and talk to them about it if helpful. You could try to create a timeline of your medical history to date. Be aware this can take time and can bring up some challenging memories. Have someone to support you with this if you can.
- When engaging with health professionals, be prepared to answer their questions, even if you feel you have told them your story many times before. For some, this will be the first time they have heard of craniosynostosis. More importantly, be clear about what you want or need from them. If you feel anxious, or that time is limited, try writing a list of questions in advance of your appointment so you feel prepared and in control.
- Remember it is your right to access safe and appropriate care. If you feel you are not being listened to, or do not have trust in the advice the health professionals are giving you, it is acceptable to ask for a second opinion.
- Make use of your craniosynostosis community! The best people to support you through any health-related challenges are those who have already walked the path you're currently on.

Jane has a sister with Crouzon's Syndrome

"My sister was born with syndromic craniosynostosis in 1965. She's the youngest, and I'm the middle child of 5 siblings in the family.

I was first aware that my sister had problems when I was around 8 years old. After lots of medical tests over a period of time, it was concluded that she had syndromic craniosynostosis, which would be life threatening if surgery was not performed. Our Mum told me my sister was very poorly, and needed operations on her head or she could go blind.

When my sister went to hospital for her first surgery, my aunt looked after my brother and me. One weekend my Dad took my younger brother and I to visit our sister in the hospital. I was very frightened, because I understood what 'seriously ill' meant. I also picked up a lot from adults talking when they thought I could not hear them or understand what was going on.

My sister was unrecognizable when I saw her, swathed in bandages. You couldn't see her head, but I knew that they had shaved all her hair off for the operation. She was a tiny child with what looked like a huge head, and her face was black and purple.

I thought she would die, and I was very afraid. I told no-one about how frightened I was, and just absorbed the impact. I tried my best to carry on as normal, but all the while I was thinking about the terrible things they did to a person in hospital, or when my sister would die - what could we do, what could I do - and worrying about Mum too. Mum often looked crushed and broken, and so sad.

Back then, my sister's surgeries were quite experimental, as they didn't have a great deal of knowledge about craniosynostosis. I didn't know when the surgeries would end, and dreaded her going to many, many hospital appointments over the years, and admitted for procedures. 'What were they going to do to her this time?' I thought.

I did worry about my sister. Mum would warn people, "mind her head!". I was scared of accidentally touching her head in case I should break it.

My friends at school thought my sister had Down's Syndrome, and trying to explain about craniosynostosis was impossible. It just went over their heads and they did not understand. It was a lonely experience, and I was angry that others appeared to not want to understand, or know how to be kind. There was certainly bullying that happened during the school years, and our brother found himself in frequent trouble for fighting with the bullies. In those days, there was nothing available in the way of counselling for families.

As an adult, my sister has continued to struggle to find support. It is clear that people with craniosynostosis, and their families, need support at all different stages of their life's journey.

If I could offer a piece of advice to other siblings impacted by craniosynostosis, it would be not to feel alone, or that there is nothing you can do. Talk, and keep talking - these days there are people you can reach out to."

Employment

Seeking employment can be a challenging experience for everyone. For people who have a health condition or disability, entering the workplace may bring additional concerns.

Applying for a job

Some people are unsure whether to disclose their condition to a potential employer. Normally, employers are not able to ask health-related questions prior to offering someone a job. One exception to this is if an employer needs to ask about any adjustment required for interview. Another exception is when an employer needs to monitor applicants as part of its diversity commitment, but this information should never be taken into account during the recruitment process itself.

Some people choose to disclose their condition as part of their job application. For example, some people feel more comfortable on the day of the interview if they have already mentioned their condition in advance. Others may use it as an opportunity to explain how their condition does or does not impact their ability to work. There is unlikely to be one 'correct' approach, and it is more important that you do what feels most appropriate for you.

Stigma and discrimination

Some adults with craniosynostosis may feel that their condition and/or the way they look impacts their work-related experiences, including finding and maintaining satisfying employment, and building a career.

"I have qualifications and experience but I feel I am not being employed due to my disability".

Stigma relates to broadly-held negative perceptions toward certain groups, often due to unconscious or known biases against specific characteristics. Employers may hold unfavourable biases against those with health conditions, disabilities and/or a 'different' appearance. If employers act on those biases, this may be unlawful discrimination.

Discriminatory acts in workplace settings may include harassment (e.g. offensive comments), bullying, and being treated unfairly. Acts may be blatant, or more subtle. Subtle acts of discrimination are often more common and more problematic, as they are more difficult to challenge. For example, a blatant act of discrimination could be a violent slur said against an individual. A subtle act could be being excluded from working on a particular project for unclear reasons.

You may have a right to be protected from discrimination at work. Although the law doesn't use the language of 'visible difference', the law may protect you if you have an impairment (such as a condition or injury) which:

- Has a substantial adverse effect on your ability to carry out normal day-to-day activities, such as dealing with pain, having a learning disability, or experiencing anxiety related to your condition; or
- Is considered to be a 'severe long-term disfigurement', which could depend on the nature, prominence, size, and location of the disfigurement, as well as its impact on you. You do not necessarily need an employment contract to be protected.

If you feel you have been treated badly at work, seek legal advice about what to do without delay, as there are often short timescales within which you can act. Your legal representative may recommend you initiate an internal grievance procedure, and/or discuss the possibility of bringing a legal claim. You can seek legal advice from:

Citizens Advice Bureau
www.citizensadvice.org.uk

Equality Advisory and Support Service helpline www.equalityadvisoryservice.com/app/home

Local law centres
www.lawcentres.org.uk

If you need to request the help of a local solicitor who specialises in employment law, there may be a charge. Speak to your legal representative about cost implications.

Guidance on creating inclusive workplaces and employment law for employers can also be found at:

Advisory, Conciliation and Arbitration Service
www.acas.org.uk/advice

Equality and Human Rights Commission
www.equalityhumanrights.com/en/advice-and-guidance/equality-act-codes-practice

Changing faces
www.changingfaces.org.uk/for-professionals/employers

Experiences of employment

Some adults may feel they are being repeatedly turned away from employment or facing barriers in the workplace due to their condition, which can be extremely stressful.

“I have found it very stressful and have wanted to give up”.

For adults who are in employment, some may experience physical health difficulties which interfere with their ability to work.

“I regularly have bad migraines that affect my potential to perform well at work”.

Others may feel they are treated differently in the workplace because of their condition, and may change their behaviour in order to cope.

“I always felt I had to work much harder than other people to prove myself capable of doing the job”.

Despite clear challenges, many adults with craniosynostosis enjoy regular employment and have built fulfilling and successful careers.

Nammie is 30 and was born with Saethre-Chotzen syndrome

"I've always loved to learn. As a child, academia was where I excelled and built my confidence – I was never very good at sports (thanks, depth perception issues and dodgy hand-eye coordination) and struggled with social anxiety and awkwardness.

Being born with craniofacial differences meant I felt rejected by my peers, but reading made me feel untouchable. Whether it was learning something new, or escaping to another world – one that wasn't mine – I'd spend hours with my head in a book, each word that passed further satisfying my curiosity.

For a long time, I couldn't settle on a long-term dream. I remember wanting to be an author, lawyer, and doctor at different times throughout my childhood, but could never quite bring about the confidence (or indeed the conviction) to commit to any of them.

It wasn't until I travelled around the world, aged 22, that something changed. I sort of fell into travel writing accidentally, through a blog used to keep my friends and family aware of my whereabouts and adventures. For ten months, I wrote several times a week about where I was, what I was doing, what I'd seen. Before long, strangers from around the world were reading it. My writing! Me!

Just like that, my confidence erupted. I'd finally – finally – found my calling.

I returned from my trip and knew what I had to do. Within two weeks, I had a place on the BA (Hons) Travel Journalism course at the University of Brighton.

I spent the following three years mirroring my childlike wonder for information. I wanted to absorb all of it, and I wanted to learn from the best. Equipped with nothing but resolute determination, I picked up several part-time jobs to pay for the travel costs needed to visit London for internships. I worked at Lonely

Planet, Cosmopolitan, Travel Trade Gazette, and an online travel agent, learning vital industry knowledge at each.

Since graduating, I've held jobs in local news, edited a local magazine, and completed work for higher-profile publications such as The Sunday Times. I've also written website copy for international airlines and other travel websites. In 2019, I decided to start my own copywriting business.

I think it's my experience as someone with craniosynostosis that encouraged me to go my own way in the world. I'd always struggled with job interviews, forever concerned my appearance or mannerisms were being judged above my skills. Now, having my own business means my skills and capabilities more than speak for themselves. It also means I can be flexible with when and where I work. Yes, this means more travel, but it also means if I get a debilitating migraine, or bunged up sinuses (both things I attribute to my craniosynostosis) then I have the ability to take an afternoon or day off to check up on myself.

I have so much advice to give to other adults or young people with craniosynostosis, but, first and foremost: don't let the things that scare you, stop you. Being born with craniosynostosis means we've already been through much more than the world can throw at us, and we've got the resilience to go against the grain, or to grab that opportunity that arises, and still come out on top.

So, be brave. Chase your dreams. And remember that what we have – what we've been through – isn't an obstacle. It's a superpower."

Returning to work after treatment

Some adults may have additional treatment or surgery related to their craniosynostosis, and this could require some time off work. You may be concerned about colleagues asking you questions, especially if the treatment or surgery changes your appearance or impacts you in other ways. You could consider talking to your employer about what to share with colleagues. For example, you could help your employer to write an email to your colleagues, which will give you some control about how the information is presented.

Think about who you want to speak to about any impacts of treatment. Your manager may be helpful in working through the practicalities, for example, but you may feel more comfortable discussing relevant medical details with someone from HR or Occupational Health. You may also want to involve your doctor who can speak to your employer on your behalf.

Your employer should help you with any adjustments you may need to return to work. For example, you may be able to work from home for a while, request additional medication breaks, or submit a flexible working request, which allows you a temporary (or permanent) change in hours. It's best to wait until your doctor agrees you are ready to return to work. If you need any financial assistance in the meantime, speak to your employer about your entitlement to sick pay and holiday, or check the Citizens Advice Bureau or the Trade Union to see if you are entitled to any benefits.

Further support

Changing Faces are a UK-based charity who have produced a range of resources to support people with appearance-altering conditions and disabilities to tackle the challenges associated with employment. These include applying for a job, attending an interview, making connections in the workplace, workplace transitions, and asking for provisions in the workplace. For more information, visit www.changingfaces.org.uk/advice-guidance/working-when-you-have-visible-difference.

Some charitable organisations offer general support with employment:

- Maximus helps people find employment, access support and remain healthy in their workplace or community: www.maximusuk.co.uk.
- Access to Work is a service for people with physical or mental health conditions or disabilities: www.gov.uk/access-to-work/eligibility.

Starting a family

Deciding whether to have a family

One of the key decisions faced by all young adults is whether to start their own family. In the case of conditions with a risk of recurrence, this decision may be more complicated.

Although we are still learning about the genetic causes of craniosynostosis, it is known that the chance of having a child with craniosynostosis is higher if one of the parents has the condition themselves. This is more likely if the parent has syndromic craniosynostosis. Around 25% of all cases of craniosynostosis are thought to have a genetic basis.

Research with craniosynostosis and other inherited conditions has suggested that the recurrence risk is not often significant enough to stop adults wanting to have children.

"I don't think it would put me off. With the right support I think I could cope".

However, some adults may choose not to have children, on the basis of genetic risk.

"I wouldn't want to put my children or grandchildren through what I've been through".

This demonstrates the need for accurate, individual, and up-to-date genetic information at the time the decisions are being made.

Genetic counselling

Adults with craniosynostosis wishing to know more about their recurrence risk prior to having children may be referred to a Genetic Counsellor or Clinical Geneticist. Where possible, this will be done by the specialist craniofacial team around the time of transition to adult care. You can also request a referral to your local Genomic Medicine department. At the appointment, information about the family's medical history will be collected. In some cases, genetic tests (such as blood tests) may be offered. This helps to ensure the individual is given the most up-to-date testing, appropriate to their specific condition. The specialist will then discuss their findings, what this may mean in terms of the recurrence risk, and any options available.

There is no right or wrong choice when it comes to having a family. The role of a Genetic Counsellor or Clinical Geneticist is to provide information and support to help each adult make the decisions that are right for them.

Having a child with craniosynostosis

Of those who choose to have a family, some adults with craniosynostosis will have a child

with medical challenges. Previous research has explored how adults with inherited conditions have felt when their child receives the same diagnosis. Some adults reported feeling distressed at this time.

“I was devastated… I felt guilty. I felt sad for my daughter”.

“I knew it would be another 20-plus years of this... I just wanted someone to say ‘I’m sorry you have to go through this again’”.

Other adults expressed having some concerns, but felt they had been able to cope with their child’s diagnosis.

“At the end of the day, I came out alright, and at a time when treatment wasn’t as good as it is now. It was a hurdle, but certainly not one we couldn’t overcome”.

Some adults have reported that having a child with craniosynostosis has had a uniquely positive impact on them.

“My son and I are very close. It’s a very unique relationship, and I wouldn’t have it any other way. My son has given me huge strength. Through him I’ve learned a huge amount from the other side”.

For adults whose children do not have craniosynostosis, some challenges may still arise.

“When I drop my son at school and the parents and children stare at me, I feel as though I’m the one who is back in the playground again. When my son’s friends come around for tea, I wonder what they think of me, and I hope he isn’t embarrassed”.

Growing older with craniosynostosis

Adults with craniosynostosis who were born before the establishment of the specialist craniofacial units may have had different experiences to children who are born with the condition today. Having a voice, and access to reliable information and support, is important no matter what your age.

Wellbeing and resilience

Mental wellbeing is fundamental to the overall health of an individual, enabling them to achieve what they want from life and to overcome any difficulties. Adults with craniosynostosis will have likely had challenging life experiences that many other people haven't. However, overcoming these challenges may have helped adults with craniosynostosis to build up a level of resilience that allows them to cope well with future adversity.

Life transitions

Life transitions are significant events that may test an individual's resilience. Examples of life transitions include starting university, moving home, entering the workforce, beginning and ending relationships, starting a family, unexpected illness, bereavement, and so on. Although some of these events can be positive, they may still pose challenges because they promote a physiological stress response. Life transitions require us to 'adjust' to the demands of our environment.

Factors that can influence adjustment

Understanding the factors that help or hinder our ability to adjust to the challenges we experience in life is important, as it helps us to identify resources that may be helpful. Research has identified a range of internal (within our control) and external (support from others) factors:

- Our childhood experiences
- The degree to which we feel we 'fit in' with our community
- How confident we feel in social situations
- Our self-esteem
- How much autonomy (independence and choice) we have over our lives
- How optimistic we are about the future

All of these factors can be impacted by having a condition such as craniosynostosis. However, there are several resources we can draw upon to help us through difficult times.

Coping strategies

No coping strategy is 'right' or 'wrong'. However, some coping strategies may be more effective than others. For example, avoiding social situations may reduce the immediate feeling of anxiety, but will not help you to feel comfortable in social situations in the longer-term. There are a range of strategies you can use to help calm you and bring about a sense of stability. Some of these strategies are listed overleaf.

Be gentle with yourself when trying these techniques out. During particularly distressing times, you may find it less helpful to try out lots of new strategies for the first time.

Different strategies work for different people. It's about finding what works for you. There are a number of apps that can support you with this. These include Headspace www.headspace.com and Calm www.calm.com/breathe. These apps may come with a cost, but they usually offer some content for free.

You can also visit Mind, a UK charity, for general mental health support. Visit www.mind.org.uk.


Seeking information about your condition
Practising meditation and/or relaxation techniques
Engaging in physical activity
Spending time on your hobbies
Drawing on faith or spirituality
Finding humour in the situation
Taking time to rest and unwind
Using grounding statements
Asking for support from friends, family members and others
Connecting with others with similar experiences

Connecting with the craniosynostosis community

Headlines Craniofacial Support

Headlines is the only national charity dedicated to supporting those with and affected by craniosynostosis and other rare craniofacial conditions. Headlines works in partnership with the health professionals providing your treatment plan, and with leading academics to improve care through research.

Headlines offers:

- A telephone helpline (07541106816) and email service (helpline@headlines.org.uk): providing free, confidential support throughout your journey
- A peer support service: putting individuals in touch with each other locally/regionally to share experiences
- An online support group at www.facebook.com/headlinescraniofacialsupport.
- Family Weekends: providing families and individuals with an opportunity to seek advice and support, meet others affected by craniosynostosis, and participate in various shared activities
- An e-newsletter and printed magazine: containing regular updates, upcoming events, member stories, informative articles, and fundraising efforts.

Headlines has more than 2,500 members, made up of families, adults, and health professionals in the UK and overseas. You can become a member of Headlines free of charge at: www.headlines.org.uk/how_to_join.asp.

Hannah's Fund

Hannah's Fund is a small UK charity supporting families and individuals affected by craniosynostosis to access emotional support. Visit www.hannahsfund.co.uk for more information.

Changing Faces

Changing Faces is another UK charity supporting people who have conditions which affect their appearance. They regularly facilitate peer support sessions for adults with a variety oconditions. Visit: www.changingfaces.org.uk/services-support/peer-group-chat. They also host an online community for people to connect further. Visit: www.changingfaces.org.uk/services-support/online-community.

Additional mental health support

If you are concerned about your mental health or wellbeing, please speak to your General Practitioner (GP).

If you are in an urgent situation, and at risk of harming yourself or others, please contact 999 (111 for non-emergency). For other support in a crisis, please call the Samaritans on 116123 (24-hour helpline) or text SHOUT to 85258.

Advice from adults with craniosynostosis

As part of the research project that underpinned these resources, we asked adults with craniosynostosis what advice they would give to others in their situation:

"Stay strong, be brave"

"Take risks and don't give up"

"Seek information and advice"

"Know that everything will be OK and you will get through this"

"Be confident and proud of who you are"

"Find a purpose and live your life to the fullest you can"

"Advocate for yourself"

"Be kind to yourself"

"Embrace your condition and find the positives"

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Research in craniosynostosis is ongoing. Please contact the team at CAR@uwe.ac.uk to be made aware of future opportunities to participate in research.