

Fact Sheet 20

UNDERSTANDING THE LONG-TERM JOURNEY WITH A CRANIOFACIAL CONDITION

Every child's craniofacial journey is different. The appointments, treatments, and surgeries your child may need will depend on their specific diagnosis and how the condition affects them.

Different craniofacial conditions can have quite different care pathways. For example, the follow-up for craniosynostosis may look very different from the pathway for cleft lip and/or palate. Even within the same condition, different craniofacial teams may have slightly different approaches to care.

Some children may only need a few surgeries and check-ins. Others may have a longer journey, involving regular input from a team of specialists over many years. Whatever your child's path looks like, your healthcare team is there to guide and support you every step of the way.



Early Months and Diagnosis

For many families, the journey begins with noticing something different — an unusual head shape, feeding difficulties, or concerns raised by a GP or maternal child health nurse. This often leads to referrals, scans, and specialist appointments. It can be an overwhelming time.

In these early stages, you may meet several new clinicians: paediatricians, plastic or craniofacial surgeons, geneticists, speech and feeding therapists, and others. Some families receive a diagnosis quickly; for others, it takes time as more information becomes available.

This is also when imaging and clinical photographs are often taken to help confirm the diagnosis and plan early care.

What to focus on in the early stages:

- Understanding the diagnosis and its management journey
- Learning what to expect in the short term
- Starting to build relationships with your specialist team

(continued overleaf)



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Infancy (0-12 Months)

This is often a time of intense medical involvement. For many children, the first year of life includes their first surgery — such as skull reshaping for craniosynostosis, or cleft lip or palate repair. These procedures are typically timed to support safe growth and development.

In addition to surgery, families may be managing feeding issues, sleep concerns, and hearing difficulties. It is common to have multiple appointments with surgeons, audiologists, speech and feeding therapists, ENT (ear, nose & throat) specialists, and others.



Things you might experience:

- Surgery and hospital stays
- Feeding support and bottle trials
- Hearing tests and ear monitoring
- Recovery, bonding, and adjusting to changes in appearance

This stage is a steep learning curve, but also a time when many families start to feel more confident navigating the healthcare system.

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Early Childhood (1-5 Years)

As your child becomes more active, independent, and verbal, their care continues to evolve. The type of follow-up needed at this stage will depend on your child's specific condition and their team's usual care pathway. Growth is closely monitored – especially facial and jaw development, speech, hearing, and learning. Some children will need further surgery in this phase, while others will be in a period of observation and follow-up.

Speech and language therapy is often a key part of this stage, particularly for children with a cleft palate or ongoing hearing issues.



Common areas of care:

- Ongoing speech and language support
- Dental and hearing check-ups
- Additional imaging or surgery, if needed
- Monitoring developmental milestones

Families may also start thinking about kindergarten and school readiness, which might include support from psychologists or social workers.

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School Years (5-12 Years)

During the school years, follow-up continues according to your child's specific diagnosis and individual needs. Some children may need more input from orthodontists, psychologists, social workers, or educational support services, while others may mainly need monitoring and occasional reviews.

This phase can also bring social and emotional challenges. Children may start to become more aware of physical differences or feel self-conscious about scars or ongoing treatments. School transitions, friendships, and confidence may become new areas of focus.



Common areas of care:

- Monitoring speech and learning
- Addressing dental and jaw development
- Supporting self-esteem and emotional well-being
- Additional surgeries if required (such as jaw, nasal, or ear corrections)

Your healthcare team may also revisit or refine the diagnosis as your child's facial structure and needs become clearer.

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Adolescence to Young Adulthood (13-18+ Years)

This is a period of major physical, emotional, and social change — and often a time when more complex surgeries (such as jaw or rhinoplasty procedures) are considered, if needed.

Some young people may feel 'done' with surgeries, while others are ready to consider further options for appearance, function, or confidence. This stage involves more collaborative decision-making between your child, you, and the medical team.



Cranio Warrior Briana

Support might include:

- Orthodontic treatment and jaw surgery
- Psychological support for body image and independence
- Transition planning from paediatric to adult care
- Guidance for navigating relationships, study, or work

This is also a time when your child's voice becomes central. Encouraging independence in appointments and decision-making can help set them up for adulthood.

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Adulthood (18+ Years)

By adulthood, some people with craniofacial conditions have completed their medical care and may not require any further appointments. Others may still need support — particularly if they've had ongoing functional issues, visible differences, or if new challenges arise with work, relationships, or mental health.

For those with less visible conditions, adulthood may feel relatively unaffected, while others continue to manage appearance-related differences or long-term effects of earlier treatments. Some adults choose to seek additional surgeries or psychological support later in life — sometimes for the first time in years.

This stage of life also might raise questions about the likelihood of their own children having a craniofacial condition. Discussions with the medical team can provide insights and support in understanding potential genetic factors or risks for future generations.

In many cases, adults transition from paediatric services to general adult health care. Some larger hospitals offer dedicated adult craniofacial services, while others may involve referrals to individual specialists as needed.

Support might include:

- Managing jaw, dental, or breathing issues
- Addressing appearance-related concerns through surgery or counselling
- Supporting body image, identity, and social confidence
- Access to psychology, speech therapy, or ENT care for residual issues

It is also common for adults with lived experience to give back — sharing their stories, mentoring young people, or becoming advocates for greater understanding and inclusion.

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What Stays the Same (Even When Everything Else Changes)

Throughout this journey, what stays consistent is the need for:

- **Good communication** — between you, your child, and their healthcare team
- **Flexibility** — plans can and do change as your child grows
- **Ongoing support** — for physical health, mental well-being, and navigating the healthcare system
- **Family-centred care** — where your expertise as a parent is respected and included

Looking Ahead

Living with a craniofacial condition is not just about managing medical needs — it is about helping your child grow into the person they want to be. That includes health, but also confidence, friendships, education, and identity.

You may not always know what is around the next corner. But understanding the typical phases, who might be involved, and what kinds of support exist can help you feel more prepared and empowered.

While the journey may be long, it can also be filled with strength, progress, and connection.

This information is based on the expertise of clinicians who work with families affected by craniofacial conditions and the lived experience of parents with children who have been diagnosed with craniosynostosis. We thank everyone who contributed to this fact sheet.



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How we can support you:

- Care packs
- Financial assistance
- Family support coordinator
- Connection to other families

