

Fact Sheet 5

HOW EACH MEDICAL APPOINTMENT SUPPORTS YOUR CHILD'S CARE

When a child is diagnosed with a craniofacial condition, families are often given a long list of medical appointments. It is completely normal to feel overwhelmed or unsure about the journey ahead. This guide is designed to help you understand who these health professionals are and why their involvement is important.

At times, you may have an appointment with multiple specialists, known as a multi-disciplinary team (MDT). This team works together to assess your child's needs, share information, and plan treatment in a coordinated way. This team approach means that you don't have to manage separate opinions or juggle conflicting advice — the team works as one to support your child.

Each of these clinicians plays an important role in supporting your child's health, development, and well-being — from diagnosis to long-term care. While not every appointment will involve the whole team, all input contributes to building the best possible care plan for your child.



1. General Practitioner (GP)

- Who they are: Your family doctor and first point of contact for health concerns.
- Why they are important: GPs provide general health care, monitor your child's well-being, and make referrals to paediatricians or other specialists when they notice early signs or concerns. They continue to support your family's overall health throughout your child's care journey.
- *For example: Your GP might notice an unusual head shape or feeding difficulties and refer you to a paediatrician for further assessment.*

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2. Paediatrician

- Who they are: A doctor specialised in children's health and development.
- Why they are important: The paediatrician monitors overall growth and development, manages general health concerns, and is often a key coordinator for referrals to specialist craniofacial teams. They ensure that health issues related to your child's craniofacial condition are addressed early and appropriately.
- *For example: They might check for feeding difficulties due to cleft palate or jaw differences and arrange early support, or help manage related medical concerns such as sleep apnoea, ear infections, or nutritional challenges linked to your child's craniofacial condition.*

3. Geneticist

- Who they are: A doctor specialising in genetics and inherited conditions.
- Why they are important: Some craniofacial conditions are caused by genetic syndromes. The geneticist helps confirm diagnoses, explains the cause, and advises on the likelihood of recurrence in future pregnancies. This information supports personalised care and family planning.
- *For example: If your child's features suggest a syndrome like Apert or Crouzon, the geneticist may arrange testing and provide guidance on what to expect.*

4. Craniofacial Surgeon

- Who they are: A plastic, oral and maxillofacial, ENT (ear, nose & throat) surgeon who has special advanced training and works in an established craniofacial team.
- Why they are important: They can correct the shape and function of the head, face, and jaw. Their work may support brain growth, breathing, feeding, appearance, and self-confidence. This surgeon often collaborates with neurosurgeons and other specialists.
- *For example: They may operate to correct craniosynostosis (early skull fusion) or repair cleft lips and palates.*

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5. Neurosurgeon

- Who they are: A surgeon specialising in the brain and nervous system.
- Why they are important: The neurosurgeon works with the craniofacial surgeon to protect the brain and manage conditions related to skull abnormalities, such as raised pressure inside the skull.
- *For example: During head surgery, they ensure the brain is safe while bones in the skull are reshaped to allow proper growth.*

6. ENT Specialist (Otolaryngologist)

- Who they are: A doctor specialising in ear, nose, throat, and airway conditions.
- Why they are important: Children with craniofacial conditions often have issues like ear infections, breathing difficulties, or nasal blockages that require treatment from an ENT specialist to support overall health and development.
- *For example: They might insert grommets to treat ear infections or help manage noisy breathing and snoring.*

7. Audiologist

- Who they are: A health professional specialising in hearing assessment and management.
- Why they are important: Hearing loss is common in children with craniofacial conditions and can affect speech, language, and learning. Audiologists monitor hearing and recommend interventions when needed.
- *For example: They may detect middle ear fluid causing hearing loss and suggest hearing aids or surgical options like grommets.*

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8. Speech-Language Pathologist

- Who they are: A therapist specialising in speech, language, and swallowing development.
- Why they are important: Structural differences such as cleft palate can impact how a child talks, eats, or swallows. Early speech therapy supports communication skills and safe feeding.
- *For example: They may help your child learn speech sounds or develop safe feeding techniques for babies with cleft palate.*

9. Dentist

- Who they are: A doctor specialising in oral health, including teeth and gums.
- Why they are important: Craniofacial conditions often affect dental development, increasing the risk of dental problems. Dentists help prevent decay, monitor tooth growth, and maintain oral hygiene.
- *For example: They might provide advice on cleaning hard-to-reach teeth or monitor for crowded or missing teeth.*

10. Orthodontist

- Who they are: A dentist who specialises in teeth and jaw alignment.
- Why they are important: Jaw growth and facial structure can affect how teeth come together. Orthodontists help correct bite issues and support facial balance, often during later childhood or adolescence.
- *For example: They may plan braces or other appliances to guide jaw development and improve chewing and speaking.*

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11. Psychologist

- Who they are: Specialists in mental health who support emotional well-being, behaviour, and coping strategies. They may also help assess your child's developmental progress and learning abilities.
- Why they are important: A craniofacial diagnosis can bring emotional and developmental challenges for the whole family — including anxiety, stress, learning difficulties, or changes in self-esteem. Psychologists help children understand and cope with their experiences, support parents in managing their own responses, and ensure children receive the support they need to thrive emotionally and academically.
- *For example: They might help your child build confidence after surgery, support you in managing stress, assess your child's learning needs, or work with the family to improve communication and coping.*

12. Social Worker

- Who they are: Professionals who support families with practical help, emotional support, and navigating complex medical systems.
- Why they are important: A social worker can help your family adjust to a new diagnosis, access hospital and community services, and manage the practical impacts of caring for a child with a craniofacial condition.
- *For example: They might help you access financial assistance, link you with local support networks, or advocate for your family's needs with schools or government services.*

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13. Medical Imaging Specialist

- Who they are: A specialist who conducts and interprets medical scans such as X-rays, CTs, or MRIs.
- Why they are important: Detailed images of your child's head and face help the team understand bone structure, brain development, and surgical needs. Imaging is often used to confirm a diagnosis or guide treatment planning.
- *For example: They might perform a CT scan to check if the bones in your child's skull have fused too early or to help surgeons prepare for an operation.*

14. Medical Photographer

- Who they are: A trained professional who takes clinical photographs for medical use.
- Why they are important: Regular photographs help the team track your child's growth and treatment outcomes over time. These images are used for planning care, monitoring progress, and teaching purposes — always with your permission.
- *For example: They may take standardised photos before and after surgery to help compare changes and plan future treatment.*

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It might feel like a lot — but there is a good reason for each appointment. Craniofacial conditions can affect multiple systems, so it takes a team approach to:

- Monitor your child's development
- Plan surgeries and treatments
- Prevent complications
- Support your child's development, including learning, speaking, hearing, and feeding
- Look after mental and emotional health — including yours

Health professionals do not always have all the answers about your child's diagnosis, treatment plan, or future right away. Each appointment helps to build a clearer picture of your child's needs over time.

Diagnosing and planning treatment for craniofacial conditions can take time because your child's needs may change and new information can emerge. This is a normal part of the process, and your care team will keep you informed as they learn more and make decisions together with you.

Understanding who each healthcare professional is and why they are involved can help you feel more informed, confident, and supported as you navigate your child's care.

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

