

CAPTURING MEMORIES OF YOUR CHILD'S CRANIOFACIAL JOURNEY

Documenting your child's craniofacial journey can be deeply meaningful – not only to track progress and milestones, but also to create a space for reflection, sharing, and advocacy.

Looking back on photos, journals, or keepsakes, however, may sometimes bring up strong emotions, even years later. This is a normal and expected reaction for many parents. These memories reflect not only progress but also the challenges your child and family faced.



Below are some creative and thoughtful ways that parents could record and reflect on their child's craniofacial journey. If it feels overwhelming, you might choose to capture photos, notes, or other pieces of information yourself, and ask a trusted family member or friend to organise them, or simply keep them safe for you, until you feel ready.

Every family's journey is unique, and not every idea will feel right for everyone. Feel free to explore these suggestions and adapt them in ways that suit you and your child best.

Photo & Video Journals

- Before & after photos around key milestones (e.g. surgery dates, first smiles, first day of school).
- Time-lapse photo series to visually show growth and healing over time.
- Short video diaries capturing thoughts, emotions, or little achievements.

Written Reflections

- A personal journal for jotting down key moments, emotions, and insights can be helpful for emotional processing and memory-keeping.
- Maintaining a milestone log including surgery dates, hospital stays, first appointments, and developmental wins.
- Letters to your child written at different points in their journey, which can be shared with them later in life.

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Creative Keepsakes

- Memory boxes of hospital wristbands, a special toy that was treasured during recovery from surgery, locks of hair from your child's first haircut, and notes or cards from loved ones.
- A scrapbook combining photos, notes, quotes, and drawings from your child, their siblings, or friends.

Digital Sharing

- Private blog or photo-sharing site for close friends and family to follow updates.
- Social media diary (public or private) to connect with other families, raise awareness, or build community.
- Be mindful of online guidelines — your child may not want certain photos or details shared without their consent, especially as they get older.

It's natural that some photos or memories may feel hard to capture or look back on at first. That doesn't mean you need to revisit them straight away. Keeping them safe, even if you don't feel ready now, may give you and your child something meaningful to reflect on in the future.

Some children have shared that they don't clearly remember, or never really knew, what they looked like before surgery. Having photos or keepsakes can help them understand their own journey and feel more connected to their story.



Involving your Child in Their Journey

Involving your child in capturing their craniofacial journey can be meaningful for both them and you. For children, it can provide a sense of ownership, help them express feelings, and build confidence in telling their own story. For parents, it can offer fresh insights into how your child is experiencing things and create moments of connection as you share the journey together.

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Ways you might involve your child include:

- **Drawing or journaling** – Invite your child to draw pictures or write short stories about their experiences.
- **Using feelings charts or age-appropriate journals** – These can help your child put words or images to how they're feeling.
- **Letting them choose what to document** – As they get older, involve them in deciding which photos, notes, or memories to include.
- **Celebrating milestones** – Some families like to mark a 'cranioversary' (surgery date) with a cupcake, a photo reflection, or looking back at keepsakes that show how far their child has come.

Not every child will want to take part in the same way, and that's okay. What matters is giving them the chance to be involved at their own pace, in ways that feel comfortable and meaningful to them.



Feelings Chart

Point to or circle the face that best shows how you feel today:

HAPPY	SAD	LOVED	TIRED
SORE	BRAVE	ANGRY	CONFIDENT
RELAXED	SCARED	EXCITED	NOT SURE

(continued overleaf)





My Journal

My Name _____

Date _____

What happened today?

I felt (circle or write):

Happy / Sad / Scared / Tired / Sore / Brave / Angry / Other: _____

One thing I want to remember about today:

One thing I want someone to know:

Draw a picture of something from today:

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

