

## Fact Sheet 12

# TRACKING YOUR CHILD'S CLINICAL PROGRESS

Keeping track of your child's medical and recovery information can make day-to-day care easier and provide a clear picture of progress over time. Recording details like symptoms, pain levels, sleep, and emotions can help you notice patterns, share accurate updates with your healthcare team, and feel more confident in your child's care. These records can also highlight the resilience and strength your child shows along the way.



## ORGANISING CARE INFORMATION

- Keep a binder or digital folder with important documents (surgery summaries, referrals, progress reports).
- Store questions and notes for specialists in one place so you don't have to rely on memory at appointments.
- Consider making a simple calendar of upcoming appointments and follow-ups.

## MONITORING EMOTIONS AND WELLBEING

Just as you track symptoms, it can be helpful to check in on your child's emotions. A simple feelings chart allows children to show how they feel in a way that's easy to share with parents and clinicians.

### 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)*



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### SYMPTOM & RECOVERY TRACKING

Use a chart or diary to record details such as pain, feeding, sleep and healing.

| Date   | Pain Level (0-10) | Healing notes         | Feeding (amount/type) | Sleep (hours/quality) | Other symptoms/notes                      |
|--------|-------------------|-----------------------|-----------------------|-----------------------|-------------------------------------------|
| July 1 | 4                 | Surgical site swollen | Breastfed 100ml       | 8 hrs / restless      | Mild irritability                         |
| July 2 | 3                 | Swelling reduced      | Formula 120ml         | 9 hrs / good          | Slight rash, but played with toys         |
| July 3 | 2                 | Wound healing         | Solid food            | 7 hrs / interrupted   | No new symptoms and was smiling and happy |

#### How to use:

- Rate pain each day from 0 (no pain) to 10 (worst pain).
- Write brief notes on healing or any changes in appearance.
- Record feeding details like quantity and type of food or milk.
- Track sleep hours and note if sleep was restful or interrupted.
- Add any other symptoms or observations to share with your healthcare team.

### MEDICATION RECORDS

- Write down medications, doses and times given.
- Note any side effects or reactions.
- Keeping this log can reduce errors and help clinicians adjust care if needed.

(continued overleaf)



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## GROWTH AND DEVELOPMENT NOTES

- Track height or weight if appropriate.
- Keep notes on speech, feeding, school progress, or other developmental milestones.
- These records can be useful when discussing progress with health or education professionals.

## WHY KEEPING RECORDS HELPS PARENTS

- Reduces stress by keeping everything in one place.
- Makes it easier to share clear, accurate updates with different specialists.
- Helps you prepare questions for appointments.
- Provides useful documentation for funding, school supports, or therapies.
- Allows you to look back and see how much progress your child has made over time.

Tracking clinical details may feel like one more task during an already busy time, but some parents may find it helps them feel more organised and empowered. Over time, these records become not just medical notes, but also a story of your child's resilience and growth.

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

