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infancy

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cleft lip & palate explained

Most mothers expect to have a healthy, “normal” baby but what if your little one was born with a cleft lip and palate? Read on to find out about this condition and what can be done

When Cheryl McKibbin was pregnant with her fourth child, she was told at her 20-week ultrasound scan that her baby would be born with a cleft lip and palate. Realising her child would not look “normal” came as a shock. To make matters worse, she was told nothing could be done about the condition until after her baby was born. She was also kept in the dark and given little to no information or support. This meant the lead-up to her son’s birth was an anxious time for the McKibbin family.

Approximately one in 600 children are born with a cleft lip or palate. In fact, conditions of the mouth and lip rank as the third most common problem at birth, behind heart and spine conditions. Thankfully, virtually all cleft conditions can be repaired. Most children are left with no scar, or only a small one, on their lip and lead completely normal lives.

WHAT IS A CLEFT LIP OR PALATE?

The cleft can involve either the lip and gum (primary cleft) or palate (secondary cleft), or both, and is caused by a failure in parts of the mouth to join during early foetal development.

With a cleft lip, a gap in the upper lip extends up to the base of the nose, and this cleft can be either unilateral (one sided) or bilateral (both). A cleft lip means there is a gap beneath one nostril, whereas a bilateral cleft lip has a gap that extends up into both nostrils. A cleft palate, on the other hand, involves a space or a “cleft” in the roof of the mouth, which is also the floor of the nasal cavity. It is possible to look right into the nose when the baby opens their mouth.

In about 50 percent of cases children have both a cleft lip and cleft palate. Of the other 50 percent, half are born with a cleft lip alone and half have only a cleft palate. McKibbin’s son Koby was one of the majority as he ended up with both a primary and secondary cleft.

WHY DOES A CLEFT DEVELOP?

The failure of fusion of the primary cleft occurs before six weeks gestation whereas the failure of palate fusion occurs between six and 10 weeks.

The cause of a cleft lip or palate is still unknown, although researchers now believe the majority of cases are genetically programmed. This came as a revelation to McKibbin, who was born with an unilateral cleft lip but was unaware that it could be passed onto her offspring. It is surprising how often a relative is found to have had a cleft after the birth of a baby with a cleft.

REPAIRING THE CLEFTS

Cleft lips are more or less a cosmetic issue and can be surgically corrected at the age of three months. Cleft palates, on the other hand, are more difficult to fix and are usually repaired at six to nine months of age, or when there is maturity of the baby’s breathing. Subsequent surgery may be needed during childhood and adolescence with the aim of making the child normal in appearance (both facially and dentally) and with normal speech.

OTHER PROBLEMS

Physical difficulties in babies include feeding problems, fluid in the middle ear, delayed speech and problems with teeth in the cleft site (which is correctable with orthodontics):

- For newborns and young babies, feeding can be difficult. Usually babies with a cleft gain weight acceptably after birth but some may not gain weight as fast as their peers, and breastfeeding can be virtually impossible. Luckily, as McKibbin found, there are many alternatives. She says, ‘A soft plastic squeeze bottle with a soft teat worked. When Koby made the suck motion, I

would gently squeeze the milk into his mouth.’

- Fluid build-up in the middle ear is also a common problem. This is because the palate is involved in the opening and closing of the Eustachian tubes. The insertion of a grommet corrects such problems.
- A speech therapist may be required to help the child learn to pronounce words. Delayed speech may be due to hearing loss and also result from underdeveloped jaw muscles.
- Abnormalities with teeth at the cleft site is a common occurrence, although this generally does not cause serious problems. Regular visits to the dentist are essential as the child grows.

SUPPORT

Having a child with an abnormality such as a cleft can be traumatic, especially prior to the surgery. It is not uncommon for parents to feel distressed and guilt-ridden.

McKibbin was taken aback by the number of people who would stare at Koby. ‘No-one understood what had happened to my son’s

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face,’ she explains. She now feels strongly about educating people on cleft lips and palates and recommends Cleftpals (go to cleftpals.org.au) for more information.

It is advisable that all pregnant women who are found on their antenatal scan to be going to deliver a child with a cleft should be referred by their obstetrician or health care worker to a recognised cleft palate team at that stage. ●