



*“Improving lives by empowering, advocating & educating all South African’s affected by cleft lip and palate”*

**UPDATED 2018-04-17**

## Misconceptions about Clefts vs Lived Experiences with Clefts

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Misconceptions about Clefts	Lived Experiences with Clefts
A cleft palate must include a cleft lip.	A cleft palate can be isolated.
It’s not a common condition	When my baby was diagnosed with a cleft lip and palate I learnt that it is more common than I thought.  The incidence of clefts is as follows: Cleft lip and palate (most common in males): <ul style="list-style-type: none"> <li>• Africans 1 in 2000</li> <li>• Caucasians 1 in 1000</li> <li>• Asians 1 in 500</li> </ul> Isolated cleft palate (more common in females): <ul style="list-style-type: none"> <li>• 1 in 2000 for all race groups</li> </ul>
It was the mother’s fault that the baby was born with a cleft because during her pregnancy she either: <ul style="list-style-type: none"> <li>• Touched a knife during an eclipse</li> <li>• Suffered an injury</li> <li>• Did not look after herself and her baby</li> <li>• Consumed alcohol</li> <li>• Smoked cigarettes</li> </ul> It is the parents fault: <ul style="list-style-type: none"> <li>• The parents did something in their past that was bad</li> <li>• It relates it to witchcraft and is a curse</li> </ul>	There is still no proper explanation for the clefts forming, except when there is a family history of clefts. Often the cause of the cleft is a mystery. However, the plastic surgeon might be able to give you some idea of why it happened to your baby.  A baby’s face develops during the early stage of pregnancy at about 9 weeks. The upper lip is made up from four parts as is the palate. When these parts do not join, clefts (gaps) are formed. There are no parts missing.
I will be shunned and need to hide my cleft affected baby because people with think I’m cursed	Cleft Friends has a community of like-minded people who have gone through the cleft journey and can walk this journey with others and encourage them through each step. Cleft Friends will help you feel encouraged, supported and be empowered to ask your team of medical professionals the relevant questions.

The term "harelip" or "haslippie" is acceptable.	The term harelip is usually perceived as insulting because it compares the deformity in humans to the normal cleft lip of a hare. The accepted term for this medical condition is <i>cleft lip</i> .
Cleft lip and palate is a disability. My child will develop slowly. My child is not normal. My child is abnormal. My child needs to go to a special needs school.	Children affected by clefts are healthy children that need plastic surgery. They reach developmental milestones and go to main stream schools. It's possible to treat all the related aspects of the cleft. As a result the new baby like any other child should grow to be a healthy adult.
I'm alone	I'm not alone. Cleft Friends met me and put me in touch with other families affected by clefts in my community. For more info go to <a href="http://www.cleftfriends.co.za">www.cleftfriends.co.za</a>
Children born with clefts won't be able to speak properly	Speaking properly can be achieved. Children born with clefts need to have regular check-ups with speech therapists. Every cleft diagnosis is different.
I will offend a cleft affected person if I ask them about the scar on their face or their child's cleft lip or scar so would rather avoid them. The first thought a person has is that they got the scar from a car accident.	Those affected by clefts would rather have someone ask them about the cleft lip and palate without any judgement. They love it when people interact with them politely versus ignoring them or making derogatory comments.
Villians and monsters in movies and video games need a cleft lip scar to make them look scary.	It would be lovely to see a hero in a movie or video game portrayed by having a cleft scar. There is nothing scary about a scar.
Those affected by clefts are ashamed of this condition.	Many people affected by clefts have accepted how they were born and are proud of the challenges they have overcome.
Cleft affected babies are malnourished	Feeding a baby with a cleft should take the same amount of time as a child who is non-cleft affected. As for nutrition and weight gain a cleft affected baby consumes breastmilk and/or formula and consumes the same amount of milk as a non-cleft affected baby.
Cleft affected babies battle to feed	Every cleft diagnosis is different. Some babies affected with clefts can breastfeed. Other methods of feeding include special needs bottles, cup feeding, syringe feeding and tube feeding. Feeding challenges include milk coming through the nose and needing to wind baby more than a non-cleft affected baby. With guidance and support from a cleft team these challenges are manageable.
Cleft lip and palate is cosmetic surgery and is not a priority surgery.	Cleft lip and palate surgery is a Prescribed Minimum Benefit (PMB) even though certain medical aids require the plastic surgeon to write a letter of motivation.
I need to sell my house because I don't have a medical aid and can't afford the cost of cleft surgery for my baby. The doctor and hospital I saw has quoted me over 100K for my baby's cleft surgery.	The Smile Foundation works alongside 8 Academic Hospitals in South Africa to ensure that transport costs are covered for all children who are not on a medical aid to attend a local clinic where they can be seen by a cleft team and have surgeries and follow up care. To refer a

	<p>patient for surgery through the Smile Foundation click here:  <a href="http://www.smilefoundationsa.org/medical/refe-r-a-patient/">http://www.smilefoundationsa.org/medical/refe-r-a-patient/</a></p>
<p>My medical aid refuses to pay for my baby's cleft lip and palate surgery.</p>	<p>There is help available in your area. Every medical aid is different, as are the various plan options within the scheme. If a medical aid refuses to pay for a child's cleft surgery you need to provide a letter stating this from the medical aid when you see the state plastic surgeon. Your baby can then be admitted in a state hospital where the operation will take place. You need to ask the state plastic surgeon what an H3 category patient is and what an H1 category patient is? You need to ask for the technical reasons for categories H1 and H3. For more info go to <a href="http://www.health.gov.za">www.health.gov.za</a> and look up the policy titled "Explanation of H patient policy1".</p> <p>For more information about the Council of Medical Aid Schemes you can call their Customer Care Service Centre on 0861 123 267 or email <a href="mailto:support@medicalschemes.com">support@medicalschemes.com</a>.</p>

If you would like to add an item to this list email [info@cleftfriends.co.za](mailto:info@cleftfriends.co.za) with your suggestions.

[#cleftfriends](#) [#closingthegap](#) [#youarenotalone](#) [#SmileFoundation](#) [#DoingGood](#) [#cleftlip](#) [#cleftpalate](#)

**References:**

- Cleft Friends Regional Whatsapp Groups
- <http://www.dictionary.com/browse/harelip>
- Cleft Lip and Palate Parent Guide © Smile Foundation

*\* We know that each cleft lip and palate diagnosis is different and that each bring with them their own challenges, but we also know that most parents experience similar emotions and we can all use a little more support when things feel like they're falling apart.*

