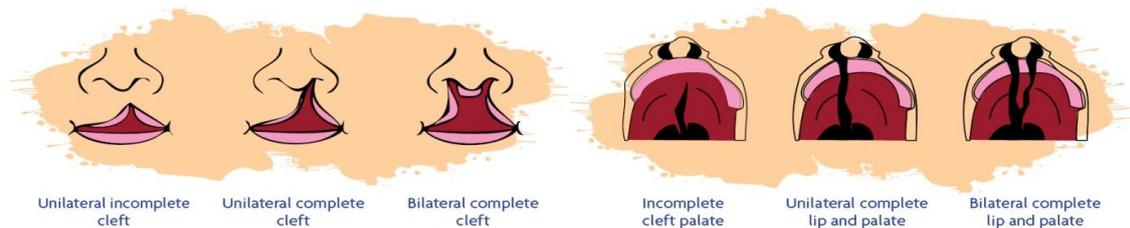


Cleft Lip and Cleft Palate FAQ

Every 3 minutes a child is born with a cleft lip or cleft palate. But if that child is born in a low or middle income country and doesn't have access to free healthcare, they'll have to live with their disfigurement. A cleft can destroy their life. Local communities often don't understand why these children look different and treat them extremely badly. For those that survive, they are often denied friends, an education, a future and a chance to live like a normal child.

What is a cleft lip and cleft palate?

A cleft lip is an opening in the upper lip; a cleft palate is an opening in the roof of the mouth. They occur when the upper lip or the palate doesn't join together properly during early pregnancy. A cleft lip and palate can occur on one side or both sides. A child can suffer from a cleft lip, a cleft palate indeed, 70% of children born with a cleft lip will also have a cleft palate



Can cleft lips and cleft palates be repaired?

Yes. Surgery provides excellent results.

Who is affected?

Clefts are the third most common birth defect in the world. Around one in every 500-700 hundred babies is born with a cleft, the ratio varying considerably across geographic areas and ethnic groupings.

Why don't you see children with clefts in the UK?

Developed countries with good a good healthcare system such as the NHS will usually repair a child's cleft lip within three months of them being born. Additional revision surgeries may also take place on the lip, so that by the time the child starts school all that remains is a tiny scar. An operation to repair a cleft palate usually happens a little later, but still before the child has their first birthday. That is why it is extremely unlikely you'll see anyone with a cleft lip or palate in the UK.



Bilateral cleft lip

Unilateral cleft lip

But in poorer countries children aren't so lucky. Families don't have access to free medical care and can't afford to pay for the operation on their own, so children have no choice but to live with their disfigurement, if they live past their first birthday. Sadly one in ten children born with a cleft will die before their first birthday.

What causes clefting?

The exact cause is unknown. Cleft lips and cleft palates are congenital defects that occur early in pregnancy. Scientists believe a combination of genetic and environmental factors, such as maternal illness, drugs or malnutrition, may lead to a cleft lip or cleft palate. If one child in a family is born with a cleft, the risk increases by 2 to 4 percent that future children in the family will suffer from the same defect.

Does a cleft lip or cleft palate cause problems for a child?

Ear disease and dental problems occur frequently, as do problems with proper speech development. Children who suffer from a cleft lip and/or cleft palate may have difficulty eating. To address these issues, a child and family may work with a team of specialists – a pediatrician, a plastic surgeon, dental specialists, an otolaryngologist (ear, nose and throat specialist), a speech-language pathologist and audiologist, a geneticist and a psychologist/social worker.

Can clefting be prevented?



Scientists are researching methods to prevent cleft lips and cleft palates. One finding, according to research studies, is that mothers who take multivitamins containing folic acid before conception and during the first two months of pregnancy may reduce their risk of giving birth to a baby with a cleft.

Operation Smile in partnership with Yale University have taken 3000 DNA samples from its patients to research the incidence of clefts across the developing world.

How do you feed a newborn baby with a cleft?

Babies with a cleft lip do not usually have many feeding difficulties. Breast or bottle feeding is possible. A newborn baby with a cleft palate may need extra help. A cleft palate can make it hard of a baby to form a vacuum in its mouth. The most common problems are: feeding slowly, taking in too much air whilst feeding, bringing milk up through the nose. When it proves very difficult to breastfeed, mothers often express breast milk for bottle feeding. Bottle feeding is usually most successful for babies with cleft palates but bottles are not readily available in the developing world.

What can I do to help prevent a cleft lip or cleft palate?

Tip 1: Do not smoke

Even though the exact cause of oral clefts is unknown, research has shown some factors that may be related to the occurrence of this deformity. Even though we cannot eradicate it completely just yet, most experts agree that some basic actions can lower the chance of having a baby with cleft lip and palate. Modifiable risk factors for cleft lip and cleft palate include **smoking** because:

- Maternal tobacco smoking during pregnancy is associated with a variety of adverse outcomes like: low birth weight, preterm birth, presence of oral cleft defects and other diseases in newborns.
- Tobacco contains substances that interfere with normal embryonic and foetal development such as nicotine, aromatic hydrocarbons, N nitrosamines and carbon monoxide. These compounds are absorbed into maternal blood and reach the developing foetus.
- The increased risk for oral cleft is around **twofold** with maternal smoking. The more cigarettes the mother smokes, the higher the risk.

Tip 2: Do not drink alcohol. Alcohol consumption affects you and your baby

Modifiable risk factors for cleft lip and cleft palate include **alcohol consumption** because:

- The cells that merge and fuse to form important structures of the face can be damaged by alcohol during the embryonic period of life, causing cleft lip and cleft palate.
- While the risk for oral clefting does not seem to increase with low quantities of maternal alcohol intake, there is increased risk of clefting with increased consumption. Women who drink five or more alcoholic drinks per sitting, at least once a week, have an increased risk of having a child with isolated oral cleft.
- Scientists have found that the interaction of at least one candidate gene currently under study with alcohol increases the odds of having a child with an oral cleft.

Tip 3: Avoid specific medications

Modifiable risk factors for cleft lip and cleft palate include **consulting your doctor to avoid using some medications** during pregnancy such as:

- Retinoids. Isotretinoin, better known as accutane or roaccutane. Isotretinoin is a form of vitamin A used for treatment of severe acne. Oral administration of isotretinoin during the first month of human pregnancy can induce severe congenital malformations. Isotretinoin-induced facial malformations in humans, including rudimentary external ears, absent or imperforate auditory canals, deformed and small skull, cleft palate, depressed midface, and anomalies of the brain, jaw and heart.
- Anticonvulsants. Maternal use of anticonvulsants is associated with an increased risk of congenital defects. Epileptic mothers managed with a multidrug anticonvulsant regime had a tenfold increased risk of giving birth to infants with cleft lip/palate when compared to non-epileptic mothers.
- Steroids. Consumption of steroids during the first 3 months of pregnancy has been associated with clefts, increasing the risk 3-5 times.

Tip 4: Folic acid and multivitamin supplementation

Modifiable risk factors for cleft lip and cleft palate include **folic acid and multivitamins** because:

- Multivitamins and some mineral supplements in early pregnancy, including vitamin B6, folic acid and zinc have been linked to **decreased risk** of orofacial clefts.
- Folic acid plays an important role in early foetal development. It has been proven that folic acid supplementation during the first 4 months of pregnancy provides significant protection against cardiovascular defects, neural tube defects (anencephaly, spina bifida) and may lower the incidence of clefting.
- The protective effects of folic acid against neural tube defects are higher than those against oral clefts; however, the protective effects of folic acid against oral cleft are still important.
- Data is strong enough to justify the recommendation of folic acid supplementation for pregnant women, especially during the first three months of pregnancy.

We have provided this information for your consideration only. Please consult your family doctor or other healthcare professional for medical advice, especially before discontinuing use of any prescribed medications.