



CLEFTPALS VICTORIA

THE CLEFT PALATE & LIP SOCIETY

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WHY ISN'T MY CHILD PERFECT

The following article is an extract from a speech given by Rosie Giddings from CleftPals. She was invited to speak at the Annual Scientific Meeting of the Aus Tetrology Society (which is the professional body concerned with all aspects of birth defects). Rosie was invited to present to this international gathering on the parents perspective and her talk was titled "Why isn't my Child Perfect". As printed in the CleftPals National Newsletter No. 88.

I have started with this rather emotive title because today, I am speaking to you as a parent of a child with a birth defect. My eldest son was born with a cleft lip. Being a parent is an emotional experience - but being a parent of a child with a birth defect may be an even deeper emotional experience.

When a couple are expecting their child they may have an intellectual understanding that they stand a 2% chance of having a child with a birth defect but emotionally they usually cannot accept this could happen to them. If they are one of the 2% it is often very difficult for them to accept emotionally that their child isn't perfect.

Parents need their own time to grieve the loss of their perfect child. For some parents this may take only a few minutes, whilst for others it may take years. Parents need understanding and support to come to terms with their grief. Parents who have dealt with these emotions are usually better able to cope with the problem themselves and thus support, care for and love their child.

Most parents have many questions. The first on is often "How will we look after this baby?" If this information is readily available and is able to be implemented, the parent and child relationship is much enhanced. For example, when children are born with a cleft in their palate they require special feeding. If the squeeze bottle and special teats are readily available, then good feeding can be established and problems relating to this do not evolve. The child is happy and the health of the whole family unit is enhanced. But for this to happen the information must be available, preferably at the time of birth ie in the maternity hospital.

Other questions that parents ask include "What caused it?" "Will it happen again?" "Can it be prevented?"

Parents may ask their general practitioner, paediatrician or obstetrician these questions or they may be referred to a genetic counsellor. The genetic counsellor is the interface between the parents and those trying to find answers to the previous questions, that is you and the scientific and medical community. **It is the genetic counsellor who interprets the data made available, by research, and applies it to the appropriate clinical situation.** The question "What caused it?" is much more difficult to answer. It seems that we do not know the causes of a large number of birth defects. We do know the causes of some but there are a large percentage of birth defects for which there is no known cause. In the area of birth defects for which I am involved it is amazing that for over half of the children born with cleft lip/palate there is no known cause for the defect.

It is often very difficult for parents to come to terms with the fact that there is no known cause. Generally parents want something to blame - the glass of wine, the flu or excessive nausea. This is why some parents will often actively look for a cause or a link.

The most practical question asked by parents is "How can this be prevented?" Parents will generally ask this when they want to have subsequent children. It is very reassuring for parents to be able to implement at least some form of prevention. They do not want it to happen again if it can be prevented. Questions may arise concerning vitamin supplements, folic acid supplements or the importance of controlling body temperature.

The ideal situation would be if there were pre-pregnancy counselling for all women of child bearing age. This could take place in schools or could be disseminated by general practitioners. Girls / Women should be informed of the precautions that should be taken during pregnancy **before they fall pregnant.**

Lastly references have been made to the importance of listening to the patient or the patient's parents. I can only endorse this. Parents are the people with a vested interest in treating the problem and in trying to prevent it reoccurring.

If we can prevent children being born with birth defects then both the parents and the community can have a perfect child.