

When your TOF is one of a twin ...

Content provided by parents of TOF children and compiled by Adrienne Alun-Jones.

Parents of a TOF twin and a non-TOF twin not only have two tiny and unique individuals to contend with but ones whose needs can vary hugely – particularly in the early stages.

They will find themselves pitched into an emotional rollercoaster and the bewildering world of paediatric surgery.

All TOF children are different, twins are no exception, but certain problems seem to emerge more frequently than others.

Many parents found that having a non-TOF twin was a huge plus when it came to peer pressure at the dinner table. The advantages of having a brother or sister of the same age happily eating was the best therapy for a reluctant TOF eater – albeit hard work.

“Her salvation was having a twin,” said one mother about her TOF child.

Or, as one mother of four year old twins said: *“It may seem like a nightmare at the time but having a twin is a huge advantage in terms of exposure to eating.”*

“We find the hardest aspect of them being twins is that the TOF twin has had to go through so much pain and suffering and he must now be thinking ‘why me?’ But we are convinced he would not be as well and as advanced without his twin to help him.”

When a consultant discovered this particular TOF twin was deaf she was amazed the child could speak at all. However, having watched the pair, she found the non-TOF child knew his brother could not hear. He would make sure he always faced his brother when he spoke or even turn his brother’s head to face him. “They say identical twins have their own language. Ours certainly do. They are our pride and our joy.”

Problems

Some of the main problems facing parents are purely logistical. What do you do with the healthy child while its twin is in hospital or at outpatients appointments? How do you find the time to cope with their different feeding habits?

“I found the medical profession often do not take into account that you have a twin. My response was to take along the twin and my

other two children as well. They have to realise you have another baby. A lot of people in this situation will be near breaking point because it is very hard to cope with that.”

“During the day when I was on my own I had to feed them at different times. I would pray someone would come to the house. It was very, very hard. They are really good but sometimes I could sit and cry.”

Often the first major practical hurdle is if a TOF twin is taken to a separate hospital for surgery while the brother or sister stays in a special baby unit elsewhere.

It is an emotional tug of war and parents often feel torn between the two.

One mother of ten year old twins still remembers it vividly. She did not see her TOF twin for two weeks after he was born by caesarean and transferred to another hospital for surgery. *“It was terrible,”* she said. *“I will never forget it.”*

Some parents feel guilty at never seeming to have enough time to devote to either child.

“I felt I could never give enough attention to my little girl” (the non-TOF twin). *“She loves her brother but in the beginning it must have had an effect. I often wonder how it has affected her. They missed out, both of them. I wished I had had more time but it was such an ordeal feeding them.”*

“It’s hard because you have one that’s well and one that’s ill and they both need your attention. The ill child gets more attention but you have to be aware the healthy one needs you as much as the ill one.”

“I always feel guilty about the time I spent away from my daughter” (The non-TOF twin) *due to the time I spent in hospital with my son. As part of a dual parent family I knew my husband would care for her but this did not assuage my feelings of guilt for actually leaving one of my children.”*

One couple makes sure their twins are treated equally even when their TOF child is in hospital. The same bed times are maintained and no presents are allowed unless they both get one. They are also anxious that the non-TOF twin does not feel responsible for his brother either at home or at school.

This information has been written for the parents of TOF children by TOFS (Tracheo-Oesophageal Fistula Support) – helping children born unable to swallow.

If you have any feedback on this leaflet, please use our leaflets feedback form which is available from either the TOFS office or our web site.

TOFS relies on money from membership fees, voluntary donations and other sources of charitable income to fund its activities.

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Development

While some TOF twins were slower to develop than their non-TOF sibling there is no noticeable difference between others. Those who do lag behind sometimes find their inability to keep up with their twin frustrating.

“It’s quite hard. We talk things over for hours. There is nothing we can do about it. We have to keep reinforcing that we love her and say that everyone is better at some things than others.”

However, as years pass parents have watched with pride as their TOFs make their own mark and clock up their own achievements.

The mother of a 14-year-old TOF twin described how, for the first time, he had been given a role in the school play while his highly academic brother hadn’t.

“He was about 18-months behind his brother but I always think ‘He will get there.’ I think he is a stronger person for it. He says ‘I can only do my best’ and, for me, that’s enough.”

“Do not compare them because you cannot. It just makes you paranoid. My TOF twin has the stronger personality. He has the drive and the willpower.”

“You have to accept your child is a TOF and accept that your child has got a disability and you cannot avoid the problems linked to it.”

Same difference

Most parents feel strongly that the two children should be treated the same.

Like any child, TOF twins want to be treated the same as their peers.

There are obvious exceptions in the early stages when some need to be fed pureed lump-free foods and this is sometimes a cause of tension.

One mother watched horrified as her TOF rejected its bite and melt food, snatched a chip from her sibling and stuffed it in her own mouth. Luckily there was a happy ending. *“She chewed and chewed and chewed and swallowed it! I gradually started to feed her bits and pieces.”*

Another mother resorted to turning her twins back to back during mealtimes so

her puree-fed TOF will not demand her sister’s lumpy food.

There are other occasions when the non-TOF twin will copy its brother or sister and take to refusing its own food.

Each family develops its own strategy for dealing with mealtimes depending on the individual children.

Information

One major stumbling block for parents was the fear of the unknown and an apparent lack of information from hospitals on discharge.

“I feel we did not get enough help and advice. We thought she would come home and everything would be fine. All they said was that we would have to liquidise her food. We just had to find out for ourselves. It is just trial and error every day. If I give her a biscuit and she chokes I feel so guilty. I feel there is not enough information.”

“I did not get any advice how to feed him. The only thing that helped me was reading an article in a TOF magazine.”

“Thinking back now we did not have the support we should have done. Hospitals are not very good at seeing the whole picture.”

Finally

One mother was able to make medical staff take notice of her concerns by using her healthy twin as a direct comparison: *“Eventually they listened to my concerns, which were proved to be right. You must believe in your instincts. Question and challenge both medical and educational authorities. I feel that in the beginning nobody listened to me, but as time went on I challenged views and had opinions of my own and then people in authority began to listen to me.”*

She added: *“My last word of advice is to enjoy your babies. You cannot alter the fact that one of your children was born with a deformity but you can fight to improve the quality of their life.”*

“Live for today and let tomorrow take care of itself.”

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