

# TOF: long term follow up

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Considerable information is available about the possible problems of TOF children – but how common are these problems and do they improve as the child gets older?

A study in 1987 invited 366 patients who had undergone TOF surgery to the hospital for review. Over 300 attended and half were adults. Patients and/or their parents were asked about their health and previous problems; height and weight was measured, examinations made and lung function tests performed.

## **FEEDING**

One in 3 under 5 years of age experienced feeding difficulties but this improved dramatically in older children. Two thirds had been readmitted to hospital due to swallowing problems, mostly in the first 5 years of life; just under half had needed a minor operation to stretch a narrowing in the oesophagus at the original operation site (a dilatation procedure).

Two thirds of adults stated that they were aware of mild swallowing difficulties, however this did not interfere with what they ate and they were able to manage such difficulties by drinking fluid with their meals. Only one adult had a narrowing in his oesophagus which needed a dilatation procedure.

## **CHEST PROBLEMS**

Nearly half had been admitted to hospital with ‘noisy’ breathing and chest infections; the majority of these episodes were in the first 5 years of life. The ‘TOF cough’ was present in three quarters under 5 years of age, but became less frequent and less severe in older children.

Just under half the adults said that whenever they coughed it was still the harsh brassy cough, but that this did not trouble them at all. Minor chest infections occurred in only 1 in 5 adults, but responded very quickly to antibiotics and did not require hospital admission. One third of adults occasionally experienced a ‘wheeze’ but in over half this was because they had asthma and was unrelated to the operation.

## **EXERCISE, EDUCATION AND LIFESTYLE**

Two thirds of older children and adults felt that they were extremely fit and regularly took part in sports where they competed equally with their peers. The rest reported only a slight reduction in ability to sustain vigorous exercise compared to their peers.

40% of 5-10 year olds missed more than one week of school per year because of illness compared to 20% of 10-15 year olds. Only 10% of adults missed more than one week of work because of any illness. They were involved in a wide variety of occupations and all said that their operation(s) had not interfered with their choice of career. The majority of adults were married and their 15 children were born with no significant health problems.

## **HEIGHT AND WEIGHT**

The height measurements in the group were similar to children and adults who had not experienced any major illnesses. 10% were extremely thin, but these were nearly all under 5 years of age, suggesting that nutrition and weight gain improved in older children and adults.

## **LUNG FUNCTION**

Tests showed that 1 in 10 had slightly reduced lung volumes and 1 in 5 had slight obstruction to the flow of air out of the lungs. The patients with these findings were in no way disadvantaged and led normal lives.

## **SUMMARY**

A number of children born with TOF will develop feeding difficulties and chest problems. These problems are always at their worst in the first 2 years of life and after 5 years of age are uncommon. Some parents experience great difficulties in the early years and need considerable support.

This large study – the largest of its kind on TOF follow up – is reassuring. The majority of children are able to participate fully in sport and to live up to their full academic potential. Furthermore, they grow up comparable to their peers and their achievements as adults are not impaired by their earlier problems.

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.

## **Web site**

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## **TOFS does not offer specific medical advice to parents.**

We work only in a supportive role, offering emotional and practical support to meet the needs of parents and providing a source of information which complements that given by the specialist hospital.

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