PST PEDIATRIC SURGERY IN TROPICS

Pediatric Surgery in Tropics
2024 (July-Sep); Volume 1, Issue 3: Pages 195-197
DOI: 10.5281/zenodo.12680236

Patient Perspective

Born Unable To Swallow

Stephen Wyles

Jewelry Polisher, Skippers Lodge, Rosemary Close, Peacehaven, East Sussex, England, United Kingdom

Keywords
Esophageal atresia
Congenital malformations
Patient perspectives

Abstract

Mr. Stephen Wyles was born with esophageal atresia. He is running a voluntary patient support group (Birth-defect.org) that helps children born with esophageal atresia in resource poor tropical countries. In this article he shares his perspectives and ordeals of a child born with esophageal atresia.

I was born in 1962 in England with a serious condition called esophageal atresia (EA) with tracheo-esophageal fistula (TOF).[1] My journey with this medical condition has been challenging, scary and complicated. It was a learning experience and reward that has given me an opportunity, especially in the latter years, to meet many different people from many different parts of the world. I would like to take this opportunity to thank all the doctors, nurses, allied health professionals and support staff, many of whom are behind the scenes. They have treated and looked after me over the last 62 years.

When I was conceived, my mother's belly became very large. My father would joke that he could see her tummy coming round the corner before he could actually see her. In those days people were not so aware of polyhydramnios and its connection with babies with EA. So, my mother did not have arrangements to be in a hospital when she gave birth to me. I was born in a small village in Hampshire England. It was noticed immediately that I was choking on secretions and I was rushed to Southampton General Hospital, where I had an operation that saved my life. I remained in the special care baby unit for many weeks, whilst my condition was stabilized.

My life as a child was a struggle at times, to say the least. No one really understood the condition I was born with. Outwardly, I also looked normal and cured; but my esophagus was very narrow which meant I could only eat certain things and my esophagus needed stretching over the years as I grew. I also developed a 'TOF cough' (a characteristic loud, barking cough). Hospital stays were hard, in those days. I was left in hospital alone; my parents were not allowed to stay with me.

When I attended nursery and primary school, teachers and assistants, did not understand how to treat me if I got food stuck in my esophagus. I remember clearly a lady forcing me to have white bread and water to help remove the blockage, which only made it worse. To date I hate being in cold water; I think this is due to one of my hospital memories as a child. They put me in a cast-iron

bath with salt water and made me to stay there till the water went cold. I also have a fear of needles and faint at the sight of them. These are all due to the treatments I had had as a child, which my body now associates with trauma and blacks out.

I still have a large operative scar on the side of my chest. I used to pretend at school that I had been attacked by a shark. I had many junior doctors examining my scar and been taught about my condition. A doctor who examined me explained that my scar had been done really neatly and that I had been lucky to have had the surgeons I did at that time. I used to know their names previously; but only remember one name now, Dr Roundtree, to whom I am very grateful. The hospital has since deleted all my records which I would like to see now. Today people are able to keep their own records thanks to the advancements in digital technology.

When I was a young adult, my mom did a drawing of the procedure that I had undergone. (Fig 1) With this she explained to me the rare condition that I suffered. It helped me to explain my problem if I need to be admitted to hospital or to see a doctor. Once I developed an ulcer in the esophagus and was vomiting blood. Doctors assumed that I was an alcoholic and had acquired the ulcer through drinking too much. They were amazed when I said that I was teetotaler and produced the drawing.

At another time, in my 20's, a young doctor dismissed my condition when she knew my age. She explained that no baby survived with TOF stricture in 1962, and discharged me after having watched me drinking sips of water. She was not even convinced by my scar. Two days later I returned to the hospital, and was greeted by the same doctor. It was then 4 days since I had managed to swallow any food. I was admitted and after 3 days of being in the ward, I was sent for a barium meal study. I invited the skeptical doctor to come with me. Standing between two large plates of metal, I swallowed the white chalky substance; and all that I heard from other side was the young doctor gasping in shock at what she was seeing - a disc of chestnut with barium sliding over it in a very thin esophagus. After 10 days of my suffering without any food, she finally believed me.

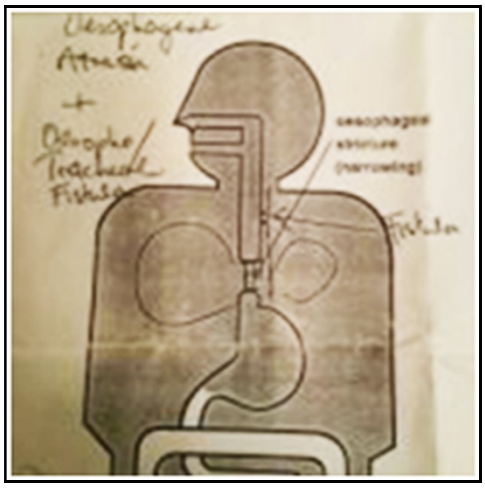

Fig 1 *Hand drawn sketch of Mom*

Every day whilst eating food it sticks going down; but I have learnt to clear it using my own techniques that seem natural to me. I help parents of TOF babies and explain that they should not panic if their children get the food stuck. They should just encourage the children to find their own ways of moving it down. Parents should reassure that it is normal to them and not something to panic about.

In 2013, I developed a website (www.birth-defect.org) to help parents of children born with TOF as I felt that there were not enough parental information materials on this condition. I also have a Facebook site and I cannot just believe as to how this has grown. I am now in communication with lots of surgeons around the world especially the resource poor tropical countries and I could provide support to parents of babies born with this condition all around the world. I help to connect parents with surgeons and assist parents to lend support to other parents of similarly

affected children by connecting them through the Facebook page.

On one occasion I was mentioned in the American News for connecting a family with a surgeon, which is amazing as I live in the UK. I have received so many grateful messages from parents. I even received an award from the Royal Family of UK, which I'm very proud of. I am also a co-author of two medical papers.[2,3] Who knew that I would get my name on a medical research paper!

In collaboration with a top research hospital in the USA, I developed an idea of making a worldwide survey of the condition. Unfortunately, due to various issues it was not as successful as I had hoped, but my dream would be to work with all the pediatric surgeons and charity groups across the world to try and achieve this. One day I hope we can all be involved in creating a world survey again. My website hits 193 countries last year, so I know we can do it.

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Address for communication: *Mr. Stephen Wyles*
Email: birth-defect@outlook.com

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Received: 9 May 2024; Accepted: 12 May 2024

Acknowledgements : None
Conflicts of Interest : None declared by authors
Source of Funding : None
Ethical concerns : None (Personal views)

Citation: *Wyles S. Born unable to swallow. Pediatr Surg Trop 2024 July-Sep; 1(3): 195-197*