

Towards a holistic model for the treatment of those born with Oesophageal Atresia from diagnosis to transition and adult care.

An abstract of the TOFS Position Paper - published September 2021.
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Background:

As the UK's patient advocacy group for OA we have developed a position concerning the lifetime care of OA patients. These considerations have been informed by the experiences of our members and their families, both in paediatric and adult services, through informal discussions with healthcare professionals, and by our growing engagement with OA-related research. Much of the vision in this paper emerged from deliberations with our colleagues and is, we believe, shared by all member associations of EAT; many of the recommendations – local/national healthcare models and the constraints of geography notwithstanding – are, we would contend, equally applicable internationally.

The TOFS Position Paper calls for:

Periodic surveillance of all adult OA patients

Irrespective of whether they do or do not routinely suffer from ongoing morbidities.

Transition of all paediatric patients to adult care

Hence no discharge from specialist care at any point in childhood.

Patient involvement in the re-design of services

We want to see patient participation in the co-design of the redevelopment of Paediatric Surgical services with NHS England, including the co-ordination of care throughout the lives of those with OA.

Establishment of specialist clinics for those adults...

requiring ongoing specialist care. these centres would link with paediatric centres, (particularly important when looking at long-term outcomes). There is limited research in adults so we are keen to see adult centres committing to research and linking internationally through organisations such as INoEA.

More sub-specialisation at the specialist surgical centres

Such that each centre has a caseload sufficient to sustain: 24x365 availability; surgical training; the establishment of aftercare programmes; engagement in research.

Comprehensive multi-disciplinary aftercare

Consistently applied by all specialist paediatric surgical centres (including leadership on pathways/guidance/support for local centres); the specialist centres should retain responsibility for the management of their patients, even where local hospitals are used for some aspects of follow-up or emergency care. A co-design framework involving the regional ODNs (Operational Delivery Networks) to develop tele-health services would enhance this model to support follow-up care, avoid unnecessary travel, and enable 'virtual' Multi-Disciplinary Clinics (MDCs).

Development of a Core Outcome Set and a lifetime Registry

With a target of full implementation within ten (preferably five) years.

How this came about:

- Substantial presentation by Mr Matthew Jones at TOFS 2019 conference, about the undesirable variability of OA surgery
- NHS "Getting it right First Time" report addressed concerns about variability (principally) in surgery for OA and some other paediatric surgical conditions
- TOFS membership and TOFS's experience has indicated huge variability in aftercare and very little care for adults born with OA

The TOFS paper cites 32 references and is freely available via the TOFS website (though subject to copyright).

Graham Slater is an adult survivor of OA/TOF, and has been actively involved in TOFS's collaboration (particularly via EAT) with healthcare professionals and organisations for more than a decade, He was founding president of EAT.

Julia Faulkner is a paediatric dietitian who has also been very much involved in TOFS's and EAT's collaboration, and is mother to an OA/TOF child.

Scan to read the paper



About TOFS:

Founded in 1982, TOFS is the UK-based support group for all those born with Oesophageal Atresia and Tracheo-Oesophageal Fistula. It is the world's largest English-language OA support group. TOFS is a Registered Charity. TOFS provides pastoral support. It runs Facebook support groups and offers a huge range of information and resources (including via webinars and conferences) to its members about various aspects of coping with the legacy of Oesophageal Atresia.

TOFS also strives for long-term improvements in care for those born with OA, through active collaboration with relevant healthcare – focussed organisations. TOFS is a founder member of EAT, the (international) Federation of Esophageal Atresia and Tracheo-Esophageal Atresia Support groups. EAT undertakes international collaboration for TOFS and other national support groups.

