NATIONAL NEONATAL SURGICAL INTEREST GROUP

BEST PRACTICE STANDARDS:

NEONATES WITH OESOPHAGEAL ATRESIA AND TRACHEO-OESOPHAGEAL FISTULA

APRIL 2025

Endorsed by

tofs lifelong support for those born unable to swallow

NEONATAL NURSES ASSOCIATION

The purpose of the document to to provide best practice standards to aid the development and review of locally produced OA guidelines. It is also a document to utilise to aid/support the development of actions plans for service improvement initiatives. It is recommended that all units/networks have a dedicated OA/TOF guideline.

Key Factors for best practice		Individual Scores	Possible Total
F:1			
F:2			
F:3			
F:4			
F:5			
F:6			
F:7			
F:8			
F:9			
F:10			
F:11			
F:12			
Overall Score			

CRITERIA FOR SCORING:
Neonatal nursing assessment of practice of infants admitted to the neonatal unit.

PATIENT GROUP:
Any new-born infant admitted to the Neonatal Unit with Oesophageal Atresia (OA) and Tracheo-Oesophageal Fistula (TOF)

DRIVERS FOR THE DEVELOPMENT OF THE BEST PRACTICE GUIDELINE:
GIRFT, BAPM, UNICEF, BLISS, Professionals working within Neonatology

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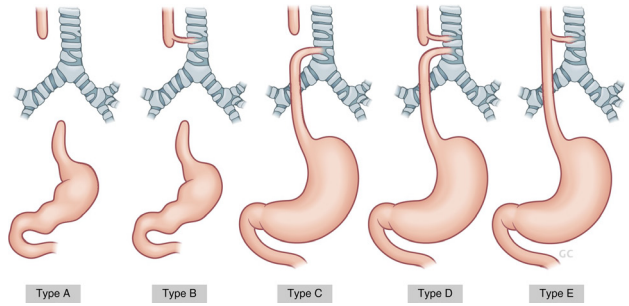
INTRODUCTION

Oesophageal atresia (OA) is a congenital malformation that occurs during the separation of the embryogenic foregut into the trachea and oesophagus early in pregnancy. OA is where the oesophagus is a blind ended pouch and therefore does not connect to the stomach. The infant's saliva therefore accumulates in the blind ending pouch and if unmanaged would spill over into the trachea causing aspiration[1]. It affects approximately 1:4000 births in Europe[2]. Most infants also have an associated tracheo-oesophageal (TOF).

The Gross classification defines five subtypes of OA/TOF based on the presence and/or proximity of the TOF (Fig. 1[3]). Gross type C (OA with a distal TOF) is the most common variant with 82-85% of cases[4].

Fig. 1 *Gross classification system of the five subtypes of oesophageal atresia/tracheo-oesophageal fistula (OA TOF)*



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OA can also be defined based on the length of the gap between the proximal and distal oesophageal pouches. 'Long-gap OA' is considered the most difficult to repair, its definition varies; 2-3cm, 2-4cm vertebral bodies. OA with fistula (Gross Type A) or difficult to repair by primary anastomosis[4]. The International Network of Esophageal Atresia (INoEA) recommends that long-gap OA should be defined as all Gross type A and type B abnormalities, regardless of the exact length of the oesophageal gap[5].

Approximately 55% of people born with OA have associated birth defects or other anomalies (Box 1[3]).

Box 1 | Anomalies associated with OA

Cardiovascular anomalies

- Occur in 29% of patients born with OA
- Tetralogy of Fallot, atrial and ventricular septal defects and transposition of the great arteries are screened for using echocardiography and/or electrocardiography
- Vascular malformations are screened for using MRI or CT when dysphagia, dyspnoea and/or cyanosis are present

Gastrointestinal anomalies

- Occur in 16% of patients born with OA
- Anorectal malformations are screened for by physical examination and ultrasonography
- Duodenal atresia is screened for using radiography ('double bubble' sign is suggestive)
- Intestinal malrotation (abdominal ultrasound or an upper GI contrast study (if needed))
- Heterotopic pancreas and hypertrophic pyloric stenosis are screened for using ultrasonography (if needed)
- Heterotopic gastric mucosa is screened for using gastroscopy (if needed)
- Dumping syndrome is screened for using the oral glucose tolerance test (if needed)

Genitourinary anomalies

- Occur in 16% of patients born with OA
- Renal agenesis, cystic kidneys and ureteral anomalies are screened for using ultrasonography

Musculoskeletal anomalies

- Occur in 13% of patients born with OA
- Vertebral and/or rib anomalies and limb reduction deficiencies are screened for by physical examination and radiography
- Tethered cords are screened for using sacral ultrasonography

Respiratory anomalies

- Laryngotracheomalacia occurs in >17%, laryngeal cleft in <5%, vocal cord paresis in 24% (in which 7% have bilateral paresis) and subglottic stenosis in 16% of patients born with OA
- These anomalies are screened for using laryngotracheobronchoscopy

Dermatological anomalies

- Skin anomalies and clinodactyly occur in 21% of patients born with Gross type A (FIG. 1) OA and are screened for by physical examination
- Malformations of the ear are screened for by physical examination
- OA, oesophageal atresia.

Approximately 10% of patients have a VACTERL Association. The word VACTERL is made up of the areas that are affected by the condition: Vertebral defects, Anorectal malformations, Cardiac defects, Tracheo-oEsophageal fistula and atresia, Renal anomalies, and Limb abnormalities. People diagnosed with VACTERL association typically have at least three of these characteristic features[6].

OA/TOF is no longer viewed as resolved once it have been surgically repaired. It is now understood as a lifelong medical condition requiring long term monitoring and management. Gastrointestinal, surgical, respiratory, otolaryngological, nutritional, psychological and quality of life issues are prevalent not only in the first years of life but also into adolescence and adulthood[7].

Therefore, centres should have a pathway for ongoing MDT follow up, and transition to appropriate adult specialists. This is something that is being called for by a recent international consensus document on transitional care[7] and being called for by patient groups[8].

When an infant has a suspected OA a Replogle tube is inserted, (Appendix 1). The Replogle tube is passed into the blind ending pouch of the upper oesophagus in the pre-operative period to provide continuous low-pressure suction along with regular flushes, allowing the secretions to be thinned and cleared.

In the majority of infants this will be for a few days, but if there is delay in attempting a surgical repair of the oesophagus, the Replogle tube may be required for up to six to eight weeks – maybe for a longer period as some infants with a long gap OA have a Replogle for a prolonged period[9]. There is now an innovative pathway used in some countries where babies with OA are managed using portable suction on short nasogastric tubes without the use of a Replogle tube[10].

The British Association of Perinatal Medicine Categories of Care define a Replogle tube as an intensive care day, and therefore requires 1 to 1 nursing[11]. An infant with an OA has specific requirements including respiratory vigilance, continual clearance of secretions to minimise the risk of aspiration, maintaining Replogle tube patency and safeguarding of the airway to maintain optimal respiratory function.

Replogle tube in situ requires constant observation and vigilance as having a blind ending oesophageal pouch leaves their airway vulnerable to aspiration and pneumonia. Their airway is only protected while the Replogle tube is in situ with continuous low-pressure suctioning and regular flushing of the tube intermittently to ensure patency[12].

FACTOR 01: ANTENATAL CARE OF FAMILIES AND FOETUS WITH SUSPECTED OESOPHAGEAL ATRESIA AND TRACHEO-OESOPHAGEAL FISTULA

After suspected diagnosis of OA there should be multidisciplinary team working including but not limited to foetal medicine, obstetrics, neonatal and paediatric surgical teams to provide care to family.

1. Antenatal counselling of family including surgeon, maternity and obstetric teams, neonatology, surgical nurse specialist with the use of an interpreter where English is not first language.
2. Provide written information on local unit, condition, early expressing of breast milk and written information and website signposting to TOF/BLISS/ VACTERL association.
3. Provide contact name and contact details for neonatal unit and surgical centre (if separate) for further information.
4. Discuss colostrum (harvesting) and general feeding with family.
5. Neonatal parental counselling/psychology service available.
6. Tour of neonatal unit/PICU/surgical ward either in person or virtual, where infant will be cared for during their journey.
7. Plan for delivery at a tertiary centre with specialist OA TOF surgical provision or plans in place for delivery at local centre and transfer to surgical centre.
8. Plan for third trimester monitoring – regular CTG & Foetal movements/monitoring polyhydramnios as per obstetric team.
9. Plan for induction from 37 weeks' gestation as per obstetric team for polyhydramnios depending on parental wishes.
10. Delivery (Vaginal or caesarean section) as per parental wishes in advice/recommendations from obstetric team.
11. Delivery room obstetric and neonatal care plan including parents' wishes.

FACTOR 01: ANTENATAL CARE OF FAMILIES AND FOETUS WITH SUSPECTED OESOPHAGEAL ATRESIA AND TRACHEO-OESOPHAGEAL FISTULA CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /11**
Factor 01: **Antenatal care of families and foetus with suspected OA TOF**		
Statement to justify best practice standards:		
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FACTOR 01: ANTENATAL CARE OF FAMILIES AND FOETUS WITH SUSPECTED OESOPHAGEAL ATRESIA AND TRACHEO-OESOPHAGEAL FISTULA CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 02: DELIVERY ROOM MANAGEMENT

1. Neonatal team informed of planned/imminent delivery by obstetric/midwifery team.
2. Surgical centre unit informed of planned/imminent delivery if different to delivering hospital.
3. Surgeons informed of planned/imminent delivery.
4. Parental written delivery care plan followed as per clinical condition of mother and foetus/neonate
5. Neonatal team role responsibilities allocated pre delivery.
6. Adhere to neonatal delivery room plan (Heated platform and room, Delayed Cord Clamping, skin to skin).
7. Ensure adequate routine neonatal thermoregulation.
8. Resuscitation and equipment as per NLS.
9. Neonatal team to update parents with the use of an interpreter where English is not first language.
10. Safe transfer to Neonatal Unit.

(Related to criteria above) Number of KPI criterion met and justify.		**Score /10**
Factor 02: **Delivery room management**		
Statement to justify score:		
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FACTOR 02: DELIVERY ROOM MANAGEMENT CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 03: INITIAL NEONATAL CARE SUSPECTED/BEFORE CONFIRMED DIAGNOSIS.

1. Local guideline in place for staff when suspected signs and suspicions of neonates with TOF OA.
2. Resusitation as per Newborn Life Support/Basic life support.
3. Insertion of an NGT to confirm or rule out OA.
4. Chest x-ray (including stomach) to review NGT placement or if curled in oesophagus to suspected OA.
5. If confirmed OA- insertion of a Replogle, on low flow suction, (Appendix 1). If no Replogle tube available, then insertion of a large bore NGT and use syringe to aspirate secretions.
6. Early surgical referral/discussion.
7. Transport to surgical centre with appropriate transport team. If intubated, it is treated as time critical transfer to surgical center.
8. Parental support and update by Neonatal and surgical team (if onsite) to be active part of care with the use of an interpreter where English is not first language.
9. Early parental support for early breastmilk expressing (within 6 hours of delivery).
10. Provide pair of scent cloths/bonding squares
    (one for mother and one for neonate).
11. Provide written information and support groups information (TOFS Charity, BLISS).

FACTOR 03: INITIAL NEONATAL CARE SUSPECTED/BEFORE CONFIRMED DIAGNOSIS CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /11**
Factor 03: **Initial Neonatal Care**		
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FACTOR 03: INITIAL NEONATAL CARE SUSPECTED/BEFORE CONFIRMED DIAGNOSIS CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 04: PREOPERATIVE CARE IN SURGICAL CENTRE

1. Continuous observation monitoring including oxygen saturations, heart rate, respirations.
2. 1 to 1 nursing care.
3. Elevated head of incubator/baby therm.
4. Replogle tube management and low-pressure suctioning.
5. Ongoing routine neonatal thermoregulation management.
6. Ensure Nil by Mouth and for routine neonatal intravenous fluid management.
7. Respiratory support as per neonate's clinical condition.
8. A full Newborn Physical Examination should be performed and documented to rule out other abnormalities that may require urgent intervention.
9. A cardiac ECHO to diagnosis structural abnormalities and aortic arch position.
10. Chest and abdominal X-ray to confirm position of Replogle tube and for stomach bubble presence.
11. Genetic DNA blood sample saved for future use.
12. Maternal/neonate blood for cross match (if required as per local guidance).
13. Support early expressing of breast milk with parents (within 6 hours of delivery).
14. Provide buccal EBM at earliest opportunity to neonate and repeat at least every 3 hours.
15. Consider antibiotics if risk factors.
16. Surgical plan from surgical team for neonatal team and family with the use of an interpreter where English is not first language.
17. Early informed written consent after verbal discussion with family including all possible options about surgery.
18. Early Speech and language therapy referral to promote positive oral stimulation.
19. Microlaryngoscopy and Bronchoscopy (MLB) pre surgery to confirm presence/location of oesophageal fistula.
20. Ensure parental expectations are discussed and ensure written information/support is provided.

FACTOR 04: PREOPERATIVE CARE IN SURGICAL CENTRE CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /20**
Factor 04: **Preoperative care in surgical centre**		
Statement to justify score:		
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FACTOR 04: PREOPERATIVE CARE IN SURGICAL CENTRE CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 05: POST OPERATIVE – ON GOING NEONATAL CARE OF A PRIMARY REPAIR

1. Procedure notes documented by surgical team in a timely manner.
2. Patient positioning keeping midline and limiting head extension to protect anastomosis site.
3. Ensure neonate is Chin to chest if instructed during all handling and procedures.
4. Sedated and paralysed as per repair and surgical team instructions.
5. Extubation in a controlled manner to reduce the risk of needing early re-intubation to prevent an over extension of surgical anastomosis site.
6. All neonates with a confirmed OA TOF should have a full VACTERL screen. (An example in Appendix 2).
7. Consideration of use of Proton Pump Inhibitor as per local surgical team.
8. Post operative evidence-based pain score (for example: NIPS, N-PASS, PIPP, COMFORT NEO).
9. Post operative evidence-based pain management (for example: regular paracetamol, Nurse Controlled analgesia infusion- Morphine infusion or continuous infusion).
10. Post operative evidence based wound care plan.
11. Use early warning score e.g. NEWTT, PEWS.
12. Trans-anastamotic tube (TAT) tube management (ensure TAT identified and labelled appropriately for safety).
13. Encouragement of parental skin to skin when clinically indicated.
14. Establishing feed plan between parents, clinical team, dietician and SALT support and involvement:
    A. Parental wishes for EBM or formula with informed consent,
    B. Ongoing support of expressing breast milk for parents,
    C. Ongoing buccal EBM and routine EBM mouthcare for neonate,
    D. Early feeding team and speech and language team involvement before oral feeding is commenced,
    E. Promotion of non-nutritive sucking and Fi Care practices,
    F. Assess the need for water soluble contrast swallow (as per surgical team),
    G. Use of parental nutrition with dietetic support (if required),
15. Early ENT review if airway concerns such as tracheomalacia.
16. Early referral to other MDTs depending on neonate' clinical condition and abnormalities. e.g. gastroenterology, respiratory, cardiology, dietitian, Orthopaedics, nephrology.
17. Regular updates for families with surgical and neonatal teams with the use of an interpreter English is not first language.

FACTOR 05: POST OPERATIVE – ON GOING NEONATAL CARE OF A PRIMARY REPAIR CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /17**
Factor 05: **Post Operative - neonatal care of primary repair**		
Statement to justify score:		
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FACTOR 05: POST OPERATIVE – ON GOING NEONATAL CARE OF A PRIMARY REPAIR CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 06: POST OPERATIVE CARE - ON GOING NEONATAL CARE OF A DELAYED REPAIR – LONG GAP ATRESIA

1. Procedure notes documented by surgical team in a timely manner.
2. 1 to 1 nursing care whilst Replogle tube insitu.
3. All neonates with a confirmed OA TOF should have a full VACTERL screen, (an example is Appendix 2).
4. Consideration of early use of Proton Pump Inhibitor as per local surgical team.
5. Post operative evidence-based pain score (for example: NIPS, N-PASS, PIPP, COMFORT NEO).
6. Post operative pain management (for example: paracetamol, nurse-controlled analgesia infusion – morphine, continuous infusion).
7. Post operative evidence based wound care plan.
8. Use early warning score e.g. NEWTT, PEWS.
9. Ongoing Replogle tube management (Appendix 1).
10. Gastrostomy tube management.
11. Oesophagostomy care and management if applicable.
12. Encouragement of parental involvement in all aspects of care.
13. Establishing feed plan between parents, clinical team, dietician and SALT support and involvement:
    A. Parental wishes for EBM or infant formula with informed consent,
    B. Ongoing support of expressing breast milk for parents,
    C. Ongoing buccal EBM and routine EBM mouthcare for neonate,
    D. Early feeding team and speech and language involvement before oral feeding is commenced,
    E. Promotion of non-nutritive sucking and FI Care practices,
    F. SHAM feeding as per local MDT discussion pre repair,
    G. Assess the need for water soluble contrast swallow (as per surgical team),
    H. Use of parental nutrition with dietetic support (if required).
14. Early ENT review if airway concerns such as tracheomalacia.
15. Ongoing developmental care with play team, SALT, Physiotherapy and Occupational Therapy support.
16. Early referral to other MDT as required e.g. gastroenterology, respiratory, cardiology, dietitian.
17. Regular updates for families with surgical and neonatal teams with the use of an interpreter where English is not first language .

FACTOR 06: POST OPERATIVE CARE - ON GOING NEONATAL CARE OF A DELAYED REPAIR – LONG GAP ATRESIA CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /17**
Factor 06: **Post Operative care - delayed repair - long gap**		
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FACTOR 06: POST OPERATIVE CARE - ON GOING NEONATAL CARE OF A DELAYED REPAIR – LONG GAP ATRESIA CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 07: PLANNING TRANSITION TO HOME

1. Consider early MDT planning meeting (including community teams, GPs, health visitor) to facilitate transition to home.
2. Early community team referrals and input for equipment requesting, teaching, general support and advise.
3. Oral feeding plan as per local team/dietitian/SLT/Infant Feeding Advisor.
4. Parental teaching on all aspects on the condition.
5. Parental teaching on RED flags for discharge (strictures – choking and food bolus obstruction, subtle signs of stricture such as blue/grey tinge of lips/mouth, milk coming out of nose, facial colour change to blue, increased oral secretions, tracheomalacia, reflux, increased risk of chest infections, feeding and growth issues, TOF cough; oesophageal dysmotility).
6. Parental teaching of Basic life support, choking and food bolus obstruction.
7. Standard baby checks are completed – NIPE, newborn hearing screening.
8. Ensure all medication for home is reviewed and supplied with teaching to parents.
9. Written contact details for parents of who to call and when (local and tertiary centres, community teams) and consider a single point of contact.
10. Provide TOFS/VACTERL association contact details.
11. TOFS book/leaflets and written information specific to condition.
12. Parental expectations managed (communication with local community services such as GP, Health visitor, community speech and language, dietitian, outreach services, Children's Community Nurses).
13. Booked outpatient appointments and early follow up.
14. Combined TOF OA outpatient appointments with all teams involved to reduce number of hospital visits.

FACTOR 07: PLANNING TRANSITION TO HOME CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /14**
Factor 07: **Planning transition to home**		
Statement to justify score:		
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FACTOR 07: PLANNING TRANSITION TO HOME CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 08: LONG TERM FOLLOW-UP

1. Local guideline/protocol in place from discharge to transition to adult services.
2. A Paediatric surgical liaison nurse specialist should be in place from transfer from NICU to transfer to adult service.
3. Telephone, home visit or early outpatients' appointment by nurse led team in first week of discharge.
4. Combined TOF OA outpatient appointments with all MDT members involved to reduce number of hospital visits.
5. Pre weaning outpatients meeting with appropriate members of the MDT such as Surgical Clinical Nurse Specialist, Surgeon, Gastroenterology; SALT and Dietitian teams.
6. Ongoing family support with MDT until established on full family food.
7. Specialist liaison nurse/member of MDT to liaise with nurseries and schools.
8. Community team referral (if not already done) for ongoing support and educational teaching.
9. Ongoing gastroenterology input and surveillance endoscopy for gastroesophageal reflux due to risk of Barrett's oesophagus at appropriate times as per local teams (e.g. age 1, 10 and pre transition to adult services.
10. Respiratory team input if poor airway clearance, those more susceptible to respiratory infections and for risk of tracheomalacia.
11. Early involvement and transitioning to adult services.

(Related to criteria above) Number of KPI criterion met and justify.		**Score /11**
Factor 08: **Long term follow up**		
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FACTOR 08: LONG TERM FOLLOW-UP CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 09: LEGAL ASPECTS AND DOCUMENTATION

1. All documentation must be in English, contemporaneous, in black ink (if handwritten), dated timed and signed.
2. Consent obtained for all surgical interventions as per local guidance.
3. Badgernet/Electronic record documentation kept updated.
4. WHO Safer surgery check list completed.
5. Parents and NHS trust to have copies of parental competencies.

(Related to criteria above) Number of KPI criterion met and justify.		**Score /5**
Factor 09: **Legal aspects & documentation**		
Statement to justify score:		
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Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 10: STAFF EDUCATION

1. Staff aware and adhere to local guidelines.
2. Staff regularly updated on risks of complications- e.g. blocked Replogle, airway management, post operative pneumothorax.
3. Regular simulation training opportunities- delivery and NICU management including trouble shooting Replogle tube management, communication, and care planning.
4. Staff knowledge of parental experiences/psychological support.
5. Written competencies for staff on Replogle tube care, gastrostomy care, oesophagostomy care.
6. Staff awareness of short- and long-term outcomes of babies with TOF OA.

(Related to criteria above) Number of KPI criterion met and justify.		**Score /6**
Factor 10: **Staff Education**		
Statement to justify score:		
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Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 11: PARENTAL INVOLVEMENT

1. Family integrated care underpinning in all aspects of care.
2. Parents have written information provided (e.g. Bliss booklet, unit information, condition specific information – TOFS charity/TOFS Book) which is given at an appropriate time.
3. Parental involvement in Replogle tube care as per local policy.
4. Parental involvement in feeding and nutritional plan.
5. All parents with learning disabilities, visual or hearing impairments or those whose first language is not English must be helped and supported through interpretation and translated documents. Liaise with parents learning support team. Unit SALT, Occupational Therapy and psychology may also be able to provide support strategies.
6. Parents are informed of any research being undertaken in the NICU, explanation about recruitment process, written information about the trial and written consent is obtained.
7. Parents kept up to date with regular contact with the MDT (including: Surgeon, Neonatologist, dietitian, SALT, Infant feeding advisor, psychologist, Surgical Clinical Nurse Specialists, physiotherapy, Occupational Therapy, AHPs as indicated) with the use of an interpreter where English is not first language.
8. Parents informed, and reason clearly explained for additional test and investigations such as ultrasounds, referrals and appointments.
9. Signpost families to support networks- local neonatal support networks, BLISS, TOFs charity, Health Visitor, General Practitioner, Paediatrician, VACTERL association, local breastfeeding support.
10. Maintaining parental awareness of ongoing complications/concerns.
11. Ongoing future support – time appropriate training.

FACTOR 11: PARENTAL INVOLVEMENT CONTINUED

(Related to criteria above) Number of KPI criterion met and justify.		**Score /11**
Factor 11: **Parental involvement**		
Statement to justify score:		
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		

FACTOR 11: PARENTAL INVOLVEMENT CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

FACTOR 12: SERVICE OUTCOME MEASURES FOR LOCAL SERVICE

1. Formal reporting and local database of patient numbers.
2. Audit ideas:
    A. Oral simulation – non-nutritive sucking,
    B. Time to initiating suck and oral feeding,
    C. Time to full oral feed,
    D. Use of Proton Pump Inhibitors (for example routine use or as per patient clinical indication).
3. BADGERNET/electronic database including:
    A. Feeding outcomes,
    B. Breast feeding at discharge,
    C. Length of stay.
4. Additional complications- morbidity/mortality:
    A. Pneumothorax /chylothorax,
    B. Oesophageal leaks,
    C. Wound infection,
    D. TAT tube dislodgement,
    E. Unplanned extubations,
    F. Strictures and dilatations,
    G. Timing of starting PPI and ongoing use.
5. CLASBSI (Central Line Associated Blood Stream Infections) rates.

(Related to criteria above) Number of KPI criterion met and justify.		**Score /5**
Factor 12: **Service outcome measures**		
Statement to justify score:		
1.		
2.		
3.		
4.		
5.		

FACTOR 12: SERVICE OUTCOME MEASURES FOR LOCAL SERVICE CONTINUED

Objective: (what to do, escalation to senior team/service)
Action Plan: (QI, service improvement projects, local metrics)

Score relates to practice in (unit):	
Date of next meeting to share good practice and compile action plan: / /	
Scored by:	Date scored: / /

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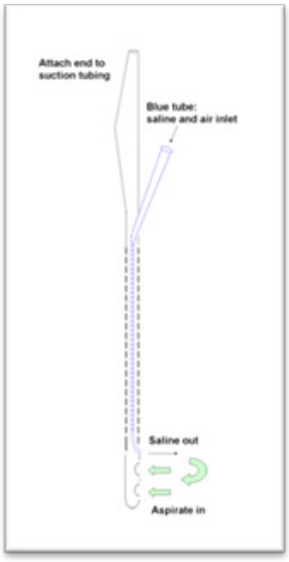
1. Useful links

- TOFS charity. https://tofs.org.uk/
  Local contacts available (experienced parental volunteers) able to speak/visit new parents.
  New parental packs available (contact TOFS charity to arrange delivery).
- VACTERL association. https://vacterl-association.org.uk/
- Feeding your baby breastmilk – TOFS, OA/TOF Support. https://tofs.org.uk/oa-tof-information/parents/the-early-days/feeding-your-baby-breastmilk/
- ERNICA. https://www.ern-ernica.eu/esophageal-diseases
- VACTERL Screening Tool – risk calculator. https://choc-trauma.shinyapps.io/VACTERL/

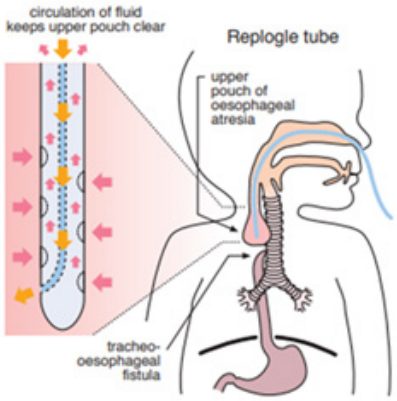
2. Appendix

Appendix A: What is a Replogle tube?

A Replogle tube is a double-lumen radio-opaque tube, allowing gentle continuous suction and irrigation of the blind end pouch of the upper oesophagus. One lumen is for drainage of saliva and the other functions as an air vent and can be used to flush the catheter if the secretions are thick. Figure 2. A Replogle tube[13].



A Replogle tube is passed as soon as the diagnosis of trachea-oesophageal atresia is suspected/ recognised. It is maintained within the pre-operative period to continuously clear secretions that put the infant at risk of aspiration from the upper blind ended oesophageal pouch. Surgical intervention is normally undertaken when the infant is stable (usually within 48hours). Figure 3. Demonstrates how a Replogle tube works[14].



Appendix B: An example of a VACTERL pathway. (Kindly reproduced from VACTERL Screening Tool, produced by, Great Ormond Street Hospital, 2023)

A VACTERL SCREENING TOOL

Named Surgical Consultant				**Date**		
CARDIAC	**Diagnosis**	Requested	Done ✓	**Findings**		
	ECHO			VSD ☐	ASD ☐	Right sided aortic arch ☐
	Cardiac review			Other ☐ Details		
	Heart sounds					
	Pulses					
	Comments					
	Referrals	Requested	Done ✓	**Additional information for referral**		
	Name					
	Cardiac appointment					
	No follow up required	Yes ☐	No ☐			
OA/TOF	**Oesophageal atresia**		**Tracheo-oesophageal fistula**		**Surgery date**	
	Short gap ☐	Long gap ☐	Gap assessment ☐			
ANORECTAL	**Anal examination**			**Stoma surgery planned**		
RENAL	**Diagnosis**	Requested	Done ✓	**Findings**		
	Ultrasound scan					
	Referrals	Requested	Done ✓	**Additional information for referral**		
	Name					
	Urology appointment					
	OPA date					
VERTEBRAL	**Diagnosis**	Requested	Done ✓	**Findings**		
	Spinal ultrasound					
	Spinal x-ray					
	Spinal MRI					
	Comments					
	Referrals	Requested	Done ✓	**Additional information for referral**		
	Name					
	Neurosurgery appointment					
	OPA date					
LIMBS	**Examination of limbs**	Requested	Done ✓	**Findings**		
	R arm					
	L arm					
	R leg					
	L leg					
	Referrals	Requested	Done ✓	**Additional information for referral**		
	Name					
	OPA date					
GENETICS	**Referrals**	Requested	Done ✓	**Additional information for referral**		
	Name					
	OPA date					
Additional notes						

List of defects often identified in VACTERL patients		
Vertebral	**Cardiac**	**Urinary tract**
Tethered cord	Ventricular septal defect	Reflux
Butterfly vertebrae	Atrial septal defect	Horseshoe kidney
Vertebral fusion	ASD and VSD	Hypospadias
Hemivertebra	Tetralogy of Fallot	Solitary kidney (agenesis)
Additional lumbar vertebra	Dextrocardia	PUJ obstruction
Additional or absent ribs	Coarctation	Cryptorchidism
	Double arch	Dysplastic kidney
Gastro-intestinal	**Oesophageal atresia**	**Limbs**
Imperforate anus	With distal fistula	Absent radius
Duodenal atresia	H type	Digital anomalies
	Pure atresia	Hip dysplasia
Other	Double fistulae	
Cleft lip and palate	Proximal fistula	
Reference: Keckler SJ, St Peter SD, Palusek PA, Tsao K, et al. VACTERL anomalies in patients with esophageal atresia: an updated delineation of the spectrum and review of the literature. Pediatr Surg Int 2007;23:309-313		
Consider overlapping syndromes		
	Features in common with VACTERL	**Features distinct from VACTERL**
Alagille syndrome	Vertebral anomalies, cardiac anomalies; may have renal anomalies	Bile duct paucity and cholestasis, ophthalmologic anomalies (especially posterior embryotoxon), neurological anomalies, characteristic facial appearance
Baller-Gerold syndrome	Radial anomalies, may also include anal anomalies	Craniosynostosis, skin anomalies
CHARGE syndrome	Cardiac malformations, genitourinary anomalies; may also include TEF	Colobomata, choanal atresia, neurocognitive and growth impairment, ear anomalies, cranial nerve dysfunction, characteristic facial features
Currarino syndrome	Sacral malformations, ARM	Presacral mass
22q11.2 deletion syndrome (AKA DiGeorge syndrome or velocardiofacial syndrome)	Cardiac malformations, renal anomalies, other VACTERL-type anomalies also reported	Hypocalcemia, palatal anomalies, learning difficulties, immune dysfunction, neuropsychiatric disturbances, characteristic facial features,

Fanconia anemia	Virtually all features of VACTERL association may occur; radial anomalies are considered an especially key feature	Hematologic anomalies, pigmentation anomalies
Feingold syndrome	GI atresia, cardiac defects, renal anomalies	Brachymesophalangy, toe syndactyly, microcephaly, cognitive impairment, characteristic facial appearance,
Fryns syndrome	GI malformations, cardiac defects, GU anomalies	Diaphragmatic defects, neurocognitive impairment, characteristic facial appearance
Holt-Oram syndrome	Cardiac malformations, limb malformations	Cardiac conduction disease (also reported in VACTERL association)
	Features in common with VACTERL	**Features distinct from VACTERL**
Müllerian duct aplasia, renal aplasia, and cervico-thoracic somite dysplasia (MURCS association); AKA Mayer-Rokitansky-Küster-Hauser syndrome type II	Vertebral anomalies, renal anomalies, GU anomalies and anorectal malformations; may also have cardiac and limb anomalies	Syndactyly and hearing loss have been described
Oculo-auriculo-vertebral syndrome	Vertebral anomalies, cardiac abnormalities, limb abnormalities, urogenital anomalies	Ear anomalies (microtia), hemifacial microsomia, neurocognitive impairment, facial clefts (also described in patients with VACTERL association)
Opitz G/BBB syndrome	Anal anomalies, heart defects, TEF, hypospadias	Hypertelorism, syndactyly
Pallister-Hall syndrome	Imperforate anus, renal anomalies, limb anomalies (postaxial polydactyly should serve as a clue for the Pallister-Hall syndrome)	Hypothalamic hamartoma, bifid epiglottis (ranging to more severe types of clefts), nail hypoplasia
Townes-Brocks syndrome	Imperforate anus, thumb anomalies, renal anomalies, cardiac anomalies	Dysplastic ears, hearing loss
Reference: Solomen BD. VACTERL/VATER Association. Orphanet Journal of Rare Diseases 2011, 6:56		

ABOUT THE NNSIG

The National Neonatal Surgical Interest Group (NNSIG) is a special interest group of the Neonatal Nurses Association. It was originally formed in 2003 by a group of neonatal surgical nurses and continues to share and promote best practice in neonatal surgical care.

NNSIG is an innovative and dynamic group of nurses and AHPs, dedicated to the delivery of high-quality care for infants with congenital conditions requiring specialist neonatal surgical management.

ABOUT THE NNA

The Neonatal Nurses Association is the national organisation representing, supporting and championing neonatal nurses. Steered by neonatal nurses we work to support every neonatal nurse to be the best they can be to the benefit of premature and sick newborns and their families.

NATIONAL NEONATAL SURGICAL *Interest Group*

NEONATAL NURSES ASSOCIATION