Paediatric tracheostomy case study

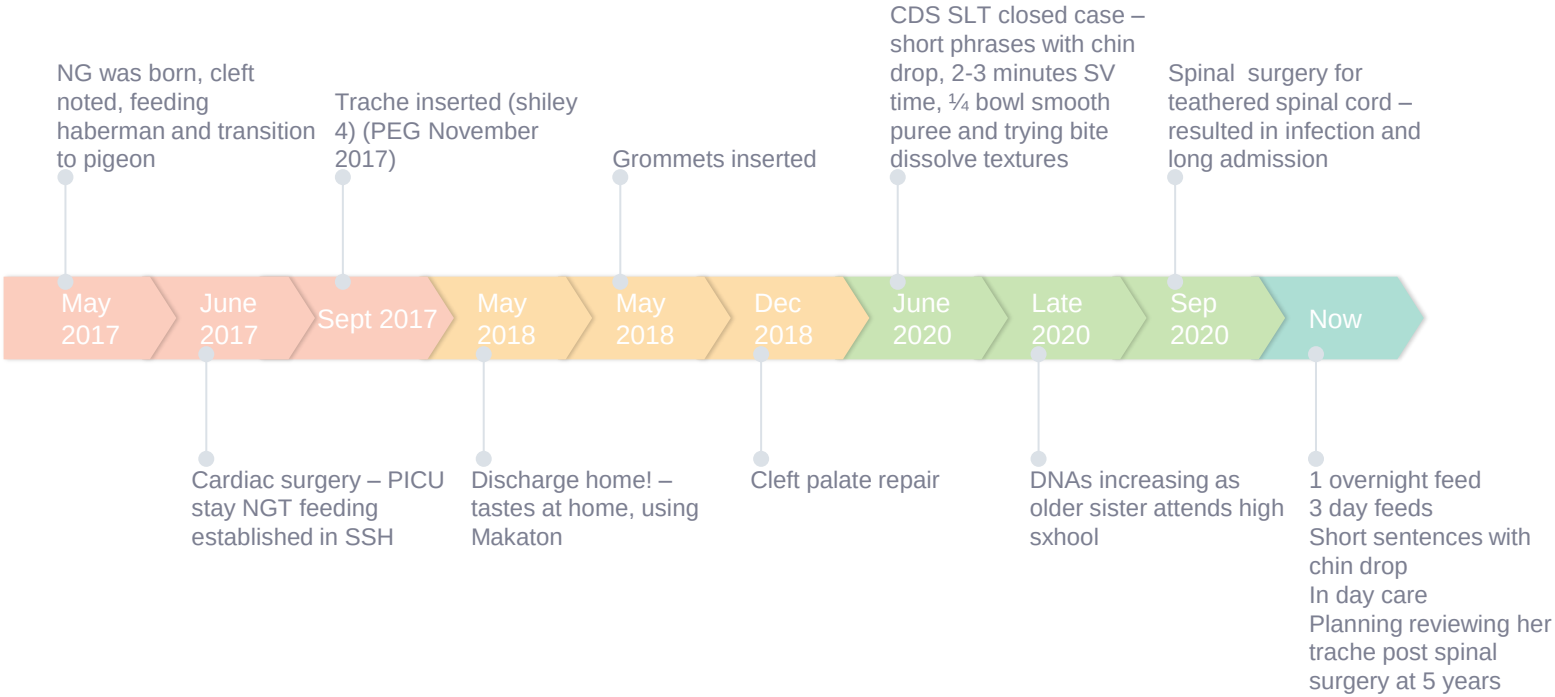
NG

A BIT OF HISTORY….

DIAGNOSES & PROBLEMS
Transient tachypnoea of newborn.
Hypocalcaemia.
Hypoglycaemia.
Presumed diabetic embryopathy with VACTERL features.
Truncus arteriosus - type A3.
Unrestricted membranous VSD and moderate, unrestricted ASD.

CONGENITAL ANOMALIES
Truncus arteriosus.
Scoliosis.
Cleft hard palate NOS.
short right femur.
Talipes NOS, asymmetric.
multiple osseus abnormalities.
wide spaced nipples.
.
Spinal cord malformations.
Hip: Congenital Dislocation of hip: unilateral.

Timeline


NG was born, cleft noted, feeding haberman and transition to pigeon
Trache inserted (shiley 4) (PEG November 2017)
Grommets inserted
CDS SLT closed case – short phrases with chin drop, 2-3 minutes SV time, ¼ bowl smooth puree and trying bite dissolve textures
Spinal surgery for teathered spinal cord – resulted in infection and long admission
May 2017
June 2017
Sept 2017
May 2018
May 2018
Dec 2018
June 2020
Late 2020
Sep 2020
Now
Cardiac surgery – PICU stay NGT feeding established in SSH
Discharge home! – tastes at home, using Makaton
Cleft palate repair
DNAs increasing as older sister attends high sxhool
1 overnight feed
3 day feeds
Short sentences with chin drop
In day care
Planning reviewing her trache post spinal surgery at 5 years

NG's Journey at home

1. Multiple congenital abnormalities thought to be secondary to diabetic embryopathy & VACTERL association
2. Congenital cardiac disease:
   Pulmonary atresia with tetralogy of Fallot and confluent pulmonary arteries
   - S/P Modified BT shunt innominate artery to RPA 2017
   - S/P Ligation of PDA
   - S/P Complete repair with closure of the VSD and PFO RV to PA conduit
   - Most recent echo November 2019, yearly follow up
3. Right multicystic dysplastic kidney:
   - Yearly monitoring of blood pressure and proteinuria
4. Multilevel airway abnormalities, tracheobronchomalacia
   - Tracheostomy September 2017, no oxygen requirement
5. Cleft of soft and hard palate
   - Repaired December 2018
6. Nissen fundoplication & gastrostomy
   due to confirmed aspiration
7. Multiple orthopaedic issues
   - Tethered spine
   - Club feet (treated with Ponsetti technique)
   - Markedly shortened right femur and right hip dysplasia
   - Congenital Hemivertebra T12 with associated spinal deformity & significant hypokyphosis - plan for hemivertebrectomy and short segment fusion in near future
8. Right-sided hemihypertrophy
9. Sensorineural hearing loss - BAHA device

Home cares

- **NG had frequent suctioning both oral and tracheal**
- **Swedish nose for humidification**
- **Continuous feed overnight and 4 bolus feeds**

Oral trials

In May 2018 NG was deemed safe for oral trials with consent from the medical team.

Feeding assessment

Assessed and consent from team

Assessed while in hospital for oral trials anmd discharged home on smooth puree with consent to move forward

Pre feeding strategies

- Upright in a supported seating system
- Suction before trials and messy play
- HME worn for trials and play to protect airway
- Careful observation throughout – pay attention to NG's cues
- No SV for subglottal pressure
- Keep upright post meals
- Winded and suctioned post

Therapy

Messy play

NG loved splashing food and engaging with wet foods.

Tasting and utensils

NG was happy to put things in her mouth and tended to overstuff.

She was happy to lick foods and family began giving her ice creams.

Chew and spit

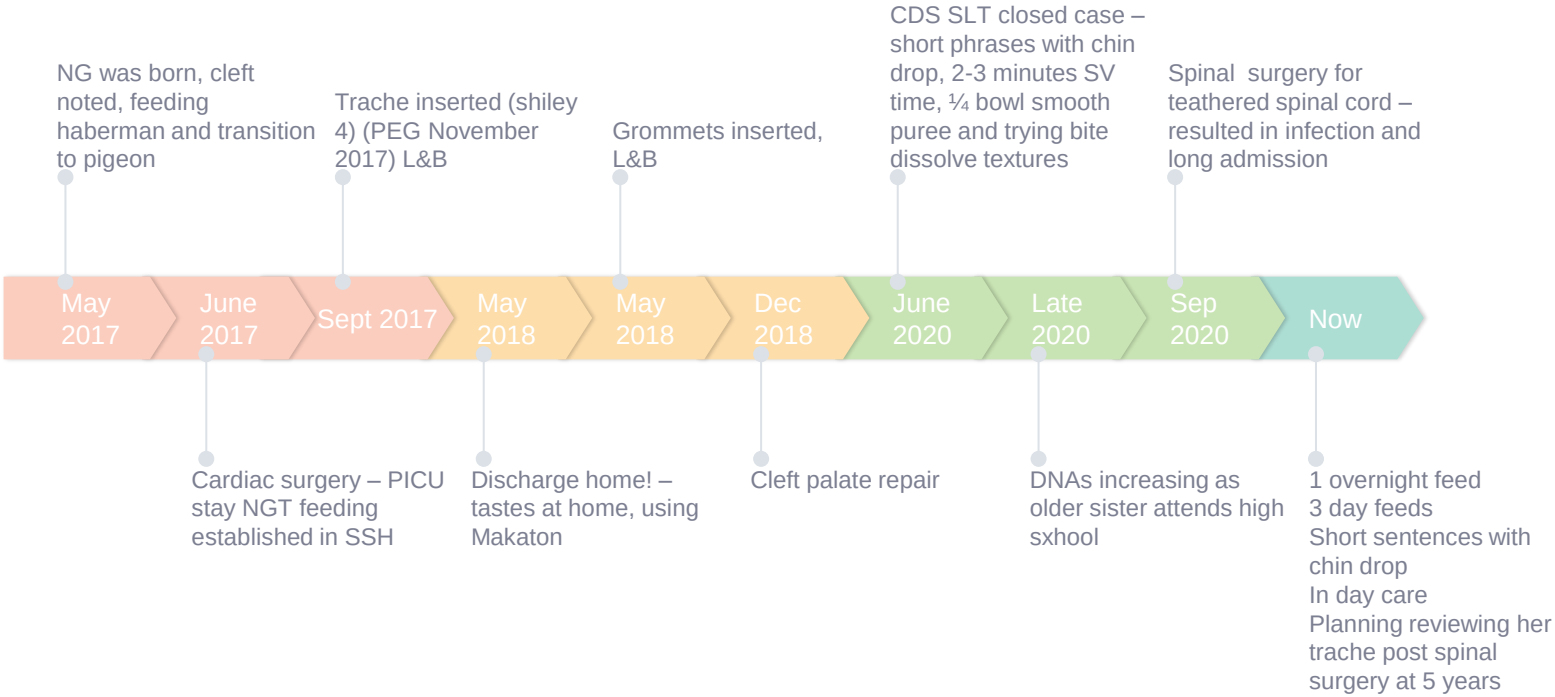
NG had a block of SOS style therapy – loved the ‘reject’ bowl!

Confidently mouths family foods.

SLT feeding recommendations:	**Fluids:** Offer [redacted] fluids (as per Dietitian advice) via a free flow sippy cup or open cup. Ensure [redacted] is sitting upright and there are minimal distractions. There is no limit on the amount [redacted] can have, offer her as much as she will accept. Be aware of her communicating that she has had enough (e.g. refusing the cup, shutting her mouth, turning her head away). When [redacted] indicates she has had enough, stop. If she starts to cough, stop offering and inform SLT. **Solids:** 1. Allow [redacted] to play with and to use a spoon or fork and at snack times when being fed. 2. Encourage [redacted] to self-feed during snack times – allow her to mouth hard munchable textures (observe and remove if she gags or chokes). 3. Continue to offer small snacks and family meals throughout the day. Main meals are be soft solids and therapy snacks are to be hard munchables. 4. Seat Nina-Grace with the family for meals.

Communication

Timeline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Early communication

Early therapy focused on preverbal communication strategies and Makaton signs.

NG loved Makaton signs and used; more, finished, Mum and turn very consistently!

Then she began to get an airleak as she grew….

Speaking valve discussions

In 2019 discussions were had with Dr Barber and consent was gained to order a speaking valve!

Speaking valve journey

- Initially trialled … with RN support and O2 monitoring
- Tolerating for short periods of a few seconds
- A few coughs and giggles when trialed

- Practice continued at home
- NG began some leak speech
- NG self occluding with chin drop
- Signs still used by NG to communicate wants/ needs at single word level

- NG mastered leak speech using 2-3 words together
- Refusal to wear SV
- Throwing away the SV when placed and loosing 3!
- Family decided not to continue with SV at home – only when out

NG turns 3

- At 3 years of age our CDT no longer provides a service
- NG was transferred to CCS Disability Action
- 3 monthly follow ups and support through feeding and nutrition clinic to continue building on her feeding skills
- NG is doing well!

Summary points

- Interesting history with lots of hospital admissions and surgeries
- She had a trache ‘later’ in her infant life
- NG and her family had so much confidence which heled her feeding
- Despite not liking her SV at all NG is a great communicator!

Any questions?

Discussion points:

- What are your local services like?
- What is your follow up for children with ongoing needs?
- What supports are out there?

Credits

- Presentation template by SlidesCarnival
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