Tube fed for good....?
Tube wean... in West Auckland?

Discontinuation of Tube Feeding in Young Children by Hunger Provocation

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ABSTRACT

Objectives: Pathological food refusal (PFR) is not rare in young children with chronic conditions requiring prolonged tube feeding. We investigated whether these children could be weaned off tube feeding with a multidisciplinary hunger provocation program. We aimed to evaluate the feasibility and effectiveness of this program in West Auckland.

Methods: A prospective study was conducted in children aged 1-10 years who had been on tube feeding for at least 3 months. The program consisted of a hunger provocation phase, during which children were encouraged to eat solid food while tube feeding was gradually reduced. The duration of the program was recorded. The primary outcome was the number of children who successfully weaned off tube feeding.

Results: A total of 20 children were enrolled in the study. The program lasted 9 to 33 days (mean 17.3 days). All children but 1 remained in clinically stable condition and started to eat within 1 week. Weight loss was 3.7% to 15.6% (mean 9.2%); in 1 child, the program was discontinued because of excessive weight loss. At follow-up after 3 and 6 months, 9 of 10 and 8 of 10 children, respectively, were eating adequately and gaining weight without tube feeding. Two children with recurrent PFR (25%-50%) tube feeding during

Conclusion: The multidisciplinary hunger provocation program was feasible and effective in weaning off tube feeding in young children with chronic conditions requiring prolonged tube feeding. Further research is needed to evaluate the long-term outcomes and sustainability of these results.
The experience

• 2 keen families
• 3 weeks, capacity to accommodate
• A committed team:
  – SLT
  – Dietician
  – Psychologist
  – Play therapist
  – Paediatrician
The process

• Pre-assessment
• Consent by family
• Reduced feeds over 5-7 days
• Clinical monitoring (up to 15% wt loss tolerated)
• Daily programme
  – Food play
  – Sensory work
  – Family support
  – Feeding behaviour
  – Confident persistence
The outcome
Some measurements
Parental stress
Some things we learnt

- Family system change
- Time – team commitment required
- Multi-disciplinary working
- Preparation is important
- ‘Yes, we can’
Public attention

Starship Hospital's rare tube weaning programme a success for Kapiti toddler

By Clare Wrigglesworth
12:48 PM Wednesday Nov 19, 2014

Tube Fed Kid

Wednesday, 19 March
Press Release: Tube Fed Kids Deserve

Tube Wean NZ, along with (Thursday 20 March) at

The petition calls on the hospital with a tube fed child to effective treatment and to

Nahalal Reid, 3, is doing well after successfully completing a rare weaning programme at Auckland's Starship Hospital.

She was so freaked out about the thought of anything going in her mouth that even the thought of it could make her sick.
Tube Wean NZ

Hello everyone, so sorry it's been ages since we last updated the page. This ‘Tube Wean NZ Campaign’ started almost 2 years ago now. After one of our founding members returned from a wean for her daughter in Graz Austria.

Our main goals of establishing the Campaign were to enable the same program to be available here.

And to get our submission and suggestions for change heard in Parliament... See More
NZ Survey 2013

• Survey, all DHB child health services
• ‘Long term Enteral Nutrition
  – NG or PEG, >3 months, in child health services
• Full response, but based on team estimations
• 630
• 65.9/100,000 <15yrs [60.5-71.3]
Age distribution

- >15y: 9%
- 3m - 1y: 16%
- 1y - 3y: 21%
- >3y - 5y: 16%
- >5y - 14y: 37%
NZ Regional rates

NZ (all) 65.9
Northern 66.4
Midland 72.1
Central 51.7
Southern 72.6
How many considered ‘weanable’?

- 130 considered suitable for transition
- Clinical estimate
- 26% of total.

- Further questions
  - Community transition?
  - Intensive programme?
  - Preventable?
### International prevalence estimates

<table>
<thead>
<tr>
<th>Country</th>
<th>Year</th>
<th>Paediatric prevalence per million total population</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poland</td>
<td>2010</td>
<td>13.8</td>
<td>Regional services survey</td>
</tr>
<tr>
<td>Italy</td>
<td>2005</td>
<td>45.2</td>
<td>National survey</td>
</tr>
<tr>
<td>UK</td>
<td>2010</td>
<td>95.6</td>
<td>British Artificial Nutrition Survey</td>
</tr>
<tr>
<td>NZ</td>
<td>2013</td>
<td>148 [136-160]</td>
<td>Based on 2013 survey</td>
</tr>
</tbody>
</table>

- Caution with comparisons – different survey approaches, different health systems, different demographics
- Consistent reports that use of long term enteral nutrition is rising.

Time trends (1) - numbers

FIG. 1. Number of patients treated with HEN between 1990 and 2000.

Time trends (2) - average age

FIG. 2. Age of patients commencing HEN between 1990 and 2000.

Risk factors

• 700 referred, Belgium tertiary unit.
• 603 (86%) specific assoc medical problem
  – Gastro (incl.GOR), neuro
• 427 (61%) oral sensory or motor problem
  – More less than 2yrs
• 127 (18%) behavioural problem

Rommel et al., J Pediatr Gastroenterol Nutr, 2003
Family experience

• “The impact of PEG feeding in children the parental perspective”
  
  Qualitative methods
  – Delayed, disturbed sleep
  – Social restriction
  – Child care challenges
  – Negative community attitudes
  – Stress experienced
  – Perceived reduced bonding
  – Impact on Quality of Life

• “Unintended side-effects of enteral nutrition support: the parental perspective”
  
  Survey methods, n = 425
  - Only 12.7% ‘no side-effects’
  - 56% gagged/retched frequently
  - 50% vomited frequently
  - 7.5% sweated during feeds
  - Free text comments:
    - Little interest in food
    - Food refusal/oral aversion
    - Throat irritation
    - Spitting, coughing

Brotherton et al, 2007, Child Care Health Dev.  
Pahsini et al, 2015, JPGN
Tube weaning interventions

• Key elements
  – Medical safety
  – Behaviour
  – Family support
  – Multi-disciplinary
  – Hunger provocation

• Types of programme
  – Behavioural, coaching
  – Inpatient
  – Outpatient
  – Online support
  – Pain rehabilitation model
What makes a difference?

RCT  n=64  Tube fed >1/12, resistant to oral.

• Nutritional only
  – weekly feeding clinic, structured schedules

  versus

• Behavioural also
  – Same schedule, + behavioural approach
    ‘extinction’

Benoit et al., J Pediatr 2000;; 137:498-503
Figure. Proportion of infants using enteral tube feeding over time by treatment group.
Overview of models

- Multiple nonrandomised studies
- Kennedy Krieger Institute (kennedykrieger.org)
- Graz (notube.com)

Key components
- Play and handling with food
- Decrease tube feedings
- Address underlying disease
- <3yrs better

Ishizaki et al, Pediatr Int, 2013
Wright et al, ADC, 2011
Moving forward

- A guideline
- A whole of system view
- A network
Guideline – tube weaning

• Criteria
  – Capable of swallow
  – Medically stable
  – Developmentally appropriate

• 3 week intensive

• Multi-disciplinary team

• How then to configure a service?
Whole of pathway view

- Information for families
- Clinical planning
- Consistent support
- Criteria for intervention
Continuous quality improvement

- Who is being tube fed?
  - Medical conditions, duration, demographics
- Natural history?
- What information is given at start?
- Planning for oral feeding
- Adequate support for difficult phases
- Informed by family experience, ongoing
Callibrating the system

n

Intensity of effort

Informed families
Enabled clinicians
Surveillance and feedback
Baby steps

• Clinical network
  – Consistency, Clinical team support, system learning

• Advocacy
  – Adequate support – information and practical

• Research
  – Need for properly controlled research studies.