

# ACH Tube Weaning Pilot Project

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## Feeding COP sessions:

- We are excited to have a collaborative and interactive meeting – please join in, speak up, ask questions, comment - this COP is for everyone across the province to connect and learn together!
- Please have your cameras on, especially in the breakout rooms as this facilitates interaction and communication
- Please reflect on your own area of practice and programs and how the content applies to you
- We encourage healthy debate, an open mind and recognition that people take different approaches to their work.

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Our work takes place on historical and contemporary Indigenous lands, including the territories of Treaty 6, Treaty 7 & Treaty 8 and the homeland of the Métis Nation of Alberta and 8 Metis Settlements. We also acknowledge the many Indigenous communities that have been forged in urban centres across Alberta.

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**Tube Weaning - ACH**

- One of the top priorities of parents from the PEAS collaborative
- Ongoing goal of feeding teams across the site and province
- Developed a pilot project to wean patients (G-tube/NG) using a defined care pathway
- Project team – RDs, SLPs, OTs, peer mentors, MD, clinical leaders, managers

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**What is tube weaning?**

- A process where a child's enteral feeds decrease and oral intake increases over time

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**What does the research say?**

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Research

- Looked at 12 studies, n=725 pts total
- Reviewed Models For Weaning Children Off Enteral Nutrition: Rapid Evidence Report (PEAS 2022)
- Spoke to a number of programs around the world

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Research

- Wean time varies
- Mostly 80-90% success rate
- Minimal weight loss (<10%) in the short term, no impact long term
- Inpatient, outpatient and virtual
- Follow up intervals vary

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ACH Project

Goals of Pilot

- 10 patients, no budget
- How much staffing needed?
- 3 months
- How many appointments needed – avg per pt? Booked vs. phone/email
- Demedicalize feeding while weaning
- Wean from tube partially vs. fully

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Tube Weaning Pilot Project

Inclusion Criteria

- Under 5 years of age
- Medically stable
- Safe swallow
- Will self-feed or accept being fed
- Will touch food and tolerate being messy
- Parents are ready to wean from the tube feed
- Parents can commit to schedule of appointments
- Parents are able to have family meals with child and follow recommendations from feeding therapists

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Tube Weaning Pilot Project

Exclusion Criteria

- Over 5 years of age
- Swallow is not safe
- Parents not ready/not comfortable with decreasing feeds
- Parent-child relationship/do we need to work on building trust/reading cues/respecting cues
- ASD (currently haven't found any research on patients with ASD and this approach)
- Medical instability
- NPO- not accepting tastes/oral aversion, not accepting items near face/mouth/touching;

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Tube Weaning Pilot Project

## Weaning Team

- Pt and family
- Feeding therapist – OT/SLP
- RD
- Peer Mentor
- SW & MD as needed
- Booking clerk

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Tube Weaning Pilot Project

## Introductory Appointment

- Describe program
- Go through family readiness assessment (FRA)
- Assign a peer mentor

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## Family Readiness Assessment

Checklist for Parents

Family Readiness Assessment

**FAMILY READINESS**

- We are ready to participate and make necessary changes
- We have time to commit to regular weekly or biweekly follow-up for the tube wean time period (at least 4-8 weeks)
- We can offer small amounts of different textures, flavours and food groups
- We know that food waste will occur and is part of the process (food play)
- We can have consistent daily routines with feeding (3 meals, 2-3 snacks daily)
- We understand the division of responsibility and responsive feeding and we feel comfortable with it
- We know that our child's weight will potentially decrease over the course of the tube wean
- We know that a peer mentor will be assigned to us and will connect with us before the wean begins. We recognize that an ongoing use of a peer mentor is optional and can be based upon our needs as a family.
- We know
  - o Our child may not complete the tube wean in the 4-8 week time frame.
  - o the tube may need to be reinserted
  - o Some children need more time or more than one attempt.
  - o if our child's medical status changes, the tube wean may need to stop.

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### Introductory Appointment

- Discuss division of responsibility in feeding and responsive feeding
- Send “Feeding Toddlers and Young Children” and Family Readiness Assessment to family

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### Program

- Scheduled for 8 weeks of appointments
- 2 x week for the first two weeks (in person and Zoom)
- 1 x week for the remaining 6
- Peer mentor calls as needed

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### Ready to Wean Checklist

#### MEDICAL STABILITY

- At stable baseline for 3 months
  - No acute illness
  - Primary care provider/pediatrician agrees pt is medically stable
  - Medications have been reviewed and can be given orally
- PCP's name and contact info: \_\_\_\_\_

#### SWALLOWING SAFETY AND READINESS

- Feeding Therapist assessment/consultation +/- instrumental assessment of safe swallow
  - o Last evaluation date: \_\_\_\_\_
- Outpatient feeding therapy established
- Feeding therapist has provided parental communication on therapies and education
- Other: \_\_\_\_\_

#### NUTRITIONAL ADEQUACY AND HYDRATION

- Growth assessment completed
- Nutrition focused physical exam as assessed by a Registered Dietitian
- Optimized reflux and bowel regimen
- Appropriate hydration status
- Other: \_\_\_\_\_

#### CHILD READINESS

- Child will self-feed or accept being fed
- Child can tolerate being messy/touching food
- Family readiness tool has been reviewed with family

#### PEER MENTOR

- The family has been told about the purpose and benefits of peer mentors
- A peer mentor has been identified
- Information about the family has been passed onto the peer mentor
- The initial conversation prior to the wean beginning has been set up (if possible with peer mentor and families availability)

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Program

- Drop feeds by 20% at the first appointment
- Drop by 10-20% each appointment after that
- Drop water flushes as you go

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Program

- Usually do a feeding observation/review at each appointment
- Discuss intake changes since previous appointment
- Ask about outputs

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Program

- Weigh patient weekly, expect weight loss (up to 10%)
- Parents monitor for constipation and signs of dehydration

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## Results

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Results

- 9 patients so far
- 7 patients are off the tube (1 still in progress, 1 got C. Diff)
- Avg weight loss = 3.5%
- Some pts gained weight the whole time, others lost the full 10%

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Results

Percentage of Intake from Food at Start of Wean

Patient	Percentage of Intake from Food at Start of Wean
9	15%
8	10%
7	75%
6	30%
5	0%
4	0%
3	20%
2	50%
1	0%

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Results

- ~half of patients still need feeding therapy after the wean is complete to progress textures
- Still need long term growth data (first patient has only been off for four months)

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Themes for discussion

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Challenges/themes – OT/SLP

(Facilitator– Louise Mills)

- What if the child won't drink?
- What kind of feeding skills are needed to start a wean?
- How do you progress with lack of experience?
- What if the child doesn't want to eat purees?

Spits not swallows?

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Challenges/themes – RD

Facilitator – Sarah McKenna

- Weight loss is stressful for families
- Lack of control over intake when used to measure EVERYTHING!
- Hard for families to follow DOR
- Processed foods

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Challenges/themes – parent perspective

Facilitator – Pam Thomson-Kai

- What does peer mentorship look like?
- Family engagement - setting boundaries
- Who are your people? Family and peer supports
- When your child is not a tube fed child anymore....

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Tube Weaning Pilot Project

Wrap Up

- What experience do other teams have?
- What long term supports need to be in place?
- What comes next? ACH pilot program and in YOUR area?

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