OUR CHILDREN EAT DIFFERENTLY: A PARENT’S PERSPECTIVE ON RAISING A CHILD WITH A FEEDING TUBE
Before and After

- On May 22, 2010, I considered myself immune to having a child with health or developmental complications.
- I gave birth to a healthy daughter in 2007, and she was a precocious 2.5 year old.
- My son Liam was born full-term, 9 lbs 1 oz. after an uneventful labor and birth.
- Everything changed on the morning of May 23, 2010, when Liam vomited after every feeding.
- At 2 weeks of age, Liam was diagnosed with failure to thrive; G-tube dependent until age 4.
MEET LIAM
NINE THINGS I WISH I’D KNOWN 4 YEARS AGO
1. IT WASN’T MY FAULT

- Feeding your child is a parent’s most primal, fundamental role
- Being unable to feed my son in the typical ways felt like the ultimate failure
- It took years to understand the medical reasons
- Having a feeding tube was Liam’s only option for survival
- His intense oral aversion was a natural response to his experience, and it wasn’t our failure
2. A FEEDING TUBE CAN FEEL LIKE A BURDEN AND A RELIEF

- No parent would ever choose to use a feeding tube (no, it’s not more convenient!)
- Our family experienced fear, grief, sadness, despair, intense loneliness
- It never felt natural to use a feeding tube, but it did feel like a relief
- In the cases where a feeding tube is necessary, it can allow parents the space to evaluate next steps
3. NOT ALL FEEDING TUBES ARE THE SAME

Last night with the NG

First day with the G-tube
## 4. It’s Still Okay to Make Mistakes

<table>
<thead>
<tr>
<th>What happened</th>
<th>What we learned</th>
</tr>
</thead>
<tbody>
<tr>
<td>NG came out daily for 7 months</td>
<td>We became experts at inserting NG and taping it to Liam’s cheek</td>
</tr>
<tr>
<td>Set Joey pump at the wrong rate; Liam vomited extra milk</td>
<td>We triple-checked the feeding rate</td>
</tr>
<tr>
<td>I took the kids to the park 7 days after G-tube surgery, tube came out, ambulance trip to the ER</td>
<td>I never again forgot that a tube is in my son’s stomach</td>
</tr>
<tr>
<td>We waited longer than 3 months to change the mic-key button, leading to pain when we did change it-- if you leave the mic-key in longer than 3 months, the balloon can harden</td>
<td>We change the tube every three months without fail</td>
</tr>
</tbody>
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5. **How to Create a System that Works for Your Family**

- Write everything down
- Consider making a schedule
- Do you want to mimic a typical approach to eating (i.e. not look at the clock)?
- Are you giving the same formula each feeding?
- Does the volume of food each feeding?
- Are you giving a water bolus 30 minutes before each feeding?
Liam’s Tube Feeding Schedule: Age 2, Homemade Blended Diet, 1,500 Cal/Day

<table>
<thead>
<tr>
<th>Time</th>
<th>Feeding Volume</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 am</td>
<td>2 oz water</td>
</tr>
<tr>
<td>8:00 a.m.</td>
<td>4 oz blended formula</td>
</tr>
<tr>
<td>9:00 a.m.</td>
<td>2 oz blended formula</td>
</tr>
<tr>
<td>10:30 a.m.</td>
<td>2 oz water</td>
</tr>
<tr>
<td>11:00 a.m. (before nap)</td>
<td>4 oz blended formula</td>
</tr>
<tr>
<td>1:30 p.m.</td>
<td>2 oz water</td>
</tr>
<tr>
<td>2:00 p.m. (during or after nap)</td>
<td>4 oz blended formula</td>
</tr>
<tr>
<td>3:30 p.m.</td>
<td>2 oz water</td>
</tr>
<tr>
<td>4:00 p.m.</td>
<td>2 oz blended formula</td>
</tr>
<tr>
<td>5:30 p.m.</td>
<td>2 oz water</td>
</tr>
<tr>
<td>6:00 p.m.</td>
<td>4 oz blended formula</td>
</tr>
<tr>
<td>8:00 p.m. (while asleep)</td>
<td>2 oz water</td>
</tr>
<tr>
<td>8:30 p.m. (while asleep)</td>
<td>2 oz food</td>
</tr>
<tr>
<td>10:30 p.m. (while asleep)</td>
<td>2 oz blended formula</td>
</tr>
</tbody>
</table>
6. **You can assemble a strong wellness team for your family**

Team may include:
- Gastroenterology team
- Pediatrician/Developmental pediatrician
- Feeding therapist/occupational therapist
- Nutritionist (blended diet or formula)
- Health insurance (public or private)
- Medical supply company
- Social worker
- Child care
- **Who will provide the medical home for your child?**
7. **Find the Right Approach to Feeding Therapy to Wean Your Child from the Tube**

- Different approaches to feeding therapy and tube weaning
- Every family needs to find the approach that is the best fit for them; if it doesn’t feel like right to you, keep looking
- Some children benefit from intensive (i.e. daily) feeding therapy
- We had great success with the STAR Center in Denver; comprehensive, sensory-based approach that involved alternating daily OT/feeding therapy for 2 months
8. Celebrate your victories
9. You don’t need to do this alone

- ***Feeding Tube Awareness Foundation: [www.feedingtubeawareness.org](http://www.feedingtubeawareness.org)
- Family Voices: [www.familyvoicesofca.org](http://www.familyvoicesofca.org)
- Parent support groups/parent mentor groups: ask the GI team if one exists and/or contact your local family resource center
- Listservs and Facebook groups: blenderized diet, feeding tube awareness, pediatric feeding disorders
- Book: *Far From the Tree: Parents, Children and the Search for Identity* by Andrew Solomon
QUESTIONS?