Living With Tube Feeding: A Sibling’s Perspective

Greta Huss and Lauren Chavoustie
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Owen sustained a mid-gut volvulus just before he turned 4 years old. He lost all his small bowel except for 36 inches of jejunum. This was ultimately reanastamosed (reattached) to the remaining part of his descending colon. He has no duodenum or ileum, or ascending or transverse colon, and no ileocecal valve.
At the same time of Owen’s original volvulus and bowel loss, he sustained a >10 minute cardiac arrest. The hospital staff told us to place Owen in an institution as he would be a vegetable. We chose to med-evac him to Denver Children’s on January 15, 1996.
Medical Summary

- Broviac IV catheter, 17 years
- Mic-Key enteral button, 21 years, surgically relocated when he reached adulthood
- Ileostomy, 3 years
- Loop jejunostomy,
- 3 years HPN, 17 years
- HEN, 21 years
- 5 episodes of sepsis in 17 years
Medical Summary Cont’d

• OT, PT, Speech, and Reading therapy, 17 years Serial casting, feet and ankles, 3 years wheelchair bound, ~3 years

• 4 Broviac line replacements in 17 years

• Surgeries: numerous—bowel resections, ostomy placements then subsequent takedowns (reanastamosed), enteral button placement, then relocation; gallbladder removal, hydrocele at 15, kidney stones.

• Latest surgery last year-kidney stone blasting.
Life With Owen Was...
Uncertain.
Funny.
Airsick, Carsick, Seasick...
Exciting.
An Adventure.
Different.
Hopeful.
Inspiring.
Buzzwords:

- Tegaderm
- Betadine
- Kangaroo pump
- Ostomy/Stoma
- Saline, Heparin
- pink foam “popsicles”
- Rehydration solution or “go juice”
- IV pole
- Syringe
- Catheter
- Peptamen
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