

A Home Enteral Feed Dietitian's Experience of a Week on Nasogastric Tube Feeding



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The challenge

On Monday 18th January, I had a nasogastric (NG) tube placed and gave up all oral diet and fluid for a week. I was undertaking this challenge in memory of my Grandad, Fred, who passed away in 1992 after being diagnosed with Motor Neurone Disease (MND). I have memories of a great man I admired and loved fading away with each visit to see him. I also had a professional curiosity to experience, first-hand, some of the day-to-day practical, social issues and psychological issues that patients on home enteral feeding (HEF) often report. To raise awareness and optimise my fund raising I kept a video blog on social media to give anyone interested a window into my life for the week.

Placement and presence of the NG tube

The placement itself was uncomfortable, but not horrendous. I heaved as it passed the back of my mouth and my eyes were watering. Once it was down and the guidewire was removed, I was left with an irritation the back of my throat, which was accentuated when I moved my head from side-to-side. I was constantly sniffing and swallowing, which must have been as irritating for anyone in earshot, as it was for me. For the first few days I was very conscious of the tube, resulting in a restless sleep, fearing I had pulled the tube out. However, as the week progressed, I adapted to the presence of the tube, eventually forgetting it was there (see **Figure 1**).

Social impact

I intended to get on with my normal day-to-day activities while trying to squeeze in the 2400 kcals of enteral feed I required. During the week:

- I went to work; visiting patients feeding at home
- I attended social occasions, such as watching my

daughter sing at a school event and playing cards at a friend's house

- I participated in my son's 6th birthday celebrations
- I continued training for the Paris marathon.

Figure 1: Post-Insertion of NG Tube by Dr McAlindon (Consultant Gastroenterologist)



You need to be well organised to feed outside of the home, remembering to: charge the pump; take my feed, water, syringes, and pH paper with me; and factoring in where I was going to feed. Everything took longer than normal, whether that be having a shave (see **Figure 2**), showering, or getting ready to leave the house.

Figure 2: Shaving with NG Tube



Any delay in starting feeding, meant I had to squeeze everything into a shorter period of time. When I did eventually leave the house, I felt like everyone was taking a second look at me, though I guess I was on the lookout for this. The uninhibited reaction of the kids entertained me most. My eight-year-old daughter, Eve, was full of frank and direct observations, such as saying: *"The best thing about you having that tube is that you don't eat all my sweets."* See **Figure 3**. In contrast to my six-year-old son, Ben, who paid all of 10 seconds interest before returning to play with his cars. Adults gave very different responses. They either showed genuine concern for my health, or avoided mentioning it at all – I guess, through a sense of not wanting to pry. It made me think how having a NG tube is a very visual reminder to both the patient, and public, that they are unwell, which explains the body image concerns reported by patients in the qualitative literature.

Figure 3: Being Bolus Fed by my Daughter



Experience of different feeding methods

During the week I wished to experience the variety of different feeding methods that I advised patients on in my day job. I confirmed the gastric position of the NG tube before administering any feed or water, recording a pH 2-4.5 with no problems on most occasions. However, on two mornings I could not get an aspirate at first attempt. I eventually obtained an aspirate after doing a little dance and lying on my left-hand side – see **Figure 4**. It was satisfying to learn that the advice I have often given to patients was effective.

Bolus feeding

I began by using the plunger in a syringe to administer three-to-five bolus feeds per day, each taking about 15 minutes including the preparation and clear up operation. I soon learnt it was important to have some tissues to hand to wipe the end of the syringe or else feed would soon drip everywhere. It was not easy to plunge the viscous 2.2 kcal/ml supplements I chose to use, down the 8F NG tube, without diluting with additional water. In practice, I would usually advise patients to increase the volume of each bolus feed as tolerated, to reduce the frequency of feeds required, lessening the burden of feeding on the patient. The largest individual bolus feed volume I attempted was ~700 mls which did make me feel quite full and I may have struggled to have every day. I intended to try gravity feeding, but due to the time it took to administer, I soon abandoned this method so that I could get some work done. There is a need for industry to bring a

stand to the market, that can hold the syringe while the feed is administered, if patients choose to use this method of feeding. Many of the patients I see feel they would benefit from such a piece of equipment and a few have even designed their own (see **Figure 5**).

Figure 5: Feeding using Gravity Method and a Bolus Feed Stand - Designed and built by a patient, that would have made life much easier



Pump feeding

I wished to experience pump feeding over the whole day, using a back pack to carry the pump. I met my requirements by administering 1500-1800 mls of a 1.5 kcal/ml feed at 200 ml/hr. Giving myself an hour to get washed, dressed, have the usual battle getting the kids ready for school, and set-up the feed for the first time was a bit of a tight run thing. It was interesting how quickly I began to cut corners for an easier life, despite knowing better. However, once I was up and running, it was a low maintenance feeding method.

Figure 4: Trying to Obtain an Aspirate



Pump feeding could have ended my week on NG feeding early, with a few 'near misses' as a result of me walking away when attached to the pump; absent minded dumping the back-pack on the floor when coming in the front door; and getting the giving set caught on a door handle. I took my feeding pump with me to play cards at a mate's house which was a bit surreal. Unfortunately, being sober and well-nourished did not result in me winning, but I took advantage of others inebriation collecting a decent boost to my sponsorship total.

The following day I set the pump to its highest rate (400 ml/hr) and fed in four hour-long sittings. I rationalised the fast feed rate by comparing to a 400 ml bolus given via a syringe in 10 minutes, equating to ~2400 mls/hour. I did not feel full and I think this would be my feeding method of choice. Once the feed was set up, all I had to do was press 'Start' and the pump would do all the hard work allowing me to get on with things. With this insight I feel pumps should allow much higher feeding rates, so that a more hassle free bolus feed could be given, avoiding some of the mess and effort of using a syringe.

Blended diet

Administering blended diet via enteral feeding tubes is a topic that has generated debate amongst both patients and health professionals. I whizzed up a chicken dinner using an old hand-blender - not the £250 blender usually recommended. I needed to dilute a half portion to about 800 mls to achieve a consistency that would go down the tube. I certainly would need to significantly fortify my diet or include some supplements in order to meet my requirements if I was going to use this method of feeding. However, the blended chicken dinner certainly smelt better than the enteral feed (see **Figure 6**).

Eating with the NG tube

As promised to one of my oncologist colleagues, I agreed to report back on how it felt eating a modified texture diet with

the NG tube in place. The liquidised diet was swallowed with no problem. However, the pureed and soft diet was not so easy. I had a sensation of food sticking to the tube on its way down, resulting in the need for multiple swallows to clear it. More disconcerting though was the feeling of the tube being sucked inwards with each swallow, making it feel tight at the bridge of my nose and nostril. These two factors would not have encouraged me to transition from enteral to oral diet.

Other unexpected experiences

I was convinced the tube had become displaced when I first fed, as it felt like a cold liquid was gushing down the back of my throat. I experienced a dry mouth for most of the week but was surprised to find that giving fluids via the NG tube quenched my thirst as a result of the saliva production stimulated. Though this was welcome for me, I can think of circumstances where stimulating salivation would not be the safest thing in people with dysphagia as it could lead to drooling or even aspiration on these secretions. Considering that I usually have a good appetite, I was surprised to find that I rarely experienced hunger throughout the week. However, I did miss food; highlighting to me the difference between feeling hungry and wanting to experience the satisfaction and social interaction that food can provide.

In common with many dietitians, I was interested to find out how enteral feeding would affect my bowels. Usually I am a regular as clockwork 'once-a-day' man. Despite including fibre in my feed plans and taking plenty of additional water, I soon became the 'once-every-three-days-man' and a little uncomfortable with it. My anecdotal experience was that fibre in enteral feed did not have the same action on my gut motility as that of normal dietary fibre. Of course, in time, my bowel may have adapted, but the change in bowel habit was marked and surprising.

Removal of the NG tube

I had a sense of guilt on removing the NG tube when reflecting on how many people have to deal with the daily challenges of home enteral feeding for the rest of their lives. The tube was removed with little fuss, though I did experience a 'phantom NG tube' continuing to try push the imaginary tube back behind my ear.

What next?

Spending a week on HEF has been such a valuable learning experience. I appreciate I only had to deal with the impact of feeding for one week without the symptoms of a debilitating condition, such as MND. I would recommend that any healthcare professional (HCP) that cares for patients on HEF have a NG tube placed, even if for just a few days. It will definitely influence my practice and inform the empathy I have for the patients I visit.

I intended to disseminate my experience as much as possible, to raise awareness and additional sponsorship. It was covered by local radio and press which made a huge difference to my fund raising coffers. It was a very strange feeling letting everyone who followed my progress on social media into my life for a week. I now hope to use the video footage I have collected to produce a short film that can be used to inform both patients and HCPs about some of challenges that being on NG feeding at home can bring.

Figure 6: Administering Blended Chicken Dinner



Charity fund raising effort

Once I have dragged my old legs around 26 miles of Paris on Sunday 3rd April 2016, I will hand over the money raised to the South Yorkshire branch of the MND Association, which will be used to help support people living with MND and their families, and to fund the research into new interventions and we all hope a cure to this dreadful condition. If you wish to sponsor me for the challenges I have undertaken, you still can at: www.justgiving.com/seanwhite77 until May 1st 2016.

You can view the video footage and diary entries at: www.facebook.com/seanwhite1977 and www.youtube.com/channel/UCdsRz_TlkBRRMERApLmmaLg