

*Please confirm receipt of the email below and that this has been brought to the attention of Ms Archer.*

Dear Ms. Archer,

I am sick with a similarly severe case of ME/CFS to Maeve Boothby O'Neil with very similar symptoms. I have had a PEG/J tube for over 8 years, since January 8, 2016. Every single day I pump food (formula) into the J part of the tube and inject 45cc of pureed food into the G part of the tube to make sure my stomach does not atrophy. I can not tolerate pumping even a small amount of food into the G tube.

I often have the food pump running into the PEG/J tube for 12 hours at a time or more, it makes no difference how long I have food pumping, the following is true regardless. I always lay flat when food is being pumped into me and laying flat has never, not once been an issue or even caused any nausea or discomfort. Not once. The tube has never pulled out, or gotten curled up, and I have never aspirated. It has also never gotten infected and I go days between cleaning it with hydrogen peroxide and also cannot change my bottom sheet more than once every few months, so it is not in a very sterile environment. Yet the tube has, for over 8 years, been completely fine, with no hint of infection or bad bacterial growth of any kind.

Every few months I have to go to the hospital to get the J-tube changed. I have to get a gurney transport to get there because I am not able to walk or move to a wheelchair, but gurney transports are readily available. The hospital is very accommodating. They give me a private room and allow me to keep the lights off and cover the computer and LED's on the equipment with towels. They don't speak with me, but instead ask my mother all questions outside the room with the door closed. My treatment is consistent with the NICE guidelines and they are very respectful of my condition. With their accommodations along with the help of the drug Lorazepam, I am not harmed by these trips. They are temporarily exhausting but my condition does not worsen for more than a week. If I did not receive both the accommodations by the hospital and Lorazepam, I would likely not recover from just a single trip to the hospital.

Before the PEG/Jtube I had TPN through a PICC line for 18 months. I never got sepsis, but I did get a few infections. They were treated with antibiotics and I got over the infections in a matter of days and was fine. The PICC line was installed at home, and when it needed changing, it was changed at home as well. The blood sugar checks needed for TPN feeding take only a few seconds and happened without me hardly noticing. They never caused distress or stress nor did they make my symptoms worse in any way. And after my body stabilized, I no longer needed to have blood sugar tests at all anymore. My parents were trained on how to change the bandage and they do it

while I'm wearing earmuffs and an eye mask so that it does not cause overstimulation that would make my health worse. The earmuffs and eye mask I use are readily available all over the world including in the UK. Changing the bandage does not cause me harm in any way. It takes an hour maximum and has never been an issue.

I still have the central line for IV fluids for hydration and haven't had an infection in many years. It is also important to note that my caregivers can't change my sheets very often because of how much energy it takes for me to tolerate. So sometimes the bottom sheet was not changed for months. Yet the issue of hygiene was managed fine. There are sterile caps you can put on the ports that prevent anything getting in, in addition to a lock on the ports themselves.

It is a travesty that Maeve did not receive nutrition like I received. I was just as sick as Maeve with very similar symptoms, including sensitivity to stimuli like light, sounds, voices and the company of other people in my room and like Maeve, I could not eat enough food to survive. If I was treated the way Maeve was treated, I would be dead just like Maeve. Luckily, I had doctors who viewed ME/CFS as the serious physiological disease that it is, and understood that the risk of needing to take antibiotics occasionally or add a few extra steps to my daily routine was better than the certainty of death from starvation, dehydration or malnutrition, which is what killed Maeve. Maeve just needed a way to get nutrition into her body. I got TPN and lived. Maeve was denied TPN and died.

Thank you for your time and for caring about Maeve's case.

Sincerely,  
Whitney Dafoe  
<https://www.whitneydafoe.com/mecfs>

*Attached are photographs of me lying flat while being fed through a J-tube posted in the public domain between 3/9/2021 to 8/20/2021.*