

Dear Royal Lancaster Infirmary,

Millie McAinsh is a patient in your care and she needs a PEJ feeding tube right now. Today.

I am a severe ME/CFS patient who has a PEJ feeding tube, and I want to speak to how wrong it is to refuse to give Millie a PEJ tube.

If I did not have a PEJ tube I would starve to death, no question. I physically cannot eat, my nervous system is so sensitive that even a crumb of food would permanently hurt my stomach and make it more sensitive and possibly make it so I could not get liquid food through the feeding tube anymore and lead to my death.

My stomach follows the exact same pattern as what is called Post Exertional Malaise in ME/CFS patients (PEM). Please use Google and learn about the physical illness Millie has called Myalgic Encephalomyelitis (ME/CFS). Google "ME/CFS PEM".

ME/CFS patients have a physical energy limit, which is much lower than healthy people. Severe patients like Millie often have 1% or less of the energy they had when they were healthy. I have something like .2% of the energy of my healthy self. Yes, that is point-two-percent. And I used to be healthy. I grew up playing all sports including running cross country.

When ME/CFS patients go over their energy limit, 2 things happen. Their symptoms get immediately worse for a period of time (this is PEM), and this energy limit gets lower permanently. So every time an ME/CFS patient goes over this limit, the limit goes lower.

The only way for an ME/CFS patient to live a sustainable life and not continue getting worse in a downward spiral is to stay below their energy limits.

My stomach follows this exact same pattern. And Millie's stomach likely does as well.

If I push my stomach, and go over my stomach's limit ie. eating more than my stomach's limit, which is now at zero, it gets more sensitive.

It's a trigger, and every time this trigger gets pulled, the whole system gets more sensitive.

This pattern happened with my stomach in 2013, but I did not get the care I needed, I kept trying to eat food to get calories and kept making tiny mistakes and hurting my stomach and it kept getting worse until I was starving to death and could only take tiny sips of maple syrup to try to keep my brain somewhat functional. I weighed 115 lbs. when I finally got a feeding tube and I am 6'3".

What you are currently doing to Millie is actually incredibly dangerous and likely the reason why hospitals kill severe ME/CFS patients in the UK when they refuse to give them a feeding tube. Yes, Millie could die and you will be 100% responsible.

Millie is currently having to force too much food into her system through her mouth and stomach, which could just continue to make that whole system more sensitive. So the longer Millie is forced to eat food orally, the more danger she is in of her digestive system completely

shutting down. And the less food she will likely be able to eat orally in the future after you inevitably HAVE to give her a feeding tube because it is what she needs.

Every single time Millie forces food into her overly sensitive stomach, it risks making her worse.

She needs a PEJ tube right now, this minute, so she can stop eating more than her stomach's limit trying to get the calories she needs to stay alive.

Every minute you wait is just one more minute of malpractice and abuse exacerbating Millie's stomach sensitivity and likely making it worse. You are forcing her to hurt herself in order to stay alive.

If Millie can get a PEJ tube put in now, while she can still eat SOME food, she might be able to slowly build back up to eating all of the calories she needs. Slowly, over months or years.

But if you keep delaying, Millie could wind up like me and not be able to eat anything anymore for years to come or for the rest of her life.

Or she could wind up worse than me and not be able to even tolerate a feeding tube.

People seem to think that digestion is so normal and "natural" it can't go wrong. But it can. The body can reject food like it is poison. Millie could just throw up all nutrients put into her system with the feeding tube or shit it all out with diarrhea non stop until she dies from malnutrition.

This is very real and very urgent.

Millie needs a PEJ tube right now, this moment. Not in a few hours, not tomorrow, not in 5 weeks when she is dead. Right now.

And Millie needs a PEJ tube not an NG tube. The reason being that the tube needs to bypass her sensitive stomach where the nerves are overreacting to food input. If I had to pump all my food into my stomach I would throw up constantly and would not be able to get enough nutrition. This is very important. An NG tube is not sufficient. The best would be a tube like mine, which has both a Gastric port and a Jejunum port so Millie can get the nutrients she needs to her Jejunum, but still get as much food into her stomach as possible to keep it active and keep beneficial flora alive.

An NG tube that leads to her Jejunum also does not work for Millie's health needs. An NG tube requires Millie to sit upright or she gets nauseous and can't tolerate food intake. But Millie cannot sit upright due to Orthostatic Intolerance, she needs to lay down flat. The point here is to give Millie the medical treatment she needs to get food. We are talking about food here, a basic human necessity. An NG tube to her stomach or Jejunum does not work, Millie needs a PEJ tube to get nutrition to stay alive.

I have had a PEJ tube here at home for 7 years now and me and my caregivers have had no trouble maintaining it. We clean it regularly and are careful not to pull on it. That's it, it's a

simple medical device. It is perfectly fine for Millie to have a PEJ tube at home, she does not need hospital monitoring to have a simple PEJ tube. I have had zero infections or issues of any kind and I don't even notice the PEJ tube is there most of the time.

The Royal Lancaster Infirmary is also causing Millie general harm to her overall health by keeping her in the hospital unnecessarily and not letting her mother see her to make sure her needs are met. As I have explained, ME/CFS patients have a reduced energy limit. When ME/CFS becomes severe like in my case and Millie's case, this limit becomes so low that just small amounts of mental exertion forces the brain to use more energy than is available and the patient gets worse. Being stuck in a hospital full of Doctors and Nurses who do not understand her illness is a worst case scenario because she is being constantly subjected to way too much mental stimulus and is constantly way over her energy limits. Her health is already going to dramatically deteriorate from the damage you have already done to her, the question now is how much worse you are going to make Millie. Will you stop before she is so severe she cannot recover?

A 27 year old severe ME/CFS patient in the UK named Maeve Boothby-O'Neill recently died shortly after being held at a UK hospital because of the exact same way you are treating Millie. Death from malpractice is not something to take trivially. Millie will die because of your actions if you do not change course immediately.

The Royal Lancaster Infirmary needs to read the NICE guidelines about how to treat ME/CFS patients, and follow them. A lot of well educated researchers about ME/CFS wrote the NICE guidelines - people who understand the illness Millie has - and they need to be followed or you are intentionally disregarding her medical needs and making her health condition worse.

This is ENTIRELY the Royal Lancaster Infirmary's fault. Having a PEJ tube put in is a very simple, routine, 1 hour procedure. There isn't even any need to keep her overnight. If you chose to, you could install a feeding tube right now, and have Millie home this evening where she would be back in a safe environment able to limit her exposure to stimulus and now able to get all the nutrition and calories she needs without risking her stomach getting worse.

The Royal Lancaster Infirmary has a choice. You can do your job and perform a simple, necessary medical procedure for a sick 18 year old girl, or you can refuse and cause permanent harm to Millie or kill her. And that death will be 100% your fault.

The entire world is watching you make this decision and will hold YOU accountable for what happens to Millie.

Millie needs a PEJ feeding tube TODAY. Make the right decision and do the simple procedure for this poor sick girl and then let her go home with her loving mother.

Signed,  
Whitney Dafoe  
Severe ME/CFS patient  
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