

# What really matters to patients?

Liz Taylor

# Introduction

- \* About me

# Facebook Extracts

So, quick update on Mum. She was admitted to hospital again last Friday night/Saturday morning, the same issue as previously and expecting to be home again after a couple of days. However, she didn't respond to the usual treatment and underwent surgery to un-bend her bowel (which was folded over like a hose pipe) and correct her hernia at the time same (which had exacerbated the bowel issue). She is recovering well although has ups and downs, to be expected and is expected to remain in hospital until after the weekend.

OK. Update on Mum. She's not brilliant but she's ok. She's starting to eat a little food now but is very bloated and feels very uncomfortable all the time, which is horrid, but she's very impatient and wants to be better and running around NOW. She was pretty positive yesterday but miserable the day before – it's harder to get her to do the things she should be doing when she's miserable, she doesn't feel like it.

Doctor thinks that Mum has an obstruction, nothing passing through since the operation. Will keep you all updated

# Facebook Extracts

- \* Mum was improving a little bit every day and then Dad rang me at 2.00 a.m. to tell me that she's gone into theatre for emergency surgery. She's now in intensive care and will remain in an induced sleep for the next 48 hours at least. She's on 3 different antibiotics to fight some infections, including septicemia. She's also had a lot of bowel removed as it was highly infected. This will probably mean that she'll need assistance in eating and feeding in the future because she no longer has enough bowel to extract nutrition from food, which means intravenously overnight, then she can eat small things in the day to keep the hunger pangs at bay.
- \* If she doesn't respond to the antibiotics over the next 2 days then she'll need to be kept asleep for a day or 2 longer, which then runs the risk of her organs thinking that she doesn't need them and shutting down. The kidneys are usually first and they were hinting at dialysis, although I think that's a worst-case scenario.

# Facebook Extracts

- \* She looks awful, all swollen and waxy but breathing (although not by herself – she's incubated so the machines are breathing for her). It's not looking good to be honest.
- \* Wow, Mums awake. Dad went in yesterday and she had started to come round and by the time we went in at 6.00 she was wide-awake and talking (they had taken the respirator tube out at about 2.00 to see if she could breathe on her own). She has a little nebulizer to give her an oxygen boots. She is responding really well to the (now 4) antibiotics and fluids and is doing really well. Not out of danger by a long way, but she's moved from ITU to High Dependency. They weren't going to bring her around till Monday at least, but she's doing so well.
- \* Mum is getting a little better each day and looks A LOT more like herself already. She has started to eat and that has made her feel hungry so she's eating better each meal. She will have to have an IV food line overnight, every night which will give her the nutrients she requires so that what she eats in the day is just to keep hunger at bay. She has said that she'd like to see people other than Dad and myself, but please don't all rush at once. She has her phone now, so best to message her.

# Facebook Extracts

- \* It's been a while since our last update and a lot has happened in the meantime. Mum was doing really well, getting a bit stronger each day and doing more physio too, getting ready to come home. The nutrition team are very happy with her progress food-wise so are now not looking at IV nutrients for her, but some supplements to a normal diet instead, as she's doing so well.
- \* She moved to Chirk Community Hospital which has no Doctors on site, it's more rehabilitation through diet and physio – she needs to improve her leg strength so that she can manage stairs by herself then she can come home. I reckoned she'd be able to come home in a week or so.
- \* Last night I got a call from Dad to tell me that she's gone back to the Maelor Hospital under blue lights as she'd collapsed in the afternoon and they suspected a blood clot. They found several clots on her lungs which, if left unchecked, would have killed her. They have some super strength anti coagulant that they keep for extreme cases and this is what they wanted to give her a big dose of, but as she has so recently had surgery there was a huge risk to her of internal bleeding which she has a weak structure.

# Facebook Extracts

- \* However, before you all start ringing me in panic, she had the anti coagulant last night and was monitored every 15 minutes for signs of hemorrhaging in the brain or internally and also checking her surgical wound, and it all looks ok...She is a pretty tough old bird.
- \* Her heart rate went p to 180bpm at one point, so she is now on the cardiac care unit, but doing really, really well and most of her obs levels have normalized.

# Facebook Extracts

- \* That's where we are at. I'm sick of the rollercoaster of making progress to nearly losing her, doing really well and talking of sending her home to nearly losing her again...It's never ending but she fights another day
- \* Mum's brilliant. We went to see her today. Her medical health is stabilized, great news. Her physio is taking a bit longer but that's because she's had yet another month in bed. She walked out of the ward and along a bit of corridor today, one hand on the Zimmer frame and one hand holding Ben's,. It was really sweet – she said I'm going to show you how I can walk and he said "I want to go too" and off he went, took her hand and started jabbering away to her, little nonsense wittering....Dad hadn't told her we were coming today, it was a total surprise and she was thrilled. She had a semi permanent feed point fitted on Friday – the op went well and it's nowhere near as obvious as I thought it would be, plus it will be even less obvious than it is now when she comes home as it won't be covered in big white plasters.

# Communications

**Call Centres**

**Ongoing support**

**Milestones**

**Mentoring**

**United**

**Needs**

**Incidents**

**Confidence**

**Answers**

**Training**

**Individuality**

**Organising**

**Nurture**

**Support**

# The Chris Evans Breakfast Show



# Travel

- \* And, fly for the first time in years with all my medication, ancillaries, tablets & feeds. And this is with a thank you to Calea, without their continued support and excellent training I would have had to have found someone to connect & disconnect me whilst in Guernsey. So thank you Calea. However, you can't just 'jump' on a plane or in a car, this is what I needed to take with me for 5 days away and this doesn't include the tpn bags for overnight or, more importantly any clothes.

