

Taking Time

A brainstrust story for families and friends

Written and illustrated by Shelley Marsh

Rebecca's mum had a brain tumour. The doctors decided to operate and so Rebecca's mum had an operation which lasted a whole day. That was nearly a year ago and today Rebecca's mum is having a check- up at the hospital. Her mum will have an MRI scan to check her brain is recovering and there are no more tumours. The MRI (Magnetic Resonance Imaging) is a way of taking pictures inside the body. The MRI doesn't hurt but it is a very noisy machine, Rebecca's mum says.

While Rebecca's mum is having her scan, one of the nurses arranged for Rebecca and her cousin Danny to visit the neurology unit where Rebecca's mum stayed after her operation.

'The word neurological is something to do with the brain so I think a neurological unit must be for people who have had brain surgery or maybe an injury to their brain,' Danny told Rebecca.

'Is that right?' asked Rebecca

'Wait a minute, I've got a good explanation of it on my phone. Let's look it up! It says, 'The word 'neurological' comes from the word neurology - the branch of medicine that deals with problems affecting the nervous system.'

'I think that sounds complicated,' Rebecca added, 'My mum told me that some people are born with neurological problems and some people, like my mum, have a brain injury or get an illness that needs treatment.'

'Yep, I know all that.'" said Danny slowly.

Rebecca laughed to herself because Danny always seems to think he knows everything.

'I would like to be a neurology doctor when I'm older.' Danny said.

'A neurologist or a neurosurgeon?' Rebecca asked.



'My mum had both a neurologist and a neurosurgical team when she had a brain tumour. It was the neurosurgical team that operated on my mum though.'

'Really?' Danny said, in a surprised voice. 'I knew your mum had a brain tumour but I didn't realise she had more than one doctor for it...'

'Yes, my mum had a lot of people who helped her. That's why I wanted to come and visit the ward she was on today. It's not very common for children to be given a tour of the

neurology unit so you had better be on your best behaviour, Danny! I know you're my cousin but we know you are a bit cheeky.' Rebecca said laughing.

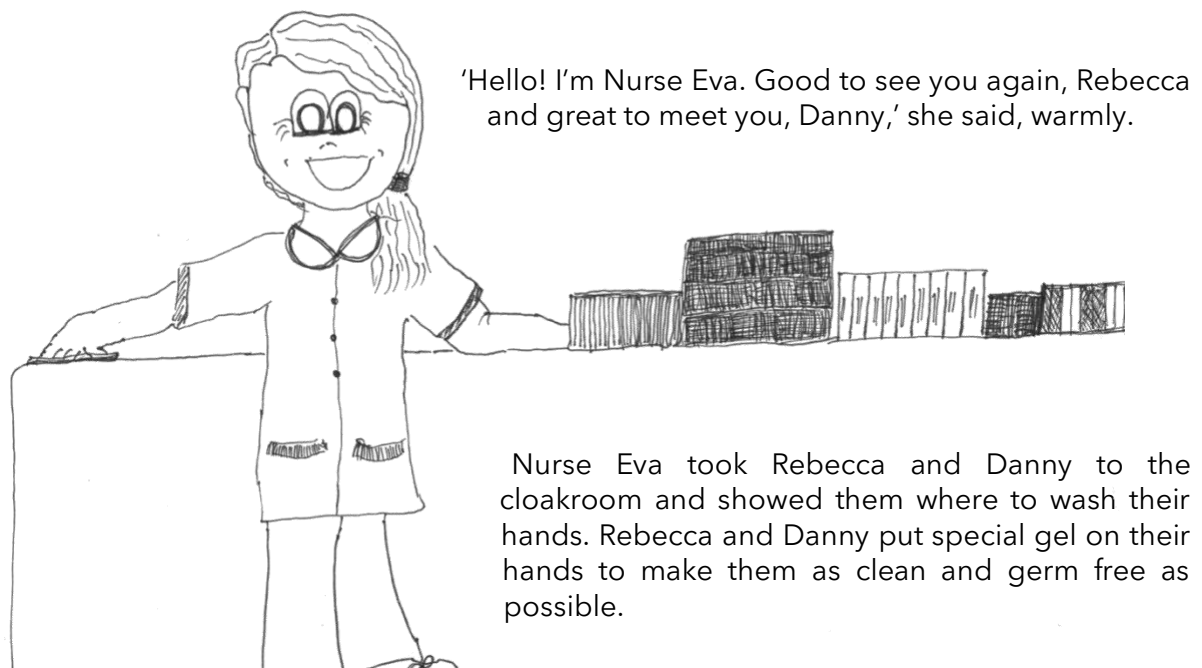
Danny giggled in response. 'I promise to be well behaved.' he said.

Rebecca and Danny pressed the buzzer outside the unit. No one answered. They pressed again.

'What's taking them so long to let us in?' Danny asked.

'Well, I guess everyone is busy taking care of the patients here. If you want to be a neurosurgeon, you are going to have to learn to be patient, Danny.'

Just as Rebecca said that, the door was opened by a nurse.



Nurse Eva took Rebecca and Danny to the cloakroom and showed them where to wash their hands. Rebecca and Danny put special gel on their hands to make them as clean and germ free as possible.

'This helps lower the spread of infection,' said Danny, as he spread the gel on his hands.

'It doesn't smell so great though,' said Rebecca, wrinkling up her nose.

Nurse Eva laughed and took the children through into the unit. There was a large reception area, called a nurses' station which had a few computers, some telephones and lots of papers. The doctors and nurses used that area as a base where they sat together on the unit.

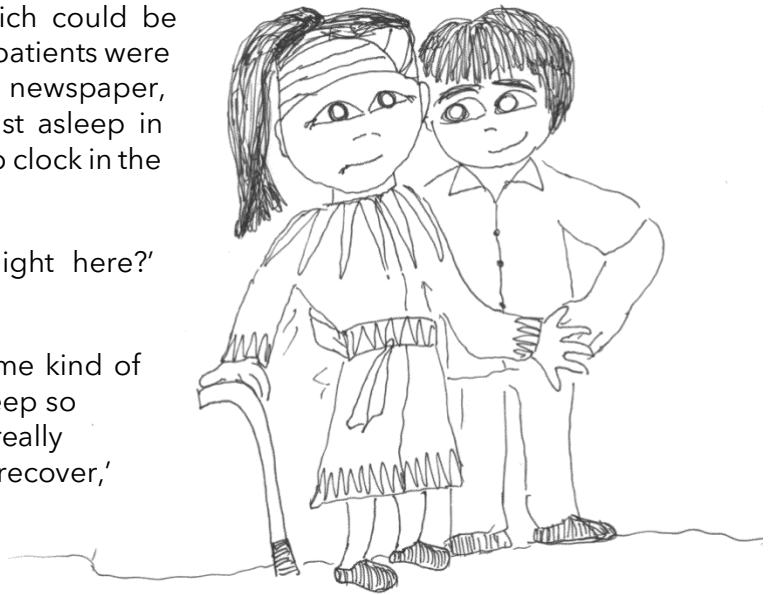
'It's a bit weird to call it a station if it doesn't have any trains...' Danny muttered to Rebecca.

There were a number of different spaces on the unit and the unit was very busy. There were some smaller rooms which Nurse Eva called cubicles and some patients were in a larger, open ward area, divided into more private spaces by curtains. The curtains were made of blue material and each space had a bed and a chair next to it. Rebecca and Danny found it hard not to stare at the beds and chairs, with patients in them.

Some patient had big bandages around their heads, some had large scars which could be seen from quite a distance. Some patients were sitting in their chairs, reading the newspaper, and some others seems to be fast asleep in their beds - even though it was 11 o'clock in the morning.

'Don't people go to sleep at night here?' Rebecca asked.

'Lots of our patients have had some kind of brain surgery and they need to sleep so they feel better. Sleep is really important in helping the brain to recover,' said Nurse Eva 'so we try to encourage our patients to get as much sleep as they can.'



'That makes sense,' Rebecca said, 'having brain surgery takes a long time and must be quite hard for people to get over. My mum had her brain tumour removed ages ago and she still needs to sleep a lot. She says she's more than tired, she's fatigued.'

'Fatigue is definitely something people who have tumours or have had their tumours removed need to manage,' Nurse Eva agreed 'and sleep is a very good way of healing.'

'I'm going to take some staples out of a patient's head, would you like to come and watch? Mrs Marco, she's the patient, said she was happy for you to watch.'

'We'd love to!' said Danny

'Errr... I think I'll wait by the nurses' station if that's ok,' Rebecca said, 'I'm not sure that's something I want to see....'

Danny was amazed at how Nurse Eva removed the staples from Mrs Marco's head.

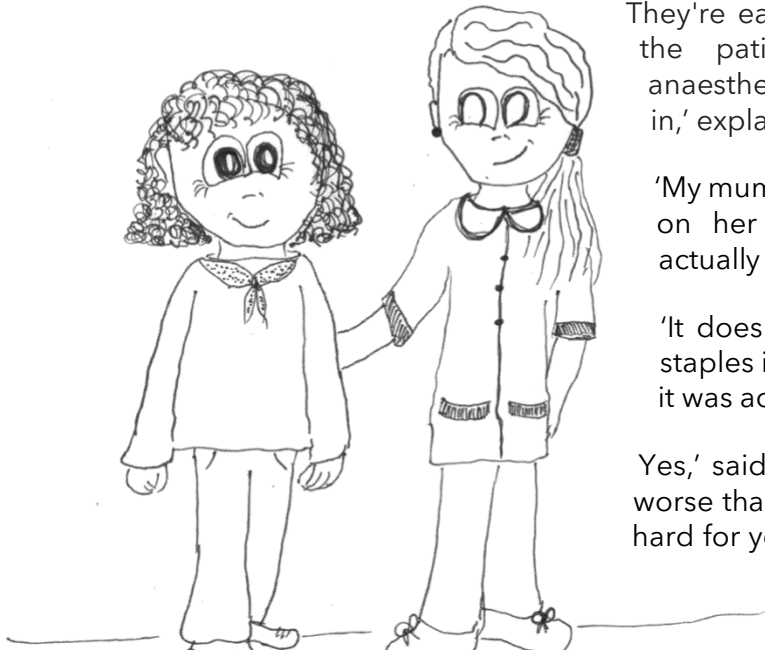
'You were super brave about that!' Danny said to Mrs Marco.

'It really didn't hurt me' Mrs Marco told Danny. 'Though I have been stressing that it would hurt and I did feel very nervous about it. Nurse Eva is marvellous.' Mrs Marco said, smiling with relief.

'Nurse Eva, why did Mrs Marco have staples in her head? I thought people had stitches after an operation, don't they?'

Rebecca came over to hear Nurse Eva's explanation of medical staples.

'For some operations, surgeons put in stitches but for the type of operation our surgeons do here, most of our surgeons close wounds with staples. They are medical staples, not ones you would use to put papers together of course, those are very different. Our doctors use big, medical staples to quickly close a wound with minimal damage.'



They're easier to remove than stitches, and the patient spends less time under anaesthetic because they are quicker to put in,' explained Nurse Eva.

'My mum had some staples in her head and on her forehead too. It was horrible actually and I really didn't like it.'

'It does sound awful having big, medical staples in our head. But Mrs Marco did say it was actually ok.' Danny said.

Yes,' said Nurse Eva, 'I think staples sound worse than they are. Rebecca, I know it was hard for you to watch your mum go through surgery and her recovery at home too.

It isn't easy at all and you can always talk to someone at braintrust if you want to do that. It is important to remember that people are there to listen and can help you with all the feelings that get mixed up sometimes. Sometimes it's helpful to talk to someone who knows how to listen and give support. People at braintrust know exactly how to do that.'

Rebecca felt a bit surprised by what Nurse Eva had said because she didn't think she really needed to speak to anyone but she thought she might chat that through with her mum later.

'I think there is a lot to see here and a lot to learn if you are going to become a neuro doctor in the future, Danny. Come on, let's go and learn more.'

Nurse Eva nodded her head and said, 'Do ask me lots of questions so that you can find out all about our work here.'

Nurse Eva showed the children some of the equipment that the medical team use on the neurology ward. She showed Rebecca and Danny lots of machines. Nurse Eva explained 'They all do different things and some of them make some very odd noises'.

'Is it the oxygen, the special air that helps the patient to breathe more easily, that makes the noise?' asked Rebecca.

'Not quite,' answered Nurse Eva. 'Try this one on.' she said, and she put a mask over Rebecca's nose and mouth for her to try out. The mask didn't make a noise and Rebecca said it actually felt quite comfortable.

'Do people need to have oxygen when they go home after having brain surgery?' Danny asked.

'Most people don't, no.' said Nurse Eva.

'My mum just felt very anxious about things when she came home. She was really nervous about the scan she is having today. There are a whole load of things that my mum is more nervous about now than before she had her brain surgery...' Rebecca added.

'Some people are quite anxious, which I completely understand of course and for some of our patients, their behaviour and even their personality can be quite different to how they were before they had their tumour or brain surgery,' Nurse Eva replied.

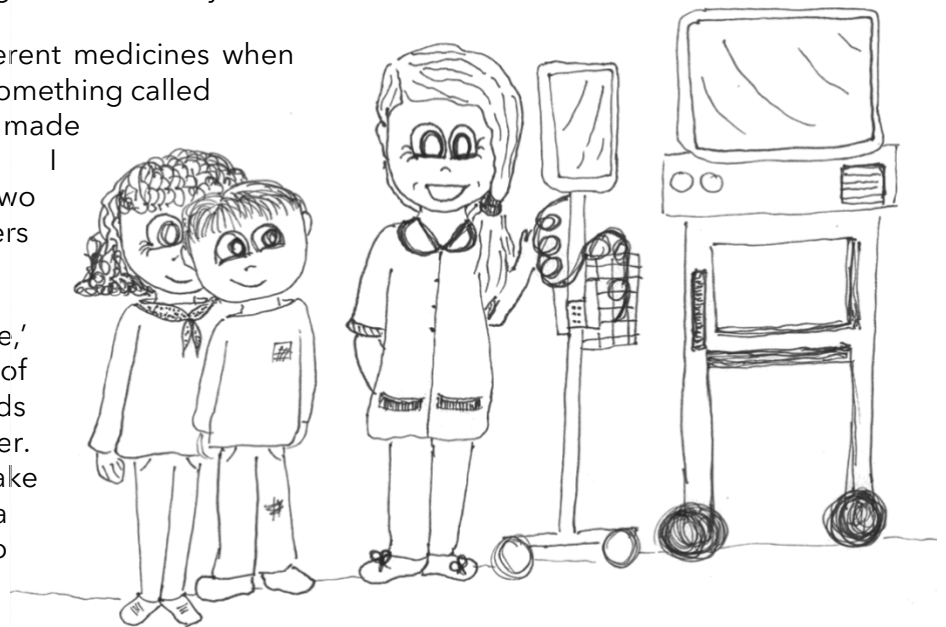
'My mum has been worried that her hair has fallen out. Some days we laugh about it and she says I should call her my egghead mum, but some days I know my mum is really upset about that too.'

'I think that is very normal, Rebecca, having a brain tumour and then going through surgery is a huge thing, you know. Some people's hair falls out because of the treatments or medicines our patients need to have.'

'Does your mum have to take a lot of medicine? Do people who have had surgery need to have medicines when they go home?' Danny asked.

'My mum had a lot of different medicines when she came home. She had something called steroids and she said they made her very, very hungry. I remember that she had two breakfasts and three suppers sometimes!'

'That makes sense to me,' laughed Nurse Eva 'most of our patients will have steroids to help them get better. Some people have to take those medicines for quite a while, even after they go home from hospital'



'Yes,' said Rebecca, 'like I said, that happened to my Mum.'

When our patients are here in hospital, we check their blood pressure and their oxygen levels using different machines. 'There are a lot of machines that you need to understand when you're a doctor or a nurse,' said Nurse Eva.

'We also give our patients different medication once they have had surgery, to prevent infection and help them to feel well.'

Rebecca and Danny tried the different machines. They all made different beeping sounds.

'We also need to ask our patients lots of questions so we can check if our patients are sleepy or feeling more alert and awake. That gives us a good indication of how their brains are recovering, especially after brain surgery because we can't just have a quick peek into someone's brain can we?'

'No, you can't, because the skull is around the brain, protecting it, so you need to find other ways to understand a patient's recovery I guess,' said Danny.

Nurse Eva asked, 'Are you two hungry, do you want to go and get a snack?'

Danny smiled and Rebecca nodded. Nurse Eva took them to the relatives' room to sit down and have a break from all the new things they had seen so far.

'It's quite scary here in some ways, isn't it?' said Danny, as he took a big gulp of apple juice.

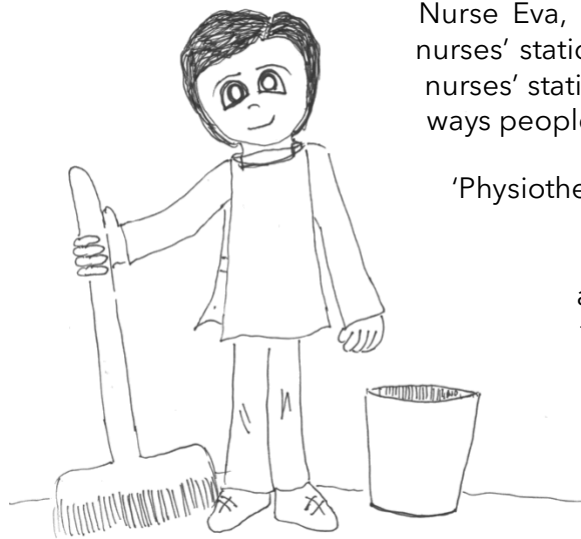
'It's very different from anything I have ever seen before really. I always wanted to see my mum when she was here in hospital after her surgery but I also didn't like being here. It was a bit confusing really,' said Rebecca, nibbling at a biscuit.

Nurse Eva nodded, 'Some patients know they are going to have surgery but some don't so it can all be a bit of a shock our patients and their families.'

Rebecca and Danny finished up their snacks. Danny thought for a moment as he ate up his last mouthful.

'It must have been hard for you and for your mum, Rebecca,' said Danny, 'I haven't really thought about that before. I just liked it that you came to stay with us for a bit...'

Rebecca shrugged her shoulders. 'It was nice being at your house, Danny but I did miss my mum a lot and I did worry about her operation...'



Nurse Eva, Rebecca and Danny went back to the main nurses' station. There were lots of different people at the nurses' station. Rebecca was surprised to learn about the ways people needed help on the neurology unit.

'Physiotherapists and occupational therapists help our patients after surgery,' Nurse Eva explained, 'ophthalmologist, check people's sight, audiologists check people's hearing. In our team we have people who help keep the hospital clean and tidy and others who do administration. Everyone who works here helps our patients to get better.'

'I can see that some people need help in moving about, is that something that happens after brain surgery?' Danny asked.

'My mum couldn't really stand up well after her surgery because she couldn't balance. Do other people have that too, Nurse Eva?' asked Rebecca.

Nurse Eva replied, 'Yes, some patients can't balance so well, some patients have a whole range of other physical changes before or after brain surgery. We try and help here on the unit before people go home. Once our patients go home, most will still need to do different types of exercises to recover. It's hard work for some of our patients when they get home.' Nurse Eva responded.

It had been a long day and Rebecca and Danny were ready to go. They thanked Nurse Eva for all the questions she had answered and said they both wanted to learn even more as they got older.

'I hope you have found it interesting, visiting the neurology unit today,' said Nurse Eva.

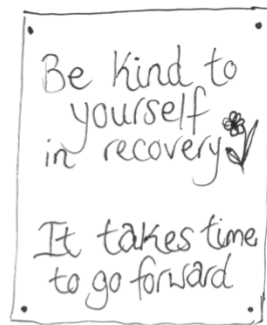
'Thank you so much, Nurse Eva. You do an amazing job. You and the team were so good at caring for my mum. Danny, when you are a doctor, I hope you will get to work with Nurse Eva.' Rebecca said.

'The neurological unit is a very unusual place. I am glad that we have met so many people who have had such a lot of training and skill. They do the best they can to help patients who are unwell to get better.'

'Thank you, Nurse Eva. It has been fascinating to see how all those machines help your patients. I hope that when I get to be a doctor, I will be able to remember which ones do what.' Danny added.

'It was great to meet you both. I'm going to go back to a ward round now, that's a meeting with all the team to see how each patient is getting on. Take care of yourselves and love to your Mum, Rebecca.'

Nurse Eva went back to the unit and carried on working with the other staff in her team, caring for the patients.



'You know, Rebecca,' Danny said, 'it wasn't easy for your mum being in the neurological unit but with lovely nurses like Nurse Eva caring for the patients there, it was a bit easier.'

'I think you're right, Danny. I hope that everyone, in every hospital, gets better soon.'

'Your mum still needs to be a very patient patient! Recovering from such big surgery takes a long time.' Danny said to Rebecca as they walked to the main reception to meet Rebecca's mum.

Rebecca saw a poster on the hospital wall and read it aloud: **'Be kind to yourself in your recovery. It takes time to go forward.'**

'I think that is the most important bit to remember.

Sometimes I just want my mum to be exactly how she was before the annoying tumour and the whole operation that went with it. I need to remind my mum to be kind to herself as she gets better. We can never go backwards and it just takes time to go forward.'

