




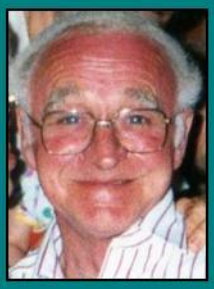









The Patients Association

listening to patients
speaking up for change

Listen to patients, Speak up for change

2. Anne Robson

By her youngest daughter, Liz Pryor

My mother was a gentle natured woman whose life revolved around her family. She was very proud of her five children, and adored her grandchildren. My parents had a very happy marriage and when my father died in 1989, Mum struggled to come to terms with life on her own. Even though she was very lonely she never complained. She enjoyed her dogs and her garden and was always careful with her appearance.

Mum had had a number of falls, which led to her having to have pins put in her hip last year. Unfortunately, the pain in her hip reduced her mobility dramatically, and after having the pins removed in August 2009, she was unable to mobilise at all, and therefore could no longer be looked after by a carer at home. She moved to a care home, where she lived until she died in January 2010. In the weeks before she was admitted to West Suffolk Hospital, she had been in particularly good spirits. She had just spent her first Christmas in the nursing home, a prospect that she was not looking forward to. However, she very much enjoyed herself, and was really beginning to settle down and make the most of life in residential care. The nursing staff were very fond of her, she had a naughty sense of humour and really enjoyed regaling them with stories about the family and her late husband. All the staff at the care home were extremely kind and welcoming to Mum and to us, and have been enormously supportive during this difficult time.

Early on the morning of Saturday 16th January 2010, Mum fell out of bed. Unfortunately she had always refused to have sides on her bed. I met Mum in the West Suffolk Hospital A&E department at approximately 9am that day - she had been there for about an hour and a half.

The staff there didn't know anything about her. They didn't know her age, where she lived, whether she could walk etc. She was very confused. She had had x-rays and been seen by the registrar on duty. It was a difficult diagnosis as they did not at this stage have any x-rays from her previous surgery to compare the new ones with. She had not been given anything to drink and was very thirsty. During the course of the day, Mum was seen by a succession of doctors, some orthopaedics and some on-duty A&E doctors. They all spoke very quickly and she couldn't understand them. They did not make any concession whatsoever for this. However, during the course of the day, I think the shock of what had happened wore off a little, and we were able to chat and laugh about what was going on around us, and she happily sat up in bed and drank coffee and ate biscuits. The registrar then came and said that Mum had not broken anything, and that she would discharge her that afternoon. Within half an hour Mum was seen by one of the orthopaedic doctors and he said that he was concerned about the angle of Mum's right leg. (her feet made a right angle – i.e. her right heel was touching the instep of her left foot). Then another doctor came in, and said that they had decided that they would operate on Sunday morning, performing a partial hip replacement – even though they had still not seen the xrays from Ipswich.

One of the doctors completed the Medical Admission notes in the A&E Department. I was present when Mum was given what they call a Mini-mental test. This asks questions such as what is your age, what date was WW1, who is the Queen, can you count backwards from 10 - 1 etc. Mum found this test hard, and I remember feeling quite concerned that she only managed to answer three of the ten questions correctly. I was very surprised to see, when I received the Medical Records, that she was given 10/10 on her notes. What is the point of the test if the results are wrongly recorded? She had some more x-rays taken and then went up to the ward.

On arrival at the ward I was told to wait outside, having been assured by the nurse who came with us from A&E that I would be allowed to accompany mum on to the ward. I waited for about half an hour, and was then told, very briskly, that it was a "closed ward" and I would not be allowed in. The hospital had norovirus, and some wards were closed in order to try and reduce the spread of infection. I tried to explain that this would be extremely disconcerting for Mum as she knew I was there, and that I was very upset that the bed had been pushed through the doors with absolutely no thought towards my mother or myself. I was walking behind the bed. It would have taken no time to say a quick goodbye before they went into the ward, - and then their infection control would have been adhered to. As it was, I explained how upset this would make mum (and me) and the nurse conceded that I could go in quickly to say goodbye. Had I been less assertive, I would not have been able to say what I now know was my last goodbye to my mother.

This was the last time I saw my mother though I visited the hospital and spoke to her on the phone. All week I had to tell myself that everything would be ok, that of course the hospital were looking after her, despite the fact that over the phone and from talking to my sisters I knew she was deteriorating.

On Sunday morning, I called and spoke to staff on the ward and was told that no operation was going to happen, but that they were monitoring her pain - she was "not fit for theatre". We now know that this was incorrect. We requested Mum's medical notes after she died, and from them can see that the nurse had read them wrongly. The notes clearly state that Mum was seen by the

Orthopaedic Consultant at 8am that morning. He had her old x-rays from Ipswich, and her hip was not fractured. What the notes had actually said was "not for theatre", which is where the first major error occurred. Had we known Mum's hip was not fractured as early as Sunday, she could have been discharged before she got an upset tummy. As it was we were not given this vital information until the Tuesday afternoon, two days later - and by this time Mum had an upset tummy and was in an isolation room.

My sister Catherine went to the ward in the evening and was allowed onto the "Closed Ward" to see Mum. Catherine told me that Mum's nighty was wet up to her armpits. When Catherine asked the nurse if someone could come and sort it out the nurse was keen to say she had checked only half an hour ago. Catherine and I agreed that one wee would not make you wet to your armpits so goodness knows how long she had been like that. We also requested that the hospital use the "pull-up" pads that Mum used at home for her incontinence. They refused, saying that they only use the flat pads, as they are easier to change, and we had to take Mum's usual pads away. Essentially Mum was expected to go to the loo in her bed. The indignity of this makes me cry to this day.

On Monday I spoke to the ward sister again, who said Mum was comfortable, that she did have a fracture, but that she remained "not fit for theatre", so they were not going to operate. Once again when I asked why she was "not fit for theatre" I was told that they didn't have any further information on this (we know now that she had no further information because there wasn't any - her hip was NOT fractured, but yet again the notes were read wrongly - or not at all). She said that when sent home she would be bedridden, as her hip was very painful. I asked whether it was normal to send a patient home with a fractured hip. She proceeded to tell me.... "When they do this – we quite often sent them home and their quality of life is not good, but when they get that infirm it really is the only course of action open to us". I stopped her and asked her to remember that we were discussing "my Mother", and please could she not talk about Mum in that way. I found it very upsetting.

The conversation with the sister made me feel extremely annoyed so I tried to speak to someone in authority to find out exactly what was happening as the nursing staff did not seem to know. The reception informed me that I couldn't speak to a consultant or a doctor, but that I should speak to the beds manager who would be able to help me (which I thought was quite strange). I did speak to the beds manager and she told me that she would do all she could to help me find out what exactly was going on - she said she is very busy and if she couldn't help she would make sure someone else did, and that they would stay in touch with me. She seemed to be very concerned and helpful. I didn't hear back from her.

On Tuesday I rang the ward and spoke to the staff nurse. She said Mum had been moved to a side room during the night as she had had an "episode" of diarrhoea and they were worried that she had contracted norovirus. I asked them to explain the move clearly to Mum, and also to explain why she wasn't having any visitors. On the ward we had arranged for Mum to have a telephone - this was our only form of communication. We had put £10 credit on it and when I asked about this and what we should do about transferring it to the side room, I was told that it was just bad luck - that she would get a phone eventually in the side room, but that they couldn't transfer the credit. The hospital has

since assured us that this is not their policy. The credit goes with the patient, not with the phone. Another example of management and front line staff doing and saying different things.

We were all so worried about Mum so Catherine and I went to hospital. We talked to the Staff Nurse, who said Mum was in good order and did not have a fracture, but that she had had an upset tummy again, and they couldn't discharge her until she had been free of this for at least 48 hours. We asked to see her, and were told we couldn't because of the norovirus. We really were as insistent as we felt we could be - even saying that we would be happy to wear protective clothing, but still we were refused. I know hospitals must take infection control seriously, but when it is your mother sick on a ward that you are worried about it is very difficult. If we had felt reassured about the quality of care she was receiving then we would have been more able to accept these rules, but it is a very different matter when you are worried that your relative is not being looked after properly. Knowing she was a matter of metres away on the other side of a few doors but that we could not see her, hug her, reassure her and ourselves. It was heartbreaking.

We realised the staff were not going to allow us to see Mum, and understood why, and so we gave a nurse a bag of goodies for her, including a card which I had written in to reassure her, explaining what was happening. I also included some drinks as every time one of us had spoken to her, she said she was terribly thirsty and couldn't reach her drink. I was assured by the nurse that she would go into Mum and open the card and read it to her, and make sure she could reach her drink at all times.

Wednesday did not bring any good news. Mum still had an upset tummy and she still had no phone in the side room, so we still couldn't speak to her. On Thursday I spoke to the ward again to get an update. They said the tummy bug seemed to be receding and that mum was "bright as a button" - which I thought a rather odd turn of phrase. I tried to ring Mum on the phone that had finally been provided for her in the side room. I continually got no answer so in the end I called the nurse's station and asked for someone to go in and help Mum answer it. When I spoke to her she sounded dreadful, very dry mouthed, and weak. She was openly crying, saying that she was unbelievably thirsty, and that she wasn't being treated very well. She told me that at a meal time that day, she had been woken by two nurses getting hold of her arms and hauling her up the bed, without first waking her up from a deep sleep. She said she told them that while she had been asleep she had unfortunately wet the bed and they said that she'd have to wait as they were busy. She was expected to sit in a wet bed and eat her lunch - on her own, without any help. She said to me that she was too weak to eat anything and all she wanted was a drink, but she couldn't open the bottle, as "my hands don't work and I'm so sleepy but no-one will tell me what's the matter with me". By the end of the conversation I could tell that just talking to me had exhausted her. Mum never complained - she was the bravest person I have ever met - she really really must have been desperate to have been telling me these things.

Not surprisingly, I was very upset after that phone call and so I rang the Sister back. She said that her nurses would never treat a patient in the way Mum has described, but that she would go in and see Mum and make sure she had a drink and was comfortable. She also assured me that she would explain to Mum what was happening.

On Friday I rang the ward. Again I was told Mum was much better, and in good spirits. That day Mum was moved back to the main ward. I still can't understand why this happened, as we had been repeatedly told that she needed to be free from diarrhoea for at least 48 hours (some told us 72

hours) before she could be moved. From the medical notes it is clear that mum still had diarrhoea when they moved her. When you haven't been allowed to see your own mother because the staff are apparently so concerned about infection control, and then they do things completely contrary to the rules, it can be hugely frustrating and difficult to understand.

Catherine went to the hospital on Friday and was allowed onto the "closed" ward. She was shocked at how Mum had deteriorated. She was very lethargic and seemed confused. She was very dry in her mouth and extremely thirsty. Mum loved ginger beer, so Catherine poured her some and she drank two glasses through a straw, with help. While she was there the on duty doctor did a ward round. He did not introduce himself, spoke quickly from the end of the bed and made no attempt to check that he was being understood. He said that she would not be discharged until at least Tuesday as he was worried about her upset tummy, and wanted the gastric team to look at her. Catherine asked whether Mum could be put on a saline drip as she was concerned that Mum was very dehydrated. He said that they would not do that as it was invasive and she was perfectly capable of drinking herself. We knew this was not the case. She needed help, and she wasn't getting it.

Catherine was also appalled that the basic personal hygiene that one would expect from nursing staff had not been carried out. She said Mum told her that she had not cleaned her teeth all week, in fact she couldn't as she had no money to buy toothpaste and the nurses had said they couldn't help. We would've brought some toothpaste in but no-one told us Mum needed some.

On Saturday I spoke to the ward staff at lunchtime and was told that if it wasn't a Saturday they would have discharged Mum as she was so much better. I was so pleased to hear this and glad that she must have made good progress since the day before.

I didn't realise that my sister Sally had been in to see Mum that morning and had had a chat with the on duty staff nurse who did not tell Sally that Mum could be discharged. Sally was in tears following her visit - she was utterly shocked at the state she found Mum to be in. She said that Mum was incredibly thin compared to how she had been one week before although her tummy seemed swollen, her chin was resting on her chest and her hands were curled into the shape of claws. She could only move her hands very slowly and had no control or movement in her arms. She could not grip anything. Sally said that Mum was too weak to say very much and she didn't recognise her own daughter, that she was so thirsty she drank nearly a whole can of ginger beer in one go – she didn't even attempt to hold the cup or move her head towards the straw. On the bedside table was a cold cup of Costa Coffee which Catherine had brought in the previous day, a cold cup of tea and a glass of flat Lucozade, which Catherine also brought. Sally said that there were a number of the little white paper pill cups that the nurses dispense pills in on Mum's bedside table - all with pills in them. One was dispersible paracetamol but there was no jug or glass of water for her to take it with. Sally asked the nurse what the pills were and she said "Oh dear , has she not taken them again?"and laughed. Sally said not only could Mum not take a pill on her own, she couldn't pick up her hand or move at all. How many times had this happened when we were not allowed in? Sally couldn't believe it when I told her that the Sister had said they would be happy to discharge her and Mum could go back to the nursing home - in fact had it not been a Saturday, they would have done this without us being involved, but they had no transport available at the weekend. Sally was amazed and we decided I should check that they were talking about the right patient. I double checked with

hospital staff that they had this right, and was assured that they were happy to discharge her. We checked with the nursing home that they were happy for Mum to come home (we were not aware of her continued diarrhoea and nor were the nursing home staff) and then Sally organised a private ambulance to collect Mum and take her home. They arrived at approximately 8pm. We knew mum wasn't well but we felt that at least she would get proper care at the nursing home.

When Sally went to the hospital earlier in the day, she found the bag of goodies Catherine and I had taken in on Wednesday, which included the card explaining to Mum what was going on, unopened. The nurse had not given the card to Mum and read it to her as she promised me she would. It breaks my heart that Mum never got the chance to read it before she died. I find it very hard to understand how a "nurse" can be so uncaring.

The nurses at the nursing home were appalled by Mum's condition on arrival. In fact her GP was keen for Mum to be returned to hospital. By the time my sister Sally, who was there, had contacted us, the nurses told her that Mum was imminently going to die, and we decided that she should stay where she was. At this point Mum was drinking from a small sponge, unable to speak, and Sally had to run her finger around the inside of Mum's mouth to separate her teeth from her gums.

She died at 3.35 am.

During this very difficult week, I was liaising directly with the nurses at the home and was and am very grateful to them for their advice and support. The on-call GP who certified her death referred the case to the Coroner's office. A post mortem examination was carried out, which concluded death by natural causes. We were advised by her GPs that her death was not expected, and that they had been successfully treating the conditions picked up in the PM. We feel strongly that Mum was neglected in hospital and one way or another this led to her death. Mum's GP told me that an infirm lady who had difficulty mobilising was sent to hospital with a bruised hip, suspected fractured. A moribund terminal patient was sent home one week later. After discussing the situation at length with the Coroner's office, the Coroner decided he had enough evidence to open an adjournment. This is due to happen during the latter part of this year, or early 2011.

Since this ghastly week in January, I have worked very hard trying to get some sort of explanation from West Suffolk Hospital. All our family agreed that we did not want to take legal action, that what we wanted was to prevent this happening to anyone else, in any way that we could. I requested the medical notes, and found a number of issues and inaccuracies that cause great concern. We noticed that there wasn't a fluid balance chart in the notes and asked for this. At first we were told that it wasn't a "legal document" so wasn't "filed in medical notes". When we questioned this, they then said it was just because they hadn't kept one because they didn't need to.

We had a meeting with West Suffolk Hospital in March 2010. Unfortunately they were unable to satisfactorily answer our questions. In fact, we found their manner patronising at the very least. They insist that Mum was "fit for discharge". They do not accept that she deteriorated at all during her one week stay in hospital - even though we were telling them whilst she was there, and even though she died only a matter of hours after arriving home.

The minutes taken during our meeting were in parts an incorrect account of what was said. One example of this was that I had asked the Matron if I would be allowed to go around the wards and

see for myself that her promises that the standard of care was excellent were correct, and she agreed, stating she would be proud to do that. In the meeting minutes we received it said that it was agreed that I couldn't visit the wards for patient confidentiality reasons. A completely inaccurate representation of what was said.

We have another meeting arranged with the new Chief Executive of West Suffolk Hospital and with Mum's consultant. The points we have put to them, and are looking to have answered are as follows:- My family and her Doctor all feel strongly that the issue of Mum's rapid deterioration in the care of West Suffolk Hospital has not been properly addressed. She was admitted on 16th January as an elderly lady with a bruised hip. She was discharged a moribund, terminal patient. In the care of health professionals our mother deteriorated unnoticed. On the day she died, when she could not recognise her own daughter, or lift her head from the pillow, she was deemed fit for discharge by staff at West Suffolk Hospital.