

Dear Sir/Madam

We're writing to you to make a complaint about the lack of care, attention, compassion, and appalling communications received from the staff at Frimley Park Hospital to both our Mother and ourselves, and the circumstances that led to our Mother's recent death.

Before our Mother Mrs Gerda Ealy (who was 88) was admitted into Frimley Park Hospital, and before the media announced the abuse of the Liverpool Care Pathway, we already feared the outcome of our Mother's admission into hospital. We also expressed our concerns to the ambulance drivers and staff at A&E.

Our Mother was not terminally ill, but was elderly and as a result of this we feel it underlines the fact that she was targeted by putting her on LCP in order to hasten her death.

- Thursday 6th June 2013 - Paramedics were called to our Mother's house after our Mother had suffered a suspected loss of balance and inability to walk properly. The paramedics performed various tests on our Mother at her home which included an ECG test, checked her blood pressure, and a blood test. She was declared perfectly fit according to the South Central Ambulance Service Trust's Falls Risk Assessment - Incident Number 1031. As stated on the incident sheet, her surgery GP was to visit her house the next day.
- Friday 7th June 2013 - Dr. X from Forest End Medical Centre in Bracknell visited our Mother at her home to confirm everything was okay and suggested that the pressure sore/ulcer on her left heel, which our Mother was being treated for was probably the reason for her inability to walk properly.
- Saturday 8th June 2013 - All was well with our Mother, we visited her every day.
- Sunday 9th June 2013 - Rosalind received a phone call at 9:00am from Bracknell Forest Care Lifeline directly from our Mother's morning carer. They told me that the carer could not get into our Mother's house as our Mother was lying in front of the door which in turn blocked the carer's entry. Rosalind alerted her sister, Marilyn, of what took place and to get down to our Mother's house as soon as possible. We both had keys to gain access through her back door. Upon arrival, after gaining access to her house, we found our Mother on the floor shaken, with her hand trapped under the stair lift. The police and paramedics had already been called. We established that our Mother had dropped her house keys by the stair lift and was trying to retrieve them. When our Mother was eventually lifted up from the floor by the paramedics, she again had difficulty with walking. This time the paramedics insisted that our Mother needed to be checked over more thoroughly in hospital. We were reluctant to do this, including our Mother, as we all feared that our Mother would be put onto the LCP and would not come out alive, but the paramedics assured us that she could come home as soon as she was checked over. When Rosalind, arrived at the hospital with our Mother, the paramedics told her that they informed the A&E staff of our concerns of the LCP, and the paramedic laughed!

Our Mother was then seen by three doctors, the third was a consultant. She was given various tests, and an injection in her stomach, which we were told was standard procedure for patients to help stop blood clots. One of the three doctors in our view seemed highly incompetent as she was very clumsy and fumbled her procedures and examination of our Mother. In fact, when the consultant came in with her later, the consultant told her off for something she didn't do correctly. They never communicated with us to explain what they were doing, so we all felt very confused and concerned.

Later that day our Mother was sent up to the MAU ward for the test results, we were encouraged, but reluctant, to go home and we were told we could ring up first thing in the morning before we came in to see how her night had been, which we did.

- Monday 10th June 2013 - When we arrived at the hospital, our Mother was sitting in a chair out of bed. There was conflicting information between staff about what our Mother had been given for breakfast. One member of staff told us that she had cereal, but the sister, A, stated she had a full bowl of porridge, which in fact was a lie as our Mother told us that she had eaten very little, barely a couple of spoonfuls. Due to the confusion, we were concerned, so we asked a nurse if we could feed our Mother ourselves, and we were told very curtly by the sister, A, "We do not have relatives feeding patients on the ward". When Marilyn expressed her concern for our Mother, she told us, "It would be unfair to the other patients". Under that regime, a patient could starve! Equally we were concerned that our mother was cold, and we insisted she be put back into bed. We later spoke to a heart consultant who stated that our Mother had a heart attack and would now be in hospital for approximately the next five days.

(Over the time we were given conflicting information about the degree of severity of her heart attack by different doctors).

- Tuesday 11th June 2013/Wednesday 12th June 2013 -
(In the early morning on Tuesday 11th June 2013): We rang again, but this time, we were unable to speak to anyone on the ward. We rushed to the hospital as soon as we could. On the ward, we spoke again with the heart consultant who then said that our Mother should stay in at least another day. As she was talking with her registrar, who was beside her, she suddenly changed her mind. As our Mother had stabilised, and we were very anxious to get her back home ASAP, in the end the consultant actually told us that she could go home that day! We excitedly told our Mother "You're going home today Mum!" Where upon she said "I don't believe it, they will find something else wrong!"

The consultant prescribed our Mother with new medication, and sent the prescription down to the pharmacy ready for her to go home. We were still concerned about her food intake, so we discussed this with the staff. Suddenly, at that point we were told that there was actually a supplement milk drink set aside for her in the fridge, but no one had given it to her! We then tried to give this to our Mother. However; we were aware that our Mother was experiencing a discomfort in her stomach. The staff were unsure as to what this pain was. We suggested that due to her lack of eating properly on the ward, her diverticulitis

history, and her acute anxiety about being in hospital, we thought that she might be constipated. We were given a sachet of movicol to administer to her, which we did. This did not help, we requested more pain relief which we constantly had to chase them for. At this time an auxiliary nurse on duty saw our frustration at the lack of support from the staff, and she could empathise with us, and alerted us that our Mother cried out in agony earlier that morning! The fact that this took place caused us great concern!

We saw a Dr. Y, who was responsible for our Mother care at that time, and he told us he was going to conduct an internal examination of our Mother and an x-ray was requested. Again, it took a long time for this to take place and there was a lack of communication. The mobile x-ray finally came to the ward and eventually we were told that there was something wrong with her stomach. We believe, as a result of this, a nasal gastro tube was put down her nose, and a massive amount of black fluid came out. A nurse said at the time, "No wonder she was in such discomfort". We were naively relieved and thought this would be the end of our Mother's pain and discomfort. However; this black liquid continued to drain out of our Mother. We asked Dr. Y why a heart attack could cause a problem with her stomach like this, whereupon he replied, "Good question. It does, and you can Google it". This was a very unprofessional response in our opinion! We then brought up our fears about the LCP, and that's when he said, "She's not on the LCP". (We did Google it later as he suggested, and could only find this happened in dogs!)

Very late that night, after a CT scan, we were finally told she had a strangulated volvulus of the stomach. A consultant with a team of various people lead us to a side room and the consultant asked us, "What do you know?". This question was always asked of us whenever we spoke to anyone. We found this very disconcerting, surely they are the 'experts', shouldn't they be telling us? We felt like we were being interrogated and intimidated! The consultant stated that there was nothing they could do to rectify our Mother's twisted stomach. We asked them why they could not operate on our Mother. They told us that she wouldn't survive the operation. We asked the question, "Well, if there was no hope, isn't it worth trying?", to which he replied, "No, because she would die with an undignified death, and you wouldn't want that for your Mother, would you?". How can anyone respond to that? Marilyn was devastated and distraught. The response of the team to the conversations Marilyn was trying to have was stilted, remote, cold, and totally unresponsive, even when Marilyn struggled to find a word, they stood there, unmoved and indeed, in utter silence. This behaviour was abhorrent to us and we were stunned at this, and considering the situation our Mother was in, even more so.

During all of this our Mother was in and out of sedation, but while she was awake, she was fully aware of what was going on around her. She was very distraught, and at one point she cried out, "I don't want to die!", and couldn't understand why no one was helping her, both to make her better and to provide her food and drink. We were totally left to get on with it, and when Marilyn asked what she was meant to say to our Mother, they shrugged their shoulders and told her that, "She is not our Mother", and they walked away. At no time did they explain to our mother what was happening to her medically and why she wasn't given any food or drink.

We were very upset and angry that our fears of our Mother being deliberately harmed and put on the LCP had come about, and both of us stated so, but the medical staff did not respond to this. A nurse then told us, "Surely you'd want the best for your mum". Rosalind said, "I can't stand this. Our Mother needs us and we are going back to her bedside to be with her". The consultant came over to our Mother and lent over to her, she was half sedated. He said to her, "Mrs Ealy, you have a bad stomach, but you don't want an operation, do you?" (as if our Mother could comprehend what the alternative was, the only alternative was death!). In fact, he was actually deceiving our Mother in not explaining that to her.

As our Mother continued to be extremely agitated and with the constant noise in the ward she was in, we pressed for her to be put into a more private room/ward. All this time our Mother was 'nil by mouth', but we only over heard this stated by an auxiliary nurse, (nothing was written over the top of the bed, to notify anyone of this fact) and she was only allowed a watered sponge stick. She couldn't understand why this was and constantly wanting a proper drink in a cup. Later on, a nurse suggested that we could give her a little yogurt and tea just to give her the sensation in her mouth, we were confused. Marilyn confirmed if this would be okay with another member of staff, to which this person then replied, "Does she have this at home?"!! What on earth were we meant to deduce from that?!! Our Mother again became very distressed with her pain, in fact she said, "Goodness me! I can take pain, but not like this!". She was calling out to her Mother and Father for help, and she even thought we (her daughters) were not helping her and she couldn't believe we could be so cruel! We were with her constantly trying to comfort her, by talking to her and holding her hand. In our Mother's agony, she let go of Rosalind's hand, and she grabbed a hold of the side bed rail, trying to pull it to her, in total pain! She was crying out, "Why don't they help me?!". Rosalind softly tried to say to our Mother, "I don't know mum", whereupon, she grabbed a hold of Rosalind's scarf, pulling it, virtually strangling her. In her chronic pain and in a distraught state, she grabbed a hold of Rosalind's glasses and pulled them off of her face, such was her desperation for help and pain relief. We were constantly asking for pain relief for our mother, they couldn't get it right, and it was a long time coming.

One of the nurses came to our Mother's bedside and said that the palliative care team were on the ward and they would be coming to see us. When they arrived, the doctor of the team said, "What do you know about the Liverpool Care Pathway?". Rosalind replied to her, "All I know is that you're killing her!", and they didn't deny it. We knew as a fact that elderly vulnerable people are used as a monetary target. At no time were we consulted as a family to discuss in full about the LCP, we never gave our consent or permission by signing forms for our Mother to be put onto the LCP. We found the following statement on a website that explains about the LCP.

'How can we meet our targets? With the increasing managerial pressures to reduce bed occupancy or meet various NHS targets the LCP may well represent an opportunity to hasten death. - See more at: <http://www.care.org.uk/advocacy/end-of-life/liverpool-care-pathway/liverpool-care-pathway-controversy#sthash.VVPBXkyc.dpuf>

We also found the following statements in an article, 'Liverpool Care Pathway - Do or Die? Compare All Care hard choices made easier: Monday September 2nd 2013':

'These decisions should be made with the family based on what was happening at that time and if it was in the patients best interests. All decisions had to be documented with a clear rationale for why that decision was made.'

'It was heavily criticised in the media in 2009, and then more recently in 2012. Concerns had been raised from families that LCP had been used without their permission and had allegedly hastened the death of their loved ones, this led to audits of end of life care across Trusts in the UK.'

Baroness Lady Neuberger (led a government commissioned review into the use of the LCP in the UK). She quotes: 'We know that communication is key, and to hear that patients and their families were not heard, or worse - avoided - demonstrates a clear lack of compassion and empathy which is the very thing they looked to staff to give. No matter how "good an innings" or how much of a relief a passing can be, this is the most painful time for any family and for them to feel let down at this time is a bitter pill to swallow and staff who choose to behave that way at this time is, in my opinion, guilty of misconduct. You could argue that it is fear that prevents some staff from approaching the real issues associated with death, as it is difficult for all concerned, having heard what we have recently following the Winterbourne review and Mid Staffs, it is clear that there are some staff that just do not care. Hard to believe but the evidence is there.'

'Dame Cicely Saunders, founder of the modern Hospice movement was quoted as saying that "how people die lives on in the memory of others". Staff have one chance to get it right, they need to ensure they get it right each and every time for those we care for and those of us left behind with the legacy of that experience....Make sure it is always a good one.'

Wednesday evening our Mother was finally moved to the Lilac ward. The attitude of the staff was indifferent. We constantly had to call for our Mother's medication and they couldn't get the dosage right. Rosalind expressed her dissatisfaction to one of the nurses who was administering a drug saying, "You think I'm stupid? I know what you're doing". She never replied to that question, but she said, "I don't think you're stupid". Again, what were we supposed to deduce from that? We were just left.

During this time our Mother constantly asked for food. In fact she was asking for us to get her a meal from her freezer or a tin of soup from her larder. She became extremely distressed because she couldn't understand why we couldn't get this for her. This was utterly unbearable for us as her daughters. We didn't know what we could say to her, and we weren't offered any help from the medical staff, we felt the responsibility was totally on us. At one point, during this time, our Mother said to us, "They're killing me!".

Later that evening a doctor appeared on the ward and we asked him if he could help us, "With what?", he replied. We pointed to our Mother and said, "Our Mother!". Again we

expressed our deep concern at what the hell was going on with our Mother, to which with his arrogant demeanour he replied, "I don't know anything about your Mother". We were dismayed at this response, which he then followed with, "I'm in charge of 3000 patients in the hospital, I'm not expected to know everybody". Again we expressed our concerns about the LCP, and he said, "Surely she's not on it, is she?" (as if it was an option!). When he later returned to our Mother's bedside, he stated the problem with our Mother's stomach, where upon Rosalind then said, "I don't believe you". He then replied, "Oh, you can read x-rays, can you?", Rosalind then said, "You can show me anything you like, how can I believe it will be an x-ray of my Mother's stomach?". Rosalind then said, "All I know is that you're killing her!", (he did not deny it) at which point he then began to walk away. Then two nurses came up to him with more medication for our Mother. They asked him, "Is this the correct amount of medication to give?", to which he shrugged his shoulders saying, "I don't know", and walked out of the ward. With that, the nurse then administered the injection very brutally into our Mother's thigh, to which our Mother then screamed out in shock and pain. Rosalind said, "Why did you administer it like that?!", but the nurse just ignored Rosalind and walked away. When our Mother was awake and conscious, she was constantly fighting bravely and even said at one point, "I will fight this!".

During the night hours, we spoke to a nurse and again mentioned the LCP, she then replied, "Your Mother is not on the LCP as we are still treating her". This led to even more anxiety and confusion as she told us that a lady opposite our Mother's bed was actually on the LCP, but we noted that during the night she was also being treated and monitored. (We stayed awake with our Mother throughout Tuesday and Wednesday day and night).

- Thursday 13th June 2013 - Dr. Y and a nurse were on duty in the morning. He came back to see us after their ward round. We then discussed again our dissatisfaction about what was happening with our Mother. He said "At a later date, you could see all of your Mother's notes and records", and indeed he said he would make a note of this on her file. This was of little consequence to us as we believed that her notes could be altered to their advantage. Again we were not given any guidance as to what to say to explain to our Mother what was going to happen to her. They deemed it was not their responsibility of what to say.

We insisted that we wanted to take our Mother home ASAP, and they accepted that. The palliative care nurse came and spoke to us about the arrangements for our Mother at home. We were in great shock, bewilderment, overwhelmed and exhausted with what was happening to us all!

We were told to go to our Mother's house ahead of her so that we could get things ready for her arrival. We assured our Mother that she was coming home, and although we would be leaving her for a short while, we would be waiting at her home when she arrived. We asked a nurse on duty if it was possible for her to stay with her until our Mother departed. Of course we have no idea if this happened.

There was an hour's delay before our Mother arrived home. When the district nurses (one of whom knew our Mother as she had been attending her pressure sore/ulcer on her foot)

came to the house, they were shocked to find that there was no medication sent out with our Mother from the hospital as there should have been! This was totally and utterly deplorable and unbelievable!! The district nurses then went to get a prescription made up locally which took over an hour. Marilyn rang the hospital to find out why the medication hadn't come home with our Mother. The Sister on duty at that time did not know anything about this and would have to make enquiries and get back to us. She said that a prescription would have to be sent to the pharmacy, and that would take over an hour. Marilyn's daughter also went back to the hospital to try to collect the medication. By this time our Mother was again in great pain and she couldn't understand why there was no medication sent home with her. We told her that they had messed up. With the long delay she said, "Why am I waiting, have they got lost?". Rosalind tried to distract our Mother by counting numbers!!

When at last the medication was given, she was sedated. We were told by the district nurses that if we needed further medication for our Mother during the night there would be a 45 minute delay due to the approaching weekend. What good would that do if our Mother was in great pain again? (In the end, our Mother never regained consciousness again until she momentarily opened her eyes just before she died.)

Marilyn stayed by our Mother's side with her daughter and partner, throughout that night.

- Friday 14th June 2013 - When the district nurses came that morning they then distanced themselves and said to Marilyn, "Do you know what to do when someone passes?", not even referring to our Mother as a person! Again Marilyn was upset and confused by this disconnection! When the district nurses came to attend to our Mother a leaflet about palliative care and dying was left. On the back of the leaflet it was stated as the 'Liverpool Care Pathway'. When our mother died we called the district nurses and the GP immediately, the district nurses came to 'layout' our Mother and the GP came out shortly after to confirm our Mother's death. We then spoke to the GP in another room about the concerns we had of our Mother's treatment in hospital and the LCP. After that we found that the district nurses had already left, even though they had said to Marilyn they would stay on for a short while. When the GP left we went back into see our Mother, in her bedroom - **the leaflet had gone**. In addition, when the district nurses came to administer drugs to our mother at home, on two occasions Rosalind heard one of them discussing (in a whisper) on her mobile phone our Mother and each time the LCP was mentioned. Our mother passed at 4.20pm Friday the 14th June 2013.

When finally the death certificate was issued by our Mother's medical practice, we were again horrified to find another discrepancy of another illness (chronic kidney disease) that our Mother was supposed to have had. We had been accompanying our Mother to her GP for approximately 9 years and at no time did any of the GPs mentioned this illness.

With all that had happened to our Mother, the discrepancies and our fears, we had called on the coroner for advice and his assistant HM Coroner's officer Z, came to meet us at our Mother's house to discuss our concerns. He informed us that if we were to request an

autopsy, every part of our Mother's body would be dissected, including the brain, which horrified us! After all our Mother had been through, we felt that we couldn't do that to her. To add insult to injury he even made a racist comment by saying, "You appear to be running down our NHS service. Why is it that immigrants are coming over to our country to use our NHS service?".

After our Mother's death, our fears were affirmed when the news broke in the media about the LCP abuse and it's 'so called' call for its abolishment!!

We want a full written response of accountability, redress and justice for our beloved Mother about all her treatment and the way we were treated too.

Yours Sincerely

Ms Rosalind Brewer

Ms Marilyn Ealy