





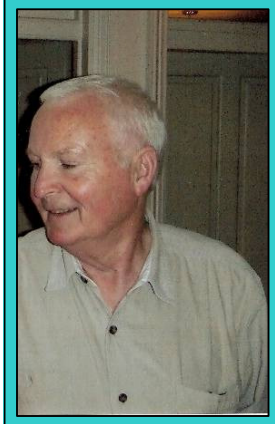
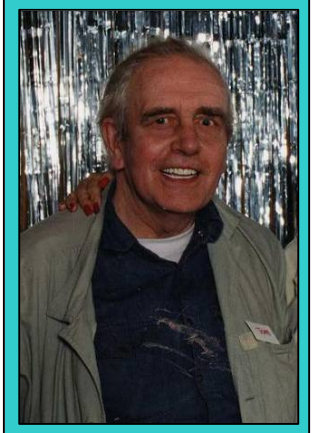
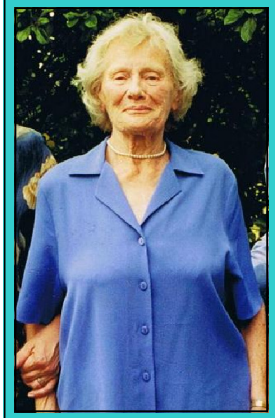

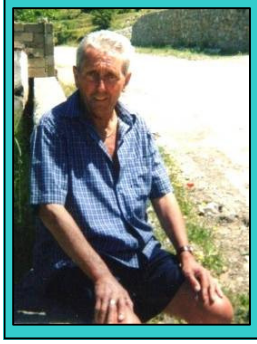

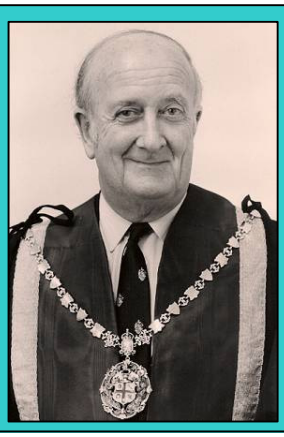

The Patients Association

listening to patients, speaking up for change

Patients... not numbers, People... not statistics

August 2009

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Foreword

For far too long now, the Patients Association has been receiving calls on our Helpline from people wanting to talk about the dreadful, neglectful, demeaning, painful and sometimes downright cruel treatment their elderly relatives had experienced at the hands of NHS nurses. Some found it helped to talk to us, for they had had scant comfort from trying to make complaints or even seek explanations about what had happened to the people they loved, never mind the supportive counselling they should have done.

One Hospital Trust has raised the spectre of legal action if we publish this material, others have been unhelpful, not answering relatives' letters and not investigating their complaints and in other cases, the service set up by the Government to help people who have a legitimate complaint has been as unhelpful as the Trust that employs them. The relatives involved in all the cases quoted in this report (a handful only of the total, which is horrific) want to be quoted, want people to know what happens in some of our hospitals, and above all want it thoroughly investigated so that culprits can be identified, systems changed, and proper supervision put in place. And a great many say, touchingly 'I want this treated seriously, so that it never happens again and hurts someone else's Mum or Dad---'

The personal accounts given here are just a few of those brought to us. Some cannot be reported now because the surviving relatives have chosen to go to law, so are sub judice and some are frankly too distressing---even worse than those on which we have based our report.

By a sad coincidence I trained as a nurse with one of the patients who suffered so much, and I know that she, like me, was horrified by the appalling care she had before she died. We both came from a generation of nurses who were trained at the bedside and in whom the core values of nursing were deeply inculcated.

I am sickened by what has happened to some parts of my profession of which I was so proud. These bad, cruel nurses may be - probably are - a tiny proportion of the nursing work force, but even if they are only one or two percent of the whole they should be identified and struck off the Register.

If only the majority of good caring nurses - and some of them figure in these case histories - would stand up for their patients and their own profession, and blow whistles it would make a difference and bring back to them the sense of pride in the provision of good, safe care that used to be enjoyed by the whole population of this country.

Claire Rayner

President
Patients Association

Introduction

The Patients Association decided to produce this report as an attempt to raise awareness of the failings in hospital care being highlighted to us every week through our Helpline phone calls, emails and letters.

This collection of stories developed organically from a review of our database of patients and relatives that have contacted us where they had expressed concern about the care they or a relative had received in hospital.

We then spoke in detail to a large number of patients and relatives to attempt to understand in more detail why they had concerns. We reviewed these accounts critically as we are aware that sometimes patients and relatives views of the quality of care they have received can not necessarily reflect the reality. Following this process we were left with a collection of cases that we felt clearly and credibly highlighted concerns. Many were not willing to be included and others were not suitable for inclusion, for example if legal action was being taken or if there was a police investigation.

When the final cases had been selected, it became remarkably apparent that there was a striking similarity between many of the cases - nearly all of them centre on concerns over basic nursing and domiciliary care. As a former nurse herself, this feature of these accounts has had particular resonance with our President Claire Rayner, reflected in her foreword. But when viewed in relation to wide ranging figures from across the NHS, it would appear problems are not limited to nursing care.

Sometimes these figures might represent a small proportion of patients. The national inpatient survey results from 2008 state that the number of patients that rated the care they received as excellent had increased from 38% in 2002 to 43% in 2008. The NHS should be applauded on this achievement. But the same survey also showed that the percentage of patients that rated their care as poor had not changed from 2002 to 2008, staying at 2%. Over the years of the survey this represents approximately 10,000 patients who personally rated their care as poor.

If this was extrapolated to the whole of the NHS from 2002 to 2008 it would equate to over 1 million patients[1].

The immobility of this percentage of patients rating their care as poor is particularly worrying when you consider the record doubling of investment that has been put into the

[1] Approximately 10,000,000 admissions to hospital per year
2% of 10,000,000 is 200,000
6 years of admissions equals 1,200,000 Source: Hospital Episode Statistics 2002-2008, NHS Information Centre
http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=193

NHS over recent years. This has to a degree been translated into frontline staff-from 1996 to 2008 the number of nurses employed by the NHS has increased by 26.2 per cent or 84,700 nurses[2].

Below is a sample of statistics from a number of other sources that directly highlight failings in care, some of which have been directly replicated in these accounts.

Palliative Care: The 2008 National Audit Office report - End of Life Care found that 56-74% of patients would prefer to die at home. However only 35% actually die at home or in a care home and only 54% of nurses and 33% of doctors have been formally trained in 1 of the 3 NICE end of life guidelines. Some trusts spend only £150 on specialist palliative care per person compared to £1700 at other trusts. The average was £504.

Hip Fracture: The 2008 British Orthopaedic Association Report found that around 1 in 5 patients who had suffered a hip fracture had to wait longer than 48 hrs for an operation and that more than half of surgeons said their hospital refused to cancel elective surgery lists to treat emergency trauma patients – stating that in those Trusts the pressure to meet waiting list targets was prioritised over the care of those needing urgent care. This is supported by the 2000 Audit Commission Report *United They Stand* found that only 7% of patients are admitted from A&E to wards within the recommended one hour, 20% were having to wait more than 48 hours for an operation and 43% of trusts were cancelling operations for potentially avoidable reasons.

Stroke Care: The 2007 National Sentinel Stroke Audit conducted by the Royal College of Physicians found that only 18% of hospitals had services to offer thrombolysis, only 18% of hospitals provide specialist acute stroke care and for patients admitted at weekends 85% had to wait more than 48 hours for a brain imaging scan. A 2009 survey of 240 surgeons from across the NHS found only 1 in 5 patients received an operation to prevent stroke recurrence within the two week time
frame recommended by NICE.[3]

Elderly Care & Malnutrition: Both Help the Aged and the British Geriatric Society have launched campaigns to highlight concerns over hospital care for elderly patients. The 2006 BGS campaign, *Behind Closed Doors* was aimed at improving toileting care and the 2006 Help the Aged campaign *Hungry to be Heard* was aimed at improving hospital food and assistance with eating. Unfortunately there are no reliable figures on toileting care standards and despite a Department of Health response to the Help the Aged campaign that promised to deliver improved nutrition for hospital inpatients figures from the NHS information centre released this year have shown a worsening problem, supported by a 2009 survey that showed nearly a quarter of NHS managers surveyed thought the Department of Health action plan had made not much difference or no difference at all.[4]

[2] NHS Information Centre, March 25th 2009
[3] British Medical Journal, Waiting times for carotid endarterectomy in UK: observational study, 2009;338:b1847
[4] Health Service Journal, 7th May 2009, Action plan fails to leave a mark on malnutrition rate in NHS hospitals

Complaints handling: The 2009 Healthcare Commission Report *Spotlight on Complaints* found that there was a 50% increase in number of complaints upheld by them from 2007 to 2008 and only 16% of 337 Trusts acted on recommendations by the Healthcare commission, made in response to complaints in 2007. It also found complaints were repeatedly around the same things - poor response to complaints, poor communication and poor nursing care. The National Audit Office 2008 Report *Feeding back? Learning from complaints handling in health and social care* found that less than half of Trusts had "integrated complaints information with data on litigation, patient safety incidents and contacts with PALS in any systematic way."

As mentioned previously, for some years now there has been a running programme of surveys for NHS service users and these surveys have shown steady improvement in a number of areas. However, even with improvement, often this still leaves significant proportions of patients reporting worrying concerns. The 2006 National Inpatient Survey found that 44% of all patients surveyed felt there weren't enough nurses to care for them properly. In the worst hospitals it was reported by nearly 66% percent of patients.

The aim of this report is to put faces, names and experiences to the 2% of patients that reported their care as poor.

These are patients, not numbers. These are people, not statistics.

These surveys and reports are not for customer satisfaction at a supermarket or a hotel. They are of an experience that can be of enormous significance to a patient. Whilst we cannot attribute this question of overall satisfaction with individual failings we must remember the kinds of things that this will inevitably relate to. It is for a period when a patient was being delivered care because they were unwell enough or required treatment that required hospitalisation-that hundreds of thousands of patients rate this experience as "poor" is extremely worrying.

We need urgently to reconsider the resources made available to hospitals and how they are spent. We need urgently to reconsider how hospitals are regulated and supervised. The public need to have confidence that the ward they will be admitted to will have enough staff with the right experience and training. The results of inpatient surveys and patient complaints should be scrutinised rigorously and followed up fearlessly. Unless we are willing to start a step change in our approach to hospital care, that 2% figure, that 1million patients from the last 6 years, will be repeated for the next decade. The next chapter, our Call to Action, highlights some of the steps we feel could be taken to help drive improvement.

Current and future Governments need to engage in a debate with the general public about healthcare spending. Even with recent increases the National Health Service has access to less funding and fewer nurses and doctors than many comparable developed nations[5].

[5] The UK has fewer acute care beds per head of population than the US, France, Germany, Austria, Belgium, Italy, Germany and others. The UK has fewer physicians per head of population than Germany, Sweden, France, Italy, Spain, Greece and Portugal and others and has fewer nurses per head of population than Ireland, Australia, Switzerland, Canada, Germany, Denmark the US and others. Source: OECD Health Data 2009: Statistics and Indicators for 30 Countries

The principle seemingly outlined through the complaint of Oenone Hewlett's family is particularly worrying. It would appear that where patient's notes contain very little information, the regulators and ombudsman are unwilling to make a conclusion about the quality of care they received. This concern should be urgently addressed by the Parliamentary Health Service Ombudsman to reassure patients and the public.

Some of the issues contained within these accounts relate to training and behaviours - but often they relate to staffing and equipment levels. A recent British Medical Association survey highlighted the willingness of the public to pay more for the NHS[6]. If they read and hear about accounts similar to those contained within this report we can expect they will be willing to invest the needed extra resources to help avoid continuation of these problems.

Every year the Patients Association will continue to hear from patients and relatives accounts where those who put their faith in the NHS have become malnourished in hospital, have developed an avoidable bed sore, have had an avoidable fall, have been given poor end of life care, have been left waiting for an urgent scan or operation or have been left in their own faeces and urine.

It is the duty of everyone connected with the NHS to do everything possible to prevent this from continuing.

[6] British Medical Association, BMA poll reveals the public's fear for future of the NHS, 28th June 2009. 40% of those polled agree taxes should rise to maintain growth in spending and 77% agree cuts should be made in other Government spending to protect the NHS.

Call to Action

- The Care Quality Commission and/or the Department of Health should conduct a review of dignity standards in hospitals with a particular focus on basic nursing care for patients for example assistance with eating, toileting and personal hygiene. This report would indicate that there are problems with elderly and end of life care in particular.

- The Care Quality Commission should introduce extensive clinical area visits into its assessment programmes to cover all aspects of hospital care with a particular focus on the quality of care being provided on hospital wards

- The Care Quality Commission should be given a role in reviewing complaints about NHS services, most sensibly through the reinstatement of the 2nd stage review role held by the now disbanded Healthcare Commission.

- The Parliamentary Health Service Ombudsman (and if once again given a role in reviewing complaints, the Care Quality Commission) should review it's processes for ensuring improvement following the upholding of a complaint to include rigorous follow up include clinical area visits to independently verify positive changes have been made

- There should be an urgent review of how a complaint should be handled and investigated when there is insufficient documentary evidence to allow the Parliamentary Health Service Ombudsman (and if once again given a role in reviewing complaints, the Care Quality Commission) to make firm conclusions based on a patient's notes

- All complaints received by a provider service (e.g. Hospital Trusts) must be passed onto and reviewed by commissioners (e.g. Primary Care Trusts)

- The Department of Health should review the quality of Patient Advice and Liaison Services at NHS Trusts to ensure a reasonable minimum level of service is being provided everywhere. The Department of Health should conduct a consultation on whether to make PALS services independent from individual NHS Trusts and instead fund them centrally.

- The National Patient Safety Agency should review fall prevention guidance being used by the National Health Service and review the standards of fall prevention in hospitals

1. Leslie Kirk

By his son Ron Kirk

My father at the age of 86 was first admitted to Nottingham City Hospital on 9th October 2007 due to a blocked catheter and a mild stroke. Having been lovingly cared for by my sisters Sheila and Debbie for the last 10 years and supported by my father's excellent GP we were about to endure what at times felt for us felt like a nightmare of NHS care.

My father had in fact been at an Accident and Emergency Department the day before he was admitted. On Monday 8th when his catheter first blocked causing him severe pain he was taken to the nearby Queens Medical Centre by ambulance. He couldn't walk and they confirmed he had had a small stroke some days before. Debbie had made it clear that she felt it wasn't right for him to be sent home but he was discharged anyway. The community nurse that insisted he needed to go back to hospital on the 9th was shocked that he'd been allowed home in his condition.

On hospital visits to see my father on the ward he was first admitted to we were shocked by what we witnessed. It was even difficult to find the right ward as there were no signs for it either from the car park or inside the hospital. When we first arrived a nurse greeted our family by saying "there is only me and I will get to you when I can".

Toilets were not cleaned properly with faeces clearly left from several previous uses. My sister often had to clean them herself before she'd let my father use them. My father's swallowing wasn't safe because of his stroke but drinks of orange juice and water were supplied when the counter instruction over the bed was nil by mouth. We saw dirty and blood stained food trays. We saw soiled and dirty linen left on floors and mixed with fresh supplies. Personal items for his own comfort frequently went missing.

At one point my father's personal alarm was taken away, making it difficult for him to get help from staff when suffering through the night from severe pain. When we challenged staff as to the reason for the removal we were told that it was because he kept pressing it. This answer we found astonishing particularly as we know it was not in our father's nature to complain unless he had a very good reason for doing so. The alarm was restored but we never had the confidence that it wouldn't happen again. His catheter bag was not changed when it was full, sometimes after nursing staff had seen it needed changing. It wasn't secured properly, meaning it dragged along the floor at times. He wasn't shaved or showered regularly. We had to bring in a blanket for him because he was cold in bed. Perhaps most importantly as he had suffered a minor stroke and had difficulty using his left arm, besides a walk to the toilet, he was given no rehabilitation exercises.

We witnessed similar problems for other patients on the ward. Patients didn't seem to be getting enough assistance with eating and drinking. We saw patients with food and drink, spilt down their chests, struggling to manage on their own. Sheila always helped one patient put on a bib, though often he would wait so long for his soup to be thickened it would go cold. One patient had fallen over several times struggling to get to the toilet on his own. This was despite specialist staff who visited him from another ward making it clear that he needed help going to the toilet. Fortunately my sister lived close by and she was able to attend my father everyday and spent many hours personally nursing him as she felt the care he would've received from staff alone wasn't good enough.

When we tried to bring our concerns to members of staff we felt they were either off-hand or just ignored the points we were raising.

At no time during my father's stay on the ward did we feel there was anyone who cared for patients enough and who took responsibility for ensuring they got the attention they needed. We often overheard staff complaining about how long they had been on duty and how much they missed working at another nearby hospital. Although staff complained to us about being overstretched we found many times it was difficult getting entry to the ward during visiting times. Had it been because staff were busy we would have understood, but looking into the ward we saw staff talking in groups at a desk. They did not respond to our request for entry unless you called them via a mobile phone.

We found the whole experience distressing particularly as our father had been a good family man who very much cared for us. We felt we had let him down at his greatest hour of need.

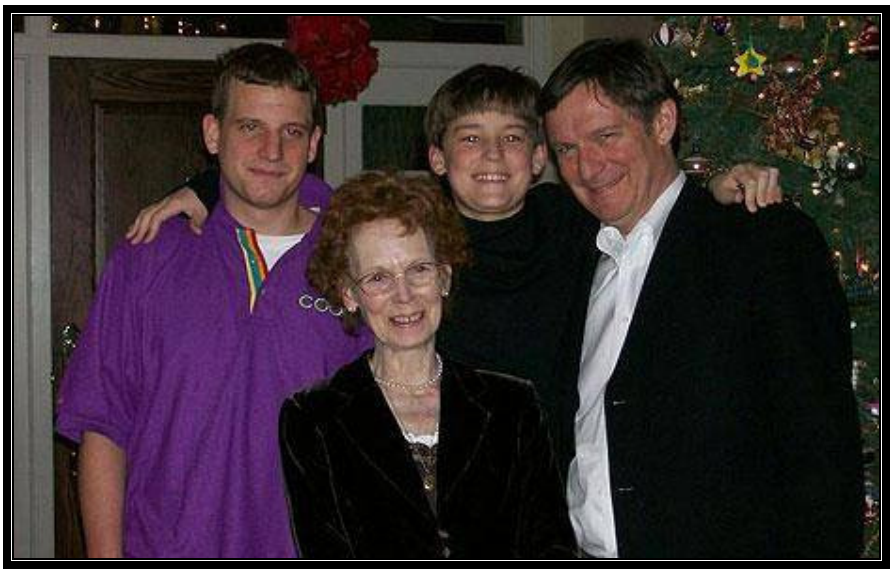
What made it even more difficult was when my father was transferred to a different ward. My sister and I cannot praise too highly the professionalism and excellent care my father received from all that ward's personnel before he died on 19th December. It demonstrated to us that it was possible to get the care patients like my father deserve.

Since our experience my sister and I tried for a long time without success to have our issues addressed even though they have not been contested. We made it clear what we felt needed changing to stop this happening to anyone else but it has taken until today (8th July 2009) for us to see at last there have been improvements on the ward. It has taken nearly two years of dialogue with NHS management, local GP and community nursing as well as my

father's MP to deliver any improvements. Whilst we are glad, we strongly believe that the basics of dignity and care we felt were missing on the ward, should never have been lost in the first place and that NHS health professionals should have never allowed the standards of care to fall well below acceptable standards. From talking to friends and family using the NHS across the country we believe our experience is not isolated, nor can it merely be explained as the natural by-product of a major organisation but as a systemic management and resource problem when caring for vulnerable patients.

2. Pamela Goddard

By her son Adrian Goddard



My mother was amply provided with that most English of virtues - - the ability to address and overcome adversity cheerfully and without complaint. She educated herself as a musician, in spite of intense opposition from her mother. She was teaching the piano 30 hours a week until her final hospitalization.

She raised three young children (4 years – 16 months) mostly without child support, after being abandoned by her husband.

Despite numerous recurrences, including more than one thought to be terminal, she survived breast cancer for more than forty years, after a double mastectomy in 1964.

Instinctively, she knew that faith, determination, and confidence were necessary to survive as she did. Faith in God and in herself, determination that she would do everything in her power to take care of herself and live her life fully, faith and confidence in the medical system that had helped keep her alive.

Breaking her leg and becoming a patient of East Surrey Hospital (ESH) ended all that. Her agonizing death from a bedsore was the culmination of several months of care in ESH and Royal Surrey Hospital Guildford (RSH). Long before her passing, any faith or confidence in those institutions and the system they are part of had been replaced in us by horror and disbelief.

In January and February 2008 she started to get severe back pain and was worried that this might be recurrence of her breast cancer. She raised this with her Consultant oncologist at Barts as part of a scheduled appointment . He examined her and told her it was probably muscular and nothing to worry about.

3 months later, with the pain still present she took herself to the outpatients department and asked to see the consultant again. Again he examined her and said it was probably muscular pain. He advised her to come back if it should worsen.

6 weeks later she broke her leg in a fall in her kitchen and was taken to East Surrey Hospital. She had an operation to fix her broken leg and after 10 days or so was scheduled to be transferred to Tandridge Heights Memorial Care Home for physical therapy. On the day she was due to be transferred we waited from the morning to the late afternoon for patient transport until I decided to to transport her myself. I got hold of a number of pillows and lay her in the back of my car.

At Tandridge it took a few days before they had received her notes and grasped her somewhat complex medications regimen. They helped with her rehabilitation and she was walking with crutches, sitting up to eat and making good progress. Unfortunately she developed problems with her breathing that the staff and Tandridge were worried about so after about 10 days she was transferred back to ESH. After recovering she went back to Tandridge only to return to ESH with the same problem on August 14. She was finally discharged into the family's care and moved in to house we rented for the purpose on August 28 with in-home physical therapy to follow on the 9th September 2008.

She was properly and thoroughly cared for by her family for the next ten days – walked, fed, helped to turn. There was some discomfort at the pressure point at the bottom of her spine, but no bedsore in evidence. We contacted the hospital when she was readmitted due to increasing immobility and arranged for a Marie Curie nurse to do so as well to (we thought) ensure that the proper treatment for preventing an incipient bedsore developing would be followed. We are still investigating whether anything along the proper lines was done.

When she was readmitted to ESH she was placed on a pressure relieving mattress to help prevent the bed sore from worsening. My family and I realized on the first day that it was broken and told staff this. We were simply told that they would try and get it fixed but this never happened.

When she had been looked after by us at home we had always made an effort to turn her regularly but this was rarely done at ESH. We asked about it and were told that it took two nurses to turn someone, and two nurses were never available.

We enquired about lifting equipment that might help. We were told it was broken and as with the pressure relieving mattress, it can't have been fixed as it was never used to help in my mothers care.

Shortly after her readmission to ESH on September 9 the doctors there, for the first time as far as we know, made the connection between the back pain, the increasing immobility and her forty year history of breast cancer

On September 13, Pamela was moved to Royal Surrey Hospital at Guildford to radiate the lesion now realised to be causing her back pain. This was done, and the back pain was largely relieved. As with ESH though, no pressure-relieving equipment was made available

at RSH and my brother's impression is that there wasn't any at the hospital. Again, she wasn't turned regularly and upsettingly for my brother who visited her frequently, she was often found in her own faeces and urine when he arrived. He would need to prompt staff to come and wash and change her. We were particularly worried that this might affect the bed sore.

She returned to ESH on September 25th without her records or drug chart, but with an aggravated bed sore. A Dr at ESH that examined her characterized it as 'early' however.

Perhaps that explains why it took almost three weeks of false starts from this point before the right therapy for the bed sore was provided and almost a month until antibiotics were given as it worsened.

She was eventually referred to a tissue viability nurse but she never came. It was only later that we found out that she was on annual leave for 10 days as staff gave no explanation to us when we enquired about it.

They decided to try maggot therapy and that took a week to organize. There was no debriding or frequent turning at all during this crucial time.

I met with another Dr on Thursday October 9, who said Pamela's progress was good, except her blood work showed 'some evidence of infection'. He said they would start treating her with an antibiotic after the weekend if things hadn't improved by then. They weren't sure what the cause was but it was almost certainly the start of the infection of the bed sore that eventually killed her.

That Dr was away the next week and the information was apparently not passed on as it was almost two weeks later that antibiotics were started. By then, it was too late, although we her family didn't know it – the idea of a bedsore as life-threatening being so outlandish to us.

On October 23 ESH informed my sister-in-law by phone that Pamela could pass away any time. My brother and she arrived to visit my mother to find she had been moved to a side room. The palliative care team had been to visit her and decided that her prognosis was poor and that she should be given palliative care. This was a terrible shock for us, as only 2 weeks before the doctor had told me she was making good progress.

They had not contacted or consulted with any of us about the decision to make her treatment palliative. When we visited her in the side room it was impossible to communicate with her. We were deprived of any meaningful end of life conversations - we couldn't say goodbye to this woman so beloved by all of us. We wish it had been made clear to us that her condition was worsening so we could have made the most of the time while she was still coherent. We had no way of knowing her state of mind while she was dying, except to know she would have been horrified and very sad.

The care didn't improve in those last few days. We had to prompt staff repeatedly-whether it was to increase her medication or to put her on a fluid drip as she became visibly dry after

two days without fluid. We watched our dear mother die in great pain over the course of four days.

We complained to Barts and ESH and their investigations, we assume, continue. In each case the first responses we received seemed to be cobbled together by hospital administrators carefully trained to deflect criticism and avoid responsibility. We felt they ignored key details and events and provided what seemed to us like implausible explanations.

I felt it was my duty to the woman we all loved and respected so much to use her experience to try and protect others. It is vital that those involved can show how they've made the changes necessary and have learned from what happened. Pamela was a woman who truly inspired those who knew her. I must for their sake show that the end of this great life was not entirely futile.

The final insult for our family was a "Rapid Response Team patient satisfaction Survey" that was mailed to my mother by Sussex and Surrey Health NHS Trust sent to her 4 months after died.

3. Florence Elizabeth Weston

By her son Mike Weston

As Christmas 2007 approached my family and I were looking forward to my Mother coming to stay with us. Despite being 85 years old, she still lived by herself and led a reasonably active existence, walking a couple of miles to the nearest town to do her shopping twice a week. Some fours years previously, she suffered a heart attack but, thanks to the intensive care unit at Russells Hall Hospital, she made an excellent recovery leaving her with very little side effects, except a slight weakening of the heart and the discovery of type 2 diabetes, all controlled by daily medication.

However, all of this was to change. Like many elderly people, Mom enjoyed a nap in the afternoon. Whilst taking this daily pleasure on Monday 17th 2007 December, she was awakened by the doorbell. Quickly getting off her bed, she tripped and fell, fracturing her hip. The initial response, by both the paramedics and the ambulance service, was excellent.

The arrival at the Russells Hall Hospital left one hopeful that the same treatment she had received before would happen again but that was not to be the case. Having arrived at 4.49pm, she was not admitted to a ward until 11.20 that evening. The hospital say they carried out the necessary tests but she could not be seen by the orthopaedic team due to workload and that availability of beds on the day did not meet the capacity of the patients needing to be admitted to the ward.

To quote the medical director of a major trust hospital who said quick diagnosis is vital "We tried to streamline how patients come in through A&E. There is a pretty rapid diagnosis – has this patient a broken hip or not? There's only one treatment if they have, so there is no point in them hanging around in A&E. They are straight up to the ward, so they are ready for the next trauma surgery list."[7] If one hospital trust can do this, why not all? I always thought that the NHS had national standards and strict guidelines - how wrong you can be.

[7] Weston Area Health NHS Trust Dr Tricia Woodhead commenting on a report by The Royal College of Physicians.
http://www.dailymail.co.uk/news/article-201124/Hip-surgery-dangers-highlighted.html

Having put the initial problems behind us, we looked forward to a quick operation to put Mom's problem right. From research that I've done since these events I understand that if operated on within 48 hours, patients have a much better chance of a full recovery and the opportunity to regain full mobility. However, some 20% of the 70,000 hip fracture victims each year who are over 60, have to wait over two days causing them to be in pain and increasing the likelihood that their future life will be impaired. This lack of prompt action also dramatically increases the patient's chance of dying. [8]

Despite us being told on a daily basis that she was on the list for surgery for that day, she was constantly removed to make way for other clinical priorities. What these priorities were, that enabled them to take precedence over her, was never explained to our satisfaction. In the end she waited some five days after admittance for her operation.

During this period of waiting for surgery she was kept nil by mouth. Though she was kept on the appropriate drips she struggled with this over the five days.

She was also told that, because of being unable to use the toilet facilities through being immobile, she should wet the bed. This was highly embarrassing for her. Even worse, on one occasion, a night nurse told her off for doing this severely enough to reduce her to tears and cause her to ask me if she could go home. Once she made me aware of this, I made a complaint to the senior nurse on duty, although the patient notes that we have since obtained, did not reflect this. Eventually she was fitted with a catheter.

Unfortunately, the operation did not work, allowing the ball joint of her leg to become separated from her hip, so yet again she was put on the trauma surgery list and awaited further surgery. All of the family were now becoming increasingly concerned by the apparent lack of speed in dealing with the situation. Despite constant questioning of the ward staff, it took a further three days for corrective action to be taken and the decision to move her to an Orthopaedic Hospital some 20 miles away.

Two days after that, a long operation took place during which a full hip replacement was carried out. Sadly, the following day she died of heart failure. Though we will never know for certain what would've happened, our family often wonder if she would've survived had she been operated on sooner.

After this distressing news of my mother's death, I began to reflect on the whole episode. I recalled the number of press stories that I had recently seen relating to the treatment of older patients.

After a period of grieving was over, my family and I felt we needed some answers. Then began a lengthy process trying to get straightforward, understandable answers from the Trust to.

[8] Taken from a poll of 124 heads of Trauma units across the UK and released and commented on by Clare Marx British Orthopaedic Association President.
Report by Dennis Campbell Health Correspondent Guardian/Observer
Published 21/12/08. http://www.guardian.co.uk/society/2008/dec/21/nhs-health-operations

Over the last 15 months, some seven or eight letters have been exchanged. I feel that most responses from them have been carefully crafted so as not to accept blame that may lead to future legal action. I didn't feel there was any genuine acceptance that my mother could've been cared for better.

What concerns my family is that this is probably happening to other families out there. Is anybody saying this is wrong and that we need change? I somehow doubt it!

Of the proportion of complaints made against the NHS in 2007/2008 that were independently reviewed, the proportion upheld increased by 50% compared with the previous year.[9]

Let us hope that, somehow, we return to the time when the elderly were respected and treated with the full dignity they deserve and given the reward for all that they have given to this supposedly great country. When they were confident that the treatment they would receive in our hospitals would be second to none and they would not be afraid to be left in there without close family constantly present.

[9] Healthcare Commission, Spotlight on Complaints, 5th March 2009

4. Oenone Hewlett

By her daughter Stephanie Hewlett

My mother Oenone Hewlett was admitted to the rehabilitation unit at St Marks Hospital on October 12th 2005. She had previously been at Wexham Park Hospital on 2005 for treatment of a leg ulcer and later had an angiogram and angioplasty.

When she got to St Mark's she was constantly nauseous. This continued even as she was getting better with her mobility. She was given anti-nausea information but it didn't help. Tests were carried out but they didn't show any cause for her vomiting. Because or her nausea she was finding it very difficult to get enough food and drink, often vomiting back up what she did manage.

By October the 31st she was even more unwell and the cause was still unknown. More tests were carried out and it was found that she was suffering from renal failure. The results were so concerning that she was taken by ambulance to Wexham Park Hospital on November 1st. Whilst there she was diagnosed with oesophagitis and stayed on a medical ward. She died two months later on January 14th 2006.

Throughout this time all our family were very unhappy with the care that she received. We watched as she deteriorated at St Mark's Hospital and we felt the staff didn't take any notice as this happened. When we complained about this after her death we wanted to know why she had been able to deteriorate without this being picked up on.

The Healthcare Commission reviewed our complaint and found that there were very poor records of her care at the time. There was little record of her vital signs, her eating, her

weight, her mobility, her urine output. Little of anything at all. We believe that these charts are accurate and represent the level of monitoring that actually took place. It is our view that these notes reflect a general lack of adequate care.

We see this as evidence of her poor care. For them to be able to do things like increase her fluid intake sufficiently for example, they would need to know what she was previously taking and how much she had been urinating. For them to be able to know she was unwell to be rapidly losing weight they would need to have records of her weight over time. We understand that there would've been a clear and steady drop in her urine output and other signs like a drop in blood pressure and weight as she became more and more dehydrated. We were with her and saw that these things weren't being monitored and then obviously couldn't be recorded. We kept asking why she wasn't getting better and what they were doing but without medical records to back up our concerns that proved she was deteriorating we couldn't make our case.

Sometimes several days went by without any records at all – this is especially so regarding food and drink intake, elimination and measures of her blood pressure and weight. This meant that as Oenone condition deteriorated there was no recognition of her decline, and when her weight loss became critical, no action was taken.

Moreover, the lack of comprehensive records meant that the few times when she was attended by a doctor or nurse, they, each in turn, failed to flag up the fact that nothing was entered in the records for the preceding times that she was attended by them or anybody else. We remember one nurse was unhappy with the record keeping but it didn't seem to make a difference.

When she arrived at Wexham Accident and Emergency following her stay at St Marks, the doctor thought she must have been at home alone and neglecting herself. We had to explain she had been in hospital. He couldn't understand how she could've become so dehydrated.

The Healthcare Commission expressed "significant concern" about the lack of note taking but exactly because of this lack of note taking they decided that they couldn't comment on whether or not my mother had actually received inadequate care. The response stated that "in the absence of any additional evidence … We consider that the lack of adequate records would preclude us from being able to add anything more to this."

If this is an acceptable approach to investigating allegations of neglect then I would advise incompetent nursing and medical staff to make as few entries in their medical records as possible – that way, no official is going to find them at fault!

We are also worried that the Healthcare Commission seemed to need constant reminding to follow up on the recommendations they did actually make about record keeping and for making sure the Trust sent us a response to our concerns. We were told deadlines when the Trust would need to write to us and the Healthcare Commission and repeatedly they wouldn't arrive. We would need to call the Healthcare Commission to ask them to chase a response. Surely they should be making sure these things are done? I know the Healthcare

Commission is gone and I hope the new Care Quality Commission will be a lot tougher with Trusts that have let people down.

If the health service professionals want to improve the services which they offer, then complaints like ours need to be taken seriously, and omissions in the records, cannot be treated as reasonable assumption that the correct procedures were carried out – to the contrary, it should be assumed that such procedures were not carried out, especially in cases such as that of Mrs Hewlett, where critical factors such as dehydration and renal failure would have been made obvious if accurate records had been kept.

Our family have refused to accept this as we feel we owe it to Oenone to get to the truth of what happened and to have the system changed so that lacks of record keeping doesn't mean staff don't have to be held to account. With the help of my husband David we have continued to write and raise our case. Only this week we received a reply from our MP who has written to the Trust on our behalf. We hope raising the issue publicly will help us to get some answers.

5. Bella Bailey

By her daughter Julie Bailey

My Mother was admitted to the Emergency Assessment Unit at Stafford Hospital and was cared for there until her transfer to a ward of the Hospital. I have only praise for the EAU nursing team who cared for my Mother. They were exceptional, efficient, kind and caring at all times.

My mother spent time on two wards at the hospital and during that period I witnessed a standard of care given to my mother and others that I found shocking and unacceptable.

On the first ward I saw an elderly confused lady brought a meal without any interaction at all. The poor soul didn't even know it had arrived. It was then taken away without a word spoken to her. Whilst staying with my mother on this and another ward I realised this was a common occurrence.

There were other simple issues. There was no clock in the bay my mother stayed in. Another elderly lady staying the bay frequently voiced that she was confused about what time it was. When I mentioned this as a minor side issue to a nurse I found their explanation baffling. The nurse said clocks aren't put onto the wards as it is more confusing for patients if they show the wrong time. Why is it not possible to ensure something as simple as the maintenance of clocks in a hospital?

When my mother was due to be moved from one ward to another there was a delay in the transfer. We waited several hours and were told it was because they were waiting for a bed to be found. When we arrived on the new ward the staff told us the bed had been ready for hours and they had been waiting for us. We were told, that because the transfer was delayed and we'd missed the evening medication round my mother would have to wait for

the midnight round. This medication included pain relief and antibiotics for her chest infection. I saw this happen several times with other patients. If for whatever reason they weren't there or the medication wasn't on the trolley they skipped giving it out.

The impression I got from the rest of my time on this new ward was one of utter chaos at times. The first weekend we had one confused man who roamed around the bays. He was threatening to staff and patients. Our first encounter was when he approached my Mother in her bed and told her to get out of his house. He used abusive language and was threatening. Other patients in the same bay pressed their buzzers to call for assistance but it wasn't answered for 20mins after we had defused the situation. A health carer arrived with a commode thinking someone wanted the toilet. The confused patient later grabbed a member of staff during that night, and had to be restrained and sedated. Several elderly patients were woken and were so concerned they went to the nurse's assistance.

The following weekend another elderly confused patient searched through other patients lockers. Hopelessly lost, but convinced he had to find his fish. The nursing team shouted at him and demanded his return to bed. The more they shouted at him the more agitated and confused he became. He later jumped on a member of staff who had earlier raised his voice at him. One patient became so frightened she threatened to leave and did pack her belongings, but was too ill to go.

On the afternoon of 28th September a health care assistant and a porter appeared and informed my Mother that she was being transported to the endoscopy department to be scoped. I simply asked the carer just to check it was my Mother who was due to be scoped as we had been told for the last 4 days that it wouldn't be necessary. I had missed the ward round that morning and my Mother wasn't aware of being told her plan of care had been changed. The carer kindly checked and reassured us that she had the right patient. After the chaos we had encountered since we had been on the ward we needed reassuring.

My Mother normally uses oxygen therapy 24hrs a day but a working cylinder for her to use whilst being transferred to the endoscopy couldn't be found. My mother didn't want to hold anyone up and agreed she could manage without but was assured she would be reattached as soon as we reached the department, which she was.

After the procedure the doctor discussed his findings with me whilst my Mother's recovered. I was told the prognosis was poor and I became tearful. I spoke to the carer who had brought us down to the unit. I informed her that I didn't want my Mother to see me crying and I would meet her back on the ward after her return. When I I left my Mother was in the recovery position with oxygen being administered.

As I didn't want my Mother to see me upset I contacted my niece Mrs Samantha Round. She went to the ward to meet my Mother who had not yet arrived back. Mrs Round hadn't seen her grandmother for 2 weeks as she had been in London. The nurse informed her that there had been a delay as a member of staff was needed to help to transport my Mother back to the ward.

My Mother returned to the ward in a wheelchair with a porter and no member of the nursing team, with no oxygen treatment. My Mother was asked by the porter if she wanted to sit in a chair she said she did. My mother was put into an armchair, with Mrs Round assisting the porter in doing this as know one else was there to help.

Mrs Round asked the porter if he could reconnect her Nan's oxygen and he informed her that the nurse had been informed and she would be along shortly to connect it. She sat with her for around ten minutes talking, but soon realised that her Nan was becoming unwell.

She pressed the nearest buzzer and 20 minutes later a health care assistant came. Mrs Round informed her that her Nan wasn't breathing properly and was unwell. The carer said she would inform the nurse. About five minutes later she went out of the bay and asked the carer if the nurse was coming. She was told the nurse had been informed and would be along shortly. A few minutes later she went to the main nursing station and informed the carer again that her Nan was ill. She was told, the nurse had been informed and was on her way. Mrs Round returned to her Nan desperate and phoned me, telling me to come quickly. I ran from the ground floor and found my Mother collapsed in the chair. I ran onto the corridor and shouted for help. Doctors and nurse appeared and attended to my Mother. The first question they asked was, "is she still breathing" they quickly gave her oxygen and got her into her bed and continued to treat and monitor her.

It was at this point that we stayed with my mother 24hrs a day. We were frightened to leave her. If it wasn't for the family being around that day I am convinced my Mother would of died sitting in that chair alone. From the porter bringing her back to the ward and a nurse seeing her, it took over an hour for her to be attended to despite the family telling them she was unwell. My Mother has had several stays in other hospital and we her family have never felt the need to stay with her out of visiting times.

The next afternoon My Mother's intravenous infusion began to leak and her arm began to swell. We informed a member of staff after waiting 40 minutes for the buzzer to be answered. The nurse disconnected the infusion and placed a pad underneath it. She informed us that someone would come and change the bed and nightgown, as they were saturated. My Mother began shivering and became cold due to her wet bedding and clothes.

My mother's bed was changed that night at 11pm after lying all afternoon and evening in a wet bed. We had tried to help her in the meantime by placing dry bedding next to her skin. The ward appeared in utter chaos and several relatives including myself searched the ward for staff. I was later told by the only trained nurse on duty that she had not been available as she had gone out of the hospital to the nearest shops to search for a missing patient.

She was also transferred onto a profile mattress after we had noticed sore areas. After spending time on the ward we now know that this is not unusual, several patients lay in wet beds shivering overnight.

My Mother recovered enough following a PEG tube insertion to be given a discharge date. My Mother should have been discharged on the Friday 26th October but she was dropped in the early hours of the previous Sunday morning.

A health care assistant came to toilet her and on transferring her back to bed alone, she slipped and dropped her onto the bed landing her, on her back. Mrs Round awoke and found her lying lengthways across her bed, gasping for breath. My Mother had a curvature of the spine and couldn't lie on her back and never did. My Mother as she described it "blacked out" after being pushed onto the bed. Over the next few days she deteriorated, her breathing became poor and she suffered what appeared to be panic attacks whenever a member of staff approached her.

My Mother wasn't seen by a doctor until the medical team saw her on the Monday, her breathing hadn't improved and she had fluid retention in her arms and legs. A referral was made to the respiratory team to assess her.

What also surprised me about the ward was the complete lack of knowledge around moving and handling. I often saw staff pull and push patients into and out of bed on their own. It was common to see staff lifting patients into bed on their own, or trying to. My Mother had several bruises on her arms and legs that seemed to me to be places where staff had lifted her into bed.
The carer who tried to transfer my Mother on her own when she dropped her was smaller than her but told Mrs Round there had been no-one else around to help her. On previous stays in other hospitals risk assessments were always on going thing to establish the number of staff required for moving and handling my Mother.

The final struggle for my Mother was a blood transfusion and it proved to be the final fiasco on the Ward.

My mother was told on the 5/11/07 during ward round that she needed a blood transfusion. The nurse on duty and a student nurse helped to reassure my Mother. They told her that they would ensure that the blood would be given slowly and frusemide would be given alongside the transfusion. Over that week since her fall my Mother had been given more frusemide. It had been increased to 40mg 3 x day and an extra 20mg if required.

On the 7/11/07 ward round, three doctors were present but no nurse. The doctor informed us that Mother would have her blood administered today and alongside this she was to be given an extra 40mg of frusemide. The same nurse and student nurse were again on duty and reiterated what she had said the day before.

Sadly, the blood wasn't given until that evening around 9pm by a nursing sister. At 10pm I asked the night nurse when my Mother would be given her extra 40mg frusemide at it was, once again impacting on the next medication round where she was due her 40mg. The nurse informed me that my Mother had not been written up for an extra 40mg.

I informed her that I had been present at the morning ward round and had heard the doctor prescribe an extra 40mg of frusemide. She once again repeated that my mother hadn't been

written up for the extra dose. As I was sure what I had heard and after speaking to the nurse and student the day before who had mentioned the extra frusemide I asked her if it was normal for patients to have frusemide alongside a blood transfusion. She informed me it was, but my Mother wouldn't as she hadn't been written up for it. I asked her to check and to ask a doctor she said she would monitor my Mother through the night and she would decide her care.

I went home in tears I had seen and heard enough. The confused man in the next bay was once again being shouted at and told to stay in bed. I was exhausted, since my Mother's fall she had not slept one night. Most nights she had needed a medic during the night as she had been gasping for breath. My daughter stayed with her that last night and I went home. In hindsight I wish I had demanded my Mother was seen by a doctor but I didn't.

We found some staff cared for the patients but most were uncaring. Confused patients often wandered around semi naked and some staff passed them by in the corridor without a care. Night time and weekends were the worst. Night time was often the most busiest and noisiest. Staff squealed and giggled whilst patients tried to grab a bit of sleep in between their discomforts. The staff disturbed confused patients, who then wandered the wards looking for attention. Buzzers often rang for 40-50 minutes whilst patients waited for the commode then they sat for another 40 minutes waiting to be hauled back into bed. Some struggled alone and sounds of patients falling and crying, was not uncommon.

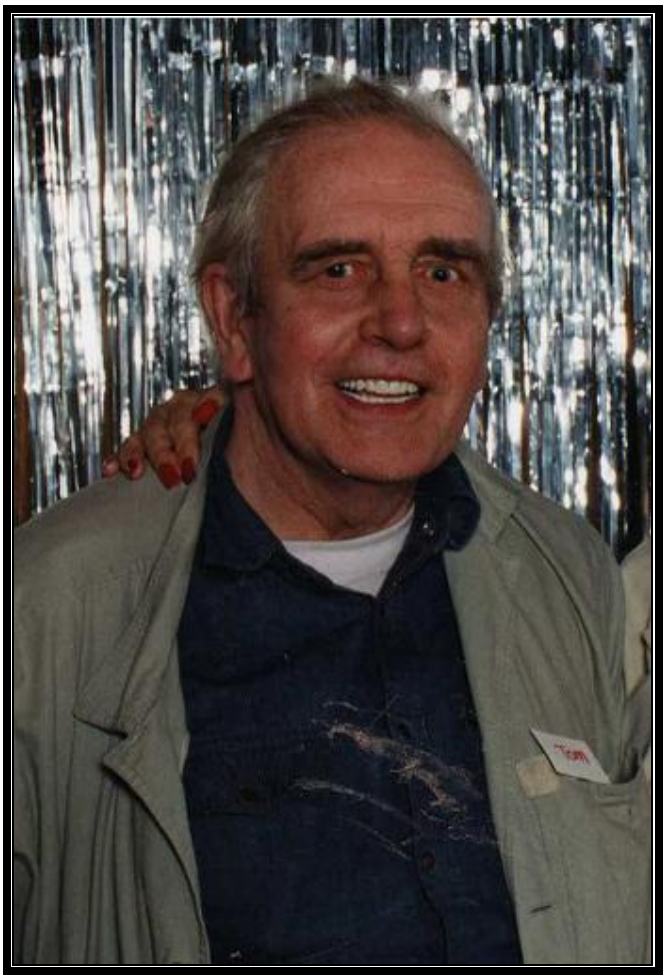
When we complained about all this to the Trust they told us that they had a new initiative that would provide guidance on standards of care regarding communication, nutrition, privacy, dignity and record keeping. Surely after three years of training, nurses should be aware of these basic needs and how to set their own standards. They acknowledged the lack of basic care and communication problems my Mother received and said that shortfalls would be addressed immediately, but failed to say how.

We all now know that the problems weren't addressed and others suffered as a consequence for many months more. I am still being told every week of similar things happening. Patients and relatives of patients contact me and say basic things like fluid charts, toileting, food and medication are still not being delivered.

We need a system where most complaints are rigorously followed up independently. We need to be reassured that genuine changes are made as a result. It should not be enough that when someone has lost a loved one and witnessed the things I did, that a simple letter of apology and reassurance is enough.

6. Thomas Milner

By his daughter Janet Brooks



My father died three and a half years ago in anguish on the Palliative Care Ward of the Northern General Hospital, Sheffield. I have gone through the NHS Complaints procedure correctly but I feel some serious questions remain unanswered.

After emergency admittance to the A. & E. Ward on Saturday 12.00 noon 7th January 2006 my father began to receive morphine and midazolam injections.

At 2.00a.m on the 9th January 2006 a syringe driver was set up containing morphine and midazolam but he was also prescribed pain relief "PRN" in case the syringe driver medication was not enough to ensure he was comfortable.

At 18.00p.m on the 9th January 2006 he was admitted to the Palliative Care Ward.

From 18.00p.m on the 9th until 8.10a.m on the 10th he needed 6 'top ups' of his prescribed PRN – given by a very caring nurse on night duty. My father kept getting agitated every couple of hours but this PRN afforded him some more restful periods. Sadly, despite the best

efforts of staff that night the medical notes state the he was still agitated, breathless and in pain.

A change of staff in the afternoon of the 10th January 2006 brought about a change of care. The new nurse now caring for my father had just come on duty and refused to give any 'top up' medication. As far as I could tell, that nurse had made this decision without even reading my father's medical notes. As the afternoon progressed my father was becoming increasingly restless and agitated. During the evening and night before the PRN medication had helped him. It allowed him to have periods of rest. He was settled and we could comfort him and talk about times and memories we shared. Without this extra medication he was given no such peace.

The nurse also failed to provide incontinence pads as had been done during the evening and night before. He was bleeding rectally and he ended up laying in urine and blood. He also wet the floor and my elderly mother wiped this up while the nurse and assistant nurse watched on and did nothing to help. They did not even bring a mop and bucket afterwards to disinfect the floor.

I asked to see the Consultant. She came and asked my father, having to shout as he was deaf, if he had a pain and he wearily shook his head. I'm not sure he really understood what he is being asked. She said that she concurred with the nurse that no PRN was needed. My family found this very difficult to understand. To us who knew him so well it was clear my father was very distressed. Even worse, in the same circumstances the evening and night before, he had been given additional pain relief. We were confused and upset but felt powerless to do anything about it.

Our relief came when on the change of staff at around 9.00p.m. 10th June, 2006 the kind and caring staff of the previous night returned. Without being asked by us they noted his agitation and immediately resumed the PRN pain relief.

The medical notes written by this night nurse at 6.15a.m on the 11th January 2006 state that 'Tom very agitated, very restless and in pain had to have a lot of PRN, request Drs. review medication.'

This nurse also changed his bed, padded him up at the back and fitted a convene to his penis to help keep him remain free of the urine and blood he had been left in during the day.

At 7.30a.m. on the 11th January, 2006 I arrived on the ward, (my mother had let me sleep on in the visitors room instead of what had been our couple of hours rotational rest periods) my father was pulling at the bed sheets with tears coming down his face. I went to the nurse's station and two seemingly young trainee nurse's said they couldn't do anything and that we would have to wait until the Dr's did their rounds.

To be told that nothing can be done for your father who seemed to be in immense discomfort because we had to wait for the ward round was very distressing. They could not even give me a time when the ward round would take place. I didn't understand why nurses had been able to give him PRN relief through the night but now suddenly we had to wait for

the doctor's ward round. You know your loved ones so well-you know when they are in distress. All the medical training in the world can't replace a family's knowledge. But we weren't listened too.

Not knowing what to do I went outside and called my father's G.P on my mobile phone. I explained what was happening and she contacted the hospital. A doctor arrived on the ward, made a note of the GPs call and doubled the dosage of pain relief being given through the Syringe Driver. 1 hour later my father died peacefully in my arms.

My daughter, who had been present on the afternoon of the 10th, wanted to disclose the affair to the Press. I, with hind sight, naively thought that by following the official complaints procedure, our family would get an apology and perhaps most importantly reassurance that this would not happen again.

I have now been given 9 explanations as to why my father was not given his prescribed PRN on the afternoon of the 10th January and again on the morning of the 11th January when he died. These range from attributing his discomfort to nicotine withdrawal though he'd stopped smoking 6 months before, that we had asked that he wasn't overly sedated, that he had indicated his refusal of extra medication, that a fizzy drink given to him by my mother was enough to comfort him, that he was overdosed on morphine and that the gap in his prescribed PRN on the 10th coincided with the set up of the morphine pump when in fact that had been setup the night before. They are conflicting and inconsistent which has added an even greater sense of confusion over what happened.

We were left even more confused by the Healthcare Commission investigation. It said that considering PRN pain relief was not being given, the dosage of the syringe driver was "low in the circumstances." They gave a list of recommendations for improvement but concluded that the care was satisfactory. That doesn't make sense to me.

For NHS staff, an hour or two to wait for a ward round might not seem like a long time. For NHS staff, a complete change in how your loved one is being treated between day and night might not seem important. But when it is your father who is living out his last few hours in hospital, when you want them to be as peaceful and comfortable as they can be that hour or two means an awful lot. The change between day and night means an awful lot.

7. Ann McNeill

By her husband Richard McNeil

My wife Ann McNeill died on the 15th January 2008. Ann was 71 when she had to undergo a succession of major operations the months preceding her death. She was a patient at both Barnet Hospital and Edgware Community Hospital, moving between the two. Ann had spent decades working as a nurse, she trained with Claire Rayner, and she put a lot of pride in the role of nurses as caring professionals.

Whilst I struggle to remember exact dates and details, during her time there were things that happened to my wife that I will remember forever. I feel that poor nursing care over a long period of time contributed to her death. Ann couldn't relate the attitude and actions of some of the nurses with how she had been trained to look after people.

In October 2007, following surgery at Barnet Hospital she was transferred to Edgware Community General Hospital in North London. It was supposed to be an intermediate step whilst she recovered. I was appalled at how my wife was treated by some of the staff.

Her legs were raw and covered in bandages both to protect her wounds, and the fragile skin surrounding them as she had developed blisters and lesions from deep vein thrombosis and other problems. The dressings were supposed to be changed regularly, every few days, but the nurses at Edgware didn't bother. One night two nurses were hoisting her into bed and one handled her very roughly, knocking her legs. She gasped in pain and the nurse said "Oh, we've got a drama queen here." That description didn't match my wife in the slightest.

Later that night, the other nurse who had been more considerate and careful came and checked on Ann. There was blood on the bed sheets and her bandages from where she had been knocked. The other nurse said to the nurse who had shown such little care to Ann, "you did this, now you clear it up".

When I came to visit Ann the next afternoon they had decided to transfer her to Barnet Accident and Emergency. They transferred her because of the bleeding on her legs and as they hadn't kept a record of the incident the night before they didn't know why it had happened. 5 hours later she was transferred back to Edgware at 10.30pm when they realized the cause.

I remember on one occasion in January 2008 I visited her at Edgware and found her sitting in a chair with her own vomit all over her clothes. It was dried so it seemed as if it must have been left there for some time. There was also dried vomit in bowl next to her. I looked up and down the ward and couldn't find a nurse anywhere. I managed to find a doctor and asked him to come and check over Ann. He went straight to find the nursing staff. It turned out they were all in a meeting. One of the nurses came in and seemed to be annoyed that she'd been called away. She wanted to know what was wrong. I explained that I was worried because Ann had been vomiting and know one must have checked on her for some time as the vomit had dried up. I felt she needed to be looked after in a more intensive way and asked for her to be reviewed. The next day the Consultant came to see her and agreed she needed to be transferred to Barnett General as she was so unwell. It was shortly after she had moved that she died.

Prior to her stay at Edgware when she had been at Barnet General Hospital there were a number of times I was shocked at the lack of dignity and compassion shown to her. She told me of one time that she had awoken in the night, dreadfully thirsty and unable to reach her drink. She pressed her buzzer for assistance. When the nurse arrived he said "What do you mean by waking me at this time of night? What to you want?"

When I visited Ann at both Barnet and Edgware sometimes I found her lying in her own faeces. She would plead with them to change her, but the answer was always firm: 'We will get to you when we have time". She didn't like disturbing the nursing staff, but she was totally compos mentis and she hated the indignity of it. One time the smell of urine from a neighboring bed on the ward became almost overwhelming. I asked to clean it for Ann's sake.

Often I would wait at the nursing station, for perhaps five minutes, to ask for help for Ann. They would keep chatting about this and that and I didn't want to interrupt them, I wanted to be polite. But then when they got to the end of their conversation, they would go off, as though I wasn't there at all. I remember once I felt so desperate, I said to them, 'Are we invisible?'

During the last days of her life in Barnet a male nursing assistant would wash Ann. Ann didn't like having to be washed by a man, but we didn't feel we had a choice. She found him to be rude and abrupt with her. Things like this ground down Ann's sense of dignity.

I know from Ann how hard it can be working as a nurse in the NHS and sometimes the care was excellent, particularly when she spent almost a week in the ITU at Barnet General Hospital. Nurses are so busy with lots of patients too look after. Sometimes the dignity of patients might not seem as important, but it really mattered to Ann. If there isn't enough staff on a ward to help with toileting or helping patients when there are accidents then hospital manager should make sure more staff are available. But I don't think there's an

excuse for some of the things that were said to Ann. There was a lack of kindness, care, consideration and friendliness at both Barnet and Edgware hospitals, all the attributes a nurse should have if they join that very noble profession.

8. Thomas George Dalziel

By his wife Christine Dalziel

My husband George had a colonoscopy in 2001 at Stafford Hospital where they removed some polyps from his bowel. He had another colonoscopy in 2002 and was told he would need to be seen again in 3 years time. We were told he would be notified when he needed to book an appointment but as time went by I kept reminding George because nothing ever came. We convinced ourselves that we must have got the follow up time wrong, maybe they'd said 5 years.

By 2007, I was sure that he should've been seen by now. I spent a week calling the hospital and got through about ten times only to be told they would call me back but never did. At first they told me that it would be in the post and that it just takes a few months. Then they confirmed he hadn't been sent one. Eventually we got an appointment for two weeks later, now June 2007. The hospital have apologised since and our family have also been told that he should have been on yearly checkups because he was a high risk group-two family members had died of colon cancer.

We went to the follow up appointment to get the results a month later and during the consultation the Dr told us he would need to be seen again in a year because he was so high risk. We had put our coats back on and got up to go when suddenly the Dr said actually, George had cancer and would need surgery.

George was admitted to Stafford hospital on the 17th July 2007 looking fit & well. The successful operation to remove the cancer and surrounding bowel was done the next day.

He was then put on a saline drip, fluid restriction, oxygen and given an epidural. George told me he was in an incredible amount of pain. George and I repeatedly told the staff but they told us it wasn't possible-he had an epidural. After we insisted they eventually agreed to give him some liquid paracetamol.

The pain continued for three days and then his legs became numb. An anaesthetist came and examined George. The epidural had been put in the wrong place. For three days immediately after his operation George had nothing but paracetamol for pain relief. I was horrified that they hadn't listened to him. After that they prescribed him morphine, but at the inquest into his death we found out he was rarely even given it.

George was a very proud man but they didn't take account of this during his time in hospital. They changed him into a set of pyjamas after the operation but they didn't help him change for days. They had blood stains all over them and eventually, on Sunday the 22nd he struggled out of bed and washed himself and changed. It was very difficult for him to do on his own and he got out of breath because he couldn't take his oxygen with him.

He remained very unwell over the next couple of days and by the 25th he was still on oxygen and we were told by staff that they were doing tests to find the cause of his continued poor recovery. I couldn't get any explanation as to what was wrong.

The following day he was given ready brek and banana sandwich and taken off drip but he began vomiting. We saw the Dr and asked if it was normal for his stomach to be so distended. We were told "well not really but we are keeping an eye on it".

His legs and feet remained very swollen and he had tube fitted through his nose to help reduce the swelling in his stomach. We were told he would have scan but it never happened. We were also told he had a low potassium level and would be given replacement but it never materialised.

On the 27th July 2007 he was put back on his fluid drip and was still on oxygen. His legs and feet were still swollen and his stomach was still distended. The tube was removed from his stomach around this time but I'm not sure exactly when.

The following day he was taken off the drip and oxygen. His legs and feet were still swollen and his stomach was still distended. It was clear to me and the rest of the family that he was losing a lot of weight but staff appeared to be unconcerned about this issue. He had great difficulty in swallowing.

Due to delays in anyone attending to help take him to the toilet, he had accidents that horrified and demeaned him. I also think this must've made the bed sores he had developed even worse. This also led to him not drinking the fluids he should, as he was fearful of having more accidents. There seemed to be a lack of equipment such as commodes and walking aids, which reduced his ability to go to the toilet when he wanted to, rather than having to call and wait for assistance. On one occasion after we pressed the buzzer a care assistant came in. We thought she had come to help but when we asked if she could assist him she

said no, she was looking after other patients. I struggled to help George go on my own because no one else arrived.

He remained in his chair for many hours for the same reason, which we believe, would not have helped his swollen legs and feet.

He was given stockings but they were taken off then put on again 3 days later.

On 30th July the Consultant came and told him he could go home the following day. I was shocked because he still wasn't eating or drinking properly, he stomach was still distended and they didn't know why. I contacted the Macmillan nurse; she said he shouldn't go home until he was better again.

I arrived for afternoon visiting and found him in tremendous pain. He had been given peppermint as they said it was just indigestion. He pressed the call button for 10 – 15 mins but there was no response. I went to the nurse's station and I asked why they were not responding to his call. The lights were not working but you could still hear the bell. I was insistent that she came with me immediately as he was in so much pain.

He told the nurse the pain was all over and a Dr arrived 20 mins later to examine him. Following the examination he was violently sick and they told us he needed the tube in his stomach again. George was very reluctant to have this done, it was very uncomfortable and he was already in pain. When they left I persuaded him it was for the best and he agreed. I went straight to the nurses station and told them. They wrote in the notes that he had refused treatment and wouldn't change it even though I had told them he had changed his mind.

I returned that evening and instead of a tube he had been given morphine. No one explained why.

On the 31st July 2007 the Dr told us he seemed better that morning I again asked what was wrong with him. She said they still didn't know and again said they were doing tests. I again mentioned his weight loss but again they didn't seem concerned. I returned in the evening with my daughter and son in law. My daughter was so shocked at the deterioration in his health from the Saturday, she ran out in tears. His normally clear blue eyes were dull and vacant. We read in his notes that food had been offered and "Refused", there were no details as to why it had been refused. He couldn't swallow without help. He was finally given Fortisip build up drinks after days of losing weight and not being able to eat properly. We wish it hadn't been left until he was nearing the end of his life when it was apparent to everyone he could not take solids and was losing weight rapidly.

The next day, on the 1st Aug 2007 George passed away in the early morning. When we arrived on the morning of his death, I asked if we could see him. The nurse asked if they could have a few moments to prepare him. When we were taken to his bed we were not prepared for the horrific sight of seeing him, eyes wide open with a resuscitation tube down his throat. This image has traumatised not only us but also my sister and brother in law for the rest of our lives! When my daughter asked if the tube could be removed the nurse

informed us that it had to stay for legal reasons. We should have been warned before hand so that we could have made an informed choice of whether to see him or not. This haunting image of a proud man who looked as if he had starved to death will stay with us forever!

9. Jayne Knowles Smith

I have been a nurse for 30 years. I used to pride myself on being a nurse and hopefully I was caring and thoughtful. I have had the misfortune of seeing nursing from another angle as a patient. It's a scary world out in the wards. I'm not sure if it's the training that's lacking, the basic skills or just understaffing.

I have a form of heart disease that affects younger people and unfortunately I suffer the effects of heart failure. During a recent admission in February 2009 to Gloucester Royal Hospital I stayed on cardiac care ward for 3 weeks.

When admitted on the cardiac care following fluid overload, as you would expect I was placed on strict fluid monitoring. It's important that my fluid balance is monitored as fluid overload is one of the main things that makes me unwell.

A fluid balance chart is a simple basic chart that we are taught to use quite early on during nurse training, you simply record fluid intake (through drips or drinks) and fluid output- basically urination.

Obviously this means my urine needs to be collected and measured. You don't just need to measure amounts, you need to get a rough idea when the fluid was lost. I was appalled that during my stay I ended up with a bathroom full of bottles of urine that would be there all day. The nurses did not come and regularly measure and dispose of the urine. Not only was there a very unpleasant smell in my room by the end of the day, but it meant they had no real way of measuring my urine output over time. This is absolutely basic to the care of my heart failure.

I was writing down all my intake (like drinks) as being in overload I was on a restriction to 1 litre a day, I was having Diuretics IV being put through in 100mls of saline, Not once in 6 days

was this recorded on my fluid balance chart by nurses, When I made a comment I was told we are the nurses not you!

Having heart failure my veins are not to good and to canulate me is difficult. It seemed to me like it had almost become a game for the nurses-who get it one placed in 3 or maybe 4 attempts. Due to the fragile state of my veins the cannula only lasted for a day before the vein became damaged and the fluid leaked into my arm. This was very painful. In the space of 4 days about 12 attempts were made. My arms were black and very bruised. After the last attempt I had had enough and wanted to use one of the more permanent ways of giving fluids, what's known as a PICC line that goes into a bigger vein closer to your main blood vessels. I told the nurse I didn't want any more attempts at cannulation and she told me to grow up.

When my cardiologist came in I asked about the option to use a PICC line and after much discussion one was fitted. This was so much better-no more daily attempts at inserting cannula's, no more pain from when they leaked.

But it wasn't long until this caused yet more problems with the nurses. It was obvious to me that they didn't know how to use the PICC line. I know nurses from different specialties aren't always familiar with every piece of medical equipment they might come across but when this happens they should ask for someone who is to help. But rather than ask a nurse who did they carried on trying.

A PICC line is much more delicate than other types of cannula and has to be used carefully. There are serious potential complications like a risk of injecting air bubbles into the bloodstream and a risk of bursting the line if it isn't used properly. It is also best practice to maintain sterile conditions when handling the line for any reason.

At 6 am one morning a nurse came in to give me my drugs and take bloods from the line. She didn't wear gloves or clean the lumen. She could not get blood from the line. She was using a 5ml syringe, when best practice guidelines recommend you use a 10 ml syringe because of the pressure the smaller syringe can create.

No blood was coming out and she began pumping the syringe to try and get some. Not only was this uncomfortable for me, it is exactly the kind of thing that can burst the line. I asked her to stop and she said "I need to bleed you." She gave up and another nurse came in to try. She did exactly the same thing. I became very worried and was asking them to stop.

Luckily for me a phlebotomist came by and heard me shouting. She saw they were doing wrong and took over. She was great. She took blood from the line and gave me the drugs without any problem by doing it the correct way. Later that day a nurse from the oncology centre came up and explained to nurses how to handle and administer drugs via a PICC line. She seemed very concerned at their lack of knowledge.

Nobody apologised to me for what had happened.

Later that day a Nurse came into my room with a trolley saying my kidneys were failing and they needed use a catheter to monitor my urine output. She said that I had been peeing

very little. I pointed out that I had been peeing regularly but they had simply not monitored. I refused to have a catheter put in and felt like I was beginning to be labeled as a difficult patient.

After discussions with my cardiologist where I explained that had been happening it was agreed that I didn't need a Cather-fluid balance charts just needed to be recorder correctly. I was discharged 4 days later when it was clear I had stabilised!

I worry about going back into hospital now because it's probably on my notes that I refused some procedures and I know from my work as a nurse it's very hard to lose the 'difficult patient label'.

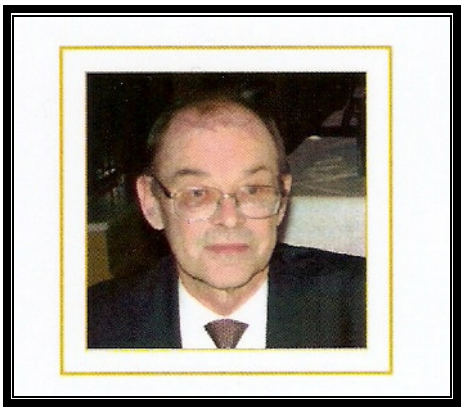
But I wanted to tell this story because I think it's important that people appreciate that staff should treat patients with the upmost care, especially when it comes to things that are a risk to patient safety. If they haven't used a piece if equipment before or if they haven't done a procedure before they should make sure they have been properly trained and know what they are doing.

I also think from my experience and talking to others that some nurses are forgetting the basics of care. Fluid monitoring might not be very exciting but it is a key job for nurses to do to make sure their patients are being looked after. And that is what should be their priority.

It's not acceptable for staff to be unable to do these things because they are overwhelmed. It's not fair on them or patients. Hospital managers need to make sure every ward has enough nurses so they can do every part of the job they've been trained to do.

10. Colin Richard Purkiss Smith

By his wife Marian Smith



My husband Colin was admitted to The Princess Royal University Hospital (PRUH) on the 10th June 2008. On the morning of Monday 16th June, after all of the suffering and indignity that my husband had to suffer at the hospital, he died.

I wanted to take part in this report because I never ever want someone else to go through what my husband and I did, in what turned out to be the last few days of his life. I never ever wanted compensation, I wouldn't dream of taking financial resources off the NHS. I just wanted to be shown by the Trust what they'd done to honour my husband's memory by making the necessary changes. They were never able to do that.

During the night of Saturday 15th March 2008 whilst watching the television my husband said that he had chest pains and as a result, I asked him whether he wanted me to call a Doctor. My husband said that he did not think that he needed a Doctor and would instead go to bed. Then in the early hours of Sunday 16th March, at approximately 1 a.m., my husband said that he was still having chest pains and after speaking to an out of hours service my husband was taken to hospital. He was supposed to be taken by ambulance but we were told none was available so a paramedic had to take him herself.

We got to PRUH where my husband was taken to A&E. He spent the night there and after they had done a number of tests they gave us the news that there was a chance my husband had lung cancer. The Doctor who told us said he would get an urgent appointment next week to get a CT scan and that a visit the Respiratory Clinic within 2 to 3 weeks would be arranged. He was sent home that Sunday evening.

Eleven days later I contacted the Trust as I hadn't received an appointment. I left an answer phone message for the PALS department after finding their number on the Trust website. By the 8th April, some 23 days after my husband had been told he would be sent an urgent appointment, still nothing had arrived. That evening he became unwell again and I contacted the out of hours service once more. A kind and considerate Doctor spoke to me and after hearing the history looked up my husband's records. There weren't any to be found. He asked me to bring my husband in straight away and waited to see us though he was due to finish work.

After seeing my husband the Doctor wrote a letter for us to take to A&E requesting that we give the letter to the Doctor that was going to see my husband and the letter requested that as my husband was very poorly that he should be admitted to the hospital.

I took my husband to A&E where he had a chest X-ray and was examined by two Doctors who said that they could not admit him as there were no beds, but would keep him in hospital but would do a blood test and decide whether he should stay depending on the result. The blood test was supposed to measure the oxygen levels in his blood but after trying twice, they couldn't do the test. But they sent him home anyway. I was upset by this as I could see how poorly my husband was and previously agreed with the out of hours Doctor that he needed to be admitted. They told us to keep contacting the hospital for the urgent appointment.

By the 9th April I was at the end of my tether with the hospital and felt that my husband's condition was being ignored and I felt that something should be done. I contacted the secretary of the Doctor who had originally seen my husband and said he should be seen urgently. She said she would see what she could do but couldn't arrange for my husband to be seen on that day.

The next day I had an appointment myself at the PRUH and I decided enough was enough. I went to the PALS Department after I had been seen and I said I wouldn't leave until I had an appointment for my husband in my hand. I was given an appointment for a CT scan the next day (a Friday). The Doctors Secretary said she would ring me on Monday and let me know whether the results showed my husband needed to come in.

At 09:30 on Monday morning the Secretary rang and asked whether we could get to the Hospital for 10:45 and I said that we would. The doctors said that my husband had lung cancer and he commenced treatment on the 16th April 2008, one month after he had been told he would receive an urgent appointment. I have often wondered how long it would have taken had I not taken such drastic action.

My husband and I had considered opting for private medical care as we have private medical cover, but due to the strange rules and regulations regarding private medical cover and NHS treatment we had decided it was too much of a risk. Had we realised the severity of my husband's condition and the lack of care that he received when he was admitted to hospital on 10th June, we would have chosen to go use private medical treatment.

Everything was going as planned, until my husband had to be admitted to the PRUH by his GP on the 10th June suffering from dehydration and then things progressively went downhill once again. Thinking about this now, this was the saddest day for me when my husband was taken into hospital, as I trusted the hospital to look after him as he was very sick and having lived through the following I now feel that the Hospital failed in their 'duty of care'.

When my husband was taken into hospital, he was taken to a Medical Assessment ward where he was seen by a Doctor, following which a saline drip was set up for him. My husband then wanted to go to the toilet and the nursing staff stopped the drip while he

went. When he'd finished I asked the nursing staff to come and start the drip again. In the end I asked three times over the course of an hour but I was ignored. A friend came in to see how my husband was and my friend also asked the nursing staff to have a look at the drip (my friend herself used to be a nurse). Her request too was also ignored.

Later that night, my husband asked me whether anyone was coming in to see him to sort out the drip (bearing in mind how sick he was, I believed that it was crucial that he should be getting some fluids) and my husband said that if he did not get seen then he would get dressed and go home. I fully understood his frustrations, my husband wanted to go home because he was not getting 'active treatment' and despite several requests made to the nursing staff the nursing staff had still not flushed his cannula and turned the drip back on, therefore in my mind my husband was being ignored and was not having 'active treatment'. Bearing in mind he was very sick, it was crucial that he was treated.

I left my husband at 11.30pm to call my Sister (who is a Barrister) and asked if she could help. She said she would call the hospital. In the meantime my husband became frustrated and dressed to leave. He began heading out of the ward and the staff called security that went after him. When they brought him back to the ward I explained that he had left because he hadn't wanted to be here in the first place and he didn't think he was getting any active treatment.

As a result of this and the contact that had been made with the hospital by one of my family, a nurse was then sent into to the room to help with my husband. This nurse was very caring and really helped my husband. Why oh why, could this have been done in the first place – why did I have to get someone to plead his case?

I went to the hospital the next morning and I was told my husband had fallen out of bed and as a result cut his head badly while trying to get himself to the toilet. There was still blood on the pillowcase and blood on the floor. When I spoke to the nursing staff asking why my husband had fallen out of bed, the comment was "we heard the terrible thump on the floor" and when I asked the nursing staff why the guard rails were not up on the bed, they said that they had "forgotten".

My husband was moved to another ward the next day (Thursday) and despite the fact that he could not eat solid food because the tumour was pressing on his oesophagus, that's all he was given. None of the staff explained to me that I could order my husband pureed food. Also, as he had difficulty drinking there was no offer by the staff to provide my husband with a straw or a beaker which would enable to have a drink. I was bringing him in drinks from home so that he could have some fluid.

No one came along to talk to me about my husband's care and I asked the staff several times when the Doctor would be doing their rounds so that I could talk to them about my husband and was advised that the Doctor did not come in until Friday.

My husband fell out of bed again! while trying to go to the toilet and when I went back in to see him, there was blood again on the pillowcase and again his head was badly cut and there was also blood on the floor. I asked why again the guard rails were not up on the bed and

the answer was again that they had forgotten. Not surprisingly, my husband wanted to go home.

That evening my husband wanted to go to the toilet. I needed help from staff to take him and so I asked staff for help. Over an hour later still no one had come and my husband had an accident in the bed.

I went outside of the room to the nursing station to get one of the staff to get clean sheets for the bed and when I looked, I noticed that one of the staff on duty was surfing the internet.

An hour later they got clean sheets and I helped him make the bed and changed my husband's gown but they said it wasn't necessary to wash him. I couldn't do this on my own and so had to accept that.

The next day I actually managed to see the Doctor and was advised that my husband could have no further treatment as he was too ill. I asked the Doctor whether I could arrange to bring my husband home and she said that she would put things in place, but because of the paperwork this would probably take about five days and because my husband was so ill he may not make it.

I since understand that if someone is so ill there is an option of no more active treatment, i.e. drips, therefore giving the patient the freedom to go home or to be admitted to a hospice where my husband could have died with dignity and peace. No one discussed this with me or my husband.

If I had known or someone had told me the severity of my husband's illness once he had been taken into hospital, I would have moved heaven and earth to ensure that he was comfortable and that he got what he wanted, which was to be bought home. I could not achieve this for him because no one sought to talk to me about his condition when he was in the hospital until that Friday. I had no idea that he was going to die in there until then.

On Saturday, my husband was able to sit in a chair and talk to his visitors and we were told by the staff that my husband was to be moved to the cancer ward later that afternoon as the ward that he was currently in was being steam cleaned. This was probably a necessity as there was about an inch of dust underneath the bed. This was even commented on by the Porter when my husband was moved.

I had bought a blanket in from home as my husband was complaining of the cold and my husband wore his dressing gown in bed to help keep him warm too. I had asked staff for extra blankets but they were never brought.

My stepdaughter, who is a nurse, was present during Saturday morning when one of the nurses came into the room to re-cannulate my husband. My stepdaughter questioned the nurse on the position of the cannula, as the vein seemed to collapse and there was no flashback. The nurse flushed the line and assured my stepdaughter that this had not tissued. Later that afternoon, my husband complained of a painful arm and we removed his dressing

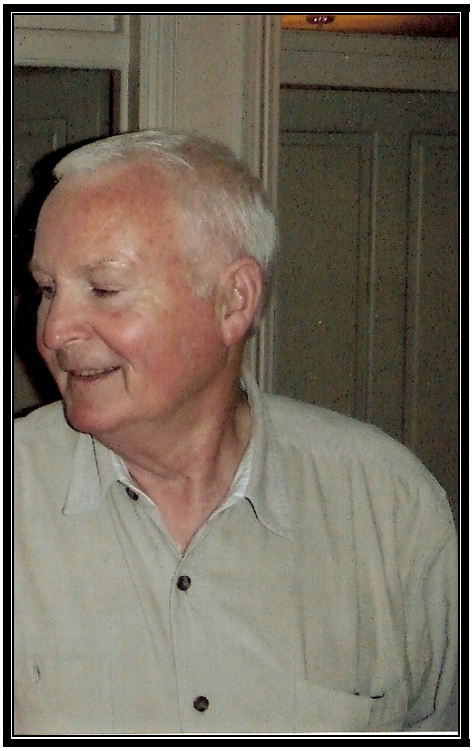
gown to find that in fact the cannula had tissued, thus meaning the whole litre of fluid he had been given was in his arm causing pain and discomfort.

Later that afternoon, my husband was moved to the cancer ward. I wish he had been there from the start. The staff were very understanding and kind and fully appreciated the nature of my husband's illness. They were very kind to both of us.
My husband died two days later at 5.45am in the morning.

I firmly believe that anyone irrespective of their illness deserves to be treated with dignity and care. This has been the most distressing time of my life and I do not want nor wish this to happen to anyone else. Something should be done to ensure that this does not happen again.

11. John David Drake

By his wife Margaret Drake



My husband John David Drake was diagnosed with prostate cancer in May 2008 and after a long battle and the help of some excellent staff at PRUH he was eventually moved to a hospice during the final few weeks of his life. He was shown the utmost care and compassion by the busy staff at the hospice but on the 28th July he was taken to Princess Royal University Hospital for an MRI scan.

I had insisted that he was taken out of the hospital the next day because I was appalled at the way nurses on the ward treated my confused and dreadfully unwell husband. Whilst it was an agonising decision, I knew on return to the hospice he would once again be looked after by people who made his dignity and comfort their first priority. On talking to my close friend Marian who had a similar experience over a number of days in PRUH I now feel it was the right decision.

After being assessed in Accident and Emergency my husband was admitted to a ward. On the journey to the ward we were accompanied by a female member of staff from A & E and two porters. When we arrived on the ward the female staff member proceeded to shout at my Husband “can you walk”? “Can you get on a bed on your own”?

I informed her that my Husband could do neither without assistance; and I asked her to please not shout at my Husband as he was neither deaf, nor senile. The girl then asked me

abruptly to “wait outside”. I didn’t feel comfortable leaving my husband at that point so I didn’t.

I stayed with my Husband for some time and told the staff that my Husband thinks that he can walk, but he cannot without assistance. My Husband also had a catheter, but was very unaware of it and would be even more unaware of it because he was so confused at the time. My Husband was most anxious about wetting the bed but I was told by the staff “don’t worry, we will look after him”. I told the staff to call me or another family member if my Husband could not settle or if there were any developments and we would come to the Hospital immediately.

On the 29th July, both my Son and I were at the Hospice where my husband had come from, talking to the Doctors about his care. On the way back from there to the Princess Royal University Hospital at approximately lunch time we received a call from the Hospital to say that my Husband had a fall. In fact, this call was made 2 hours after my Husband had fallen. Both my Son and I then went to the Hospital and when we arrived at the Ward, we were both shocked to see the state that my Husband was in. My Husband appeared very de-hydrated and even more confused. My Husband had not been washed and neither was there water on my Husband’s locker. I washed my Husband myself and gave him a lot of water to drink. It took some time as it was hard for him to swallow but with some patience and care he was able to drink plenty of water to quench his thirst.

On discovering that my Husband had fallen, I asked how this had happened and the Staff Nurse said to me in what I perceived as a rather aggressive manner that “I was talking to the Bed Manager”. I responded by asking “is the Bed Manager more important than a patient who is desperately ill”? The other nurse that was with the Staff Nurse at the time then said to me that “we told him to go back to bed”!

I was absolutely shocked that they must have seen my husband walking and not rushed to help him. I had made it clear that he wasn’t safe walking on his own. I also asked no cot sides had been put on the bed and was told this was because it was “dangerous.”

As my husband was so thirsty when I arrived and didn’t appear to have been given any water to drink I asked why he had not been put on a saline drip. They said that they had given my Husband three packets of crisps, despite having been told that my Husband had difficulty eating.

I felt completely bewildered and powerless. The demeanour and attitude of the staff seemed so different to those at the hospice. I was determined that my husband would not live out the last few days of his life in their care. I said to the staff that “I wanted my Husband out of there and taken back to St. Christopher’s Hospice”.

At one point a Staff Nurse told me that my Husband was not their only patient and that it was not a one-to-one nursing situation. The hospice was also not a one-to-one nursing situation, but the staff their dealt with many more difficulties with patients and did so with compassion and care.

My last words to some of the staff were that “your lack of compassion disgusts me”. All nurses should remember what the definition of a nurse is.

Nursing is the care of the sick. A Nurse is a person trained for the care of the sick. One who looks after the comfort of a sick or infirm person. To tend as a Nurse; to manage skilfully.

My Husband died in my arms on the 26th August under the very kind attention of the Nurses at the Hospice.

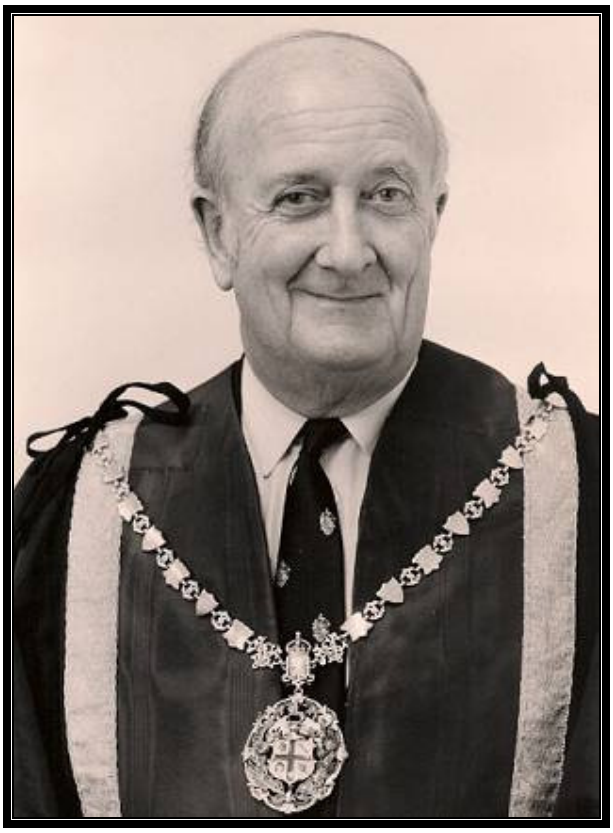
I wrote a letter of complaint to the Trust as I wanted to ensure that this will never happen to a dying person in need of care, compassion, dignity and respect again. This is not how patients in the last months or so of their life and indeed any patient that is being seen in Hospital should be treated.

I asked them not to reply with anything like “The Bromley Care Guarantee in which your Trust promises is delivered through getting the basics right. The Bromley Care Guarantee is about high quality care, delivered by caring people, in safe and clean hospitals”. This is what Trust that manages PRUH states on its website. That is what I received.

I have been told by many people that there is little point in complaining but I wish more people would. We need to make it clear that we want our loved ones to be given the very best care. This doesn’t need to be expensive. It just means that every patient should be treated with dignity, compassion and respect.

12. Professor Leslie C Vaughan

By his daughter Sian van der Welle



I found myself in the unhappy position of making a formal complaint about the treatment that my father, Professor Leslie C Vaughan received at Hemel Hempstead hospital in the two weeks leading up to his death on November 14th 2008. The illness of a close relative is enormously difficult to cope with and I think we all look to the NHS to support them and us through it and to provide care with dignity.

My father was diagnosed with stomach cancer in July 2008 and it was decided that the best approach to the problem was to carry out a gastrectomy operation and this was done mid July at Watford General Hospital.

Although there were many kind and efficient nurses on the ward especially many of the student nurses I did have concerns about the nursing care at Watford General. There was a lack of information given to patients and opinions voiced by medical staff at different levels often conflicted. We quickly realised that if you do not ask you do not get to know.

There were examples of unsympathetic handling of patients by portering staff when my father was taken to other units in the hospital for scans and tests. I could list numerous day to day examples over the course of his stay. On one occasion a porter taking my father for a scan pushed the wheel chair with such force that the side of the chair slide out of position and trapped a catheter tube.

On another occasion a student nurse wrongly labelled my fathers sputum pot with the name of another patient but when we spotted this she repeatedly denied this and then when she was proved wrong denied that it would have been a problem.

There were some basic hygiene failures. I remember seeing a wound dressing left on the floor when I left one evening. It was still there when I came back in the morning.

Drips and feeding tube pumps frequently set off malfunction alarms although for the most part they were not malfunctioning and busy ward staff would then have to reset them. It was then usually necessary to find a member of staff to do this when they were busy on another task. I was told that pumps were often labelled as 'broken' without any detail about the problem. This meant that they had to be retested to find the nature of the problem.

In a busy ward some problems like these are probably unavoidable but it did worry me that people without family or friends visiting were very much on their own when it came to sorting things out.

I was also concerned that when he was cleared to start feeding my father was not given the little and often, high calorie food that he needed and did not really re establish eating. Very soon after his operation a nutritionist visited to tell my parents about the diet that he would require. She issued diet sheets for use at home and asked that he bed fed nutritional supplements. The food provided in the ward bore no resemblance to the suggested diet.

Although there were very definitely some short comings at Watford, many of them I believe due to staff shortages there were also some positive points. The staff were sympathetic to the needs of my elderly mother, who has macular disease, and as a result has very little vision. Many nurses were sympathetic and caring. In light of this, when he returned home and we were asked to comment on his stay we did not list any complaints.

Following his discharge from Watford General Hospital my father spent almost one month at home under the care of his GP, district nurses, Macmillan nurse, health visitors and physiotherapists. The health visitors and nurses who supported us during this time were without exception kind and caring but despite this care my father failed to thrive and developed a bladder infection.

He was persuaded by the GP and some other health professionals to go to St Albans Hospital. The purpose of this was to rehydrate him and feed him. He was admitted on Wednesday 29th October but the staff were unable to set up intravenous fluids for him so they put in a subcutaneous drip instead. They also failed to give him his prescribed antibiotics. I was told that this was because they had not been issued by the hospital although because my father had had his spleen removed he needed to take antibiotic for the rest of his life as a precautionary measure and these were prescribed regularly by the GP.

He was by now finding it difficult to eat and by Thursday 30th he was having a problem with his swallow and it was found to be unsafe. Due to his general weakness his ability to speak

was affected and after being seen by a Consultant he was transferred to Hemel Hempstead Hospital under this doctor's care.

He was admitted to Hemel Hempstead during the evening of Thursday October 30th. There was a long delay in A and E finding him a bed and in taking his details which for an elderly person who was by now very uncomfortable was an additional trial. The wait for a bed was not longer than 4 hours. This might be reasonable in some circumstances but I think it's too long for an elderly unwell man and his equally elderly, blind wife. Especially when you consider they knew he was coming in advance.

The cubicle opposite was occupied by a drunken man and two police officers. The noise and bad language was unacceptable. I had to make a decision to take my mother home because she was tired and distressed but that meant leaving my father alone to wait for admission. This was a dreadful choice to make.

I understand that he was found a bed at about midnight but feeding and intravenous fluids were not sorted out until the following day, even though this was the reason he had been moved from St Albans.

We were hopeful that some of my fathers problems would be dealt with on the ward but found the staff to be uncommunicative, defensive and unsympathetic.

By this time my father was finding speech almost impossible which was obviously distressing and frustrating for him. He was a highly intelligent and articulate person and had a 59 year career as a surgeon in the veterinary profession. The speech problem made it very difficult for him to communicate and it seemed that the response to his inability to answer was to shout loudly as if he was deaf. When I gave him a notepad and pen to write what he wanted to communicate he was able to write what he wished to say. The hospital has in fact reported that my father was deaf when in fact he had no hearing problem at all.

On further discussion with the Consultant, my fathers Macmillan nurse and a local palliative care Consultant my mother and I agreed that a hospice place would probably be the best option. We visited a local hospice where the palliative consultant worked we discussed the hospice option and I arranged a visit.

Following our visit to the hospice on the afternoon of Tuesday 7th November I arrived on the ward for visiting only to find that staff were in the process of moving my father to another ward. They had made no effort to get in touch with either my mother or I to discuss this move or at the very least let us know it was happening.

When I asked why this was they explained that they needed a bed and the bed Manager had authorised it. I asked which ward he was being moved to and whether he would still be under the care of the Consultant who had been looking after him. They said that this would not be the case. This worried me because we were so close to moving him to a hospice with the current Consultants help. The staff suggested that 'he would be nearer intensive care which would be an advantage since he needed extra care'. I found this comment very unhelpful. When I said that I would call the Consultant to ask her opinion on

the move they decided to move another patient instead. This attempted move of a dying man without any consultation with his family or Consultant was upsetting for my mother and I and disturbing for my father.

I later found out that the ward he was on was supposed to be for short stays only and they were moving him to a ward that would have suited his needs much better. It has been very difficult for me to know I halted this change and I only wish staff would have explained this too me at the time.

During the rest of that week his condition did seem to improve slightly within the limits of the prognosis. On Friday during visiting time the Consultant came to visit my father and discussed the possibility of a place at the hospice. We had described it to him and had said how wonderful it would be for him and my mother. We had been assured by hospice staff that since the Palliative Consultant had suggested the hospice was the right place for him he was likely to be offered one and he started to ask my mother when they would be going.

For the first time he acknowledged that he felt that was dying and wanted to go with her. This was a heartbreaking moment for us all. The forms for the hospice place were filled in and they were faxed before the end of Friday. The consultant told him his chest sounded a lot better and told staff that he should be put into a chair for periods over the week end which would help his chest and relieve the pressure on his bed sores. This never happened.

Staff explained this by saying that it was their call whether a patient was well enough to be put in a chair and despite what the consultant had said they had not felt this was the case. However I was lead to believe that the Consultant was not pleased that this had not been done when she learned of it. In fact on the following Monday my father was provided with a chair and did spend some time sitting in it.

Over the week end my father telephoned my mother in a panic several times. On one occasion a member of staff took his mobile phone from him as he tried to phone. We did not get to the bottom of what caused this upset but he seemed to think that he was being moved to another ward. His speech, although improved, was limited and again the frustration of not being able to communicate must have been very difficult and upsetting for him not to say frightening.

Often the call device was out of reach for him and he was unable to call for assistance. I couldn't understand this because every time I left my father at the end of visiting I made sure that he had the bell to hand so that he could call staff in a dignified way especially since he was finding speech difficult.

He was at points in a soiled bed until staff were available to clean him up. These periods may not have been unreasonably long given the staff workload but he and others on the ward had to attract the attention of staff by calling out and this was upsetting and degrading.

Additionally, at a point during this last week his urinary catheter was removed because it was blocked. It was replaced with what I understand is a sheath type device. This replacement device leaked urine so that the bed and his hospital gown were soaked. Staff

said this was because ‘he interfered with the device’. I would suggest that in that case it was not a satisfactory solution to the problem and an alternative might have been sought. A Macmillan nurse told me that she had been told that my father removed the original catheter himself. This was not the case it was done by a ‘catheter nurse’ while my mother was visiting and she scanned his bladder at the same time.

That same week end my mother also noticed that his hair was matted at the back of his head with blood. This was due to ‘lesions’ (my term) on his head which had rubbed against his pillow ‘because he will keep moving his head’ to quote one nurse. When my mother asked staff about dealing with these a nurse collected his medical notes to show her that these ‘lesions’ were present when he was admitted to Hemel Hempstead. This was not a useful response since whenever they had developed, what they really needed was bathing and in any case since my mother has macular disease she could not read the records she was shown. Another nurse said that she would ask a dermatologist to come and look at them. This offer was repeated a few days later but never materialised and in fact on Sunday when I visited I asked a nurse how I could clean his head for him since nothing had been done by then.

The weekend, which as it turned out was the last weekend of my father’s life was very miserable. The ward has no view on the outside world and is very bleak. But we were hopeful of a move to the hospice early the following week. However on the Monday morning we were told that no hospice place would be available because my father had so improved. We were told that the hospice can only take patients for a few days and in my father was no expected to live longer than this. This was very distressing news as we had been preparing my father and ourselves for this move. It felt as if all of a sudden there was no loner a plan. I had promised him that he would go to a hospice to be with my mother and not die in hospital.

I was so concerned about losing the place that I asked for a meeting about what to do next. This meeting on Tuesday 11th turned out to be a multi disciplinary meeting. As I write this I can hardly believe what I remember about the meeting which I would only describe as a farce.

My mother and I were taken to a disused ward where a large number of medical and social work staff assembled.

There were two social workers, one nurse social worker who organises discharges from hospital, a dietician, a junior, a Macmillan nurse, a senior ward nurse and a physiotherapist.

The young doctor had only just skimmed my father’s notes and kept referring to the consultant as he when in fact she was female. She had no knowledge of the case at all and little understanding his needs

The senior nurse suggested that my father (whom she had not nursed over the weekend and who had told us that he hadn’t been not been moved out of his bed as requested by the Consultant because he was apparently not well enough to be) was actually now stronger and

more mobile and this comment just about exemplifies the ridiculousness of the meeting we sat through.

It was agreed to try two other hospices, and we were told that they would look into this as a priority. I have never really understood why it was suddenly decided that my father couldn't attend the hospice we had chosen. I appreciate that there is very limited availability of these kinds of places. That is a real shame. But even so, I was never given a clear explanation of why they felt his condition had improved so much.

Progress in the application for an alternative hospice was fast tracked and by Thursday we heard that one was available. However by Thursday evening my father required oxygen which he hadn't before. He was alert and able to communicate though and we told him as we left that we would be back in the morning to go with him to the hospice. One nurse told my mother that she would let her know when the transport arrived in the morning.

The following morning (Friday) the nurse rang my mother and said that my father had deteriorated and that she might like to travel with him in the ambulance. We rushed to the hospital and when we entered the ward he was alone behind the drawn curtains with an oxygen mask on. My mother sat and held his hand and very soon after he died.

I find it unacceptable that a man at this point so obviously close to the end of his life should be left alone behind a curtain on a busy ward. The staff had phoned us and knew we were coming so that they surely could have spared a sympathetic nurse to sit with him until we arrived. It wouldn't have been longer than 30 minutes. It might also have been sensitive to watch out for our arrival so that at least they could have warned me and I could then in turn have spoken to my mother.

When you witness the end of someone's life the memory remains with you forever and this uncaring and insensitive attitude has made the grief much more difficult. When my father died I asked a nurse on the ward if it would be OK for my niece to see him since she had been very kind to him during his illness. The nurse replied quite sharply 'How long will that take?' I had to explain it would take about 20-30 minutes before she said it would be OK. This again seemed an unnecessarily uncaring attitude.

End of life care in the NHS needs to be much better than it is. Might it not be possible to have staff in the hospital who could sit with dying patients who are alone? I think the comfort this could bring to patients and their relatives would be immeasurable if staff were in a position where they could do this. Instead my father spent his last few hours alone surrounded by the noise of a busy ward. The thought that he held on until my mother came to sit with him is actually heartbreaking.

The final insult in this episode was, about a week after his death, my mother received a letter addressed to my father asking him to rate his stay at Hemel Hempstead Hospital.

13. Margaret Bristo

By her daughter Elaine Hutchings

My mum, Margaret Bristo, was admitted to A&E at Queen Elizabeth Hospital in Woolwich on Thursday 22 January 2009 with severe hypothermia.

She had had a thyroidectomy a number of years ago and blood tests revealed her thyroxine levels were dangerously low. She had been on replacement thyroxine for many years but at some point it had been stopped. To this day we're not sure why or by whom the thyroxine was stopped.

She eventually went into hypothyroid coma and was taken to ITU where she had excellent care. After 4 days in ITU mum was transferred to another ward. We were expecting that the care would not be so intensive but were disturbed by the laxity of looking after her.

When we came to visit her the first evening she had been moved there were no cot sides on the bed. We had to ask for them to be added. Our impression of the ward was that it was overwhelmingly busy and there wasn't enough staff.

I would arrive at lunchtime to visit my mum and go to the nurses station to find out whether the doctor had seen her and what they had said. Often you would stand right in front of them but staff would keep their heads down and avoid eye contact with you. All my brothers and sisters felt the same. One even said asked "am I invisible" after being ignored time and time again.

It was a constant back and forth to the nurses to ask for things to be done. Whether it was replacing mums drip or helping to proper her up because she had slipped and lay awkwardly on her neck-unless we went out and prompted staff, things weren't done.

Mum couldn't have drinks which left her with a very dry mouth. She got some relief if we sponged her mouth with some water. We would always ask staff when we left to do it for her but whenever we came back her mouth was always very dry. It didn't seem as if anyone had actually done it.

When it was clear the Doctors could do nothing for Mum the palliative team were called in. They stopped the deep lung aspirations that mum had been having to help with the fluid on her lungs. They were distressing for Mum so they said aspirations just from her throat would be fine. However after this, when my sister was with her, the nurses asked her to leave the side room she in so they could care for her. They carried out another unnecessary deep lung aspiration because they hadn't read in the notes that they were supposed to be stopped.

The palliative team also said mum could have ice cubes to suck on as her thirst was getting worse. They said that was often a great relief for patients. In the 4 days between them telling us this and mum passing away we couldn't give her a single ice cube as the ice cube machine on her ward and the nearby ward was broken. Staff just told us they had asked for it to be fixed but didn't know when it would be.

It was decided that mum should be transferred to a hospice. On the day of transfer Mum my sister was with her and thought mum's condition was rapidly deteriorating. She became very concerned and asked staff to look at her. They did and decided Mum should have another shallow aspiration. My sister saw the staff nearby chatting while she waited for them to come and help mum. She began to struggle because of the fluid. My sister felt she was choking. She called the staff again but mum died shortly afterward.

14. Alice Fowler

By her daughter Susan White

When I went to meet with staff from the Trust to discuss the issues laid out in the account below I took a picture of my mother with me. I wanted to remind everyone that we were talking about a person who had lived a full and productive life and whom my family and I cared deeply about. I wanted to take part in this project to highlight not only the problems with care but the complaints process as well.

My 93 year old mother Alice Fowler was admitted to Barnet General Hospital on 18th March 2007. She arrived at Accident and Emergency with breathing difficulties and after assessment was admitted to a ward where she stayed for four weeks. During that time I was very unhappy with the level of nursing care she received, and how my concerns were dealt with when I raised them.

Throughout my mother's stay I spent a great deal of time on the ward with her and was disturbed by the poor level of care given to her and other patients. It was apparent to me that there was not enough staff and the continuity of care between shifts, particularly at weekends, was woefully inadequate. For instance, I had to tell a nurse, drafted in from another ward, that a patient was nil by mouth when she attempted to give her water.

Despite being very unwell herself, my mother used her call button numerous times on behalf of other patients because they were too ill to use the buttons themselves.

Nurses spent a great deal of their shift at the nurses station (located some distance away from most of the bays) writing up notes and ordering supplies etc. – the time spent actually nursing was minimal. Between the regular taking of temperatures, blood pressure and giving medication, there was little or no contact with patients.

Communication between staff, relatives and patients was very poor. The staff on the ward regularly seemed not to know what was happening and there were no regular ward rounds, when a family member could speak to a Consultant or Registrar. Nursing staff couldn't tell me when there would be ward rounds. I therefore resorted to contacting the Consultant through his secretary to get an update on my mother's care.

On one occasion I arrived to find all the bedding stripped from her bed but my mother's name was still above it. I thought that she had died. It turned out that she had simply been moved to another bay, but the main board at the nursing station had not been changed and I hadn't been told. All it would've taken was a quick phone call. Worst of all for my mother (who was on oxygen) was that she was "dumped" on the side of the bed opposite to the call alarm, her drink and the cabinet containing her things. I had to help round to the right side myself as the nurses were just too busy.

My mother and other patients could be left on commodes for up to ½ an hour at a time. Having left her to go and get myself a coffee from the cafeteria and to have a breath of fresh air, I returned to the ward to find her still slumped on the commode. Here was a lady of nearly 94 with end stage heart failure left like a sack of potatoes, with no means of calling for help. There was another occasion when my mother had blood taken and some of it had spilled onto the floor. After several requests for the floor to be cleaned, I gave up and did it myself. My mother's embolism stockings were not changed for more than three weeks and would not have been even then had I not pointed out how dirty they were.

There were problems with the availability of porters after usual working hours. One evening my mother was taken at 7.30 pm for an X-ray, which was done relatively quickly. In spite of being on oxygen, she was then left *alone* with no means to call anyone or access to a drink for over two hours, not getting back onto the ward until 9.50 pm. I was *appalled* that she had been left alone for so long.

The quality of the food was low but more importantly there was little or no assistance given to elderly patients when trying to eat. I witnessed patients struggling to open plastic packages of sandwiches and/or fruit juice. Sometimes if patients weren't awake during meal times their food was left uncovered without any attempt to wake them or encourage them to eat. The food would then be taken away untouched. Hot drinks were served in paper cups in ill fitting plastic holders (if they were available), with no help offered from those serving them.

The ward was so stiflingly hot I had to ask for a fan but was told that none was available. I could not use one from home as it needed to have safety checks – no electrician was available to do the test. Thanks to a diligent junior sister a fan was eventually found the next

day. On another occasion I remember one elderly female patient who had had a stroke being brought back to the ward and left lying with her head in direct sunlight next to a window. I drew the curtains to protect her as no member of the nursing staff came to check on her.

After four weeks, it was a great relief when my mother was discharged (as sadly there was no more that could be done for her) Once mum was back at her nursing home, I felt a duty to raise my concerns to try to ensure that improvements were made which would benefit other patients..

I wrote a letter of complaint to the Chief Executive of Chase Farm and Barnet General and Chase Farm Hospitals NHS Trust on the 22nd April 2007. As a result I attended a meeting which took place on the 15th June 2007 with a Matron, two Senior Sister's on the ward and a Complaints Manager. At the meeting I was treated very courteously and the Matron was very apologetic for any distress caused but I was assured that many of my concerns were already being addressed.

I was told that minutes of the meeting would take approximately six weeks to produce. After waiting 8 weeks for them to arrive and being assured that they were "in the post" twice, I wrote to the Complaints Department on 11th August 2007 copied to the Chief Executive, seeking an explanation. Eventually, after another two weeks I received a holding email informing me that the minutes were "being checked" and would be with me shortly. When I eventually received them I wasn't convinced there was anything in them that showed me clearly how the issues I had raised were being dealt with. I thought they were pretty useless and sent them back with my comments.

The matter would probably not have gone any further, but my suspicions had been raised by the holding email from the complaints department. Suspicions that I had been misinformed arose because if the minutes "had already been sent out" and been lost in the post (twice), why then did they need to be checked before they were sent to me late August? I phoned the Chief Executive's very helpful PA, to discuss my concerns.

Following this conversation, I had a call from the Deputy Head of Nursing inviting me to another meeting at Barnet General to discuss my complaint about the Complaints Department. The meeting took place on 20th September 2007. Also present was the Head of Patient and Public Involvement. They explained to me that the issue had been discussed with the complaints Department in detail and a record had been made of the events.

At the meeting I received a full verbal and then later a written apology from. I also accepted an invitation from a Matron to go back to the ward on 24th October to see at first hand the improvements which had been put in place.

Pleased though I was to see the considerable practical improvements which had been made on the ward, a person's experience of hospital relies on the quality and morale of the staff working in it. I was left feeling that even after all the hours of meetings I had had none of it would have been necessary had the *basic levels of nursing and ancillary care* been in place during my Mum's stay in Barnet General.

15. Barbara McVernon

By her daughter Lynne McVernon

My mother, Barbara McVernon, was a vibrant and popular woman. She was a keen artist, a member of the Lions Club raising money for charity by organising fund raising events, she had a wide circle of friends, drove her own car and enjoyed entertaining. She was fun, she was generous, resourceful, creative, immensely loving and astoundingly brave.

In early 2006 it was discovered, at the Royal Berkshire Hospital, that she had a tumour in her left eye socket, skull and brain she was given an appointment to see a Consultant Neurologist at the John Radcliffe Infirmary, Oxford. The first set of scans were lost. My brother feels that it was only on his firm insistence that another set were ordered promptly.

It then took ten days for her scans to reach the Consultant. The urgent scans were sent by post because the two hospitals did not have compatible software to transfer them electronically. Nick and I complained and received a letter from the Royal Berks in which they stated that they were not made aware the scan request was urgent. This conflicts with what we have been told by the Consultant's secretary.

Between 10 April and 22 June, my mother was in three hospitals, during which time I believe she was subjected to an appalling catalogue of overdosing, neglect, NHS intransigence and

poor care. Her treatment, it seemed, was given only at the convenience of hospitals themselves. I called the Patients' Association in March 09, the first time I had felt able to talk publicly about what had happened.

Following neurosurgery on 11 April 2006 at the John Radcliffe Infirmary, my mother was recovering well. However, her forehead, hair and left ear were caked with congealed blood. Every day, I would, very gently, clear a little more of it with damp cotton buds. The nurses did not have time. She was transferred late at night on 19 April 2006 to the Royal Berkshire Hospital. I had expected a proper ambulance to take her but, in fact, it was a minibus. When I visited her the next day at the Royal Berks she said that the driver had taken a detour to take a member of staff home, that she had been frightened as they bumped along dark country roads on her own with him from Oxford to Reading.

At the Royal Berks she was admitted to a geriatric ward. Barbara was 76, but a very youthful woman in looks and outlook. Sharing the side ward with her were just two very elderly women with dementia. This depressed her as she had no stimulation, no one to talk to and her recuperation was impeded by the disturbances caused by the other patients. I approached her admitting Consultant to ask if she could be moved as the depression she was slipping into as a result of her surroundings was not helping her to heal. He seemed to take offence, claiming that he was very proud of the ward he ran. He refused absolutely to transfer her to another ward or even another bay.

Following a painful bone marrow test that was done on her bed in Mortimer Ward while I stayed with her, she was diagnosed with multiple myeloma. Her Haematology Consultant later said that she could have another 5 years of life.

I kept family and friends up to day with Mum's progress by email. This series of emails has formed the basis of a diary of the events. I also paid to have copies of her notes from the Royal Berks.

With multiple myeloma confirmed she was moved to an oncology ward where the nursing staff took infinite care of her, working hard to ensure that she had adequate pain control without clouding her mind. Even so, Barbara complained of pain in her hip. Eventually she was X-rayed and a fracture was discovered. She then waited 10 days whist the doctors debated whether to pin the fracture (which would be done at the RBH) or have a replacement hip joint fitted, which would require a transfer to the Nuffield Orthopaedic Hospital.

During this time, she was in great pain and discomfort. She was required to use a bedpan, which exacerbated the pain of the broken hip. The pain control drugs by now had her constantly disoriented, her spirits waning. The treatment for the multiple myeloma was delayed in the expectation that the hip operation was to be imminent, when the delay dragged on the myeloma treatment was started. Two days after the four-day course of steroid treatment was started, the decision was finally made to transfer Barbara to Oxford for a replacement hip joint. The reason for the wait appeared to be one of communication between the two orthopaedic departments. On reflection I wonder if this period of enforced immobility was the precursor to the pressure sores that she later suffered from.

I travelled with her in the ambulance this time. Her admission to a ward was done by a doctor who seemed uncertain of how to take blood, staining the sheets with Mum's blood. It transpired that he had done it incorrectly and more blood had to be taken the following morning, on the day of the operation. She had been receiving steroid treatment for the cancer at the Royal Berks and her accompanying notes said that she was on a four-day course. However the admitting doctor did not pick up on this and she was continued on the high dosage steroids.

Following the hip replacement operation, her notes were not available on the recovery ward despite the fact that her bed was on a ward a few hundred yards away. Brother Nick, my sister in law and husband were with her and offered to fetch them, but the nurses refused and tried to ascertain from her which painkillers she was on. They put her on a type of pain relief that we explained she didn't tolerate very well.

In the following days Mum became very distressed and incoherent. She told me she would cry at night because she was so frightened. One nurse there, gave her comfort and confidence, she told us. The nursing staff at the Nuffield Oxford had never met my mother before but seemed to treat the drugged disorientation as her normal mental state. Nick and I insisted that she was not normally confused, that she was a bright, intelligent woman but staff refused to listen. A male nurse said "We're used to how people are after operations. You're not". My stepson, Jon, was in Mum's room when a nurse came in and, before noticing him, said "Your family are saying that there are problems. But there aren't, are there?"

There was no phone in her room and she was too confused to pick up her mobile phone when it rang. Unless we were actually in the room with her, we had no form of contact. Our mother had a catheter fitted and we frequently had to tell staff that the bag was full and they needed to change it.

We were anxious to arrange for her to be transferred back to the Royal Berkshire but this seemed to be taking a lot of time. I rang the Admissions Manager at the Royal Berkshire Hospital to find out why and discovered the reason. My mother had MRSA and had to be admitted to a single room. No one had told us at the Nuffield Orthopaedic Centre. When I asked a nurse when they were intending to tell us, she burst into tears. We had an interview with the Senior Sister who was placatory. But the other ward staff seemed to have us marked as trouble makers and would ignore us when we went to the nursing station to ask a question. I insisted, eventually, on seeing a doctor and waited until late in the evening. The young doctor I saw, unlike his colleagues, had the sensitivity, the humanity to ask "What should your mother be like?" I told him. Through my contact with him, we discovered that an overdose of dexamethazone (the steroids my mother had been kept on) had induced diabetes and contributed to my mother's consequent distress and confusion.

Eventually Barbara was put in an ambulance on insulin drip to go to the Royal Berks. I learned this only by default when ringing the Nuffield. I rushed to Reading and found her in a corridor on an orthopaedic ward at the Royal Berkshire Hospital. Two nurses were so appalled at her circumstances that they set to and cleaned a room themselves to allow her

some tranquillity. That evening, I had to stay an hour and a half with the admitting doctor explaining the sequence of my mother's treatment because the handwriting on the notes from the Nuffield Orthopaedic Hospital was illegible.

The ward she was on was very busy where a diverse section of patients were admitted, including victims of road traffic accidents. Barbara was given hourly blood tests for her blood sugar and her fingernails were caked with blood. Again, the nurses did not have time to clean her fingers and family had to do this on every visit. It seemed to us that the staffing levels were too low to cope with a high dependency patient but we felt attempts to raise this were simply deflected by hospital management. By this time my mother also had bedsores that needed regular attention. This affronted her dignity profoundly and caused her both pain and deeper depression. Where she had had an air mattress on the oncology ward, at the Nuffield she had had only a standard mattress and a strap above her on which she could pull herself up to change position. She had an air mattress after a day on the orthopaedic ward but she was not able to adjust her position easily. We were told nursing staff are not allowed to lift patients. Nursing standards on this ward ranged from compassionate to perfunctory. When we pointed out Mum's deepening depression due to the diabetes and other issues, the ward sister – clearly not appreciating the full weight of my mother's recent experiences – responded that her father had diabetes and described the effects of high blood sugar as 'feeling a bit sugary'.

A few mornings after Mum's admission, I arrived to discover a patient with dementia in her room, going through her belongings. When the old lady refused to leave and became aggressive, I rang the nurses' bell but no one responded. I was reduced to shouting down the corridor. Eventually a non-uniformed woman came and led her away. My mother had no way of alerting staff-we don't know how long she was in the room with my unwell and confused mother.

She had no follow up appointment after the neurosurgery as she was too ill to travel back to the Radcliffe Infirmary and her consultant would not visit her in Reading.

Despite being asked constantly, and being given cogent reasons, the Orthopaedic Consultant refused to allow my mother to be transferred to the more peaceful oncology ward. Tragically, for her and us, she eventually lost the will to live and asked us to help her die. Ironically, shortly after this I was advised that she would not survive and was asked by the medical team in a side room "How do you want your mother to die?". The options were for her to die of cancer by withdrawing chemotherapy or infection by continuing it.

When a bed became available, Nick and I accompanied Mum to a Hospice where she died just over a week later. I held her hand for three nights as she succumbed to pneumonia. Again, care was variable. The admitting doctor was gentleness and tact itself. Another doctor chatted brightly about her daughter's school trip to France – and, commenting on my constancy at Mum's side, "Are you doing this for your mother or for yourself?"

The cause of death was stated to be pneumonia and Multiple Myeloma. Nick and I insisted that MRSA also be included on the death certificate.

The conclusion of the investigation into the steroid overdose that caused the diabetes arrived on the same day. It admitted fault.

My husband and I spent many days at my mother's bedside. My brother Nick, who lives and works in Devon travelled up to Reading & Oxford when possible to take over. This, we all felt was essential as the care being provided fell well short of adequate.

At both the Nuffield and when she returned to the Royal Berks food would be supplied by an orderly, and left on the bed table, where my mother was unable to reach it. The untouched tray would be removed later on the assumption she didn't want it. The family, working in relays had to be present to ensure that Barbara was fed.

We decided to publicise this to try and stop it happening again. What is also imperative is a key worker to oversee transfers so that someone ensures overall communication.

I often wonder and ask the question was she a low priority because she was elderly?

Nick and I are not looking for compensation – we both feel that taking money out of the NHS, even via the NHS insurance company, is a pointless exercise. Already, thousands of pounds' worth of treatment and hundreds of hours of clinical skill go to waste through 'procedure', lack of communication and poor standards of care. Compensation would not bring our mother back, nor lessen her or our suffering.

We were shocked at the response the Royal Berkshire Trust gave when the story was featured in the Sunday Telegraph. They said they were "disappointed" we hadn't raised concerns since my mothers death. We had raised them throughout my mothers stay. By the time of her death we were thoroughly *disappointed* in the apparent futility of doing this and decided it would make little difference. We hope participating in this project will.

We want to see lessons learned, culture changed and applied to future patients.

16. Patient A

By her daughter

It has now been a year since my mother, left the Royal Surrey County Hospital. My brother and I had long discussions with my mother about taking part in this report. We felt this was the right thing to do and she agreed. We're sure she understands what we're doing. On discussion with the Patients Association we decided to make the account anonymous anyway.

Firstly may I say I do not want to blame any of the nurses on the ward my mother was on as I feel they do a tough job under difficult circumstances. It is the system that I blame. Imagine my mother being your mother, your wife/husband or, worse still your child.

It all started when Mum suffered a Subarchnoid Haemorrhage in of July 2007. She was admitted to the RSCH where we were told she had a bleed on the back of the brain; she was then transferred to St Georges Hospital in Tooting for this to be investigated. The bleed was treated there and Mum was transferred back to the RSCH in August 2007.

It was a very difficult time, Mum was very unsettled when she arrived and the ward quite different to what we had been accustomed to. The care at St George's had been outstanding in comparison. I thought it was cleaner and felt the nurses were so much more supportive. It was like one big happy family. Being back at the RSCH was awful.

Mum was unstable on her feet as it was and could easily get out of bed and injure herself. There was nothing prepared, no risk assessment and nothing to prevent a fall. The bars on the bed were not going to keep her there as she would climb round them; they were from her waist up to her shoulders and nothing to stop her moving her legs off the side of the bed. I wondered why they couldn't have offered an alternative bed. Mum was also very confused, would pull catheters out, drips, you name it; it wouldn't stay in for more than an hour.

The toilet was disgusting. It was soiled and had a soiled toilet brush. The public toilets downstairs were bad enough, often dirty and blocked. It's horrifying to see this in a hospital let alone on a ward. There are countries poorer than us yet their hospitals clean and immaculate.

It was very emotional the evening Mum arrived. We discussed with the nurses about Mum's mobility, that she was unable to walk independently and warned them that she could fall. We were told there was nothing they could do that late at night (it was about 8pm by this time). Due to Mum having problems with her sodium level she could become very agitated, especially if she needed the toilet. We were told to keep the call button by her side. I wondered how on earth would she know how to use this as she barely knew where she was, her memory all over the place, she had no idea what the button was for.

At this point we didn't know that Mum had suffered brain damage. We were very distressed worrying what a fall could do to her following the surgery and felt helpless that there was nothing we could do. I would have stayed the night but there was no suggestion I would be allowed to. She was placed in the ward opposite the nurse's office but three beds down where they wouldn't see her from the desk. I made it very clear that I was worried she would fall and asked them to help her.

The following day I called the hospital and our nightmare had started. Mum did have a fall during the night, she was found on the floor. I was told (after *I* asked how she was), she had a 'little cut' on her brow. When I actually saw her she had a black eye (on the side of her surgery), a swollen cheekbone and pain in her knee and right hip. This was not recorded in her careplan and there was still no risk assessment of her falling.

My brother and I spoke to the sister about Mum's fall I found the following comments both unprofessional and very uncaring.

She told us 'St.George's care is very good but their handover is not so good'. The sister at RSCH went on to tell us 'our care is very good here, unfortunately you haven't seen that yet' and told us 'it was just a bad day and we're only human'. She explained that there were staffing issues and it was difficult to get staff especially at short notice. I couldn't believe it when she asked if I was 'quite protective of my mother',

Of course we were protective!

She also told us when we asked if an accident form had been completed for Mum's fall, 'Oh we have lots of accident forms, not just for patients but also for staff'. I don't think I did receive a straight answer about whether it had been recorded, I don't think that all her falls were ever recorded, perhaps three may have been.

There were other issues. There were times when Mum had not been changed and was in wet pyjama bottoms (most of the time we cleaned and changed her, after a while this just became the norm). Wet pyjamas had been put in a bag on her table next to her food, soiled pyjamas were put in her cupboard and not in a bag. Used needles were left on Mum's table within her reach; I recall two occasions where my sister and I handed these back to the doctors. If ever given to the nurses they'd say 'it's the doctors'. The beds weren't always cleaned after urine, after soiling they weren't always cleaned thoroughly. I remember a time when Mum was calling for the toilet as I walked in and due to the waiting she ended up wetting the bed; she was distraught that she had done such a thing. The memory still upsets me.

Due to her agitation Mum would strip her clothes off, it seemed no-one on the ward made any attempt to protect her dignity when she did this; it was only when she was later moved onto HDU that an effort was made.

Seeing my Mum go through this and having to write it all down again is heartbreaking but I feel it is important to tell our story. It seemed no-one really did anything to maintain Mum's

dignity. I work in care and dignity amongst many others is paramount, should it not be the same in hospitals?

On the 13th August 2007 Mum had another fall in HDU where she was moved after being tachycardic; this was when she finally had some one-to-one care. No-one called me despite informing them that I would like them to call us anytime if there are any problems. We were told she had had a little bump and 'lowered' herself to the floor. Apparently the doctors left her in the chair.

Mum had various carers looking after her, some lovely and some with an attitude that they knew more than us but we were grateful someone was by her side. One told me 'she'll be better by tomorrow', oh how I wished she would be. Do they not get handovers? Was she not told Mum had Brain Injury?

Mum had another fall on the 16th of August 2007 witnessed by a patient in HDU. This time she bumped her head and ended up with a bruise.

Also, I found anti epilepsy tablet dissolved left in a cup on Mum's cabinet saved for later. Surely it shouldn't be left unattended? Often Mum would pack all her things thinking she was going home and twice I found dissolvable paracetamol in her bag, once I found one open. They'd have no idea if she had taken some, and she was capable of doing so.

Mum was prescribed oral thrush treatment that was also left on her cabinet and it seemed to me that it hadn't moved over a period of time yet it should be administered 4 times daily. When I asked the sister she said it was being given, though I hadn't seen Mum have it for a number of occasions. I felt like we were being taken for being stupid and being constantly fobbed off.

For some time we felt very unsupported. It was uncomfortable for a while, obviously we had complained and knew the staff would be aware of this. We wondered if Mum's care would be any different because of this, we certainly felt that we were treated differently until we all got to know and understand each other better. I certainly felt that the sister didn't like Mum and had no time for her. She told me 'we get patients like this all the time, we're used to it', yet Mum's 'stroke' consultant told us she was an 'unusual' case.

There was a time when Mum pulled her cannula out (for the 100th time!), there was blood everywhere yet the sheets remained unchanged. I wondered constantly about infection control.

On the 24th of August 2007, another fall, again no-one called to let us know. Mum had cut her lip, bruised her cheekbone and her chin. Apparently the nurses spent ages looking for her front tooth….the one she had to have removed some years earlier!

Mum had her fifth fall on the 28th of August 2007, the worst of all. We were told that two nurses turned their backs and before they knew it Mum had fell, I have to say I think the two nurses at the time genuinely felt terrible. Once again no-one called her next of kin-I or my brother.

I have to say I was furious. I walked in only to find my Mum with a split lip. Quite literally, it had split in two and was hugely swollen. She had a bruised cheekbone and small cut on her chin. I was distraught. Not only would I have to explain to her the scar on the side of her head but now the one on her lip. Mum had already had plastic surgery on the same place when she had a car accident in her teens which we were told could make stitching difficult.

I told a Dr that I did not ever want to walk in and find my Mum in this state again and told him someone should have informed us. In discussion he said he didn't feel that Mum was affected by the fall. I found this remark deeply insensitive.

Finally they decided to turn Mum around in the bed to prevent further falls, that's how long it took, they waited until the big one to do just that. I seem to recall this was about the time when Mum stopped communicating to us, she stopped talking, eating, drinking, she was so withdrawn and just looked so sad.

On the 31st of August only three days following her last fall my brother found our Mum alone behind a curtain soaked in her pyjamas, she was lying at an awkward angle hitting her split lip on the bar causing it to bleed. When asked why she was alone he was told they were short staffed, yet we were told by the SHO that she would not be left on her own again after her recent fall.

Mum had an obvious infection on her wrist at one point, I informed one of the nurses and a doctor yet it took some time before someone came to look at it. I couldn't understand why no-one else had noticed it. It seemed obvious to me that it was where she had a cannula.

Mum had to have consistent fluids. Her sodium level was always too high or too low so if she didn't have the correct amount of water it would cause agitation and confusion or worse still be fatal. It wasn't easy getting fluids into her, she wouldn't always drink and as mentioned before would pull out cannula's. Yet one day especially she was left from 1500 to 1930 without fluid. This was not the only occasion this happened.

I often wonder why the RSCH couldn't get her sodium level stabilised yet within approximately two weeks of being in the nursing home her GP had got it right.

I discussed Mum's fluid intake with her consultant on the 3rd of September 2007 who informed me that she had 3 litres of fluid that weekend. I corrected him telling him this was impossible and explained that she didn't receive any fluids during the time mentioned above and that she had pulled out another cannula. Her care plan had stated that she had 10mls of water with her meds and although it said she had her smoothie she had only drank a quarter of it.

I also discussed record keeping at this time and asked why all her falls hadn't been put in her care plan. I was given no explanation. I wonder if it was recorded in her confidential notes, which of course I am unable to read. How can they possibly check a patient's fluid intake when the patient is in a room on her own and the nurses only going in when she is due for medications?

Other incidents included finding scissors and pyjamas with vomit on them left on Mum's table.

I had a meeting with the Senior Sister, on the 8th of September 2007 to discuss some of the issues above. I found her to be understanding and supportive. At last! I dislike complaining but I had to protect my Mum.

Mum eventually needed a PEG which took what seemed like an age to get. Understandably they didn't want to do this at first but when the decision was made it seemed ridiculous that it would take so long. At this point Mum was not taking food or fluids that she so desperately needed. It became even more unbelievable when she is not to have food/fluids to prepare her for the procedure only for it to be cancelled and arranged for the next day! It was ridiculous they were now stopping her from eating and drinking for over 24 hours.

Once Mum had her PEG, which has taken her such a long time to accept, there were a number of occasions when she had faeces under her nails. Surely this should be checked to prevent cross infection when there is a patient who constantly touches an open wound/stoma site? It was not surprising when she eventually got an infection in her stoma site.

There was another fall on the 27th of September 2007. Despite asking the doctor at the time of the last fall to call us if it happened again we received no call. How can we have faith in those looking after our loved ones? We just want to be told that's all. Apparently Mum fell out of bed. How? Did she try to get up or was the bedrail down? This time she had a cut to her forehead, now counting three scars from the ward. This is a ward that deals with unstable patients particularly the elderly.

Sometimes you think you're going mad or you're imagining things, you get told all sorts of things and come away thinking 'maybe it's me, maybe I am just being fussy'.

My sister found sandwiches and vomit in my Mum's bed. When I asked the care assistant about it she admitted giving them to her. I can only assume that Mum had choked which made her vomit. One of the nurses apologised for this when I told her about it, she explained that they are in the process of changing over and using different carers and things should improve. Thankfully they did eventually.

We sometimes relied on relatives, there was a day when Mum had been left in her chair from about 1000, at approx 1300 a relative asked if they could move Mum as she has fallen asleep and her head was leaning over onto the bed rail. Could this have prevented another fall? Quite possibly.

A relative also told me on the 3rd of October 2007 that Mum had another fall that morning. We were told by the staff it was from her chair but the relative of next door told us Mum was standing when she fell. I do believe this is now the 7th time Mum has fallen. I can't help but wonder how many other falls has Mum had that we don't know about?

On the 5th of October 2007 one of the doctors informed us that Mum was found on the floor that morning following another fall and had to be hoisted back in to bed. How many more? We were now exhausted by it all and really concerned for Mum's safety. If she is not safe in hospital then where is she safe? To top it off when my sister-in-law went in to see Mum, the sheets were all over the floor along with water from the jug that was on Mum's table. Mum was very agitated which was hardly surprising, all she wanted was a drink and at the point she couldn't drink without assistance. Why is it food and drink are put at someone's side in hospitals even though it is known that they can't feed themselves, staff later remove it and record that the patient hasn't eaten yet they are probably sitting there looking at it starving hungry! Also I have seen care assistants put piping hot soup on my Mum's table which she could easily burn herself on. Mum wasn't the only one this happened to.

Mum has complained for a long time of pain in her arm, this went on for months and was never X-rayed. We were told she was 'attention seeking'.

6th October I found a rash on Mum's torso, the nurse suspected shingles; I personally think it was a urine burn judging by the urine marks on her pyjamas that I found these on her the day before. The on call doctor was called and thankfully it was not shingles. I'm not quite sure what they said it was in the end.

On the 12th October I asked the SHO if Mum would be having any further scans, her reply was 'No, not unless there are any further head injuries'. She explained that the last scan Mum had showed a bleed to the right side of the brain which would have dispersed by now. What bleed? Why weren't we told about this bleed? When I approached her again about this she told me and my sister-in-law that the bleed had been there prior to RSCH. When at St Georges at a later date they told me had she had this when she was there they would have not discharged her. I was very confused and didn't feel I was getting the whole story.

By the 23rd of October 'one of the bleeds' had got slightly bigger. Another doctor told us it was an existing bleed but I was so shocked I didn't find out further details. Another bleed? When I asked the nurses they didn't know either but surely they can check Mum's notes? Unfortunately the steroids they gave Mum to shrink the bleed didn't work.

Mum went back to St George's on the 10th of November 2007 for further surgery to release the bleed. That was where we discovered she had a Subdural bleed that we were told was likely to be caused by falls. I believe that had she not had the falls at RSCH she would not have to undergo further surgery, let alone everything else that comes with it.

The nurses who had nursed Mum previously at Atkinson Morley were shocked to see how Mum was when she returned, after all most people who survive a SAH recover quite differently to how Mum had. They were horrified at the amount of falls Mum had and met quite a different person to the one who had left their ward only a few months earlier. Immediately after her surgery, once I had explained the falls they gave Mum one-to-one care. I can't say how relieved we were; we could come home knowing she was in good care.

In April 2008 Mum had yet another set back. In the early hours of the morning she was found to be non-responsive. By this time our relationships with the nurses had improved.

One of them called me and told me to prepare for the worst, they weren't sure what had happened but she was taken to intensive care where she was intubated. It is still a bit of a blur, I just remember being convinced Mum wasn't going to make it, that she had given up. All I can recall is that something happened with her potassium level. I was sure this was due to her doctor taking her off fluids two weeks previously. Not only were we devastated but the nurses were too, we were touched by just how much the nurses became so fond of Mum and really did care. When I said to the nurses 'what on earth is he doing taking her off fluids?' their reply was 'we are only the nurses, we don't know what we are talking about, they don't listen to us!' Was he completely out of his mind? She was soon put back on her fluids and once again continued her fight. I will never know if taking her off her water caused this but all I know now is that she lost a lot of her mobility that day. She still doesn't walk around like she did before that day.

I cannot possibly fit everything that happened over this period in to this letter. Thankfully after Mum returned from St George's the second time on the 17th of November 2007 things had improved and there were things we just got used to. There were cleaners that I had not seen before and new cabinets, beds etc, it was such a relief, but I am sad to say that does not excuse what happened to my Mum, she should NOT have had 8 falls. We will never find out what really caused her Brain Injury or when it happened but I will always wonder if the falls contributed to it.

I also witnessed many incidents in the time my Mum was in the RSCH not just involving my Mum. There was an elderly lady in a bed next to Mum, I don't know what her diagnosis was but it was clear she didn't know where she was or what she was doing. The first day I met her she was in a hospital gown, no underwear and walking around with dried blood down the gown and her foot. I was horrified to see not only had she not been washed and changed but also that she was sitting on my Mum's bed and even tried putting her foot in my hand bag. I also witnessed her standing by the door urinating, as she went to walk, she almost slipped over, at which point my husband went to grab her to stop her fall whilst calling out for one of the nurses who were standing only two feet away chatting. On another occasion the same lady fell in the toilet next to my Mum's bed, we heard a loud crash, she had fallen into the shower screen and smashed it. She had wet the floor so the nurses covered it with paper towel and put her back in bed. The shower screen was cleared up but when I took my Mum to the toilet the following night the floor was exactly how the nurses had left it the previous night, urine all over the floor.

There was an elderly lady in a room next to my Mother's. One day I saw the lady on the floor, immediately I informed the nurses and they rushed in. As I was still outside her husband came, suddenly a nurse ushered him off telling him to wait a while as they were changing her. I still wonder to this day if they ever told him the truth.

Once I was waiting outside the ward my Mum was in and there on a trolley was a box of Co-codamol and a sharps bucket, this was there for weeks.
It concerns me not just for what we went through and more importantly our Mum, but also for others, no-one should go through that, young or old, with or without a disability.

Mum is now in a nursing home, albeit she doesn't fully realise where she is but she is happy. If Mum's happy I'm happy. She will never fully recover but she is in a place where we know she is cared for and the staff love her. That is my peace at last. I will never stop worrying about her but I can rest now knowing she is safe. I am sad that Mum is an hour away and I can't just pop in, I miss her terribly but I am so grateful for where she is and for those who care for her. I will always grieve for her, that's what comes with Brain Injury but it does get better. I have now found the support group Headway and they have been a huge help.

We don't speak out because we are afraid, or because we don't have the knowledge to give us the confidence to know what we're saying is right and that we aren't going crazy. Thankfully I have been given a chance to tell my story and I am grateful for that. I speak also on behalf of my family and my Mum, who I love so very much.

Responses from organisations involved

All of the NHS Trusts responsible for the provision of care to the patients featured in these stories were sent the accounts and offered the opportunity of including a response to be printed in the report. Responses that were sent can be viewed below.

Leslie Kirk
Nottingham University Hospitals NHS Trust

Caron Swinscoe, Clinical Lead for Acute Medicine at Nottingham University Hospitals NHS Trust, said:

"The Trust has taken Mrs Gerrard's concerns extremely seriously, and we have worked with her to address the issues she has raised. We have been extremely disappointed with what Mrs Gerrard has told us, and it is not a picture we generally recognise. As a Trust, we pride ourselves on continuing to reduce infection rates, improve cleanliness and maintain high levels of patient safety.

"We are proud of an excellent patient safety record, among the lowest mortality rates in the country and significantly reduced infection rates. We want to ensure that by working with staff, patients and visitors we can prevent such distressing stories and deal with the cause immediately.

"Every day the hospitals treat and serve thousands of patients, the majority of which have positive things to say about their care and experience at our hospitals.

"Mrs Gerrard has recently visited the ward and I understand was reassured by the current standards of care and cleanliness. She has asked to have more involvement with the Trust and our Patient and Public Involvement Manager is working with her to help to fulfil her request."

Pamela Goddard
Surrey and Sussex Health NHS Trust

Surrey and Sussex Healthcare NHS Trust Director of Nursing, Mary Sexton, said: "We offer our sincere condolences to the family of Pamela Goddard on the loss of their mother. We are committed to providing high quality patient care and are sorry that on this occasion the family feel that that standard has not been met. We have received a formal complaint which we have responded to but are carrying out further investigations at the request of the family. The presence of pressure sores is associated with a twofold to fourfold increased risk of death, but this is because pressure sores are a marker for underlying disease severity and other co-morbidities. Mrs Goddard was receiving complex treatment for a number of medical conditions from a number of healthcare organisations at the time of her death."

Royal Surrey County Hospital NHS Trust

Mrs Goddard was primarily at East Surrey Hospital and came to the Royal Surrey for emergency radiation treatment. A pressure relieving mattress was not used initially because of concerns around Mrs Goddard's cord compression, but was provided once the team caring for her deemed it to be appropriate and safe.

Mrs Goddard's case has already been thoroughly investigated by the team who was responsible for her treatment and records show that the correct nursing care was given for pressure sores and there is no evidence that she was not kept as clean as possible.

We would like to express our condolences to the family and reassure them that we did all we could at the time Mrs Goddard was a patient at the Royal Surrey.

Barts and The London NHS Trust

"We have conducted an internal review of the medical care of the case that is the subject of this complaint and Barts and The London NHS Trust is satisfied that the patient received appropriate care and correct treatment while at Barts Hospital.

Under the NHS complaints procedure we seek to do everything in our power to resolve any complainant's issues. Because the patient's family was unhappy with our written response and has since raised more questions, the patient's notes are being reviewed in order to respond again.

The family have also been informed that if they are not satisfied they can seek an independent external review through the standard NHS complaints procedure and that the Trust will cooperate fully in any such review."

Florence Elizabeth Weston
Dudley Group of Hospitals NHS Foundation Trust.

From Paul Farenden, Chief Executive

The Trust would firstly like to express our sincere condolences to the family at their sad loss. We would also like to reassure all patients, their carers and families that we take all complaints about the care they receive very seriously and all complaints are subject to a thorough investigation, to ensure we learn from patients experiences.

We can confirm that we received this complaint which was investigated thoroughly and we made every attempt to resolve all concerns locally. A number of explanations and responses were given and the complainant referred their complaint to the HealthCare Commission. The Healthcare Commission looked at the case and advised us to make further local resolution

attempts and that the review would be closed from their perspective. Further local resolution was made.

The family raised concerns about the length of time it took for the patient to receive treatment and this was addressed. We have made many improvements to our services, one of which is our target for patients to receive surgery for fractured hip is less than 24 hrs from admission.

Over the last 12 months we have introduced several measures to improve access to hip fracture surgery including appointing a matron with experience in this field. Changes have included, making sure all hip fracture patients are now nursed in the hip fracture suite, a dedicated area for this purpose, to ensure that staff and services are concentrated on the patients when they are at their most unwell.

Other improvements include the introduction of an operational policy which sets key patient care targets, a transfer time of 90 minutes to move patients to the hip fracture suite, a maximum surgery target time of 24 hours (unless the patient is medically unfit for surgery) and new high-quality air mattresses on each bed with a matching gel seat cushion to prevent pressure sores.

The key patient care targets are audited every month to ensure care standards are being maintained and action is taken if necessary.

These changes are part of a continual process of learning from experience. The Trust not only uses its complaints information but also maps this against other sources of patient experience such as our quarterly patient survey so we have real time patient feedback to help the Trust to provide the best possible care to all our patients.

Bella Bailey & Thomas George Dalziel
Mid Staffordshire NHS Foundation Trust

Eric Morton, Interim chief Executive of the Trust said “These patient stories refer to care given in 2007 when concerns raised by these families were investigated and addressed under the NHS Complaints Procedure. These concerns were also reviewed as part of the Healthcare Commission investigation during 2008/9 which reviewed care provided by the Trust between April 2005 and April 2008.

The Trust Board would like to take this opportunity to reiterate its sincere apology to all the families for the failure to provided care to the standard they had a right to expect. Since that time, the quality of care delivered to our patients has improved as a result of significant investment of £5.9 million including additional clinical and front line staff since April 2008.

An ambitious Transformation Programme launched in May 2009 sets out 107 goals; 28 of these have already been completed. The investment in nursing together with the actions being taken show that the Trust has continued to improve care since 2007; whilst recognising that there is still more to do before we achieve our aim to be ‘One of the safest hospitals in England’”.

Thomas Milner
Sheffield Teaching Hospitals NHS Foundation Trust

Dr David Throssell, Deputy Medical Director at Sheffield Teaching Hospitals NHS Foundation Trust said **"**Mr Milner sadly passed away in 2006 after suffering from Leukaemia. There has been a thorough review by the Trust and the Healthcare Commission of the medication Mr Milner received during the day and evening of January 10th. Both the Trust and the Healthcare Commission found that staff acted appropriately and within professional guidelines. When asked by a doctor, Mr Milner indicated he was not in pain and therefore the doctor agreed with the nurse that further medication was not required. In palliative care there needs to be a careful balance between making the patient comfortable and giving too much medication. This is because multi organ failure can alter the absorption, metabolism and excretion of some medication, potentially causing an earlier death. Too much medication can also make patients sleepy and therefore unable to communicate their wishes or talk with their family. Later in the evening Mr Milner's condition deteriorated and as a result he was given appropriate additional medication."

Jayne Knowles Smith
Gloucester Hospitals NHS Foundation Trust

A spokeswoman for the Trust said: "We are very sorry to hear of the experience of this patient. We are committed to improving the experiences of patients and we would encourage her to contact our Chief Executive. This will allow us to investigate, respond and makes changes where needed as unfortunately to date this has not been brought to our attention."

Professor Leslie C Vaughan
West Hertfordshire Hospitals NHS Trust

The West Hertfordshire Hospitals NHS Trust can confirm that it responded to a complaint by Mrs Sian Van de Welle relating to care provided to her father at Hemel Hempstead Hospital.

We would like to reiterate our sincere condolences, given to the family in our letter of 12 February. The Trust takes all complaints seriously and investigates each one to ensure that, where appropriate, lessons are learnt.

In line with the national complaints process, everyone who is dissatisfied with the outcome of the local process has the right to make representation to the Health Service Ombudsman.

We understand that this has been done in this case. The Trust is awaiting the outcome of the Ombudsman considerations and will co-operate fully with any subsequent requests for information.

Margaret Bristo
South London Healthcare NHS Trust

We are very sorry to hear that the Bristow family had a bad experience in one of our hospitals. We do receive occasional complaints from patients who have had a bad experience and we treat them very seriously and investigate fully. We always apologise and learn from these complaints to reduce the chances of similar experiences happening again and this must be balanced by the number of good experiences people have with our services across the three boroughs. We apologise once again to the Bristow family.

Alice Fowler
Barnet and Chase Farm Hospitals NHS Trust

Many of the concerns and issues raised by Mrs White are addressed in our Patient Experience Strategy which aims to improve the experience patients receive in our hospitals.

The experiences of Mrs White and her family helped inform our Patient Experience Strategy (PES) which was being developed at this time.

Our Patient Experience Strategy include campaigns 'Getting the basics right - providing the best possible care to our patients', 'Keeping clean and preventing infections - preventing infections and maintaining', ' Dignity in care - making sure that our patients are treated with dignity and respect', 'Dignity in death - caring for our patients with kindness and compassion at the end of their life and supporting those they leave behind', 'Food for life - delivering the best food and nutrition for all our patients' and 'First impressions last - communicating clearly and with respect'

We would like to thank Mrs White for taking the time to visit us where she met with senior staff. The constructive feedback we received has helped us to develop practical improvements, such as the introduction of Steamplicity – a new meal system which Mrs White tasted when she visited the Trust.

The Trust has apologised for the failings on the handling of her complaint and a full explanation for the circumstances leading to this has been given to Mrs White.

Patient A
Royal Surrey County Hospital NHS Trust

The staff on Hindhead stroke and neurology unit where this patient was cared for are very disappointed and upset by this account of her treatment. This does not at all reflect the

record we have of her stay on our specialist stroke ward and, in fact, we received a number of thank you letters and cards from the family who were extremely grateful for the care we provided for their mother over a very lengthy period of time.

Treating patients with a severe brain injury like this patient is very complex not only because of their medical problems, but also because the behaviour of these patients can be very unpredictable and challenging. However, she did receive one to one nursing care and the ward sister and clinical team devoted a great deal of time to supporting the family through the lengthy and difficult inpatient period. They were also instrumental in ensuring that the patient was placed in an appropriate community facility that would be able to provide the level of care she requires.

We would be very happy to meet with the family to try and resolve any issues and always do our utmost to deal with any problems while patients are being treated at the Trust.