Patient Stories
2013: Time for Change
With thanks to the many people who kindly volunteered to take part in this project for the benefit of others, and thanks also for the many others that contacted us but unfortunately couldn’t be included. Everyone’s experience is valued, published or otherwise, and all contributions are gratefully received.
Foreword

Katherine Murphy, Chief Executive

This is our fifth annual collection of patients’ stories. The first was written in the fevered atmosphere of the run up to the General Election. The next three were produced against the backdrop of colossal upheaval as the Health and Social Care Act made its way through the parliamentary process to its implementation one year later.

I believe that this fifth report however, published in our fiftieth year, comes at the end of one of the most tumultuous periods in the history of the NHS. What a year 2013 has been, with ramifications that will impact on all patients for decades.

The publication of the recommendations of the public Inquiry into Mid Staffordshire was swiftly followed by the coming into law of the NHS reforms. Then we had reviews by Keogh, Berwick, Cavendish, and Clwyd/Hart. Alongside this came the news that the NHS is facing a potential £50 billion “black hole” over the next twenty years.

At the heart of these times of upheaval are patients and relatives. They don’t want to hear about reviews and finances, and they don’t want to know any more about the reforms. What they want more than anything else is an NHS they can trust, and when they or a loved one will need it, they will be treated with compassion and dignity and cared for appropriately. Every NHS manager, decision maker and policy proposer in and around the NHS needs to remember that patients today have the same anxiety and fear they have always had. However, the situation has been worsened by the failings at Mid Staffordshire and the number of poorly performing hospitals that have raised concerns and led the Care Quality Commission to inspect as a priority.

This year’s collection of stories is different to those that we have used before. In previous years the focus of these reports, and our CARE campaign, has been on the care of the elderly. This remains a concern, despite the huge amount of hard work that is taking place to improve care in this area.

This year the focus is on what could be the single biggest development in healthcare since the launch of the NHS plan over a decade ago- the publication of recommendations of the Inquiry conducted by
Robert Francis QC into failings of care at Mid Staffordshire. We are delighted Robert Francis is now our President and will help us all as we strive for a more honest, open and transparent NHS.

It is the opinion of the Patients Association that the recommendations that the Inquiry put forward are a comprehensive blueprint for a safer, more caring NHS.

Each and every case contained in this report should make the Government think again about its position. Each could potentially have been prevented if the Francis recommendations had been enacted in full.

The Patients Association has had one simple message for the Government since the recommendations were published - don’t let patients down any further, please agree to implement the recommendations in full.

Katherine Murphy
Chief Executive
Introduction

The aim of this report remains the same as it has always been, to amplify the voices of individual patients in order to highlight wider trends.

However, this year there is a difference. Ordinarily we would publish a collection of stories and then a series of calls to action which we believe would improve the care that patients receive. But this year those calls to action already exist. The recommendations of the Francis Inquiry point the way forward for the NHS, and we call on the Government to commit to adopting them in full, with a timetable for doing so.

For those few readers who won’t already know the report, which was published in February of this year, it identified numerous warning signs which were missed. The Inquiry stated that this was caused by:

- a culture that doesn’t put the patient first;
- an institutional culture that gave more weight to positive information about the service than to information that could cause concern;
- failure of communication between agencies to share their knowledge of concerns;
- too great a tolerance of poor standards and of risk to patients;
- assumptions that monitoring, performance management or intervention was someone else’s job;
- a failure to appreciate the risk of disruptive loss of corporate memory and focus resulting from repeated reorganisation;

With 290 recommendations made by the Inquiry it is not possible to analyse them all here. However we would identify the key themes as including the need to:

- Foster a common culture shared by all, of putting the patient first;
- Develop a set of easily understood fundamental standards that should not be breached;
- Make sure all those who provide care for patients are regulated and properly accountable for what they do;
- Ensure openness, transparency and honesty about matters of concern;
- Strengthen the regulatory system;
- Enhance the recruitment, education, training and support of all key contributors to the provision of healthcare;
- Improve the complaints system.

At the time of the report’s publication the Patients Association was cautiously optimistic about its recommendations, with our Chief Executive Katherine Murphy saying “We welcome the report. It is a comprehensive review of nearly every aspect of the NHS, and when it is such a key part of all of our lives, patients and carers deserve nothing less. This is a watershed moment for our health service.

It will take time to digest all of the findings and 290 recommendations that have been made. But it is clear that Robert Francis has understood some of the very real failings that patients and their families face day in and day out. He has recognised what we hear on our Helpline every day - too
many parts of the NHS have lost their way and forgotten that care and compassion should be at the heart of what staff do. He wants to give nursing a powerful voice. He wants the ward sister back in charge and we welcome that. The concept of a registered older people’s nurse is a great idea and should be pursued wholeheartedly. Whilst he recognises it will take some time to implement, he has seen that there can be no other option but to regulate healthcare assistants. The Government has been wrong to resist this idea.

We have always believed good complaints handling can do so much to improve our health service. We need standards, we need more independence and we need to empower and support patients and carers when they highlight poor care. It is clear from the report that very many people share the responsibility for what happened in Stafford. Unfortunately too many people have escaped being held to account. What is important now though, is to focus on ensuring the Government doesn’t ignore this report – it needs to focus on making the most of this unique opportunity to improve the NHS for everyone’s benefit.”

Since that time it has become clear to us that each of the recommendations has merit and the Government should commit to implementing them in full in the months following the publication of the Francis report.

The Government commissioned a series of further reviews. Some, such as the Keogh review of trusts with higher than expected mortality rates, are vital for patient safety and have a great deal of merit. The Patients Association was proud to have been involved, and fully supports the work that has been done to tackle areas of concern.

Others seemed to dilute the recommendations of the Francis Inquiry. The Cavendish review, for example, disagreed with the proposal for a proper system for the regulation of Healthcare Assistants. The Patients Association believes strongly that regulation of healthcare assistants is essential to enable high quality care to be delivered to all patients, including the most vulnerable, whose care is often provided exclusively by these carers.

“We are awaiting the publication of the Berwick report and we would be extremely pleased if Professor Berwick agrees with Francis and suggests that healthcare assistants should be regulated. We would also welcome the introduction of minimum staffing levels to enable the necessary improvements in care.

Healthcare professionals, patients and relatives are constantly contacting our Helpline to tell us that they don’t think that the wards at their hospital have sufficient numbers of staff to keep patients safe, and this problem has to be addressed. We welcome the new emphasis placed on individual candour. Everybody working in the health service needs to understand the importance of openness and transparency. Many NHS staff, including doctors and nurses, already have a duty of candour under their respective professional codes of conduct.

What we need to see is a clear blueprint for implementing Francis, not more enquiries. The goal has to be to move towards an open, honest and transparent NHS where everybody is accountable for their actions. This has to be across the whole system, including primary care and a vital step towards
achieving it will be a complete change in the culture of the NHS and the way professionals interact with patients and relatives.

For an NHS that is truly safe and transparent we also need for patients to be able to access meaningful data about performance and patient safety records, as well as infection rates on individual hospital wards. Above all we need to see a clear distinction between the need to cut costs and manage finances, and the need to ensure that patients remain safe.

We are very pleased, therefore, with the Government’s recent positive response to the Francis report and also with its announcement in relation to improved staffing levels. We will seek to work constructively with the Government to progress this work and to eradicate the kind of appalling care that is evidenced in the patients’ stories publication.”

The future facing the NHS is one of great potential opportunity. The Patients Association acknowledges that implementing the Francis Recommendations will be challenging and will have financial implications. But once the short term pain has been overcome we are confident that the long term gain of an NHS which has the safety and dignity of its patients at the centre will have made it seem very worthwhile.
Positive Comments

Many of the stories included in this report also contain examples of positive care, and we feel that these should be recognised.

“On 9th November, Elisabeth was discharged by ambulance to a local care home, where she is now reasonably comfortable and the care seems to be good.” Charles Flood

“(This whole process has been) rewarding because I feel that I have made the hospital management focus on its treatment of patient concerns with fresh insight. I am sure that if the Ombudsman did not exist I might not have succeeded because without that independent process NHS Trusts would not be so readily accountable.

“I believe that most people at my local hospital at all levels do a great job almost all of the time but complaints are an important means of maintaining public confidence and improving clinical vigilance. They are an opportunity to make patient experiences better. I still have tremendous respect for clinicians and the NHS. Most have the best interests of their patients as their absolute priority.” Andrew Brown.

“The consultant at Wythenshawe was remarkable. He explained all the risks involved and the seriousness of the operation, and also said my father was right to explore other possibilities rather than just leave the cancer because of his age. As a result, my father’s cancer was removed during an operation and he spent some time in intensive care in 2001. He had another lobe removed at a later date in 2002, but he never suffered from lung cancer again.

“He had excellent follow-up appointments at Stepping Hill Chest clinic. I felt that nothing was too much trouble for the staff at this clinic. If my father had any concerns about his health he would contact the Chest Clinic and they would make an appointment for him to see one of the consultants at Wythenshawe Hospital more or less straight away.” Doreen Hadfield.

“My wonderful GP came the following day and explained what was likely to happen in the coming weeks. The district nurses were amazing, as were the Crossroads Carers. Macmillan and Marie Curie offered support too. I have nothing but praise for the care John received during normal hours.” Lyndsey Wright

“I was kept informed of her progress by the ward doctors and I was very pleased with the service they provided.” Gillian Sargent

“Averil stayed in hospital for nearly ten months on the S3 ward. Here, with good treatment and therapy, Averil regained much of her weight loss and zest for life.” Averil Hart’s family
1. Olive Burns
By her daughter, Gillian O'Hearns

Gillian O’Hearns’ mother was admitted to Tameside Hospital when she thought she might have fractured her hip. Her condition deteriorated so drastically that her family thought she had been placed on the Liverpool Care Pathway; instead they were horrified to discover that nursing staff appeared to have ‘forgotten’ to treat their mother over a busy bank holiday weekend.

My mother, Olive Burns, was diagnosed with lung cancer in late March 2012 and had been receiving various investigations and scans at Tameside Hospital to help treat this condition. At the time of the diagnosis, my mum was otherwise well, healthy and leading an independent life and taking care of her own needs. Although she was 84 years old, she looked and acted twenty years younger.

On the 24th April at 8.30pm, my mother needed to be admitted into A&E at Tameside Hospital, as she had been having difficulty putting any weight on her left foot and had pain from her thigh to her knee; she was unable to weight bear. The paramedic who dealt with her at home felt she may have broken her hip.

When my mum was admitted, I never, ever thought I would witness what I was forced to during her hospital stay. I work in hospitals every day; I trained as a nurse over 20 years ago and have worked in the pharmaceutical industry for the last 18 years. I am aware of the lack of resources and cost savings needed in the NHS, but at what cost - human lives?

When my mum was admitted into A&E, a hip x-ray was done and no obvious breaks were seen, but she had to undergo some blood tests which revealed she had a chest infection. She was taken to the Medical Assessment Unit (MAU) where hospital staff could monitor her condition. I noticed that my mum was in very obvious pain and when any movement to her lower body took place she screamed out in pain.

The following day, my mum was moved to Ward 40. Her chest infection was quickly controlled and for the first few days mum sat in the chair next to her bed and chatted away quite happily, although she commented that was still in pain from her back/hip.

An MRI scan on Friday 26th April revealed ‘she has a very old back’ and two slipped discs, this was cited as the cause of mum’s continuing pain. The doctor who rang to tell me this news said she had
spoken with the Spinal Unit at Hope hospital and they advised that painkillers and physiotherapy were the recommended course of action to help treat mum.

Over that first weekend, my mum was sat in a chair, obviously in pain from her back but otherwise in very good spirits, she had lots of visitors who all said they felt she would be home soon, once she was walking again.

I did notice on Sunday 28\textsuperscript{th} April that mum seemed to be under the influence of a lot of medication and painkillers and she was a ‘little slowed down’ as a result, but still in good spirits. She commented on the amount of tablets the nurses were giving her, saying it was ‘far too many’.

Indeed, when I looked at the medication list, I was shocked to see 17 drugs had been prescribed. I am aware these were not all given on the same day/time and some were to be given as required but over the course of six days since being admitted the following drugs were written on her drug sheet:

1. Aspirin
2. Zopiclone
3. Paracetamol
4. Codeine
5. Oromorph
6. Clarithromycin
7. Oxygen
8. Dalteparin
9. Adalat
10. Simvastatin
11. Candesartan
12. Gapapentin
13. Omeprazole
14. Diclofenac
15. Lactulose
16. Senna
17. Deramethasone

On Monday 29\textsuperscript{th} April, the physiotherapist visited my mum and he carried out a stair assessment, walking her up and down the stairs between the lower ground and ground floor. In my mum’s words, ‘he nearly killed me’. She did not walk after that day.

On Tuesday 30\textsuperscript{th} April I asked the Senior House Officer (SHO) on the ward to go through the drug list with me, I was concerned about the amount of medication being used on an 84 year-old lady who was admitted into hospital taking just three tablets.

The doctor went through the list quickly with me, discussing each drug in turn. I expressed quite strongly that I felt my mum should not have so many drugs prescribed.
By Wednesday 1st May, my mum started to have severe diarrhoea which she said kept her awake all
night, and that she was unhappy with the doctor for putting her on so many tablets to ‘loosen’ her
up when she felt she did not need them. She told the doctor not to give her these tablets again.

On Thursday 2nd May, I received a call at 8am asking me to get to the hospital as soon as possible. I
was told the medics were with my mum and she had been unresponsive in the morning when the
day staff came on the ward.

When I arrived, she was having a CT scan, having suffered a stroke.

My immediate thought was the cocktail of medication she had been on had lowered her blood
pressure over the previous days (one of the nurses had stopped giving her the blood pressure tablets
for this reason).

I discussed this with the registrar on the 2nd May, and he said he did not think the medication was to
blame for the stroke but admitted he had not met my mum before so would look at her medication
list. A couple of hours later, I noticed at least seven drugs had been crossed off the list.

My mum’s recovery from the stroke was good and her speech returned quickly, as did the
movement in her right side. When her speech returned her first words were: ‘It is too many drugs.’

Unfortunately two weeks after the stroke, my mum’s health rapidly deteriorated. She contracted C-
Diff and received the appropriate treatment, but as a family we received no information about the
risks of this disease at the time of diagnosis. I remain concerned about the hospital’s management
of C-Diff infection if visitors are not given adequate information on how to prevent further
contamination.

As I was so concerned about my mum’s negligent care, I asked to meet with her consultant, to go
through my concerns regarding her medical and nursing care. We met on Wednesday 8th May for
one hour. During the meeting, he listened to my concerns, made notes and said he would speak to
the ward manager. At the time, I thought my mother’s care would improve following this meeting.

On Wednesday 15th May, the final blow came. My mum was told the results of a bone scan that had
been conducted at least a week before had shown a fracture to her left hip, the report by the
radiologist had only been received that day. The medical team then looked back at previous x-rays
and admitted to missing the fracture on at least one other x-ray including an abdominal x-ray done
the week before. I discovered the fracture had been missed because the x-rays had not been read by
a radiologist, but the consultant who had requested the x-rays. He was a chest consultant and
admitted that hip x-rays were not his ‘speciality’.

My mum was told she would be seen by the orthopaedic surgeon that day and a decision made
about operating. The Anaesthetist visited that evening and said the operation should take place
within 24 hours.
That afternoon, after seeing so many appalling mistakes being made I contacted PALS and made a complaint and asked for a formal investigation to take place.

On Thursday 16th and Friday 17th May, my brother and I had two meetings with the medical team and ward manager. The operation had to be cancelled because my mum was medically too unwell and the risk of anaesthesia or C-Diff infection getting into the surgical wound would make the operation too high risk.

My mum was then given palliative care as there was nothing the hospital could do other than treat her medical needs. She also developed Pneumonia. As a family, we were given numerous apologies about the missing the fracture on x-rays, but I felt it was too little, too late, for my lovely mother. The chest consultant also made a formal complaint to the radiology department for not reporting the findings of the bone scan earlier.

We felt that if the fracture had been discovered much earlier she may have been well enough to operate on. Before having a stroke and developing C-Diff infection, she would not have suffered so much pain in three weeks, which my mother said also included being ‘thrown in bed like a sack of potatoes’. She reported this to the medical and nursing staff the following day.

On Friday 17th May, my mum was given a private room because of the C-Diff infection, even though she had had it for nearly two weeks. I was told it is policy to isolate patients with C-Diff. It seemed rather late to us, and we also received an information leaflet that day.

Despite my mum’s health deteriorating, she did show some improvement and her fighting spirit returned. So much so, that she told the doctors herself how angry and upset she was about coming into hospital unable to walk but otherwise feeling well and now being bedbound and reliant on nursing care for nearly all her daily needs.

On Tuesday 21st May at 7pm, a Senior Consultant Orthopaedic surgeon visited my mum unannounced to give a second opinion. He was not with any of her doctors and we were unaware he was visiting. When my brother arrived at 7.15pm he was told by one of the nurses my mum had ‘one of the top guys’ visiting her and reviewing her notes. My brother said the surgeon spent an hour with my mum and in my brother’s words; it was the first time anyone had given my mum good news in three weeks. The surgeon had told her that if she continued to recover from the chest infection he would operate himself the following week and he provisionally booked her in for May 30th. This was obviously subject to change depending on my mum’s condition the following week.

My mum and brother were delighted, it was the first time anything positive had been said and we all knew that if she could not have her hip repaired she would deteriorate rapidly due to being bedbound.

On Wednesday 22nd May, my brother and I were asked to attend a meeting with my mother’s consultant at 1pm. When we arrived separately, we went to see our mum, the cubicle doors were closed, and we were both utterly shocked when we saw our mum surrounded by doctors. She was
clearly critically ill, but we had not been told that she had seriously deteriorated that day or asked to come in earlier.

We were told she was suffering from Atrial Fibrillation and possibly heart failure. We could not believe our eyes as she had been so well the last couple of days and seemed to be recovering from the chest infection. Her observations were done hourly; all our immediate family came to see her as we were told she would not live past the weekend. By 5pm she was looking a little better, was making us laugh and had a small amount of chocolate, some jelly and a drink of Lucozade.

The next few days were long and she had clearly had enough, but she was still talking and communicating with us, her brain was active and she was asking questions and reminiscing about the past.

On Friday, mum’s consultant told the nurses to carry on treating my mum over the bank holiday weekend, though he said he did not expect her to live till Tuesday when he returned to work.

My brother and I spent most of our days in the hospital and this carried on over the bank holiday weekend, it was clear at this time that the ward was run on half staff, with junior on call doctors who had no knowledge of patient’s case histories.

On Saturday morning when I visited mum she was very sleepy, she had pain in her foot the previous day and her Oromorph was increased to 10mg. Her nurse felt this may be the reason why she was so sleepy. He asked the on call doctor to see mum and then she met my brother and me. We told the doctor that we felt she should not suffer anymore and should not have any more oral tablets as she was unable to swallow them. We wanted her to be comfortable and pain free. The doctor and nurse agreed with this plan of action.

Later that day my brother went home for 40 minutes, when he returned my mum’s lips were blue. When he looked further he realised this was because her lips were stained with dye from tablets. He then noticed two blue capsules on my mum’s nightdress under her hand. The nurse had given these to mum after my brother left. Although my mum clearly couldn’t swallow them, the nurse must have put them in her mouth and left her, not checking if she swallowed them. When my brother asked mum’s nurse why he had given our mum tablets when he had already agreed that morning not to administer any more oral tablets, he did not answer.

On Sunday 26th May, I received a call from the hospital saying mum’s consultant wanted to meet with the family at 11am. It was clear mum was deteriorating and was spending most time of her time sleeping, although she could still speak to us when she wanted to. During the meeting with her doctor (he had come in to see my mum on his weekend off) he said he felt it was now time to stop treating mum with drugs other than for pain relief, he felt she would not live beyond Tuesday and we agreed with this decision. The ward manager and nurse were also in the meeting and we were told about the Liverpool Care Pathway (LCP). We were told that we could go to the hospital at any time to visit mum and use their tea making facilities. We were both given leaflets on the LCP and told to read them so we would have an understanding of what would happen next, the fact that active treatment would stop, regular observations would stop, etc. We were also told the LCP was
reversible and treatment could start again if my mum was more responsive. We spent all day Sunday and Monday at the hospital, no observations were taken, as we had expected since the meeting. We gave mum sips of Lucozade and jelly to eat, but other than that no food or drink was offered her by hospital staff. She was made comfortable by the nursing staff and only pain relief was administered.

By Tuesday morning, my brother and I both said the same thing; that we weren’t sure if the LCP was the right thing to do and we wanted to get our mum home. My brother had asked on Monday night to see a discharge nurse from Marie Curie the first thing Tuesday morning.

My brother went to the hospital at 8am. When he went into mum’s cubicle he realised the floor was covered in urine because her catheter bag hadn’t been closed properly and the staff had failed to notice.

During this visit, he asked for a meeting with the doctors. We met with a registrar and a junior doctor (who we had already met on Saturday 25th May); they asked us what our concerns were. We informed them that we had had a meeting with mum’s consultant on Sunday and had agreed for treatment to stop and that mum had been placed on the Liverpool Care Pathway. We said we were not sure that this was now the right decision as mum was ‘still here’ (her doctor had said he did not expect her to live until Tuesday) and she is still responsive and able to talk to us.

The bombshell that came next was not expected. The Registrar said: ‘Your mum is not on the Liverpool Care Pathway.’ It was like a blow to the head. What followed were lots of questions, such as: if she wasn’t on the LCP, why had we been told about it? Why had we been given the LCP leaflets? Why had hospital staff not taken any observations for two days since that meeting on Sunday? Why had they not offered our mum any food, fluids or treatment?

A lot of the questions they could not answer so I rang the Chief Executive’s office and asked for a manager to come to the ward. I rang PALs and asked them to come down too. We decided that enough was enough and to get our mum out of that hospital as soon as we could. The junior doctors contacted mum’s consultant and by lunchtime we had a meeting with him, the matron, a PALS representative, a Marie curie nurse and the nurse who had been looking after my mum that weekend.

The meeting got very heated and the matron was very direct with mum’s consultant asking him about the LCP, he said he had written in his notes LCP to be considered. This was news to us! I asked the matron if mum had not been placed on the LCP, why was no food or fluids offered? I asked if this was normal, she replied that no, it wasn’t. I asked why no observations had been done during the day shift since Sunday? She could not answer.

After the meeting, which gave us no answers, just more questions; my brother and I made plans for mum’s discharge with the Marie Curie nurse. She said the two options were the local hospice or home. My brother walked to the hospice - it is opposite the hospital - and he said it was lovely. We asked the Marie Curie nurse to start the paperwork for mum to go there the following day. At 4pm, she informed me the hospice would not take my mum because of the risk of C-Diff; I completely
understood this although it was another blow. I asked the Marie Curie nurse to make plans for discharge to my mum’s home for the following day.

A bed and oxygen were ordered and delivered on the morning of Wednesday 29th May. We managed to get my mum home in an ambulance by 2pm on Wednesday. All her close friends and family came to see her at home. She lit up our lives that night with her jokes, humour and smiles; I do not think she could ever believe she would go home.

Our mother passed away peacefully in her sleep in the early hours of the following day, Thursday 30th May. We were so glad we managed to get her home.

Following our devastating loss, the cause of my mum’s death on her death certificate was attributed to lung cancer. As a family we disagreed with this; she went into hospital unable to walk but otherwise well and was living an independent life and within a week she had a stroke, at two weeks developed C-Diff, at three weeks was told she had a broken hip (missed on the x-rays from weeks before) and at four weeks she suffered heart failure. She died after five gruesome weeks spent in Tameside Hospital.

The local coroner reviewed the case and asked for an independent pathologist to conduct a post mortem. The conclusion was that my mum died from Bronchopneumonia directly attributed to C-Diff infection. An Inquest has been called and this will be held in the next six months.

What also concerned me was that the very ill patients who did not have family members there asking questions on their behalf each day, were unable to have someone speak out on their behalf and also witness the lack of care from some staff. During my mother’s hospital stay, I witnessed some basic lack of nursing care, such as no water jugs or empty jugs being left on patient’s tables; ignoring call bells / buzzers; nursing assistants mimicking patients; not washing/changing patients - including my mum; patients ‘dreading the nights’ as there are so few staff and they are too busy; the list goes on.

I really hope that what happened to my mum never has to happen to any other patients or their families. I do not want anyone to suffer as we have.
2. Averil Hart
By her Family

Averil Hart had spent over a year recovering from anorexia when she accepted a place studying creative writing at university. Her family were assured that she would be closely monitored by a community eating disorder and university primary care team. However, when these two NHS organisations failed to communicate with each other or perform regular health checks to ensure she was coping, her condition deteriorated and she was found collapsed in her flat by a cleaner. Averil was taken to hospital but tragically died aged just 19.

When a young person dies as a result of an accident or incurable illness it is a tragedy.

Averil, our daughter and sister, died at the age of 19 from a treatable illness.

Averil was a wonderful daughter and sister; she was born at home with her family around her. She was the cheeky, lovable, fun girl at the front of family and school photos, always with a smile and a song. Averil was academically brilliant, she loved writing and literature and the world around her. She also had a black belt in karate and was extremely sociable and outgoing. She loved life and she loved her family and friends.

In the run up to and during her A-levels, Averil succumbed to an eating disorder, which spiralled out of control after she had completed her studies. A late diagnosis by her GP resulted in her being in a very poor state of health before she was admitted for treatment to Addenbrooke’s Hospital in Cambridge.

Averil stayed in hospital for nearly ten months on the S3 ward. Here, with good treatment and therapy, Averil regained much of her weight loss and zest for life. She fought to regain her independence and made many good friends amongst the patients and staff. Each day, she placed a positive message or quote on the meeting room board to inspire others to fight for recovery too.

During Averil’s stay in hospital, our family attended therapy days at Addenbrooke’s Hospital with two other families. They recounted how the Norfolk community eating disorder service (NCEDS) had been established after the death of a young girl who had been neglected by the local NHS trust. The families also told us about the near misses that their own daughters had experienced when being cared for in the community and how they had ended up at A&E after periods of neglect. These
harrowing accounts of the lack of care were somewhat brushed aside by the staff and we were told of the wonderful new organisations that were now in place to provide care in the community.

During her recovery on the S3 ward, Averil arranged to transfer her place from Durham University to the University of East Anglia (UEA) so that she could be close to friends and family. Although she had not reached her target weight, Averil was discharged from Addenbrooke’s Hospital in August 2012 and then, like many other students, started the term at UEA living in a flat on the campus. She attended lectures in her chosen subject of English and Creative Writing and when we visited her she told us how much she was enjoying both her course and life at the university after being in hospital for so long.

Averil’s discharge notes from Addenbrooke’s stated that she was at ‘high risk of relapse’ and in her Care Programme Approach (CPA), written in July 2012, it states that ‘Averil’s weight loss may suffer and she may become frail and prone to falls’. Averil’s overall care was to be provided by the primary care team at University of East Anglia medical service (UEAMS) and also the Norfolk community eating disorder service (NCEDS) secondary care team. Together these two NHS providers were assigned to look after Averil’s basic health care: measuring and checking her weight, blood pressure and physical strength weekly as well as blood characteristics at regular intervals. In addition, NCEDS would have weekly sessions to ensure Averil’s mental well-being. A care coordinator was appointed to monitor her clinical and psychological health.

In the event, Averil had to wait three weeks before these organisations started to take an interest in her care, but by this time her health had started to deteriorate again (during this period of transition between services the risks are well known to be particularly high for anorexia patients).

It is reasonable to assume that a care coordinator of a ‘high risk’ patient would have some experience in that particular illness, however, in Averil’s case a junior trainee was appointed by NCEDS who had no practical experience of her illness at all.

Averil visited her primary care team at the university’s medical service who had been instructed in her discharge plan to weigh her weekly, take regular blood samples and check her physical condition. In the ten-week period that Averil was alive and at university, the medical centre only weighed Averil three times and failed to undertake proper physical examinations or any blood tests. Both the medical centre and NCEDS failed to communicate with each other to check that Averil’s care plan was being implemented.

There were no checks by the commissioning NHS authority that the NCEDS service was being properly run and administered. From the information we have obtained, it appears that the Cambridge and Peterborough Trust were taking nearly a million pounds a year without providing an ‘adequately staffed’ service for the high risk patients that were under NCEDS care – citing staff shortages among their excuses for Averil’s death.

During the following five weeks, Averil lost more weight and her health further deteriorated, which was unchecked by either NHS organisation. Averil was seen on six occasions by the NCEDS trainee psychologist, who had minimal prior experience of dealing with patients suffering from anorexia. In
our opinion the team failed to measure Averil’s weight accurately and to recognise the obvious and significant signs that her health was seriously deteriorating. Averil was now at risk of water loading and was using other techniques to falsify her weight.

The clinical team leader from NCEDS failed to co-ordinate Averil’s care or check on Averil’s health and wellbeing despite her reducing BMI and also failed to oversee the junior team member involved with Averil’s care plan. The clinical lead only became involved after the emergency call and when it was too late to change the outcome of her illness.

Averil’s father and older sister visited her in Norwich in late November 2012, a few weeks before the end of term. We were both shocked by her very poor physical appearance (her BMI was obviously less than 13, the level at which she had previously been when first admitted to Addenbrooke’s Hospital the previous year) and she slurred her words as she tried to talk to us about her studies and about Christmas, which was fast approaching. We were both in tears as we drove home, worried sick about Averil’s condition and unable to contemplate how - despite her care plan and risk analysis - her health had been allowed to deteriorate by her carers in the short time since she had started university. On arriving back home, we made an emergency call to our only point of contact at Addenbrooke’s S3 ward. This phone call was documented by the ward, and we were assured then, and by a further call the following day, that our emergency call was being taken very seriously and that the NCEDS service would follow up with all haste to check Averil’s condition.

In spite of this emergency call, absolutely nothing was done in order to save Averil’s life; she was literally starving to death.

Averil desperately wanted to stay at university rather than return to hospital as an inpatient, but the care she so badly needed to maintain her health in the community simply was not provided. The healthcare professionals were not communicating with each other and certainly not looking after Averil’s basic health requirements as she struggled to stay at university and also bravely struggled to stay alive.

In her university flat, her flatmates and cleaner were becoming increasingly worried. Averil would sit each morning in the communal kitchen trying to eat in order to regain her strength, because she knew that failure would mean a return to hospital and leaving the university and studies that she loved.

A further emergency call was made a few days later by the university cleaner, who recognised that Averil was seriously ill and that ‘she should be in hospital on a drip’, but no further action was taken.

Two days later Averil was found unconscious in the kitchen at her flat and an ambulance attended her after a 999 call was made by the cleaner.

Averil was taken to Norfolk and Norwich Hospital where we immediately visited her. The acute team at the hospital clearly had little experience of how to deal with a patient with severe anorexia, who was critically ill. They allowed Averil to fall on the ward, sustaining a head injury and expected...
her to feed herself from a food trolley. The specialist MARSIPAN guidelines (for anorexic patients) were ignored at this critical time.

Despite being based a few miles from the hospital, NCEDS did not attend the emergency to check on Averil for three days and it was during this critical time that Averil’s life started to slip away. Without the care she so badly needed her chances of survival diminished by the hour.

It was clear that Norfolk and Norwich Hospital did not have the expertise to save Averil’s life and, at our request, she was transferred to Addenbrooke’s Hospital where she was taken to the acute ward. Averil was placed on a glucose drip although this was later removed at the direction of the consultant with a view to nasogastric feeding the following day. NCEDS finally attended but failed to implement the Mental Health Act to ensure Averil’s safety.

That evening, Averil’s father stayed with Averil to help nurse her along with a bank nurse who was on duty from a geriatric ward. For a patient in a critical condition the staffing situation seemed totally inappropriate and inadequate.

After her father left the hospital that same night, Averil became hypoglycaemic and this condition was not corrected in time. As the Addenbrooke’s internal report indicates, Averil’s ‘vital parameters had not been maintained as the consultant had instructed.’ We feel it was a total failure of the health service at a critical time.

Later that night Averil arrested and became unconscious; she then slipped into a deep coma from which she never recovered. Averil’s friends and family were at her bedside with her until she died.

During those last days and hours we stayed in Averil’s room as she lay on her hospital bed attached to the machines and drips and was nursed by excellent palliative care staff that knew our desperate situation. We sang Christmas carols to Averil, we played her favourite music, we hugged and cradled her in our arms and we all loved her for each and every single small breath that she took as we had done every day during her wonderful but short life.

Anorexia is a treatable illness, so why did this tragedy occur?

- There was no proper transitional handover from Addenbrooke’s Hospital to NCEDS when Averil started university and serious delays occurred. We strongly feel that this was the result of poor management by both Addenbrooke’s and NCEDS.

- The NCEDS team was poorly run and short-staffed, they failed on numerous counts to look after Averil’s health and welfare (and in our opinion this organisation was clearly not fit for purpose). Even when one of their high risk patients was dying they failed to react in a co-ordinated or timely way.
The Norfolk and Waveney commissioning team that paid Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) for the NCEDS service did not check on the quality of the service provided by NCEDS or undertake patient safety checks of any sort.

NCEDS failed to communicate with the primary care team at UEA to ensure that the care and risk plans were carried out for a high risk patient.

A junior psychologist at NCEDS with minimal experience of anorexia was the main carer for a high risk patient and without proper supervision the team failed to recognise Averil’s deterioration.

When the alarm call was raised externally, no appropriate action was taken by NCEDS. Had appropriate and timely action been taken, even at this late stage, this tragedy could have been averted and Averil’s life saved.

The Norfolk and Norwich Hospital did not provide appropriate and correct treatment (as per MARSIPAN) in the critical hours when Averil was admitted.

NCEDS – who had the experience to assist the acute team at the hospital – did not attend the hospital for three crucial days (despite being based only four miles distance from the hospital).

Addenbrooke’s Hospital’s acute ward did not maintain Averil’s blood sugar levels correctly or use the mental health act to instigate correct treatment at an early stage, allowing her to become hypoglycaemic, despite being cared for on a specialist ward.

After Averil’s death, the enquiry undertaken by CPFT has failed to bring together the full facts of this tragedy and both the primary and secondary care teams are now delaying or refusing to answer questions fearing litigation; despite the call for ‘openness and honesty’ following the Mid-Staffordshire Inquiry. Sadly, these individuals in both primary and secondary care organisations are further disrespecting both Averil’s memory and her family by refusing to answer questions about the care she received in the last few weeks of her life.

We also discovered that the head of the NCEDS team made additional notes on Averil’s medical file two weeks after she died, and we find this practice highly questionable.

Nothing will bring Averil back to us. Averil’s loss has devastated our family and it is impossible to adequately say how much it has affected each of us in so many ways. Zoe and Imogen, Averil’s sisters, are bravely trying to rebuild their lives, but living without Averil by our side is so very hard, we think about her throughout our daily lives.

We strongly feel that an independent Inquiry into our late daughter’s treatment is required, which we will be pressing for at every level in the coming weeks, months and, if needs be, in the coming years until the truth is established. This tragedy should not have been allowed to happen and should never happen again. Until the truth is known and changes implemented we fear for the lives of other patients that are in their ‘care’.
3. Elisabeth Ann Flood
By her husband, Charles Flood

Mr Flood’s wife was admitted to Northampton General Hospital with a fractured shoulder and was later discovered to have a fractured neck, with severe lacerations to her upper body after a fall at home. She was transferred to Longlands Specialist Care Centre where some of the nursing staff refused to help her eat and drink and asked Mr Flood to visit her every day so he could feed her instead. Mrs Flood developed bed sores and was admitted to A&E after a hospital consultant noticed her frail physical appearance during an out-patient’s appointment. She is still in a care home and unlikely to return to her marital home.

My wife, Elisabeth, has a very friendly and pleasant personality and was dedicated to her career in nursing. She started nursing in 1950 at Charing Cross Hospital, London, to obtain her SRN, which led to her working at the Royal National Orthopaedic Hospital to obtain her ONC. This involved her dealing with all types of fractures, together with TB and Polio patients, including those in iron lung breathing apparatus. We married in 1958 whilst she continued her nursing at Harrow Hospital and she then took the position as Practice Nurse at a local GP surgery, where she continued to work for 20 years until her retirement in 1990 when we moved to Northamptonshire. In her younger days she was a keen tennis player but has also always enjoyed knitting, embroidery, gardening, having pet dogs and country walks.

On 29th May 2012, Elisabeth fell at home and was badly bruised. She had fractured her left arm and shoulder and had severe lacerations to her right forearm. As Elisabeth was in shock and had also suffered a head injury, I called 999. The paramedics who responded to the call were very helpful and assisted my wife with her injuries; they also gave her gas and air to help ease her pain.

We arrived at Northampton General Hospital’s Triage Department at approximately 5:30pm. Upon our arrival, I realised that the A&E department was very busy and I became increasingly concerned as Elisabeth remained unattended in her wheelchair. One of the ambulance paramedics returned and administered some Morphine to help with her pain. As the waiting time continued to increase, I asked members of staff to attend my wife and, while they promised to help her, it was some time before any help was given, and only then because my wife was desperate to go to the toilet and needed assistance. Staff did suggest that I should help Elisabeth to the toilet, but I was unable to do so because I had a bad back and felt it would have been dangerous to try and assist Elisabeth...
without causing further injury, as she had hurt both her arms in the fall and would have needed my full support.

After being assisted to the toilet, Elisabeth was taken to a cubicle and waited for a member of staff to check her blood pressure and echocardiogram (ECG), etc. It was during this time my wife and I were informed that a temporary back slab plaster would be administered and she would be sent home. As I was very concerned about my wife’s condition and felt that she needed to be kept in hospital as an inpatient, I had to have many discussions with hospital staff to convince them that it would be impossible for me to continue caring for my wife at home, at least until some of her injuries had healed. As an elderly man with a bad back, I did not feel confident that I would be able to help Elisabeth with all her daily needs. At about 10:30pm, it was decided that I should leave Elisabeth in the hospital and contact A&E the following morning to find out what had happened.

At 7am on 30th May, I phoned A&E for an update on Elisabeth’s condition and was told she had been admitted to the Emergency Assessment Unit (EAU) and was comfortable. She was waiting for the Orthopaedic Surgeon to arrive and I was advised to call later in the morning to get more information then. Elisabeth was in the EAU unit for two to three days, before she was transferred to the Cedar Ward where she stayed for nine to ten days. Following this, she was transferred to the Abington Ward on 11th June, where she stayed for seven to eight days.

On 19th June 2012, Elisabeth was transferred to Longlands Specialist Care Nursing Home in Daventry, by Northampton General Hospital’s discharge officer. I was unhappy with Elisabeth being discharged and sent to this care home, as I was worried that it might not be the best place for her to go for continuing care with her injuries, but was assured she would receive the correct treatment. I was told that she would be under the care of a local GP practice or doctor who would visit her once a week. Elisabeth ended up staying at Longlands for five weeks and during this time I became increasingly concerned about her treatment and wellbeing.

During her stay at Longlands, Elisabeth became very dehydrated and was unable to eat properly due to an osteoporotic fracture in her neck. This meant that her chin rested down on her chest and made eating very difficult. She frequently vomited food because she had difficulty swallowing. Although some staff at Longlands helped feed Elisabeth, other staff generally considered it was not part of their job to feed a patient and also complained that lifting and moving Elisabeth together with having to help her to the toilet and attend to her other needs, was not part of their job description. One day, the care home sister / manager suggested that ‘it would be better’ if I visited and fed my wife every day, as it was not for them [care home staff] to carry out these duties.

To date, I remain very concerned about the attitudes of staff at Longlands Nursing Home, whose responsibilities I feel are to ensure that elderly patients are well cared for and that those with limited mobility receive all the necessary assistance. If staff at Longlands were not responsible for providing my wife with such a high level of help and support during her time there, why were Elisabeth’s care needs not properly assessed by Northampton General Hospital prior to her discharge? And why didn’t staff at Longlands Specialist Care Centre raise these issues and attempt to find more appropriate NHS continuing care for my wife?
After the care home sister / manager asked me to visit the home and feed my wife, I made sure I visited her at Longlands every day at 11am. I would try to feed Elisabeth during the lunch and tea periods, and would often leave at 4pm. Our daughter would also come straight from work to help feed her mother in the evening, and would also look after her general skin care.

On one occasion, my wife complained of having sore feet, and on closer examination our daughter noticed ‘a large black area on her heels’, and called me to report her findings and concerns. I advised our daughter to ask one of the nurses / assistants to look at Elisabeth’s heels and report it, which she duly did. It was found, upon further diagnosis, that she was suffering from Grade Three / Level Three severe ulcerations of both heels. The condition was so bad that it has taken until May 2013 for Elisabeth’s heels to heal, after receiving regular treatment from the district nursing team. After making a formal complaint to the care home, I was informed that the severe ulcerations on my wife’s heels were ‘only partly substantiated due to a lack of documentation’. This statement appears to indicate that my concerns about my wife’s medical notes being incomplete and improperly maintained at the time were valid.

After we discovered the marks on her heels, Elisabeth became very ill with severe diarrhoea, which was confirmed by the visiting GP. I attempted to speak with her GP on two occasions after she became ill with diarrhoea and also a Urinary Tract Infection (UTI), as I was so concerned about her condition, but nothing was ever arranged to help improve her health. As Elisabeth’s condition continued to deteriorate, I again asked for a GP to see her but was told in response that I could visit the GP’s surgery if I was so worried, which I did to request the GP visit Elisabeth urgently. A female GP arrived the next day to examine my wife and said she would try to get her admitted into another hospital close to Longlands, but nothing more was done.

On 11th June, during Elisabeth’s outpatient appointment at Northampton General Hospital with an Orthopaedic Consultant, I explained how concerned I was about the position of her head and the difficulties I had experienced trying to feed her. The consultant arranged for a CT scan to take place on 13th July and said that he would see Mrs Flood with the results on 18th July. I reminded staff at Longlands of this appointment on several occasions so that they could arrange transport for Elisabeth, but no travel arrangements were made by the home, resulting in Elisabeth missing the appointment. This was rescheduled for the 25th July. This failure to arrange my wife’s travel to hospital for a CT scan delayed the prospect of my wife receiving the appropriate medical attention. I did raise this issue in a formal complaint, but in a response provided by Longlands Specialist Care Centre I was informed that there is no record of any such request being made. This is again indicative of poor record keeping.

On 25th July, my wife was able to attend an out-patient appointment at Northampton General Hospital with an escort from Longlands. She was first seen in clinic by the consultant’s registrar; however, as Elisabeth’s condition had deteriorated so badly during her time in Longlands, I felt I had to ask the consultant to take a look at Elisabeth, as I was so worried about her health. He did and immediately arranged for her to be admitted into A&E.

On arrival at A&E, Elisabeth was immediately put on a drip, with blood and urine tests taken and a catheter was inserted. The doctor on duty was ‘very concerned’ about Elisabeth’s condition and
asked me if he would object to his needing to insert a tube down her throat to help her breathe, as ‘she was very ill’. Throughout the day, staff continued to change Elisabeth’s drips and take blood tests until about 9:30pm. She was then admitted to EAU. A nurse in EAU was so upset about my wife’s poor condition, especially the bedsores on her back and buttocks, combined with the ulcerations on both her heels, that she told me she was going to report the matter. Elisabeth stayed in the EAU ward for about four to five days until she was moved to another ward.

On 30th July, Elisabeth was moved to the Brampton Ward Room 10. She stayed on this ward for three to four days before she was again moved to Room 19. During this time Elisabeth caught C-Diff and had a CT scan together with repeated blood, urine and faeces tests, later followed by a colonoscopy. The colonoscopy revealed four lumps in Elisabeth’s colon, but the biopsies taken revealed these lumps were benign. Elisabeth had to stay on this ward for five weeks.

On 30th August, Elisabeth was moved to the Althorp Ward under another new consultant. Whilst she was an in-patient, Elisabeth continued to suffer from ‘level three’ ulcerated feet, some abdominal discomfort with incontinence and irregular bowel movement, which led to her making a very slow recovery from her poor condition.

Each time my wife was moved to a new bed and ward, my daughter and I found it necessary to reiterate and explain to members of staff that she had a fracture in her neck and left arm, despite this information being available in her medical notes. On one occasion, I was so worried that I contacted the consultant’s secretary who advised me to speak to the ward sister. I was passed to a doctor to report my wife’s injuries and was duly informed that he was ‘totally unaware’ of Elisabeth’s condition.

On 18th October, I received a message that the consultant on the Althorp Ward wanted to talk to my daughter and me about Elisabeth, but this was never arranged. I also received a call from our daughter to say that the Althorp Ward Co-ordinator would call the next day, but she never did.

On 19th October, I called the Althorp Ward. An arrangement was made to have an ‘informal talk’ about Elisabeth’s future, which the ward co-ordinator would attend. An occupational therapist and physiotherapist would also be present. They requested that my wife should not be informed of the meeting as they ‘didn’t think it was advisable at this time.’ The meeting was scheduled to take place on 24th October at 10am.

On 23rd October, I received a telephone call from a woman from the discharge office, who informed me that she would not be present at the meeting, but her assistant would attend in her place. This was the first time I became aware that a discharge officer was going to be present at the meeting. My daughter and I were very concerned that history was about to repeat itself and Elisabeth would again be inappropriately discharged. We were also concerned that a discharge officer would be present at what was supposed to be an ‘informal meeting’.

On 24th October, as arranged, the meeting took place. The physiotherapist, nurse and care manager from the hospital were present, as were my daughter and I. The staff present at this meeting then decided that Elisabeth should also attend, despite the fact that my daughter and I had been
instructed not to say anything about the meeting to her. My daughter and I felt very uncomfortable
and upset when Elisabeth was assisted into the meeting room using a wheelchair, as she still had
very limited mobility.

During this meeting, my daughter and I were told by hospital staff that they ‘wanted a bed’ and that
we would need to find alternative accommodation for Elisabeth, such as a care home. My daughter
and I had to spend a number of days searching for a care home with a vacancy, which was a very
difficult and stressful experience, as we wanted to ensure she would receive the correct level of help
and support this time. Eventually, we were able to find one near our home.

On 9th November, Elisabeth was discharged by ambulance to a local care home, where she is now
reasonably comfortable and the care seems to be good.

On Elisabeth’s discharge from hospital the Care Manager provided me with a copy of a report which
states:

‘Mrs Flood was readmitted to hospital back in May 2012 with fractured shoulder – from hospital she
was discharged to Longlands Specialist Rehab Unit. She was at the rehab unit approx. 6 weeks and
her health deteriorated, she was not eating or drinking properly, husband was told to come and feed
her.

On a visit by her daughter Mrs Flood complained of sore heels, she investigated and found her heels
were ulcerated. On an outpatients appointment with the consultant seeing her admitted her to
hospital with dehydration, malnutrition, acute kidney injury and UTI. Mrs Flood also had pressure
sore on her back and grade three ulcerated heels.

PMH Irritable bowel syndrome, degeneration of osteoporotic spinal fracture, hypertension, hiatus
hernia, left fracture shoulder and left fracture hip, left hemi, polymyalgia.’

Whilst I am now satisfied that the care my wife is receiving is more suited to her specific needs and
that she is comfortable there, she still has ulcerations on both heels, is weak, needs two carers to
assist her and has been deprived of her home life for the past few months. Elisabeth is also very
distressed that her poor health is likely to continue for the rest of her life and that we are unable to
continue living together as husband and wife after fifty-five years of marriage. I strongly feel that
Elisabeth’s poor care at Longlands Specialist Care Centre contributed to her long-term ill-health and
the present financial cost to me of her having to stay in a home.

Our daughter is feeling the stress and strain of visiting her mother on a daily basis together with the
worry that her mother will never recover and return to her normal home life. This has had a
negative impact on both our daughter’s employment and her personal life.

I feel that since my wife’s deteriorating health and poor care became visibly apparent, I have been
living a very unhappy life and taking anti-depressants under the supervision of my GP. When I had
to visit Elisabeth at Longlands care home each day to feed her, my own health suffered and I wasn’t
eating properly or looking after my own care needs.
The Patients Association have helped me process a series of formal NHS complaints addressed to both Northampton General Hospital and Longlands Specialist Care Centre, but at this moment in time I remain dissatisfied with their investigations and subsequent responses.
Andrew Brown was shocked to discover he had been labelled a ‘vexatious complainant’ after making a formal complaint about his treatment at Worcester Hospital. He was also discharged from the cardiology team despite needing a follow-up appointment for palpitations. Mr Brown was so concerned by the hospital’s ‘oppressive’ reaction that he contacted the Parliamentary Health Service Ombudsman and the Patients Association for assistance to change the Trust’s NHS complaints policy.

I attended Worcestershire Royal Hospital ENT Department in November 2011 having been referred by my GP in relation to congestion and post nasal drip. During the appointment a nasal endoscopy was performed, but I wasn’t offered any local anaesthetic or decongestant. As a result, I squirmed and protested in discomfort. I was unhappy with the treatment I received that day and concerned that other patients would experience the same unnecessary discomfort, so duly complained and was offered a meeting with clinicians. I wrote and accepted the offer. Unfortunately, this meeting never took place because before it could ever be arranged the management decided to label me ‘vexatious’ under their complaints policy.

The letter referred only to the ENT complaint as the basis. This meant the Trust would not reply to my complaints including any future ones. The sanction was open ended meaning that it applied for as long as the Trust wished. I was really shocked at this sudden labelling and its implications.

Around the same time as deciding to label me vexatious, the Trust also discharged me from Cardiology, which resulted in a scheduled follow-up appointment to check my heart palpitations having to be cancelled. The consultant wrote to my GP advising that my care would no longer be undertaken in Worcester Royal Hospital.

The letter advising me of vexatious status enclosed the Trust’s policy which astonishingly included such conditions that can justify vexatious status as ‘attention-seeking behaviour’. The examples given included a patient seeking the support of their MP or telling their ‘horror story to all and sundry’. I was shocked by Trust’s response to what I knew to be a relatively straight-forward complaint. My only intention had been to raise my nasal endoscopy treatment as a concern, which would hopefully be used to help improve the ENT’s healthcare services, and I had only expected to receive a fairly standard response and apology.
I thought these vexatious complainant definitions were oppressive and was very concerned by the Trust’s failure to provide me, the patient, with any kind of any warning or appeal system. As I was so concerned by the Trust’s handling of what was a genuine and straight-forward complaint, I felt that I needed to take action to improve the situation for others, as well as contest the misuse of the term ‘vexatious’ in my own case. I applied to the Ombudsman to challenge the way my complaint had been handled and I drew attention to the situation through the local press.

I also wrote to the Trust Chairperson in detail explaining why I thought the policy and its application to my case was wrong. In particular, I wondered how such oppressive provisions could be devised by Trust staff and blessed by the Board.

Within a few months, the Trust changed the system and provided a right of appeal which I was invited to use and my appeal succeeded. A new twist developed in that the successful appeal was allowed on condition that I would not complain about any ‘past episodes of care’ which I felt was oppressive and implied that the Trust still viewed me as vexatious despite formally allowing my appeal.

Later on in the year, the Ombudsman decided on two issues. One was that the Ombudsman would not take further action on the ENT complaint as the Trust had conceded a ‘service failure’ had arisen in that they ought to have discussed the possible option of local anaesthesia during my appointment and that such anaesthesia for flexible endoscopy of the nose is not the subject of universal practice in healthcare.

However, the Ombudsman did decide that the conditions of removal of my vexatious status did require an Inquiry. I later encouraged the Ombudsman to expand the scope to include whether vexatious status should have been applied at all. I had also contacted The Patients Association for assistance with this matter and the organisation’s Helpline staff expressed their serious concerns that a NHS Trust sought to label patients as vexatious, when they might need the assistance of their MP to navigate the NHS complaints process or draft a formal, written complaint on their behalf. Katherine Murphy, the Chief Executive, wrote to the Trust to request that their definition of vexatious complainant policy be accordingly amended, to ensure that those patients and relatives who need additional help and support are not incorrectly labelled under this unfair policy.

Before the eventual outcome of the Inquiry this summer, the Trust changed its policy to remove the examples of people approaching their MP or telling their story. They also reversed my permanent removal from access to Cardiology and wrote to me to that effect. I was invited to a meeting with the Chief Executive and other staff and received an apology in person.

The Ombudsman report completely vindicated my position. At the time of my being labelled vexatious, I was waiting for a meeting to discuss the complaint. The way in which I was treated amounted to what was described as a ‘blanket ban’ on future complaints. A sum of £250 compensation for distress caused was recommended and has now been received.

All in all, it has been a distressing and gruelling experience but also rewarding because I feel that I have made the hospital management focus on its treatment of patient concerns with fresh insight.
Their policy was oppressive as it expressly provided for sanction of drawing wider attention to one’s concerns, including approaching one’s MP. However, I am sure that if the Ombudsman did not exist I might not have succeeded because without that independent process NHS Trusts would not be so readily accountable and I am sure the support of The Patients Association helped me encourage change to the Trust policy.

I believe that most people at my local hospital at all levels do a great job almost all of the time but complaints are an important means of maintaining public confidence and improving clinical vigilance. They are an opportunity to make patient experiences better. I still have tremendous respect for clinicians and the NHS. Most have the best interests of their patients as their absolute priority. But it is an organisation creaking under the pressure of demand and so things are bound to go wrong. I am a little worried I might be a ‘marked man’ as far as some hospital clinicians are concerned but hopefully I will not be treated any differently to anyone else. I would do it all again if it was necessary.
5. Annie Carroll
By her granddaughter, Sarah Carroll

Sarah Carroll and her family remain unhappy with the hospital treatment their grandmother received at Aintree University Hospital. Despite making a number of formal complaints, contacting the CQC and Parliamentary Health Service Ombudsman, the hospital has failed to provide answers to the family’s key concerns and provide them with a detailed response. Ms Carroll and her family feel strongly the NHS complaints process needs to be more ‘robust’.

I don't recall a day of my life that my Nan Annie hasn't been there for me. I have either seen her or spoken to her on the phone every single day since I was born, 32 years ago. She is a mother of six, a grandmother to 14, and a great-grandmother of 11. Sadly, my granddad died in 1985 so my Nan has been a widow since then.

Before my Nan's health deteriorated a few years ago after her first in-patient stay at Aintree Hospital with anaemia, my Nan (now 86) was a very active and independent 82 year-old. She would cut the grass in her back garden twice a week to keep it manageable, she would go to the local town centre a couple of times a week shopping and while there would move from bench to bench sitting and chatting to all of the other senior residents of the town, who she has been friends with since she moved there over 50 years ago.

After surviving two brain Haemorrhages in 2012, she came to live with my mum and me, and now needs 24 hour care and supervision. She has carers who come in and help with her personal care four times a day, and my mum and I help her with her food, drink and medication and everything else that she needs. One of us has to be with her at all times to make sure that she doesn't fall, but when she is well she keeps us entertained in exchange, as she loves having a sing along, and we sing all the old war songs that she taught me when I was young. It can be very hard caring for her sometimes, but every now and again she will say something like, ‘you're a part of me and I'm a part of you,’ and that’s what makes it all worthwhile, and there is nowhere else I would rather be. She is my Nan and she has always been there for me, and now it is my turn to be there for her.

On the 23rd May 2012, my Nan was taken by ambulance to Aintree University Hospital in Liverpool after she had fallen backward from a standing position in her care home and hit her head on the wooden floor. I went with my Nan, then aged 85, in the ambulance to the hospital and she was very shaken and dazed by the fall. She was complaining of headaches and feeling sick and she was leaning to the side all of the time. She also had a very large black lump on the back of her head.
During the ambulance journey my Nan experienced an episode of slurred speech which then corrected itself.

We got to the hospital at 3:30pm and were left waiting in the Accident and Emergency department. My Nan was very upset at the time and said she felt as though she was being left to die. I kept promising her that someone would come and see her soon.

At 5pm, my Nan’s speech started to get slurred again and her left side became weak and she appeared to lose vision in her left eye. I shouted to the nurses who were working outside the cubicle that my Nan was getting worse. A young man came in, I don’t know how long afterwards, and he explained he was a medical student and he wanted to know if it would be okay if he asked a few questions. He said he would relay the information onto the consultant when he came to see my Nan. I told him that my Nan was getting worse and that I was really worried about her because she had been brought in with a head injury. He said he would try and find the consultant and let him know.

Finally, at 6:15pm, the consultant came in to see my Nan. As soon as he saw the lump on the back of her head he said it was a collection of blood on the brain. When I told him about her symptoms, he assessed her and said she would need to go for a CT scan straight away. So, at 6:45pm, my Nan finally went for a scan. One of the doctors then came in to see me and explained that my Nan’s scan had showed that she had suffered a subdural hematoma and subarachnoid haemorrhage. As a result, they said they were waiting for a consultation from the neurosurgeons based at the Walton Centre for Neurology & Neuro Surgery, a hospital just next door to Aintree.

When the doctor returned, he informed us that the neurosurgeon had said that they thought the best thing to do at the time was to monitor my Nan and wait to see if her condition improved on its own (with the help of IV fluids and IV paracetamol to reduce the swelling and keep her strength up) or whether she deteriorated. He didn’t want to operate at the moment because it was ‘too risky’, however, if she showed signs of further deterioration he would have no choice but to operate as it would be Nan’s ‘only chance’. We were then told that my Nan would be getting transferred to the Walton Centre where she could be closely monitored. Whilst we were waiting for the transfer the doctor returned and said that my Nan would now be moving internally within the hospital to the Stroke Unit, not the Walton Centre, as the nurses there would be able to provide the same level of intensive monitoring. We were told my Nan could still be transferred to the Walton Centre if her condition deteriorated. In the meantime, whilst she was waiting for a bed on the Stroke Unit, my Nan would be temporarily moved onto the Medical Assessment Unit (MAU), which was quieter than A&E, so she could get some rest.

My Nan’s transfer onto a specialist ward never happened. In total she spent five days on the MAU because we were told that someone who had actually had a stroke had been transferred to the bed on the Stroke Unit.

During her time on the MAU, my Nan was given IV fluids and IV paracetamol as promised, and she did initially show slow signs of improvement, but she was understandably very tired. But on Friday 25th May, during visiting hours, we told the staff that we were concerned about my Nan’s speech
because it had ‘gone funny’ again; and she was seeing red spots in her vision and her hands were trembling when she tried to hold anything.

A doctor came to see my Nan and said he thought that she was fine but said it was possible that she had a water infection so he would send a sample off to the lab. We felt as though the doctor wasn’t taking our concerns seriously so we contacted the local private hospital to see if there was any chance that my Nan could be transferred there as we didn’t feel confident that she was getting the appropriate level of care at Aintree Hospital – although we weren’t sure how we could have afforded the private fees - but at the time we felt it was Nan’s only chance, as she was still on the MAU after two days, she seemed to be getting worse and we felt that no-one was doing anything about it.

Unfortunately, the private hospital said we would need to find out who my Nan’s named neuro consultant was as they didn’t normally take acute cases unless their own neuro consultants were already familiar with it, which might have been the case as they all also worked at the Walton Centre.

When we asked the MAU for this information we were told that my Nan ‘didn’t have a named neuro consultant’, and that she only had a temporary consultant on the MAU, as this was just a waiting bed until a bed became available on the Stroke Unit, when she would then get a named consultant. As a result, she couldn’t be moved to the private hospital.

Finally, on Monday 28th September, five days after her admission, we were told that my Nan would be getting moved onto Ward 25. However, when we asked what Ward 25 was, they said it was a General Medical Ward.

On Wednesday 30th September, while she was on Ward 25, the staff got my Nan, (a patient recovering from a head injury due to a fall, a patient who had an extensive falls history for which she had had three previous hospital admissions in the last nine months, and a patient who had previously been diagnosed with dementia) out of bed and left her unattended in her chair. When she saw the bed next to her chair, my Nan tried to get herself back into bed, but fell off as she tried to climb into it, and hit her head on the floor.

We got a phone call from the nurse informing us about the fall and we went in straight away to find my Nan hallucinating. Although my Nan has dementia, her only previous symptoms were memory loss in that she didn’t know what day it was. Now she thought she was in the hairdressers, she was seeing a blackbird on the wall chasing a mouse on the floor and she was telling us how multiple relatives (all of whom had been dead for decades) had all been in to see her. She hadn’t been behaving like this after the first fall so we were terrified about what was happening to her. We told the nurse of our concerns and she suggested that we speak to my Nan's doctors. The consultant spoke to us that afternoon and we told him about the changes we had noticed in my Nan since her fall on the ward but he told us that she was fine and that when she had been diagnosed with dementia she had probably been misdiagnosed and must have Alzheimer’s instead, so the hallucinations were normal. He then said that my Nan was ‘medically fit’ and that she could go back home that day. We were very concerned to hear she would be discharged that day. It was only
after we refused to allow my Nan to go back to the care home - because we didn’t think it was safe to discharge her there after the fall and wanted her to come home with us – that the doctor said he would send her to the Rehab Ward instead.

While she was waiting on Ward 25 that night for a bed on the Rehab Ward to become available, my Nan got diarrhoea and was placed in a side room. She had also become increasingly drowsy and her eyes had become puffy like they were swollen but there were no bruises.

On Thursday 31st May, my Nan was transferred onto the Rehab Ward at Aintree Hospital. My Nan continued to deteriorate over the next several days, forgetting the names of objects and what they were used for; she poured a cup of tea over herself because she thought that was what it was there for. When we explained that it was there for her to drink, she said she didn’t know what that meant. As a family, we found this extremely distressing to witness, especially as we were given no explanation for it.

We continued to express our concerns for my Nan’s health to the nurses on the new ward, but because the Rehab Ward was not an Acute Medical Ward there were no doctors based there all the time and because it was the double bank holiday weekend the doctors wouldn’t be back for several days. The ward nurses felt that because the doctor on Ward 25 had declared my Nan medically fit, she should be fine, and they continued to treat her like she was medically fit, which involved trying to get her out of bed every day.

When the doctor finally came back onto the Rehab Ward on Thursday 7th June, she met with us and as soon as we described my Nan’s symptoms to her she agreed my Nan had delirium and she sent her for an immediate CT scan. Whilst we were waiting for the results, I came in to find my Nan wandering the corridor unattended, because she had been left alone in her chair again – instead of her bed – even though she had just been for a CT scan. When the scan came back it showed that not only had my Nan’s first brain bleed gotten worse after her admission, which hadn’t been picked up on despite the fact she was supposed to have been observed for signs of deterioration; but my Nan had also had a second subarachnoid haemorrhage in the occipital region of her brain - the area of our brain that covers vision and was causing Nan’s hallucinations. We were told to prepare ourselves that my Nan would not be coming home.

But my Nan proved them wrong and, despite the hospital’s appalling level of care, she did come home.

Before she was discharged, when my Nan started to get better on the Rehab Ward, and the nursing staff started to mobilise her, she began complaining of severe neck and back pain when walking. She said the pains were shooting all the way down to her feet and every time she turned her neck sideways the same would happen and her neck would click whenever she turned it to the left. This was duly reported to the medical team but my Nan’s pain was dismissed as arthritis, despite her having had arthritis for years and never having this problem before. And despite her first fall, and the fact she had osteoporosis, my Nan was never assessed when she was first admitted in A&E for any neck or back injuries, even though when she was first admitted into hospital she was complaining of neck and shoulder pain.
She complained about this pain for months when she came home, and it was only when she was re-admitted into hospital in September 2012 with sepsis, and given about four weeks bed rest on that ward, that the pains finally eased off, but her neck still clicks when she turns her head left or right or tilts it back, which is very disconcerting for her especially when she is eating and she frequently comments that she thinks her neck is going to break.

Additionally, prior to her discharge, we were never given any clear indication from the hospital about how my Nan would be affected by her two brain injuries and what level of care she would need. After researching NHS Continuing Care on the internet, we were told by hospital staff that my Nan didn’t qualify for it. It was only after we insisted on speaking with the hospital’s discharge planner – who was a very lovely, understanding and helpful lady – and I presented her with a document containing the reasons why we felt my Nan qualified for NHS Continuing Care; that she was awarded the funding after her case was presented to a local panel.

Frighteningly, what happened to my Nan on this admission was not an isolated incident, as it was not the first time my Nan experienced poor care at this hospital, nor, sadly, has it turned out to be the last.

Because of this catalogue of poor care we have had to submit three formal complaints to Aintree University Hospital. We waited until my Nan had been discharged after the brain bleed to submit the first complaint. This was submitted in September 2012, and our second complaint was submitted in January 2013, and as part of both complaints we requested the hospital send us the relevant hospital notes. We finally got the notes we had requested in our first complaint, in January 2013, (as we were told every consultant involved had to give their permission for the notes to be released and they also questioned whether we had the right to access this information, as they claimed my Nan didn’t have capacity to consent to her records being released – even though I have the right as her next of kin). Despite this, we are still waiting on the notes requested in our second complaint.

Once we received the notes relating to our first complaint, we discovered that while my Nan was being observed on the MAU for deterioration she had been listed as ‘not for MET (Medical Emergency Team) calls’ and ‘not for resus’, which meant there would be no emergency action if she did deteriorate. These points made in her medical records were not discussed with members of her family at any stage.

The hospital wrote to us on 1st February 2013 to say they had now begun an official investigation into both complaints. But by the 18th June 2013 we had heard nothing further from the hospital about our complaints so we felt we had no choice but to escalate them to the Parliamentary and Health Service Ombudsman (PHSO). On the 5th July, we submitted a third complaint to the hospital and the hospital again told us they would investigate.

On the 20th July 2013, the Ombudsman wrote back and told us that they can only investigate complaints once a hospital has replied to the complaint as they only get involved if people remain unhappy after the hospitals have provided a response. However, the Ombudsman did contact the hospital to find out what was happening with our complaints. The hospital told the Ombudsman that they were still investigating our complaints and aimed to provide a response soon. The
Ombudsman had asked when we were likely to receive a reply, but the hospital said they were unable to provide a response at that particular time (July 2013). The Ombudsman then asked whether the hospital had updated us of the position, and were told that whilst they hadn’t, they would do so shortly. As a result, the Ombudsman asked us to give the hospital another two months to respond and asked us to get in touch if we hadn’t heard anything by this time. The date when we should have received a response from the hospital came and went on 20th September.

As we were unhappy with the NHS complaints process, we contacted The Patients Association for advice and they told us we could also inform the local Clinical Commissioning Group (CCG) about our complaints. We spoke to the CCG on 8th August but were informed by staff that they could only investigate complaints about hospitals that had been sent directly to them. As we had already submitted our complaints to the hospital, the CCG’s ‘hands were tied’ by NHS regulations which state that one NHS Trust cannot investigate a complaint already being investigated by another. Just like the Ombudsman, the CCG told us they would contact the hospital, and they said they would tell them that they were aware of our complaints and that they needed to keep us informed as to the progress of their investigations.

By the Ombudsman’s two month extension date on the 20th September we had still heard nothing further from the hospital and had to notify the Ombudsman. We have also had to make our local MP aware of the situation and it is now a full 14 months after our first complaint, 11 months since our second and four and a half since our third complaints were made. Despite the hospital’s complaints process stating they normally resolve complaints within 25 days and if they are unable to do this they will keep you informed and set new deadlines, we have still had no resolution. What is worse is that nothing has changed inside the hospital, no lessons have been learnt. My Nan was admitted again in June 2013, hence our third complaint and she once again received an appalling level of care.

Because of our experiences with Aintree Hospital we have also sent regular and multiple reports to the Care Quality Commission (CQC) about the level of care my Nan has received there dating back to our first complaint. The CQC were grateful for the information that we provided and said that they would use it as the basis of planning the hospital’s next inspection, when it was due, however once again they didn’t have any power to act, as they do not deal with individual complaints, and they advised us to submit our formal complaints to the hospital.

They have been very helpful in other areas though such as informing us in a later instance of our right to request a second medical opinion, our right to have our comments and concerns written in the medical notes and our ability to refuse an unsafe discharge, and the right of carers to be informed about all relevant information before a patient is discharged.

After our third complaint however, given the details that we provided to the CQC, the hospital’s inspector told us that what we had reported raised concerns in terms of the hospital’s compliance. Because of this, they said that they could now inform the authority in charge of the hospital about the potential breaches of compliance, and forward the emails we had sent raising our concerns. Since then, on 22nd November, I received a call from the hospital apologising for the delay. They said that they recognise this has been an issue in their complaints handling which they hope to rectify.
and we should receive a response to our September 2012 complaint within the next few weeks. They said that there may be some points that we raised in our complaint which they are still working on but we should receive the bulk of the answers we asked for in the response. They also said that the Chief Executive would want to meet with us regarding the issues we had raised. I told them we would discuss the option of meeting with them once we had received the response and had a chance to read through it thoroughly.

However, despite this my family and I strongly feel that the NHS complaints process needs to be more robust in order to tackle serious patient neglect to ensure that the same mistakes are not made time and time again, and that complaints are dealt with promptly and thoroughly. Hospitals should not be allowed to investigate themselves, and more powers should be given to external bodies to enable them to act sooner. As it stands the Ombudsman, the Clinical Commissioning Group, the Care Quality Commission and our Local MP are all aware of our complaint, but no-one has any power to do anything. We have even sent an email to the Health Secretary Jeremy Hunt regarding our concerns about Aintree Hospital, but his office told us we needed to contact the Ombudsman if we were unhappy with the hospital’s response, which we have already done. Because no formal response has been provided and no assurances made that her care will improve if she is re-admitted into hospital, my family and I remain increasingly concerned about my Nan’s health - even more so when she is admitted into Aintree Hospital. As a result, every time she is admitted we have to be there every single visiting time to make sure that she is okay, and every night she is an inpatient we don’t get any sleep due to the anxiety of her being in their care.

We are extremely grateful to The Patients Association for giving us a voice by allowing us to write this story to highlight our situation and the situation of others up and down the country.
Janet Kite’s father became ill following a preventative operation that led to end stage kidney disease and loss of mobility. When his family made enquiries into NHS continuing care packages, they were wrongly informed that their father did not meet the criteria because he ‘wasn’t terminally ill’. To date, Janet is still trying to get her father properly assessed so that he may have access to NHS continuing healthcare services.

My father Stan was identified as having an aortic aneurysm in June 2003 and an iliac aneurysm in Oct 2004. These were monitored until the decision was made that an operation was necessary as the aortic aneurysm had reached critical size. Stan was subjected to a battery of tests to ensure he was fit for the operation and to plan his endograft (a procedure to repair the aneurysm), the tests for which included a renal scan and a cardiac scan.

Stan travelled to University College London Hospital (UCLH) on the morning of his operation (24th February 2010), travelling from Enfield on the tube. He had been due to go into hospital the day before, but this was cancelled by UCLH due to a lack of beds. The operation was complicated, attended by several consultants and took approximately seven hours, longer than expected due to a complication with the stent at the left kidney. Seven stents were fitted in all. Concerns were shared with us just after the operation, but were never mentioned after this. Stan had an extended stay in Critical Care and was discharged on 9th March 2010.

Stan did not recover as expected from the operation and was referred to the Low Clearance Team, which provides specialist treatment for patients with kidney diseases. He was suffering from very bad back pain and finding it difficult to walk any distance, struggling to get into the car, having a number of falls and struggling to get up at night to access the toilet. He had very limited mobility and his post-operative creatinine levels indicated acute kidney failure. Stan was put on a range of drugs and healthcare training was provided to my mum so she could attempt to care for him at home. He was assessed for suitability for peritoneal dialysis (a treatment for patients with severe chronic kidney disease).

On 26th October 2010, Stan was admitted to the Royal Free for the peritoneal dialysis (PD) catheter insertion. He was discharged on 3rd November but had to be readmitted due to bleeding at the
insertion site within less than 24 hours. He had an IV iron infection and was discharged again (9\textsuperscript{th} November). During this period, Stan had investigations regarding a possible enlarged prostate. Stan was due to attend training with my mum to enable her to perform a PD dialysis from home – I was also to be present to receive the same training in order to help both my parents. However, on 25\textsuperscript{th} November 2010, Stan had to be admitted to the Royal Free with a Urinary Tract Infection (UTI) and was also unable to make his feet move - rather like they were stuck to the floor. The Royal free completed a CT head scan which suggested Normal Pressure Hydrocephalus (‘water on the brain’) when reviewed by neurosurgeons, a therapeutic lumbar puncture led to transient improvement.

Stan was also started on peritoneal dialysis but developed PD peritonitis. Due to repeated infections with his dialysis (and as his kidney function had stabilised, unfortunately still at post-operative levels), it was decided that a more conservative management of Chronic Kidney Disease (CKD) was the best option.

Stan was reassessed by neurologists who discussed his case with the neurosurgeons. They did not believe that the mobility problems were due to ‘water on the brain’. Their differential diagnosis provided on discharge included: Parkinsonism, Myopathy and Anterior Horn Cell Disease (a form of Motor Neuron Disease).

Unfortunately, as a family we did not have access to the discharge or diagnosis information whilst Stan was in hospital and he was transferred to Chase Farm. Mum contacted the Royal Free to request the discharge information on 10\textsuperscript{th} April 2011. This information would have been passed on to Chase Farm when Stan transferred to them.

I asked Chase Farm for the results of the CT scan of the spine that I knew had been taken at the Royal Free before Stan’s transfer took place. Despite my enquiries, Chase Farm claimed they could not get any response from the Royal Free Hospital. Yet I received a call from the consultant within one day of my request made through The Royal Free PALS. I felt I needed to remain closely involved and kept up-to-date with Stan’s health and hospital treatment, in order to assist him - especially whilst he was unwell. I questioned staff at Chase Farm about the ‘water on the brain’ diagnosis regarding mobility. The differential diagnosis from the Royal Free (Parkinsonism, Myopathy and Anterior Horn Cell Disease) were never discussed / mentioned / followed up by Chase Farm. Yet these diagnoses had been formed at The Royal Free over a period of two months following observation of the decline in Stan’s mobility, treatments and thorough investigations.

Stan was transferred to Chase Farm on 18\textsuperscript{th} January 2011. He was transferred to access intensive physio and to be nearer to home. My mum had been visiting him every day, having to travel into London on the Tube at the age of eighty-one. On transfer, it was noted that Stan was to be hoisted only and at the Royal Free he needed a frame, although he was barely able to stand/walk. Access to physio/physio input was limited due to recurrent infections and back pain which made it impossible for him to sit for any length of time when hoisted into a chair. He was often asleep at the times the physios attended (and we were told that, as he was on a stroke ward, ‘stroke patients were prioritised’). The physios and occupational therapists (OTs) set tasks for Stan to meet, for example, he had to be able to sit to stand in order to go on to access convalescence locally. Unfortunately, Stan was unable to complete any of these tasks.
During Stan’s stay at Chase Farm Hospital, I felt it was necessary to request information regarding a NHS continuing healthcare assessment, so a family meeting was arranged. On the day of the family meeting, Stan was convinced he could get out of bed and I asked the physios to let him try. It was heartbreaking seeing two of them unable to get him into a sitting position on the bed, he could not support himself at all, and heartbreaking to see just how much weight he had lost. At this point he had suffered significant weight loss. He now weighed 55kg, some 12kg loss since post-operative weight June 2010 (18% bodyweight) and some 19kg loss since pre operation (26% of bodyweight). The issue of back pain was never addressed in hospital and this lack of communication continued when he was transferred to Nairn House care home. Stan was also placed under the care of the pain management team at Barnet on 12th July 2011. The neurologist at Chase Farm suggested irreversible dyspraxia (impairment of movement) as the likely cause for his mobility decline. The Royal Free neurosurgeons’ diagnoses were not considered or discussed with us. Stan had not been able to take a single step in all of the time he spent at Chase Farm Hospital.

During the family meeting, the physio stated Stan needed hoist transfers for safety and pillows/blankets to support his position in the chair. The Occupational Therapist recommended 24-hour care, stating that Stan had not met the continuing care checklist so a comprehensive assessment should take place. I strongly feel that, as a family, we were not involved with compiling this checklist and therefore we were unable to provide additional medical information that would have helped the medical team gain further insight into his medical condition(s) and particular care needs. No nursing input was recorded at this meeting but it was made very clear to us that Stan must have 24-hour nursing care. At this point, I also felt that his hospital care had been inappropriate: he had fallen out of bed, sliding gradually down and unable to move himself; had to toilet on the ward and had about one decent wash a week.

I also noticed that the feedback recorded in the minutes of the family meeting was not in the order it had occurred and some information was missing. I felt some particular attention had to be given to the question asked relating to Stan’s continuing care and kidney involvement. The ward’s Charge Nurse explained continuing care looks at the ‘functional’ side of things. During the meeting, one of the doctors explained only terminally ill patients with likely rapid deterioration would trigger off continuing care. I strongly feel that this is maladministration and that we were not treated in a clear and transparent manner, we were literally told by the end of the meeting that Stan wouldn’t get NHS continuing care. If we wanted an assessment Stan would have to stay in hospital for another month to wait for the panel to make a decision, and even then he still wouldn’t get it!

We now know this is not correct - Stan could have been moved to Nairn House and had an assessment completed there with input from all the involved parties. We also know that it is not accurate to state that only terminally ill patients with rapidly deteriorating illness are eligible for NHS Continuing Care.

Stan was transferred to Nairn House on 28th March 2011 with no support - he had funds so we were told to ‘get on with it’ ourselves. He weighed 55kg (BMI approximately 18) on admission and was unable to toilet independently. He had limited movement, was unable to weight bear and at risk of developing sores and bruising due to his medical conditions. He was at high risk of developing pressure sores (use of pressure mattress / positioning / electric profiling bed) and at high risk of falls
(bed rails, hoist, prescribed wheelchair) and in need of food supplements. He could not settle in bed independently due to immobility.

As a family, we now have full access to The Royal Free diagnosis that explained the continued deterioration in Stan’s motor functions. Stan was transferred to Nairn House on 28th March 2011 with no support - he had funds so we were told to ‘get on with it’ ourselves. He weighed 55kg (BMI approximately 18) on admission and was unable to toilet independently. He had limited movement, was unable to weight bear and at risk of developing sores and bruising due to his medical conditions. He was at high risk of developing pressure sores (use of pressure mattress/ positioning/electric profiling bed) and at high risk of falls (bed rails, hoist, prescribed wheelchair) and in need of food supplements. He could not settle in bed independently due to immobility.

Physios who visited dad at Nairn House confirmed that he had / has poor sitting balance, no weight bearing through his feet and poor extension of lower limbs and trunk, he leans left, has very poor trunk control, and that he deteriorated despite their attempts at input and was exhausted. A nursing care assessment completed on 30th March 2011 recorded Stan as having good sitting balance, concluding a full assessment was not necessary. I feel that this assessment is clearly flawed. We were not invited to provide any additional medical information about Stan’s condition (much of which he is unaware of) and did not receive a copy of the tick list until I requested one. Even more worryingly, this assessment was updated on 16th August 2012 with the comment ‘no changes to the earlier tick list’. Again, we were not involved and the home’s information was clearly not properly interrogated.

I have recently discovered (October 2013) that the community matron visited Stan, once in hospital and twice at Nairn House (shortly after he moved in). On her first visit to Nairn House she recorded that she talked only to Stan, on her second she asked the nurse for information as ‘he was very vague’. Unfortunately, the nurse did not know if Stan was still under the Low Clearance Clinic for his kidney condition. We were never contacted. Stan had been so ill, he knew very little of his hospital history to inform the assessment. I cannot help but wonder had there been a proper understanding of his history; would the mobility diagnosis have been investigated further? Would they have understood the need for intensive physio to have any hope of regaining the ability to sit up/stand? One thing is certain, it’s definitely too late now.

Leading on from this, I remain increasingly concerned about Stan’s treatment following more recent hospital admissions to Chase Farm Hospital. From the period of 11th February to 21st February 2013, we noted the following:

- Inaccurate recording re. waterlow score, long wait for pressure mattress
- Scores for waterlow, nutrition and nursing needs not requested from the nursing home
- Nursing home took photo of Stan’s soreness on his return from hospital
- Treated for MRSA – my family and I were not told for three days of that my father had received this treatment, nor was it recorded on the original discharge. This raises serious concerns about the hospital’s management of serious infection(s)
- A nurse and carer manhandled dad into a chair and back into bed because the nurse thought he could walk - communication between staff and shifts was poor
• The discharge date was incorrect

From the period of the 12th March to 20th March 2013, we recorded further problems:

• On the same ward, still recorded waterlow score at 12 (27 plus in nursing home)
• Stan was tested for diabetes until I queried this. The patient on admission list above dad was diabetic so a nurse had to go through dad’s admission with me and replace the original paperwork. Once again the nursing home had not been contacted for information
• The discharge states Stan went home in a permanent catheter, but he actually went back to the nursing home as he had left it, wearing incontinence pads!
• He received treatment for MRSA; again, this was not recorded on the original discharge notes.
• On the discharge day, my father was left in a side room, unable to reach the emergency bell, no access to water, wearing a wet incontinence pad. This resulted in his skin being bright red – the nursing home took a photo on his return to the home.
• The discharge date was incorrect.
• The second (corrected) discharge still incorrect – the hospital changed permanent catheter to convene, yet Stan had gone back to the nursing home wearing incontinence pads. I believe the ward doctors thought dad had been admitted in a permanent catheter - this was inserted in Accident and Emergency. I feel there is a serious issue here with medical staff not referring to my father’s medical notes before administering treatment(s).
• Pre-existing conditions - records dad as bed bound - when he is in actual fact wheelchair bound (which impacts on waterlow score, etc). Issue with medical records not being correctly maintained, etc.

Having realised that dad had not been properly assessed, in October 2012 we started the process of trying to get funding for NHS continuing healthcare. This has involved meetings and assessments that have led to an Independent Review Panel. At every stage of assessment recording has been poor. In their report, the Independent Review Panel (IRP) stated:

‘Mrs. Kite was critical of what she cited as evidential errors made during the care journey of her father and clearly has a genuinely held view that those assessing his abilities and care needs have made errors both in fact and perception.’

Indeed I do! For example, within the IRP notes they report that dad has paracetamol for pain relief relating to a knee replacement. He doesn’t have a knee replacement. They have made clinical judgements about his mood without any clinical tests.

The IRP has confirmed what I knew they would say all along - that Stan is not entitled to NHS continuing healthcare. I would suggest that the IRP chair reads the National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care. However, solicitors now advise that barristers believe it will be very difficult to challenge the guidance used to decide if a person has a primary healthcare need and is therefore eligible to access NHS healthcare services.
Stan is poorly at the moment again, suffering from another infection which is not responding to antibiotics. My mum did not participate in the IRP as this process has been too difficult for her - having to revisit misfortune is not a healthy exercise. I will continue to pursue dad’s case to the Ombudsman with support from the Patients Association. Without their support I would have thrown in the towel. This has been a very damaging exercise; it literally puts your own mental health in jeopardy. And that’s the point, vulnerable elderly people are being treated appallingly and we need to stand up and say this is wrong.
7. Patient A

Patient A was diagnosed with breast cancer in late 2012 and received treatment at Royal Bournemouth Hospital. Patient A feels the information she received about her treatment was not open and transparent, and that she had to use valuable recovery time to check her medical records because she was ‘so concerned about the muddled information I had received’. Patient A also discovered a tissue sample that had been sent to the lab after her surgery, had been handled so poorly that it prevented a proper analysis taking place.

I am 65 years old. I think of myself as a cup half full person and can usually see the positives in most situations, although I do get angry when I am on the receiving end of bad service, and always give feedback on those situations. I worked as a secretary and administrator for the medical and legal professions during my working life. I needed to give up work when I was 50 due to a progressive disabling disease, but I have over last few years used my experience to become involved with a local support group which raises funds for a national charity, and that keeps me fairly busy. My hobbies are genealogy research, gardening, visiting historic places, and helping my husband with the various charitable groups he is involved with. My recent illness and treatment has been mostly an inconvenience as I'm too busy to be ill! However, there was at least one positive - losing my hair due to chemo meant I had the opportunity to realise how much easier it is not to have too much hair to waste time on. It has also caused me to think about how cancer patients are treated and maybe that is a campaign I need to get involved with.

In September 2012, I was diagnosed with breast cancer and was asked at the diagnostic consultation where I wanted to be treated. As I didn't have much time to research or consider my options, I chose Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust.

After I received a short course of chemo, it was decided that it was necessary to carry out a mastectomy as the tumour was not responding to the treatment. I saw my consultant on 27th December 2012 when he said an operation would take place in early January 2013, which would be a mastectomy. He did not discuss exactly what the operation would entail; this was left to the breast care nurse who gave me lots of leaflets to read and I was told I would get an appointment before the surgery to discuss it in detail. The following day, I received a call to say the surgery could be brought forward and as I detected there was some urgency, I agreed. Two days before the surgery, I met with the breast care nurse who described how the mastectomy would be performed. During the meeting, she explained that a radical axillary clearance (removal of all the lymph nodes on the affected side) would also be performed. I was shocked about this as I was aware of the implications, and so queried why it was necessary. She said evidence of axillary involvement had been found on a previous investigation. I had not been informed of these findings previously. I was only informed in May 2013 that there had been suspicions of axillary involvement following an ultrasound carried out in August 2012, although this was not confirmed by a biopsy carried out at the same time.

Following the surgery and a follow-up appointment, I requested to see a copy of the pathology report and subsequently my notes. There was no reference in any of the ultrasound reports to
axillary involvement and I discovered the following statement in a referral note to the Oncology team: ‘Axillary lymph node not involved. Not a lymphoma’.

At a meeting with my consultant in May 2013, I raised this query and he replied that evidence of inflammation had been found in the lymph node, but having read back through all the hospital notes again I can still find no reference to this. In any event, I was told that inflammation in itself does not confirm disease. This was the first time I had been told of this suspicion of lymph node involvement.

This meeting was not very constructive and I was still left with a number of questions, and felt that the only way of getting answers was to raise a number of complaints:

1) I was told at one of my oncology appointments that the lymph nodes would be tested prior to surgery to see if there was any disease involvement, and if there was then the lymph nodes would need to be removed. This testing was not done prior to surgery. The pathology report following surgery found no disease in the lymph nodes and only some scarring, probably due to the effects of chemo. If I have been given copies of all my test results/pathology reports and relevant notes then I can see no evidence that it was necessary to carry out a radical axillary clearance without first testing if this was necessary. This aspect of my disease should have been discussed with me by my consultant and/or his team prior to surgery, when I would have had the opportunity to raise these queries. Leaving it to the breast care nurse to tell me two days prior to surgery was not good enough. This part of the procedure has put me at risk of developing lymphodoema.

2) The pathology report under the 'Histology' heading has a sentence which reads 'But, assessment of tumour architecture, tumour size and lymphovascular space invasion is greatly hampered by poor fixation.' During a follow-up appointment on 17th January 2013, I was just told the cancer had been ‘completely removed’ and there was no disease found in the lymph nodes. At no time has this pathology report been discussed with me by any member of the surgical team; I have spoken with a charity helpline who had to explain to me what poor fixation meant – as the hospital had neglected to do so. By contacting a helpline for additional information, I learnt that because the surgery had taken place on Friday 4th January and the path lab received the specimen on Monday 7th January, there was the possibility that due to poor handling it had decayed so badly a full analysis was unable to take place.

I do not think it is acceptable for any cancer patient to undergo surgical removal of cancerous tissue which is then handled so poorly as to prevent proper analysis. At a meeting with my consultant to discuss my concerns, he was unable to look up a computer programme which would have given information regarding likely long term outcome in my case, but merely told me I had 'serious breast cancer'. At no time was the Grade or Stage of my cancer discussed with me, and only after asking for the opinion of a pathologist friend did I discover what the Stage was.

After my cancer treatment was completed, I spoke with another healthcare professional about my hospital experiences. It was only after I obtained their expert feedback that I realised I needed to make a complaint, if only to hopefully cause the Trust to reconsider some of its practices.
With that in mind, I sent a formal letter of complaint to Bournemouth Hospital on 26\textsuperscript{th} July 2013, mainly because I wanted to know exactly what surgery had been performed as there seemed to be a discrepancy between what I had been told prior to surgery and subsequent notes. Two weeks after writing, I sent an email to ask if my letter had been received and I received an acknowledgement stating that I would receive a reply by 4\textsuperscript{th} September. On 4\textsuperscript{th} September, no reply had been received so I emailed again and received an apology and told I would receive a reply by 13\textsuperscript{th} September. I received a reply on 18\textsuperscript{th} September.

The response to my complaints has been informative in that it tells me exactly what surgery I had to the axillary area. I have now been informed that the surgeon who performed the surgery, who was not the consultant in charge of my care, examined the axillary glands and decided to perform a limited axillary node operation. For nine months I believed I had an extensive surgical procedure, but have now been told that the surgery was limited. The consultant’s recollection of events differs in a number of ways from mine, and he recalls a detailed consultation that never actually took place with him.

I wrote again to the Hospital to respond to the replies given to my complaints and point out the inaccuracies and subsequently received a telephone call asking whether I expected to receive an answer to my second letter.

I remain very concerned about the lack of information that was made available to me by the team responsible for providing my cancer treatment. I feel that the treatment I received was not open and transparent, and I question whether it is appropriate for only the breast care nurse to brief a patient prior to such important surgery taking place. Throughout this whole process I have felt completely isolated. When I should have been recovering from surgery, I felt I had to use that time to check my medical records because I was so concerned about the muddled information I had received. I was also incredibly concerned to discover that a tissue sample that had been sent to the lab had been allowed to decay so badly that a full analysis was unable to take place. This raises a number of safeguarding issues about ensuring patient safety – especially cancer patient safety - and sanitation if such practice is allowed to take place without any form of reprehension. I question how cancer patients can be confident in their diagnosis and treatment if similar situations to what I have experienced are allowed to continue.

Lastly, the hospital’s failure to provide me with an accurate response has caused additional stress, because I have not yet been given the opportunity to find a satisfactory resolution. Unfortunately, this complaint is still ongoing. Throughout my cancer treatment and in the months following, my worry and distress has been aggravated by my having to research ways to complain about my treatment and the NHS complaints process. I am now having my follow-up appointments at another hospital and already have received explanations about my treatment which it would have been useful to have been told at my first follow-up appointment following surgery as it would have saved a lot of unnecessary worrying on my part.


8. John Munday
By his niece, Lyndsey Wright

*When Mrs Wright’s uncle had been diagnosed with advanced lung cancer, she asked him to move in with her and her family because she was confident he would receive the necessary ‘Out of Hours’ treatment. In the last few weeks of his life, the out of hours care he actually received ‘made his life extremely difficult, painful and unpleasant’.*

My uncle, John Munday, was born in South East London, the second child of eight and the eldest boy. They were a loving, tight-knit family. John didn’t particularly excel in school - he told me that he missed a great deal of it one year when one by one his siblings caught measles, causing him to be quarantined! During the Second World War, he fought with General Montgomery in Africa and Italy and was present at the hanging of Mussolini, which he told me was ‘unpleasant’! After the war, he trained as a fitter with British Gas, or Segas, as it was then called, and this was to be his profession until retirement.

John was a private man, proud and independent. He worked hard all his life and was a very ‘British’ gentleman. He loved crosswords, sport, detective series and animals, especially dogs. Indeed, our Jack Russell spent a great deal of time by John’s bed in his last few weeks, and our cat could always be found curled up on his feet! I was glad that he allowed us to look after him in the final weeks of his life.

Before his death, my uncle had lived alone in a council flat in London. He had been a big part of my life as a child but, as families do, we had drifted apart; indeed, I hadn’t seen him for 15 years, although we corresponded regularly. When Guys Hospital called my elderly mother in January 2013 and told her that John, then aged 89, had been diagnosed with advanced lung cancer, she and I went straight down to London to see him. What we saw was appalling. John had had no overhead electric lighting since a flood the previous year; he had no cold water in his bathroom; he cooked by torchlight; his flat was full of small flies. He was completely deaf so unable to use the telephone to complain, nor able to hear anyone at the door. It was a sorry state of affairs, to put it mildly. A GP and a member of the Palliative Care team met us there and, as John was terrified about going into a care home, I persuaded him to come and live with me in Cheshire. To my surprise, he agreed.

I spent the next few days rearranging my house so that John could have a nice room, where he would be warm and comfortable. He was transferred on February 7th 2013 and we began to get to know each other again and communicated using a whiteboard. Mentally, he was completely on the ball but physically he was very frail and obviously very unwell.

My wonderful GP came the following day and explained what was likely to happen in the coming weeks. The district nurses were amazing, as were the Crossroads Carers. Macmillan and Marie Curie offered support, too. I have nothing but praise for the care John received during normal hours; indeed, I must make it plain that I do not blame any individuals for any of the difficulties we had. It is the system that is so wrong. People are sick 24 hours a day, 365 days a year, not just during ‘office’ hours. Time and again we came up against a brick wall when dealing with Out of Hours (OOH) care, from a ‘couldn’t care less’ attitude to a ‘sorry, but our hands are tied’ one. I have seen a male district
nurse on the verge of tears, begging that my uncle, who so wanted to die at home, be allowed to do so but being told that it wasn’t ‘correct policy’.

In the end, John did die at home with us at his side but the OOH treatment he received really did make some of his last few weeks extremely difficult, painful and unpleasant. The only time I saw him lose his temper was when we were in Stepping Hill Hospital and, having had no food, not even a cup of tea, my poor, thin uncle was made to sit on a trolley, whilst his private parts were examined in front of the niece he hadn’t seen for so long. All because the staff running the OOH system had no time for pleasantries and were entrenched in red tape.

I suppose my main reason for sharing my uncle’s OOH care is to make a plea for the service to be completely overhauled. One ambulance driver told me that Macclesfield OOH service is a ‘laughing stock’ - what an indictment. I know the NHS is cash strapped; I understand that there is no never-ending pot of money; I know that savings have to be made. But I was saving the NHS a great deal of money by caring for my uncle at home and I dread to think what it must be like for people who are carers for years. I cared for John for a month and during that time I saw the very best and the very worst of the NHS - I cannot imagine doing that for years.

Listed below is the appalling OOH treatment my uncle received, from the period of February to March 2013:

1) John had been in Macclesfield General Hospital for five days, recovering from a chest infection. He was sent home to me on the Friday. By the following Thursday, he had finished his course of antibiotics and his breathing quickly deteriorated again. My GP and the district nurse advised me not to call the OOH number, as they would almost certainly readmit John, but to call the district nurse if I was worried over the weekend.

By Saturday evening, John’s breathing was very laboured so I made the decision to call the district nurse. She said that she would be unable to attend for at least four hours. At 11.30pm, I called again and was told to ring 999. The paramedic who came was great but said she should really call for John to be admitted. Although we had a Do Not Attempt to Resuscitate (DNAR) form, John clearly did not want to go back into hospital. The paramedic gave him an antibiotic shot and called the OOH doctor to explain the situation. John was now much better and breathing ok. I then had to wait up for the rest of the night until the doctor and district nurse came at 4.20am, prescribed antibiotics and left. This was a night with no sleep for me and very little for John.

2) John began to use much more oxygen. He went from occasional use after exertion to wanting it pretty much full time. Again, it was a Saturday. I called Air Liquide, who supplied the oxygen, and they said they needed the OOH doctor to fax them a prescription. The OOH doctor refused, saying he was unable to do this. John would have to go through the admissions process in A&E (including x-rays, blood tests, etc.) then they would issue him a new prescription for the oxygen. I felt this was too much for my poor uncle to go through, especially whilst he was so unwell. As the district nurse was present at the time, she took over the call and explained my uncle’s situation (last weeks of life, on his Pathway etc) but the doctor refused to budge. Eventually, one of the respiratory nurses from our GP practice accessed John’s case and it was resolved within a few hours. I am at a complete loss
to understand why the OOH doctor could not issue a prescription – John was already prescribed oxygen, it wasn’t new. This caused more trauma because he thought he would have to spend another night in hospital.

3) On the final Monday of John’s life, he was too exhausted to get out of bed to use the commode so agreed to be catheterised. This was done at 12 noon. By 4.30pm, he had still passed no urine. By 8.30pm, he was very distressed so I called the district nurse who came immediately. He realised there was a problem with the catheter; he also warned me that we would end up in Stepping Hill Hospital’s A&E department, as, in his experience, Macclesfield Hospital would refuse to re-insert the catheter. He was right. Despite his pleas to allow this elderly, frail gentleman to be re-catheterised either at home or in the local hospital, he was told that Macclesfield would not see him and that we must go all the way to Stepping Hill Hospital.

When we arrived at Stepping Hill, the place was literally heaving. The young nurse who admitted John told me that this was a constant irritation for them, that Macclesfield Hospital insists on sending their catheter patients to them, where the catheter is then replaced and the poor patient must spend the rest of the night on a trolley until an ambulance can take them home. John was examined and it was found that the problem was with his enlarged prostate and they would need to call in a more experienced doctor to do the procedure. By the time it was eventually done, it was 1.30am and I had had nothing to eat since lunchtime and the only drink John and I had had was the small bottle of water I had with me. Because of John’s deafness, I couldn’t leave him alone. We sat together, me in a chair, him on an uncomfortable trolley, with John getting increasingly agitated. He was examined with me in the room - much to his embarrassment - and I finally asked for him to be admitted for one night as I needed to get home and get a couple of hours sleep so that I could care for him properly the next day. Despite there being a queue of ten for the beds, one was eventually found. I took a taxi home (which cost me £30) and got some food and a couple of hours sleep. It was a horrid experience for all concerned.

4) John passed away the following Saturday at 5pm, just as the day and evening shifts cross over. As I had been instructed, I called the district nurse who said they could not verify the death and I should phone ‘Out of Hours’. I was then told that there was only one doctor on call for the whole of East Cheshire and we would have to wait. The poor doctor finally came at 10pm; we had had an incredibly distressing five hours of watching my uncle’s body change in the most unpleasant way. Bear in mind, he was 89 years old, had lung cancer, Chronic Obstructive Pulmonary Disease, heart disease and had not eaten for ten days, nor had any fluids since losing the ability to swallow on the Thursday before. By the time the Funeral Directors came, rigor mortis had already started, which meant taking John’s watch off was particularly unpleasant.

Since contacting The Patients Association to share my experiences and to report the chronic problems I feel are associated with the NHS ‘Out of Hours’ healthcare services in East Cheshire, I have been encouraged to raise my concerns to highlight the problems my late uncle and I experienced. I don’t wish to blame anyone in particular, just the present system, as some of the care my uncle received during normal hours was wonderful and above and beyond what we had expected. However, I am concerned that some these professionals will be tarred with the same brush.
9. Gloria Mary Butcher

By her daughter, Gillian Sargent

Mrs Sargent was away on holiday when her mother, Mary, was admitted to Addenbrooke’s Hospital after staff at her care home thought she had had a stroke. Mrs Sargent was pleased with the hospital care her mother received, until the day she was discharged. The hospital contacted Mrs Sargent at 11:10am to inform her that her mother was being discharged, but Mary didn’t return to the care home until 8:10pm. Mrs Sargent feels that trying to track her mother, a dementia patient, during this period was ‘like trying to track a parcel in transit’.

My mum is 85 years old and was diagnosed with dementia in the summer of 2012 following a fall in which she broke her hip. Prior to her fall, she had been living independently in Ely and although we knew she had problems with her memory, we had been able to manage.

Mum has always lived in Cambridgeshire. She was born in Prickwillow and moved to Little Downham when she married my dad in 1952. She spent most of her life in Little Downham until they moved into sheltered accommodation in Ely. She and dad worked on the land and mum continued with manual work until she was in her sixties.

Mum has always been a very caring person. Throughout my childhood she cared for both her parents and dad’s parents for a number of years as they had a several health problems, such as cancer and diabetes, which led to my nan losing her sight and having her leg amputated. In addition, my mum helped to look after an elderly neighbour with dementia and gave many hours of her time to the care of others. She then cared for dad when he became ill with Parkinson's disease and was his main carer at home until he died in 2007.

I am an only child so I am close to my mum and she has always been there for me throughout my life and is someone I can turn to for advice and support in any situation. She loves her grandchildren and enjoys spending time with them and hearing their news.

Mum moved into a care home in August 2012 and has settled into the home. She still likes to be busy and enjoys helping with chores. Sometimes I think she is too helpful as she likes to take away the cups for washing up before people have finished their tea!
Whilst I was away on holiday in Dorset at the end of July, I received a call from my mum’s care home and was informed that she was being admitted to Addenbrooke’s Hospital because they thought she had had a stroke. Her speech was slurred and she was unable to hold anything in her left hand.

Upon admission to hospital, it transpired that she had a chest infection and she was treated for this and her medication for anaemia and an irregular heart beat was restarted - this had ceased following a medicine review in June 2013. I had not been informed of this medicine review and was annoyed at the lack of communication. My mother had been on medication for an irregular heart beat for many years and has iron supplements for the past seven years.

I was kept informed of her progress by the ward doctors and I was very pleased with the service they provided. However, on Thursday 1st August at about 10am, I was informed by her care home that she was going to be discharged from hospital that day. The home told me that they had made it very clear to the hospital that they could not accept a patient after 7pm because of the ‘disruption to other patients and the problems associated with settling a patient late in the evening’. This seemed reasonable but I thought at the time it was all a bit unnecessary as it was quite early in the morning and I assumed mum would be back at the care home well before 7pm.

At about 11.30am, I received a phone call from the hospital informing me of mum’s discharge and I reiterated the time restriction about her needing to return to the care home before 7pm. At this point, no-one I spoke with at the hospital indicated this would be a problem.

As the day wore on and I continued to hear nothing and took this as a sign that she hadn’t returned to her home yet, as they would have called to let me know she was back safe. I tried to phone Addenbrooke’s at about 5pm but had problems with my phone signal due to my location. I phoned again at about 6.45pm and was informed that mum had left the ward at lunch time and been sent to the discharge lounge. The person I spoke with assumed my mum ‘was on her way and the delay may be due to traffic’. I checked with the care home who again reminded me that their policy was not to accept patients after 7pm, and that they had received no further communication from the hospital and had therefore assumed my mother was staying another night. I rang the hospital again and they tried to put me through to the discharge lounge but there was no-one there to take the call so they continued to assume that my mother must be on her way, but they did not know what time she had left.

At 7.10pm, I received a phone call from the care home informing me that the discharge lounge had rang and told them that my mother’s transport had left Addenbrooke’s at 6.55pm. When the care home manager expressed her concern and reiterated the policy of not accepting patients after 7pm, the woman brusquely dismissed her concerns and said there was nothing she could do about it. My mum arrived at the care home at 8.10pm with no information regarding what, if any, medication she had taken since the morning so the staff were unsure when she needed her next dose.

This has caused me grave concern, I understand that the discharge lounge has a nurse, but are they trained to deal with the needs of dementia patients? Is there a sufficient number of staff in the discharge lounge who are able to cope with a number of patients with complex needs? From my experience, most people arrange for someone to collect them after discharge so those who need
hospital transport are likely to be the most vulnerable. I understand that there are incentives for hospitals to discharge patients in the morning to free beds, but surely shunting a vulnerable patient to a discharge lounge is not good for their recovery and should not be the result of target setting? Even without government targets, one assumes that hospitals are not seeking to hold onto patients longer than necessary and are quite aware of the pressure on beds.

I acknowledge that I was away at the time of mum’s hospital admittance and discharge, but at any other time I would have collected my mother if there was any delay to make sure she was back at the care home in time. At no point was I asked if I was able to collect her or arrange for someone to do this on my behalf. If there is a problem with hospital transport, surely it would make sense to communicate this to relatives as many may be able to help?

I find it strange that the discharge lounge failed to communicate with the care home. They knew the care home’s policy on accepting patients in the evening yet they allowed my mum’s hospital transport to leave knowing that the care home had stated that they could not accept her. I think this is a bullying tactic and presumably accounts for the lack of communication earlier in the day when staff at the hospital realised there was a problem.

In my phone calls to the hospital I felt like I was trying to track a parcel in transit rather than locate my 85 year-old, confused, poorly mother. I cannot help but feel that this experience did little to aid her recovery and certainly made it difficult for her to settle in the care home again on her return.

Staff at the care home are keen for me to complain as this is not the first time it has happened and they feel that the hospital ignores their opinions. I am not sure what is reasonable but to me this treatment seems totally unacceptable.

I would like to reiterate I was pleased with the medical care mum received on the ward and my motive for raising this issue is to improve practice. I appreciate the hospital deals with many thousands of patients each day but if this is common then it is an area that needs to be discussed and an improved practice developed.
10. Patient B
By her brother

Patient B, who has the ‘mind of a child’, was admitted to Colchester General Hospital after suffering from four seizures. Her relatives feel hospital staff did not listen to concerns about their sister’s condition. Patient B experienced problems eating and swallowing but was repeatedly left with food and drinks but given no assistance when eating or drinking. She was discharged but needed to be re-admitted to hospital some months later. Her family was concerned that the poor communication still hadn’t been addressed despite making a formal complaint.

My sister (‘Patient B’) was born in 1950 and is the eldest of seven children. She has a phenomenal memory and although she often repeats her jokes and stories, she tells them as if they’ve only just happened and we’ve never heard them before. She frowns at the thought of anything which hurt her (albeit in the 1950s) and laughs hysterically at her own mischievous childhood antics (like stealing currants from the kitchen). She also has an endearing habit of laughing (innocently) at other people’s little misfortunes and she still roars with laughter when recalling how our dad fell into a stream and was unable to pull himself out!

She was very much the big sister in the early days and loves to tell how she used to keep my brothers in check when they squabbling - on one occasion with a broom – and she took great pride in helping my other sister and me (the youngest) to dress in the mornings; but inevitably she has become like our little sister over the years. She also took on the mantle of housekeeper. If the phone rang or someone knocked at the door, you’d have to be very quick to answer before her.

She also had a passion for (pop) music and I attribute my love of 1960s music to her. We used to sit on her bedroom floor playing 45s by Elvis, the Beatles, various Motown artists and especially The Monkees. When we weren’t doing that, my sister invariably had her radio (‘my tranny’) on and the only time when she wasn’t singing (very loudly, if it was a favourite) was when she was listening to The Archers - her evening ritual.

Our sister has the mind of a child but is fully aware of her own condition. She used to describe herself as ‘backward’, or mentally handicapped (before the intervention of political correctness) and show people her crooked toes and bent finger and say that she could have an operation to correct some of her defects before adding, ‘But I’m happy as I am’. She is a great example of someone who accepts what she is and who embraces life in a simple and happy way. She is less mobile now - a crooked spine is one of her physical defects and it has worsened with age – but she still helps out in the kitchen at her care home and they do what they can do get her out and about and involved in the goings-on.

My older sister now lives in a care home that provides sheltered housing accommodation for adults with learning difficulties. She was eventually diagnosed with Dandy Walker Syndrome and has the academic age of a young child; however, I would describe her as being loving, kind and talkative, and perfectly normal in many respects. My sister used to have seizures but these have been controlled by medication; and I had previously been unaware of her experiencing any more seizures in about 20 years.
During the afternoon of 15th February 2013, my sister’s care home contacted my brother – who is our sister’s designated next of kin - to report that our sister was unresponsive and unable to move one of her legs. The care home thought she might have had a stroke and called the GP. The GP concluded that my sister had oral thrush as a result of not eating or drinking enough, ‘but nothing else was wrong.’ She spat the water out when she was helped to drink, which I felt was uncharacteristic behaviour.

On the evening of 15th February, the care home contacted my brother again to inform him that our sister had had four seizures in twenty-five minutes, and was ‘unresponsive, her head was rocking from side-to-side’. She was subsequently taken to Colchester General Hospital by ambulance. When my brother arrived at the hospital, he was informed that our sister was having a brain scan. When he finally saw our sister, he noticed that she was staring blankly and totally unresponsive to speech or touch. A doctor informed him that this was not unusual given her seizures, and wondered if the medication for a Urinary Tract Infection (UTI) had ‘clashed’ with her anti-convulsant medication. Our sister would need to be assessed in the Emergency Assessment Unit (EAU).

On the morning of 16th February, one of my sister’s carers called my brother from the hospital to inform him that no assessment had taken place and that our sister was ‘still staring blankly.’ The brother contacted EAU and was informed that the patient was comfortable and ‘not complaining’. When my brother challenged the nurse about her last comment, she admitted that our sister was still staring blankly and wasn’t talking at all. Her blood pressure was normal but no diagnosis had been given.

Later on that same day, my brother visited our sister in EAU. My brother later told me that whilst our sister had water she ‘had no inclination or ability to drink it.’ He had to help our sister drink out of her cup but noticed that she was unable to retain water in her mouth. He also noticed that she was no longer staring blankly but remained unresponsive to and unaware of him. She did have a cannula fitted (‘which she pulled at compulsively’) but no drip attached. A staff nurse informed my brother that our sister had had a drip inserted but it had been emptied and she needed a new one. A member of staff from the care home who sat with our sister stated that at no point had a drip been attached to the cannula on 16th February. A nurse did eventually insert a drip upon request; however, the hospital strongly disputes this carer’s account.

A care home staff member, who was in constant attendance during her visits, informed my family that our sister had convulsed ‘about twelve times’, but a nurse reported that she had had ‘no convulsions at all’ since her transfer from A&E. This same nurse also appeared unable to respond to any questions about scans, drugs or the cause of our sister’s poor health, and advised my brother to talk to the consultant the following day. This nurse then told my brother that our sister would ‘probably’ be discharged the next day (17th February) and would have her swallowing reflex tested on 18th February. During a meeting with the medical team involved with my sister’s care in October, the consultant conceded that she might well have had convulsions in hospital and this could have accounted for the slow pace of her recovery – despite no medical staff witnessing these convulsions. On 17th February, my brother visited our sister in EAU again for the 9am – 1pm visiting hours, and a carer from the home also watched her from 10am – 2pm. However, my brother was informed that he wouldn’t be able to see the consultant before 10pm, as there were sixty patients in the same
ward. At this point, our sister was still not speaking or showing signs of recognition, but my brother noticed that she was gradually becoming more aware of her surroundings.

My brother did manage to speak to a doctor about our sister’s condition and said that the family had been told nothing since Friday evening (15th February). He was informed that they [hospital staff] were awaiting blood test results, that our sister was receiving penicillin for a UTI and there was nothing in her medical file about her having a brain scan (despite my brother being told that she was having one on 15th February). The doctor said that her symptoms were not consistent with a stroke and that she would have had a brain scan if the hospital thought she’d had a stroke. My sister wasn’t placed on a drip again because she’d pulled it out at 6am. This was subsequently re-attached at 11:30am but only after my brother and one of our sister’s carers mentioned it to the nurses ‘several times’, because they were worried our sister would become dehydrated. My family would like to emphasise that our sister was left without fluids for over five hours, and had previously had some difficulty swallowing water.

During this visit, my brother noticed that our sister had a bowl of porridge nearby which the nurse had tried to feed her, but had to ‘give up’ to prevent her from choking because she was unable to swallow the food (although my brother was told that she had eaten soup and yoghurt the night before). My family and I feel hospital staff need to take note of the fact that despite my sister being unable to eat or drink properly, we were told she would ‘probably be discharged’ on 17th February and have her swallow reflex tested on 18th February. I am concerned that the hospital did not discuss whether or not it would be appropriate to discharge my sister at that time, with members of her own family and carers. My brother eventually managed to feed our sister some soup and mash and one of her carers fed her ice cream ‘without any problems’.

On the evening of 17th February, another one of my brothers visited our sister in EAU and helped her drink three glasses of water. This brother states that a nurse told him our sister had been in a ‘catatonic state’ earlier on but was now ‘picking up’. The nurse also informed him that the consultant hadn’t been able to see our sister today but had seen her yesterday (16th February).

On the evening of 17th February, two of my sister’s carers from the home visited her in EAU. They fed my sister and gave her some water. They reported that my sister had indicated (with a squeeze) that she recognised them, as prior to this she had been unresponsive.

On 18th February, two more of my siblings visited their sister in EAU. They were informed that our sister was not attached to any drips because she was ‘drinking independently now’. The patient was having her lunch when her sister arrived and didn’t seem to know what to do with the food in her mouth. My other sister had to mime chewing to her and when she copied this she managed to swallow the food. She only ate mashed potato and some yoghurt. My sister also took her some chocolate buttons but the patient needed her sister to show her how to eat those too, but she did enjoy them. During this visit, our sister failed to recognise her siblings and looked frightened whilst talking ‘incoherently’. She also failed to recognise picture of her siblings in a photograph or recall her late boyfriend. My brother and sister reported that our sister seemed disorientated and confused, and were concerned about her condition. They were also concerned that she had been left alone with food when she had a reported difficulty eating and swallowing.
Afterwards, my other sister spoke with a nurse who informed her that our sister was ‘about to be discharged’ as staff thought this was her ‘normal state’. My sister had to state ‘emphatically’ that this was not the patient’s ‘normal state’ and enquired what had caused the decision for her to be discharged? The nurse had to call a consultant who arrived to speak with my sister, who reiterated that our sister’s present condition was not normal, and the consultant replied that she had ‘ruled out’ the connection between her present condition and a UTI. The consultant repeated that an infection can reduce the effects of anti-convulsant medication. The consultant also told my sister that they [hospital staff] didn’t know why the patient ‘was like this’ because they assumed it was her normal state. My family and I were very concerned that hospital staff had failed to check if our sister’s condition was ‘normal’ with her family and carers. My sister states that the consultant then told her she would arrange a CT scan but couldn’t commit to a time or date because she was ‘very busy’. However, our sister was taken for a CT scan later on.

On 19th February, my sister phoned the care home and was informed that our sister’s key worker was sat with her in the hospital. Our sister had recently moved to a bay in the Easthorpe Ward, Gainsborough Wing. The key worker was told the results of my sister’s brain scan but she didn’t understand. The key worker then relayed incorrect information on to my family, based on her misunderstanding. She thought that there should have been significant recent change to the brain when in fact there had been NO significant change. This is why my sister’s next of kin should have been informed. At this point, the care home staff were still none the wiser about what had happened to our sister, and were unsure how to treat her when she was discharged because they hadn’t been provided with any information about her condition. I have since learnt, following a formal investigation into our complaint, that somebody did call the care home, however, we don’t know if it was missed because staff just didn’t see it or because it was somewhat buried in paperwork. However, whilst this was call made to establish the patient’s usual state, as directed by the consultant, it did not provide any information to the care home about her current state.

On 19th February, my other sister visited again and noticed that our sister had been placed in a separate room. She remembered that her sister had visited her yesterday but still didn’t know who she was and became hysterical before relapsing into blankly staring at the wall again. My sister was informed by a member of staff that the CT scan showed no recent change to her brain, and a nurse told her that it can ‘take a while to recover if fits occur after a long time and changes in the body can happen at any time’. The nurse told my sister that they will ‘keep an eye’ on the patient until she shows signs of being herself again.

A junior doctor then tried (unsuccessfully) to test our sister’s strength by asking her to push against her. The junior doctor said that our sister’s CT scan and blood results showed no ‘recent change’ which indicated her condition was ‘probably temporary’, but the doctor didn’t know how long it would last. My other sister told the doctor that our sister ‘keeps chomping’ (which we recognised she used to do immediately prior to a fit) and pushing her tongue to one side of her mouth. The doctor told my sister that she would discuss this with her superior and come back to her, but she did not return. My sister also noticed that our sister’s evening meal had been left by her bed with nobody around to help her eat it. As a family we feel that if one of our siblings hadn’t been present to feed our sister, she would not have eaten that evening.
On 20th February, we stated that we were considering lodging a formal complaint and arranging a transfer to Ipswich General Hospital because of the lack of communication and care given to our sister during her time in that hospital.

Our sister’s care home contacted my other sister upon hearing that the hospital were about to discharge the patient after she had seen a physiotherapist and arranged an outpatient neurology appointment. Her medication (carbamazepine) was increased and staff noticed that our sister had fed herself that morning. However, as a family, we would like to point out that because our sister had been unable to eat or drink unaided the previous day, we remain concerned about the fact she was repeatedly left alone with food and drink. The care home was unsure what to expect if our sister was discharged that day, but told us they were prepared to call an ambulance again ‘if necessary’ (if her condition deteriorated). My family told the care home they would prefer their sister to go to Ipswich Hospital if an ambulance had to be called again.

On the evening of 20th February, my brothers visited our sister on the ward and saw a doctor. They noticed our sister was now eating and drinking independently and that her recognition was ‘dramatically improved’. However, they were concerned to note that her speech was not very clear and that a discharge was still being considered with ‘no cause being given for her condition.’ Hospital staff told my brothers that a ‘full recovery will happen now’ and that she will need to see her GP to determine whether or not she will still need to attend a neurological appointment as there is ‘nothing else the hospital can do’. This appears to be inconsistent with what our sister’s care home had been told, which was that the hospital would be arranging the neurology appointment for my sister. One of my brothers told the doctor that our sister hadn’t had any fits for about twenty years, to which the doctor replied: ‘Twenty? I thought it was three.’ We were concerned that hospital staff did not appear to have consulted our sister’s medical file or that this information was not readily available to those responsible for her care. We also feel her records should have been read and updated accordingly.

On 21st February, my sister was discharged. She returned to her care home – where staff still didn’t know why their patient had been admitted into hospital or what her condition was now she had been discharged. My sister and I visited her at the care home and noticed that she was very dozy and lethargic but able to recognise them and hold a conversation for a short while.

On 25th February, following (informal) discussions with the care home and an exchange of views, we decided to make a formal complaint about the perceived lack of care, absence of communication between hospital staff and with the family and the perceived lack of honesty. One of my brother’s commented that the lack of care we – as a family - feel our sister experienced was ‘not necessarily down to an individual nurse, so much as the lack of staff’. The same brother referred to an incident that occurred one day when our sister visited the ward and couldn’t find any staff in EAU to speak to, except for one doctor who instructed her to ‘go and find a nurse’.

I also remain concerned about the hospital’s complaints department. After experiencing a number of delays when attempting to make a formal complaint, I contacted The Patients Association for assistance with the NHS complaints process and only then do I feel that our concerns were fully investigated.
Unfortunately, my sister needed to be readmitted into hospital on 2nd October 2013 and my family and I were very worried to note that the issues we experienced during her last hospital stay (such as poor communication, etc.) were still ongoing, and did not appear to have been addressed or resolved by the hospital’s management team. During this recent admission, we experienced the following problems:

My family and I were treated rudely and ineffectually on the phone when calling to ask about our sister’s condition. One nurse only provided us with monosyllabic answers when more information and reassurance about our sister’s condition was required.

We were given conflicting information about our sister’s actual illness and her prescribed drugs. All we knew was that our sister had been referred by her GP with suspected pneumonia. The hospital actually diagnosed a ‘chest infection’ but someone in the EAU incorrectly said ‘asthma’ when one of my siblings first called on 3rd October.

Our sister was left waiting in a wheelchair on the evening of her admission. One of my brother’s sent a text message at 10:36pm to report that our sister was still in her wheelchair. He had arrived at 8:30pm and noticed our sister was sitting in a wheelchair at that time, so we know she was left in that position – with suspected pneumonia and an urgent GP referral – for at least two hours. My sister’s carers had no idea what was going on due to poor communication (they still thought she had pneumonia).

I remain unhappy with the hospital’s decision to discharge our sister the following day. I feel that the hospital needs to understand it is hard for my family and I to accept such decisions based on trust (especially when the discharge decision was not passed on to us, rather we received the information second hand), given our previous experiences.

My sister is a kind, loving, sweet-natured person and an integral part of our family. She is intelligent enough to comprehend her own medical condition and to read and write, but she has the mind of a child, rendering her vulnerable to the outside world. Our parents were always fiercely protective of her and the shock of her first convulsion was exceeded only by our fear of what was happening to our beloved sister. There have been difficult times over the years, because of people teasing her (as a child) or problems with her medication, but she remains special to the family and her siblings have all inherited our parents’ sense of protectiveness. Our late-mother’s biggest fear was what would become of my oldest sister after she died, because she was so dependent upon our mother, but she accommodated my sister’s desire to leave home and live the life she wanted.

Although my sister has had a number of carers over the years, our mother was always there if needed, yet she died knowing that my sister – her oldest daughter - was very happy in her care home and that her children (notably my older brother and other sister) had taken on the parenting role. This role was never so important as when my sister was out of the protection of her carers, such as when she was admitted into hospital. She should not have needed protecting from a hospital, but with individual carers (however well intentioned) not always well equipped to fight her corner and challenge the hospital’s ignorance of and prejudice towards her condition – and our family has had a long experience of prejudice towards handicapped, elderly and vulnerable patients -
this is exactly what she did need; especially as she was unable to answer for herself. It would’ve been insulting to our mother’s memory and more importantly, it would have been letting our sister down, not to have acted upon this experience. We witnessed first-hand that her care was lacking; that there was a lack of staff; that staff couldn’t differentiate between her baseline state and her current condition; that we were being given inconsistent and incorrect information, not to mention the hospital’s apparent eagerness to discharge her before finding out what was wrong – and we will never stand for that. The recent repetition in October only served to endorse our fears and although it transpires that my sister may have received more appropriate care this time, we cannot simply ‘trust’ that that happened. Trust has to be earned, our trust in this hospital has been lost and it will take time to rebuild it again.
11. John Moore  
By his daughter, Caroline Donald

Caroline Donald’s father was diagnosed with an aggressive brain tumour in April 2013, but experienced a critical delay at Frimley Park Hospital before he was able to receive urgently needed surgery at St George’s Hospital. Mrs Donald and her family have since discovered the operation was delayed after a junior doctor at Frimley forgot to make the critical referral. In St George’s, Mr Moore learned that his condition was terminal and although he was informed that he had a life expectancy of 1-2 years left. He sadly died after four and a half months, aged 72.

I am writing on behalf of my father, John Moore, who was a very fit 72 year-old and took no medication. He enjoyed country sports, such as fly fishing in the summer and beagling in the winter. He played bridge every week and was Chairman of his local club. He was also a keen astronomer and an active member of his local astronomy club. In his quiet, unassuming way, he helped in any way he could, whether it was with weed clearing in the river or repairing the bridge dealing machine. He was a very kind man, who had been happily married for fifty years to his university sweetheart. After a career in the Royal Air Force as a pilot/engineer, he had semi-retired as an electronics consultant. He had his perfect life, surrounded by family and friends, who loved and respected him. Most of his close relatives had survived until their nineties so we thought we were safe with him.

My father was a patient at three separate hospitals as a result of suffering a seizure, which led to him being diagnosed with an aggressive brain tumour in April 2013. My father was transferred to St George’s Hospital in London from Frimley Park Hospital on Sunday 7th April 2013. He had been diagnosed with a right parietal brain bleed caused by a tumour and was assigned to the care of the neurosurgery team at St George’s. His operation was on Monday 8th April. The operation to ‘debulk’ the tumour was clinically successful in that they removed all that they could and he made a good recovery. My father then started a palliative radio treatment program on Monday 13th May at St Luke’s Cancer Centre in Guildford.

Some aspects of his care were shockingly bad and have raised serious concerns.

Firstly, the system of referrals between Frimley and St George’s let my father down badly. My father had suffered various seizures and was diagnosed with an intra cranial brain bleed for which he was admitted to Frimley on Monday 25th March. My father had an MRI done at Frimley, on or around this time. The consultant at Frimley suspected that it might be a brain tumour from the radiologist’s report and advised my father of this fact. St George’s saw the MRI on 26th March and advised a repeat MRI 24-48 hours later due to blood obscuring the relevant area. Frimley Park did
the repeat MRI on March 28th but did not send it to St George’s or discuss it with them again. It was only when we, the family, at a time of enormous pain and stress, pushed very hard for the senior neurosurgeons to look at the MRI scan results ten or so days later that my father was then immediately admitted for surgery.

On Friday 5th April, my husband and I went to Frimley Park to meet my parents as my father had suffered further seizures and had been discharged by a junior doctor from A&E.

It quickly became apparent to us through our own investigation that St George’s (who we then contacted directly) had not been given any information post 26th March. The Patient Advice & Liaison Service (PALS) at Frimley, who we contacted for help, then arranged for the later MRI to be sent but because there were no accompanying notes at that stage there was more confusion. St George’s didn’t want to speak to us directly before they had spoken to a clinician at Frimley.

Since making a written complaint, I had a formal meeting with them to discuss the difficulties which mainly seem to stem from their end – a junior doctor forgot to make the critical referral and the Frimley epilepsy nurse who checks the St George’s referral lists was away on holiday and no cover had been arranged.

Once the St George’s neurosurgery business unit manager’s team got involved (and we had to speak to them ourselves numerous times) they did a good job of getting the neurosurgeons to look at the MRI over the weekend and sort out an admission for my father, who was taken into hospital on Sunday 7th April. We were also told that my father was hopefully going to be operated on the following morning. At 7:30pm (just as visiting hours were about to end), my father received a visit from the professor of neurosurgery who was going to lead the operation. Due to the speed of the referral, the oncology nurse specialist had not had a chance to catch up with us.

On a public ward, without drawing the curtains first – which I frantically got up to do as I could see this was going to be an upsetting conversation and we would need some privacy – the senior neurosurgeon informed my father that it was not going to be possible to remove all of the tumour without paralysing him on the left side (my father had already lost left side function in his hand). He also stated that the operation was likely to last around an hour and in itself was relatively straightforward. He then stated that the tumour was an extremely aggressive one and that my father had one or possibly two years to live, but if he was not operated on it would be a matter of months. He said that at my father’s age (he was 72) ‘if it [the tumour] wasn’t going to get him then something else would.’ He also stated that my father just had to ‘accept it and get on with it’ and even though it was unfortunate, that at his time of life he should expect some sort of health issue.

From our point of view, it was brutal, breathtakingly insensitive and the most important part of all, my father’s choice was taken away. He and my mother were not asked at any point whether he wanted to know or talk, at this very early stage, about survival time periods or whether he understood how serious it was, or anything of a preparatory nature. He was then left on his own, without his family, all night; the night before a major operation. My father’s family have mainly lived to their nineties and my father has been in near perfect health so this was, simply put, enormously difficult to hear. The strong and lasting effect, of the way this first conversation about prognosis was
handled, on my family, will never leave us.

The conversation about prognosis – which clearly had to happen - would have been better left until after the operation, and possibly until the histology report was back. We also think that it would have been better to take the cue from the patient (who was highly educated and intelligent and completely able to follow conversations about medical issues so there was no risk of him not understanding) and respond to questions rather than (as the consultant later said himself, complacently and arrogantly) deciding on the correct course of action himself.

A senior clinician who we got a second opinion from in Harley Street - who knows the senior neurosurgeon who spoke with us that night - was shocked and horrified by what he did and the manner in which he did it. There do not seem to be any protocols for how medical professionals deliver a terminal prognosis to a patient and their family, and we have since contacted NHS England to ask them about the lack of consistency, and give them twelve separate pointers on things that NHS professionals need to think about when they deliver a terminal prognosis.

Leading on from this devastating meeting with the senior neurosurgeon, the oncology nurse specialist had to pick up the pieces. She also reported back on the histology report by chasing it down a day or so earlier than expected. Unfortunately, it was very bad news in that the tumour was a Grade 4 glioblastoma multiforme and the treatment was expected to be palliative radiotherapy (the senior neurosurgeon had told me that chemo would likely be available and that one of his friends was on it and experiencing no side effects – this later turned out to be wholly inaccurate). We have received a heartfelt and lengthy apology from the neurosurgeon who has also since revised his prognosis from 1-2 years to 4-6 months. We have accepted the apology but we remain shocked and horrified not only by his behaviour but also by his mistakes.

Despite undergoing treatment on Monday 8th April, my father very sadly died on August 11th 2013. I had been aware that the prognosis given to us may well have been wrong; as I sought a separate private opinion where the prognosis was given to us as 6-9 months (they didn’t have the post operative information). I decided not to discuss the shorter prognosis with either of my parents. This has had enormous ramifications including emotional issues such as feeling enormous guilt. The whole situation would have been far worse had I not known the truth on every level. My employer, a U.S. investment bank in London, where I am chief of staff for the legal department, gave me six months sick leave on full pay so that I could look after my parents and manage my father’s case – which of course I should not have had to do. This would never have been afforded to me had I not had a realistic prognosis from a private consultant.

My two overwhelming feelings are of being appalled and betrayed by the various consultants involved: from the consultant at Frimley who continues to work without any enquiry, within a team where critical referrals are made by junior doctors with no checks, to the consultant at St Georges who traumatised my family and gave a wholly inaccurate prognosis, to the consultant at the cancer centre who was ‘too busy’ to take a critical first meeting with his patient and left it to another junior doctor to repeat the mistake on prognosis made by the neurosurgeon. These consultants / teams need to take a serious look at how they practice. I feel I have no trust in doctors at any level as they seem to either withhold information or give wrong information even at the most senior levels. I am...
now in counselling, arranged through my amazing employer, to help me get through the emotional trauma. Not only did we suddenly lose my father, I also had to do battle with a system that should not have got so many things wrong. I also feel very strongly that, as a qualified lawyer and as someone who has access to a great deal of medical advice through my employer, that I am in a privileged position to be able to make the written complaints that I have made. I also feel that many other families will have been treated in the same way and will not have complained. My father’s lasting wish was for me to try to improve the situation so that other families will not have to go through what we did.
Mrs Hadfield strongly believes that Tameside Hospital ‘failed in its duty to care for elderly patients’ after witnessing the treatment her late-father and mother received. Mrs Hadfield was unaware that her father ‘didn’t have long’ after staff failed to communicate with his family effectively before his death. Following this, Mrs Hadfield was appalled to discover that her mother, a dementia patient, had been discharged from the hospital in February wearing just a nightgown. Despite numerous complaints, Mrs Hadfield is not confident that lessons really have been learned.

My father, Herbert, was a very lovable person who gave his all to his wife and family. He liked going away on holiday, eating out and he especially enjoyed gardening. My father had worked in the engineering trade and in the Second World War was in the Royal Engineers engaged in removing land mines, where he was very badly wounded.

My father died in Tameside General Hospital on 29\textsuperscript{th} August 2011. He was admitted by ambulance on the same day after experiencing severe abdominal pain at his home and had to wait in A&E just under the 4 hour target. I felt that his condition at that time was critical, as he was in considerable pain, but the hospital staff did not seem to address this situation for ages. He was then taken for an x-ray, but by this time he was not responding to anything I said to him. In fact, we never spoke again.

My father’s medical team tried to insert a tube up his nose which was very distressing to witness because it failed. After this, he was then transferred to one of the hospital wards. My family and I were still unaware that my father was critically ill and actually dying, due to the lack of communication.

On the ward there was no privacy for my father and his family. The curtains weren’t even closed. We sat for hours with him and although he was on nil by mouth a nurse offered him a hot drink. I angrily replied that he couldn’t speak, let alone drink tea. The sister of the ward was too busy to even see how my father was but she had some sympathy because when we left the ward she gave me a hug.

Following this, I was distressed to learn that my father’s medical team had once again tried to tube him, but had been unsuccessful on this occasion too. There was blood everywhere and the healthcare assistant who changed my father’s bed left him covered with blood all over his face. As I write this, I am not ashamed to say that my heart is broken and tears are just pouring down my face,
because it is so vivid: the picture of his face as I tried to tenderly wipe his face clean. I felt lots of love for my father at that moment, but he wasn’t conscious at the time.

We were then advised they were moving my father to a surgical ward. We were not sure why because earlier we had been told he was not stable enough to undergo surgery.

Additionally at no time did a member of staff ask if my father had a wife or other family members who needed to be with him.

We spent hours sitting with our father in a side room before he died, holding his hand but were always unsure as to what was going on. Was he going to recover or was this the end? On the day he died, 29th August, the door opened and hospital staff asked us to leave the room as they were going to try and insert a tube again. We waited outside as instructed and when the medical team left the room we asked if they had been successful this time, and a sister replied ‘yes’, but in the same breath added, ‘he hasn’t got long’. It seemed only seconds later when we were told that he had died.

It felt so unreal; we had wanted our father to die with dignity and had also wanted to be with him at the time that he passed away. We felt we had failed him.

Unfortunately, this is not the first time our family has been distressed by the hospital treatment our parents received over the years.

On being diagnosed with lung cancer at Tameside Hospital in 2001, a doctor advised my father that because of his age he was not ‘suitable’ for an operation. He would be sent Macmillan Nurses to help him cope with the illness. I felt it was almost as if my father was being treated for a simple cold. He had had no tests and only one x-ray, but no biopsy. During that consultation, I became so angry with the doctor’s lack of compassion that I told him my father was not leaving hospital without a referral letter. I managed to obtain one, and within a week my father had an appointment at Wythenshawe Hospital.

The consultant at Wythenshawe was remarkable. He explained all the risks involved and the seriousness of the operation, and also said my father was right to explore other possibilities than just leave the cancer because of his age. As a result, my father’s cancer was removed during an operation and he spent some time in intensive care in 2001. He had another lobe removed at a later date in 2002, but he never suffered from lung cancer again.

He had excellent follow-up appointments at Stepping Hill Chest clinic. I felt that nothing was too much trouble for the staff at this clinic. If my father had any concerns about his health he would contact the Chest Clinic and they would make an appointment for him to see one of the consultants at Wythenshawe Hospital more or less straight away.

After my father’s death, I made a formal complaint. As I was unsatisfied with the hospital’s numerous responses, a series of meetings was arranged to help me meet a local resolution. The final meeting I attended on 13th March 2013 to discuss my late-father’s treatment at Tameside Hospital was very stressful. Although I work for a NHS hospital in a clerical capacity, I felt I was
unable to address all the issues involved with my father’s poor hospital care, so a friend who is medically trained also attended the meeting with me.

I cannot really recall much from the meeting, but remember thinking that over the years I had had the same feedback but this time my father had actually died, and all the hospital staff in the room during the meeting could have communicated with my family more and attempted to provide us with some comfort and transparency. If the hospital staff knew my father was dying, why didn’t they inform his family so we could have had the opportunity to say our goodbyes? A doctor informed me that it can be difficult to predict what will happen to a patient when they are given medication. If this is the case, then I feel a gentle warning should be given to the patient’s family. The doctor also told me that as the lead clinician he will discuss the communication aspect with his staff, patient surveys will be relayed to staff and mandatory communication training course for staff instigated.

The medical team’s response during the meeting was to inform me that ‘lessons had been learnt and action plans will be formulated and implemented as a result.’ Apologies were offered. I felt like saying to them: ‘Yes I lost my beloved father, but you really couldn’t give a damn.’

I strongly feel that basic human kindness towards patients and their relatives is not practised at Tameside Hospital. Since my father died, my mother has also been treated with no respect by hospital staff and I have had to consult PALS yet again.

On the 8th February 2013, my mother, Irene, needed to be admitted to the A&E department at Tameside Hospital following a fall at her nursing home. From A&E, she was sent to the Medical Assessment Unit (MAU), before being moved to Ward 43. She was discharged on 13th February.

The ward contacted my husband to say that my mother was being discharged, but my husband was unable to contact me because I was in a meeting and my phone was switched off. After contacting my husband and being informed my mother was coming home, I called the hospital to tell them that I wanted to take some of my mother’s clothes to the hospital and accompany her to the ambulance. However, I was informed that my mother had already left and on her way back to the nursing home, so I went straight there instead.

On arriving at the home, I was told that the carers had had to document the way my mother had arrived at the nursing home. She was wet through and had only been wearing a short cotton sleeve night dress and was unsurprisingly complaining of being cold. It was February and the temperature was two degrees centigrade outside. The carers also stated that one of the blankets was soaking wet.

My mother is 89 years of age and has dementia. My family and I always accompany her when she is discharged from hospital because she is easily frightened. I have written to the hospital to complain and to suggest that the staff read their own displayed leaflets on professional dementia care.
Afterwards, I discovered my mother’s clothes were not in her locker because there was not enough room for her coat, and my husband had had to take the rest of her clothes home with him because they were still in the green bags that had been used during the ward transfer and were soiled.

The following day, 14th February, the nursing home called to say that Tameside Hospital had stopped my mother’s insulin prescription on the drug charts and that my mother’s carers had had to contact them to ask for an explanation, but this was later revealed to have been a ‘mistake.’ Before this, a district nurse had visited my mother every day to administer the insulin, as she had been diabetic for years.

I feel that all of the above is not acceptable. I am yet again disgusted with Tameside Hospital’s treatment of elderly patients and am still grieving for my father. All of this is extremely traumatic for a family who has lost their father and is trying to do their best for a mother with dementia. Tameside Hospital has a duty of care and has failed yet again.

I have file upon file on my father’s previous admissions, all of which detail the nursing staffs’ failures to meet standards of professional and compassionate care. Each time I have been assured that it will change. I think not. Perhaps if the hospital’s management team did not expect nurses to interrupt their patient care duties to meet so many targets, then things may improve. Some of the elderly do not have relatives and a voice to speak for them and it’s time for things to change, and not just at Tameside Hospital. The Government still has plenty of work to do to ensure that the NHS is performing to standards of professional nursing care and quality healthcare services, because at present, it is not.
Edith Jamieson  
By her daughter, Lynne Hambleton

Mrs Hambleton’s mother was admitted to hospital in March 2013 after falling over a loose paving stone. Mrs Hambleton, a qualified nurse, is ‘ashamed’ of the profession she has worked in after witnessing the poor care her mother received. This included going without food and drink for long periods and not being assisted with toileting. Her blindness and confusion prevented her from being able to use a call bell.

My mother became a patient at the Royal Victoria Infirmary and Freeman Hospital in March 2013. Things became so bad that I started to keep a diary before deciding to bring her home in April. I do not think I could ever allow my mother to be treated by the above hospitals again. I am ashamed of the nursing profession I worked in for 40 years and the hospital I trained in 43 years ago.

Before her hospital admission, my mother was a 94 year-old lady with macular degeneration, this meant she only had a small amount of peripheral vision. Despite this, she was independent in her personal care and able to use the stairs. She could manage some cooking and cleaning with the assistance of family and friends. She was also able to use public transport and would travel on both the metro and bus alone.

On 20th March 2013 my mother tripped and fell over a lose paving stone. There was no evidence of a fracture but pain on weight bearing got progressively worse. Later on at 4pm, my mother had an outpatient appointment at the Freeman Hospital to see her Gastroenterologist due to incidental iron deficiency anaemia. The Gastroenterologist was informed of my mother’s fall, but no interest or concern was shown – despite the fact my mother was limping and in obvious pain. The only decision made during this appointment was to order a scan and gastroscopy. Whilst I appreciate this specialist might not have been the correct person to treat my mother’s injuries after her fall, I find the lack of interest or compassion shown to an elderly person who was in significant pain during a consultation deeply concerning.

Following this appointment, I made the decision to take my mother to a Walk-In Centre with some difficulty as I was unhappy about driving into town. The nurse at the Walk-In Centre could not exclude the possibility of my mother having a fractured femur, and ordered an ambulance to take her to the Royal Victoria Infirmary (RVI) at about 6pm. My mother was taken to the RVI by ambulance and the paramedic did a handover to a young male nurse, but no further assessment was carried out by that nurse. I was left to stand in a corridor with my mum and eventually had to ask a passing clerical worker if I could have a chair, which she had to locate elsewhere because the two
chairs in the corridor had a sign on them to say they were broken. When my brother arrived at the hospital he had to sit in a wheelchair next to us.

Eventually a care assistant arrived and took my mother’s blood pressure and pulse; no-one checked the neurovascular state of her leg/foot. We were then moved to a side room after a further wait of 90 minutes. At about 9pm a nurse came into the room to check who my mother was, and I told the nurse I was worried about her pressure areas. The nurse asked if my mother had a pressure sore and I replied that she didn’t, but that I was worried she would soon have one if she was left to wait on a hard trolley for much longer. The nurse replied by telling me that the department was very busy and there was nothing she could do about it, but my point would be noted. Soon after this a doctor arrived and sent my mother to have an x-ray. He said sometimes a fracture does not show up on an x-ray at first and thought my mother might also have a Urinary Tract Infection (UTI).

At about 10pm my mother was transferred to the Assessment Suite. I informed an A&E nurse that my mother hadn’t had anything to eat or drink since midday and I know that this information was passed on during the handover. I asked mum if she could eat a slice of toast and she replied ‘yes’. As I left the ward I spoke to the registered nurse working in that bay and repeated that my mother hadn’t eaten anything and could manage some toast. The nurse replied that they were ‘not allowed to do toast’ but she would give my mother something. I wasn’t convinced that she considered getting my mother something to eat important so on the way out I mentioned it to the nurse in charge of the department who looked like she was busy with an extremely sick patient. As we were walking along the corridor I told my husband that I was still not convinced she would be given anything to eat, and should I go and get some biscuits for her? I decided not to in case I risked alienating the staff, but I feel very guilty about not going back to give my mother some food.

On Thursday 21st March my brother arrived at the hospital in the morning and took some toiletries in for our mother. During that visit, he learnt our mother had been given nothing to eat until breakfast time. I telephoned the nurse in charge of the unit and spoke with the matron. I was very angry that my mother hadn’t been fed last night, despite my speaking with numerous nursing staff. This also came about the day after the Stafford Inquiry had been in the news again and I was concerned for my mother’s wellbeing.

Later on that day my mother had a CT scan which I understand excludes an impacted fracture and fractured pubic rami, but my niece – who had been present at the time - was told it was a scan of her abdomen, so I then assumed she had had an ultrasound scan. I am also unsure how much water she was given to drink that day.

On Friday 22nd March at 9am I received a call saying my mother was becoming very aggressive and could I come to see her. A patient later told me she had hit a nurse. When I arrived she was very upset and confused, her urine was concentrated, mucus membranes dry and her skin stayed folded when pinched. The nurse told me she had been drinking, however, later that morning I was told by the pharmacist that the diuretic had been omitted because the medics thought she was a bit dehydrated. I encouraged more fluids.
Later on, I spoke with a nurse on the telephone who informed me that she had spoken with the nurse responsible for not feeding my mother the night she had been admitted into hospital. Apparently, this nurse had offered my mother a sandwich, which she refused. My mother would have refused to eat a sandwich if she thought the nurse was busy that night, so as not to inconvenience her because she thought the nurse would have to make it for her, but whatever happened to gentle persuasion or encouragement? It is of utmost importance that elderly patients are encouraged and assisted to eat their food in hospital.

At about 4pm, my mother vomited coffee grounds, according to a doctor my niece had spoken with at the Freeman Hospital, however, I was later told by a nurse in the Assessment Suite my mother had coughed up blood. That evening, she was transferred to the Freeman Hospital. She was confused but her urine was clear and we had a very good reception on the ward by two members of staff, which really gave me confidence that her care would improve.

Over the next few days, my mother’s condition seemed to improve and she would be less confused, but the next day she would complain about being in pain and the staff tried to sort out her bowels with little success.

On Monday 25th March I spoke to the charge nurse on the telephone and requested to see the doctor later on that day. I was told this might not be possible if they were busy, but I could talk to the charge nurse again if the doctor was unavailable, which I ended up having to do. I told the charge nurse that I was concerned about my mother’s condition because she seemed to be in a lot of pain and I asked if they had excluded an impacted fracture by doing a MRI scan? The nurse replied that he didn’t know about impacted fractures because it was not an orthopaedic ward and they couldn’t be expected to scan everyone with a painful hip, however, he would pass my concerns on. His communication skills and body language did not give me much confidence.

On Wednesday 27th March at 1am I received a call asking me to come into the hospital again because my mother was very upset. At 2am I arrived to find my mother’s bed at the nurses’ station, under the bright lights, with the nurses talking constantly in normal tones and the telephone ringing in the background. I discovered that my mother was having hallucinations about being locked in a box in a tunnel by people wearing a uniform. I later realised this was because my mother had had a CT scan, which her family knew nothing about. If I had been given that information during the day, when I specifically asked the charge nurse if she was going to have a MRI scan, I would have been able to reassure her it was a special x-ray and that she would be ok. I had to stay with my mother until 8.30am and left a message saying I wanted to speak with her doctor any time that day.

At 2pm my mother was still very confused and hallucinating for no apparent reason – a UTI and chest infection had already been excluded. A patient in the next bed told me that my mother hadn’t eaten any lunch, and another patient said my mother had been upset in the night when the nurses didn’t answer her call bell and it had resulted in incontinence. She was still very confused later on that evening when my brother visited.

On Thursday 28th March I rang the hospital at 6am and was told she had spent another night at the nurses’ station because she was so agitated. Later that morning my niece was told they were going
to stop giving my mother Tramadol because they thought that might be causing the hallucinations. My niece told the nursing staff she hadn’t realised my mother was on Tramadol, to which the charge nurse replied they [hospital staff] were not in the habit of giving information to relatives about changes in a patient’s treatment. What happened to the charge nurse doing a round during visiting hours to improve communication and create more transparency? As a qualified nurse, I question the use of Tramadol on elderly patients.

My husband visited my mother later that afternoon and she was still very confused and hallucinating, but seemed happy with it. Later that evening when my niece visited again my mother was very agitated, she was moved to a side room and my niece said she would stay until my mother had settled down.

On Friday 29th March I rang two pharmacists and both said they would not use Tramadol in that age group and recommended paracetamol instead. One even said the use of Tramadol was ‘poor medicine’ and can cause hallucinations in elderly patients. When I visited my mother later on I discovered that she had had a much better night with hardly any hallucinations.

Over the following days my mother seemed much better and seemed to stop suffering from any hallucinations, although she was grumpy.

On the 1st April I asked to speak with a senior doctor and also requested if my mother could be moved back into the main ward, because she was very lonely. On the 2nd April, I spoke with a consultant who informed me that he had ‘given up’ deciding which analgesic was best, because some people react to Tramadol and some do not. He looked at my mother’s abdominal scan and confirmed there were no fractures. When I replied that no-one had told us this (and there had been many opportunities during the eight day period after the scan had been taken), he replied: ‘Well I’m telling you now.’ He also told me the gastroscopy ordered by the gastroenterologist had been cancelled, but that since then he thought two might have been booked for my mother by mistake – I was told to ring and cancel the other one. He was not interested in any of the problems I tried to raise with him and I felt like I was wasting my time talking to him.

When I called to cancel the gastroscopy on 3rd April, I discovered it hadn’t been cancelled at all.

During this time my mother was very worried about using the toilet at night, because she was almost blind and unable to adapt to using new equipment / technology easily; as a result could not use her call bell. She also didn’t like to call out and disturb other patients. I would question whether or not the nurses are doing frequent patrols around the beds, because it is difficult for patients who cannot use the buttons to call for attention and I am sure there must be other elderly patients in my mother’s position. At the resolution meeting the chair of the meeting said my mother’s blindness and cognitive inability to use her call bell was ‘unusual’, but I reminded him that macular degeneration in the elderly is a very common problem.

On Sunday 7th April I brought my mother home. A staff nurse offered to go through my mother’s medication to take home but I told him not to worry. Later that day, I discovered there was no Bendroflumethiazide, which my mother had been taking for 15 years – I did wonder why her ankles
were more swollen than usual. I rang the ward and the nurse in charge went through my mother’s medical notes with me. She said that the diuretic had been stopped the day after admission to the RVI because my mother’s blood pressure was low. I asked the nurse what my mother’s blood pressure was now and was fortunately able to continue administering Bendroflumethiazide the next morning when I discovered I had this medication at home. This was yet another instance of poor communication, and if her ankles were swollen why didn’t anyone do anything about it? I cannot help wondering what would have happened if my mother had gone home to relatives without nursing experience – would something have been done if she went into cardiac failure.

On the 8th April I spoke with another senior doctor about the above issue and he was very apologetic and gave me advice about the diuretic. I feel the consultant I spoke with on the 2nd April could learn a great deal from him relating to his attitude.

Throughout this whole experience I have to say that some of the staff I met on Ward 15 at the Freeman Hospital were first class - in particular, a male staff nurse who always tried to give patients and relatives up-to-date information. It is the medical and senior nursing staff I have concerns over because their communication and ‘transparency’ skills were seriously lacking. As a result, I remain deeply concerned about the patients and relatives who have no medical training and feel they must follow the medical advice and treatments made available to them.

Partly due to her experience in hospital, my mother is frightened of falling and has not left the house alone since she was discharged. It is my belief that she never will again. She is more nervous about everything and I am sure this is because of the treatment she received. If senior hospital staff were more approachable, then I probably wouldn’t have had to go along the route of making a formal complaint and attending a resolution meeting, which I found very intimidating even though I had been used to talking with doctors in my professional capacity as a nurse.
Trust Responses

Tameside Hospital - Olive Burns

“These patient concerns highlight that, on occasions in the past, the care we offered our patients did not meet the standards they rightly expected and for this we are truly sorry.

“We are now on a journey of improvement. We have a new leadership team and our focus is on large scale improvement projects which include all the recommendations made by the Keogh Review in its report. We are committed to making determined and decisive changes to deliver the highest quality, most compassionate and best care for our patients.”

University of East Anglia Medical Service (UEAMS) - Averil Hart

“We wish to extend our deepest condolences to Averil’s family for their sad loss. We are unable to comment on individual cases because of our duty of confidentiality. However, we would welcome a further opportunity to discuss any concerns with the family.”

Cambridge and Peterborough NHS Foundation Trust – Averil Hart

Andy Burrows, Communications Manager at Cambridge and Peterborough NHS Foundation Trust, has said: “The death of Averil Hart was tragic and we have sent our deepest sympathies to her family and friends.

“A formal investigation has been carried out involving all relevant health organisations and submitted to the North Norfolk CCG along with an action plan to ensure that lessons can be learned from this case.

“Actions from the investigation were implemented some time ago. They include ensuring care plans remain as robust as possible and ensuring our most complex cases are dealt by our most senior and experienced staff. A further review is planned to ensure that the steps we have taken are working. “We have arranged a meeting with Averil’s family and they will be invited to help us audit the changes to our service.

“Our staff remain committed to helping each and every person we see on the path to recovery.”

Norfolk and Norwich Hospital – Averil Hart

Norfolk and Norwich University Hospitals NHS Foundation Trust said:

“We offer our sincere condolences to Averil’s family for their sad and tragic loss.

“Care for patients with anorexia nervosa at NNUH is led by the MARSIPAN guidelines which we have had in place for the last three years.

“Averil was cared for by a consultant who specialises in clinical nutrition and was seen by this consultant within an hour of admittance to hospital and received all the support, treatment and specialist care appropriate for a patient with anorexia nervosa who was very unwell.”
“The consultant responsible for Averil’s care decided that she needed to be transferred into the care of Addenbrooke’s Hospital because of a particular complication connected to her condition in which Addenbrooke’s specialises as one of six centres in England.

“Any patient with anorexia nervosa who is admitted to NNUH is cared for by a consultant who specialises in clinical nutrition and supported by a full multi-disciplinary team, working closely with the Norfolk Community Eating Disorders Service which provides psychiatric support. Dieticians plan meals for patients with anorexia to avoid re-feeding syndrome and daily checks and blood tests are conducted. Where necessary, additional specialists are brought in to manage any other health conditions which might arise due to a patient’s vulnerable condition.”

Northampton General Hospital – Elisabeth Flood

“We were very sorry to hear of Mr Flood’s concerns about his wife Elisabeth’s experience at NGH, and that her care did not meet the high standard we aim to provide to our patients.

“Our A&E department was extremely busy on 29 May 2012 and, although Mrs Flood was triaged within the hour and assessed as being in no immediate danger, we accept that there was a delay in her being seen by a doctor and we apologise for the long wait that she suffered. We have since recruited additional nursing and medical staff, and introduced new ways of working in the department to help reduce waiting times.

“We believe that the decision to discharge Mrs Flood after hospital treatment to the specialist care centre was correctly made by all the experts involved in her care – and that the centre was an appropriate and qualified place to look after her. We are sorry that her rehabilitation did not go smoothly.

“We have already learned much from Mr Flood’s complaints, particularly around the need to improve communication, and we have responded in detail to him. We have invited Mr Flood to meet relevant members of our staff so that he can further discuss his concerns and we can continue to learn from them.”

Worcester Hospital – Andrew Brown

Rebecca Bourne, Head of Communications at Worcester Hospital, said: “We would like to apologise for the undue anxiety that this process has caused Mr Brown. We have had a number of positive and helpful meetings with Mr Brown over a number of issues he has raised in the past, and taken on board his concerns.

“Listening to patients and putting things right following complaints are very important to our trust, and following our discussions with Mr Brown we have updated our complaints policy to reflect this. “We’ve taken the ombudsman’s findings on board, and are following the recommendations made in the report.

“We are pleased that Mr Brown recognises the positive work being done in our hospitals, and would like to assure him that any future care he receives from the Trust will not be adversely affected in any way.”
Aintree University Hospital – Sarah Carroll

“Ms Carroll’s complaint was complex but we recognise there have been serious failings in addressing her complaint. We are extremely sorry for this and have spoken to Ms Carroll about the delay confirming that a response will be with her by the beginning of next week at the latest.”

Barnet and Chase Farm Hospitals – Stan Norman

“The Trust would like to thank Janet Kite, the daughter of Stan Norman, for bringing this case to our attention. We regret any inconvenience that may have been caused to Mr Norman over the course of his treatment and will be looking into mistakes that may have been made, as well as working with our partners in other NHS trusts involved in his treatment to see what could have been done differently.

“As we were only made aware of the complaint last week we have not yet completed our investigation and so it would be impossible for us to comment until we have looked into all the details further.”

The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust – Patient A

“We are sorry that this patient felt the experience at the Royal Bournemouth Hospital was not the best that it could be. We strive to listen and learn from patient feedback so that we can continually improve the patient experience and address any concerns that patients may have.

“We are aware of this patient’s particular experience as part of an open and ongoing investigation. We have made further contact with the patient to address any outstanding concerns that they have. We hope a satisfactory outcome can be reached shortly.”

Stepping Hill Hospital – John Munday

“We are sorry to hear that Mrs Wright did not think that her uncle’s dignity needs were being met when he was examined.

“Normal practice would be to check with both the patient and family as to whether family members should be present in an examination of this kind. We are unable to explain why it didn’t happen in this instance as no complaint was received and therefore the matter was not investigated. Protecting patient dignity is of the utmost importance for us, and our patients’ survey results support this.

“We are also sorry to hear that Mrs Wright was unhappy about the food and drink provided for her uncle, as we did not receive a complaint from her.

“Providing the correct nutrition to patients is one of our top priorities. In all our wards and waiting areas patients can have tea, coffee and water to drink, and toast and cereal to eat. Snack boxes are also available. This is in addition to the main hospital meals given to all our inpatients.

“This should have been available for Mr Munday and Mrs Wright and we apologise if this was not the case on this occasion.
“We would like to reassure patients and their families that food and drink is always available to them, and if they believe they have been waiting too long for this they can ask a member of staff for assistance.”

Colchester General Hospital – Patient B

“Firstly, we would like to express our sincere and deepest apologies to the whole of family for the poor care experienced and for the distress that we caused them during her in-patient stay. We take all complaints extremely seriously and we have thoroughly investigated the care that we delivered. We have recognised the need to improve our services and support our staff in delivering care, ensuring that they really understand the complexity of the care needed by specific patients.

“Following the investigation, an action plan has been developed which includes developing a stronger relationship between the ward staff and the learning disabilities team. Staff need to feel confident in seeking the learning disabilities teams’ expert knowledge and support wherever necessary. There has also been a concerted effort to train our staff to deliver our ‘At our Best’ training to ensure that they have the right values and principles for the delivery of exceptional care at top of mind. In November 2013 some 77% of the EAU staff have attended.

“We have had a meeting with the family in the last two weeks and we were able to go through the action plan with them. We are pleased to say that the family are satisfied with the outcome of the meeting and are supportive of the actions we have put in place to ensure that this never happens again.”

Frimley Park Hospital – John Moore

“We have fully investigated Frimley Park Hospital’s role in Mr. Moore’s care and met with his family in June to share the findings up to that point. We were particularly concerned about the failure to document Mr Moore’s referral to St George’s Hospital for treatment.

“While this does not appear to have made a material difference to the timing of Mr. Moore’s surgery, we fully accept that it caused him and his family considerable distress at a very difficult time and we have apologised unreservedly.

“The junior doctor who omitted to record the transfer request has written a reflection of their actions in order to learn from the experience and improve their practice. It will also form part of the doctor’s annual review of competence and of their training and assessment record. In addition all junior doctors have been reminded about the need for prompt referrals of this nature and the process for doing so has been reviewed to ensure it is robust.

“Our investigation into the details surrounding the case remains open and we will be sharing further findings and improvement actions with Mrs Donald.”

St George’s Hospital – John Moore

“We would like to repeat the heartfelt apology previously made to Mr Moore’s family. The trust fully acknowledges that some aspects of the care provided to Mr Moore caused him and his family considerable distress.

“The sad circumstances regarding his death are a tragic reminder that even the most experienced clinicians need to take great care with communication, especially when delivering bad news. The
A doctor involved has described this as “the most painful complaint he has dealt with over a 30 year career. He read the letter of complaint to his colleagues as part of his reflection on his performance and also to stimulate a meaningful discussion with them on the importance of careful and compassionate communication.”

**Tameside Hospital – Herbert & Irene Boswell**

“These patient concerns highlight that, on occasions in the past, the care we offered our patients did not meet the standards they rightly expected and for this we are truly sorry.

“We are now on a journey of improvement. We have a new leadership team and our focus is on large scale improvement projects which include all the recommendations made by the Keogh Review in its report. We are committed to making determined and decisive changes to deliver the highest quality, most compassionate and best care for our patients”.

**Freeman Hospital – Edith Jamieson**

Sir Leonard Fenwick, Chief Executive of Newcastle upon Tyne Hospitals NHS Foundation Trust has said: “As Chief Executive of the Newcastle Hospitals I personally receive and address all patient care and treatment related formal complaints as the Accountable Officer. Each and every grievance is scrutinised by my goodself and I can give an assurance that no stone is left unturned as we constantly strive to bring about on a consistent basis, optimal and compassionate care based on evidence based best practice and supportive good communication.

“In this particular instance and upon receipt of the letter of complaint in respect of Mrs Jameson, I telephoned Mrs Hambleton, (Mrs Jamieson’s daughter) left a message on her answering machine and when Mrs Hambleton came back to me, discussed the issues in question and how matters could be taken forward. I apologised unreservedly that the most reasonable of expectations were simply not met.

“At the very outset, I recognised and spoke of there being no excuse whatsoever that such a series of manifest failings were encountered. A most thorough review was undertaken and the Trust promptly agreed with Mrs Hambleton that time was of the essence in addressing the concerns face to face and with the respective healthcare professionals directly involved. This was facilitated in a timely manner.

“Whilst there are understandably aspects of various points of care actions that could not be fully reconciled, all in all, lessons were learnt. Also the lead Consultant Physician responsible for the admission advised directly in personal correspondence with Mrs Hambleton to clarify a misunderstanding that had arisen in relation to drugs that were prescribed and which she felt brought about hallucinations and to allay fears in that regard.”
About the Patients Association

The Patients Association is a healthcare charity which for 50 years had advocated for greater and equitable access to high quality, accurate and independent information for patients, for greater and equitable access to high quality care and for involvement in decision making as a right.

The charity provides an opportunity for patients to share their experiences of healthcare so that the Patients Association can use this knowledge to press for improved services and assist people in accessing best treatment. Through our Helpline and website we are “listening to patients, and speaking up for change”. Our Helpline acts as an informed and independent source of information for patients.

How can you help?

The Patients Association is a small charity that heavily relies on the support of members and donations and legacies from the public to carry out its vital work. We also receive support from corporate members. If you would like to become a supporter of the Patients Association for £20 a year, please visit the website below:

www.patients-association.com

Or contact us directly for an application form:

Patients Association
PO Box 935
Harrow
Middlesex
HA1 3YJ

Email: mailbox@patients-association.com

Tel: 0208 423 9111

Enquiries regarding corporate and organisational membership should be directed in the same manner.

You can become an E-member free of charge. You will receive our weekly health news round-up and have the chance to participate in our surveys. To become an E-member please visit our website:

www.patients-association.com

Patient Stories 2013: Time for Change
By Sarah Coles & Michael Watson
Published by the Patients Association
November 2013