

Care and compassion?

Report of the Health Service Ombudsman on
ten investigations into NHS care of older people



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ten investigations into NHS care of older people

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Foreword by Health Service Ombudsman, Ann Abraham



I am laying before Parliament, under section 14(4) of the *Health Service Commissioners Act 1993* (as amended), this report of ten investigations into complaints made to me as Health Service Ombudsman for England about the standard of care provided to older people by the NHS.

The complaints were made about NHS Trusts across England, and two GP practices. Although each investigation was conducted independently, I have collated this report because of the common experiences of the patients concerned and the stark contrast between the reality of the care they received and the principles and values of the NHS.

Sadly, of the ten people featured in this report, nine died during the events described here, or soon afterwards. In accordance with the legislation, my investigations were conducted in private and their identities have not been revealed.

I encourage Members of both Houses to read the stories of my investigations included in this report. I would ask that you then pause and reflect on my findings: that the reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital, is not being fulfilled. Instead, these accounts present a picture of NHS provision that is failing

to respond to the needs of older people with care and compassion and to provide even the most basic standards of care.

The report is also available to read and download on our website at www.ombudsman.org.uk.

A handwritten signature in black ink that reads "Ann Abraham". The signature is written in a cursive, flowing style.

Ann Abraham
Health Service Ombudsman for England



Introduction

This report tells the stories of ten people over the age of 65, from all walks of life and from across England. In their letters to my Office, their families and friends described them variously as loving partners, parents and grandparents. Many of them were people with energy and vitality, active in their retirement and well known and liked within their communities. Some were creative, while others took pride in their appearance and in keeping fit. One enjoyed literature and crosswords and another was writing a book.

One woman told us how her father kept busy, despite recurring health problems: *'My dad really enjoyed his work as a joiner. Even after he retired he still did that kind of work, usually for me and my siblings. We used to ask: "Dad can you do this, Dad can you do that?" and he always would'*. Another relative described her aunt to us: *'She was very adventurous and very widely travelled. She even took herself off, at the age of 81, to Disneyworld in Florida'*.

These were individuals who put up with difficult circumstances and didn't like to make a fuss. Like all of us, they wanted to be cared for properly and, at the end of their lives, to die peacefully and with dignity. What they have in common is their experience of suffering unnecessary pain, indignity and distress while in the care of the NHS. Poor care or badly managed medication contributed to their deteriorating health, as they were transformed from alert and able

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individuals to people who were dehydrated, malnourished or unable to communicate. As one relative told us: *'Our dad was not treated as a capable man in ill health, but as someone whom staff could not have cared less whether he lived or died'*.

These stories, the results of investigations concluded by my Office in 2009 and 2010, are not easy to read. They illuminate the gulf between the principles and values of the NHS Constitution and the felt reality of being an older person in the care of the NHS in England. The investigations reveal an attitude – both personal and institutional – which fails to recognise the humanity and individuality of the people concerned and to respond to them with sensitivity, compassion and professionalism. The reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital is not being fulfilled. Instead, these accounts present a picture of NHS provision that is failing to meet even the most basic standards of care.

These are not exceptional or isolated cases. Of nearly 9,000 properly made complaints to my Office about the NHS in the last year, 18 per cent were about the care of older people. We accepted 226 cases for investigation, more than twice as many as for all other age groups put together. In a further 51 cases we resolved complaints directly without the need for a full investigation. The issues highlighted in these stories – dignity, healthcare associated infection, nutrition, discharge from hospital and personal care – featured significantly more often in complaints about the care of older people.

These complaints come from a population of health service users that is ageing. There are now 1.7 million more people over the age of 65 than there were 25 years ago and the number of people aged 85 and over has doubled in the same period. By 2034, 23 per cent of the population is projected to be over 65. As life expectancy increases, so does the likelihood of more years spent in ill health, with women

having on average 11 years and men 6.7 years of poor health. Nearly 700,000 people in the UK suffer from dementia, and the Alzheimer's Society predicts that this figure will increase to 940,000 by 2021 and 1.7 million by 2051. The NHS will need to spend increasing amounts of time and resource caring for people with multiple and complex issues, disabilities and long-term conditions and offering palliative care to people at the end of their lives.

The nature of the failings identified by my investigations suggests that extra resource alone will not help the NHS to fulfil its own standards of care. There are very many skilled staff within the NHS who provide a compassionate and considerate service to their patients. Yet the cases I see confirm that this is not universal. Instead, the actions of individual staff described here add up to an ignominious failure to look beyond a patient's clinical condition and respond to the social and emotional needs of the individual and their family. The difficulties encountered by the service users and their relatives were not solely a result of illness, but arose from the dismissive attitude of staff, a disregard for process and procedure and an apparent indifference of NHS staff to deplorable standards of care.

Sadly, of the ten people featured, nine died during the events described here, or soon afterwards. The circumstances of their deaths have added to the distress of their families and friends, many of whom continue to live with anger and regret.

Such circumstances should never have arisen. There are many codes of conduct and clinical guidelines that detail the way the NHS and its staff should work. The essence of such standards is captured in the opening words of the NHS Constitution: *'The NHS touches our lives at times of basic human need, when care and compassion are what matter most'*. Adopted in England in 2009, the Constitution goes on to set out the expectations we are all entitled to have of the NHS. Its principles include a commitment to respect the human rights of

Introduction

those it serves; to provide high-quality care that is safe, effective and focused on patient experience, to reflect the needs and preferences of patients and their families and to involve and consult them about care and treatment. Users of NHS services should be treated with respect, dignity and compassion.

It is against these standards and my own *Ombudsman's Principles* that I have judged the experiences presented here. I also expect the NHS to take account of the principles of human rights – fairness, respect, equality, dignity and autonomy – that are reflected in the NHS Constitution. Some of the events recounted in this report took place before the NHS Constitution came into effect, but this does not excuse a dismissive response to pain, distress or anxiety or a failure to take account of patients' needs and choices.

When an NHS user complains to my Office, having failed to resolve their complaint locally, we first seek to establish what should have happened and then to investigate what did take place. We consider whether the shortcomings between what should have happened and what did happen amount to maladministration or service failure. In each of the accounts included here, a complaint was first made to the NHS body or trust concerned. Not only did those who complained to me experience the anguish of the situations described, but throughout the NHS complaints process their concerns were not satisfactorily addressed.

The first priority for anyone with illness is high-quality effective medical treatment, available quickly when needed. The outcome should be a return to health or as near as possible. If illness is terminal, the priority should be palliative care, with adequate relief of both pain and anxiety. This is not always easy or straightforward. Often, older people have multiple and complex needs that require an understanding of the interaction between a variety of different medical conditions to ensure that one is not addressed in ignorance

or at the neglect of others. A person's physical illness may be compounded by a difficulty with communication or by dementia. Inattention to the suffering of older people is characteristic of the stories in this report. Inadequate medication or pain relief that is administered late or not at all, leaves patients needlessly distressed and vulnerable.

Alongside medical treatment, effort should be put into establishing a relationship with the individual that ensures their needs will be heard and responded to. Where older people are not able to take part in decisions about their care and treatment, families or carers must be involved. Above all, care for older people should be shaped not just by their illness, but by the wider context of their lives and relationships. Instead, our investigations reveal a bewildering disregard of the needs and wishes of patients and their families. One family, whose story is recounted here, suffered very great distress when the gravity of their loved one's condition was not communicated to them properly or appropriately, and his life support was later turned off against their express wishes.

The theme of poor communication and thoughtless action extends to discharge arrangements, which can be shambolic and ill-prepared, with older people being moved without their family's knowledge or consent. Clothing and other possessions are often mislaid along the way. One 82-year-old woman recalled how, on being discharged from hospital after minor surgery, she was frightened and unsure of how to get home. She asked the nurse to phone her daughter. *'He told me this was not his job'*, she said.

It is incomprehensible that the Ombudsman needs to hold the NHS to account for the most fundamental aspects of care: clean and comfortable surroundings, assistance with eating if needed, drinking water available and the ability to call someone who will respond. Yet as the accounts in this report show, these most basic of human needs

Introduction

are too often neglected, particularly when the individual concerned is confused, or finds it difficult to communicate.

Half the people featured in this report did not consume adequate food or water during their time in hospital. I continue to receive complaints in which, almost incidentally, I hear of food removed uneaten and drinks or call bells placed out of reach. Arrangements such as protected meal times, intended to ensure a focus on nutrition and that nurses have time to support those who need assistance with eating, have been distorted. Carers or members of the family who might wish to help the patient eat and drink are not permitted to do so, and help with eating is not forthcoming from nursing staff.

Older people are left in soiled or dirty clothes and are not washed or bathed. One woman told us that her aunt was taken on a long journey to a care home by ambulance. She arrived strapped to a stretcher and soaked with urine, dressed in unfamiliar clothing held up by paper clips, accompanied by bags of dirty laundry, much of which was not her own. Underlying such acts of carelessness and neglect is a casual indifference to the dignity and welfare of older patients. That this should happen anywhere must cause concern; that it should take place in a setting intended to deliver care is indefensible.

As Health Service Ombudsman, I have sought to remedy the injustice experienced by the people whose complaints are set out in this report. There is no adequate redress for the distress or anguish at the death of a loved one, but my recommendations to trusts often require them to apologise and prepare action plans addressing the failings that have been identified. My intervention can also lead to financial remedy where appropriate. But financial resource alone will not ensure such circumstances are not repeated. An impetus towards real and urgent change, including listening to older people, taking account of feedback from families and learning from mistakes is needed.

I have yet to see convincing evidence of a widespread shift in attitude towards older people across the NHS that will turn the commitments in the NHS Constitution into tangible reality.

I am grateful to all the people who have given permission for their stories, and those of their loved ones, to be told here. These often harrowing accounts should cause every member of NHS staff who reads this report to pause and ask themselves if any of their patients could suffer in the same way. I know from my caseload that in many cases the answer must be 'yes'. The NHS must close the gap between the promise of care and compassion outlined in its Constitution and the injustice that many older people experience. Every member of staff, no matter what their job, has a role to play in making the commitments of the Constitution a felt reality for patients. For the sake of all the people featured here, and for all of us who need NHS care now and may do so in the future, I hope that this will be their legacy.

‘My aunt’s basic human rights as a person, never mind her special needs and rights as a person with several disabilities, were totally disregarded and neglected. I am certain that she was in great distress and felt totally alone and abandoned. It makes me feel so angry.’

Mrs H’s niece
(page 33)



Mr and Mrs J's story

**'Care and compassion
are what matter most'**

NHS Constitution

**'A shabby, sad end to my
poor wife's life'**

The story

Mrs J was 82 years old. She had Alzheimer's disease and lived in a nursing home. Her husband visited her daily and they enjoyed each other's company. Mr J told us *'She had been like that for nine years. And I was happy being with her'*. One evening, Mr J arrived at the home and found that his wife had breathing difficulties. An ambulance was called and Mrs J was taken to Ealing Hospital NHS Trust at about 10.30pm, accompanied by her husband. She was admitted to A&E and assessed on arrival by a Senior House Officer who asked Mr J to wait in a waiting room.

Mrs J was very ill. She was taken to the resuscitation area, but was moved later when two patients arrived who required emergency treatment. Mrs J was then seen by a Specialist Registrar as she was vomiting and had become unresponsive. It was decided not to resuscitate her. She died shortly after 1.00am. At around 1.40am the

Mr and Mrs J's story

nursing staff telephoned the nursing home and were told that Mr J had accompanied his wife to hospital. The Senior House Officer found him in the waiting room and informed him that his wife had died.

In the three hours or so that Mr J had been in the waiting room, nobody spoke to him or told him what was happening to his wife. As a result he came to believe that her care had been inadequate. He thought that he had been deliberately separated from her because hospital staff had decided to stop treating her. *'They let her slip away under the cloak of "quality of life" without stopping to think of any other involved party.'* He felt the hospital had denied them the chance to be together in the last moments of Mrs J's life and he did not know what had happened to her.

Mr J complained to the Trust. Their response was timely, and he met with staff in an attempt to address his concerns. The Trust apologised that staff had forgotten that Mrs J had been accompanied to hospital by her husband, describing that as *'a serious breakdown in communication'*, but then took no appropriate steps to tackle this failing.

What our investigation found

We investigated the circumstances surrounding Mrs J's death and the Trust's response to Mr J's complaint. Our investigation found that Mrs J was not monitored properly after she arrived at the hospital. No observation chart was started, no further assessments were documented after the first assessment and she waited for a medical review which did not take place. No attempt was made to contact the nursing home or a family member until after she had died. The Trust's care fell below the level set out in national guidance.

We sought expert advice on the decision not to resuscitate Mrs J. Our Clinical Adviser's opinion was that attempts to resuscitate a patient

as ill as she was would have been *'futile and undignified'*. The hospital failed, however, to involve Mr J in the decision-making process and nobody told Mr J what was happening to his wife until she had died. It was crucial that Mr J was involved in the decision-making and the move to compassionate and supportive care in his wife's last moments. Mrs J was denied the right to a dignified death with her husband by her side. In Mr J's own words, *'They decided that enough was enough without bothering to include me in'*.

Aspects of Mrs J's care and treatment and the Trust's failure to involve Mr J in decisions about them, fell below the level set out in national guidance and established best practice. The impact of these failings on Mr and Mrs J was that Mrs J did not receive the appropriate level of care and did not have her husband with her when she died. Mr J was understandably distressed that he was not told what was happening; not involved in his wife's care; and was unable to be with her at the end of her life. In addition to this, the Trust's failure to address the issues in Mr J's complaint unnecessarily prolonged the complaints process. *'It was a shabby, sad end to my poor wife's life.'*

We upheld Mr J's complaint about the Trust.

What happened next

The Trust apologised to Mr J for their failings and paid him £2,000 in recognition of the distress he had suffered. The Trust's Chief Executive met with Mr J and explained the procedural changes they had made, which included asking patients attending A&E if they are accompanied, recording the response and ensuring that staff keep the accompanying person informed about what is happening to the patient.

At the conclusion of the investigation, Mr J thanked the Ombudsman's staff for *'pursuing his case so faithfully and with such dedication'*.

‘I wanted the Ombudsman to ensure that the treatment my grandmother received would never, ever happen again to any other vulnerable and dependent elderly person.’

Mrs G’s granddaughter
(page 47)



Mr D's story

'We respond with humanity and kindness to each person's pain'

NHS Constitution

'His tongue was like a piece of dried leather'

The story

Mr D was first admitted to the Royal Bolton Hospital NHS Foundation Trust with a suspected heart attack and discharged a week later with further tests planned on an outpatient basis. Four weeks later, Mr D was readmitted with severe back and stomach pain. He was described by clinicians and nurses at the hospital as a quiet man, well-liked, who never complained or made a fuss. He did not like to bother the nursing staff.

Mr D was diagnosed with advanced stomach cancer. His discharge, originally planned for Tuesday 30 August, was brought forward to 27 August, the Saturday of a bank holiday weekend. On the day of discharge, which his daughter described as a '*shambles*', the family arrived to find Mr D in a distressed condition behind drawn curtains in a chair. He had been waiting for several hours to go home. He was in pain, desperate to go to the toilet and unable to ask for help because

Mr D's story

he was so dehydrated he could not speak properly or swallow. His daughter told us that *'his tongue was like a piece of dried leather'*. The emergency button had been placed beyond his reach. His drip had been removed and the bag of fluid had fallen and had leaked all over the floor making his feet wet. When the family asked for help to put Mr D on the commode he had *'squealed like a piglet'* with pain. An ambulance booked to take him home in the morning had not arrived and at 2.30pm the family decided to take him home in their car. This was achieved with great difficulty and discomfort for Mr D.

On arriving home, his family found that Mr D had not been given enough painkillers for the bank holiday weekend. He had been given two bottles of Oramorph (morphine in an oral solution), insufficient for three days, and not suitable as by this time he was unable to swallow. Consequently, the family spent much of the weekend driving round trying to get prescription forms signed, and permission for District Nurses to administer morphine in injectable form. Mr D died, three days after he was discharged, on the following Tuesday. His daughter described her extreme distress and the stress of trying to get his medication, fearing that he might die before she returned home. She also lost time she had hoped to spend with him over those last few days.

Mr D's daughter complained to the Trust and the Healthcare Commission about very poor care while in hospital. When she still felt her concerns had not been understood she came to the Ombudsman. She described to us several incidents that had occurred during her father's admissions. She said:

- he was not helped to use a commode and fainted, soiling himself in the process
- he was not properly cleaned and his clothes were not changed until she requested this the following day

- the ward was dirty, including a squashed insect on the wall throughout his stay and nail clippings under the bed
- he was left without access to drinking water or a clean glass
- his pain was not controlled and medication was delayed by up to one and a half hours
- pressure sores were allowed to develop
- no check was made on his nutrition
- his medical condition was not properly explained to his family
- he was told of his diagnosis of terminal cancer on an open ward, overheard by other patients.

What our investigation found

We found that Mr D's care and treatment fell below reasonable standards in a number of ways. Those failings in care and treatment, and also in discharge planning and complaint handling, caused distress and suffering for Mr D and his family.

We found no service failure in the time taken to diagnose Mr D's cancer, nor in the way the Trust communicated the diagnosis to his family. However, there were a number of service failures during both of his admissions. There was no care plan for his melaena (blood in his stools), and no risk assessments relating to pressure ulcers or falls were carried out. Mr D's nutritional status was not properly assessed, while a lack of records meant that it was impossible to assess his fluid or food intake.

Mr D's story

Even as Mr D's condition deteriorated and his needs increased, no further detailed nursing assessments were undertaken, nor was an appropriate care plan drawn up. Pain relief for Mr D was not always effective, yet no formal pain assessments were completed. In his daughter's own words, she was *'disgusted that a dying man was left in a chair for almost a month, with no-one ever trying to make him comfortable in bed, no-one relieving his pain adequately, checking for pressure sores or ensuring he ate or drank'*.

Considerable guidance existed at the time of Mr D's discharge relating to discharge and care for terminally ill patients, and in some respects the Trust's discharge planning was good. For example, they contacted Macmillan and District Nurses and social services. But other aspects of the discharge planning were not good. In particular, the change of Mr D's discharge date should have prompted a complete review of his condition, needs and discharge arrangements. That did not happen; the palliative care team were unaware of Mr D's changing medication needs, and the medication prescribed on discharge did not meet his needs. His daughter graphically described to us the family's experiences on the day of discharge and the frantic efforts they made to obtain pain relief for Mr D. The uncertainty about whether he would still be alive on their return from their trips, or how much pain they would find him in, must have been harrowing.

The Trust's response to Mr D's daughter's first complaint contained inaccuracies, and a later response did not address all of the new concerns she had raised. The Trust apologised to her for the shortcomings in Mr D's care, but did not give her evidence that they had fully implemented improvements recommended by the Healthcare Commission.

We upheld this complaint.

What happened next

The Trust apologised to Mr D's daughter and paid her compensation of £2,000. They also told us what they would do to prevent a repeat of their failings. Their plans included a review of all nursing documentation; the introduction of a five-day pain management course available to all Trust staff; and the introduction of an 'holistic assessment tool' to be used by the palliative care team to make sure that a person's care needs are met and their discharge is properly planned.

‘From the moment cancer was diagnosed my dad was completely ignored. It was as if he didn’t exist – he was an old man and was dying.’

Mr D’s daughter
(page 19)



Mrs R's story

'We do not wait to be asked because we care'

NHS Constitution

'There was a lack of concern and sympathy towards patients ... and the family'

The story

Mrs R lived with her husband in a warden-assisted flat. She had limited mobility and was very dependent on him for support to walk. In March 2007 Mrs R was admitted to Southampton University Hospitals NHS Trust with worsening mobility, recurrent falling and confusion. She was diagnosed with dementia the following month. Her health deteriorated and she was given palliative care. She died in July 2007.

Her daughter complained to the Trust and then to the Ombudsman about various failings in nursing care during her mother's time in hospital before she died. She said that staff had not offered Mrs R a bath or shower during her 13-week admission. She told us that when she and her sister had tried to bath Mrs R themselves, they were left in a bathroom on another ward, without support from staff or instructions on how to use the hoist. They felt unable to risk using

Mrs R's story

the equipment and so Mrs R went without her bath. Her hair was unwashed and her scalp became so itchy that, at the family's request, nurses checked her hair for lice.

Mrs R's daughter complained that staff had to be asked on four consecutive days to dress an open wound on Mrs R's leg, which she said was '*weeping and sticky*'. She said that when she raised concerns about this with staff on the ward she was told there was no complaints department. Mrs R's daughter said that her mother was not helped to eat, even though she was unable to do it herself. She said this had once happened when several nurses were '*chatting*' at the nurses' station. Nurses left food trays and hot drinks out of reach of patients and Mrs R's family felt she would not receive food or drink unless they gave it to her. Her daughter felt the fact that staff did not give her mother food or drinks was effectively '*euthanasia*'.

Mrs R's daughter also said Mrs R had suffered four falls in hospital, including two in 24 hours (she was unaware that her mother had actually suffered nine falls), and that the family's requests for cot sides to be used had been declined on the grounds that their use might compromise her mother's rights. One fall led to Mrs R sustaining a large facial haematoma with bruising, which greatly distressed her family when they viewed her body before the funeral. Mrs R's daughter described her father as a robust man but he was in tears seeing the bruises. He died shortly afterwards and she felt he had '*died of a broken heart*'.

Overall, Mrs R's daughter was left feeling that '*there was a lack of concern and sympathy towards patients/deceased and [the] family*'.

What our investigation found

We found that Mrs R had nine falls while in hospital, yet only one fall was noted in the nursing records; the *Identification of Risks of Falls*

and Intervention Tool was completed just twice; and both entries were reviewed only once. There was no evidence that Mrs R's risk of falling was kept under review, no detailed care plans, or any incident forms following her falls. No advice or support was sought from a specialist falls practitioner.

We found that no consideration was given to offering Mrs R help to bath or shower, although she was washed in bed. There was no further assessment of her nutritional needs, and no evidence in the nursing records that she was offered frequent fluids to prevent dehydration or encouraged to drink. Nurses failed to co-operate with medical recommendations and requests to provide hip protectors for Mrs R, to place a mattress next to her bed and to encourage her to drink. Dressings were applied to Mrs R's leg wound but we could not judge from the nursing records if the wound was appropriately treated.

In response to her daughter's complaint, the Trust apologised for the lack of bathing facilities and acknowledged the need to support families wishing to use facilities on other wards. The Trust said they had introduced protected meal times (times when patients can eat without interruption) and a system to identify patients who may need help. Volunteers were being recruited to help with this. The Trust apologised that Mrs R's family were told that cot sides could not be used as they would compromise her rights, when it would have been better to say it was her safety that might be compromised. The Trust also acknowledged Mrs R's daughter's concern about repeatedly having to ask for the leg wound to be dressed.

However, the Trust did not identify failings in meeting Mrs R's nutritional needs and in relation to her falls, and they did not discuss the issue of cot sides at their falls group, as they had told Mrs R's daughter they would. Her complaint about the leg dressing was not addressed.

Mrs R's story

We found that the nursing care provided for Mrs R by the Trust fell significantly below the relevant standards, causing her and her family considerable and unnecessary distress. The Trust's handling of the subsequent complaint left her without full explanations or assurances that they had learnt lessons. She was understandably dissatisfied with the Trust's responses and she had to come to the Ombudsman for further answers.

We upheld this complaint.

What happened next

The Trust apologised to Mrs R's daughter and put together an action plan to address their failings in nursing care and complaint handling. Their plans include ensuring that patients and their carers are offered a choice in how their personal hygiene needs are met; changing the way patient meals are delivered so that staff are able to help with eating; centralised complaint handling so that all complaints are dealt with consistently and best practice is shared; and removing the distinction between complaints made informally, formally, orally or in writing.



Mrs Y's story

'Providing a comprehensive service'

NHS Constitution

'I am concerned that an otherwise healthy elderly lady was allowed to deteriorate so quickly'

The story

Mrs Y lived on her own. Her relative described her as always being in good health, and having *'excellent energy and vitality for her age'*. In May 2008 Mrs Y had a fall at home which she did not report at the time; her relative said she was of a generation who *'tended to put up with things'*. A week later Mrs Y's family persuaded her to attend the A&E department at Epsom and St Helier University Hospitals NHS Trust, as she was obviously in some discomfort. Mrs Y was diagnosed with a fracture of part of her pelvis. She was kept in overnight, and discharged the next day with painkilling medication that included ibuprofen.

No follow-up care was arranged for Mrs Y and it was only five days later on 2 June that the hospital faxed a discharge summary to Mrs Y's GP. The summary did not contain details of the medication which had been prescribed.

Mrs Y's story

Mrs Y began to feel sick after returning home and she developed severe constipation. Her relative said she was not her usual lively self and was 'unusually low'. She was eating little and losing weight. Eventually, Mrs Y's neighbour telephoned the GP on 10 June to ask her to carry out a home visit. The GP telephoned Mrs Y but did not visit. She recorded that Mrs Y was constipated and had a poor appetite and advised her to phone again the next day if she remained concerned.

The following day another neighbour drove to the surgery to say that Mrs Y seemed confused. The GP telephoned Mrs Y again, offering to visit that afternoon. Mrs Y said that would not be convenient: a visit was arranged for two days later, which was the day after her 88th birthday. During the visit the GP assessed her mental condition and prescribed paracetamol. She told Mrs Y that arrangements would be made for a carer to visit.

Sadly, Mrs Y was found dead on the upstairs landing of her home the next day, by a neighbour who had become very concerned that she was not answering her telephone. A post-mortem established that Mrs Y had died from peritonitis and a perforated stomach ulcer.

Her relative and his wife complained to the Trust that the hospital had not arranged follow-up care for Mrs Y after her discharge, and did not inform the GP promptly about her attendance at the A&E department. They also complained that the GP did not see Mrs Y until three days after a home visit had been requested and that the GP's assessment of Mrs Y had not been sufficiently thorough.

As her relative put it, *'I am concerned that an otherwise healthy elderly lady was allowed to deteriorate so quickly following her self-admission, in circumstances known to be potentially serious'*.

What our investigation found

Although Mrs Y's hospital discharge was appropriate, planning for the discharge should have started earlier. There should have been an earlier referral to the GP and Mrs Y should also have been referred to a specialist falls service. The discharge summary gave no details of the medication prescribed for Mrs Y. This was significant, because it is quite likely that her ulcer developed as a result of taking ibuprofen.

The likelihood is that Mrs Y was showing significant symptoms related to her ulcer when the GP examined her, and we concluded that the GP's assessment of her was not thorough enough. We could not say that Mrs Y's death definitely resulted from the failure to identify the symptoms from the ulcer, but the opportunity to treat it was missed.

We concluded that the GP had not met the General Medical Council standard that good clinical care must include adequately assessing a patient's condition taking account of their history. While a telephone assessment might initially have been appropriate, the GP should have arranged to visit when she received a message of further concern from the neighbour the following day.

We upheld the complaints about both the Trust and the GP Surgery.

What happened next

The Trust and the GP Surgery both apologised to Mrs Y's relatives and drew up plans to prevent recurrences of their failings. Among the actions taken or planned were new procedures for ensuring that discharge summaries were completed promptly; a matron-led review of the nurse's role in the A&E observation bay; and regular teaching sessions for A&E doctors about prescribing and monitoring medication. The Trust also said that they would share the lessons

Mrs Y's story

learnt from the complaint to reduce the risk of others suffering the same experience.

For their part, the GP Surgery drew up a protocol for the care of elderly people living alone, who have problems after their discharge from hospital.



Mrs H's story

**'High-quality care
focused on patient
experience'**

NHS Constitution

**'Little attempt was
made to ascertain that
she ... fully understood
her situation'**

The story

Mrs H was a feisty and independent woman of high intelligence who loved literature and crosswords. She was a dignified woman whose clothes were important to her. She lived in her own home until the age of 88, needing relatively little support. Mrs H was deaf and partially sighted and communicated through British Sign Language and deaf-blind manual although she could still read large print. She was an active member of her local deaf community and one of the founder members of the local Institute for the Deaf. Her only relative, her niece, lived in New Zealand but maintained close contact and held power of attorney for her.

Following a fall at home, Mrs H moved to an intermediate care centre for treatment. From there she was admitted to the Elderly Care Assessment Unit of Birmingham Heartlands Hospital (part of Heart of England NHS Foundation Trust) with acute confusion. She remained

Mrs H's story

there for about four months. Social workers identified a care home for residents with dementia, which Mrs H's niece declined because it had no facilities for residents with sensory impairment. This led to a longer stay in hospital. Her niece eventually found a place at a care home in Tyneside and arranged for Mrs H to move there. While Mrs H was in hospital:

- she had a number of falls, one of which broke her collar bone, but her niece was not informed. Several injuries and falls were not included on her discharge summary
- poor nursing records were kept and no personalised plans for her non-medical needs were developed
- although at low risk of malnutrition at admission, Mrs H lost about 11 lbs during her first three months in hospital
- communication with Mrs H was difficult and her specific needs were not met. No activities or stimulation were provided for her
- her valuables and clothing were brought to the ward but there was no record of their receipt
- communications around the discharge arrangements were poor with no handover to the home
- despite her niece's requests, no arrangements were made with social services for Mrs H's clothes to be laundered.

During a lengthy journey to the home, Mrs H was strapped onto a stretcher in the back of an ambulance for her safety. (The Trust told us that this was because the potential consequences of her becoming more distressed and confused on the journey could have been very serious.) Mrs H was accompanied by a male nurse who had nursed

her on the ward. She was agitated and distressed but was not given any medication despite it being available. (The Trust told us that this was because it could have increased her confusion.) When Mrs H arrived at the care home, the Manager noted that she had numerous injuries, was soaked with urine and was dressed in clothing that did not belong to her which was held up with large paper clips. She had with her several bags of dirty clothing, much of which did not belong to her, and few possessions of her own. Mrs H was bruised, dishevelled and confused. She was highly distressed and agitated and the following day was admitted to a local hospital due to concerns about her mental state and her physical condition.

Sadly, Mrs H died in August 2010 shortly before the conclusion of our investigation.

Mrs H's niece complained that Mrs H's right to dignity was not respected and that she had been treated with contempt and disdain. She complained that Mrs H's property and clothing had not been taken care of whilst in hospital, and that no arrangements had been made to launder her clothes. She said that her aunt suffered distress and indignity, her mental health had suffered premature deterioration and she needed to be admitted to another hospital on her arrival at Tyneside. She also complained that some of Mrs H's property and clothing had been lost.

Mrs H's niece complained that Mrs H sustained unexplained injuries in hospital and that she was not informed of these. She believed the discharge and transfer arrangements for Mrs H were wholly inadequate and inappropriate.

What our investigation found

We found evidence that the care given to Mrs H fell significantly below the applicable standard in relation to meeting her cultural

Mrs H's story

and linguistic needs, maintaining her comfort and wellbeing and safeguarding her property and clothing. We also found serious shortcomings in the Trust's communication with her niece. Underpinning these serious shortcomings were failures to carry out appropriate assessments and to develop personalised care plans, failures to understand Mrs H's relationship with her niece and failure to follow local and national policy and guidance. Taken together, this amounted to service failure.

As a result of this we found that Mrs H suffered additional unnecessary distress which could have been minimised by care tailored to her needs, which allowed her to exercise choice and control and have her preferences met. The failure to personalise her care meant that her dignity and individuality were compromised. She suffered financial loss through the Trust's failure to safeguard her property.

Mrs H's niece also suffered unnecessary distress as a result of the Trust's failure to keep her informed about Mrs H's falls and condition.

We upheld these complaints.

What happened next

The Trust apologised to Mrs H's niece for the distress and indignity that Mrs H had suffered and for losing her property. The Trust also paid her niece compensation totalling £1,500 and reimbursed her £300 for the loss of her aunt's belongings.

The Trust also drew up plans to prevent the same failings from happening again. The actions taken or planned include the development of study days to determine staff's attitude, knowledge and beliefs surrounding dementia; the introduction of a password-protected system to enable staff to give confidential

information to family members over the telephone; reminders to staff about how to access interpreting services for patients with impaired hearing; and the appointment of an Admission and Discharge Co-ordinator.

‘The nurses completed all the discharge forms and told me I would be leaving. I was quite frightened. I was recovering from minor surgery. I am 82 years old and did not know how I was to get home. I asked the nurse if he could phone my daughter. He told me this was not his job.’

Mrs N
(page 55)



Mr C's story

'We find time for those we serve and work alongside'

NHS Constitution

'Staff decided that we had been given as much time as we were allowed'

The story

Mr C was described by his daughter, Miss C, as mentally active and creative – he was in the process of writing a book.

He became unwell and underwent heart surgery (a quadruple coronary artery bypass) at Oxford Radcliffe Hospitals NHS Trust, an operation which started at midday and was expected to last for three hours. Mr C's wife and daughter remained alone in the waiting room for five hours. They told us that during that time they tried unsuccessfully and with increasing desperation to find someone to give them some information. They eventually found the Consultant, who indicated that the surgery had gone well.

Sadly, about two hours after the operation, Mr C's condition deteriorated and he suffered a heart attack.

Mr C's story

Mr C underwent open heart massage, while his wife and daughter waited nearby for news, occasionally '*wander[ing] the corridors looking for someone to tell us what was happening*'. A Registrar spoke to Miss C, but his English was '*very poor and broken*'. The exchange left Mr C's wife and daughter unclear as to whether Mr C had died – '*my question asking if he was alive kept getting sidestepped yet the question – is he dead – also got a no. The confusion was terribly distressing*'. They asked to see Mr C and did so at around 9.30pm. At 9.15pm, unknown to Mr C's family, a 'Do not attempt resuscitation' note was made in his medical records.

A nurse told Miss C that her father was only being kept alive by the ventilator and that he had '*flatlined*' (meaning that there was no heart beat). His wife, who was totally distraught, wanted to telephone her sons.

Miss C told the nurse that they were going to make a phone call and stated expressly that the life support was not be switched off as she was coming back to sit with her father. She was still hopeful of a recovery. Miss C later told us that, had she known her father was going to have his life support switched off, she would have wanted to help him '*go peacefully after being battered by so many medical procedures and surrounded by strangers*'. However, she and her mother returned to find that Mr C's ventilator had already been switched off. Miss C felt that '*the staff decided that we had been given as much time as we were allowed*'. Mr C was pronounced dead at 10.25pm.

Mr C's daughter complained first to the Trust, and then to the Ombudsman that she had been left with no clear understanding of her father's condition during his final hours, and why his life support had been turned off against her express wishes. As she observed in one letter to the Trust '*This is just one of many such events in the working life of your staff but it has lifelong repercussions for us*'.

What our investigation found

We found that the Trust's communications with Mr C's family were below standard. There were several examples of this.

Staff did not explain to Mr C's family that his condition had worsened, nor tell them about the 'Do not attempt resuscitation' decision. This was counter to the Trust's own policy which says that discussion with families should aim to secure an understanding of why the decision was reached. Although a nurse spoke to Mr C's family after he had stopped responding to treatment, there was little information about what they were told. The use of the term '*flatlined*' in a conversation with his daughter was inappropriate and insensitive and did not communicate the clinical significance of Mr C's heart having stopped.

The Trust have no formal policy that indicates when it is appropriate for nurses to turn off a patient's life support, but in practice the Trust allow senior nurses to do this, if the patient's family is present and in agreement. If the family disagrees, nurses must seek a medical opinion. Here, by turning off Mr C's life support against his family's wishes, staff acted contrary to the Trust's practice. Staff could reasonably have accommodated the family's wishes and delayed switching off Mr C's ventilator for a few minutes, even if he had already died and life support was no longer serving any purpose. As his daughter said later '*We would have liked the opportunity to have the peace of mind of sitting with my father and of praying for him. I have the feeling that I failed my father*'.

The records do not show if Mr C had died before or after his life support was turned off, and so we could not say for certain whether that action denied Miss C the opportunity to be with her father when he died. Nevertheless, the Trust's actions caused her unnecessary distress. Indeed, his daughter has told us she is '*very aware of how deeply this handling of my father's death has affected me*'.

Mr C's story

We upheld Miss C's complaint.

What happened next

The Trust apologised to Mr C's daughter for the distress they had caused her and paid her compensation of £1,000. They also began to review some of their policies and arranged further training for staff in end of life care. The Trust also drew up plans to share the lessons they had learnt from Miss C's complaint, and acknowledged the need to promote effective communication.



Mr W's story

'Everyone counts'

NHS Constitution

'Probably as good as he is going to get'

The story

Mr W was 79 years old. He suffered from dementia and depression, was frail and had not long been widowed. He was admitted to St Peter's Hospital (part of Ashford and St Peter's Hospitals NHS Foundation Trust) with recurrent dehydration and pneumonia.

The hospital treated Mr W with intravenous fluids and antibiotics, which were stopped when his chest infection cleared up. A week later, his daughter, herself a former nurse, told a doctor caring for Mr W of her concerns that his general condition had deteriorated during his admission and that he would be better off receiving intravenous fluids. The doctor said he could not do this as it would '*prevent his leaving hospital*' and that '*he can meet his needs orally*'. Mr W's daughter disagreed as he frequently refused to eat and drink more than very small amounts. The doctor said that Mr W was medically fit for discharge, but that he was frail and prone to further infection and

Mr W's story

any further treatment should be palliative. He told Mr W's daughter that Mr W was *'probably as good as he is going to get'*.

Over the next few days Mr W continued to eat and drink very little, refused most meals and drank only about one cup of fluids each day. Feeding him through a percutaneous endoscopic gastrostomy (PEG) tube was considered but ruled out because of the high risk of death associated with PEG feeding of patients with advanced dementia.

Despite his daughter's concerns about Mr W's condition, the hospital discharged him to a care home on Christmas Eve. He weighed just 6 st 7 lbs. They did not communicate with his family who therefore *'could do nothing to stop it'*. Mr W's daughter said *'Our Dad had this big move on his own even though I had made it clear to the ward that I wanted to be with him when he moved ... upset[ting] us all greatly'*.

Three days later, at 2.00am, Mr W was admitted to a different hospital with breathing difficulties. He was severely dehydrated and had pneumonia. That hospital treated Mr W's pneumonia and fed him through a PEG tube. His daughter told us that once the tube had been inserted and Mr W received adequate nutrition and fluid, he had been *'transformed'*. She told us that following this treatment not only was Mr W still alive, but he had not needed to be hospitalised since, enjoyed life, and participated in the activities in the care home, including playing dominos.

After complaining first to the Trust and then to the Healthcare Commission, Mr W's daughter came to the Ombudsman. She felt the Trust had put Mr W's life in danger by discharging him when he was not medically fit. In one letter she wrote *'As yet we haven't even been able to mourn our mother as we have and are continuing to fight for any kind of quality care for our Dad'*.

What our investigation found

In Mr W's case, the Trust did not follow their own discharge policy or national guidance which state that patients should be fit for discharge. The Trust's policy also notes that a patient's fitness for discharge does not necessarily indicate that it is safe to go ahead. Indeed, taking account of Mr W's very low weight, his inadequate nutrition and hydration and the development of suspected C.diff (a serious hospital-acquired infection), we concluded it had not been safe to discharge him.

Mr W's nutritional and fluid intake needs were not being met, and this continued until his discharge. His medical fitness for discharge was not reviewed or addressed and no plan was made to increase his nutrition and fluid intake, other than by simple encouragement. This was wholly inadequate, yet the doctor saw no need for further consideration or intervention. His daughter's repeatedly expressed concerns about her father's deterioration were not taken seriously or acted upon. This lack of respect for her views caused her considerable unnecessary distress.

We uncovered very troubling possible explanations for the failure to review Mr W's fitness for discharge. The doctor caring for him was no longer actively treating him; the implication being that he would develop another chest infection from which he would die. The tone of emails exchanged between a social worker and Trust staff suggested they regarded Mr W's daughter's concerns as a nuisance, and as potentially preventing a bed being freed over Christmas. This appeared to be their priority.

The lack of treatment given to Mr W put his life at risk. His discharge and subsequent treatment at a different hospital saved his life. His daughter had pushed to have Mr W admitted to St Peter's Hospital because she was anxious about his condition and thought he would be safe there. The opposite was true.

Mr W's story

We upheld this complaint.

What happened next

In line with the Ombudsman's recommendations, the Trust apologised to Mr W's daughter and paid her £1,000 compensation for the distress they had caused her. They also drew up plans to stop the same mistakes from happening again. The actions the Trust planned included a review of their discharge policy; more junior doctors working at weekends; advanced communication skills training for doctors; and the introduction of a Pledge, setting out the behaviours expected of all clinical and non-clinical staff.



Mrs G's story

'Aspiring to the highest standards of excellence'

NHS Constitution

'I just feel let down by the system'

The story

Mrs G, who was 84 years old, had played an important part in her granddaughter's life. She had looked after her as a small child and had lived with her for almost her entire life. Her granddaughter described her grandmother as *'an amazing lady'* who was *'perfectly healthy'* before she suffered a fall and underwent hip surgery.

Following surgery, Mrs G was discharged to a nursing home with a prescription which included diclofenac (a non-steroidal anti-inflammatory drug – NSAID), and given a two-week supply of the discharge medications. Mrs G was described by her granddaughter as being at this time *'very mobile ... and had most of her faculties with her'*. She said Mrs G was looking forward to moving out of the home to live with her.

Mrs G's story

In the meantime, following receipt of the hospital's discharge summary, administrative staff at Mrs G's local GP Practice added the medications, including diclofenac, to her list of repeat medications. The Practice continuously prescribed diclofenac to Mrs G for the next eleven months, without review and without an accompanying proton-pump inhibitor (which may help protect against NSAID-associated duodenal ulcers). Mrs G went to live with her granddaughter as arranged. Her granddaughter soon noticed that Mrs G was having difficulty with food and that her health was deteriorating. Things came to a head on Christmas Day, when Mrs G was '*violently sick, was as white as a ghost, could not move and was in pain*'. She was taken to hospital and underwent emergency surgery for a perforated duodenal ulcer. Sadly, she died two months later from septicaemia, acute renal failure and urinary tract infection.

Mrs G's death caused her granddaughter '*immense grief due to the fact that I only recently lost my mother*'.

Realising that Mrs G had taken diclofenac continuously for eleven months, her granddaughter complained to the Practice about what had happened. The Practice accepted their failure to check and review Mrs G's medication, and they also conducted a significant event review. The learning from that review was that doctors (not administrative staff) should add medication to repeat medication lists so that they can consider appropriate co-prescribing, and that they should prescribe NSAIDs in accordance with the Practice's protocols. (The Practice's first audit found 20 other patients taking NSAIDs without a proton-pump inhibitor, but a subsequent audit revealed that this had been rectified.)

A 22-year-old student doing her final year exams, still getting over the loss of her mother and grandmother, Mrs G's granddaughter then brought her complaint to the Ombudsman. She said that although the Practice had admitted errors, they had not said why they had

occurred. She wanted to know why it had taken her grandmother's death to highlight the mistakes, and whether her death had been preventable. She said '*I just feel let down by the system and that my Nan died to save others*'.

What our investigation found

The errors in Mrs G's case occurred partly because the Practice's administrative staff were inappropriately involved in the processing of her medication. However, the major cause was the failure by doctors at the Practice to follow their protocols, or the professional standards relating to prescribing and reviewing medication. They issued repeat prescriptions for the entire eleven months that Mrs G received diclofenac. As a result, no consideration was given to whether Mrs G still needed diclofenac, or whether a proton-pump inhibitor should be prescribed.

The advice at that time from the *British National Formulary* (the standard reference book for prescribers describing drugs, dosage and contraindication) was that NSAIDs should be used with caution in elderly patients and that a proton-pump inhibitor may be considered for protection against NSAID-associated gastric and duodenal ulcers.

Mrs G's granddaughter specifically asked whether her grandmother's death had been avoidable. We could not say that the ulcer and the chain of events which led to her death were the consequence of the diclofenac prescription. However, the prolonged prescription, especially without a proton-pump inhibitor, put Mrs G at increased risk of developing the duodenal ulcer.

We upheld this complaint.

What happened next

The Practice apologised to Mrs G's granddaughter for their failings.

Our report was discussed at a significant events meeting, attended by all their doctors, nurses, receptionists and clerical staff. Robust procedures were put in place for prescribing and reviewing medication, and the Practice increased awareness of the need to follow their review processes strictly and to monitor the prescription of NSAIDs. The Practice Nurse is now qualified in prescribing and conducts the medication reviews.

Commenting on our report, Mrs G's granddaughter said that she was very happy with the outcome and pleased that her complaint '*will hopefully make a difference to other patients' lives*'.



Mr L's story

**'We value each person
as an individual'**

NHS Constitution

**'They took away every
last ounce of dignity my
husband had left'**

The story

Mr L was 72 and suffered from Parkinson's disease. His wife described him as a brilliant architect, and someone who had enjoyed keeping fit all his life. He was taking medication to manage his symptoms, but this disturbed his mental health and was stopped. Mr L experienced further episodes of hallucinations and paranoia, disturbed and aggressive behaviours which were sufficiently frightening for his daughters to administer diazepam and take him to A&E at Epsom General Hospital. From there, Mr L was transferred to West Park Hospital (part of Surrey and Borders Partnership Foundation NHS Trust), which specialised in assessing elderly patients with mental health difficulties.

On arrival at West Park Hospital, Mr L was moved to Bluebell Ward for assessment at around 3.00am and was said to be *'in a calm and pleasant mood'*. Nevertheless, he was given 10mg olanzapine,

Mr L's story

an antipsychotic drug. Mrs L visited her husband later the same day and was 'devastated' by what she saw. Before his admission, his wife said he had been able to eat, drink, talk coherently, see to his personal care and do some weight training, but now he had been 'turned into a zombie, a ragdoll'.

Over the next few days, despite his family's concerns, Mr L was given more antipsychotic and tranquillising medication, which his family say robbed him of his dignity. Mrs L said the '*image of [Mr L] haunts us to this day*' – he had to be taken to the toilet, could not walk unaided, had to be fed and could not speak coherently.

Five days after his admission to West Park Hospital, Mr L was transferred back to Epsom General Hospital for a routine echocardiogram, but on arrival, he complained of shortness of breath and a cough. On examination, crackles were heard in both lungs and he was dehydrated. A chest X-ray indicated that Mr L had pneumonia and he was admitted. He did not recover from this and died two weeks later.

Mrs L and her family complained to the Trust that Mr L had been given antipsychotic drugs unnecessarily, which they said had led directly to his death. Dissatisfied with the Trust's response, the family complained to the Healthcare Commission and then to the Ombudsman. Mrs L said that her husband should not have been given olanzapine, which had reduced him to a state in which he could not function, and that he had developed pneumonia which had not been recognised. These failings had '*fast-tracked her husband to his death*' and the Trust '*took away every last ounce of dignity my husband had left*'. Mrs L wanted assurance that future patients would not be treated in a similar way.

What our investigation found

We found that although it had not been unreasonable to prescribe olanzapine to Mr L, the initial dose was incautious and too high for an elderly man with his symptoms. Once it was realised that Mr L was over-sedated, the prescription was changed to a lower dose, to be given as required if he became very agitated or psychotic. However, this new instruction was not written up on the drugs chart and the nurses continued to give Mr L olanzapine on a regular basis, even though he did not meet the criteria for its administration.

Shortcomings in the nursing and medical care meant that Mr L's deteriorating physical health was not noticed. There was no evidence that care plans were drawn up to meet Mr L's physical needs. Fluid charts, poorly kept as they were, showed that he was at severe risk of dehydration. Nurses recorded that Mr L had passed very concentrated urine, yet did not draw the correct conclusions or act appropriately to address his developing dehydration. The nursing records, which fell short of the standards required by the Nursing and Midwifery Council, led to a failure to recognise the implications of the observations that were made, or to take appropriate action to tackle the problems that were developing.

Despite concerns and a specific request by doctors that Mr L should be monitored, there was no evidence that regular nursing observations were taken and none were recorded. This meant that while we found no evidence that Mr L showed signs of pneumonia during the time he was in Bluebell Ward, staff did not put themselves in a position to be able to state confidently that Mr L was well when he left them. (For their part, Mr L's family are convinced that he had contracted pneumonia while in Bluebell Ward and that he was already seriously ill when he arrived at Epsom General Hospital. There is nothing to contradict this view.)

Mr L's story

We concluded that the care and treatment given to Mr L fell significantly below the applicable standard and this was service failure. Although we could not be certain that Mr L's death was avoidable, the service failures put him at greater risk, probably contributed to his decline in physical and mental health and loss of dignity, and compromised his ability to survive pneumonia. All of this was an injustice to Mr L. It also affected Mrs L and her family who found it 'heartbreaking' to see his condition deteriorate to the extent it had. The length of time taken to complete the complaint process, which included two separate reviews by the Healthcare Commission, meant the complaint was not concluded for more than four years.

We upheld this complaint.

What happened next

The Trust apologised to Mrs L for their failings and agreed to pay her £1,000 compensation for the distress and anxiety caused to the family.

Mr L's family did not seek compensation and did not wish to accept the Trust's compensation payment. They have told us that their complaint was never about compensation and that the award added insult to injury.

As Mrs L and her family were keen that the Trust should learn lessons from this complaint, we asked them to prepare plans aimed at ensuring that lessons were learnt and mistakes not repeated. The Trust told us about a number of actions they were taking, which included: wards carrying out their own monthly record keeping audits; identifying training needs around the Care Programme Approach and medication; and benchmarking themselves against the *Essence of Care* standards for privacy and dignity involving people who use their service and their carers.



Mrs N's story

'Reflecting the needs of patients, families and carers'

NHS Constitution

'Our mother continued to suffer for too long'

The story

In October 2007 Mrs N was provisionally diagnosed with lung cancer by her GP. She went to Scunthorpe General Hospital (part of Northern Lincolnshire and Goole Hospitals NHS Foundation Trust – the Foundation Trust) for tests to confirm the diagnosis. The results were inconclusive and a biopsy was carried out. When Mrs N next saw her Consultant, he said it was very likely that she had lung cancer, but further tests were needed to confirm this. Mrs N underwent tests at Castle Hill Hospital (part of Hull and East Yorkshire Hospitals NHS Trust) where a scan showed that the cancer had spread to her chest and spine.

While waiting for the results of the Scunthorpe General Hospital tests, Mrs N began to suffer from severe pain. Her daughter told us that because her mother had not been given a diagnosis, she was not given adequate pain relief. The lack of a diagnosis also prevented Mrs N claiming full attendance allowance – something that would

Mrs N's story

have helped the family to care for her. The Christmas period was a particularly distressing time for everyone, as Mrs N's family witnessed her suffering without being able to help. Another daughter, who spent a large part of each day caring for Mrs N, became ill herself as a result of the distress.

In January 2008 Mrs N attended Scunthorpe General Hospital for the test results. A different Consultant confirmed that she had lung cancer, but that the particular type of cancer could not be identified. He told Mrs N that there had probably been enough evidence from the first tests to diagnose inoperable lung cancer.

A few days later Mrs N – who described herself as *'disorientated and in extreme pain'* at the time – was admitted to Scunthorpe General Hospital to control her increasing pain. A pain management plan was drawn up specifying that Mrs N should receive medication on an *'as required'* basis, but it was five days before she received adequate pain relief. Mrs N said that she was in *'unbearable pain'*. On one occasion Mrs N had asked for pain relief, only to be told that she had already taken it. However, when the Macmillan Nurse checked the drugs chart, that was not the case. As her daughter observed *'our mother continued to suffer for too long'*.

Mrs N was then moved to a different hospital for radiotherapy treatment, but was still unaware that the cancer had spread to her spine. She was transferred back to Scunthorpe General Hospital and then discharged home. Mrs N complained to the Foundation Trust about several issues including poor communications between the departments and hospitals caring for her, and delays receiving test results. She queried if some of the tests (which she found distressing) had actually been necessary. She sought *'some reassurance that everything possible will be done to stop anyone else experiencing the problems I have experienced'*.

In March 2008 Mrs N had an MRI scan. Only then did she learn that the cancer had spread to her spine. She died the following month, aged 82. Seven months after Mrs N's death, the Foundation Trust sent their full response to her daughters. During the local resolution process, the Foundation Trust acknowledged failings in Mrs N's care, offered their apologies and described actions they had taken to improve their practices. However, Mrs N's daughters escalated matters to the Ombudsman, seeking a more detailed response and apologies.

What our investigation found

The Foundation Trust should have concluded in October 2007 that it was likely that Mrs N had inoperable lung cancer. Instead, they focused on obtaining a full diagnosis and neglected to manage her pain. Both this and delays in scheduling investigations and reporting the results contributed to Mrs N not being treated for her symptoms within two months of her referral (in line with Department of Health guidance). The delayed diagnosis also meant that Mrs N was ineligible for full attendance allowance, which could have helped the family to care for her, until January 2008.

Although a pain management plan was in place for Mrs N, nurses seemed unaware of her specific pain management requirements. That was not in accordance with the Nursing and Midwifery Council's guidelines. The lack of adequate pain relief greatly distressed Mrs N and her family. Mrs N should also have been told that the cancer had spread to her spine before the MRI scan. The Foundation Trust delayed unnecessarily providing a full response to Mrs N's complaint. The fact that she did not receive the response before she died compounded the family's distress.

We upheld the complaint about the Northern Lincolnshire and Goole Hospitals NHS Foundation Trust.

Mrs N's story

For their part, Hull and East Yorkshire Hospitals NHS Trust communicated poorly with Mrs N about the investigations at Castle Hill Hospital and contributed to the delay in her receiving the results. We did not uphold the complaint about them, however, as these shortcomings added little to the delay in treating Mrs N's cancer and the Trust had already apologised for them.

What happened next

Northern Lincolnshire and Goole Hospitals NHS Foundation Trust apologised to Mrs N's daughter and paid her compensation of £2,000. They also drew up further plans to improve their service, by taking such steps as arranging training for ward staff in pain and symptom control; improving systems for scheduling investigations and reporting the results; and planning to appoint an additional lung cancer nurse.

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