



listening to patients,  
speaking up for change

## **The Patients Association**

**Parliamentary and Health Service Ombudsman  
The 'Peoples' Ombudsman – How it Failed us**

**November 2014**

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## Foreword Jacqueline Coles, Deputy Chief Executive



The Patients Association was formed over fifty years ago. Since then, it has listened to patients concerns and spoken out on their behalf. Not long after the Patients Association took up its role, legislation was enacted by the government to establish the Parliamentary and Health Service Ombudsman (PHSO).

Both organisations have similar values and agendas, intended to help and support the public, the difference being, one is an independent charity, the other a government body afforded all the power and legislation to act with credibility.

Over the last fifty years or so, the Patients Association has honoured its values to listen to patients and speak up for change. We have pro-actively adapted to the demands of an ever changing National Health Service. The PHSO on the other hand, have remained entrenched in outdated 1960's procedures, attitudes and investigative techniques, having failed to adapt to the expectations and demands of a modern society or bring about change in NHS accountability.

For many years we have advised people who had contacted our National Helpline to go to the PHSO when they have received an unsatisfactory response from their local health service providers. Sadly we can no longer recommend this course of action to patients, as we have no confidence in the PHSO to carry out an independent, fair, open, honest and robust investigation.

The Ombudsman is frequently quoted as saying patients who suffer harm or poor care in hospitals are failed by a "toxic cocktail" within the health service, whereby complaints go unheard and lessons unlearned. In our view, the PHSO are the final and fatal mix of that toxic culture.

Through our national helpline we receive thousands of calls and correspondence every year. Over the last few years we have witnessed a dramatic change in the complexity of the majority of requests for support and advice. Fundamentally, this has been due to the poor handling of complaints at a local level and subsequently, the devastation families feel at the treatment they are subjected to by the very service established to help them - the PHSO. As one of our recent callers said "you may as well ask a poacher to investigate the missing pheasants."

The PHSO reportedly costs the public £40 million pounds a year; we believe the real cost to be far greater than that, as many families are impacted by the personal financial burden of dealing with the PHSO. Prolonged investigations, which rely on families to produce all the evidence, can lead to patients or their families having to give up their employment to deal with the demands and inadequacies of the PHSO. The real financial cost to society is undoubtedly far greater than the official figures.

However, no price can be placed on the emotional cost to families who frequently tell us of how their dealings with the PHSO have pushed them further into despair and frequently to ill health. The impact on those families of the inadequate, untimely and unacceptably flawed investigations by the PHSO simply cannot be measured in financial terms alone.

The Patients Association recently published a report into the failings of complaints handling by NHS Trusts. We described the difficulty those making complaints experience navigating their way through an often challenging complaints process.

Our Person Friendly Charter on complaints handling pictures a boat as its symbol, to demonstrate how difficult it is to navigate the cold unfriendly waters of the NHS complaints systems. Hidden beneath the surface of those very cold waters, is the iceberg of the PHSO - still and silent, a very uninviting entity. It leaves the victims and families seeking help regarding health concerns cold, alone and frozen out. The PHSO fails them on a regular basis.

Whether it is an NHS Trust or the PHSO, the same set of values referred to in our Charter must apply to the handling of all complaints.

There are many cases, already known to the public, which highlight the failings of the PHSO. Earlier this year the Patients Association supported the parents of Sam Morrish, a three year old boy from Devon who tragically died through a catalogue of NHS failures of care. Sam died in 2010 and yet it was only this year, 2014, that the PHSO pronounced its findings. Sam's parents have been very critical of the PHSO, raising concerns regarding the competence, capability and accountability of the Ombudsman.

In another case, James Titcombe has repeatedly asked the PHSO to carry out an internal review into the appalling decision not to investigate the death of his baby son Joshua. James is quoted as saying "From Dame Julie Mellor, all we hear is the sound of silence"

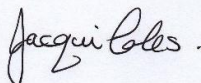
There are many other families who have suffered the impact of the PHSO. Some of those have spoken out in this report, in order to highlight how the PHSO have made their suffering even more unbearable. The stories featured are written personally by people who thought the PHSO would make the pain of losing loved ones more bearable by at least bringing about change. Anyone reading their stories will realise how those families have been so badly let down and have had to fight to stay afloat in the icy waters we have described above; ironically and so tragically, let down by the very organisation established to throw them a life line.

The Ombudsman states: "We are the last resort for complaints about the NHS. We listen to individual complaints and where things have gone wrong, help to get them put right."

The Patients Association, in partnership with the families of those who have contributed to this report, challenge that statement. Nearly 50 years after the PHSO was established, it is time for real and robust change, not just promises and more recommendations.

We have a clear request to the Government and Public Administration Select Committee - read our patients stories, listen to their concerns, consider our conclusions, recommendations and finally, hold the PHSO to account for its actions.

**.Jacqueline Coles, Deputy Chief Executive**



## Background

Each year, millions are treated by the NHS, but still too many mistakes are made. When this happens, many vulnerable people make the significant effort of raising a concern, often with the ultimate intention of ensuring that lessons are learned and steps taken to prevent the incident happening again.

Each concern should be a learning opportunity; a chance for a Trust or provider of healthcare to genuinely apologise. It is also essential that Trusts are committed to their statutory obligation of openness and accountability, demonstrating a willingness to learn and bring about change. This is overwhelmingly what patients and their relatives want.

The Patients Association Helpline receives thousands of calls and correspondence every year. The majority of those who contact us have done so out of desperation at the failings of the NHS complaints processes at a local level. Those complaints often involve poor care, neglect, a lack of dignity and basic compassion. Many of those who complain are met with hostility, defensiveness and a lack of compassion, in essence, an inhumane process. For a family coming to terms with the degrading treatment of a relative or death of a loved one, such insensitivity only worsens the distress they are experiencing.

The Patients Association's recent report into complaints handling by Trusts highlighted its serious failings. As well as a need for significant overhauling of the NHS systems to ensure a person friendly approach to complaints handling.

Following failure of a satisfactory outcome at a local level, many families turn to the Parliamentary and Health Service Ombudsman as a last resort. Trusts recommend this course of action to those dissatisfied with complaints responses. Similarly, the Patients Association has always advised people to take their complaint to the PHSO. In recent years we have increasingly received correspondence from those families asking us why we told them to go to the PHSO, as they were distressed and left totally worn down by a very uncaring organisation.

During the last few years, through our Helpline and individual case work, we have witnessed worrying trends in our interactions with the PHSO. Many of the cases referred to the PHSO have not been investigated and when they are, the investigations appear to be very light touch. The burden of providing evidence is all too often placed firmly at the door of those complaining. There is clear evidence that if families do not provide evidence, the PHSO cannot be bothered to look for it. Very often when families provide significant evidence, it is ignored. The case of Elsie Brooks, featured in this report, clearly highlights this. Her daughters Maggie and Janet Brooks identified that the Trust had withheld over one hundred clinical records from the Ombudsman's investigation. These records were of paramount importance to the investigation. However, the Ombudsman's investigator, with no clinical expertise or knowledge stated, "My instinct is that this is not significant to our overall findings."

Maggie and Janet Brooks said "The Ombudsman states that her office represents 'the gold standard of complaint handling. It has forced us to spend almost three years of our lives, trying to limit the harm the Ombudsman's so-called investigation process has done to us."

Earlier this year, the Ombudsman's report into the death of Samuel Morrish acknowledged that it had taken far too long to investigate the case. This is only one of the failings. Sam's parents have been very open in their criticism of the PHSO handling of the investigation into their son's death. Scott Morrish has raised concerns regarding the competence and capability of the Ombudsman, stating how they had to work constantly to "maintain accuracy, ask challenging questions, identify gaps in the understanding and to explain the significance of information for the Ombudsman."

It is unacceptable for grieving families to be dealing with the burden of 'overseeing' the Ombudsman's investigations. The public deserve an Ombudsman who will **actively listen** to their concerns and carry out robust, thorough, open and flawless investigations.

This report includes the journeys of some of those families who have felt desperation and despair following their contact with the PHSO. Several of them give very moving personal accounts of what happened to them. They all identify serious failings on behalf of the Ombudsman.

As one of our very recent experience supporting Averil Hart's family highlights, had it not been for the family, (supported by the Patients Association), allocation of a PHSO case worker and face to face meetings may not have occurred. The family had to push for progress at every stage.

The Brook's family case highlights the ombudsman lack of integrity or rigour during an investigation. As Janet and Maggie Brooks said "The Ombudsman's report was accorded all the respect and gravitas of a report produced by an official body that reports to Parliament. We have found the Ombudsman's complaints process to be gruelling and destructive."

The mother of a disabled child (Child B) refers to the handling of her complaint to the PHSO in early 2012. Significant delays in investigations, flawed reports and wholly inadequate and incorrect investigations has resulted in B's mother devoting a significant amount of time to resolving gross errors made by the Ombudsman.

The PHSO's second draft report specifically prohibits B's mother from sharing the letter or its contents publicly. The PHSO cited section 15 of the Health Service Commissioners Act 1993 and the case of R (Kay) v Health Service Commissioner [2008] EWHC 2063 (Admin) to support its assertion, that complainants are not allowed to discuss its draft findings, in other words, a 'gagging' clause.

However in the case of Elsie Brooks, the PHSO circulated a report full of inaccuracies to the inquest and refused to take the report out of circulation until a review takes place. The family have been told that the review will not take place until after the inquest. How can the PHSO attempt to apply certain legislation to families, but then not the same legislation to themselves?

Mr Sam Holt whose wife Jennifer died following a serious fall in an NHS Trust was left devastated when he discovered, that as part of the investigation, it was revealed that a "Do Not Attempt Resuscitation (DNAR)" form had been completed in respect to Jennifer. This was something Mr Holt and his family had been completely unaware of. He said, "Although I requested that this be investigated and included in the report, the Ombudsman declined to do so, leaving me with yet more unanswered questions." On the recommendation of the Ombudsman, Mr Holt was offered £250 as compensation by the Trust. No one can imagine

the distress, hurt and insult this must have caused him. As he said, “It is up to me to continue to challenge the Trust and ensure any recommendations that were made are followed up. I now have nowhere to go because the PHSO failed me and my wife. Jennifer did not deserve what happened to her – she did no harm to anybody.”

Jo Deering’s family have been left feeling totally alone and unsupported as a result of the Ombudsman’s investigation. Whilst detained under the Mental Health Act, Jo was allowed leave; this was without prior knowledge or consultation with her family. Jo lived with her elderly mother, who was also very vulnerable. Whilst on extended leave Jo committed suicide. Jo’s sister Maureen said, “It appears no account was taken of the fact that Jo was still psychotic and the burden would fall on her vulnerable elderly mother.” A risk assessment with family members is part of the Trust policy prior to granting extended leave, however this never happened.

Jo’s sister Maureen took her case to the PHSO, as she was unhappy with the way the Trust concerned had responded with denials and a lack of regard.

The PHSO have failed to investigate the key factor in Maureen’s complaint, stating that decisions made by clinicians taken under the Mental Health Act 1983 are taken in a ‘personal capacity’, rather than on behalf of the Trust. Therefore even though the clinician was employed by the Trust and should adhere to Trust policy, the Trust has no legal responsibility for actions taken which result in the death of a patient under their care. This raises very many questions, as to who is accountable and why has the Trust escaped any investigation into the decision to grant leave to Jo, directly leading to her death?

These and other stories highlight key trends which raise many questions. How can the public have confidence that the PHSO, a supposedly independent arbitrator, is taking all the right steps?

The Patients Association is currently supporting several of families who have experienced difficulty during the Ombudsman’s handling of their cases. Those featured in this report are just the tip of the iceberg. Many are too frightened to speak out for fear that they will be victimised and their complaints jeopardised. In fact, some have received draft reports informing them that they can not disclose content, as we have already highlighted, effectively gagging them.

In the Patients Association recent complaints report, we spoke of how those complaining are frightened about the impact a complaint may have on their care. Investigations are neither open nor honest and frequently deliver unsatisfactory outcomes. We recently published our *Person Friendly Charter* - a plea from patients to be treated with dignity and respect throughout the complaints process. This also applies to the PHSO.

In the PHSO’s own report *NHS Governance in Complaints Handling*, published 5<sup>th</sup> June 2014, they call for improved timelines of sharing information, improved data quality and addressing defensive organisational cultures. We ask the PHSO to lead by example and get its own house in order as well.

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Last month, the PHSO announced it was reviewing investigations into 250 patient deaths, acknowledging that some may have been victims of “appalling” failings. This is just a further vindication of many of the concerns raised.

As our Chief Executive, Katherine Murphy recently stated, “Imagine if a police force suddenly announced it was reviewing 250 murder cases because it had no faith in its own investigative system? There would be an outcry and calls for a public inquiry, but the PHSO carries on as though it is just doing a bit of everyday house-cleaning, by re-looking at these cases. We need a better more accountable system than this that serves the public.”



## Elsie Brooks by Maggie and Janet Brooks



Mrs Brooks was admitted as a healthy woman to King George Hospital, Ilford for elective keyhole surgery for hernia repair on 12 December 2009.

At every stage of the pre-assessment, the consultants told Mrs Brooks that a High Dependency Unit (HDU) bed was a pre-requisite, and that the operation would not go ahead if an HDU bed was not available. It was on this basis that she gave her consent.

The surgery was more complicated than planned. However, when she was unconscious and dependent, the decision was made, without her knowledge or consent, to consign her to a short-staffed, under-resourced temporary contingency ward. Here the nursing care was inadequate and, as a result, she came to serious harm.

When she later experienced faecal vomiting, a known complication which should have been easily resolved, she was left without nursing care and without the insertion of a nasogastric tube for over 7 hours. In that time she inhaled the vomit, which subsequently led to her death.

In the crucial 2 day period following the inhalation, Mrs Brooks needed urgent specialist treatment to maximise her chances of survival. Instead, she was left without the care of senior doctors, and allowed to lapse into respiratory failure, kidney failure and sepsis.

When she was finally taken to ITU, she improved with intensive care. After 2 weeks in ITU, she was about to be discharged to a ward when she showed signs of a recurrence of sepsis.

We were told an antibiotic would be given to her to treat this, but there appears to have been a 27 hour delay in prescribing this antibiotic.

Mrs Brooks died in ITU of septicaemia 25 days after her admittance to the hospital for elective keyhole surgery.

The death certificate was inaccurate and did not reflect what Mrs Brooks died of, nor the sequence of events that led to her death.

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## **NHS Trust complaints process**

Barking Havering and Redbridge NHS Trust began an investigation into our mother's death. This took 16 months but brought no facts to light.

The Health Service Ombudsman agreed to take our case on.

## **The Parliamentary and Health Service Ombudsman**

We told the Ombudsman's Assessor that there were clinical records missing at every point where my mother had come to harm and we had not been able to get these from the Trust.

The Assessor told us not to worry, that the Ombudsman had the powers of a high court judge and would make the Trust disclose records if necessary.

She said it would take the Ombudsman a year to investigate our complaint.

A year went by. In April 2012, the Ombudsman's Investigator sent us her Draft report.

## **The Draft Report**

The Ombudsman fully upheld our complaint.

But we were shocked to find that the report was full of inaccuracies and that the Ombudsman had not investigated the central issues.

The report said that my mother should not have gone to the temporary contingency ward but did not investigate how this had come about.

The nurses on the contingency ward had not been asked to explain why they refused to help my mother while she was vomiting.

We had been left alone trying to keep our mother sitting up while she vomited for over 7 hours. We had been the only ones present when she inhaled the vomit. But the Ombudsman had discounted and ignored our eye witness accounts.

After this, my mother had needed urgent emergency treatment. Yet the Ombudsman had not asked the doctors who should have attended her over the weekend why they had not done so.

The Ombudsman had not looked at serious, unexplained events in Intensive Care as she had said she would. She had not given any reason for this.

It was as though the Ombudsman had decided to take the substance out of our complaint.

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We had written our complaint clearly and accurately but the Ombudsman had gone on to misrepresent what we'd written, to misquote us and to ignore the most important facts.

### **Our comments on the Draft report**

We spent 2 weeks going through our mother's medical records, checking everything against the 30 odd pages of the Ombudsman's Draft report.

We sent the Ombudsman copies of 40 or so medical records which the Ombudsman's office did not appear to have seen.

We assumed she would send these crucial records straight to her Nursing and Medical Advisers for their opinion.

And that large parts of the Ombudsman's report would need to be rewritten.

### **The Ombudsman's final draft**

Two months later, the Ombudsman published the Final draft of her report.

We were shocked to see that the Ombudsman had ignored the medical records we had sent to her and made no significant changes to the report.

Instead, she'd added two footnotes noting that some clinical records had come in after the investigation, but that these did not alter her findings.

The Ombudsman's Investigator was not medically trained yet the records had not been sent to a medical adviser.

The Ombudsman was supposed to conduct 'evidence-based investigations' but the Investigator did not seem to understand that findings and conclusions had to be based on the relevant evidence.

### **The set of records the Ombudsman relied upon**

We requested the set of medical records the Trust had supplied to the Ombudsman.

When we checked them against our set, we found the Trust had withheld more than 100 records from the Ombudsman's investigation. Records were missing at every point where the Trust could have been accused of neglect.

As well as this, records had been taken out and substituted with irrelevant records.

For example, all 12 pages of pre-assessment records had been taken out and been replaced with a single undated Planned Procedure record.

This was from an earlier, unrelated episode of care when my mother had been prepared for an emergency operation which had not then taken place.

The substituted record gave a completely false impression of my mother's preoperative state of health.

This record had misled the Medical Assessor, who stated quite wrongly that our mother's surgery was 'life or death' and that 'her daughters had been told this'.

His opinion had coloured the opinions of the Medical Advisers, which, in turn, undermined the integrity of the whole investigation.

Had the Medical Assessor seen the actual records, he would have known that my mother was in a good state of health at the time of this elective keyhole hernia surgery and that she had been assessed by the surgical team as fit for surgery.

The fluid charts had also been taken out and this allowed the Ombudsman to say, 'I do not disbelieve Ms Brooks but given the discrepancy in the available evidence, I cannot conclude that her mother was left unattended as she suggests.'

The fluid chart clearly confirmed that my mother had vomited for 7½ hours before the nasogastric tube was inserted at 1.00am. We had supplied this chart to the Ombudsman at the draft stage but she had chosen to ignore it.

There were records missing from ITU. This explained why the Ombudsman had decided there was nothing to investigate in ITU.

### **Request for Ombudsman to conduct review**

The Ombudsman has a review process for those who are dissatisfied with her investigations. However, only a tiny fraction of these appeals were accepted.

The Review team warned us that in laying out our request for this, we should not go over the same ground of the complaint:

“a review does not mean we will look at your original complaint again. Instead it means we will look to see if we took account of all the relevant evidence and made a fair decision based on this.’

This meant we had to focus on the way the Ombudsman's investigation had handled the issues of our mother's suffering and death, rather than on the issues themselves.

However, it still obliged us, again, to go over and over the painful details of our mother's medical records.

We asked for a Review on the grounds that the Ombudsman:

1. Had allowed the Trust to withhold records.
2. Would have known that copies of these records existed if they'd read the complaints correspondence.
3. Knew they were publishing inaccurate statements that were not supported by the medical records.

4. Showed bias in allowing the Trust to influence the Ombudsman's report.

We offered to send them the set of medical records we had so that the Review team could compare them with their own.

The Review Team said this was not necessary as they would 'only be looking at the complaint handling' and not at the original complaint.

We did not see how they could judge whether they had all the relevant evidence if they didn't look at the clinical records that the Trust had withheld from them.

### **The Ombudsman's Review**

In August 2012, the Ombudsman accepted our case for Review. We were told that this would take 4 months.

Fifteen weeks passed. We were anxiously awaiting the outcome of the Review.

We no longer had any confidence in the Ombudsman's office. If the Ombudsman were to find against us at the Review, this would be final. There was no right of appeal against the decision of a Review.

We had endured over 2 years of investigations. Not only had no facts come to light but the Ombudsman's report unjustly challenged our eyewitness account.

If the Ombudsman found against us, this was likely to block any further investigation of our mother's case, and the Ombudsman's flawed report would be set in stone.

### **Inquest**

However, at this point, we got the news that the Coroner had granted an Inquest into our mother's death.

We felt as though a weight had been lifted off us.

The Coroner would conduct a rigorous, impartial investigation and establish the facts. We thought we no longer needed to worry what the Ombudsman's Review team decided.

We did not understand that the Ombudsman's investigation could have a negative effect on the Coroner's Inquest.

### **Review put on indefinite hold**

As soon as we told the Ombudsman that there was going to be an Inquest, she immediately put the review on hold until after the Inquest.

We wrote back, insisting that it was a matter of urgency for the Ombudsman to look into the fact that the Trust had withheld crucial records from the investigation.

We sent an 8 page list of the 100+ missing records to them.

We thought the Ombudsman would be alarmed to learn that so many crucial records had been withheld from her investigation.

However, the Ombudsman seemed strangely reluctant to investigate this.

It seemed almost as if it were normal practice for the Trust to take out records that indicated negligence before the Investigation took place.

Internal papers show that the Reviewer sent our list of records to the Investigator and asked her if anything on it 'gave her significant cause for concern'.

The Investigator, who had no medical training, gave her opinion on three of the medical matters, then concluded, 'My instinct is that this is not significant to our overall findings...'

Since the Investigator's actions regarding these records were the subject of our complaint, her opinion of them could not be considered objective.

However, the Reviewer must have been satisfied as he didn't ask us to supply the records and he didn't give the list of records to a Medical Adviser for a clinical opinion.

### **The Review on hold but the Ombudsman's report left in circulation**

The NMC's solicitor rang to tell us that the Trust planned to introduce the Ombudsman's report into evidence at an NMC hearing.

It only now occurred to us that the Trust would also be able to quote the Ombudsman's report at the Inquest.

We wrote to the Ombudsman saying that the report needed to be withdrawn from circulation while the Review was on hold, as the inaccurate facts and findings in it could be quoted to the Inquest.

The Head of the Review Team refused. She said, 'it may be that these facts and findings are wrong but that is for a Review to decide'.

She said that the Trust was perfectly entitled to quote from the flawed report until the Review took place. And, as they had already told us, the Review would not take place until after the Inquest.

### **Recommendations**

The Ombudsman had asked the Trust to hold off compliance with the recommendations of the report until the Review had taken place.

However, now the Investigator contacted us to say she was going to allow the Trust to comply with the recommendations.

Internal papers showed that the Ombudsman's Office thought that it was 'unfair' to the Trust that they should appear 'non-compliant' due to the Review having been put on hold.

We protested that to implement the recommendations would be to pre-empt the Review and treat its outcome as a foregone conclusion.

Since we didn't accept that the Ombudsman's Investigation had accurately identified the systemic issues in our mother's case, it followed that we didn't accept that the recommendations made in the Ombudsman's report were relevant.

It was important to us that the recommendations should be relevant and flow from what had happened.

These should have concerned the opening of understaffed contingency wards, the treatment of respiratory failure, staffing at weekends, and the prompt treatment of sepsis.

However, despite our protests, the Ombudsman told the Trust to go ahead and put its irrelevant action plan in place.

The recommendations were arbitrary and unrelated to our mother's case, therefore there could be no shared learning from them.

The Ombudsman had not established what had actually happened, so there was no way these recommendations could reduce the likelihood of the same mistakes happening again.

### **How the Ombudsman's report could affect the Inquest**

By September 2013, there had been no movement on the Inquest for nine months. We did not know why this was.

Internal papers show that the Coroner's court rang the Head of the Ombudsman's Review Team to say that there was 'a Mexican stand-off'.

This meant that the Trust was not willing to release witness reports to the Coroner until they knew the Ombudsman's stance on our complaint.

We did not understand why it was so important to the Trust to know where the Ombudsman stood. We later found out this was because of Article 2.

If the Trust barrister can argue at the Coroner's Court that the Ombudsman's investigation has been completed and its findings and report have been shared, he can use this to petition the Coroner that Article 2 of the Human Rights Act is not relevant as the case has already been investigated by the State.

If the Coroner accepted the Trust's arguments, this could persuade him to turn down the family's submission for Article 2.

So, the Trust, having withheld the records from the Ombudsman in the first place, would be able to use the Ombudsman's report to limit the range and scope of inquiry at the Inquest.

This would mean that the wider circumstances of the death and the systemic issues involved would be unlikely to be investigated.

The Ombudsman's report could be used to create a closed circle to ensure that the events are never investigated, effectively covering them up.

### **How things stand**

The Ombudsman has had over two years to conduct its review of our complaint. It has caused us a vast amount of work, frustration and distress.

We've written countless letters, sent countless freedom of Information requests and been forced to repeatedly go over the medical records that chart our mother's suffering and death.

We've tried, over years, to get the Ombudsman's office to follow fair procedures and to act logically, but there was no hope of them ever doing so.

More than two years since the review was put on hold, Dame Julie Mellor has now told us an External Reviewer is starting a Review of our case.

## **Conclusion**

As we wrote to the Parliamentary Administrative Select Committee in 2012:

'The Ombudsman claims to operate 'thorough and rigorous processes to reach sound evidence-based judgments'.

She has the powers of a high court judge yet her investigation into our mother's case demonstrated an:

- inability to accurately summarise our case
- indifference to the gathering of evidence
- lack of understanding that conclusions must arise from the evidence

In our case, the Ombudsman's Investigation had no integrity and it had no rigour.

Yet the Ombudsman's report was accorded the respect and gravitas due to a report produced by an official body that is accountable to Parliament.

The Ombudsman states: 'We are the last resort for complaints about the NHS. We listen to individual complaints and, where things have gone wrong, help to get them put right.'

We have found the Ombudsman's complaints process to be gruelling and destructive.

We have never before experienced a comparable situation where our statements have been systematically misquoted and altered, our eye witness accounts disbelieved in favour of accounts drawn up by the Trust's lawyers, and our legitimate objections to the publication of false information, ignored.

The investigation established no facts, gave us no explanations and did little more than highlight some of the failings which had already been conceded at the Local Resolution meeting by the Trust.

At the same time, the Ombudsman's report signalled the 'end of the NHS process' and, as such, was likely to stand in the way of the facts ever coming to light."

The Ombudsman states that her office represents 'the gold standard of complaint handling'."

From our experience, this is a hollow claim.



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We do not believe the Ombudsman's office is capable of investigating complaints. It is not capable of investigating or putting right its own failings, let alone investigating serious matters such as hospital system failure and avoidable deaths.

## Jo Deering



Jo Deering began to display symptoms associated with paranoid schizophrenia in the years leading up to the millennium. Her family tried to get her the help she needed, but she insisted that she was well.

Jo was later sectioned under the Mental Health Act when the Police became involved in a series of incidents relating to her psychotic and delusional behaviour. In 2010, Jo became unwell again, and was once again sectioned.

Sadly, Jo never fully recovered and in 2011 her health was deteriorating once more. As her condition worsened, she isolated herself from her friends. Life at home, with her frail and elderly mum, was extremely problematic. The mental health team ignored the concerns raised by the family.

Jo's sister, Maureen, provided care and support for their mum who was severely arthritic, had mild dementia and, following a fall in hospital, needed careful supervision and full-time care. Jo's paranoid and delusional behaviour made it difficult for her sister to provide the care and support required by their elderly mother.

In May 2011, Jo's psychosis and deteriorating health was finally addressed. She was sectioned under Section 2 of the Mental Health Act and admitted to Windsor Ward at Woodhaven Hospital with severe psychosis and in need of careful monitoring.

She appealed this decision at a Mental Health Tribunal, but her doctor submitted detailed evidence explaining that she was "acutely unwell" and needed treatment for the protection of herself and others.

However, within two weeks of her admission into hospital Jo was permitted "extended leave", of which only one day's notice was given to her mother and sister. Neither had been consulted about the proposed leave. The impact this had on all their lives was significant and Maureen had to deal with the indifference and lack of support from the clinical team involved in this decision.

It appears no account was taken of the fact that Jo was still psychotic, or the consequences this might hold for her vulnerable elderly mother when she was sent home. Clinicians involved with leave did not know Jo when she was well, so failed to recognise how ill she actually was when leave was granted, and also failed to listen to the concerns of the family in this regard.

During the subsequent months, the treatment provided to Jo was insensitive and inappropriate to her needs. She suffered significant side effects from medication, which she tried to bring to the attention of staff, but these were not taken seriously. She was also poorly counselled by the clinical team who had sanctioned and encouraged Jo to take on the role of caring for her mother, despite the fact that she was mentally and emotionally unable to do so.

In October 2011, Jo told her psychiatrist she was 'feeling very depressed,' but this insight was not followed up with action. A few days later, Jo committed suicide. At her inquest, the Coroner stated there was a 'significant link' between the decision to grant leave and the 'sad conclusion' to Jo's life.

### **The Complaints Process:**

Jo's sister, Maureen, made a written complaint to the Trust involved – Southern Health NHS Foundation Trust – because of the insensitive and unsafe care provided. The Trust's response was based on interviews with the relevant clinicians, but contained significant errors, omissions, distortions and false claims.

The response makes frequent and repeated references to the extent to which Jo had recovered, and also claims Jo had recovered sufficiently to be discharged. There was no evidence to support this. Their mum's suggestion, that she was 'looking forward' to Jo's return home, was taken out of context and used to justify the decision to grant leave. It was also claimed that Jo was fit to provide for her mother's care needs. This could not have been further from the truth.

Throughout the letter, the Trust appears to blame Maureen for the tensions between Jo and herself, without reference to the paranoia and aggression associated with Jo's mental health. Most significantly, the response failed to acknowledge and recognise the evidence provided as to the impact on her family caused by the granting of extended leave, and misrepresents their views.

### **The PHSO:**

The Trust's response, characterised by pure denial and disagreement, was referred to the PHSO for investigation. Maureen explained that she was unhappy with the way in which the care had been handled, and the clinicians' lack of regard for her family's wellbeing during that time. The seriousness of this impact, and its role in Jo's eventual suicide, warranted investigation.

The PHSO, however, has failed to tackle the key matter at the heart of the complaint: the decision to grant a period of home leave to Jo so soon after she was detained under the Mental Health Act and which subsequently ended with Jo's suicide.

The root of this failure is that decisions taken by clinicians under the Mental Health Act 1983 are taken by them in a personal capacity, rather than on behalf of a Trust. For this reason, the PHSO believes it cannot investigate, as its powers extend only to the administration of the trusts involved.

Having raised concerns regarding the significance of the decision to grant leave, and the limited investigatory remit of the PHSO, Maureen received a response that explained that

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she could refer the case to the Care Quality Commission (CQC), which does have the authority to investigate, or she could ask the CQC to review the Trust's policies.

The CQC, however, states that the events took place too long ago to investigate the decision. The CQC also do not investigate individual cases.

The regulatory system is clearly inadequate. The context in which care is provided should not affect the way in which it is investigated, and there should not be hard jurisdictional lines and ill-defined organisational boundaries between different agencies in investigating decisions.

Whilst the PHSO has agreed to continue investigating other elements of this case, the gravity of the complaint is severely compromised by the failure to investigate the key decision regarding leave, and as a consequence it appears that the clinicians involved remain unaccountable for this type of decision.

## Child B. By his mother

B is a disabled child. He requires Special Educational Needs (SEN) support, including Speech and Language therapy, which he was meant to receive from X NHS Trust. In January 2011, a statement of SEN was issued, establishing a programme of treatment. The local authority is statutorily obliged to ensure the statement provision is in place but the Trust was bound to provide it under its contract with the Local Authority (LA). However, provision was not put in place until May 2011, and had only been put in place after significant efforts by B's mother to chase the Speech and Language Therapy staff. The local authority apologised for the delay but, in July 2011, speech and language therapy reports indicated that B had been receiving speech and language therapy from the Trust since October 2010.

In July 2011, B's school placement broke down, and he was removed in favour of home education until another could be located. In September 2011, he was discharged from the Speech and Language Therapy services without notice, and only days after B's parents received a letter offering B an appointment. The removal of a child from school was not a recognised ground for discharge, and the lack of notice was directly inconsistent with the advice of the Royal College of Speech and Language Therapists. Throughout this time, B's family had to pay for private Speech and Language Therapy.

### **The Complaints Process:**

B's mother, a qualified solicitor and legal researcher with a PhD, received a letter from the Head of Speech and Language Therapy in June 2011 attempting to close down communications by answering a complaint B's mother had not made. B's mother was told she must go to the PHSO if she wanted to engage further on the matter. The head of service also wrote an inappropriate e-mail, claiming that B's mother had "substantially affected" the quality of care provided due to the complexity of her e-mails.

B's mother attempted to engage with the Trust to obtain further information about their conduct. Specifically, she requested information about a meeting held in July 2011 with Trust and LA staff. Throughout this time, the Trust's failings were numerous. The Patient Advice and Liaison Service (PALS) team failed to respond to email requests for the release of B's medical records, failed to respond to an e-mail asking for details about the complaints process, and failed to arrange a meeting with B's mother to discuss the care provided even after this had been promised to the PHSO. B's mother had gone to the Ombudsman in September 2011 when she had not been able to obtain the information she had requested. The PHSO was then told by the Trust that, despite the head of service's letter, local resolution had not been completed. The PHSO refused to investigate further but said the Trust had promised the release of B's records and a meeting.

However, this did not occur and B's mother had to go back to the PHSO on several occasions to report the delay. Eventually, PALS was stated to be unaware of the e-mails or the complaint to the PHSO and in December 2011 the information was sent again by B's mother. B's records were eventually released in December 2011. A meeting with senior Trust staff took place in March 2012. B's mother also raised concerns that the Trust had breached information governance principles, and their common law duty of confidentiality to B. For example, a Therapist sent a report on behalf of the local authority to SEN Tribunal

covertly, without involving the family, and without any face-to-face interaction with B. Additionally, the Trust shared information with the local council without any authorisation. They later attempted to rely on a year-old consent form, which did not cover the relevant referral and did not include disclosure to local authorities. At the meeting, the Trust promised a full investigation and a report. Their response subsequent was incomplete and inconsistent with the evidence.

### **The PHSO:**

B's mother referred the handling of her complaint back to the PHSO in early 2012. The case was accepted and investigated during 2012, and a preliminary response was sent in December 2012. However, this response did not adequately deal with the concerns raised. The PHSO accepted that there were flaws in the report and agreed to undertake a fresh review in early 2013. Since then response, B's mother has devoted a significant amount of time to resolving the errors made by the Ombudsman.

A second decision was not issued until April 2014. Significant delays during the PHSO's second investigation remain unexplained. The reasons given to B's mother were that there had been significant difficulty obtaining a suitable clinical advisor, and there had been further enquiries made of the Trust. However, B's mother has seen no evidence to support this and there has been no adequate explanation for the seven-month delay between the Trust's response to the PHSO and the publication of the Ombudsman's second decision.

The PHSO's second draft report specifically prohibits B's mother from sharing the letter or its contents publicly. The PHSO cites s 15 of the Health Service Commissioners Act 1993 and the case of *R (Kay) v Health Service Commissioner* [2008] EWHC 2063 (Admin) to support its assertion that complainants are not allowed to discuss its draft findings. B's mother has endeavoured to clarify this with the PHSO as s 15 relates to information and material gathered in the course of an investigation rather than the PHSO's opinions but she has been unable to obtain a definitive view from the Ombudsman and staff have failed to respond to her emails asking them to explain their position. She has also offered to share this statement with the PHSO but this offer has not received a response. This means that, despite the inordinate delay in this case, B's mother is prevented from speaking out publicly on the letter she received in April 2014.

However, B's mother does not believe she is breaching the PHSO's 'gagging clause' by making the following points as they relate either to her own information or do not disclose information gathered by the PHSO in the course of the investigation or they reflect information obtained other than via the draft decision.

First, the PHSO decided that B was receiving speech and language therapy required by his statement of SEN but it is unable to point to any evidence it has gathered to support this;

Second, the PHSO (in a letter after the decision letter) created their own reason to justify B's discharge saying he had 'moved out of the area' when he had not.

Third, B's mother has expressed her concerns that the PHSO has delegated too much of its discretion to an unnamed clinical advisor and that the Ombudsman instructed a speech and language therapist to comment on issues outside her sphere of expertise, e.g. on information governance.

Fourth, the Ombudsman has persistently refused to confirm whether it believes the information disclosures required consent, and whether they were lawful.

Finally, B's mother has presented carefully compiled, contemporaneous evidence to support her complaint on several occasions to the PHSO. This has come from numerous sources. B's mother believes that PHSO has ignored much of it.

It seems to B's mother that the PHSO has actively tried to obstruct any findings against the Trust, specifically in relation to issues of care, requiring significant evidence to be submitted by B's mother on several occasions and then ignoring it. B's mother has even been asked to set out for the Ombudsman the law and codes of practice (including the relevant sections and paragraphs) she seeks to rely on. She feels this is unfair as many complainants would simply be unable to do this and it has taken a considerable amount of her time. Since April, B's mother has gone to great lengths to set out the substantial errors in the draft decision. She feels that the PHSO has refused to engage with her and has become intransigent as it does not wish to admit it has made multiple mistakes in this straightforward investigation. B's mother has asked several times that the draft decision be rescinded and that 'next steps' be agreed between herself and the Ombudsman so that a fresh draft can be issued for her comment. She has also made repeated requests for a meeting with PHSO staff so she can discuss the case without having to submit yet more written submissions. All requests for a meeting have been refused. The latest refusal coming in a letter on 11 November 2014.

In September, B's mother's written concerns were put to Mr Martin directly in a meeting with a PHSO campaign group but she has received no formal written response to this document. She specifically asked that the Ombudsman address the failings in its second preliminary decision and withdraw it. She also asked for a meeting to discuss 'next steps'. The PHSO telephoned her and said the matter would be passed to the same investigator for a review. B's mother contended that this was unacceptable and it was agreed that a new investigator would be appointed. The PHSO also promised to revert to B's mother setting out what further action the Ombudsman intended to take after staff had met to discuss this with the Director of Investigations, Russell Barr. She was told further inquiries would be made of the Trust. In October, she was also told that the matter had been escalated via the Ombudsman's personal casework team to ensure that it was given priority.

However, B's mother heard nothing further of substance save for the name of the new investigator. After asking the PHSO to clarify what it intended to do, she received a letter on 11 November purporting to suggest that staff had been waiting for *her* to file written comments on the draft decision and informing her that if she did not do so by 24 November, their decision would be made final. This means that the PHSO is potentially content to permit a flawed decision to be made final should B's mother not have time to submit written comments (which would be extensive) on the flawed decision by this date. The letter again refused her request for a meeting and made no acknowledgement of the detailed concerns she had raised, or her request for information. B's mother concludes that the Ombudsman

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intends to finalise this decision because once a decision is made final, B's mother will have to have recourse to judicial review to challenge its errors.



## Averil Hart



Averil Hart succumbed to anorexia following her A-Level exams. She lost a significant amount of weight and was admitted as an inpatient at Addenbrooke's with a BMI of just over 11. As she recovered, she accepted a place at University in Norwich to study creative writing. She was discharged from the Addenbrooke's unit to the Norfolk Community Eating Disorder Service (NCEDS), run by Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), with her medical monitoring the responsibility of the UEA Medical Centre.

After a significant delay, Averil had her first appointment with a psychologist, who took on the responsibility for weighing her, telling the Medical Centre that it would not be necessary for them to continue. Shortly after this, her appointments with her doctor ceased, leaving her only point of contact as her psychologist. During this time, her weight was recorded as declining, while her physical deterioration was dramatic. The cleaner in her flat thought she should have been in hospital on a drip, while her family, seeing her only three days after her last psychological appointment, realised she looked worse than she had been when admitted as an inpatient. Despite an emergency call, the only response was to schedule a review over a week later, by this stage, Averil had been admitted to hospital, and a week later, she had died.

### **Complaints to the NHS:**

The family raised complaints with the trusts involved, but received variable responses. The Norfolk and Norwich Hospital commissioned an independent external review, acknowledged mistakes and made a full apology for the deficiencies in their care. Addenbrooke's Hospital has also agreed to carry out an external review following further explanation of the family's concerns. These approaches reflect the seriousness of what happened, the wishes of the Hart family, and the need to acknowledge and learn from mistakes.

In contrast, the response from both UEA Medical Centre and CPFT has been less helpful, and suggests a focus on "reputation" at the expense of the quality of the service provided. A

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review into her care in the community was commissioned, but the family had grave concerns about the reviewer chosen, and were not given a separate opportunity to submit further questions. Having attempted to raise these questions this summer, the family has received an exasperated response, suggesting that answering questions such as “Did Averil’s psychologist have any experience of treating patients with anorexia?” was too much of a burden. The family didn’t even receive her full medical records on their original request. This culminated with a complete refusal to answer further questions.

**The PHSO:**

In August, the Hart family submitted an 80-page summary of Averil’ case to the Ombudsman. It detailed the manner in which the care was deficient, and the ways in which the Hart family’s concerns were handled by the different organisations involved. This was accompanied by a ring binder containing detailed logs of the e-mails sent and received, the reports produced and the various questions and responses received from the Trusts. However, it took over two months for an investigator to be appointed, and any information that the family received was given as a result of continuing inquiries and requests from Averil’s father.

After pressing for several weeks, the family arranged a face-to-face meeting with the investigator in order to discuss their main concerns and the practical considerations that would have to be taken in the course of the investigation. An agreed timescale has been reached, but at 12 months, it is lengthy given the amount of information provided. The

Patients Association continues to work with the Hart family, and will be following this investigation closely over the coming months.

## Jennifer Holt by Sam Holt



My wife Jennifer was suffering from Non- Hodgkin's Lymphoma and was in the process of receiving a second round of treatment at Ealing Hospital. Having reacted badly to the treatment and suffering from dizzy spells and falls at home, she was admitted to Ealing Hospital on 13th June 2011. Jennifer stayed on the clinical decision unit for two days and whilst there had further falls. She was then transferred to the Haematology Unit.

On the 15<sup>th</sup> June I received a telephone call advising me that my wife had incurred a serious head injury as a result of a fall in her room. An urgent CT scan had identified a blood clot on the brain and a possible fracture. I was told she was in a critical condition.

Over the next few days, my wife's condition moved from an (unconscious but agitated) coma-like state to being awake for short periods but non-cognisant. This improved over the next few days with her being able to converse with visitors and staff. However, a progressive loss of control was to the left side of her face was noticed over this period which caused difficulty in eating etc. She also complained of pains to the left side of her head and shoulder.

During this period, a member of my family was present at all times with me sleeping in a room at night.

It was decided that the cancer treatment would be stopped in order to re-assess her condition and she was discharged to my care on 23/06/11. Over the next few days her condition deteriorated, with the facial paralysis affecting the whole left side of her face (and left arm), making it extremely difficult to communicate, swallow food and liquids (administered by syringe in later days) and to clear her throat of congestion brought up from her lungs. My wife sadly died on 29/6/11.

Due to "communication problems" between the hospital and support organisations, no after care support was provided for several days after her hospital discharge (and only then due to my frantic phone calls) which left both my wife and I, as her carer, severely distressed.

A motorised bed turned up several days after her death.

I found it heart breaking when my wife finally saw herself in the mirror having arrived home (I was helping her clean her teeth before she became immobilised). The look on her face was one of horror and sadness and something which will stay with me forever.

In the last 3 days of her life she lost the use of speech and her left arm and hand which meant that she was unable to communicate with myself and her family and the things that should be said were not. When she passed away beside me in bed her eyes and mouth were open as though trying to speak to me. The wait of 6 days for the post mortem was very hard for me and my family, a process that would have been unnecessary had the hospital displayed more care in its duties. If risk assessment had been properly cascaded and / or adhered to, her last few weeks or months would have been one of dignity and in full body and soul.

I was promised an immediate investigation by the Hospital into the circumstances surrounding the fall. However, when I made enquiries regarding this a month later, I found that no investigation had started. This made me very angry and began the erosion of trust (in the Hospital) which has worsened with each subsequent meeting.

Whilst the Coroner's report confirmed that bronchial pneumonia (caused by her progressive disease) was the cause of death, it is my firm believe that the injury sustained in hospital was responsible for the speed in her decline and the difficulties experienced over her last few days.

Had this injury not occurred, I believe that my wife would have been alive for a while longer and would certainly have been more comfortable in her final days. Her inability to communicate also prevented her from being able to share her feelings with those around her.

Whilst there she suffered a further three falls, the last very serious which the family believed was avoidable, shortened her life and removed her dignity in her last few days. Given the reason for admission and the initial falls in hospital, we believed that insufficient care was taken to ensure her safety which was also demonstrated in the lack of attention paid to her discharge and palliative care.

### **Complaint to the NHS Trust**

The original complaint made to the Trust was in regards the quality of care received by my late wife from Ealing NHS Trust during her last admission as an in-patient in June 2011. The two key issues were:

A serious fall experienced by my wife in her room which we believed was avoidable.

The lack of palliative care arranged for my wife following her discharge from the hospital.

My wife was terminally ill and we believed that these two issues shortened her life and affected the quality of that life experienced during the few short days between hospital discharge and her death.

However, during our many meetings with the trust and a review of the hospital case notes, a number of additional concerns were raised around the general quality of care, poor adherence to procedure and poor records.

Although we have received an (inadequate) acknowledgement from the Chief Executive of the NHS Trust that “the care provided to your late wife in several ways fell short of the standard we aim to provide to all our patients”, The Trust have failed / declined to address the key issue regarding the fall and whether actions taken by individuals on behalf of the Trust were in error when considering hospital’s own risk assessments completed only hours before. In addition, there are still questions outstanding from our post meeting correspondence which identified discrepancies in the prognosis offered by the Macmillan team and the consultant in charge of the case. The Trust has confirmed that no further investigation or correspondence will be entered into.

I was promised an immediate investigation by the Hospital into the circumstances surrounding Jennifer’s fall. However, when I made enquiries regarding this a month later, I found that no investigation had started. This made me very angry and began the erosion of trust (in the Hospital) which has worsened with each subsequent meeting.

A number of meetings (commencing in August 2011) were held but apart from a number of concessions, the hospital declined to make an apology for the key issue (the fall and whether it could have been avoided with better nursing care and attention).

I spent 2 months on sleeping tablets and lost over 3 stone in weight due to the added stress caused by this incident and the ongoing attitude of the NHS Trust. I still find it difficult to sleep as I continue to think about the details of the case and feel that I have not been allowed to grieve in the normal way. I see my wife’s face at it was in the terrible condition after the fall every day in my mind and wonder if I could have done more to protect her.

## **The PHSO**

Due to the failings of the NHS Trust to investigate thoroughly, my sons and I wanted an independent assessment of the circumstances surrounding my wife’s fall and a review of the Trust’s findings and final response. In particular, we wanted a follow-up statement from the attending nurse who has been on maternity leave throughout the course of our meetings with the trust in order to establish whether she was made aware of the risk assessment before making her judgement call. For this reason we submitted a complaint to the PHSO.

The findings and final letter from the Ombudsman left many more questions than it answered. The final report, whilst finding against the Trust on a number of issues, stopped short of any overall damning indictment, ignoring the previous partial apologies made directly by the Trust. It also declined to cover; to our satisfaction, several areas which had been brought to light by its own report (the presence of a “Do not attempt to resuscitate” form which was never discussed with anyone from the family and the use of a coloured wristbands (in this case to highlight patients susceptible to falls - a procedure employed by the hospital but not used in Jennifer’s case). Indeed the report actually contained incomplete and incorrect information on the latter. What was particularly upsetting was the response from the Trust - paying lip service only to the Ombudsman’s direction (a routine letter of

apology, an action plan and a directed offer of compensation - **£250.00** - which was subsequently returned).

Unfortunately, the deadline to challenge the Ombudsman's process was missed due to a number of reasons. However, I continued to ask questions where possible and managed to arrange a follow up meeting at the Trust.

The Trust suggested that I approach Macmillan on site for more information regarding the facts around my wife's discharge (no apparent hospital-Macmillan handover meeting and no pro-active after care received). The on-site staff were unhelpful so I approached their head office. Whilst initially understanding and responsive, the organisation's attitude changed dramatically when it became apparent that they had; with my authority, made contact with the hospital. Several days of phone calls and messages remained unanswered and I had to resort to getting one of my sons to call to get anyone to pick up. When a call was finally received, it was made by an individual who advised they were unable to discuss the matter as they were calling from a public place!

I have now been advised in writing from Macmillan that their staff are, to all intent and purpose, Trust employees which currently leaves me nowhere to go but still with questions which need answering.

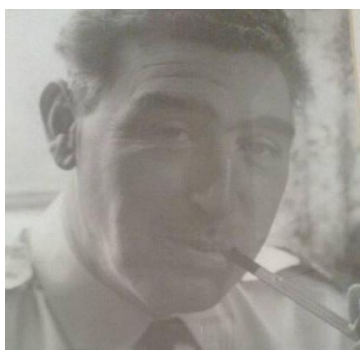
In essence The Ombudsman failed to thoroughly investigate my complaint. They fell short of making appropriate recommendations and directed the Trust to pay an insulting £250 compensation which was returned (please note – the complaint was never about money – only justice and a suitable level of recognition from the parties involved. However, when these authorities pay tens of thousands to their own staff for “hurt feelings” .....!). Having been interested in how the Trust's conduct had impacted on me and my family, the Ombudsman's final report was dry and detached.

Where was the damning indictment of the Trust's overall conduct?

It is up to me to continue to challenge the Trust and ensure any recommendations that were made are followed up. I now have nowhere to go because the PHSO failed me and my wife.

***Jennifer did not deserve what happened to her – she did no harm to anybody.***

## Stanley (Geordie) Nicholson by Linda Nicholson



My family and I originally complained to York Teaching Hospital NHS Foundation Trust regarding the poor treatment of my father during his time spent in their care. The Trust handling of my complaint was dealt with extremely poorly with poor communication, lengthy processes and a change in investigator 3 times. When we called to enquire if the response was running to date I found out it hadn't started. I asked for a letter to summarise where they were at and was informed of the change of a 3<sup>rd</sup> investigator. It raised concerns that our complaint was not being taken seriously.

When we received the final report none of our questions had been answered properly. Overall, the report was so contradictory and questions were added and replied to that were not ours that we were left with more questions than answers and we wrote back expressing we were not 'happy at all with it'.

The Trust answer to this was that the consultants involved were 'sorry but they feel they have nothing more to add at this time' and we were advised by them to contact the Parliamentary and Health Service Ombudsman to review the case. They also advised us to have a face to face meeting with consultants. We had been meeting with the consultants 'face to face' for 2 years twice a week and this had led to nothing. We felt very let down.

We submitted a Freedom of Information request (FOI) to the Information Governance Team (IGT) asking if we could have all the information used in the report undertaken by the Trust. This was denied to us and we were sent only a letter with the reasons why we couldn't have the file along with the Trusts complaints policy. Following advice I explained to the Trust that if they failed to respond we would make an application to the courts for pre action disclosure. The Trust then sent the report along with another letter, 'Alert to your concerns through your contact with the Complaints office, the Head of Patient Experience, is conducting a review of the conduct of the investigation'. We have never received this.

I wrote back to ask them to clarify we had all of the report. Only following involvement of the Information Commissioners Office did we receive correspondence some 8 months after our initial request with a letter explaining that some txt was covered for patient confidentiality. Yet they had sent it with the first report.

It turned out that even though we submitted our complaint on 31<sup>st</sup> December 2012, receiving a letter of acknowledgement on 2<sup>nd</sup> January 2013 informing us that an outcome would be with us by 11<sup>th</sup> March 2013 nothing had been done until I called in to check on the progress of the report on 23<sup>rd</sup> February 2013. We eventually received the final report on 23<sup>rd</sup> April

2013. It had taken only one month to investigate 2 years of our father's care. We did not mind how long it took if it was done properly.

Consequently our MP wrote requesting a separate FOI request on our behalf and was also refused. He had to write a personnel letter to the Chief Executive of York Hospital and received it with a letter of apology.

The unsatisfactory outcome and poor handling of our complaint led us to get in touch with the PHSO hoping that they would be able to investigate our complaint properly, as stated below this turned out not to be the case.

## **Complaint to PHSO**

In July 2013 we submitted our complaint regarding the Trusts investigation to the Parliamentary and Health Service Ombudsman, our MP also wrote on our behalf. We had a letter of acknowledgement within a week. There were phone calls from an investigator to clarify and summarise our complaint and we received a letter in September stating, "We propose to investigate your complaint. We summarise your complaint as follows."

I called and said that some of the facts in the investigators summary were not correct and we went through it. My brother also emailed his version to help and offered to meet the investigator as he works close by. There were further occasions through phone calls where the investigator for the Ombudsman continued to ask us to summarise our complaint. As well as the manner at which I was spoken to which was rude and rushed, I felt concerned that I was constantly having to summarise my complaint.

The investigator called me in early December and asked me to clarify, once again, some points in our complaint. I felt she did not have a grasp of the complaint and continued to be rude. I spoke to her manager who informed me the investigator was, 'good at her job and it was too late to change investigators'. We decided that if the investigator did a good job we could ignore the rest.

We received a letter in December 2013 confirming their acceptance of our case for investigation. Further communication came through in February 2014 saying they were finding it difficult to locate a specialist clinical advisor who would be able to take on our case, eventually one was found and a phone call confirmed this to us on the 5<sup>th</sup> March.

We received no further communication from the Ombudsman until 22<sup>nd</sup> May 2014 when we received a letter stating that 'no further action' was to be taken against York Teaching Hospitals NHS Foundation Trust and 'after careful consideration, we have not identified any failings by the Trust'. We were told that we only had until 5<sup>th</sup> June to respond to this if we felt there were, 'significant gaps or facts that are not correct', within their report.

We were totally shocked with this outcome and could not believe that the Ombudsman had found no failings with York Hospital and was further surprised that we only had **2 weeks** to respond to this. *We had spent nearly a year putting everything together, going through our father's medical notes and compiling our complaint. We had also spent 8 months writing back and forth to the IGT and the ICO due to our FOI request and then a further 6 months summarising it all to the Ombudsman. We now had only 2 weeks to respond to a mass of reasons why they found no failings. We now had to defend their decision.*



I called the investigator expressing our concerns at the findings and the thoroughness of the investigation. I re-emphasised to her manager, when she called me, our disappointment and explained that we had done our best as lay people to express the pain and horror our father had gone through during the two years at York Hospital. I also explained my surprise at not being interviewed face to face by either the Ombudsman or the Specialist Clinical Adviser. It also concerned me that the consultants, outside of York hospital who guided us through my father's care had also not been interviewed.

What worried me further was that whoever had made the final decision had made it based on the contradictory and misleading information given by the consultants at York hospital in response to our original complaint.

I explained that we now only had **two weeks** to go back through everything again and respond to the ombudsman's investigation which I felt had not been investigated at all. She asked me how long I would need and I explained that I would again have to get my father's medical notes and letters out, spanning 2 years and find the relevant points and do the investigation I hoped the Ombudsman would. We agreed to the 1<sup>st</sup> of July.

On 23<sup>rd</sup> June I requested a further extension to submitting evidence as I was finding it difficult, being a lay and not an academic, and had been unwell. I explained that I was struggling to complete all the evidence needed. I requested an extension until 1<sup>st</sup> September but this was refused and I was only given until 1<sup>st</sup> August or appeal would not be considered.

I heard on the radio of a family who felt a proper investigation had not be done by the Ombudsman and had to do it themselves. Dame Julie Mellor, Head of the Parliamentary and Health Service Ombudsman, had apologised and said it was an isolated case. I knew this not to be the case as were experiencing the same so I called her secretary. I spoke to Dame Julie Mellor's secretary on 2<sup>nd</sup> July. She said she knew the right person to speak to and said she would get them to email me. I have heard nothing to date.

Eventually the extension date was agreed but this was only following very lengthy and emotional contacts with the Ombudsman.

We submitted our complaint to the Ombudsman investigation on 1<sup>st</sup> September.

I was concerned that information regarding the nursing care my father received had not been submitted in our initial response and I had not been able to summarise it before sending in our appeal on 1<sup>st</sup> September. I enquired if this important information could be added to our evidence. This request was declined by the PHSO.

We were told they would get back to us, 'in due course' and as I had not heard anything for nearly 2 months I called and emailed to find out how they were proposing to respond to our complaint Then after several calls and emails to the Ombudsman which were not responded to and ignored it turned out nothing had been done and the re investigation did not commence until 1<sup>st</sup> November. This was at my instigation due to my calling to see how it was progressing. In addition we were not notified of significant management staffing changes which impacted on our case.

The PHSO most recent responses indicate that they have not yet started responding to our complaint because we were told they are 'currently' considering our comments. There are serious communication failings on behalf of the Ombudsman.

## Kate Griffin - in her own words



I had a hip replacement operation on 7 January 2010. This was an NHS operation done in the private sector: the BMI Hospital in Huddersfield.

A hip replacement carries the highest risk of deep vein thrombosis and pulmonary emboli. This is very generally acknowledged and there have been very clear NICE guidelines (since at the very least 2007) on the prevention of these complications. Aggressive anti-coagulant, usually low molecular weight Heparin, (one named brand of which is called Clexane and is in very common use) is strongly recommended, to be given to the patient by injection within six hours of the operation, and every twenty four hours thereafter for 35 days. The very, very small cohort of patients for whom such treatment is not recommended are those who are likely to suffer bleeding and can be easily screened beforehand.

I told the surgeon, who performed my operation that there was a history of thrombosis in my family, unfortunately there was no one else present at that consultation, so I cannot prove what was said. NICE guidelines on thromboprophylaxis were not followed. The only chemical thromboprophylaxis offered by the hospital was 150mg of aspirin within twenty four hours of the operation and to be repeated daily for six weeks. In my case I was not given any aspirin at all for the first forty eight hours by which time I was already experiencing chest pain which I later realised was the first evidence of the pulmonary embolism (PE).

I became breathless within a few days, was admitted to Huddersfield Royal on suspicion of pulmonary emboli which was confirmed by CTPA scan. There were extensive, multiple, bilateral PEs, which have caused permanent, irreversible damage and left me with extreme, worsening breathlessness and chest pain. I have recently been diagnosed with chronic thromboembolic disease.

### **Complaint to the Primary Care Trust**

I initiated a complaints procedure against the hospital on several counts: the inadequate thromboprophylaxis, as well my concerns about poor record keeping and the pre-operative assessment.

I felt very let down by the Primary Care Trust, (they were still in existence then). It seemed that it was down to me to make the complaint. I kept stressing to the PCT complaints manager that my complaint was against the PCT as the commissioning agent and the funder of the operation in the first place. This lack of support from the PCT left me feeling very isolated and as though I had no hope.

My husband and I, had many meetings at both the Kirklees Primary Care Trust and the Huddersfield BMI Hospital. Finally, on 11 July 2012, a response from the Huddersfield BMI

Hospital was provided, and although I found it unsatisfactory they were able to “close” the matter. I could have taken it to the chief executive of the BMI, Stephen Collier, a barrister, but that would be the route of a private patient, and then it would have gone to a private patients’ complaints tribunal. As mine was a NHS operation I wanted it kept in the NHS. After some discussion I was allowed to go to the Ombudsman.

### **Complaint to the PHSO**

Complaint to the PHSO about inadequate thromboprophylaxis following an NHS operation for hip replacement performed at the Huddersfield BMI Hospital resulting in extensive pulmonary emboli which have developed into chronic thromboembolic disease.

I had a hip replacement operation on 7 January 2010. This was an NHS operation done in the private sector: the Huddersfield BMI Hospital.

I found the Trust response unsatisfactory and I contacted the Ombudsman on 19 September 2012.

### **The PHSO**

The PHSO consulted one orthopaedic surgeon who said that aspirin was perfectly adequate thromboprophylaxis even with a family history of thrombosis; NICE guidelines, it seems, can be ignored. It didn’t matter that I didn’t get any aspirin for 48 hours, (in spite of it being prescribed on my drug chart for operation day onwards) because: “it was well recognised” that no one got deep vein thrombosis or pulmonary emboli’s during the first few days after an operation. I was stunned by his response on two counts:

- There is plenty of evidence of patients getting deep vein thrombosis and pulmonary emboli’s very soon after an operation, (and in my case I was experiencing chest pain before I was given my first aspirin).
- And surely the point of prophylaxis is to prevent, i.e. prepare the body in advance of a possible insult. Neither aspirin nor any other anti-coagulant would be effective after the event. What anti-coagulation does is to prevent any further clotting, and it does not — in spite of current mythology — “dissolve” clots.

This response to my concerns about the drain bag were to say that nurses had never seen any clots in one of those drain bags. This was illogical and irrelevant.

The final adjudication from the PHSO was on 23 April 2013. None of my complaints were upheld. The nurse who was consulted about the poor record keeping expressed concern but this was not followed up.

I felt a sense of despair, I know that I could marshal an army of surgeons whose opinion and practice would counter that of the surgeon brought in by the PHSO, but that road was not available for me.

## The Patients Association Findings

1. The jurisdiction of the PHSO is unclear, leaving ill-defined boundaries between the organisation and other public funded bodies such as the CQC.
2. The PHSO hides its failings behind legislation.
3. Individual cases take far too long to be assigned to an investigator and subsequently, the investigations are far too lengthy.
4. The current process relies heavily on families providing the burden of evidence. If evidence is not presented by the families, the PHSO does not look further to find it.
5. There are too many gaps involving clinical decisions that the PHSO refuse to investigate, therefore families fall into a bureaucratic no man's land, for example, cases under the Mental Health Act or where there is a case of Do Not Attempt Resuscitation (DNAR).
6. The right people, with the right skills, are not always assigned to cases and as a consequence, can negatively impact on the outcome of an investigation.
7. Investigations are not diligent, robust or thorough.
8. The PHSO investigators fail to appropriately consult medical and clinical advisors who might be available to them.
9. Complainants are refused the chance to meet with the person investigating their case, in order to explain their concerns, agree the remit and terms of reference of the investigation, timelines and communication pathways.
10. The PHSO fails to acknowledge that many relatives have intimate knowledge of the care received by their loved ones and detailed facts relating to their particular case.
11. The PHSO also declines requests from families for additional crucial information and evidence to be submitted, once a written complaint has been made and an investigation has begun – they frequently ignore evidence from families and carers.
12. Linked to this, there is little evidence that PHSO investigation conclusions are entirely evidence based. Crucial mistakes in investigations result in flawed decisions and recommendations.
13. As a consequence, the PHSO continually make errors of judgement and mistakes, which ultimately leads to re-investigations, which then result in additional cost to the public purse and considerable further distress to the families.
14. The PHSO compound their errors by frequently re-assigning the same investigators to re-investigations. As a consequence, mistakes made the first time round remain

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unchallenged and are even, on some occasions, repeated. The investigators are in effect re-investigating themselves.

15. If and when the PHSO appeal process agrees to a re-investigation and despite their possession of the papers from the initial investigation, the families are expected to submit all the relevant papers all over again and are only afforded two weeks in which to do so.
16. The PHSO requires families to keep the outcomes of draft reports confidential under dubious application of the law, effectively gagging the families concerned.
17. Families are not consulted prior to finalisation of reports and as a consequence, have no influence or say regarding the final recommendations.
18. Even when recommendations are made, there is little evidence that they are followed up, reviewed or the Trusts held to account for failing to implement any recommendations.
19. Throughout the whole PHSO process, families are left distressed, exhausted and distraught by the failings of the body to carry out their public function in an efficient, effective and caring manner.
20. In real terms, the total cost to society and families of the PHSO far exceeds the £40 million funding the body receives.
21. The PHSO appears to be both unaccountable and untouchable.

## Conclusions

The cases highlighted in this report and described in their own words by the families who have dealt with the PHSO, reveals just how poor the service provided by that body has become.

The PHSO claims that it is changing the way in which it treats patient deaths and historic cases, is unmatched by the reality. Stating publicly that there needs to be more “care and compassion and an end to the toxic culture in the NHS” is one thing, but further action must be taken to ensure that the Ombudsman actually helps people, rather than just adding to their suffering or indeed that toxicity. Their claims designed to sound impressive actually lack sincerity or meaningful content.

We continually hear from distressed and grieving relatives who are refused meetings by the PHSO or unable to understand how crucial mistakes in investigations, make final decisions flawed. Families describe feeling ‘stonewalled’ by the PHSO and totally kept in the dark throughout non transparent and inadequate investigations.

We need an Ombudsman that adopts the same set of principles it expects NHS Trusts to adopt when handling complaints.

If it is wrong at the top of the complaints process, it will be wrong all the way through the system. We cannot expect Trust’s to handle complaints appropriately, when they know the PHSO are unlikely to carry out thorough investigations and therefore find failings.

The evidence we have gathered gives a public perception of the PHSO as lacklustre, weak, secretive, unaccountable, untouchable and ineffective.

The total cost to society and families of the PHSO far exceeds the £40 million funding the body receives. The emotional cost for many families left exhausted and distressed through their experience with the PHSO far outweighs the huge financial cost. The Patients Association therefore continue to be drawn to the conclusion that the PHSO remains unfit for purpose.

If the PHSO was transparent and if complainants were involved, listened to and engaged with the PHSO, the emphasis and remit of the investigation would be clear to all parties. The investigators would be looking at and understanding fully what happened, what went wrong, how and why it went wrong. Most importantly and of paramount importance, sharing the learning on how to avoid the same thing happening again would be commonplace. The PHSO would be the crucial catalyst for change in the NHS.

## Recommendations

1. It is time for an independent review of the role and accountability of the Ombudsman.
2. A more publically accountable PHSO.
3. Legislation applied to the PHSO should be reviewed.
4. The statutory duty for NHS Trusts to adhere to the principles of *being open* should be extended to the PHSO handling of complaints.
5. Clearly defined organisational boundaries and jurisdiction must be established.
6. A review of case by case costings by the National Audit Office.
7. PHSO's paper-based procedures need to be completely overhauled.
8. An independent appeals process for PHSO investigations.
9. A code of practice for investigators.
10. Terms of reference for each investigation must be agreed with the families at the commencement of an investigation.
11. A review of time lines for the completion of investigations.
12. Face to face meeting with the complainant/s at the commencement of an investigation.
13. Agreed regular face to face meetings with complainants at each stage of the investigation.
14. Independent advocacy support available for all complainants.
15. Time lines for submissions of appeals must be extended.
16. It should not be under the remit of the PHSO to recommend monetary settlements to complainants.
17. To ensure learning the PHSO must influence change and ensure Trusts adhere to recommendations following appropriate investigations.

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## *Mission Statement*

*The Patients Association is a healthcare charity which for more than 50 years has advocated for better access to accurate and independent information for patients and the public; equal access to high quality health care for patients; and the right for patients to be involved in all aspects of decision making regarding their health care. By listening to patients, we are able to campaign to improve services. We will work with all healthcare providers to improve services. Very often patients think they are alone with the problem or complaint they have. When patients talk to us we are able to track problems arising in more than one place and realize there is a nationwide issue that needs change.*