



NHS accused over deaths of disabled patients  
*the Guardian*: 3 January 2012



## **Death by *indifference*: 74 deaths and counting**

### **A progress report 5 years on**

## Contents

Introduction	1
74 cases and counting	4
The contributory factors	8
Lack of basic care	9
Poor communication	10
Delays in diagnosis and treatment	12
Failure to recognise pain	14
Do Not Resuscitate orders and the Mental Capacity Act 2005	15
Fighting for justice and change	17
Progress on the <i>Healthcare for all</i> recommendations	20
Conclusion	29
Appendix	31
References	36



## Introduction

In March 2007, Mencap published *Death by indifference*, which reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. The report put the spotlight on the tragic consequences of the healthcare inequalities experienced by people with a learning disability. These inequalities had been clear for years, but it took the deaths of Emma, Mark, Martin, Ted, Tom and Warren – and the bravery of their families in telling their stories – to bring about change.



*Death by indifference* triggered an independent inquiry and an investigation of the six cases by the Parliamentary and Health Service Ombudsman. This resulted in the government accepting all the recommendations of the inquiry and setting out their delivery in the Department of Health strategy for people with a learning disability, *Valuing People Now*<sup>1</sup>.

### Key reports

**2004:** *Treat me right!*, Mencap

**2007:** *Death by indifference*, Mencap

**2008:** *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*, Department of Health

**2008:** *Six Lives*, Parliamentary and Health Service Ombudsman

**2009:** *Valuing People Now*, Department of Health

**2010:** *Six Lives Progress Report*, Department of Health

Mencap knows there are parts of the NHS, as well as other organisations and individuals, that are making a real effort to address the problems of access to equal healthcare for people with a learning disability. More than 200 healthcare organisations have signed up to our *Getting it right* charter. We have also been extremely impressed by the work of some Strategic Health Authorities and key individuals, such as learning disability liaison nurses, and the excellent examples of good practice that have been shared with us. But equal healthcare is a legal obligation that should be embedded in the everyday running of the NHS, in every GP practice and in every hospital ward, not an exercise in identifying pockets of good practice.

The publication of the Death by *indifference* report also prompted a number of families to contact Mencap, and they continued to do so in the weeks, months and years that followed. It is these cases – a total of 74 to date – that form the basis of the article published in *the Guardian* on 3 January 2012. Mencap believes they are only a tiny proportion of the actual number of such cases. They do, however, highlight an NHS that continues to fail people with a learning disability, doctors whose practices appear to show no regard to the Equality Act or Mental Capacity Act, and nurses who fail to provide even basic care to people with a learning disability.

These shocking cases, each as serious as the six in our Death by *indifference* report, must also be seen in the wider context of the strong criticisms made about the performance of the NHS in regard to other vulnerable patients, such as older people.<sup>2</sup> These accounts echo our own concerns that the NHS is too often failing to provide the most basic nursing care such as nutrition, hydration and pain relief, and is denying people dignity and respect. This lack of dignity and respect, together with the poor nursing care that is too often experienced by people with a learning disability, is illustrated by Alan's story.

## Alan MacDonald



Alan MacDonald died suddenly in Lister Hospital, Stevenage, on 20 December 2009, aged 53. Alan had lived independently with his wife, supported by carers. Alan had Down's syndrome and a moderate learning disability, and was considered by his family to have a "full and active life". He enjoyed going to the day centre and local cricket club.

Three days before admission to hospital, Alan was noted by his family to be "in fine form". However, on 15 December 2009, he was admitted to hospital with abdominal pain and diarrhoea. From the time Alan was admitted, his family felt they had to "beg" staff to treat him, only to be met with "hostility".

On one occasion, for example, a member of Alan's family who is a doctor asked nurses to give him paracetamol intravenously to treat his dangerously high temperature. She said that this request was "again met with hostility". Summing up her feelings about Alan's nursing care at the hospital, she said: "I felt the nurses on the ward did not respect a gravely ill patient with special needs and a grieving family. Instead of using respect, tact, care and understanding, I and the rest of Alan's family were faced with hostility, disrespect and no consideration for the distressing situation." The cause of death was multiple organ failure, sepsis and bronchopneumonia.

After a protracted complaint against it by Alan's family, the hospital has finally apologised for the attitude of some of its nursing staff. But, for the family, the lack of respect shown for their loved one is something that will never be forgotten.

It is now nearly five years since Mencap published *Death by indifference*<sup>3</sup>. In this report, we consider the steps that have been taken, the progress made as a consequence and what we believe still remains to be done. We pay particular attention to deaths that have been reported to us between 2009 and 2011. We do this because it is these cases that illustrate most strongly our serious ongoing concerns that not enough progress has yet been made in addressing the health inequalities experienced by people with a learning disability.

## 74 cases and counting

“Every person who reports their concerns about their relative’s death is a person too many.”

Dr Pauline Heslop, Director of the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities<sup>4</sup>

### **What do the deaths of 74 people over the last decade tell us about the progress of the NHS in tackling the health inequalities of people with a learning disability?**

This section of the report explains how we gathered the 74 cases and what they have in common in terms of the factors that we and the families of the deceased believe contributed to their deaths.

It must be said at the outset that these 74 cases were all brought to our attention because of someone’s strong belief that their loved one’s death, or the distress they experienced up until their death, could have been avoided; they are not drawn from any sort of scientific study. They do not, therefore, tell us how many other cases there were across the country or, indeed, in the same hospital, or where else there were similar failings in treatment and care. The scale of the problems will only be known when the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities reports to the Department of Health in 2013.

These 74 cases do, however, provide a litmus test of progress. They are sufficient and serious enough for Mencap to raise strongly held concerns that progress is neither wide nor deep enough to have effected real change in all parts of the NHS.

The 74 cases are listed in the appendix to show each person’s name or initials, the date of their death, the place of death, the contributory factors and the stage of complaint. Many families simply wanted to tell us their story and to say that what happened to their loved one echoed the stories in our *Death by indifference* report. For most of these cases, either it was far too late to complain to the NHS or this was not what the family wanted (see table 1 in the appendix).

With the families’ agreement, we have summarised these stories and included them in our submission to the Michael inquiry and in our oral evidence session in the autumn of 2007<sup>5</sup>. We have categorised them into three groups:

## 1. Deaths before 2007: 15 cases

Represented in this first group of cases are 15 families who, struggling with the NHS complaints process, asked for our help. We have given this by providing case work services to each one, and our knowledge of the events leading to the death of their loved one is detailed (see table 2 in the appendix).

Name	Date of death	Hospital/Trust/PCT
<b>Sophie Ham</b>	Jan 02	Poole Hospital NHS Foundation Trust
<b>Kirsty Pearce</b>	Aug 03	Basildon & Thurrock University Hospitals
<b>Mark Cannon</b>	Aug 03	Barking, Havering and Redbridge Hospitals NHS Trust
<b>Lisa Sharpe</b>	Feb 04	Basildon & Thurrock University Hospitals
<b>Barbara Thomas</b>	May 04	Queen Alexandra Hospital, Southampton
<b>Ted Hughes</b>	May 04	Buckinghamshire Hospitals NHS Trust
<b>Tom Wakefield</b>	May 04	Gloucestershire Partnership NHS Foundation Trust
<b>Emma Kemp</b>	Jul 04	Royal Berkshire NHS Foundation Trust
<b>Warren Cox</b>	Sep 04	East Sussex Hospitals NHS Trust
<b>Daisy Healy</b>	Oct 05	Kettering Hospital
<b>Martin Ryan</b>	Dec 05	Kingston Hospital NHS Trust
<b>Chantel Edwell</b>	May 06	Bedford Hospital
<b>Carole Foster</b>	Oct 06	Fairfield Hospital
<b>Kyle Flack</b>	Oct 06	Basildon & Thurrock University Hospitals
<b>M A R</b>	Oct 06	Hospital – Surrey

## 2. Deaths in 2007–2008: 10 cases

This category covers the period from the publication of *Death by indifference* in March 2007 until December 2008. The cases in this group illustrate many of the contributory factors set out in our original report (see table 3 in the appendix). In the two years that followed the publication of *Death by indifference*, inquiries and investigations were underway. While it would not have been reasonable to expect the recommendations in Sir Jonathan Michael's report (July 2008)<sup>6</sup> to be implemented, it would have been reasonable to expect some progress to be made after revelations in *Death by indifference*.

Name	Date of death	Hospital/Trust/PCT
<b>A B</b>	Jan 07	Hospital – Staffordshire
<b>D B</b>	Feb 07	Hospital – South East London
<b>Betty Dennis</b>	Apr 07	North Middlesex Hospital
<b>Maria Manitará</b>	Apr 07	Barnet Hospital
<b>Barbara Dyson</b>	Nov 07	Royal Hallamshire, Sheffield
<b>Christian Harrison</b>	Feb 08	Queen Elizabeth II Hospital, Margate
<b>L H</b>	Feb 08	Hospital – Avon
<b>T B</b>	Feb 08	Hospital – Essex
<b>Karen Mansbridge</b>	Jun 08	Royal Berkshire NHS Foundation Trust
<b>L R</b>	Nov 08	Hospital – Southampton

### 3. Deaths in 2009–2011: 28 cases

These recent and extremely serious cases cause us great concern (see table 4 in the appendix). They are in no way representative of the scale of the problem but are significant enough for us to raise questions: ‘Is enough being done?’; ‘Is it being done fast enough?’; ‘What more should be happening to stop more people from dying while in the care of the NHS?’

Name	Date of death	Hospital/Trust/PCT
<b>Clive Sanders</b>	Jan 09	Royal Berkshire NHS Foundation Trust
<b>Paul Ridd</b>	Jan 09	Morrison Hospital
<b>Tina Papalabropoulos</b>	Jan 09	Basildon & Thurrock University Hospitals
<b>Brian Nicholls</b>	Feb 09	Royal Berkshire NHS Foundation Trust
<b>Christopher Peters</b>	Feb 09	Aintree University Hospital
<b>E M C</b>	May 09	Hospital – South West
<b>G G</b>	May 09	Hospital – East London
<b>Ronnie Eaton</b>	May 09	Salford Royal Hospital
<b>Kelly Doherty</b>	Jun 09	Newham University Hospital
<b>E D</b>	Sep 09	Royal Free Hampstead NHS Trust
<b>E L</b>	Sep 09	Hospital – Gloucestershire
<b>David Ingleby</b>	Oct 09	University Hospitals Birmingham NHS Trust
<b>Michael Cosgrove</b>	Nov 09	Kettering Hospital
<b>Alan MacDonald</b>	Dec 09	Lister Hospital
<b>E W</b>	Feb 10	Multiple hospitals – South East
<b>Sandra Baker</b>	May 10	Southampton General Hospital

Name	Date of death	Hospital/Trust/PCT
<b>Anne Clifford</b>	Jul 10	Croydon University Hospital
<b>Nicholas Garside</b>	Aug 10	UHCW Coventry & Warwick
<b>B M</b>	Dec 10	William Harvey Hospital
<b>David Tait</b>	Dec 10	Royal Berkshire NHS Foundation Trust
<b>A G</b>	Jan 11	Hospital – Greater Manchester
<b>Sammy Roberts</b>	Jan 11	Northamptonshire General Hospital
<b>Susan Read</b>	Feb 11	Lewisham Hospital
<b>Noel Tomlinson</b>	Mar 11	Hull Royal Infirmary
<b>Raj Vohra</b>	Mar 11	West Middlesex Hospital
<b>F C</b>	Jul 11	Hospital – Birmingham
<b>M Q</b>	Oct 11	Hospital – London
<b>Jasseke Van Dok</b>	Nov 11	North East Essex PCT

### Stage of complaint

Later in this report, we deal with the inadequacies of the NHS complaints process. Here, it is important to note the timescale in which detailed responses to complaints are received from the individual hospitals and GP practices and, where appropriate, from the Parliamentary and Health Service Ombudsman. On average, it takes between 18 months and two years to complete the local stage, and between two and four years to complete the ombudsman stage. For legal purposes, the article in *the Guardian* relied on case studies that had completed the whole process. However, this in no way invalidates the serious nature of the complaints where we are actively supporting families through the earlier stages of the process.

## The contributory factors

The data in the appendix broadly categorises the common factors that have been identified across the cases. In this part of the report, we consider these in more detail and illustrate them through case summaries. In our Death by *indifference* report, we accused the NHS of institutional discrimination. Five years on, we stand by this.

Our cases show that, despite some encouraging evidence of a better understanding of the concept of reasonable adjustments across the NHS, a lack of compliance with the Disability Discrimination Act (now the Equality Act) underpins the failures identified by families. They illustrate both direct discrimination from NHS staff and a failure to take the steps required by the law. These failings, combined with a striking lack of compliance with the Mental Capacity Act, make it clear that the very people this legislation was designed to protect remain at risk.

Central to all of this is the lack of value placed on the life of someone with a learning disability. It may not be recorded in medical notes, but it is unmistakably clear in the experiences that families of people with a learning disability have shared with us.

Since the article in *the Guardian* was published, the family of a 22-year-old man with cerebral palsy and a learning disability who died in hospital in 2008 contacted us to ask for help.

“I have never been happy with his care whilst in the hospital. To me it was minimal at best. I got the impression that they made a judgement about his quality of life and decided that his life was not worth preserving.”

Families should never have to fight to convince doctors that the lives of their loved ones are worth saving. Assuming that the life of a person with a learning disability is a burden – to both themselves and their carers – and that it would be better for everyone if they were just ‘let go’, leads their families to absolute desperation.

Many people with a learning disability do not have family and carers to advocate for them. It is vital that all NHS staff take responsibility for challenging underlying assumptions. They must give the same quality of care and treatment to all patients, including those with a learning disability.

## Lack of basic care

“We’re not geared up for people with a learning disability.”

**26 families reported that there had been a lack of basic care in the hospital.**

In most of the cases that Mencap has been told about since publishing *Death by indifference*, families and carers told us that they have had to carry out caring duties such as cleaning, feeding and administering medication to patients with a learning disability during their time in hospital. One parent told us: “I worry for those people who don’t have families or carers who are able to stay with them”.

Duty of care is a legal requirement due to all patients, but for people with a learning disability it is often overlooked. Families have told Mencap that they have had to give round-the-clock nursing care and that they are too concerned for their relative’s wellbeing to leave their side. They tell us if it were not for them being there, basic tasks such as feeding, providing drinks, washing and changing would not get done in a way that would properly meet that person’s basic needs.

Too often, hospitals rely on family members or paid carers to take on this role without proper care plans being in place. If family carers want to take on caring responsibilities in the hospital environment, staff should support them to do so, but clear definitions of exactly what they are taking on must be drawn up. Administering medication and other medical procedures should never fall to families or carers.

### Susan Read



Susan died on 1 February 2011 in St Christopher’s Hospice in Sydenham, having been transferred the previous day from Lewisham Hospital. She was 59 and had cancer. Although Susan had been diagnosed with breast cancer some years previously, she had lived happily with her sister Brenda. Both were actively involved with their local Mencap in Lewisham and Susan often volunteered at events and outings.

Susan was admitted to Lewisham Hospital on 15 January 2011 with vomiting and jaundice. Like so many other family members and carers, Brenda visited Susan every day and made herself known to staff as Susan’s main carer.

As there was no learning disability specialist nurse available on the ward, Brenda found herself regularly explaining to staff about Susan's care needs and becoming increasingly frustrated by the general lack of understanding and awareness about learning disability, which seemed to permeate the hospital. At one low point, Brenda was told by the matron that her staff "don't encounter people with learning disabilities in hospital that often".

Consequently, no adjustments were made to accommodate Susan's needs, leaving Brenda fearful and anxious for Susan's treatment unless she was there on an almost round-the-clock basis.

Despite a complaint to the hospital by Brenda about a potential breach of the Equality Act for a failure to make reasonable adjustments to accommodate Susan's learning disability, progress has been slow. Even now, a year after Susan's death, it has yet to be demonstrated that staff have any more awareness about learning disability and their duty of care and duty to provide equal access to healthcare to patients with a learning disability.

It is shocking that any hospital would view a patient's learning disability as an excuse for not having met their basic nursing and care needs. If patients have complex needs, staff need to have access to specialist support such as that offered by learning disability liaison nurses. Many hospitals now use hospital passports which, together with the crucial advice that families or paid support staff can provide, give the information needed to provide good quality care.

## Poor communication

**24 families reported that there had been poor communication between themselves and hospital staff.**

**“If medical staff had listened to the concerns of David's family, he may still be alive today.”**

## David Tait



David Tait died at Royal Berkshire Hospital, aged 49. He had a moderate to severe learning disability and lived in a supported living service. He visited his family often and loved to go on family holidays with them. David's family remember him as a very spiritual person. His favourite time of year was Christmas and he particularly loved singing carols. He was hugely looking forward to Christmas 2010, but sadly was not able to see it as he became ill and died in December of that year.

Margaret Tait, David's mother, remembers clearly the day when David was admitted to hospital, as he was taken there from her house, where she had witnessed him having three seizures, each time unable to breathe. David eventually passed out. The paramedics who attended David were very worried about his abnormal heart rhythm and wrote a detailed report about their concerns. Unfortunately, this report was not passed to the hospital.

This is just one of many examples of the poor communication that Margaret feels contributed to David's death. Another was the hospital's failure to listen to Margaret's warnings about David's heart condition and a previous medical diagnosis of a thickening in his heart valve. Even now, Margaret does not understand why David was treated solely for asthma rather than for the heart problems he was clearly presenting. David subsequently died of a heart attack at the hospital on 13 December 2010.

At Margaret's insistence, the hospital has agreed to conduct a full investigation into the circumstances surrounding David's death. The results of the investigation are not yet known.

Many families and paid carers report the difficulties they face in getting health professionals to take crucial information about the needs of the person with a learning disability into account. Rather than seeing attempts to share such knowledge as a hindrance, professionals should use it to help them meet the needs of their patients. There are now excellent tools to assist in passing over this

essential information, such as hospital passports, grab sheets and communication books.<sup>7</sup> It is disturbing to hear that some hospital staff are still ignoring advice and information that could improve treatment and save lives.

## Delays in diagnosis and treatment

**26 families reported that there had been delays in making a diagnosis and starting treatment.**

“Diagnosis may be difficult in people with learning disabilities if they cannot describe signs and symptoms clearly. ‘Watch and wait’ will only work if the watching is close and skilful, with a full history taken from those who know the person well and appropriate additional investigations used if the diagnosis is unclear.”<sup>8</sup>

### Jasseke Van Dok



Jasseke was 27 years old when she died of kidney failure due to high calcium levels in her blood. She had a severe learning disability, autism and no verbal communication. Her family described her as a “super-fit” young lady who liked sport and outdoor games. This was one of the reasons that her carers became concerned when they noticed a rise in her blood pressure and the fact that she seemed unusually tired.

Jasseke also started vomiting so they took her to see her GP on 16 September 2011. Despite having raised their serious concerns about her worsening condition, Jasseke’s family recall that they were told very rudely that they were “worrying over nothing and that Jasseke was perfectly fit,” so they took her away for a short holiday. Over the following weeks, Jasseke continued to deteriorate. She became increasingly weak and the vomiting came back but, despite return visits to her GP, no action was taken.

On 3 November, Jasseke collapsed and was eventually admitted to the critical ward of the local hospital. Here, her family were told that Jasseke's kidneys had completely failed. She died on 4 November 2011.

Jasseke's parents believe that the death of their daughter was "wholly preventable" and that she died due to the failure of the GP to take their concerns seriously. The family have complained to NHS Northeast Essex – the Primary Care Trust (PCT) responsible for Hilton House Surgery – that the doctor refused to investigate Jasseke's symptoms or even to take a simple blood test, despite the pleadings of her family and carers.

“It is also important to be aware that decisions about the risks and benefits with specific treatments may be affected by spoken or unspoken assumptions about the current or future quality of life of an individual, and to guard against this.”<sup>9</sup>

Failures and delays in reaching a diagnosis clearly result in delays to the onset of the appropriate treatment. But in Mencap's view, this is often not the only reason. Making a diagnosis when someone cannot communicate their symptoms directly to NHS staff can be a challenge. This can be compounded by dangerous assumptions that the ways people have available to them to express pain or that they are feeling very unwell, such as changes in behaviour, are just characteristics that are part of their learning disability.

Some of the Mencap cases also show that health professionals mistakenly believe that there are some procedures and treatments that someone with a learning disability would not be able to tolerate. There is no evidence that people with a learning disability cannot tolerate particular treatments. As with any patient, treatment and interventions for someone with a learning disability should be considered on a case-by-case basis and, where reasonable adjustments are given proper consideration and planning, most treatments can be administered.

If someone lacks capacity to decide for themselves, a best interest decision must be made. An apparent lack of cooperation should never be automatically associated with lack of consent.

## Failure to recognise pain

“ They said they didn’t think she was in pain, that her screams were just the noises people like that make.”

### 11 families reported a failure to recognise pain.

As highlighted in *Death by indifference*, there is an entirely false but widespread belief among health professionals that people with a learning disability have a higher pain threshold than the rest of the population.

### Christopher Peters



Christopher Peters was a fun-loving young man who was a fan of Michael Jackson and a much-loved member of his family.

Christopher was admitted to Aintree Hospital on the evening of 25 February 2009 with severe abdominal pain. Despite a rapid deterioration in his condition, Christopher was not operated on until 4am the following day and tragically died soon afterwards of small bowel ischemia and septic shock. The family consider that, had Christopher been operated on soon after admission, he would at least have had a chance of survival.

Christopher’s family were with him throughout those agonising hours in hospital. For most of this time, Christopher was in terrible pain, but despite his mother Wendy’s constant pleas to the ward staff to get relief for her son’s pain, it took almost two hours for any of the surgical team to attend. By this time, Christopher’s abdomen had extended to “the size of a football” and he was bleeding profusely. Subsequently, Christopher’s hospital records were found to contain comments including one that said “this gentleman did not get the care and attention he deserved”.

This case is currently with the Parliamentary and Health Service Ombudsman for investigation. The results are not yet known. Meanwhile, Wendy, who tells us that she still misses her son terribly, waits to see if his death could have been avoided.

As this example shows, a range of factors contribute to patients with a learning disability being left without appropriate pain relief. Tools do exist to assist staff in assessing the pain of disabled patients who cannot communicate verbally. Such tools, used in conjunction with family carers' knowledge and appropriate training, can be used to prevent unnecessary pain. Every member of staff whose role involves pain treatment needs to be aware of the potential difficulties in diagnosing pain in patients with a learning disability. This is especially important in cases that involve people with limited verbal communication. Staff must be trained to overcome issues around communication in order to bring about the best outcome for the patient.

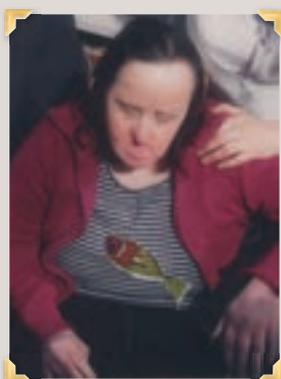
## Do Not Resuscitate orders and the Mental Capacity Act 2005

“The doctor took one look at my son and said that he was not for resuscitation.”

**5 families complained about the inappropriate use of Do Not Resuscitate (DNR) orders.**

The inappropriate use of DNR orders has remained a constant feature of many Mencap cases. There have been circumstances where DNR notices have been applied without the knowledge or agreement of families, and applied hastily in inappropriate situations, solely on the basis of the person's learning disability.

### Anne Clifford



Anne Clifford died of pneumonia in the Mayday Hospital in Croydon on 20 July 2010, aged 53. Anne had Down's syndrome and a severe learning disability. Although she had no verbal communication, her sisters, Monica and Mary, describe her as a “feisty character who was able to show what she liked and disliked”. Before her admission to Mayday Hospital, Anne lived in a residential care home in Surrey, where she was very happy.

When Anne was first admitted to the Mayday Hospital, she was put in the intensive care unit (ICU) and placed on life support as she was having difficulty breathing. She was diagnosed with pneumonia. From the moment of Anne's admission, Monica contacted the hospital every day to enquire about the treatment her sister was receiving. She also made it absolutely clear to staff that she and her sister Mary were to be kept fully informed about Anne's progress.

When Anne was eventually able to breathe unassisted, she was placed on a general ward. Monica and Mary viewed this as a very positive step and began to believe that Anne could recover.

However, during one of Monica's regular phone calls to the ward, she was told that Anne's pneumonia appeared to be returning. Monica then naturally enquired if Anne would be returned to the ICU and put on life support. It was then that she learned that Anne's notes stated that she was not to be returned to the high dependency unit and that she would not be resuscitated. This was the first that the family knew of this. Alarmed, Monica began to seek advice and, with the assistance of the adult safeguarding team, a best interest meeting was called. But the consultant responsible for Anne's care informed Monica that he had agreement from other doctors on the DNR decision. Monica strongly disagreed with the decision.

Following a formal complaint by Anne's family against the hospital, a full investigation is taking place into the circumstances surrounding Anne's death. As part of this investigation, Anne's family want to know why the process for making decisions for people who lack capacity, as set out in the Mental Capacity Act, was ignored, why they had to struggle to have their sister's best interests met and why, ultimately, their wishes were ignored.

Most insidious of all is what we have come to refer to as 'flawed best interest decision-making'. This happens when, despite the process being technically followed, the medical advice given in the best interest decision meeting has been weighted in favour of a decision not to proceed with active treatment and the application of DNR orders. Families, who naturally do not want to prolong the suffering of their loved one, have sometimes agreed with the decision, only later to find that there was a better prospect of recovery with treatment than they had been told. This is devastating for families who sometimes blame themselves ever after for not having fought harder for their loved ones.

The Mental Capacity Act 2005 and its code of practice have been fully in force since 2007. But our cases strongly indicate that the principles the Act sets out are far from embedded in medical practice. Mencap has received many accounts from families of treatment not being given under the guise of concern about consent. However, this situation should never arise if the law is followed properly. The law is clear that if a person lacks capacity to consent to treatment, a decision must be made on their behalf in their best interests, and the family should be involved in this decision.

Many of the accounts reported to Mencap have involved situations where the proper process of best interest decision-making has not been in place and families have been totally excluded from the process. They have also not been informed of their right to challenge a decision when they believe it is not in the person's best interests. These misunderstandings and neglect of the law are depriving people with a learning disability of their chance to survive.

## Fighting for justice and change

Mencap believes that the NHS complaints process is not fit for purpose. We believe that it should be completely overhauled to end the scandal that, when complaints are pursued with the hospital, it is often impossible to find out what really went wrong. All too often, families are forced to 'jump through hoops', for many months, if not years, and are left feeling that their concerns have not been taken seriously or dealt with thoroughly.

This also results in a lack of learning across the NHS. It is simply not right that some families have been forced to wait years for an apology or an explanation for the death of their loved one.

Mencap has supported families through all stages of the complaints process. It has taken most of those families many years to reach the stage where the ombudsman has issued a final report.

## Carole Foster



Carole Foster died on 2 October 2006 after Pennine Acute Hospital Trust and Pennine Care NHS Foundation Trust failed to treat her for gallstones. Instead, staff interpreted the change in her behaviour as symptomatic of her learning disability and mental ill health.

Carole's family complained to the hospital. In September 2007, they wrote to the chief executive of the Trust to express their concerns that, one year on, no satisfactory explanation had been given as to why Carole had died:

“We want the truth and someone ultimately held responsible for Carole's untimely death. We are shocked that it has taken so long to investigate something so obvious. Please, no more excuses.”

The case was referred to the ombudsman in December 2007, but the final report was not published until November 2011, just over five years after Carole died. The ombudsman's investigation identified a catalogue of service failures and concluded that Carole's death could have been avoided.

Just as worrying as the delays and responses that fail to answer the fundamental questions are the responses that show how embedded the discrimination against people with a learning disability is in the health service. Often, those investigating the complaint, including some of the experts commissioned, display discriminatory assumptions themselves, lack sufficient understanding of the risks that people with a learning disability face in the NHS and fail to properly assess compliance with the Equality Act and Mental Capacity Act.

### Professional regulation

It is appalling that – even when the ombudsman has found service failure, made serious criticisms of medical practice and, in some instances, found that death could have been avoided – it is rarely the case that doctors are appropriately sanctioned by the General Medical Council (GMC).

## Kirsty Pearce



Kirsty Pearce died on 28 August 2003 after she had been admitted to Basildon Hospital suffering from acute respiratory distress syndrome (ARDS), a condition caused by pulmonary oedema, or fluid on the lungs.

The Parliamentary and Health Service Ombudsman investigation into Kirsty's death found that her condition was not monitored adequately and that there was considerable delay in starting treatment. Kirsty's father referred the senior paediatric registrar to the GMC.

The case progressed to the scheduling of a tribunal hearing, but this was cancelled just before it was due to take place. Kirsty's family were informed that although the GMC believed that the doctor was negligent, he was not negligent enough to face a hearing.

In November 2011, an inquest finally took place into Kirsty's death. The expert commissioned by the coroner concluded that "the delay in [Kirsty] getting the sort of treatment required for her from the outset of her presentation contributed to her death".

Kirsty's family remain firmly of the view that the doctor should be held to account for his actions:

"When our beautiful daughter Kirsty died, like us she still believed that the hospital staff would save her. They failed her and allowed her to die in pain and without dignity. There were a catalogue of errors and significant failings by the medical and nursing staff on the night of Kirsty's death and for this the staff responsible should be ashamed. There is no doubt that those responsible for Kirsty during the night she died broke their duty of care."

Mencap has written to the GMC asking it to reconsider the case, and awaits the outcome. We believe that the GMC and all other bodies responsible for the regulation of health professionals have a vital role to play in ensuring that the lives of people with and without a learning disability are valued equally.

## Progress on the *Healthcare for all* recommendations

Significant steps have been taken since the government inquiry led by Sir Jonathan Michael reported in 2008. *Healthcare for all* set out ten key recommendations, all of which the government accepted and set out in the *Valuing People Now* delivery plan in January 2009. In particular, Mencap has welcomed:

- the setting up of the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities
- the creation of the Public Health Observatory known as Improving Health and Lives: Learning Disabilities Observatory (IHAL)
- the introduction of annual health checks via the Directed Enhanced Services
- the creation of the self-assessment framework.

Mencap is not in a position to provide a full picture of progress. However, reflecting on what we do know about each of the recommendations set out below, it is evident that there has been no systematic monitoring by the Department of Health to ensure that these have been implemented. The disbanding of the *Valuing People Now* team in March 2011 has resulted in limited resources with a focus on people with a learning disability within government. Alongside the challenges created by the emerging NHS structures, our concern is that there is little prospect of these recommendations now being fully achieved. We have set out below what we think should happen now to implement the recommendations.

Below we set out the specific recommendations set out in *Healthcare for all* (points 1 to 10), published in 2008. We then update on progress made since then.

---

**Recommendation 1:** Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.

**Progress:** Mencap is aware of an increase in the provision of training on learning disability in hospital settings and in some professional training programmes. In particular, we have welcomed the training provided by learning disability liaison nurses within some hospital settings and the training provided by family carers and people with a learning disability to GPs signed up to the Directed Enhanced Services. However, there has been no progress on establishing mandatory training of all health professionals. Training is still left to the discretion of the training bodies concerned and in our view, this is not acceptable.

**Mencap wants:**

- all healthcare professionals (including those who have already qualified) to receive training that challenges the assumptions made about people with a learning disability and the unknowing discrimination against them
  - all health professionals to be taught how to make reasonable adjustments and how to put their legal responsibilities under the Equality Act and the Mental Capacity Act into practice.
- 

**Recommendation 2:** All healthcare organisations, including the Department of Health, should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.

**Progress:** This has not happened. There is no consistent ‘tag’ or ‘read code’ for learning disability in use across the country, or even across Strategic Health Authorities. This makes it impossible to measure both inequalities and outcomes for this group.

Research conducted by IHAL has shown that only 20% of trusts could provide specific information about the number of people with a learning disability who had used their services in the past year, despite two-thirds claiming that they had a way of identifying if someone had a learning disability.<sup>10</sup>

The Parliamentary and Health Service Ombudsman echoed this recommendation in the *Six Lives Progress Report*: “All healthcare organisations[...]should ensure that they collect the data and information necessary to allow people with learning disabilities to be identified by the health service and their pathway of care tracked.”<sup>11</sup>

This was later supported in the NHS Operating Framework 2011/12, which included a requirement for Primary Care Trusts (PCTs) to gather data on people with a learning disability in their local area to reduce health inequalities.<sup>12</sup> Mencap was extremely disappointed that this was not included in the Operating Framework for 2012/13.

**Mencap wants:**

- the Department of Health to design and test a read code or flagging system to be used across the whole of the NHS.

**Recommendation 3:** Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

**Progress:** We are aware of examples of good practice where hospital staff are working with and supporting family carers, especially during planned admissions and where there are learning disability liaison nurses in post, but this remains very patchy. The evidence from our cases strongly supports the fact that the views and needs of family carers are often dismissed. The lack of understanding by hospital staff of the reasonable adjustments required compounds this problem. There remains a mixed picture in terms of how the needs of families are properly accommodated in the hospital when they are an integral part of supporting their family member.

IHAL conducted a survey in 2010 which looked at the forms that reasonable adjustments can take and the extent to which they were being employed by healthcare authorities. The results are worrying. Although 75% of Trusts had information for family carers to take away, only 10% reported having a carers' policy, just 13% involved carers in planning and only 11% have facilities for carers to stay.<sup>13</sup>

IHAL reports that “areas of reasonable adjustments relating to the actual face-to-face treatment of people with learning disabilities and carers were only reported by a minority of trusts, including support for carers (beyond providing accessible information), and all stages of the patient journey, from first contact through diagnosis to clinical intervention and discharge/follow up”.

Only 30% of all NHS trusts responded to this important survey.<sup>14</sup> Mencap feels that the poor response rate illustrates the lack of importance placed on caring for people with a learning disability within the NHS.

**Mencap wants:**

- the Department of Health to audit the extent to which hospitals' policy and practice supports this recommendation
- the Care Quality Commission (CQC) to routinely monitor this when it inspects hospital services.

**Recommendation 4:** Primary Care Trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.

**Progress:** There is evidence that some Joint Strategic Needs Assessments (JSNAs) cover people with a learning disability, but in general there is more of a focus on age, gender and ethnicity. There is also little evidence of their impact on the commissioning of services.

**Mencap wants:**

- the self-assessment framework, which has to be signed off by Partnership Boards, to be used to inform JSNAs
  - the Public Health Observatory to be asked to monitor JSNAs for inclusion of learning disability health objectives
  - the CQC to monitor commissioning by PCTs and the emerging clinical commissioning groups to ensure that JSNAs are rigorous and have informed the commissioning process.
- 

**Recommendation 5:** To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning difficulties to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

**Progress:** Mencap sits on both the advisory and monitoring groups for the Confidential Inquiry and Public Health Observatory, and we are pleased with the progress to date. Both are now halfway through their three-year funding programmes. There have been some concerns expressed that although the Public Health Observatory is producing very helpful evidence papers, these have no immediate benefit to people with a learning disability or their families. The Public Health Observatory has begun work to address this.

**Mencap wants:**

- funding for the Public Health Observatory and Confidential Inquiry to continue beyond the three-year term of their contracts
- the Confidential Inquiry to be asked to make interim findings available, where

clear trends are evident, so that action can be taken before 2013

- the Public Health Observatory to be asked to disseminate its evidence in a form that empowers people with a learning disability and family carers to be safer when accessing the NHS.
- 

**Recommendation 6:** The Department of Health should immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make ‘reasonable adjustments’ to the provision and delivery of services for vulnerable groups, in accordance with disability equality legislation. The framework that is planned to replace these core standards in 2010 should also include a specific reference to this requirement.

**Progress:** The core standards in *Standards for Better Health* were used by the then Healthcare Commission to regulate healthcare. These were replaced by the guidance given in *Essential Standards of Quality and Safety*<sup>15</sup> when the CQC took over responsibility for regulating healthcare. This guidance defines 28 outcomes; there is some mention of healthcare for people with a learning disability, but it is unclear how rigorously this is monitored. Some of the outcomes in the new outcomes framework could be useful, but they do not specifically mention learning disability.

**Mencap wants:**

- the CQC to rigorously monitor the quality of healthcare delivered to people with a learning disability and in particular ensure that the legal requirements of the Equality Act and the Mental Capacity Act are met
  - the NHS Operating Framework and the new NHS Outcomes Framework to explicitly cover the need to deliver good quality healthcare to people with a learning disability.
- 

**Recommendation 7:** Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and in the community where primary care providers are located. The aim is to support appropriate, reasonable adjustments to general health services for adults and children with learning disabilities and their families, and to ensure compliance with and enforcement of all aspects of the Disability Discrimination Act. Healthcare regulators and inspectors (and the Care Quality Commission, once established) should strengthen their work in partnership with each other and with the Commission for Equality and Human Rights, the National Patient Safety Agency and Office for Disability Issues.

**Progress:** The CQC began but then abandoned an audit of physical healthcare of people with a learning disability using NHS services. The Department of Health was required to report on progress to the Parliamentary and Health Service Ombudsman within 12 months of the *Six Lives* report, published in October 2009. The *Six Lives Progress Report* was published in October 2010. The self-assessment framework process was used to enable Strategic Health Authorities to self-audit progress. While regarded as a useful exercise, the Department of Health only reviewed reports at a Strategic Health Authority level. This means it was not able to report on progress in individual hospitals. We do not feel, therefore, that there is sufficient evidence of progress at an individual hospital level. Our case evidence shows that there has been more than one death in some hospitals and a significant number in others.

**Mencap wants:**

- the CQC to be required to assess how hospitals meet the healthcare needs of people with a learning disability by including this in the routine inspection of all hospitals
- the CQC to conduct a thematic inspection on learning disability in a sample of hospitals, especially where there has been more than one death of a person with a learning disability
- hospitals to be asked to: provide evidence of compliance with the Equality Act and the Mental Capacity Act; identify the number of people with a learning disability treated; and provide a record of the number of deaths and their causes and the number of complaints received about the care or treatment of people with a learning disability
- the CQC to review the use of DNR notices and the roles of independent mental capacity advocates in them
- as recommended by IHAL, a risk assessment of individual need to be conducted on admission, with the input of carers. Any issues identified should be included in the care plan. If an incident is reported, the reporting systems should have a flag to indicate whether it has involved a person with a learning disability, including safeguarding alerts.

---

**Recommendation 8:** The Department of Health should direct Primary Care Trusts (PCTs) to secure general health services that make reasonable adjustments for people with learning disabilities through a Directed Enhanced Service. In particular, the Department should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care.

**Progress:** The Directed Enhanced Services have been in place for the last three years. Annual health checks have been made available to people with a learning disability known to social services. There has been wide variation in the number of GPs signing up to the scheme across the country and even greater variation in the number of actual health checks being delivered. In 2010/11, annual health checks still only reached 49% of those eligible.<sup>16</sup> There has been concern that not all provider organisations are ensuring take-up of health checks for those they support.

Some concerns have been reported by families and people with a learning disability about the quality of health checks and the risk that these can be a ‘tick box’ exercise. IHAL published evidence on the effectiveness of health checks and designed an audit tool to enable GP practices to evidence their quality. Some PCTs have commissioned primary care liaison nurses or health facilitators to work with GP practices on delivering health checks. Mencap has heard of excellent work from these post holders in ensuring that people with a learning disability are also part of national screening programmes for diabetes and cancer. Funding for the Directed Enhanced Services has been agreed on an annual basis until 2012/13.

Other straightforward reasonable adjustments can make a real difference to the health of people with a learning disability. Examples include sending appointments to people with a learning disability in easy read format and increasing appointment times. However, Mencap is concerned that these measures are not being put in place. A survey conducted by IHAL revealed that only 4% of the Trusts surveyed changed appointment times, just 9% altered opening hours and only 9% had access to learning disability liaison staff.<sup>17</sup>

**Mencap wants:**

- annual health checks to be permanently secured via commissioning contracts
- PCTs (and the newly emerging clinical commissioning groups) to be asked to provide evidence in terms of both quantity and quality of health checks
- PCTs to routinely commission primary and secondary care liaison nurses or health facilitators
- social care providers to be commissioned to ensure they support people with a learning disability to take up annual health checks.

---

**Recommendation 9:** Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.

**Progress:** Mencap has limited evidence on this. LINKs schemes are reported to have very limited inclusion of people with a learning disability and their families. Where hospitals have learning disability liaison nurses, there is evidence of user involvement in influencing policy and practice within the hospital. We are not able to comment on the scale of this or on whether it is influential at board level. Making complaints is one means of getting issues addressed, but this is time consuming, defensive and often ineffective.

**Mencap wants:**

- LINKs or Local HealthWatch to ensure user representation from people with a learning disability and their families
- a statutory duty on all trusts to publish details of all complaints involving people with a learning disability and for meaningful action plans to be developed and acted on
- a complete overhaul of the NHS complaints system to ensure complaints are handled quickly and effectively at the local level. The response to a complaint should directly answer the questions posed by those making it. It should be written in jargon-free, accessible language and should admit where failures have taken place – and show how changes will be made to prevent such incidents happening again. Independent investigations by someone with appropriate expertise should be conducted where there are serious complaints
- professional regulatory bodies to review their processes and expert advice and ensure that they are investigating cases rigorously and fairly.

---

**Recommendation 10:** All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, ‘reasonably adjusted’ health services for those people who happen to have a learning disability. This should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALS from all client groups including people with learning disabilities.

**Progress:** The *Six Lives Progress Report* (October 2010) stated that the NHS was demonstrating a better understanding of reasonable adjustments but that staff still need more training in understanding how to put them into practice. It raised serious concerns about compliance with the Mental Capacity Act. In 2011, the Public Health Observatory (IHAL) published an ‘evidence into practice’ paper aimed at commissioners and providers of NHS care on providing reasonable adjustments for people with a learning disability.

The NHS Operating Framework 2010/11 recommended “particular emphasis should be given to ensuring staff are trained to make reasonable adjustments, communicate effectively and follow the Mental Capacity Act (2005) Code of Practice in all their interactions with patients with learning disabilities to ensure full compliance with the law in respect of capacity, consent and best interest decision making.”<sup>18</sup>

According to the Access 2 Acute Network, 7 out of 10 hospital Trusts have at least one learning disability liaison nurse employed in hospital settings. Access 2 Acute Network reports that some hospitals are now cutting these posts, some nurses are recruited on lower pay bands, which reduces their influence, and some cover insufficient hours or are on short-term contracts. There is good evidence that when there are liaison nurses, a wide range of reasonably adjusted health services are being provided. Evidence shows that Trusts rely heavily on learning disability liaison nurses, particularly when a patient has limited verbal communication.

**Mencap wants:**

- a lead for learning disability within all Acute Trusts and PCTs who is accountable to the board
- acute learning disability liaison nurses, employed by every acute service, linked to senior leadership – these nurses have a strategic role in supporting ward staff to make reasonable adjustments
- a review of the most effective way for the role of learning disability nurses to be created and carried out
- a senior executive at Trust Board level with a remit to ensure that issues for people with a learning disability and their carers are discussed at board level and appropriate actions are taken
- further development of the Essence of Care tool<sup>19</sup> for use for learning disability
- a single equality scheme, alongside an appropriate action plan, detailing reasonable adjustments, with the plan monitored by the board.

## Conclusion

**We call on the NHS to act to stop more people with a learning disability dying unnecessarily.**

It took the deaths of Emma, Mark, Martin, Ted, Tom and Warren to bring about an inquiry into the inequalities that people with a learning disability face in the NHS. The unnecessary pain and deaths of yet many more people are detailed in this report. We know that their deaths are but the tip of the iceberg.



That people with a learning disability are dying prematurely and experience serious inequalities when accessing the NHS is not in dispute. The actions needed to address these inequalities are now well understood. But, while some of these requirements have been acted on, others have not. The failure to do so is costing people their lives, and it cannot be allowed to continue.

All those who have contacted Mencap to tell the heartbreaking stories of the deaths of their loved ones have done so in the hope that sharing what has happened will prevent others suffering in the same way. Like Mencap, they are not yet convinced that the government is taking the issues seriously enough or that the changes underway within the NHS will mean that people with a learning disability are a priority.

People with a learning disability have a right to the same quality of healthcare as those without a learning disability. Getting it right for them will also mean getting it right for all vulnerable people, such as older people and those with dementia. On 6 January 2012, David Cameron told BBC Radio 4:

“Politicians, frankly, have done nurses a disservice by not talking about this. Such is our respect for nursing that we’ve almost hidden away concerns about this.”<sup>20</sup>

He added: “You’ve seen the Care Quality Commission report, I’ve seen constituency correspondence with some chilling stories about how some people’s relatives have been treated, and so it’s time to speak up about this issue.

“We have not had a public discussion about the issue and who better to do that than the Prime Minister?”

We agree with the Prime Minister. The government must act to make all the changes necessary to make good healthcare a right for all.

### **Mencap calls on the government to ensure that:**

- **annual health checks become a permanent part of the GP contract to ensure early detection of health conditions**
- **all health professionals act within the law and get training around their obligations under the Equality Act and Mental Capacity Act so they can put this into practice when treating patients with a learning disability**
- **regulatory bodies such as the Care Quality Commission, General Medical Council and Nursing and Midwifery Council conduct rigorous investigations and deliver appropriate sanctions where health professionals clearly failed in their obligations to patients with a learning disability**
- **the NHS complaints process is overhauled: it is not fit for purpose, it is time consuming and defensive, and it does not enable the NHS to learn important lessons quickly enough to prevent further deaths**
- **acute learning disability liaison nurses are employed by every acute service, and are linked to senior leadership, who have a strategic role in supporting ward staff to make reasonable adjustments**
- **a standard hospital passport is made available to all people with a learning disability**
- **all hospitals sign up to Mencap’s *Getting it right* charter<sup>21</sup> and put in place the good practice that we know saves lives.**

## Appendix

**Table 1: Minimal or no casework – 21 cases**

**Note:** These cases were prompted by the publication of Death by *indifference*, and therefore some information may not have been given at the time of contact. Some families have requested to remain anonymous.

Name	Hospital/Trust/PCT	Date of death	Contributory factors							Stage of complaint	
			Failure to recognise pain	Poor communication	Diagnostic overshadowing	Delays in treatment	DNR	Lack of basic care	Other		
S R	Health Centre – North West	Jul 05		Yes		Yes			Yes		Local
B B	Hospital – South	Oct 05	Yes	Yes		Yes			Yes		Courts
A H	Hospital – Newcastle	Jan 06		Yes		Yes			Yes		None
M E	Hospital – West Midlands	Jan 06		Yes		Yes			Yes		Local
<b>Philip Blakemore</b>	GP Surgery – West Midlands	Jan 06				Yes					None
V B	Hospital – North London	Jan 06	Yes	Yes	Yes	Yes			Yes		Local
M B	Hospital – South Yorkshire	Nov 06		Yes					Yes		Local
M G	Hospital – Worcestershire	2007	Yes			Yes					Courts
A S	Hospital – Birmingham	Jan 07		Yes					Yes		Local
<b>Ayesha Louise Wyatt</b>	Ysbyty Gwynedd, Bangor	Feb 07									Courts
A T	Health Centre	Aug 07									
A C	Unknown Hospital	Jan 08			Yes	Yes					Local
C H	Hospital – Sussex	Apr 08									
C N	Hospital – East Surrey	Jun 08									Local
S R	Hospital – Hertfordshire	Jun 08	Yes		Yes				Yes		Local
<b>Duke Tugman</b>	Hospital – East London	Sep 08		Yes	Yes	Yes	Yes	Yes			
<b>Linda Munslow</b>	New Cross Hospital	Dec 08	Yes	Yes		Yes	Yes	Yes	Yes		Local
C T	Hospital – Berkshire	Feb 09		Yes	Yes	Yes	Yes		Yes	Yes	Local
M G	Hospital – Suffolk	Dec 09							Yes		Local
N W	Hospital – Berkshire	Dec 10			Yes				Yes	Yes	Courts
<b>Muqaddasah Khanom</b>	Heartlands Hospital	Nov 11		Yes	Yes	Yes	Yes			Yes	Local

**Table 2: Deaths before 2007 – 15 cases**

Name	Hospital/Trust/PCT	Date of death	Contributory factors							Stage of complaint	
			Failure to recognise pain	Poor communication	Diagnostic overshadowing	Delays in treatment	DNR	Lack of basic care	Other		
<b>Sophie Ham</b>	Poole Hospital NHS Foundation Trust	Jan 02	Yes		Yes	Yes					Courts
<b>Kirsty Pearce</b>	Basildon & Thurrock University Hospitals	Aug 03	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Mark Cannon</b>	Barking, Havering and Redbridge Hospitals NHS Trust	Aug 03	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Lisa Sharpe</b>	Basildon & Thurrock University Hospitals	Feb 04	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Barbara Thomas</b>	Queen Alexandra Hospital, Southampton	May 04		Yes		Yes	Yes	Yes	Yes		Ombudsman
<b>Ted Hughes</b>	Buckinghamshire Hospitals NHS Trust	May 04		Yes	Yes	Yes			Yes		Ombudsman
<b>Tom Wakefield</b>	Gloucestershire Partnership NHS Foundation Trust	May 04	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Emma Kemp</b>	Royal Berkshire NHS Foundation Trust	Jul 04		Yes	Yes	Yes					Ombudsman
<b>Warren Cox</b>	East Sussex Hospitals NHS Trust	Sep 04	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Daisy Healy</b>	Kettering Hospital	Oct 05	Yes	Yes	Yes	Yes		Yes	Yes		Ombudsman
<b>Martin Ryan</b>	Kingston Hospital NHS Trust	Dec 05	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Chantel Edwell</b>	Bedford Hospital	May 06		Yes		Yes			Yes		Ombudsman
<b>Carole Foster</b>	Fairfield Hospital	Oct 06	Yes	Yes	Yes	Yes			Yes		Ombudsman
<b>Kyle Flack</b>	Basildon & Thurrock University Hospitals	Oct 06	Yes	Yes		Yes			Yes		Courts
<b>M A R</b>	Hospital – Surrey	Oct 06				Yes					Local

**Table 3: Deaths in 2007–2008 – 10 cases**

Name	Hospital/Trust/PCT	Date of death	Contributory factors							Stage of complaint	
			Failure to recognise pain	Poor communication	Diagnostic overshadowing	Delays in treatment	DNR	Lack of basic care	Other		
A B	Hospital – Staffordshire	Jan 07	Yes	Yes					Yes		Ombudsman
D B	Hospital – South East London	Feb 07				Yes			Yes		Ombudsman
Betty Dennis	North Middlesex Hospital	Apr 07	Yes	Yes				Yes	Yes		Local
Maria Maniara	Barnet Hospital	Apr 07	Yes	Yes	Yes	Yes	Yes	Yes	Yes		Ombudsman
Barbara Dyson	Royal Hallamshire, Sheffield	Nov 07				Yes			Yes	Yes	None
Christian Harrison	Queen Elizabeth II Hospital, Margate	Feb 08		Yes			Yes		Yes	Yes	Ombudsman
L H	Hospital – Avon	Feb 08	Yes	Yes		Yes			Yes		Local
T B	Hospital – Essex	Feb 08		Yes		Yes	Yes		Yes		Ombudsman and NMC
Karen Mansbridge	Royal Berkshire NHS Foundation Trust	Jun 08	Yes	Yes	Yes	Yes	Yes		Yes		Local
L R	Hospital – Southampton	Nov 08		Yes			Yes		Yes		Ombudsman

**Table 4: Deaths in 2009–2011 – 28 cases**

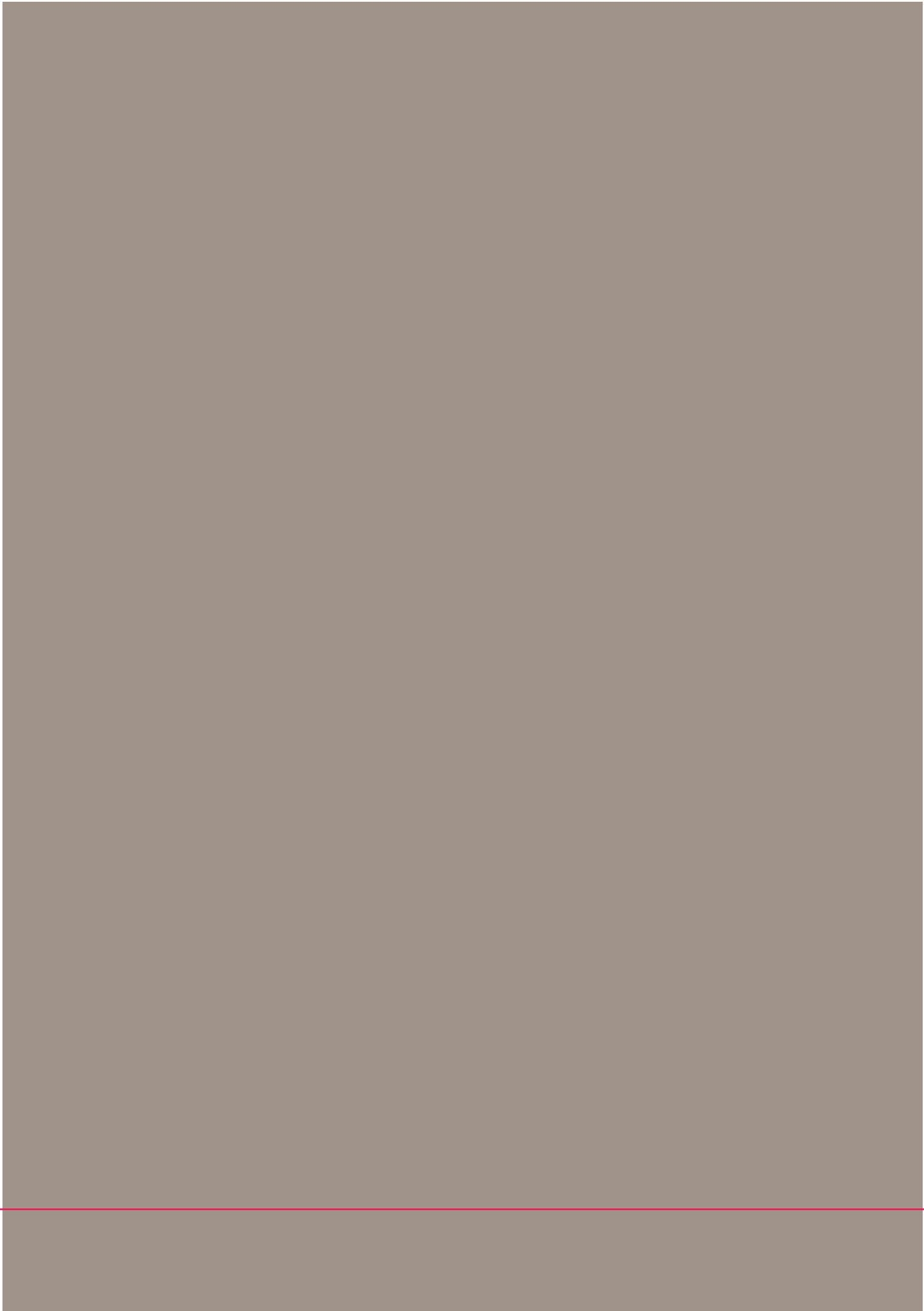
Name	Hospital/Trust/PCT	Date of death	Contributory factors							Stage of complaint
			Failure to recognise pain	Poor communication	Diagnostic overshadowing	Delays in treatment	DNR	Lack of basic care	Other	
Clive Sanders	Royal Berkshire NHS Foundation Trust	Jan 09	Yes	Yes		Yes	Yes		Yes	Local
Paul Ridd	Morrison Hospital	Jan 09		Yes	Yes					Ombudsman
Tina Papalabropoulos	Basildon & Thurrock University Hospitals	Jan 09		Yes		Yes				Ombudsman, GMC
Brian Nicholls	Royal Berkshire NHS Foundation Trust	Feb 09	Yes	Yes		Yes			Yes	Local
Christopher Peters	Aintree University Hospital	Feb 09	Yes	Yes		Yes			Yes	Ombudsman
E M C	Hospital – South West	May 09				Yes			Yes	Local
G G	Hospital – East London	May 09		Yes		Yes	Yes		Yes	Local
Ronnie Eaton	Salford Royal Hospital	May 09		Yes		Yes			Yes	Courts
Kelly Doherty	Newham University Hospital	Jun 09		Yes		Yes			Yes	Courts
E D	Royal Free Hampstead NHS Trust	Sep 09	Yes	Yes		Yes			Yes	None
E L	Hospital – Gloucestershire	Sep 09		Yes			Yes			Local
David Ingleby	University Hospitals Birmingham NHS Trust	Oct 09		Yes		Yes			Yes	Local
Michael Cosgrove	Kettering Hospital	Nov 09		Yes		Yes			Yes	Local
Alan MacDonald	Lister Hospital	Dec 09	Yes	Yes		Yes			Yes	Local
E W	Multiple hospitals – South East	Feb 10				Yes			Yes	Preparing complaint
Sandra Baker	Southampton General Hospital	May 10	Yes	Yes		Yes			Yes	Local

**Table 4: Deaths in 2009–2011 – 28 cases (continued)**

Name	Hospital/Trust/PCT	Date of death	Contributory factors							Stage of complaint
			Failure to recognise pain	Poor communication	Diagnostic overshadowing	Delays in treatment	DNR	Lack of basic care	Other	
Anne Clifford	Croydon University Hospital	Jul 10		Yes		Yes	Yes	Yes	Yes	Local
Nicholas Garside	UHCW Coventry & Warwick	Aug 10		Yes		Yes	Yes	Yes		Local
B M	William Harvey Hospital	Dec 10	Yes	Yes		Yes	Yes	Yes	Yes	Local
David Tait	Royal Berkshire NHS Foundation Trust	Dec 10		Yes	Yes	Yes	Yes	Yes	Yes	Local
A G	Hospital – Greater Manchester	Jan 11						Yes		
Sammy Roberts	Northamptonshire General Hospital	Jan 11	Yes			Yes		Yes		Local
Susan Read	Lewisham Hospital	Feb 11		Yes		Yes		Yes		Local
Noel Tomlinson	Hull Royal Infirmary	Mar 11	Yes	Yes		Yes		Yes		Local
Raj Vohra	West Middlesex Hospital	Mar 11	Yes	Yes		Yes		Yes	Yes	Local
F C	Hospital – Birmingham	Jul 11		Yes		Yes		Yes		Local
M Q	Hospital – London	Oct 11	Yes	Yes		Yes		Yes		Local
Jasseke Van Dok	North East Essex PCT	Nov 11		Yes		Yes		Yes	Yes	Local

## References

- <sup>1</sup>Department of Health (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities*.
- <sup>2</sup>Parliamentary and Health Service Ombudsman (2011). *Care and Compassion?*
- <sup>3</sup>Mencap (2007). *Death by indifference*.
- <sup>4</sup>Bawden, A and Campbell, D (3 January 2012). NHS accused over deaths of disabled patients. *The Guardian*, p. 1.
- <sup>5</sup>Mencap's oral evidence to the Michael inquiry.
- <sup>6</sup>Michael, J (2008). *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. London: Department of Health.
- <sup>7</sup>Blair, J (2011). *Nursing Management, Volume 18* (no. 8).
- <sup>8</sup>Giraud-Saunders, A (2009). *Equal access? A practical guide for the NHS: creating a Single Equality Scheme that includes improving access for people with learning disabilities*. London: Department of Health.
- <sup>9</sup>Turner, S and Robinson, C (2011). *Reasonable Adjustments for People with Learning Disabilities: Implications and Actions for Commissioners and Providers of Health Care. Evidence into practice report no. 3. Improving Health and Lives: Learning Disabilities Observatory*.
- <sup>10</sup>Turner, S and Robinson, C (2011). *Reasonable Adjustments for People with Learning Disabilities: Implications and Actions for Commissioners and Providers of Health Care. Evidence into practice report no. 3. Improving Health and Lives: Learning Disabilities Observatory*.
- <sup>11</sup>Parliamentary and Health Service Ombudsman (2009). *Six Lives: the provision of public services to people with learning disabilities*. Norwich: TSO.
- <sup>12</sup>Department of Health (2010). *The Operating Framework for the NHS in England 2011/12*.
- <sup>13</sup>Turner, S and Robinson, C (2011). *Reasonable Adjustments for People with Learning Disabilities: Implications and Actions for Commissioners and Providers of Health Care. Evidence into practice report no. 3. Improving Health and Lives: Learning Disabilities Observatory*.
- <sup>14</sup>Turner, S and Robinson, C (2011). *Reasonable Adjustments for People with Learning Disabilities: Implications and Actions for Commissioners and Providers of Health Care. Evidence into practice report no. 3. Improving Health and Lives: Learning Disabilities Observatory*.
- <sup>15</sup>Care Quality Commission (2010). *Essential standards of quality and safety*.
- <sup>16</sup>Emerson, E, Copeland, A and Glover, G (2011). *The Uptake of Health Checks for Adults with Learning Disabilities: 2008/9 to 2010/11*. Improving Health and Lives: Learning Disabilities Observatory.
- <sup>17</sup>Turner, S and Robinson, C (2011). *Reasonable Adjustments for People with Learning Disabilities: Implications and Actions for Commissioners and Providers of Health Care. Evidence into practice report no. 3. Improving Health and Lives: Learning Disabilities Observatory*.
- <sup>18</sup>Department of Health (2009). *The Operating Framework for 2010/11 for the NHS in England*.
- <sup>19</sup>Department of Health (2010). *Essence of Care 2010*.
- <sup>20</sup>Kirkup, J and Holehouse, M (7 January 2012). Concerns over care have been 'hidden' to avoid rows, says David Cameron. *The Daily Telegraph*.
- <sup>21</sup>Mencap (2010). *Getting it right charter*.



**Mencap**

123 Golden Lane

London EC1Y 0RT

Telephone: 0808 808 1111

Email: [info@mencap.org.uk](mailto:info@mencap.org.uk)

[www.mencap.org.uk](http://www.mencap.org.uk)

---

This report was published in February 2012