FOR HEALTHCARE LEADERS
HSJ

The NHS must stop victimising bereaved families

10 December, 2015 **By Shaun Lintern**

Bereaved families of systemic failure-related deaths have far too often become second victims, due to the NHS's misguided secrecy and focus on reputation management, writes Shaun Lintern

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Losing a loved one is painful enough especially when that loss results from a mistake, a system error, or worse, clinical negligence.

In too many cases the NHS fails to be open and transparent with grieving families, compounding their loss with obfuscation and secrecy. Insult is literally added to injury for people who, in the most part, are just desperate for the truth about what happened – as well as an assurance that it won't be repeated.

- Duty of candour: why the NHS needs to be more open
- The case for patient safety: Financially, Professionally and Ethically

Fighting back

The problem for the health service is that times have changed. Families are no longer prepared to just accept what they are told. Many are fighting back with a rage and a fury the health service has perhaps not faced on such a scale before.

HSJ has reported the stories of a number of families whose individual struggles for the truth date back years and the journey has left them with permanent emotional scars.

In these and many other cases, the effect on those families cannot be underestimated. They are traumatised by their treatment at the hands of a health service that is supposed to have compassion as a core value.

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The NHS must stop destroying bereaved families' lives as its belief in misguided secrecy and a focus on reputational management undermines the great work done by thousands of NHS staff, day in and day out. It's a betrayal of them, too.

For the parents of baby Elizabeth Dixon, who died in December 2001, their struggle is as raw and painful as ever. Ignored by the system, they have persevered to expose a systemic failure that is only now being realised, more than a decade after their daughter's death.

A promised joint inquiry by NHS England and the Care Quality Commission was cancelled at the last minute in 2014 as Lizzie's parents travelled to London – a decision made more for organisational self-interest than anything to do with Lizzie.

Her parents turned to the Parliamentary and Health Service Ombudsman – and nine months of "torture" followed before the PHSO decided it wouldn't take on the case. It was only after *HSJ* highlighted the issues that health secretary Jeremy Hunt intervened to order an independent inquiry be carried out.

Getting to the truth

Consider also the case of three-year-old Jonnie Meek, who died at Stafford Hospital last year. An inquest proved fruitless, with key witnesses not called and key lines of enquiry not pursued.

It was only down to Jonnie's father's sheer determination that they obtained their son's medical notes and internal reports submitted to a child death review panel.

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Imagine their shock and anger when they discovered incorrect statements about their son's medical history, including claims of cardiac arrests that never happened and, worse, a false statement in the name of a healthcare assistant who later confirmed to *HSJ* it was wrong and she had never made it.

I sat for more than two hours with Jonnie's parents and saw the pain etched on their faces. As his father explained: "There has been a complete disregard for our family. We lost Jonnie and then it's like they have just walked all over him and disrespected him as if he never mattered anyway… Each process has been an insult to him."

Similarly, in the case of baby Kate Stanton-Davies, who died amid a catalogue of mistakes by midwives in 2009, her parents have had a six-year fight to get to the truth. They had to threaten a judicial review in order to get an inquest, which concluded that Kate's death was avoidable.

Only this year, a flawed investigation report was overturned, but even then NHS England was forced into a U-turn last month after it initially said a national audit sparked by Kate's case would remain secret.

Kate's mother, Rhiannon Davies, told *HSJ*: "The pain I live with as a result of this process causes me huge anguish on a daily basis."

No answers

These are just three examples where *HSJ* has helped families in the public interest, but there are many more who don't get the answers they should.

None of these families want fame or fortune, but rather than show them some humility and compassion, the NHS hurts them all over again.

It is quite simply unspeakably cruel.

Some positive steps have been taken towards a more open and transparent NHS, but so far these have relied on new regulation, beefed up codes of conduct and, as a last resort, new laws and threats of prosecution.

The cultural change needed in the NHS will require a personal determination to act differently by everyone from frontline staff to individuals in system leadership roles.

In 2011, as the Mid Staffs Public Inquiry was nearing an end, Sir Robert Francis warned: "There is a tsunami of anger heading towards the NHS, which will overwhelm people paddling in their canoes acting as if nothing is happening."

Four years on, his warning to the health service is as prescient today as it ever was.

Shaun Lintern is *HSJ* patient safety correspondent

Readers' comments (5)

- **Kenneth Lownds** 10 December, 2015 2:23 pm

  Excellent Shaun, well done.

- **Umesh Prabhu** 13 December, 2015 11:45 am

  Dear Shaun, please do come to Wrightington, Wigan and Leigh FT where Martin Farrier works and look at our culture, values, governance, leadership, clinical engagement and staff and patient engagement.

  I have already invited you once and hope you will accept the invitation this time so that a well respected journalists like you can tell the real story to the World.

  I have been criticised as bragging by many. Hope you can convince the world otherwise.

  It is wonderful colleagues like Martin Farrier and many other amazing staff who have made us so successful.

- **Janet Martin** 14 December, 2015 10:29 am

Unfortunately as someone who has recently accompanied relatives to hospital appointments or visited while they are on longer stays, patient and their family's experiences of poor "customer care" in the NHS (and Social Services too) ranges from the really serious issues raised in the article, to everyday contact. I'd love to hear more from a hospital that is really working to engage families and to learn and most importantly to act on what they hear.

- **Anonymous** 15 December, 2015 4:03 pm

  Is this article really written to promote the cause of families who have suffered at the hands of the health service?

  Or ... is it written to promote the HSJ?

  Promoting the HSJ is fine, but please do not try and dress this up as something else (and particularly with this topic - most distasteful)

- **Cheryl Vander** 16 December, 2015 11:18 pm

  Keep on shining your light into those hidden corners of the NHS, HSJ journalists. The simple fact is that there is inadequate funding and amateurish investigating skillset in the majority of hospitals when running serious incident investigations....in other words they are inept and ignorant of the specalist nature of such a delicate task.until they are required to use someone who's not answerable to a line manager then the situation will remain the same.When you start to run an investigation you never know where it will take you.
