Complaining about complaints

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One woman's courageous search for answers

If a member of the public neglects, kills or injures another, criminal investigations proceed. If the action was unintentional the consequence can still be jail for manslaughter, a ban for life from driving, a criminal record. In the UK a victim does not have to bring charges voluntarily, the state will do it on his/her behalf, even for domestic violence. If NHS treatment has caused death or injury, the victim has the NHS complaints system and a fight which nobody will fight for them, even though the NHS has a duty of care to the victim.

The NHS complaints system may be set up to deal with errors of a trusted, talented and dedicated workforce, but to the physically or psychologically injured, or those mourning a life that could have been saved, it is no less impor tant than injury or death caused outside the NHS. A life lost is a life lost, a life long injury is a life long injury. Many who complain do not wish responsible health professionals to lose their jobs and rarely seek monetary compensation, all they want is simple justice. Justice in these cases may be an explanation and apology for fault and action to prevent something similar happening again. The British public is being accused of turning into a compensation culture, yet nearly all of NHS complainants want three simple things - an explanation, an apology and a change[1]

I am currently in my fourth year of an unresolved complaint about my care in maternity services, looking to go into a fifth. I too was like most who wanted simple justice, but if I had known I would have to fight with sweat and tears for so long I never would have believed it and probably never would have even tried.

In July 2005 I was admitted to hospital where I suffered an inevitable, late miscarriage. That would have been enough to deal with in itself, but little did I know that I would end up fighting for my own life as well because of negligent treatment over my five days in hospital. Ignored when asking for help whilst in a life threatening condition, refused pain relief, starved of food and water for four days, how much did they expect someone to cope with having just lost a baby? The word torture kept going through my head, yet I was in a place where I expected quality care, not where I felt my existence ignored. I could no longer think just about my baby I had lost and started wondering if I was going to make it and if anyone in the world would care to save me. Discharged whilst still seriously ill, the horror continued as my son found me unconscious on the sofa at home.

Without any explanation of my condition to my GP, I was again left alone to survive unaided, afraid to fall asleep in case I didn't wake up again. I had my family, but not those who I expected to aid me medically. Months later I began to recover my physical strength, enough at least to write a letter of complaint to the Trust. Up to that point I had worked for the NHS for five years and it was a big thing for me to send in a serious complaint about my care, but I had no idea I was going to have to go through far tougher things to get anywhere with my complaint. Little did I know that I was going to have to fight to prove anything was wrong at all with my care. How naive of me to think that they would want to reply swiftly to put things right with an overwhelming apology, telling me it would never happen again. That would have put my mind and heart at rest. Alas, I am still awaiting such relief.

Little did I know that my complaint was going to take me through literally hundreds of letters, emails, phone calls, to even get a reply. That it was going to take me to the Healthcare Commission, to solicitors, to the Healthservice Ombudsman, to my MP and that I would need an advocate from ICAS (Independent Complaints Advocacy Service) to help me on my way. Countless times I have questioned whether it was all worth the effort, many times I felt the delays were deliberate, intended to get me to just give up. I have only continued because I feel I owe it to myself to defend myself, to not let my life being put in danger become just a matter of lost paperwork.

Following the letter I sent to the Trust in October 2005, I got the standard 'we will reply within a month' letter. After no reply in January 2006 I rang to ask what was happening. I was dreading the letter as I was not looking forward to revisiting the horrendous details of my care. Between January and April 2006 I rang several times, to be given one excuse after another - leave, lack of staff, each time promised the dreaded letter within the following two weeks. By this time the Trust knew I had been unable to return to my job since the experience, and that I was suffering from post traumatic stress disorder. This had as little effect on their urgency to reply as did the initial complaint. Any hope that anyone cared in the slightest about how the Trust had treated me was gone. I gave up on the Trust replying and took it to the Healthcare Commission (HC) in May 2006.

Filled with new hope that the powers and expertise of the HC would finally provide me with some answers, I waited patiently to go through their system. By June 2006 I finally received a reply from the Trust, which explained nothing. I was shocked at the total refusal to accept any blame whatsoever, but kept the hope the HC would back me up. By November 2006 I had got to the top of HC's complaints pile, and my caseworker persuaded me to ask the Trust to comment on my response to the Trust's reply. As the Trust had taken a painful nine months to reply to my first letter I doubted it was worth sending anything to them, but to cooperate with the HC I made it clear that I would give the Trust one month to reply and then I wanted the investigation to continue. The caseworker assured me that if I wanted the case to continue at anytime all I had to do was call and my case would be fast tracked through. Cheekily he asked if he could close the case while they were waiting for the reply, and as I had foolishly believed his assurance they would reopen the case at anytime I agreed.

As I had predicted, the Trust did not reply within a month, or two months or three. Between January 2007 and April 2007 I asked the caseworker to reopen my case, this time I was literally bullied into waiting longer for the Trust to reply as this HC transcript of a telephone conversation between my caseworker and me shows:

She has not heard anything from the Trust since the decision letter apart from being told that it is being dealt with (i.e. the further local resolution). She wants to give up on the Trust and come straight back to the Healthcare Commission. I explained that I did not consider this appropriate, the complainant seemed a little annoyed at that and said she refused to wait six months again for them to answer. I explained that I would speak to the Trust to establish the position. [...] The complainant said yet again that she just felt like coming back to the Healthcare Commission and giving up on the Trust. I reiterated what I had said earlier about the new issues and said it would be best if I chased the Trust first to establish the position. The complainant yet again asked about coming back to the Healthcare Commission and I further repeated the above discussion and said I would contact the Trust and revert to her. The complainant did not seem particularly happy with this but agreed.

If I had felt small-fry when I first complained to the Trust, now I felt completely powerless. There was I naively thinking my complaint would cause concern and action as soon as it was read when I first sent it, and now I felt there was absolutely nothing I could do to get anyone to even give me the courtesy of a reply of any kind. So I approached ICAS and was helped enormously by an advocate assigned to my case who came to understand all the details of my complaint and rang tirelessly on my behalf to try and get something moving. If I hadn't had someone to believe in the value of my complaint and to make so many frustrating phone calls I would have stopped there. If I had felt I had been treated cruelly during my hospital stay, I felt treated cruelly again and again during this complaint process. The Trust and the HC were fully aware that I was grieving a lost baby, suffering PTSD and unable to return to work. How cruel did they think it was to allow this complaint to be unresolved for so long, to be treated with such a lack of importance? Each phone call, letter, email, each time I heard the post come was another trigger for the PTSD, it seemed nobody had a duty of care to my current condition let alone the original care. Worse than that there seemed nothing anyone would or could do about it. How necessary was it to be treated like this by the NHS that is set up to care for people?

The Trust took seven months to reply to the HC, and again denied any fault. By the time the letter came I had given up hope in the ability of the HC to resolve my case and rang the Health Service Ombudsman (HSO) to ask if they could take it on given the way the HC had behaved. They insisted I had to finish going through the HC first. By then the HC told me I had to put in a new application as my case was closed, so I had to start all over again with them. With no other option, and with the support of my advocate I did this and received a letter saying they would try and be quicker with my case this time. With a new caseworker and her manager to assure me they would do better this time, I gave them a second chance, but added to my complaint a complaint about the way the HC had dealt with my case until then. Despite my patience they did not fulfil their promises and my advocate entered another series of multiple emails asking why many months had passed and the HC hadn't even requested my notes from the Trust.

By March 2008 I finally gave up on the HC and asked the HSO again if they would take on my case. I also added a full complaint about the HC. I received a standard letter saying they would tell me within a month if they would take my case on or not but did not get a decision until January 2009. In this letter they said they had decided not investigate the HC because the HC was due to close in April 2009 so they said there would be no point. 'No point for whom?' I asked them. How can someone under so much stress be treated so badly and nobody be responsible to answer for it?

I was happy they were to investigate my complaint about my hospital care fully, but appalled they could just write off the HC complaint. I asked my MP to help, and my advocate sent another series of emails to the Ombudsman. The conclusion was that I would have to send in a complaint about the HSO! How many complaints is it actually possible for one person to have going at any one time? I have been made dizzy by so many complaints and such an unreasonable amount of time and energy necessary for an original complaint, unresolved years after it happened. If someone told me the system was designed to get people to give up I would believe them, I felt it many a time, but am not prepared to give up, unless it is my choice to end the complaint, not because the NHS has yet again failed me.

I sent in a complaint about the Ombudsman not wanting to investigate my complaint about the Healthcare Commission taking two years to deal with my complaint and bullying me into waiting. They replied to say that they will not investigate because 'given the Commission's role in the NHS complaints process has now come to an end, I agree with our earlier conclusion that there is little to be gained by conducting a formal investigation of their role in your case.' Little point for them possibly, but an apology and acknowledgement for me would have been hugely beneficial. I am also suspicious of their recent repor t citing few or no cases taking as long as mine.

Somewhere along the line I was so fed up with the eternal waiting for a reply I sought legal advice. I discovered I could cover legal costs through my home insurance, including an independent medical investigation of my case. I found new hope in this that a thorough investigation would at last take place. I was also shocked to find myself in this position. Feeling like taking possible legal action was a huge step for me personally. Alas I found this process no more fruitful. The junior solicitor assigned to my case did not show me the letter of instruction to their medical expert so I had no say in what they investigated. When I finally did see a copy of the letter I saw the solicitor had made 14 factual errors about my case and hadn't even managed to get my date of birth right.

By the time the three year time limit for legal action was nearly up proceedings were filed against the trust just to give me more time, but the firm was nowhere near ready to advise me on whether the case had any chance of success. I managed to change solicitors at that point, but again was unable to have any input into enquiries to the medical expert. I saw a new letter of instruction, but the solicitor refused to accept any of my changes on grounds that either I was questioning his legal expertise, or that I might be insulting the expertise of the medical expert. I wasn't surprised they were finally unable to find enough fault to justify my home insurance covering my legal expenses. They were looking only for breach of duty that would have high financial compensation, I was looking for my questions to be answered. Many times I was told that of course a miscarriage would be stressful, as if there was no way traumatic life-threatening care could coincide with a miscarriage.

Having gone through both legal and NHS routes I actually found little difference. In both systems fault cannot be found unless it is clearly documented in the hospital notes taken at the time. My hospital notes were appalling, several visits from doctors and nurses were not recorded, no record of being kept nil by mouth for most of four days was recorded, some medications given were not noted, blood loss unestimated, several visits from doctors and nurses not noted. On the night I spent five hours pleading for pain relief saying my pain score was 12 out of 10, it was unbearable, not one single pain score had been recorded. My account of what happened was irrelevant because it did not count as solid evidence, and the complaint had taken so long staff could not be interviewed to verify my account. It is almost as if that incomplete, vague note-taking is deliberate and to the total advantage of the Trusts. No matter what the patient claims had happened, nobody can prove any of it if it is not clearly written in the notes. You can't even prove how many things were missing in the notes. The worst that can happen with incomplete notes is that they get their wrists slapped for poor administration, but it is hardly media worthy, unlike the many fatal and serious incidents of negligence that can be covered up by such vagueness.

Has it all been worth it? I can't answer that because I am looking at possibly another year of waiting while the HSO investigates. I am no longer expecting an acknowledgement or an apology, although that would be a pleasant surprise.

Quite probably none of my trauma was intentionally caused, it may well be explained by untrained staff, staff and bed shortages, inadequate practices etc. What shocked me was that not only did I have to suffer what I did, there was such little concern about resolving the situation, and allowing me to gain some closure on something I wish I could have laid to rest many years ago. The complaints process has been almost as shocking as the original experience. There seems such a fear to admit mistakes, fear that we have become a litigation culture, but it is the very complaints process that is driving many people to seek litigation. With maternity services complaints taking up a third of NHS litigation costs they need to look seriously at how maternity complaints are dealt with by the NHS. Some parents will continue to sue to seek necessary costs for a lifetime of care for a child unnecessarily disabled during bir th, but others just want that simple, swift apology and reassurance it won't happen to another poor soul. How easy do they think it is for women who have lost a baby or have a newborn (ill, disabled or healthy) to look after to complain about maternity services? What about families who have lost their partner, daughter, mother in childbirth? How easy is it for someone with PTSD to have constantly to relive the experience through a complaint remaining unresolved for years?

Some people just aren't able to complain. As someone said to me, 'I can't fight the system, I am too ill to.' Do they not think that these people at the very least deserve not be failed again by a complaint system currently functioning to protect the Trusts and ignore their duty of psychological care to patients and their families and to learn as much from their mistakes as possible?

I cannot know what the true effect of my complaint is behind the scenes. A friend once told me, 'They'll never let you know it, but you're probably making them sweat!' I will never know. Neither will I ever know whether the Early Pregnancy Unit opened recently in the hospital I complained about was partially because of my complaint. That would mean they would have to admit fault with my care, which they seem unable to do. To have known I might have made a difference would have meant the world to me, but that I will never know.

References

1. Healthcare Commission (2009) *What people want from complaints*. Spotlight on Complaints Feb. 2009