Case Study

Learning out of tragedy case

In memory of John, a loving husband and father whose death has changed 111 and 999 responses to identify Sepsis more quickly.

Healthwatch West Sussex Independent Health Complaints Advocacy Service (IHCAS) supported Sandra and Jess to raise their shared complaints and have their voices heard since the death of John* (husband and father) in early 2019.

* Clients names have been changed in this case study

healthwatch West Sussex

Sandra's Story

John and I were married for 30 years. We shared and enjoyed holidays, concerts, galleries, and theatre visits. John was a lifelong Brighton and Hove Albion football supporter, and he and Jess had been season ticket holders for a number of years. John had taken early retirement from academia in 2015, enabling him to do voluntary work which he found very rewarding. He was thoroughly enjoying his retirement. There were holidays booked, and so many things he had planned, all of which were denied him.

After John's discharge from Worthing Hospital in the new year, we were waiting on an urgent outpatient appointment at another hospital. Did I consider the events over the next 11 days would change my whole world and my daughter's going forward. The answer is NO.

With John's health continuing to deteriorate we called out a GP, who visited six days after he had come out of hospital. The GP reported that all his vital signs were normal but still he continued to decline. I finally asked for help at the weekend (three days after the GP visit) and it was then that John was failed at each point of contact. There was a delay of nearly 14 hours for the out of hours doctor (via IC24) to make contact and complete the assessment which took place in the early hours of the next morning. **On reflection, at that time of the day, is it a good time to call back and ask people to make decisions?** Perhaps it would have been best to have gone with a home visit, a decision that I will have to live with.

The Serious Incident Report carried out by the Out of Hours service states 'with the benefit of hindsight a home visit may have identified 'Red Flags' for sepsis or signs of acute abdominal pathology (which may not have been apparent via the telephone conversation).' **I now understand that if I had been given more information about sepsis the outcome may have been different.**

The delay in the ambulance service arriving to my husband resulted in a delayed admission to hospital, where he died the next day. As a direct result of Sandra's complaint, and why having your voice heard is so important, the national NHS Pathways for 999 calls has been updated to increase sensitivity for spotting critical illness (Sepsis).

I am still struggling coming to terms with life on my own, which has become more difficult with the onset of COVID. My world has closed in and I feel my options and choices in life have greatly diminished. I have the guilt of thinking that had I been more insistent and assertive in my interactions with 111 and 999 that John would have received the help he needed and could still be with us. What has happened has had a massive impact on my daughter's mental health, which in turn has greatly increased my levels of stress and anxiety both now and for the future. I have lost confidence in the NHS. The failures in the complaints process seem to confirm to me that John's life was without value, as too are our subsequent feelings of loss and grief.

It concerns me greatly that every time John *asked* for help it was not given appropriately - considering that he was at risk of sepsis. This is something I've discovered through the complaints process. At no point did anyone say that John may be at greater risk of sepsis due to having pancreatic necrosis.

Jess' Story

My mental health and wellbeing have been significantly impacted since Dad died. My anti-depressant dosage has increased, and in the months after Dad's death, I was also prescribed anti-sickness tablets due to regular dizzy spells.

I have received counselling through several services, and whilst I recognise, I would benefit from further counselling, I am unable to afford regular private sessions.

I have found the complaints process extremely emotionally taxing, and have had to take time off work due to having felt overwhelmed and distressed after meetings with agencies; these meetings have left me reliving the events that happened to Dad and as a result have left me feeling very stuck in my grieving process. I worry about my Mum and the impact this has had on here and her life.

Advocates Reflections

I have reflected on how best to support this family at different stages and been aware that continuing with the complaints process may have been harmful, particularly on Jess's mental wellbeing.

However, I am proud of the way the family has tenaciously sought to get answers and that this has led to some important changes. It has been challenging working with 5 organisations on this complaint and very frustrating that it took nearly 2 years to get to the end of the local process.

It brings into question, if Sandra and Jess had not accessed advocacy support would they have been able to have managed such a complex complaint and if this happens to others in the future would they need advocacy support too and the public awareness of the service needs to be increased when Serious Incident Reports are raised.

The response from the hospital consultant was that they "did not expect John to die" yet there were mildly elevated inflammatory markers and as below shows that the spread of infection to the blood (sepsis) is a very real risk in patients with John's condition.

Events after the end of the local process

When we came to the end of the complaints process at the local level, the advocate met with Sandra and Jess and spoke about how they were feeling especially when they had just been informed the Trust did not expect John to die. It was agreed that the advocate would make an application to West Sussex Coroners to raise all the concerns that had been found during the complaint's investigation. The application was submitted in December 2020, and notification was received in May 2021 there was a need for a full inquest into John's death.

Sandra and Jess attended a two-day inquest with the support of the advocate in December 2021. The outcome was to update John's death certificate "Narrative Conclusion - Death was consequent upon a background of existing illness and delay in medical recognition of need for urgent hospital treatment." The coroner also wanted to write a Preventable Future Death Report concerning sepsis and also share the recording of the calls made by Jess to 999 with NHS Digital for future learning.

Feedback from client

I contacted Healthwatch West Sussex in early 2019 seeking help and guidance in pursuing complaints and concerns I had relating to the 101 and 999 services, and Worthing Hospital. In response I soon received a call from the advocate, introducing themselves as my appointed advocate. From the outset the advocate was approachable and friendly, but always very professional.

I felt I was able to voice any thoughts, concerns, or questions, and that I was always listened to. The advocate was methodical and thorough in their approach and always checked that I was happy with documents/emails that she was sending to other agencies on my behalf.

There was a real sense we were working together. The advocate explained clearly what each next step entailed so that I knew exactly what to expect. It was made clear that I could stop the complaints process at any point if I so wished. Nothing was too much trouble. Without the advocates help I would never have been able to navigate the lengthy and complex complaints process, which took almost 3 years from start to finish. I cannot praise and thank Katie enough.

NHS.uk states:

Pancreatic necrosis and infection

Sometimes people with severe acute pancreatitis can develop a complication where the pancreas loses its blood supply. This can cause some of the tissue of the pancreas to die (necrosis).

When this happens, the pancreas can become infected, which can spread into the blood (sepsis) and cause organ failure.

People with necrosis and an infection may need injections of antibiotics and surgery to remove the dead tissue. This is a very serious complication that needs treating, and it can be fatal.

Summary issues identified

- The referral correspondence did not stress an urgency for John to be seen by the onward hospital, instead there is a suggestion that he would be seen through the 'next available appointment'. The referral information was not included in his medical records.

- The discharge summary to the GP failed to suggest the need for monitoring and the risk of Sepsis, that may have evoked additional tests to detect the onset of Sepsis.

- The hospital did not inform the patient of his medical condition, the information came to light when Sandra read the discharge summary however, she did not understand the potential serious complications that could arise and therefore the family did not carry out any independent research.

- The complaints process has been frustratingly long, even with the professional advocacy support and the knowledge the Healthwatch Independent Health Complaints Advocacy Service (IHCAS) brings to this process. This has been particularly due to information being missing in the medical records, and complaints handlers being on shift/call and therefore not having the time to deal with the complaint investigation in a timely manner.

- The family were not alerted to the potential of complications of pancreatic necrosis and the warning signs to look out for – which is something Healthwatch believes should be detailed on the discharge summary.

- On the whole, the general population remains unaware of Sepsis and the importance of recognising early the signs and symptoms of this deadly infection.

- The importance of pathway questions has been demonstrated by this case, but it is also important to recognise that peoples' health literacy is very varied. John was an articulate man but would not necessarily have been aware of his condition and what to do if something happened whilst waiting for the referral.

  Organisations should not assume people will:

  a)be able to fully describe their condition (particularly when they are so poorly), and

  b)be alert to the potential seriousness of their situation.

Many people have a natural trust in the NHS and will not speak out, or question the situation, regardless of how much the individual's health is deteriorating.

- Organisations have taken too long to investigate the complaint and to respond.

    - The family had to experience a cancellation of a complaints meeting with only 30 minutes notice, staff arriving late to a meeting, not phoning, or providing updates or offers of apology.

    - It took South East Coastal Ambulance NHS Foundation Trust nine months to update one page of the Serious Incident Report and this has caused mental harm to the family.

    - Care and attention not given to the content of Serious Incident Reports (in one case there was a reference to the patient's Mother, when it should have read wife.)

    - Organisations do not demonstrate empathy or sensitivity around their complaints handling, which then gives little confidence that much will be learnt from the process.

    - What has been learnt from hindsight to ensure a home visit is actioned?