Parliamentary and Health Service Ombudsman

Spotlight on sepsis: your stories, your rights

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Foreword from the Ombudsman

As the national health Ombudsman, I see time and again patients and families not being listened to after something has gone wrong with their care.

Too many patients and families have been left without a voice and their concerns not taken seriously. When the mistakes relate to sepsis, the outcomes are often fatal.

Although action has been taken to improve the recognition and treatment of sepsis since our last report ten years ago, evidence from our casework shows there is an urgent need for much more to be done. Crucially, NHS staff must be sepsis-aware. They also need to have a culture that is open, accepts mistakes when they happen, and then learns from them. It is the responsibility of NHS leadership to build this environment of honesty and accountability. This is a big step in making patient safety an absolute priority.

I've heard harrowing stories about sepsis through the cases my office investigates. The cases in this report demonstrate some of the recurring issues in sepsis-related casework. They show the importance of listening to patients and families, and why early detection and treatment is crucial.

In the Radio Ombudsman episode which accompanies this report, I speak about these issues with Melissa Mead MBE.

Melissa is a dedicated campaigner on sepsis whose 12-month-old son tragically died from the condition. Her story, like those highlighted in this report, is deeply moving. I know that people working in the health service want to do a good job, and most people using NHS services do experience safe, high-quality care, but Melissa's experience of how her family was treated is not an isolated case. It is far more common than people may believe. Her episode of Radio Ombudsman is vital listening and a powerful reminder for staff, leaders and organisations to make sure lessons are learned from her story and others' devastating loss.

I hope by sharing in this report people's experiences of where sepsis-related care has gone wrong, others will feel empowered to speak about their own experiences. This collective voice must contribute to shaping urgent action on sepsis and making sure complaints about this life-threatening condition count.

Rob Behrens CBE
Parliamentary and Health Service Ombudsman

Introduction

Sepsis is a life-threatening reaction to an infection. It can affect anyone of any age. It happens when your immune system overreacts to an infection and starts to damage your body's own tissues and organs. Sepsis is sometimes called septicaemia or blood poisoning.

According to the UK Sepsis Trust, 48,000 people in the UK die of sepsis every year. This number can and should be reduced. It is often treatable if caught quickly.

In this report, we look at some of the sepsis complaints people have brought to us, to shine a light on their experiences and encourage others to let their voices be heard.

We share case summaries and guidance to help people complain and help NHS organisations understand and learn from the issues raised.

Sepsis care and treatment issues

Sepsis is an extremely important patient safety and public health issue. It should be a priority for people involved in providing care and treatment, health regulators and policymakers.

Sepsis causes approximately 1 in 5 deaths globally, with an estimated 49 million cases and 11 million sepsis-related deaths each year. The World Health Organisation is leading worldwide efforts to prevent, manage and treat sepsis. It published a report in 2020 about the global burden of sepsis.

In the UK an estimated 245,000 cases of sepsis happen each year with deaths totalling more than breast, bowel and prostate cancers combined. The Academy of Medical Royal Colleges has made it clear that: 'Sepsis still kills far too many people – tens of thousands in the UK each year, and we know that if infection is identified and treated early, some cases of sepsis and some sepsis-related deaths may be preventable.'

The UK Sepsis Trust has been doing invaluable work to improve the outcomes of patients, including publishing 'The Sepsis Manual' for medical staff. Health Education England has also been leading on raising awareness of sepsis.

We recognise that significant investments of time and money have been spent to improve sepsis care, with initiatives like Think Sepsis that are helping medical staff to diagnose and treat it. We also recognise that substantial and long-term investment is needed to ensure better outcomes for patients with sepsis.

Evidence from our casework

Ten years ago, our 'Time to act' report highlighted the death of ten NHS patients after failure to diagnose and rapidly treat sepsis. We identified issues including:

- unnecessary delays in diagnosing sepsis
- failures in starting treatment quickly
- insufficient staff training
- delayed referrals to critical care
- failure to provide adequate plans for patients' care.

In response to our recommendations, the National Institute for Health and Care Excellence (NICE) published a guideline (NG51) and quality standard (QS161) to help NHS staff recognise and treat sepsis more quickly. Public Health England (the organisation that was responsible for protecting and improving the nation's health at that time) and the UK Sepsis Trust launched a national campaign to increase awareness of sepsis symptoms.

Despite some improvements, we still see complaints where we find that someone has died from sepsis because they did not receive the right care at the right time. It is disappointing to see that the issues we identified ten years ago are still the same as we see in our casework today.

Earlier this year, we published 'Broken trust: making patient safety more than just a promise'. In the cases we looked at in the report, sepsis was the most frequent clinical issue leading to avoidable death. 'Broken trust' highlighted complex patient safety issues and the need to create a system that is easier to navigate, based on evidence and engagement with patients, families, NHS staff and leaders.

Listening to patients, families and carers

Families affected by sepsis have explained to us that they want what happened to them to matter. They want to make sure voices like theirs are listened to and acted on. They want NHS organisations to make meaningful changes so that what happened to them will not happen to others in future.

In the last ten years, campaigns and training have improved public awareness of sepsis. But we still see too many failings in sepsis care and treatment.

We hope the stories and guidance in this report will help more people share their experiences and understand their right to complain. Our experience gives us evidence every day of the power of complaints. They can make a real difference by showing how the issues are affecting people's lives and helping organisations to learn from mistakes and improve services for everyone.

Case summaries: sharing people's stories

The following case summaries show some of the themes we found in the most serious complaints about sepsis. These include delays in diagnosis and treatment, poor communication and record-keeping, and missed opportunities for follow-up care.

Where we found failings, we looked at how these affected the patients and their families, and what the organisation needed to do to address them.

When we make recommendations to put things right, we follow up on them until the organisation acts on them. If an organisation refuses or fails to put things right, we may tell regulators or integrated care boards about this. As a last resort, we can make a special report to Parliament.

Delay in diagnosing and treating sepsis after a procedure

The complaint

Mrs B complained about the treatment that Sandwell and West Birmingham Hospitals NHS Trust gave her mother, Mrs A.

Mrs A was in her seventies and had existing health conditions including a previous heart attack. In 2018, she went to a clinic for a hysteroscopy (a procedure to look inside the womb). The surgical team identified her as a high-risk patient and booked her into a ward for monitoring. During the procedure, the surgeon diagnosed and drained pyometra (an infection where pus fills the womb).

At 4.15pm, a couple of hours after the procedure, Mrs A had nausea and diarrhoea. Her blood pressure dropped and she had a very low white blood cell count. She was moved to the acute medical unit (AMU) for close monitoring.

The AMU doctor assessed Mrs A at 6.45pm and recommended an immediate dose of antibiotics. This did not happen. The consultant gynaecologist (a doctor who specialises in the female reproductive system) was told about Mrs A's deteriorating condition at 7.30pm but did not suggest antibiotics. The record of the conversation did not say whether they were told about the AMU doctor's recommendation.

Mrs A continued to get worse and was given a single dose of antibiotics at 10.40pm. Doctors decided not to move Mrs A to intensive care due to her existing health conditions.

The next morning, Mrs A had a CT scan (a scan that creates detailed images of the inside of the body) and more antibiotics. She was moved to intensive care to get medication to help her heart to pump. She did not get better and doctors started end of life care. She sadly died a few days later and sepsis was one of the reported causes of death, with severe heart failure as a contributing factor. Sepsis can cause multiple organ failure if it is not recognised early and treated quickly.

What we found

We found that the Trust did not give timely treatment for sepsis. There was a significant delay of almost four hours in giving antibiotics. Mrs A should have been given antibiotics when the AMU doctor recommended it. The consultant gynaecologist should have recommended antibiotics. If Mrs A had been given prompt antibiotic treatment in line with NICE guidance, it is more likely than not she would have survived.

We found that the Trust did not move Mrs A to intensive care at the earliest opportunity for her to get life-saving support. There was a misunderstanding about how her treatment should have been escalated after the procedure, because the Trust did not clearly record her post-operative care requirements and agreements.

Mrs A should not have died when she did. This caused her family a lot of distress and affected their ability to grieve.

Putting things right

We said the Trust should write to Mrs B to accept the failings and apologise for how they affected Mrs A's family. We said it should make a payment to Mrs B to recognise the injustice suffered. We also said the Trust should make an action plan setting out how it will stop the same mistakes from happening again and send a copy of the report to the Care Quality Commission (CQC) and NHS Improvement.

Mrs A should not have died when she did. This caused her family a lot of distress and affected their ability to grieve.

48-hour delay in diagnosing and treating signs of sepsis

The complaint

Mrs G complained about the care and treatment that Leeds Teaching Hospitals NHS Trust gave her late grandfather, Mr H, after he fell at home in 2018.

The Trust initially treated Mr H for a suspected stroke but moved him to a respiratory ward due to concerns about him becoming increasingly breathless. He received treatment for a pneumothorax (a collection of air outside the lung causing the lung to collapse). He was assessed as having a moderate risk of sepsis and sadly died two days later.

Mrs G complained that the Trust did not diagnose or treat signs of sepsis, which was recorded as Mr H's main cause of death.

What we found

The Trust was monitoring Mr H's National Early Warning Score while he was in hospital. (NEWS is a system used to assess and respond to acute illness, including sepsis – the current version was updated in 2017 and is called NEWS2.) When his NEWS had risen to five, the point at which sepsis should be considered, the Trust completed a sepsis screening tool and assessed Mr H as having a moderate risk.

The Trust says it considered that a pneumothorax found on an X-ray was the cause of Mr H's health getting worse. It inserted a chest drain to treat the pneumothorax.

Later that evening, Mr H's NEWS had risen to nine. His scores included a high temperature and a low blood pressure level that suggested a possible underlying infection. Records did not show that the Trust recognised the possibility of infection at this time or investigated it further.

Two days later, Mr H's blood test results showed an increased lactate measurement (increased lactate in the blood can be a sign of sepsis). The Trust prescribed antibiotics. By the time the prescription was ready it decided not to give Mr H the medication because his health continued to get worse.

The Trust did not measure Mr H's lactate levels when his NEWS had risen to nine. It should have done this, following NICE guidelines. If it had, it would likely have produced a result like the measurement taken two days later.

There was a 48-hour delay in the Trust identifying the possibility of sepsis and prescribing antibiotics for Mr H. This failing seriously affected his chances of survival.

Putting things right

We said the Trust should write to Mrs G accepting and apologising for the failure to diagnose and treat her grandfather's sepsis.

We also said the Trust should tell us and Mrs G how it will address the failing and reduce the risk of this happening again in the future.

Failure to treat sepsis before and after a fall in hospital

The complaint

Mrs C complained about the care and treatment that Blackpool Teaching Hospitals NHS Foundation Trust gave her mother, Mrs D, in November 2017.

Mrs C found her mother unwell at home. In hospital, she was diagnosed with worsening chronic obstructive pulmonary disease (COPD is the name for a group of lung conditions which cause breathing difficulties) and moved to the acute medical unit.

Almost two weeks later, Mrs D fell while still in hospital. She had a cardiac arrest (where the heart stops pumping blood around the body) the next day. Mrs D did not recover and sadly died.

Mrs C says her mother died avoidably and unexpectedly from pneumonia (inflammation of the lungs) and a cardiac arrest because the Trust missed opportunities to provide the care she needed. She was devastated when her mother died, and this has caused her long-term and ongoing upset and anger.

We saw an internal Trust document, written after the events, where a medical consultant wrote that Mrs D was 'clearly unwell' after her fall 'and had shown a very rapid deterioration within a short period of time which was likely due to developing ... pneumonia with sepsis secondary to her severe underlying lung disease'. We did not see any evidence that the Trust shared this information with Mrs C.

What we found

We found that Mrs D had signs of sepsis and the Trust missed opportunities to identify and treat it.

A CT scan suggested that Mrs D had pneumonia when she arrived at hospital. She was treated with antibiotics and her condition improved. The Trust stopped antibiotics after the five-day course.

A few days after the course was finished, blood tests showed that Mrs D had acidaemia (when the lungs cannot get carbon dioxide out of the body quickly enough) and type two respiratory failure (low oxygen levels and a build-up of carbon dioxide). A chest X-ray the next day showed that Mrs D's health had deteriorated since being admitted to hospital. There was a new pleural effusion (fluid around the lungs) and worsening consolidation (when the air spaces in the lung are filled with something other than air). Our clinical adviser said these results were likely caused by worsening pneumonia and suggested that Mrs D had recurring sepsis. The Trust should have suspected sepsis and restarted antibiotics.

Our clinical adviser also said sepsis was likely the reason Mrs D fell the day before she died. Mrs D had high NEWS scores, low oxygen levels and a high respiratory rate, which meant she was in the high-risk category for suspected sepsis.

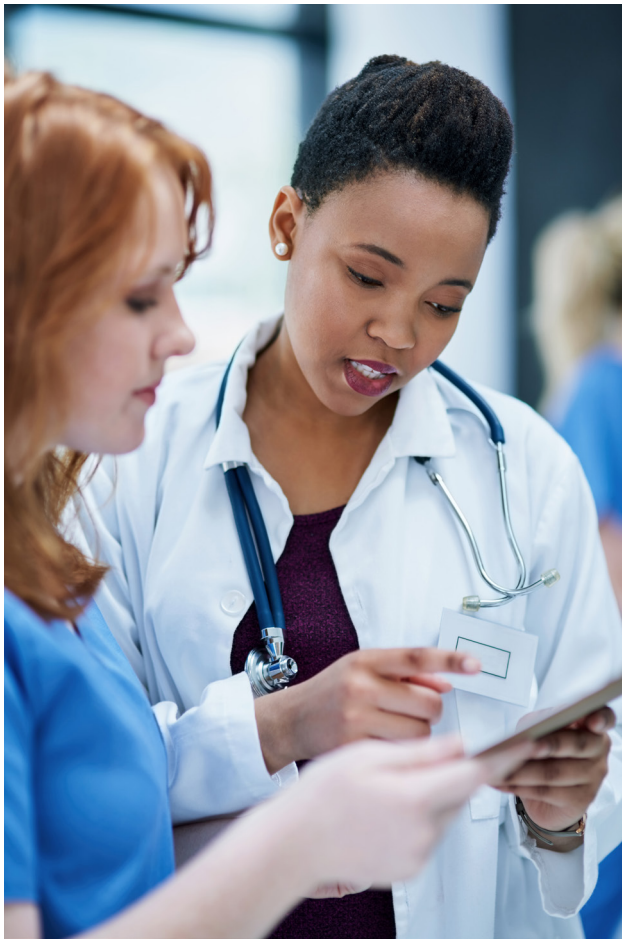
There was no evidence that the Trust considered sepsis as a medical reason for the fall, escalated the concerns to a doctor, or took the actions it should have done in line with the Trust's and NICE guidance on sepsis. A medical

consultant reviewed Mrs D later that morning and wrote a plan to consider restarting antibiotics, but the Trust did not prescribe them until 6pm.

The Trust's failings meant that it missed opportunities to treat sepsis, which might have prevented Mrs D's worsening health, fall, cardiac arrest and death.

Putting things right

We recommended that the Trust write to Mrs C to accept and apologise for the failings in Mrs D's care and explain how it will stop them from happening again. We recommended that it make a payment to Mrs C to recognise the injustice that she and her family will never know whether things could have been different.



Mrs D had signs of sepsis and the Trust missed opportunities to identify and treat it.

Sepsis caused by an untreated pressure sore

The complaint

Miss O complained about the care that Tameside and Glossop Integrated Care NHS Foundation Trust gave her father, Mr O, between November 2017 and January 2018.

Mr O had multiple health conditions, including dementia, and his family supported his daily living. On 16 November 2017, he collapsed and went to A&E in an ambulance. He went home a few days later.

He went to A&E again on 25 November with a temperature and sleepiness. The Trust suggested that he had a urinary tract infection and treated him for possible sepsis. He was moved to the medical assessment unit and then to a ward.

On 27 December, the Trust noted a moisture lesion (sore skin, which sometimes blisters, caused by exposure to wetness over a long period of time) to Mr O's sacrum (bone at the base of the spine). A few days later his condition got worse again. The Trust treated him for possible hospital-acquired pneumonia and his condition improved.

On 4 January, the Trust noted a grade 2 pressure ulcer (damage to the skin caused by pressure) and moisture lesion to Mr O's sacrum. Four days later, they applied barrier cream.

The Trust took blood cultures on 15 January, which grew a type of bacteria. The Trust gave Mr O antibiotics and fluids. The Trust noted the likely cause was the pressure ulcer.

Mr O's condition got worse on 21 January. The Trust decided to stop active treatment and told his family there was nothing more it could do.

Mr O moved to a hospice the next day, where staff documented a grade 4 lesion to his sacrum, with moisture damage. Mr O sadly died a few days later. The cause of death was sepsis caused by the sacral pressure sore that had remained untreated.

What we found

We found that the Trust did not assess Mr O's risk of developing a pressure ulcer and did not put in place an individualised care plan. This meant the Trust did not consistently assess Mr O's skin, provide pressure relief or reposition Mr O. The documentation of the care it provided was poor. The Trust did not refer Mr O to the tissue viability nurses at the right time.

These failings led to Mr O's skin integrity deteriorating, developing sepsis, and then sadly to his death. This would have been avoided if the failings had not happened.

We found failings in the Trust's record-keeping, particularly relating to care plans and fluid balance. This cast doubt on the care provided and made it harder for us and the Trust to be able to address Miss O's concerns.

Mr O got the pressure sore while in hospital. This was a patient safety incident, which should have been discussed with Mr O's daughters who were his main carers. The Trust should have communicated with the family earlier about the damage to Mr O's skin.

We found that Mr O's death was avoidable and happened because of the Trust's actions.

Putting things right

We said the Trust should write to Miss O to accept responsibility for the failings and apologise for the effect they had. We said it should produce an action plan explaining how it will stop the failings from happening again, and send a copy to Miss O, us, the Care Quality Commission and NHS Improvement.

This was a patient safety incident, which should have been discussed with Mr O's daughters.

Sepsis caused by poor discharge and lack of follow-up

The complaint

Mr M complained about the care and treatment that George Eliot Hospital NHS Trust gave his partner, Ms R.

Ms R was diagnosed with an aggressive type of bowel cancer and had surgery to remove part of her bowel. The wound did not heal well and she developed abdominal abscesses so she stayed in hospital. After the second abscess was drained, Ms R was discharged home with a wound bag over it to collect fluid and pus. She did not have a drain in place and did not receive a follow-up outpatient appointment to review her ongoing treatment.

Ms R went back to hospital around two months later with a large abdominal abscess and septic shock. On the day of her emergency admission, the Trust surgically drained 1.5 litres of pus. In the days that followed, Ms R had a cardiac arrest, continued to get worse and sadly died.

What we found

Although Ms R was seriously ill with cancer, it did not appear to have caused her death.

We found that the Trust did not follow relevant guidelines and did not discharge Ms R with a drain in place for the abscess when it should have done. It was more likely than not the lack of drain caused a large build-up of fluid and pus in her abdomen.

This led to Ms R developing sepsis and septic shock, which led to her death.

The Trust did not arrange outpatient appointments in line with the relevant guidelines, which increased Ms R's risk of developing sepsis. If the Trust had arranged a follow-up, it could have identified that Ms R did not have a drain and taken steps to put its mistake right. This was a missed opportunity to prevent Ms R's avoidable death.

Putting things right

We said the Trust should accept the failings and write to Mr M to apologise. We said it should complete an action plan looking at how these events happened and how it will avoid them in the future. We also recommended that the Trust make a payment to Mr M to recognise Ms R's avoidable death and the distress this caused.

Making a complaint to the NHS in England

If you are not happy with the care you have received, in relation to sepsis or any other service provided by the NHS, you have the right to make a complaint.

Hearing from patients when things go wrong is so important. Sharing your experience can improve services for everyone and help stop mistakes happening again.

This guide tells you how to complain to the NHS in England and what to expect.
You can also read our top tips on how to make a complaint.

How to make a complaint

1. Speak to a member of staff

Before you make a complaint, you could share your views and experiences with a member of staff. Many problems can be sorted out quickly by telling staff about your concerns at the place where you received care. This could be your doctor. Feel confident in raising your concerns. Staff should welcome your feedback because it can help to improve services.

2. Get advice from someone not involved in your care

If you want help and advice about making a complaint, there are lots of organisations that can support you. For example, you can speak to your local Patient Advice and Liaison Service (PALS), the Patients Association or your local Healthwatch.

3. Make a formal complaint to the NHS

If you want to make a formal complaint, it is best to do this as soon as possible and you must do this within 12 months of what happened. You can complain to the NHS organisation you are not happy with (such as a hospital or GP practice). Or you can complain to the commissioner of the service, which will either be NHS England or your local integrated care board.

NHS organisations all have their own complaints process, and you can usually find this on their website, at reception, or by asking staff. If your complaint is about more than one organisation, you only need to make one complaint. The organisation that receives your complaint will work with the others to make sure you get a coordinated response.

After you have sent your complaint, the organisation should contact you within three working days to say they have received it. They should explain what will happen next, how they will handle your complaint and how long it will take.

The organisation must deal with your complaint properly and investigate it as quickly as they can. Some complaints will take longer than others. Communication is really important - they must keep you updated throughout the process so you know what is happening.

The organisation should respond to your complaint in writing. This should tell you how they carried out the investigation and what they found. If they have made mistakes, they should apologise to you. They should explain any lessons learned or changes they will make to put things right.

4. Complain to the Parliamentary and Health Service Ombudsman

If you are not happy with how the NHS handled your complaint, you can speak to us to look into it. As the national Ombudsman for the NHS in England, we work to inspire a better relationship between people and public services. We aim to encourage a relationship based on decency, honesty and respect where people are put first. We are an independent organisation and we do not take sides. Our service is free.

You can complain to us if:

- you have reached the end of the NHS complaints process and you still feel the issue has not been sorted out
- the organisation has not dealt with your complaint after six months (unless it has explained why it is taking a long time and given you an expected completion date).

There are time limits for making your complaint to us, and these are set out in law. For complaints about the NHS, make sure you get it to us within a year of when you became aware of the problem you are complaining about. Our website has more information about what we will do if we receive a complaint outside these time limits.

Find out more about how to complain to us and how we deal with complaints.

What to expect when you make a complaint

The NHS Complaint Standards explain how NHS organisations should approach complaint handling. They are based on My Expectations, which says what patients want to happen when they make a complaint.

The Complaint Standards say organisations should:

- welcome complaints in a positive way
- be thorough and fair
- give fair and accountable responses
- promote a learning culture.

When organisations meet the Complaint Standards you should feel:

- confident to speak up
- that making your complaint was simple
- listened to and understood
- that your complaint made a difference
- confident to make a complaint in the future.

Where to get more help

If you need help making a complaint, there are organisations that can support you:

- our website has more information about getting advice and support
- The UK Sepsis Trust provides information, help and support for people affected by sepsis.

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